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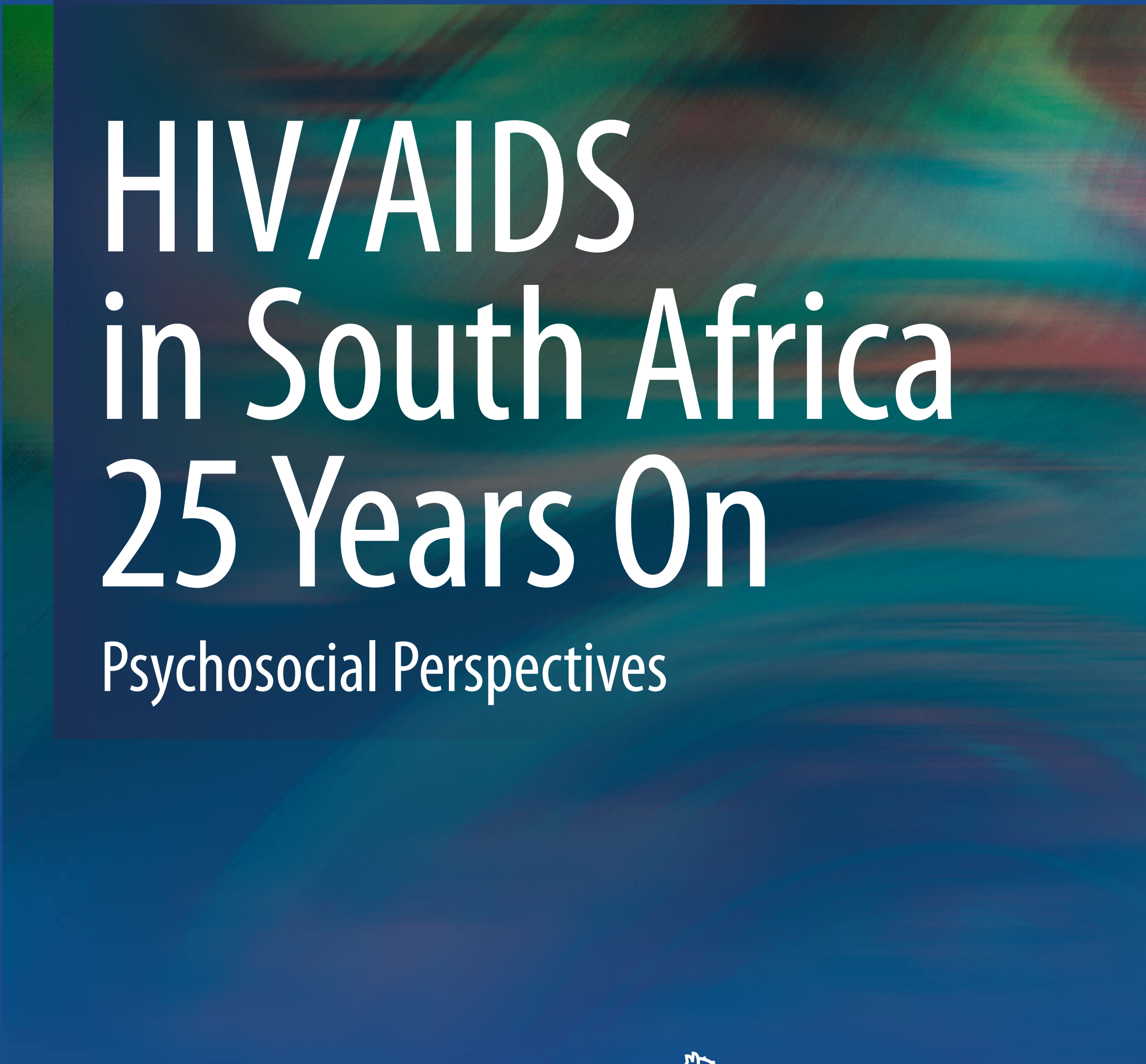

HIV/AIDS in South Africa 25 Years On

Psychosocial Perspectives

Springer

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Foreword by Edwin Cameron

Springer

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ISBN 978-1-4419-0305-1 e-ISBN 978-1-4419-0306-8
DOI 10.1007/978-1-4419-0306-8
Springer New York Dordrecht Heidelberg London

Library of Congress Control Number: 2009931924

Printed on acid-free paper

Springer is part of Springer Science+Business Media (www.springer.com)

Foreword

AIDS has been one of the defining challenges of our time. On our continent Africa, more so, because its greatest global burden is here, where wealth is least and human systems frailest. And in South Africa most acutely, not just because 5 or 6 million of us are living with HIV and AIDS, but because of the gross political mismanagement of the epidemic, rooted in presidentially instigated AIDS denialism in the early years of this century. Its disabling effects still linger, even as new political purpose is at last bringing order and hope to the epidemic.

No corner of our social effort or investment – from health care to social security, education to the economy, correctional services or the judiciary – escapes AIDS. Amongst the many lessons the epidemic has taught us is that health is only partly the domain of medical science – every aspect of life is subject to, and in turn influences, AIDS.

Hence, no single approach can begin to secure the proper prevention, containment, treatment and care we need. The words "holistic" and "multi-sectoral", though grievously over-used, have practical meaning: that imagination, cohesion and commitment are what we have to start with. Then we need effective knowledge and systems and resources.

But we also need understanding. To deal effectively with an epidemic that threatens the lives of so many demands insight. And for that, we have to confront controversy – indelicately where necessary. It also requires us to innovate, and to confound convention wisely.

This impressive book will, I hope, help us with all of this. It brings together many of the "usual suspects" – those authoritative experts from our region whose clinical and analytical and academic work has placed them at the global forefront of AIDS.

Their common interest here, reflected through their broad range of collaborators, is in psychosocial approaches to the epidemic. Each writes about a fascinating and important aspect. All do so with a view to increasing our understanding, and thus our capacity to do more.

The contributions are generally of high quality; some are innovative; and most are of real interest. The emphases differ. Across chapters, there are differences of opinion. Good.

This book shows how far we have come over the past quarter-century in moving to greater psychosocial understanding of HIV/AIDS in South Africa. It also tells us how far we still have to go.

What is good is that we now have between the covers of one volume a range of authoritative reviews of what we know – and of what we still need to learn.

The editors collected these chapters to provoke debate. The best compliment you could return would be to read the chapters critically, in a spirit of challenge, response and further inquiry.

So I congratulate them and the authors on this impressive compendium of ideas, data, and challenges. This book is quite a landmark in HIV/AIDS scholarship in South Africa.

If it helps us to think more deeply, and to work more effectively in this still dire epidemic, it will have been worth the contributors' effort, and your investment in buying it.

Edwin Cameron
Justice of the Constitutional Court of South Africa
March 2009

Acknowledgments

The contributors to this volume come from a broad range of disciplines and institutions, both in South Africa and internationally. We have attempted to put together a book that reflects a diversity of psychosocial issues and perspectives involved in approaching the HIV/AIDS epidemic in South Africa. We have tried to be as inclusive as possible in addressing various topics, and of course there remain some areas that we did not have the space to include. This has turned out to be a large volume, and we would like to thank all the contributors for putting together their knowledge and thoughts into this book, for thinking about what has been learnt and still needs to be learnt about HIV/AIDS in South Africa, and for doing so within our deadlines. In some cases, authors had to put up with ongoing emails and some difficult requests from the editorial team. We thank all authors for their contributions, without which this book would not be possible.

We would also like to thank Janis Kritizinger for her meticulous final editing and formatting of the manuscript and her attention to detail. As our deadline for submission was approaching, her work on the manuscript was a blessing.

We would also like to thank the team at Springer, especially Bill Tucker and Ian Marvinney for their enthusiasm and support of this project. A special thank you also to Judge Edwin Cameron for his endorsement of the book and agreeing to write the Foreword.

Finally we would like to thank our partners and our families for their patience while we worked on this volume.

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Chapter 1
Introduction and Overview

Poul Rohleder, Leslie Swartz, Seth C. Kalichman, and Leickness C. Simbayi

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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Part I
Psychosocial Issues

Chapter 2
The Sociocultural Aspects of HIV/AIDS in South Africa

Suzanne Leclerc-Madlala, Leickness C. Simbayi, and Allanise Cloete

2.1 Introduction

In 2005 the Commission for Africa noted that ‘Tackling HIV and AIDS requires a holistic response that recognises the wider cultural and social context’ (p. 197). Cultural factors that range from beliefs and values regarding courtship, sexual networking, contraceptive use, perspectives on sexual orientation, explanatory models for disease and misfortune and norms for gender and marital relations have all been shown to be factors in the various ways that HIV/AIDS has impacted on African societies (UNESCO, 2002). Increasingly the centrality of culture is being recognised as important to HIV/AIDS prevention, treatment, care and support. With culture having both positive and negative influences on health behaviour, international donors and policy makers are beginning to acknowledge the need for cultural approaches to the AIDS crisis (Nguyen et al., 2008).

The development of cultural approaches to HIV/AIDS presents two major challenges for South Africa. First, the multi-cultural nature of the country means that there is no single sociocultural context in which the HIV/AIDS epidemic is occurring. South Africa is home to a rich tapestry of racial, ethnic, religious and linguistic groups. As a result of colonial history and more recent migration, indigenous Africans have come to live alongside large populations of people with European, Asian and mixed descent, all of whom could lay claim to distinctive cultural practices and spiritual beliefs. Whilst all South Africans are affected by the spread of HIV, the burden of the disease lies with the majority black African population (see Shisana et al., 2005; UNAIDS, 2007). Therefore, this chapter will focus on some sociocultural aspects of life within the majority black African population of South Africa, most of whom speak languages that are classified within the broad linguistic grouping of Bantu languages. This large family of linguistically related ethnic groups span across southern Africa and comprise the bulk of the African people who reside in South Africa today (Hammond-Tooke, 1974).

A second challenge involves the legitimacy of the culture concept. Whilst race was used in apartheid as the rationale for discrimination, notions of culture and cultural differences were legitimised by segregating the country into various ‘homelands’. Within the homelands, the majority black South Africans could presumably

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_2, © Springer Science+Business Media, LLC 2009

find a space to give free expression to their own culture and language. During this era, language and culture was employed as strategies for cultural preservation and as instruments of resistance to reclaim and reaffirm an African identity (Garuba and Raditlhalo, 2008). A desire to revive and re-dignify African culture and traditional practices, long denigrated through colonial and apartheid processes, has characterised the African Renaissance project of the immediate post-1994 democratic period. Today the cultural terrain remains a highly contested terrain and public debates on culture are often avoided in anticipation of offending personal and political sensitivities. For purposes of this chapter, culture is defined in its most holistic sense following Geertz (1973, cited in Gorringe, 2004) as, ‘not only the arts and letters, but also modes of life, fundamental rights of the human being, value systems, and traditions and beliefs that are all suspended in webs of significance that people themselves have spun’ (p. 71).

2.2 Contours of the Local Web of Significance

In most African communities of South Africa, Christian influence predominates. Common practices often take the form of religious syncretism whereby people who profess to be Christian and may regularly attend a church and partake in Christian rituals do nonetheless continue to maintain many traditional beliefs and often perform traditional rituals. Such rituals are done mostly to honour dead ancestors and solicit their protection against misfortune. In addition to the formal Christian churches, there are numerous African independent churches that combine aspects of Christian ritual with aspects of traditional culture and religion, and there is currently a growing Christian charismatic movement that extends across the region. Belief in sorcery and witchcraft is deeply rooted and is not uncommon among people who are well educated as well as those who are poor. This seemingly dualistic belief system is visible in peoples’ health-seeking behaviours, whereby western biomedicine and modern hospitals and clinics are popular and are widely utilised alongside the services of traditional healers. For the most part, people are able to manage the co-existence of what are essentially logically inconsistent religious traditions (Hopa et al., 1998; Mzimkulu and Simbayi, 2006). While on the whole there is no particular concern with the relationship between the teachings of the Church and traditional religious beliefs, the two religious systems espouse different values with regard to certain behaviours. For example, most African groups are traditionally polygynous and have made allowances for men to continue pursuing women and seeking wives after marriage. While many men today marry monogamously in accordance with Christian rites, many continue polygynous relationships in an informal way through extramarital concurrent partnering.

Across African communities the nature and implications of marriage, descent and residence are very similar. While local variations do occur in the details of different systems, it is largely to the common features of the systems that attention will be directed. The broad similarities in the manner in which marriage is brought about arise from the common acceptance of three basic marriage rules that have long been prescribed. These are (1) *polygyny* – a man is allowed to have more than one wife at a time if he chooses; (2) *patrilocality* – a woman is expected to join her husband after marriage, either at his own homestead or at that of his father or brothers; (3) *patriliny with bride wealth* – marriage is legitimised in all these societies with the transfer of bride wealth from the husband's family to the wife's family, which traditionally takes the form of cattle. With this transfer a man and his family obtain considerable jural rights over his wife and children. Children born to a union were and are considered to be children of the father, and descent is traced through males. While various historic and modern pressures continue to undermine these traditional social arrangements, the combination system of polygyny, patrilocality and patriliny with bride wealth continues to have important repercussions and influences on the nature of marital relations and social relations more generally.

In traditional times a woman, upon marriage, was taken to the homestead of her husband's family. Once at her new husband's home, she would normally be installed in her own hut where she was expected to live and sleep with her children. In the event that her husband would acquire additional wives, each new wife was entitled to her own separate hut. As a daughter-in-law, the woman was subject to numerous prescriptions for demonstrating 'respect' that defined the way she was expected to interact with and be subordinate to members of her husband's family. Most older written accounts of married life in the various local communities contain descriptions of the sometimes harsh rules and regulations that young in-marrying wives were expected to follow and obey. Still today women are very aware of cultural prescriptions to show respect by deferring to husbands and in-laws. Full acceptance within a woman's patrilineal home was only complete with the birth of her first born child, and especially when that child was a boy. From then on, culture dictated that a woman's term of address within the home would no longer be a term that translated into 'young wife', but henceforth a term that translated into 'mother-of-so-and-so'. As a mother of a child of a particular home and lineage, a woman was then more fully incorporated and accepted into her husband's family. These prescriptions continue to inform ways of thinking about marriage, motherhood and the role of fertility and children in society.

With patrilineal descent, children born to a married woman are socially considered to be the children of the father. It is important to note that while family life has undergone considerable changes over time, with urbanisation, poverty and the migrant labour system continuing to play major roles in the destabilisation of the family, the cultural *ideals* of behaviours related to patrilineal descent, polygyny, bride-wealth exchange and a patrilocally derived social order remain. These cultural ideals have survived generations of colonial and apartheid history in the region and continue to play significant roles in shaping the attitudes, beliefs and values that people hold in relation to their expectations of family life, parent–child relations, husband–wife relations and gender and sexuality more generally.

The shared heritage of polygyny, patrilocality and patrilineality with bride wealth are characteristic of not only a majority of societies in South Africa but across southern Africa. Taken together as the foundation of traditional social life, these three elements continue to provide important reference points for people living in this part of the world and form the basis of the fundamentally similar sociocultural institutions and practices that are found in the region.

2.3 From Contours to Practices

The sociocultural context contributes to legitimising and giving meaning to the common assumptions, expectations and values that people hold in relation to their day-to-day activities. Some behaviours found to increase the vulnerability of people to HIV infection in South Africa include practices such as multiple and concurrent sexual partnering, age-disparate and intergenerational sex, dry sex practices, unequal gender power relations, high levels of sexual violence, on-going AIDS-related stigma and denial and a variety of practices relating to cultural rites of passage around puberty, marriage and death. Below is a brief discussion of some of the sociocultural factors that play a role in the spread of HIV/AIDS in South Africa. Some of the issues are also discussed in more detail in later chapters.

2.3.1 Unprotected Sex with Multiple and Age-Disparate Partners

Whilst traditional polygyny has declined in many African societies, men in present-day South Africa commonly engage in multiple and concurrent partnerships. This is done as much in the pursuit of social and individual validation as it is done in the pursuit of reproductive success, as male virility is often measured by how many sexual partners one has at any given time. Even though polygyny in contemporary South Africa is not the only norm prescribing husband–wife relations, the cultural heritage of polygyny continues to legitimise sex with multiple and concurrent partners and presents a challenge to HIV prevention. In southern Africa, including South Africa, sex with multiple and concurrent partners in the context of poor and inconsistent male condom usage has been identified as the key behavioural driver of HIV (Mah and Halperin, 2008; SADC, 2006).

Negative attitudes towards condom use in sub-Saharan Africa are often based on cultural factors, for example, the desire for children and female sexual compliance are often ways used by women to achieve economic status (Campbell, 1997; Macphail and Campbell, 2001). The use of condoms is believed to be unnatural, a tool used by men to prevent disease or children (Meyer-Weitz et al., 1998; Ulin, 1992). According to these authors, condom use is seen as a ‘waste’ of sperm and that this conflicts with the emphasis on fertility in African culture (Caldwell et al., 1994; Grieser et al., 2001; Lachenicht, 1993). Such beliefs encourage people to engage in high-risk sexual behaviour and risk HIV infection in order to produce male offspring. Despite such beliefs, studies of condom usage continue to reveal that reported levels of condom use are high in South Africa (Department of Health, 2007, Shisana et al., 2005). Nonetheless, as Versteeg and Murray (2008) point out, the behaviour of having multiple partners remains risky and the use of condoms can give a false sense of safety if not applied consistently in all sexual encounters.

Among the more worrisome forms of multiple partnering are intergenerational relationships where large age disparities between partners are combined with gender power differentials to make young women's involvement with older men especially risky. Since the older men would likely have been sexually active for many years and therefore more likely to be infected by sexually transmitted infections (STIs) including HIV, the younger women risk being infected by these older partners. Rates of HIV among young South African women in the 15- to 24-year age group is disproportionately high, approximately four times that of young men, and in 2007 accounted for 90% of new infections in that age group (Rehle et al., 2007). A further analysis of the same survey data on the intergenerational relationships showed that having a sexual partner 5 years older poses a high HIV infection risk for youth (Shisana et al., 2005). In addition to poverty that prompts many women to engage in transactional sex, South Africa's rapidly expanding economy is creating new needs and wants amongst young women who often view relationships with older, employed men as a relatively easy way to meet their growing desire for consumer commodities (Leclerc-Madlala, 2008).

2.3.2 Gender Inequalities

The patriarchal social arrangements discussed above ultimately serve to coalesce power and privilege into the hands of men while simultaneously curtailing the autonomy of women. The gender dynamics that result from this system put women in South Africa at greater risk of HIV infection than their male counterparts. These inequalities have serious implications for choices that women are able to make in their lives, and provide a supportive backdrop for gender based violence.

- In the first instance, it affects women's capacity to decide with whom, when and how sexual intercourse takes place (Pettifor et al., 2004). Indeed, such decisions are frequently constrained by coercion and violence in the women's relationships with men (Jewkes and Abrahams, 2000).Young girls are often coerced by older men, including male school teachers, into having their first sexual experience with them (Shell and Zeitlin, 2000).
- Second, women are generally not socialised to initiate sexual activity. This task is normally considered to be part of a man's role (Varga, 1997).
- Third, men perceive themselves to be naturally superior to women and often consider it a cultural right to have multiple partners. Such behaviour is generally equated with notions of normative masculinity (Eaton et al., 2003).
- Finally, women are commonly implicated for bringing HIV into a relationship while their male counterparts are culturally absolved of blame for the disease (Leclerc-Madlala, 2002).

2.3.3 Stigma, Denial, Exclusion and Discrimination

Rates of denial are still high in South Africa and continue to present an enormous challenge to tackling the epidemic. Cultural manifestations of denial, AIDS-related stigmas and discrimination varies from culture to culture (UNESCO/UNAIDS, 2002). Even so, in many traditional African cultures, illness is attributed to spirits and supernatural forces (Aids Weekly, 2001; van Dyk, 2001), and these beliefs may be associated with stigmatising afflicted persons. Schoepf (1995) argued that the meanings ascribed to heterosexual penetrative sex with ejaculation contribute to the denial of risk. Heterosexual penetrative sex is considered as 'normal and natural', and is invested in cosmological significance, strongly valued by many as the essence of life, beauty and survival of the individual, family and community (Schoepf, 1995). These significations according to Schoepf (1995) contribute to the denial of risk, to stigmatisation of the afflicted and their families and to withdrawal of social support. As elsewhere, HIV/AIDS is widely perceived to be an outcome of sexual excess and low moral character. At the time when those infected really need social support the most, people living with HIV/AIDS who reveal their status are often subjugated to victimisation and discrimination (Rankin et al., 2005; Siyam'kela Project, 2003). This happens everywhere starting from their own homes, within the communities they live in, as well as at work. Consequently, there is a strong culture of silence by people living with HIV/AIDS because of fear of rejection and isolation from both close relatives and the community at large (Johnston, 2001). The stigma is particularly more severe for women than for men (Petros et al., 2006; Skinner and Mfecane, 2004). One of the consequences of the problem of ongoing stigma, exclusion and discrimination of people living with HIV/AIDS is that it forces those who are infected to hide their condition by going 'underground' and to continue engaging in high-risk behaviour (Qwana et al., 2001; Strydom, 2000).

2.3.4 Substance Abuse

South Africa, like most other countries in southern Africa, consumes great quantities of alcohol. Like in other parts of the world, alcohol use has a long history in southern Africa, dating back hundreds of years and spanning social, cultural and economic spectrums (Nielsen et al., 1989). Alcohol has long been used during cultural rituals and ceremonies to celebrate various occasions, ranging from weddings, the birth of children, during initiation, during harvests and after people have passed away. Indeed, such occasions are also used extensively for sexual networking (Pattman, 2001).

It has been estimated that South Africans consume 6 billion litres of alcohol per year (Patta, 2008). There is growing local empirical evidence that suggests a link between substance abuse and HIV infection. A number of studies have advanced the alcohol-risky sex hypothesis and have found some evidence which supports the hypothesis that alcohol intake increases sexual risk-taking behaviour (Fisher et al., 2007; Kalichman et al., 2007; 2008; Kiene et al., 2008; Morojele et al., 2005). When alcohol or any other illicit drug is consumed in excessive amounts, it has been found to inhibit a person's ability to engage in safer sex practices such as using condoms correctly and consistently. Thus, a person under the influence of alcohol or drugs is highly unlikely to be able to protect him or herself from being infected by HIV when having sexual intercourse with an infected person. With both alcohol and drug use on the increase in South Africa, the HIV infections linked to this route are also bound to increase. In particular, the use of hard drugs such as cocaine, mandrax (especially in the Western Cape Province of South Africa) and dagga among the youth appear to be growing rapidly (Parry et al., 2004).

2.3.5 Dry Sex or Vaginal Douching

Dry sex or vaginal douching is practiced primarily for increasing the sexual pleasure of men (Baleta, 1999; Beksinska et al., 1999). Pleasing men in this way is important to women, either for economic survival as in the case of sex workers (Abdool-Karim et al., 1995), or for maintaining a good marriage, as in the case of a wife meeting the sexual desires of her husband. The combination system of polygyny, patrilocality and patriliny with bride wealth prescribe certain cultural expectations of the 'young wife' that are steeped in norms and values that effectively promote cultural ideals aimed at pleasing her husband. Cultural conceptions of what it means to be a 'young wife' and a woman usually conform to notions of femininity as sexually innocent and inhibited. According to Leclerc-Madlala (2002) and Levin (2005) in the context of cultural influences in modifying vaginal function, this behaviour usually conforms to pervasive patriarchal cultural concepts that 'wet sex' is indicative of female infidelity, uncleanliness, possible infection and moral 'looseness' on the part of the woman.

This practice often involves either cleaning the vagina with a variety of substances, including antiseptics and detergents, or inserting traditional herbs into the vagina and drying it with paper or cotton prior to or after having sexual intercourse (Louria et al., 2000). Some drying and tightening agents are used as 'love potions' to retain the affections of a partner. These practices have implications for the acceptability of HIV prevention strategies such as the use of condoms and vaginal microbicides (Bagnol and Mariano, 2008; Morar et al., 2003). By disturbing the vaginal flora or causing extensive local irritation and inflammation of the vaginal walls, this practice could possibly impact on the female infection with and the spread of HIV (Levin, 2005).

2.3.6 Cultural Practices and Ritual Activity

A host of rituals surrounding the life transitions of birth, puberty, marriage and death have been identified as cultural factors specific to the African continent that are influencing the spread of HIV (UNECA, 2008). In South Africa, these include the following:

- *Traditional male circumcision*. Circumcision has long been practised in various forms among various ethnic groups. Youth who have reached puberty among the Xhosa, Ndebele, Pedi, South Sotho and Venda partake in initiations, which include circumcision. For the most part, these are conducted by traditional surgeons in deep rural areas under highly unhygienic conditions using the same unsterilised instruments on several of the initiates. In some cases, the newly circumcised young men are encouraged to engage in sex soon after initiation with a woman whom they do not intend to marry. Moreover, according to Vincent (2008), for many initiates circumcision has come to be viewed by many as a permit for sex within a context of gender relations characterised by coercive sex. Considering these wider contextual issues, more scientific evidence is required to ensure that the benefits of circumcision outweigh any potential risks (Byakika-Tusiime, 2008). Even though there has been sufficient evidence of empirical studies conducted in southern Africa of the protective effect of male circumcision against HIV infection (Byakika-Tusiime, 2008; Halperin and Epstein, 2007; Westercamp and Bailey, 2007) many authors warn that male circumcision should be examined and promoted with sensitivity to the specific local cultural contexts (Connolly et al., 2008; Peltzer et al., 2007; Vincent, 2008).
- *Virginity testing*. While this method has been a part of traditional prevention measures to guard against the early onset of sexual behaviour, there has been a resurgence of interest in virginity testing over the past decade to encourage sexual abstention among young women (Leclerc-Madlala, 2002). Especially popular in Zulu and Swazi communities, virginity testing today is largely conducted by elderly women who often use the same latex glove to insert their fingers into the vaginas of dozens of girls. In order to avoid the social stigma that results from being found to be a non-virgin, girls sometimes engage in unprotected anal sex as a way to retain their virginity while satisfying their boyfriends (McKerrow, 2000). This puts young women at great risk of HIV infection.
- *Fertility and virility testing*. The importance that African culture places on fertility often prompts young women to fall pregnant during their first relationship as a way to prove their fertility before getting married. Wechsberg et al. (2005) argue that this cultural tradition encourages early unprotected sexual activity. Similarly, a major way for a man to prove his virility and potency is by making a woman pregnant (Lesetedi, 1999).
- *Fertility obligations*. Due to social inequality between the sexes and ideas of male superiority, a wife is automatically blamed for infertility and accused of witchcraft as well as being ostracised by society even if it is the husband who is infertile. In some cases, members of the family meet to discuss the problem often without the knowledge of the couple, and encourage a close relative to befriend the wife with the intention of impregnating her and subsequently producing an offspring for the infertile couple (Nxumalo, 1999). Sometimes a sister

or brother is asked to assist an infertile sibling or close relative to have children. In both cases, the large degree of jural rights over a woman that a man's family acquires through the payment of bride wealth gives women little choice in the matter, otherwise facing the risk of being divorced from her husband should she refuse. These fertility obligations encourage the spread of HIV infection among the people involved if one of them is HIV positive.

- *Post-partum sex and breastfeeding taboos.* In many African communities, post-partum sex was traditionally discouraged between the husband and wife for sometimes up to a year or until the child has been weaned from breast-feeding. Sexual activity during this period was seen as polluting the blood of the nursing mother and thus detrimental to the health of the child. The association of sexual taboos with childhood health conditions is widespread among African societies in South Africa and continues to be a factor in men's involvements with women outside of marriage. During confinement and breast-feeding, men are often expected to seek other women to satisfy themselves sexually.
- *Death rites.* There are two main customs that continue to be practised to varying degrees in South Africa. The first is the *levirate*. This refers to a situation whereby when one of the two partners in a marriage dies, a brother or sister of the dead partner inherits the remaining spouse. In South Africa, patrilineal descent dictates that it is usually the woman who will be 'inherited' by one of her dead husband's male relatives. The second is known as the *sororate*. As noted above, in order to ensure that the relationship developed by the two families at marriage produces some offspring and does not dissolve, a widower or sometimes a husband of a barren woman marries his wife's sister. In cases where one partner in the new relationship may be infected with HIV, this increases the chance of the new partner will also become infected.
- *Indigenous healing practices.* In most African countries and indeed throughout the world, modern (i.e., western) and traditional (i.e., indigenous) healing systems co-exist side by side (Hopa et al., 1998). Even though the western system is dominant in terms of both official status and scientific acceptability, the traditional counterpart is more widely accessible as well as being used due to pervasive traditional health beliefs. People who live in rural areas, which generally have poor western medical services, depend mainly on the services of traditional healers. Consequently, a majority of the people, estimated to be about 80% of the South African population, consult with traditional healers for treatments of most ailments (UNAIDS, 2006). There are two main indigenous healing practices that are thought to contribute to the spread of HIV in South Africa. First, the use of unsterilised sharp instruments, such as knives, blades, spears, animal horns, quills and thorns, as surgical tools when treating patients is problematic. Second, and more importantly, healers sometimes have sex with their clients as a way to cure a number of ailments, including infertility and depression. Some healers also recommend that their clients have sex with virgins as part of their treatment regime for illnesses such as STI and HIV infection. Both practices enhance the chances of acquiring HIV.

2.4 Conclusion

In South Africa, many customary and contemporary influences have combined to result in present-day practices, beliefs, norms and values that play significant roles in impeding the adoption of safer sex practices. Some elements of culture have changed through time while some have persisted, others have mutated and still others have disappeared while the ideals and values that they reflect continue to shape the way people think and feel about certain behaviours. New elements of culture have also arisen and have been added to the milieu in which sexual decision making, amongst other things, is taking place. Foreign media densification along with a host of more recent globalising and modernising processes are adding their own shaping influences to the sociocultural environment in which the HIV/AIDS epidemic is occurring.

Making HIV prevention more effective in South Africa will require approaches that are better attuned to the cultural specificities of the people concerned. This in turn will require a deeper understanding of the role of culture in the production and management of disease. Culture is far more than a collection of easily identified and measured beliefs and practices; it is about that which gives meaning and purpose to human life. Taking a cultural approach to the problem of HIV/AIDS means taking into account the particularities of the sociocultural domain at each stage of the intervention process, from conceptualisation and design of policies and programmes to evaluation of outcomes and impacts. Thus far, there has been little evidence of any serious attempt to do this either at the level of HIV policy making or programming in South Africa. There remains a need to engage more directly with the sociocultural factors that make our local communities so exceptionally vulnerable to this disease.

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Chapter 3
HIV and Women

Rachel Jewkes

3.1 Introduction

South Africa has one of the most extensive HIV epidemics in the world, and one where the burden of the epidemic is most conspicuously borne by young black women. In the interests of epidemiological pragmatism, its course has until fairly recently been mapped through women's infections. One consequence of which has been to render men relatively invisible, both as HIV-related health-service users and as agents of sexual risk (Greig et al., 2008). Yet women's subordinate position in a highly patriarchal society has critically shaped their HIV risk, just as the racial patterning of the epidemic has its roots in the political and economic subordination stemming from colonisation and the era of apartheid. This chapter is largely an account of influences on the lives of African women, who carry the overwhelming burden of infection.

Until 2002 when the Human Sciences Research Council undertook its first population-based survey of HIV prevalence, the subclinical (and clinical) course of the infection was followed in antenatal populations. Anonymous surveillance in antenatal clinics by the Department of Health has mapped an initial exponential rise in national prevalence of HIV among pregnant women from 0.7% in 1990, 16.0% in 1997 to 24.5% in 2000. The first decade of the millennium has seen the prevalence plateau and the most recent rate was 29% in 2007 (Department of Health, 2008). HIV does not equally affect all South Africans. There are marked racial differences, with national prevalence estimates showing that white and Indian men and women in the general population have very low prevalence (0.6% and 1.9%, respectively), while the highest is found in Africans (13.3%) (Shisana et al., 2005).

The sexually transmitted portion of the epidemic starts in the teenage years, when women begin to be infected. This starts approximately 5 years younger than infections in their male peers (Shisana et al., 2005). A national survey of youth aged 15–24 years found that 15.5% of women and 4.8% of men were infected (Pettifor et al., 2005). Women sustain this vulnerability throughout their lives. Among adults aged 15–49 years, nearly twice as many men as women have HIV (11.7% versus 20.2%) (Shisana et al., 2005). An inescapable conclusion drawn from these gendered patterns of infection is that the epidemic in women is disproportionately

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_3,

driven by the behaviour of a relatively small group of HIV-infected older men who have a large number of partners. Little wonder that studies describing factors associated with HIV in young women have consistently pointed to the importance of older partners (Jewkes et al., 2006a; Pettifor et al., 2005). Other identified risk factors in young women are having more partners (Jewkes et al., 2006a; Pettifor et al., 2005), more sex (Jewkes et al., 2006a) and getting sexually transmitted infections and using condoms inconsistently or not at all (Pettifor et al., 2005).

These factors reflect some well-recognised biological aspects to women's vulnerability. HIV is more readily transmitted from men to women than women to men (Gray et al., 2001), with explanations related to the larger surface area of the vagina and frequency of tears during sexual intercourse. Older men are more risky for women because they are generally more sexually experienced and so are more likely to have STIs that can be transmitted to women. This is seen in their higher age-specific prevalence of HIV and HSV-2 (an established HIV co-factor) than the women's male peers (Pettifor et al., 2005). STIs have been shown to increase vulnerability to HIV acquisition, particular herpes simplex type 2 virus which may convey as much as threefold increased risk (Freeman et al., 2006). In mathematical terms, having more partners increases the likelihood of having one who is HIV infected. While the biology is indisputable, it does not particularly help answer the important questions about the social and cultural origins of and social processes that sustain patterns of sexual practices that place women at risk of HIV. These questions relate to a level of causation that is deeply rooted in the social fabric of life in South Africa, the understanding of which is absolutely critical for the development of effective approaches to reduce sexual risk taking. In this chapter, we reflect on major historical processes that have influenced the shape of present-day sexuality and discuss some of the impacts of apartheid and urbanisation. Recognising women's sexual practices as both influenced by and influencing a broader set of ideas about womanhood (or femininity) which are shaped by sets of power relations that critically pertain between women and men, as well as between women and others in their social environment, we then discuss sexuality in the context of constructions of femininity, gendered power relations and gender-based violence. We conclude with thoughts on the implications of this for reducing women's vulnerability to HIV.

3.2 Legacy of Apartheid, Patriarchy and Urbanisation: Historical Perspectives

The dominant feature of the socio-political landscape of South Africa in the last century was the growing institutionalisation of racial discrimination, which culminated in the policies of apartheid. So perhaps it is inevitable that a narrative that seeks to locate women and the modern-day epidemic of HIV within a broader social context should find roots within the major social influences of apartheid and urbanisation. These impacted very directly on the position of women in society. Pre-colonial South Africa was characterised by the subordination of women to men, but the convergence of this society with emerging capitalism and the legislative framework of institutionalised racial discrimination led to transformation in gender relations with massive accentuation of gender inequalities, most visible in new black urban areas where women were mostly totally dependent on men (Walker, 1990). These processes at a fundamental level influenced the position of sex in society: how it was viewed, its relationship to marriage and family life and women's sexual power.

Discourse and practices related to sex and sexuality in southern Africa are characterised by an interplay of two, very contrasting, sets of ideas. One views sex through a lens of missionary prudery, where it is seen as requiring control and repression (Epprecht, 2004). A contrasting set of ideas, rooted in southern African cultural traditions, is characterised by a degree of openness and frankness about sex. Sexualised games played by children and ribaldry between adults and children have been a long-standing feature of normal childhood in many parts of the country. Authors, writing about quite different historical moments and contexts, have described 'sex play', which sometimes includes penetration, as very common among girls and boys from a young age (about 6 or 7 until early teenage years) (Longmore, 1959; Mager, 1999; Ntlabati et al., 2001). Indeed, sexualised play between adults and children has been described as an established feature of rural black South African childhood (Jewkes et al., 2005). Historically, dating and sex have been seen as key aspects of African teenage socialisation and have been accommodated socially within youth peer group activities and structurally within houses that were available for them (Mager, 1999). There was a prohibition, however, on full penetrative sex, which was driven by a need to prevent pregnancy. This was historically regulated by peers and those found practicing it were punished by them (Mager, 1999; Mayer and Mayer, 1970). The growth of urbanisation in the second half of the twentieth century, and spread of Christianity, however, brought with it both restrictions on the space available for open discussion of sex between generations and sexes, and a rejection of limited sex, which was seen as old fashioned (Mayer, 1961). Thus, in a somewhat contradictory way, sexual openness which had previously provided the opportunity to regulate sexual activity of young people was constrained, at the same time that forces of modernity were pushing young people towards patterns of sexual activity that were much more risky for them in terms of both pregnancy and sexually transmitted infections.

Historically, full intercourse was intended to be confined to marriage so as to prevent pre-marital pregnancy. Marriage after loss of virginity resulted in the bride wealth (*lobola*) being reduced in value, but historically there has been no expectation that sex should be confined to marriage or that after marriage men should stick to one partner. The last 50 years, however, have seen pre-marital pregnancy become the norm for Africans, and half of women become pregnant before their 21st birthday (Department of Health, 2007). The present-day median age at marriage is 28.5 years for women (Department of Health, 2007), but many women never marry or are only intermittently partnered in their lives. A total of 42.4% of households in South Africa are female headed, which reflects the high proportion of adult women who at any stage are living, very often with their children, without cohabiting men (Department of Health, 2007).

The late age at marriage and high prevalence of children being raised without fathers are both part of the legacy of apartheid (Wilson, 2006). Throughout the twentieth century, migrant labour was a key foundation upon which the wealth of the apartheid state was created. Legislation regulated residence in urban areas through the influx control (pass) laws, and these prevented rural wives and families living with men in 'white' areas without work or permits. Fathers became increasingly absent figures from home, and thus played ever-diminishing roles in the lives of their children. Indeed, many children were raised by grandparents and other relatives in rural areas, as low wages coupled with demands of women, and often new families in urban areas, meant that remittances home were infrequent or ceased, and many mothers themselves went to seek employment in urban areas (Delius and Glaser, 2002). Unmarried men found that low wages meant they had to work longer to raise bride wealth, and historians argue that from the 1950s marriage became increasingly unaffordable for an average working-class family and increasingly cohabitation and child-rearing in other family contexts were socially tolerated (Delius and Glaser, 2002; Hunter, 2006). A further consequence of migration for women was the tacit recognition that both partners would need to satisfy their sexual needs outside of a main relationship during periods of separation, which promoted practices of having multiple concurrent partners (discussed in Chapter 2). The extent to which women, as well as men, took advantage of this can be seen in the finding of research that among sero-discordant migrant mine workers from Hlabisa, in KwaZulu Natal, one-third of the infections over the period of observation were found to occur in the wives of the migrant workers (Lurie et al., 2003).

In the cities, life was tough. Work was scarce, poorly paid and often dangerous, and workers faced violence and humiliation at work, in daily encounters with apartheid laws and the enforcing police. In this context, many of the migrant men from rural areas, together with the increasingly established urban population, adopted more exaggerated constructions of masculinity, predicted on the control of women, conspicuous displays of strength, the use of violence and risk taking. Such ideas of masculinity were forged in the harsh environment of mine hostels, urban gangs and prisons (Delius and Glaser, 2002). Whilst there were at any one time competing constructions of masculinity, and extremes were seen in the harshest conditions among men in gangs and prison, the core elements of power and control of women, a willingness to use of violence, and elements of sexual and other risk taking were fairly ubiquitous (Morrell, 2001).

Whilst the impact of apartheid on families forced some women into patterns of living that entailed considerable separation from men or male partners, poverty drove other African women into relationships of dependence. During the apartheid years, there were numerous barriers to black women joining the labour market, not least Bantu education[1] and restrictions on access to tertiary-level study. Just after the

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[1] Under apartheid, schools were racially segregated and differentially resourced. Africans were deliberately under-educated. The ethos underlying black African education was explained by Dr. HF Verwoerd, Minister of Native Affairs, Senate in 1957, when he said "There is no place for [the Bantu] in the European community above the level of certain forms of labour. . .Until now

advent of democracy, in 1995, 39% of workers were women (Statistics SA 1996), a statistic that changed little over the next decade, and generally women were also less well paid (Casale and Posel, 2005). This economic reality, coupled with the frequent absence of children's fathers, has placed many women in an economically vulnerable situation, which could ultimately be made tolerable through attachments to available men (Hunter, 2002). Thus, poverty has driven many women into relationships of financial dependence, in which they have very little power and are open to exploitation and abuse, whilst at the same time having very limited ability to exert the ultimate sanction of leaving.

3.3 Women, Femininities and Sexuality

The emerging body of literature on sexuality in South Africa, a product of research over the last 15 years, has overwhelmingly tended to discuss gender in terms of violent and controlling masculinities and passive, victimised femininities. Indeed, in the health literature, women's sexuality is predominantly discussed in terms of what women do (or what men do to women) and much less attention is given to the broader web of power, agency and meaning within which women's sexual actions and experiences are embedded. Whilst there has been a very appropriate recent increase in awareness of the impact of gender inequalities on women's health, women's sexuality cannot be properly understood without reflection on alternative narratives of female agency and power, albeit constrained by the context of overwhelming male power, that have struggled to emerge, but form an important part of the landscape of sexuality in South Africa. Understanding these is also crucial for understanding women's risk of HIV.

For teenage girls and older women, boyfriends are a means through which esteem is evaluated, and provide an irrefutable testament of beauty and desirability, which are generally seen as positioned centrally within dominant ideals of femininity. Coercion notwithstanding, both teenage girls and boys are generally active agents in their sexual relationships (O'Sullivan et al., 2006), and research on teenage sexuality shows that by the age of 17, half of all teenagers are sexually active (Manzini, 2001). Relationships are also mechanisms through which teenage girls come to experiment with and explore their power as women (Nduna and Jama, 2000). In a context where most African teenage girls grow up with very limited access to material resources, yet are constantly bombarded with messages that promote conspicuous consumption, beauty and desirability are deployed to leverage resources through their relationships, whether these be access to opportunities to party and have fun, or material goods such as a cell phone, airtime, cosmetics or, most often, cash (Dunkle et al., 2004a). These may then be deployed in competitions for status where women seek to gain the respect and admiration of other women.

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he has been subjected to a school system which drew him away from his own community and misled him by showing him the green pastures of European society in which he was not allowed to graze."

There is a growing literature on ‘sugar daddies’ and transactional sex, which differentiates relationships where there is a strong expectation of material gain from activities of prostitution, where there is an agreed fee (Hunter, 2002). In South Africa where the norm is of gift giving by men to women who are romantic partners, and to some extent vice versa, there can be difficulties distinguishing predominantly transactional sexual relationships from those established for reasons of romance and desire. Affirmative motivations for relationships are generally found on a spectrum between love and pure transaction that spans feelings of affection, affirmation, reflected status, possibility of future financial security and obligation. Whilst researchers often define transactional relationships as ones that would not exist if it were not for the material exchange, they may nonetheless be driven by several of these motivations at one time, and these may shift (Dunkle et al., 2004a). A sense of the commonness with which African women have transactional sexual relationships was given by the finding that 21% of women in interviews with a Soweto antenatal population disclosed having had transactional sex with a non-primary partner (Dunkle et al., 2004a). Research with impoverished rural men shows that they not infrequently have transactional relationships based on their receipt of gifts from women too (Dunkle et al., 2007).

Whilst women may engage in these relationships in an active process of securing material benefits and exerting power over their lives in contexts of poverty (Hunter, 2002), the realities of the power dynamics are such that they have severely limited capacity for influencing the terms on which sex takes place once the relationship is established (Dunkle et al., 2007). Economic dependency that is definitionally entailed in transactional relationships provides one set of constraints on women’s power, but still others stem from the nature of the men who engage in them. Given high levels of youth unemployment, men who are positioned to have transactional sexual relationships are usually older and more powerful than their women partners, or otherwise engaged in crime and violence. South African society is structured by dominant age and gender hierarchies, which doubly disadvantage women in age-disparate relationships. Transactional sex has been shown in men to be associated with a range of other risky sexual behaviours, which increase the likelihood of the men who engage in it being infected with HIV (Dunkle et al., 2007), so it is not surprising that women who have had transactional sex are more likely to have HIV than other women (Dunkle et al., 2004b).

Relationships with older men also very commonly co-exist, on the woman’s part with more equitable relationships with peers and on the man’s part often with a wife or main partner, and so feed into complex sexual networks through these multiple points of concurrency. This enhances the likelihood of spread of HIV if it is present in the sexual network (Epstein, 2007). Partner concurrency is common for men and women. Whilst endeavouring to have a main partner, who is publicly known as their boyfriend, women may also have secret partners (termed *khwapheni* in Xhosa *or nyatsi* in Sotho) with whom they illicitly meet for sex, sometimes over many years (Selikow et al., 2002). This is very common when men and women have had a child together. They may continue to have this sort of relationship long after they ceased to be each other’s main partner (if indeed they ever were), particularly if some form of financial support is given (Dunkle et al., 2004a). There is often a transactional element to relationships with *khwapheni*, if not always, but the element of concurrency is always present on the part of one or both partners. For women who are unhappily married, or have boyfriends who are violent, or otherwise do not meet their emotional needs, *khwapheni* may provide the source of love and affirmation they need in their lives. Counting sexual partners of South African women in surveys is often inaccurate as these relationships are often not reported unless specially asked about; the same applies to once-off sexual encounters. Qualitative research, which followed methodologies where women are befriended and interviewed over long periods of time, has shown us that *khwapheni* and once-off relationships are much more common than surveys usually report. Amongst pregnant women in Soweto, 40% reported having had a *khwapheni* in the last year (Dunkle et al., 2004a).

The complex patterns of sexual partnerships reflect the very great importance attached to them in women's lives. Having a male partner is a central feature of South African femininity and seen as essential for validating self-esteem and peer-group status. Having more than one partner is often referred to as 'walking on two legs' (Jama and Jewkes, 2002), with the implication being that this is a stronger position as it reduces the chances of being without a partner. Having a main partner is particularly important as it positions women to enjoy the economic and social security of cohabitation, and possibly marriage. There is movement between the partner categories, and research shows that women who are *khwapheni* may be promoted to main partners, and so there is considerable competition between partners. This may occasionally break into the open in the form of fights, but more commonly, competition is covert, and may take the form of trying to prove that sex is better with them. In this context, insisting on condom use is a strategy that few women would risk. This partly explains the well-documented resistance of women, as well as men, to condom use (Wood, 2003).

Ethnographic researchers, such as Janet Wojcicki and Cathy Campbell, have described the lives of women engaged in sex work in mining areas and central Johannesburg as well as transactional sex in small towns (Campbell, 2000; Wojcicki, 2002; Wojcicki and Malala, 2001). These accounts, on the one hand, reflect the desperate vulnerability of many South African women with their childhoods of abuse and neglect, and their moves from these into contexts of survival through selling sex. On the other hand, these accounts also powerfully reflect the way in which, in a context of severe hardship and very limited options, selling sex may be a decision women make and an option for a lifestyle with features that are less awful than a range of possible alternatives (Campbell, 2000). Whilst describing selling sex for survival, these accounts are also infused with images of female solidarity and the enjoyment of time spent drinking and hanging out with women friends. Although there are powerful images among South African women of female chastity, obedience and abstinence from alcohol, which are ideals of femininity that are heavily infused with Christian morality, these compete with more traditional models of femininity which accord women more social, sexual and economic freedom (Epprecht, 1993; Gaitskell, 1982; Marks, 2002). Indeed norms of alcohol consumption among women who drink are quite high, and drinking and socialising often provide a context in which risky sexual encounters occur, and often casual sex, motivated by both reciprocity for drinks bought and sexual desire (Crush and Ambler, 1992).

Whilst there is considerable heterogeneity among South African heterosexual femininities and their construction in their relation to male power (as there is among masculinities, see Chapter 4), they are substantially positioned on a spectrum ranging from marked subordination to femininities that entail areas of resistance to male control of the forms described above. The epidemiological evidence does not indicate that the common ways in which women assert sexual agency that have been discussed here translate into agency that is useful in protection from HIV. Indeed, having multiple partners, transactional sex or older male partners and drinking alcohol are generally found to be highly risky (Dunkle et al., 2004b, Jewkes et al., 2006a, Pettifor et al., 2005). It seems likely that the reason for this is that these acts of sexual agency do not in themselves challenge the dominant structure of gendered power relations. Notable is how infrequent, at any level of South African society, it is for femininities to be constructed in relation to male power in a way that is largely premised on gender equity and an absence of control of either partner. This is explained by the absolutely central role of control of women in constructions of masculinity (Delius and Glaser, 2002; Morrell, 2001; Wood and Jewkes, 2001).

3.4 Men and Control: Gender Inequities and Gender-Based Violence

Delius and Glaser (2002), in their work on historical perspectives on sexuality, argue that the emphasis on masculinity in power and control over women has been part of processes of socialisation of men throughout the period for which historical evidence exists. This intensified and became increasingly violent in the second half of the twentieth century. They argue that sexual violence directed against women who were not partners became particularly prominent in urban areas from the 1930s with the growth of gang culture, and there were multiple accounts of gangsters perceiving that women who lived in their territory were their sexual possessions (Delius and Glaser, 2002). The accounts of ethnographers in rural areas point to very similar assumptions of sexual entitlement among rural men (Delius and Glaser, 2002; Schapera, 1933).

The growing body of research on rape in South Africa suggests that the core elements of these ideas remain highly prevalent today. South Africa has the highest rate of rape reported to the police of any country in Interpol (Interpol, 1996). Research with men has found that a very high proportion disclose having raped. In one study of young men from the rural Eastern Cape, 21% disclosed rape of a girlfriend or another woman, and the most commonly reported act was of gang rape (Jewkes et al., 2006b). Qualitative researchers have observed that young women often had limited opportunities for determining the timing and circumstances of sex and particularly first sexual encounters are quite commonly forced or pressurised (Jewkes et al., 2001; Wood et al., 1998). Within sexual relationships, women generally perceive that they have very limited scope for declining requests for sex. Sexual coercion has been reported as an experience of about one in four pregnant women in Soweto (Dunkle et al., 2004b), and by approximately two-thirds of sexually active teenagers in research in Cape Town (Jewkes et al., 2001).

Men often use physical violence to secure sexual submission and assert control over women. In dating and marital relationships, very high levels of physical violence have been reported by women in studies, often disclosed by 40–50% of women (Dunkle et al., 2004b; Jewkes et al., 2001, 2006a). Men also engage in a range of strategies to assert a position of dominance and control within relationships, which may not entail the use of physical violence or not require it to be used very often. These include threats, verbal abuse, asserting a right to be told where she is at any time, controlling access to friends and family, demanding attention or sex when requested and expecting her to be at home whenever he visits. Controlling behaviours often also include accusations of infidelity and monitoring of all contact with other men, expectations of not being challenged on one's own infidelity and refusing to use condoms.

One of the most commonly mentioned barriers to condom use by couples is that they are not needed because they trust each other, and research has shown that this is commonly asserted by partners who are well aware that their relationship is or has recently been non-monogamous. Whilst, on the one hand, discourses of trust appear to reflect an aspiration of how relationships should be, research suggests that men who argue that condoms are not needed because of trust have been shown to be generally much more controlling of their partners (Shai et al., in press). Trust appears to be deployed as a manipulative strategy by which to further entrench the sexual control of women (Shai et al., in press). In similar ways, research has found that teenage women often report their partners forbidding them from using contraception and begging them to get pregnant to 'prove love' (Wood and Jewkes, 2006), despite the norm being that men take little financial or other responsibility for children fathered in such circumstances. Indeed, seeking a teenage pregnancy on a man's part appears as one of the group of related practices that are indicative of a very gender-hierarchical ideal of masculinity, including having multiple partners, with payment for sex, controlling the behaviour towards female partners, with violence if necessary, and alcohol abuse (Hunter, 2005).

There is a growing body of epidemiological evidence that violent and controlling behaviours of men are associated with HIV risk in women. Research by Dunkle et al. (2004b) with women who were in antenatal care in Soweto aged 16–44 years showed the likelihood of having HIV to be elevated in women who had relationships characterised by greater gender power inequity, and who experienced physical or sexual intimate partner violence. They were also more likely to have HIV if they had used drugs, drank heavily, had more lifetime partners and had engaged in transactional sex. An analysis undertaken on a data set generated from interviews with much younger women (mean age 19, range 15–26 years) found that having more partners, more frequent sex or an older or more educated main partner was associated with greater HIV risk, and intimate partner violence was more commonly experienced by women with each of these risk factors (Jewkes et al., 2006a).

Violent and controlling practices impact on women's risk of HIV in multiple ways. On the one hand, women who are raped are vulnerable to acquiring HIV in the course of the rape. Whilst this is of huge concern to women, and compounds the violation of the rape, desk-based modelling suggests that it probably does not result in many HIV infections each year (probably less than 0.05% of new infections) (Christofides et al., 2006). More important seems to be the general climate of powerlessness that is engendered by violent and controlling male behaviour. Indeed, there is considerable evidence that women who experience this have more frequent sex, and thus more opportunities for infection, and are less likely to use condoms (Dunkle et al., 2004b; Jewkes et al., 2006a; Pettifor et al., 2005; Shai et al., in press). Experience of rape, including abuse in childhood, and physical violence has a well-documented, long-term impact on substance abuse and sexual risk taking (Dunkle et al., 2004c; Jewkes et al., 2006a) compounded by the increased risk of re-victimisation associated with certain kinds of sexual risk taking (Dunkle et al., 2004c; Wojcicki, 2002). Post-traumatic stress disorder (PTSD) has been hypothesised as providing part of the explanation for this, as women reach for alcohol and other substances as a way of coping with the debilitating, and if untreated, long-standing symptoms (Wang and Rowley, 2008).

Men who are violent and controlling are inherently more risky for women because they are more likely to be infected with STIs, including HIV. Recent research from a random sample of men in the community (aged 18–49 years) found perpetration of intimate partner violence significantly associated with HIV (Jewkes et al., 2008a). In understanding the relationship between violent and controlling behaviours of male partners and women's risk of HIV, it is critical to see these as part of a construction of masculinity, which also entails other risky sexual practices, including having multiple partners, engaging in transactional sex, coercing non-partners into sex, heavy drinking and drug use (discussed further in Chapter 4) (Dunkle et al., 2006, 2007; Jewkes et al., 2006b). Indeed, it was particularly interesting that the HIV-prevention behavioural intervention *Stepping Stones*, which sought to prevent HIV by building more gender equitable relationships, not only reduced men's sexual risk taking tangibly (as shown by a reduction in new herpes infections over 2 years follow-up in a randomised controlled trial) but also reduced perpetration of intimate partner violence, sustained to 2 years after the intervention, and impacted on alcohol consumption, drug use and transactional sex (Jewkes et al., 2008b).

3.5 Prevention of HIV in Women, Challenges and Future Directions

African women in South Africa are in the forefront of the HIV epidemic, carrying the largest burden of illness, caring and other social responses. Preventing the continued spread of the virus amongst women is a very high priority. In recent years, there has been an overwhelming emphasis on the development of gender-sensitive technologies, with the hope that if successfully designed and deployed these will enable women to be empowered to protect themselves from HIV. Yet analysis of the broader social context of sexuality and HIV risk in South Africa suggests that biomedical interventions, which can be used by women without male cooperation, are unlikely to make much difference because they will not address the underlying constructions of masculinities and femininities that make such interventions necessary in the first place. Similarly, it is quite unclear what contribution interventions, which have been shown to reduce HIV infections in men, such as male circumcision, will have on HIV prevalence among women in the longer term. Broader transformative programmes that link promoting gender equality, economic and social empowerment and preventing sexual risk taking are also needed.

The apartheid legacy of poverty, poor educational attainment, lack of opportunities and high youth unemployment critically shape women's perceptions of their lives, relationships and sexuality. These influences undoubtedly play an important role in explaining, for example, the very marked racial differences in HIV prevalence that are found in South Africa (Shisana et al., 2005). Structural change that strengthens economic opportunities for women and men is of vital importance. The IMAGE study evaluated an intervention, which included microfinance, a 10-hour attitude- and behaviour-change intervention focusing on gender and HIV that was delivered to groups of women at their two-weekly loan meetings and community action around violence against women (e.g. protest marches). The randomised controlled trial showed that programme participants in the intervention arm experienced 55% less intimate partner violence, although they were not shown to change their condom usage. This study is an important example of the potential impact of structural interventions on women's lives and HIV risks (Pronyk et al., 2006).

Analysis of the broader context of women's HIV risk suggests that transforming gender roles in a manner that increases gender equity and promotes health is vitally important. While the scale of change needed to fundamentally transform gender norms may seem overwhelming, there are signs of hope and promising strategies on the horizon. Research in South Africa shows that gender relations and the degree to which men and women negotiate aspects of sexual encounters can be made more equitable, have changed over the last decade and – importantly – can be changed by interventions (Jewkes et al., 2008b; Reid and Walker, 2005). The major contribution to sustainable, long-term HIV prevention could be made if it were possible to successfully promote such changes. Changing men is clearly critical for HIV prevention in women. Work with women is essential to ensure that as ideas about gender change women support these changes and are empowered to reduce their HIV risk.

Acknowledgments Many thanks to Robert Morrell for comments on the manuscript.

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Chapter 4
Masculinity and HIV/AIDS

Graham Lindegger and Michael Quayle

4.1 Introduction

In the early stages of the HIV/AIDS pandemic, it was primarily men who were infected with HIV, but that trend has now reversed (WHO, 2003). In many countries the infection rates for young women are five times higher than young men (RHO Archives, 2005), and young women are generally infected at an earlier age than young men (Walsh cited in RHO Archives, 2005) (see Jewkes, Chapter 3 of this volume). In South Africa, over 50% of new infections of HIV occur among the 15–24 years age group, with black women affected significantly more than other demographically defined groups (Health24, 2006). Further, more women are dying of HIV/AIDS than men (Matlin and Spence cited in RHO Archives, 2005). In South Africa, the mortality rate for young women in the 25–30 years age group has increased 350% over the past 10 years, almost exclusively as a result of AIDS-related deaths.

There is a growing realization that it is not only biological differences in susceptibility that result in these gendered differences in HIV transmission, incidence and prevalence (RHO, 2005), but gender inequalities of all kinds (see Jewkes Chapter 3 of this volume for further details). It is increasingly apparent that the social construction of masculinity plays a major role in putting women (and men) at risk of HIV infection and that gender-related interventions, including and especially among men, need to be an integral part of HIV prevention campaigns. This perspective also suggests that effective intervention requires far more than information transmission and technological solutions (such as increased use of condoms) to modify male behaviour. Rather, we suggest, it is the construction of masculinity and the identity of men as gendered persons which needs to be challenged if there is to be any effective and sustained intervention in the HIV pandemic.

4.2 Introducing Masculinity

The dominant theoretical framework for understanding gender in general, and masculinity in particular, is social constructionism. This theoretical perspective

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_4,

proposes that, although integrated with biological sex, gender is primarily a socially constructed phenomenon, through which men are broadly privileged over women in most domains (Connell, 2008). Connell, one of the most influential theorists in the field of masculinity research, argues that male privilege and social power is produced and perpetuated through the construction of hegemonic masculinity, which refers to the production and maintenance of a nexus of ideas, institutions and behaviours that generate, normalize and, in fact, demand male dominance. As such, the power of hegemonic masculinity is deeply embedded in forms of social activity, giving it the appearance of inevitability and ensuring that it is 'naturally' produced and reproduced in ordinary social interaction. In this sense, hegemonic masculinity is 'an ideal or set of prescriptive social norms, symbolically represented, (and) a crucial part of the texture of many routine, mundane, social and disciplinary activities' of men (Wetherell and Edley, 1998, p. 336).

While the social construction of gender undoubtedly produces a 'patriarchal dividend' that privileges men over women in most respects, Connell (2008) suggests that men benefit from this gendered set of privileges in very unequal ways, with some men benefiting greatly and others not at all. Connell argues that there are multiple masculinities, each of them existing at the intersection of race, social class and history. These versions are arranged hierarchically, and there is considerable pressure for young men to avoid subordination by aligning themselves with hegemonic masculinity – which results in the perpetuation and maintenance of masculine hegemony (Edley and Wetherell, 1997). However, Wetherell and Edley (1998) argue that as well as being complicit with, subject to or resistant to hegemonic versions of masculinity, boys/men might adopt multiple parallel positions in different contexts and for different audiences.

The pressures on men to attempt to live up to the demands of hegemonic forms of masculinity are ubiquitous and powerful. Seidler (2006) argues that, ironically, the pressure to enact the physical and emotional toughness required by hegemonic masculinities results in fundamentally vulnerable positions for individual men and, simultaneously, obstructing acknowledgement of emotional vulnerability. This, according to Seidler, leads young men to 'an instrumental [functional] relationship with their bodies' and to 'deflect these emotions into anger and violence, which affirms their male identities' (p. 117). The emotional vulnerability of young men and the concurrent emphasis on emotional control also makes it difficult for young men to deal with intimacy, so that they tend to construct 'sex as performance' (Seidler, 2006, p. 120) rather than as a relationship.

4.2.1 Masculinity, Risk Behaviour and HIV/AIDS

Many elements of hegemonic masculinity (Connell, 2008) are closely related to the typical high-risk behaviours associated with HIV transmission. These behaviours include multiple sexual partners, unprotected sex, use of alcohol before sex and, in some cases, sexual violence. This association is so strong that, in some places, being

HIV-positive itself has become a badge of manliness (e.g. Brown et al., 2005). Boys and men recognize the importance of these behaviours as markers of successful masculinity, and therefore feel considerable pressure to perform them, and to be seen to be performing them. Ironically, girls and women play a critical role in the appraisal and maintenance of these hegemonic behaviours, despite the fact that they are often subordinated by them (e.g. Talbot and Quayle, 2008). Although there are variations in specific forms of hegemonic masculinity, there is remarkable empirical consistency in constructions of hegemonic masculinity related to high-risk behaviour for HIV transmission across geographical, cultural and linguistic divides in Africa and elsewhere.

First, and underpinning many other elements, is the importance of risk-taking to the construction of hegemonic masculinity (Barker and Ricardo, 2005; Pattman, 2005; Tshabalala cited in Peacock, 2005). Since taking risks is a marker of successful masculinity, increased knowledge of risk has not resulted in decreased risky sexual behaviour, as it has imbued it with more symbolic power as an enactment of hegemonic masculinity.

Second is the centrality of an essentialized and uncontrollable sex drive. One expression of this is that hegemonic masculinity is often constructed around and through sexual conquest (Barker and Ricardo, 2005; Simpson, 2008; WHO, 2003) and the desirability and number of sexual partners may be an important indicator of masculinity. This is well demonstrated in South African *isoka* or *ingagara* identities, which refer (with admiration) to men who are highly successful in demonstrating their masculine potency with multiple sexual partners (Selikow et al., 2002; Walker, 2005). (See further details in Chapter 2.) Men who fail in this regard are othered through labels such as 'cheeseheads' or *isithipa* (ibid). However, if Seidler (2006) is correct, then these sexual enactments of masculinity are more likely to be instrumental or performative activities than relational engagements.

Third, hegemonic masculinity is defined in terms of compulsory heterosexuality in spite of considerable evidence that even heterosexual men may engage in sex with other men. Such practices are usually highly stigmatized, for example, being considered 'un-African' (Barker and Ricardo, 2005; Varga, 2001), making them very difficult for men to acknowledge and to talk about in ways that reduce their own risk and the risk of their sexual partners (Potgieter, 2006; WHO, 2003).

Fourth, hegemonic masculinity requires male dominance and the appearance of physical and emotional toughness, strength and stoicism (Erasmus, 1998), as well as independence and self-sufficiency. These demands make it difficult for men to acknowledge vulnerability. In medical terms, this may translate into a failure to access medical and other forms of help (Peacock et al., 2006). In personal relationships 'love becomes problematic, as emotions [with the exception of anger] are a sign of weakness' (Seidler, 2006, p. 70). Therefore men come to 'relate to their [own] bodies as machines they need to control' (Seidler, 2006, p. 100) and to the bodies of others as objects in relation to their own masculinity: such as the demonstration of sex-drive by penetrating them; or the demonstration of strength by dominating them. Thus, even the most intimate of interactions, including sexuality, become performative and instrumental rather than relational.

Fifth is the pressure for men to be materially successful and to be able to 'provide for' girlfriends, wives and families (Khunou, 2008; Luyt and Foster, 2001; Waetjen and Mare, 1999). The increasing equality of women in the labour market and high levels of unemployment in the region undermines the ability of many men to adequately satisfy this requirement of hegemonic masculinity. While this expectation provides men with social powers, it may also be a source of intense vulnerability because it, firstly, subordinates poorer men to richer men (cf. Pattman, 2002) and (most often) younger men to older men (Barker and Ricardo, 2005). Secondly, it produces anxieties about obtaining enough money to access women and may result in worries that women may be 'loving' them only for material benefits (Pattman, 2005). However, even where women may be financially superior, it seems that hegemonic masculinity still demands – and allows – men to control financial affairs (Silberschmidt, 2004; Smuts, 2006).

Sixth, since masculinity is constructed around the subjugation of women, the reproduction of hegemonic masculinity requires men to control sexual decisions (Horizons Report, 2004) including if, when and how sex takes place and whether or not condoms are used (Bujra and Bayllies, 2001; Foreman, 1999; Noar and Morokoff, 2002, cited in Peacock, 2005; Scalway, 2001; Shefer and Ruiters, 1998; Simpson, 2008). (See Jewkes Chapter 3 of this volume for further details.) It has been suggested that this is especially the case for married men, as social constructions of marriage – including cultural practices such as *ilobola* (Hunter, 2004) – bestow on men the right to be in control of all aspects of their wife/wives, including and especially their sexuality (WHO, 2003) (see Leclerc-Mdlala et al. Chapter 2 for further details). Men may have a similar sense of entitlement whenever relationships involve material transfer from men to women (Campbell et al., 1998; Selikow et al., 2002). Then, when masculine power intersects with entrenched beliefs, such as the idea that condoms reduce men's sexual potency (Doyal, 2002; Simpson, 2008; WHO, 2003), or that 'regular "flesh-to-flesh" sex is necessary for a man's good health in order to maintain balanced levels of blood/sperm within the body' (Campbell et al., 1998, p. 52), it becomes difficult for the behaviour to be resisted or negotiated. Many aspects of hegemonic masculinity which are associated with high risks of HIV infection are related to this imperative for men to dominate women (see Jewkes, Chapter 3 of this volume), ranging from apparently benign, patriarchal decisions such as whether women should undergo HIV testing (WHO, 2003) to male-on-female violence and rape.

There has been considerable empirical evidence for the association between these behaviours associated with hegemonic masculinity and HIV risk. For example, there are reports that the highest incidence of HIV-related health-risk behaviour are among young men aged 15–24 years (Panos/UNAIDS, 2001; Selikow et al., 2002), and that these behaviours include having multiple sexual partners, treating women as sex objects and using sexual conquests as a means of proving masculinity (Panos/UNAIDS, 2001). Endorsement of hegemonic masculinity has been shown to be empirically related to negative attitudes to condom use and decreased condom use (Noar and Morokoff, 2002, in Peacock, 2005). The Horizon study (2004) in Brazil revealed high levels of 'detrimental gender norms', including male dominance of women, lack of emotional expression, high levels of risk taking and the norms that men should have multiple sexual partners and maintain control over female partners. The findings showed a definite association between support for traditional gender norms and HIV risk, such as correlation with STI symptoms. Similarly, the Horizons study in Tanzania (Horizons Report, 2004) found that HIV-positive women reported significantly higher level of partner violence and that the most frequently reported triggers for violence were suspicions of infidelity by men or accusations of infidelity by women.

What evidence has there been for these patterns of hegemonic behaviours in contemporary African and South African contexts, and for their association with HIV risk? *First*, many recent studies (Bhana, 2005; Brown et al., 2005; Bujra, 2000; Burnard, 2008; Davies and Eagle, 2007; Hunter, 2004; Kent, 2004; Khunou, 2008; Luyt and Foster, 2001; Moletsane, 2004; Mork-Chadwick, 2007; Mtutu, 2005; Naidoo et al., 2004; Pattman, 2002; Pattman, 2005; Pattman and Bhana, 2006; Selikow et al., 2002; Sikweyiya et al., 2007; Silberschmidt, 2004; Smuts, 2006; Thorpe, 2002) have found that masculinity in the region is strongly characteristic of hegemonic masculinity, including elements such as: risk-taking and audacity with respect to rules; male dominance that often justifies coercion; a demand for toughness and strength that may be expressed violently; stoicism and aversion to signs or expressions of weakness or vulnerability; exclusively heterosexual and frequent sex with multiple partners; and pressure to achieve material success and demonstrate it by the display of high-status items such as fashion, cellphones and cars. These norms are unlikely to be experienced as identity *choices*, but as essentialized and inviolable biological or cultural imperatives (Thorpe, 2005). Even blind adolescent boys (Joseph and Lindegger, 2007) strongly aspired for exactly the same hegemonic masculine norms as their peers despite the enormous challenges they faced in attempting to attain them.

Second, there has been much evidence in Africa of peer norms, which involve the 'proving' of masculinity through early sexual conquests and having multiple sexual partners (Buve et al., 2002). Reference has already been made to *isoka* and *ingagara* masculinity in South Africa. Lindegger and Maxwell (2005; 2007) found that late adolescent boys experience extreme peer-based pressure to demonstrate their masculinity through claims of multiple sexual partners, and that inability to measure up to these expectations produces enormous anxiety. Exposure of such failures may result in immensely shameful experiences (Zakwe, 2005), which play a key role in policing behaviours associated with hegemonic masculinity.

Third, male denial of vulnerability and the construction of masculinity around power, strength and control may be key factors that contribute to health risk and gender-based violence in South Africa (see Jewkes, Chapter 3 of this volume). Related risk behaviours include substance abuse and risky sexual practices (Blackbeard, 2008; Leclerc-Madlala et al., Chapter 2 of this volume), such as resistance to condom use because of issues of dominance, control and fidelity (MacPhail, 1998). These features of masculinity also contribute to limiting male help-seeking behaviour, which is an obstacle to creating norms of health-protective behaviour amongst men (Hoosen and Collins, 2004). Additionally, men are less likely to undergo HIV testing in the early stages of infection and tend to seek anti-retroviral treatment later than women (Magongo et al., 2002; Hudspeth et al., 2004, cited in Peacock et al., 2006; Pinnock, 2007). These features are also associated with high rates of violence against women and exploitative or coercive sexual practices (MacPhail, 1998; Strebel and Lindegger, 1998). Recent studies in South Africa have revealed that between 15 and 20% of men acknowledge that they have used force to get women to have sex with them (Jewkes et al., 2006; Kalichman et al., 2007; Sikweyiya et al., 2007) (further details are provided in Jewkes, Chapter 3 of this volume). MacPhail (1998) argues that social norms and practices that endorse gender inequality and coercive sex as expressions of love place South Africans at particular risk of HIV transmission.

Walker (2005) claims that current gender violence in South Africa, ironically, is related to the intensification of traditional constructions of masculinity in response to the perceived threat of human-rights-based gender norms. (See Jewkes, Chapter 3 of this volume, for other threats to traditional norms of masculinity.) There are also indications that changes in cultural structures governing courtship, marriage and intimacy have resulted in a shift in power towards men in that idealized notions of traditional masculinity are now operating without their traditional complementary restraints (See Leclerc-Madlala et al., Chapter 2 of this volume). For example, although historically the *isoka* – the young Casanova – was admired by men and women alike, unplanned pregnancies were punished by requiring the young man's family to pay a fine to the family of the young woman. This practice required young men to share responsibility for contraception and pregnancy (cf. Hunter, 2005).

There are two features of these HIV-related features of hegemonic masculinity that we would like to explore further. The first lies in the pressure to conform to hegemonic patterns in the midst of the contest of masculinity that all boys and men face and is well explained by the work of Connell (e.g. 1995, 2008). To date, most of the work around masculinity and HIV risk, as described above, has focussed on these hegemonic patterns of behaviour. To modify the behaviours associated with masculinity in this paradigm, gender issues must become part of the mainstream of HIV intervention, which would require challenging beliefs and assumptions about masculinity based on biology and culture; the psychological empowerment of women to resist control by men and to play an active role in sexual decision making; and the economic empowerment of women to reduce their dependency on men. Like the Horizons project, such interventions would ideally also involve creating spaces for boys and men to critically reflect on the social construction of gender and consider alternate patterns of masculinity.

However, we argue that problematizing negative features of masculinity is not enough – we must also explore the private vulnerabilities of boys and men. As argued by Hunter (2005, p. 156) 'Gender is more than simply the one dimensional expression of male power but, as historical analysis of the *isoka* masculinity demonstrates, it is embodied in male vulnerabilities and weaknesses.' These vulnerabilities have been exacerbated since 1994 in what Reid and Walker (2005a) describe as 'the troubled, unsettled world of masculinity and sexuality in a country in transition' (p. 2).

It is striking that most studies referred to above are silent about the vulnerable subjectivity of boys and men, and about the issues faced by men in dealing with the powerful and unattainable demands of these constructions of masculinity. In the process, men and masculinity are only seen as part of the problem and not an integral part of the solution (Seidler, 2006) to HIV/AIDS. Many might agree with Connell that, given the power and privileges accruing to men from their enactments of hegemonic masculinity, their precious subjectivity is an irrelevant consideration. However, we have already argued that many of the negative outcomes of hegemonic masculinity are due to its demands that engagements with real people are stripped to their functional or instrumental value, for example, by reducing sex to a performance and accomplishment. Most research and intervention in masculinity, sexuality and HIV has emphasized functional aspects of sexuality such as condom use while challenging sexuality as a means for boys and men to prove their masculinity through multiple sexual partners and the sexual conquest and control of women. This is understandable, since there must be a change in these high-risk sexual behaviours if there is to be any real influence on the HIV pandemic. However, by concentrating on the negative aspects of functional sexuality such as sexual conquest, or failure to use condoms, these projects and interventions may unintentionally reinforce the notion for men/boys that 'their bodies (are) machines that they need to control' (Seidler, 2006, p. 100). Even campaigns focussing on abstinence treat sex as an event (in this case to be avoided), thereby stripping-off the vulnerability and relational complexity of sexuality and reinforcing the instrumental construction of sex so central to South African masculinity. It is here that Seidler's work becomes especially helpful, because he suggests that the over-commitment to the structural aspects of gender relations (relying especially on the work of Connell) has tended to overshadow the personal struggles of individual boys and men, and especially struggles with personal emotion, sexuality and the capacity to relate.

4.3 Changes in Patterns of Masculinity

A range of socio-political and legal changes have played a major role in initiating changes in the gendered order of South African society since 1994, and have triggered 'a rethinking of masculinity which offers new ways of imagining masculinity and, for men, suggests new ways of being a man' (Morrell, 2001, p. xiv). While this especially refers to forms of African masculinity, this does not only refer to African men. Major legislative changes during the first 15 years of our democracy have played an important role in contesting the established and privileged position of men and masculinity and have opened the door to new forms of masculinity in South Africa. The new South African constitution embraced a liberal understanding of sexuality, incompatible with many traditional aspects of masculinity, such as the unacceptability of gay masculinity. Forms of masculinity that were patriarchal, violent and often authoritarian have increasingly been called into question in South Africa (Reid and Walker, 2005a). Sideris (2005) argues that a culture of revelation and 'confession' facilitated by the development of a free press has led to the large-scale exposure of abuse by men on women, especially rape. The intolerance of such abuse has been further reinforced by a growing human rights culture in South Africa. The increased importance of women in public space, and the growing economic independence of women, has probably also played a major role in unsettling many of the traditional assumptions and practices of masculinity.

However, the response to these changes is variable and ambivalent. For example, Sonke Gender Justice (2007) reports that a recent survey of men in Johannesburg found about equal numbers of men for and against government attempts to promote gender justice. Morrell (2002) argues that there have been three general responses. *First*, there are many who fought to preserve male privilege, such as the South African Association of Men (Lemon, 1995) and less organized but probably more powerful voices who fear that the erosion of male privilege is part of an onslaught against traditional culture (Ndlazi, 2004) and against men themselves, such as the respondent in Attwell's (2001) study who said that 'women have stolen men's place in society.' *Second*, some men have reacted to changing gender roles as an emerging 'crisis of masculinity' – a position that has been criticized by feminists as yet another attempt by men to foreground and privilege masculinity at the expense of women. *Third*, there have been those groups of men who have identified with the transformation of masculinity and fought for gender justice, and some examples of these will be discussed later in the chapter. We add that *fourth*, and the least visible in the masculinity and gender literature, there are many women who do not welcome all of the shifts that changing patterns of masculinity require of their own gender identities (Talbot and Quayle, 2008) or the encroachment by men on previously female domains such as maternity wards (Mullick et al., 2005).

While the factors outlined above are playing major roles in changing the gendered structure of society, we argue that the HIV pandemic has also begun to play a role in escalating or facilitating these changes by forcing acknowledgement of the importance of misogynistic masculinity in public and private life and facilitating public conversation about sex and sexual practice. Additionally, Hunter (2005, p. 151) argues that HIV/AIDS is challenging *isoka* masculinity in South Africa by 'transform[ing] some of the most virile and popular bodies into barely living skeletons, shunned by friends and neighbours. . . . previous 'players' are buried by their friends who were once envious of their ability to attract women.'

Our concern in this chapter is specifically with the link between gender and HIV/AIDS, or more specifically the constructions of masculinity and patterns of HIV risk. We are especially interested in whether there is evidence of changes in the construction of masculinity, and more specifically, whether new forms of masculinity, which are likely to be associated with reductions in HIV risk behaviour, are emerging either spontaneously or as a result of organized interventions.

The Sonke Gender Justice (2007) in the *South Africa Country Report* claim that there is evidence in South Africa of growing numbers of men taking a stand against gender-based violence, and challenging many of the customs endangering the health of women, and standing for greater gender equality. This report quotes the research by EngenderHealth and the *Men as Partners* NGO showing that the majority of men participating in their workshops supported gender-based rights and opposed control and abuse of their female partners. Walker (2005, p. 173) conducted a study of young men in Soweto, and she reports that ‘present in all these narratives was the interviewees desire to have an alternative experience of being a man – an experience different from their fathers, uncles or elder brothers. For these men, the costs of hegemonic masculinity – certainly of male violence – outweighed the benefits. Indeed, all explicitly rejected the use of violence.’ Such findings are hopeful signs of the transformation of masculinity, but she goes on to say that these young men did not find the process of change to be an easy one, as they were caught between ‘traditional masculinities’ and ‘being a modern man who is in control, respectable, rational and responsible’ (Mullick et al., 2005). This conflict between ‘traditional’ and ‘modern’ masculinities seems to be a common experience in South Africa and is echoed by a group of men who participated in a study with Sideris (2005) who were highly motivated to embrace and live out a more just and equitable form of masculinity, but reported feeling caught between these conflicting versions of masculinity. (See Leclerc-Madlala et al., Chapter 2 of this volume, for fuller discussion of culture and masculinity in Africa.)

Despite the evidence of a growing number of men engaging with issues around the construction of masculinity (critically or otherwise), there are a number of obstacles to further transformation. *First*, there are elements of the ‘transformed’ masculinity that are not much changed, such as ‘control’ and ‘responsibility’ in Walker’s (2005) study quoted above. Other examples of this type of sanitization can be found in the commitments that came out of the national mens’ *imbizo* held in 2002 that included ‘to respect and protect every woman as our own mother, wife, daughter, sister and friend’ and to ‘organize ourselves to be able to provide’ (Gobind, 2005). All of these ‘transformations’ are discursive wolves in sheep’s clothing that allow the most powerful aspects of hegemonic masculinity to persist in apparently progressive masculinities. Burnard (2008), in his study of young men in the Shosholoza soccer movement, found that their motivation to make changes to traditional hegemonic behaviours was primarily motivated by their interest in their own self-protection, rather than because of agreement with egalitarian gender-rights arguments. Similarly, Sikweyiya et al. (2007) found that Eastern Cape men opposed gender violence and rape because of the negative consequences (such as prosecution) for men.

Second, Thorpe (2002) notes the emergence of a brittle and thin ‘education responsive’ masculinity that may briefly emerge in formal settings such as school life-skills programmes and HIV interventions. This identity draws upon the language of human rights and knowledge of the ‘correct’ answers but does not engage with personal experience or extend outside of the educational context. If this identity is widely accessed by participants in gender research and interventions, then their masculinities in other contexts may be more profoundly patriarchal and misogynistic than we realise. *Thirdly*, in the discursive struggle with patriarchal (e.g. ‘traditional’) versions of masculinity, it may be that the human rights discourse is losing momentum, or at least failing to penetrate in meaningful ways beyond bounded contexts such as schools, universities (Mork-Chadwick, 2007) or workplaces. *Fourthly*, changes in idealized versions of ‘traditional’ masculinity, economic and cultural shifts, and genuine advances in gender rights may destabilize socio-cultural limits that have previously held those versions of masculinity in check. For example, as already mentioned, the erosion of traditional social institutions, along with advances such as increased access to female contraception, have allowed men to revise versions of ‘traditional’ masculinity to completely abdicate responsibility for pregnancies that historically they would have been held accountable for. This, in turn, has impacted on the actual practices as well as the symbolic meanings of courtship and sex (Hunter, 2004; van der Riet, 2008). On the other hand, some socio-cultural structures have failed to adapt to the rapidly changing social conditions. For example, the traditional practice of *ilobola* has not adapted to the extreme rates of unemployment in South Africa, thereby disqualifying a vast number of men from many of the positive features of traditional masculinity.

Although many people talk of ‘traditional’ and ‘modern’ masculinity as fixed constructs, it should be clear from this discussion that neither can be taken as fixed or static entities. Rather, they are simultaneously social resources that are exploited to produce or police particular instantiations of identity and, at the same time, sites of intense contestation within individual men and also within and between social groups. Individual men, then, can be seen as ‘entrepreneurs of identity’ (Reicher, 2004; Reicher et al., 2005) and, specifically, entrepreneurs of masculinity and need to have the skills to evaluate the identity resources available to them and to contest the attempts of others to police them into particular masculine norms. This has been hinted at by studies that have found that HIV interventions are more effective in changing behaviours if they involve a critical gender component encouraging reflection on the construction of masculinity (Hoosen and Collins, 2004; Strebel and Lindegger, 1998). Given the fluidity of these constructs, and their importance in producing individual and group identity, leaders in groups that are important to men and those with influence over media such as advertising, sports and entertainment also have a massive responsibility to reinvent both ‘traditional’ and ‘modern’ masculinities to incorporate gender equity and simultaneously respond to the challenge of HIV/AIDS.

4.4 Conclusion

As important and effective as many of the campaigns and interventions have been, levels of violence and coercion against women are still unacceptably high, and there is still much to improve, including: generating greater clarity on the goals of working with men (Sonke Gender Justice, 2007); more coordination between organizations working to change patterns of gender injustice, and its effects of HIV risk; more systematized efforts to involve boys in achieving gender equity from an early age (Sonke Gender Justice, 2007); more widespread penetration compared to the reach of the relatively small workshops and groups currently targeted by most interventions, including greater community involvement and follow-up and the use of other strategies such as advocacy for policy change or rights-based activism (Sonke Gender Justice, 2007). There is also ongoing need for the organization of sexual and reproductive health services, and HIV-related services such as Voluntary Counselling and Testing (VCT) or treatment of STIs in such a way that they are more accessible and attractive to men.

Changes in masculinity and patterns of gender equity in South Africa require much greater involvement with three broad intellectual projects. *Firstly*, activists, leaders (especially cultural, traditional and religious leaders), politicians, those with influence on media messages, celebrities and ordinary South African men need to actively engage in re-inventing 'traditional' and 'modern' masculinities to accommodate the rights of women and children, to reduce HIV risk and to give men a platform to engage in satisfying egalitarian relationships with women, children and other men. *Secondly*, and as a pre-requisite for the first, the notion that masculinity is essentialized or unchanging (e.g. in cultural, biological or religious discourses of masculinity) must be undermined in everyday and common-sense understandings. For example, histories of cultural practices (Thorpe, 2002) demonstrate that 'traditional' masculinity is neither stable nor fixed. Until this reality is accepted and widely disseminated by people who have the power to shift and define social identities (such as politicians, religious leaders and traditional leaders), men will still have recourse to arguments of essentialism to avoid engaging with change and to continue to produce new and even more misogynistic versions of traditional masculinity. Although this is a particularly problematic issue when 'modern' forms of masculinity intersect with 'traditional' forms (and especially so when issues of race are also invoked) as they do in many interventions, essentialization is also a keystone of 'modern' constructions of dominant masculinity (Talbot and Quayle, 2008). *Thirdly*, the vulnerability inherent in hegemonic masculinity – such as the constant threat of shame – must be acknowledged and addressed in society and in interventions. Critical engagement with and reflection on these vulnerabilities, as well as the skills for managing them, are essential for men, individually and collectively, to live out more positive masculinities, and so reduce the risk of increased HIV transmission and infection.

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Chapter 5
HIV and Youth: A Behavioural Perspective

Arvin Bhana and Inge Petersen

5.1 Introduction

The human immunodeficiency virus (HIV) represents one of the most challenging and serious threats to the development and well-being of young people everywhere. These challenges are massively exacerbated in contexts of poverty and under-development, and made worse by periods of conflict and political intransigence. This is especially true for sub-Saharan Africa, host to the largest number of people with HIV and AIDS in the world.

In this chapter, we begin by highlighting the critical importance of a continued focus on youth given the large spikes in HIV incidence in this age cohort, and also because youth continue to offer the best opportunities for prevention intervention efforts (as anti-retroviral (ARV) treatment cannot succeed on its own) and which will begin to make an impact on the scourge of HIV and AIDS. We provide arguments and evidence for a continued focus on competency enhancement and the development of resilience through strengthening the protective factors among youth. This is followed by a review of South African and relevant international evidence of effective interventions that help to address the multifaceted risk and protective factors for behaviour change to occur. By focusing on the multifaceted nature of youth risk and intervention, we hope to encourage the development of intervention models that incorporate change interventions at the individual, interpersonal, community and, more distally, at societal structural levels to impact on poverty reduction.

5.1.1 Background

While a definition of youth can vary widely, we have used an age definition that is widely used and allows for appropriate comparisons to be made. Specifically, youth refers to young people between 9 and 24 years of age (Breinbauer and Maddaleno, 2005). Youth account for 45% of all new infection of HIV globally, with almost 90% of this number living in sub-Saharan Africa (UNAIDS, 2008). The most critical finding has been that relative to 2002, when the prevalence of HIV among 15–24-year-olds was 12.0%, in 2005, the overall prevalence for 15–24-year-olds in South

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_5,

Africa was 10.3%, with female and male rates at 16.9% and 4.4%, respectively (Shisana et al., 2005). Other nationally representative surveys have established similar rates for this age cohort (Pettifor et al., 2004). In 2007, UNAIDS reported similar declines, with a prevalence rate of 12.7% for females and 4% for males, though the overall prevalence rate had increased to 18.1% of individuals between 15 and 49 years of age (UNAIDS, 2008). In keeping with the notion that there is no 'magic bullet', it is generally accepted that multiple factors contributed to this decline.

While prevalence rates help confirm that HIV rates continue to be hyper-endemic among youth, it is incidence rates that really point to the extraordinary levels of ongoing HIV transmission in South Africa. Rehle et al. (2007a) examined 2004 antenatal data for 15–24-year-olds in a single year age cohort analysis using smoothed prevalence data. Table 5.1 shows that the incidence rates increase rapidly with age and peaks at 5.2% among 20–21-year-olds. They conclude that the HIV incidence for youth aged 15–24 years is 2.2%, which in absolute terms translates to 192,000 new infections per year. Those who reported a single sex partner in the last year were less likely to be HIV positive than those with two or more partners (incidence of 2.1% and 3.1%, respectively) as were those who reported condom use at last sex (2.9% versus 6.1%), confirming that increased number of partners and inconsistent condom use increase the risk of HIV infection in youth.

It is also unlikely that in the short term the prevalence of HIV among youth is likely to decline sufficiently. The most recent Actuarial Society of South Africa's model (ASSA, 2006) indicates that the current incidence level of HIV at age 15 is approximately 2.2%. This youth incidence rate is expected to increase year on year until 2012, when it is expected to stabilize (Table 5.2).

Table 5.1 Incidence rates from single year age cohort prevalence in 15–24 year old antenatal attendees

Age (years)	Smooth age cohort prevalence (%)	Difference in prevalence (%)	Proportion population at risk	Incidence (%)
15	9.130	–	–	–
16	10.568	1.438	0.909(90.9%)	1.6
17	13.200	2.632	0.894(89.4%)	2.9
18	16.673	3.473	0.868(86.8%)	4.0
19	20.634	3.961	0.833(83.3%)	4.8
20	24.732	4.098	0.794(79.4%)	5.2
21	28.615	3.883	0.753(75.3%)	5.2
22	31.930	3.315	0.714(71.4%)	4.6
23	34.324	2.394	0.681(68.1%)	3.5
24	36.400	2.076	0.657(65.7%)	3.2

Rehle et al. (2007a) *Assessing the Impact of HIV and AIDS Prevention and Care Programmes in South Africa.* Report to the Department of Science and Technology. Human Sciences Research Council: p. 35.

Table 5.2 Projected percentages of young people aged 15–24 who will be infected with HIV between the years 2008 and 2018

Year	Incidence (%)									
	15	16	17	18	19	20	21	22	23	24
2008	2.21	3.56	4.62	4.91	4.98	4.81	4.56	4.10	3.43	2.81
2009	2.19	3.54	4.59	4.89	4.96	4.78	4.53	4.06	3.40	2.76
2010	2.18	3.52	4.58	4.88	4.95	4.77	4.52	4.04	3.37	2.74
2011	2.17	3.51	4.57	4.87	4.94	4.76	4.51	4.03	3.36	2.73
2012	2.16	3.50	4.56	4.87	4.94	4.76	4.50	4.03	3.35	2.72
2013	**2.15**	**3.50**	**4.56**	**4.87**	**4.94**	**4.75**	**4.50**	**4.03**	**3.35**	**2.71**
2014	2.15	3.49	4.55	4.87	4.94	4.75	4.50	4.03	3.35	2.71
2015	2.15	3.49	4.55	4.86	4.94	4.75	4.50	4.03	3.55	2.71
2016	2.15	3.49	4.55	4.86	4.94	4.76	4.50	4.03	3.35	2.72
2017	2.14	3.49	4.55	4.86	4.94	4.76	4.51	4.03	3.35	2.72
2018	**2.15**	**3.49**	**4.55**	**4.86**	**4.94**	**4.76**	**4.51**	**4.03**	**3.36**	**2.72**

Source: ASSA Model, Dorrington et al. (2006)

The model estimates are derived from a default scenario that assumes that a number of intervention strategies are in place, which include information and education campaigns, improved treatment of STDs, voluntary counselling and testing, prevention of mother-to-child transmission and ARV treatment (Dorrington et al., 2006).

With the advent of ARV treatment becoming more widespread over time, there will be increasing numbers of sexually active HIV-positive youth. While most young people in South Africa acquire HIV and AIDS through risky sexual behaviour (Sinha and Kiso, 2008), specifically through unprotected sex and sex with multiple partners, there are also youth infected through vertical transmission (mother-to-child transmission or through breast feeding or postnatally). International evidence suggests that at least a third of youth will continue to engage in risky sexual behaviour after learning their serostatus (Rotheram-Borus et al., 2001). The possibility of re-infection, which may accelerate disease progression, including the presence of other STIs associated with substantial morbidity independent of HIV illness, suggests an extremely high-risk scenario among youth who are HIV positive (Gore-Felton et al., 2005).

While it is acknowledged that the provision of ARV treatment has increased tenfold in the past 5 years, Lay (2008) makes the point that in 2007, for every 5 new infections, 2 people are on treatment and that treatment alone cannot provide the basis for a response to the HIV epidemic. Multiple approaches need to be used over a period of time. Regrettably, the health and mental health services meant to accompany such prevention efforts are wholly inadequate, reaching less than 10% of at-risk individuals globally (Merson et al., 2008). Moreover, while it is generally accepted that behaviour change efforts have been instrumental in prevention successes, the absence of an effect on HIV prevalence in South Africa must give a pause.

5.2 Understanding Risk Influences for HIV Infection Through Sexual Transmission in Youth in South Africa

In sub-Saharan Africa and South Africa, where HIV is largely sexually transmitted, behaviour, which places youth at risk, involves inconsistent condom use and sexual intercourse with multiple partners, including multiple concurrent partners. Risk reduction or HIV-prevention behavioural interventions are concerned with reducing the incidence and prevalence of HIV infection through reducing these high-risk behaviours that put a person at risk.

In the context of poverty, which characterizes many communities in South Africa, there is an increase in influences for youth to engage in high-risk sexual behaviours (Brook et al., 2006; Simbayi et al., 2004). In these contexts of adversity, it is particularly important that a competency enhancement approach to HIV prevention, which promotes resiliency, through strengthening the protective factors in the face of risk, be adopted. The construct of resilience refers to a dynamic process whereby children and adolescents display a positive adaptation in the face of adverse and traumatic experiences (Luthar and Chicchetti, 2000). Building resilience in youth occurs when promotive factors are strengthened to the point where they overcome or ameliorate the negative effects of risk exposure (Fergus and Zimmerman, 2005).

Further, the impact of risk and protective influences across the life span varies according to the different development challenges associated with each developmental stage. Developmentally timed interventions that are designed to mediate temporally related risk influences are thus important. The adolescent phase across all societies is characterized by three sets of developmental transitions: biological changes as a result of the onset of puberty; cognitive changes with a shift from pre-operational thinking to more formal operations, which characterizes advanced cognitive abilities; and socio-emotional changes associated with the transition to new roles in society (Steinberg, 1999).

Risk and protective factors are multifaceted. They include individual level, interpersonal, community and societal structural factors. High-risk behaviours amongst youth are likely to be a product of the interplay of multiple risk factors at these different levels in the context of a paucity of protective influences.

Risk and protective influences at the *individual level* include physical and psychological influences, which may be a product of genetic and/or socio-environmental factors. Psychological well-being is understood as a person's belief in their own self-worth and abilities (Petersen and Govender, in press). Flay and Petraitis' (1994) understanding of how psychological health affects health-related behaviours is useful for understanding the role of these individual-level influences on sexual risk behaviour in youth. They understand self-efficacy in relation to performing a particular behaviour to be influenced in the first instance, by behavioural and emotional control, which incorporates the concept of self-regulation. The attainment of self-regulation is an important developmental task of adolescence and is achieved when youth are able to monitor and control their emotions and behaviour through cues and feedback from the outside world as well as internal cognitive assessment and affective processes (Breinbauer and Maddaleno, 2005). The ability to self-regulate is compromised by poor cognitive abilities as well as emotional distress, with rebelliousness, delinquent behaviour, depression as well as impulsivity having been identified as risk factors for high-risk sexual behaviour for youth in the US and Europe (Brook et al., 2002; DiClemente et al., 2001; Kahn et al., 2002; Ketterlinus et al., 1992); and indirectly through association with deviant peers in South Africa (Brook et al., 2006).

Second, self-efficacy to perform health-related behaviours is also understood to be influenced by sociability (Flay and Pretraitus, 1994), which influences a person's social skills. With respect to youth, experience plays an important role in the development of self-efficacy (Breinbauer and Maddaleno, 2005), with the development of heterosexual competence being an important developmental task of adolescence. Low perceived self-efficacy with regard to sexual social situations compromises a person's ability to successfully negotiate safe sex. A review of international studies suggests that adolescents are more likely to practice safe sexual behaviours through refraining from sexual intercourse or using condoms in casual sexual encounters if they have perceived self-efficacy with respect to managing sexual situations (Breinbauer and Maddeleno, 2005).

At the *interpersonal* level, the influence of peers, parents and other significant adults such as teachers on sexual risk behaviours amongst youth are important to consider.

With regard to poor *parent–child relationships*, international studies indicate that an authoritative parenting style, characterized by high support (warmth and responsiveness) as well as high demandingness (monitoring and developmentally appropriate control) is associated with decreased sexual risk behaviour and teenage pregnancy through improved individual-level influences of greater self-control, peer resistance and decreased psychological distress (Breinbauer and Maddeleno, 2005; Pantin et al., 2004). Authoritative parenting contrasts with authoritarian parenting, characterized by high control and low support; permissive parenting, where there is high support and low control; and uninvolved or neglectful parenting, characterized by low support and low control, all of which has been found to be less protective.

Contexts of poverty threaten the protective parent–child relationship as the stressors of poverty mitigate against parental involvement as well as monitoring and control. Parents in poorer contexts internationally and in South Africa have been found to provide less warmth and structure, be less nurturing and involved, as well as provide harsher treatment in the context of setting fewer limits and behavioural controls for their children's behaviour (Govender and Moodley, 2004; McLoyd, 1990; Paruk et al., 2005; Steinberg, 1999). In general, South African adolescents report poor communication with parents about sexual matters (Eaton et al., 2003).

Several studies suggest that poor parent–child relationships increase sexual risk behaviour in youth in the South African context. Brook et al. (2006) found that poor parent–child relationships were linked to vulnerable personality and behavioural attributes of delinquent behaviour, depressed mood and rebelliousness in youth, which increased vulnerability to association with deviant peers, which was found to be associated with high-risk sexual behaviour. Nair and Campbell (2008) reported that one of the key impediments to behaviour change in a rural area in KwaZulu-Natal was inadequate support and guidance for young people from the family unit, low involvement of parents in their children's school activities and a general struggle by parents to recognize young people as having anything of value to offer the community.

With respect to *peer influences*, negative peer influences have been identified as the strongest mediating predictor of high-risk sexual behaviour in youth, particularly for males, in South Africa (Brook et al., 2006). Given that identity development is a major developmental task of adolescence, there is a heightened need for peer group affiliation and separation from parents and individuation, as this assists in identity development.

Peer influence is therefore an important factor in adolescents' sexual decision-making and sexual risk-taking (Campbell et al., 2005). Its impact comes from both adolescents' perception of their peers' attitudes, values and sexual risk behaviours, as well as their actual attitudes and behaviours (Pedlow and Carey, 2004). Existing evidence shows that adolescents with sexually active friends are more likely to have sex themselves and to have multiple partners. By the same token, those who perceive that their peers dislike or avoid condom use are also less likely to use condoms themselves (Marston and King, 2006). It has been found, for example, that for some adolescents in South Africa, and males in particular, that there exist fairly strong levels of peer disapproval of condom use and peer pressure to be sexually active that results in reduced levels of condom use and an increase in sexual activity (Campbell and MacPhail, 2001). Morojele et al. (2006) found that South African youth engaged in drug use with peers were more prone to engage in unplanned and unprotected sexual intercourse.

It should be noted, however, that peer pressure does not have the same negative influence on all youth. In South Africa, young men appear to be influenced to a greater extent than are young women (Brook et al., 2006; Eaton et al., 2003). Among boys, peer pressure often has to do with proving manliness, or winning status and admiration by having many sexual partners, while for girls the pressure sometimes comes from sexually experienced peers who exclude inexperienced girls from group discussions because they are still 'children' (Eaton et al., 2003). Peer pressure is also not necessarily a negative influence, in that positive examples set by friends and role models can promote safer sexual behaviour. For example, studies have shown that young people whose friends favour delayed sexual initiation tend to delay sexual debut themselves (Eaton et al., 2003; Pedlow and Carey, 2004; Le and Kato, 2006).

At the *community level*, risk-enhancing social norms which emerge from peer group networks described under the interpersonal level, poor socio-economic conditions and lack of opportunities as well as a poor school environment can enhance high-risk sexual behaviour. International and local South African studies have highlighted the association between poverty and high-risk behaviour in youth (Breinbauer and Maddaleno, 2005; Brook et al., 2006; MacPhail and Campbell, 2001; Simbayi et al., 2004). Further, there is an increasing body of literature which demonstrates the importance of school connectedness as a protective influence for youth against risk behaviour, including high-risk sexual behaviour (McNeely et al. 2002), although, to date, no such studies have been conducted in South Africa. School connectedness is associated with positive classroom management, participation in extra-curricular activities, tolerant school discipline and small class sizes.

At the *structural societal level*, socio-cultural norms and socio-economic circumstances serve as important distal influences on high-risk sexual behaviour in youth. Young girls from impoverished family and community backgrounds are at greater risk of dropping out from school, marrying at an earlier age or engaging in sex for material and economic gain (Campbell, 2003; Campbell and MacPhail, 2002, MacPhail and Campbell 2001; Richter et al., 2005; Shisana et al., 2005; Weiss et al., 2000). Evidence from various countries, including South Africa, indicates that poverty exacerbates young women's vulnerabilities to HIV infection by encouraging them to engage in transactional or commercial sex for economic survival, and to obtain money to meet education-related and other material expenses (Chatterji et al., 2005; Ganyaza-Twala and Seager, 2005; LeClerc-Madlala, 2004).

Historically, youth in sub-Saharan Africa have had many rituals to mark their entry into adulthood and their sexual inception. These rituals helped to formalize the social control of female sexuality and fertility within a marriage exchange (Van den Bergh, 2008). However, these ritual processes have undergone dramatic changes, partly through modernity and partly due to the influence of colonial and apartheid mechanisms of social control. The advent of migration and inter-ethnic marriages in Southern Africa resulted in a loss of value of these traditions. Because sexuality was controlled through these societal processes, advice about sexuality was not a parental responsibility exclusively, nor was puberty discussed, as this was part of the instructions provided at formal rituals. The formal rituals also reinforced male domination (Van den Bergh, 2008). The breakdown of family systems through labour migration in South Africa, where children were often left in the care of older siblings, appears to have further curtailed traditional instruction and diminished parent authority (established over time through gerontocratic institutions) and social sanctions (Van den Bergh, 2008).

Youth in urbanizing settings thus appear to enter into sexual life less constrained by these rituals, and the commodification of sexuality has increased youth vulnerabilities. With the movement of urbanizing societies to increasingly relying on a cash economy, the lines between reproduction, pleasure and money have also became increasingly blurred (Van den Bergh, 2008). In the context of an emerging materialist youth culture and a dominant patriarchal system, young females are increasingly vulnerable to the development of social identities, which render them vulnerable to being coerced into having unprotected sexual intercourse, with 90% of new infections in the 15–24-year age group in South Africa occurring in females (Rehle et al., 2007b).

5.3 Reviewing the Evidence for Effectiveness of Interventions at Various Levels of Influence for Youth in South Africa

While eradicating poverty and wealth inequalities at a structural societal level should remain an overarching goal in the fight against HIV infection in youth, interventions should also strive towards strengthening resilience in the context of widespread poverty and inequality through strengthening protective influences that mediate the impact of poverty on sexual risk behaviours amongst youth.

5.3.1 Individual Level

At the individual level, there has been a plethora of HIV prevention, sexual health and life-skills intervention programmes for youth in South Africa. The majority of these programmes have been implemented in schools. A review of such programmes by Mukoma and Flisher (2008) suggest that while some of these programmes demonstrate positive effects with regard to knowledge, attitudes and increased communication about sexuality, they have, however, demonstrated limited success in relation to youths' perceptions of susceptibility to infection, self-efficacy, behavioural intention or actual behaviour change.

Further, these individual level programmes have paid scant attention to personal factors such as depression, impulsivity and rebelliousness, which mediate self-efficacy and have been found to be associated indirectly with youth high-risk sexual behaviour in South Africa (Brook et al., 2006). Educational programmes alone cannot address these issues. The need for mental health programmes and services for youth in South Africa to address these issues is thus highlighted.

5.3.2 Interpersonal and Community Levels

At the interpersonal level, while studies have shown that poor *parent–child relationships* are associated with youth high-risk sexual behaviour in South Africa (Brook et al., 2006), and that protective parenting is compromised in conditions of poverty (Govender and Moodley, 2004; McLoyd, 1990; Paruk et al., 2005; Steinberg, 1999), there is a paucity of programmes aimed at strengthening the parent–child relationship in poor South African communities. Indeed, families provide the most proximal and fundamental social system for influencing positive family relations, communication about sexuality and safer sexual behaviours, as well as the monitoring of peer activities (Perrino et al., 2000). One notable programme which has had positive effects is the Collaborative HIV/AIDS Mental Health Project (CHAMP). CHAMP is a developmentally timed family intervention targeting pre-adolescent children and their caregivers with the view to strengthening the key family influences of caregiver–child connectedness, warmth and communication as well as active caregiver monitoring and control, which have been found to serve as protective factors against sexual risk behaviour in adolescents. The outcomes of a randomized control trial in a semi-rural setting in KwaZulu-Natal showed small-to-medium positive effects with regard to improved parent–child communication about sensitive topics, improved parental monitoring and control and strengthened primary social networks for caregivers (Bell et al., 2008).

Also at the interpersonal and community levels, *peer influence* has been identified as a mediating predictor of high-risk sexual behaviour amongst youth (Brook et al., 2006). While peer education has been widely utilized in HIV prevention programmes worldwide as well as in sub-Saharan Africa, a recent review of programmes using this strategy reveals great diversity in how the concept is applied (Bastien et al., 2008). Also, there is evidence that despite being led by peers, many of these programmes adopt a purely educational didactic approach, and the content tends to focus largely on factual information about the HI virus (Campbell and MacPhail, 2002). They are thus more appropriately understood to intervene at the individual level of influence.

In South Africa, a notably large-scale educational programme using peer education methods has been provided by *Rutanang* (a Sotho word for 'learning from each other'), which was a collaboration between government, NGOs and educational institutions (Deutsch and Swartz, 2002). The collaboration aimed to set standards and review the practice for peer education in South Africa as well as provide technical assistance and to encourage implementation of *Rutanang* materials in educational settings (Deutsch and Swartz, 2002). In general, while the programme content appeared to be adequate, the application faltered because of inadequate attention to local needs and the capacity of schools (training, supervision, monitoring and evaluation) to run the programme (Ward et al., 2008).

Many peer education programmes in sub-Saharan Africa have thus merely focused on using peers to provide educational messages and have not shown better outcomes than professionally led programmes (Bastien et al., 2008). Their use in promoting protective social norms with respect to sexual behaviour has thus been limited. Notable exceptions has been the work of Campbell and MacPhail (2002), who explored the use of homogeneous peer groups in schools to stimulate awareness of how gendered identity and associated normative behaviour put youth at risk. This served as a catalyst for the renegotiation of more health-enhancing social identities and associated normative behaviour. Further, Mathews et al. (2001) explored the potential of using the 'popular opinion leader' model in high schools, as a mechanism for facilitating a change in social norms, with promising outcomes. The popular opinion leader model has its roots in diffusion of innovation theory with the idea that a popular, respected and influential member of a group network can influence social norms in their social network to the point where there is sufficient critical mass to invoke a 'tipping' in the social norms towards the alternative (Breinbauer and Maddaleno, 2005).

The coalescing of these perspectives which have demonstrated potential to facilitate the development of protective social norms relating to sexual behaviour requires further research.

Also at a community level in South Africa, there have been a number of national mass media campaigns aimed at changing social norms as well as increasing information and awareness at an individual level, using print, radio and TV media. The most well known among these include the Soul City Project (initiated in 1994), loveLife (initiated in 1999) and Khomanani (initiated in 2001). Others include TV programmes such as Gazlam, Tsha Tsha, Takalani Sesame and Beyond Awareness. The most ambitious of these, at least in terms of reach, viz., loveLife, specifically targeted young people with the idea of integrating HIV prevention messages into youth culture and by creating brand awareness. It also operated a network of telephone line clinics and youth centres that provide sexual health facilities, as well as an outreach service that travels to remote rural areas, to reach young people who are outside of the formal educational system, thus providing more community resources for youth as well.

The South African National Prevalence, HIV Incidence, Behaviour and Communication Survey (Shisana et al., 2005) showed that these programmes were well known among youth, though less so among rural youth, with most youth reporting that they found the programmes useful as a source of information. Hutchinson et al. (2007) found similar results regarding their impact on providing information but not on facilitating actual health-promoting behaviour, such as disclosure of HIV test results and condom use. Bertrand et al. (2006) review of 24 mass media studies on changing HIV-related knowledge, attitudes and behaviours in developing countries was equivocal about the mass media campaigns ability to reduce risky sexual behaviour.

5.4 Conclusion

While research related to reducing HIV prevalence among youth has accelerated significantly over the last 25 years, from school-based intervention studies to community-based interventions using randomized control trials, with the current suite of existing interventions, prevalence rates appear set to remain at current levels for a number of years (Dorrington et al., 2006).

Scaling up efforts may appear to be the answer, but what should be scaled up? It is widely accepted that a ‘complex combination of strategies and several risk-reduction options with strong leadership and community engagement that is sustained over a long period of time’ (Coates et al., 2008, p. 37) may be the best solution to what to date appears to be an intractable problem.

A review of prevention efforts for youth in South Africa reveal that the bulk have been educational and awareness programmes and campaigns either at schools, through life skills and peer educational programmes or through various forms of mass media interventions. As valuable as this type of programming may be to raise levels of knowledge and provide important information, their limited effect on the key sexual risk behaviours of inconsistent condom use and multiple concurrent partners may require circumscribed or targeted media combined with various school-based or clinic-based programming (Bertrand and Anhang, 2006).

Programming efforts that moves beyond facilitating increased information, awareness and skills are also needed to address the risk influences that have been identified as operating at various levels. Given that negative peer influences have been identified as a strong mediator of high-risk sexual behaviour amongst youth, resources should be directed towards developing theory-driven and scientifically sound interventions to promote protective peer influences for youth at the interpersonal and community levels. The potential for using popular opinion leaders to promote the development of health-enhancing group social identities may provide one resource and requires greater exploration. Further, the relationship between family-level and personal vulnerability risk factors calls for increased attention to be paid to interventions that strengthen protective parenting practices as well as health and mental health services for youth at risk. In the final analysis, these relative risk influences for youth sexual risk behaviour must be countered against a backdrop of continued efforts to impact on the critical distal influence of poverty and wealth inequality in South Africa.

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Chapter 6
Infants and Young Children Affected by HIV/AIDS

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6.1 Introduction

The first suspected cases of paediatric AIDS were recorded in 1981 in the United States, but were only reported in the medical literature in December 1982 (Ammann, 1997; CDC, 1982a, b; Shilts, 1987). The existence of paediatric AIDS, along with the possibility of transmission vertically and through blood products, was not widely accepted until the end of 1983 (Ammann, 1997). In South Africa, there is little information on children infected with HIV prior to 1997's emergence of Nkosi Johnson's story. However, the already high level of HIV prevalence among pregnant women when data first became available in 1990 suggests that significant numbers of children must have been born with HIV since the early 1980s.

Despite their being part of early HIV and AIDS history, the response to HIV-affected children has differed markedly from that to HIV-affected adults. Children have seldom made it into the serious sections of HIV and AIDS journals, or even past the back pages of the main HIV and AIDS broadsheets, except as recipients of vertical viral transmission. Instead, they have been swathed in sentimentality and sensationalism, with photographs and stories of celebrities hugging and adopting 'AIDS orphans', and headlines giving numbing figures of children whose parents are presumed to have died from AIDS (Meintjies and Giese, 2006).

Moments of protest to this bias have come largely from affected parents and children. In 1984, Ryan White's parents fought against the prevailing stigma and discrimination to have him re-admitted to school in the United States, after he was diagnosed with AIDS following a series of blood transfusions. In South Africa, Gayle Johnson fought a similar battle on behalf of Nkosi Johnson (Wooten, 2005). At the 13th International AIDS Conference in Durban in 2001, Nkosi Johnson became a powerful, but lone, spokesperson for children affected by HIV and AIDS. Child advocacy has taken a long time to exert an influence. For example, before South Africa's Constitutional Court ordered the government to make the drug nevirapine available to pregnant women to help prevent vertical transmission of HIV to children, HIV prevalence among pregnant women attending public antenatal services in South Africa rose from 0.8% in 1990 to 24.8% in 2001.

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_6,

The omission of children from serious academic study has been most evident in the major international HIV and AIDS forums, where, for nearly 23 years, children did not once appear as the subject of a plenary presentation. Even in 2004, the subject *children* appeared in only 3.6% of the accepted abstracts for the conference. This rose to 7.4% in 2006, albeit with an increase in posters and a decline in oral presentations (Sherr, 2006, Sherr and Varrall, 2007).

But this has started to change. In 2004, at the 15th International AIDS Conference held in Bangkok, child advocates came together to express their disappointment at the exclusion of children's issues from mainstream AIDS concerns and at the manner in which children were portrayed at the conference. Stage-sized pictures of tearstained children's faces had been alternated with dancing groups of semi-clothed young girls, billed as 'children from orphanages' in Africa (Richter, 2004). The Coalition for Children Affected by AIDS (CCABA) was formed to advocate for more urgent and appropriate attention to children in the AIDS response and organized a 2-day symposia before the Toronto (2006) and the Mexico City (2008) International AIDS Conferences. In Mexico City, the first plenary paper on children affected by HIV and AIDS was presented (Richter, 2008).

Unfortunately, however, the gains made in international advocacy for children and families affected by HIV and AIDS still need to be achieved in South Africa. The gains made in advocacy also still need to be matched by knowledge, funding and the implementation and scale up of prevention, treatment and care for children affected by HIV and AIDS.

6.2 Children Affected by HIV and AIDS

Children are both infected by HIV themselves and affected by the infection of adults. The effects of adult infection on children may be proximal, when their caregivers are living with HIV or AIDS, or distal, through the disease's burden on households, communities, health, education and social welfare services for children.

This chapter deals primarily with young children, by which we mean those below 6 years of age, who have generally not entered formal schooling. In studies of infection, some attention has been given to young children, though often mechanistically, with respect to transmission during pregnancy, delivery and infant feeding. However, with respect to proximal and distal effects, children have received little attention, and young children have received far less than those in middle childhood and adolescence.

6.2.1 HIV Infection in Young Children

Children up to the age of 14 years currently comprise about 17% of new HIV infections annually (UNAIDS, 2008). Most of these infections occur through vertical transmission (Newell et al., 2004b). As vertical transmission is the subject of Chapter 13, by Lorraine Sherr, it is not treated in detail here. However, recent national household surveys from, among others, South Africa and Swaziland, indicate higher than expected prevalence in children at ages older than infancy.

A South African household survey in 2005 found HIV prevalence among children 2–14 years of age to be 3.3%, but 4.8% among 5–9-year-olds. Extrapolating these findings to the wider population indicates that about 215,000 of the 4.8 million 5–9-year-old children in South Africa are HIV-positive. This raises a number of questions around the possibility of long-term survival of children peri-natally infected with HIV and about the risks of infection to which slightly older children are exposed, including sexual abuse, unprotected care for sick people in the home and infection in public health facilities (Brookes et al., 2004; Shisana et al., 2008).

6.2.1.1 The Virgin Cure and Child Rape

The possible role of sexual abuse in child HIV infection raises questions regarding the so-called *virgin myth* or *virgin cure* (Richter et al., 2004a). Belief in the curative power of virgins has been reported since the sixteenth century in Europe, and in many other parts of the world. Documents from the nineteenth century Victorian England indicate widespread belief that sexual intercourse with a virgin could cure sexually transmitted diseases (Jewkes, 2004). This form of the virgin myth also surfaced in South Africa's Eastern Cape, when troops returning home from World War II sparked a significant outbreak of sexually transmitted infections (Earl-Taylor, 2002).

South Africa has the highest reported incidence of child rape in the world. The Police Services receive reports of 60-plus child rapes a day, including the rape of infants and young children (Richter and Higson-Smith, 2004). As police estimate that only about 1 in 35 rapes are reported, it is possible that nearly three-quarters of a million children are raped each year. Although child rape is widely believed to be driven by the virgin myth, there are several arguments against this.

While qualitative studies tend to highlight the salience of beliefs in the virgin myth, a 2002 representative household survey found that fewer than 2% of individuals thought that sex with a virgin could prevent or cure AIDS (Shisana and Simbayi, 2002). Similarly, documentation from clinical files shows little support for the virgin myth motivating the rape of young children (Jewkes, 2004). Finally, no precedent for the association of the virgin myth with the rape of infants and young children has yet been identified (Earl-Taylor, 2002).

Other explanations for the coexistence of high rates of child rape and high levels of child and infant HIV infection include the high level of violence perpetrated by South African men against women and children generally (Jewkes, 2004). It has been argued that loose ties of affinity between children and families, due to the absence of formal marriage and marital commitments, have been argued to leave children unprotected and exposed to sexual and other forms of abuse. Additionally, in some circumstances, children born to the 'urban women' of rural migrant workers are considered to not belong to any man and are therefore vulnerable to abuse (Guma and Henda, 2004; Ramphele, 1993).

6.2.2 Young Children Living with HIV

According to UNAIDS estimates (2008), some 280,000 children under the age of 15 are living with HIV in South Africa. Children have low levels of access to treatment and comprise less than 10% of people receiving anti-retroviral therapy in South Africa. Many of these HIV-positive children are chronically ill, experience multiple hospital admissions and may develop a range of neurological, cognitive and other difficulties, before they succumb to illness and die (Newell et al., 2004a). Access to palliative care for young children is severely limited, as is support for their caregivers, at home or in health facilities (Govender et al., 2006; Luo and Coulter, 2002).

In South Africa, more than 40% of deaths in children under the age of 5 are attributable to HIV and AIDS (Bradshaw and Nannan, 2006). Without access to anti-retrovirals, about a third of vertically infected young children die during the first 12 months of life, 50% by 2 years and 60% by 3 years. Developmental delays have been reported in close to half of those who do survive to 18 months of age (Potterton, 2007; Varga et al., 2005).

HIV destroys neuronal tissue in the central nervous system, which is associated with developmental delay and/or dysfunction in all modalities. Studies from Europe and the United States show that vertically infected infants are at increased risk of impairments in mental, motor and emotional development (Abubakar et al., 2008; Richter et al., 2006; Stein et al., 2005). There is, however, inconsistency in the literature as to the exact nature of the impairments suffered, and some studies suggest that impairments may change over time (Knight et al., 2000).

In South Africa, HIV infection occurs together with multiple environmental stressors, including poverty and other forms of deprivation. In such conditions, the neurological effects of HIV on children's development are likely to be amplified. Sherr (2005) reviewed 27 studies of the impact of HIV on the development of young children, all of which found significant negative effects on growth, motor and mental development, language acquisition, adjustment, behaviour and school performance. Twelve African studies showed similar results: growth faltering and failure to thrive (Bobat et al., 2001; Miller et al., 2001; Potterton, 2007; Sandison, 2005), as well as neurodevelopmental and language delays (Bam et al., 2003; du Toit and van der Merve, 2006; Kauchali and Davidson, 2006; Kotras, 2001; McGrath et al., 2006; Popich et al., 2007).

6.2.3 Treatment and Support for Young Children Living with HIV and AIDS

As previously indicated, without treatment 80% of vertically infected children die before the age of 5 years. However, highly active anti-retroviral treatment (HAART) can significantly enhance the survival, growth and health of these children (Brown et al., 2000). The HAART treatment can reduce mortality fivefold, resulting in survival rates to age 5 of over 80% (Koekkoek et al., 2006; Meyers et al., 2006).

Roll-out of treatment for children in resource-poor countries has been slow, with many reasons cited for the delay (Van Damme et al., 2006). Infant and child formulations are up to eight times more expensive than adult drugs, they have been difficult to handle, bad-tasting and medical staff report feeling inadequately trained to treat children (Michaels et al., 2006; Rochat et al., 2008). Although South Africa launched its national ARV treatment campaign in 2003, the operational plan for comprehensive HIV and AIDS care, management and treatment did not address children's issues beyond technical considerations. Less than a quarter of eligible children are currently estimated to receive ARV treatment, and only a small minority of these are infants. Most children are still managed in tertiary care facilities, which further limits expansion of access (Shun-King et al., 2006).

While technical problems with paediatric treatment remain (Naeem-Sheik and Gray, 2005), innovative examples of material, programme and support services are now found (Rochat et al., 2008). A study by Potterton (2007), for instance, illustrated that a basic home programme could significantly improve both the cognitive and motor development of young children living with HIV.

Rochat et al. (2008) explored the social, psychological and developmental needs of young children receiving treatment. They found that early testing, diagnosis and initiation of treatment were critical for caregivers and children and that the complexity of anti-retroviral treatment was less of a barrier to treatment than issues of disclosure and support. Failure of prevention of mother-to-child transmission (PMTCT) was found to be particularly challenging for caregivers, and services for this group are urgently needed. Because ARVs very rapidly improve a child's condition, parents accepted treatment very positively and reported few persistent side effects among children. Parents did not struggle to encourage children to take medication, and most said that they had 'made it a way of life.'

Disclosure of HIV infection to children, however, is a challenge. Caregivers expressed feeling helpless and guilty about their role in the child's infection through vertical transmission and feared discrimination. Parents found it easier to disclose the child's status to close adult family members than to siblings. Very few had disclosed their child's status to members of the wider community, including teachers and day-care providers. Although most caregivers interviewed by Rochat et al. (2008) had not experienced stigma or discrimination directly, they feared it and were determined to protect their child. However, lack of disclosure in day-care settings, for example, limited the support caregivers could draw on, and complicated daily management of the child's treatment. Adherence has not presented a substantial problem in the treatment of young children in South Africa. Recently, 89% of children receiving ARV treatment had adherence of 95% or more, far higher than rates generally found in Europe and the United States (Reddi and Leeper, 2008).

Approximately half of the HIV-positive children seen at clinics in South Africa are cared for by an HIV-positive adult. The Reddi and Leeper (2008) study found that those children cared for by an HIV-positive adult were less likely to die than those whose caregiver was HIV-negative or untested. Using a family-centred approach to treatment management, the investigators hypothesized that HIV-positive caregivers, themselves on ART, may provide more informed treatment support for their children, improving outcomes. Far from being rendered powerless by the virus, families affected by AIDS and able to access treatment may have unique reserves of knowledge, sensitivity and skill that can be harnessed to deliver better results for children. Given improved survival, many young children now living with HIV will reach middle childhood, adolescence and adulthood and will need assistance in facing the evolving challenges of adjustment, disclosure and treatment.

6.3 Effects of HIV and AIDS on the Care of Young Children

The biological effects of vertical HIV-infection for child health include encephalopathy, delayed development and frequent ill health, as mentioned above. These effects are often compounded by parental death or separation, parental illness and/or parental anxiety and preoccupation. In the case of infants and young children, whose parents, and mothers in particular, are very central to their lives and well-being, this can be significant.

Even uninfected children born to mothers with HIV are at risk. Evidence from a number of African countries, including Uganda, Tanzania and Zimbabwe, shows that the infant mortality rate of uninfected children of HIV-positive mothers is significantly higher than among uninfected mother and child dyads (Marinda et al., 2007). Although most of the data on developmental disturbances in the children of HIV-positive mothers comes from the West, and is based on older children, it also points to higher levels of attentional, social adjustment, and behavioural problems (Potterton, 2007; Stein et al., 2005).

As most children of infected mothers are uninfected, these children and their families are a very significant group for intervention and support. Understanding the mechanisms behind the indirect effects of maternal HIV on infants is critical to developing appropriate interventions. A number of studies show that the caregiving ability of HIV-positive mothers is significantly compromised, which affects the quality of their interactions with their young children (Peterson et al., 2001), and their ability to supervise the children's activities (Kotchick et al., 1997). Some effects also appear to occur through compromised parenting and childcare practices resulting from, among others, maternal mental state, deepening poverty, stigma and isolation. This is particularly plausible in light of research demonstrating that a positive HIV diagnosis renders an individual vulnerable to depression and diminished social support, and findings that postnatal depression and diminished social support more generally have a major impact on the way mothers interact with their young children, and on young children's emotional, behavioural, intellectual and even physical development (Barnes and Stein, 2000; Murray and Cooper, 2003; Patel et al., 2003). However, the good ARV adherence of HIV-positive children being cared for by HIV-positive parents suggests that, with support, other aspects of child care could be improved.

Bronfenbrenner's ecological model (1986) puts young children at the centre of multiple, interacting layers of influence. Proximal to the child are relationships with caregivers and the everyday caregiving environment. More distal are school and community influences, followed by policy and environmental factors that determine the context of child development. Key to this theoretical framework, and supported by research on risk and resilience, is the counter-balancing of the effects of these forces acting on each other, and on the child, and the effects of the child's initiatives acting on her external environment. These effects are represented graphically in Fig. 6.1.

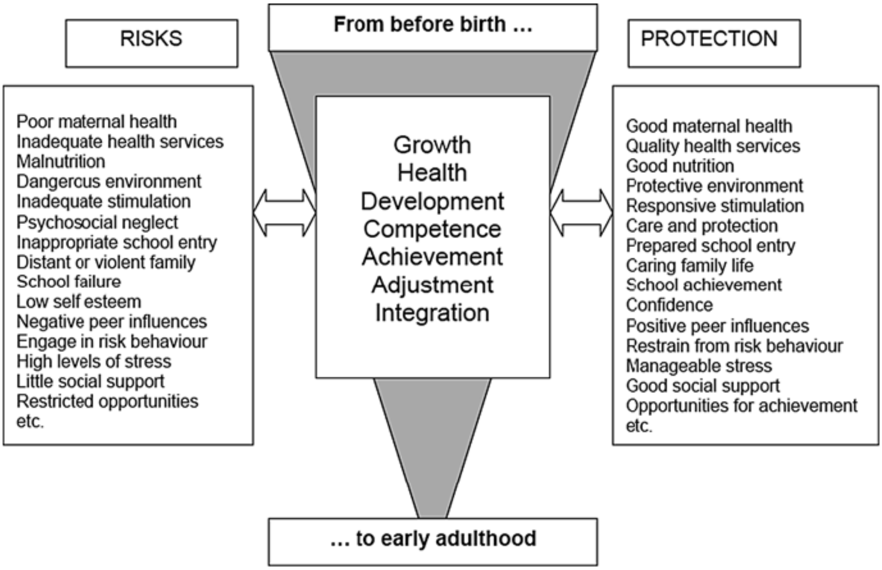

Fig. 6.1 Balance of risks and protective factors in children's lives

For young children affected by HIV and AIDS, parental, especially maternal, well-being and mood are extremely important. So too is what Belsey (2006) calls 'family capital' – the relationships, resilience and resources of the people and networks comprising the broad family environment surrounding the child.

6.3.1 Maternal Mental Health

Most HIV-positive women in Africa are diagnosed during pregnancy, through antenatal screening programmes. Diagnosis poses enormous emotional and motivational dilemmas for the woman who is simultaneously bringing a new life into the world and is told that she has a serious illness and may pass it on to her unborn baby (Rochat et al., 2006). HIV diagnosis also brings doubts about partner fidelity, and fears of stigma and rejection, all of which can undermine emotional and material support systems. Women attending antenatal clinics in heavily burdened HIV areas appear to have high levels of depressive symptomatology, including significant suicidal ideation. In one study, women with depression believed that having HIV would lead to discrimination against them in the health-care system. This belief could result in reluctance to access health-care services and could affect their adherence to PMTCT (Rochat et al., 2006). Encouragingly, there are indications that depression can be effectively treated in comparable African populations using interpersonal psychotherapy (Bolton et al., 2003).

6.3.2 Parenting in the Context of HIV and AIDS

As discussed, HIV diagnosis can have a major impact on a mother, her mental health and her support networks, and may affect her parenting in an ongoing way. Stigma also puts enormous pressure on HIV-positive mothers and their children (Antle et al., 2001; Hackl et al., 1997; Silver et al., 2003) and may make it difficult for them to form and maintain meaningful relationships outside their immediate family. Many HIV-positive mothers report feeling lonely and friendless, and humiliated and ostracised when trying to access health and social care. They are more likely to report depression and lower levels of parental confidence (Silver et al., 2003).

In sub-Saharan Africa, HIV clusters in families and households, because most adult infection occurs among co-habiting couples and most child infections occur vertically (Newell et al., 2004b; Richter, 2008). By extension, the burden of care for those infected and affected by HIV will also tend to cluster in families and households.

Children living with HIV often require additional care and nurturance, placing a very substantial burden on primary caregivers who are themselves likely to be HIV-positive and in need of support (Reidy et al., 1991). Several studies now show that caregivers are often preoccupied with worries about their HIV infection and health, and their children's health, and future, and may feel unable to adequately meet their children's needs (Adler, 2000; Linsk and Mason, 2004; Reidy et al., 1991; Weiner et al., 1994).

Poverty generally has a substantial adverse effect on parenting, causing parental stress, exhaustion, distraction and frequent absences due to poorly paid, labour-intensive and menial work (McLoyd, 1998; Richter, 1994). The main impact of adult HIV on family and household behaviour is impoverishment. Studies in Uganda and Botswana show that households spend about 25% of their monthly income on each person living with HIV (Basaza et al., 2007; Cornia and Zagonari, 2007). Nutrition of children is affected as family food expenditure and consumption is cut to finance AIDS treatment and funeral costs, and as the number of dependents increases when other affected or vulnerable children and family members are taken in. Families increase their labour supply by drawing on the work of women, children and the elderly (Cornia and Zagonari, 2007). They also reduce expenditure on education, sometimes by half or more, while increasing spending on health several fold (UNAIDS, 2004).

Poor families have limited capacity to deal with morbidity and mortality, mainly because of low income, poor food security and having few assets or savings. There is no cushion to absorb reductions in income, livelihood and labour, or increases in human and financial costs of home care, medical and other treatment, burial and potential relocation (Richter, 2008). Migration for work, housing and food security increases. In South Africa, the youngest children are most mobile, moving with and without caregivers into new households to balance needs and resources in extended families (Ansell and van Blerk, 2004; Ford and Hosegood, 2005). How these experiences of change and potential separation from primary caregivers affect young children has not yet been explored in the context of HIV.

6.3.3 Parental Death

Without treatment, HIV-positive adults generally experience decreasing health and quality of life, eventually succumbing to opportunistic infections, often after drawn-out illness and loss of capacity. Parental illness and death is extremely difficult for a child at any age – and may have very long-lasting effects – but is especially so for infants and preschool children, who are highly dependent on one or more primary caregiver (Bowlby, 1969). Studies have shown poor health among young children with AIDS-unwell caregivers (Graff Zivin et al., 2006; Gray et al., 2006). Children who have lost a parent to AIDS experience emotional distress and appear to be at greater risk of HIV infection during adolescence than their peers (Cluver and Gardner, 2007; Cluver et al., 2007; Cluver and Operario, 2008).

According to several surveys of children who lose parents to AIDS, the largest proportion (50%) lose one or both parents between 10 and 14 years of age, 35% between 5 and 9 years and only about 15% when they are infants and toddlers (0–4 years) (Monasch and Boerma, 2004). As a result, there are few interventions to support very young children who lose parents, despite their particular vulnerability (Engle, 2008).

In 2007, approximately 2.8 million South African children had lost at least one parent, with 49% of them, some 1.4 million, presumed to have lost a parent to AIDS (UNAIDS, 2008). This equates to about half a million infants and toddlers losing a parent to all causes, and some 250,000 to AIDS. As 80% of children who lose a parent to AIDS are estimated to have a surviving parent, support for these surviving caregivers and for family care is essential.

More than 95% of children who lose one or more parents to AIDS or other causes live with members of their extended family, including grandparents (UNICEF, 2006). Several studies in sub-Saharan Africa report that grandparents are challenged in caring for very young children, and value material and psychosocial support and assistance (Andrews et al., 2006; Bock and Johnson, 2008).

6.4 Responses to Children Affected by HIV and AIDS in South Africa

From the start of the HIV and AIDS epidemic, families have been responding to the needs of children affected by illness, death and dislocation as best they can, given their resources. They have taken in children, cared for sick relatives, diversified income and livelihood options to meet increasing expenses and, as a last measure, cut food and educational consumption (Richter et al., 2004b). Community-based groups, many faith-based, also responded quickly, providing affected families and children with psychosocial support, food, clothing and help with school fees (Foster et al., 2005). International agencies also increased their activities as donor funds to assist children and families in severely affected communities began to flow, and more recently, increase (UNICEF, 2008).

Governments have generally been slower to step up to the plate. In part, this is because children have little voice to make strong policy demands. Additionally, there has been little direction regarding effective policy options, particularly in countries where levels of poverty-driven vulnerability among children were already high. Sub-Saharan African countries have tended to view national social and economic development as a priority and have framed the needs of specific groups within this prioritization.

Governments are, however, beginning to respond to children, for example, through national plans. Beginning in 2003, UNICEF and its partners have driven the development and revision of National Plans of Action (NPA) for Orphans and Vulnerable Children. A recent review of NPAs from 17 countries in sub-Saharan Africa – including South Africa, whose first plan was formulated in 2005 – found that the most common actions recommended for young children were birth registration, nutrition and health care. About half the plans made provision for child-care centres or community centres and a few listed psychosocial care of young children. Overall, though, NPAs are vague and generally unfunded (Engle, 2008). Their relationship to mainstream national priority setting and fiscal commitments is not clear, and they are seldom articulated with national HIV and AIDS plans. However, the new South African National Action Plan (2009–2012), contains more wide-ranging provision, including psychosocial support and Child Care Forums.

6.4.1 Policy Responses

In South Africa, the policy framework for ‘Orphans and other Vulnerable Children affected by HIV/AIDS’ (OVCAHA) was published by the National Department of Social Development in 2006. The policy is broadly based on the provisions of the Convention of the Rights of the Child (1995) and the Constitution of South Africa (1996). The policy framework has six key strategies, mainly drawn from the widely endorsed UNICEF/UNAIDS (2004) *Framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS.* The six strategies are to: strengthen and support the capacity of families to protect and care for children; mobilise and strengthen community-based responses for the care, support and protection of orphans and other children made vulnerable by HIV and AIDS; ensure that legislation, policy, strategies and programmes are in place to protect the most vulnerable children; assure access for orphans and children made vulnerable by HIV and AIDS to essential services; raise awareness and advocate for the creation of a supportive environment for orphans and children made vulnerable by HIV and AIDS; and engage the civil society sector and the business community in playing an active role to support the plight of orphans and children made vulnerable by HIV and AIDS.

South Africa is inundated with policy and legislation, and it is challenging to understand how the OVCAHA relates to the existing and parallel policy and legislation, including the National Integrated Plan for Children Infected and Affected by HIV and AIDS (2000); the National Policy Framework and Strategic Plan for the Prevention and Management of Child Abuse, Neglect and Exploitation (2004); the Social Assistance Act (2004); the Department of Social Development Service Delivery Model (2006); the Children's Act (2005); and the draft National Family Policy, among others.

Nonetheless, the policy framework is intended to guide the National Action Plan, which was written in 2005, and has been updated in June 2009. In this, the following components are listed as important: development of a national database on orphans and vulnerable children, psychosocial, food security and material support to households with OVC, succession planning and support to caregivers, and strengthening the capacity of civil society organizations and Community Child-Care Forums (CCFs) providing services to children and families.

The South African government's response to children and families affected by HIV and AIDS has been limited by a sectorally partitioned structure, with challenges in coordination between the departments of health, education, social development and others. Policies have been limited in scope, national application and integration have been delayed, and funding has been short. Some plans are also extremely difficult to enact effectively, such as creating a database of vulnerable children, which will require much technical development and tracing of people.

What stands South Africa in good stead, though, is a coherent, rights-based social protection system, with its poverty-targeted income transfer programme that currently reaches some 8.3 million children. Close to 80% of the 66% of South African children eligible to receive the Child Support Grant (CSG) of R220 per month currently receive it. The CSG appears to have had a very positive effect on child poverty, reducing the rate from 43 to 34% (Woolard, 2003). Other research indicates that the CSG and the Old Age Pension have together helped to sustain families in the context of widespread unemployment and poverty.

Income transfers and increasingly universal access to education and health care form a solid basis for a national response to young children affected by HIV and AIDS. Child protection services (both responsive and preventative) must be improved, and better control of residential care facilities and orphanages and their admission criteria is required. Residential facilities must be required to demonstrate that all avenues for family fostering and family replacement care have been exhausted before children are admitted into institutional care. Non-family residential care is especially detrimental for young children, and every effort should be made to avert it (Frank et al., 1996; Nelson, 2007).

Early psychosocial interventions among young children affected by HIV and AIDS have the potential to protect and enhance their development. In disadvantaged communities in the western world, antenatal and early childhood psychosocial interventions have been shown to provide long-term benefits to children and their families (Chandan and Richter, 2008; Olds et al., 2007; Shonkoff and Phillips, 2000). For example, a 15-year follow-up study by Olds (2006) of a group of mothers randomly allocated to home visiting by nurses during pregnancy and early childhood demonstrated considerable benefit. Various early child development programmes implemented in the developing world, including nutrition, health and stimulation, also show promising results (Engle et al., 2007).

6.4.2 Programme Activity

Among the many actors involved in the South African programmatic response to HIV and AIDS, civil society organisations (CSOs) provide the majority of crucial services and on-the-ground care for children and families living in highly affected communities (Berry and Guthrie, 2003). Despite their clear willingness to help, and the existence of many apparently beneficial interventions, to date, there is still no comprehensive, knowledge-based ‘package’ of interventions (Dellis, 2007).

Although documents such as *The framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS* (UNICEF/UNAIDS, 2004) provide guidance for CSOs, no organized attempt to examine how evidence-based directives can be drawn into the civic landscape exists. As a result, many current programmatic efforts proceed somewhat speculatively, with little direction from research, and concern about CSO interventions has been emphasized in a number of recent reviews. Hunter (2000), for example, says that current programme activity is ‘all over the place,’ with no consistency of approach or target group. Williamson (2000) points out that most initiatives are inappropriate to the scale and magnitude of the problem, and Subbarao and Coury (2004) highlight the ‘sporadic’ and ‘piecemeal’ nature of interventions, along with the lack of rigorous evaluations, or even studied success stories.

Because of widespread and deep poverty, which seriously compounds the impacts of HIV and AIDS on already vulnerable families, many CSOs provide poverty-relief measures such as food, school fees, school uniforms and other forms of assistance to affected households and children. However, these are of unknown effectiveness, and generally less efficient than direct income transfers to the poorest households. CSOs carry a long chain of intermediary costs, including donor costs, staff salaries and other infrastructural expenses (Foster, 2005; Richter and Desmond, 2007). Supplementing the work of faith-based organizations, many CSOs also provide psychosocial support to children and families, such as home visiting, memory work, peer support groups for children, play groups and holiday camps for young people. However, few of these programmes have been evaluated (Richter et al., 2006). Apart from early child development centres and their outreach activities, and palliative care programmes, very little assistance is targeted directly to infants, young children and their caregivers (Govender et al., 2006).

6.4.3 Developments on the Global Front

In 2006, two publications significantly changed the discourse on support for children affected by HIV and AIDS. These were *The role of the health sector in strengthening systems to support children's healthy development in communities affected by HIV/AIDS,* commissioned by the World Health Organization (Richter, 2006), and *Where the heart is: Meeting the psychosocial needs of young children in the context of HIV/AIDS*, commissioned by the Bernard van Leer Foundation (Richter et al., 2006). The authors argued that scattered, small-scale projects simply could not rise to the challenge that the epidemic was posing for family and child well-being. Rather, the situation demanded national-level interventions, led by government, on which CSO interventions could build. They also argued that to ensure appropriate protection, prevention and intervention, the impacts of HIV and AIDS on children needed to be understood in the context of environmental poverty, stress and dislocation, and from the perspective of what is already known about child development.

In the same year, the Joint Learning Initiative on Children and HIV/AIDS (JLICA) was initiated, as a global, multi-sectoral research effort to review the best evidence available and to make recommendations for practice, principally for governments in affected countries. The major recommendations of JLICA are to increase rapidly the access of children and families to ARV treatment, as well as to health care and education; to provide family-focused prevention, treatment and care services to affected households; to support families through the immediate introduction of income transfer programmes in the worst affected countries; and, specifically for young children, to integrate prevention of vertical transmission programmes with early child development services (Richter, 2008, www.jlica.com).

6.5 Conclusions

HIV and AIDS are having severe, generational impacts on children, affecting them directly, and indirectly through their detrimental impacts on families, communities and social services. The youngest children, although most vulnerable because of their dependency on caregivers, have received the least attention.

Prevention of vertical transmission is less available and less effective than it could be, and children's access to treatment is growing more slowly than adults' access. Few sustained global or national programmes to support children affected by HIV and AIDS have been developed or implemented.

To some degree, this is because children tend to be invisible and unheard. But it is also because families – as they always do – have stepped in and provided immediate assistance and protection to affected children. This response by families and communities is unobtrusive, often unnoticed, seldom counted as significant, and very rarely funded.

This must change. The main thrust of programmes to support children affected by HIV and AIDS must be to strengthen and support families and communities. This support must include economic strengthening through income transfers, universal access to services such as health and education for children, and family-focused HIV and AIDS prevention, treatment and care. Such initiatives will be especially beneficial for the youngest children and will help to protect their food consumption, health care and the stability of their relationships with caregivers. Programmes that link the prevention of vertical transmission to early child development should support mothers, couples and families to provide appropriate security, protection and care for young children, regardless of their HIV status.

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Chapter 7
Poverty and HIV and AIDS

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7.1 Introduction

In recent years there has been an increased interest to study and understand poverty and how it impacts on disease and epidemics (Boucekkine and Laffargue, 2007). In particular, the focus has been to understand the relationship between poverty and HIV/AIDS, especially in sub-Saharan Africa, where HIV prevalence is high and consequences are also harsh on already vulnerable communities (Cohen, 1998). The worsening economic situation is likely to continue to impact negatively on health and development, especially in countries that are already severely affected by HIV and AIDS. In the context of this background, it is important to review the link between HIV and AIDS and poverty in order to further understand the relationship between the two.

7.2 Understanding the Relationship Between HIV and AIDS and Poverty

The relationship between HIV and AIDS is complex and dynamic. Some have argued that the relationship may be bi-directional, that is, downstream and upstream (Greener, 2008). In the upstream direction, poverty is seen as having a catalytic role in increasing vulnerability to HIV infection by, for example, increasing the likelihood to engage in risky sexual behaviour as a means of economic survival (Kalichman et al., 2006). Early sexual debut particularly in households that have experienced an income loss either through illness, death or job loss is common (Gillepsie et al., 2007). Such poverty-related stressors have been said to increase sexual risks (i.e. in the form of multiple sexual partners and/or transactional sex) among the poor in order to secure the financial and human resources they lack (Hunter, 2007; Nattrass, 2004; Pettifor et al., 2004). Poverty can also make it difficult for people affected to concern themselves with long-term risks. They may believe that their lives will be short because of poverty, thus they have nothing to lose by risking infection in the quest for survival. To explain this phenomenon Tladi (2006) employs the behaviourist "drive" theory. According to this theory, "drives"

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_7,

are forces that motivate human beings to behave in a particular manner. The theory maintains that there are particular essential factors without which human beings cannot survive, which means that when a certain need arises, individuals are compelled to behave in ways that ensure that such a need is satisfied. This theory may explain why transactional sex has become common and even acceptable as a means of survival for women (Béné and Merten, 2007; Pettifor et al., 2004). Research has however shown that in the context of poverty, individuals are likely to engage in risky sexual behaviours as an attempt to remedy their situation. For instance, poor individuals are likely to make a decision around the constant assurance of human resources such as food, shelter etc. and not necessarily around HIV/AIDS prevention (Gillespie et al., 2007; Loewenson, 2007). This illustrates that poverty exposes individuals to situations that make them vulnerable to HIV infection.

Greener (2008) posits that little evidence exists to demonstrate that poverty and social deprivation increase vulnerability to HIV, with the exception of education, which provides a protective effect (Coombe, 2000). The evidence cited for a negative relationship between poverty and HIV/AIDS is based on the recent analysis of demographic health survey data from eight African countries, which show that people in the wealth quintile when compared to the poor quintile have a much higher HIV prevalence (Mishra et al., 2007). They further argue that infections are concentrated among the urban employed and more mobile members of society who fall in the wealthier groups. However, the South African population-based data show that unemployed people have a much higher HIV prevalence than employed persons (HSRC, 2005), which contradicts the position espoused by Mishra et al. (2007). Mobility is a confounder of the relationship between poverty and HIV. Employed people who are away from home for longer periods are at increased risk of contracting HIV (Gebrekristos, 2001; Lurie et al., 2003; Williams et al., 2002; Zungu-Dirwayi et al., 2007). Separated from their support systems, spouses and other family members, many find anonymity attractive and the relaxed local norms may lead to a change in values, resulting in the likelihood to engage in risky sexual behaviour that may result in infection (Lurie et al., 2003; Williams et al., 2002). Furthermore, the urban working population is not monolithic, it includes the working poor. It is evident that the assertion that poverty increases vulnerability to HIV is complex and is also contextual (Gillespie et al., 2007).

Another potential source of bias in the findings on the negative relationship between poverty and HIV is methodological. The use of mathematical models that show that countries with high HIV/AIDS are those that also have high incomes is another reason why it has been suggested that there is no relationship between HIV/AIDS and poverty (Greener, 2008). Countries in Southern Africa, such as Botswana and South Africa, are often cited as prime examples. However, the models used to plot the graphs that compare countries according to income and HIV/AIDS are prone to ecological inference fallacy, meaning conclusions regarding the causal relationships between HIV/AIDS and high income countries tend to be drawn from data that focuses on aggregates. Another factor that may contribute to the apparent negative relationship between HIV/AIDS and poverty is the lack of a uniform measure of poverty. The World Bank measure of poverty is $1 per day or $2 per day, and this is not applicable in all countries.

Empirical data collected within countries show a clear positive relationship between poverty and HIV. In 2004, the Human Sciences Research Council (HSRC) team conducted a survey using a probability sample of nearly 16 000 teachers in the public education sector and concluded that low socio-economic status is positively related to HIV status (Shisana et al., 2005a). The teachers who said they did not have sufficient income to meet their basic needs such as food had a higher HIV prevalence (15.5%) when compared to those who have most of the basic necessities, but few luxury goods (10.7%) and to those who had some money for extra luxuries such as going away for holidays and luxury goods (3.8%). Even when using objective measures such as salary earned per annum, those who earned less (US$7 894) had a much higher HIV prevalence (17.5%) than those who earned more ($US17 368) (5.4%). The same was observed among those who had less education (less than a high school diploma) compared to those who had a degree or higher (Zungu-Dirwayi et al., 2007). In a population-based survey of all South Africans aged 2 years and older, those living in informal settlements had a much higher HIV prevalence (17.6%) compared to those who live in urban formal areas (9.1%) (Shisana et al., 2005b). The four measures all show that poverty is positively related to HIV/AIDS.

Higher income groups are more likely to have access to HIV prevention information and resources. Poverty increases the risk of infection in several ways. The poor in many countries are likely to be uneducated and illiterate, which can make it difficult to reach them with written information about preventing HIV infection (Kalichman et al., 2006; Loewenson, 2007). At times, interventions are designed without taking into account the realities of the poor as well as those that might be outside urban areas where these programmes are piloted. Interventions that promote condom use often fail to take into account the role of power relationships between men and women and possible negative consequences such as violence that can impact on condom use (Gregson et al., 2002; Jewkes et al., 2003; Lary et al., 2004).

In a study conducted in Vietnam (Bloom et al., 2001), individuals in the wealthiest quintile were more than twice as likely as those who were in the poorest quintile to be aware of the benefits of using condoms in HIV prevention, of avoiding sex workers as an HIV-preventive measure and to know where to access condoms. Having more education was also beneficial in preventive knowledge. Those with tertiary education compared to those without were more than six times as likely to be aware of HIV-preventive benefits of condom use. An association between condom use, knowledge of prevention methods and the level of education has also been reported in Mozambique (Font et al., 2006). The findings from the two studies show that being poor and having less education increases vulnerability to HIV.

7.3 Reasons for Poor People Having Increased Risk of HIV

The understanding of who is vulnerable to HIV infection has changed over time. When the epidemic started, HIV infection was reported not among the poor nations of the world but among the developed countries such as the United States and later in Europe (UNAIDS, 2000). At an individual level, it was common among the well-off individuals who where mostly at risk because they were mobile or had a different sexual orientation. Later as the epidemic spread, we began to see a shift as the men who have sex with men decided to mount effective HIV prevention programmes. Consequently, developed countries galvanized their resources and were able to reduce not only new infections but also began treating those with AIDS, thereby changing AIDS from a fatal disease to a chronic condition that can be controlled by antiretroviral medication (CDC, 2006). The epidemic spread rapidly in developing countries with some countries having HIV prevalence of up to 30% among pregnant women by 2006 (UNAIDS, 2006; 2008). Today evidence suggests that globally HIV prevalence is indeed high in the poor countries of the world, as illustrated in Table 7.1 (UNAIDS, 2008). However, this picture does not adequately explain some of the differences seen when evidence is viewed at a regional level, especially in the sub-Saharan region.

Within countries, national household data suggests that it is the poor in urban informal settlements that are severely affected by HIV, not the rich. Poverty creates both a social and environmental situation that renders the poor more susceptible to HIV infection (Ganyaza-Twalo and Seager, 2005; Hunter, 2007; Kalichman et al., 2006; Loewenson, 2007; Shisana et al., 2002, Shisana et al., 2005b). In a South African National household HIV prevalence study, it was found that HIV infections are high in poor areas in the general population. The study estimated an annual incidence rate of 7% in urban informal settlements as compared to a 1.8% in urban formal areas; 2.8% in rural formal areas and 2.7% in rural informal areas (Shisana et al., 2005b). Other complexities are the gender dimension and the intergenerational aspects of poverty. A variety of data sources have linked gender inequality with HIV infection (Dunkle et al., 2004; Gregson et al., 2002, Jewkes et al., 2003; LaFraniere, 2006). It is widely accepted that women are at risk of HIV due to their gender and

Table 7.1 Prevalence of HIV in developed, developing and poor countries

Country	Estimated population in Millions	Number of people living with HIV	Adults aged 15–49 years HIV prevalence (%)	Number of children aged 0–14 years living with HIV	Orphans aged 0–17 years due to AIDS
U.S.A	3016210	1200000	0.6	–	–
Japan	1277708	9600	–	–	–
South Africa	475875	5700000	18.1	280000	1400000
Botswana	18814	300000	23.9	15000	95000
Malawi	139201	930000	11.9	91000	550000
Ethiopia	790869	980000	2.1	92000	650000

Source: UNAIDS (2008)
*2007 The World Bank

social standing. In many societies women tend to be dependent on men, making it difficult for them to protect themselves from HIV infection (Hallman, 2004; Haram, 1995; Leclerc-Madlala, 2006).

7.4 Is HIV a Function of Poverty or Income Inequality?

Evidence suggests that countries with greater inequality have higher HIV prevalence. South Africa is an example of such a country. Cohen has suggested that to understand the relation between HIV and poverty one has to understand the complex socio-economic processes that are part of the African society (Cohen, 1998). Although Ethiopia and Malawi are poorer countries than South Africa and Botswana, the income disparity is significantly less. Interestingly, the featured countries with a lower Gini coefficient (measuring society's level of wealth distribution) (The World Bank, 2009), Ethiopia and Malawi, also have a lower HIV infection levels (3.5% and 14% respectively) compared to South Africa and Botswana with an almost twofold Gini coefficient and significantly higher HIV prevalence levels (approximately 20.7% and 24.1% respectively). The growing evidence linking inequality and HIV suggests a need to investigate the role of not only inequality but also the role of economic transition in the spread of HIV infection (Barnett and Whiteside, 2006). Greener (2008) suggests that economic growth that does not address the needs of the poor and leads to greater income inequality may even increase vulnerability to HIV. Inequalities that were racially enforced continue to be a challenge in many countries, including South Africa. Unequal distribution of resources and denial of access to resources, such as education and limited employment opportunities, may force certain groups to menial jobs. This cycle of intergenerational poverty eventually leads to all kinds of vulnerability, including HIV.

Table 7.2 Income and inequality in selected African countries

	Between-country income inequalities		Within-country income inequalities	
Country	Per capita gross National income (dollar rate)*	Percentage of people with less than US$2 a day*	Gini coefficients of income inequality #	Adults aged 15–49 years HIV prevalence
South Africa	10960	34.1%	57.8 (2000)	16.8–20.7%
Botswana	8920	50.1%	60.5 (1993)	24.1%
Ethiopia	810	80.7%	30.0 (2000)	0.9–3.5%
Malawi	620	76.1%	39.0 (2004)	14.1%

*Source: UNAIDS (2006) # (Source World Bank, Word Development Indicators Report 2007). Note on Gini Coefficient: Perfect Income Equality = 0, Perfect Income Inequality = 100

7.5 Impact of HIV/AIDS and Poverty on Society and Health

Evidence suggests that HIV and AIDS take a heavy toll on the poor who are mostly found in the developing world. The two conditions together (poverty and HIV/AIDS) can create a vicious cycle. The intensification of poverty resulting from being affected with AIDS is not limited to morbidity and mortality due to AIDS but has a negative impact on those left behind. The survivors who are mostly likely to be women and children are left to live on diminished assets and income (Crampin et al., 2004). In many cases those left behind may also be infected. Increasingly, data suggest that families with infected individuals are likely to have another member who has been infected, thus deepening the vicious cycle of poverty even further (Barnett and Whiteside, 2002).

The impact of HIV on a household is dependent on numerous factors that interact to cause vulnerability within the affected family (Barnett and Whiteside, 2002). Factors include the number of cases within a family. In many cases of HIV infection, the child is the first to be tested due to failure to thrive or other health problems affecting development; if the child is positive, the mother is often also positive and her partner too. Colvin (cited in Barnett and Whiteside, 2002) suggests that 60–80% of infection found among women are among those who have only had one sexual partner. The father is often the first to die followed by the mother, clustering becomes a problem for the household as repeated deaths and associated funeral cost in one single family leaves devastation and poverty (Barnett and Whiteside, 2002).

The effects of poverty due to HIV and AIDS infection is also evident amongst widowed women (Ganyaza-Twalo and Seager, 2005; Kurschner, 2002; River and Aggleton, 2001). For instance, studies highlight that in a patrilineal system, wives are likely to receive less support after the death of their husbands from their in-laws and may even be blamed for infecting the partner. They may be barred from accessing land and resources of their late husbands while at the same time they have to remain sole providers for their dependants (Crampin et al., 2004). Woman and children may consequently be forced to engage in survival sex in order to bring income into the family (Wojcicki, 2002a; Wojcicki, 2002b).

To understand the impact of HIV on households, one has to examine the characteristics of the individuals affected such as age, gender, income etc. Other important factors include the household composition, meaning that a household with two adults who are employed is more likely to be cushioned from impact compared to a family where there is no other adult who is employed (Crampin et al., 2004). The remaining adult may be able to take over financially from the infected or deceased person, and the family may fare better than the one with only one adult (Crampin et al., 2004). However, sex and gender roles have their own challenges. Females might be forced to leave their employment to take care of the male member of the family, leading to a decrease in income in the family and deepening poverty. Household coping abilities will also be determined by availability of assets and the ability to get assistance from other sources such as government, community etc.

On the downstream direction, being HIV infected may cause people to migrate downward in the socio-economic ladder; this is especially the case for large households (Bachmann and Booysen, 2003). One of the challenges with AIDS is that the AIDS-related illness may last over a long period of time, marked by episodes of wellness and illness; thus making it difficult for the sick individual to work and support his or her family. Where there is more than one case of infection, there will be a cycle of illness and death (Barnett and Whiteside, 2002). Evidence shows that households that have an HIV-positive person feel the impact through increased health-care expenditure, and loss of income when the person gets sick and dies prematurely (Bachmann and Booysen, 2003; Foster and Williamson, 2000). For example, a study by Bachmann and Booysen (2003), based on a panel of 355 South African households, found that poverty was higher for households affected by HIV/AIDS than those not affected. Furthermore, those affected are likely to see income raking that is deteriorating and are less likely to improve compared to other households. After the adults have passed away, the family may need to be dissolved; in many cases, children are taken over by grandparents or close relatives who may already have their own families (Barnett and Whiteside, 2002).

HIV and AIDS also affects businesses, where high absenteeism increases leading to low productivity, increased training costs and poor quality resulting from work performed by unskilled employees (Bollinger et al., 1999; Ellis and Terwin, 2004). Governments feel the impact of HIV and AIDS as they need to provide more money for HIV prevention, treatment and care, with more tax money being diverted to support HIV and AIDS programmes. Some governments have introduced social grants to support those whose health has been affected by HIV as well as the orphans and vulnerable children who now depend on the state for support. The HIV and AIDS epidemic may also reduce the growth in the economy, with the gross domestic product being reduced by 0.5–1.5% (Greener, 2002; Greener et al., 2005). HIV and AIDS has a micro- and macroeconomic impact.

The impact of HIV and AIDS on the economy is often attenuated because of the use of projections that exclude critical micro-level data. Many lack detailed household data usually collected through household surveys. Such surveys provide data on HIV incidence and prevalence by sex, age, race, formal urban and rural, informal urban and rural areas. Similar data on the workforce is often lacking. Data on the stages of disease progression in the population and HIV is also scarce. Instead, the modellers focus on the direct financial impacts that are related to the illness or death of the infected person (Shisana and Letlape, 2004). Usually excluded are temporal micro-economic impacts on the HIV-negative members of households, such as number of child-headed households, households headed by grandparents, the number of orphans and vulnerable children and anticipated financial losses arising from the possible death of an HIV-positive person (Freire, 2003). If such models were rich with this micro-economic data, it is likely that the modelled impact of HIV and AIDS on the economy would show a substantial impact.

In addition, poverty impacts on the individual's health and his/her ability to access effective health-care resources to treat infections. At times, many poor people die needlessly because they present late at health facilities and die waiting for further diagnostic tests to be performed or results to return from overloaded state laboratories. Crowded living conditions prevalent in informal settlements, for example, increases the chances of infections with other opportunistic diseases, such as tuberculosis (TB), which complicates treatment for those who might already be suffering from AIDS. Globally, TB is becoming a leading cause of HIV-related morbidity and mortality. Approximately one-third of the world's 40 million people living with HIV and AIDS are co-infected with TB, and the mortality rate for HIV–TB co-infection is fivefold higher than that for TB alone (The forum for collaborative HIV research and TB/HIV working group of the stop TB partnership, 2007). Without proper treatment, it is estimated that 90% of people living with HIV die within months of contracting TB (The forum for collaborative HIV research and TB/HIV working group of the stop TB partnership, 2007). In developing countries, HIV-infected people run a 10% annual risk of developing TB (Corbett et al., 2003). HIV fuels the TB epidemic, since it promotes progression to active TB in people with mycobacterium tuberculosis infections, either acquired recently or in the past (Harries et al., 2002). Increased risk of TB is present across the entire spectrum of immunodeficiency.

It is said that the HIV epidemic has completely destabilized TB control in regions with high rates of HIV, for example, in one community it was reported that of the 13,000 people outside of Cape Town, South Africa, the TB patient caseload increased six-fold between 1996 and 2004, from 30 to 180 per year (Lawn et al., 2006). This is coupled with rates of multi-drug-resistant tuberculosis (MDR-TB) and extreme drug-resistant TB (XDR-TB), which are increasing dramatically and also often associated with HIV co-infection (WHO, 2006).

7.6 How AIDS Exacerbates Poverty and Impacts Negatively on Orphans

Children are severely affected by AIDS-related deaths. The most obvious way children are affected is through orphaning (de Waal and Whiteside, 2003). According to Whiteside, orphaning is a series of events, culminating with the death of the parent. With AIDS killing young adults, children may find that there are no family members to look after them. For example, a study in Zimbabwe found that in 65% of rural and urban households with a deceased female, there was no surviving member both in urban and rural sites (Mutangadura, 2000). The safety net provided by the extended family has been eroded by premature deaths and economic hardships. HIV has now led to the birth of households headed by children (albeit small in number) or grandparent/s etc.

In cases where children orphaned as a result of AIDS are taken in by relatives, there is a possibility that poverty could be worsened in households (De Waal and Whiteside, 2003). Such cases are particularly rife in various African societies, which consider it *ubuntu* (you are because I am) and tradition for relatives to take over raising children of deceased relatives, this is regardless of whether the prospective family is financially capable of doing so. This means with the accommodation of new household members poor households are likely to sink even deeper into poverty (Barnett and Whiteside, 2002; de Waal and Whiteside, 2003).

Children who have lost parents may face extreme emotional loss (Skinner et al., 2004). Children can also be stigmatized within the community because their parents are infected, further stressing the child through isolation and lack of community support (Deacon and Stephen, 2007). Poverty and lack of resources may discourage children in need, leading them to drop out of school (Makame et al., 2007; van Donk, 2002). Children in poverty may be pushed into "sugar daddy and sugar mommy" relationships, which increase the risk of infection as these partners are not only older but tend to be in multiple sexual relationships. In this situation young people are dependent and powerless to negotiate safe sex, which leads to early infection, with HIV seen especially among young girls (Shisana et al., 2005b).

Some children are taken out of school to look after the sick and may be even expected to take more responsibility for looking after siblings as the mother spends more time looking after the father or is sick herself (Unicef, undated). Loss of innocence and care-free days impacts on the children affected by AIDS and poverty. Those who moved to the homes of relatives may need to adjust while dealing with the imminent loss. Children may not be treated equally in that family or may be rejected by members of the new household as they are seen as a threat to the already scarce resources (Barnett and Whiteside, 2002). The mechanisms employed by families (e.g. selling off assets or borrowing money) to ease the financial burden often provide temporary expense relief. Removing children from school translates into limited or lack of educational skills, thus exposing them to higher chances of unemployment or low-paying jobs. The principle of education being utilized as a tool to fight poverty would be diminished for such individuals, thus the lack of or limited education would push them down and lead to impoverishment instead. This impoverishment in turn creates another vicious cycle of HIV infection susceptibility and poverty in the next generation.

7.7 The Impact of Poverty on HIV/AIDS Interventions

Poverty tends to have a negative impact on HIV interventions from prevention to treatment. We have alluded above to some of the challenges that are poverty driven, such as malnutrition, food insecurity, risky sexual behaviour and survival needs that often supersede the need to prevent HIV infection. Many prevention interventions are found to be ineffective because the target population is unable to implement changes in behaviour due to poverty. For example, a study in Nigeria among female prostitutes found that 35% had joined that industry because of poverty and a lack of means to obtain food on a daily basis (Oyefara, 2005).

7.7.1 Condom Use

The ability to use condoms and negotiate safe sex is deeply embedded in power relations that cannot be separated from financial independence. Even when individuals know about HIV and how it is transmitted it is possible that they may not practice what they know because of poverty and food insecurity (Kalipeni and Ghosh, 2005). Research shows the link between poverty and low or inconsistent condom use. Oyefara (2005) found a significant relationship between poverty, food security and inconsistent use of condoms among sex workers (Oyefara, 2005; Weiser et al., 2007). Weiser and colleagues (2007) found that transactional sex was common amongst women in Botswana and Swaziland who lacked control over decisions related to food production and consumption but were expected to bear the responsibility of feeding their children and their ailing or elderly relatives. These women were found to be more likely to engage in multiple sexual relationships in return for money and were seldom able to insist on condom usage with their non-primary partners (Weiser et al., 2007).

Furthermore, evidence suggests that the poor and less educated are more likely not to use condoms compared to non-poor people (Tladi, 2006). Possible explanations advanced include economic dependence on partners. A study in Cape Town also found that young men in households with 10% higher poverty rates were less likely to report condom use at last sex (Dinkelman et al., 2007). Education and a high economic status is said to be associated with increased condom use and reduction in multiple partners (Hargreaves et al., 2007). In view of this evidence, it is clear that interventions that fail to take into account poverty and food insecurity as contributors to HIV infection rates will not have an impact in reducing the number of new HIV infections.

7.7.1.1 ARV Treatment and Poverty

Food security is the greatest threat to the scale-up of antiretroviral (ARV) treatment provision in some of the countries most heavily affected by HIV. In places where there is no source of income, the poor are faced with challenges such as unemployment and food shortages. Not having any income means that the poor do not have access to basic necessities and those on ARV treatment do not have the assurance that they will have regular and nutritious meals necessary for taking their medications and boosting their immune system. The lack of or poor access to food in turn affects their already compromised immune system as their chances of illness are increased (Stillwaggon, 2001).

Furthermore, poor individuals may have difficulty paying for transport to their points of ARV collection and may struggle to access their medication regularly. This is even worse for individuals who are bedridden and who need special transport to health facilities where they can receive their treatment. Once the family of the sick person or patient can no longer afford to pay, previously relied on transport gets terminated, thus threatening the course of accessing treatment duly.

Threats to adherence are many but a recently reported threat has to do with availability and withdrawal of disability grants for those with AIDS (Nattrass, 2005). In an attempt to ensure that they do not lose their disability grants, stopping treatment has been reported to be one of the strategies employed by poor HIV-infected individuals to sabotage their ARV adherence to ensure a low CD 4 cell count. The Nattrass

(2005) study found that it was prevalent among temporary (16 months) disability grant benefactors to default on treatment adherence a few weeks before testing their eligibility to continue with the disability grant and then resume treatment adherence after the test has been performed. This practice has many implications, including issues around resistance.

In addition, another strategy utilized by temporary HIV beneficiaries in order to ensure a low CD4 count was the non-use of condoms weeks before the testing due date (Leclerc-Madlala, 2006). Seeing that counsellors in their initial counselling sessions with individuals who had just discovered an HIV diagnosis had put emphasis on condom use, participants interpreted this emphasis to mean that non-condom use prior the due date of testing would expose them to a variety of viruses, which in turn would impact on their immune system leading to a low CD 4 count. This has public health implications in that individuals that are infected are likely to infect others and to expose themselves to re-infection with other strains of the virus, which can be more vicious than the strain they already have, and this complicates treatment.

Although such strategies may appear to be "reckless," they represent genuine lived experiences of how poverty shapes people's experiences of HIV together with the financial assistance linked to it. Therefore, not having access to an income in the form of a grant not only creates a vicious cycle of sickness and health and robs the person's ability to buy nutritious food that works in conjunction with the ARV treatment aimed at improving one's health.

7.8 Conclusion and Recommendations for Further Research and Interventions

There is ample evidence to suggest that poverty increases vulnerability to HIV and in turn HIV/AIDS exacerbates poverty. The relationship is complex and is often mediated by social factors such as mobility, gender, education and stigma. The provision of conditional social services may present an incentive not to comply with treatment plans, which increases public health concerns with regard to resistance and adherence. HIV prevention and treatment programmes should therefore take into account the socio-economic status of affected groups and individuals. The threat to society resulting from failure to develop interventions that take into account the relationship between poverty and HIV/AIDS may have dire consequences to public health, which include default on condom use leading to high HIV infection rates and X-treme drug-resistant TB associated with HIV. For families, this means high premature mortality, leading to orphan-hood and other social problems. Research is needed to test new HIV prevention interventions that take into account the socio-economic status of individuals. These intervention trials should investigate the impact of poverty on HIV.

South Africa's antiretroviral therapy (ART) programme is funded through the government's programme as well as the US President's Emergency Plan for AIDS Relief (PEPFAR) programme. It is crucial to conduct an impact assessment study to evaluate whether those receiving treatment were able to resume economic activity that reduced poverty and vulnerability. In South Africa, the government provides a disability grant for all people affected by different diseases and conditions that are debilitative, including any condition that might be short term or long term but impacts on the individual's health and their ability to earn an income to support themselves. The disability grant includes AIDS and at times this has been interpreted as an AIDS grant and linked to the persons CD4 count that is below 200, increasing this misconception about an AIDS grant and what patients need to do to keep it, that is, keep the CD4 count below 200. Like in all disability grants, recipients attend grant reviews to assess if they still qualify for the disability grant, improvement in health may lead to re-classification and loss of the grant. Studies on the impact of the disability grant on adherence to ART are needed. Anecdotal information on treatment cessation or engagement in risky sexual behaviour as a means of retaining the disability grant needs to be investigated empirically. Preliminary information suggests that this is a problem warranting further investigation and intervention.

The paper has highlighted some methodological problems in the study of the relationship between HIV and poverty. In the absence of a standard measure of poverty that applies to all countries it is difficult for researchers from different countries to conduct comparative research on the relationship among poverty, HIV and AIDS. It is crucial that a tool to measure poverty be developed and checked for reliability and validity. Such a measure may be an index that takes into account the perceptual issues as verifiable by material resources such as financial, economic and resources to meet the basic needs of the communities. A common definition of poverty will go a long way in unravelling the relationship between poverty and HIV/AIDS.

Some of the critical questions still needing investigation include the impact of HIV/AIDS on the domestic economy. Mathematical models might include household-level data on HIV and AIDS morbidity and mortality, disaggregated by demographic variables such as age, gender, race, education, etc. Such analysis need to include in one model the macro- and micro-variables that might help to shed light on the relationship with HIV/AIDS on the gross domestic product. However, the models should not be so complex as to depart significantly from reality.

Most studies investigating the relationship between poverty and HIV/AIDS use cross-sectional studies. However, longitudinal studies may be necessary to study the relationship between poverty and HIV. In order to develop meaningful policies and programmes, it is necessary to investigate the temporal sequence of these variables: what came first, HIV or poverty? This is complicated by the observation that death of the breadwinner from AIDS may impoverish the family; and some of the members of the family may engage in transactional sex to meet the basic needs that were previously met by the deceased breadwinner. When the information is collected cross-sectionally, questions might only focus on the transactional sex component and not ask questions about the death of the breadwinner. In conclusion, poverty and AIDS is an important area that warrants further research.

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Chapter 8
HIV and Stigma in South Africa

Harriet Deacon, Leana Uys, and Rakgadi Mohlahlane

8.1 Introduction

Jonathan Mann (1996) was one of the first and most important lobbyists for HIV and AIDS-related stigma research on the international stage. He argued that stigma exacerbated the effects of the epidemic and reduced the efficacy of AIDS programming efforts. During the 1990s and 2000s there was thus an increase in the amount of research on HIV and AIDS-related stigma internationally. This research suggested that stigma and discrimination reduces the impact of prevention programmes, inhibits treatment take-up and adherence, exacerbates the psycho-social effects of HIV-infection and reduces the quality of life of people living with HIV and AIDS (for a review, see Deacon et al., 2005 and Deacon and Stephney, 2007). The United Nations agency for AIDS, UNAIDS, thus chose stigma as its campaign theme for World AIDS Day in 2003.

South Africans were jolted into sharp awareness of the effects of stigma and discrimination by the 1998 murder of a 36-year-old HIV-positive woman, Gugu Dlamini, 3 weeks after she had disclosed her HIV status on a local radio station. She was accused by the local community of shaming them by announcing her HIV status. Many similar cases have been recorded. One of the most important public figures to highlight the problem of stigma in relation to HIV and AIDS in South Africa has been HIV-positive judge Edwin Cameron (2005). Although South African researchers have made key contributions, there has until recently been relatively little research on HIV and AIDS-related stigma compared to other kinds of AIDS-related research in southern Africa. In social science research there has been more emphasis on understanding the behaviour that increases HIV risk, such as early sexual debut, transactional sex and gender violence, and on monitoring treatment access and human rights, than on stigma.

8.2 South African Contributions to Stigma Theory

South Africa is a society in transition coming from a troubled and divided past with high levels of social tension, gender-based violence and inequality. At the same time, the South African legal system has been hailed as one of the most progressive

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_8,

in the world since the development of a new human-rights-based Constitution in 1996. This combination of factors has made South African researchers particularly interested in understanding HIV and AIDS-related stigma within the broader context of theories about other kinds of prejudice and within the context of socio-economic and gender inequality.

8.2.1 Definitions of Stigma

Defining stigma sets the terms of the debate for how to measure it and how to address it. Defining stigma has proved to be rather difficult and a point of contention within the field (Link and Phelan, 2001). The definition of disease stigma today owes much to Goffman (1963), who suggested that people who possess a characteristic defined as socially undesirable (such as HIV infection) acquire a 'spoiled identity', which then leads to social devaluation and discrimination.

Various authors have challenged the tendency to see stigma as an individual attribute and have highlighted the importance of social power relationships in shaping stigma, through sociological analyses (Parker and Aggleton, 2003), and cognitive and psychoanalytic approaches from social psychology (Joffe, 1999; Link and Phelan, 2001). South African scholars have contributed to this debate by offering some new theoretical directions on stigma (Deacon et al., 2005; Jennings et al., 2002; Joffe, 1999; Stein, 2003), which were influenced by approaches to the study of social psychology and racism developed by Professor Donald Foster at the University of Cape Town during the 1980s (Foster, 1991). This work attempted to bridge the gaps between individualistic explanations for stigma (and racism) and broader socio-economic explanations. Along with collaborative research initiatives like ICRAAS (the International Consortium for Research and Action Against health-related Stigma), South African researchers have underlined the importance of understanding health-related stigma through comparative studies.

Joffe (1999), for example, suggests that stigma is a fundamental emotional response to danger that helps people feel safer by projecting controllable risk, and therefore blame, onto out-groups. Stigmatisation thus helps to create a sense of control and immunity from danger at an individual and a group level. HIV and AIDS-related stigma allows individuals to distance themselves from other ('promiscuous', 'gay', 'black', 'white', 'non-religious', 'young', 'urban') people who are presumed to be at greater risk of contracting HIV because of their behaviour. These socially constructed representations only result in discrimination and the reproduction of structural inequalities when other enabling circumstances (such as the power and opportunity to discriminate) come into play (Joffe, 1999).

One of the debates raised by this work was the relationship between stigma and discrimination. Stigma can affect people negatively even where active discrimination does not occur, so only investigating it when it results in discrimination is problematic (Jennings et al., 2002). Drawing on some of this work, Deacon (2006) suggested that stigma can be defined as a social process in which illness is constructed as preventable or controllable; 'immoral' behaviours causing the illness are identified; these behaviours are associated with 'carriers' of the illness in socially stereotyped 'other' groups; some people are thus blamed for their own infection; and status loss is projected onto the 'other', which may (or may not) result in active discrimination.

The social context of stigma is thus a very important factor in defining the way in which it is expressed and experienced. Following the work of Ogden and Nyblade (2005), South African research has started to refine our understanding of the drivers of stigma (Campbell et al., 2007) such as

> fear, the availability and relevance of AIDS-related information, the lack of social spaces to engage in dialogue about HIV/AIDS, the link between HIV/AIDS, sexual moralities and the control of women and young people, the lack of adequate HIV/AIDS management services, and the way in which poverty shaped people's reactions to HIV/AIDS (p. 403).

Holzemer et al. (2007a) also used Southern African data (from 43 focus groups in five African countries) to develop a conceptual model of HIV/AIDS stigma that seeks to understand both contextual factors (such as the health-care system) and the stigma process itself (such as the different types of stigma and stigma triggers).

8.2.2 Stigma Typologies

Various kinds of stigma have been differentiated in the international literature. Instrumental stigma (fear of infection from casual transmission) has been distinguished from symbolic stigma (moralistic shaming and blaming) and felt (internal) stigma from enacted or expressed (external) stigma (Herek, 2002). People who are stigmatised can internalise stigma (i.e. accept negative judgements) and make judgements about how much stigma they expect to experience, termed perceived stigma. Courtesy stigma is stigma directed at the families or friends of HIV-positive people. South African research (Siyam'kela Project, 2003) has used similar typologies.

The Southern African literature (Maughan-Brown, 2006a; Moon et al., 2002; Orr and Patient, 2003 cited in Stein, 2003) has contributed to this array of topologies by elaborating a category called resource-based stigma that describes stigma based on resource concerns due to judgements about the likely social contribution of a person living with HIV/AIDS. It is important to understand these 'types' of stigma not as separate entities, but as different dimensions of the same phenomenon. A growing understanding of the way in which stigma is shaped by its form and context will shape research and inform interventions.

8.3 South African Stigma Research

South African stigma research has documented the negative effects of stigma and discrimination and has provided qualitative and quantitative analyses of the nature and extent of stigma in the country. Broadly speaking, it has followed international methodological trends, although some new quantitative instruments and analytical insights have been developed.

8.3.1 Developing Stigma Instruments for South Africa

Quantitative measurement instruments for stigma were developed relatively early in the epidemic in the United States, measuring knowledge, attitudes and behaviours or some of these factors (Herek and Glunt, 1988). Most studies initially investigated knowledge and attitudes in the 'general population', without establishing their HIV status. Later it became evident that there was a need to research HIV-positive people's experiences of stigma (Berger et al., 2001) and the attitudes of health-care workers towards them. There was, however, initially no comprehensive stigma index designed to measure attitudes, knowledge, perceived stigma and the effects of stigma (Nyblade, 2006).

Stigma instruments have only recently been developed and validated for southern Africa. Nyblade et al.'s (2005) work for USAID on measuring stigma in Tanzania proposed comprehensive new indicators that were appropriate for the southern African context. A comprehensive set of internal and external stigma indicators were also developed by the Siyam'kela Project (2003). The study did not validate a new instrument but suggested how the indicators could be verified in different settings and listed conditions for use of the indicators.

Maughan-Brown (2004) published an instrument to measure HIV stigma in the community using 26 items on a five-point rating scale with reasonable statistical qualities. Kalichman et al. (2005) developed another validated instrument to measure HIV stigma in the general South African population: a nine-item AIDS-Related Stigma Scale with internal consistency, reasonable stability over time and some indications of construct validity, available in three languages. The University of KwaZulu Natal/University of California San Francisco (UKZN/UCSF) research project in five African countries produced two validated instruments. The first, the HIV/AIDS Stigma Instrument for persons living with HIV/AIDS (PLHA) (HASI-P) is aimed at measuring the stigma experienced by PLHA (Holzemer et al., 2007). It is a 33-item instrument, covering six factors (verbal abuse, negative self-perception, health-care neglect, social isolation, fear of contagion and workplace stigma), with acceptable internal consistency reliability, construct and content validity. The second, the HIV/AIDS Stigma Instrument for Nurses (HASI-N) is a 19-item instrument, comprised of two factors (nurses stigmatising patients and nurses being stigmatised) with a Cronbach alpha of 0.90 (Uys et al., 2009). It can also be adapted for use by other health professionals.

8.3.2 Research Findings in South Africa

Although the Demographic and Health Surveys South Africa and HSRC/Nelson Mandela studies (Shisana et al., 2002, 2005) have included questions on knowledge and stigmatising attitudes, there have been few national surveys that use internationally or locally validated stigma instruments. More recently, the UKZN/UCSF study, one of the most comprehensive African stigma studies to date, has measured stigma experienced by a group of 1457 PLHA and 1384 nurses in five African countries, including South Africa, in three waves, 6 months apart (Greeff, et al., 2008b: Makoae et al., 2008a).

Most quantitative research in South Africa has used smaller localised samples and has focused on identifying stigma as one of a number of factors affecting access to testing, disclosure, treatment or support (Hutchinson and Mahlalela, 2006; Peltzer et al., 2007). A few stigma researchers have used local quantitative studies to explore the drivers of stigma in greater depth, for example, the relationship between stigmatising attitudes and behaviours and levels of biomedical knowledge, trust in biomedicine, traditional beliefs and other social and economic characteristics (Kalichman and Simbayi, 2003, 2004; Kalichman et al., 2006). Analysis of University of Cape Town's (UCT) Centre for Social Science Research (CSSR)'s Cape Area Panel Studies (CAPS) has explored relationships between different kinds of stigma and class, religion and other socio-cultural and economic factors (Maughan-Brown, 2006a, b).

Qualitative research on the nature and effects of HIV and AIDS-related stigma in South Africa includes a number of studies describing HIV-positive people's experiences of stigma (Campbell, et al., 2005a, b; 2006; 2007; Greeff and Phetlhu, 2007; Greeff et al., 2008b; Hosegood et al., 2007; Mills, 2006; Niehaus, 2007; Patient and Orr, 2003; Petros et al., 2006; Siyam'kela Project, 2003; Skinner and Mfecane, 2004). A limited number of studies have investigated courtesy stigma (Orner, 2006).

The nature and extent of stigma changes over time, as death rates from HIV in the community increase or decrease, as more people disclose their status and as testing and treatment becomes more widely available. Jewkes (2006) suggests that stigma could be decreasing as HIV becomes normalised, but recent research suggests that stigma is a significant problem in the country, that it has negative effects and that it may even be increasing. Opinions about the extent of stigma depend on how stigma is measured. Early surveys found relatively low levels of reported stigma in South Africa (Parker et al., 2002; Shisana et al., 2002; Whiteside et al., 2002). But Stein (2003) and Maughan-Brown (2004) argued that low levels of reported stigma could have been found in such studies because they focused on measuring intended stigmatising behaviour and not other aspects of stigma such as othering and blaming (symbolic stigma) and stigma based on fear of infection (instrumental stigma).

Access to ARV treatment seems to be associated with higher rather than lower rates of perceived stigma (Makoae et al., 2008b). Negative judgements (symbolic stigma) against PLHA and fear of HIV infection (instrumental stigma) were expressed by up to half of the respondents in the CAPS study in Cape Town, and measures of stigma are showing an increase over time (Maughan-Brown, 2006a, 2008). The UKZN/UCSF study showed that Quality of Life (QoL) measures for HIV-positive South Africans, which were associated with increased levels of perceived stigma, were among the lowest in the African countries studied (Greeff et al., 2008b). The AIDS Law Project identified numerous cases of discrimination against

HIV-positive people across the country (Jennings et al., 2002; Kohi et al., 2006; Richter, 2001), while Greeff and Phetlhu (2007) described incidents of neglect and abuse. Caregivers and medical professionals stigmatised and discriminated against PLHA, especially where there are limited resources for care (Shisana et al., 2003). Campbell et al. (2005a) described HIV-positive people being hidden in back rooms and kept from care in Kwazulu Natal. Cluver and Gardner (2007) identified stigma as a risk factor in the psycho-social adjustment of children affected by HIV and AIDS.

Expressing stigmatising views against PLHA was associated with delayed testing and treatment in a Cape Town study (Kalichman and Simbayi, 2003). Many other studies reported that stigma seems to inhibit or delay access to HIV treatment and testing services and affects adherence (Cameron, 2007; Doherty et al., 2006; Hutchinson and Mahlalela, 2006; MacPhail et al., 2008; Maughan-Brown, 2007; Mills, 2006; Nachega et al., 2005). In a study of PLHA in a Cape Town township, Maughan-Brown (2007) found that both experienced stigma and perceived stigma were related to inconsistent condom use, fear of disclosure, depression or anxiety and lack of self-efficacy or confidence. South Africa seems to be characterised by low levels of disclosure (Kouyoumdjian et al., 2005; Pawinski and Lalloo, 2001), and relatively late disclosure, which may be linked to stigma (Almeleh, 2006). Low rates of disclosure are correlated with lower access to services (Norman et al., 2007). Levels of perceived HIV stigma were the strongest predictor for job satisfaction in nurses (Greeff et al., 2008b).

HIV and AIDS-related stigma is generated and expressed in different symbolic, economic, political and institutional contexts (Campbell et al., 2005b). People may stigmatise friends and family differently (Maughan-Brown, 2006b). Women may be less stigmatising than men towards PLHA, perhaps because of their gender role as caregivers in families (Visser et al., 2006). The South African work has confirmed that stigma shares many common features across contexts (Ogden and Nyblade, 2005). For example, in the context of a generalised heterosexual epidemic, HIV infection is commonly associated in shaming and blaming discourse with sex and specifically with promiscuity (Harrison, 2008; Petros et al., 2006; Preston-Whyte, 2003). In a Kwazulu Natal study, Campbell et al. (2005a) reported that 'Virtually every informant reported that stigma originated in the association between HIV/AIDS and sex' (p. 810). In this kind of blaming discourse, some people are commonly characterised as 'innocent victims' and others are seen as more blameworthy, often depending on their age, gender, class or the mode of infection. Women who test HIV-positive through antenatal services are often blamed for infecting their partner, because the mother is highlighted as the recipient of treatment in Prevention of Mother to Child Transmission programmes, mothers are also often blamed for infecting children (Siyam'kela Project, 2003). In a survey of 843 women at 26 primary health-care clinics in South Africa, Myer et al. (2006) found that less than half of these women thought that PLHA should remain sexually active and only 13% said that PLHA should be allowed to have children if they so wished.

Patient and Orr (2003) and Niehaus (2007) have highlighted the importance of the ways in which HIV and AIDS has been associated with death. Late disclosure and treatment seeking heightens this association in the Southern African context (Almeleh, 2006). Niehaus (2007) sees the construction of persons with AIDS as 'dead before dying' (p. 845) as more important than promiscuity in defining stigma locally. He conceives of the association between AIDS and death as 'an outcome of the manner in which biomedical discourses have articulated with religious and popular ones' rather than as an outcome of folk beliefs. These beliefs may develop specific features because of the association between 'witchcraft' and AIDS (Ashforth, 2001). Thus, there are specific ways in which HIV and AIDS-related stigma is expressed in South Africa. Some research points to the highly gendered and culturally specific nature of HIV and AIDS-related stigma (Clark, 2006; Petros et al., 2006). Derogatory terms such as 'winning the Lotto' (Uys et al., 2005) or stigmatising gestures using three fingers to denote the three letters of HIV (Mills, 2006) are sometimes local and sometimes more widely used and understood.

Stigma is of course only one of the problems facing PLHA and their families. Other problems include ill health, increased poverty, gender-based violence, inheritance issues and lack of control over areas such as reproductive and sexual decision making. Focusing on stigma and discrimination in isolation from these other factors in decision making, and on investigating failures in caring for PLHA rather than successes, might be problematic in itself. Jewkes (2006) argues that stigma researchers need to explore the diversity of social responses to AIDS, including contexts where 'HIV/AIDS has become part of the repertoire of normal misfortune' (p. 431). HIV and AIDS-related stigma also has to be understood in the context of other forms of stigma and prejudice (Link and Phelan, 2006). New research on TB-related stigma in South Africa and Zambia has shown that it has a close relationship to HIV and AIDS-related stigma (Bond and Nyblade, 2006; Moller and Erstad, 2007).

While stigma research is often tagged on to studies focusing on other aspects of the pandemic, it has now developed into a research area in its own right in South Africa. While confirming the negative effects of instrumental, symbolic and enacted stigma, South African research has highlighted the ways in which internalised and perceived stigma also affect the quality of life and health-related behaviour of PLHA. Further research is needed to understand the contexts where stigma is low and HIV has been normalised. The development of instruments and the extensive descriptive studies that has been done now allows the research agenda to move to intervention studies and the evaluation of such interventions.

8.4 Stigma Interventions in SA: Politics and Pragmatics

Interventions to address stigma are particularly important in countries like South Africa with high levels of HIV/AIDS and a long history of discrimination and prejudice. A number of interventions have been developed, and a few have been implemented in Southern and Eastern Africa, but most have not been formally evaluated. The relative lack of interest in anti-stigma interventions is part of a broader emphasis on providing biomedical treatment and changing the behaviour to reduce HIV risk in South African AIDS programming. But it is also a consequence of dissatisfaction with, and disputes about, the value of various kinds of anti-stigma interventions.

Initially, anti-stigma interventions in South Africa focused on mass media campaigns to increase knowledge about HIV and AIDS, such as Soul City and LoveLife. Anti-stigma messages are often simply added to existing information campaigns. However, in a review of stigma interventions, Brown et al. (2003) showed that mass media education campaigns are not particularly effective by themselves. Anti-stigma interventions should combine educational programmes, for example, with counselling, coping skills acquisition and contact with PLHA, coupling education and awareness programmes with the empowerment of PLHA. Campbell et al. (2007) have proposed that facilitated community-led group discussions about stigma in safe spaces should not impose views of stigma from outside but should build on community experiences and understandings of the problem and link solutions into broader social activism around poverty and human rights.

Workshop tools have been developed to create platforms for addressing problems of knowledge and attitudes towards PLHA, but there have been a limited number of interventions using them and no formal studies evaluating their impact in South Africa. Although not exclusively developed for Africa, one of the first anti-stigma interventions to be used in South Africa was the information-based Engender Health manual (2004). In 2003, Uys developed a similar information-based workshop manual, aimed at nurses, and with the UKZN/UCSF collaboration developed and tested another workshop intervention for nurses. Francis (2006) developed two visual arts-based anti-stigma interventions for university students called ‘Diversity and Education’ (Francis and Francis, 2006a) and ‘Hope and Healing’ (Francis and Francis, 2006b). The International Council of Nurses (ICN) has also developed an information and action toolkit for nurses entitled, *TB and Stigma: A Double Burden, Nursing Interventions for a TB Stigma-free Health Care Facility* (ICN, 2003). In 2003, the CHANGE project published a toolkit for NGOs, community groups and HIV educators based on research in Ethiopia, Tanzania and Zambia called ‘Understanding and Challenging HIV Stigma’, revised and republished in 2007 (Kidd et al., 2007). (The CHANGE Project, a USAID cooperative agreement with the Academy for Educational Development, in collaboration with the Manoff Group between 1998 and 2005, aimed to make health and nutrition programmes more effective by developing and applying practical solutions to behaviour change problems.) The CHANGE and ICN toolkits have not, to our knowledge, been tested in South Africa.

Some stakeholders see stigma as part of the ‘second generation’ agenda – something that will be dealt with, if it still exists, after structural inequalities, service delivery and human rights issues have been tackled (Parker and Aggleton, 2003). Reducing poverty, gender inequality, integrating anti-stigma interventions into the health-care system (Klein et al., 2002) and providing better human rights protection can help to minimise opportunities for stigma and discrimination. But these aims are very broad and long term, and the impact of legislation on improving access to human rights has been limited. A collaborative study conducted by the Centre for the Study of AIDS (CSA) and the Norwegian Centre for Human Rights (NCHR) thus recommended a focus on HIV and human rights training for AIDS service organisations and the creation of para-legal human rights champions within communities (Viljoen, 2005). South Africa's Treatment Action Campaign (TAC) has focused on human rights and treatment provision as its central agenda, tackling ignorance, internalised stigma and discrimination as by-products of these campaigns. PLHA support groups have been shown to be effective in reducing stigma (Dageid and Duckert, 2007) and have been widely implemented in South Africa by TAC and other organisations. The signature 'HIV-positive' TAC T-shirts have come to symbolise the role of disclosure in challenging stigma (although some of their activists have been targeted for attacks because of this openness).

Integration of anti-stigma interventions into the health-care system has not happened very effectively in South Africa. PLHA experience of stigma is affected by the structure of health-care services. Cameron (2007) suggests that the exceptionalisation of HIV, especially in testing procedures within the health-care services, reinforces internalised stigma. Receiving special services may result in involuntary disclosure (Doherty et al., 2006) and more stigma and discrimination from community members (Kelly, 2005). Alongside the development of the National Strategic Plan (NSP) for HIV/AIDS and STIs (South Africa, 2007), the Department of Heath developed a National Stigma Framework and Plan of Action to mitigate stigma, but the two processes were not well integrated. The National Stigma Framework focused more broadly on a range of anti-stigma initiatives across a number of sectors besides health. Within the NSP, stigma was covered in a separate section called 'Key Priority Area 4: Human Rights and Access to Justice' that focused mainly on legal rights and protections and did not highlight the importance of developing anti-stigma programmes integrated into testing, treatment, care and support services.

Jewkes (2006) argues that since educational and legislative interventions have not been very effective in changing behaviour, we should focus on research and interventions into positive role modelling in care and support instead of dwelling on the negative aspects of stigma. Both research and interventions to address stigma need to focus more on successes than failures of social support for PLHA, but, as with racism, combating stigma requires not only positive role modelling but also the development of critical tools to 'expose, confront, and resist the webs of signification and practice that sustain stigma' (Campbell et al., 2005a, p. 814).

Stigma is hard to define and research, it is easy for health-care services to deploy as an excuse for non-delivery, and the efficacy of existing interventions has not been fully investigated. Although stigma is often mentioned as a problem, interventions to reduce stigma are thus in their infancy in the South African context and too little work is being done to evaluate them. Because of the complex and multi-layered array of factors feeding into HIV/AIDS stigma, it needs to be tackled at a number of levels in addition to the level of health education (Campbell et al., 2007). The best kinds of interventions will probably combine social activism like that of the TAC that models positive images and supportive care with targeted programmes to develop social support for supportive communities that is based on a critique of stigmatising ideology. These will be combined with integrated initiatives to ensure that stigma does not limit access to health-care services and social support for HIV-positive people and their associates.

8.5 Funding and International Collaborations in Stigma Research

Stigma research in South Africa has been characterised by a number of international collaborations. This chapter will focus on the Siyam'kela collaboration between the POLICY Project (now the Health Policy Initiative), the National Department of Health and the Centre for the Study of AIDS (CSA) at the University of Pretoria; and the UKZN/UCSF collaboration between the University of Kwazulu-Natal (UKZN), various other African universities and the University of California at San Francisco (UCSF). Other significant collaborations include those between researchers at the HSRC and the University of Connecticut (Kalichman et al., 2006); and the collaboration between researchers at the London School of Economics and the Centre for HIV/AIDS Networking (HIVAN) (Campbell et al., 2007).

An analysis of funding priorities for AIDS programmes showed that comparatively few public sector resources were made available in education and social development – public sector funding has focused on the Department of Health (Ndlovu, 2005). Donor-funded and international collaborative projects have thus been particularly important in gaining financial support for 'soft' issues like stigma research. For stigma research as much as for other AIDS research, external funding provides an opportunity to conduct larger studies than would otherwise be possible. Given the scientific brain drain in South Africa, it can also help to support projects with additional skills where capacity gaps exist.

At the same time, external funding priorities and the needs of collaborating organisations do affect the way in which research is done and services are provided (Birdsall and Kelly, 2007). Tucker and Makgoba (2008) have suggested that there continues to be a 'neo-colonial' relationship between regions like Africa and these global public–private partnership organisations that contract out the majority of clinical trials to address AIDS, TB and malaria in the developing world. They have called for more significant African involvement in these partnerships and the relocation of some of them to developing countries to reduce the brain drain. The real dangers that these critics identify, which could apply to locally driven projects as much as to international collaborations, is that the agenda for research is sometimes not locally relevant, that beneficial outcomes do not filter down to the country where the data is collected and that local skills are not recognised where they exist, and developed where they need further capacity. These issues have to be addressed both within specific projects and in the broader research planning process for AIDS research within the South African National AIDS Council (SANAC) Research Sector.

The way in which collaborations are organised can ensure that developing country agendas and strengths become a priority. On the UKZN/UCSF collaboration, Uys (pers. comm., 2008) commended the leadership of Bill Holzemer from the School of Nursing at UCSF in creating a collaborative working arrangement in which country coordinators from the five African countries could contribute ideas and insights in managing the project. This level of collaboration was possible because of a generous budget for communication and face-to-face meetings between the collaborators. The partners used the meetings to review and finalise the analysis of data and review articles prepared by members in the latter stage of the project. The structure of the UKZN/UCSF project aided collaboration. Country PIs (senior academics in the African university nursing schools) were responsible for all the work in their own countries, the general African PI (Uys, pers. comm., 2008) was responsible for giving support and collating all country work, managing the finances and meetings and assisting with data entry, analysis and article writing and submission. The UCSF PI (Holzemer) managed the relationship with the funding agencies (NIH, Fogarty, etc.), gave major input into the planning of each phase, the analysis of data and the submission of articles for publication.

One of the ways in which collaborative projects often seek to ensure implementation of research findings is to involve local service providers, often government departments. The Siyam'kela collaboration (meaning we accept or together we stand) aimed to develop tools to better understand and mitigate HIV/AIDS stigma. The project conducted a national research process to understand the shape and form of stigma in three main areas: the faith sector, government workplaces and the relationship between the media and PLHA. These sectors were chosen because they were seen as influential in shaping attitudes. The project developed indicators for measuring stigma as well as a stigma-mitigation capacity-building intervention in each of these settings that included a resource document for trainers, opinion leaders, PLHAs, community members and anyone interested in finding out more about HIV/AIDS stigma and how to challenge and address it. The Project also helped develop and evaluate the National Stigma Framework with the National Department of Health. Because of the challenges faced by the Department, however, these initiatives have not been implemented as fast as would have been desired. The UKZN/UCSF collaboration also worked with local government departments, developing a stigma intervention based on their research, implementing it in one setting in each of the five countries and describing the results. This has led to real engagement with the issue of HIV and AIDS stigma in countries and policy change in countries like Lesotho and Malawi.

The better collaborations also include capacity-building initiatives. The Social Aspects of HIV/AIDS Research Alliance (SAHARA) ran a capacity-building project, sponsored by the Ford Foundation to mentor local researchers doing work on HIV and AIDS stigma in a number of Southern African countries. To date, the UKZN/UCSF collaboration has produced 11 published articles, 2 more are in press and 6 more are in review. A total of 27 presentations and posters have been presented at conferences, and two more have been accepted for 2008. Local scholars have been the first authors on a majority (8 of 11) of published papers generated by the collaboration (Dlamini et al., 2007; Greeff and Phetlhu, 2007; Greeff et al., 2008a, b; Kohi et al., 2006; Makoae et al., 2008a, b; Naidoo et al., 2007; Uys et al., 2005).

8.6 Conclusion

Research in South Africa has highlighted the importance of understanding both the socio-economic contexts of stigma and its local manifestations. It has improved our theoretical understanding of the problem and shown how different dimensions of stigma affect the health-related behaviour of PLHA and their associates. It suggests that stigma will not recede as HAART becomes widely available, and indeed it may be that certain forms of stigma are on the increase. The effects of stigma in the South African context seem to be very broad and deep: stigma is more than just an injury to an individual, but an indicator of the health of the social environment. Researchers should now focus on developing and evaluating targeted anti-stigma interventions that can be owned by communities and integrated into the provision of health and social services. Donor funding and international collaborations should help develop local capacity building and agency in this process.

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Part II
Prevention and Treatment

Chapter 9
The Politics and Psychology of AIDS Denialism

Nicoli Nattrass and Seth C. Kalichman

9.1 Introduction

South Africa is in the midst of a catastrophic HIV/AIDS epidemic with over 12% of the national population infected with HIV. Although representing less than 1% of the world's population, nearly 10% of people living with HIV/AIDS reside in South Africa. Probably the most perplexing aspect of South Africa's battle with AIDS is former President Thabo Mbeki's rejection of AIDS science in favour of the 'questioning' stance of a small group of 'AIDS denialists'. The story of denialism in South Africa and its political influence is well documented (Cameron, 2005; Gevisser, 2007; Gumede, 2005; Heywood, 2004; Nattrass, 2007) but nevertheless remains an enigma: why did President Thabo Mbeki go down this path? Why did he and his Health Minister reject all expert scientific opinion on AIDS pathogenesis and treatment – even in the face of rising social anger, loss of political standing both domestically and abroad, and at the cost of thousands of unnecessary deaths? How the government not oppose Mbeki and remain silent for so long?

This chapter examines the politics and explores the psychological bases of AIDS denialism in South Africa. We start with a brief discussion of the nature of AIDS denialism and Thabo Mbeki's championing of it in South Africa. We then reflect on various explanations that have been offered – the overall assessment being that none of them is entirely satisfactory and that a more psychological approach might offer additional insights into the politics of AIDS denialism.

9.2 Overview of AIDS Denialism

In general, AIDS denialists either follow the views of a few Australian pseudoscientists who calls themselves 'The Perth Group' who propagate the belief that HIV does not exist at all, or follow the University of California at Berkeley's rogue molecular biologist Peter Duesberg who claims that HIV is a harmless passenger virus. All stripes of AIDS denialists are, however, united by their unshakable belief that the existing canon on AIDS science is wrong and that AIDS deaths are caused by malnutrition, narcotics and antiretroviral medications (ARVs), particularly Zidovudine

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_9,

(AZT) themselves. Thus, when Nelson Mandela's son died of AIDS in 2005, South African attorney and AIDS denialist Anthony Brink accordingly blamed ARVs for his death (Nattrass, 2007: 23). AIDS denialists also attributed the death of Thabo Mbeki's presidential spokesman Parks Mankahlana to ARVs (Mbeki and Mokaba, 2002). Although there have been instances of AIDS denialists in South Africa blaming AIDS on illicit drug abuse, most denialists blame ARVs or poverty for AIDS deaths. It is common for AIDS denialists to take the extreme to the point of absurdity. Illustrating the extremist thinking of denialists, Anthony Brink accused Treatment Action Campaign leader Zackie Achmat of 'genocide' for his role in bringing about policy changes to increase access to ARVs, even trying, unsuccessfully, to get the International Criminal Court to investigate the matter.

Most of those actively advocating AIDS denialism are freelance journalists or fringe academics with no scientific training in medicine. One prominent exception is Kary Mullis, who won a Nobel Prize in chemistry for inventing the polymerase chain reaction. Dr. Mullis has never done any scientific research on HIV, although his autobiography (Mullis, 1998) documents his scepticism about the relationship between HIV and AIDS as well as his encounters with extraterrestrial aliens, his belief in flying saucers, and astrology. The most noteworthy AIDS denialist is Peter Duesberg, who is a member of the National Academy of Sciences and the first person to isolate cancer-causing genes. But his credibility to speak on AIDS is tarnished by the fact that he has never conducted any scientific research on HIV and has no evidence to support his erroneous claim that AIDS is caused by recreational and ARV drugs rather than HIV. Even when presented with clear evidence to the contrary (such as the link between HIV and AIDS in haemophiliacs and the decline in death rates following the advent of ARVs), Duesberg holds fast to his unsubstantiated beliefs (Cohen, 1994). One of the last academic articles on AIDS that Duesberg published (Duesberg and Rasnick, 1998) was accompanied by a point-by-point rebuttal (Galea and Chermann, 1998) in the same journal. This, however, had no impact on the denialists. Peter Duesberg continues to maintain that HIV is harmless and that AIDS cannot possibly be caused by an infectious agent. He is also marginalized by mainstream science and is embraced as a cult figure by AIDS denialists.

AIDS denialism is driven by an international network that promotes its agenda primarily through the Internet, the 'independent' print media and occasionally through public meetings. Many of the links on AIDS denialist websites promote 'alternative' untested treatments for AIDS from vitamins to ozone therapy. The AIDS denialist movement includes entrepreneurs such as Matthias Rath, who has built a large international business (the Rath Health Foundation) claiming that multivitamins can 'reverse the course of AIDS' (Geffen, 2005). Another vitamin cure-allist Gary Null claims that HIV does not cause AIDS and sells vitamins and nutritional products for treating AIDS. Another infamous pseudoscientist and self-proclaimed nutritionist is Roberto Giraldo who describes himself as a 'natural health counsellor' and runs a clinic of 'integral psychoimmunology' in Brazil. AIDS curist entrepreneurs have spoken out against the use of ARVs in South Africa in favour of untested nutritional interventions. Despite a lack of evidence to back up their claims, these individuals have a history of support for their endeavours by the South African Health Minister (Geffen, 2005; Nattrass, 2007).

AIDS denialists downplay their links with the purveyors of alternative therapies, preferring instead to characterize themselves as brave ‘dissidents’ attempting to engage a hostile medical/industrial establishment in genuine scientific ‘debate’. Protected by a cloak of hubris (only they have the intelligence and moral courage to see the world for what it is), they portray themselves as lone, persecuted standard-bearers of the truth. They complain that their attempts to raise questions and pose alternative hypotheses have been unjustly rejected or ignored at the cost of scientific progress itself. This is, however, disingenuous because AIDS denialists continue to champion views that have long since been discredited, and ignore evidence that does not fit their beliefs (Cohen, 1994; Kalichman, 2009; Nattrass, 2007; Smith and Novella, 2006). Given their reliance on pseudoscience, resistance to any contrary evidence and use of disinformation tactics, those who may have once been more aptly termed AIDS dissidents are now more appropriately known as AIDS denialists.

9.3 AIDS Denialism and Former President Thabo Mbeki

As Nelson Mandela’s deputy president, Thabo Mbeki headed up AIDS policy at the start of South Africa’s AIDS crisis. But AIDS was not a central problem of the Mandela years where greater focus was placed on reconciliation and on reforming the old apartheid system of governance. It is as president that Mbeki appears to have been lured into AIDS denialism, most likely sometime in 1998 by journalist Anita Allen (Sparks, 2003). He subsequently followed this up with Internet research of his own and contacted Duesberg and his collaborator David Rasnick in the United States (Bialy, 2004), and Eleni Papadopulos-Eleopulos (the leader of the ‘Perth Group’ which claims that HIV does not exist) in Australia. Soon after becoming South Africa’s second democratically elected president in 1999, he started raising doubts about AIDS science, about the benefits of ARVs (especially AZT) and even the nature and extent of South Africa’s AIDS epidemic. He advised members of the National Council of Provinces to follow his lead and conduct their own AIDS research on the Internet.

The issue gained international notoriety in 2000 when, in the same year that the International AIDS Conference was held in Durban to put the spotlight on the terrible African AIDS epidemic, Mbeki invited all the major international AIDS denialists onto his ‘Presidential Panel’ to debate credible South African AIDS scientists on the causal link between HIV and AIDS. The AIDS denialists Mbeki summoned included Peter Duesberg, David Rasnick, Elani Papadopulos-Eleopulos, Etienne de Harven (former head of a network called ‘Rethinking AIDS’), Roberto Giraldo (who subsequently became an adviser to the Health Minister) and Sam Mhlongo who, along with Rasnick and Brink, subsequently worked for the Rath Foundation in South Africa where they became involved in spreading disinformation on

AIDS while Rath was selling vitamins and running unethical and unlawful clinical trials (Kapp, 2008; Nattrass, 2007, 2008a). By giving equal representation to AIDS denialists and AIDS scientists, Mbeki's Presidential AIDS Panel created the illusion of a genuine scientific contestation. The panel also gave the impression of credibility to fringe academics and pseudoscientists, most of whom exploit their position on the panel to this day. As virologist John Moore observed dryly, the panel comprised 'pretty well everyone on it who believes that HIV is not the cause of AIDS, and about 0.0001% of those who oppose this view' (Cherry, 2000).

Predictably, the presidential panel was entrenched in the circularity of pseudoscientific arguments and obviously could never come to agreement. Despite being presented by evidence from South African scientists that showed HIV-infected babies succumbed rapidly to AIDS and that AZT reduced maternal transmission of HIV substantially (Presidential AIDS Advisory Panel Report (PAAPR), 2001), the denialists on Mbeki's panel simply asserted that 'AIDS would disappear instantaneously if all HIV testing was outlawed and the use of antiretroviral drugs was terminated' (PAAPR, 2001). Instead, they recommended that ARVs be avoided and that all forms of immune deficiency be treated with vitamins and 'alternative' and 'complementary' therapies including 'massage therapy, music therapy, yoga, spiritual care, homeopathy, Indian ayurvedic medicine, light therapy and many other methods' (PAAPR, 2001).

The Presidential AIDS panel served as a means for President Mbeki and his Health Minister to portray AIDS science as deeply divided, thereby giving them the space to resist the introduction of ARVs. But this generated furious resistance from civil society, most notably the Treatment Action Campaign and condemnation from the world's medical and scientific communities. Faced with criticism from home and abroad, Mbeki responded by defending the AIDS denialists in a letter to world leaders. He claimed that attacks on the 'dissidents' were akin to the fanatical repression of heretics and by continuing to argue that the science was too contested to justify the use of ARVs, which in his view, only served the interests of the West, in particular, large pharmaceutical companies (Nattrass, 2007). Mbeki even tried to convince his cabinet that there was a conspiracy between pharmaceutical companies, the US CIA and AIDS treatment activists to infuse dangerous drugs into developing countries (Feinstein, 2007). These sentiments directly parallel the paranoid statements expressed by David Rasnick discussed later.

In the end, Mbeki was eventually prevailed upon by his own party to 'withdraw' from the public debate on AIDS science, although it appears he did not change his mind and continued to question rather than endorse the science of AIDS – for example, by refusing to have an HIV test because it would be confirming a particular paradigm (Gevisser, 2007; Nattrass, 2007). He also presided over a situation in which the Rath Foundation, assisted by Rasnick, Brink and Mahlongo, promoted AIDS denialism in order to get people off ARVs and onto Rath's vitamins.

After his public withdrawal from commenting on AIDS, Mbeki's agenda had been taken forward by his loyal ally, Health Minister Manto Tshabalala-Msimang. As is well documented elsewhere (Nattrass, 2007), Tshabalala-Msimang delayed the use of ARVs for mother-to-child transmission prevention (MTCTP) – until forced to do so by the Constitutional Court in 2002 – and delayed the introduction of ARVs to treat people with AIDS, until protests from civil society forced government to back down. Even after being instructed by Cabinet to provide ARVs, the Health Minister, continued to stress the benefits of alternative untested treatments and to describe ARVs as toxic. Despite having had a public ARV rollout since 2004, South Africa's relative performance in terms of ARV coverage is amongst the worst in the world (Nattrass, 2008b). This is in large part a direct legacy of Mbeki's questioning and undermining of AIDS science.

Does this questioning stance make Mbeki an AIDS denialist? His spin-doctors and some academics (e.g. Ndebele, 2004) think not because he never overtly said in public that HIV does not cause AIDS, although he did say that a single virus could not cause a syndrome. However, this focus on Mbeki's verbal gymnastics is misplaced. As Mark Heywood observes, Mbeki's AIDS denialism can be gleaned from the fact that he questioned rather than affirmed the link between HIV and AIDS and 'left a paper trail of his questions about HIV and hints about his sympathies with the denialists, the impact of which can be traced through what was not done by his government as well as what was questioned and resisted' (Heywood, 2004).

On September 22, 2008 Thabo Mbeki resigned the presidency of South Africa after being voted out of the presidency of the ANC. In one of his first acts on his first day as president of South Africa, Kgalema Motlanthe removed Manto Tshabalala-Msimang from her post as Health Minister. In less than 48 hours, the politics of AIDS in South Africa turned away from denialism. A new government immediately set new policies into motion and the country seemed optimistic that a concerted effort from the top of government would forge a new way forward. The legacy of denialism, however, was sure to endure far beyond Mbeki's days as president. Messages that it is not HIV but rather poverty that causes AIDS and that ARVs are toxic poison have misinformed an entire country. HIV prevalence is climbing and HIV testing is resisted. We now know that hundreds of thousands of South Africans died as a direct result of AIDS denialist policies, especially those that interfered with HIV testing, access to ARVs and use of treatment for preventing mother-to-child HIV transmissions (Chigwedere et al., 2008; Nattrass 2007, 2008a). The legacy of AIDS denialism in South Africa is therefore clear. However, the origins of Mbeki's attraction to denialism remain somewhat of a mystery.

9.4 Possible Explanations for Mbeki's Denialism

Why did President Mbeki champion the views of a small group of discredited AIDS denialists at the clear cost of thousands of South African lives as well as his international reputation? Some analysts try to find an objective institutional/economic rationale for the policy, thereby implicitly arguing that AIDS denialism was a smokescreen for a despicable, but rational, strategy. For example, Nattrass (2004) hints that the failure to provide ARV treatment for people with AIDS was because the (employed) elite preferred to let unemployed people with AIDS die than pay the extra taxes that would be needed to save them. Bond (2006) takes the argument one step further, suggesting that the state was pursuing a naked capitalist class agenda, whereas Fourie (2006) and Butler (2005) argue that the state simply lacked the economic and institutional capacity to deal with AIDS.

The problem with these narrow economic arguments, however, is that they fail to consider the many ways in which government could have reduced the costs of ARVs, including negotiating with pharmaceutical companies for bulk discounts, accepting donor country assistance, issuing compulsory licenses to produce or import generics, and designing less resource-intensive ARV delivery systems, if it had chosen to do so (Nattrass, 2008c). The position also fails to consider that providing ARVs for MTCTP, for example, would have *saved* the government money by limiting the number of AIDS sick children needing treatment in already over-burdened hospitals (Nattrass, 2004). More fundamentally, perhaps, this kind of argument requires us to believe that President Mbeki was the public face of a deeply cynical government agenda to mislead the public on AIDS in order to protect the government budget. Such a claim is inconsistent with the resistance Mbeki experienced from within government and from provincial leaders, and the subsequent willingness of the Minister of Finance to allocate resources to the ARV rollout (Nattrass, 2007). While the idea of an otherwise apparently intelligent state president becoming an AIDS denialist may seem implausible to some, the alternative supposedly 'rational' economic explanation seems even more so.

It has also been suggested that Mbeki's challenging AIDS science is best understood as part of a political struggle with civil society (including activists, scientists, and physicians) over the nature of state power itself. This is obviously true in a bland descriptive sense – as illustrated in this letter to opposition leader, Tony Leon, Mbeki was hostile to having government dictated to by expert opinion:

> The idea that as the executive, we should take decisions we can defend simply because views have been expressed by scientist-economomists, scientist-agriculturalists, scientist-environmentalists, scientist-pedagogues, scientist-soldiers, scientist-health workers, scientist-communicators is absurd in the extreme. It is sad that you feel compelled to sink to such absurdity, simply to promote the sale of AZT (quoted in Nattrass, 2007: 70)

The fact of his hostility to experts is evident. However, what requires explanation is why he chose to set himself, and his government, above the advice of scientists, and why he assumed that scientific opinion had been corrupted by pharmaceutical interests.

A related argument, also focusing on political determinants, emphasizes Mbeki's revolutionary political socialization, which may have predisposed him to seeing science as corrupted by industrial interests (Lodge, 2002; Sheckels, 2004). Even so, none of this explains why he fought the battle so hard – even when it was costing him political support – or why his supposedly revolutionary AIDS policy was so out of step with his own support for the government's orthodox economic policies. It certainly appears that his 'revolutionary' stance extended only to AIDS – and in this respect, his views are best explained with reference to AIDS denialism than to revolutionary socialism.

A different set of explanations for Mbeki's position on AIDS highlights his anti-colonial, Africanist ideology and his desire not to see Africa 'blamed' for a sexually driven epidemic (Cameron, 2005; Fassin and Schneider, 2003; Mbali, 2004). However, this does not explain why he then opted to support the United States, European and Australian AIDS denialists rather than world-class scientists and clinicians in Africa. As Mark Schoofs (2000) comments in his Pulitzer Prize-winning journalism on the problem:

> What makes this all so extraordinary is that Mbeki – who constantly speaks of leading an "African renaissance" in economics, culture and science, and who says he consulted the dissidents to help avert a "superimposition of Western experience on African reality" – apparently chose to slight African science in his search for an African solution. Instead, he gave disproportionate credence to a group of mostly Western theorists who seem especially ignorant – indeed, almost contemptuous – of science conducted in Africa and the clinical experience of African physicians.

Indeed, Mbeki's approach was dismissive of senior African scientists, notably Makgoba (head of the Medical Research Council), and Zolile Mlisana and Kgosi Letlape (successive chairmen of the South African Medical Association). For example, Letlape, in a televised debate with Rasnick, reacted furiously to David Rasnick's claim that there was no evidence that ARVs extended the lives of AIDS patients, accusing him of treating South African doctors 'as idiots.'

AIDS denialists, of course, treat everyone who is not a fellow AIDS denialist as an idiot and a dupe. Such hubris and arrogance is necessary in order to disregard the mountains of scientific evidence on AIDS pathogenesis and treatment. It is also necessary to silence any possible internal voices of doubt that may be enquiring whether the person is really sure enough to put the lives of others on the line. In other words, psychological mechanisms are clearly important in explaining AIDS denialism. Here we explore the psychology of AIDS denialism.

9.5 A Psychological Autopsy of AIDS Denialism

AIDS denialism shares a common psychological basis with other forms of denialism, such as those who claim the Nazi holocaust is a historical lie, that man never stepped on the moon, and that the 9/11 terrorism attacks on the United States were orchestrated by the US government. It is in fact common for denialists to bleed across denialisms. For example, David Crowe, a prominent Canadian AIDS denialist also proclaims that pharmaceutical companies conspire to promote toxic cancer chemotherapies that also offer minimal medical benefits. Another example is the once reputable scientist Lynn Margulis who claims that the 9/11 attacks resulted from a US government conspiracy and that HIV does not cause AIDS. Denialism therefore stems from a general sense of suspicion that ultimately culminates in conspiracy thinking. Conspiracy theories themselves grow out of suspicions that government, industry, science, and medicine are motivated by intertwined sinister agendas. Suspicion, which is the core feature of paranoia and paranoid personality, drives individual attention towards ideas, issues, and anecdotes that confirm preconceived notions of wrong doing. Suspicious thinkers are predisposed to biased perceptions and selective attention aimed towards sustaining their belief systems.

The worldview of the suspicious thinker and paranoid personality can become rigid and impermeable by facts that contradict preconceived notions. Like others with suspicious personality styles, the AIDS denialist selectively attends to confirmatory evidence to bolster his or her existing beliefs. Denialists also manipulate objective reality to fit their preconceptions. The parallel between the suspicious personality style and AIDS denialism is compelling. As described by psychotherapist David Shapiro (1965),

> A suspicious person is a person who has something on his mind. He looks at the world with fixed and preoccupying expectation, and he searches repetitively, and only, for confirmation of it. He will not be persuaded to abandon his suspicion of some plan of action based on it. On the contrary, he will pay no attention to rational arguments except to find in them some aspect or feature that actually confirms his original view. Anyone who tries to influence or persuade a suspicious person will not only fail, but also, unless he is sensible enough to abandon his efforts early will, himself, become an object of the original suspicious idea.

The sense of grandiosity that is central to the paranoid style is also apparent in the AIDS denialist. The denialist sees the ‘real truth’ whereas others are blinded by the conspiring forces of government and industry. In AIDS denialism, the science of AIDS is ‘deconstructed’ by untrained observers to examine evidence that is misunderstood and taken out of context. Journalists, nutritionists, lawyers, and politicians without any scientific or medical training proclaim expertise in what may very well be the most complex biological phenomenon encountered by modern medicine. For example, Canadian naturalist and AIDS denialist David Crowe, who has no scientific credentials beyond a bachelor’s degree, disputes the medical consensus of the World Health Organization, US National Institutes of Health, and every other established group of scientists. Similarly, South African attorney Anthony Brink professes to be an autodidactic AIDS expert who ridiculously claims to know more about AIDS than trained scientists working with HIV/AIDS. Self-proclaimed experts add to the growing pseudoscience propagated on the Internet that is easily confused with credible science and real experts. There is no scientific debate about the cause of AIDS and yet denialists hang on to the argument derived from their own misperceptions.

The grandiosity that is characteristic of paranoia is apparent in the writing and speech of the most visible denialists. For example, David Rasnick in his contributions to the 2000 South African Presidential panel on AIDS stated,

> I don′t have to point out to the government of South Africa that the involvement of the FBI, CIA, and NSA in AIDS represents a far greater threat to our democracies than HIV. The most astounding thing to me about all of this is that the greatest threat to our democracies has turned out not to be goose-stepping soldiers in camouflage but rather the chronic fear peddled by white-coated scientists and physicians and their sycophants in the media who have squandered billions of dollars of taxpayers′ money annually.

Like Rasnick, Matthias Rath also sees a global conspiracy to promote HIV medications and has actually stated that the global AIDS conspiracy is directed at him.

In fact, Rath has claimed that Bill Gates is monitoring his website along with other extraordinary ego-centric beliefs,

> If the governments of the developing world realize that the ARV genocide is the dirtiest way yet to replace the old colonial dependencies between the rich and poor nations of this planet, they will terminate this business. They will, like South Africa choose a health care system independent of the sickening and economically devastating dependency from the pharmaceutical colonialism. The equation is simple: the end of the AIDS business with disease will destroy the entire credibility of the pharmaceutical industry and will terminate the drug investment business worldwide. The collapse of this multi-billion dollar investment business, in turn, will lead to a major crisis in the whole investment industry. In other words, the 'Mother Theresa' PR-stunt of Bill Gates is a desperate, self-serving activity trying to stop this meltdown. If Gates is not successful, and the AIDS genocide by the drug cartel is ended, then the whole paper-wealth of Billy Gates is worthless.

As evidenced by their own words posted on the Internet, books, and interviews, it is apparent that denialism stems from a conspiracy-theory-prone personality style (Kalichman, 2009). From this perspective, the conspiracy-thinking-prone personality represents a disposition towards denialism. People who see only malevolence in governments, industry, and science will identify with claims that events too horrific to understand, such as genocide propagated by Nazi Germany, or devastating terror attacks, or a global pandemic can most easily be explained by those malevolent forces they know to exist. Conspiracy beliefs take on the character of what psychiatrists call encapsulated delusions, where a person who is seemingly otherwise grounded in reality in nearly every facet of their life can have a circumscribed entrenched belief system that is not reflective of reality and not refutable by facts. Although it is not psychologically accurate to state that denialists are delusional, their beliefs specific to the denialist claim certainly have delusional qualities. Most critically, the conspiracy thinking and encapsulated delusional beliefs that are apparent in AIDS denialism can lead to destructive behaviour, including avoidance of HIV antibody testing, rejection of ARV therapies, and even the failure to face an impending epidemic.

Turning back to former President Mbeki, we can ask the question as to whether his denialism is explained by a conspiracy-thinking-prone personality. In his authoritative biography of former President Mbeki, Mark Gevisser (2007) provides a glimpse into the workings of Mbeki's denialism. Gevisser argues that Mbeki is both intellectually arrogant and stubborn – refusing to give way to please the crowd. It would appear that Mbeki knew that he was going to run into major political problems when he started championing the cause of the denialists. It was reported that when the journalist Anita Allen gave him a dossier of denialist literature and suggested that he convene a panel to let their views be known, he said 'I am going to be slaughtered, you know' (Allen quoted in Farber, 2000). It was thus a deliberate decision to march into the line of fire, fully believing he is right while questioning the international medical establishment.

Thabo Mbeki is said to have researched AIDS himself, scouring the Internet for as much information on AIDS as he could find. Like anyone else untrained in science who searches the Internet, Mbeki came across AIDS denialist websites and made the common error of mistaking credentials for credibility. Gevisser (2007) tells us that Mbeki insisted on reading and interpreting the 'science of AIDS' first hand, without filtering and explanation. Suspicious of the medical establishment and pharmaceutical companies, he placed equal value on the views of fringe scientist Peter Deusberg and leading South African scientists. In fact, Mbeki saw the medical establishment as actively silencing the views of 'dissident scientists', as is evident in his saying:

> We have been as it were bought up on an orthodox view. Certain things that one thought one knows – HIV equals AIDS equals death. One of the things that became clear, and which was actually rather disturbing, was the fact that there was a view which was being expressed by people whose scientific credentials you can't question. I am not saying that they are necessarily correct, but it seems to me that there had been a determined effort to exclude their voice – to silence it. (President Thabo Mbeki, South Africa, Interview 2000)

Another common feature of conspiracy-prone thinking that we see in President Mbeki is an actual experience that validates a worldview. For Mbeki, his central involvement in the infamous Virodene scandal may very well serve as just such an event. Early in his presidency, Mbeki backed the South African development of Virodene, a drug that was hoped would cure AIDS, which turned out to be primarily an industrial solvent that demonstrated no benefit and became mired in scandal regarding its funding. The Virodene fiasco may have fuelled a sense of mistrust in medicines and medical authorities that rejected Virodene, planting the seed for Mbeki's denialism.

Perhaps the most compelling account of Mbeki's AIDS conspiracy thinking comes from Andrew Feinstein, a former member of the African National Congress (ANC). Feinstein (2007) tells of an address Mbeki gave to the ANC parliamentary caucus in which he stated:

> There is a huge amount of literature on these issues that we must read so that when we are bombarded with huge propaganda we can respond. If we say HIV = AIDS then we must say = drugs. Pharmaceutical companies want to sell drugs which they cannot do unless HIV causes AIDS, so they don't want this thesis to be attacked. That is one problem. The other one is the international political environment where the CIA has got involved. So the US says we will loans to Africa to pay for US drugs. (p. 124)

From his biographers and observers, we can discern that former President Mbeki shares a core set of beliefs that are common to AIDS denialists. Establishing a presidential AIDS panel that included among the world's greatest AIDS scientist and the world's most discredited AIDS denialists created an illusionary AIDS debate that justified scepticism of scientifically established knowledge.

9.6 Conclusions

AIDS denialism found its way into politics and policies in South Africa. AIDS denialism thrives in the distrust in science and medicine. AIDS denialists such as Anita Allen and Anthony Brink gained access to President Mbeki simply because he was open to questioning what science had firmly established – that HIV causes

AIDS. In that sense, President Mbeki was psychologically vulnerable to the rhetoric and pseudoscience of AIDS denialism. Using his presidential AIDS panel to legitimize the denialist perspective, former President Mbeki set back HIV prevention and care in South Africa and elsewhere. Only with a reversal in AIDS policies that are grounded in denialism will South Africa address the devastation caused by HIV/AIDS.

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Chapter 10
Local-Level Responses to HIV/AIDS in South Africa

Kevin Kelly and Mirjam van Donk

10.1 Introduction

There has been little documentation of the scope and scale of local-level responses to HIV/AIDS in South Africa, although it is apparent that across cities, towns, villages and isolated rural homesteads there have been growing efforts to mount responses to the epidemic. Individuals, informal associations, civil society organisations, businesses and some government departments are supporting or promoting local efforts to address the spread and impact of the epidemic at local level.

In this chapter we review the role of local-level responses in HIV prevention and AIDS responses in South Africa and how these might be optimised. We examine the significance of 'locality' in HIV/AIDS responses, and two main ways in which local responses to HIV/AIDS have been promoted in South Africa: through civil society initiatives and local government. We make a case for a locality-based approach to HIV/AIDS and then develop an overview of the state of local-level responses.

10.2 A Local-Level Orientation to HIV Infections and AIDS Responses

10.2.1 HIV Prevalence at Human Settlement Level

Recent reviews aimed at understanding HIV transmission barely mention the human geography of the epidemic. The characteristics of human settlements and communities, including housing, living conditions and spatial characteristics of neighbourhoods, and the cohesion of communities, have been largely neglected in HIV epidemiology and, ultimately, in HIV-prevention planning.

Much of the work that has been done relates to early understanding of the HIV epidemic when HIV infections were understood as concentrated in, or associated with, particular localities, notably mining hostels, and the implications of labour migration. Now that South Africa is experiencing a generalised epidemic, the dynamics of HIV infections have grown more complex and the effects of another,

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_10,

underlying set of influences, related to community living conditions, are becoming clearer, although it is yet to be fully recognised and understood.

There has been surprisingly little analysis of the differences in HIV prevalence that are often found across communities in close geographic proximity. An exception is a study on the heterogeneity of antenatal HIV prevalence data in the Western Cape Province, which shows remarkable variations in HIV distribution across the districts of the province (Shaikh et al., 2006). In 2005, nearby communities within the Cape Town Metro ranged in antenatal HIV prevalence from 32.6% in Khayelitsha to 5.1% in Mitchell's Plain (Shaikh and Smit, 2005). Shaikh et al. (2006) conclude that the province does not have a single epidemic, but that sub-epidemics within the province are spreading and maturing at various rates.

It has been well established that there is a relationship between urbanisation and HIV prevalence in Africa. A 2005 review of antenatal seroprevalence data across the African continent shows 1.7 times greater median-value HIV prevalence in urban areas (Garcia-Calleja et al., 2006). Comparisons of rural versus urban HIV prevalence, using antenatal clinic data from ten southern African countries (Asamoah-Odei et al., 2004), also found that HIV is more prevalent in urban areas.

In South Africa, HIV prevalence is much higher in urban informal settlements than in other types of settlements (Shisana et al., 2005). There was 5.1% annual HIV incidence in urban informal settlements in 2005 compared to 0.8% HIV incidence in urban formal settlements. Furthermore, these areas accounted for 29% of new infections in the country in 2005 (Rehle et al., 2007). This is all the more notable considering that less than 9% of the South African population lives in urban informal settlements.

To understand high prevalence in informal urban areas (and hence to mount appropriately targeted prevention campaigns), we need to examine the social conditions in situations of rapid urbanisation. This topic remains under-researched. Most research on this subject has focused on social conditions at the individual and household level, and there has been little articulation of the relationship between community living conditions and HIV prevalence.

It is not adequate to ascribe the observed differences across settlement types to behavioural or cultural differences. Although it makes sense to expect behavioural correlates of infection, the determinants of both risk exposure and prevention behaviour must be systematically related to the systemic and structural conditions in the life circumstances of individuals, couples and families within communities. Risk behaviours are systematically elevated in particular types of communities and meaningful prevention behaviours are correspondingly systematically reduced. We need a more nuanced understanding of locality types, which goes beyond the four settlement types – urban formal, urban informal, rural formal, rural informal – used as South Africa's population census categories.[1]

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[1] These four categories were used in the two national HSRC-led national HIV surveys.

10.2.2 Variation in HIV/AIDS Responses at Community Level

There is rationing of ART services in South Africa (Jacobs et al., 2008) according to geographic catchment areas that do not include specific considerations of need, such as the geographic concentration of the HIV epidemic. This has perpetuated long-standing inequities between urban and rural environments and across urban communities (McIntyre et al., 2006; Rangaka, 2007). There are other significant disparities in HIV/AIDS services and responses across settlement types in South Africa, including awareness of antiretroviral therapy, having been tested for HIV and access to forms of HIV/AIDS education media (Shisana et al., 2005). Access to welfare and social support services and efficient bureaucracies is poorer in more remote areas and in urban areas with weak infrastructure and pressure on services due to rapid population influx, such as informal settlements. Basic services essential to care and support differ significantly by place of residence. These factors together mean that not only is HIV epidemiology significantly affected by place of residence, but so too is the likelihood of efficient and effective responses. All basic municipal services, including access to shelter, water and electricity, follow a similar pattern of unequal distribution (Kelly and Ntlabati, 2007), leading to vastly differing contexts of living in close proximity to one another.

Communities may also differ in their responses to HIV/AIDS according to qualities of social interaction. The concept of social capital offers some promising leads in understanding the relationship between HIV/AIDS responses at a community level.'Social capital' – the shared norms and values within a society that enable its members to engage in collective action towards the common good – was first used by sociologists to describe the ability of individuals to access benefits or resources through the social networks to which they belong (Bourdieu, 1985; Coleman, 1988; Loury, 1977). Now the concept is often drawn upon to explain why certain communities may be, for example, more or less prosperous, safe or healthy than others.

Two main forms of social capital are noted in the literature – 'bonding capital,' which resides within relatively homogeneous groups and accounts for their closeness and solidarity, and 'bridging capital,' which describes linkages that reach beyond the confines of the close community and intersect with other homogeneous groupings', for example, as exemplified by networks for people with HIV/AIDS. It has been argued that the cohesiveness of a society is dependent on the existence of 'bridging capital' (or 'cross-cutting ties') (Narayan, 1999).

HIV/AIDS may undermine social cohesion by straining households, kinship ties and various community structures (OSAA, 2003). In many societies, HIV/AIDS adds to household costs, endangers livelihoods and food security, deepens poverty, increases the vulnerability of women and children and leads to the adoption of coping mechanisms such as the selling of household assets, which can result in irreversible destitution. These processes may strain community safety nets, undermine extended kinship ties and alter civic and cultural norms, including values linked to reciprocity and collective action.

Bonds within communities may help to prevent large-scale AIDS epidemics and to mitigate the impact of HIV/AIDS in areas of high prevalence. Linkages have been made between levels of social capital and public health. Societies with high social capital and social cohesion may have better overall population health (Kawachi, 2001; Wilkinson, 1997). The pathways through which social capital may act to shape health are contested, but may include social networks (sharing of health-related information; emotional and physical care and support), civic engagement and activity (community advocacy on health issues and needs), and normative processes that shape health-related behaviours and lifestyle choices and bolster people's sense of self-efficacy. Bridging social capital, through the activities of civil society organisation, may act as cross-cutting ties which link otherwise isolated communities to knowledge, resources, services and opportunities which they might not otherwise have access to (Nauta, 2004).

In South Africa, one of the few studies in this area (Campbell et al., 2002) investigated whether there is a link between associational membership and HIV prevalence in a large South African township. The study found that HIV prevalence was lower among some age and gender groups belonging to specific types of associations (such as sports clubs), but was higher among those belonging to other groups, such as *stokvels* (savings associations). Their findings may reinforce concerns about 'negative social capital' – *stokvels*, for example, were linked with alcohol consumption and a greater likelihood of sexual activity with casual partners.

Noting the various structural determinants of HIV transmission in South Africa (including poverty, migration and gender inequality), Pronyk (2002) has suggested that strengthening the stock of social capital in South African communities could mitigate HIV transmission and impact. According to Pronyk (2002), social networks may help to diffuse health-related information (e.g. in relation to risk reduction), to shape community norms and showcase positive role-modelling behaviours and to provide members with material, emotional and social supports which ensure a measure of stability and could therefore mitigate high-risk behaviours. Communities with high social capital may also be more able to advocate for people's health needs, create a more tolerant and positive environment for people with HIV/AIDS and join together to undertake collective action in response to challenges.

The possible links between social capital and HIV/AIDS, particularly the 'positive' effects of social capital in curbing the spread of the epidemic, have been discussed more extensively in the case of Uganda, which is widely held up as an example of a society in which broad-based social mobilisation has helped to curb the spread of the epidemic. Thornton (2003) has chronicled the unique synergy of governmental and community action that emerged in Uganda during the early stages of the epidemic, paying particular attention to the role of community networks, churches and other structures in spreading information about HIV/AIDS, supporting affected individuals and families and reducing stigma. Thornton (2003) argues that the success of the Ugandan response can be attributed to the open and proactive position of the Ugandan government in relation to the epidemic, a decentralised approach which devolved control over AIDS programmes to the grassroots, a free press which openly addressed AIDS, the active engagement of religious communities and the proliferation of grassroots AIDS-related organisations. According to Thornton (2003), 'Major international donors provided most of the financial resources, but very little of the actual implementation. Overwhelmingly, Ugandans themselves identified the problems, generated solutions, and integrated these into close knit networks of mutual support that brought to bear the concerted action of society at large' (p. 2).

Jamil and Muriisa (2004) have also considered the role of social capital and community responses to AIDS in Uganda, arguing that non-governmental organisations (NGOs) concerned with fostering social relations between people with HIV/AIDS and communities (as opposed to more 'individualised' approaches to HIV/AIDS response, such as counselling and testing) have played a crucial role in building social capital in the Ugandan context. Organisations that emphasise social support, empowerment, care and reduction of stigma and exclusion have helped to facilitate the inclusion of people with HIV/AIDS, have made a difference in the lives of their beneficiaries and have promoted social solidarity in the face of the epidemic.

10.3 A Review of Local Responses to HIV/AIDS

Inasmuch as there is need to understand HIV epidemiology in more localised terms, we must think further and more seriously about how to localise responses to the epidemic. The idea that responses must manifest 'on the ground' and in the context of people's lives is by no means new or novel. But there has been insufficient critical examination of how this has developed and been supported.

We consider two broad areas: (1) civil society responses to HIV/AIDS at local level; and (2) local government initiatives to support local responses.

10.3.1 Civil Society Responses to HIV/AIDS at Local Level

10.3.1.1 A Regional Orientation

The past two decades has seen a steady deepening of the involvement of civil society organisations in the provision of social services, emergency and humanitarian relief, and development programmes in many countries. Although there is a long history of social service provision by non-governmental institutions and church-based health-care systems in some sub-Saharan African countries dating back more than a century, the role of non-state actors has become much more pronounced and widespread during the 1980s, when Structural Adjustment Programmes severely curtailed levels of spending and constrained the capacities of states. Fuelled in part by an economic and governance climate that favoured outsourcing roles to non-state 'service providers,' NGOs moved into this gap and began to take over the provision of services in certain sectors, such as health, sanitation, education and rural development – in some cases, surpassing the role of the state itself (Clayton et al., 2000). During the 1990s, NGOs emerged as one of the main vehicles for delivering official development aid to its intended beneficiaries (Fowler, 2000).

Worldwide growth in numbers of civil society organisations over the past two decades has been termed a global 'associational revolution' (Salamon, 1994). There has been limited documentation of the size and scope of development of the civil society sector, but certainly in East and southern Africa during the early 1990s, donor agencies 'discovered' civil society and embraced it both rhetorically and programmatically. Although development agencies in donor countries have long channelled some support to their own international development NGOs for work overseas, the 1990s saw a major shift from 'support for NGOs' to the less clearly defined 'support for civil society'. Civil society came to the forefront as part of a package of normative concepts, including 'good governance,' 'partnership' and 'participation' (Wickramasinghe, 2005), which have since become embedded in development assistance strategies.

Research in seven East and southern African countries (Birdsall and Kelly, 2007; Kelly and Birdsall, 2008) shows that growth in numbers of HIV/AIDS-oriented civil society organisations commenced in the early 1990s, and reached a peak between 1996 and 2004, where some countries experienced growth well in excess of 1,000 civil society organisations. Growth was a response to the emerging realities of HIV/AIDS at community level and increasing funding support for civil society responses on the part of international donors.

There is much we don't know about the extent, shape and impact of community responses to HIV/AIDS. There has been little systematic study of local-level responses to HIV/AIDS, although the grey literature contains many case studies of locally oriented projects. Some of the clearest successes in confronting the HIV epidemic have been linked to the active role played by local-level actors (Low-Beer and Stoneburner, 2004; Panos, 2003; Rau, 2006; Thornton, 2003).

Civil society action on HIV/AIDS long predated the idea of 'comprehensive programming' and the large-scale funding that is now enabling its implementation. Many of the activities that have become institutionalised in national- and global-level plans were in fact pioneered on the ground by community welfare organisations, churches and groups of infected and affected people (Rau, 2006). The official embrace of civil society organisations as 'partners' in multi-sectoral response, public acknowledgement of their contributions and attention to the need to make funding and resources available to them have all lagged behind civil society organisations practical involvement in HIV/AIDS response activities.

Civil Society Organisations have commonly been cited as the leading forces in the evolution of community-based models of care and support to affected people and households, including orphaned children (Foster, 2002; 2004; Iliffe, 2006; Rau, 2006). In the absence of strong social safety nets, associations of community members have proliferated across the continent to meet social and material needs. Formal policies and frameworks – for example, national plans for support to orphans and vulnerable children – were only promulgated years after the burden of support had effectively, and by default, devolved to communities (Iliffe, 2006; Rau, 2006).

Foster (2002, 2004) describes the spontaneous, informal and 'ordinary' actions that are undertaken within African communities to support orphans and vulnerable children. He notes that such community initiatives are usually started by small groups of motivated individuals who are driven by a sense of obligation to care for those in need, against a backdrop of limited or non-existent public services. According to Foster (2002), these initiatives, which are 'non-sensational and almost invisible to outsider and insider alike' (p. 99), generally share the same fundamental principles: reciprocity and solidarity; consensus-based decision making (particularly around understandings of vulnerability and identifying those who need care); self-reliance (resources mobilised locally); local leadership; voluntarism (altruism emanating from sense of community ownership); and innovation in problem solving. Local-level faith-based organisations' involvement in orphan care is burgeoning, and initiatives already supporting significant numbers of children are expanding without large-scale funding and technical assistance, and with considerable resources in the form of volunteer support. The study concludes that the cumulative impact of this local-level activity is significant and that, in the long run, local actors are better placed to respond to changing needs in orphan care than are large, external agencies (Foster 2004).

Epstein (2007) suggests that it is not finance, or technical solutions, or programme management expertise that has made the critical difference in reducing HIV incidence and improving impact mitigation. The key to successful AIDS projects resides in 'something for which the public health field currently has no name or program. It is best described as a sense of solidarity, compassion, and mutual aid that brings people together to solve a common problem that individuals can't solve on their own' (Epstein, 2007, p. xii). Collective efficacy, or the capacity for people to come together and help others they are not necessarily related to, and which surpasses what individuals can do for themselves, may be the key concept here. This spirit of collective action and mutual aid is difficult to measure or quantify, but may be the decisive feature of successful HIV/AIDS projects. This does not discount the value of higher levels of action and leadership, the provision of essential technologies and services and the need for strategic development.

There are profound implications for the way in which local HIV/AIDS responses are developed, conducted and supported, which will be addressed below.

10.3.1.2 The South African Context

South Africa has a strong history of an active civil society sector, which in the past has operated through community-based activism and human-rights advocacy. This is to some extent mirrored in the HIV/AIDS field by South Africa's advocacy-oriented 'Treatment Action Campaign' (see Chapter 11, this volume). But this is in many respects an exception to the norm. There has been considerable evolution of civil society structures and forms of organisation in the post-apartheid era (Nauta, 2004), which has seen strong emergence of semi-professional non-governmental organisations involved in service delivery, diversification and specialisation of community-based organisations and growth of faith-based organisations addressing a wide range of social issues at a service-delivery level.

The only attempt to take stock of the size and scope of the non-profit sector in South Africa (Swilling and Russell, 2002) reports on a 1998 national survey. The research identified 98,920 non-profit organisations with the majority (53%) being less formalised community-based organisations concentrated in poorer communities. The non-profit sector at the time employed 645,316 full-time workers and in 1998 mobilised nearly 1.5 million volunteers.

A provincial-level appraisal (Humphreys, 2005) found that there were 2,341 registered non-profit organisations in the Eastern Cape in 2004. Of these organisations, however, fewer than 5% had a stated objective that was linked to HIV/AIDS. But this data reflects only a fraction of the total number of organisations involved in supporting or providing AIDS response services. Many civil society organisations are not registered as non-profit organisations with the Department of Social Development, and most small towns in South Africa have community service organisations engaged in HIV/AIDS response work (Birdsall and Kelly, 2005).

There have been a few attempts to research the scope and scale of community-level responses to HIV/AIDS in South Africa (Birdsall and Kelly, 2005; Campbell et al., 2005; Russell and Schneider, 2000; Teljeur, 2002). It is clear that over the last 10 years at least, localised projects have emerged across the country to fill gaps in HIV/AIDS service provision in almost every area; but most commonly in prevention education, HIV support groups, home-based care, support for orphans and vulnerable children and impact mitigation through activities such as food-gardening or savings schemes. But there are also civil society organisations providing more technical services such as antiretroviral therapy and other biomedical services, and developing high-end mass-media communications. The types of organisations range from strongly regulated and highly professional to threadbare organisations with little training and limited connections to the HIV/AIDS industry, international funders or government, as well as volunteer associations.

The number of such initiatives can only be guessed at, but counting the members of a few networks, civil society sub-partners of the PEPFAR funding programme and a number of multi-site programmes, a count of 1,000 organisations is quickly passed. The final tally may be a few multiples of this: especially if those organisations not primarily oriented to HIV/AIDS but having a significant component of HIV/AIDS in their objectives are counted.

In 2000, many of these initiatives were in their infancy and quite ‘precarious,’ operating with limited resources, in single communities, with only occasional and limited external support and often not working with reference to guidelines or external parameters. This situation appears to have regularised due to the need to meet operating and reporting demands of funders. Funding can force organisations to formalise and this often requires organisational development. Serving this need are capacity-building efforts on the part of funders with the help of organisational development programmes.

Supported by international funding, there has emerged a growing group of national NGOs that have multiple projects in different communities, and they have effectively become sub-granting agencies to smaller community-based organisations. They build the capacity of these organisations to implement standard programmes, often allowing variations in how a basic programme is implemented, but requiring reporting on a standardised set of outputs.

But there remain many organisations that are based in a single community, focused largely on support activities such as promoting household food production, income-generating projects and community savings schemes. The scale of organisations in this category, many of which receive only occasional funding, is not known. Also many such community support activities fall under churches or community organisations that are not primarily HIV/AIDS oriented, and may not be recognised, even in the area of their operation, as significant contributions to harnessing community resources for AIDS response.

It is also significant that there has been no attempt to understand the contributions of volunteers, which are not always part of civil society organisations. There is likely a significant contribution to more formal programmes through education of others about access to formal services, provision of psychological and spiritual support, monitoring of health and basic health care (Campbell et al., 2005; Kelly and Mzizi, 2005). This work is often done with few supplies, little support and no compensation. Such volunteer carers exist in many communities across South Africa and represent an already mobilised, but under-utilised resource for AIDS support.

Civil Society Organisations in South Africa are beset by multiple challenges, and they often become chaotic and unmanageable (Birdsall and Kelly, 2005). They are often led by well-intentioned community members who have insufficient management and planning capacity to ensure that their organisations are strategically and sustainably developed. It is often funding opportunities rather than local needs and organisational capacity that determine what they undertake.

Looking beyond South Africa and HIV/AIDS responses, it has been said that global institutions have ‘consumed’ local initiatives and formations and local civil society organisations have increasingly struggled to define and sustain their own agendas in the face of financial dependency on external sources of funding (Fowler, 2001; Wickramasinghe, 2005). The result is a high end of professional organisations and networks led by experts, who effectively become prime partners of major funders. Ultimately they become sub-granters to smaller organisations, including single-community organisations, with few inter-organisational linkages, little community contact and inadequate training for what they undertake.

There are encouraging signs that the HIV/AIDS civil society sector in South Africa is becoming progressively more organised. There are active civil society networks in the following sectors: disability sector, children affected by AIDS, law and human rights, men’s and women’s issues, faith-based responses, traditional healers, traditional leaders, people with HIV/AIDS and higher education, among others. The structure of the National AIDS Council and the emerging provincial AIDS councils allow for and encourage organised representation by sectors; although the complexity and layering of the civil society sector makes notions of representation difficult to envisage, except at local level. The most promising efforts towards this end have been conducted at local government level. These will be reviewed below.

10.3.1.3 Support for Local-Level Responses

Government Engagement with Civil Society Responses

There have been numerous symbolic expressions (e.g. summits and declarations) of the need for partnerships between government and civil society: notably the 1998 national ‘Declaration of Partnership against AIDS’. However, these did not make a notable impact on cooperation between government and civil society working in the HIV/AIDS field, which, until recently, with some provincial and local government exceptions, have been *ad hoc*, often adversarial and inconsistent.

The official national response to HIV/AIDS in South Africa has traditionally relied strongly on provincial public health systems for interventions such as condom distribution, voluntary counselling and HIV testing, prevention of mother-to-child transmission and the roll-out of antiretroviral therapy. Inadequacies in government responses in these areas have led to massive involvement of civil society in filling the gaps and extending services; and in the face of this, there are signs of growing tendencies to increase and systematise processes for working together with civil society agencies in fulfilling these functions. Recent consultative processes leading to development of a new National Strategic Plan have shown evidence of a more collaborative relationship between government and civil society, expressed mainly through the South African National AIDS Council, which has among its objectives to create and strengthen partnerships for an expanded national response to HIV/AIDS in South Africa. It employs a full-time ‘NGO sector coordinator’ and expresses a desire to engage the civil society sector. But the efforts of some provincial health departments to engage civil society predate such developments by a number of years (Kelly and Marrengane, 2004). Gauteng and Western Cape provinces are notable for initiating programmes for coordinating and supporting community-level HIV/AIDS responses 5 or more years ago: engaging with communities directly, through civil society organisations and also cooperation between provincial and municipal government structures.

In other provinces, there has been some government funding for community-level HIV/AIDS responses. For example, in 2007, the Eastern Cape Department of Health (ECDOH) funded 212 NGOs and community-based organisations to provide home-based care and provided stipends to over 2,000 community health workers based in clinics to provide basic care and support services to people affected by HIV/AIDS at community level (EC DOH, 2007). However, during our own fieldwork, we have found that such funding is often provided ‘once-off’ and with no follow-up or attempt to develop longer-term services through these organisations, or to assess the quality and effectiveness of such support. Even when there is a longer-term relationship between government and civil society organisations, such relationships have been unreliable and unpredictable.

Looking beyond the health sector, the National Department of Social Development, with international donor support, has over the past 3 years conducted a pilot programme in five provinces, involving capacity building of 140 ‘home- and community-based care’ organisations. The programme is currently being evaluated with a view to adopting it as a large-scale national programme to engage community-based organisations in partnerships with the Department, involving capacity-building and financial support. This innovative programme constitutes a significant interest on the part of a national government department in enlisting civil society actors to fulfil primary government functions.

It has been suggested above that civil society organisations and programmes of action have substituted for government inadequacies. But it is also unsurprising, even given political will, that government services are not capable of meeting existing and future needs. Now that a large array of civil society organisations are in place and progressively more organised, there is need for a significant effort to ensure coverage, equity and quality of support and services.

No matter how strong they are civil society initiatives cannot and should not be seen as an alternative to the state in issues of development and service delivery (OSAA, 2003). An interesting situation prevails in South Africa, not unlike the situation in other hyper-epidemic countries in east and southern Africa. The civil society sector has grown to scale independently of the state, and efforts to work together have not led to enduring and predictable cooperative relationships. It is a major challenge to ensure that government and civil society efforts complement and support each other, and it will require a specific and enduring programme of support to ensure this, which must begin with recognition of the vast, if not yet specifically researched, scale and scope of the sector.

Funding

Research on the civil society funding environment in other countries (Birdsall and Kelly, 2007) shows how the emergence of the new stratum of local-level initiatives has been driven by unmet needs as well as drawn by funding opportunities, and the effectiveness of the civil society sector continues to be sensitive to changes in the funding environment

There has been very little research on funding for civil society HIV/AIDS responses in South Africa. There is apparently no consolidated information about the amounts being spent by provincial departments on civil society support, and the donor funding matrix maintained by the National Department of Health (Ndlovu, 2005) keeps tally only of the amount of external funding provided to the department.

The total amount of funding provided by donors to South African HIV/AIDS responses has grown significantly. The US President's Emergency Plan for AIDS Relief (PEPFAR) has allocated US$ 591 million to support comprehensive HIV/AIDS prevention, treatment and care programmes in South Africa for the 2009 financial year. In 2007, there were over 90 prime-partners and 300 sub-partners, and given the 49% increase in funding since then, the number in 2009 is likely to be considerably higher. Some of these are government institutions, but most are non-state actors. Not all of the prime partners are South African, and in 2005, a little more than half were South African entities and the remainder international, mainly American. Most of the larger non-state recipients are international NGOs, which sub-grant within South Africa. Other large-scale funding programmes, including the Global Fund to Fight AIDS, TB and Malaria have also provided large amounts to non-state actors in South Africa and the UK Department for International Development has funded the Department of Social Development pilot programme for support of community and home-based care programme.

It has been shown in other countries that international funding agreements and modalities of assistance can have a profound impact on the growth and development of civil society agencies working in the HIV/AIDS field (Birdsall and Kelly, 2007; Kelly and Birdsall, 2008). It is likely that South African civil society is being shaped in ways that have not been documented or discussed, and there is reason to question the sustainability of a large cohort of funded organisations, many of which are largely service providers rather than organisations based in and staffed by community members. The result is a far cry from the model of community response discussed above (see 10.3.1.1).

There has been little understanding of how civil society organisations would best develop: for example, whether they should strive for specialisation in particular areas or whether they should grow progressively more comprehensive. A study of civil society organisations in South Africa (Birdsall and Kelly, 2005) showed that many are beset by multiple challenges and often grow into increasing chaos and unmanageability. They struggle to meet the reporting requirements of multiple funders and it is often funding opportunities rather than local needs and organisational capacity that determine what they undertake. It is as well that there have emerged a good number of organisational development service providers to support the many new and growing organisations (Goudge et al., 2003).

Some models are emerging that tie funding to capacity-building and try to fund into the capacities of organisations to deliver services at appropriate levels. A good example among these is Ikhala Trust, a small grant-making facility that operates as a micro-fund for existing community-based organisations operating within the Eastern Cape. The trust assesses and builds on existing community ‘assets’ and targets smaller organisations which tend to be overlooked by donors. It not only provides seed funds, but assists in building organisational management capacity and linkages. This approach raises the possibility of intermediary civil society organisations or networks raising block grants from donor agencies, including government, which are then disbursed as multiple small grants to successful community-based organisations and providing assistance to promote their efficiency and effectiveness.

Given the scale of civil society involvement in HIV/AIDS responses, the funding and development of the sector should receive much more attention.

Model-Driven Approaches

An encouraging development that has accompanied the growth of civil society engagement in HIV/AIDS responses is systematisation through model-driven approaches.

This has happened in most areas of HIV/AIDS responses with the possible exception of HIV prevention. Arguably, the most successful general programme of local-level responses across the country is home-based care, which is also the area in which provincial governments have most closely engaged civil society as a service provider (principally Hospice Palliative Care Association of South Africa). The Integrated Community-Based Health Care model of hospice has established a model and standard for services in this area.

There have emerged a range of service models that are adaptable for conditions in different communities. Notable are models for supporting community responses to the needs of orphans and other children made vulnerable by HIV/AIDS. Richter et al. (2004) discussed ways in which external agencies can best support local-level work with orphans and vulnerable children. Also, the 'Isibindi' community care model has been developed and promoted by the National Association of Child Care Workers and is being implemented by community-based organisations throughout the country, as well as provincial government. Yet another model has been developed and implemented by the national NGO Nurturing Orphans of AIDS for Humanity in multiple community sites throughout South Africa.

Rather than rely on innovation in each new site, community-based responses, which are guided by tried and tested models and which can be supported to grow and adapt at community level, appear to be the most viable approach. This promising trend which marries strategic development with community engagement and ownership appears to be growing apace in South Africa.

10.3.2 Local Government Responses

The National Strategic Plan 2007–2011 does not specifically define the role of local government in HIV/AIDS response. It is left to provinces and municipalities to work out how to support local responses and to find ways of co-ordinating their efforts.

However, through an August 2008 resolution, the South African National AIDS Council committed itself to developing provincial and local AIDS council guidelines. This follows an April 2007 launch by the Department for Provincial and Local Government (DPLG) of the 'Framework for an Integrated Local Government Response to HIV and AIDS'. This document promotes a common understanding of what development and governance responses to HIV/AIDS entail; it specifies the role of municipalities and provides guidance on what they can do to respond to HIV/AIDS within their existing mandates, programmes and strategies; and it defines a strategy for supporting municipalities and other role players towards these ends (DPLG, 2007a). The framework, with its accompanying implementation plan (DPLG, 2007b), is a clear attempt to locate local government's responsibility for HIV/AIDS within its mandate of maximising social development and economic growth, although it is too new to have made any impact as yet on municipalities and their responses to localised HIV/AIDS epidemics.

There is no statutory mandate that explicitly defines district or local municipality responsibilities for responding to HIV/AIDS. The mandate for local government HIV/AIDS responses might however be regarded as implicit within the more general set of mandates around: ensuring the provision of basic services; maximising social development and economic growth; promoting a healthy environment; encouraging the involvement of communities and community organisations in local development; assessing and responding to development needs of communities; planning and co-ordinating local development; establishing sustainable and liveable settlements; bringing together coalitions and networks of local interests that co-operate to realise shared visions; responsive problem solving and a commitment to working in open partnerships with business, trade unions and community-based organisations; and directing community energies into projects and programmes that benefit the area as a whole.

In terms of the Municipal Systems Act of 2000, all municipalities must undertake planning processes to produce an integrated development plan (IDP) for a 5-year period. The IDP defines and guides all planning, budgeting, management and decision-making in a municipality. The IDP is required to be reviewed annually in consultation with communities and stakeholders and amended should this be necessary.

The IDP process holds the promise of facilitating and embedding integrated and collaborative local-level response to HIV/AIDS. In reality, however, few IDPs reflect what could be termed effective mainstreaming of HIV/AIDS into municipal functioning. More often than not, HIV/AIDS is relegated to a particular section of the IDP, without linkages to specific functions or developmental outcomes expressed in the IDP, let alone accompanying resource allocations. Also, HIV/AIDS components of IDPs (Ambert et al., 2006; Versteeg, 2006) have shown that they are often not based on adequate situation analyses of the unique context of HIV/AIDS within municipalities. There is such a rapid proliferation of HIV/AIDS responses on the part of NGOs and other local actors that IDPs tend to lose alignment with HIV/AIDS development priorities which may be addressed by non-governmental organisations' to NGOs' and provincial government agencies. There is little evidence that an integrated approach to HIV/AIDS response planning is being adopted on a wide scale, and much local government effort remains sector bound, with dominant emphasis on awareness-raising activities.

In reality, the government's own assessment has shown that only 37% of municipalities have independent capacity to prepare effective IDPs, 35% have basic institutional capacity but require continued support to prepare their plans and 28% struggle to prepare an IDP, even with support (Harrison, 2008). This sobering assessment suggests that much more support than has been forthcoming until now is needed before the promise of dealing with HIV/AIDS in the context of integrated development planning can come to fruition, and effective alignment of the different spheres of government and civil society action can occur at local level.

However, there are some strong examples of well-led, comprehensive municipal responses to HIV/AIDS, especially in the country's cities (Kelly and Marrengane, 2004), but also in some local and district municipalities (Ambert et al., 2006) where local government has played a catalytic role in the development of co-ordinated community-led responses to the epidemic.

Notable exceptions aside, municipal responses to HIV/AIDS are often limited to activities such as organising occasional HIV/AIDS awareness events, putting up billboards with HIV prevention messages and similar activities aimed at behaviour change and personal health. Recent years have seen a growing number of municipalities adopting HIV/AIDS workplace programmes. But most of these programmes reflect an equally narrow conceptualisation of HIV/AIDS as largely a behavioural and health issue and do not fulfil the hope that local councils might support more integrated local responses (van Donk, 2008). Whilst these kinds of initiatives must have generated some value, there is certainly no strong evidence that local AIDS councils are a strong emerging force in the co-ordination and management of local AIDS responses.

One of the key implications of adopting a 'mainstream' approach to HIV/AIDS in municipal planning, service delivery and governance is that more attention needs to be paid to the human geography of HIV/AIDS – or, put differently, rediscovering 'space' in developing localised responses to HIV/AIDS. This implies recognising when there is uneven distribution of HIV within municipal boundaries, and paying attention to spatial and built environment considerations that are important in providing local responses to HIV/AIDS. It is here where municipalities can make the strongest impact on both reducing vulnerability to HIV infections and on strengthening coping capabilities and social cohesion in the face of the epidemic (Isandla, 2007). However, this remains an under-developed area of work.

Yet, as much as it is desirable to create local governance systems that take greater responsibility for developing and supporting HIV/AIDS responses, there are a number of reasons to be cautious about passing on too much responsibility for dealing with the crisis of HIV/AIDS. Well-functioning systems of local government cannot be assumed to exist; and some municipalities have large service delivery backlogs and lack funds for basic services. Against this backdrop, responding to HIV/AIDS may be seen as an add-on responsibility. This is made all the less likely by the fact that the mandate for local government HIV/AIDS response is largely unfunded. But the more general goal of human settlements planning, service delivery, development strategies and governance that are informed by an explicit HIV/AIDS perspective is not unrealistic. It is not an add-on requirement to take HIV/AIDS into account as a key development concern, and this falls squarely to the responsibility of local government.

This brings us back to the importance of recognising and supporting existing community-based initiatives and the necessity of partnership building at the local level – to enhance co-ordination between various actors, to strengthen referral networks and information sharing and to emphasise the integration of various HIV/AIDS-related services.

10.4 Prospects for Responding to HIV/AIDS at the Local Level

International evidence suggests that local-level responses are key to curbing and mitigating effects of HIV/AIDS; but the way in which local responses are initiated and supported is subject to influences that may jeopardise their value. In South Africa, we have had 25 years of skirting around the need to localise HIV/AIDS responses. Yet policy and strategies in this area remain poorly formulated and inadequately supported. There is ample anecdotal evidence of a burgeoning civil society sector, largely supported by international funding programmes but with some South African business and foundation support. There is also increasing national and provincial government support for local-level initiatives.

Local-level community activity can never be a replacement for large-scale, government-led responses to the epidemic, even though community organisations appear to be playing the leading role in certain areas of HIV/AIDS response. Community initiatives, by their very definition, are localised and lack broad 'political economic leverage' (OSAA, 2003). They cannot operate at the scale needed to address the many impacts of the epidemic across society as a whole. Their greatest strength is that they emerge from, reflect and are positioned to engage with local needs and conditions; and if national strategies can be developed to more effectively engage with CSOs, there is much to be gained.

Much attention has been paid to the co-operative relationship that emerged between government and civil society in Uganda, where the state effectively contributed to the creation of social capital in society by encouraging CSO activity, by publicly reiterating government commitment to and support of people living with HIV/AIDS and by mobilising financial support for community institutions (Jamil and Muriisa, 2004). On a much smaller scale, localised networks, such as Children in Distress Network in KwaZulu-Natal (Kelly and Marrengane, 2004), demonstrate that it is possible for civic and state entities to work together in partnership in a way that enhances overall effectiveness of their efforts.

10.4.1 What Is Needed?

We have discussed local-level responses at civil society and local government levels and have highlighted the need for strengthening localised responses to HIV/AIDS. Following is a list of key interventions that would contribute to this end.

1. *Local programmes based on more sensitive HIV surveillance and response analysis*: HIV surveillance and response analyses to date have provided very little information to help in shaping local responses. Efforts to curtail new HIV infections must begin with understanding where they are most likely to occur, and response efforts must be based on an understanding of existing services and unmet needs. There is need for higher concentration of programmes, for example, in urban informal settlements, where HIV incidence appears to be highest and ironically where there are least likely to be adequate programmes in place, or supportive municipal infrastructure.

2. *An appraisal of* civil *society responses*: There is need for an appraisal of civil society responses to HIV/AIDS. This should consider models of co-operation and integration of services at local level; co-ordination within the civil society sector and harmonisation with government programmes; provincial government strategies

for engaging civil society organisations; and the funding and support environment for civil society responses.

3. *A long-term agenda located at local government level*: It must be recognised that the dominant emphasis in HIV prevention on behavioural outcomes is insufficient and to some extent inappropriate, given apparent locality-determined influences on HIV infections. The realisation of integrated and sustainable human settlements with adequate access to basic services and social, economic and public infrastructure is vital if South Africa is to address the HIV/AIDS epidemic effectively in the long term. A long-term, development-oriented agenda and strategy for HIV/AIDS responses should be established for the country as a whole. The foremost opportunity for operationalising this is through municipal integrated development planning processes, and there is an opportunity to build on recent efforts to develop frameworks and guidelines for more effective municipal responses.

4. *A strategy for improved local HIV/AIDS governance*: As the epidemic in South Africa becomes progressively more complex in its infection dynamics and impacts, and local-level HIV/AIDS responses burgeon and diversify across South Africa, questions of effective HIV/AIDS governance take on ever greater importance. There is need to take stock at the provincial level of government, of strategies for engaging civil society organisations and municipalities in localising provincial implementation plans, and this should feed into a national-level strategy for attaining comprehensive and co-ordinated local responses to HIV/AIDS through complementary action on the part of national, provincial and local governments, and non-state actors.

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Chapter 11
Social Movements and HIV/AIDS in South Africa

Christopher J. Colvin and Steven Robins

11.1 Introduction

There are few places where HIV and AIDS have not inspired fervent social and political controversies. Conflicts over the nature and meaning of the disease and the best ways to control its spread and care for its victims have been numerous, intense, persistent and diverse in their forms. As Paula Treichler (1999) put it, HIV has indeed been an 'epidemic of signification' as much as it has been a biological catastrophe for millions of people. This virus, though, has not only aroused multiple and competing meanings, symbols and discourses about death and disease in the contemporary world, but also inspired the creation of a vast global web of non-governmental organisations (NGOs) and community-based organisations (CBOs). It has catalysed new networks of communities, activists and academics and it has become the object of an entirely new global architecture of aid institutions and development policies aimed at controlling its spread and treating its victims. Many of these important social and political developments were made possible by the work of the numerous social movements, local and global, that have emerged in response to the epidemic.

Though the politics of HIV/AIDS has not been simple anywhere on the globe, few places have been as battered by the kind of sustained and bruising battles around the disease as South Africa (Posel, 2008). In their intensity, scale and persistence, the political conflict during the last 10 years in South Africa around HIV/AIDS has its closest parallel in the dramatic struggles of AIDS activists in the United States in the late 1980s and early 1990s. In both cases, conservative political ideologies and stigmatising public opinion were seen by many to be the key obstacles to an effective response to the epidemic. Strong social movements emerged in both countries that refashioned the social and political landscape in lasting ways.

But why has South Africa suffered from this level of controversy? The initial emergence of HIV in the United States and the strength of its gay rights movement help to explain some of the activism that emerged in that country (Epstein, 1996). The particular challenges and contexts in South Africa, though, are very different. The scale of the epidemic, its dominant modes of transmission and the political, legal and scientific contexts have changed significantly since the 1980s. So why did South Africa become such a hotbed of AIDS politics?

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_11,

Ironically, the controversies in South Africa have not been driven by the uniquely large scale of its epidemic but by individual personalities and local histories that have collided at a particularly vulnerable time in South Africa's social and political development. The epidemic started to really hit South Africans at just the time that most were looking forward to enjoying their new-found liberation. More than rising crime, persistent racism, or deepening inequality, the HIV/AIDS epidemic has been the feature of life after apartheid that most threatens to unravel the 'miracle' of South Africa's democratic rebirth. Compounding this difficult and precarious historical moment, though, have been the unexpected and increasingly disruptive interventions of the state president, minister of health and other key political figures who have introduced a discourse of 'AIDS denialism' into the political debate around HIV/AIDS (Fassin, 2007; Gevisser, 2008; Nattrass, 2007; Robins, 2004). Their support for alternative or 'African' approaches to the epidemic (see Chapter 9 on AIDS denialism in this volume for many examples) quickly became the public face of the AIDS controversy in South Africa.

Despite the unique and, to many observers, bizarre features of South African AIDS politics, the history of social movement activism around HIV/AIDS in South Africa reveals some important insights and lessons. This is true not only with respect to the development of local South African political culture, but also in terms of more global shifts in the politics and practice of public health, the possible forms and expressions of political activism and the intersections of states, NGOs, communities, academics and the private sector.

In this chapter, we take a broad view of 'social movements', one that includes not only those fairly organised strategies deployed at the national level to challenge reigning social and political orthodoxies, but also those more local shifts and transformations in collective practice that seek to 'establish a new order of life' (Crossley, 2002) at a community level. What is common in all these enterprises is an attempt to mobilise people and coordinate action for social change without always going through the usual institutional structures and procedures. As we will see, not all social movements work for the same kinds of change. But they do all share a frustration with what they perceive to be the *status quo*.

From a psychosocial perspective, social movements around HIV/AIDS are important for the ways they channel individual and community energies, motivate for change at all levels, challenge key meanings, values and practices and, in general, reshape the imaginative conditions of possibility for those struggling to understand and respond to the epidemic. Because of their often 'high degree of popular participation' and their reliance on 'non-institutional channels' (Jelin, 1990) for much of their action, social movements can provide individuals with powerful new ways of 'articulating' – in both its senses, of expressing and of connecting together – the personal, the social and the political. For many of those involved in these social movements, AIDS activism has indeed been transformative on all of these levels.

11.2 The Treatment Action Campaign

One of the most transformative HIV/AIDS social movements in South Africa has been the Treatment Action Campaign (TAC). This social movement has, in fact, become iconic of AIDS activism in contemporary South Africa and was also one of the most visible social movements to emerge after the end of apartheid. TAC has not only recast the political and legal environment in South Africa through its lengthy, vigorous and creative campaign to ensure access to anti-retroviral treatment (ART) in the public sector; it has also changed the social landscape of many communities and improved the personal lives of its many members and supporters.

TAC was established on 10 December 1998 when a group of about fifteen people protested on the steps of St George′s Cathedral in Cape Town to demand medical treatment for people living with HIV. By the end of the day, the protestors had collected over a thousand signatures calling on the government to develop a treatment plan for all people living with HIV. TAC's membership has grown dramatically in the decade since it was established. Its rank-and-file members consist of mainly young urban Africans, mostly female and unemployed, and with secondary schooling. However, the organisation has also managed to attract middle-class health professionals, journalists, academics, university students as well as garnering support from a large number of civil society organisations. Drawing on the political culture and mobilisation strategies of anti-apartheid movements such as the United Democratic Front (UDF), TAC was extremely successful in mobilising support across racial, ethnic and class lines.

The international face of the organisation is Zackie Achmat, a former anti-apartheid and gay activist. Until recently, Achmat, who is himself HIV-positive, had made it known publicly that he refused to take anti-retroviral drugs (ARVs) until these were available in the public health sector. When TAC was founded, it was generally assumed that anti-AIDS drugs were beyond the reach of developing countries, condemning 90% of the world's HIV-positive population to a painful and inevitable death. In 2004, however, following concerted pressure from AIDS activists and their supporters, prices were brought down an the government finally agreed to 'rollout' a national ARV programme.

While TAC's main objective has been to lobby and pressurise the South African government to provide AIDS treatment, it has over the years begun to address a much wider range of issues. These included tackling the global pharmaceutical pricing structures through campaigns in the media, the courts and the streets; challenging the government's lethargic response to the epidemic; litigating against AIDS dissidents and their government supporters; lobbying for better conditions for health workers; conducting treatment literacy programmes in schools, hospitals, at the workplace and through door-to-door campaigns in the townships; collaborating with *Médecins san Frontières* (MSF) to introduce innovations in public health service delivery at MSF's pilot anti-retroviral treatment (ART) programme in Khayelitsha, Cape Town; fighting local expressions of violence, discrimination and stigma against HIV-positive people and lesbians and gays; and campaigning against crime and violence, particularly against women and foreigners.

TAC also launched campaigns to support doctors, hospital superintendents and medical researchers from the Medical Research Council (MRC) who, by virtue of their reported findings or provision of ARV treatment, found themselves on the wrong side of government, and subject to high-level political interference and intimidation.

This extraordinary range of activist interventions is testimony to the vibrancy and reach of this social movement. In the process, TAC has contributed towards expanding conventional understandings of rights, citizenship and what actually constitutes 'politics'. In particular, TAC, along with the AIDS Law Project (ALP), re-appropriated an anti-apartheid tradition of legal activism that was developed by human rights lawyers from the Legal Resources Centre and the Centre for Applied Legal Studies. This genre of legal activism was particularly powerful precisely because it articulated closely with grassroots mobilisation.

Soon after its establishment in 1998, TAC, together with the South African government, became embroiled in a lengthy legal battle with international pharmaceutical companies over AIDS drug patents and the importation of cheap generics to treat millions of HIV-positive poor people in developing countries. Largely as a result of highly successful global and national media campaigns by TAC and its allies, the global pharmaceutical industry backed down and allowed developing countries to manufacture ARV generics.

In December 2001, shortly after this court victory, TAC's legal representatives were back in court arguing that the South African government had a constitutional obligation to promote access to health care, and that this could be extended to AIDS drug treatment. TAC's lawyers demanded that the state introduce a national Prevention of Mother-To-Child Transmission (PMTCT) programme with immediate effect. These claims were possible because the South African Constitution recognises access to water, housing, health care and a clean environment as basic rights in the Bill of Rights. Yet, as TAC's lawyer Geoff Budlender noted, this legal victory was not simply the result of the Constitutional Court judges' 'technical' interpretation of the letter of the law; the judges were also listening to the moral arguments that were being articulated by TAC activists in 'the streets' and in the media. This historic Constitutional Court judgement on PMTCT ultimately pushed the government into introducing a national ART programme in October 2003.

In recent years, TAC has moved beyond strictly health-related concerns, for instance, by supporting trade union and social movement calls for a basic income grant (BIG). Similarly, when violence against foreigners erupted in May 2008, TAC, MSF and the ALP became centrally involved in responding to the refugee crisis that followed the expulsion of tens of thousands of foreigners from various communities throughout the country. TAC and ALP coordinated the response of a group of Western Cape civil society organisations to the crisis. This included the provision of food and shelter to thousands of refugees and displaced people, as well as lobbying and pressuring the United Nations and local, provincial and national government officials to respond to the needs of this displaced population.

11.3 Rights, Citizenship and 'Globalisation from Below'

MSF and TAC activists and health workers have been extremely successful in straddling local, national and global spaces in their struggles for 'rights to health'. The 'Christopher Moraka Defiance Campaign' was a defining moment in the development of TAC's strategies of 'citizenship from below'. It began in July 2000, after HIV-positive TAC volunteer Christopher Moraka died, suffering from severe thrush. TAC's spokesperson claimed that the drug fluconazole could have eased his pain and prolonged his life, but it was not available in the public health system because it was too expensive.

In October 2000, in response to Moraka's death, TAC's Zackie Achmat visited Thailand where he bought 5,000 capsules of a cheap generic version of fluconazole. When TAC announced Achmat's mission in a press conference, the international public outcry against the pharmaceutical giant Pfizer intensified as it became clear how inflated the prices of name-brand medications were; no charges were brought against Achmat, and the drugs were successfully prescribed to South African patients. By March 2001, Pfizer made its drugs available free of charge to state clinics.

This David and Goliath narrative of TAC's successful challenge to the global pharmaceutical giants captured the imagination of the international community and catapulted TAC into the global arena. Preparation for the court case had also consolidated TAC's ties with international NGOs such as Oxfam, *Medicins Sans Frontières*, the European Coalition of Positive People, Treatment Action Group, ACT UP, Health Gap, and Ralph Nader's Consumer Technology Project in the United States. This success, and the many others that followed, was a glimpse into what health citizenship could become as a rights-based politics that operated simultaneously at local, national and international levels. It was indeed a form of global citizenship 'from below'. However, it was at the national level that TAC concentrated most of its energies. TAC's transnational networks, which also included donor agencies, allowed TAC to steer clear of government and drug company funding that could have compromised its strategic objectives and political credibility.

A key factor in TAC's success in lobbying and pressuring the South African government to provide AIDS treatment to its citizens has been its highly effective international campaigns and networks. TAC activists, however, have stressed that grassroots mobilisation was in fact the real key to their success. This mobilisation occurred through AIDS awareness and treatment literacy campaigns in schools, factories, community centres, churches, *shebeens* (informal/illegal drinking places) and homes in the townships. These strategic engagements at the local level involved mobilising and educating poor and working-class communities around HIV issues as well as using the courts to challenge the 'trials' and marketing of scientifically untested 'AIDS cures' in the townships.

These grassroots campaigns contributed towards changing local attitudes towards HIV. Notions of 'positive living' were disseminated through treatment literacy and media campaigns as well as the visibility of the iconic TAC T-shirt. The wide dissemination of treatment narratives and the presence of HIV-positive role models have also been effective in demonstrating ‘new life’ after treatment (Robins, 2006). However, TAC’s emphasis on public disclosure has not been without costs; for instance, it has meant that some individuals and groups have avoided TAC and shied away from this open approach, and there have been incidents of violence against TAC members.

TAC’s stress on ART and scientific literacy, and its perceived intolerance towards alternative health approaches, has also opened it up to claims that it follows a technicist approach to public health. This embrace of biomedicine also contributed towards accusations from its detractors that it is a ‘front’ for the global pharmaceutical industry. These local-level dynamics have also been replicated at the national level with senior government leaders making similar criticisms of TAC. However, by 2008, it appeared as if TAC had won the ‘AIDS science wars’ at the national level.

While the thrust of TAC’s challenges to the South African government focused on citizens’ rights to health care, these campaigns also raised broader national questions relating to scientific authority and expertise. TAC raised troubling questions relating to science and citizenship, and drew attention to the ongoing contestation over the scientific ‘truth’ on AIDS that raged between TAC, the trade unions and health professionals on the one side, and President Mbeki and his inner circle on the other (Fassin, 2007; Friedman and Mottiar, 2004; Nattrass, 2007; Robins, 2004). TAC and MSF also attempted to develop new conceptions of health citizenship and scientific literacy among its member and the wider citizenry through the establishment of treatment support groups and AIDS awareness and treatment literacy campaigns. These programmes also involved the dissemination of reports, scientific studies, website documents, newsletters and media briefs. These health citizenship initiatives refuted government and dissident claims that ART was dangerously toxic, ineffective, too costly and could not be implemented due to infrastructure and logistical problems such as inadequate management structures, shortages of trained staff and so on.

These examples of health citizenship are largely a product of the globalisation of HIV/AIDS that is emerging as a result of the dramatic spread of programmes promoted by international donors, NGOs, health agencies and social movements such as TAC. These global health initiatives have in turn contributed to the emergence of a proliferation of community-based AIDS organisations that draw on practices of ‘self-help’ and what Vihn-Kim Nguyen refers to as ethical projects of self-fashioning and ‘care of the self’ (Nguyen, 2005). For Nguyen, these projects of self-refashioning can also produce new forms of therapeutic citizenship characterised by political claims and demands based on individual responsibility.

This idea is captured in the linking of rights and responsibilities. In order to access life-enhancing ART in the public sector, HIV-positive individuals are required to be ‘responsible’ in their sexual lives, diets, lifestyles and adherence to treatment regimes and medical check-ups. These ideas about ‘responsibilised’ or biological citizenship reflect the prevailing imperatives of liberal rationalities of government in advanced liberal democracies in the North (Petryna, 2002; Rose and Novas, 2005). They also imply forms of exclusion or ‘social triage’ whereby NGOs and medical practitioners, often funded by global donors, have to decide who lives and who dies. For example, those considered to be 'irresponsible' in their sexual behaviour and lifestyles can be excluded from accessing ART by virtue of not meeting certain psychosocial criteria.

11.4 Social Movements at the Community Level

Despite the fact that TAC has strong bases in a number of urban townships and is able to mobilise thousands of people for its marches and demonstrations, it is not a mass-based or grassroots social movement in the way parts of the anti-apartheid struggle were (e.g. the UDF) or in the way that other social movements in South Africa like the Anti-Eviction campaign are. There has always been a structural tension between its well-educated, media-savvy, middle-class leadership and its support base of mostly poor- or working-class women in urban townships. The same tension exists in its work. Despite its many community-level interventions – support groups, workshops, treatment literacy programmes – TAC remains best known for its high-profile political and legal battles with the national government. In fact, many of its most important contributions have been at the national level of law, policy and public discourse.

TAC, though, has certainly been critical in inspiring a host of other smaller and more community-based responses to the epidemic. Other chapters in this volume engage with many of these forms of community-based response, including home-based care, support groups, nutritional support and education around HIV and AIDS. In this chapter, we are particularly interested in those forms of community-level action that are less about service provision and more about advocating for social and political change within the community context. These forms of social action for change might be considered 'social movements in miniature'. While frequently less organised, and always less resourced than national movements like TAC, these forms of local-level practice share many of the same features and concerns as their larger cousins. And they are an important part of the story of the collective response to HIV and AIDS in South Africa.

The past decade has witnessed the emergence of a wide range of NGO/CBO networks and coalitions relating to HIV. It has also seen a number of related campaigns, some big and some small, around HIV (e.g. campaigns around masculinity and gender-based violence). In addition, individual social entrepreneurs can also be found in every community, trying, for example, to change the behaviour of churches that expel HIV-positive members. These small groups might also run their own treatment literacy programmes or organise local marches against stigma or gender-based violence.

Finally, support groups, like Khululeka, a Cape Town-based support group for men living with HIV (Robins and Colvin, 2009), bridge the conventional therapeutic support group space (an individualistic and apolitical space) and broader, more politically driven social movements. There is clearly a wide variety of types of support groups, and Phumzile Nywagi, the founder of Khululeka, has criticised those groups that encourage ‘dependency’ and are reluctant to publicly disclose their HIV status. Despite the persistence of stigma and fear in many communities around HIV/AIDS, and the confusing messages that have been coming out of government for the last 10 years, Khululeka represents a kind of ‘social movement’ for change that can be found throughout South African communities.

11.5 The Power of AIDS Dissent

Another important, but under-recognised, HIV/AIDS social movement deserves attention. This movement has been explicitly at odds with the aims and objectives of TAC and those groups TAC has inspired. Matthias Rath is a German doctor whose foundation has been promoting vitamin and micronutrient supplements as an alternative to what it describes as ‘lethally toxic’ ARVs. Rath has had the tacit, but strong, support of the National Minister of Health and his foundation and its volunteers have been able to make significant inroads in Khayelitsha and other urban townships in South Africa. He has also become one of the TAC’s primary targets in recent years. They have confronted Rath in numerous legal, political and media battles and have recently won significant judgements preventing some of the activities of the foundation.

Matthias Rath, his foundation and its volunteers are often identified with President Mbeki and the Minister of Health and interpreted as another expression of the denialist discourse emanating from the highest levels of government. Rath’s project to promote alternatives to ART is seen, thus, as an extension of the state orthodoxy, and as the target of social movements like TAC, rather than as a social movement itself. However, this constitutes a rather narrow definition of what qualifies to be a social movement (Edelman, 2001).

Though there is an element of truth to the close connection between Rath and senior political leaders, this analysis ignores a crucial element of Rath’s success in South Africa, and a crucial dynamic in the history of HIV/AIDS social movements in South Africa. Rath has been successful in the places his foundation has worked, not because of the political protection of national politicians, but because of his careful recruitment of and engagement with local-level political structures in township communities. In particular, he has been able to work with, and map many of his activities and agendas onto, local branches of the South African National Civics Organisation (SANCO).

SANCO as an organisation represents an element of local South African political culture that is increasingly under threat after apartheid – the local ‘civics’ and street committees. Civics were vital during the struggle against apartheid in coordinating the political resistance to apartheid security forces and policies on the ground. They were also crucial in enforcing the discipline of community members and ensuring that everyone in the community worked towards the same purpose. As a highly decentralised form of local political control, civics and street committees had a great deal of power over the lives of community members. This power was not always democratically exercised, and local networks of patronage and patriarchal political control became entrenched in many communities.

With the end of apartheid, political power was rapidly centralised under the mantle of the newly unbanned ANC party and the state mechanisms it now controlled. Though there has been a push to decentralise decision making as far down as possible – this is in fact a constitutional mandate – the reality is that civics and street committees quickly lost their control and relevance in the new political environment. They haven't disappeared, though, and have instead increasingly become fora for those citizens who are frustrated and disillusioned with the current shape of political power in the country.

It is this discontent that the Rath Foundation has tapped into. In promoting his vitamin and micronutrient supplements as politically progressive alternatives to toxic state-provided ARVs and the big drug company interests behind ART, he has made his critique of mainstream HIV science part of a larger, stronger and growing community-level social movement against everything it perceives the current government to represent – the interests of capital, the academic and political elite and the power of foreign governments and companies to dictate the fortunes of the poorest South Africans.

The Matthias Rath Foundation does not by itself represent an HIV/AIDS social movement in South Africa (it is not sufficiently broad), but its successes in generating community-level support and in challenging the conventional scientific and social movement orthodoxies around the treatment for AIDS reveal an important undercurrent of social and political feeling and action in many South African communities. Rath has been successful not (only) because of his implicit endorsement by the Minister of Health, but because he has tied his critique of Western medical science to deeper and more powerful movements in social sentiment in the poorest South African communities. These movements, like other social movements, reflect unhappiness with the status quo and struggle to realign the organisation of political power in the country in fundamental ways. It is important that the Rath Foundation, and the discourse of denialism in general, not be seen simply as expressions of the current political state of affairs under the Mbeki administration (against which social movements like TAC advocate), but as reflections of the possibility of another, bigger social movement in the making.

What is particularly interesting here is that the Rath phenomenon may also reflect a broader global backlash against scientific authority (Beck, 1992). This would suggest that the Rath Foundation has managed to tap into widespread citizen distrust of the 'collusion' of the state, science and big business. The Rath Foundation then is simply part of a proliferation of 'anti-science' popular responses in South Africa that include beliefs that AIDS is a product of the evil machinations of white doctors, witchcraft, 'Big Pharma' and the CIA. Recognition that Rath is simply one of many 'counter-science' popular responses to HIV should serve as a cautionary tale that draws attention to the challenges facing scientific/treatment literacy approaches to the fight against HIV. It also draws attention to the limits of litigation and rights-based interventions. Clearly, TAC, MSF and their public health allies have their work cut out for them.

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Chapter 12
Approaches to HIV Counselling and Testing: Strengths and Weaknesses, and Challenges for the Way Forward

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12.1 Introduction

South Africa has the highest rates of HIV infection of any country in the world. The two main goals of the *National Strategic Plan on HIV & AIDS and STIs, 2007–2011* (NSP) are to reduce the incidence of new HIV infections in South Africa by half by 2011 and to ensure that at least 80% of those who are already HIV-positive have access to treatment (National Department of Health, 2007). Knowledge of HIV status is considered critical for both these prevention and treatment goals. Once an individual has been tested for HIV, prevention can be reinforced and referral made to available treatment, care and support services. A potential added benefit is that increasing the number of people who know their HIV status through expanded access to HIV counselling and testing may also result in a decrease in HIV-related stigma, leading to a "normalisation" of the HIV epidemic (Anderson, 2006; De Cock et al., 2002).

12.1.1 Current Availability and Use of CT Services in South Africa

HIV counselling and testing has become increasingly available in South Africa in recent years, with 2,369 facilities providing CT in 2004 (UNAIDS, 2006). While CT has been shown to be an effective method of HIV prevention and is a critical point of entry into HIV treatment, care and support services among persons who are HIV-positive, and despite increasing availability at public health and non-governmental sites in South Africa, uptake of CT remains low (Metcalf and van Rooyen, 2008). Recent studies have estimated that fewer than 20% of South Africans have been tested for HIV and are aware of their HIV serostatus (Pettifor et al., 2004; Shisana and Simbayi, 2002). Moreover, only one in five South Africans who are aware of CT have actually used the services that are available to them (Kalichman and Simbayi, 2003).

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_12,

12.1.2 Reasons for and Barriers to CT Uptake

Reasons for the low uptake of CT services exist at the individual level, as well as at the broader institutional and structural levels that influence individual behaviour. Personal factors include fear of testing positive for HIV and the ramifications of a positive test, as well as fears of stigmatisation, disease and death (Day et al., 2003; Kalichman and Simbayi, 2003; UNAIDS, 2001). HIV prevalence surveys also indicate that self-perception of risk of HIV infection is low (Shisana et al., 2005) and that this could contribute to the poor uptake of CT services.

In South Africa, system factors that limit CT uptake include a general lack of trust in the health-care system (van Dyk and van Dyk, 2003); perceptions of lack of confidentiality of CT services (Coovadia, 2000); fear of being discriminated against by health-care workers; and fear of disclosure of one's HIV-positive status to sex partners (van Dyk and van Dyk, 2003).

Real and perceived stigma and discrimination remains the biggest barrier to widespread implementation of CT in many high-prevalence developing contexts. In particular, there is evidence that for many women, fear of violence is a major barrier to testing and to disclosure of HIV status to sexual partners (Maman et al., 2001; Taegtmeyer et al., 2005).

The low uptake of CT in South Africa suggests weak or absent social norms promoting the knowledge of one's status. Norms supporting knowledge of status appear to be undermined by beliefs about the negative consequences of knowing one's HIV status, as well as the conviction that there is nothing to be done if infected by the virus – a form of "HIV/AIDS-related fatalism" – noted by Leclerc-Madlala (1997).

12.1.3 The Need to Scale up CT

A growing awareness of the importance of knowledge of HIV status and increased access to treatment has sparked debate about how to scale up CT in high-prevalence, resource-constrained countries with generalised epidemics, such as South Africa. The gap between those who *should* know their HIV status and those who *do* know their status has consequences for public health efforts to redress the HIV epidemic. All individuals, and in particular high-risk individuals, who are not aware of their HIV status but continue unsafe sex practices are major drivers of new infections. In addition, those who are infected with HIV but do not know their status, are not linked to the necessary prevention, treatment and support available to them (Swanepoel, 2004); these services can prolong health and help prevent the spread of infection to others.

12.2 Client-Initiated Counselling and Testing or VCT

The current standard of client-initiated counselling and testing – a voluntary, rights-based encounter – is typically an individual intervention consisting of two counselling sessions performed before and after a (usually) rapid HIV test. The approach referred to as client-initiated counselling and testing (CICT) is also known as voluntary counselling and testing (VCT). By combining personalised counselling with knowledge of one's status, VCT is an opportunity to motivate people to change their behaviours and prevent transmission of the virus (Denison et al., 2008; Swanepoel, 2004).

12.2.1 Evidence Supporting VCT

A two-session HIV-prevention counselling model with a strong risk-reduction focus (the risk reduction model) has been evaluated extensively in several international and developing contexts and found to be acceptable to clients and counsellors and feasible for use in busy public clinic settings (Kamb et al., 1998; Metcalf et al., 2005; Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000). Predominant counselling models in Africa (such as the Egan model in South Africa and The AIDS Support Organization [TASO] model from Uganda) are less structured to achieve behaviour change than the risk reduction model. There have been some efforts to train national, provincial, district and local service providers in South Africa in the risk reduction model, including in research trials (such as Project Accept, also known as HPTN 043, discussed later in this chapter), but there is as yet no widespread implementation.

Several reviews and meta-analyses of VCT studies in international and developing contexts suggest that the evidence for behaviour change following VCT is strongest among sero-discordant couples tested together and among HIV-positive individuals, particularly with their non-primary partners (Denison et al., 2008; Higgins et al., 1991; Kamb et al., 1998; Metcalf et al., 2005; UNAIDS, 2001; Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000; Weinhardt et al., 1999; Wolitski et al., 1997). The effectiveness of VCT as a prevention strategy for HIV-negative people, as well as the long-term preventive effects of VCT for all testers, remain unclear (Higgins et al., 1991; UNAIDS, 2001; Weinhardt et al., 1999; Wolitski et al., 1997).

Counselling of couples and/or partner testing appears to be effective in altering risk behaviour, and more effective than individual counselling when the two are compared (Allen et al., 1992; Kamenga et al., 1991; The Voluntary HIV -1 Counselling and Testing Efficacy Study Group, 2000; van der Straten et al., 1995). While efficacy studies have shown that counselling couples together results in significant behaviour change, less than 1% of couples in Africa have been tested together (Kamenga and Sangiwa in the International Counselling and Testing Workshop Report, 2008). The reason for this low uptake is that individuals appear reluctant to disclose their status to their partners. This represents a dilemma since disclosure of their results to each other is one of the key prevention benefits of couples counselling over individual testing approaches.

Reviewers have identified various ways in which people come to CT: i.e. self-referred, provider or researcher referred. Weinhardt et al. (1999) showed that greater behaviour change occurred among participants who actively sought counselling and testing compared to those who were approached by researchers. Denison et al. (2008), in a recent review of VCT studies in developing countries, point out that given the current debates regarding scaling up CT services, we need to better understand how these variations in the implementation of VCT impacts behavioural outcomes.

The supportive goals of VCT – more associated with counselling than the other CT approaches that follow – are to help reduce the psychological and social morbidity associated with HIV disease (Allen et al., 1999). Research shows that VCT assists people to cope with a range of psychosocial sequelae associated with an HIV-positive diagnosis (Baggeley, 1997; Krabbendam et al., 1998; Lie and Biswalo, 1994; 1996). Findings from a prevention of mother-to-child-transmission study in South Africa highlight the role that VCT played in helping women manage potentially negative reactions of spouses or family members, and also in encouraging partner support, co-counselling and HIV testing (Chopra et al., 2004).

While VCT is an effective prevention strategy for HIV-positive clients and couples, it is but one component of HIV prevention interventions. Its effectiveness is likely to be increased when it is integrated and combined with other prevention services. VCT should be viewed in the context of "Highly Active HIV Prevention" that acts as a "gateway to biomedical prevention strategies, can diagnose and link people to treatment, and is also necessary to fulfil the human right of access to life saving information" (Coates in International Counselling and Testing Workshop, 2008, p. 6).

12.2.2 Criticism of VCT

In recent years, VCT in its current two-session format has come under strong criticism. The argument is that in the busy health-care settings where most counselling and testing takes place, the informed consent and counselling components typically accompanying HIV testing create a service delivery "bottleneck" (De Cock et al., 2002). Consequently, this limits the number of people who are tested, and potentially restricts the number of people who could be accessing treatment.

There have been some adaptations of the standard two-session individual VCT model in South Africa. For example, in antenatal clinics, the individual pre-test session has been converted into a group information session with a shorter individual session used to obtain individual consent for testing. It is clear that consideration needs to be given to the utility of different modalities for providing VCT in medical settings in order to ease the time and resource burden of providing VCT in its current format.

12.2.3 Innovative Approaches to VCT Are Required

To reach the goals of the NSP requires approaches to counselling and testing that are radically different in orientation than VCT as practiced in health-care settings. VCT as a health-service-based approach requires users to *come to the service* and involves significant investment of time, effort and resources – all of which may act as disincentives and barriers to HIV testing. Novel and innovative approaches to CT, which take services to people (in either their homes or via mobile facilities), have been developed in response to the aforementioned weaknesses of service-based models of VCT. These approaches are offered in locations easily accessible to people and have the potential to reach a range of target groups – men, all women, young people, and possibly couples – not easily accessed by the service-based VCT model.

Some of the different types of CT approaches being used in South Africa, and in other African countries with generalised HIV epidemics, are summarised in Table 12.1.

12.2.3.1 Home-Based VCT

The Rakai research project in Uganda has offered home-based VCT as part of its sentinel surveys in that country since 1990 (Matovu et al., 2002). The approach of offering CT in the homes of participants, whether as part of sentinel surveys or as part of general CT services, is gaining in popularity. Home-based VCT involves taking both counselling and phlebotomy staff to participants' homes, where the CT service is offered.

12.2.3.2 Evidence that Home-Based VCT Is Effective

Matovu et al. (2002) show that home-based testing in Uganda has contributed to doubling the number of people accepting and receiving VCT in the 6 years prior to 2002. In another study in rural Uganda, Wolff et al. (2005) demonstrate that home-based testing increased uptake from 10% to 36.7% in all age groups 15 years and older. While the total uptake increased from 13.1% to 46.3% in adults aged 25–54 years, there was a marginally significant difference between uptake in men and women in this age group. Women in this age group showed an uptake from 10.5% to 44.4% and men in this age group showed an uptake from 17.6% to 49%.

Both Ugandan studies found that home-based testing was generally acceptable to adults in the household. Focus group discussions in the Wolff et al. (2005) study revealed that participants preferred home-based testing because it was more convenient; the tester was not at risk of being seen waiting for his results at high-visibility public facilities (which could lead to stigmatisation); and the vulnerability a person felt in receiving results in more public spaces, such as clinics, was reduced. Fylkesnes and Siziya (2004) found that ease of access may have been a contributory factor to the marked difference they found in acceptability between clinic-based and home-based VCT in Zambia.

12.2.3.3 Criticism/Concerns About Home-Based VCT

Home-based testing was found to be less effective amongst adolescents. Young people appeared reluctant to access CT services in the home because of concerns that

Table 12.1 Summary of different counselling and testing approaches

Model/approach	Key features	Advantages/benefits	Disadvantages/concerns	Additional considerations
Client-Initiated Counselling and Testing (also known as Voluntary Counselling and Testing [VCT])	• HIV testing requested (initiated) by the client. • Provided in a variety of fixed health facilities (including primary health-care clinics) as well as at stand-alone counselling and testing facilities.	• Evidence of behaviour change among HIV-positive individuals, particularly with their non-primary partners • Evidence of reducing risk behaviour among serodiscordant couples • Couples-based counselling is more effective than individual counselling • Can help tester manage psychosocial consequences associated with an HIV-positive result	• Time devoted to informed consent and counselling services can create a service delivery "bottleneck," limiting the number of people testing	• Has been adapted in some settings to convert individual pre-test counselling component into a group information session (in conjunction with a shorter individual informed-consent session)
Provider-Initiated Counselling and Testing (PICT) (also known as "Routine Counselling and Testing") PICT "opt-in": clients actively choose to be tested PICT "opt-out": onus is on the client to refuse testing	• HIV testing recommended (initiated) by a health-service provider.	• Improves uptake of testing services • Facilitates earlier referral and access to care • May be more acceptable to women in antenatal settings because it focuses on the benefit to the child • Evidence of acceptability and feasibility in a range of African settings	• Limited data about behavioural outcomes • Concerns around psychosocial impact given limited counselling in some contexts • May act as a barrier to accessing health-care services if individuals fear pressure to test	• In South Africa, widely used as part of prevention of mother-to-child transmission (PMTCT) programmes. • Careful measures need to be taken to ensure that the principle of informed and voluntary consent is not violated.

Table 12.1 (continued)

Model/approach	Key features	Advantages/benefits	Disadvantages/concerns	Additional considerations
Home-based CT	• HIV counselling and testing is conducted in people's homes	• Convenient for the tester • Eliminates the visibility and potential stigma associated with clinic-based testing, where the tester risks being seen waiting for his/her results • Provides access to individuals in rural areas lacking VCT services	• Adolescents express concern that the arrival of the service provider in the home will generate speculation and questions from family members regarding their status • May be unacceptable for couples with conflicting attitudes about testing or concerns about disclosure • Lack of privacy in urban settings • High operational costs	• Working with young people requires careful consideration of factors like age-of-consent, parental involvement in the decision to test, and confidentiality and coercion
Mobile VCT	• Provides counselling and testing services in tents and caravans situated at convenient locations in the community	• Reduces opportunity costs associated with facility-based VCT – ease of access, convenient locations and operating times • More acceptable to youth, men and women not reached by standard VCT services	• Concerns about privacy and anonymity • Fear of being labelled HIV positive • High operational costs	• Issues of stigma need to be addressed

the arrival of the service provider would generate speculation and questions from other family members who might demand to know their status (Matovu et al., 2005; Wolff et al., 2005). In order to address these service barriers identified by young people, the Rakai group was considering implementing a community-based adolescent health and CT promotion programme as well as youth counselling centres placed in convenient locations in the community. In scaling up CT for young people in developing countries, issues such as age of consent, parental involvement in decisions to test, confidentiality and coercion to testing will vary and merit careful consideration (Family Health International, 2002; Family Health International/YouthNet, 2002).

Wolff et al. (2005) found that home-based testing was less acceptable for couples who may have conflicting attitudes about testing or those who were afraid that disclosure may result in abandonment and/or marital problems. Other implementation issues relate to the potential lack of privacy of the model in busy urban settings as well as the high operational costs involved in taking services to people, i.e. travel costs, and the establishment of counselling offices in the field (Matovu et al., 2005). However, researchers conclude that providing results in people's homes, if resources allow, remains one of the best ways of bringing services nearer to the people, particularly those in the rural communities with no easy access to VCT (Wolff et al., 2005).

12.2.3.4 Mobile VCT

As mentioned above, young people cite concerns about privacy and confidentiality, cost and access to services as a barrier to CT service usage (Family Health International, 2002; Matovu et al., 2002). Mobile CT involves the provision of CT services through tents or caravans or other temporary accommodation at convenient locations in the community and may address some of the identified barriers to HIV testing for various hard-to-reach groups. In South Africa, Society for Family Health has increased CT uptake amongst young men by offering mobile services in busy urban areas, such as train and bus stations, shopping malls, churches and workplaces (International Counselling and Testing Workshop Report, 2008).

12.2.3.5 Evidence that Mobile VCT Is Effective

Two feasibility studies in Zimbabwe (Morin et al., 2006) and Thailand (Kawichai et al., 2007) evaluated the feasibility and acceptability of a mobile VCT intervention. The services provided at study sites included mobile VCT and same-day results, along with HIV/AIDS education. Both studies reported high uptake rates of testing. Morin et al. (2006) showed that mobile VCT seemed to attract a range of target groups to the service: women at high risk of contracting HIV from their partners; men who abused alcohol and used the services of commercial sex workers; and people who had identified symptoms of HIV such as illness and weight loss. In Thailand, more than 50% of the participants came for testing because they felt that they needed to know their status; whilst just under half of these felt they needed to test as they had recently engaged in risky behaviours. More than half of the participants also reported that the reason for accessing the mobile VCT service was because it was free and convenient (Kawichai et al., 2007).

The results from the feasibility and acceptability studies conducted in Zimbabwe and Thailand are borne out in the larger intervention trial – Project Accept HPTN 043 – that is currently underway. Project Accept, a large-scale and potentially groundbreaking HIV/AIDS prevention trial, is a multi-country community randomised controlled trial in 34 communities in Africa (in South Africa, Tanzania, and Zimbabwe) and 14 communities in Thailand (Genberg et al., 2008; Khumalo-Sakutukwa et al., 2008). The study aims to test, with recent HIV incidence as the endpoint (together with reports about behaviour and attitudes), the comparative advantage, including cost-efficacy, of two approaches to HIV prevention using VCT.

Project Accept suggests an exciting alternative model to the standard facility-based VCT services – i.e. community mobilisation for testing, testing made available by mobile services in communities, rapid testing and immediate results and linking testing to post-test support services for both HIV-positive and HIV-negative individuals and their social networks. Data from the rural South African site shows that mobile VCT is effective in recruiting relatively equal number of males (47%) and females (53%) to testing. In addition, across both genders, approximately 75% of testers are in the 16–32-year age group, with a median testing age of 24 years (Fig. 12.1).

Mobile VCT services have several benefits. Firstly, the opportunity costs associated with health-based VCT – inconvenient locations, transport costs and incon-

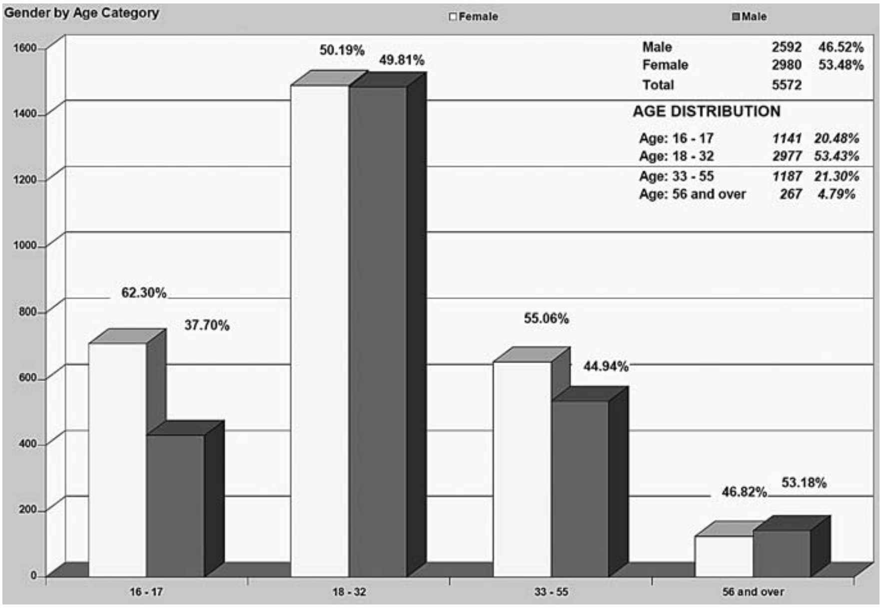

Fig. 12.1 Community-Based VCT in KZN, South Africa: Gender By Age

venient hours required to attend VCT – are reduced (Kawichai et al., 2007; Morin et al., 2006). Secondly, mobile CT is able to reach men, women and young people not typically serviced by health facilities.

12.2.3.6 Concerns About Mobile VCT

Project Accept qualitative cohort interviews with selected community participants reveal a primary concern about the mobile VCT model. Some participants expressed a concern about being visible at mobile testing venues in the community – and not having the privacy and anonymity that comes with testing in busy hospital settings that offer integrated services. In particular, there was a concern that community members might infer that participating in mobile VCT must mean that you are HIV positive. Ellen et al. (2004) argue that whilst mobile testing is effective, the cost effectiveness of this approach might undermine its utility.

12.3 Provider Initiated Counselling and Testing (PICT)

To promote greater access to HIV testing, UNAIDS and WHO (2004)[1] are encouraging expansion of CT models to include provider initiated counselling and testing (PICT). The policy suggests that providers routinely offer HIV testing to clients at increased risk of HIV infection in health care settings, such as STI and TB clinics, antenatal care services, and in clinical and community-based health services in places where HIV prevalence is high. PICT is also recommended for those who are asymptomatic, but who fall into the at-risk age categories.

According to this model, all patients who enter the health care system will be routinely asked if they would like to be tested (often referred to as "opt-in testing"); alternatively they will be informed that they will be tested for HIV as part of routine testing procedures in the facility, unless they refuse (opt-out testing). The central difference between PICT and VCT is that the health care provider offers testing, rather than testing being initiated by the client seeking out the service. The policy recommends that PICT adhere to the core principles of HIV testing and counselling, namely that the services must be implemented with the informed and voluntary consent of clients, and testing must be confidential and accompanied by counselling (UNAIDS/WHO, 2004).

Increasingly, the international policy position on CT is to promote provider initiated CT in addition to client-initiated models such as VCT as a means of rapidly increasing the numbers of people who know their HIV status. In South Africa, provider initiated counselling and testing has not yet been widely adopted by policymakers other than as part of PMTCT programmes. Proponents of PICT argue that

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[1] The UNAIDS/WHO policy refers to Provider Initiated Testing and Counselling (PITC), but the acronym Provider Initiated Counselling and Testing is preferred in South Africa. Both terms refer to the same thing, i.e. counselling and testing initiated by the provider.

instituting PICT would reduce the exceptionalism associated with HIV, in that by approaching the diagnosis of HIV infection like other diseases, more people would be tested, and the stigma associated with HIV testing and HIV infection would be reduced (Metcalf and van Rooyen, 2008).

12.3.1 Evidence that PICT Is Effective

Research shows that PICT is effective in improving testing uptake, identifying previously undiagnosed HIV infections, and facilitating earlier referral and access to care in a range of settings where it has been implemented (Bassett, 2002; Delva et al., 2006; Perez et al., 2006; Rennie and Behets, 2006). For example, Botswana, the first country to implement the approach in 2004, showed a 19% increase in HIV testing from 2004 to 2005 using the opt-out model (Rennie and Behets, 2006). Studies show that the introduction of PICT in Botswana has had no negative effects on the proportion of people receiving test results in Botswana (Steen et al., 2007) nor on post test counselling rates in Zimbabwe (Miller cited in Obermeyer and Osborn, 2007).

There were some initial concerns that the PICT model might create an additional burden on women and girls – already marginalised, disempowered and vulnerable – by routinely testing them in health care settings (WHO, 2006). A few studies indicate that rather than creating a burden on women, women are more inclined to be tested if they think that it can benefit their baby (Etiebet et al., 2004; Perez et al., 2006; Simpson et al., 1998). Obermeyer and Osborn (2007) suggest that routine testing, presumably done for the benefit of the baby, does not make assumptions about women's sense of moral worth, and thus may be more acceptable to women for these reasons.

12.3.2 Concerns About PICT

Studies are increasingly showing that PICT in a range of African settings is acceptable and feasible, and is likely to play a key role in scaling up CT in this context. However, apart from the acceptability and feasibility studies, little data about the behavioural outcomes and psychosocial impact of PICT approaches has been accumulated. This evidence is important for supporting the positive claims that provider initiated approaches to CT could have an impact on prevention, behaviour change, treatment, stigma reduction and normalization of the epidemic.

12.3.3 Expanding Paediatric Testing

As discussed, in South Africa PICT is not widely implemented, other than as part of prevention of mother-to-child transmission services. Rollins et al. (2007) argue that despite the extensive investments in PMTCT programmes many of these programmes function poorly. In addition, antenatal programmes are poorly integrated with care and treatment for mothers and children in the post-natal period.

Consequently, many children fail to be identified as HIV infected until they become ill and require hospitalisation.

Simple methods for definitive, early infant diagnosis remain a challenge in the expansion of paediatric testing and treatment services (International HIV Counselling and Testing Workshop, 2008). Barriers to paediatric testing and treatment include inadequate or non-existent policies on age of consent and disclosure, a reluctance of health care providers to test children, inadequate trained staff to counsel children, lack of testing technology and a concern about sustainability of supplies (*ibid).*

12.3.4 Preliminary Evidence in Support of Paediatric Testing

Preliminary findings from routine, unlinked HIV testing at 6-week immunization visits in KwaZulu Natal, South Africa[2] revealed that while many women said they were negative, 31% of their infants were detected to be HIV infected at their 6-week immunisation visits. Rollins et al. (2005) suggest that it is likely that many of HIV positive babies were (a) born to mothers who reported testing negative during pregnancy or (b) born to mothers who did not report their HIV status and therefore would not have been identified by current testing algorithms. These authors argue that routinely testing children at 6-week immunisation visits, with their mothers' consent, could achieve two important goals in paediatric testing. First, it will help to identify HIV infection in children known to be HIV-infected at an earlier age and second, it will help to identify HIV infection in children born to infected mothers whose serostatus is either negative or unknown during pregnancy. Significantly, early identification of infection could help to prevent much of the early morbidity and mortality experienced by HIV-infected children in many resource-limited settings (Rollins et al., 2005).

12.3.5 Concerns

This is a relatively new approach to testing. More feasibility and acceptability studies in high-prevalence developing countries are required to determine the acceptability and feasibility of this type of testing (where testing the baby reveals the baby and the mothers HIV status) for service users and service providers. In addition, more studies are required that assess whether testing at 6-weeks leads to better uptake of testing and thus earlier referral of children to treatment and care than traditional ANC testing methods allow.

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[2] Rollins, N., et al. (2005). Assessing the impact of the PMTCT programme on vital child health indicators in KwaZulu Natal. Unpublished proposal.

12.4 Challenges for the Way Forward

The poor coverage and the predominantly health-based location of both CICT and PICT models are limiting factors that discourage, rather than facilitate, testing uptake. The capacity of African health systems is severely hampered by a number of factors – limited access, an acute shortage of health personnel, poor management and inefficient resource allocation and utilization (Asante, 2007). Given the weakness of these health systems it seems unlikely that the addition of PICT on its own (without simultaneously addressing some of these systemic factors) would lead to any drastic improvement in HIV/AIDS treatment or care.

Key populations to reach in the health facility setting include pregnant women and HIV-exposed children, as well as TB and STI patients. South Africa may wish to expand PICT to include all patients who come into contact with the health system. Many environments do not yet have the means to effectively apply new strategies, including PICT, in which health care workers purposely offer (and provide) more testing (UNAIDS/WHO, 2004). Policy and programme planners need to consider the consequences of widespread PICT implementation for health system provisions.

Optimistic claims of the benefits of provider initiated CT need to be substantiated with evidence. A focus on the number of people tested, without attention to the short- and long-term effects of behaviour change among these individuals, would not be to the benefit of our prevention efforts, and is not likely to encourage positive health-seeking behaviours over time (Gruskin, 2006). Furthermore, as PICT models are implemented, consideration needs to be given to the three C’s (informed consent, confidentiality and counselling) in the model.

In order to expand CT in medical settings, consideration needs to be given to how best to attract men – who don’t typically access public health facilities – to these services. Bond et al. (2005) point out that on the whole, men are less likely to be exposed to services offered in health care facilities because they are less likely than women to have healthcare insurance, to access usual sources of care or to go to the doctor on a regular basis. The lack of male partner involvement in PMTCT settings is a missed prevention opportunity (Bassett, 2002; Delva et al., 2006). Consideration needs to be given to how best to get men to test in these contexts and how to make services more appropriate for male testing.

Health facility-based testing alone will not be enough to achieve the prevention and treatment goals of the NSP. To achieve CT scale-up, massive expansion of VCT services through home-based testing and mobile CT models needs to be implemented. Strong evidence exists that these models are capable of reaching target groups thus far missed through the predominant health facility-based CT that currently pertains in South Africa. These groups include: youth at risk and men and women who don’t typically access reproductive health services.

The VCT efficacy literature shows the strongest benefits to couples who test together. Thus far, in South Africa, couples-based VCT has not been widely implemented. Consideration needs to be given as to which settings would be best suited and appealing to couples. Mobile VCT facilities may be ideal for couples-based testing, given their convenience and ability to successfully attract men to services. In addition, counsellors need to be equipped with specialised skills to deal with issues of concurrent partnerships, as this can be a particularly complex matter to navigate within the couples counselling context (Kamenga and Sangiwe in the International Counselling and Testing Workshop, 2008).

12.5 Policy and Research Gaps

Several policy gaps impact CT scale-up in South Africa and need to be urgently addressed. In particular, as outlined by the Joint Civil Society Forum Monitoring Group in 2006, the following issues pertaining to lay counsellors need to be addressed: (1) recognised positions for lay counsellors within the health care system, as well as professional counsellor associations are important for ensuring the sustainability of CT programmes; (2) the issue of remuneration for lay counsellors needs to be resolved, and (3) the scope of practice needs to be revised so that nurse assistants and lay counsellors are permitted to conduct a finger prick or oral saliva test. The last point, is particularly important, to facilitate the kind of scale-up of CT required in both medical and non-medical sites necessary to reach the testing and treatment goals of the NSP.

While the NSP has set clear targets in terms of numbers of people tested, a parallel goal should be to ensure the delivery of the highest quality and standard of counselling to VCT clients. The risk-reduction model of counselling, with theoretically sound and evidence-based behaviour-change outcomes, needs to be widely implemented across the country. Quality issues that impact the delivery of VCT – such as the lack of minimum standards guiding counsellor training, practice, supervision and support – need to be addressed.

Promotional campaigns have proven to be effective in encouraging counselling and testing. More social marketing “know your status” campaigns that attempt to make HIV testing normative are required. Dixon-Meuller and Germain (2007) suggest that normative messages about CT should encompass a sense of responsibility that testing is the right thing to do for oneself and one’s sexual partner: “that being regularly counselled and tested for HIV and other STIs – individually and with one’s partner – and keeping one’s partner informed, is not only a right, but also the right thing to do” (p.287).

As we consider implementation of these various approaches we need to simultaneously encourage evidence-based decision-making on CT strategies. In particular we need to:

1. Explore the relationship between HIV testing and prevention, treatment, and stigma-reduction outcomes. We also need to consider how the prevention outcomes of CT can be improved.
2. Compare uptake for the different HIV testing approaches and understand the decision-making process for each approach, considering the role of different lev-

els of coercion or voluntariness on decisions to test and their associated consequences (Strode et al., 2005).
3. Explore the role of fear of stigmatization, and self-stigmatization in the context of VCT and how they impact on VCT uptake and how they can be addressed.
4. Understand perceived advantages and disadvantages of *not* going for VCT, particularly among asymptomatic individuals. (Swanepoel, 2004).

12.6 Conclusions

South Africa has articulated ambitious HIV testing and treatment goals in the *National Strategic Plan on HIV & AIDS and STIs, 2007 – 2011.* Achieving the counselling and testing goals outlined in the NSP requires a similar boldness in implementation. The evidence is clear – we need to embrace and promote more than one CT model. Each of the models has strengths and limitations, and works better for some target groups, and in certain settings and contexts. Implementing a combination of models allows for a comprehensive and expanded CT approach – a necessity given the extent of the epidemic in South Africa.

Acknowledgments The authors thank Lauren Kleutsch for her contributions in editing this chapter.

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Chapter 13
Vertical transmission of HIV – Pregnancy and Infant Issues

Lorraine Sherr

13.1 HIV Prevention in Pregnancy

HIV/AIDS responses during pregnancy can maximally help in terms of prevention treatment and care. Such interventions mark an opportunity for multidisciplinary action enhanced by a truly integrated approach. Pregnancy marks a point where couple relationships are paramount, a point where all provisions for the new infant are concentrated and a point where biomedical and psychosocial models converge. It also typifies the challenge facing the future evolution of HIV/AIDS strategies and a possible turning point in prevention with dramatic long-term ramifications.

In 1996, the dramatic findings of the 076 trial (Connor et al., 1994) revealed the efficacy of antiretroviral treatment in preventing transmission of HIV from mother to child. This marked a turning point in HIV prevention. Yet this intervention has been slow in global implementation with marked barriers created by inadequate responses, political barriers, simplistic models and misunderstandings. This biomedical intervention brought with it a multitude of questions that required a multidisciplinary approach. These included issues around HIV testing in pregnancy, facilitators and barriers to test uptake, treatment uptake and adherence, counselling around decision making, uncertainty, adjustment, behavioural and understanding parenting. This chapter will review many of the complex factors around HIV in pregnancy with a specific focus on psychosocial factors. It will provide an overview of transmission, HIV testing, HIV in pregnancy, interventions and many of the challenging considerations that HIV raises for the mother, the father and the infant. These include consent, decision making, infant feeding, bereavement and the difficult issues associated with gender and young children that are highlighted when HIV and reproduction are considered. Finally some comment on the contribution of social science to understanding the full complexity of the problem will be highlighted.

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_13,

13.2 HIV Transmission to the Baby ‘Vertical Transmission’

It is well established that HIV infection can occur vertically. This can happen during pregnancy, delivery or post-partum, notably via breast feeding. Most infant infections occur in this way (Gray and McIntyre 2007). The risk of transmission in untreated women is related to maternal health (especially viral load), obstetric factors especially mode of delivery, time between membrane rupture and birth, and infant factors such as premature birth (De Ruiter et al., 2008). Although there is great concentration of interventions and knowledge around the time of pregnancy, it is important that a longer-term view is taken of infant prevention in that prevention of HIV infection to women in the first place would directly reduce rates of infant exposure to HIV. This must clearly be part of a comprehensive HIV prevention response. In addition, the issues of family planning and fertility control also need consideration in that the prevention of unintended pregnancies in women generally, and HIV-positive women specifically, should feature as a component of a comprehensive response to HIV prevention in transmission. Indeed, a recent study (Dube et al., 2008) showed that in Zimbabwe declining maternal HIV prevalence was the major driver of reduced vertical transmission despite the presence of a single-dose Neviripine programme. These works, utilising complex mathematical models, show that a more efficacious and complex regimen may have doubled the number of averted infections (Dube et al., 2008).

Without any intervention, the rate of HIV transmission to newborns has varied from 13 to 45% in international studies (Sherr, 2005). This variation is difficult to explain and may be a complex effect of stage of infection, background health factors, timing of exposure, virus strain, biomedical factors in both the mother and infant and nature of exposure. It is also well established that the majority of infant infections occur through vertical transmission (Little et al., 2008). Approaches which include the utilisation of combination antiretroviral therapy, elective caesarean section and breastfeeding avoidance all contribute to much reduced transmission –2% or lower, in environments where all avenues are available (ECS, 2005). The setting may define the relative safety of interventions such as caesarean sections and avoidance of breastfeeding, and the current knowledge base on the relative benefits and hazards of these interventions is complex. A number of recommendations have provided for reduced intervention packages in resource or facility constrained environments. Although these have been effective in reducing transmission, there are confounding problems of resistance, elevated transmission and uptake (WHO, 2006; Gray and McIntyre, 2007).

13.3 Antiretroviral Treatment in Pregnancy

Antiretroviral treatment in pregnancy has revolutionised the prognosis and marked substantial policy changes and developments. As early as 1994 the ACTG 076 trial demonstrated that antiretroviral treatment reduced infant infection (Connor et al., 1994). Since the 076 trial the treatment has evolved and been refined. The nature of the regimen, the duration, initiation and consequences vary and has been well studied. The efficacy of ART for prevention of vertical transmission of HIV has been reported in numerous studies in a variety of settings in low-, middle- and high-income countries (Lallemant, 2000; Lallemant et al., 2004; Mandelbrot et al., 2001). Efficacy seems to vary according to breastfeeding, type of regimen, number of compounds, adherence and timing. Although transmission to infants has been lowered, it has not been eliminated (Dabis et al., 1999; Guay et al., 1999; Jackson et al., 2003; Leroy, 2003; Leroy et al., 2002; Petra study group, 2002; Wiktor et al., 1999). The findings of a number of key studies are summarised below by way of example of variation, setting and outcome (Table 13.1). Psychological considerations relate to uptake, adherence and concerns around the effects of treatment on the mother and the infant.

As medical intervention and treatment are efficacious, availability, testing and access rights have been a challenge (Hudson et al., 1999). As a result, many countries have operationalised programmes to offer HIV testing to all pregnant women, with the idea of identifying positive pregnant women and providing treatment (Suksomboon et al., 2007). This straightforward strategy, however, is fraught with policy and implementation challenges (JLICA 2008). Clearly the successful implementation of this strategy, in its fullest form, is the single-most dramatic intervention currently available to prevent children from being infected with HIV, and as an entry for mothers (and fathers) into treatment and support programmes. In Europe, over the period 1997–2003, HIV-positive women have been provided with antiretroviral treatment at an accelerated rate from 5 to 92% (European Collaborative Study, 2005). Transmission rates have been reduced to 0.99% in Europe (European Collaborative Study, 2005), and 2% in the USA (Mofenson, 2004). However, in low- and middle-income countries such programmes have not achieved universal coverage. HIV testing in pregnancy varies dramatically according to resources and by 2007 only 34% of those eligible to receive antiretroviral treatment actually did (UNAIDS, 2008). This figure may be a gross overestimation as it is directly affected by the success of HIV testing programmes and only refers to known HIV-positive pregnant women.

Future concerns around treatment need to be considered in ongoing monitoring, and as the evidence base develops policy and practice should evolve (Coovadia and Schaller, 2008). Issues that require long-term monitoring include logging and monitoring any toxicities, heightened pre-eclampsia in the presence of treatment, abnormalities, long-term effects on those born to be HIV negative and birthweight.

13.4 Mode of Delivery

Early twin studies showed that both infants were not necessarily infected. This led researchers to highlight the timing of infection around delivery and proposed that elective caesarean section may avoid infection. Trials of this procedure showed, indeed, a significant protective effect. However, in the presence of antiretroviral

Table 13.1 Studies of interventions to reduce vertical transmission

Study	Regimen	Initiation/duration	Efficacy	Consequences
Connor et al., 1994	AZT	36 weeks	65% reduction	First trial
WHO, 2006 Cooper et al., 2002	ART triple therapy (AZT,3TC, NVP)	28 weeks	<2%	Variation depending on maternal CD4 count (<or>350 cells/mm Resistance offset by AZT/3TC tail
HIVNET 012 Jackson et al., 2003	Single dose NVP	Onset of labour Single dose to infant	8.1%	Needs to be taken >2 hours before birth. 45% NVP resistance in infants (Martinson 2006) and mothers (Shapiro 2006)
ANNECCA 2006 (Modified Thai) Lallemant 2000, Shaffer 1999	AZT	34–36 weeks initiation and hourly during labour. Infant 7-day regiment	4.7–10.5%	
Partners in Health Cooper et al. 2002	Triple therapy AZT, 3TC NVP	28 weeks, 14-day AZT/3TC tail post-partum 7-day AZT to infant	<2%	Good history and variations according to clinical status, previous exposure to antiretroviral treatment and time of presentation
Lallemant et al., 2004	AZT, NVP	28 weeks, 3 hourly AZT in labour and NVP at onset. 7 day AZT and single dose NVP to infant.	2.8%	Extended infant treatment if mother presents late and has reduced treatment.
Shapiro et al., 2006	AZT and NVP	34 weeks start and NVP in labour. Infants AZT 1 month and single-dose NVP birth.	4.3%	NVP resistance -– strategy of targeting infants only for NVP to reduce maternal resistance
WHO and PIH Cooper, 2002	ART (AZT,3TC, NVP)	28 weeks. AZT 3 hourly 7-day AZT and 3TC and single-dose NVP to infant	<2%	Variation depending on time of presentation and treatment to mother.

treatment, this effect is now unclear and it would be difficult to have a sufficiently powered trial to address this question, given the very low transmission rates in the presence of treatment. In a developing setting, surgical delivery may have special considerations based on availability of subsequent treatment, infection risk and hospital provision. Furthermore, complex issues of psychological ramifications of caesarean section on the mother need to be considered.

13.5 Infant Feeding

Currently, there is also debate around the best way to manage risk of infection via breastfeeding. Many options have been considered, including recommendations to avoid breastfeeding, exclusive breastfeeding, early weaning or treatment of the mother during lactation to reduce the chances of transmission to the infant. There is a balance between the availability of options, the social pressures and benefits of breastfeeding and the desire to avoid or minimise this route of transmission. Early recommendations that suggested avoidance of breastfeeding in the west with different suggestions for resource poor settings entrenched the problems rather than solving them. Currently, there is still much debate and the benefits of breastfeeding, especially for an ill infant are weighed in the balance. Breastfeeding is an emotive topic and any interventions must consider such cultural and emotional factors if they are to resonate with women (Coovadia et al., 2008).

13.6 Contribution of Social Science

Although the basic medical intervention may be relatively straightforward, social science has shed light on many of the complexities around initiating PMTCT programmes and understanding the wide implications of HIV in pregnancy. The intervention seems straightforward: identify all pregnant women with HIV, administer prevention medication and ensure a number of risks are avoided such as breast feeding. The reality is much more complex. Social science has shown the complexities of operationalising HIV testing in pregnancy. It has pointed out the many barriers to test uptake and provided insight into counselling which may facilitate the process as well as address risk behaviour in a broader public health model of provision. Once tested for HIV, social science has provided some insight into the experience of HIV diagnosis especially in terms of emotional trauma, stigma and relationship strains. Furthermore, studies have shown which factors are associated with treatment uptake and thereby point out pathways to enhance uptake and ameliorate the burden of HIV. Much of the current PMTCT model is individually based with a perspective from either the pregnant woman or the infant. However, social science has clearly pointed to the family-based nature of HIV infection and provided a model of provision and care based on a family perspective. Both mental health and cognitive development are relatively neglected areas.

13.7 HIV Testing as the First Step in Prevention

Intervention availability is contingent on establishing HIV status. Thus HIV testing has been integrated into routine pregnancy care and quite considerable attention has been paid to mechanisms of offer, patient entitlement, type of testing, type of counselling and efforts to extend the reach of HIV diagnosis in or before pregnancy. Historically, all HIV testing was accompanied by pre- and post-test counselling. This was seen as a vital component for various reasons. The test itself may potentially signify a lifelong and fatal condition, preparation for the test may enhance coping and adjustment, understanding risk and introduction of prevention and future risk avoidance was seen as opportune.

The policy rollout of antenatal HIV testing and treatment seems to have two major limitations. The first is that it has failed to be comprehensively rolled out in those settings where the epidemic is most severe. And the second is that it is a narrow-focused strategy which overlooks parents and family in treatment. It thereby contributes little to the long-term sustainability of intact families, HIV prevention and HIV treatment through family networks. At the same time, individually oriented services mark women out with diagnosis, stigma, trauma and unmet provision (Sherr et al., 2008).

Treatment is contingent on establishing HIV status, either pre-pregnancy or in early pregnancy (Bergenström et al., 1999). For treatment to work it needs to be available, introduced and accepted. The science around the exact compounds and the regime of administration is not fully established (Dabis et al., 2000; Jackson et al., 2003; Petra study group, 2002). In addition to preventing HIV infection to the baby (primary prevention), treatment of the mother represents urgent secondary prevention. This will ensure her ongoing good health and keep the family intact, which is of fundamental importance to a developing child. This has been clearly established as policy, but is often not reflected in current practice (BHIVA, 2007; WHO, 2006). As HIV can be transmitted during breastfeeding, there is a need to continue prevention efforts until the baby is weaned. In resource-poor settings, this is a challenge. There is a hiatus in clear, implementable recommendations, and the challenges around breastfeeding have still not been resolved (Coovadia and Kindra, 2008).

Treatment for the infant only is short sighted. Many of the regimes still rely on one compound, despite the fact that it is well established that exposure to monotherapy affects efficacy and resistance development (Phillips et al., 2002; Arrivé et al., 2007). This remains problematic in terms of the regimens on offer for many pregnant women. Current state-of-the-art provision relies on combination therapy (De Ruiter et al., 2008).

13.8 Situation in Sub-Saharan Africa and South Africa

Given the high HIV prevalence in women and infants in South Africa, a number of programmes have been initiated and monitored. These clearly demonstrate the need for evidence-based evolution in policy and reveal the efficacy of roll out in many settings. A number of delays have impeded the full roll-out treatment in South Africa (Lancet, 2008). Yet roll out seems feasible as shown by Geddes et al. (2008) who describe a comprehensive service offered to 2,624 pregnant women in a Durban state-aided hospital where all received HIV counselling and 91% tested for HIV. Thirteen percent were HIV positive and 89% completed their delivery at the hospital. Furthermore, this study managed to reach 668 partners for HIV testing. Interventions resulted in 70% caesarean section deliveries and 98% roll out of Neviripine. Seventy-five percent also were given AZT. At 6-week follow-up, 81% of infants were given a polymerase chain reaction test revealing a transmission rate (of those tested) of 2.9%. Government policies in South Africa marked a severe interruption to provision for infant prevention.

13.9 Psychological Considerations

For all women, it is well documented that an HIV diagnosis has a profound emotional impact. Knowledge of status affects mood, relationships, social functioning, legal and human rights. This is compounded by the fact that for many women HIV diagnosis comes during pregnancy, which brings with it urgent decisions, complex adjustment and a need for quality medical support. Kwalambota (2002) in Zambia noted heightened psychological trauma for those diagnosed during pregnancy compared to those who knew their status prior to conception. In South Africa, Rochat et al. (2006) have documented heightened levels of depression in HIV-positive pregnant women. Psychological provision in terms of therapy, response and programme integration varies according to the skill base, the availability of time and resources, the historical provision of mental health services and the quality of services. Psychological need and effects do not seem to differ dramatically between women in very different settings; however, resources to provide and respond to these do differ.

13.10 Reproductive and Sexual Health Counselling for all HIV-Positive women

Studies have shown that HIV infection disrupts sexual functioning (Bell et al., 2006; Florence et al., 2004; Keegan et al., 2005). Brown and Rundell (1993) in a small study of 20 women noted lowered sexual drive and decreased frequency of sex, with 50% of the sample abstinent. In a follow-up study, Brown showed that 32% of their sample reported reduced sexuality on entry and 33% showed similar findings after more than 2 years follow-up. The loss of joy was seen as chronic in a third of women. Hankins et al. (1998) showed that 66% of Canadian HIV-positive women continued or resumed sexual activity, with 44% being sexually active within 1 month of HIV test results. However, many (85%) reported sexual adjustment problems. Madge et al. (1998) in a study of 505 women note that for half (49%) HIV was the first sexually transmitted disease.

All HIV-positive women and men should have an opportunity to discuss and explore sexuality and reproduction. This needs to be done in an objective and constructive way to overcome any reluctance to talk by those who fear discrimination and pre-set attitudes condemning or discouraging childbirth. The desire for parenting is universal and many women with HIV actively desire a child and many have unprotected sex in the absence of contraception of any form. The presence of HIV may affect pregnancy desire, and indeed the advent of treatment may, in turn, also affect such plans. General pregnancy decision making should be understood especially in relation to factors that may be relevant in the presence of HIV. Some couples are unaware of their partner's HIV status and the absence of family or couple testing often contributes to this. Clearly, a policy-level provision of couple testing would facilitate informed couple decision making. In discordant couples (i.e. one partner is positive and the other negative) conception and pregnancy poses a risk of exposure to HIV for the negative partner (Sherr et al., 2000). There is growing evidence that HIV-positive women may have reduced fertility (Brunham et al., 1991; Brunham et al., 1993; Coll et al., 2002; Waters et al., 2007). A recent study in Europe noted that one in six pregnant HIV positive women had sought assistance with conception (Fiore et al., 2008), while pregnancy rates were greatly reduced in a population study in Uganda (Gray et al., 1998).

The advent of improved diagnosis, treatment, management and prognosis may affect women's decisions about becoming pregnant (Ergin et al., 2002). Pregnancy decision making is affected by a number of contextual factors (Nyamath and Stein, 1997) including social expectation (Semple et al., 1993), partner influences, psychosocial factors, traditional gender roles (Sowell et al., 2002) and a wish to create something of value, which will survive beyond the woman's death (Ahluwalia et al., 1998). Motherhood has special meaning for women in terms of its fulfilment as well as its vision as a career in itself (Kurth, 1993). A recent study in Europe (Fiore et al., 2008) showed that maternal well-being, having an uninfected partner and no previous children were associated with conception.

In discordant couples, where one partner is HIV positive and the other HIV negative, the risk of transmission depends on factors such as treatment, viral load and other sexually transmitted infections. The literature clearly shows that there is a risk of transmission (Fakoya et al., 2008). In seroconcordant couples – where both partners are HIV positive – there are no studies which provide definitive risk of superinfection and clearly the issue of resistance must be one to consider in counselling. Parenting options that can be considered in the presence of HIV in one or both members of a couple include semen washing, donor insemination and adoption (depending on resources available), artificial insemination to reduce exposure for HIV-negative men and an array of assisted fertility treatments. Special considerations of facilities available should inform such decisions given the infection control and universal precautions needed and the inability to apply some infection control techniques to human gametes and embryos (Gilling-Smith et al., 2005).

13.11 HIV Counselling for All Pregnant Women

Knowledge of HIV status is a key turning point to a stream of actions. An HIV test has been available from early in the epidemic. Although a simple biological test, this is a test with complex psychological and medical ramifications. Couple testing is seen as most cost-effective (Postma et al., 2000), yet in most environments, testing is targeted at women, with little policy or provision for men.

Over the last decade, there has been marked increased testing availability in pregnancy, yet termination and family clinic provisions are slower to follow (Bergenström et al., 1999. There is much debate on the procedures associated with HIV testing in pregnancy. How should the issue be raised? Should the tests be optional or routine? Should the paradigm on offer be one of 'opt in' or 'opt out'? Who should do the counselling and how should this be carried out? In resource-poor settings the questions relate to quality and effectiveness of counselling. Where there is no tradition of counselling and limited trained staff, counselling is often reduced to lay counselling, menu-driven information provision or brief discussions. Counsellor dynamics are pivotal in determining test uptake (Varga and Brookes, 2008). The literature suggests that competent counselling includes five key components:

1. *Informed consent* – whereby the test is introduced and the recipient understands and agrees to the test.
2. *Risk assessment* – this discussion helps understand risk behaviour, HIV transmission and future prevention. It is relevant irrespective of eventual test outcome.
3. *Behaviour change* – this complex component addresses a variety of behaviours, most notably sexual risk and also health protection behaviours and issues such as relationship navigation and disclosure (Simbayi et al., 2007).
4. *Therapeutic care* – counselling around care include an understanding of available interventions, coping, support needed and linking into care systems.
5. *Decision making* – this is a vital component and is relevant at all stages from the decision to test, to the decision to disclose, undertake treatment and delivery/feeding options.

The chapter on 'Voluntary counselling and testing (VCT)' (Chapter 12 in this volume) describes many of these issues. It highlights the important components of risk reduction, HIV testing and how they apply to pregnancy. Testing uptake is affected by the mode of offer, the motivation of the pregnant women, the availability of interventions and a number of additional psychosocial components which either facilitate or hinder uptake. Counselling support extends beyond pre- and post-test counselling. Emotional trauma, decision making and coping are all challenges during a positive pregnancy.

13.12 Intervention Pathways and Decision Making

The decision pathway and intervention opportunities for parents during pregnancy are quite complex. The pathway includes pregnancy, pre-test counselling, HIV testing, result provision, post-test counselling, intervention decision making, post-partum testing of infant and post-partum follow-up. Clearly, comprehensive and reliable systems need to be operational and functioning in order to help families navigate the system and in order to prevent drop out. To date, the success has been low. For example, by 2006 only 9% of women who were known to be HIV positive during pregnancy received interventions to prevent infant infection. Two years later, by 2008, this figure had climbed to 34%. This marks a steep increase, but falls dramatically short of target. Two-thirds are lost and figures only relate to those who are known to be HIV positive. The figure is probably considerably higher given that HIV testing is not universal in pregnancy care. Data derived from two studies, Manzi et al. (2005) in Malawi and Shetty et al. (2008) in Zimbabwe, is used to demonstrate the uptake and pathway through the system. In Malawi where 3,136 women attended antenatal clinics, the data shows 2,996 counselled, 2,965 receiving HIV testing, 2,965 post-test counselling (31–1% refusal), 646 testing HIV positive, and only 288 receiving Neviripine interventions and 122 attending for 6-month post-natal check up with their infant. In Zimbabwe, where there were 19,279 pregnant women, 18,817 underwent pre-test counselling, 10,513 went on to test for HIV, of which 1,986 were HIV positive. Results were collected by 9,696. Only 288 men tested (no such data provided for Malawi). From the 1,986 positive, 1,387 were given a Neviripine tablet to take home, and 691 were reported to take NVP at onset of labour and 615 infants received Neviripine. At the 6-week follow–up, 396 mothers returned and 209 completed three follow-up visits. Both these show severe attrition throughout the process. This picture is not atypical and clearly sets out the challenge of comprehensive service delivery and engagement if continuity of care is to be achieved. Clearly, the focus on HIV testing and uptake has been efficacious, but the programmes tail off, like so many others, when the ongoing comprehensive care and engagement is monitored.

13.12.1 Mother/Father and Couple Testing

The majority of programmes in pregnancy have focussed on mothers. Although mothers play a key role and clearly are a priority group entitled to have HIV testing available, there are strong arguments that this should be extended to fathers as well. Shetty et al. (2008) note that of 19,279 pregnant women of whom 10,513 test for HIV, only 288 men test for HIV (despite the fact that 1,986 women test HIV positive). Using a family rather than an individual lens to observe infant exposure to HIV, it is clear that the priorities for the family is to avoid infection of all members, to maintain good health of those who are infected and to ensure parental survival and quality family environment for optimum child development. Field studies have shown that much stigma and discrimination are associated with positive HIV status, and couple testing would obviate the erroneous assumption of ‘first tested first infected’. Many women report social recriminations and are fearful of disclosure because of such ramifications. ‘Women only’ testing compounds this. Couple testing has been seen as feasible in many settings (Guthrie et al., 2007). If a woman tests HIV negative, it is important to establish if her partner is HIV positive. Unprotected sex during pregnancy is common (it is difficult to convince women already pregnant to consider or negotiate condom use). Thus women are particularly vulnerable to new infection. Furthermore, it is well established that newly infected people will have a heightened viral load, and this is associated with elevated transmission. Another option to monitor new infections during pregnancy would be repeat HIV testing in late pregnancy. Both of these procedures are seen as highly cost-effective (Postma et al., 1999; Postma et al., 2000)

13.12.2 Consent and Result Collection

Consent and informed consent are important considerations in HIV testing (Irwin et al., 1996). As with any medical test, the considerations include the ability of the individual to provide full consent, the environmental context of the HIV test offer and provision (Sherr, 1999; Sherr et al., 2000). Historically informed consent has been seen as vital in all HIV testing situations, specifically pregnancy, given the lifelong ramifications of a positive test result. Full understanding as well as the power imbalance of medical interviews may make people unable or inhibited to decline testing as a result of a variety of fears or misconceptions, a willingness to please or fear of negative consequences (Fitzgerald et al., 2002; Abdool Karim et al., 1998; Sherr et al., 2001). Given treatment efficacy, the benefits of testing outweigh the benefits of ignorance. Care and attention is needed to protect consent and informed consent, and pre- and post-test counselling has resulted in benefits in terms of preparation for results and addressing risk behaviour. Many studies have documented a discrepancy between testing uptake and result collection. This has been documented with different client groups, in different geographic environments and with different HIV testing schedules (home/clinic; rapid same day results vs. delayed results) (Cartoux et al., l998). This may be associated with consent where those who felt coerced or unclear actually decline by default by not returning for their results. It may also be associated with practical issues such as costs of repeat attendance or the time gap between testing and results. Streamlined provision has allowed for rapid and same-day testing to overcome the latter.

Consent is a problematic area, and there are numerous studies testing for women who ‘declined’, ‘refused’ or ‘withheld consent’ (Sherr, 1999). Larsson et al. (1990) report on ‘a blind analysis of the blood specimens from the 58 women who declined the test was performed.’ Hull et al. (1988) discuss an HIV prevalence rate of 3.8% among STD clinic attendees who declined HIV antibody testing. Similarly, Jenum (1988) notes that 2% of women who declined HIV testing were positive. Barbacci ‘assess the prevalence of HIV in women who did not volunteer for testing’ and Simon et al. (1996), in a study of 20,125, note a refusal of 35%. Jones et al. (1993), ($n = 1{,}926$) describes 21% of HIV test refusers being tested, as does Behrendt et al. (1994), ($n = 2{,}842$) where 53% of refusers were tested and MacDonald et al. (2001) who records ‘no pre test counselling prior to HIV testing by 25% obstetricians, 9% family practitioners and 5% hospitals.’ Henry reported on HIV-testing practices in 371 US hospitals where consent was obtained and documented in only 50% of the cases, and counselling was provided in only 51% of cases. Denayer et al. (1990) found that 49% of Belgian gynaecologists tested for HIV without informing patients and Dalzell et al. (1995) using a sample of 538 women found that 77% were invited to undergo testing, 15% for which 'no consent' was recorded, some who agreed were not actually tested. With the changes over time, HIV testing in pregnancy has increased, but consent and counselling seem to have been enhanced. For example, Rey et al. (1998) in France (1992, 1994 and 1996) report that routine prenatal HIV screening has not changed (89%) but that, with time, systematic consent was more often requested (38.2% vs. 65.5%). In recent years, the advent of 'opt out testing' and 'provider initiated testing,' are both systems to enhance HIV testing uptake. This has specific benefits for pregnant women, but needs to be balanced with quality provision in terms of both testing and counselling procedures as well as follow-up resources for longer-term care for those who have been identified as HIV positive.

13.12.3 Stigma and Disclosure

Test outcome knowledge of HIV status – whether positive or negative – involves issues of disclosure, which is often not universal or immediate (Antelman et al., 2001). Reluctance is often as a result of fears of violence, rejection, abandonment, judgement or avoidance (Medley et al., 2004; Simbayi et al., 2007). There are many studies which have documented such experiences (Jones, 2008), but, on the other hand, there are also those describing acceptance and setting out how strong social support is a predictor of coping and adjustment (Maman, 2003). Thus disclosure issues need to be considered during counselling in order to prepare support and provide skills if needed (Sullivan, 2005). The burden of secrecy and non-disclosure has a high mental health cost (Mayfield et al., 2008). South African studies have described how young women would go to extreme lengths to avoid disclosing their status to obstetric staff, even if this meant no antiretrovirals (Varga and Brookes, 2008). Such barriers and stigma need to be overcome and novel approaches to both counselling and other provisions may enable women to disclose, such as the provision of legal services and materials within pregnancy clinics (Maman et al., 2007).

Studies of partner testing have shown that between 20 and 80% of partners of women testing HIV positive are themselves HIV negative (Freeman et al., 2004). Disclosure patterns reveal that disclosure of status is not automatic, increases with time and lack of disclosure to sexual partners is systematically recorded in many studies (Table 13.2).

13.12.4 After Testing HIV Positive

An HIV-infected pregnant woman will have a wide range of needs. These can be summarised as psychological, practical, social and medical.

Table 13.2 Disclosure of HIV status to sexual partner

Study	% Non-Disclosure	Finding
Niccolai et al., 2006 $n = 63$ USA	44%	Delayed 22% none 24%, full disclosure 54%,
Niccolai et al., 1999 $n = 147$ USA	24%	24% did not disclose to last partner, 23% no condom when no disclosure
Marks and Crepaz, 2001 $n = 206$ USA	48%	48% no disclosure 25% unsafe sex, disclosure not associated with safer sex
Raj et al., 2006 $n = 124$ USA		Buying sex and >1 partner (6/12) associated with non-disclosure
Olley et al., 2004 $n = 69$ South Africa	78%	78% not disclosed 46% did not know partner's status
Parsons et al., 2004 USA IDU		More disclosed to positive partner than negative partner
Dawson et al., 1994 UK $n = 677$	72%	72% of partnerships with UAI did not involve mutual knowledge
Ciccarone et al., 2003 $n = 1421$ USA	42% gay 19% het. men 17% women	42% gay, 19% heterosexual men, 17% women sex no disclosure
Kalichman, 1999 USA $n = 266$	41%	41% not disclosed to sex partners
Antelman et al., 2001 Rwanda $n = 1078$ women	78%	78% not disclosed by 2 months, 60% not disclosed by 4 years
Mamam et al., 2003 Tanzania $n = 245$	36%	36% positive and 21% negative not disclosed result to partners
Wolitski et al., 1998 USA $n = 771$	11%	11% non-disclosure primary partner 66% non-disclosure to other partners
Stein et al., 1998 USA $n = 203$	40%	40% did not disclose to all partners
Petrak et al., 2001 UK $n = 95$	32%	32% did not disclose to significant others
Geary et al., 1996 USA $n = 321$ adolescents	58%	58% did not disclose
Simbayi et al., 2007. South Africa ($n = 1054$)	42%	42% had not disclosed to sexual partners

Psychological Needs – This relates to the trauma of discovery of status, the desire to experience and express severe emotions, the immediate requirement for support and the ability to adjust and gain in coping skills. There is the need to identify and explore ways of addressing difficulties, sharing emotions, talking to others who face similar experiences and adjust to life in the face of HIV.

Practical Needs – Often these needs take precedence and until they are addressed, the deeper emotional needs may be delayed, suppressed, ignored or bypassed. Access to health-care provision, information and detailed personalised education are immediate. Treatment options for all affected (mother, father, infant, siblings) need careful dialogue and action. The direct effect on employment, economics and relationships present an urgent need.

Social and Family Needs – These refer to avenues of support from either service providers, family or peer groups. They involve help with everyday life and subsequent challenges that may be linked to HIV status, such as discrimination, the needs of other children and future planning. Relationships, future sexual behaviour and partner considerations also represent an immediate need.

Pregnancy and disease progression. Although early data seemed to correlate pregnancy with disease progression, these findings have not been endorsed, and it seems that time was probably a confounder when this has been studied systematically.

13.13 Fathers

A chapter on pregnancy cannot be complete without specific mention of fathers. They are involved in conception, relationships and parenting. As such, they should not be marginalised and the issue of fathering has been seen to be a consideration for most HIV-positive men. Currently, much of pregnancy and maternity care is women focussed. Traditional gender roles may have highlighted the front-line roles of women and the biology of pregnancy enhances this focus. However, fathers play a key role and a holistic approach to pregnancy should include fathers at all stages such as:

- Inclusion in antenatal HIV testing
- Inclusion in decision making
- Inclusion in risk management
- Fathering

Studies of fathers have shown that in the presence of HIV, many report elevated levels of parenting and psychological stress. Wiener et al. (2001) in a study of 31 fathers of 6–16-year-olds with HIV reported that over half revealed elevated levels of parenting and psychological stress and almost all (97%) needed services. Family configuration is important to understand in terms of parenting and support. Pelton et al. (2001) looked at 249 families and found 40% had an HIV-positive mother. Such families were less likely to have a father at home or in contact with them. Sherr and Barry (2004) looked at pregnancy and fathering intentions of HIV-positive men and found that many would consider adoption or fostering. A total of 50% heterosexual men would consider unsafe sex in order to conceive. Sadly, nearly a quarter would withhold their status at the antenatal clinic for fear of discrimination. Three-quarters felt that fatherhood was important and the majority (81%) described fatherhood as giving meaning to their life.

13.14 Infant Testing

It is vital to establish the HIV status of the infant for a number of reasons. Firstly, the simple feedback to the parents is needed. Secondly, given that HIV-related illnesses may rapidly affect infants, it is important to know the status in order to intervene early with prophylaxis as well as antiretroviral treatment. Yet, HIV testing in infancy is made complex by the fact that maternal antibody is present in infant blood samples for as long as 18 months of age. Thus straightforward antibody tests are of limited use. If the infant tests negative, clearly there is no antibody. However, the converse is not true. If infants test positive, it is not possible to differentiate between maternal- and infant-generated antibody. The infant may well not be HIV positive. Polymerase chain reaction tests can establish the presence of HIV DNA for a more definitive diagnosis. Yet these are costly and require specialised laboratory facilities. Innovative facilities have utilised dry spot techniques which allow for easy collection, storage and transport to a specialised centre for such results to be made available within rural, isolated or resource-poor settings (Sherman et al., 2005). Clearly, counselling and support needs to be supplemented by accurate knowledge and targeted coping and treatment (WHO, 2006) which is hampered by unknown HIV status.

13.15 Child Development in the Presence of HIV

Child development can be affected in the presence of HIV directly by the virus for HIV-positive children, potentially due to exposure for HIV exposed by negative children and indirectly through family infection to HIV-negative children living in families where one or many members are positive. As HIV clusters in families, children are often multiply affected.

HIV in the family or community may affect a variety of environmental factors, which contribute to a greater or lesser extent to child development. HIV in the family can affect a number of environmental factors in different ways. At the most extreme, parental illness and death has a profound effect on a child's future. Both illness and death may affect the quality of the environment in which a child grows up. Social stimulation, parental availability and emotional environment may affect social learning, cognitive development and stability. A family with a sick or struggling carer may have reduced time, inclination or ability to provide optimum environments for healthy child development. HIV-positive children may themselves be ill, which limits their availability to take in such stimulation either by way of their ill health, their hospitalisation episodes or medication effects. Cognitive effects on children have been systematically monitored. A variety of standardised tests have been used, most of which, when sufficiently powered and controlled, have demonstrated deficits (Sherr et al., 2008). The shortcomings in this area are the absence of standardised measures, and the absence of studies in the highest prevalence countries (vast majority of studies are US based – vast majority of affected children are Africa based). Yet studies have used an array of measures, which are revealing. A more important barrier is the absence of systematic and regular monitoring and the linking of such outcome to treatment and care strategies. Clearly, prevention coupled with special provisions may be required. Thriving, nutrition, schooling, growth and emotional well being is often associated with good functioning families.

13.16 Bereavement and HIV

Grief reactions have been monitored at many stages of HIV life course. They can occur at the point of HIV diagnosis, illness, premature birth and death. Bereavement studies are surprisingly few. Multiple bereavement is the norm, and literature suggests that adaptation and accommodation after multiple bereavement is more difficult than single bereavement. Life changes that are linked to bereavement also have emotional ramifications. These are associated with job loss, separation, movement, couple dissolution, abandonment, economic loss, housing loss and poverty.

13.17 A Way Forward – Integrated Provision

Existing medical models divide reproduction into obstetrics and paediatrics. The divisions are carried through in services where there is a disconnect between paediatric and obstetric services. On closer observation, the vertical care model not only divides into departments, but does not integrate other child- and pregnancy-related services such as early child development, social welfare, mental health and education. HIV interventions at the point of pregnancy have been well established since the mid-1990s. These interventions marked a turning point in prevention as well as a turning point in the worldview of treatment and care as a global right. Yet after 12 years of knowledge, progress has been slow. The reach of the straightforward interventions has not been total, and there has been a steep learning curve as the psychosocial aspects of HIV infection have been inadequately understood and inconsistently addressed.

Dedication This chapter is dedicated to Lilian Isaacs, Pnina Koorlander, Susan Cohen, Cherry Cornell, Andrea Whyte, Lyne Joseph, Danielle Wagerman, Zoe Klaff, Kate Laws and Liora Sherr – the intergenerational social support team.

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Chapter 14
HIV/AIDS, Nutrition and Structural Interventions in South Africa: A Move in the Right Direction

Mark Tomlinson, Scott Drimie, Leslie Swartz, and Poul Rohleder

14.1 Introduction

There has been a systematic imbalance between the treatment and prevention responses to the AIDS pandemic (Horton and Das, 2008). One of the consequences has been a dramatic rise in the number of people receiving antiretroviral therapy in South Africa (3 million), but at the same time there will be 2.5 million new infections this year (Horton and Das, 2008). Approximately two-thirds of people living with HIV live in sub-Saharan Africa, though only 10% of the world's population lives in this region (Global Health Council, 2009). This startling imbalance, coupled with the continuing rising prevalence in HIV, suggests that HIV prevention efforts have failed. There are a number of reasons for this, but one is that preventive efforts must begin to focus on social, economic, and cultural factors, in addition to individual risk factors. The aim of this chapter is to provide an analysis of some of the intersections between HIV/AIDS, nutrition, agriculture and the school as a platform for the delivery of interventions. This is a huge area, and we will not attempt a comprehensive review but rather argue that a structural focus on the intersections combined with a gendered poverty relief programme promises a long-term and more sustainable approach to the prevention of HIV/AIDS.

We begin by outlining some of the reasons for the relative failure of individually focused HIV prevention programs. In the next section, we discuss the role of HIV/AIDS in contributing to food insecurity, which in turn facilitates risky sexual behaviour and diminishes opportunities to transfer skills about food production. In this context, we suggest that a focus on a more structural approach to the empowerment of women through micro-financing, together with a more intensive approach to using the school as a platform for delivering interventions to children affected by HIV, has the potential to make a significant medium- and long-term contribution to HIV prevention.

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_14,

14.2 Failure of HIV Prevention

Health psychologists have developed models of health behaviour, such as the Health Belief Model (Rosenstock, 1974), Protection Motivation Theory (Rippetoe and Rogers, 1987; Rogers, 1975), and the Theory of Reasoned Action (Ajzen and Fishbein, 1980), which are used to explain and understand individuals' health behaviours. These models have been used to try and understand individuals' sexual behaviours in the context of HIV/AIDS and attempt to change risky sexual behaviours by trying to change individual's knowledge and thinking, their attitudes and motivation to act, and their sense of personal risk. HIV prevention programmes have been dominated by a behavioural approach, which aimed to change individuals' risky sexual behaviours by educating individuals about HIV/AIDS and HIV transmission, about their risk for infection, and safe sex practices.

However, the continuing rising prevalence in HIV, particularly in southern Africa, suggests that such HIV prevention efforts have failed. It is clear that, despite an increased knowledge about HIV/AIDS and HIV prevention, individuals continue to engage in sexual behaviours that place them at risk for infection. An important issue to consider in the failure of prevention efforts thus far is the individualised perspective of HIV prevention and behaviour change. As Campbell (2003) points out, HIV prevention programmes assume that sexual behaviour is "shaped by the conscious decisions of rational individuals" (p. 7), and have not always taken into consideration how the social context influences individual's behaviour. The Theory of Planned Behaviour (Ajzen, 1985; 1991) for understanding health behaviour has considered the extent to which individuals perceive themselves to have control over their intention to behave. However, the emphasis of the model remains on individual cognitive, attitudinal, and motivational factors. As well as there being a number of personal factors that influence individual sexual behaviour, there are a number of proximal and distal social factors that interact in encouraging continued risky sexual behaviours that the behavioural models of health do not capture (Eaton et al., 2003).

Campbell (2003) further argues that these health behaviour models have been important in helping us understand which personal cognitive and motivational factors influence health behaviour, but do not detail how to change them. HIV prevention efforts have thus been generally directed at the individual, through providing education, testing, and counselling. They have not always been aimed at changing the social factors that influence sexual behaviour. One key social factor that has been explored in previous chapters (see Chapters 3 and 4) is the unequal power in gender relations, where, in a patriarchal society, women are not in a position of power to be able to negotiate healthy sexual behaviours (Eaton et al., 2003; Pettifor et al., 2004). HIV prevention efforts will fail as long as women continue to be in positions of powerlessness regarding their own sexual health and safety. This is compounded by poverty and the economic marginalisation of many women.

Another factor to consider is the extent to which individuals consider themselves to be at risk, and the perceived significance of that risk. Although HIV prevention models have attempted to inform individuals of the severity of HIV/AIDS and their risk for infection, HIV has, from the start of the epidemic, been associated with marginalized and deviant social identities – homosexuals, drug addicts, prostitutes – making HIV the most stigmatized disease in recent history (Sontag, 1991). In an effort to protect themselves from these stigmatized aspects of HIV and threats to their own social identities, individuals may perceive themselves to be outside of those groups who are understood to be most at risk (Joffe, 1999; Rohleder, 2007).

HIV has also been thought of as an "African disease", with early connections being made to Africa and Haiti. Global statistics indicate that southern Africa is the epicentre of the epidemic (UNAIDS, 2007), emphasising the association of HIV with Africa. However, with the continuing presence of HIV-related stigma and blaming of others for the disease (Petros et al., 2006; see also Chapter 8), individuals living in these high-prevalence areas may continue to position themselves as outside of risk in an effort to protect their social identity (Rohleder, 2007). This is reflected in the reported low levels of perceived HIV risk among youth in South Africa (Eaton et al., 2003; MacPhail and Campbell, 2001). The perception of risk and the significance of that risk are further compounded by poverty (see Chapter 7) and associated social problems. For individuals living in conditions of poverty, and facing persistent problems of malnutrition, other diseases (for example tuberculosis), security, violence, and safety, HIV prevention may not be an important enough concern in the context of trying to survive from day to day (Lindegger and Wood, 1995). Furthermore, poverty and associated food shortage and malnutrition affect the individual's immune system. An already impaired immune system has implications for HIV risk and the progression of HIV disease (see below).

Given the centrality of nutritional issues to multiple layers of social and health concerns in Africa, we focus in this chapter on the issue of nutrition as a key variable to consider in HIV prevention efforts.

14.3 Malnutrition and HIV: A Vicious Cycle

The relationship between malnutrition and poor economic growth is well known, with poor physical status resulting in productivity loss, increasing health costs and poor cognitive functioning and the consequent deficits in schooling, all contributing to diminished economic growth (World Bank, 2006). More recently, it has become clear how HIV/AIDS interacts with nutrition and food security at a number of different levels (Chopra, 2003; Gillespie, 2006). At one level the disease gets straight to work in the human body directly after an individual has become infected with HIV, with poor nutrition leading to a more rapid deterioration of the person. The importance of nutrition for immune function was understood 40 years ago when the term NAIDS (Nutritionally Acquired Immune Deficiency Syndrome) was first used (Scrimshaw et al., 1968). HIV compromises the immune system and increases susceptibility to opportunistic infections, which can lead to decreased food intake which may exacerbate the progression of HIV to AIDS (Panagides et al., 2007). Piwoz and Preble (2001) have shown how HIV+ individuals require 50% more

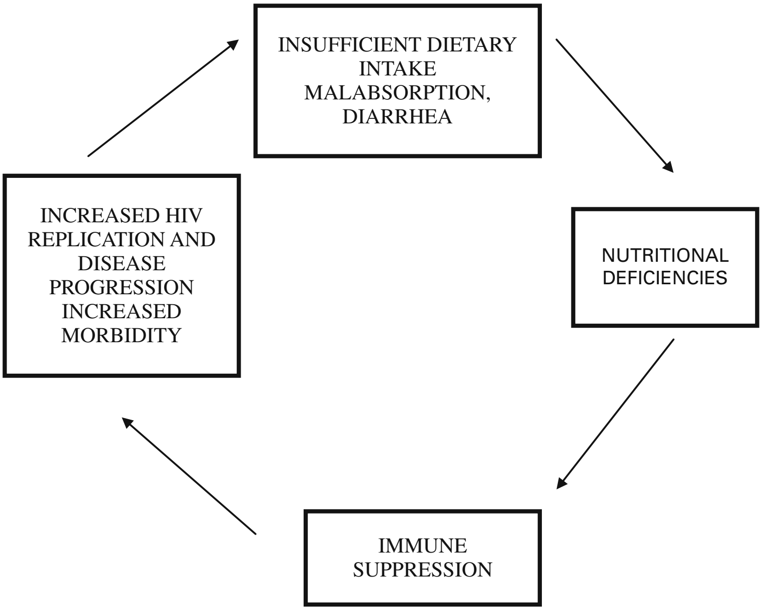

Fig. 14.1 The vicious cycle of malnutrition and HIV
From: Semba and Tang (1999)

protein and up to 15% more calories than the general population. Malnutrition in turn compromises the immune function of the body (see Fig. 14.1). Macro and micronutrient deficiency are significant risk factors in the survival of HIV+ individuals (Chopra, 2003). Finally, adequate nutrition also plays a role in the uptake of, and adherence to anti-retroviral therapy (Panagides et al., 2007). Commentators (Drimie and Mullins, 2006; Semba and Tang, 1999) have described this as the vicious cycle of malnutrition and HIV.

Another vicious cycle revolves around a household's degree of access to the food it needs (Gillespie, 2006). On the upstream side of viral transmission, food insecurity may put poor people at greater risk of being exposed to HIV – for example, through forced migration to find work (Zuma et al., 2003), or through poverty-fuelled adoption of transactional sex as a "survival" strategy (Gillespie, 2006; Weiser et al., 2007). And on the downstream side, the various impacts of chronic illness and premature mortality on household assets and resources are well documented (Yamano and Jayne, 2004; Gillespie, 2006). Thus many of the ways in which HIV infection has been considered has been in terms of the proximal factors that drive risk or vulnerability such as unprotected sex. When considering the structural contributors to HIV vulnerability, the more distal factors should be considered although they may operate through a more intermediate link (Gupta et al., 2008). Gupta et al. (2008) provide a description of how gender inequality leads to male control over economic resources, increasing the dependence of women on men, which in turn leads to a difficulty in being able to negotiate condom use because of a fear of abandonment which then leads to unprotected sex. Unprotected sex may be a proximal act, but the factors and causal pathways leading to it are all distal factors. Throughout, it is the poor and especially poor women, who are least able to respond. In eastern and southern Africa, the AIDS epidemic is already having serious consequences for agriculture, the dominant livelihood base, by affecting adults at the height of their productive years, making it difficult for poor people – and again especially poor women – to provide food for their families (Gillespie, 2006).

To elaborate this further, Save the Children and Oxfam (2002) provide a model of the relationship between HIV/AIDS and food security (see Fig. 14.2). HIV/AIDS is both a consequence of food and nutrition insecurity as well as a determining factor of food insecurity. As a result of poverty and inequality, there is an increase in food insecurity which leads to malnutrition and risky survival activities. Not only does this result in new HIV infections but also a faster progression from HIV to AIDS, which in turn leads to higher levels of poverty and inequality and the cycle begins again. Pieterse and van Wyk (2006) describe this relationship between HIV/AIDS, food security and African agriculture as a synergistic one. Hawkes and Ruel (2006) have shown how agriculture not only provides the conditions conducive to the spread of disease, but can also provide the conditions for the prevention and control of disease.

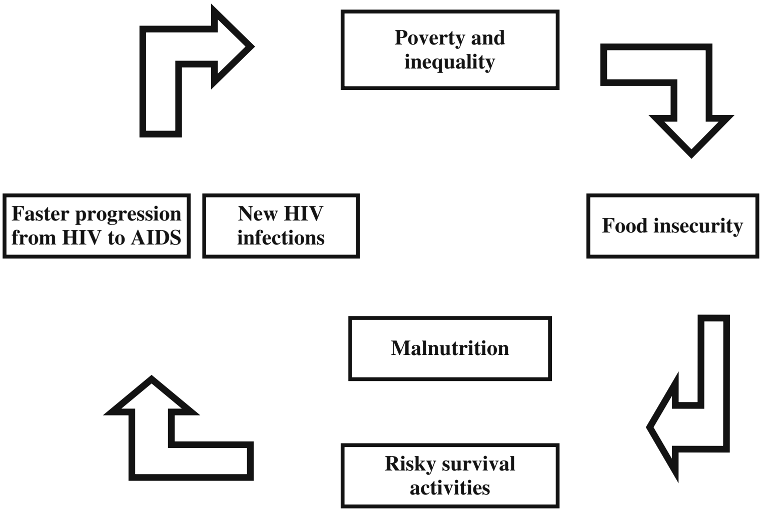

Fig. 14.2 Bi-directional Relationship Between HIV/AIDS and Food Security
Source: Save the Children and Oxfam (2002)

Pieterse and van Wyk (2006) make the point that while HIV has not led to sizeable famine on its own; it undoubtedly exacerbates chronic food security. In this regard, Chopra (2004) has shown how recent droughts in southern Africa have been exacerbated by HIV/AIDS, so while the drought in southern Africa in 1991–1992 was far more severe than more recent droughts, there were fewer reported deaths.

It is clear that the ability of communities to cope with the challenges that poverty brings has been undermined by HIV/AIDS (Chopra, 2004). The mechanisms of this synergy include the fact that as HIV+ family members become ill, health-care expenses increase. In addition, income declines as family members become too ill to work, or because they are vulnerable to the demand for seasonal labour in the agricultural sector (Pieterse and van Wyk, 2006).

A paper by De Waal and Whiteside (2003) goes so far as describing this situation as a "new variant famine." The authors argue that these new aspects to the food crisis can be attributed largely to the role played by the generalised AIDS epidemic looking particularly at four key issues, namely changes in dependency patterns; losses of assets and skills associated with adult mortality; the burden of care for sick adults and orphaned children; and the vicious interaction between malnutrition and HIV infection. As a result the sensitivity of rural communities to external shocks such as drought has increased, and their resilience has declined. Thus the prospects for a sharp decline into severe famine are increased, and the possibilities for recovery reduced. Chopra (2004) emphasizes the point that as household assets are reduced as a result of HIV/AIDS, nutritional status and health of families are affected by a shift away from less capital-intensive crop systems and a shift to less nutritious but more easily cultivated crops such as cassava. Important here is the fact that younger family members (in many cases, children) are increasingly responsible for having to engage in food production, but without the necessary agricultural apprenticeship from parents and other community members there is no transfer of agricultural skills between generations (Chopra, 2004). Finally, women account for 70–80% of household food production in Africa with profound implications, given the numbers of female-headed households (Sibanda-Mulder, 2004).

14.4 Promising Interventions

Given the cycles mentioned above and the importance of structural issues, we now review four approaches to intervention, which attempt to take theses issues into account. The first two focus on food and resource issues, the third on using schools as delivery platforms, and the final one on using child networks as a mode of delivery.

14.4.1 Structural Contributions to HIV Infection

With so many dimensions to the AIDS epidemic, it is clear that there is no simple solution. To ensure that responses are appropriate and effective and to take into account the multitude of causes and impacts, responses must be long term and be able to integrate the different aspects of securing livelihoods. The evidence demands that while economic growth is imperative, a greater focus on human welfare improvement supported by adequate investments in health and nutrition to broaden and sustain growth, as well as protect vulnerable segments of the population, is also necessary. A recent review has highlighted how structural factors such as social, economic, political, cultural, and environmental factors directly affect HIV risk by way of impeding or facilitating efforts to avoid HIV infection (Gupta et al., 2008). There is evidence of how when HIV prevention strategies address the structural issues of poverty, gender imbalances and power differentials success is greater (Coates et al., 2008). Implicit in the notion of structural interventions is the idea that the cause of public health problems lies not solely in individual characteristics but rather in contextual or environmental factors (Blankenship et al., 2006). Link and Phelan (1995) argue that behavioural or proximate risk factors are simply the mechanism through which the more fundamental societal and contextual factors operate. Evidence of the distal and structural connections affect HIV risk include the positive correlation between HIV prevalence and poverty,[1] as measured by GDP, income inequality or the Human Poverty Index (Fenton, 2004).

Blankenship et al. (2006) outline four broad types of structural interventions that they argue are relevant for HIV prevention. The first is community mobilization, which involves raising consciousness about rights of marginalized groups. The Treatment Action Campaign (TAC) is an example of this form of action (see Chapter 11). The second form of structural intervention is the integration of HIV services. Blankenship et al. (2006) argue that STI treatment, reproductive health services, and family planning are usually offered separately in poor countries resulting in a narrow focus and missed opportunities. A third type is that of contingent funding, where receiving national or federal funding is made contingent upon the implementation of laws or policies that promote public health (Blankenship et al., 2006). The final form is economic and structural. A review by Mahmud (2003) has highlighted the way in which micro-credit programmes promote the household bargaining power of women, which provides the basis to demand safer sexual practices. The resulting increase in women's social capital and the shifting relationships of power offer income opportunities for women outside of the sex industry (Blankenship et al., 2006). Educational interventions at school level (discussed in detail later in this chapter) such as eliminating school fees in order to increase the enrolment of girls in school have been associated with increased condom use (Greig and Koopman, 2003). Structural interventions are not without their weaknesses. Micro-loans to start up businesses may result in women taking their children out of school in order to assist with the resulting small business (Blankenship et al., 2006).

14.4.1.1 A Structural Intervention in South Africa

In South Africa, women and girls make up 55% of new infections, and 25% of South African women describe themselves as being in an abusive relationship (Pronyk et al., 2006). Pronyk et al. (2006) argue that entrenched inequalities (resources,

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[1] The relationship is however a complex one with relatively richer countries in sub-Saharan Africa such as Botswana and South Africa having the highest prevalence figures (Mishra et al., 2007).

power imbalances) in South African society create the conditions that support high levels of partner violence and HIV infection. The Intervention with Microfinance for AIDS and Gender Equity was implemented in a rural province of South Africa and combined a microfinance initiative targeting the poorest women, combined with a participatory curriculum of gender and HIV curriculum (Pronyk et al., 2006). The microfinance component consisted of individual borrowing and repayment of loans over 10- or 20-week cycles and centre meetings every 2 weeks, coupled with continuous business assessment and monitoring. The gender and HIV training programme comprised ten sessions every 2 weeks facilitated by trained women. The final component was a community mobilization aspect.

The intervention had an effect on household economic well-being, empowerment of women, and levels of partner violence were reduced by 55% in women in the intervention group (Pronyk et al., 2006). Disappointingly, there was no effect on the rate of unprotected sexual intercourse or on HIV incidence. While the results do not provide direct evidence of a link between structural interventions and HIV prevention, it does provide evidence of the importance of women's economic participation in reducing gender inequity and violence (Pronyk et al., 2006).

14.4.2 Schools as a Platform for the Delivery of Health Interventions

Interventions using the school as a platform for the delivery of health interventions need to be considered. Health and education are the two cornerstones of human capital and are the basis of an individual's economic productivity (World Health Organization, 2001) and are both valuable instruments in ensuring a healthy economy and creating a literate society. There is considerable evidence of how education plays a central role in the empowerment of women, which in turn is linked to numerous long-term benefits, such as smaller family size and increased agricultural production. Large numbers of children, however, particularly in the developing world, do not attend school. In low- and middle-income (LAMI) countries, an estimated 99 million children of primary-school age are not enrolled while only 78% of those who are enrolled actually go on to complete primary school (UNESCO, 2005). Combined with this is the reality that many of the children that do attend school are suffering from malnutrition, are stunted, or are experiencing short-term hunger. The greater focus on educational objectives arising out of the Dakar 2000 commitments has seen an increase in the number of school feeding programmes (SFPs) funded by governments, donors and NGOs (Bennett, 2003).

14.4.2.1 HIV, School Health and Nutrition

Health initiatives addressing school health are much wider in scope than simply school feeding. These may include HIV/AIDS prevention and education, deworming, life and health skills education, and interventions aimed at reducing alcohol or drug consumption. Many school feeding programmes have significant health intervention components and are often an important platform in which to deliver health interventions such as de-worming and iodine supplementation. In low-income countries, poor health such as chronic protein-energy malnutrition, iron-deficiency anaemia, iodine deficiency, or helminth infections contribute significantly to poor educational outcome. Increasingly, the link between health and education is being acknowledged, and there is compelling evidence of the benefit to child education of broad health and nutrition interventions (Del Rosso and Marek, 1996).

Despite the fact that there are huge numbers of children not attending school, there are in fact many more children attending school in the developing world today than two decades ago. Schools, because of their existing infrastructure, have the potential to be important sites for the implementation of health and education interventions that are cost-effective. The increasing number of children enrolling in primary school in Africa in general (and the high primary school enrolment in South Africa in particular), and the fact that in sub-Saharan Africa 12.3 million children have lost one or both parents to HIV (rising to 18 million by 2010) make the school an important platform (Cortina et al., 2008). One aspect of the school as a delivery platform is that of school feeding. School feeding programmes are controversial (Bundy, 2005) and often characterized by poor delivery and corruption (Tomlinson, 2007). They are however common in many parts of Africa, often for the political capital they bring (Tomlinson, 2007).

14.4.2.2 Junior Farmer Fields and Life Schools

An issue of direct concern both to long-term agricultural development and to shorter-term social development is that of children made vulnerable or orphaned as a result of HIV and AIDS. It is clear that children are profoundly affected as their parents fall sick and die, which can destroy their vision and hopes for the future. Furthermore, agricultural education and knowledge, values and beliefs may not be passed to the younger generation, leaving children with few skills to survive and build their livelihoods. Thus meeting both the immediate livelihood needs and future livelihood opportunities (in particular, innovative agricultural programmes) for children vulnerable to and from HIV and AIDS is an increasing challenge.

One innovative attempt to respond in this way is demonstrated in the Junior Farmer Field and Life Schools (JFFLS) approach.[2] The JFFLS in Swaziland attempts to integrate policies or strategies that address both the short- and long-term needs of children affected by HIV and AIDS through agriculture and education. The JFFLS have not yet been formally evaluated in Swaziland and Mozambique as the Food and Agricultural Organization, its main facilitator, consider it too early in its life cycle. However, in 2006, an independent assessment, initiated to inform

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[2] This case study was detailed in a recent conference paper as an example of the need for convergence between Social Services Provision and Productivity Enhancing Investments in Development Strategies (Gillespie and Drimie, 2008).

the scaling up of the JFFLS (Drimie, 2006), provided a number of insights into the impact of the programme and was used to design a longer-term strategy. The JFFLS focuses on children and their future livelihoods in a context of high AIDS impact, attempting to impart new agricultural skills and life skills to children living without their parents. The provision of education and training, particularly around livelihoods and basic health-care practices, together with food relief, provides an interesting example of mainstreaming AIDS.

The JFFLS approach in Swaziland is an adaptation of practices for developing knowledge and life skills among farmers in difficult circumstances such as Farmer Field Schools and Farmer Life Schools, combined with creative and expressive activities rooted in local culture. At each JFFLS site, specifically trained community facilitators use a participatory methodology to pass on agricultural knowledge and life skills to boys and girls between the ages of 12 and 17. The 1-year learning programme is linked into the crop cycle; links are established between agriculture, nutrition, gender equality and life-skills knowledge so that young participants learn to grow healthy crops while making informed decisions for leading healthy lives. Participatory field activities include crop selection and cultivation, land preparation, pest management, cultivation of medicinal plants and income generation; theatre, art, dance, and song are also integral aspects of each JFFLS day. An equal number of boys and girls participate in all schools, and the JFFLS stresses gender equality as well as child rights and protection.

National strategic partnerships play a crucial role in this multi-sectoral approach: the institutional home for the JFFLS programme lies within the Ministry of Agriculture and Cooperatives, while the National Plan of Action for OVC provides the policy framework. The FAO, which has initiated this approach in Southeast Asia and parts of southern Africa, such as Mozambique and Zimbabwe, has worked closely with the Ministry and other UN Agencies to establish the project. In particular, they have brought in technical expertise around livelihoods, largely agricultural based, as a basis for the "schools in the field". The World Food Programme (WFP) shares its expertise and logistics in the area of "food for training" and UNICEF is utilizing its comparative advantage of providing technical expertise and learning materials in the areas of life skills and child protection. Working under a joint programme, diverse expertise is intended to provide a solid basis for providing OVC with the skills necessary to secure their future.

As such, the schools provide classrooms in the fields that are directly relevant to the dominant livelihood strategies practiced in an area, but with a focus on improved techniques to move beyond subsistence. Social services, such as education provision, are thus complemented together with bringing in productivity enhancing investments such as agricultural extension, inputs, and infrastructure. Immediate welfare needs are also met through the provision of food on a regular basis as an additional incentive for children to attend classes.

A recent assessment of the programme recommended that the JFFLS should be anchored within existing contextual systems (The Ministry of Agriculture and Cooperatives as well as other government departments such as education and health), frameworks (National Plan of Action for OVC), and processes (reinvigorating the extension services), even where these may be imperfect (Drimie, 2006). This, in essence, is necessary to provide the "package" of services, both short- and longer-term, to address the situation of OVC in a context of high HIV prevalence.

A serious challenge to the programme and its sustained impact through the MOAC was that the Ministry had among the highest recorded rates of AIDS mortality in the Swazi workforce (of an establishment of 3000 workers, there recently were around 500 vacancies, with a large shortage of extension officers (Whiteside et al., 2006). Not all of this was due to AIDS as there had also been a large increase in retirements, health-care expenditure and pension payouts (MOAC, 2003).

14.4.2.3 School Feeding

The two major goals of school feeding are education and food security (Bennett, 2003). The educational goals include increased attendance (particularly for girls) and enrolment, as well as improved concentration during teaching aided by the food provided. The goal of food security includes the reduction of short-term hunger, as well as the improvement of the nutritional status of school children and in so doing reduce levels of malnutrition. Keeping children in school is an important aim of health and nutrition initiatives at school level. The longer a child stays in school the less likely they are to be susceptible to HIV/AIDS or early pregnancy (Bennett, 2003). Furthermore, improvements in female literacy are associated with declining fertility (Child Health Unit, 1997). For every extra year of schooling that a mother receives, there is a 1% decrease in levels of infant mortality (Psacharopoulos and Woodhall, 1985). Finally, ensuring that girls complete as much schooling as possible is likely to lead to the potential later use of new technologies that might lead to greater agricultural output (Sibanda-Mulder, 2004).

A core aspect of school feeding has been a strategy to combat food shortages during crises such as drought or war. In the acute stages of a crisis (in certain instances schools may not even be operational), SFPs are not a priority and are rather a supplement to the food aid that is provided at household level (Bennett, 2003). In a crisis situation children are often withdrawn from school in order to assist with income generation, and in this context an SFP can be useful as an incentive to encourage the re-enrolment of children. In addition, where schools are operational, SFP can operate both as an indirect transfer (school meal) as well as take home ration (direct transfer). Bennett (2003) argues that in fact the HIV/AIDS pandemic should be seen as a "permanent emergency" (particularly in sub-Saharan African) given the huge increase of orphans and the withdrawal of children from school to assist in sibling care and income generation in households where a parent is sick or has died. In East and southern Africa, one of the effects of the HIV/AIDS pandemic is the increasing number of orphaned and vulnerable children and child-headed households. This has implications for food security, levels of childhood malnutrition and, in turn, for the nature of the nutritional interventions that governments implement in response. The best evidence for the effectiveness of SFPs is in terms of increasing enrolment (Bundy, 2005; Jamison and Leslie, 1990). While school meals are an incentive for school attendance, it should be borne in mind that some of the difficulties of access to school are, in fact infrastructural. Porter and Blaufuss (2002) have shown, for example, how bad roads, inadequate or expensive transport, and the chores that many children have to perform each day before they go to school commonly prevent (particularly rural) children from attending school.

In looking at the possible impact of SFPs on short- and long-term food security, Hicks (1996) distinguishes between three variables of food security: *availability* (crop yields, diversity of food production), *access* (household income, female control of resources, safety nets), and *utilization* (nutritional status – protein energy and micronutrient – of schoolchildren). So, for example, Hicks (1996) argues that with regard to *availability*, the short-term impact of SFPs on crop yields, diversity of food production and natural resource management are nil. On the other hand, if SFPs are targeted properly, they may have an impact on short-term food security in terms of *access* to take home rations – an income transfer to the household. With regard to *utilization*, short-term food security may be enhanced by way of benefits to the protein energy and micronutrient status of children, if the SFP is targeted properly and if the meal that is provided is appropriately fortified and has the necessary energy content. The benefits of long-term food security (with regard to availability, access, and utilization) are all linked to improvements in literacy, numeracy, and other educational variables.

14.5 Key Lessons

The main argument of this chapter is that social and contextual factors underpinning the individual's condition in society, for example, living in gender-exclusive environment or having a low level of empowerment, have not been adequately addressed in the response to the AIDS epidemic. Focusing only on the risk factors which are directly linked – or on the causal pathway – to HIV infection such as concurrent partners, frequent partner change, sharing contaminated instruments, and low condom use is a vital component of the response but should be embedded in a broader approach that takes cognizance of vulnerability factors.

In April 2005, the International Conference on HIV/AIDS, Food and Nutrition Security was convened in Durban, South Africa. The conference concluded with an emphasis on what is basically a twin-track strategy aimed at strengthening household and community resistance to HIV and resilience to AIDS through (a) preserving and augmenting livelihood opportunities (including agriculture) for affected communities, and (b) ensuring appropriate social protection systems (including food and nutritional assistance) for those who need them. The case studies described above provide clear examples of how this can be achieved through focusing on particularly vulnerable groups (marginalized women, OVC) through engaging the structural underpinnings of their situation.

Because agriculture is the fundamental livelihood base of most people affected by HIV and AIDS and because food security is an increasing concern to them as impact waves hit, there is a real need for the agriculture sector to take a proactive stance in the face of the epidemic. Stakeholders (from farmers to policymakers) need to progressively re-view agricultural situations through an HIV lens in order to respond more effectively (Gillespie, 2006). If the agricultural sector in Africa fails to proactively take HIV and AIDS into account, it will not be able to achieve its primary objective of improving food production and access. Similarly, international agricultural organizations supporting African agriculture need to mainstream AIDS to remain relevant and to contribute to the eradication of extreme poverty and hunger.

14.6 Conclusion

In sub-Sahara Africa, the increasing number of HIV/AIDS and orphaned and vulnerable children will place an increasing burden on both the health and education systems. While school-based delivery systems may encourage enrolment and reduce drop-outs, they are unlikely to present enough of an incentive to severely labour-constrained households, and particularly child-headed households. Combining a school delivery-based system of health and nutrition elements (school feeding may be one), with a food sovereignty approach and thus passing on agricultural and indigenous knowledge will equip orphans and vulnerable children with greater skills to grow food (Slater, 2004). Basic education affects small landholders and subsistence farmers' productivity immediately and positively, and that a farmer with 4 years of elementary education is, on average, 8.7% more productive than a farmer with no education (Gasperini, 2006).

As Piot et al. (2008) point out every magic-bullet solution to HIV/AIDS has thus far failed. The structural interventions that we outline in this chapter will also not be a magic bullet for HIV prevention. However, if prevention efforts continue to be focused on individual behaviour change (a one-dimensional approach), HIV/AIDS is likely to remain an intractable problem in southern Africa, and the search for the next magic bullet will continue. The recent optimism about the role of male circumcision as the next magic bullet (see Chapter 21) is further telling evidence of this tendency. We would argue that the search for a magic bullet lies at the heart of why structural interventions have not properly been investigated in South Africa. The investment in structural interventions implies a long-term view and a comprehensive approach. In addition, at the heart of many structural interventions are complex ideological and moral questions – gender imbalances, poverty alleviation, the role of the state in the private sexual lives of their citizens, and violence against women. When we view many previous attempts at prevention with sobriety, we are forced to be cautious at the very best about a new approach. There is on the other hand enough evidence to suggest that a basket of interventions including micro-credit, using a food-sovereignty approach to lower levels of food insecurity, using the school to deliver interventions, and using a child-to-child approach to extend beneficiaries of interventions, should be researched for its potential significantly to contribute to a sustainable model of HIV prevention. The challenges for research of this nature are substantial, not least of which is that of how to control for and measure multilevel interventions, but these are challenges worth facing.

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Chapter 15
Strengthening Community Responses to AIDS: Possibilities and Challenges

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15.1 Introduction

Many AIDS programmes in sub-Saharan Africa have had disappointing results (Gregson et al., 2007), with HIV rates continuing to rise, stigma remaining stubbornly resistant to change, and access and adherence to treatment and support remaining inconsistent. Other interventions have worked well in carefully controlled research conditions, but these have been difficult to scale up in less highly monitored 'real-world' settings (Binswanger, 2000; Chopra and Ford, 2005; Greig et al., 2008). One key reason for the less-than-optimal outcome of many programmes is that they fail to resonate with the worldviews and perceived needs and interests of their target groupings, or to take adequate account of the complex social relations into which programmes are inserted (Gruber and Caffrey, 2005; Pfeiffer, 2003). Too many programmes are imposed on communities in 'top-down' ways by outside experts. In such settings, target communities are seen as passive recipients of prevention, care and treatment services rather than active participants working in partnership with health professionals to improve their health (Campbell, 2003).

Community involvement is increasingly being cited as a vital precondition for effective HIV/AIDS management. It is said to play an important role in enabling health-related behaviours and reducing HIV transmission (van Wyk et al., 2006), and in the reduction of stigma (Poku and Sandkjaer, 2007). It is also vital for facilitating timely and appropriate accessing of health and welfare services where these exist (Bak, 2004; Hadley and Maher, 2001; Segall, 2003), and for supporting optimal treatment adherence (Coetzee et al., 2004). International and national policy repeatedly advocates the need for community participation in HIV/AIDS work (South African Government, 2007; UNGASS, 2001). Yet much remains to be learned about how best to facilitate such involvement (Campbell and Foulis, 2004).

There are two reasons for our particular interest in community involvement. The first is a practical one. With the overall scarcity of health workers, exacerbated by the so-called brain drain of African health professionals, volunteers are earmarked for an increased role in HIV/AIDS management, with a growing number of projects relying on grassroots community members to provide HIV prevention and AIDS-care services in their communities (Ogden et al., 2006; Schneider et al.,

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_15,

2008; van Damme et al., 2006). The second reason for the importance of community involvement – which forms the context of this chapter – is a social psychological one. Community participation provides a vital opportunity for the development of community-level AIDS competence – the ability of communities to respond as effectively as possible to the challenges of HIV/AIDS.

In this chapter we discuss community participation in the light of our 3-year involvement in a community-led HIV/AIDS management programme in rural KwaZulu-Natal (Campbell et al., 2007a, 2008d). Entabeni is located some distance from the nearest town. Geographical isolation, poor roads, high costs of transport and lack of confidence limit peoples' access to formal health and welfare services. Polygamy is common, and women have limited power to protect their sexual health, particularly within marital relationships where their husbands have paid *lobola* (bride wealth) for them. Levels of HIV/AIDS are 34.6% amongst pregnant women, and AIDS deaths, especially of young people, are a common occurrence (Barron et al., 2007). Despite this, there continue to be high levels of AIDS denial and stigma (Campbell et al., 2007b).

This chapter's authors constitute the 'Community Responses to AIDS' team at the Centre for HIV/AIDS Networking (HIVAN) at the University of KwaZulu-Natal. They were invited to conduct research in Entabeni, to identify the most effective local community responses to HIV/AIDS and to work with local people to see how these could be supported and developed. The research highlighted the existence of a strong, united team of volunteer health workers – nearly all women, though with a male leader – who were the main source of assistance to families and households with members dying of HIV/AIDS (Maimane et al., 2004). The volunteers had been mobilised and trained through the uncoordinated and often temporary inputs of religious missionaries, government interventions and NGOs. Most worked for no pay, and with little or no training, walking long distances on foot up steep hills, often in searing heat, to AIDS-affected households.

Their work was often gruelling, fetching wood and water, cooking, cleaning sick and dying patients and supervising the transport of people in wheelbarrows to distant roads to seek transport to the hospital 30 km away. Their efforts were often constrained by their lack of literacy, of formal HIV/AIDS training and of any form of payment or even stipend to cover their expenses. Their commitment persisted despite the lack of supportive health and welfare systems, with little recognition from local leaders or the church (the most established community network), dealing with the most challenging of health problems in a climate of hunger, poverty and often hopelessness (Campbell et al., 2008d).

Over the course of 1 year, HIVAN conducted detailed research in Entabeni. In the next year, the team reported their findings to key community groupings, working with community members to formulate a 3-year project proposal (Campbell et al., 2008e). HIVAN was able to raise money to fund this project. It sought to strengthen local community responses to HIV/AIDS through enhancing volunteer skills and building support networks for their work both within and outside of the community. Before discussing the project's activities, progress and challenges, we will outline the concept of an ‘AIDS-competent community’ which informed our work in Entabeni.

Our discussion below showcases many of the challenges facing the project. At the outset we emphasise that we have no doubt that meaningful community participation is a vital precondition for optimally effective programmes. Furthermore, our experience suggests that there is tremendous will, talent and energy, particularly amongst grassroots women, to make a significant contribution to the AIDS struggle. Starting from these assumptions, this chapter aims to generate ‘critical thinking’ about the determinants of effective participation – to generate debate and dialogue about the challenges involved, and how they might best be tackled.

15.2 Conceptualising the ‘AIDS-Competent Community’

Current social psychological approaches to HIV/AIDS often draw heavily on social cognition models of behaviour, which focus on individual-level determinants of health-related behaviours – such as individual attitudes, perceived self-efficacy, perceived social norms and motivation to comply with these. However, the likelihood that people will engage in health-enhancing behaviours depends not only on individual-level factors, but also on the extent to which people live in social environments which enable and support health-enhancing behaviours (Campbell, 2003; Tawil et al., 1995). Against this background, we seek to develop understandings of the contexts in which HIV/AIDS interventions are located, and the extent to which they enable or limit the likelihood that community members will respond effectively to the challenges of HIV/AIDS prevention, care and treatment.

People are most likely to act in ways that enhance their health and well-being when they live in what we call ‘AIDS-competent community contexts’ (Campbell et al., 2007a; Campbell and Nhamo, 2008). We define an AIDS-competent community as one where community members work collaboratively to support each another in achieving: sexual behaviour change; the reduction of stigma (often deterring people from accessing prevention and care services); support for people living with AIDS and their carers; co-operation with volunteers and organisations seeking to tackle HIV prevention and AIDS care; and effective accessing of existing health services and welfare grants. Underlying these behaviour changes are five key psycho-social characteristics of an AIDS-competent community.

15.2.1 Knowledge and Skills

In an AIDS-competent community, residents have knowledge about how to prevent HIV, basic skills for nursing people with HIV/AIDS and an understanding of how to access the health and welfare system. However, knowledge and skills are only the first step. At this stage of the epidemic, many people have good factual information about HIV/AIDS. The problem is that this information is often presented in such a way that people cannot *translate* it into action plans in their own lives.

15.2.2 Social Spaces for Dialogue and Critical Thinking

What people often lack is not so much information as safe ‘social spaces’ in which they might, through discussion, start to collectively examine ways in which they might use this information in their own lives, renegotiating individual and social norms that undermine their own and others’ health and well-being. Low-Beer and Stoneburner (2004) emphasise the value of informal interactions between community members. These provide contexts in which people feel confident to engage in dialogue and debate about the highly stigmatised topic of HIV/AIDS, gradually taking ownership of alien medical facts, airing any doubts or confusions they may have about them and discussing ways in which the new information conflicts with their existing worldviews and practices.

Over time, people gradually process AIDS information in ways that do not conflict too starkly with their key pre-existing life goals or values – and in ways that they can realistically apply in their own daily lives. This might involve taking precautions to protect their own sexual health, offering appropriate care and support to AIDS-affected people and developing less stigmatising ways of talking about the problem. Such social spaces might include conversations between neighbours, families or peers – in living rooms, on buses, at school or in the street – in any place where people meet on a day-to-day basis and co-construct the social knowledge that shapes their worldviews and behaviours (Farr and Moscovici, 1984).

Three concepts influence our understandings of social spaces. The first is Freire’s (1970; 1973) concept of *critical thinking*. People are most likely to develop health-enhancing attitudes and behaviours when they have opportunities to engage in collective dialogue about the obstacles to behaviour change, and about ways in which they might – individually and collectively – resist such obstacles. The second is Habermas’ (1992) idealised concept of the *public sphere*, which characterises the optimal conditions for effective critical thinking and dialogue. Participants in debate meet as peers, engaging in discussion in conditions of equality; ideas are evaluated in terms of the sense that they make to participants, rather than in terms of the extent to which they support the status quo (Jovchelovitch, 2001). The third concept is that of *social identity*. People are most likely to change their attitudes and behaviours when they see that liked and trusted peers are changing theirs (Campbell, 2003).

15.2.3 Ownership/Responsibility

Effective social spaces provide contexts where community members can develop a sense of ownership of HIV/AIDS and a sense of responsibility for tackling it. In conditions of denial and stigma, people may fail to acknowledge its existence altogether. However, even when they do so, they might respond with a sense of helplessness and fatalism, passively waiting for government or NGOs to come and tackle the problem – and distancing themselves from any responsibility, rather than acknowledging that they too have a role to play (Barnett and Whiteside, 2006).

15.2.4 Solidarity and Common Purpose

Ideally, such social spaces provide a trusting and safe environment where people can reach collective decisions to behave in more health-enhancing ways and develop a sense of solidarity and common purpose around implementing these decisions. This sense of solidarity and common purpose amongst local community members constitutes the fourth criterion for an AIDS-competent community. Cornish and Ghosh (2007) point out that geographical communities – such as Entabeni – often consist of groups who have very little in common, whose relationships are characterised by varying degrees of co-operation and conflict, and whose lives are centred around the pursuit of competing interests (e.g. leaders/subjects, adults/youth, men/women, employed/unemployed). An AIDS-competent community is one where local people are able to reach out to one another, in spite of their differences, to create a sense of common purpose to tackle the impact of HIV/AIDS on the community, both through working to prevent transmission and through offering support and care to AIDS-affected people.

Such ‘strategic alliances’ (Spivak, 1988) form the context in which people work together to formulate strategies for how they can tackle the problem – both individually and through existing social networks. At an individual level, people can contribute to the fight against AIDS through efforts such as praying for people with AIDS and their carers, helping affected families with daily tasks such as housework, showing kindness to people living with AIDS and so on. At the community level, there is much that existing social groups such as youth groups, women’s groups and church groups can do to support AIDS patients and carers and to provide safe and supportive group contexts in which people can share information and debate how best to apply HIV/AIDS-related information in their own lives.

15.2.5 Bridging Social Capital

The fifth and final criterion for an AIDS-competent community is the awareness of, and the ability to forge links with, external organisations (e.g. in public sector or civil society) capable of supporting community members in tackling HIV/AIDS. Members of marginalised social groupings seldom have the power to tackle serious social problems without the support of outside agencies that have the political and economic clout to assist marginalised social groups in meeting their goals. Thus bridging social capital is a key precondition for effective community responses to AIDS (Evans, 1996; Woolcock, 1998).

15.3 The Entabeni Project

The aim of the Entabeni Project was to promote these five criteria for HIV/AIDS competence through two strategies. The first strategy was to strengthen the ability of the existing volunteer team to lead the local response to HIV/AIDS through facilitating their access to the skills they said they needed in three areas: (i) home-based nursing and counselling skills to improve their care work; (ii) peer education and training skills to disseminate their knowledge to the community and generate social spaces; and (iii) networking skills to enable them to advise AIDS-affected families on how to access health and welfare services and grants.

The second strategy was to strengthen support structures for the volunteers both within and outside of the community. In our baseline research, volunteers said the most valuable sources of within-community support would be local leadership and church leaders, both of whom had traditionally kept a distance from the volunteers. They also spoke of the need to get more young people and men involved in HIV/AIDS-related activities. Men were also identified as a key group to mobilise because of a community-wide perception that many men refused to recognise the dangers of HIV/AIDS and that they refused to use condoms with their wives, even when they had multiple partners.

The Project also sought to link volunteers with potential partners in government health and welfare departments and NGOs. These would aim to make local health and welfare services more responsive to community needs, and support volunteers in various ways. Initially, several potential outside partners expressed an interest in being part of a ‘community strengthening’ project of this nature, saying they had previously lacked the community contacts and access to do this.

The volunteers were keen and willing to take on leadership of the Project, but said they could not do so without substantial external support. Against this background, the Entabeni AIDS Partnership was formally constituted, consisting of a three-way partnership: (i) representatives of the local community, including local leaders and volunteers; (ii) external partners from the public sector (health, welfare, regional municipality) and two small NGOs; and (iii) HIVAN in a co-ordination role. HIVAN raised funding for two full-time staff (the second and third authors of this paper), who served as the Project’s ‘External Change Agents’. Their role was one of co-ordination – to convene regular 3-monthly partnership meetings of local and external partners, to monitor the implementation of decisions made at partnership meetings and to work to link Project participants with external sources of support in areas such as training, fund-raising and the development of management skills.

15.4 Building Volunteer Skills

The Project’s goal of building AIDS-related skills in the volunteer group was relatively easy to achieve. The volunteers were already a mobilised and united group. They participated enthusiastically in various training programmes facilitated by NGOs that HIVAN linked them to. Once they were trained, they worked hard to train other lay women in these skills. A core group of predominantly female volunteers worked tirelessly to deliver assistance to AIDS-affected households, lead peer education programmes, organise local HIV/AIDS awareness events, staff the AIDS outreach centre set up by the Project, advise people on how to access health and welfare grants and services and so on. However, the task of building support networks for the volunteers – both within the community and with outside partners – was beset with challenges, as discussed below.

15.5 Building Bridges Between Volunteers and External Partners

The Project's 3-year attempt to build sustainable bridging relationships between community representatives and external support agencies (the 'external partners') proved almost impossible (Nair and Campbell, 2008). At the outset, various public-sector health agencies expressed interest in being part of the Project, but the challenges of turning intentions into action were immense. The first partner was the nearest government hospital. There were many obstacles to community uptake of hospital services – poor roads, unaffordable transport, long queues at the hospital and community members' lack of skills and confidence to make optimal use of services. The hospital superintendent expressed his appreciation of the value of building partnerships with remote communities to improve their access to hospital services. However, the hospital faced huge resource constraints in providing traditional care, let alone engaging in complex and unstructured activities such as community liaison. Senior hospital staff were too busy to attend Project meetings, and sent junior representatives. These junior representatives lacked the authority to make decisions on behalf of the hospital, so their participation in meetings was tokenistic, seldom leading to concrete action.

The second potential external partner was the nurse at the local Primary Healthcare Clinic. She was specifically charged with supporting local volunteers. However, she lacked personal motivation to engage with the Project. She had no training in community liaison, and few channels or skills to communicate with volunteers, or with her own supervisor. At her request, impoverished health volunteers battled to find pens and paper to write monthly reports for her about their activities. She summarised their reports for her superior. However, she didn't receive any feedback from her supervisor, nor did she give any feedback to the volunteers, nor advise them on how to deal with the problems described in reports.

There was also a District AIDS Office in the town nearest to Entabeni. This office paid the volunteer leader a small stipend. HIVAN co-ordinators encouraged him to visit the office to discuss problems arising in his volunteer team and his coordination role. His visit to the District AIDS Office was greeted with hostile incredulity. The health professional who met with him was affronted that a humble community member had visited her office without an invitation. She refused to engage in any discussion – saying he was wasting Health Department money by being away from the community where he was paid to work and that she would ensure his stipend was reduced to compensate for the day he had 'wasted' away from the community.

The fourth partner the Project tried to engage was the regional municipality office, which is specifically charged to assist communities with social development projects. A senior official was keen to participate in the Project. Participation in the Entabeni Project fitted into his job description, and he hoped our Project style of partnering could serve as a ‘best practice’ model for his organisation. However, it soon became clear he did not have the time to participate in the Project or even answer our telephone calls. His secretary said he was ‘drowning in projects’, and working on a shoestring budget in a huge catchment area overwhelmed by poverty and HIV/AIDS. He was also limited by his accountability to a pool of competitive local councillors. When he enthusiastically explained the potential of the Entabeni Partnership as a pilot project for the region, they forbade him from offering special assistance to a single community, saying that anything he did for one community should be done for all.

Over 3 years, the Project’s sustained efforts to build long-term partnerships with public-sector bodies specifically charged with facilitating greater community involvement in AIDS and health in Entabeni were disappointing.

The most promising partners have been two NGOs – small, under-funded and run by deeply committed individuals. The first is the Entabeni Development Committee, run by a Norwegian woman, with no formal institutional links. Driven by religious convictions, she has lived in Entabeni for several years – working closely with local people to set up a crèche, community gardens and craft projects. When HIVAN first entered the community, she had already put a lot of work into training local people to build and staff a small AIDS hospice. She has been an important participant in the Project, playing a key role in supporting and advising carers, assisting with transport and catering at Project events and so forth. Her involvement is characterised by her strong commitment to proper community ownership of all activities. She is determined never to control or take credit for the group’s achievements and is well-liked and trusted by local Project participants.

The second NGO is the regional branch of national counselling charity run by a retired British business woman, who raises her own funds. This NGO has played a key role in various forms of home-based care and peer education training, both of health volunteers and of schoolchildren. The NGO has also been involved in setting up, running and paying a part-time administrator to manage a local Entabeni AIDS Outreach Centre in vacant buildings donated to the Project by a local leader.

These two NGOs have played a key role in the Project, never missing a meeting, always being on hand with well-informed advice and networks and shaping their activities in response to needs and problems articulated by the Project and by community members.

15.6 Building Within-Community Support Networks for the Volunteers

Historically, the health volunteers had operated with little local support, in a context of AIDS stigma and denial. At the start of the Entabeni Project, there was little recognition of their work and little practical support for their efforts by local leaders or community residents. A key goal of the Project was to create social spaces where people could talk about AIDS in a constructive and positive way – with particular efforts to engage the church, local leaders, young people and men.

The church is the biggest formal community network and a significant potential resource for sharing information and offering support and prayer to the sick. However, whilst many individual church leaders and members were nursing AIDS-affected relatives, this was done in private, seldom acknowledged in formal church meetings. The few references to AIDS tended to be judgemental, for example, 'God's punishment for immoral behaviour' (Campbell et al. 2007a). Many churches discouraged condoms, ignoring the fact that many members engaged in sexual activities outside monogamous marriages. The Project had some success in involving church leaders in its training and awareness activities. In independent Project evaluations, Entabeni residents pointed to increased openness and opportunities for discussion of AIDS in local churches as one of the Project's positive achievements (Campbell et al., 2008a; Mqadi, 2007).

Prior to the Project's inception, health volunteers repeatedly complained that their efforts were undermined by the lack of support from local leaders (Entabeni is governed by a traditional leader, who delegates day-to-day local power to lower-level ward leaders). A key Project goal was to build these local leaders' support. The Project had little success in mobilising ward leaders – many of whom continued to ignore the existence of the volunteers and avoided any participation in AIDS activities. Very few attended the Project's AIDS and leadership training workshops.

The Project had more success in getting support from the community's traditional leader. As the supreme community gatekeeper, the Project could not have operated without his permission. He spoke openly about AIDS at community meetings, and participated in the Project's formal events, including the opening of the Outreach Centre and the graduation ceremonies held after Project training courses. However, his style was often at odds with Project goals (Campbell and Gibbs, 2008a). Thus, for example, he often used speeches at Project events as a forum for celebrating his own masculinity, frequently referring to his 6 wives and 5 girlfriends. He also used speeches to express his view that polygamy was not related to HIV transmission, since wives and girlfriends should be virtuous and faithful. Furthermore, in an indirect way, his authoritarian style of governance, and his conservative attitudes to women and youth, were undermining of the project's 'empowerment via participation' agenda. They created a social environment that stifled the creativity, initiative and 'thinking out of the box' that are hallmarks of successful social development (people enthusiastically collaborating to develop new ways of getting by and getting ahead). The traditional leader's authoritarian style also hampered the development of the confidence and empowerment central to the Project's ideal of AIDS competence outlined above.

Another goal of the Project was to get young people more involved in local AIDS work, as a springboard for their wider social development – through skills building and leadership training. In the Project's baseline research, young people expressed a strong desire for opportunities to participate in community activities, seeing this as a stepping stone to future self and career development (Campbell et al., 2009).

Despite this, the project had little success in recruiting or retaining youth. In later research into this problem (Campbell et al., 2008b), youth cited various reasons for their poor participation in the Project. They said local adults were reluctant to recognise the value of young people's inputs, or to respect them as equals in Project structures. This resulted in tokenistic youth representation on committees, further discouraging their participation. They also expressed bitterness about the way the concept of volunteering was 'abused' to get youth to provide unpaid labour for local projects. Yet when local paid work opportunities arose they always taken by adults, and youth were excluded.

The Project's final challenge was to target men for AIDS training and awareness and to involve men in Project activities. Very small numbers of men became involved in the Project. Those that became involved tended to be unmarried youth, church leaders or the few men who dominated the small number of paid jobs associated with the Project. Nearly all the volunteer work has been done by women. Project research has pointed to various reasons for this. Given men's greater access to paid work than women, and the ideology of the male breadwinner, men were unwilling to work without payment, seeing this as pointless and as demeaning to their status. Many men also regarded issues relating to health and caring as 'women's work'. Furthermore, for many men, taking risks and having multiple partners is part of their socially constructed masculinity –messages of AIDS prevention, which urge caution and partner reduction don't appeal to many men (Campbell, 1997). Finally, in a remote rural community, the most motivated and able men are either in full-time work, without time for Project participation, or are away as migrant workers. Unoccupied men were described as the least skilled and employable, and thus the least confident and motivated for involvement in projects such as this.

15.7 Volunteer Challenges

As discussed above, members of the volunteer team have worked tirelessly to enhance their nursing and counselling support for AIDS-affected families. The training provided by the Project has increased their confidence, and they have engaged in numerous activities – running peer education and home-nursing courses for local people, helping set up and run the Project's Outreach Centre and organise several high-profile AIDS-awareness events (Campbell et al., 2008c). Furthermore, a core group of volunteer representatives have represented the Project at regular Partnership meetings with external partners and at numerous conferences and policy workshops in the region.

However, over the 3 years of the Project, the Project's failure to secure a sustainable long-term stipend for most volunteers has meant that the turnover of volunteers has been high – with women often attending the training and initially participating energetically in supporting households, but eventually dropping out. The Project has retained a small but solid core of older religious women whose husbands support them. But the volunteer team depends heavily on the input of younger women, who are more difficult to retain since many have children to support. For several years volunteers have engaged in a yo-yo process of hope and despair in the face of a string of ambiguous and unmet promises by various government agencies, suggesting the volunteers will eventually receive small stipends. However, the Entabeni volunteers have never quite managed to qualify for the conditions attached to these. The failure of stipends to materialise has exacerbated the drop-out rate.

At various stages, HIVAN has been able to raise donor funds for small temporary stipends to cover volunteers' expenses, but these are not the sustainable and institutionalised public sector recognition and support that younger volunteers hoped for. Furthermore, the Project has not had the capacity to monitor the performance of volunteers receiving these stipends. This has led to bitterness and despondency amongst more hardworking volunteers – when they see some of their peers receiving equal stipends for doing much less work.

Other tensions have also arisen in the volunteer group. Despite the Project's very explicitly defined 'women's empowerment' focus, and although nearly all the volunteer workers are women, as stated above, the team's handful of paid leadership positions have been dominated by men. In formal Project meetings, these men pay lip service to delegating and sharing responsibility with women volunteers; however, in reality, they have failed to do this. They have also sometimes responded in ways that women volunteers found aggressive and intimidating on the few occasions the female volunteers have timidly attempted to challenge their male leaders to be more accountable to them.

15.8 Conclusion

Our starting assumption has been that community participation can greatly enhance the AIDS competence of marginalised communities where HIV is high and formal support and services are low. We have presented our longitudinal case study of a project that sought to promote such participation – through building HIV/AIDS-related skills and knowledge, facilitating opportunities (social spaces) for dialogue about HIV/AIDS, promoting solidarity and common purpose across diverse community groupings, an enhanced sense of ownership and responsibility for tackling the problem and supportive bridging relationships with outside agencies.

What has the Entabeni Project achieved over 3 years, framed in terms of our five-factor concept of the 'AIDS-competent community'? Whilst no formal outcome evaluation has been conducted, our personal involvement in the community as well as two separate process evaluation exercises (Campbell et al., 2008a; Mqadi, 2007) suggests it has been very successful in building the skills of a core group of volunteers to provide nursing care and counselling to AIDS-affected households, skills that have been used in offering a vital and valued enhanced nursing and counselling support service to many AIDS-affected households. The Project has also been successful in increasing the social spaces available to local people (particularly young people and church members) to talk openly about AIDS and in building the confidence of volunteers to tackle the problem. It has also mobilised the open support of the community's traditional leader, though in the ambiguous way outlined above.

However, the Project has been less successful in building widespread support and solidarity amongst the wider community beyond the volunteers, and it has been unsuccessful in mobilising men and local ward leaders. Whilst many youth have attended Project training courses at various stages, the drop-out rate has been high, and the Project has had disappointing results in retaining the involvement of youth who completed these courses.

Finally, whilst the Project has been successful in mobilising the involvement of two extremely effective NGOs, these have been small and under-funded agencies. Whilst these have the advantage of flexibility and the desire to be responsive to community needs, they are not necessarily long-term or sustainable supports. Such links would have to be continually renewed as different NGOs rise and fall with changing donor priorities. Efforts to build long-term institutionalised partnerships with formal public sector agencies have also had disappointing outcomes.

What are the lessons for those seeking to promote community participation in AIDS programmes in under-served rural areas? Our experience suggests that there is a pool of remarkable energy and talent amongst rural women to participate in community health projects. However, their efforts and motivation are severely constrained by lack of any formal recognition of their value and their hard work. Furthermore, the majority of volunteers in Entabeni lack the educational levels and formal institutional links that would qualify them for government stipends. Until some way of tackling this problem is developed, their potentially major contribution to HIV/AIDS management will be undermined.

Gaining the support and participation of local leaders, youth and men in projects is a major challenge – much work remains to be done in developing policies and strategies for engaging them. In the conservative rural setting of Entabeni, many traditional leaders rely heavily on their self-styled roles as 'guardians of tradition' to justify their hold on power (Campbell and Gibbs, 2008a). A key aspect of the way in which they interpret 'tradition' involves the power of adult men over women and youth, and a conservative interpretation of masculinity, including the right of men to have multiple wives/sexual partners. These so-called 'traditional' norms were at variance with the 'empowerment via participation' agenda of the Entabeni Project, which sought to strengthen the role of youth and women in leadership of community projects, and also to get men to take greater responsibility for their role in the transmission of HIV/AIDS. Our experiences highlight the irony that many of the most powerful members of the Entabeni community have a vested interest in preserving the very social relations that facilitate HIV transmission and undermine the well-being of people with AIDS.

The efforts of the Entabeni volunteers are actively undermined by the lack of appropriate capacity amongst those government agencies specifically mandated to support them. There is an urgent need for the government to prioritise the development of community outreach and support skills amongst relevant agencies in the health and welfare sectors and to acknowledge and institutionalise grassroots community members' key role in tackling HIV/AIDS. Elsewhere (Campbell and Gibbs, 2008b) we have argued that dominant representations of the HIV/AIDS struggle in the public sphere in South Africa depict it in an overwhelmingly top–down way as the responsibility of senior political leaders and health experts. There is virtually no recognition of the fact that the major burden of HIV/AIDS management in poor communities is already carried by unpaid women, or of the fact that communities could play a vital role in ensuring optimally effective outcomes for prevention, care and treatment efforts.

Once again we must emphasise that whilst this chapter has focused heavily on the challenges that faced the Entabeni Project, this by no means indicates any doubts on our part about the vital role that community participation has to play in HIV/AIDS management in South Africa or about the need for redoubled efforts to think of ways in which the challenges outlined can best be negotiated. Our case study is presented to promote critical thinking about the obstacles that stand in the way of effective participation. Many of these obstacles are rooted in wider socio-economic inequalities that lie beyond the reach of small community programmes. However, as Frederick Douglass (cited in Seedat, 2001) says, 'power is never conceded without a demand'. Elites (such as men, adults, leaders or public-sector employees) seldom voluntarily give up power without vociferous demands from the oppressed (be they women, youth or people stigmatised because they are living with AIDS). Aside from their important value in providing vital health and welfare support to desperately under-served groups, small-scale efforts such as the Entabeni Project have a key role to play in the long-term struggle of equipping such groups to make these demands in increasingly confident and forceful ways.

Acknowledgments We thank Professor Eleanor Preston-Whyte and Debbie Heustice of HIVAN for enabling this research. Zweni Sibiya was involved in many of our early discussions of this work, and his input to our collective views is gratefully acknowledged. Thanks also to Kerry Scott for insightful comments on the first draft.

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Chapter 16
HIV/AIDS, Religion and Spirituality

Yoesrie Toefy

16.1 Introduction

Two-and-a-half decades into the epidemic, AIDS continues to exact a significant toll on southern Africa. Studies have pointed to a host of local factors, such as the co-morbidity of the AIDS virus with sexually transmitted infections or tuberculosis (Nelson and Lipman, 2006); prevalent pre- and extra-marital sexual behaviour (Brockerhoff et al., 1996); socio-economic factors such as poverty, circumcision, the cultural position of women, poor social health services and migratory pressures (Caldwell, 2000; Susser and Stein, 2000); and civil unrests and conflicts (Mills et al., 2006), as important determinants of the causes and course of the epidemic in the region. Researchers have, however, neglected religion and its effects on AIDS-related behaviour in Africa.

Recent studies by Takyi (2003) and Lagarde et al. (2003) have studied the role of religion and religious practices in Africa's HIV/AIDS behaviour, but have concentrated on one aspect of religious influence such as the study that Takyi (2003) did of measuring the impact of religion in African women's lives and Lagarde et al. (2003) who focussed on male circumcision within the context of culture and religion. Therefore, while southern Africa remains one of the epicentres of the AIDS epidemic, very little empirical evidence exists on how religion intersects with other processes to impact on the dynamics of HIV/AIDS behaviour.

In the continent of Africa and indeed in South Africa, religious beliefs play an important role in society. These beliefs affect the way people see themselves, how they think, how they act and how they view disease. Religion, as a driving force of societal behaviour, has been explored by several authors in the past. Adongo et al. (1998) looked at the role of religion in the social construction of wellness and health risks, including reproductive preferences; Fosu (1981; 1995) examined the religious influence on how communities classify disease and how health services were used (Kirby, 1997). The social value of the networks of relationships and church-based social interactions has long been held as a critical element in the successful dissemination of AIDS-related information, and depending on the size, type and context of the network, these social groups could also constrain individual actions, thereby influencing how people react to the epidemic. A study conducted in a

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_16,

KwaZulu-Natal township on the level of extra- and pre-marital sex among members of different church types, Garner (2000), showed evidence that especially Pentecostal churches significantly reduced these types of sexual behaviour among members by maintaining high levels of social control through four critical elements: indoctrination, religious experience, exclusion and socialisation.

Consequently, there are at least four main areas in which the religious organisations could play an important role in helping to reduce the burden of HIV/AIDS: (a) prevention of new infections especially among youth, (b) reducing denial, stigma and discrimination, (c) treatment and care of PLWHA and (d) dealing with the challenge of orphans affected by HIV/AIDS.

This chapter will look at some of the initiatives undertaken by faith-based institutions for the last two decades in the HIV/AIDS epidemic in South Africa, and it will attempt to link these activities with the traditional role religious organisations have played in society. The chapter will also look at the impact of religious stigma and the impact of the condom-use debate on the progression of the disease in South Africa. Finally, attempts will be made to lay some ground rules and recommendations for future co-operation between the two seemingly incompatible paradigms.

16.2 Religion and Society

16.2.1 The Value of Faith-Based Organisations (FBOs)

The religious fraternity considers a good and effective health system as one that does not just treat disease and illness, but produces, promotes and preserves good health. Therefore, it views an individual in terms of his or her health status, process of healing and the concept of wholeness (body and spirit). This goes beyond the concept of health as perceived by the medical world (ARHAP/WHO, 2006).

The value of religious groupings and FBOs in the fight against HIV/AIDS lies in the extent of the influences they assert in the communities in which they operate (ARHAP/WHO, 2006). They are ideal in creating a ready audience for the intended community programme. Therefore, new messages carry religious validity with members of the congregation when disseminated in this manner, and the congregation takes these messages into their communities and places of work. There is an instinctive level of trust in the religious structure and its leaders and what they say, that the integrity of the programme's messages are inextricably linked to the established credibility of the FBO.

Religious institutions are also in a unique situation as they have ready access to established religious congregations and gathering points. By integrating the programme of the intended project with an established FBO in the area, gate-keeping protocols by which fieldworkers gain access to the community, are neatly circumvented and managed. Through the participating FBO, programmes have ready access to committed and caring community workers that have been active in their communities for a while. Community AIDS programmes that incorporated the

FBOs' care, support and counselling structures into the existing intervention programme faired the strongest and ensured that the project reached everyone in the community (Weaver, 2004).

16.2.2 The Challenges FBOs Face

It is an established fact that all religions subscribe to high moral values such as promoting abstinence if people are not married and sex within a faithful marriage. Although these practices are good insofar as the spread of HIV/AIDS is concerned (i.e. they help reduce HIV infection), they are also problematic for the following three reasons:

(a) The promotion of sexual abstinence leads to a moral dilemma whereby some religions are refusing to promote the use of condoms. In an editorial, Christianity Today (2002) quoted the CIA's National Intelligence Council's admission that the avoidance of high-risk behaviour is the only proven way to prevent AIDS, and laments the 'wastage' of donor funds on billions upon billions of low-cost condoms that are rarely used consistently and costly drug cocktails that are hard to administer and distribute fairly. In the same editorial, Samaritan's Purse president Franklin Graham states that the Church objects to fund condom-centred programmes that allows the world to continue in their sinful lifestyle.

(b) The high moral value teaching leads some religions to be against sex education in educational settings. Denial is a powerful enabler for the spread of the disease because it creates a collective mindset that refuses to face the reality of HIV/AIDS, which means that people will avoid facing the reality of the epidemic (Golliher and Tuatagaloa-Matalavea, 2004).

(c) The practices in marriages create psychological blocks among religiously inclined partners from engaging in open sexual communication. Teresa Okure, an African theologian, attributed the inferior status of women in African societies and global economic injustice in the form of abject poverty as additional enablers for the AIDS virus to spread in the manner it did through African societies (Golliher and Tuatagaloa-Matalavea, 2004). The inferior status of women in society perpetuates rampant infection among women, not only among single women but also married women who lose all capacity to negotiate safe sex. The traditional manner in which religions in Africa have viewed women has been identified by many as a major stumbling block (Akwara et al., 2003; Kibombo et al., 2007; Mbweza et al., 2004; Whetten et al., 2004). Tsevat (2006) and Agadjanian (2005) found the gender differences more pronounced in the 'Prophet-Healing' Churches, such as the Assembly of God, Zionist and Apostolic Churches.

Among all FBOs, the role of proselytising or spreading overt religious doctrine varies. Some declare this outside their mandate to serve the community, but other organisations, such as Living Hope, an FBO working in the townships in Cape

Town, explicitly share their faith with the community they serve. ‘We are here to share the Gospel of our Lord Jesus Christ in a meaningful way’ said interim director Trevor Gray. ‘We do not lie down [sic] that you have to listen to our Bible thumping, although it is part of our ethos. We take the approach that we’ve got to earn the right to share the Gospel. We′re here to share the love of God, and, if necessary, we’ll tell them why’ (IRIN PlusNews, 2006).

FBOs are often accused of using donor funds to propagate their own religious dogma and to convert helpless sections of the population that have already been ravaged by the AIDS epidemic. Faith-based donor organisations are often accused of choosing service providers on ideological reasons, rather than on proven performance. This results in FBOs being given projects to do despite their lack of a proven track record. They often have weak monitoring and evaluation measures in place in their organisations which makes it difficult to assess their impact in the community and to compare them against other service providers.

There is little empirical evidence supporting the claim that FBOs can deliver the required services. There has been some empirical proof sought in this intangible arena of religion and health, and one of the more notable is the McCullough study where the analysis of more than 40 research studies investigating the role of religion in health, in which 126,000 people were interviewed, has established that religious involvement was helpful in the prevention of specific medical problems such as cancer, heart disease and mental illness (McCullough et al., 2000). These type of studies have been refuted by several other counter-studies such as the one by Sloan and Bagiella (2002), which claimed that studies that claim that religious activity provides health benefits, have virtually no grounding in the medical literature and that there is little empirical support for such claims.

Secular opinion of FBOs is one of suspicion, and this sentiment is reflected in communication and literature that are produced. As an example, in a landmark publication co-published partly by UNAIDS, which acts as a guide for secular HIV service providers in their collaboration with FBOs, entitled ‘Scaling up Effective Partnerships: A guide to working with faith-based organisations in the response to HIV and AIDS’ (Lux and Greenaway, 2006), contains a section on ‘Potential obstacles’ for working with each FBOs and none on their ‘potential benefits’ (Steinitz, 2006).

16.2.3 The Impact of the Compassion vs. the ‘Divine Punishment’ Doctrines

Nowhere has there been a greater temptation to point fingers of accusation of sinful behaviour than to those who suffer from HIV/AIDS. The disease is primarily sexually transmitted, and according to many, became an epidemic partly because of promiscuous behaviour. People living with HIV/AIDS (PLWHA) are vilified as sinners and the AIDS epidemic is seen as the direct result of their illicit behaviour. This stigmatising discourse on HIV is common in many religious groups.

Many FBOs have used their influence to maintain the status quo rather than to challenge negative attitudes towards marginalised groups and PLWHA. During the international symposium, ‘Religious Health Organisations Break the Silence on HIV/AIDS’, organised by the African Regional Forum of Religious Health Organisations during the 13th International AIDS Conference in July 2000, it was noted that religious doctrines have principally helped to create the perception that those infected have sinned and deserve their ‘punishment’ (Singh, 2001). This has increased the stigma associated with HIV/AIDS (Parker and Aggleton, 2002). AIDS activists are often angered by the clergy’s statements that this disease is a divine punishment, and also at some Muslim Imams quoting the Prophet Muhammad as saying that ‘a disease without cure and sudden death is the punishment for adultery’. The theological indictment is usually softened by stating that AIDS, as all naturally occurring afflictions, is a punishment that affects those who do good, and those who do evil (IRIN PlusNews, 2007).

In the ‘Theology of HIV/AIDS’, as proposed by van Wyngaard (2005) of the Swaziland Reformed Church, it would be essential to formulate a Biblical view on the relation between HIV/AIDS and sin, obviously not with the intention of stigmatising those who are HIV positive, but to better understand the tragic effects that sin has had upon God’s creation throughout history – HIV/AIDS being one of the most vivid examples of the consequences of the power of sin today (Rubingh, 2002). To refute the negative messages coming from the pulpit, a faith-based organisation, Positive Muslims, which was organised in 2000 to raise awareness and to provide support to Muslims living with HIV/AIDS, developed a theology of compassion; a way of reading the Qur’an and understanding the Prophetic precedent that focuses on a God who cares deeply about all creation (Positive Muslims, 2004).

Most religious bodies have publicly distanced themselves from the claims that the AIDS epidemic is a curse from God, although it remains firmly in religious rhetoric. The general messages remain that God warns us to stay away from sin, because it kills (such as AIDS); and that God′s moral law was not given to take away our happiness; it was given to protect us from our own destructive passions and sinful practices (which leads to dire consequences, such as contracting AIDS). This way the stigmatic issues remain a hurdle, even in the re-evaluated stance of religious bodies towards the epidemic.

16.3 Religious Institution-Based Initiatives in AIDS Prevention and Care in South Africa for the Past 25 Years

Foster (2004) identified the area in which faith-based organisations in southern Africa had the largest impact, which was the area of care and support of those infected and affected by HIV/AIDS. It is calculated that more than 9,000 volunteers working out of more than 650 FBOs support more than 150,000 orphans and vulnerable children on an ongoing basis. This was mostly through community-based initiatives combining elements of spiritual, material, educational and psychosocial support.

Donors, such as the UK Department for International Development (DFID), have also identified FBOs as viable avenues to fight the AIDS epidemic. In 2003, they awarded the Church of the Province of South Africa (CPSA) with £3.5 million, through Christian Aid, for a church-based programme to combat HIV/AIDS in South Africa, Lesotho, Mozambique and Namibia (Church of England, 2004).

This new shift towards a more comprehensive role has caused many FBOs to feel that they are moving away from their core competency of providing spiritual and pastoral support, home care and basic health services in their local communities, to other additional roles such as scaling up current initiatives; addressing stigma and discrimination; carrying out preventative education to bring about behaviour change; and providing health services including the provision of anti-retroviral therapy. There are current initiatives, such as TEARFUND, under way that seek to develop an appropriate framework for how donors might fund and support FBOs and other community-based organisations responding to HIV/AIDS (Weaver, 2004).

A national survey on FBO responses to the AIDS epidemic, conducted by the Centre for AIDS Development, Research and Evaluation (CADRE) in 2005, showed that faith-based organisations are significant actors within South African AIDS response. Among FBOs listed in the survey, there has been a 50% growth in the number of faith-based projects working in rural areas since 2000, compared to only a 32% growth among those in urban settings. The survey found that because AIDS-related work seems often to be embedded within broader service portfolios provided by the FBO, and services are concentrated in the realms of prevention (e.g. awareness activities, counselling and testing) and care and support, with some provision of medical care. Condom distribution does not feature prominently among FBOs' activities, which is in keeping with the importance placed on abstinence by many religious institutions (Birdsall, 2005).

Many FBOs, who were unable to offer their own health services, gave support to existing private or public services. The Methodist and Baptist Churches are still involved with their former hospitals offering chaplaincy services and moral and material support. Teachers from Hindu Ashrams teach therapeutic yoga at two Tuberculosis hospitals in the Cape Flats; the Ikamva Touch Resource Programme (Lighthouse) supplies used wheelchairs and similar equipment to a township health NGO; and the New Apostolic Church provides the South African National Tuberculosis Association with medicine boxes. Volunteer medical specialists of the Muslim and Hindu clinic services supplement the primary health services at these facilities (Schmid et al., 2004).

We will now look at some of the religion-specific initiatives that have been conducted in the region. It must be emphasised that these activities have not been critiqued in terms of their social impact, nor is it an exhaustive or comprehensive list, but must be seen as an indication of where FBOs are headed in the fight against the AIDS epidemic.

16.3.1 Christianity

The increasing resurgence and revival of Christianity in many African countries (Bediako, 1995; Gifford, 1994; Jenkins, 2002; Ojo, 2000) suggests that Africa and other southern regions have now become the centre of worldwide Christianity. The nature of the relationship between the African church and its community has always been a close one, where the church would be a focal point of much that happens in the congregation and community. Weaver (2004) found that FBOs are important in communities which are facing desperate situations as a result of AIDS or other calamities. They offer a combination of practical, emotional and spiritual support to households affected by AIDS, or with orphans and vulnerable children in the community. The activities of a FBO provide a means to bring affected people together where otherwise they would be isolated.

The Kathleen Voysey Clinic, run by the Musgrave Methodist Outreach Project in Durban, is an excellent example of a traditional role a FBO plays in the community where it provides health-care services to homeless and indigent people. The clinic operates in conjunction with a soup kitchen supported by the churches in the Berea area of Durban. The clinic utilises the services of voluntary registered doctors and nurses and has a licence to dispense medication to patients. The need for such services became evident when observing homeless people attending soup kitchens hosted by churches in the area. The clinic attended to 5305 patients during 2004.

An example of a FBO programme that incorporates ‘new’ methodologies into existing infrastructure is the Moravian Masangane ARV programme that was set up in the Eastern Cape communities where the Moravian or Lutheran church had an established presence. The organisation provides care and support to the infected and the affected, with a specific focus on the provision of ARV treatment to those who need it. In addition to this, Masangane provides care and support to children affected by HIV and AIDS. Health workers had access to congregations and their infrastructure which allowed them to reach these often remote communities with relative ease. This reach of religious congregations into the most inaccessible regions is widely acknowledged as a factor favouring collaboration with FBOs (Schmid et al., 2006).

The Anglican Church of Southern Africa (ACSA) covers six countries and is divided into 26 dioceses with current membership of 4 million baptised people. Nineteen of these dioceses fall in the Republic of South Africa, representing approximately 2.5 million Anglicans in over 815 parishes (Council of Anglican Province of Africa (ACSA), 2007).

The first public commitment from the Anglican Church to address the HIV/AIDS epidemic was made during the ‘All Africa Conference’ of August 2001 in Boksburg, South Africa. In April 2003, ACSA officially launched its first comprehensive and provincial-wide response to the epidemic in southern Africa, the Isiseko Sokomoleza (Building the Foundation) HIV/AIDS Programme. The main purpose of Isiseko was to reduce stigma and the impact of HIV and AIDS in southern Africa (Deacon and Simbayi, 2006). The Isiseko Sokomoleza Programme looked at strengthening the capacity of the church to advocate for and provide an effective and expanded community-based response to HIV and AIDS in partnership with other regional stakeholders. The programme also addressed HIV vulnerability through increasing knowledge, encouraging responsible behaviour and promoting positive attitudes to people and families living with AIDS (ACSA, 2007).

The UK Department for International Development (DFID) funded this programme and was implemented in partnership with Christian Aid. Through this programme, over 600 projects have been managed in partnership with other denominations, NGOs and government departments. These projects include the care of orphaned and vulnerable children, care for care-givers, home-based care, wellness management, skills training, food security, promotion of voluntary counselling and testing, support groups, pastoral care, retreats for Christians living with HIV, counselling as well as capacity building, raising awareness, HIV education programmes (including peer education) and empowerment projects (ACSA, 2007).

Two other programmes of note being coordinated by the Anglican Church, which are being funded by the Presidents Emergency Plan For AIDS Relief (PEPFAR) through USAID, are a youth programme called Siyafundisa (Teaching our Children) and the Anglican Care for Orphaned and Vulnerable Children (OVC) Project. Siyafundisa targets young people between the ages of 10 and 24 years with the aim of reducing the incidence of HIV through promoting abstinence before marriage and faithfulness within marriage. This programme is implemented in partnership with Fresh Ministries Inc. The OVC Programme mobilises Church communities to provide care and support to children who have been orphaned or otherwise made vulnerable by the HIV epidemic, as well as those caring for them. The latter programme was initially funded by the Desmond Tutu Trust and Johns Hopkins.

The Catholic Church's response to HIV/AIDS got off to a slow start in South Africa, influenced by socio-political realities, by ethical dilemmas and by an inability on the part of church and community leadership to recognise signs of impending calamity. Today, however, the Catholic Church is a major provider of care, treatment and support to infected and affected people. Programmes in South Africa and other southern African countries, under the umbrella of the Southern African Catholic Bishops' Conferences, respond in diverse ways at a grassroots level (Munro, 2002). The care of the chronically ill and their families is an area where the Church has been at the forefront, with established hospices for the dying; opportunities for respite care for people who may still be able to spend time with their families when they have regained some strength; home and family care within communities; spiritual counselling and support to the dying, to their families and to the carers.

Orphan care is provided at some Catholic institutional facilities, such as Nazareth House, a faith-based organisation located in Cape Town, which was the first Catholic orphan care institution in South Africa to provide paediatric antiretroviral therapy for the HIV-positive orphans it cares for. The Church, however, has promoted care within a family or extended family setting as the ideal, and there are some highly successful day-care centres for OVC throughout the country. Some children are fostered or adopted by family or community members, and some live together with other children under adult supervision.

Often in Church projects the required skills are not directly related to AIDS. Capacity-building projects such as vegetable gardening, sewing projects, jam and candle making, and various other income-generating activities are well established with church groups (Munro, 2002). There are several successful initiatives being managed by other Christian denominations, whose aims and objectives are covered by the examples given above.

16.3.2 Islam

Muslims have always seen themselves as protected against the AIDS epidemic because of the social value system prescribed by their religion. There is some evidence that attest to this fact (Gray, 2004), and in terms of an overall lower HIV prevalence rate, a study conducted in 2005 of three Muslim residential areas in the Cape Town area found that 2.56% of Muslims living there were HIV positive (Kagee et al., 2005). This is significantly lower than the antenatal data estimate of 15.1% (Health Systems Trust, 2007). Nevertheless, a rapid increase in rates of infection throughout the Muslim world suggests that Islamic values are not an adequate defence (Hasnain, 2005). The US Centre for Disease Prevention and Control, in a 2007 report, cited a 300% increase in the number of people infected throughout the Middle East and North Africa during the past 3 years. According to Hasnain (2005), the association of ethical and moral issues with HIV risk behaviours makes the social stigma associated with HIV/AIDS more pronounced in Muslim societies.

Islamic values systems also do not immunise Muslim communities from perceived social ills such as unprotected pre- and extra-marital sex, as a study in the Muslim community in Cape Town found. Muslim women were almost 4 times more likely to report infidelity as a reason for divorce than men (Toefy, 2002). In the same study, more than half of the sample of 600 divorced couples got married to legitimise a pre-marital pregnancy.

As in other communities in South Africa, gender-based violence also remains a concern (Jeenah, 2006; Shaikh, 2003). During August 2001, Positive Muslims volunteers initiated eight workshops for women from various socio-economic backgrounds on AIDS, Islam and women. These workshops resulted in the empowerment of hundreds of women to be leaders themselves (Positive Muslims, 2004).

The Islamic Medical Association (IMA) operates a number of clinics in urban and semi-urban areas of KwaZulu-Natal and Johannesburg. Medical specialists offer voluntary service in addition to the trained nurse who is constantly available (Schmid et al., 2004).

16.3.3 Judaism

Synagogues play a vital role in addressing the AIDS crisis by undertaking education and prevention programmes, providing welcome and support for people living with HIV/AIDS and their families and friends and by working with AIDS service and advocacy organisations in South Africa. Following a 4-day International Jewish Catholic Liaison Committee conference in Cape Town, leading cardinals and rabbis addressed the plight of AIDS orphans and the role of religious leaders in fighting

HIV/AIDS. Although the meeting differed with regard to prevention strategies, they called for unrestricted palliative care and appropriate attention for all those suffering, threatened or victimised by the AIDS epidemic. They also called for an end to HIV/AIDS stigma (The Body, 2006).

Care within the Jewish faith is also community based. The community mainly provides welfare services, including homes for seniors and disabled people mainly from the Jewish community (Schmid et al., 2004). Outreach programmes such as MaAfrika Tikkun, a Jewish charity organisation, sponsors a food kitchen in the township of Delft located on the outskirts of Cape Town, which serves 300–500 people every day, including a weekly project to support those living with HIV/AIDS (IRIN PlusNews, 2006).

16.3.4 Hinduism

Strong parallels exist between Hinduism and the Abrahamic religions (Judaism, Christianity and Islam) in how it describes its ideal way to God through love and compassion for others. In the first decade of the disease, Hinduism did not feature prominently in international discussions of the work of faith-based organisations in the fight against HIV, mainly because of the low prevalence of HIV among Hindus during the 1980s and 1990s. This situation has dramatically changed, as there are 2.5 million HIV infections in India alone and prevalence rates are likely to exceed 1% of the total population by 2010 (UNAIDS, 2007). There is no study at present that projects the potential impact of a Hindu response to HIV beyond what is surmised from an understanding of its traditions and moral values, but there are at least two reasons to be encouraged. First, there is historical precedent for a Hindu response to disease and suffering that can be seen in the many associations addressing the needs of people in Hindu communities. Secondly, today it is the norm, not the exception, for Hindu faith leaders to be engaged with leaders of other faith groups in discussions of the role of faith-based organisations in responding to HIV (Faith in Action, 2008).

In South Africa, Hindu groups, together with other faith-based organisations, have played a significant role in the AIDS response since the early 1990s and have mobilised strongly against AIDS in their communities (UNAIDS, 2008). They supplement health care in numerous poor areas of KwaZulu-Natal through the Sai Baba medical camps and the Ramakrishna Clinic. Both organisations utilise provincial clinic facilities and bring in volunteer medical specialists and donate medication on weekends. The Ramakrishna Clinic also runs paediatric camps every 2 months for 500 children (Schmid et al., 2004).

16.3.5 African Tradition

Considering the important role of the traditional healer within the community with over 300,000 traditional African healers in South Africa, HIV programmes and STI testing and treatment programmes should develop stronger linkages with traditional healers providing treatment of STIs, secondary infections, pre- and post-counselling for the individual and the family (Rogerson, 2002).

Early attempts to combine the best of both systems included a variety of projects that looked at the usefulness of traditional herbal remedies for the treatment of HIV-related illnesses. Studies looking at traditional healers' perceptions of sexually transmitted infections and HIV infection were also conducted. With this information, collaborative projects started training traditional healers as educators and counsellors to disseminate information on HIV and sexually transmitted infections in their communities and to their peers. One such project involved the Inanda healers from the Valley of a Thousand Hills, KwaZulu-Natal, South Africa. In 2000, community leaders called for help in strengthening their response to the AIDS epidemic. They identified local traditional healers as having an important role to play. In response to their request, social scientists and medical doctors began working in partnership with the local traditional healers on HIV prevention projects. Discussions took place around traditional and cultural sexual practices that could prevent HIV transmission and safer sexual practices involving more than just condoms (UNAIDS, 2007).

Collaboration started in the Western Cape in 2005 to encourage medical co-operation between doctors and traditional healers and cross-referrals between them in HIV/AIDS interventions; to avoid potential disruptions and interactions with ARV regimens through prescriptions by traditional healers and to persuade more male clients to know their HIV status. Nine traditional healers were recruited to work with five community health workers in five townships on the outskirts of Cape Town, and it has been fairly successful (Wreford, 2006).

16.4 Conclusion

Research has shown that faith-based organisations of all denominations are involved with multiple aspects of AIDS response in South Africa, with particular focus on HIV prevention and care services (Steinitz, 2006). These activities are, however, fairly limited in reach, occur at grassroots level and do not appear to be integrated into larger service-delivery frameworks. Rural organisations appear to be under-resourced, less independent (as evidenced by higher levels of networking), but more closely connected to people and communities.

There is a dire need for a comprehensive approach to fighting the AIDS epidemic, which includes both the religious and the public health stakeholders. ARHAP (2006) developed an excellent framework for such a dialogue to occur:

1. The medical fraternity needs to acknowledge the presence of religion in African views on health. The religious fraternity, because of this reality, needs to accept the responsibility for engaging in social life, and for taking on the tasks in the

field of public health and preventative issues, such as clean water, sanitation, nutrition, hygiene, sexual health, reproductive health and mental health.
2. Both stakeholders need to appreciate and acknowledge the convergences of the other in the lives of African communities. There must be a realisation of how significant religion is for African well-being as well as how essential public health is for the betterment of African lives.
3. There must be mutual respect for each others' frames of reference and rhetoric. At face value, the language of public health and the language of religious organisations can be at odds, but if religion is so vital for African well-being, then public health sector has to be more attentive to it. The religious fraternity, on the other hand, needs to make a genuine attempt to work on and translate the language and concepts so that they can facilitate dialogue and interaction with the public health sector.
4. There must be paradigm shift in the way that public health policy is discussed in Africa. All attempts must be made to get all the relevant stakeholders around the discussion table to ensure an appropriate and lasting solution.
5. Dialogue needs to happen in an environment of solidarity. All the stakeholders must realise a common purpose to strive for well-being in the midst of a world economy and political system that create suffering and poverty. There is a symbiotic relationship that exists between religion, which strives to transform this world into a better one, and the commitment of public health to create the conditions where this is possible.

Religious entities are perceived as contributing to health, well-being and the struggle against HIV/AIDS through tangible and intangible means. Leading tangible factors comprise compassionate care, material support and health provision; leading intangibles are spiritual encouragement, knowledge giving and moral formation. It is this combination that distinguishes the religious bodies and gives them strength.

Religion, health and well-being are locally and contextually driven. For those seeking to engage religious fraternities, religion cannot be viewed as a single, simple cultural 'variable' – no 'one size fits all'. Religious involvement in health and HIV/AIDS is increasing – particularly since 2000 – and religious entities have expressed a strong local commitment and desire to be more effective in the area of HIV/AIDS. Interfaith engagement and dialogue require further exploration.

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Part III
Persons Living with HIV/AIDS

Chapter 17
Experiences of People Living with HIV

Lumka Daniel and Corinne Squire

17.1 Introduction

You are HIV Positive
YOU ARE – HIV POSITIVE
YOU ARE
YOU, HIV POSITIVE
YOU ARE POSITIVE
YOU ARE
YOU ARE
YOU ARE
HIV POSITIVE

I AM
I AM?
Nay, I am not
I am who I am
And
I am not HIV Positive

I may be living with HIV
That does not make me
HIV does not make me

I am who I am
And I still am who I am
And I live,
I live,
I live with HIV
HIV?
Humano
Immuno – def
Deficiency
V-Irus
HIV lives in me

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_17,

I have not died
I am and HIV is within me
I am, I still am

There's no name for HIV
They can't find it
They can help me fight it
It is not detectable
It deteriorates,
Deteriorates my immunes

I was not born with it
God did not create me with it
Somebody got it
Somebody passed it on
Passed it on to me
Somebody whispered
You are HIV Positive

They cannot tell me, they cannot tell me
When I,
When I became, errr when I became HIV Positive
They cannot tell me
When I,
When I received the, errr the v-irus
They cannot tell me,
They cannot tell me who passed it on to me

The only thing they tell me
Is errr, my body's struggling
There's a battle in my immunes
Awakening my anti bodies
Ant-I bodies to battle with the v-irus
The trespassing curse
In my body
In my blood

They tell me,
They tell me,
You are HIV Positive

I feel like Judas in Passion of the Christ
Only that, only that I did not betray the Messiah
Only that, I did not sell the Messiah, nor my body
Only that, only that I have not killed myself
Maybe I have, maybe I did
By allowing them to change me
From who I am and who I am meant to be

To
You are HIV Positive

Who cursed me?
Why me?
Why now?
Why?

Should I kill?
Should I kill the cheater, the bastard, the moron?
If I was born with it, would I have to kill my parents?
Or would they have killed each other already by now?
Mhhh, errr should I kill the government?
Why wasn't there PMTCT?
Should we all die?
Am I?
Am I dead alive with the V-Irus?

I live
I am alive
And I,
I live with HIV!!!

(Lumka Daniel, 2008)

This chapter reviews research on experiences of people living with HIV in South Africa, and suggests that in addition, poetry, fiction, visual arts, music, autobiography and documentary are crucial to understanding HIV experiences (Cameron, 2005; Dangaremgba, 1996; Health and Development Africa/Soul City, 2007). Research on HIV experience needs to include not just statistical and qualitative studies, but also writing and images by and about people with faces and names whose lives have been changed by the epidemic.[1]

The chapter adopts experience's broadest meaning: that of practical acquaintanceship with an object, event or phenomenon. It deals with the HIV experiences of two women researchers – one South African, black, and one British and white. Squire came to do research about people's support for living with HIV in South Africa through a combination of previous experiences: volunteering with US HIV support groups; researching UK understandings of HIV support; and interest in South African HIV services and activism, and South Africa's critical intellectual traditions in psychology and gender studies. In South Africa, everyone experiences HIV/AIDS, regardless of 'personal' HIV status. Efforts are made to make sure that everyone in the country engages in the battle against the pandemic. Daniel worked with various organized groups, in churches and schools, as well as with individuals, on HIV prevention campaigns. She collaborated with Squire on the HIV support

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[1] A longer version of the chapter can be found in the UEL depository: (insert URL which should be available in early 2009)

study, conducted during 2001–2004 through semi-structured interviews in the Cape Town area with 37 participants (Squire, 2007). Through this work, a relationship with TAC emanated; as a result, she co-founded the University of Cape Town branch of the Treatment Action Campaign (TAC). 'Voices' arose from this work. It includes internal and external 'voices' that one often hears in connection with HIV-positive status. The character that hears the voices could be anyone diagnosed with the virus.

17.2 Common Experiences of Living with HIV

Below, we describe four experiential fields that seem, 25 years after the start of the South African epidemic, to be 'common' in two senses: frequent and held in common among people living with the virus. These fields can be described, using terms current within the epidemic, as those of 'knowing your status;' 'othering' and depression; status acceptance and 'living positively' with HIV; and 'speaking out'.

17.2.1 Recognising Status

The moment of diagnosis is generally described as dramatic and deracinating (Abdool Kareem, 2005; Flowers et al., 2006). In Squire's (2007) and Daniel's interview study of support for HIV-positive people in South Africa, participants repeatedly described the physical and emotional 'shock' of a positive result, even when, like Phumla (like all other names, this is a self-chosen pseudonym), who tested as part of a Prevention of Mother To Child Transmission (PMTCT) treatment programme, they were partly expecting it:

> *Phumla:* Okay. Firstly, at that time when we were being told about doing blood tests, taking three blood tests, they told us about those three blood samples. I told myself that I should take the HIV test so that I could save my baby. Truly then, I did the test and then I was told that I have HIV. I thought, I was shocked I must say as a result when I got to the taxi {minibus}, I was crying, I did not know what to do.

'Voices' too starts with diagnosis: insistent, largely capitalised 'voices' – doctors, nurses, counsellors, and perhaps, an internal voice – repeating life-changing words 'You are HIV Positive/YOU ARE-HIV POSITIVE/YOU ARE/YOU, HIV POSITIVE/YOU ARE HIV POSITIVE...' As in many interviewees' accounts, 'HIV positive identity reverberates over and over, as if the ordinary world of life experiences is suspended and shifting into another shape'.

17.2.2 'Othering' and Depression

Experiences of accepting HIV and 'living positively' have particular salience in South Africa, where the HIV epidemic was contested and acknowledged late. There is considerable variation in the elements constituting such experiences, which makes a 'stage' account unreliable. However, on the resistant side, the elements often involve status disbelief or rejection; 'othering'; stigmatization; and post-diagnosis depression, suicidal ideation and anxiety (Olley et al., 2005).

Status disbelief can be helpful initially, diverting people from post-diagnosis despair. Phumla used a disbelief encouraged by her healthy appearance, alongside an avoidance of HIV's name and a displacement of her status to medical professionals' diagnosis, to live with her status:

> *Phumla:* I gave myself hope, 'no man, maybe {I am not HIV positive}, I cannot see this thing they say I have', then I handled it well.

Usually, however, respondents in the HIV support study connected status disbelief to neglecting their health and ignoring transmission issues, within a general climate of lack of education, treatment and care. Michael, for instance, did not believe his 1997 diagnosis, his sisters told him 'there is no such thing', and he continued being 'busy with girlfriends' and having undiagnosed, hard-to-treat illnesses:

> *Michael:* I took it light and I ignore it just like that, 'no, this is not a truth that I'm HIV positive'. I just ignore it and the doctor didn't give me the guide lines, how to live with HIV, I must do this and this.

Michael's disbelief was enabled by a general climate of 'AIDS denialism' (Mbali, 2003) and 'othering' – locating HIV in other people or places – a response noted in a number of countries (Joffe, 1997; Joffe and Bettega, 2003; Rohleder, 2007):

> *Michael:* We had the problem of, of us the people in South Africa. We took, it, we took the HIV issue light and we compare it to the places like the countries like, like America. . .then we didn't compare it to in South Africa that HIV can be here you know.

Interviewees commented frequently on people's 'othering', blaming and stigmatization of the HIV positive. Stigmatisation is associated with testing delay and with negative reactions, post-diagnosis, in many epidemics (see also Chapter 8, this volume). Interviewees reported being stigmatized ubiquitously and relentlessly, on the basis of their own or partner's known status, their own, partner's or child's illnesses; how ill or thin they looked; what foods they cooked and ate; whether they took clinic-issued vitamins; whether they talked about HIV; and as in other high-prevalence epidemics, and in African-origin communities in the developed world (Flowers, 2009) whether they had caesareans – rare in South Africa – or formula-fed their babies. Mere fear of stigmatization can lead to isolation and alienation. But interviewees experienced stigmatization even from those who claimed to accept them. Busisiwe's mother took her in, along with her HIV-positive child, but repeatedly positioned her as promiscuous and blameworthy:

> *Busisiwe:* So, my mom embarrasses me with that {HIV} even in front of people because I'm HIV positive. It makes me feel not at home, as if I'm lost. It makes me want to stay outside. Even when I've made a minor mistake like spilling sugar, she would say, 'This is because you are thinking of guys and AIDS and all that'. So you see those things hurt me. They make me realise that I'm alone, there is no one who would tell me not to worry.

Where HIV is politically controversial, treatment, care and prevention under-resourced, and HIV reaches high, hard-to-comprehend prevalence, blaming, while not a rational or effective health strategy, makes some sense. With 1000 deaths a day (UNAIDS, 2008), every weekend in South Africa sees massive funerals of people dead from AIDS-related illnesses. We need to know who to blame for losing breadwinners, parents, children, colleagues, leaders and peers. We demand to know who is responsible for these massive killings, so we can stop them. For people like Busisiwe's mother, blaming renders it easier to deal with the emotional and economic crisis. This woman was contemplating the imminent deaths of all her children and some grandchildren, and decades of care for other grandchildren, in a low-employment rural village.

'Voices' acknowledges the blaming response, tracing it from passing-the-buck suspicion: 'Somebody passed it on to me....They cannot tell me who passed it on to me....' to formulate the virus as a 'trespassing curse' – the consequence of social hostility, an unknown transgression or political neglect: 'Who cursed me?/Why me?. . .should I kill the government?/Why wasn't there PMTCT?' Blaming can be, as 'Voices' shows, part of the process of internalizing the diagnosis, 'taking in' the news first by shutting it out. First, you blame the health practitioner who informs you, for sharing the sad truth and not having all the answers. Next, you blame the person that gave HIV to you – partly because people generally decide on whether to pity or blame you on the basis of how you contracted the virus. Thirdly, you blame whoever could have done something – government for not making or enforcing policies; NGOs for not effectively teaching prevention; religious institutions for not enforcing morality, abstinence and faithfulness; academic institutions; pharmaceutical companies. After blaming and yet more blaming, you come to engage with HIV.

Another set of often-described responses translates blame inward into depression, withdrawal, self-disgust and suicidal feelings. *Sowetan* columnist, Lucky Mazibuko (2008a), openly HIV positive since 1999, records the self-punishing guilt of those who think they have 'killed' those they loved. Comedian and HIV activist Pieter-Dirk Uys (2003) says HIV has made fear and shame endemic in South Africa. Withdrawal and reflection may be useful responses to the shock of diagnosis. But many interviewees in the HIV support study described self-destructive despair: incorrigible sadness; retreat from people, and the activities and pleasures of everyday life; recurring images of illness and death; a wish to 'disappear' under a train, or by self-poisoning or drowning:

> *Nomazwe:* When I first heard, I used to think a lot, I thought I would drown myself, I felt like disappearing, I did not want to be around but just that I didn't know how to do it. My heart was always aching even when I was trying to rest or relax. When I was alone I would cry, everytime when I was alone I'd cry.

HIV does not silence the 'voices' in Daniel's poem; but still the writer wonders whether s/he has indeed 'killed' her/himself, 'by allowing them to change me/from who I am and who I am meant to be/To/You are HIV Positive'. Secreted within the poem is HIV's potential social fatality. Diagnosis can turn you into a result, 'HIV Positive', which suppresses your identity, making you lesser, incapable, even when there are no external signs of weakness.

17.2.3 Acceptance and ‘Living Positively’

The positive experiences clustered around status acceptance are usually represented socially and often start with explicitly ‘accepting’ one’s status, as many other studies have found. This generally happens in dialogue with a medical professional, community organization or relative. Linda, ‘shocked’ by her diagnosis, fled from the counsellor and got a minibus home, then came back to talk to her. But she needed more prolonged exchanges with her support group friends to ‘accept’ her status:

> *Linda:* When I got home, I realised that I might have missed something by not listening to that lady {counsellor}, so I went back again. I went in and she told me to accept it because I am not alone there are many people with the virus. But I could not accept it, I only accepted it after joining the group, that was the only time I was able to accept it.

Interviewees often said that ‘acceptance’ involved gaining knowledge about the virus and how to live healthily with it. Again, they usually achieved this socially, in discussion with health professionals and support groups. The socio-emotional aspect of acceptance involves moving away from solitariness, the voice crying out in the poem, ‘Why me?/Why now?/Why?’, and defining yourself as one of many living, not dying, with HIV. This experience shapes many fictional and documentary representations of the epidemic, for instance, the annual television series *Siyanqoba Beat It!*which since 1999 has been ‘promoting and role modelling people living positively with HIV’. In everyday life, the collectivity of HIV acceptance disseminates powerfully through what Phumla called support group ’families’, in South African and other sub-Saharan epidemics. Support groups also operate as exemplars for wider family and community support (Kaleeba et al., 1997; Squire, 2007).

A ‘simple yet powerful philosophy’ (Mazibuko, 2008a) of HIV acceptance does not indicate over-hasty or superficial responses, but rather, acceptance’s contextual nature. Given other demands in their lives and HIV’s ubiquity, interviewees described themselves moving quickly towards a degree of self-acceptance, even in the face of the negative representations of HIV around them, which let them continue living. As Sipho put it, ‘It’s a must that I accept it, as I have children in the house’. Acceptance has a strong connotation of active welcoming in Xhosa, carried into its usage in South African English, which renders its rapid achievement even more effective. Nevertheless, acceptance changes as you live with HIV, progressing from ‘taking it in’, through trying to understand what HIV is, how you will function, what will change and what will stay the same; towards establishing a relationship with the virus – at its most explicit, perhaps, a kind of symbiosis, as Michael described at the end of his interview: ‘{I’ve} came in a long way with HIV. . . I take the HIV now as my friend, big friend. . .I talk to it, psychological’.

Experiences of ‘living positively’ were always represented by interviewees in the support study as involving sociality. HIV’s ‘interpretive communities’ (Plummer, 1995), support groups, families and friendship networks, spread knowledge and acceptance; but they also enable ‘positive’ HIV identities. The experience of multiplicity is, Scott (1990) suggests, a kind of ‘theory’ of what is possible. Nomthandazo’s support group’s collectivity offers a powerful ‘theory’ of living as an HIV-positive person, rather than dying.

> *Nomazwe:* I was released by the support group from those suicidal thoughts. As a result now I don't even think about it.

What the group talks about becomes the basis for her own theory of self-care, how 'I think about my health'.

Alongside this sociality, the 'living positively' experience involves disclosure to partners, family, friends and work colleagues. Studies in different national contexts report good effects of disclosure. In the support study, interviewees rarely disclosed freely, and spent considerable time and effort considering possible reactions. However, they reported mostly helpful reactions from partners, parents and siblings, indicating perhaps South Africa's expanding HIV 'interpretive communities' during 2001–2004, the time of the research. Popular media and public health HIV education were building such communities, as were people's experiences of HIV diagnoses, illness and death amongst them. Disclosure was represented as a more immediate imperative than in much developed-world research (Flowers, 2009), partly because some treatment protocols, activism and public HIV education were encouraging it, associating it with people being able to access resources and having better physical and psychological health; partly because of the paucity of biomedical support, which enhanced the value of openness as a kind of medicine in itself; and also because of strong familial psychological support and socioeconomic dependencies, and in response to the country's previous silence about the epidemic.

To disclose was to declare oneself, as many interviewees put it, 'the same person', unchanged by HIV. Networks of HIV-positive friends were said to 'live positively' by chatting about all kinds of things, constructing sociality in a way that was not HIV determined. Some interviewees were moving away from HIV services; for them, as for people living long term with HIV elsewhere, 'living positively' meant foregrounding other aspects of their lives (Squire, 1999, 2003). 'Minimising', 'avoidant' representations of HIV status have long been accepted as valuable strategies, particularly when people are well (Carricaaburu and Pierret, 1995; Ezzy, 2000). Within representations of 'living positively', they operate strategically, to affirm the social personhood of someone living with the virus but not determined by it. The 'Voices' writer similarly declares to us both her/his acceptance of living with HIV, and her/his continuity with a pre-HIV self: 'I am who I am/And I still am who I am/And I live,/I live,/I live with HIV'. The narrator's life story settles with the epidemic's practical truths, without denying it or being taken over by it.

17.2.4 'Speaking Out'

A final element among 'living positively' experiences is 'speaking out', telling about your HIV-positive life to others. Interviewees' 'living positively' descriptions almost always ended with accounts or plans of not just disclosing, but educating. For Busisiwe, learning about her status and vanquishing HIV-related illness led quickly to this socio-moral speaking out. She takes responsibility for other people's ignorance and commits to positive transformation:

> *Busisiwe:* I want to talk about that {HIV} with my friends. ‘I have a problem like this’, so I must take them to the clinic. But me, my sister, I am not ashamed. I have sacrificed myself {by being open} and I’m not ashamed even before my parents to come forward and be seen that Busisiwe is talking, you see. What I’m saying is that I have accepted it. It’s not that now that I’m HIV positive I’m no longer a person. I can make a contribution in certain areas too, helping other people or else one would say ‘come and help me’, {and} talk saying that ‘you also have this’, because I’m also like a person who has this, it’s just that I’ve got it inside it hasn’t manifested on the outside.

It is not surprising that constructing yourself as an ethical, testifying HIV subject is a key element of ‘living positively’ experiences in South Africa, given the country’s prolonged early silencing of the epidemic. However, ‘speaking out’ seems a key factor in other high-prevalence national epidemics: in the initial support and activist group activities of the Ugandan HIV-positive community (Kaleeba et al., 1997); in that country’s commitment to making the epidemic speakable (Epstein, 2006); and in other African countries’ explicit declarations that HIV is indeed their problem (Iliffe, 2006). Unsurprisingly, ‘speaking out’ does not figure so strongly in ‘living positively’ experiences when effective policy, treatment, care and education are in place, and prevalence is low.

Interviewees’ experiences of ‘living positively’ can thus be summarized as involving a continuing existence as the ‘same’ person, yet with HIV constituting a new sociality around you. HIV sociality involves being able to live, rather than die with HIV; and declaring this to others is an ethical and political necessity. Campbell et al.’s (2007) description of ‘HIV-competent’ communities converges with this description, identifying five highly social aspects out of six. If accounts of the pandemic in the developed world have left behind their socialized early incarnations for an individualization seen as the consequence of HIV’s biomedical management, this has not yet happened in resource-poor countries, and still may not.

17.3 Heterogeneous HIV Experiences

HIV experiences are mediated by many factors that shape, intensify or displace them. Material circumstances are perhaps the most powerful. Learning about HIV, or knowing people who are HIV positive but who are distressed about their status, does not generate positive experiences. Availability of resources, including income and housing, as well as HIV medication, care and prevention, strongly affects how South Africans speak about being positive (Brandt, 2004; Squire, 2007). As has been found elsewhere, for instance Haiti (Farmer, 1999), improved resources help shift entrenched negative beliefs about HIV. Support groups have proved a valuable stimulus to ‘living positively’; they also encourage treatment access. ART provision is key: it raises life expectancy, reduces vertical and horizontal HIV transmission, mitigates stigma, enables disclosure and – not least – improves job satisfaction of low-resource countries’ medical professionals, already stressed, underpaid, overworked and migrating to richer countries.

Other important shapers of HIV experiences are social formations that intersect with HIV identities: those of gender, generation, class, sexuality, ethnicity and religion. In South Africa, prevalence differences between historically and socially racialized groups generate large differences in everyday HIV experiences. The majority black South African group are much more likely than people historically described as 'coloured', 'Indian' or 'white' to be living with an HIV diagnosis. There are provincial and age differences in prevalence, rural–urban differences and higher prevalence among women. Women seem from the support study and much other research to experience stigmatization most intensely and find disclosure most problematic. Women's greater HIV-related and other responsibilities around child and partner care, their economic dependence, social subordination, and susceptibility to gender-based violence can impede them seeking diagnosis and treatment. South Africans' different sexual orientations also affect their HIV experiences; so do religious and 'ethnic' differences. Difficulties that people experience with other chronic health problems such as epilepsy or asthma, responsibilities for family care, refugee or migrant status and histories of abuse and loss, may marginalize their HIV experiences – something that is also true for other chronic illnesses. Studies across several epidemics have suggested that HIV positive women, too, frequently shift focus after diagnosis towards other aspects of their lives (Brandt, 2004; Ciambrone, 2001; Squire, 2003). Economic stratification is a particularly acute issue, partly because the legacy of apartheid is extreme inequality, and partly because of black South Africans' uneven economic development over the past decade and the perception among many, including our interviewees, that people 'outside' poor neighbourhoods do not care about them. The experience of being HIV positive is thus always the experience of being other kinds of subjects, too. Not everyone is 'living with' HIV in the same way. What we see is something close to what Mouffe (2005) describes as 'equivalent' HIV identities, sharing some experiential fields on the basis of which common actions can be taken, but distinct in other areas.

Heterogeneities within the epidemic itself also structure HIV experiences. How ill and incapacitated you are (Brandt, 2004; Flowers et al., 2006), length of time diagnosed and when diagnosed, affect your experiences. The extreme experiences associated with imminent fatality are attenuated in the 'treatment era', with varying, much-debated consequences for sexual practices. Younger people are reporting more HIV awareness across South Africa (Flisher et al., 2006); ART is reducing mortality and reaching and retaining more and more patients (Boulle et al., 2008).

To a degree, HIV citizenship is also shared across statuses. Our three interviewees of unknown or negative HIV status developed this equivalence through their political and work affiliations. Zanele, for instance, a lay counsellor, refused to test – a rational decision, since she was well and no treatment was available – because she did not want to distinguish herself from the people she worked with; she reported that this identification extended to her fellow counsellors:

> *Zanele:* After we did that {HIV counseling training} course we take even us as, a HIV people. Even now I take I took myself as an HIV people because I don't know my status/mhm/that is why I told myself that maybe I've got this HIV. So I side I'm on the, s, on the side of HIV people. I don't say I'm not or I will not I took myself as an HIV people

This area of equivalent HIV citizenship has limits. People who are HIV positive often will not disclose to the 'affected' because they do not understand the latter to be ‘living with’ HIV as they are. However, several interviewees described this understanding being overturned by their experiences with people of all statuses working in HIV-oriented community-based organizations and NGOs. Experiences of HIV are thus heterogeneous in themselves, as well as across statuses; and are at the same time experiences of many other life contexts, of which in South Africa perhaps the most salient are poverty, gender and lack of treatment and support (see Chapters 7, 3, 4, and 11).

17.4 Signifying HIV

In phenomenological uses of the term, ‘experience’ signifies internal, personal phenomena that are best known by the person containing them, and that define the person. But we are writing about HIV ’experiences’ more broadly. They need not have this ‘interior’ character, they may be expressed in objective, non-emotional terms; they may come from ‘parasocial’ experiences of TV soaps like *Soul City*, or radio talk shows; they may refer to what others said or went through, as well as happening to you. When an interviewee described how ‘some people’s boyfriends leave them’ after diagnosis, she was signifying a common experience, not just describing her own. When Michael declared that ‘we’ the people of South Africa ‘took the HIV issue light’ he was not displacing attention from himself, but describing an important, erasing representation in neighbourhood and nation. When the narrator of ‘Voices’, realizing that allowing her/himself to be crippled by the ‘voices’ is to live passively, as if sleeping, awakens, s/he affirms this awakening in a way which lets everyone engage imaginatively with it, as a collective as well as a personal declaration. The poem was, indeed, inspired by Daniel’s appreciation of performances’ ability to affect collectivities: expressing ‘taboo’ issues, allowing identifications, unlocking captivated mentalities and unleashing possibilities.

Poems can function as exemplary autobiographical representations that, like South American *testimonio* (Plummer, 2001) convey collective truths, condensing individual lives and foregrounding instructive experiences within them. Songs, like the one accompanied by dancing that young women in the Western Cape who were campaigning for PMTCT made up in 2001 for rallies and demonstrations, complete with gestures and gait mimicking pregnancy, are also powerful collective expressions, working to express things that women, especially, cannot say. Songs have biblical precedents important in South Africa, and in traditional ceremonies, women often use them to express how they are oppressed by illnesses, spouses, in-laws or governing structures. Other women join in to sympathize and to encourage the initiator whose struggles they identify with (Guzuna, 2000). Youth ‘open mic’ poetry sessions and hip-hop performances now work in similar ways around the epidemic.

Experience is made *by* and *within* representations, and these experience-representations work, have effects and make a difference: That is, in several senses, they *signify*. Art and literature can therefore convey experiential knowledge, just like apparently more direct academic, documentary or autobiographical representations. And experience is always a specific form of culture, mediated by its significations. In the HIV support study, interviewees seemed to draw on a variety of cultural narratives to produce HIV story genres that, working together, yielded intertextualities of experience (Squire, 2007). As we have seen, one set of stories described ‘living positively’ as a progress towards moral and social ‘speaking out’, a ubiquitous genre in popular media and activist discourse at that time. Interviews also contained translations and appropriations of the medical lexicon, and stories of HIV citizenship that drew on the country’s recent stories of political struggle, and its current imbrication in Truth and Reconciliation Commission testimony.

In addition, interviewees deployed South Africa’s strong currency of Christian and traditional faith narratives to talk about HIV life as a matter of ethical ‘conversion’ to acceptance and ‘living positively’, forgiveness, which allows the relinquishment of blame; hope that belief in the right way of life, despite suffering, will ‘heal’ metaphorically, if not literally; and witnessing. Linda ends a story about ‘converting’ her husband to living positively and striving for ethical openness about HIV, with the Biblical foreshadowing of HIV’s difficulties:

> *Linda:* I feel alright, most importantly I thank God. God said these things before, he said there will be these incurable diseases, so I believe in God truly. What he talked about, is happening today.

Linda’s Messianic account of PMTCT, ‘I was happy to save my baby’, echoed by many interviewees, implicitly constitutes her as an ethical subject who cannot be pilloried as sinful because of her HIV status. Part of knowing your status, is gaining means to protect those you care about. In the PMTCT and ART eras, testing enables not just responsible sex, healthy lifestyle and educating others, but also healthy babies and treatment-enabled longevity as partners and parents. At the same time, South African Christian discourse about HIV now emphasizes equivalence across statuses: as each is known and loved by Christ, so whole congregations must exercise reciprocal love and grace to each other.

‘Voices’ maps this ethical progress, starting from HIV’s apparently contradictory moral character, punitive, yet directed at the ‘innocent’: ‘I feel like Judas in Passion of the Christ. . ./Only that, I did not sell the Messiah, nor my body/Only that, only that I have not killed myself’. There is religious guilt and betrayal in the poem, as if the writer, a Judas-like backstabber, has killed the Messiah within. Like the writer, many interviewees scrutinized their life stories for moral answers, asking sangomas about witchcraft, asking pastors for prayers: ‘who cursed me?/Why me?/Why now?’ But some kind of redemption could be reached simply by staying the same, ethical person, not ‘killed’ by the label ‘HIV’, overwriting Judas and winning lives through ‘sacrificial’ testimony, like Busisiwe’s, and salvational PMTCT programmes, like Linda’s.

17.5 Problems of HIV Experiences

In social research, we read participants’ HIV experiences through the researcher, as we read ‘Voices’ through the poet’s voice. Yet most HIV research originates in institutions that are socially, economically, culturally and in terms of ‘race’, 'outside' the pandemic. We hear relatively little from the people living most intimately with HIV epidemics. Paying attention to the intricate HIV significations that appear in art, literature and popular culture, helps address these omissions.

As Nkosi (in Lombardozzi, 2006: 137–8) describes it, poetry 'lives on iron rations'; it is not 'omnivorous', in thrall to saying everything, like prose. But not all prose is omnivorous. Research writing, like poems, has the power to condense and generalise. The researcher's power lies in citing participants; the poet *becomes* the participant. Research translates people's experiences conceptually; poetry does this rhetorically. Nevertheless, research participants‘ and poetic subjects' signified experiences shape research and poetry in strong and enduring ways, claiming a place among the intertextualities of poetic and research 'voices'. Moreover, when research materials are archived, as with the HIV support study, a direct experience-representation will continue, and may be read differently, when the research itself is forgotten.

A considerable amount of HIV research suggests that the experiential patterns we have so far described are too simple. The virus itself remains hard to understand: physiological complexity and mutations compound treatment uncertainties. Even where treatment is accessible and effective, stigmatization is persistent and widespread (Flowers, 2009). Women continue to be blamed for transmission; 'othering' and fear still shape many men's reactions to the epidemic. 'Living positively' can become a coercive signification, marginalizing experiences that do not fit. In the HIV support study, some experiences – the transgressiveness associated with a sexually transmitted fatal disease, particularly for women; death, especially of children; status disclosure, especially to mothers – were replete with ambiguities, repetitions and silences. These representational elisions belong to the realm Kristeva calls the abject (1984), on the borders between subject and object, body and language; in the gaps between signification; characterized by a kind of inarticulate horror. For Kristeva, narratives provide a web within which abjection gains some expression, though it cannot really be represented. We propose that narrative genres provide a means of articulating parts of the self failed by symbolic language. This happens, Kristeva suggests it, *across* stories, though not within what we think of as stories themselves. Busisiwe for example, telling of her 4-month-old child's stillbirth 6 months before, which led to her own diagnosis, spoke quickly and was hard to follow, comparing the baby to our voice recorder and seeming to declare the baby was born alive, though we asked later and found the child was indeed stillborn:

> *Interviewer:* Why did you say 'I would have the test'?
>
> *Busisiwe:* I was pregnant. I went to {hospital} and the baby came out when the child was four months old and s/he was as small as this radio {voice recorder} {gestures}. I discovered that I was HIV positive. I accepted it in that way. I realised that I had to accept it since I had seen both the tummy and the baby and there is nothing I can dispute.
>
> *Interviewer:* Was the child alive?
>
> *Busisiwe:* Yes, I was also having nightmares at night and when I was dreaming, I saw people showing me {lifts beads into shape of AIDS ribbon} it's okay.

Busisiwe's story of accepting and learning to live with HIV finishes ambivalently and abruptly with the child's unspoken death. She turns immediately to another story genre: that of 'conversion' to faith in the right way to live with HIV, a narrative with particular resonance for her since she is in 'treatment', or training, to be a sangoma, a traditional healer, as her beads signify. In the gap between the stories lies, perhaps, a struggle to communicate painful feelings for which words are lacking, but that find expression through striking analogy, incoherence and the sudden narrative shift. Similarly, the affirmative ending by the 'Voices' is overhung by unanswered questions about the universality of death in this high-prevalence epidemic, and the liminal, abject place between death and life to which HIV consigns you: 'Should we all die?/Am I?/Am I dead alive with the V-Irus?'

The abject is constructed, *abjectified,* within social formations of discrimination and exclusion (Young, 1990). Like stigmatization, to which it provides a foundation, abjection can be undone by changes in external circumstances and worked against; but it has to be engaged with repeatedly because it reappears with different focuses. The recurrence of HIV's stigmatization around different signifiers – at first weight loss; later, particular illnesses; today, ART side effects like lipodystrophy and its disturbing challenges to gendered bodies – exemplifies this persistence. Undoing HIV's abjection does not involve rejecting it, but rather tolerating ambiguities, contradictions and incompleteness within HIV experiences, and approaching them in diverse ways. In the HIV support study, participants sometimes dealt with emotional impasses by obvious routes, getting advice from nurses, counsellors and support groups; they also watched *Soul City*, listened to the radio, worked in local income-generation groups for HIV-positive people and talked about HIV in their churches, and with sisters, brothers and friends. Some HIV research suggests that dealing effectively with the epidemic involves people with new institutional practices. Counsellors go beyond their usual professional boundaries; social workers take a therapeutic role; neighbourhoods develop structures of 'HIV competence' (Campbell et al., 2007). In South Africa, HIV activism has invented itself out of transnational as well as local political histories, and from new and older local cultural formations (Mbali, 2005; Robins, 2004). These new formations, avoiding structural and procedural rigidity, mobilize abjection alongside 'living positively', without being overwhelmed by it. Similarly, newly developed HIV narrative genres of speaking out, testimony and political citizenship mediate people's difficult HIV experiences through deploying familiar but polysemic story forms. The poem achieves this too: declaring that many are living positively with HIV, while also asking, 'what it will take for me, for us, for the nation to wake up – and will we?'

17.6 Future Experiences

One of the voices in 'Voices' is that of a child asking who to blame. There is relatively little research on how South African children live with being positive; such poetic versions of experience start to theorize this future. There are many other aspects of the epidemic, presently under-researched, of which knowledge will probably come first from experiential accounts. The strengths of HIV sociality in the support study interviews might lead us to ask whether this experiential element will continue as treatment becomes more accessible and the epidemic more openly addressed. The issues of a large, chronically ill population living on medication for the foreseeable future; dealing with side effects; needing new generations of ARTs; developing conditions related to long-term infection and medication; balancing uncertain health with employment and domestic responsibilities; and facing long-term concerns, particularly around mental health issues and relationships – all these will need addressing. Death will not disappear from the epidemic: ARTs will not always work, and some people will not access treatment. Experience of death as peaceful, dignified and in the midst of those who love you is an important part of the epidemic's imagined future. There have been and will be, also, millions of deaths of people without treatment access, occasioning especially conflicted grief. The epidemic's multiple bereavements are an immense burden with largely unknown psychological and social effects. The overarching requirement for men's as well as women's economic empowerment is becoming more and more acknowledged as key to prevention work (see Chapter 7, this volume). Finally, HIV-positive and affected people are increasingly likely to identify and act as a political group, something Mazibuko (2008b) points out in the context of continuing treatment deficits:

> There is absolutely no way in which any political leader can take for granted as emotive an issue. . .which has directly infected more than 6 million people in our country, excluding those who remain affected. This massive community of people affected and infected by this incurable disease forms a very critical and strategic constituency for any political leader.

17.7 Experience as Theory

Experience is a form of knowledge, as we declared at the beginning of this chapter and as the examples gathered together throughout it have shown. We can, then, usefully understand HIV experiences as forms of theory. One of the etymological roots of 'experience' lies in the Latin verb *experio,* 'to try'. HIV experience, within art, culture, social research and everyday representations, is an attempt to generate knowledge about phenomena that mainstream HIV research has under-investigated, misunderstood or ignored. Like the canonic medical, social, religious and political knowledge with which it negotiates, experiential HIV knowledge is historically and socially situated. But its differences from this canonic knowledge are marked and important.

'Voices' traces experiential knowledge building, from the moment of diagnosis, 'YOU ARE HIV POSITIVE', where a medical subject of HIV is constituted; through attempts at negotiating with medical, ethical and political understandings of HIV, to a final affirmation of 'living' with HIV that is also a wake-up call. It works like a performance, with one voice sounding out at a time amidst others.

Some voices, though they have good intentions, bring harm and confusion; others are intentionally destructive. Through all this, the narrator comes to realize that the right choice is to live actively and positively. The poem describes a multiple, contradictory HIV subject, engaged in dialogue and contest with dominant HIV discourses and haunted by things that can hardly be said. This complexity appeared too in the HIV support study, and in other qualitative research on and popular representations of HIV experiences. It is a problematic but crucial element of efforts to understand the epidemic, and to plan and implement policy.

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Chapter 18
Positive Prevention: HIV Risk Reduction for People Living with HIV/AIDS

Seth C. Kalichman and Leickness C. Simbayi

18.1 Introduction

Over the history of the HIV/AIDS pandemic there have been remarkable successes in stemming the spread of HIV, including reductions in unsafe sex in United States and European gay communities in the early 1980s and averting an AIDS catastrophe in Uganda in the 1990s. Effective HIV screening programmes have yielded universally safe blood supplies, antiretroviral (ARV) therapies have the potential to all but eliminate perinatal HIV transmission and male circumcision has been proven to reduce the risk of female-to-male HIV sexual transmission. Along with these successes have also come several prevention disappointments. The search for new approaches to preventing HIV transmission has included cervical protective barriers, suppression of herpes simplex virus, vaginal microbicides and most notably a safe and effective prophylactic HIV-1 vaccine, none of which has yet demonstrated efficacy. In light of the discouraging progress in biomedical approaches to HIV prevention as well as the continued amplification of the HIV/AIDS pandemic, there is renewed interest in behavioural strategies for preventing new HIV infections. In particular, there is considerable interest in approaches that are aimed to reduce HIV transmission risks among people living with HIV/AIDS, or what has been termed positive prevention (Kalichman, 2005). More than a decade of research in the United States has demonstrated significant transmission risk reduction behaviour changes in people living with HIV/AIDS who participate in positive prevention interventions (Crepaz et al., 2006). Positive prevention is now the standard for HIV prevention in the United States, and these intervention models are being instituted in South Africa.

In this chapter we discuss the rationale for positive prevention and define its parameters, namely what positive prevention is and what it is not. We also discuss the principles derived from the evidence-based literature that can be used to guide the adaptation of effective positive prevention interventions. Looking ahead to future positive prevention efforts in South Africa, we highlight why positive prevention has the potential to make a substantial impact on the course of South Africa's HIV epidemic and we caution why positive prevention could fail in South Africa.

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_18,

18.2 Rationale for Positive Prevention

Positive prevention is consistent with public health approaches that focus on controlling the spread of disease by stemming the source of infection. Because positive prevention depends entirely on people knowing they have HIV infection and coming forward to participate in a preventive intervention, it is necessary for positive prevention approaches to be linked to a well-resourced health-care infrastructure, particularly systems for detecting and identifying infected persons, e.g. HIV voluntary counselling and testing (VCT) programmes with widespread coverage. Although VCT has limited effects on the risk behaviour practices of people who test HIV negative, there is considerable evidence that people who test HIV positive significantly reduce their HIV-risk behaviours after learning their positive test results (Weinhardt et al., 1999). However, these behaviour changes are often short lived and a significant minority of those who do initially change their behaviour revert to high-risk practices.

In contrast to population-based primary prevention approaches that seek to influence the behaviours of masses of uninfected persons to protect them from becoming infected, positive prevention aims to intervene with a relatively small number of individuals who know they are HIV positive and yet maintain transmission-risk practices. Positive prevention is therefore an inherently intensive prevention approach, typically involving multiple face-to-face contacts to develop and sustain behaviour change. Because most people who test HIV positive do cease engaging in transmission-risk behaviours, positive prevention seeks to establish long-term transmission risk reduction among those individuals who may in fact be most resistant to change. When positive prevention is effective its benefit-to-cost ratio is likely to be very high due to the potential to avert HIV infections in large numbers of people by intervening with a relatively small number of infected persons.

The rationale for positive prevention is most compelling in the context of scaling up ARV therapies. Access to effective treatments can induce people who are at risk for HIV to seek antibody testing. When ARVs are available testing can be framed as an opportunity to receive life-extending treatments. ARV medications result in people living longer and healthier lives, calling attention to their long-term psychosocial needs, including assistance with maintaining safer sexual behaviours. Scaling up access to ARVs also builds a treatment infrastructure that provides a platform for delivering positive prevention services. In fact, ARV treatments and positive prevention interventions may synergize, resulting in mutually enhanced outcomes. For example, there is evidence that Ugandans and South Africans who initiate ARV therapies demonstrate significant reductions in their sexual risk behaviours (Bunnell et al., 2006a; Eisele et al., 2008), and it is likely that improvements in health behaviours resulting from positive prevention interventions will generalize to ARV treatment adherence. It is therefore not surprising that positive prevention became the US standard of care for HIV prevention following the advent of combination ARVs (CDC, 2003) and that positive prevention was included in the South African National Strategic Plan for HIV prevention only after the national ARV rollout commenced (South African Department of Health, 2007). The interplay between positive prevention and HIV treatment can ultimately lead to an integration of prevention and care.

18.3 Parameters of Positive Prevention

To be effective, positive prevention cannot be all things for everybody (Kalichman, 2005). Positive prevention best serves the interests of public health when it is focused on reducing the risk of HIV transmission between sexual and drug-using partners where one member is HIV positive and the other is HIV negative or of unknown HIV status (HIV serodiscordant). Positive prevention also pertains to partnerships where both members are HIV positive (HIV seroconcordant). The term positive prevention has unfortunately been diluted to include an array of activities and services that target people living with HIV/AIDS well beyond HIV transmission risk reduction. For example, at the 2008 International AIDS Conference in Mexico, several sessions addressed 'positive prevention' that included human rights (Park, 2008), and the use of HIV treatments for prevention, mental health and coping, delaying HIV disease progression, improving reproductive decisions, and preventing mother-to-child transmission of HIV (Bernard, 2008; Trossero, 2008). A summary of one conference session concluded 'Positive prevention is about far more than HIV transmission' (International Council of AID Service Organizations, 2008). The broadening of positive prevention to encompass everything from mental health to wellness can undermine its potential implementation as prevention strategy.

In a highly influential article aimed at providing a framework for positive prevention in Africa, Bunnell et al. (2006b) expanded the horizons of positive prevention to an array of features, including ensuring that individuals with HIV learn their HIV status, testing and counselling of partners of people with HIV, providing ARV therapies, selecting low-risk persons as blood donors, preventing unintended pregnancies among HIV-positive women, universal access to effective neonatal prevention measures for pregnant women, and promoting leadership of people with HIV infection. Each of these strategies surely represents a laudable public health priority and folding them under the umbrella of positive prevention may help draw resources to a broader HIV prevention agenda. However, overreaching the aims of positive prevention also carries the risk of diffusing and detracting resources from the three elements that Bunnell et al. (2006b) include in their framework which do represent the core of positive prevention; behavioural interventions for individuals living with HIV infection, supporting HIV status disclosure by people living with HIV/AIDS, and aggressive screening and treatment of sexually transmitted infections among persons with HIV and their sex partners. The public health is best served by positive prevention remaining focused on HIV transmission risk reduction with infected persons delivered in concert with other essential health services.

18.4 Positive Prevention Interventions Tested in the US Clinical Trials

Several randomized controlled trials have tested the efficacy of positive prevention interventions in the United States. In each case, the interventions have demonstrated significant reductions in HIV transmission risks with diverse populations, including adolescents, women, heterosexual men, men who have sex with men, and injection drug users in clinical and community service settings (Crepaz et al., 2006; Johnson et al., 2006). Effective positive prevention interventions have incorporated social and behavioural skills for sexual communication and safer sex practices. The most effective interventions have also addressed the social contextual issues that encompass HIV transmission risk behaviours. Crepaz et al. (2006) showed that the most promising approaches to positive prevention were grounded in sound behavioural theory, focused on reducing HIV risk behaviours, were delivered by health-care providers, employed behavioural skills training, and addressed health and mental heath issues.

One positive prevention intervention designed for delivery in clinical-care settings is *Partnership for Health* (Richardson et al., 2004). This intervention uses message framing, repetition, and reinforcement during routine HIV-positive patient visits to enhance knowledge, skills, and motivations to practice safer sex. *Partnership for Health* is aimed at improving patient–provider communication about safer sex, disclosure of HIV serostatus, and HIV transmission risk reduction. The intervention is delivered at the clinic level, meaning that buy in of all clinic staff is sought and all providers within a clinic are trained. This intervention was tested in a cluster-designed randomized clinical trial (Richardson et al., 2004). The core elements of the intervention, defined as those features deemed essential to its implementation, state that (a) the intervention is delivered by providers to HIV-positive patients in HIV outpatient clinics; (b) the intervention is integrated into the clinical services as an essential component of patient care; (c) all clinic staff are trained to implement prevention counselling into standard practice; (d) posters and brochures are placed in waiting areas and used to reinforce prevention messages delivered by the provider; (e) supportive relationships are built and maintained between patients and providers; (f) providers initiate at least a 3- to 5-minute discussion during routine clinical care with patients about safer sex that focus on self-protection, partner protection, and disclosure; (g) providers incorporate good communication techniques and use of consequences-framed messages for patients engaged in high-risk sexual behaviour; (h) providers make referrals to meet patient needs; and (i) prevention messages are integrated into clinic visits so that every patient is counselled at every visit. *Partnership for Health* therefore seeks to change routine clinical practices to deliver positive prevention at the point of health-care service delivery.

Another example of a positive prevention intervention was developed and tested with adolescents. *Together Learning Choices (TLC)* is tailored for youth aged 13–29 living with HIV/AIDS (Rotheram-Borus et al., 2001). The intervention is delivered in small groups similar in style to small and focused social support groups. *TLC* is designed to help young people living with HIV/AIDS enhance their effective use of health care, decrease sexual risk behaviours and substance abuse, and improve their quality of life. The intervention emphasizes the contextual factors that influence risk behaviour and an adolescent's ability to respond effectively to stressful situations, solve problems, and effectively reach their personal goals. The intervention has five core elements: (a) to help participants develop awareness and identify feelings, thoughts and actions for healthier living; (b) teach, model, and practice four core skills regarding emotional regulation, problem solving skills, goal setting, and assertiveness; (c) reinforce positive behaviour through the use of 'thanks tokens'; (d) assist participants to identify their ideal self and motivate behaviour change; and (e) deliver sessions in highly participatory, interactive small groups. *TLC* may be a particularly critical intervention model for positive prevention in South Africa because it is tailored for the age group that encompasses one in four males and over half of females living with HIV/AIDS in South Africa (Shisana et al., 2005).

A positive prevention intervention for adults that has been widely used in the United States and has been adapted for use in South Africa is *Healthy Relationships* (Kalichman et al., 2001). *Healthy Relationships* is a five-session small group-style intervention that emphasizes building skills for managing HIV-status-disclosure decisions and skills for practicing safer sex. The intervention has three major components that are focused on decision-making skills for disclosure of HIV status to friends and family, decision-making skills for HIV-status disclosure to sex partners, and safer sex negotiation and behavioural self-management skills. The core elements of *Healthy Relationships* are: (a) defining stress and reinforcing coping skills as applied to disclosure decision making and establishing healthier and safer relationships; (b) using behavioural rehearsal and role-play modelling with feedback to teach and practice coping skills; (c) teaching decision-making skills for HIV-status disclosure; (d) providing personal feedback reports to motivate risk behaviour changes; and (e) using movie clips from popular films to set up scenarios about disclosure and risk reduction to stimulate discussions and role plays. *Partnership in Health, TLC* and *Healthy Relationships* are all part of the US CDC program for Disseminating Effective Behavioural Interventions (DEBI) programme. Descriptions of all DEBI interventions available at the Internet website http://www.effectiveinterventions.org.

18.5 Cultural Adaptation of Two Positive Prevention Interventions for Use in South Africa

In response to the pressing need for positive prevention interventions in countries hit hardest by HIV/AIDS, the Human Sciences Research Council in Cape Town South Africa has worked with the US researchers to adapt two intervention models, *Healthy Relationships* discussed above and another intervention named *Options for Health*. The adaptations of these two interventions are described briefly.

18.5.1 Healthy Relationships

The adaptation of *Healthy Relationships* occurred in formative research conducted in Botswana, Lesotho, South Africa and Swaziland. The general structure of the intervention was retained, such as its delivery in five small support group sessions in community settings. The Core Elements of the intervention model, described above, were also retained. The process adapted all of the relevant intervention materials including the manual, in-session guides, and videos used for skills training. For example, the intervention activity that requires participants to describe their perceived stress in disclosing their HIV status to various people in their lives was adapted to include locally specific relationships. The video materials used for skills building were also adapted by identifying scenes from local television shows. The videos were also converted to static displays to create storyboards for participant skills training. The storyboards met the same need as the use of videos by providing stimulus material for participants to role play and discuss challenges of disclosure and practicing safer sex. These adaptations stayed true to the intervention core elements while meeting the need to embrace local culture.

The adapted *Healthy Relationships* intervention was piloted during early 2007 in Botswana with 10 groups of people receiving HIV-related health care at wellness clinics. The project was well received and demonstrated excellent attendance. Participants provided positive feedback regarding the group activities and interactions. The researchers collected survey data from participants prior to the groups and again 1 month and 3 months after. The results were encouraging, with the *Healthy Relationships* intervention suggesting significant reductions in unprotected sexual behaviours.

18.5.2 Options for Health

This intervention model is based on an approach designed for provider delivery in health-care settings. First demonstrated efficacious in a non-randomized quasi-experimental evaluation, *Options for Health* has been adapted for use in South Africa (Fisher et al., 2006, 2008). Formative research showed that the health care and social context in which the intervention is delivered required considerable adjustment to the intervention delivery format. Whereas the original iteration of *Options for Health* in the United States had used physicians to counsel HIV-positive patients in clinical care, the South African context has a shortage of physicians whose patient rolls and severity of illness make a counselling intervention infeasible. The intervention was re-tooled for delivery by lay voluntary counselling and testing (VCT) counsellors. The intervention was also culturally adapted for health-care and social contexts of AIDS in South Africa. In the first test of the model using a randomized design, 152 HIV-positive patients at a major ARV treatment clinic in Durban participated in the intervention. The researchers found *Options for Health* was both feasible and acceptable to the patients. Delivered by counsellors, the intervention demonstrated evidence for efficacy, calling into question the necessity of burdening physicians with an added responsibility for delivering prevention counselling. The results of this pilot study were encouraging, and *Options for Health* is being tested in a major clinic-level randomized trial in Pietermaritzburg, South Africa.

18.6 Principles of Positive Prevention

Interventions designed to reduce HIV transmission risks by targeting people living with HIV/AIDS such as those described above have demonstrated consistent evidence for significant risk behaviour change. These interventions, as well as our own experience in developing, adapting, and implementing positive prevention interventions in the United States and South Africa, provide a basis for deriving the following principles of positive prevention.

18.6.1 Detect HIV Infection Early for Maximal Impact

Prior to the availability of ARV therapies, there were few good reasons for a person to want to know their HIV status. At that time it seemed reasonable that a person could just assume that everyone had HIV and to practice safer sex to avoid becoming infected and infecting others. In those days, it was common for people who were HIV infected only to learn so when they became ill. The double jeopardy of being diagnosed simultaneously with HIV and AIDS had significant psychological ramifications. Today, late diagnosis of HIV infection represents lost opportunities for life-extending medications and also for positive prevention. HIV transmission occurs during the entire course of HIV infection, not just in the early acute phases (Galletly and Pinkerton, 2008). The earlier a person knows they are infected the greater their chances of forestalling AIDS by engaging in proactive health practices as well as their stemming HIV transmission through positive prevention.

18.6.2 Effectively Intervene Within Risk Contexts

The personal, interpersonal, and social contextual factors that influence behaviour and facilitate a person becoming HIV infected do not disappear when a person becomes HIV infected. Several factors are reliable predictors of HIV transmission including gender-power imbalances, non-injection substance use, alcohol use, depression and emotional distress, maladaptive coping, non-HIV sexually transmitted infections (STIs), high levels of stigma, homelessness, and food insufficiency (Kalichman, 2005; Weiser et al., 2007). These same factors continue to influence behaviour after a person has contracted HIV. For example, Lurie et al. (2008) found that urban residence and history of alcohol consumption were independent predictors of sexual activity in people living with HIV receiving services from South African wellness clinics. In a household survey conducted in a Cape Town township, Smit et al. (2006) found a significant association between experiencing forced sex and transactional sex with depression, post-traumatic stress, and substance use. Contextual factors such as emotional distress and substance use are therefore likely to be more concentrated among people living with HIV/AIDS than they are in risk populations. The high prevalence of co-occurring contextual factors may tax health systems unless they are specifically designed to deliver multiple services for multiple diagnoses. Positive prevention interventions will only be effective to the degree to which they address the context of transmission risk behaviours.

18.6.3 Systematically Reduce Institutionalized AIDS Stigma

Positive prevention is hampered by AIDS stigmas. People infected with HIV are less likely to get tested for HIV and are less likely to seek treatment when tested positive because of AIDS stigmas (Kalichman et al. 2001). A comprehensive HIV prevention plan will include serious attention to reducing AIDS stigma and discrimination. An effective positive prevention programme must also include elements for managing the stress of experiencing AIDS stigmas and recourse for AIDS discrimination. Coping and adjustment skills can be useful in dealing with stigma encountered in friendships, families, work, religious organizations, and other facets of daily life. People with AIDS are protected from discrimination in the South African Constitution, and there are well-developed advocacy groups that can assist people with HIV protect their rights against discrimination.

18.6.4 Support HIV-Status Disclosures and Responsible Non-disclosures

HIV-status disclosure creates the interpersonal context for HIV-positive individual's sexual decision making (Galletly and Pinkerton, 2008). When a person with HIV chooses to disclose their HIV status to sex partners, they are risking rejection and other adverse social consequences. However, it is only through disclosure that sex partners can acknowledge their potential risks and negotiate safer sex. The potential for adverse reactions, however, legitimizes one's choice to not disclose HIV status to sex partners (Simbayi et al., 2007). Non-disclosure demands that the person with HIV does everything necessary to protect partners from contracting HIV. Because it is never acceptable to transmit HIV to another person under any circumstances, the person who knows they have HIV infection must make the critical decision to either disclose their status or take whatever measures are necessary to protect their partners, including refusing sex or demanding protected sex. It is therefore essential that positive prevention not become synonymous with names reporting, partner notification, or other public health initiatives that require HIV-status disclosure.

Rather, positive prevention interventions are most effective when they emphasize the advantages and disadvantages of HIV-status disclosure within a cognitive decision-making framework and support people living with HIV/AIDS in their personal disclosure decisions.

18.6.5 Debunk the Myth that Undetectable Viral Load Equals Non-infectiousness

People living with HIV/AIDS remain sexually infectious throughout the course of HIV disease. It is well established that HIV infectiousness is greatest during the early acute phase of infection, when viral burden is high and the T-helper cells are overwhelmed, and at the end stage of disease when viral burden resurges and T-helper cells are depleted (Quinn et al., 2000). People are also infectious during chronic HIV infection and the minimal ‘dose’ of HIV required for infection is not established (Galletly and Pinkerton, 2008). When people with HIV receive treatment with suppressive ARVs, their viral burden in peripheral blood is even further diminished and their infectiousness through genital fluids is likely lowered. Nevertheless, it is irresponsible to suggest that HIV-infected persons who are on a suppressive regimen of ARVs are sexually non-infectious (UNAIDS, 2008). HIV transmission dynamics are not well estimated by peripheral blood viral load. In a review of studies that examined the correspondence between HIV viral loads in blood and semen, Kalichman et al. (2008) showed an average correlation of 0.44, hardly representing a one-to-one relationship. In addition to the unreliable correspondence between viral load in blood and genital secretions, other influences such as local immunity factors in the genital tract, differential treatment resistance in the peripheral circulatory system and genital tract (Kozal et al., 2004; Ross et al., 2007), HIV that is harboured in genital tract immune cells (cell-associated virus), and host factors such as increased susceptibility from non-HIV STIs all mean that undetectable does not equal non-infectious (Cohen et al., 1997; Dyer et al., 1998). Positive prevention interventions debunk myths of non-infectiousness and inform people with HIV that ARVs can improve their health, reduce their viral burden, and should be strictly adhered to. However, positive prevention should avoid misinforming people that if they are taking ARVs and adhere to their medications they are protected against transmitting HIV to their sex partners.

18.6.6 Aggressively Detect and Treat Co-occurring STI

The success of a positive prevention intervention may very well hinge on the degree to which co-occurring STIs are controlled in the HIV-positive population. Co-occurring STIs dramatically increase HIV shedding and therefore viral burden in the genital tract, without influencing peripheral blood viral load. Studies show that with co-occurring STI, HIV viral load in semen and vaginal fluids reach concentrations that mirror those seen when a person with HIV is most infectious, namely during acute and end-stage disease (Pilcher et al., 2004). In addition to the importance of co-occurring STI on infectiousness, STIs also pose significant health threats to people living with HIV/AIDS. Bacterial infections in the context of immune suppression can be complicated and difficult to treat. Sexually transmitted viral infections such as cytomegalovirus, Epstein–Barr virus, and herpes simplex viruses can all complicate HIV infection and are related to AIDS-defining conditions. Positive prevention interventions should integrate STI symptom recognition, education, detection, and treatment.

18.6.7 Integrate Positive Prevention Interventions with Routine Clinical and Supportive Services

Positive prevention interventions can be delivered in clinical care or in community support services. In either clinical or community services, positive prevention is enhanced by an established clinical-care system. However, positive prevention that is restricted to those receiving ARVs will do too little too late for preventing HIV infections just as later initiation of ARVs decreases their potential preventive value (Diamond et al., 2005; Wilson et al., 2002). This is especially true when treatment guidelines recommend medications for people at the more advanced stages of AIDS rather than earlier stages (Auvert et al., 2004). Linking positive prevention to ARV treatment misses the opportunity to reduce HIV-transmission risks for years that a person is living with HIV and not receiving treatment. In addition to linkages to medical care, positive prevention should be linked to psychosocial services such as mental health care, substance use treatment, and support group services for people diagnosed with HIV infection. Ideally, a comprehensive approach to positive prevention will start with post-test counselling and referral services for people who test HIV positive, with a continuum of integrated supportive and clinical services where positive prevention can be sustained for the duration of an individual's HIV disease. A valuable side effect of increasing access to ARVs in South Africa has been a co-occurring increase in HIV/AIDS care and prevention services, which can then in turn support positive prevention (Levy et al., 2005).

18.7 The Promise of Positive Prevention in South Africa

Positive prevention has the potential to significantly contribute to South Africa's HIV prevention efforts. Perhaps the most important indicator of positive prevention succeeding is the level of interest the country has expressed in this approach. Scientists at the Medical Research Council and the Human Sciences Research Council have undertaken research on continued HIV-transmission risk behaviours among people living with HIV/AIDS and the adaptation of positive prevention interventions. The South African National Strategic Plan in 2007 included positive prevention as an essential element to the country's way forward.

People living with HIV/AIDS face lifelong challenges to protecting their partners from HIV and protecting themselves from co-infection with STIs and potential re-infection with HIV. Traditional communities in South Africa have strong social bonds that can be harnessed to support people in getting tested for HIV, disclosing their HIV status, and assisting people living with HIV/AIDS. Community-based VCT programmes have experienced considerable success in moving entire communities towards HIV testing in Africa (Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000). Many communities have established support groups for people affected by AIDS, often bringing together families and friends as well as those who are infected. These community support structures bode well for implementing positive prevention programs. Positive prevention is most likely to succeed in preventing HIV infections in South Africa simply because of the number of people infected with HIV. By the end of 2007 there were over 5 million people living with HIV in South Africa. With more than 10% of the national population HIV infected, and over 30% in some local communities, a critical mass of the population could potentially be engaged in positive prevention programmes (Shisana et al., 2005).

18.8 Why Positive Prevention could Fail South Africa?

Several trip wires threaten the potential success of positive prevention in South Africa. First and foremost, positive prevention must remain part of a comprehensive approach to HIV prevention and not become the only approach. South Africa has a generalized HIV epidemic, which demands a comprehensive HIV prevention plan such as that set forth in South Africa's 2007 National Strategic Plan (South African Department of Health, 2007). Diverting attention and resources to positive prevention at the cost of generalized prevention will ultimately fail because the vast majority of those infected with HIV do not know they have the virus. Given the dynamics of HIV transmission and the nature of HIV antibody tests, it is infeasible to ever test people frequently enough for a majority of infected persons to know they are infected. Interventions must stay focused on reducing HIV-transmission risks among those who may be infected and undetected as well as those at greatest risk for contracting HIV infection. Shifting attention and resources from generalized prevention interventions to positive prevention interventions can also make infected persons scapegoats for the HIV epidemic, potentially increasing AIDS stigma and therefore causing backlash against positive prevention.

Another factor that could hamper positive prevention interventions if ignored is gender and its power imbalances. The national HIV prevalence in South African men is 8% compared to 13% in women. Among 20- to 24-year-olds, 23% of women are HIV positive compared to 6% of men, and in the 25- to 29-year-old age range, 33% of women are infected compared to 12% of men. This means that positive prevention will be ineffective if it is gender neutral. Many women test HIV positive in prenatal care, and men are less likely to get tested in general. A challenge to positive prevention is to increase testing and detection of HIV among older men, who are increasingly infecting younger women. Gender power imbalances exist in every society, and they inhibit the ability of women to initiate safer sexual behaviour. Women with HIV may also be unlikely to disclose their HIV status in fear of losing their home, endangering their children, and sustaining physical harm. Positive prevention will therefore fail if it is designed as a one-size-fits-all strategy.

18.9 Conclusions

Positive prevention has great appeal in countries with significant HIV prevalence. The advent of positive prevention occurs in the context of increased access to effective HIV treatments, where large numbers of at-risk persons can be induced to get tested for HIV. Although positive prevention emerges in concert with HIV-treatment access, it cannot become completely enmeshed with HIV treatment. Simply put, positive prevention should be an early intervention strategy that starts at post-test counselling whereas ARV therapies are administered later in the HIV disease process. Positive prevention should also not detract attention or resources from generalized prevention strategies in generalized epidemics. When implemented within a comprehensive HIV prevention plan, positive prevention has the potential to avert HIV infections. However, if implemented at the expense of generalized prevention strategies in a generalized epidemic the results could be disastrous because the vast majority of infected persons in a generalized epidemic will not know they are infected. Public health policy demands a balanced approach to HIV prevention, and positive prevention should be part of any comprehensive HIV prevention plan.

Acknowledgments Preparation of this chapter was supported by grants R01-MH71164 and R01-MH74371 from the US National Institute of Mental Health (NIMH)

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Part IV
New Directions in HIV Research

Chapter 19
HIV/AIDS and Persons with Disabilities

Poul Rohleder, Leslie Swartz, Arne Henning Eide, and Hayley MacGregor

19.1 Introduction

Despite the severity of the HIV epidemic worldwide, and particularly in southern Africa, persons with disabilities have until recently been generally excluded from consideration in HIV prevention campaigns. This chapter outlines the situation with regard to HIV/AIDS as it affects persons with disabilities. The chapter will begin by first providing an outline of the experience and prevalence of disability in South Africa, highlighting how little is known about how HIV affects persons with disabilities in South Africa. An outline of some of the international literature, including a recent global survey on HIV/AIDS and disability, will be presented. With the background of findings from international studies, we shall then look at the issue of HIV/AIDS as it affects persons with disabilities in South Africa, with reference to recent research in this area. The chapter will also discuss and highlight some of the current contested issues involved with regard to HIV/AIDS as a disability and the disability grant.

19.2 Disability in South Africa

It has been estimated that 10% of the world's population are reported to be disabled and that the majority of persons reported as being disabled live in the 'developing world' (World Bank, 2004). These are also regions most affected by HIV/AIDS in the world (UNAIDS, 2007).

However, there is some contestation about the definition of disability. A medical model approach generally equates disability with a physiological or biological impairment caused by an underlying disease or genetic disorder (Johnston, 1996). Disability studies theorists have developed a social model of disability, which emphasises disability as an experience of social exclusion as a result of the physical and social barriers experienced by individuals who have impairments (Marks, 1999; Oliver, 1986, 1990). Partly because of the difficulty around reaching a consensus in defining 'disability' (McLaren et al., 2004), there is a paucity of data available as to the prevalence and experience of disability among South Africa's population.

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_19,

There are two more recent national surveys that provide some data on the prevalence of disability in South Africa: the National Population Census of 2001 (Statistics South Africa, 2005) provided some information about more serious and largely visible disabilities. The only national disability survey that has been carried out in South Africa is the Community Agency for Social Enquiry (CASE) National Baseline Disability Survey conducted for the Department of Health (Schneider et al., 1999). Data from these surveys estimated the prevalence of disability in South Africa at 5% of the population (Statistics South Africa, 2005) and 5.9% of the population (Schneider et al., 1999), respectively. These data then estimated the number of South Africans experiencing a disability as being between 2.25 million and 2.5 million, respectively. As the CASE National Baseline Disability Survey (Schneider et al., 1999) has been the only national disability survey conducted, it provides more detailed and comprehensive statistics on the experience and prevalence of disability. Table 19.1 details the prevalence of disability per type of disability as reported by the CASE National Baseline Disability Survey.

Table 19.1 Prevalence rates by type of disability

Type of disability	Prevalence rate (%)
Movement activity	2.0
Daily life activities	1.8
Seeing	1.7
Moving around	1.7
Learning	1.2
Emotional	1.1
Intellectual	1.1
Hearing	1.0
Communication	0.8

(Data taken from Schneider et al., 1999, p. 17)

The survey further indicates that the majority (58%) of the respondents reported having multiple disabilities, with almost a third of respondents reported having more than three disabilities.

Given that an estimated 10.8% of South Africa's population is HIV positive (Shisana et al., 2005), and the prevalence of disability most probably underestimated at 5–5.9%, it is probable that a considerable number of persons with disabilities are infected and affected by HIV/AIDS. However, very few prevalence studies are available which indicate how persons with disabilities are affected by HIV/AIDS. The international literature suggests that persons with disabilities are potentially at higher risk for HIV. At the time this book was about to go to press, latest prevalence of HIV/AIDS from the national survey undertaken in South Africa (Shisana et al., 2009) was released. Data from the survey study shows a prevalence of 14.1% (CI: 9.9–19.6) among persons with disabilities, compared to 10.9% (CI: 10.0–11.9) for the general population. The confidence intervals for the disabled and the general population do overlap, and the wide CI for disabled people suggests an estimate which is less accurate than would be desired. However, these data provide the first national HIV prevalence for persons with disabilities in South Africa. This is an important start in collecting further data on how persons with disabilities are affected by HIV. The findings from the survey support further research exploring the possibility that persons with disabilities may be at increased risk for HIV infection.

19.3 Persons with Disabilities and HIV Risk

In many parts of the world, the main mode of transmission of HIV is through unprotected sex. Perhaps a reason why there has been a relative lack of research on HIV/AIDS and disability is that persons with disabilities are often perceived as being asexual (Milligan and Neufeldt, 2001). However, a recent review of the international and southern African literature (Rohleder et al., 2009) indicated that persons with disabilities are at risk for HIV, and possibly at increased risk:

Poverty: Chapter 7 in this book has discussed the implications of poverty for HIV risk and transmission. Literature suggests that persons with disabilities are more likely to be underemployed and unemployed, and poorer than the general population in many countries (Elwan, 1999). Studies among people with disabilities in various southern African countries, including South Africa, have found that persons with disabilities in these regions are more likely to live in conditions of poverty relative to the general population (Eide and Loeb, 2006a, 2000b; Eide et al., 2003; Emmett, 2006; Loeb et al., 2008). Women with disabilities may be particularly disadvantaged in this regard (Hanna and Rogovsky, 1991), leading some women to turn to transactional sex and prostitution, increasing their risk for sexually transmitted diseases (McCarthy, 1993; Smith et al., 2004).

Lack of education: Persons with disabilities are more likely to have lower levels of education than persons without disabilities (Elwan, 1999). Children with disabilities may be excluded from formal education as it may be seen to be unnecessary (Groce, 2003a). In South Africa, children and adults with disabilities have been found to have received lower levels of education or no formal education than persons without disabilities (Saloojee et al., 2007; Soudien and Baxter, 2006; Statistics South Africa, 2005). This experience of poor education has implications for employability and earning of an income.

Lack of sex education and HIV education: With lower levels of education, persons with disabilities may also be excluded from general sex education. Additionally, as persons with disabilities have often been considered as being either asexual or as hypersexual, sex education has been regarded as unnecessary or potentially dangerous (Craft, 1987; Milligan and Neufeldt, 2001). Parents and carers may be resistant to providing sex education (Heyman and Huckle, 1995; Martorella and Portugues, 1998) or feel uncomfortable doing so as they feel inadequately trained (Christian et al., 2002; Howard-Barr et al., 2005; Parritt and O’Callaghan, 2000).

Lack of sex education may result in a lack of education about safe sex and unhealthy sexual behaviours. This is a risk for the general population, but the international literature suggests that persons with disabilities receive less sex education than the general population. In a review of the literature by Milligan and Neufeldt (2001), a significant number of persons with disabilities reported having received little or no information or counselling about sexuality and disability, particularly women. Many earlier studies have indicated that persons with disabilities have not received any sex education (Berman et al., 1999; Heyman and Huckle, 1995; McCabe, 1999; Pueschel and Scola, 1988). More recently, there is a recognition of the rights of persons with disabilities to live fully sexual lives, yet carers may experience a tension in attitudes towards recognising the needs of persons with disabilities to lead fully sexual lives and a need to control the sexual expression of persons with disabilities in their care (Rohleder and Swartz, 2009).

The lack of sex education may result in a lack of knowledge about HIV/AIDS and safe sex. Furthermore, Groce (2004) conducted a global survey on HIV/AIDS and disability in collaboration with the World Bank (discussed further below) and found that persons with disabilities are not being reached by general HIV prevention and education campaigns. Research conducted in various countries, including South Africa, have found low levels of knowledge about HIV/AIDS and HIV transmission among persons with disabilities (for example Bat-Chava et al., 2005; Munthali et al., 2004; Philander and Swartz, 2006; Wazakili et al., 2006; Yousafzai et al., 2004); lower than among persons without disabilities (for example Yousafzai et al., 2004). In addition, the international literature suggests that there is a lack of knowledge about modes of HIV transmission among persons with disabilities, resulting in misconceptions about how HIV is contracted (Groce et al., 2007; McCarthy, 1998; Yousafzai et al., 2004).

Lack of sex education also has implications for persons with disabilities (particularly learning disabilities) understanding about inappropriate and abusive sexual contact. For example, McCabe et al. (1994) found that knowledge about sexual abuse among persons with mild intellectual disability in Australia was less than for students without disabilities. For example, persons with intellectual disabilities were less likely than students without disabilities, to understand and know the meaning of ‘incest’ and ‘rape’. Persons with intellectual disabilities were also less sure about what to do and how to say ‘no’ to unwanted touch.

Vulnerability to sexual abuse: There is an abundance of international literature that suggests that persons with disabilities are at increased vulnerability for sexual abuse and rape. For example, Sullivan and Knutson (2000) conducted an epidemiological study in North America and reported that children with disabilities are 3.4 times more likely to be maltreated and abused (including sexual abuse) than children without disabilities. Research has found that persons with disabilities are vulnerable to abuse both in institutions (Furey et al., 1994; Sobsey and Doe, 1991) and at home (Hassouneh-Phillips and Curry, 2002; Sobsey and Doe, 1991). The high prevalence of sexual abuse has been reported for a variety of types of disabilities (Sobsey and Doe, 1991), also reported in more recent studies focusing on specific disabilities, including:

- intellectual disability (Furey et al., 1994; McCabe et al., 1994)
- autism (Mandell et al., 2005)

- physical disability (Nosek et al., 2001)
- visual impairments (Kvam, 2005)
- hearing impairments (Kvam, 2004)
- psychiatric disabilities (Collins, 2001; Collins et al., 2001)

In studies conducted in South Africa, including studies on the abuse of people with disabilities, it was found that in most cases the perpetrators of sexual abuse and rape were known to the victim (Dickman and Roux, 2005; Kelly et al., 2002).

There are various reasons that have been put forward as to the increased vulnerability to sexual abuse of persons with disabilities, including their physical vulnerability to attack, the experience of many of being dependent on others for care, as well as perpetrators' perception that they are less likely to be discovered or the survivors of abuse will not be believed (Nosek et al., 2001). Poverty may be regarded as an important cause as low levels of education, employment, income, and information reduce individuals' resistance against exploitation.

Substance abuse and sexual risk behaviours: Substance use, particularly when used in dating situations or during sexual intercourse, may increase the possibility of individuals engaging in unsafe sexual practices, as sexual inhibitions are reduced as an effect of substances (see Chapter 2 this volume). Persons with disabilities are not excluded from this, with research indicating that some persons with disabilities have reported using substances during sexual intercourse (Blanchett, 2000; Kelly et al., 1992). Substance abuse has been argued to be a serious issue for persons with disabilities (Bachman et al., 2004), as alcohol and drugs may often be used as a means to cope with the frustrations of living with a disability (Njoki et al., 2007). Some studies have suggested that persons with disabilities may be at increased risk for using substances, with some research reporting higher rates of substance use among persons with disabilities than persons without disabilities (Blum et al., 2001; Li and Ford, 1998; Peinkofer, 1994).

Another risk factor for HIV is the engagement in unprotected sex. A number of studies have included an investigation of unsafe sexual practices among persons with disabilities, and indicate that, as with persons without disabilities, many persons with disabilities do not always wear condoms during sexual intercourse (Blanchett, 2000; Chuang and Atkinson, 1996; Cook, 2000; Jackson and Wadley, 1999; Nosek et al., 2001). This has also been found in studies in African countries. For example, in Malawi (Munthali et al., 2004) and in Uganda (Mulindwa, 2002), the majority of persons with disabilities participating in these studies reported not always using a condom during sex.

Stigma and social isolation: As discussed in Chapter 8, stigma creates a significant barrier to accessing HIV prevention education, testing and treatment. This may be compounded for persons with disabilities as they face additional stigma around their disability. Stigma around disability may result in low sexual self-esteem among men and women with disabilities (White et al., 1992; White et al., 1993). A finding also reported in a South African study among adolescents with physical disabilities (Potgieter and Khan, 2005). This may result in making it difficult for a person with disability to negotiate safe sex or may result in a reluctance to reject sexual relationships that may be risky (Becker et al. 1997; Yousafzai and Edwards, 2004).

For example, in a South African study, Wazakili and colleagues (2006) found that the need to be accepted and loved among youth with physical disabilities was more important than concerns around practising safe sex. Adolescent boys with visual impairments, living in KwaZulu Natal, reported to a researcher that because they were unlikely to be attractive as sexual partners because of their impairments, they would probably engage in sexual intercourse under any circumstances for fear of not having many opportunities to have sex (Joseph, 2006).

Similarly, women with disabilities may often be perceived as pitiful and thus fortunate to have any man wanting to 'marry, date, or have sex with them' (Beck-Massey, 1999; p. 270). In a study on sexual abuse and violence against disabled women in Malawi (Kvam and Braathen, 2008), it was found that disabled women in many cases entered into a relationship with a man as this was regarded as 'their only chance'. When they became pregnant, the man would in many cases disappear. Key informants discussing HIV issues for South Africans with visual impairment made similar points about the particular vulnerability of disabled women (Philander and Swartz, 2006). Stories are told of women with visual impairments who enter into transactional sexual arrangements with taxi drivers so that they can have access to safe transport and have some control over their sexual lives – they are perceived as 'easy prey' for sexual predators.

Persons with disabilities, because of the myth of asexuality, may also be perceived as virgins, putting them at risk for sexual abuse and rape, in contexts where beliefs that HIV and other sexually transmitted diseases can be gotten rid of by having sex with a virgin (Groce and Trasi, 2004). The 'virgin cleansing' hypothesis as an explanation for rape of people who are perceived to be virgins is not uncontroversial amongst social scientists (Jewkes et al., 2002; Leclerc-Madlala, 2001). Groce and Trasi (2004) show that there is a long, and international, history of abuse of people perceived to be virgins, including disabled people, for cleansing purposes – a practice which long predates the HIV/AIDS epidemic.

The question has also been raised as to the extent to which the focus on needing to 'normalise' HIV (as a way of combating the stigma associated with it) may contribute to the epidemic being driven further underground for persons with disabilities, paradoxically increasing their risk for HIV infection (Swartz et al., 2006). This issue as well as the intersection of HIV-related stigma and disability stigma remains relatively unexplored.

Barriers to accessing health-care services: Persons with disabilities may experience a variety of physical and attitudinal barriers to accessing health-care services, including HIV-related health care. Physical barriers, for example, would include facilities that are not accessible for wheelchair users (Anderson and Kitchin, 2000; Becker et al., 1997), or inaccessible to persons with sensory disabilities (Anderson and Kitchin, 2000). Attitudinal barriers would include negative attitudes from health-care staff, who may perceive persons with disabilities as not in need of sexual health-care services (Becker et al., 1997; Nosek et al., 2001; Welner, 1999). This has been reported as the experience for some women with physical disabilities in South Africa attending family-planning clinics (Mgwili and Watermeyer, 2006). A study on environmental barriers experienced by disabled people in the Eastern and Western Cape provinces of South Africa clearly demonstrated the relevance and magnitude of barriers related to both support and attitudes from health workers (Maart et al., 2007). This may impact on the accessibility of health-care facilities where HIV testing and counselling is available, although this has not yet been researched in South Africa. There may also be barriers to accessing health care as a result of carers and family attitudes and perceptions; for example, in a study in India it was found that the families and carers of persons with disabilities may not always recognise the potential risk for HIV for persons with disabilities, and thus their need for HIV prevention education (Morrow et al., 2007).

19.4 The Global HIV/AIDS and Disability Survey

Yale University in partnership with the World Bank have recently conducted a global survey on HIV/AIDS and persons with disabilities (Groce, 2003b, 2004, 2005). The survey made use of a questionnaire, which was sent to 2,800 organisations worldwide, and made available on various electronic newsletters and websites of various organisations. It is estimated that the survey was eventually reached by approximately 5,000–6,000 organisations across the world (Groce, 2004). Responses came from 57 different countries from all continents, although the response rate was reported as not being very high (Groce, 2004).

The survey study found that persons with disabilities across the world were reported as being at significant risk for HIV infection, with the perception being that risk factors for HIV infection being increased for persons with disabilities. These risk factors have already been discussed above. The survey further reported that persons with disabilities were not being reached by general HIV prevention campaigns, primarily because information is inaccessible to persons with disabilities, either because the information is presented and delivered in a format that is not accessible to specific disabilities, or because they lack the education to be fully able to obtain and process the relevant information. For example, written information is not accessible to those persons with visual disabilities and radio campaigns about HIV prevention are not reached by persons with hearing disabilities.

19.5 HIV/AIDS and Persons with Disabilities in South Africa

Recently published data from South Africa, suggests that the prevalence of HIV/AIDS among persons with disabilities is higher than that of the general population (Shisana et al., 2009). However, although there is some research about broader issues of sexual health and sexuality of persons with disabilities, there is a paucity of published research about HIV/AIDS. Research among youth with physical disabilities (Wazakili et al., 2006) and key informants working with persons with visual impairments (Philander and Swartz, 2006) suggest that there is limited knowledge about HIV/AIDS. In response to this lack of knowledge, the authors of this chapter have been variously involved in recent research looking at HIV/AIDS as it affects persons with disabilities.

A recent national survey was conducted of disability organisations and schools for children, adolescents and youth with disabilities (Rohleder, 2008; Rohleder et al., in press). The survey made use of a modified version of the questionnaire used by the Yale University/World Bank Global Survey on HIV/AIDS and Disability (Groce, 2004). The survey was sent to 601 disability organisations and schools across South Africa. Similar to the global survey study, the overall response rate was not good, although a response rate of 57% was achieved from national disability organisations (national representative bodies for persons with disabilities in South Africa). Part of the challenge of conducting survey research of this nature is that surveys are known to attract a relatively low response rate, although additional measures can be taken to improve response rates (Goodwin, 2003). Response rate may be affected by the level of resources within an organisation. This may reflect a better response rate for national disability organisations, which are generally better resourced and funded than smaller localised organisations and schools. Another factor to consider is the possibility that many organisations who work with persons with disabilities may not recognise the risk for HIV, and thus not see this as a relevant issue for them or the persons with disabilities they work with. This is reflected, for example, in the responses given by two organisations when declining participation in the survey study stating the reason as:

> We are a school for mentally disabled learners and most of the survey is not applicable to us.
>
> Our people are not supposed to have sex . . . they are sterilized
> (Rohleder, 2008, p. 92)

From the responses to the survey questionnaire given by national disability organisations (Rohleder, et al., in press), all felt that persons with disabilities were at risk for HIV, with half stating that they thought there was an increased risk for HIV. However, no organisation had any statistics regarding HIV prevalence among persons with disabilities. The most commonly given reason for risk of HIV was that persons with disabilities are vulnerable to sexual abuse and rape. Most organisations were concerned about HIV and were involved in some way in providing HIV prevention information and education for persons with disabilities. This took the form of workshops or providing of information. Few had established a dedicated HIV prevention programme.

The majority of organisations felt that persons with disabilities were excluded from general HIV campaigns and were receiving less information about HIV prevention than persons without disabilities. For youth with disabilities attending schools, some HIV prevention is taught as part of the national curriculum for schools, in a subject on general health care. However, a recent evaluation of this HIV education (Visser et al., 2004) indicated that there was inconsistency in the provision of the programme across schools, with some schools finding it difficult to prioritise HIV prevention education in conditions of poor resources. Qualitative descriptions of HIV prevention education at schools provided by staff (Rohleder,

2008) reflected an inconsistency as to the quantity and quality of the education given, ranging from the provision of basic, periodic information about HIV to more regular educational sessions. Teachers also reported some challenges faced in providing HIV prevention for persons with disabilities, with having to use educational materials which were not always suitable for students with particular disabilities (Rohleder, 2008; Rohleder and Swartz, 2009). Furthermore, staff who were involved in providing sex education and HIV prevention education for youth with intellectual (learning) disabilities at times struggled with what they regarded as the right for persons with disabilities to lead fully sexual lives, and the need to restrict behaviour which was perceived as immoral, inappropriate or potentially harmful (Rohleder, 2008; Rohleder and Swartz, 2009). From this work it is clear then that persons with disabilities in South Africa are understood to be at risk for HIV, and recent prevalence data suggests they are at increased risk, but are excluded from general HIV prevention campaigns and in instances where HIV prevention education is provided there is no evaluation as to its appropriateness, quality and effectiveness.

Further research is currently being conducted by some of the authors of this chapter in collaboration with colleagues from Stellenbosch University, the Human Sciences Research Council in South Africa (HSRC), SINTEF Health Research in Norway, South African National AIDS Council and Disabled People South Africa. This is a study of knowledge, attitudes and practices of people with disabilities in relation to HIV and AIDS and sexuality; and an assessment of access to voluntary counselling and testing services (VCT) by people with disabilities.

19.6 HIV/AIDS and the Disability Grant

The Disability Grant in South Africa was introduced a few years after Independence and has gradually been expanded over the years. A study in the Eastern and Western Cape Provinces has shown that in 2006 the grant was received by the majority of men and women with disabilities (Jelsma et al., 2008). Many eligible, however, still did not receive it for various reasons, indicating in particular, knowledge and information among disabled themselves and the gate-keeping role of the medical doctors as important explanatory factors. In another publication from the same study, Loeb et al. (2008) argues that the disability grant had contributed to improve the financial situation of households with a disabled family member, but that other measures of poverty remain divisive for those with disabilities. The disability grant can be regarded as one important step to reduce poverty among individuals with disabilities, although its relationship to improved access to health services needs to be studied further.

In South Africa, the definition of disability for the purpose of allocating disability grants has been a contested area, and debate appears in fact to have been stimulated by a consideration of the relationship between HIV/AIDS and disability.[1] Much of the argument has postulated a difference between those who are HIV positive and those persons with so-called ‘visible’ or ‘physical’ disability. When this separation is made from within the disability sector, it has often been linked to an assumption that a hierarchy exists that can be mapped according to an idea of the nature of disability. This hierarchy is then translated into an assumption of greater legitimacy with respect to grant receipt (For a more detailed justification of this argument using the example of persons with diagnosed mental illness, see MacGregor, 2006). In fact, as the findings discussed in this chapter indicate, this is an artificial boundary to draw and especially given the likelihood of increased vulnerability of persons with disability to HIV/AIDS. In addition, infection by HIV can cause a range of severe impairments, both mental and other.

Yet the politics of disability and HIV/AIDS has been complex, given the focus around access to resources such as a grant and free state health care (available for persons with disability since 2004). A significantly larger than predicted increase in the uptake of disability grants in 2004 was blamed in part, within government departments and in popular and media interpretations, on an increase in HIV-positive people and the overly liberal allocation of grants to such and other chronic illnesses. The disability sector appears to have objected to this characterisation. Undoubtedly, it can be perceived to add additional stigma to an already marginalised identity. Anxiety about resources also appears to have played a part in such disquiet: an anecdotal example cites anxiety in the disability sector when fewer wheelchairs were available on account of their allocation to the AIDS sick (personal communication, Margie Schneider at the Human Sciences Research Council, October 2008). In fact, a separating line has also been drawn from the other side, for example, the National Association of People with AIDS (NAPWA) has also pointed out that being HIV positive does not mean their members are ‘disabled’. However, this lobby group has argued strongly in consultations about the disability grant for access to a permanent disability grant and have recently protested to raise attention to their call for social security provision for HIV/AIDS to be addressed specifically by government.

This position is also currently being pursued by activist groups such as the AIDS Law Project and the Treatment Action Campaign, although through the structures of the South African National Aids Council (SANAC). There is also talk in the national Department of Social Development of a need for a specific chronic illness benefit, not only limited to those with HIV/AIDS. A new Harmonised Assessment Tool has been developed for the Departments of Social Development and Health (with input

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[1] The observations presented in this section are based upon interviews conducted with government and civil society stakeholders in South Africa by Hayley MacGregor during a period of research on grants in October 2006.

from the Human Sciences Research Council) as an instrument for the assessment of disability for the purposes of grant allocation and access to free health care. If this new tool were to be implemented, it would result in a narrowing of the definition of disability to one limited to an assessment of the degree of 'activity limitation'. There is general agreement that eligibility hinged on this criterion would in future exclude from grant receipt many people who currently draw grants for a range of chronic illnesses. In the case of HIV/AIDS, the condition might lead to activity limitation, but this would not necessarily be the case. The suggestion thus of a separate chronic illness benefit is based on a rationale that a different kind of state payment should provide for anyone with a confirmed diagnosis from a specified group of illnesses. This resource would enable them to access transport to attend clinic services, and sustain adequate nutrition or fulfil any special dietary requirements, thus assisting to halt the progression of disease and associated activity limitation. Such a benefit could thus be seen to have a 'prophylactic' rationale. Prior to the national roll-out of antiretrovirals, persons living with HIV/AIDS were reportedly using the disability grant to pay for medications (Natrrass, 2004).

Members of the SANAC working group currently developing recommendations for such a provision are particularly focused on the issues related to people with HIV/AIDS and have been documenting the difficulties caused by the lack of standardised criteria for the allocation of the current disability grant for HIV/AIDS. The allocation of temporary grants, and the suffering due to their withdrawal when health improves, has received particular attention as this issue raises concerns about non-adherence to treatment regimes. As Swartz et al. (2006) have pointed out, a person living with HIV who may be unable to work because of his illness may be awarded a disability grant. Once their health improves as a result of antiretrovirals, they may be able to work and thus not be eligible for the disability grant; a serious concern given the high rates of unemployment in South Africa. The civil society stakeholders in the SANAC process have focussed also on tuberculosis and the ways in which a permanent chronic illness benefit could aid treatment adherence.

It is not clear at this point how the issues around social security and disability and social security and HIV/AIDS will evolve in the coming months. This chapter was completed at a time of considerable political turmoil in South Africa, and with an upcoming general election. However, it is clear that the relationship between HIV/AIDS and disability is complex and the perception of doubled stigma encourages both AIDS activist organisations and the disability sector to favour more specific, dedicated grants. However, the concept of a benefit dedicated entirely to HIV/AIDS and the associated condition of tuberculosis has raised concerns on equity grounds. The context in South Africa of severe economic need further complicates the situation of grant provision. Given widespread poverty and unemployment, the issue of benefits for those with chronic illnesses who look well is not uncomplicated. These debates about notions of 'disability' have thus also stimulated the ongoing discussion about a revision of the broader social security net in South Africa and the possible introduction of a Basic Income Grant.

19.7 Conclusions

As this chapter highlights, there is a serious need to consider how HIV/AIDS affects persons with disabilities and the issues involved with the disabling aspects of HIV/AIDS. It is surprising that little systematic research has been conducted in this area, particularly in South Africa, although, thanks due in part to the work of Nora Groce and the global survey on HIV/AIDS and disability, more attention is currently being given to the issues. However, there is a lot that we still need to know and clarify. The literature and recent prevalence data suggests that persons with disabilities may be at increased risk for HIV, but we need to know more. Research in this area presents some challenges, for example with regards ethical issues around consent, confidentiality and the potential to stigmatise. around consent, confidentiality and the potential to stigmatise. Any research involving persons with disabilities should be developed and conducted in partnership with the disability sector.

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Chapter 20
HIV/Aids and the Prison System

Lukas Muntingh and Chris Tapscott

20.1 Introduction

In this chapter a review is undertaken of how the prison system has experienced the effect of HIV and AIDS. In many regards, the negative consequences of HIV and AIDS were the results of a poor and at times belligerent response from government to the epidemic. While human rights activists drew attention to the plight of prisoners resulting in significant advances, the impact of the epidemic on the staff of the Department of Correctional Services (DCS) have been largely ignored. The two are inextricably linked in the daily operations of a prison. The chapter deals first with prisoners and HIV and AIDS and focuses on risk, safety and responses by the DCS. Particular attention is given to sexual violence in prisons. The second part of the chapter deals with the effect of HIV and AIDS on officials of DCS, the problems in this regard and makes recommendations regarding remedial steps.

20.2 Inmates

20.2.1 Prisoners Are Part of the Community

Annually an estimated 360,000 people move through South Africa's prison system (Office of the Inspecting Judge, 2005). The bulk of them will spend several months in prison as unsentenced prisoners (Office of the Inspecting Judge, 2008). Only half of the awaiting trial prisoners will ultimately continue to trial as the rest will be released because their cases have either been withdrawn or struck from the roll (Karth et al., 2008). In such instances, their detention was without purpose, but the combination of poor conditions of detention, sexual abuse, violence and substance abuse leads to prisons being 'incubators' for HIV, hepatitis C and tuberculosis for all prisoners (UNAIDS, 2006). Most prisoners are from poor communities, male (98%) and black (98%), and 40% are under the age of 25 years (Office of the Inspecting Judge, 2008). Prisoners, furthermore, are more likely to come from high-risk communities with higher rates of teenage pregnancy and STIs than the general population (Clear, 2007; Muntingh,2008a; Thomas and Torrone, 2006).

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_20,

20.2.2 Reaching High-Risk Demographics of the Prison Population

20.2.2.1 Imprisonment, Health Care and Early Mortality

In 2004, 1,689 people are recorded as having died in prison due to natural causes in South Africa, the highest for any year (Office of the Inspecting Judge, 2008). Imprisonment has a direct health impact on individuals as it is traumatic in itself (as discussed by Gonin, 1999), but in a prison system unable to provide proper health care, the effect can be devastating. The Judical Inspectorate for Prisons reports that 37% of all natural deaths occur within the first year of imprisonment, a further 15% in the following year, and 10% in the third year (Office of the Inspecting Judge, 2007). In total, 62% of deaths due to natural causes occur in the first 3 years of imprisonment. The conclusion is drawn that people are admitted to prisons with a compromised health status (not only arising from HIV infection but also as a consequence of asthma, tuberculosis, diabetes, and other illnesses). Due to inadequate health-care services in the prisons, superficial health status examinations, and unhealthy detention conditions, the state of health of many prisoners deteriorates rapidly leading to their death. Health-care facilities in prisons are commonly woefully inadequate (Department of Correctional Services, 2008a; Office of the Inspecting Judge, 2007; Sifunda et al., 2006).

20.2.2.2 HIV Prevalence

In 2006, the DCS commissioned an HIV/AIDS and syphilis prevalence survey amongst staff and sentenced prisoners (Department of Correctional Services, 2008b). Despite some methodological shortcomings, the survey reports results that are, for the first time, accepted and endorsed by the DCS. The survey found that the HIV-infection rate amongst the sentenced prison population is 19.8%, slightly above the national infection rate of 16.25% (Department of Correctional Services, 2008b). Of the prisoners who tested HIV positive, nearly 60% were below the age of 35 years and the highest infection rate (46.6%) was in the 26- to 35-year age category. The results of the 2006 survey indicate that the HIV infection rate in the prison population is much closer to the infection rate in the general population and earlier estimates (Goyer and Gow, 2001) that as many as 60% of prisoners may be HIV positive are not supported by the survey results. This lower-than-expected rate may suggest that the primary mode of infection is through unsafe sex prior to entering prison, rather than sexual contact within prison (UNODC, 2006).

20.2.2.3 Access to ARV

Access to antiretroviral medication (ARV) remains a contentious issue in the light of litigation embarked upon by a group of prisoners in 2005; *EN and Others* v *Government of the RSA and Others* (2007). After much wrangling, the DCS commenced with setting up accredited antiretroviral therapy (ART) centres and by 2008 there were 12 (Department of Correctional Services, 2008a). Although there was a reduction in the mortality rate of prisoners due to natural causes from 2006–2007 to 2007–2008 from 8.3 deaths per 1,000 prisoners to 7.0 (Department of Correctional Services, 2008a), it must be assumed that given the small number of accredited ART centres, access to ART for qualifying prisoners remains a challenge. Given the period (described above) during which prisoner mortality is highest, it follows that time is of the essence in ensuring that HIV-positive prisoners are tested and counselled and that qualifying prisoners are given access to an accredited ART site. During 2007–2008 a total of 4,294 prisoners received ART (Department of Correctional Services, 2008a).

Access to ARV is, however, not only curtailed by the limited number of accredited sites, but perceptions amongst prisoners regarding stigmatisation present a further obstacle. Sifunda et al. (2006) report that 'a positive HIV test posed potential stigmatisation as inmates would immediately have to start receiving a special diet of extra fruits, which are collected from health workers' (p. 2305). The special diet is apparently commonly referred to as the 'Aids diet'. The fear of stigmatisation was also observed in establishing a support group for HIV-positive women at a South African prison and at least one woman left the group after the first session out of fear that she may be stigmatised and discriminated against by other prisoners (Rohleder, 2008). Officials similarly may hold stigmatising views (Tapscott, 2008). It is unlikely that officials who harbour such views would provide the necessary personal leadership and guidance at operational level to prisoners.

20.2.3 High-Risk Behaviours

Little is known about high-risk behaviours in South African prisons. Research on HIV/AIDS in prisons elsewhere has focussed on issues that are not necessarily problems in South African prisons, such as intravenous drug usage (Dolan et al., 2007). Research from the Africa continent on transmission provides some insight. In Zambia, it was found that 4–16% of prisoners reported sex with other men, 17% reported tattooing during imprisonment, 63% reported sharing razor blades while only 2% had injected drugs while in prison (Simooya, and Sanjobo, 2005).

Tattooing is extremely common in South Africa's prisons, especially amongst gang members, and is mostly done with makeshift equipment and materials (e.g. shoe polish) by amateur tattoo artists. Gang tattoos form an integral part of gang culture, not only indicating gang membership but also rank in the gang, especially the so-called number gangs (Minnie et al., 2002). According to DCS Departmental Orders, newly admitted prisoners are to be advised about the 'dangers of tattooing' and then reminded of this on a monthly basis by section heads (B-Order 1, Chapter 1, para. 19.2 (e) and B-Order 1, Chapter 22, para. 1.2 (b)). The DCS *Framework on Managing HIV/Aids* does not provide any further guidance and merely states that programmes to address tattooing need to be developed and implemented (Department of Correctional Services, 2007b, p. 10). Whether prisoners of their own accord take any precautionary measures to prevent HIV infection when tattooing, is unknown. The recently released *Guidelines for the Prevention and Treatment of HIV in Arrested, Detained and Sentenced Persons* advise that disinfectant (e.g. bleach) should be available to prisoners to clean needles (Bulbulia and Berger, 2008). It should also be added that in prisons where bleach is available, no serious safety or security concerns were reported and once it was available and part of prison life, initial security concerns abated (UNAIDS, 2007).

While the *sharing of shaving blades* has been reported as extremely common in other African countries (Simooya and Sanjobo, 2005), this does not appear, based on available information, to be the case in South Africa. The use of razor blades for shaving is reportedly managed by providing male sentenced prisoners with razors on a regular basis and in a controlled manner.[1] Whether the same system is used with unsentenced prisoners is unknown. The strict controls in place around shaving blades for sentenced prisoners is in all likelihood a function of security protocols and not the prevention HIV transmission.

Drug and substance abusers may end up in prison for property or violent offences; non-users may start using drugs inside prison, while imprisonment may provide the opportunity for others to stop using drugs, or change their substance of choice. Only a small proportion (2.3% in January 2008) of the prison population had been incarcerated for drug-related offences, but substance abuse is extremely common prior to and during imprisonment (Muntingh, 2008a).

The intravenous use of drugs remains, fortunately, fairly rare in South Africa, and smoking, snorting and oral administration are the dominant modes of drug consumption (SACENDU, 2007). On the other hand, clear increases in drug use, and the use of particularly addictive drugs, have been observed at monitored treatment centres. The appeal of methamphetamine to a younger age cohort and the increased use of heroin are cause for concern (SACENDU, 2007).

20.2.4 Sex and Sexual Violence in Prisons

Given that HIV is primarily transmitted from one individual to another through sexual contact, sex in prisons amongst males requires particular attention. It should furthermore be added that it was only in 2008 that the DCS acknowledged in a public forum that sexual violence was a problem in the prison system, reflecting a reluctance to discuss this issue (along with others, including gang membership). It is generally accepted that sex between (male) prisoners is common.

Sex in prisons appears to exist on a continuum of consent and coercion, and with consent often manufactured under the threat of coercion. First-time prisoners are often tricked and manipulated into providing sex in exchange for cigarettes, protection or other commodities. Untangling consent and coercion, not only in relation to a particular incident but in the broader context of sex in prisons raises complex

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[1] Telephonic interview with Director: Office of the Inspecting Judge of Prisons, 27 November 2008.

questions with respect to law enforcement, protecting victims and prosecuting perpetrators.

Three modes of sexual practices have been identified. The first and seemingly most prevalent mode relates to sex inside power-defined 'prison marriages' (Gear and Ngubeni, 2002). This is because prison marriages reportedly provides the 'most common site of sexual interaction between prisoners' and is 'sanctioned and institutionalized by inmate power structures' (Gear and Ngubeni, 2002, p. 10). Sex in the form commonly referred to as *unchincha ipondo* (to exchange a pound) is a second mode, where each participant in the sex act exchanges sexual favours with the other. This mode contrasts sharply with the first mode in the sense that here the sexual activity is mutual and consensual (Gear and Ngubeni, 2002) and is often between lower ranking gangsters, 'wives', and non-gangsters who exchange sexual favours with each other for gratification. The third mode is similar to the second and thus also consensual, but relates more to matters where participants share feelings of love, care or affection towards each other. It differs from *unchincha ipondo* in the sense that the former does not necessarily involve passionate feelings and is aimed more at sexual gratification (Gear and Ngubeni, 2002).

The exact extent of sexual assaults and coerced sexual relations in prisons is unknown and will probably never be known as it is shrouded in secrecy. Research has, however, described in startling detail the complex relations taking place as well as the involvement of officials in sex trade (Gear and Ngubeni, 2002). Widespread sexual assault involving anal penetration and other forms of coercive sex have been described in a number of studies (Gear and Ngubeni, 2002; Harvey, 2002; Mashabela, 2003). An important finding in respect of the prevalence of coercive sexual relations was that one-third of a group of prisoners at a juvenile facility admitted to having had coercive sex with a person (inside or outside of prison) (Gear, 2007).[2] Of the same sample, 2% of respondents stated that they had had sex at that prison out of fear, and a further 2% said that they had been pressured into having a long-term relationship. A similar proportion said that they had been given food, cigarettes, or protection in exchange for sex. Research elsewhere indicates that male rape in custodial settings occurs with frightening frequency and that between 7% and 12% of respondents in several surveys reported being raped an average of nine times (Robertson, 2003).

Rape is the most egregious form of sexual violence in prisons and is generally open, condoned, often encouraged and usually involves repeated assaults after the initial rape (Mashabela, 2003). The victim is forced into a system of 'perpetual abuse' and must therefore unwillingly devote his existence to servicing his rapists for years after the first violation (Knowles, 2000). Prison rape may take many forms and the most brutal form is gang rape. Anal penetration, oral penetration and thigh sex are dominantly practiced. Insertion of objects into the anus often occurs during

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[2] It should be noted that Barberton Youth Correctional Centre, where this research was done, is for sentenced prisoners aged 18–21 years and findings can therefore not be generalised to the general prison population.

the rape (Harvey, 2002). Anecdotally it is known that new prisoners are often identified at court holding cells as potential victims prior to arriving at prison and are coerced to smuggle drugs into the prisons that are forced into their rectums; a practice known as a 'poke' (DCS Workshop on Sexual Violence, held at Pollsmoor 2008). Once a prisoner has been victimised in this manner, he is reportedly a known target for further sexual victimisation. There have also been reports of deliberate HIV infections, known as a 'slow puncture', meted out by gang members as punishment against other members (Maclennan, 2002).

The act of rape plays an important role in structuring prison society, and for creating the hierarchy of 'manliness' in which prisoners function (Harvey, 2002). Senior gang members gain financially, sexually, psychologically, as well as politically, through the sexual violation of other prisoners (Knowles, 2000). Prison officials are also known to use the threat of male rape to 'divert prison aggression, destroy potential leaders, and intimidate prisoners into becoming informers' (Knowles, 2000, p. 275). While individual perpetrators and corrupt officials are also implicated, gangs are to a large extent the architects and functionaries of institutionalised sexual violence that permeates prison life. By intertwining rape and coerced sex with initiation rituals and hierarchical structures (Steinberg, 2004), gangs effectively create and control sex as a 'commodity within the prison economy' (Gear and Ngubeni, 2002, p. 19).

The Jali Commission was left shocked at the attitude of prison officials in preventing and dealing with sexual assault cases (Report of the Jali Commission, 2005) and drew on the notion of 'deliberate indifference' to describe this (*Farmer v Brennan*, U.S. 1994). The notion of 'deliberate indifference' on the part of officials finds expression in views that rape is 'part of the punishment', 'rape is part of prison life', and that 'they deserve it'. The Jali Commission also found evidence of officials actively involved in trafficking of prisoners for sex (Gear and Ngubeni, 2002; Van den Berg, 2007). While the DCS has made significant advances in addressing grand corruption, rooting out operational-level corruption, such as trafficking in prisoners, has not been a priority and it is uncertain how prevalent the problem is, but that it happens is certain (Muntingh, 2008b).

Male rape and other forms of coercive sexual relations do not occur as isolated incidents but are profile driven. It is possible to identify, with a reasonable level of accuracy, those individual prisoners most at risk. First-time, non-violent offenders often lack the experience and 'street smart' to protect themselves and they are therefore disproportionally subjected to sexual assaults in detention facilities (Stop Prisoner Rape, 2006). Overcrowded conditions and inadequate facilities increase the chances of these detainees being placed with violent predatory offenders. Younger persons aged 13–18 years are at a particularly high risk when detained with adults. Gay and transgender individuals are perhaps at the highest risk of sexual assault.

Multiple factors facilitate the prevalence of sexual violence in prisons. Critical among them is the general lack of supervision of prisoners by staff due to overcrowding, high warder to prisoner ratios and long lock-up periods. Further, the DCS does not currently have a sexual violence prevention policy in place either, and officials at operational level are thus uncertain about how to prevent sexual violence, and how to respond to reports of sexual violence; assuming that they are willing to do so (Law Society of South Africa, 2004). Furthermore, as noted above, it was only in 2008 that the DCS acknowledged that sexual violence in prisons is a problem, but whether this acknowledgment has filtered down to operational level is uncertain. The reporting of incidents is furthermore undermined by a 'culture of silence' subscribed to by both prisoners and staff. Prisoners are reluctant to report rapes due to fears of reprisal. Corruption, official indifference, poor response time, lack of knowledge by staff on how to respond, inadequate reporting mechanisms, and collusion between officials and gang leaders further aggravate the problem. Access to medical staff may also be restricted due to the shortage of nurses in the department. The sporadic absence of Independent Prison Visitors (IPVs) at certain prisons prevents victims from using this reporting route.[3] The DCS internal complaints mechanism for prisoners (the G365 register) has also been shown as an ineffective mechanism for dealing with serious and sensitive complaints, and prisoners generally lack confidence in it (Law Society of South Africa, 2004).

A more positive and recent development was the enactment in legislation of a gender-neutral definition of rape and other forms of coercive sexual relations (South Africa's *Criminal Law (Sexual Offences and Related Matters) Amendment Act,* 2007). Although more research needs to be done to understand the exact implications of this legislation for the DCS, it should result in improved management and security practices in prisons if the Department is indeed serious about reducing the extent of sexual violence in prisons. Reducing sexual violence through prevention as opposed to law enforcement should, however, be the focus of the DCS.

20.2.5 Managing People Entering the Prison System and People on Parole and Supervision

For many prisoners, the DCS health-care system will be their first contact with proper medical attention (Sifunda et al, 2006), even though the prison health-care system leaves much to be desired. The high turnover of prisoners creates significant logistical challenges with respect to health care for the DCS, and it must be assumed that in the case of unsentenced prisoners only the most basic and urgent health-care services are rendered. Once inside prison, access to health-care services is also restricted by security staff as a prisoner seeking medical attention first requires permission at this level to see a doctor or nurse (Sifunda et al 2006). These restrictions are motivated by security concerns in an attempt to prevent that prisoners misuse access to health care in order to move between sections and possibly engage in illegal activities, such as smuggling contraband.

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[3] In November 2007, 47% of Independent Prison Visitor (IPV) positions were vacant and by November 2008, 23% of these positions were vacant (Telephonic interview with Director of the Office of the Inspecting Judge, 27 November 2008).

It was also noted above that health examinations of new admissions appear to be undertaken in a superficial manner and unless the admitted prisoner reports specific information regarding his/her medical history, it is unlikely that it will be detected and followed-up. In the case of sentenced prisoners, especially those serving longer sentences, a more comprehensive approach can be followed, although short-term sentenced prisoners may also be excluded from more comprehensive services. Little is known about how released prisoners are linked to the public health-care system and according to legislation the DCS has limited responsibility, they are only obliged to provide such care or enable access to care in the recovery from an injury sustained while imprisoned (Correctional Services Regulations, No. 26626, 12a).

The DCS 'Framework for the Implementation of Comprehensive HIV and Aids Programme and Services for Offenders and Personnel' (the Framework) does not contain an explicit and specific objective relating to the health-care management of released or about-to-be-released prisoners, especially those being released under community corrections (Department of Correctional Services, 2007b). The reference to 'offenders' in the title of the Framework is not incidental as it excludes un-convicted prisoners. However, a sentenced offender also includes a person sentenced to correctional supervision. Only one objective in the Framework vaguely implies facilitating post-release access to ART: '[To] facilitate access for offenders to antiretroviral treatment by referring them to the nearest accredited public health facility or an internal accredited Correctional Centre' (Department of Correctional Services, 2007b, p. 13). Whether officials interpret the objective as such is unknown and requires further research. Sifunda et al. (2006) reports that the DCS does not have a protocol in place to refer HIV-positive prisoners after release to public health-care facilities nor to notify their partners, and it is left to prisoners to notify their partners if they have contracted an STI.

Health promotion and prevention services focussing on HIV and AIDS are in place, but due to capacity constraints, only a small number of prisoners are reached annually. The following highlights some of the DCS outputs during 2007–08, indicating that some effort is being made to address HIV and AIDS in the prison system:

- 54,557 offenders (excluding unsentenced prisoners) participated in 'HIV and AIDS sessions';
- 25,576 offenders participated in pre-test counselling and 23,229 in post-test counselling, with 22,303 tests performed;
- 1,182,750 condoms were distributed;
- 296 support groups were established;
- 4,294 offenders are on ART;
- 320 professional staff were trained on Voluntary Counselling and Testing (VCT);
- 168 professional nurses, social workers and custodial officials were trained on HIV and AIDS;
- 146 nurses were trained as master trainers in correctional-centre-based care; and
- 125 offenders and 16 officials were trained as master trainers in Peer Education in HIV and AIDS (Department of Correctional Services, 2008a).

The numbers above confirm the observation by Sifunda et al. (2006) that despite the availability of VCT, the uptake is very low. Again the fear of stigmatisation appears to be the main inhibitor.

The *Guidelines for the Prevention and treatment of HIV in Arrested, Detained and Sentenced Persons* pay particular attention to ensuring continuity of care as this is of critical importance to ensure effective treatment (Bulbulia and Berger, 2008). The guidelines emphasise proper health screenings upon admission to ensure that when a prisoner is on chronic medication that this is not interrupted, or resumed as soon as possible. The guidelines further acknowledge the mobility of the prison population, not only in respect of releases but also internal transfers and the problems that this may create. Emphasis is also placed in the guidelines on preparing prisoners with HIV for release, which should include a good medical summary and clear instruction for continued care and medication access. The extent to which released prisoners and in particular those who are re-imprisoned are able to continue with HIV treatment while moving between DCS and Department of Health facilities is uncertain and further research is required. The DCS does, however, not regard this as its responsibility and sees the Department of Health as the responsible department to ensure that released prisoners have access to ARV (Department of Correctional Services, 2007c).

For several years the JIOP has noted in its annual reports the high number of prisoners dying of natural causes contrasted with the miniscule number of releases on medical parole; in 2004, 1,689 prisoners died but only 76 were released on medical parole (Office of the Inspecting Judge, 2008). The purpose of medical parole is very specific in the legislation: it is a release sanctioned by the Commissioner, Correctional Supervision and Parole Board or a Court based on medical evidence to allow the prisoner ‘to die a consolatory and dignified death’ (*Correctional Services Act*, 1998, section 79). The low number of medical parole releases is apparently motivated by the fear that prisoners who have AIDS may be able to access ARV if they are released, recover and continue with a life of crime and that the Department will have no mechanism to revoke their parole. An attempt to amend this provision in 2007 in the Correctional Services Amendment Bill (32 of 2007) failed due to pressure from civil society (Civil Society Prison Reform Initiative, 2007). The solution is, however, that prisoners qualifying for ART while in prison should receive it in prison. Medical parole should not be regarded as a mechanism to access medical treatment but remains a mechanism to be used as intended in the Act (Muntingh, 2006).

20.2.6 Government’s Response to HIV and AIDS in Prisons

The DCS’ response to HIV and AIDS in the post-1994 era must be viewed against, firstly, the general response of government towards the pandemic, and secondly, the internal transformation challenges faced by the DCS. Denialism, inaction, and confusion at national government level in the post-1994 era made a proactive, goal-directed, and evidence-based approach to HIV and AIDS impossible (Nattrass, 2007). Government's overall response to HIV and AIDS created a particular environment in which the DCS was operating in, one in which HIV and AIDS were not priorities. Secondly, after 1994, the situation in DCS quickly became critical from a governance and corruption perspective. Loss of skills and the appointment of persons lacking the necessary skills, an overemphasis on changing the race profile of the DCS staff corps, lack of discipline and accountability, frequent changes in leadership and general corruption created a department that had lost the ability to deliver on its mandate. Ultimately, the Minister of Correctional Services at the time (Ben Skosana), in what must be seen as a tacit admission that government had lost control of the DCS, asked the president to appoint a judicial commission of enquiry which lead to the appointment of the Jali Commission in 2001.

Seen in tandem, the national government's confused response to HIV and AIDS and the DCS' own internal woes placed prisoners at tremendous risk of rights violations in general and, more specifically, of HIV and AIDS. The period 1994 to 2002 was indeed characterised by poorly conceptualised plans, knee-jerk reactions to problems, failed projects and lack of leadership (Sloth-Nielsen, 2003). Even after the appointment of the Jali Commission the situation in DCS did not improve rapidly, although some stability at senior management did bring an improvement.

Policies and practices of the Department frequently fell short of an appropriate response to HIV and AIDS in the past 15 years. The first policy, formulated in 1992, required that HIV-positive and high-risk prisoners be segregated from the general population but was changed 2 years later to bring it into line with WHO guidelines and the segregation of prisoners was removed from the DCS policy (Goyer and Gow, 2001). The policy amendment also provided for a number of specific programmes, one of which was the establishment of STD clinics at all prison hospitals. The clinics would be run by nursing staff that would provide testing, counselling, treatment, and information regarding STDs. Nurses would also arrange and monitor diets and access to support services (Goyer and Gow, 2001). An additional policy described condom distribution, which required that condoms would be distributed on request and following the prisoner receiving information and/or counselling from a nurse trained as an AIDS counsellor regarding the use of condoms and high-risk behaviour (Goyer and Gow, 2001). The 1996 policy remained in place until the *Framework for the Implementation of Comprehensive HIV and AIDS Programmes and Services for Offenders and Personnel 2007–2011* (the Framework) was adopted in 2007. At conceptual level, the Framework represents an important shift in thinking as it targets both prisoners and officials of the Department.

A discussion about AIDS and prisoners would not be complete without also analysing how the prison system has been affected, through its human resources, by the epidemic. The relationship that prison officials have with their employer regarding AIDS is inextricably intertwined with their responses to the issue of prisoners and AIDS. In the DCS, the relationship between employer and employee has in general been strained over the past 15 years, and there is good reason to believe that operational staff is alienated from senior management. What is increasingly clear is that the department's ability to deliver on its mandate is also undermined by the impact of HIV and AIDS.

20.3 HIV and AIDS and Prison Governance

20.3.1 The Impact of HIV/AIDS on DCS Officials

Pharoah and Schönteich (2003) note that the HIV epidemic presents a major threat to the public service in general, including the prison service. The 2006 DCS HIV Prevalence Survey (Department of Correctional Services 2008b) found that the national HIV infection rate amongst all staff was 9.8%, lower than the national estimate of 16.25%.[4] However, disaggregated, the DCS survey reveals regional patterns similar to national norms, with infection rates amongst DCS officials ranging from a high of 22.7% in KwaZulu-Natal to a low of 2.6% in the Western Cape. The survey found that the majority of those infected (87.2%) were in the age cohort of 26 to 45 years. It further found that 93.6% of HIV-positive staff was employed at the 'production level', meaning that they were involved either in the direct management of offenders or in providing support services.

Whilst there is no published record of the causes of death amongst prison officials, the mortality rate of officials nationally who died in office, increased from 3 per 1,000 in 1993 (Department of Correctional Services, 1994) to 6.1 per 1,000 in 2001 (Department of Correctional; Services, 2002), and to 7.8 per 1,000 in 2007 (Department of Correctional Services, 2007a) – more than doubling over the 14-year period. To an extent, this increase follows the growth in the mortality rate of inmates, which has increased from 1.65 deaths per 1,000 in 1995 to 9.2 per 1,000 in 2005 (Judicial Inspectorate of Prisons, 2006), and which is generally accepted to be related to the AIDS epidemic.

20.3.2 Fear of Stigmatisation

Even though correctional officials are encouraged to undergo VCT, not all prisons offer this service (Tapscott, 2008). However, it is unlikely, under the circumstances prevailing, that even if VCT was available that this would have influenced officials to undergo testing, as is reflected in the low participation rate of officials in the sero-prevalence survey (Lim'uvune Consulting, 2007). The reluctance to undergo testing offered in the prisons was principally due to the fact that the process is believed

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[4] It must be noted that the DCS prevalence survey was not without flaws, as only 37.1% of those selected in the sample agreed to participate. This amounted to 3.4% of the total number of officials in the Department. No indication is provided in the survey report as to how this might have influenced the validity of the sample. It is also not clear whether non-participation occurred evenly across all categories of employees, for example at production level, middle management or top management.

to be too public and, linked to this, the very fact that an individual had decided to undergo a test raised suspicions that he or she might have contracted the virus. A related factor is that there was a strong socio-cultural resistance to discuss any matters related to sexual practice. A further factor mentioned is that individuals were afraid to know their status, even when symptoms of the disease were evident (Tapscott, 2008). Prison officials are subject to the same stigmatisation issues as the general population (Deacon et al., 2005; see also Chapter 8, this volume). In addition, Correctional Service officials generally live in relatively closed communities, whether within the precincts of a prison itself or in close proximity to it. Furthermore, the nature of correctional work is such that staff (and particularly those in operational positions) tend to socialise more frequently with each other than with outsiders. Under such circumstances, the fear of ostracisation is acute.

20.3.3 The Impacts of HIV/AIDS on Prison Governance

The Department's Policy Framework acknowledges the threat to correctional services by HIV and spells out a range of measures to combat the spread of the disease. However, the Framework is noticeably silent on the impact which HIV/AIDS might have on the governance of prisons, and on the measures which might be introduced to mitigate the negative impact of the disease on running of these institutions (Department of Correctional Services, 2007b).

The findings of the DCS prevalence data indicate a major problem in human resource management, the extent of which is yet to be fully recognised by DCS officials while it is steadily growing in magnitude. It also points to a situation which, if left unchecked, will unquestionably compromise the operations of many prisons across the country and will materially affect the goals and strategic plans of the Department due to staff attrition, and full or partial incapacitation of those still working.

20.3.3.1 Staff Attrition

The DCS prevalence study revealed that infection rates amongst DCS officials roughly track those in the surrounding population, implying that at least a proportion of staff have full-blown AIDS. It is likely, furthermore, that the incidence of the disease is on an upward curve and that its fullest impacts have yet to be felt. Staff attrition, furthermore, does not only occur due to deaths, but also to illness and a general inability to fulfil work responsibilities. Attrition is a particular problem when those with special skills are lost (Portfolio Committee on Correctional Services, 2008), and illness and death of officials add to the workload of surviving colleagues, quite apart from the emotional toll they carry. When ill staff members continue to come to work, they may lack the energy to do their jobs effectively, and this may have implications for inmate morale and discipline. Inmates themselves are not unaware of illness amongst staff (Tapscott, 2008). The silences around HIV severely hamper succession planning for those who are ill, as well as the accessing of appropriate health care, despite the recognition by Employee Assistance Practitioners (EAPs) of these needs. Work overload experienced by EAPs is a further limiting factor. It appears that, at best, staff members are alerted to the dangers of contracting the disease whilst on duty, either through needle-stick injuries incurred whilst treating HIV-positive inmates, from stab wounds inflicted by gang members, or by any way coming into contact with contaminated blood (Department of Correctional Services, 2008).

In the absence of formal policy guidelines to direct them, prison managers, recently surveyed, reported that they resorted to ad hoc measures in their attempts to manage officials that appear to be suffering from HIV/AIDS (Tapscott, 2008). These include the reassignment of staff from operational to administrative duties and reduction of their working days to a 4-hour shift.

20.3.3.2 The Role of Leadership in Combating HIV/AIDS

It is axiomatic that the leadership has a critical role to play in advancing any new policy and in ensuring its effective take-up by subordinate officials. It was reported by prison health officials that, with notable exceptions, centre managers displayed little direct interest in the HIV/AIDS programmes presented to DCS officials and none was willing to undergo VCT as an example to others (Tapscott, 2008). Successive Commissioners and Ministers of Correctional Services since 1994 have shown little interest in how the staff members of their Department are affected by HIV and AIDS. The lack of leadership on this issue at the top must be seen as direct consequence of the Mbeki regime's position on HIV and AIDS, as described by Nattrass (2007).

20.3.4 Remedial Measures

The launch of the Department's Framework policy, as indicated, represents an important initiative in addressing the impact of HIV/AIDS in the prison system. In addressing the challenge posed by HIV/AIDS, nevertheless, it is clear that the DCS will need to embark upon a multi-dimensional programme to mitigate the impact of the disease on the governance of prisons. It is evident that the management of HIV/AIDS amongst prison officials cannot continue to be considered as an 'add on', which merely forms another component of human resource management. The challenge, as Pharoah (2005) succinctly states, is to develop an integrated approach, and one which recognises the importance of a multipronged inter-sectoral response (Strode and Grant, 2004).

Whilst the Framework represents an important departure point in the battle against HIV/AIDS, it is important to note that as a policy document it merely provides an outline of the documents to be followed (Department of Correctional Services, 2007b). Details on the content of these programmes and their resource implications have yet to be made public. It is important furthermore that implementation of the Framework should be based on a process of broad consultation. Such an approach will require an implementation plan at the level of individual centres, and it will also require appropriate budgetary provision to ensure that officials are appointed to oversee its implementation. A risk assessment study and a knowledge, attitudes, practice and behaviour study amongst prison personnel may also be helpful. Management buy-in will be key, and the issue of stigma needs to be urgently addressed.

20.4 Conclusion

The response to HIV and AIDS in the prison system in respect of both prisoners and staff has been characterised by political foot-dragging and a lack of progressive administrative leadership. This should be seen against the backdrop of the former Mbeki governments' position on HIV and AIDS. Whilst it might be argued that, in this context, prisoners were not necessarily more neglected than other citizens in the country, it is certain that the conditions of their confinement have adversely affected the way in which the disease has taken its course. It is also evident that the illness of officials has a direct impact on how prisoners experience the daily routine of imprisonment. Of particular concern is the fact that prisoners' access to ART has not been viewed as a strategic priority by the DCS, as evidenced by the fact that the implementation of this policy became the subject of litigation. Significantly, even following the court's decision, the Department had to be pressured into giving effect to the ruling. Nevertheless, whilst some attention has been paid to the rights of prisoners and their access to health care, the officials of the Department are probably more marginalised on the issue. Not only has the devastating effect of the epidemic on officials been ignored, but the overall impact of the epidemic on governance and service delivery has been swept under the carpet as well.

Against this background, the Department's new Policy Framework represents an important starting point in its efforts to contain and manage the HIV and AIDS pandemic. As a framework, however, it merely sets out the parameters within which policy might be formulated and programmes developed. The challenge of articulating a fully fledged programme of action with clearly defined outputs, time frames, resource implications, and budgets remains ahead. At present, many of the proposed interventions are derived directly from the National Strategic Plan. As generic interventions, however, they appear not to have been adapted to the particular circumstances and challenges of a prison environment. Of further significance is the fact that the proposals are noticeably short on the specifics of how different interventions might be introduced. Thus, for example, the critical challenge of overcoming stigma and its impact on voluntary testing is addressed in terms of a need to 'conduct campaigns to increase uptake of personnel in VCT services' (Department of Correctional Services 2007b, p. 10) as if this process was in some way self-evident and unproblematic. Similarly, most of the proposed interventions, group personnel and offenders together and treat them as undifferentiated group. Thus, the Framework proposes establishing 'support groups for HIV and AIDS infected and/or affected offenders and personnel' (Department of Correctional Services, 2007, p. 11) and the conducting of 'awareness raising events for special categories of offenders and personnel' (Department of Correctional Services, 2007b, p. 13).

The most significant weakness of the Framework, however, lies in the fact that it is silent on the crucial question of how the impact of HIV/AIDS on the DCS workforce might be managed. The report emphasises the need to 'Receive and review comprehensive reports on the implementation of HIV and AIDS programmes and services for offenders and personnel and develop effective Risk Management reports indicating the level of adherence to identified risks' (Department of Correctional Services, 2007b, p. 15). Beyond the need to identify (unspecified) risks, the Framework says nothing about how to manage officials infected with (and sometimes dying of) AIDS or how to implement succession plans so that there is minimal impact on the daily operations of prisons and correctional programmes are not compromised.

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Chapter 21
HIV and Circumcision

Dirk Taljaard and Chiweni Chimbwete

21.1 Introduction

Since the publication of a number of articles on male circumcision (MC), including three randomised controlled trials (RCTs) that have shown a protective effect of around 60% for male-to-female transmission of HIV, the topic of MC has taken centre stage. In this chapter we first consider biological plausibility of MC preventing HIV infection, before turning to MC in the history of the HIV pandemic. We explore the three RCTs, and the subsequent Montreux meeting on evidence around MC. Finally, some programme issues as well as some issues around traditional MC and developments in African countries will be described.

21.2 Biological Plausibility

Bailey et al (2001) in their review of the links between MC and HIV indicated that a number of mechanisms have been proposed by which the protective effect of MC on the acquisition of HIV could be explained These conditions in the uncircumcised penis included:

- Increased presence of inflammatory conditions
- Increased occurrence of scratches, tears and abrasions during sexual intercourse
- The presence of a warm moist environment where the virus is able to survive outside the body for longer time
- The keratinisation of the glans after MC
- The high density of Langerhans cells in the mucosa of the inner but not the outer layers of the foreskin (Bailey et al., 2001).

A study by McCoombe and Short in 2006 investigated the distribution of HIV-1 receptors and degree of keratinisation in the human penis. Although they found HIV-1 receptors in all the penile epithelia, the Langerhans cells in particular were closest to the surface in the inner foreskin and frenulum. They also found that the inner foreskin had significantly thinner layers of keratin than the outer foreskin and

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_21,

even thinner layers than the glans as well. The authors noted that the superficial Langerhans cells in the inner foreskin were poorly protected by keratin and that this could be the entry point for HIV virus cells into the male body (McCoombe and Short, 2006).

21.3 Scientific Evidence

Male circumcision for HIV prevention has been a controversial subject. While there is general consensus on the biomedical results that show a protective effect, some social scientists and activists have warned against its inclusion as a strategy for the prevention of HIV infection. Some of the studies on MC and HIV date back to when the HIV epidemic was in its infancy. Scientists like Fink (1986) and Alcena (1986) proposed a link between MC and HIV as far back as in 1986. Since then, many studies have been published, but it was not until 2005 when the results from the first RCT became known that MC as a preventative strategy was taken seriously by the global health and development partners.

21.3.1 Ecological and Cross-Sectional Studies

In 2001, Bailey et al. conducted a review of studies that have noted a link between HIV and MC. These included cross-sectional, ecological studies and prospective studies. The authors noted that in Africa about 90% of infected men were infected through heterosexual contact (Bailey et al., 2001). Bailey, Plummer and their other co-researchers point out that in sub-Saharan countries in Africa where less than 20% of men were circumcised, the prevalence rates were several times higher than in countries where more than 80% of the men were circumcised (Bailey et al., 2001). A number of other ecological and cross-sectional studies provide evidence highly suggestive of the protective effects of male circumcision (Alcena, 1986; Auvert et al., 2005; Bailey et al., 2007, 2008b; Fink, 1986; Gray et al., 2007; Hammond-Tooke, 1974; McCoombe and Short, 2006; O'Farrell and Egger, 2000; van Howe, 1999; Weiss et al., 2000; WHO/UNAIDS, 2007). A meta-analysis conducted by Van Howe (1999) of 35 articles and a number of abstracts found – contrary to all the other reviews – that MC did not have a protective effect against HIV acquisition. He concluded that recommending routine MC on the basis of all the studies published up to that date, as a prophylactic measure to prevent HIV infection in Africa or elsewhere, was scientifically unfounded (van Howe, 1999). This meta-analysis by Van Howe (1999) had several statistical and epidemiological limitations and a re-analysis of the data in his report indicated that in fact uncircumcised men were at increased risk of HIV acquisition (O'Farrell and Egger, 2000; Weiss et al., 2000). Soon after Van Howe's (1999) meta-analysis, the RCTs followed and clearly provided the scientific proof required to recommend MC as a prophylactic measure.

A comprehensive meta-analysis of cross-sectional studies that examine the link between HIV and MC was then made by Weiss et al (2000). According to them, it was clear from some ecological studies that there might be such a link, since it was by then established that there was a connection between MC and STIs, both ulcerative and non-ulcerative (Weiss et al., 2000).

The analysis by Weiss et al (2000) differed from the Van Howe (1999) analysis in that it focused on female-to-male transmission in sub-Saharan Africa where transmission of the virus is mainly heterosexual and the epidemic is mainly a generalised epidemic. Their review included 28 studies, of which 19 were cross-sectional, five were case control, three were cohort and one was a partner study. Weiss et al (2000) concluded that their meta-analysis provided compelling evidence that MC reduced the risk of HIV acquisition in men. They stated that although they had found the strongest link in men at high risk, they also found an effect in the general population. They indicated that the effect should be heterogeneous across different populations due to a number of different factors (Weiss et al., 2000). In fact, more recent anecdotal evidence suggests that the amount of skin removed during different traditional or ritual MC differs greatly and this would of course produce great variance in the amount of protection MC offers.

The problem with observational studies in general is of course the confounding factors, for instance, religion and ethnic group. As mentioned above, the self-reporting of MC status is inaccurate, the amount of foreskin removed cannot be determined unless a physical examination is part of the design. Observational studies thus cannot establish causal effects definitively. This was one of the reasons why RCTs were needed (Weiss et al., 2000).

21.3.2 Randomised Controlled Trials

Although there were frequent discussions about the feasibility of conducting RCTs for MC, it was not until well into the 2000s that such discussion led to proposals to funding agencies and eventually to three different trials: one in South Africa, in a semi-urban area called Orange Farm; another trial in Kisumu, a large town at the edge of Lake Victoria in the Nyanza province of Kenya; and a third trial in Rakai in rural Uganda (Auvert et al., 2005; Bailey et al., 2007; Gray et al., 2007). The main protagonists and principal investigators in the three trials, Prof Bertran Auvert for Orange Farm, Prof Robert Bailey for the Kenya trial and Prof Ron Gray for the Rakai trial had held discussions before they started. However, the situation in which the three trials were to be conducted differed greatly and therefore each trial would be unique in its own right.

Table 21.1 contains a quick summary of the main similarities of and differences between the three trials. The most important differences were found in the prevalence of MC and the calculated incidence of HIV.

All three trials were powered to show a 50% reduction in HIV acquisition and all three were stopped by their data safety and monitoring boards (DSMBs), respectively. In November 2004 the DSMB for the Orange Farm trial stopped the trial on

Table 21.1 Similarities and differences between RCT trials

	Orange Farm, SA	Kisumu, Kenya	Rakai, Uganda
Type of setting	Semi-urban	Urban	Rural
MC rate	20%	10%	16%
HIV incidence	1.6%	1.8%	1.3%
Age range	18–24 years	18–24 years	15–49 years
Sample size	3,128	2,784	5,000
Stopped	Nov2004	Dec2006	Dec2006

the basis that efficacy had been sufficiently proven and there was no need to continue the trial – in fact, it would be unethical to do so. Thus this trial was stopped and MC was offered to all the participants in the control arm who had remained uncircumcised. The two other trials continued up until December 2006 before they too were stopped by their respective DSMB. At this point, the boards for these two trials were also convinced of the protective effect of MC and deemed it unnecessary to continue.

The results of the three trials were remarkably similar as can be seen in Table 21.2. According to Bailey et al (2007), such consistency of clinical, observational and biological data has not been reported for any intervention that aimed to reduce HIV infection in adults. During the 2008 AIDS conference in Mexico, Prof Bailey reported more in-depth analysis and re-evaluation of the sero-conversions of the trial in Kisumu. The study team amended the number of sero-conversions in the control and intervention arms of their study. (This is indicated in brackets in Table 21.2.) The number of sero-conversions in the intervention arm changed to 19 and in the control arm to 45. According to Prof Bailey, this re-analysis of the data had a minimal impact on the results. The study in Kenya continued to follow up participants, and they now have data for at least 42 months. After this extended time they still observe the same protective effect as during the trial (Bailey et al., 2008b).

Table 21.2 Results of the trials

	Orange Farm	Kisumu	Rakai
Sero-conversions	69	69	65
Circumcised (Intervention arm)	20	22 (19)	22
Uncircumcised (Control arm)	49	47 (45)	43
% reduction in risk (Intention-to-treat analysis)	61%	53%	48%
% reduction in risk (Per protocol analysis)	76%	59%	55%
Sample size	3,128	2,784	4,996
Rate of adverse events	3.6%	1.5%	3.0%

It is important to note that the fact that these were RCTs meant that the participants in both the control and the intervention arms were treated exactly the same during the course of the trial. They received the same number of visits and the same safe sex counselling and underwent the same biomedical testing. All study investigators were blinded to the arm the participant belonged to, except for the study nurse or doctor who performed the physical examination of each participant (as they could obviously see whether the person was circumcised or not).

Participants were not paid to be circumcised in any of the trials, but circumcision was provided free of charge. They were given an honorarium as part of the stipulations of ethics and review boards of the honoraria that should be given to participants in RCTs. Participants from both the control and the intervention arms received these honoraria. Participants in all three trials (whether in the intervention or control arms) received condoms free of charge, while all participants also received personal counselling during each visit.

During the analysis of the Orange Farm Trial, possible effects of the differences in behaviour of the participants in the control and the intervention arms were controlled for. Participants were questioned on their risk behaviour, which was defined as at least one unprotected sexual contact since the previous interview; number of sexual partners; marital status; self-reported STI symptoms; and number of partnerships with just one sexual contact, regardless of whether these sexual contacts were with concurrent or consecutive partners. None of these behavioural and demographic factors had any impact as none of them were significantly different between the two arms. In fact, the only variable that could be established to be significantly different between the intervention and control arms was the number of sexual contacts with the same number of partners in the intervention arm. In other words, men who were recently circumcised had more sexual acts, but not more partners than those who were from the control arm. The study team put this down to the curiosity and novelty aspect of the newly circumcised men. In the Orange Farm trial the study team concluded, based on this finding, that there was no visible risk compensation during the study (Auvert et al., 2005).

For the analysis of the Kisumu trial, the research team found small differences between the control and intervention arms on the number of participants who had had two or more sexual partners in the last 6 months, unprotected sexual intercourse and consistent condom use. The participants in the control group had the safest practices for all three types of behaviours. The differences were however small and not significant. The study team for the Kisumu study also concluded that risk compensation did not occur in the 24 months after surgery (Bailey et al., 2007).

During the analysis of the Uganda trial in Rakai, the study team also investigated possible confounding factors. Researchers did not find any evidence that the intervention group had, after MC, engaged in any higher-risk behaviours than did the control group. In the Rakai trial, 3% moderate adverse events were reported for participants after and during MC (Gray et al., 2007). It should be noted that the adverse events recorded were inconsistent between the three trials and could not be directly compared. In all three trials, this rate was well below acceptable levels of complication and in all cases these events could be resolved with no permanent damage to the genitalia of participants (Gray et al., 2007).

The RCTs provided invaluable information about MC and its protective effect and for the first time provided ‘gold-standard’ scientific data on the relationship between HIV and MC. Decision makers took note, and a series of events and much enthusiasm followed during which some modelling studies showed remarkable effects that MC intervention could have in societies where HIV prevalence was high.

21.4 Montreux 2007

In March 2007, scientists, activists and decision makers met in Montreux in Switzerland to discuss the evidence around MC and HIV. This meeting was preceded by a number of consultation meetings in eastern and southern Africa countries. At this meeting a number of resolutions were adopted, including the following:

- Evidence on MC for HIV prevention is compelling (about 60% reduction in female-to-male transmission).
- MC does not provide complete protection.
- Appropriate communication and messaging would be essential.
- The socio-cultural setting concerned should inform MC programming (including traditional MC).
- Human rights, legal and ethical considerations should inform service delivery.
- Gender considerations are important.
- Programmes should maximise the public health benefit.
- Health services need strengthening to provide safe MC service access.
- Additional resources should be mobilised for safe MC expansion.
- MC for HIV+ men is not recommended.
- Research is needed to guide programme implementation.

At this meeting, UNAIDS and WHO formally accepted MC as an HIV prevention strategy that should be promoted in specific areas, prioritising low male circumcision and high HIV prevalence settings, such as those in eastern and southern Africa (WHO/UNAIDS, 2007).

21.5 Implementation and Operations Research

Once the results of the Orange Farm trial were published in May 2005, there was an increase in the interest of using MC for HIV prevention. UN health agencies, as well as technical and development partners from the United States and France have supported countries to translate the research knowledge into action. The priority settings have been those with high HIV prevalence and low male circumcision rates, which were found to be located mainly in southern and eastern Africa. In 2005 the UN developed a 2-year ‘readiness’ male circumcision work plan. The aim of the plan was firstly to improve the safety of existing male circumcision practices. Secondly, it was to develop frameworks and tools to support policy and programming with regard to decision making of countries on male circumcision. These included rapid assessment tools to identify both supply and demand factors of male circumcision; human rights, ethical and legal considerations; surgical manuals to ensure safety; and male circumcision service management tools, including monitoring and evaluation.

The 'readiness' work plan included the facilitation of stakeholder consultations on MC and HIV at country, regional and global level. The consultations involved reviewing emerging evidence and discussing implications for national male sexual and reproductive health services and HIV prevention. Discussions focused on follow-up actions and indicated support needs. Lesotho, Kenya, Malawi, Swaziland, Tanzania and Zambia were the first countries to be involved in this process in 2006 and 2007. Countries in eastern and southern Africa met in Nairobi to consider conclusions of country consultations, to share experiences and to identify support needs and cooperation opportunities at regional level.

Both authors of this chapter supported the UN-initiated consultation process by providing the evidence of the protective effect of MC against HIV infection and facilitating the consultations. During the round of consultations, varied reactions were received from policymakers and partners at country level. MC is associated with cultural practices in most settings in southern and eastern Africa. For those countries where MC is common, it is largely practised as a traditional rite of passage symbolising the transition from boyhood to manhood. Traditional MC is therefore most frequently performed in late adolescence. However, rather than being linked to physical development or maturity, it is a significant social act that culminates in the integration and acceptance into the community of all males who successfully undergo it. In Kenya, approximately 85% of males are circumcised, an overwhelming majority of these procedures comprising traditional rites of passage. South African evidence of traditional circumcision among different ethnic groups is not dissimilar, and traditional circumcision practices have been maintained among the Venda, Ndebele, Pedi, South Sotho, Shangaan-Tsonga, Tswana and Xhosa. Up to 10,000 Xhosa males undergo traditional circumcision in the Eastern Cape annually. Traditional circumcision is not entrenched in all Xhosa-speaking groups; for instance, it is not practised amongst the Bhaca, Mpondo, Xesibe or Ntlangwini. Although, historically, the Zulu practised MC, this institution has largely been abandoned (Hammond-Tooke, 1974; Shisana and Simbayi, 2002; Vincent, 2008b).

Circumcision is a social device that extends beyond ritual cutting to the transfer of cultural knowledge and social values and norms to incumbents. Constructs of sexuality and masculinity are central to this rite of passage, which affords males adult status and designated duties as 'men' within the community (Meintjies, 1998; Rain-Taljaard et al., 2003). Education in social and sexual behavioural norms, as well as tests of endurance, dietary taboos and seclusion are inextricably linked to the institution. In the absence of such instruction, the transition from boyhood to manhood cannot be made (Vincent, 2008a).

Despite the importance of traditional MC as a social institution, social and cultural change over time has contributed to its erosion. Consequently, it is important to frame MC not only as artefact, but within a contemporary context where HIV prevalence is high. For example, recent evidence in Xhosa communities suggests a breakdown in the function of traditional circumcision schools in facilitating sexual socialisation in male adolescents. This research contends that little educational instruction regarding sexual behaviour, constructs of masculinity and social values and norms remains. In modern South Africa, where sexual behaviour is marked by high rates of sexual risk behaviour (including frequent sexual partner change, concurrency and partner violence), MC is construed as becoming a mechanism not so much for teaching sexual restraint, but for assigning decreased value to previously held social values and norms (Vincent, 2008a).

The pace of reaction by governments in the region to MC for HIV prevention is highly dependent on the government officials' own experience. In addition, the adoption of MC as an additional HIV prevention strategy is also determined by the holistic AIDS response of the specific country. For example, Rwanda – with an HIV prevalence rate of 3%, down from 10% (Rwanda demographic and health survey 2005, 2006) in 2000 – initially reacted cautiously to MC. At the Third National Conference for Exchange and Research on HIV and AIDS in Kigali in March 2007, the Minister of Health categorically stated 'No male circumcision for Rwanda'. He argued that he was concerned that MC would shift resources from other interventions in the AIDS response. However, by the end of 2007, Rwanda had adopted a strategy of scaling up MC by targeting most-at-risk populations and reaching boys before they become sexually active. The military and high school boys would be the two groups targeted.

Swaziland has an HIV prevalence of 26% for the adult population aged 15–49 years (19% for population aged 2 and older) and MC below 20% (Swaziland demographic and health survey 2006–7, 2007). Swaziland is populated predominantly by one ethnic group, the Swazi people. It is alleged that Swazis used to practise MC as a rite of passage. However, due to wars, the king at the time banned it since it took young men away from military duty. When the Orange Farm trial results became known, there was increased awareness of MC as an intervention to reduce HIV infection. This was followed by an increased demand for MC services. A government urologist, Dr Adam Groeneveld, with the support of a number of doctors, started performing MC services to meet some of this demand. However, there were long waiting lists since it was not offered routinely due to limited theatre space. Dr Daniel Halperin, Southern Regional HIV Prevention Advisor for USAID, was resident in Swaziland at the time. He has been a keen advocate of MC and co-published the article 'Male circumcision and HIV infection: 10 years and counting' in 1999 (Halperin and Bailey, 1999). This publication was written in reaction to the slow pace at which the world reacted to the evidence provided by scientists like Moses and Plummer (Moses et al., 1994), de Vincenzi and Mertens (1994) and Moses and Bailey (Moses et al., 1998) about the link between low MC rates and high HIV prevalence in sub-Saharan Africa.

Early in 2006, NERCHA and UNICEF supported MC training for doctors in Swaziland. Dr Kasonde Bowa, a urologist from the University Teaching Hospital (UTH) in Lusaka, was a facilitator at the training. The UTH programme had already started providing male circumcision services in 2004 with the support of Jhpiego. It was the centre of influence in the implementation of MC for HIV prevention in the region. The UTH became involved in the training of doctors for surgical MC with the WHO and Jhpiego. Due to the enthusiasm of Dr Halperin, the availability of a urologist and the support of partners, some response was possible to meet the initial demand for MC services in Swaziland. However, these services were still unable to meet the demand and there were waiting times as long as 6 months. MC services were provided at the government hospital in Mbabane and two other mission hospitals. One service provider, Family Life Association of Swaziland (FLAS), eventually got some funding to start performing MCs as a routine procedure. FLAS has become one of the significant providers of MC services in the region.

Swaziland and Zambia have implemented vertically based services in secondary health-care settings. The WHO recommends that MC should be part of a comprehensive minimum package that includes HIV testing and counselling, STI screening and treatment and follow-up care (WHO/UNAIDS, 2007). The MC providers in these two countries soon realised the need for national guidelines and policies. Swaziland has launched a number of pilot MC projects to meet the demand and prepare for the scale up of safe MC:

- The Family Life Association of Swaziland (FLAS) started a pilot project in the Mbabane urban area in January 2006. By October 2006, a total of 371 MCs had been performed (NERCHA/UNAIDS, 2006). In the second half of 2007, an average of 40–50 procedures per week were performed in all health facilities in Swaziland.
- The Swaziland Male Circumcision Task Force sponsored three 1-day events called ‘Circumcision Saturdays’ in 2006 and 2007, held at Mbabane and Mankayane government hospitals. A total of 135 men were circumcised by a surgical team. These special events were used to train doctors, assess the capacity to conduct a large number of circumcisions; calculate the cost per procedure; and identify ways to integrate HIV testing and counselling into the service provision.
- In 2007, FLAS formed a partnership with the Jerusalem AIDS Project under which teams of surgeons came to Swaziland for 2 weeks at a time to train doctors and perform circumcisions as part of a MC scale-up strategy. During the first visit in October 2007, 74 males were circumcised. Neonatal circumcisions and training of some Swaziland Male Circumcision Task Force members also took place.

Swaziland has since developed a national policy and draft strategy on MC for HIV prevention.

As mentioned before, for MC to have a significant impact on HIV incidence at a population level, large proportions of males, at least 80%, need to be circumcised. Southern African countries that are worst affected by AIDS have a national MC prevalence of around 20%. Although some areas may have a higher prevalence, there are still large numbers of males who will have to be circumcised before MC will prove to have a public health effect on HIV infection.

The challenge lies in meeting such demand in the southern African countries of Lesotho, Namibia, South Africa and Swaziland, where only surgeons and doctors are allowed to perform circumcision surgery in clinics and hospital settings. A large number of health centres and clinics need to be equipped and improved to a level where minimum quality assurance standards for safe MC service delivery can be met. An evaluation of services provided at a public sector hospital in Soweto showed effective current service provision, with a need to improve capacity to meet future caseloads to realise the public health impact of MC interventions (de Bruyn et al., 2007).

In order to scale up MC in the first few years, some innovative catching-up strategies will have to be developed. Task-shifting strategies aimed at delegating some of the surgical tasks to nurses, midwives and other mid-level health-care providers will be a key component of enhancing numbers of service providers (WHO/UNAIDS, 2007). By re-organising the workforce in this way, task shifting presents a viable solution for improving health-care coverage by making more efficient use of the human resources already available and by quickly increasing capacity while expanding training and retention programmes.

While the implementation of circumcision in hospital settings in South Africa may be considered feasible, the preference for ritual circumcision over hospital-based services among males of ethnic groups who practise this institution poses a major barrier to service uptake. Despite widespread awareness of the associated dangers (e.g. death, disability, sepsis, dehydration, increased risk of infection with HIV and other sexually transmitted infections through the use of contaminated equipment), traditional circumcision remains entrenched as a socio-cultural construct (Crowley and Kesner, 1990; Meintjies, 1998). Social pressure and tradition have been reported by traditional surgeons and nurse assistants as the two leading reasons for the continuation of this practice (Peltzer et al., 2008a). Social hierarchies place men who have undergone traditional circumcision above those who access medical circumcision, consequently fuelling the debate over the regulation and medicalisation of cultural traditions. Traditional leaders argue that medical circumcision is not recognised in societies that practise traditional circumcision. Those who undergo hospital-based procedures risk not only being treated as social outcasts, but also forfeiting community privileges and marriage opportunities. Hence, traditional circumcision has been contested both as a cultural right and a human right (Meissner and Buso, 2007; Vincent, 2008b). Traditional circumcisers will also have to be shown and taught about the amount of skin to be removed for the traditionally circumcised man to have the same protection that is referred to.

Amidst this debate, evidence on the safety of medical circumcision in developing countries is favourable, albeit limited. Results from a prospective study in Kenya show that males who underwent traditional circumcision were 2.5 times more likely to report circumcision-related complications than those who had been medically circumcised. More than a third of participants who had been circumcised traditionally reported circumcision-related adverse events (Bailey et al., 2008a). Although evidence from South Africa is scant, increased reporting of fatalities and adverse events associated with traditional circumcision schools in recent years has resulted in calls to regulate circumcision practices and promoted investigative research. Research results demonstrate that regulatory measures have proven difficult to monitor and safety continues to be a major concern. For example, a recent study of Xhosa initiates in the Eastern Cape found high rates of post-circumcision complications, including 21% of initiates with mild delayed wound healing, 16% with mild infection, 11% with mild pain and 10% with insufficient skin removed. Furthermore, more than half of the traditional surgeons in this study continued to use a customary spear (*assegaai*) rather than sterile surgical blades to perform the procedure (Peltzer et al., 2008b). There would thus have to be engagement with the traditional authorities in order to change practises and make surgery safer.

21.6 Social Scientists' Reaction

RCTs in different population groups are viewed as important to provide 'gold-standard' evidence of the protective effect of MC and for the promotion of research findings. Despite the evidence from three RCTs, some social scientists and ethicists argue that the UN and partners are moving too fast and that this could have negative repercussions for HIV prevention efforts in the region. They state that we need field-based operational research to provide data on the protective effect of MC in real-life situations and not in the controlled settings of well-resourced clinical trials. However, in his opening remarks at the Montreux meeting, Dr Kevin de Cock of WHO agreed that the MC RCTs were converse to the norm. The trials confirmed observational effectiveness data from epidemiological evidence that we have had the last 20 years. He argued that we can assume that 'the cart is spanned before the horse' unlike the case with vaccine trials, for example. It is this position that social scientists such as Gary Dowsett from Melbourne University argued against.

In Orange Farm, an intervention study has started to offer the benefits of MC to the community. The study was implemented as an ethical obligation to offer a beneficial treatment or prevention strategy (as in this case) to the community where the trial was conducted. The study does however offer the opportunity to perform a lot of operations and social science research, while social science studies will also be included. Similar studies have been launched in Kenya and Uganda where the other two trials were done.

One concern about rolling out MC for HIV prevention is to ensure that condoms, which are viewed as the only 100% effective intervention in HIV prevention, are not displaced by the addition of MC to the prevention choices available to people. However, modelling work by Nagelkerke et al. (2007) has demonstrated that since consistent condom use is low in many of the settings in the region, risk compensation would need to be considerable to have an impact on condom use (e.g. consistent condom use from 20 to 0%) and to counteract the protective effect of MC at community level.

The view by some was that the social science arguments were being driven by non-Africans who were associated with ethicists who view MC as a mutilation of the body. Countries in the region highly regard WHO/UN as a neutral body to provide guidelines on interventions such as MC. UNAIDS and the Centre for the AIDS Programme of Research in South Africa (CAPRISA) convened a global consultation forum to discuss social science perspectives of MC for HIV prevention. It was resolved at this meeting that SAHARA (Social Aspects of HIV/AIDS Research Alliance) should take the lead in social science research on MC for HIV prevention. In its November 2007 journal issue, SAHARA published an article entitled 'Editorial review: Male circumcision, gender and HIV prevention in sub-Saharan Africa: a (social science) research agenda' (Peltzer et al., 2007). In it the following research agenda was advocated:

- To assess the situation of MC in various countries in Africa, its meanings and social and cultural factors associated with MC
- To analyse types of MC (in relation to age, type of procedures, traditional or clinical mode) in association with HIV/AIDS risk
- To analyse the involvement of women and gender roles in MC decision-making processes, as well as acceptability among women and marginalised groups (such as commercial sex workers and men who have sex with men)
- To analyse social effects and ways to mitigate or avoid the adverse effects of MC
- To develop models for scaling up (including synergies between traditional and modern settings) and including legal, structural responses
- To determine when keratinisation occurs and when the protective effect of MC commences
- To determine easier and quicker MC techniques

It is clear that the greatest need now is for operational research to show how and whether MC can be scaled up to be used as a public health intervention for protection against infection with HIV. Some studies have started, but there is still a lot to be done. There is a remarkable dearth of social science studies on the research agenda by SAHARA will help to address the gap. As pointed out above, MC is a social, cultural and religious issue.

21.7 Conclusions

It should be clear that MC is not a 'silver bullet' as far as the devastating HIV pandemic is concerned. However, it is giving us something new with which to fight the disease, as well as the opportunity to offer something extra to those suffering the enormous burden of HIV, especially in southern Africa. MC as a strategy for preventing HIV may not even be appropriate in all settings, but for the settings where up to now most of the prevention strategies have failed to have an impact on the rapid infection of the youth, it might assist in the fight against such infections.

It also gives us the opportunity to add a new message to those of abstinence, faithfulness and condomise, which have been the standard behavioural intervention messages for so long and which have rendered little results in the settings where HIV prevalence is high. Programmes will give the opportunity to engage young men who have often not had a single opportunity in their life to discuss their sexual behaviour and risk with a counsellor. Young men often do not go to clinics and health facilities, except for emergencies.

Current studies will focus on whether it will be possible to implement MC in a community and even at country level to such an extent that it might reduce the prevalence of HIV in countries, regions or communities. As stated before, MC is a controversial intervention in some settings. Science has provided good evidence though, and therefore MC cannot be ignored, especially in settings where its prevalence is low and HIV prevalence is high.

In South Africa, the South African National AIDS council is currently doing a round of consultations with all the different sectors in order to formulate a policy regarding MC. The debates include discussions about traditional circumcision, risk compensation and concern from female groups about the impact MC rollout might have for women. There is a lot to discuss and the road might be long, but all parties are very aware that with 1,500 new infections in South Africa every day we need to move fast.

Acknowledgments The authors would like to thank Kathryn Stinson for her contribution to an earlier draft of this chapter.

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Chapter 22
Participation in HIV Vaccine Trials

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22.1 Introduction

South Africa's AIDS epidemic has been classified as amongst the worst in the world and shows no evidence of declining (UNAIDS, 2006). While existing behaviour change initiatives to reduce the incidence of HIV have been proven efficacious in research settings, they have had limited success when implemented in real-world settings. In the HIV prevention arena, it has been widely argued that a safe and affordable HIV preventive vaccine will offer the best hope of halting the spread of HIV (Esparza and Bhamarapravati, 2000; Kahn, 2005). However, the vaccine development process is a lengthy one and has historically been beset with many challenges and setbacks. The complexity of the HI-virus means that a longer timeline and innovative approaches will be required to achieve the ultimate goal of the HIV vaccine enterprise, i.e., an effective HIV vaccine. Efforts to develop an HIV vaccine have been underway for more than a decade and while researchers have managed to generate evidence for the feasibility of candidate HIV vaccines in animal models, they have not yet managed to illustrate that it provides the same benefit in humans. The development timeline of an effective HIV vaccine for use in humans is, therefore, a long one. Concomitantly, testing candidate vaccines in clinical trials is crucially dependent on the participation of individuals who reside in communities at high risk of HIV infection.

There is a small but growing body of social science research on the socio-behavioural aspects of HIV vaccine trials. While this research represents a crucial starting point for examining the human dimension of HIV vaccine trials, many questions related to the social and behavioural dimensions of HIV vaccine trials remain unanswered. This chapter will outline existing socio-behavioural research as it relates to HIV vaccine trial participation with specific reference to the South African context, discuss the challenges associated with conducting work in this area and briefly sketch the future of HIV vaccine research in South Africa and globally.

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_22,

22.1.1 Impact of HIV/AIDS in South Africa

South Africa has the fastest growing HIV/AIDS epidemic in sub-Saharan Africa (McClure et al., 2004), with an average prevalence rate of 10.8% in the general population (Shisana et al., 2005). The impact of the pandemic is enormous in terms of human lives lost, diminished quality of life due to opportunistic infections among HIV-infected persons, the financial burden of health care and funeral costs borne by families, psychosocial consequences such as loss, grief and bereavement, and the increasing number of child-headed households.

Social and economic factors play an important role in fuelling the HIV pandemic in South Africa. For example, southern Africa's system of migrant labour creates conditions where men leave their homes in rural areas in search of work in cities, mainly in the mining industry. This separation from their homes and families places them in situations in which they engage in sexual relationships with multiple partners. Within this context, young women, who are often particularly impoverished and disempowered, may engage in transactional sex with older males in return for money, transport, food or shelter (Harrison et al., 2006). In addition, the high prevalence of sexual violence in southern Africa (Jewkes and Abrahams, 2002), the lack of availability and poor distribution of condoms, and the early average sexual debut of young persons contribute significantly to HIV transmission.

Poverty and bearing the burden of care for HIV-infected family members has been shown to be the greatest negative consequence of the HIV pandemic in a survey of over 700 South African households in which one member was living with HIV (Steinberg et al., 2002). While HIV/AIDS is more prevalent among poor households, such households are even further impoverished through loss of income of the ill family member and the high cost of medical care, both of which can be financially ruinous to families most affected by the pandemic. In addition, the cost of a funeral in the event of the death of a family member from AIDS adds to the financial burden. In a longitudinal study of rural and urban households in the Free State Province of South Africa, HIV/AIDS-affected households were on average poorer (mean of $130 vs. $215, respectively), had higher expenditures ($119 vs. $90, respectively) and fewer employed members (11 and 20%, respectively) than non-affected households (Bachman and Booysen, 2003). It has also been demonstrated that the household income in families in which one member was living with HIV/AIDS was 35% lower than families that were HIV/AIDS unaffected (Oni et al., 2002). In addition to the increased costs associated with health care, funerals, transportation and other costs related to the disease, expenditure on education and housing were reduced by 4.7% and 11.5%, respectively, when comparing HIV/AIDS-affected households with non-affected households (Bachman and Booysen, 2003).

The phenomenon of orphans and vulnerable children is one of the most severe social consequences of the AIDS pandemic in sub-Saharan Africa. It has been estimated that 12 million children in sub-Saharan Africa have lost a parent to the pandemic (UNAIDS, 2004). The number of child-headed households will, therefore, increase and consequently, school enrolment may decrease as these children leave formal education environments to dedicate their time to the labour market and care-giving responsibilities. The HIV pandemic thus disproportionately affects the economically active members of the population, while also changing social, cultural and family structures.

22.1.2 Strategies for HIV Prevention

When considering the impact of social, political, cultural and environmental factors on HIV transmission in South Africa, HIV prevention interventions that focus primarily on promoting behaviour change are likely to have limited success in halting the spread of HIV. Behavioural interventions that have been the focus of HIV prevention activities to date include interventions that focus on promoting individual risk reduction by adopting protective behaviours such as increasing condom use, reducing the number of sexual partners and delaying sexual debut. In addition, structural interventions that focus on changing the social, political and economic environments that fuel HIV risk behaviours are also increasingly gaining prominence in the HIV prevention arena, for example, microfinance interventions that offer loans to impoverished women who are exposed to intimate partner violence to reduce their vulnerability to HIV infection (Pronyk et al., 2006). Broadening the spectrum of HIV prevention interventions to include the development of HIV prevention technologies, such as HIV vaccines, microbicides and oral Pre-Exposure Prophylaxis (PrEP) (i.e., using ARVs to prevent HIV infection) (McEnery, 2008), holds much promise for reducing HIV incidence in South Africa. While there is currently no effective HIV vaccine or microbicide available to prevent HIV infection, there are several trials underway to test the efficacy of these technologies, both of which have been hailed as being the most cost-effective in preventing new infections.

There are common behavioural issues involved in recruiting and enrolling large numbers of participants in all types of trials testing new HIV prevention technologies. These include: preparing communities for the advent of a clinical trial; evaluating participants' willingness to participate in clinical trials to test pharmaceutical prophylactics; retaining participants over the life span of the clinical trial; evaluating the potential for sexual disinhibition amongst trial participants; and identifying strategies to reduce the stigma and discrimination that trial participants may potentially have to endure. In addition, clinical trial site staff also face the challenge of dealing with the issue of co-enrolment, that is, the possibility that participants in an HIV vaccine trial may also be simultaneously participating in a microbicide trial (and vice versa), if such trials run concurrently in a given community. Thus HIV vaccine and microbicide trials may be competing for a limited pool of eligible participants necessitating close collaboration and cooperation between research teams and clinical trial staff running trials in the same geographical area.

22.2 Developing an HIV Vaccine

22.2.1 The HIV Vaccine Clinical Trial Context

Planning for and conducting HIV vaccine trials and other vaccine-related studies raises complex and challenging issues for the social and behavioural sciences. Central to these issues are two over-arching questions: (1) how to recruit and retain participants in HIV vaccine trials for the required period of time and (2) how to implement HIV vaccine trials that conform to the highest quality standards whilst simultaneously leaving communities better off as a result.

While the aforementioned questions, which are intrinsic to HIV vaccine trials, are without a doubt important, there are also important extrinsic socio-behavioural questions. One central extrinsic question relates to how preparations at, for example, community level interface with other HIV/AIDS campaigns, which may include broader risk reduction campaigns and the rollout of antiretroviral treatment.

HIV vaccine efficacy trials must for practical reasons take place in communities with a high incidence of HIV infection. In South Africa, however, these tend to be the same communities in which poverty, suboptimal access to health care, high rates of substance abuse, violence and instability through migration are common features. These issues, in conjunction with each other and individually, pose operational challenges as well as a host of human rights and ethical dilemmas for HIV vaccine researchers. Current HIV vaccine research and development timelines should, therefore, be considered in order to ensure the relevance and utility to potential participants at a particular point in time. In addition, social scientists engaged in research related to HIV vaccine trials need to carefully consider differences in language and culture, which may include different sexual, social and religious mores, as well as differing experiences and understandings of health and how these differences will impact on the conduct of the trial.

The number of clinical trials being conducted in low-income settings, which are often characterized by complex socio-political and economic climates, has increased 16-fold since the early 1990s (Petryna, 2006). The increase in the number of trials and the ease of access of investigators to participants have heightened concerns about the rights of communities of vulnerable individuals who are asked to participate in clinical research.

The case of community participation in HIV vaccine research is a particularly complex example of relatively higher risk involvement of communities in clinical trials. HIV vaccines are complex for a number of reasons, including the fact that a preventive vaccine does not have therapeutic value but is designed to have a prophylactic effect. The fact that it is a global enterprise involving the active participation of a range of stakeholders, including international and national organizations, multidisciplinary researchers, community organizations and community representatives, all of whom have specific interests (Baylies, 2004; Lindegger et al., 2006) further contributes to the complexity of the HIV vaccine development process.

In addition, community participation in HIV vaccine trials is often assumed to be a broad social good, especially for those communities whose members are most at risk of HIV infection (Swartz and Kagee, 2006). However, trial participation may constitute significant personal risk for participants due to the social stigma that participants may face by virtue of their involvement in HIV-related research (Baylies, 2004; Buchbinder et al., 2004; Lesch et al., 2006; McCluskey et al., 2005; Milford et al., 2007). Developing an HIV vaccine is also complex from an immunological point of view. This level of complexity relates to issues such as the side effects associated with receipt of a candidate vaccine (Buchbinder et al., 2004) and the possibility that participants may become immune to future vaccines (Kerns, 1997). These issues all point to the fact that the assumption that trial participation facilitates community empowerment is potentially contradictory, as it obscures some of the complexities that such participation may involve (Swartz and Kagee, 2006).

In trying to meet the operational needs of running large, multinational clinical trials, the complex social issues surrounding community participation in scientific research are regarded as peripheral issues or obstacles to overcome in developing an effective HIV vaccine, rather than serious research questions in their own right. Thus, rather than a detailed examination of community participation as a key research issue, there is a tendency in the community research literature to focus on the ‘performance’ of community participation as a bureaucratic requirement in the conduct of clinical trials, rather than as an essential component upon which the success or failure of the trial rests.

There are potentially two reasons for the current status. Firstly, within clinical trial research, biological models predominate and the primary issue of concern is the efficacy of the drug or vaccine being tested. Secondly, from an operational perspective, the sheer complexity and infrastructural challenges of conducting high-level biomedical research in poorly resourced contexts makes the direct focus on trying to disentangle issues around community participation an unattractive and often daunting prospect.

22.2.2 Stakeholders in the Clinical Trial Process

As has been highlighted above, success in the HIV vaccine enterprise hinges on the involvement of individuals who reside in communities at high risk of HIV infection. These communities are, therefore, key stakeholders in the clinical trial process, and their involvement is crucial in attempts to develop a safe, affordable and efficacious HIV vaccine. One of the most profound challenges in the HIV vaccine development process is identifying who these stakeholder parties are. There is, at present, no single definition for who constitutes the ‘community’ in HIV vaccine research. The ‘community’ in this context simultaneously exists at many levels, ranging from clinical trial volunteers, community advisory boards (CABs) and policymakers to clinical trial site staff and so on. Attempting to define ‘community’ in HIV vaccine research is further complicated by the fact that different communities are required for participation depending on the phase of the vaccine trial. HIV preventive vaccine trials are conducted in three main phases. Phase I trials include small numbers of low-risk volunteers (approximately 50–100 participants) and tests the safety of, tolerance to, and immunogenicity (whether it generates an immune response) of the candidate vaccine. Phase II trials are carried out with larger numbers of low-risk volunteers (usually a few hundred) to identify the optimal dosage and form of administration of the candidate vaccine. Phase III trials involve thousands of volunteers and aim to determine the efficacy of the candidate vaccine in HIV-negative participants who are at high risk of HIV infection (Kerns, 1997).

22.3 Socio-behavioural Aspects of HIV Vaccine Trials

Socio-behavioural research on HIV vaccines is a relatively new area of focus in the clinical trials context and has been steadily growing as HIV vaccine researchers begin to implement clinical trials and think through the human dimension of such trials. The existing body of research on socio-behavioural aspects of HIV vaccine trials is organized around a number of key areas that include issues related to recruitment, willingness to participate (WTP), retention and attrition; adolescent involvement in HIV vaccine trials; social harms that trial participants may be exposed to by virtue of their involvement in HIV vaccine trials; and the challenges involved in preparing communities to participate in HIV vaccine trials.

22.3.1 Recruitment, Willingness to Participate (WTP), Retention and Attrition

For statistical reasons, phase III HIV vaccine trials require large numbers (several thousands) of HIV-negative volunteers at high risk of HIV infection to enrol in the trial and return to the trial site regularly for assessment over a number of years (Grinstead, 1995). Participants in such trials will have to endure inconveniences that include substantial time investments, regular visits to the trial site, responding to invasive questions about their sexual behaviour and also dealing with potential stigmatization and negative reactions from their friends and family (McCluskey et al., 2005). These requirements raise the question of whether persons at high risk of HIV infection will be interested in participating in HIV vaccine efficacy trials, as a lack of interest may result in a decline in recruitment rates and may significantly delay the onset of a trial. In addition, it cannot be assumed that a positive attitude about HIV vaccine trials may necessarily translate into actual enrolment in a trial (Buchbinder et al., 2004). A further concern is whether participants can be retained over the long time periods required by efficacy trials (Mugusi et al., 2002). The issues of recruitment, willingness to participate, retention and attrition and the factors driving participation are therefore crucial aspects for researchers to consider. If trial participants cannot be recruited and retained in significant numbers to make statistical comparisons between the placebo and control conditions of the HIV vaccine clinical trial, the efficacy of the candidate vaccine cannot be shown and success in developing an HIV vaccine is likely to continue to elude researchers (Kafaar et al., 2007).

In addition to these scientific concerns, there are also ethical issues that require consideration. Participants recruited into a phase III HIV vaccine trial will be asked to provide informed consent before enrolment (Temoshok, 1994). True informed consent requires the ability to process complex information regarding vaccine technology and clinical trial methodology and operations (Grinstead, 1995). In low literacy populations, prospective participants may not fully understand trial information and may in fact be coerced into participation by trial incentives such as free medical care or monetary compensation offered (Lindegger et al., 2006). Trial investigators, therefore, have an ethical obligation to assess potential participants' knowledge of research procedures and HIV vaccines before enrolling them onto a clinical trial.

In a qualitative study conducted with community members across three different HIV vaccine trials sites in South Africa, participants cited a number of enablers and inhibitors to their willingness to participate in a future HIV vaccine trial (Lesch et al., 2006). Factors that were raised as inhibitors to trial participation included: fear of illness or death; the possible financial costs of trial participation; fear of being tested for HIV; concerns about negative reactions from family or their immediate community; the need for additional information about what enrolling in a trial would entail; concerns about being stigmatized due to being associated with HIV-related research; and general mistrust of research and researchers. Enabling factors cited by research participants included altruism (for example, that their participation would contribute to reducing the number of HIV infections), the possible financial rewards associated with participation, the novelty of trial participation, positive family and community responses to their participation; and the opportunity to emulate role models who would participate in future trials. These enablers and inhibitors were consistent with that found in the international literature (refer to Mills et al., 2004 for a systematic review of barriers to HIV vaccine trial participation) and may be used to inform the design and implementation of community preparedness and education programmes.

22.3.2 Enrolling Adolescents in HIV Vaccine Trials

The high HIV incidence in South African adolescents is driven by complex socio-cultural and political factors that include high-risk sexual behaviours, an early age of sexual debut and gender inequalities. Despite high rates of HIV infection, considerable publicity given to the epidemic in the media, and high levels of knowledge about HIV/AIDS amongst adolescents (Richter, 1996), young people continue to engage in high-risk sexual behaviours and do not perceive themselves to be at risk of HIV infection (Eaton et al., 2003). In addition, the early sexual debut of South African adolescents (Eaton et al., 2003; Health Systems Development Unit, 1998), with the mean age of first sexual encounter reported as 17 years for women and 16.4 years for young men (Reproductive Health Research Unit, Medical Research Council, 2004), may also partially account for the steep rise in HIV prevalence with age. In the context of living in conditions of extreme poverty, gender inequalities may also increase the risk of HIV acquisition in adolescent girls who may enter into transactional sexual relationships with older men (Jewkes and Abrahams, 2002). All of these drivers of high-risk sexual behaviour need to be taken into account in attempting to understand and intervene in changing adolescent sexual behaviour.

Vaccination of adolescents prior to sexual debut has been suggested as potentially one of the most effective ways to intervene in addressing high-risk adolescent sexual behaviour and curbing the spread of HIV (Kahn, 2005; McClure et al., 2004; Stevens and Walker, 2004). Thus, against the backdrop of a rampant epidemic to which adolescents appear to be particularly vulnerable, there have increasingly been calls for the inclusion of adolescents, especially those under the age of 15 years, in HIV vaccine trials (Clements et al., 2004). Paradoxically, though mass vaccination with an efficacious vaccine has the potential to circumvent the complex socio-cultural and political drivers of the epidemic in adolescence, the research development process, especially for Phase III trials is likely to be challenged by precisely these drivers.

22.3.3 Social Harms

Social harm refers to any negative trial-related experience, including adverse social incidents, trial-related discrimination, social reactions of others, psychological risks, psychosocial risks and social impacts experienced by individuals who participate in HIV vaccine trials, by virtue of their participation in such research (Milford et al., 2007). The most common form of social harm reported in the literature is trial-related discrimination resulting from the stigma associated with HIV/AIDS.

HIV-related stigma is highly prevalent in sub-Saharan Africa and may seriously hamper HIV prevention interventions (Baleta, 1999; Castro and Farmer, 2005; Kalichman et al., 2005). HIV-related stigma, therefore, presents HIV vaccine researchers with the challenge of recruiting sufficient numbers of study participants and also has implications for the ethical conduct of such research. HIV vaccine research may expose participants to the risk of being stigmatized due to their involvement in the research process. According to ethical guidelines set out in South Africa, HIV vaccine trial investigators must take reasonable steps to anticipate these potential harms and act to minimize them (Medical Research Council, 2001). Trial investigators must therefore ensure that potential participants are aware of the risk of trial-related discrimination or social harms that they may be exposed to (Allen et al., 2001) and take reasonable steps to protect trial or research participants from such harms.

Both locally and internationally, fear of stigma and discrimination has been identified as a salient factor in decision making with regard to HIV vaccine research participation and has frequently been cited as a barrier to research participation (Lesch et al., 2006; Mills et al., 2004; Strauss et al., 2001; Thapinta et al., 1999). In South Africa, research participants reported that being mistakenly presumed to be HIV infected because of their involvement in HIV vaccine research and the possibility of being stigmatized and discriminated against would significantly inhibit their willingness to participate in such research (Lesch et al., 2006). However, in spite of the concerns raised by research participants in willingness to participate and HIV vaccine feasibility studies, in vaccine trials themselves (for example, Allen et al., 2001; Sheon et al., 1998) levels of social harms reporting have remained low. For example, among a sample of 1,516 volunteers in Phase I and II HIV vaccine trials in the United States, 90 incidents of trial-related discrimination were reported by 76 (5%) of volunteers (Allen et al., 2001).

To date, most of the research on social harms has been conducted in the United States and Thailand. There have been no South African or African studies on this issue, and hence there is currently no data to suggest the extent to which incidents of trial-related discrimination are experienced in the South African context. There are also no documented reports of processes for social harms monitoring in South African HIV vaccine trials. The issue of social harms in the South African context is, however, addressed in a recent review by Milford et al. (2007). The authors highlight the fact that the social harms associated with HIV vaccine trial participation in other HIV vaccine trial contexts are also likely to be experienced in South African HIV vaccine trials. They suggest, however, that these social harms may have different manifestations in the South African context, for example, as domestic violence in the context of gender inequalities in sexual relationships that may place women at risk of violence and abandonment by their partners due to misperceptions of their HIV status (Milford et al., 2007).

It has also been suggested that improved data collection methods aimed at collecting detailed information about the social harms experienced by HIV vaccine trial participants may improve the reporting of such events (Allen et al., 2001; Sheon et al., 1998). Building an effective system of social harm monitoring into HIV vaccine research is therefore an essential component in planning for the successful conduct of such research and may go a long way towards monitoring the social harms being experienced by HIV vaccine trial participants (Milford et al., 2007). Such a system will facilitate trial investigators' ability to protect participants from experiences of social harms during their time in the study, assist in the development of support services to help research participants deal with any negative experiences that they may be exposed to, and ultimately make it easier for volunteers to enrol in HIV vaccine research. Insight into the social harms experienced by research participants may also inform community engagement efforts.

22.3.4 Community Participation in HIV Vaccine Trials

HIV vaccine trials require the participation of substantial numbers of people who reside in communities with high HIV prevalence rates. These communities therefore occupy a crucial role in efforts to develop a safe, affordable and effective preventive HIV vaccine (Wakefield, 2005). Without buy-in and support of the community, efforts to develop an effective HIV vaccine are unlikely to succeed. The need to prepare communities to participate in HIV vaccine trials and build public understanding of science is therefore a pressing one and raises questions relating to how to achieve the scientific goal of developing an effective HIV vaccine, whilst simultaneously leaving communities better off as a result of their involvement in the research process (Swartz and Kagee, 2006).

Addressing community issues in HIV vaccine research is challenging for a number of reasons. Firstly, as mentioned above, there is no single definition of who constitutes the community of interest in HIV vaccine research. Defining community in this context is further complicated by the fact that community exists at many levels and may include a broad range of stakeholder parties. In HIV vaccine research, therefore, it may be most appropriate to refer to 'the community' more broadly as all those involved in the global HIV vaccine research enterprise including HIV vaccine trial participants, their representatives, for example, CABs, trial site investigators and staff, multinational pharmaceutical companies, vaccine educators, funders and international organizations such the International AIDS Vaccine Initiative and other local stakeholder groups. In South Africa, stakeholders include government and national organizations (such as the South African AIDS Vaccine Initiative (SAAVI)), and clinical trial site staff who target local communities in order to elicit their participation in trials to test candidate HIV vaccines. All of these parties actively participate in the scientific process.

Secondly, there are also methodological challenges associated with studying community participation in HIV vaccine trials. From one perspective, HIV vaccine research and clinical trials are conducted within a scientific framework that uses epidemiological language to assign lay community members the role of research 'subjects' (Heyward et al., 1994). A contrasting perspective promotes community participation as essential to achieving success in developing an effective HIV vaccine (Wakefield, 2005). This stance promotes community participation as a key success factor, and frames HIV vaccine trial participation as a human rights issue that engages lay communities at each stage of the scientific process as research 'partners'. The differing notions of participation inherent in these two perspectives present researchers with the challenge of creating partnerships with local communities and educating them about the scientific research process, in order to facilitate informed decision-making regarding research participation, individually and as communities.

Thirdly, there are also issues involved in community education and preparedness activities that present significant challenges to researchers attempting to build public understanding of science that can serve as the foundation of community participation in the clinical trials process. Factors such as being aware of the potential risks associated with participation, understanding complex scientific information relating to HIV vaccine trial methodology (for example, the notions of placebo and randomization that are core components of clinical trial methodology), ethical considerations and the informed consent process are therefore particularly salient for participants in HIV vaccine trials (Lindegger et al., 2006).

Understanding the concept of vaccination is complicated, regardless of the context (Murphy et al., 2007). Obtaining informed consent remains a controversial process in any setting, particularly when the social understandings and language are greatly dissimilar between the researcher and participants, or when consent is rendered questionable because of low levels of literacy (Jost, 2000; Rothman, 2000). The ability of potential participants to make informed decisions regarding their participation depends on how knowledge dissemination occurs, how knowledge impacts on potential participants and how they understand this information. Assessment of how potential participants understand information about vaccine trials may therefore facilitate the development of a suitable model for the optimal diffusion of HIV vaccine trial-related knowledge to potential participants, in order for them to make informed decisions regarding trial participation. The controversies surrounding the premature closure of the recent STEP/Phambili HIV vaccine trial and the media attention that it received further contributes to the complex challenge of community education and preparedness that will need to be taken into account in the design and implementation of future community engagement interventions.

Finally, there is an expectation that clinical trials should aim to leave communities better off as a result of their participation in such research. In some instances, clinical trials may represent a social good to communities, with the potential to leave them better off in the long term (for example, should the trial lead to the development of an efficacious HIV vaccine, this is a benefit for communities who are impacted by the HIV/AIDS pandemic). However, on an individual level, no benefits will necessarily accrue to those who participate in the clinical trials to test such biomedical interventions. Hence, balancing the individual good with the social good must be a priority for HIV vaccine researchers (Kafaar et al., 2007).

The benefit of promoting community participation in HIV vaccine research is a strategic one in which communities can assist in translating research findings into practice, speed up the clinical research process and assist in making the research more efficient (Zerhouni cited in Aungst et al., 2003). However, there are currently no best practice templates for achieving meaningful community participation in HIV vaccine research, and one of the biggest challenges that researchers face is that of generating answers to the question of how best to achieve meaningful community participation in such research. Other questions that become salient in conducting activities aimed at facilitating community participation in HIV vaccine research include how best to provide communities with appropriate knowledge about clinical trials. Such knowledge must permit them to make informed decisions regarding participation, as well as help individuals to identify the contextual factors (social, cultural and community) that may influence and constrain their decision making with regard to participation in HIV vaccine clinical trials.

22.4 The Future of HIV Vaccine Research in South Africa: Challenges and Opportunities

While there have been substantial advances in social and behavioural work relating to HIV vaccines, this field of research is relatively new internationally. Existing socio-behavioural research on HIV vaccines has been able to answer descriptive questions with respect to, for example, barriers and facilitators to trial participation. More importantly, it has provided researchers working in this area with insight into the experiences and concerns that trial participants and communities who are being targeted for participation in HIV vaccine clinical trials encounter. To this extent, this body of research provides evidence that can inform the design and implementation of future clinical trials and community engagement interventions that form part of the HIV vaccine enterprise. There are, however, many explanatory questions that originate out of the current practice of HIV vaccine clinical trials that remain unanswered. Amongst the most salient of these questions within the South African context (and also globally) is: how to facilitate meaningful community participation in HIV vaccine research; how to build research literacy and public understanding of science in the context of low levels of education; and continued engagement with how to deal with the ethical challenges inherent to conducting clinical trials of this nature with vulnerable populations.

The HIV vaccine research landscape has undergone fundamental changes over the last few years. This may largely be attributed to the closure of a number of trials internationally. In South Africa, the HIV vaccine research arena has been significantly changed by the premature closure of the STEP/Phambili phase III HIV vaccine trial and the halted Ushercell microbicide trial. However, questions remain and these trial closures offer researchers the opportunity to set up networks of collaborations between all stakeholders in the HIV vaccine enterprise. These networks might include both social and biomedical scientists collaborating to generate answers to these questions and collectively reflecting on the lessons learnt from the trials that have concluded. The challenge is, therefore, to work together to build on the foundation of knowledge that currently exists to identify priorities and existing gaps in HIV vaccine research and develop a comprehensive agenda of work to provide a strong theoretical foundation and evidence to support future HIV vaccine trials.

It is widely acknowledged that the success of the HIV vaccine enterprise rests on its ability to achieve success in involving communities in the research process. However, processes of community participation have been largely ignored or at best received scant attention. It has been suggested that what is required at this juncture in HIV vaccine research is to use the lessons learnt from trial closures to address the complex community participation challenges that continue to plague work in this area (Newman, 2006). The challenge is, therefore, to use the scientific process and the interrelated activities of theory building and theory testing to generate a science of community engagement. The challenge and the opportunity that exist are to develop best practice models for community participation in HIV vaccine research that are based on evidence and rigorous design to support the successful implementation of future HIV vaccine trials. Such models will be adaptable across contexts both locally and globally and serve to guide efforts to develop a safe, efficacious and affordable HIV vaccine.

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Chapter 23
Bridging the Gap Between HIV and Mental Health Services in South Africa

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23.1 Introduction

Where AIDS is most prevalent, poverty and limited treatment render illness and death a frequent occurrence. Unlike other calamities, AIDS often comes in secret, bearing shame and the risk of rejection in addition to the anticipation of suffering and death. Many who live in settings with few resources for care can only witness the progression of the epidemic in a state of relative helplessness. Medical staff experience burnout, emotional numbing, and disengagement when AIDS cases overwhelm hospitals where treatment options are limited (Raviola et al., 2002). In settings where substantial numbers of nursing and other staff have been reported to be infected with HIV, health-care providers, a valuable community resource, are severely handicapped in their ability to provide support (Uebel et al., 2007). The epidemic seems bound to exact an emotional as well as physical toll on affected communities.

The reality in many resource-limited, high-prevalence settings is that needs for psychosocial support are not adequately met. Mental health services beyond those offered by indigenous healers are often lacking altogether (WHO, 2005). While communities have developed traditional ways of coping with the stresses that confront them, the depletion of resources alters social life and caregiving networks. These sources of support and resilience may also be undermined by the stigma associated with HIV/AIDS as families and communities are seriously constrained in seeking overt help by secrecy and fears of rejection. Moreover, the sheer weight of numbers of families affected by HIV/AIDS creates barriers to support. According to UNAIDS, South Africa remains the country with the greatest number of people living with HIV and AIDS. As of the end of 2007, an estimated 5.7 million South Africans were living with the virus (UNAIDS, 2008).

These conditions exist in a shifting global health environment—both for mental health services and HIV care and treatment. The gap between mental health service provision and need took centre stage in 2007 when the *Lancet* published a set of reviews highlighting these disparities (Jacob et al., 2007; Lancet Global Mental Health Group, 2007; Patel et al., 2007; Prince et al., 2007; Saraceno et al., 2007; Saxena et al., 2007). Even more accelerated advocacy and action have moved AIDS from the periphery of global public health concerns. Over the last 5 years,

P. Rohleder et al. (eds.), *HIV/AIDS in South Africa 25 Years On*,
DOI 10.1007/978-1-4419-0306-8_23,

we have witnessed a dramatic increase in funding and implementation of HIV care and treatment programs in sub-Saharan Africa. The Global Fund for AIDS, TB and Malaria has helped provide funds that have allowed more than 1.4 million people receive antiretroviral medication. The majority of the recipients have been in southern Africa and around 115,000 in South Africa (www.theglobalfund.org).

A key question is: How can the mental health and emotional support needs of individuals and communities be met in the context of South Africa's AIDS epidemic? To answer this question, we first describe the relationship of mental health and the prevention, treatment, and care of people living with HIV or AIDS (PLHA). We examine the South African literature on HIV prevalence and prevention for people with mental illness. We describe novel programs and explore strategies for strengthening mental health services in the context of the AIDS epidemic.

23.2 Mental Health and HIV/AIDS

Just as health is not merely the absence of disease or infirmity, mental health cannot be reduced to mental illness, disorder, or disability. Rather, individuals fall on a 'mental health continuum' with positive and negative poles. Where a specific individual falls along this continuum depends on both subjective and objective criteria. Classification systems (such as the International Classification of Diseases and the Diagnostic and Statistical Manual) have been developed so that at particular points on this continuum people are considered to have a mental disorder. This is helpful in informing diagnoses and treatment as well as identifying points at which a person may require professional intervention – both of which are critical in the setting of a complex medical illness like HIV.

Mental illness and physical illness interact in several ways in the setting of HIV infection (Cohen, 2008; Cournos and McKinnon, 2008). There may be psychiatric or psychological complications of HIV and its treatment. For example, depressive symptoms can occur in conjunction with HIV-associated dementia, as a side-effect of certain antiretroviral or other medications, or may occur as PLHA struggle emotionally at pivotal points that mark disease progression. Unfortunately, in non-mental health-care settings, clinicians treating people with AIDS often have difficulty recognizing mental health problems like depression since many of the symptoms (e.g., weight loss, fatigue, loss of appetite, and disturbed sleep) resemble those of chronic HIV infection. The reality of limited mental health resources in most high-prevalence countries simply compounds the diagnostic and treatment challenges; thus, people with HIV and mental illness are at great risk of receiving inadequate care for mental disorders.

In addition to depression, other neuropsychological manifestations of HIV occur because the virus affects the central nervous system indirectly and directly (Durvasula et al., 2008). Indirect effects can occur through opportunistic infections in the central nervous system associated with AIDS, such as toxoplasmosis. Direct effects of the virus lead to neurocognitive impairment that can include disturbances in learning, concentration, attention, information processing, language, memory, and motor functioning (Foley et al., 2008). HIV-associated dementia, HIV-associated mild neurocognitive disorder, and asymptomatic neurocognitive impairment constitute the three main categories of HIV cognitive impairment (Antinori et al., 2007). HIV-associated dementia is more likely to be seen in the absence of highly active antiretroviral therapy (HAART) and, in a Ugandan study, was found to be associated with older age and low CD4 count (Wong et al., 2007).

Mental health research among PLHA often emphasizes the assessment of distress and disorder, which are critical to ascertain in order to relieve suffering and to understand how HIV affects psychological functioning. People living with HIV, however, fall onto every point of the mental health continuum, and though there are many factors related to being HIV positive that pull PLHA towards poorer mental health at particular times, many PLHA cope extremely well emotionally. For some, their positive HIV status is the very force that has facilitated their psychological well-being and may even have been a trigger to finding meaning to life.

A growing body of research explores the impact of positive emotional states and meaning-making on life with HIV (Courtenay et al., 1998; Ickovics et al., 2006). The idea of ‘positive living’, which traditionally describes a lifestyle that involves routine taking of medication, eating well, not smoking, having safe sex, etc., should certainly include those factors that facilitate a positive attitude and help construct meaning from living with HIV/AIDS. In interviews with HIV-positive individuals in South Africa, Freeman et al. (2004) found that, while many gave devastating accounts of the difficulties of living with HIV, a number asserted that being HIV positive brought significant benefits to their lives. Some participants felt that prior to learning of their infection their lives had little meaning. But through their actions since becoming infected – mainly through helping others who are HIV positive – their lives had changed for the better. Study participants said, ‘People would come to me and I would help them and see how this had a positive effect on them, then I would ask myself what if I’d gone drinking as I had planned to, how would that person have been helped?’ and, ‘I felt good about myself and because I was living what I was teaching, the whole thing fed on itself. I was doing good for others, which in turn was doing good for me’.

23.3 Mental Illness and Its Correlates for PLHA

For many people an HIV-positive status is associated with poor mental well-being, and, for some, mental disorder at certain points during the course of the illness. A number of studies both internationally and in South Africa have shown high correlations between a range of mental disorders and HIV/AIDS (Bing et al., 2001; Ciesla and Roberts, 2001; Olley et al., 2004). Several international studies have also documented high risk for suicide among PLHA (Carrico et al., 2007; Cooperman and JM, 2005; Robertson et al., 2006). Collins et al. (2006) reviewed 39 studies that examined neuropsychiatric disorders and HIV in low- and middle-income countries and found that though many of these studies had methodological problems such as small sample sizes and no control groups, almost all studies found a high prevalence of mental disorder. In those studies that had control groups, PLHA had consistently higher levels of mental disorder than sero-negative people. More recently, Adewuya et al. (2007) reported a three-fold higher rate of psychiatric disorder among a clinic-based sample of PLHA compared to community controls in Nigeria.

Over the past 2 years, several South African studies have looked beyond the prevalence of mental disorders to explore their relationship to other factors relevant to the epidemic in South Africa. These studies link variables including discrimination, stigma, stage of HIV infection, immunologic status, and more preliminarily, adherence to mental disorders or substance use. We highlight selected studies.

Freeman and colleagues (2007) recruited 900 HIV-positive people from clinics and other HIV service centres in five provinces of South Africa, and found that nearly 44% had a diagnosable mental disorder. The sample was predominantly female, young (45 years old or younger), single, unemployed, and impoverished. Thirty percent suffered from depressive disorder (11.1% major depressive disorder), 12.4% had an alcohol use disorder and 2.9% alcohol dependence. Participants in stages 3 and 4 of HIV disease had higher rates of mental disorder. Half of the participants joined support groups after learning their seropositive status. In this highly economically disadvantaged sample, a number of factors were associated with mental disorder, including being unemployed, having children, experiencing discrimination and isolation, and having lost a close person due to AIDS. Participants in a support group were significantly less likely to have a diagnosis of a mental disorder.

In the first South African study to follow the mental health status among PLHA longitudinally, Olley et al. (2006) showed that mental disorders prevalent at the start of their study remained prevalent six months later, with some exceptions. Among the disorders, depression and PTSD were most prevalent at baseline (34 and 18%) and at follow-up. At follow-up, nearly half (48%) of the participants met criteria for at least one disorder. More than half of the depressive disorders had resolved, but the researchers identified four new cases. Symptomatic HIV and the presence of major depression at baseline were associated with a decline in CD4 counts over the course of the study. Of note, the majority of the participants did not receive any formal mental health intervention during the study period.

Stigma, a potential barrier to supportive interventions that may sustain mental health, remains a critical presence in the South African AIDS epidemic. Simbayi and colleagues (2007) studied the relationship between internalized stigma and depression in 420 men and 643 women with HIV receiving social and health services in Cape Town. Forty percent of the participants had experienced discrimination since learning their status. Men reported more internalized stigma than women, and women reported more depression. More than 30% of the sample met criteria for a depressive syndrome, and internalized stigma was an important predictor of cognitive–affective depression. Internalized stigma was associated with greater substance use and with not being Black African. Social support protected against depression and internalized stigma.

South African researchers have also begun to look more closely at the validity of psychological assessments for the many cultural groups in the country. Myer and colleagues (2008) assessed PLHA at three HIV primary care sites in the Western Cape and discovered different rates of mental disorder among the two main cultural groups in the study. They observed a higher prevalence of disorders among Afrikaans-speaking participants (largely of mixed race) compared to Xhosa speakers. The authors note that cultural differences in the expression of and importance of feeling states may, in part, account for the differences in prevalence of disorders. The study underscores the importance of creating instruments relevant for the cultural group and interpreting study findings within a context of deep cultural understanding.

23.4 Other Vulnerable Groups and Risk for Mental Illness

The AIDS epidemic carries mental health consequences for populations uniquely affected by its scourge. South Africa's 1.8 million AID-related deaths have left a flood of children orphaned due to AIDS (UNAIDS, 2008). These children struggle with the effects of poverty, stigma, and psychological distress (Cluver et al., 2008). Cluver and colleagues (2007) recruited 1,025 children and adolescents from schools, NGOs, and other community settings. The research team was able to compare mental health indices among children orphaned due to AIDS, those orphaned due to other causes, and non-orphans. They discovered significantly higher rates of depression, PTSD, and suicidal ideation among children orphaned due to AIDS.

Young sexually active women bear the brunt of the epidemic in South Africa. Women attending antenatal clinics in KwaZulu-Natal mirror the relentlessness of the epidemic, and their mental health status reflects the burden. Among 242 pregnant women receiving PMTC services at three rural antenatal clinics in KwaZulu-Natal, 41% met criteria for depression (prior to learning their serostatus) and 19% 'reported thoughts of self-harm' in the preceding 2 weeks (Rochat et al., 2006). Depression was associated with perceptions that being diagnosed with HIV would reduce access to health care due to discrimination. This high rate of depression has implications for the course of HIV disease among the 41% of the sample that tested positive as well as for the well-being of the women's children.

23.5 Mental Illness and the Course of HIV

Increasing evidence shows that where HIV infection and mental illness co-occur, physical health suffers (Antelman et al., 2007; Cook et al., 2004; Greeson et al., 2008; Hartzell et al., 2008). Depression has been linked to mortality due to AIDS in North American and African studies. AIDS-related deaths occurred more often among North American women with chronic depressive symptoms, and symptoms were more severe among women in the terminal phase of their illness (Cook et al., 2004). Women who used mental health services survived more often than those who did not. Similarly, a recent study of Tanzanian women with HIV showed that 57% experienced depression at least once during the study period, and depression was associated with disease progression and mortality (Antelman et al., 2007). The authors emphasized the importance of ensuring that women have access to and engage in psychosocial support activities in low-income settings.

Mental illness adversely affects adherence to care. Depression, traumatic life events, and psychosis have been linked to poor adherence to medication in adults and adolescents (Mugavero et al., 2006; Williams et al., 2006). In a review of HIV medication adherence studies done around the world, ‘feeling depressed’ was the second most cited barrier to adherence (Mills et al., 2006). Moreover, people with depression and/or anxiety have been found to be less likely to initiate anti-retroviral therapy compared with those without mental illness (Tegger et al., 2008). While no large-scale South African studies have systematically explored the link between adherence and mental health, substance use has been implicated. Two qualitative studies revealed that participants attributed poor adherence to their own alcohol use (Dahab et al., 2008) or to a reduced network of potential adherence support due to alcohol use among family members (Nachega et al., 2006).

23.6 HIV Infection and Risk Among People with Mental Illness

Whereas mental disorder among PLHA can be a consequence of the stressors of a positive HIV status or the effects of HIV on the central nervous system, mental disorder also precedes HIV infection and can be an important risk factor for contracting the virus. Certain psychiatric disorders, including substance abuse, increase vulnerability to HIV infection (Anonymous, 2000; Chandra et al., 2005). International studies show that HIV risk among people with serious mental illness has been associated with lack of condom use, multiple sexual partners, trading sex for money or goods, and injection drug use (McKinnon et al., 2002; Meade and Sikkema, 2005). Lack of appreciation of risk, impaired social interactions, lower levels of assertiveness, coercive sexual encounters, social exclusion, and homelessness also contribute to high infection rates (McKinnon et al., 2002; Meade and Sikkema, 2005). A recent South African study documented decreased levels of HIV knowledge among hospitalized people with schizophrenia compared to a control group (Koen et al., 2007).

Elevated HIV seroprevalence in South African psychiatric facilities confirms the need for HIV prevention activities in these settings. Unpublished pilot studies have shown an HIV prevalence of 9% in a state psychiatric facility and 29% in a psychiatric ward at a tertiary-care hospital (Singh et al., 2002; Zingela et al., 2002). A systematic assessment of HIV prevalence among patients discharged over 5 months from a public psychiatric hospital in KwaZulu-Natal, found a prevalence of 26.5%. Women were more likely to be infected than men (33.3 vs. 19.7%) (Collins et al., 2009). Three studies have examined how South African providers in psychiatric settings perceive and respond to HIV prevention needs for people with mental disorders (Collins, 2001; 2006; Moors, 2000). In most settings, HIV prevention activities were inadequate and staff felt inadequately trained to manage HIV-positive patients or deliver HIV prevention messages to people with mental illness.

Collins and colleagues worked with a core group of mental health providers at three psychiatric institutions in South Africa (Collins et al., 2006). The providers acknowledged that many of the patients were at risk of HIV infection, and they identified problem areas in which they needed further training. In response to their concerns, the research team designed a training curriculum that incorporated basic HIV/AIDS education, skills for communicating about sex and HIV prevention with patients, understanding local AIDS treatment resources, and understanding legal responsibilities associated with HIV prevention in institutional settings. The training intervention successfully increased knowledge of HIV/AIDS. Providers reported greater comfort with working with people with HIV/AIDS, and they felt more knowledgeable about providing prevention and support after the intervention (Collins et al., 2006).

The research team subsequently worked with the providers to tailor an HIV prevention curriculum for the South African setting. The curriculum manual, *Shosholoza for Health*, provided the clinical team with materials for leading prevention groups with patients admitted to the hospital. This work, as well as work in North America, showed that providers across disciplines can be trained to administer behavioural interventions and that low-cost behavioural interventions can be successfully applied in clinical settings. Thus far, however, no trials have tested the efficacy of HIV prevention interventions for people with mental illness in South Africa.

Community-based studies also support the relationship between commonly occurring mental health problems and HIV risk behaviours. One study found no correlation between sexual risk behaviour and knowledge of HIV transmission amongst a group of youth but *did* find a correlation between sexual risk behaviour and depression. This suggests that mental health status may be as important, or even more important, in determining risky sexual behaviour among youth as their understanding of HIV transmission (Moghraby et al., 2005). The relationship persists among adults, but all risk behaviours are not uniformly affected. Smit and colleagues (2006) found a relatively high prevalence of mental disorders in a Xhosa community. Among study participants depression was associated with having had coerced sex and previous treatment of a sexually transmitted infection. People who abused alcohol were more likely to have sex while under the influence of alcohol or drugs. People with PTSD were more likely to engage in transactional sex, or have sex with a casual partner. Unexpectedly, the investigators found a positive relationship between having any mental disorder and condom use, that is, having a disorder increased the odds of using a condom.

As a group, these studies suggest that successful HIV prevention will require family members, community members, teachers, and primary health-care providers to be able to recognize mental health problems, understand their consequences, and facilitate access to mental health services when they are needed. Similarly, specialist mental health providers must be aware that mental disorders can enhance risk for HIV infection. To that end, assessing the risk factors for HIV infection among people with mental illness and devising relevant prevention plans becomes another responsibility for mental health professionals and primary care providers.

23.7 Addressing the Mental Health Consequences of HIV

Given the prevalence of mental disorders among PLHA and their serious negative consequences for HIV care, it is surprising that mental health interventions have not yet become integral to HIV/AIDS interventions in South Africa. In the United States one study found that 27.2% of HIV-positive patients took psychotropic medication while many more received psychotherapeutic intervention (Vitiello et al., 2003). While the proportion of PLHA receiving mental health interventions in South Africa is not known, it is likely to be very low.

Reasons for the lack of attention to mental health care are complex. But in many respects they are very similar to the reasons why mental health is neglected in health-care services in most countries more generally and in low- and middle-income countries specifically. Chief among the barriers are lack of financial and human resources, insufficient understanding of what mental disorder is, limited identification of mental disorder in clinical or community settings, and a perception that mental health problems are not treatable. Just as people with mental illness are stigmatized, mental health services and the settings for care also carry a stigma. In a context where acute illnesses demand much attention and resources, the belief that mental health problems are not ‘real’ health problems may be more prominent.

In relation to HIV/AIDS there may be the added problem that PLHA and the community of AIDS service providers already juggle responding to multiple medical and social problems with limited resources. Integrating yet another issue – mental health – may simply seem unrealistic. PLHA and service providers may also be concerned that associating HIV with mental illness adds to the stigma of being HIV positive. Other reasons may be out of the hands of providers. Funding streams that pay for pre- and post-test counselling, antiretroviral drugs, and training of staff to provide HIV care and treatment often do not provide the funds for training or implementation of mental health interventions. Nor are these activities included among project goals. Whereas renewed funding is contingent upon providing testing and medication, programs are not rewarded for engaging in these activities. On the contrary, diverting time and resources to address mental health problems could, in certain cases, jeopardize funding. Despite the evidence that these programs need mental health services, it is often overlooked.

AIDS service providers also may not see mental health as part of their purview. After all, public mental health services exist and can receive referrals from AIDS-related health providers. The reality, however, is that mental health services are under-resourced and highly stigmatized, and even when providers refer patients, a relatively small percentage of people may actually receive services. While destigmatizing mental health problems and strengthening services should be a health system goal, a concurrent activity should be to integrate mental health services into programs that provide AIDS care and treatment. This would facilitate access for patients and increase the likelihood of follow-up.

The organization of current HIV services provides a number of opportunities to integrate mental health into programmes that serve PLHA. Currently post-test counselling in South Africa lasts for around 20 minutes (Magongo et al., 2002). Some people may require more time and emotional support than the encounter affords. If this session is conducted with adequate empathy it can open the door for people to return for more in-depth counselling as they adjust to their new status. Post-test counselling and follow-up counselling present an occasion to screen for mental health problems and provide ongoing intervention for mild and moderate problems. Evidence-based interventions for depression, like interpersonal psychotherapy, which have been used successfully in African settings, could be administered in individual or group encounters (Bolton et al., 2003). Adherence support counselling provides another space for assessing mental health needs. Support groups help to extend the supportive social network for PLHA and provide an important resource. HIV care providers can also be trained to know the local mental health resources available, make referrals to mental health services when necessary, and educate families about the mental health needs of PLHA and their caregivers.

Despite the neglect of mental health for PLHA, some innovative initiatives have started in South Africa, and we briefly describe two of these.

The Psychiatric Unit at Chris Hani Baragwanath Hospital in Soweto (Gauteng) recently started a Psychiatric HIV clinic together with Aurum Institute for Health Research as vulnerable psychiatric patients were being marginalized from antiretroviral roll-out. They renovated a disused ward and, subsequently, patients began receiving both their antiretroviral medication and psychiatric treatment in one visit. A psychiatrist, an occupational therapist, and a psychologist who assist at the clinic – over and above their regular duties at the hospital – run the unit. In addition to medical treatment, the clinic also provides a counselling group, an activities group, a support group, ARV initiation, and psychosocial assessment and individual counselling.

Volunteer counsellors who provide basic education about HIV/AIDS, psychoeducation, and adherence counselling run the counselling group. This group is vitally important to psychiatric patients, many of whom have poor cognitive functioning and require repetition of basic HIV care principles. The occupational therapist runs the activities group, which has rehabilitative services in the form of beading, fabric painting, and work assistance. The team has also established a food garden. All of the activities provide income-generating skills for this particularly marginalized group: people with mental illness and HIV. Run by a volunteer clinical psychologist, the support group provides emotional and group support to higher functioning patients in terms of both psychiatric as well as HIV/AIDS issues. A psychiatrist assesses patients to determine need for ARV and directs the ARV initiation and follow-up clinic. Finally, a nursing sister conducts psychosocial assessments and individual counselling. This nursing sister also attends to the day-to-day functioning of the clinic.

Interestingly, the popular press has initiated another mental health support service. The *Sunday Times* newspaper, one of the highest circulation newspapers in South Africa, started offering the services of two clinical psychologists free of charge in 2006. This initiative was intended to increase availability of services for people infected with or affected by HIV and AIDS. In particular, the service aimed to provide for people who could not afford private services and who were unable to access services in the public sector due to its lack of mental health human resources. The psychologists currently see two to three people per week. The clientele ranges from children who have been orphaned (and brought or referred by relatives) to domestic workers who themselves are infected or who are trying to come to terms with the diagnosis of their children to human resource managers who are grappling with ways to handle an employee who reports to them that they are HIV positive. Some clients attend because of crises relating to a long-accepted HIV-positive status, such as the impact on the marital relationship. The therapists have also counselled some people who were afraid to be tested.

It came as quite a surprise to the counsellors that a number of senior professionals with adequate medical aid have been utilizing the service. This can be explained to some extent by low literacy rates and the higher income readership of the *Sunday Times*; however, according to one of the counsellors this might also reflect an unwillingness to utilize mental health services associated with a medical environment (personal communication, K Kometsi).

23.8 Strengthening Mental Health and HIV Services

How do we ensure support for existing programs that provide mental health services for PLHA and help to develop adequate mental health programs to meet community needs? We suggest three interrelated approaches. First, use the chronic disease infrastructure developed by AIDS care and treatment programs to benefit mental health services. Second, formalize the integration of mental health and HIV services where possible. Third, organize advocacy, education, and research activities in order to keep mental health on the agenda. We discuss each below.

23.8.1 AIDS and Infrastructure

Recipients of global AIDS funding assert that resources for HIV must be used with a view toward benefitting and transforming broader health services (El-Sadr and Abrams, 2007). Funding for AIDS treatment has permitted the renovation of treatment centres, the construction of new clinics that prioritize private space for clinician-patient interactions, updating of laboratory facilities, and increased efficiency in drug procurement and maintenance of medication supplies. Multidisciplinary teams aim to address the physical, psychological, and social needs of people receiving care. Some programs have particularly emphasized family-centred models of care, encouraged engagement in care in the absence of acute illness, and have implemented effective systems of outreach and follow-up.

All of these measures can improve the management of chronic disease, including mental disorders. In fact, for years, mental health programs in rich countries have used many of the approaches used by HIV treatment programs in South Africa. Peer support programs play a key role in the management stigma for PLHA – something advocates for people with mental illness have long emphasized. Multidisciplinary teams emerged as psychiatry moved away from the asylum in the mid-twentieth century. The management of psychiatric illness in the public health systems of low- and middle-income countries has always integrated families, of necessity. But in poor settings lack of resources curtails the extent to which multidisciplinary treatment teams, community outreach and follow-up have been used. In South Africa, the resources allocated for public mental health services are insufficient.

23.8.2 Service Integration

Integration of mental health and HIV services requires articulation of goals at various levels of care (Dodds et al., 2004). In Table 23.1we have adapted Thornicroft and Tansella's matrix model of mental health services to illustrate how integration of mental health and HIV services could occur at the patient level, the local/community level, and the national or provincial level (Thornicroft and Tansella, 1999).

Using this model, we show what inputs, processes, and outcomes could be planned. Briefly, the goals of such a project include a shared commitment by HIV and mental health services to provide comprehensive care, prevention, and early intervention; co-location of mental health and HIV services; joint planning, resource, and information sharing; joint programmatic activities; and effective case referral, service planning, and follow-up (Dodds et al., 2004).

23.8.3 Advocacy, Education, and Research

Advocacy, education, and research represent three kinds of action that influence health system inputs, processes, and consequently, outcomes.

23.8.3.1 Advocacy

The Global Task Team on Improving AIDS Coordination among Multilateral Institutions and International Donors described a plan for helping countries take action on national AIDS plans. Many of the suggestions are relevant for increasing attention to mental health in the AIDS epidemic.

- Integrate advocacy for mental health into South Africa's AIDS action plans. Mental health leadership at the national and provincial levels, mental health advocacy

Table 23.1 Matrix model for integration of mental health and HIV services

	Input Phase		Process Phase		Outcome Phase	
	HIV Care	MH Care	HIV Care	MH Care	HIV Care	MH Services
Country/ Regional	• Resource sharing for mental health services and HIV services • Increase/retain human resources for HIV and MH services • Facilitate linkages/working relationships between MH Directorate, HIV division, Primary care in the Dept of Health • Establish mechanisms for collaborative planning and programming • Establish reliable communication • Facilitate linkages/working relationships between health and social service • Policies and strategic planning for integration of MH and HIV care • Include MH and HIV in poverty reduction strategies for the country		• Establish clinical guidelines and protocols for the care of people with SMI and HIV • Establish protocols for HIV prevention, testing, and care in inpatient and outpatient psychiatric facilities • Establish guidelines for MH and psychosocial support for PLHA and HIV care facilities • Establish performance and activity indicators • Minimum standards of care		• Physical morbidity • Mortality due to AIDS • Suicide and suicide attempts • Lost occupation	

Table 23.1 (continued)

	Input Phase		Process Phase		Outcome Phase	
	HIV Care	MH Care	HIV Care	MH Care	HIV Care	MH Services
Local level	• Train local HIV doctors and nurses in mental health • Train peer educators in mental health • Train mid-level counsellors in evidence-based psychotherapies;	• Train MH providers in HIV care, treatment, prevention, risk assessment; drug interactions; CNS effects of HIV • Establish working relationship and referral guidelines with AIDS care services	• Monitor number of clients with mental health needs • Document Pathways to MH services	• Monitor number of patients with HIV • Monitor number of patients receiving risk assessment, prevention education • Document pathways to HIV care	• Lost occupation • Physical morbidity • Suicide • Homelessness • Symptom severity • Impact on care givers • Satisfaction with services • Quality of life/subjective well-being • Met needs for care	
			• Establish/strengthen referral pathways between HIV and MH services • Assess continuity of care for patients needing both services • Co-location of mental health and HIV services			

Table 23.1 (continued)

	Input Phase		Process Phase		Outcome Phase	
	HIV Care	MH Care	HIV Care	MH Care	HIV Care	MH Services
Patient level	• View patient as a partner in care • Address stigma related to HIV and/or mental health in groups and individual counselling • Provide for range of social and health needs (e.g. assist with grants, employment, etc.). • Adopt a longitudinal approach		• Private settings for support groups, counselling and other MH interventions • Continuity of clinicians • Frequency of appointments/follow-up		• Lost occupation • Physical morbidity • Homelessness • Symptom severity • Impact on care givers • Quality of life • Level of disability • Met needs for care • Satisfaction with services	

Adapted from Thornicroft and Tansella, 1999. MH, mental health; CNS, central nervous system organizations, service users, and provider organizations should help shape AIDS program and budget priorities. These are all key stakeholders and should view themselves as such.

- Include mental health and its relevance to the AIDS epidemic in South Africa's poverty reduction strategies.
- Include marginalized populations, such as people with severe mental illness, in the National HIV/AIDS response and develop mechanisms to ensure that their voices are heard.

23.8.3.2 Education

The education of HIV care providers on mental health and the education of mental health-care providers on HIV prevention and treatment are critical inputs for successful integration of mental health and HIV services. Additional educational objectives should include the following.

- Educate PLHA on promotion and maintenance of mental health as well as recognizing signs of mental illness.
- Include emotional health in explanations of 'positive living' with HIV. Work with communities of varying cultural backgrounds in order to convey these messages in ways that are culturally appropriate.
- Convene joint training for HIV service providers and mental health service providers so that these groups can support each other and develop models of service integration.

23.8.3.3 Research

Government- and foundation-sponsored 'requests for applications' focused on mental health and HIV/AIDS services should stimulate research that leads to policy and service development and enables the monitoring and evaluation of both systems.

On 7 August 2008, day 5 of the International AIDS Conference in Mexico City, an official press release describing renewed commitment to expand primary health care and strengthen health systems in poor countries quoted Dr. Pedro Cahn, International Co-Chair of AIDS 2008 and President of the International AIDS Society and Fundación Huésped in Buenos Aires, Argentina (Official Press Release, Day 5, 2008):

> If the urgency of AIDS and the sheer magnitude of human loss we are now experiencing is not enough to compel us to provide even the most basic level of health care to those living in low-income countries, then we, as a global community, are morally bankrupt. . .If, in the context of AIDS, we walk away from this challenge, we may never get another chance.

Mental health care must be included in this challenge.

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