

AN HISTORICAL ANALYSIS OF THE HIV/AIDS
TRAINING OF HEALTH CARE WORKERS
IN THE WESTERN CAPE, 1989-2004

by

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Declaration

I, the undersigned, hereby declare that the work contained in this dissertation is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

Date: 20 FEBRUARY 2007

ABSTRACT

An Historical Analysis of the HIV/AIDS Training of Health Care Workers in the Western Cape, 1989-2004

The conventional view is that HIV/AIDS training organisations simply provide training to health care workers, and have no other role in the genesis and ongoing HIV/AIDS narrative. Thus, researchers have given this area little attention. With the emergence of the epidemic, training organisations have become a central constituent of HIV/AIDS responses. While they are at the forefront of much of the innovative action research in the field, little of this experience is documented. Training organisations are thus significant new sources of information about the disease. The goal of this study is to conduct an historical examination of HIV/AIDS training of health care workers in the Western Cape from 1989-2004 in order to contribute to a better understanding of this unrecorded history. By analysing how HIV/AIDS training was constructed and conducted in terms of the shifts in training content and methodology and organizational issues, links to wider historical factors were established. This study is based on qualitative historical research methods, and utilizes primary sources, secondary sources, and oral history. This analysis showed that there were significant changes in the HIV/AIDS training narratives during the period under review. The changes accord roughly with the time periods: 1989-1994, 1995-1998, 1998, and 1999-2004. These changes are discussed and analysed in terms of the underlying historical, political, socio-economic, cultural, and gender factors. The HIV/AIDS training of health care workers was intricately linked to the massive historical changes in the country during this period. It is concluded that HIV/AIDS training organisations are significant new sources of information. The depth and breadth of the information and the dynamic exchange of information between patients, health care workers, and trainers opened up fresh historiographical questions. This study fills important historiographical lacunae. The need for continued historical research in this area is highlighted. This study surmises that the critical historical perspective is valuable for the development of ongoing HIV/AIDS training and management.

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OPSOMMING

'n Historiese ontleding van MIV/vigs-opleiding vir gesondheidsorgwerkers in die Wes-Kaap, 1989–2004

Die konvensionele siening is dat MIV/vigsopleidingsorganisasies slegs gesondheidsorgwerkers oplei en geen ander rol in die ontstaan en deurlopende MIV/vigs-narratief speel nie. Gevolglik het navorsers tot dusver min aandag aan hierdie area geskenk. Met die verskyning van die epidemie het opleidingsorganisasies 'n sentrale deel van MIV/vigs-reaksies geword. Hierdie organisasies is aan die spits van 'n groot deel van die innoverende aksienavorsing in die veld, maar min bevindinge word gedokumenteer. Opleidingsorganisasies is dus belangrike nuwe bronne van inligting oor die siekte. Die doel van hierdie studie is 'n historiese bestudering van MIV/vigs-opleiding vir gesondheidsorgwerkers in die Wes-Kaap (1989–2004). Dit word gedoen om 'n bydrae te lewer tot 'n beter begrip van hierdie onopgetekende geskiedenis. Deur die ontleding van hoe MIV/vigs-opleiding saamgestel en uitgevoer is ten opsigte van die skuiwe in opleidingsinhoud, opleidingsmetodologie en organisatoriese kwessies, is skakels met wyer historiese kwessies bewerkstellig. Hierdie studie is op kwalitatiewe historiese navorsingsmetodes gegrond en maak gebruik van primêre en sekondêre bronne asook mondelinge geskiedenis. Die ontleding het getoon dat daar beduidende veranderinge in die MIV/vigsopleidingsnarratiewe was in die tydperk wat die studie uitgevoer is. Die veranderinge stem min of meer ooreen met die tydperk 1989–1994, 1995–1998, 1998, en 1999–2004. Hierdie veranderinge word ten opsigte van die onderliggende historiese, politieke, sosio-ekonomiese, kulturele en gender-faktore bespreek en ontleed. Die MIV/vigs-opleiding van gesondheidsorgwerkers is nou verbind met die belangrike historiese veranderinge wat in hierdie tydperk in die land plaasgevind het. Die gevolgtrekking word gemaak dat MIV/vigsopleidingsorganisasies belangrike nuwe inligtingsbronne is. Die omvang van die inligting en die dinamiese uitruil van inligting tussen pasiënte, gesondheidsorgwerkers en opleiers het nuwe vrae oor geskiedskrywing na vore laat tree. Hierdie studie vul belangrike leemtes in geskiedskrywing en die behoefte aan voortdurende historiese navorsing in hierdie area word beklemtoon. In hierdie studie word die vermoede uitgespreek dat die kritiese historiese perspektief waardevol is vir die ontwikkeling van voortdurende MIV/vigs-opleiding en -bestuur.

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CHAPTER ONE: Introduction

In May 2006, the Joint United Nations Programme on HIV/AIDS (UNAIDS) estimated that there were approximately 38.6 [33.4 - 46] million people living with HIV/AIDS worldwide.¹ The number of persons newly infected with HIV in 2005 was 4.1 million, while the number of AIDS deaths was 2.8 million. These new infections included 800,000 children, 90% of whom were infected through mother-to-child transmission (MTCT). Sub-Saharan Africa is the worst affected region in the world. The region has 24.5 million adults and children living with HIV/AIDS, that is, 64% of all global infections. Approximately 2 million of those infected in the region are children. In 2005, an estimated 2.7 million persons were infected, while AIDS killed approximately 2 million persons. AIDS affects women disproportionately: three quarters of all women living with HIV are in sub-Saharan Africa. UNAIDS argued that this is a result of the “highly unequal social and socioeconomic status of women and men.”² The region had approximately 12 million AIDS orphans in 2005. Historically, the disease has spread from a mysterious fatal disease that killed five men in the USA in 1981 and an undocumented number of people in Africa before this, to the leading cause of death among men and women between 15 and 59 years of age in 2006.³

Southern Africa is the global epicentre of the epidemic.⁴ South Africa has one of the worst epidemics in the world: it is estimated that 5.5 million South Africans were living with HIV/AIDS at the end of 2005. The Department of Health’s HIV

¹ UNAIDS, “2006 Report on the Global AIDS Epidemic,” May 2006, <http://www.unaids.org/en/HIV_data/2006GlobalReport/default.asp> (Accessed: 24 July 2006).

² UNAIDS, 15.

³ P. Piot, “AIDS: From Crisis Management to Sustained Strategic Response,” *Lancet*, 368 (2006): 516-530.

⁴ UNAIDS, 15.

antenatal survey of 2005 (the most recent one published) showed a national prevalence rate amongst antenatal clinic attendees of 30.2%.⁵ The HIV prevalence rates by province are: KwaZulu-Natal (39.1%), Mpumalanga (34.8%), Gauteng (32.4%), North West (31.8%), Free State (30.3%), Eastern Cape (29.5%), Limpopo (21.5%), Northern Cape (18.5%), and Western Cape (15.7%). Extrapolation of HIV prevalence to the general population is approximately 12.5%.⁶ For adults between the ages of 15 and 49, the prevalence rate is 18.78% (with approximately 60% females and 40% males). A 2004 survey found that Blacks had a prevalence rate of 12.9%, Whites 6.2%, Coloured 6.1%, and Indians 1.6%.⁷ Informal settlements in urban areas had the highest prevalence rate of 21.6%.

While the Western Cape has the lowest national HIV prevalence (15.7%), concern was expressed in 2002 about the 44% increase in prevalence from the previous year (8.6% in 2001 to 12.4% in 2002).⁸ Moreover, the relatively lower rates for the Western Cape have been questioned. A 2004 survey suggested that the statistics for the province were significantly higher than reported by the antenatal survey.⁹ For example, the 2001 antenatal survey found a prevalence rate of 8.6%, while the Nelson Mandela/HSRC Survey found a prevalence rate of 20.7%. It was argued that the antenatal survey “may not have included sufficient numbers of people living in informal settlements and Black townships.”¹⁰ Whatever the true rate, the prevalence rates are expected to significantly increase over the next five years. In 2004, a district survey of the province showed that Gugulethu and Nyanga have the

⁵ South Africa, Department of Health, “National HIV & Syphilis Prevalence Survey, South Africa, 2005,” 2006, <<http://www.doh.gov.za/docs/hiv-syphilis-f.html>> (Accessed: 25 July 2006).

⁶ Department of Health, 17.

⁷ C. Connolly et al., “Epidemiology of HIV in South Africa: Results of a National, Community-Based Survey,” *South African Medical Journal*, 94, no. 9 (2004): 776-781.

⁸ Comments made by Fareed Abdullah (Deputy Director-General of Health, Western Cape) in J. Smetherham, “Shock Rise in HIV/AIDS Figures in Province,” *Cape Times*, 12 September 2003.

⁹ Connolly et al., 781.

¹⁰ Connolly et al., 781.

highest regional HIV prevalence rate of 28.1%, followed by Helderberg (19.1%), Oostenberg (16.1%), Knysna/Plettenburg Bay (15.6%), Caledon (14.2%), and Cape Town Central (12%).¹¹ Bredasdorp (3%) and South Peninsula (6%) have the lowest infection rates in the Western Cape.

The conventional view is that HIV/AIDS training organisations simply provide training to health care workers, and play no other role in the establishment and revision of the HIV/AIDS narrative. As a result, training organisations have received little attention from scientific enquiry. Health care workers play a crucial role in the prevention and treatment of HIV/AIDS, and their training is vital to the management of the epidemic. In this study, *health care workers* refers to professional and student doctors, nurses, psychologists, social workers, and counsellors involved in HIV/AIDS prevention, treatment, support, and care. Trainers and staff in HIV/AIDS non-profit, community, and faith-based organisations are also included. Finally, because of their central role in providing HIV/AIDS prevention, care, and support, home-base carers, community health workers, traditional healers and peer HIV/AIDS counsellors and educators were also included. There have been calls to broaden the definition of HIV/AIDS health care workers, in order to make it more inclusive of all the various people involved with HIV/AIDS treatment and care.¹² Training organisations have, over time, become a central component of any HIV/AIDS strategy. They are at the forefront of much of the innovative action research in the field, yet little of this experience is documented.¹³ As a result, training organisations

¹¹ A. Thom, "Western Cape Plots HIV by District," Centre for the Study of AIDS, 7 October 2004, <<http://www.csa.za.org/article/articleview/326/1/1>> (Accessed: 25 July 2006).

¹² See, for example, WHO, "The World Health Report," 2004, <<http://www.who.int.who/2004/en>> (Accessed: 10 January 2005).

¹³ University of the Witwatersrand, HIV/AIDS Conference Webpage, 2001, <<http://www.wits.ac.za/fac/arts/history/events/aidsconf>> (Accessed: 3 May 2004).

are significant new sources of information, opening up fresh historiographical questions.

The understanding of social and historical factors in HIV/AIDS has been described as “crude and undifferentiated,”¹⁴ and seldom going beyond the issues of migrancy and poverty. The theoretical premise of this research is that the lack of critical and historically based examination of HIV/AIDS training has resulted in decontextualised and ahistorical responses in training content, methodology, and management. This research aims to fill an historiographical lacuna in the realm of the social history of medicine and disease in southern Africa, thereby improving both our historical understanding and our concomitant insights into contemporary society. Finally, it is hypothesized that a better understanding of the underlying historical contributing factors will improve the training of health care workers, and thus enhance HIV/AIDS prevention, treatment, support and care.

The goal of this study is to conduct an historical examination of HIV/AIDS training of health care workers in the Western Cape in order to analyse: firstly, how HIV/AIDS training has been constructed and conducted; secondly, the historical shifts in training content and methodology, and organizational issues; and thirdly, the underlying historical factors – political, socio-economic, cultural, and gendered – that contextualised and precipitated these shifts over time.

This study wishes to contribute to the ongoing intellectual conversation initiated by Grundlingh and James into the historicising of HIV/AIDS. It offers a new input within the discipline of history in that there is no previous historical study of HIV/AIDS training of health care workers. It fills the fissure that exists in the social history of medicine by examining the HIV/AIDS training of health care workers.

¹⁴ P. Delius and L. Walker, “AIDS in Context,” *African Studies*, 61, no. 1 (2002): 5-12.

The HIV/AIDS debate is central to the future political, economic, and social development of South Africa. This study proposes to examine the previously silent and silenced parts of the debate in order to provide an historical delineation of HIV/AIDS training and management (this is discussed in chapter two). The relevance of this study for the South African context lies not only in its examination of historical factors influencing the HIV/AIDS training of health care workers, but also in the practical recommendations on the future of HIV/AIDS training that may be drawn from other social sciences from the historical bedrock. Although it offers no policy suggestions itself, remaining strictly historical in approach, the hope is that the study will disaggregate issues historically that can then be further utilised by researchers, training organisations, NGOs, government departments, universities, administrators, and health care workers. This has broader implications for HIV/AIDS prevention, treatment, support, and care. Ultimately, how health care workers are trained in HIV/AIDS has political, economic, and social implications for South Africa and the southern African region.

The study is structured in the following way. In chapter two, the historical analysis, literature review, and methodology of the study are provided. An overview of the research trends and analyses of these trends are provided. The overview is comprised of the historical documentation of the epidemic in the USA and Europe in the 1980s, the search for the origin and early transmission of HIV/AIDS, and the research within the discipline of history. Finally, the specific historical research of HIV/AIDS prevention strategies (for example, information, education, counselling, and training) is discussed. This chapter discusses the sources that this dissertation draws on, and outlines how this study is part of the ongoing intellectual conversation in this area. The historical gaps in the literature are highlighted, and how this study

contributes to filling these gaps is outlined. This chapter discusses the initiatives that have been made by historians like Grundlingh, Fassin, Schneider, Phillips, Glaser, Delius, and Denis, and the historiographical problems and challenges in South Africa.

In chapter three, the historical changes in HIV/AIDS training content, methodology, and organisational issues are presented. These findings are organised temporally: 1989-1994: The Early Days, 1995-1998: The Growing Epidemic, 1998 onwards: The Questioning of Orthodoxy, and 1999-2003: The Generalised Epidemic. This chapter discusses the main changes in training content, methodology, and management in HIV/AIDS training over these four periods, within the context of the history of HIV/AIDS training in the Western Cape.

This chapter and those that succeed it engage with issues of discrimination and stigma, which are central to this study primarily because of their important explanatory value. Whether one is describing government or civil responses, discrimination and stigma play an important role in describing attitudes and responses. Thus, in order to understand how politicians, trainers, health care workers, and patients construed HIV/AIDS, it is useful to outline the conceptual views regarding discrimination and stigma of some of the leaders in the field of HIV/AIDS. Three phases of the HIV/AIDS epidemic have been identified: the epidemic of HIV, the epidemic of AIDS, and the epidemic of denial, stigma, and discrimination.¹⁵ In 2000, Peter Piot (Executive Director of UNAIDS) argued that the third phase was as central as the disease itself. He claimed that the issues of stigma and discrimination remain one of the “continuing challenges” to HIV/AIDS responses.¹⁶ Parker and Aggleton argued that in order to understand HIV/AIDS stigma and discrimination, it

¹⁵ J. Mann, Statement at an informal debriefing on AIDS to the 42nd Sessions of the United Nations General Assembly, New York, 20 October 1987.

¹⁶ P. Piot, Report to the Executive Director, Program Coordinating Board, UNAIDS, Rio de Janeiro, 14-15 December 2000.

is useful to first understand the pre-existing stigma and discrimination associated with sexuality, gender, race, and class.¹⁷ They held that this pre-existing stigma and discrimination resulted in particular popular misconceptions about HIV/AIDS. For example, that 'HIV is a gay plague' (sexuality); 'HIV is a women's disease' (gender), 'HIV is a White man's disease' or 'HIV is an African disease' (race), and 'HIV is a disease of the rich/poor' (class). According to UNAIDS/WHO (2001), "HIV/AIDS-related stigmatisation is not something that simply springs from the minds of individuals, it is instead linked to power and domination in the community as a whole, playing a key role in producing and reproducing relations of power and control."¹⁸ While these views describe HIV/AIDS-related discrimination globally, they are useful indicators of the historical responses to HIV/AIDS in South Africa because it followed the same path.

In chapter four, an historical analysis of the first underlying factor is presented, that is, the political factors. This chapter outlines the political responses to HIV/AIDS of the National Party government (1982-1994), the Mandela government (1994-1999), and the Mbeki government (1999-2004). The impact of government responses on health care workers and trainers are analysed. The next two sections explore the role of provincial political factors and HIV/AIDS leadership in the HIV/AIDS training of health care workers and the delivery of services in the Western Cape. This chapter seeks to contribute to the social history of medicine by examining the HIV/AIDS training of health care workers.

¹⁷ R. Parker and P. Aggleton, *HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action* (New York: The Population Council, 2002), <<http://www.popcouncil.org/pdfs/horizons/sdcncptlfrmwrk>> (Accessed: 22 April 2005).

¹⁸ UNAIDS/WHO, "Fighting HIV-related Intolerance: Exposing the Links between Racism, Stigma, and Discrimination," 2001, <<http://www.unhchr.ch/html/menu2/7/b/hivbpracism>> (Accessed: 27 April 2005).

In chapter five, a contemporary historical examination of the socio-economic factors that influenced the HIV/AIDS training of health care workers between 1989 and 2004 is presented. This chapter argues that health care workers and trainers lived and worked in specific historical and socio-economic contexts, which influenced their attitudes and responses to HIV/AIDS training and programs. The discussion begins with an examination of the socio-economic factors involved in the changes over time of health care workers' attitudes towards transmission issues, and the establishment of HIV/AIDS prevention, treatment and support programs. The next section examines these changes over time from the perspective of training organisations and health care workers. Finally, the role of training organisations in challenging and perpetuating certain socio-economic conditions in the period under review is analysed.

In chapter six, the cultural factors underlying the delivery of HIV/AIDS training to health care workers in this period is analysed. This chapter delineates the cultural factors in the perceptions of health care workers and trainers regarding the origin and transmission of HIV, the role of traditional healers in the treatment of HIV/AIDS, the provision of sex education, and the training of first language trainers. Historically, these cultural factors were important in terms of the changing political, economic and social changes that South Africa underwent with the 1994 elections.

In chapter seven, a gendered historical examination of the issues in the HIV/AIDS training of health care workers is outlined. Firstly, an historical outline of the relevant gender research is provided. This discusses the comparative dearth of HIV/AIDS gender research. Second, specific gender issues are then analysed: the biological factors in HIV transmission, violence against women, disclosure to partners, condom usage, the prevention-of-mother-to-child-transmission (PMTCT)

program, and the role of men in the pandemic. The historical responses of training organisations and health care workers to these issues are provided.

This study is concluded with a summary of the historical analysis. This précis is followed by a discussion of the important themes. Finally, the limitations of the study and the recommendations for further research are provided.

CHAPTER TWO: Historiographical analysis, literature review, and methodology.

“What can a historian say about the AIDS epidemic?” Shula Marks asked.¹ Fee and Fox have argued that AIDS has stimulated more interest in history than any other modern disease.² Researchers from various disciplines have raised historical questions, particularly in relation to epidemiological and social history: for example, historical questions have been asked about the origin of the virus and the spread of the epidemic. Yet, while the output of biomedical HIV/AIDS research is considerable and well established, there is a noticeable lack of social scientific,³ and especially historical research in Africa.⁴ This chapter provides an overview of the research trends and provides explanations for these trends. This is done by outlining the response of historians to the epidemic and discussing the development of historiographical schools through the examination of the existing historical research of HIV/AIDS in Africa. There are three primary research trends: the documentation of the epidemic in the USA and Europe in the 1980s; the search for the origin and early transmission of HIV/AIDS; and specific historical research. In terms of the thesis of this dissertation, an overview of the historical research of HIV/AIDS prevention strategies, for example, information, education, counselling, and training is provided. This is followed with a discussion of the sources that this dissertation has drawn on, and an outline of how this dissertation fills the historiographical gaps. This chapter concludes with the methodological underpinnings of this dissertation.

¹ S. Marks, “An Epidemic Waiting to Happen? The Spread of HIV/AIDS in South Africa in Social and Historical Perspective,” *African Studies*, 61, no. 1 (2002): 13-26.

² E. Fee and D. M. Fox, eds., *AIDS: The Burdens of History* (Berkeley, University of California Press, 1988), 1.

³ P. Delius and L. Walker, “AIDS in Context,” *African Studies*, 61, no. 1 (2002): 5-12.

⁴ P. Denis, “Conference Introduction: The HIV/AIDS Epidemic in sub-Saharan Africa in an Historical Perspective,” Louvain-la-Neuve, Belgium, 11-13 March 2004.

History of HIV/AIDS in the USA and Europe

Most of the history of HIV/AIDS has been written about the emergence of the pandemic in the USA and Europe in the 1980s. This is due to a number of factors. One, it is held that the initial epidemiological patterns of transmission in the 1970s are from Central Africa to Europe and the USA. Two, despite the origin of HIV in Africa and the reports of AIDS-related symptoms in African clinics as early as 1962, scientists and public health officials in the USA and Europe responded quickly to the reported symptoms of this new disease. Three, the USA and Europe had well-established systems for surveillance of diseases. Linked to this is the fact that much of the documented history of sexually transmitted diseases (STDs) was either American or British.⁵ Four, unlike Africa, the USA and Europe had the economic resources to research and respond to the disease. Five, initially the significant public response in Europe and the USA to the disease was largely due to the fear and associated historical discrimination of gay and drug user transmission. Six, in the USA and Europe there was a multidisciplinary response to HIV/AIDS, which included biomedical, social, and historical research. Seven, HIV/AIDS in Africa was neglected because of the initial and ongoing denial of HIV/AIDS by African governments and colonial powers, and the history of neglect of African diseases by the West.⁶ Notably, there is little comment on the fact that both the colonial powers and post-colonial governments in Africa in the 1970s largely ignored the disease. This issue is discussed below in the outline of African HIV/AIDS research.

⁵ V. Berridge, "Book Review of Milton Lewis, Scott Bamber, and Michael Waugh (eds.), *Sex, Disease, and Society: A Comparative History of Sexually Transmitted Diseases and HIV/AIDS in Asia and the Pacific* (Westport: Greenwood Press, 1997)," *Bulletin of the History of Medicine*, 72, no. 4 (1998): 821-822.

⁶ P. Kocheleff et al., "HTLV3/LAV Infection in Burundi, Central Africa. A Countrywide Seroepidemiological Study," (1985). Results not published because of censure by the Burundian government. Private communication with author. St. John's, 23 February 2005.

It is not the goal of this study to provide a detailed historical account of the early American and European HIV/AIDS history, and there are many comprehensive resources outlining this early history.⁷ Instead, this historical outline is provided as an introduction to the principal concepts of this dissertation. On 4 June 1981, the *Morbidity and Mortality Weekly (MMWR)*, the newsletter of the Centre for Disease Control (CDC), reported five unusual cases of pneumonia in Los Angeles.⁸ This was the first published report (outside of Africa) of what became known as the *acquired immunodeficiency syndrome (AIDS)*. On 4 July, the *MMWR* reported forty-one cases of a rare skin cancer, *Kaposi's sarcoma*.⁹ In December 1981, the first AIDS symptoms were reported in the United Kingdom.¹⁰ By the end of 1981, reports had highlighted the symptoms of the disease, yet little was known about its transmission.

At the beginning of 1982, the disease did not have a name and it was referred to by its symptoms (for example, lymphadenopathy) and by its assumed transmission sources (for example, gay compromise syndrome).¹¹ In July 1982, state health authorities in the USA reported thirty-four cases of a serious immune disorder among Haitians.¹² On 13 August 1982, the term *Acquired Immune Deficiency Syndrome*

⁷ For example, R. Bayer, *Private Acts, Social Consequences: Aids and the Politics of Public Health* (New Brunswick, NJ: Rutgers University Press, 1991); R. Bayer and G. M. Oppenheimer, *AIDS Doctors: Voices from Within* (Oxford: Oxford University Press, 2000); A. M. Brandt, "AIDS in Historical Perspective: Four Lessons from the History of Sexually Transmitted Diseases," *American Journal of Public Health*, 78 (1988): 367-71; S. Epstein, *Impure Science: AIDS, Activism and the Politics of Knowledge* (California: University of California Press, 1996); E. Fee and D. M. Fox, eds., *AIDS: The Burdens of History* (California: University of California Press, 1988); E. Fee and D. M. Fox, eds., *AIDS: The Making of a Chronic Disease* (California: University of California Press, 1992); and R. Shilts, *And the Band Played On* (New York: St. Martin's Press, 1987).

⁸ Centre for Disease Control (CDC), "Pneumocystis Pneumonia - Los Angeles," *MMWR*, 30, no. 21 (4 June 1981): 1-3.

⁹ CDC, "Kaposi's Sarcoma and Pneumocystis Pneumonia among Homosexual Men - New York City and California," *MMWR*, 30, no. 25 (4 July 1981): 305-308.

¹⁰ R. M. Dubois et al., "Primary Pneumocystis Carinii and Cytomegalovirus Infections," *Lancet*, II (1981): 249-251.

¹¹ Avert, "The History of AIDS," 12 February 2003, <http://www.avert.org/his81_86> (Accessed: 16 February 2005).

¹² CDC, "Opportunistic Infections and Kaposi's Sarcoma among Haitians in the United States," *MMWR*, 31, no. 26 (9 July 1982): 353-354, 360-361.

(AIDS) was first used to describe the emerging disease.¹³ On 10 December 1982, the first case of mother-to-child-transmission (MTCT) was reported, which indicated that an infectious agent in blood caused AIDS.¹⁴

On 7 January 1983, the heterosexual transmission of the disease from men to women was reported.¹⁵ In May 1983, the Pasteur Institute in France reported that it had isolated a virus that they believed caused AIDS.¹⁶ A sample was sent to the CDC and the virus was named lymphadenopathy-associated virus (LAV). Thus began the intercontinental feud between researchers in France and the USA about the discovery of the disease's viral agent.¹⁷ In Europe, researchers noted two distinct AIDS epidemics.¹⁸ One epidemic was linked to central Africans living in Belgium and France, while the other epidemic was linked to gay men who had visited the USA. This research was important for tracing the origin and transmission of AIDS to Africa. On 20 November 1983, Dr. Joseph Sonnaben and Dr. Anthony Fauci debated the cause of the syndrome, the former argued in the favour of multiple causes; while the

¹³ J. L. Marx, "New Disease Baffles Medical Community," *Science*, 217, no. 4560 (1982): 618-621.

¹⁴ CDC, "Epidemiologic Notes and Reports Possible Transfusion-Associated Acquired Immune Deficiency Syndrome, AIDS - California," *MMWR*, 31, no. 48 (10 December 1982): 652-654.

¹⁵ CDC, "Epidemiologic Notes and Reports Immunodeficiency among Female Sexual Partners of Males with Acquired Immune Deficiency Syndrome (AIDS) - New York," *MMWR*, 31, no. 52 (7 January 1983): 697-698.

¹⁶ Avert, "The History of AIDS," 12 February 2003, <http://www.avert.org/his81_86> (Accessed: 16 February 2005).

¹⁷ On 22 April 1984, Dr. Mason of the CDC reported the isolation of the virus responsible for AIDS (See: Avert, "The History of AIDS," 12 February 2003, <http://www.avert.org/his81_86> (Accessed: 16 February 2005). On 23 April 1984, it was announced that Dr. Gallo of the National Cancer Institute had isolated the virus that caused AIDS. It was named HTLV-III, and on the same day patent applications were filed that covered Gallo's work. In December 1985, the Pasteur Institute sued the National Cancer Institute (NCI) for its share of the royalties from the NCI's patented AIDS test. On 31 March 1987, the Pasteur Institute and U.S. Department of Health and Human Services made an agreement concerning the discovery of the viral agent. It was agreed that if the Pasteur Institute withdrew its legal claim, it could share in the profits of the HIV antibody test with the U.S. Department of Health and Human Services. The issue of whether the French or American researchers discovered the AIDS virus remained unresolved, even though it is generally accepted that the French did isolate the virus a year before the Americans (See: J. Palca, "Settlement on AIDS Finally Reached Between US and Pasteur," *Nature*, 326, no. 6113 (1987): 533).

¹⁸ I. Weller et al., "Homosexual Men in London: Lymphadenopathy, Immune Status, and Epstein-Barr Virus Infection," *Annals of the New York Academy of Science*, 437 (1984): 248-249.

latter claimed that there was a single infectious agent.¹⁹ This was the start of the causation debate that continues to this day: the most recent example of the infamous 'dissident debate' that was championed by South African President Thabo Mbeki in 1999. In 1983, AIDS was reported in Zaire,²⁰ which was the first report of HIV/AIDS in Africa. An overview of the historical reports of HIV/AIDS in Africa follows below.

In January 1985, various reports claimed that LAV and HTLV-III were the same virus.²¹ On 25 July 1985, it was announced that actor Rock Hudson had AIDS, the first American public figure to publicly announce their HIV-positive status.²² Hudson died on 2 October 1985, and his diagnosis and death did much to raise public awareness of the disease.²³ In May 1986, the International Committee on the Taxonomy of Viruses stated that both the names for the virus LAV and HTLV-III should be dropped and replaced with *Human Immunodeficiency Virus* (HIV).²⁴ In September 1986, research showed that AIDS was slowed down by the drug azidothymidine (AZT).²⁵ In January 1988, delegates from 148 countries met in London to discuss an international HIV/AIDS strategy. This meeting led to the London Declaration that promoted education, information, and human rights.²⁶ The global mobilisation for HIV/AIDS prevention and treatment was thus instituted. By the end of 1989, many of the defining HIV/AIDS concepts and debates were well

¹⁹ New York Times, "The AIDS Epidemic: 1981-1987," *New York Times (Science)*, 1999, <<http://chora.virtualave.net/timeline>> (Accessed: 15 February 2005).

²⁰ World Health Organisation (WHO), "Acquired Immune Deficiency Syndrome Emergencies," Geneva, 22-25 November 1983.

²¹ J. L. Marx, "A Virus by any Other Name," *Science*, 227 (22 March 1985): 1449-1451.

²² New York Times, "The AIDS Epidemic: 1981-1987," *New York Times (Science)*, 1999, <<http://chora.virtualave.net/timeline>> (Accessed: 15 February 2005).

²³ The involvement of public figures in HIV/AIDS awareness and prevention remains a complex issue because of the issues of confidentiality and fear of discrimination and stigma. This is true of HIV/AIDS public figures in South Africa too.

²⁴ J. Coffin et al., "What to Call the AIDS Virus?," *Nature*, 310 (1986): 10.

²⁵ M. A. Fischl et al., "The Efficacy of Azidothymidine (AZT) in the Treatment of Patients with AIDS and AIDS-Related Complex: A Double-Blind, Placebo-Controlled Trial," *New England Journal of Medicine*, 317, no. 4 (1987): 185-191.

²⁶ J. M. Mann and K. Kay, "Confronting the Pandemic: The World Health Organisation's Global Programme on AIDS, 1986-1989," *Current Science*, (1991): S221-S229.

established. For the purpose of this dissertation, the discussion will turn to the research trends beginning with the origin of the virus and the early transmission patterns. This research resulted in Africa becoming the focus of ensuing HIV/AIDS research, especially in terms of the early reports of the disease in Central and West Africa.

The Shift to Africa: Research into the Origin and Transmission of HIV/AIDS

This section provides an overview of the initial speculations that HIV was linked to Africa and the early documentation of the disease in Africa. The historical chronology shows that biomedical scientists conducted all of this research from 1983 to 1987. In 1987, the first social scientific research that dealt with HIV/AIDS in Africa was published.²⁷ There are few comprehensive historical analyses of this biomedical HIV/AIDS research in Africa in the early to mid 1980s - the most notable exceptions are Grmek²⁸ and Iliffe,²⁹ which are discussed below.

The documented history of HIV/AIDS in Africa began in 1983 with Fleming's letter in the *Lancet* that suggested that HTLV was linked to Africa.³⁰ This letter suggested that chronic lymphatic leukaemia (CLL) – a common presentation of AIDS – was frequently reported in young adults, particularly women, in West Africa (Nigeria). This letter was the first published suggestion that AIDS was linked to

²⁷ See: M. Caraël, "Le Sida en Afrique," in *Le Sida, Rumeurs et Faits* (Paris : Cerf., 1987), and D. B. Hrdy, "Cultural Practices Contributing to the Transmission of Human Immunodeficiency Virus in Africa," *Review of Infectious Diseases*, 9 (1987): 1112-1118.

²⁸ M. D. Grmek, *Histoire du Sida. Début et origine d'une pandémie actuelle* (Paris: Payot, 1989), trans. Russel C. Maulitz and Jacalyn Duffin, *History of AIDS. Emergence and Origin of a Modern Pandemic* (Princeton: Princeton University Press, 1990).

²⁹ J. Iliffe, *The African AIDS Epidemic: A History* (Oxford: James Curry, 2006).

³⁰ A. F. Fleming, "HTLV: Try Africa," *Lancet*, 321, no. 8314 (1 January 1983): 69.

Africa. Many letters and articles followed in the remainder of 1983 that explored the African genesis of the virus.³¹

In the April 1983 publication of the *Lancet*, two letters documented AIDS cases in Africa from the late 1970s.^{32,33} These letters supported the earlier reports of AIDS symptoms in Africa from at least 1976. In October, Robert Gallo et al. suggested that HTLV in the Caribbean, USA, and South America originated in Africa.³⁴ This letter was important because an eminent American AIDS researcher had agreed with the earlier letters and reports in the year that AIDS was linked to Africa. In summary, 1983 was an important year in the documentation of AIDS symptoms in Africa, most notably Zaire. Retrospective clinical cases were used to show the existence of AIDS in African patients as early as 1976. Most of these observations took the form of letters in the *Lancet*, with other letters and articles in the *New England Journal of Medicine* and the *Annals de la Société belge de Médecine tropicale*. The link between AIDS and Africa was thus established.

³¹ On 19 March 1983, Belgian researchers reported five AIDS cases of Black patients from Zaire and Chad. This was the first report of the African link of AIDS based on clinical research (N. Clumeck et al., "Acquired Immune Deficiency Syndrome in Black Africans," *Lancet*, 321, no. 8325 (1983): 642). On 26 March 1983, French researchers reviewed twenty-nine cases of AIDS in France. This letter was important because the researchers argued that the earliest AIDS diagnosis went back to 1976 to a French woman who had travelled in Africa (J. B. Brunet et al., "Acquired Immunodeficiency Syndrome in France," *Lancet*, I, no. 8326 (26 March 1983): 700-701). On 31 March 1983, French researchers documented the case of a woman from Zaire who presented with AIDS symptoms in France in June 1981. Based on the woman's reported heterosexual history, these researchers concurred with the suggestion that AIDS was not restricted to the homosexual community and drug abusers (G. Offenstadt et al., "Multiple Opportunistic Infection due to AIDS in a Previously Healthy Black Woman from Zaire," *New England Journal of Medicine*, 308, no. 13 (31 March 1983): 775). On 12 November 1983, British researchers noted that AIDS symptoms had been documented in a man in 1959. This man was in the navy and he had travelled abroad between 1955 and 1957. No direct mention of travels to Africa was made (G. William, T. B. Stretton, and J. C. Leonard, "AIDS in 1959?," *Lancet*, II, no. 8359 (12 November 1983): 1136).

³² I. C. Bygbjerg, "AIDS in a Danish Surgeon (Zaire, 1976)," *Lancet*, 324, no. 8330 (23 April 1983): 925.

³³ J. Vandepitte, R. Verwilghen, and P. Zachee, "AIDS and Cryptococcosis (Zaire, 1977)," *Lancet*, 324, no. 8330 (23 April 1983): 925-926.

³⁴ R. C. Gallo, A. Sliski, and F. Wong-Staal, "Origin of Human T-Cell Leukaemia-Lymphoma Virus," *Lancet*, 2, no. 8356 (22 October 1983): 962-963.

From 1984 to 1986, further research explored cases of AIDS in Africa.³⁵ By the end of 1986, the widespread geographical distribution of the disease in sub-Saharan Africa was established, with an epicentre in Central Africa. Two studies deserve mention with regards to the early documentation of AIDS in Africa. One, in 1987 Sonnet et al. reported a 1962 case at the University Hospital in Kinshasa, that is, fourteen years earlier than 1976 as suggested by Bygbjerg in 1983.³⁶ Two, Rémy, in a series of six papers, traced the origins of HIV/AIDS in West Africa.³⁷ These papers are an important source of HIV/AIDS history in Africa, particularly the history of HIV-2 in West Africa.

A final point concerns the difficulties of searching historical records for early cases of AIDS. Bowker argued that the International Classification of Disease (ICD) was organized in such a way that AIDS cases before the 1980s would have been

³⁵ AIDS was reported in Zambia (R. G. Downing, R. P. Eglin, and A. C. Bayley, "African Kaposi Sarcoma and AIDS," *Lancet*, I, no. 8375 (3 March 1984): 478-480), Rwanda (P. van de Perre et al., "Acquired Immune Deficiency in Rwanda," *Lancet*, 324, no. 8394 (1984): 62-65), Egypt, Tunisia, Ghana, Uganda, Nigeria, and South Africa (W. Saxinger et al., "Human T-Cell Leukemia Virus (HTLV-I) Antibodies in Africa," *Science*, 225, no. 4669 (1984): 1473-1476). In 1985, AIDS was reported in West Africa (F. Barin et al., "Serological Evidence for Virus Related to Simian T-lymphotropic Retrovirus III in Residents of West Africa," *Lancet*, 8469, no. 70 (1985): 1387-1389) and Burundi (P. Kocheleff et al., "HTLV3/LAV Infection in Burundi, Central Africa. A Countrywide Seroepidemiological Study," (1985). Results not published because of censure by the Burundian government. Private communication with author. St. John's, 23 February 2005). In 1986, AIDS was reported in Cameroon (M. Merlin, C. Bailly, et R. Josse, "Rapport de l'enquête séroépidémiologique par sondage menée à Nkongsamba, en république du Cameroun du 18 au 27 novembre 1985, pour évaluer la prévalence des anticorps anti HIV-VIH," RT 593/OCEAC/SG/SES, 1986) and the Central African Republic (M. Merlin et al., "Séroprévalence en Anticorps Anti-Virus Immunodéficitaire Humain (VIH-HIV) au sein d'échantillons représentatifs de population en Afrique Centrale," *Bull. OCEAC* (1986): 27-34).

³⁶ J. Sonnet et al., "Early AIDS Cases Originating from Zaire and Burundi (1962-1976)," *Scandinavian Journal of Infectious Diseases*, 19, no. 5 (1987): 511-517.

³⁷ G. Rémy, "Éléments d'une pré-histoire des infections à VIH. Traces sérologiques anciennes en Afrique de l'Ouest," *Médecine d'Afrique Noire*, 40, no. 1 (1993a): 9-12; G. Rémy, "Image géographique des infections à VIH en Afrique de l'Ouest. Faits et interrogations," *Médecine d'Afrique Noire*, 40, no. 1 (1993b): 15-21; G. Rémy, "Image géographique des infections à VIH en Afrique de l'Ouest. Faits et interrogations. II. Épidémiologie géographique des infections dans la population générale," *Médecine d'Afrique Noire*, 40, no. 2 (1993c): 81-86; G. Rémy, "Image géographique des infections à VIH en Afrique de l'Ouest. Faits et interrogations. III. Dynamique socio-spatiale des infections à VIH," *Médecine d'Afrique Noire*, 40, no. 3 (1993d): 161-164; G. Rémy, "L'espace épidémiologique de l'infection par le virus de l'immunodéficience humaine VIH2 en Afrique Sud-Saharienne," *Médecine Tropicale*, 53, no. 4 (1993e): 511-516; and G. Rémy, "Traces sérologiques anciennes des infections par le virus de l'immunodéficience humaine VIH-1 et VIH-2 en Afrique Sud-Saharienne. Une géographie différente," *Médecine Tropicale*, 53, no. 1 (1993f): 33-43.

distributed throughout the classification system under a number of opportunistic infections.³⁸ Thus, it is possible that earlier AIDS cases are hidden and remain unavailable in historical records. Grmek argued that contingent AIDS cases are available only because of the detailed documentation of specific cases or medical curiosities (for example, the unexplained death of a Norwegian family in the 1950s).³⁹ Thus, the history of HIV/AIDS shows that medical classification systems are determined by political factors and technological limitations.

After these early papers that documented the first AIDS cases in Africa, the most visible evidence of historical research is seen in the debate into the origin and early transmission of HIV/AIDS. This debate has produced much interest and controversy.⁴⁰ Much of this debate has resulted in the blaming of regions for the origin and spread of the disease. For example, Africa has been blamed for being the possible source of the virus, while the USA has been blamed for manufacturing the virus and experimenting on the African population. These accusations and conspiracy theories divert the discussion from the fact that this research is important in mapping the future course of the epidemic, advancing effective prevention programs, and developing sustainable treatment options, for example, vaccine development.^{41,42}

Biomedical scientists (for example, Hahn, Gao, Korber, Sharp, and Peeters), and independent researchers (for example, Hooper) have produced the principal

³⁸ G. C. Bowker, "The History of Information Infrastructures: The Case of the International Classification of Diseases," *Information Processing and Management*, 32, no. 1 (1996): 49-61.

³⁹ M. D. Grmek, *Histoire du Sida. Début et origine d'une pandémie actuelle* (Paris: Payot, 1989), trans. Russel C. Maulitz and Jacalyn Duffin, *History of AIDS. Emergence and Origin of a Modern Pandemic* (Princeton: Princeton University Press, 1990).

⁴⁰ A. Kanabus and S. Ellen, "The Origins of HIV and AIDS," 5 January 2005, <<http://www.avert.org/origins>> (Accessed: 4 February 2005).

⁴¹ L. K. Altman, "New Book Challenges Theories of AIDS Origins: Review of *The River*," *New York Times*, 30 November 1999, D1 & D6.

⁴² A. Plant, "The Origins of AIDS: On the Trail of an Epidemic," 24 June 1998, <<http://hivinsite.ucsf.edu/insite?page=spot-00-01>> (Accessed: 4 February 2005).

theories about the origins of AIDS. Historians are noticeably absent from this particular debate, and thus no clear historiographical schools have emerged.

There are two main groups of hypotheses used to account for the origin of HIV in the human population: the *natural transfer* theories, and the *iatrogenic* theories. The natural transfer theories hold that the simian immunodeficiency virus (SIV) was transferred to humans in the course of hunting and consumption contact between chimpanzees and humans, that is, the so-called “bush meat theory.”⁴³ The most recent endorsement of this theory by an historian was in 2006, when John Iliffe (Professor of Modern History at the University of Cambridge) outlined the origin and spread of HIV.⁴⁴

Determining where and when this transfer occurred has proven difficult. West central Africa is seen as the source area because of the SIV found in the chimpanzees in this area. However, chimpanzees might not be the original reservoir for HIV-1, and the virus might have been transmitted to humans on a number of occasions.⁴⁵ In 1998, a 1959 plasma sample from a man from the Democratic Republic of Congo was analysed, and it was concluded that HIV-1 was transmitted to humans in the 1940s or 1950s.⁴⁶ This research remains the earliest example of HIV from an actual blood sample. In 2000, a phylogenetic statistical analysis of the evolution of the retroviral genome of HIV suggested that the human origin of the virus was 1930.⁴⁷ This research pointed out that a 95% confidence level would cover the period 1910-1950. In addition, in 2000, research that used technology for tracing the family tree of

⁴³ E. J. van Rensburg, “The Origin of HIV,” *South African Journal of Science*, 96 (June 2000): 267-269.

⁴⁴ J. Iliffe, *The African AIDS Epidemic: A History* (Oxford: James Curry, 2006).

⁴⁵ E. Bailes et al., “Hybrid Origin of SIV in Chimpanzees,” *Science*, 300, no. 5626 (2003): 1713.

⁴⁶ T. Zhu et al., “African HIV-1 Sequence from 1959 and Implications for the Origin of the Epidemic,” *Nature*, 391 (1998): 594.

⁴⁷ B. Korber et al., “Timing the Ancestor of the HIV-1 Pandemic Strains,” *Science*, 288, no. 5472 (2000): 1789-1796.

viruses suggested that the separation between SIV and HIV occurred between 1675 and 1700.⁴⁸ This finding is limited in that the oldest blood sample is from 1959, and determining the molecular clock of a virus is difficult given that different strains are evolving and mutating at different rates. In 2006, Paul Sharp argued that Kinshasa has the greatest genetic diversity of HIV-1, which suggests that it has been there longer than any other place.⁴⁹ The above studies established two prominent hypotheses: one, that HIV is African in origin, and two, HIV originated as early as 1910.

The iatrogenic theories hold that the transfer of the virus took place as a result of the accidental or deliberate introduction of chimpanzee-derived materials into humans. Edward Hooper's *Oral Polio Vaccine* (OPV) theory is the most well known of these theories.⁵⁰ Hooper argued "polio vaccines prepared in chimpanzee tissue cultures (at least some of which were certainly contaminated with chimpanzee SIV) were administered to up to one million African "volunteers" in the 1957-1960 period."⁵¹ This hypothesis is not new: at least three researchers (namely, Tom Curtis, Louis Pascal, and Jane Alexander) were working independently on versions of this hypothesis. Of South African interest is Professor Jennifer Alexander (Head of the Department of Microbiology at the University of the Witwatersrand), who proposed the polio vaccine hypothesis in the *South African Medical Journal* (1989) and the *Lancet* (1992).⁵² As to the credibility of the polio vaccine hypothesis, there are scientists who believe that the theory deserved further investigation.⁵³ The eminent

⁴⁸ M. Salemi et al., "Dating the Common Ancestor of SIVcpz and HIV-1 Group M and the Origin of HIV-1 Subtypes Using a New Method to Uncover Clock-like Molecular Evolution," *The FASEB Journal*, 15 (2001): 276-278.

⁴⁹ J. Cohen, "Novel Attacks on HIV Move Closer to Reality," *Science*, 311 (2006): 943.

⁵⁰ E. Hooper, *The River: A Journey to the Source of HIV and AIDS* (New York: Little, Brown, 1999).

⁵¹ E. Hooper, "The Latest Scientific Evidence Strongly Supports the OPV Theory," 26 January 2005, 16, <<http://www.aidsorigins.com/badscience/bm7b>>, (Accessed: 8 March 2005).

⁵² A. Donaldson, "Heart of Darkness Revisited: Commentary on *The River*," *Sunday Times (South Africa)*, 14 November 1999.

⁵³ W. D. Hamilton, "Of Vaccines and Viruses: An African Legacy," *South African Journal of Science*, 96, no. 6 (2000): 263.

evolutionary theorist, the late W. D. Hamilton argued that Hooper's *The River* provided a good history of the epidemic, especially in sub-Saharan Africa, and that even if the OPV theory is disproved it is a reminder of the possible dangers of treatments on humans that use live products from animals.⁵⁴

There are many critics of the OPV theory: most of whom hold that the bush meat theory has been proven correct.⁵⁵ Hooper's position has shifted since the publication of *The River* in 1999: he now believes that both methods of transfer (natural and iatrogenic) may be responsible for the origin and spread of HIV.⁵⁶

Iatrogenic theories continue to flourish, linking the origin of HIV/AIDS to unsafe needles⁵⁷ and racist bias in scientific data collection.⁵⁸ For example, Harrison-Chirumuuta and Chirumuuta claimed that the scientific evidence for the African origin of AIDS is "contradictory, insubstantial or unsound, whilst the possibility that AIDS was introduced to Africa from the West has not been seriously investigated."⁵⁹ They held that it was inevitable that Black people would be blamed for the emergence of a new and deadly sexually transmitted disease. They conclude that racism has informed much of the HIV/AIDS research, which has resulted in "escalated racism, created conflict between African and Western countries, diverted resources away from areas where they are much needed, and has wasted time."⁶⁰ Crewe and Aggleton argued that the 'African AIDS' discourse has produced colonial and postcolonial images of

⁵⁴ Hamilton, 265.

⁵⁵ For example, see: (1) M. Worobey et al., "Contaminated Polio Vaccine Theory Refuted," *Nature*, 428 (2004): 820, and (2) WHO, "Statement on the Hypothesis that an Experimental Polio Vaccine was the Origin of HIV," Information Office, Statement WHO/4, 12 September 2000.

⁵⁶ E. Hooper, "How Did AIDS Get Started?," *South African Journal of Science*, 96 (2000): 265-267.

⁵⁷ P. A. Marx, P. G. Alcabes, and E. Drucker, "Serial Human Passage of Simian Immunodeficiency Virus by Unsterile Injections and the Emergence of Epidemic Human Immunodeficiency Virus in Africa," *Phil. Trans. Roy. Soc. Lond.*, 356 (2001): 911-920.

⁵⁸ R. C. Chirumuuta and R. J. Chirumuuta, *AIDS, Africa and Racism* (Derbyshire: Brentby House, 1987).

⁵⁹ R. J. Harrison-Chirumuuta and R. C. Chirumuuta, "AIDS and Africa: A Case of Racism vs. Science?," in *Africa and the Caribbean*, G. C. Bond, J. Krensike, I. Susser, and J. Vincent (New York: Westview Press, 1997), 165.

⁶⁰ Harrison-Chirumuuta and Chirumuuta, 180.

Africa as helpless and in need of assistance from the outside.⁶¹ They concluded that a more empowering discourse was required if HIV/AIDS was to be addressed properly.

In 2006, Carmichael argued that it is not a question of whether the natural transfer or iatrogenic theory could have occurred, but rather which one is correct.⁶² In order to disprove the OPV theory, researchers need to find HIV-infected human tissue that predates the polio vaccine trials. In order to prove the OPV theory, researchers need to find ancestral SIV in batches of vaccine that were made in Kisangani. The likelihood of either of these happening seems remote.⁶³

An attempt to combine natural transfer and iatrogenic theories is seen in the work of Chitnis, Rawls, and Moore, who argued that socio-cultural factors during the postcolonial period had an important role in the spread of the disease.⁶⁴ They held that the origin of HIV lies in the reciprocity of colonial practices (for example, labour camps and vaccination campaigns) and traditional bush meat hunting in French Equatorial Africa prior to World War II. They argued that workers were exposed to the virus because of an increased reliance on bush meat, which was the result of forced labour practices and decreased farming in the harvesting of rubber. The virus was then rapidly transmitted by the large influx of people to cities. Labour camps and hostels were set up for men which encouraged multiple partners and prostitution because these men were isolated from their families for long periods of time. Finally, Chitnis, Rawls, and Moore argued that the transmission of the virus was aided by the large-scale vaccination campaigns. While the validity of this theory has been

⁶¹ M. Crewe and P. Aggleton, "Racism, HIV/AIDS and Africa: Some Issues Revisited," *South African Journal of International Affairs*, 10, no. 1 (2003): 139-149.

⁶² M. Carmichael, "How it Began: HIV before the Age of AIDS," *Frontline*, 30 May 2006, <<http://www.pbs.org/wgbh/pages/frontline/aids/virus/origins>> (Accessed: 16 August 2006).

⁶³ Carmichael.

⁶⁴ Chitnis, Rawls, and Moore argued that socio-cultural factors might even be important to understanding the origin of HIV. This point shall be addressed in more detail below. See: A. Chitnis, D. Rawls, and J. Moore, "Origin of HIV Type 1 in Colonial French Equatorial Africa?," *AIDS Research and Human Retroviruses*, 16, no. 1 (2000): 5-8.

questioned,⁶⁵ such studies highlight the attempts to document the history of the origin and transmission of HIV in Africa. Researchers like Schoofs have argued that the origin of the virus is biological, while the origin of the epidemic is both biological and social.⁶⁶ Thus, historians have an important part to play in the documentation and analysis of both the origin of the virus and the origin of the epidemic. Some of the factors examined in the shaping of country responses to HIV/AIDS – for example, colonialism, urbanisation, economic growth, labour migration, gender and economic inequality, sexual morality, religion, war, border issues, nationalism, health services, and political factors⁶⁷ – need further examination in the historical analysis of the origin of HIV and transmission of HIV/AIDS.

Historical Research

The historical analysis of HIV/AIDS in Africa is both relatively limited and recent. This section examines the reasons for the restricted involvement of historians and provides an overview of historical HIV/AIDS research in Africa. In examining historical HIV/AIDS research, it is useful to highlight the mix of professional disciplines and perspectives in the historical accounts of the epidemic. Journalists were responsible for some of the historical documentation of the early days of the epidemic in the United States⁶⁸ and Africa.⁶⁹ History has also been combined in interdisciplinary initiatives with science, sociology, anthropology, political science, and

⁶⁵ For example, E. Hooper, "A Response to Chitnis et al.," 2000, <<http://weber.ucsd.edu/~jmoore/publications/hivhooper>> (Accessed: 9 March 2005).

⁶⁶ M. Schoofs, "AIDS: The Agony of Africa," *The Village Voice*, 1-7 December 1999, <<http://thebody.com/schoofs/africa4>> (Accessed: 9 March 2005).

⁶⁷ V. Berridge, "Book Review: Sex, Disease, and Society: A Comparative History of Sexually Transmitted Diseases and HIV/AIDS in Asia and the Pacific," *Bulletin of the History of Medicine*, 72, no. 4 (1998): 821-822.

⁶⁸ For example, R. Shilts, *And the Band Played On* (New York: St. Martin's Press, 1987).

⁶⁹ For example, C. Braechman, *Le Sida à Ses Debuts et la Mystere du MMI (The Initial Stages of AIDS and the Mystery of MMI)*, conference paper, The HIV/AIDS Epidemic in sub-Saharan Africa in an Historical Perspective Conference, Louvain-la-Neuve, Belgium, 11-13 March 2004.

activist theory.⁷⁰ Berridge noted that this blend of contributions has added to the vitality in the field, but, nevertheless, historians have a unique contribution to make.⁷¹ She did not cite the reasons for the absence of historical contributions. Recent international HIV/AIDS conferences stressed the important role of sociological, anthropological, and historical approaches to the study of HIV/AIDS.⁷²

Social scientists have made a significant contribution to the history of the disease, particularly in the 1990s,⁷³ and the output of African related HIV/AIDS social research has become vast.⁷⁴ Social scientific HIV/AIDS research can be divided into Anglophone and Francophone research. This delineation reflects the bulk of HIV/AIDS research in Africa conducted in the biomedical sciences, social sciences, and humanities. Little HIV/AIDS research in Africa has been produced in any other than these two languages.⁷⁵ The details of this research are beyond the scope of this dissertation.⁷⁶ This early research by social scientists was important because it

⁷⁰ Berridge, 6.

⁷¹ Berridge, 6.

⁷² For example, the XIII International AIDS Conference, Durban, 2000; the XIV International AIDS Conference, Barcelona, 2002; the XV International AIDS Conference, Bangkok, 2004; and the XVI International AIDS Conference, Toronto, 2006.

⁷³ For a detailed historical bibliography of this research, see: S. van Houten et C. Becker, "L'histoire du sida en Afrique subsaharienne : un bilan bibliographique," in P. Denis et C. Becker, eds., *L'épidémie du sida en Afrique subsaharienne. Regards historiques* (Louvain-la-Neuve et Paris: Academia Bruylant et Karthala, 2006), 359-405.

⁷⁴ See for example: *Sociétés d'Afrique et Sida*, <http://www.ssd.u-bordeaux2.fr/sas/base_doc>.

⁷⁵ S. van Houten et C. Becker, "L'histoire du sida en Afrique subsaharienne : un bilan bibliographique," in P. Denis et C. Becker, eds., *L'épidémie du sida en Afrique subsaharienne. Regards historiques* (Louvain-la-Neuve et Paris: Academia Bruylant et Karthala, 2006), 359-405.

⁷⁶ Anglophone HIV/AIDS research included the exploration of the social context of HIV/AIDS in Africa (J. C. Caldwell, P. Caldwell, and P. Quiggin, "The Social Context of AIDS in Sub-Saharan Africa," *Population and Development Review*, 15, no. 2 (1989): 817-848), and the relationship between migrant labour, sexually transmitted diseases, and AIDS (C. W. Hunt, "Migrant Labour and Sexually Transmitted Disease: AIDS in Africa," *Journal of Health and Social Behaviour*, 30, no. 4 (1989): 353-373). Moreover, further research explored the allocation of health resources in southern Africa (S. Marks and N. Anderson, "The State, Class and the Allocation of Health Resources in Southern Africa," *Social Science and Medicine*, 28 (1989): 515-530), the role of ethics, religion and AIDS in development issues (C. de Sweemer, "Ethics, Inequity, Religion and AIDS in Developing Countries," in ed. L. d'Almeida, *Plurale*, 1, no. 1 (1989): 149-152), and there was also research into the origins and diffusion of HIV/AIDS from the perspective of medical geography (G. W. Shannon and G. F. Pyle, "The Origin and Diffusion of AIDS: A View from Medical Geography," *Annals of the Association of American Geographers*, 79, no. 1 (1989): 1-24).

Francophone HIV/AIDS research examined issues like the socio-political factors of HIV/AIDS in Africa (J.-P. Dozon et D. Fassin, "Raison épidémiologique et raisons d'Etat. Les enjeux socio-

highlighted the social context of HIV/AIDS, set the agenda for research that followed, and challenged the predominance of biomedical HIV/AIDS research. The discussion now turns to specific historical HIV/AIDS research.

In 1986, two papers provided examples of historical analyses of HIV/AIDS in their comparative analysis of HIV/AIDS to previous epidemics. Porter argued that the history of other epidemics showed that heavy-handed and moralistic public responses did little to curb or manage epidemics.⁷⁷ This position was in response to the early calls for stricter public health measures to what was perceived as the gay transmission of AIDS in the United Kingdom. Mathews Smith asserted that attention to the prevention of other diseases throughout history would assist with the management of HIV/AIDS.⁷⁸ These papers illustrate the importance of comparative historical analyses in which HIV/AIDS was compared to previous diseases and plagues, particularly sexually transmitted diseases. This approach can be criticised on the grounds that such comparative historical analyses are limited because no two epidemics are the same and thus each one needs to be approached in terms of its unique contributing historical factors.

In 1988, two important American publications appeared. Fee and Fox edited a book, which they argued was an attempt to introduce a more historical approach to

politiques du Sida en Afrique," *Sciences Sociales et Santé*, 7, no. 1 (1989): 21-36), anthropological analysis of HIV/AIDS in Lobaye, Central African Republic (A. Epelboin, "SIDA et sida: Réflexions anthropologiques à propos du phénomène sidaique en Lobaye, en République centrafricaine," *Bull. Soci. Path. Ex.*, 82, no. 2 (1989): 260-266), and legal and ethical issues (C. Sané, "Quelques problèmes juridiques soulevés par le sida au Sénégal," *Plurale*, 1, no. 1 (1989): 141-148). Collignon and Becker published a bibliography of health and population research in Senegal and Gambia (R. Collignon et C. Becker, *Santé et population en Ségambie des origines à 1960. Bibliographie annotée* (Paris: INED, 1989), 9-554, <http://www.tekrur.org/Biblio_departement.htm>). This bibliography is a useful historical document of health policies and implementation, and the precursors of HIV/AIDS in that region.

⁷⁷ R. Porter, "History Says No to the Policeman's Response to AIDS," *British Medical Journal*, 293 (1986): 1589-1590.

⁷⁸ H. Mathews Smith, "AIDS: Lessons from History," *MD* (1986): 43-51.

HIV/AIDS.⁷⁹ They contended that up to 1989 there had been a superficial use of history in discussions of the HIV/AIDS epidemic, and that this had led to crude generalisations. They provided examples of these generalisations: “authority has always prevailed over liberty during periods of social terror about infectious disease,” and “medical progress for more than a century has made plain the fundamental biological origins of disease.”⁸⁰ They held that history has an important part to play in challenging such generalisations. Moreover, Fee and Fox concluded that the historical method had an important part to play in the HIV/AIDS debate, especially in the formation of public policy. The importance of the historical method in the HIV/AIDS debate is supported by this dissertation. In the second publication, Brandt argued that the history of sexually transmitted diseases provided important lessons⁸¹ that were still relevant to HIV/AIDS prevention and management initiatives.⁸² These two books outlined the importance of history to the HIV/AIDS debate, and raised important questions about contemporary social and epidemiological history.

In 1989, Grmek, the French classicist and historian, published a book on the history of HIV/AIDS.⁸³ Grmek argued that AIDS was not a new disease, but that it had already existed in the past.⁸⁴ AIDS appeared again, he held, as an epidemic because of agreeable biological, ecological, and social changes.⁸⁵ Grmek also

⁷⁹ E. Fee and D. M. Fox, eds., *AIDS: The Burdens of History* (California: University of California Press, 1988).

⁸⁰ Fee and Fox, “Burdens,” 1.

⁸¹ The first lesson is that medical approaches and public health policy are influenced by how much the disease is feared. The second lesson is that education will not control the HIV/AIDS epidemic. The third lesson is that compulsory public health measures will ultimately not check the epidemic. Finally, the fourth lesson is that effective treatment and vaccines will not end the epidemic. Notably, all four lessons are still relevant to the prevention and management of HIV/AIDS today.

⁸² A. M. Brandt, “AIDS in Historical Perspective: Four Lessons from the History of Sexually Transmitted Diseases,” *American Journal of Public Health*, 78 (1988): 367-371.

⁸³ M. D. Grmek, *Histoire du Sida. Début et origine d'une pandémie actuelle* (Paris: Payot, 1989), trans. Russel C. Maulitz and Jacalyn Duffin, *History of AIDS. Emergence and Origin of a Modern Pandemic* (Princeton: Princeton University Press, 1990), 109.

⁸⁴ M. D. Grmek, “Le concept de maladie émergente,” *Hist Phil Life Sci*, 15 (1993): 281-296.

⁸⁵ M. D. Grmek, “Some Unorthodox Views and Selection Hypothesis of the Origin of the AIDS Viruses,” *Journal of the History of Medicine*, 50 (1995): 253-273.

questioned how AIDS could be observed if the biological tools and concepts to correctly identify AIDS did not exist twenty years before. He stated that, since in “the tropics, the wealth of lethal infectious pathology is matched by the poverty of diagnostic facilities, rendering undetectable sporadic appearances of AIDS, it is entirely possible that localised or even moderately large epidemics have passed unnoticed.”⁸⁶ Biomedical scientists still largely undervalue Grmek’s work because of his historical questioning of their basic empirical concepts and methodology, and the fact that his hypotheses have been taken up by the proponents of the iatrogenic theories of the origins of AIDS. Despite the criticism of certain of his assertions, Grmek’s work illustrated the importance of a detailed historical enquiry of HIV/AIDS.

In 1990, Hooper published a reporter’s account of AIDS in East Africa.⁸⁷ This was the beginning of Hooper’s historical research into the origin of the virus, as outlined above. In 1993, Berridge and Strong edited a book dealing with HIV/AIDS and contemporary history.⁸⁸ The book is organised around the themes of ‘AIDS as history’ (recent events) and the ‘pre-history of AIDS’ (distant events). In analysing the history of HIV/AIDS, Berridge argued that the relationship between HIV/AIDS and history changed between 1983 and 1993.⁸⁹ Initially, historical research focused on the ‘lessons of history’ by comparing HIV/AIDS to previous epidemics.⁹⁰ This was done in order to draw parallels between issues like transmission, treatment, and societal reactions. The HIV/AIDS focus in history shifted towards issues in

⁸⁶ M. D. Grmek, *Histoire du Sida. Début et origine d’une pandémie actuelle* (Paris: Payot, 1989), trans. Russel C. Maulitz and Jacalyn Duffin, *History of AIDS. Emergence and Origin of a Modern Pandemic* (Princeton: Princeton University Press, 1990), 109.

⁸⁷ E. Hooper, *Slim: A Reporter’s Own Story of AIDS in East Africa* (London: The Bodley Head, 1990).

⁸⁸ V. Berridge and P. Strong, eds., *AIDS and Contemporary History* (Cambridge: Cambridge University Press, 1993).

⁸⁹ V. Berridge, “Introduction: AIDS and Contemporary History,” in *AIDS and Contemporary History*, eds. V. Berridge and P. Strong (Cambridge: Cambridge University Press, 1993), 1.

⁹⁰ For a recent example of this approach, see chapters 3 and 4 of S. Hunter, *Who Cares? AIDS in Africa* (New York: Palgrave, Macmillan, 2003).

contemporary history, thus changing the form and function of history from distant events to more recent events.

In the introduction, Berridge asked what historians could contribute to HIV/AIDS research.⁹¹ This question was raised in the context of British, European, and American HIV/AIDS policy development, but its wider historiographical implications have contemporary relevance in Africa and other regions with increasing HIV/AIDS rates. Berridge argued that the strength of the historical approach lies in “the historian’s sense of chronology; the historical sense of continuity as well as change; and, within the overall chronology, a synthetic and critical ability to interweave and assess different forms of source material and different levels of interpretation.”⁹² Berridge concluded with the following observations. First, many areas of ‘pre-history’ and ‘AIDS as history’ have not been researched. This statement is still true over a decade later. Second, these papers highlight the vitality of the historical method when applied to HIV/AIDS. Third, the cross-fertilisation from other disciplines is vital to the historical analysis of HIV/AIDS. Berridge’s work remains essential to the history of HIV/AIDS.

In 1994, the Belgian historian based in Senegal, Charles Becker, published two papers on HIV/AIDS. The first paper explored the history of social responses to epidemics in Senegal.⁹³ The second paper provided a history of the church and HIV/AIDS in Africa.⁹⁴ Becker’s continuing research is important in the historical examination of HIV/AIDS, particularly in West Africa. His areas of interest include: HIV/AIDS ethics, public health, the effects of colonialism on health, and prevention

⁹¹ Berridge, “Introduction,” 12.

⁹² Berridge, “Introduction,” 12.

⁹³ C. Becker, “Past Social Responses to Epidemics and the Present Outbreak of HIV-AIDS in Senegal: Community Responses of the Past and Current Ethical Issues,” in *African Network on Ethics Law and HIV*. Proceedings of the Intercountry Consultation, Dakar, Senegal, 27 June - 1 July, 1994 (Dakar, UNDP, 1994a), XIV-220.

⁹⁴ C. Becker, “L’église et le sida en Afrique,” *Afrique & Parole*, 39 (Février 1994): 2-4.

strategies. Other relevant Francophone HIV/AIDS research includes that of Didier Fassin, who publishes germane historical HIV/AIDS research with a primary focus on HIV/AIDS and African immigration to France, and the history of South Africa's response to HIV/AIDS, especially the response of President Mbeki's government.

Between 1995 and 1997, there was further historical HIV/AIDS research produced in southern Africa,⁹⁵ and South Africa.⁹⁶ At this point few South African historians, besides Grundlingh and Campbell, were contributing to the HIV/AIDS debate. The reasons for this remain unclear, and there are no analyses by South African historians as to why this is so. Grundlingh's contribution to the history of HIV/AIDS in South Africa, as discussed below, was groundbreaking and remains essential.

In 1999, Tessa Marcus, the South African sociologist, published an important history of the impact of HIV/AIDS on South African children with a focus on KwaZulu-Natal.⁹⁷ Grundlingh argued that the government failed in their response to HIV/AIDS because of stigmatisation and discrimination, particularly against gays and Blacks.⁹⁸ In 2000, two papers were notable for their focus on the history of Apartheid

⁹⁵ For example, brief histories of HIV/AIDS in Namibia (R. A. Sloten, "AIDS in Namibia," *Social Sciences and Medicine*, 41, no. 2 (1995): 277-284), and Botswana (R. Mandeva, "Botswana: Where Young Girls are Easy Prey," *AIDS Analysis Africa*, 5, no. 4 (1995): 12-13).

⁹⁶ In 1995, Whiteside and Van Niftrik examined the history of the ANC's response to HIV/AIDS in South Africa (A. Whiteside and J. Van Niftrik, "AIDS in South Africa: Government and ANC Responses," *AIDS Analysis Africa*, 3, no. 4 (1995): 1 & 9). In 1996, Williams and Campbell published a paper on the history of mining labour and HIV/AIDS in South Africa (B. Williams and C. Campbell, "Mines, Migrancy and HIV in South Africa: Managing the Epidemic," *South African Medical Journal*, 86 (1996): 1249-1251). In 1997, Campbell provided further research on migration and HIV/AIDS on South African gold mines (C. Campbell, "Migrancy, Masculine Identities, and AIDS: The Psycho-Social Context of HIV Transmission on South African Gold Mines," *Social Science and Medicine*, 45, no. 2 (1997): 273-281). Grundlingh outlined the development of HIV/AIDS historiography in South Africa (L. Grundlingh, "The Nature and Development of HIV/AIDS Historiography," *Acta Academica*, 29, no. 2 (1997): 1-26). Finally, Schaay explored the history of HIV/AIDS NGOs in South Africa (N. Schaay, "The History and Development of NGO-Based HIV/AIDS Work in South Africa," *The South African STDs/HIV/AIDS Review Report*, 1997).

⁹⁷ T. Marcus, *Wo! Zaphela Izingane, It is Destroying the Children: Living and Dying with AIDS* (Pietermaritzburg: The CINDI Network, 1999).

⁹⁸ L. Grundlingh, "HIV/AIDS in South Africa: A Case of Failed Responses because of Stigmatisation, Discrimination and Morality, 1983-1994," *New Contree*, 46 (1999): 55-81.

and HIV/AIDS. Crewe examined the history of South Africa to explain President Mbeki's response to HIV/AIDS.⁹⁹ Fassin outlined the link between the high rates of HIV/AIDS and post-Apartheid political structures in South Africa and Namibia.¹⁰⁰ Mbeki's dissident views were examined historically, and this was probably the first HIV/AIDS topic to be taken up by many historians, as opposed to single topics being addressed by a few historians.¹⁰¹

In 2001, the *Aids in Context: Explaining the Social, Cultural and Historical Roots of the Epidemic in Southern Africa* Conference (University of the Witwatersrand, South Africa) brought mostly South African historians together to examine HIV/AIDS.¹⁰² The goal of this conference was to examine the specific interaction of historical, social, political and cultural factors that have formed the nature of the HIV/AIDS epidemic. This was the first history conference on HIV/AIDS in Africa: the conference was important not only for this fact but also for the huge response to the conference and the wide range of topics covered in the over one hundred papers that were presented.

Also in 2001, the *South African Historical Journal* published an issue dealing with the history of sexually transmitted infections (STIs) and HIV/AIDS in South Africa.¹⁰³ This publication utilised the strategy previously used in the USA and the

⁹⁹ M. Crewe, "South Africa: Touched by the Vengeance of AIDS," *South African Journal of International Affairs*, 7, no. 2 (2000): 23-39.

¹⁰⁰ D. Fassin, "Une crise épidémiologique dans les sociétés de post-apartheid. Le sida en Afrique du sud et en Namibie," *Afrique contemporaine*, 195 (2000): 105-115.

¹⁰¹ For example, P. Denis, "La croisade du président Mbeki contre l'orthodoxie du sida," *Esprit*, 271 (2001): 81-113; D. Fassin and H. Schneider, "The Politics of AIDS in South Africa: Beyond the Controversies," *British Medicine Journal*, 326 (2001): 495-497; V. van der Vliet, "AIDS: Losing 'The New Struggle'?", *Daedalus*, (2001): 130, no. 1 (2001): 151-184; U. Kistner, "Necessity and Sufficiency in the Aetiology of HIV/AIDS: The Science, History and Politics of the Causal Link," *African Journal of AIDS Research*, 1, no. 1 (2002): 53-63; D. Fassin, "Embodied History. Uniqueness and Exemplarity of South African AIDS," *African Journal of AIDS Research*, 1, no. 1 (2002): 65-70; and H. Schneider, "On the Fault-Line: The Politics of AIDS Policy in Contemporary South Africa," *African Studies*, 61, no. 1 (2002): 145-167.

¹⁰² Explaining the Social, Cultural and Historical Roots of the Epidemic in Southern Africa Conference, <<http://www.wits.ac.za/fac/arts/history/events/aidsconf>>.

¹⁰³ *South African Historical Journal*, 45 (November 2001).

UK of grouping STIs and HIV/AIDS in order to highlight historical similarities and lessons in the prevention, treatment, and legislation.¹⁰⁴ Grundlingh published two papers: one, an examination of responses to HIV/AIDS in South Africa from 1983 to 1988,¹⁰⁵ and two, the examination of the response of the South African government to HIV/AIDS as represented in the media between 1983 and 1994.¹⁰⁶ Historiographically, the latter paper is particularly important in terms of the wealth of data collected and the specific pronouncements of government and religious leaders concerning the purported transmission of the disease by gays and Blacks. No other historian has captured the nuances and power of those discriminatory attitudes in the early responses to HIV/AIDS in South Africa.

In 2002, *African Studies* published nine papers in a special HIV/AIDS issue: these papers were selected from the *Aids in Context* Conference the year before.¹⁰⁷ In the introduction, Delius and Walker claimed that there is a limited understanding of the interaction of historical, social, political, and cultural factors in HIV/AIDS.¹⁰⁸ In the first paper, Marks placed the HIV/AIDS epidemic in South Africa in a social and historical perspective.¹⁰⁹ In answering the question “What can a historian say about the AIDS epidemic?” Marks argued that one of the lessons of history is that individuals and communities can be empowered to transform behaviour, even high-risk behaviour.¹¹⁰

¹⁰⁴ For example, Berridge and Strong.

¹⁰⁵ L. Grundlingh, “Early Responses, Attitudes and Behaviour regarding HIV/AIDS in South Africa, 1983-1988,” *Journal of Contemporary History*, 26, no. 1 (2001): 86-103.

¹⁰⁶ L. Grundlingh, “A Critical Historical Analysis of Government Responses to HIV/AIDS in South Africa as Reported in the Media, 1983-1994,” *South African Historical Journal*, 45 (2001).

¹⁰⁷ See *African Studies*, 61, no. 1 (2002).

¹⁰⁸ Delius and Walker, 5-12.

¹⁰⁹ Marks, 13.

¹¹⁰ Marks, 22.

In 2002, with regards to historiography, Ellis argued historians had failed to properly examine the HIV/AIDS epidemic in Africa.¹¹¹ Ellis argued that HIV/AIDS formed an important part of African life and historians should contribute to the debate in order to assist with the management of the epidemic. In South Africa, Grundlingh, in an unpublished paper, outlined the history of HIV/AIDS education in South Africa in the 1980s and 1990s.¹¹² He provided an important history of the first education campaigns as well as the origins of training organisations like the establishment of the AIDS Training, Information, and Counselling Centres (ATICC) in the country.

In 2003, various historical publications included papers dealing with HIV/AIDS in South Africa.¹¹³ In March 2004, the *HIV/AIDS Epidemic in Sub-Saharan Africa in an Historical Perspective* Conference, (Louvain-la-Neuve, Belgium, 11-12 March 2004) brought together international historians, social scientists, and health professionals in order to contribute to the field of historical HIV/AIDS research.¹¹⁴ The conference objectives included the biomedical, epidemiological, anthropological, economic, political, and cultural documentation of the history of the epidemic in Africa, especially sub-Saharan Africa. It was concluded that more research by African and international historians and other researchers using an historical methodology is needed. The main papers of this conference were

¹¹¹ S. Ellis, "Writing Histories of Contemporary Africa," *Journal of African History*, 43, no. 11 (2002).

¹¹² L. Grundlingh, "Neither Health nor Education? An Historical Analysis of HIV/AIDS Education in South Africa, 1980s-1990s," Development Studies Seminar, RAU, South Africa, 24 May 2002, <<http://general.rau.ac.za/sociology/Grundlingh2.PDF>> (Accessed: 1 August 2005).

¹¹³ For example, Carton provided a social history of South Africa, which included the impact of HIV/AIDS on people (B. Carton, "The Forgotten Compass of Death: Apocalypse Then and Now in the Social History of South Africa," *Journal of Social History*, 37, no. 1 (2003): 199-218). Denis examined sexuality and HIV/AIDS in South Africa (P. Denis, "Sexuality and AIDS in South Africa," *Journal of Theology for Southern Africa*, 113 (2003): 63-77), while Phillips provided an historical perspective of HIV/AIDS and epidemics in South Africa (H. Phillips, "AIDS in South Africa: An Historical Perspective," *Society*, 40 (2003): 72-76). Gisselquist and Potter explored the role that poor health care played in the transmission of AIDS in South Africa (D. P. Gisselquist and J. J. Potterat, "Let it be Sexual: How Health Care Transmission of AIDS in Africa was Ignored," *International Journal of STD AIDS*, 14 (2003): 148-161).

¹¹⁴ For the conference outline, see *Institut des études du développement*, <http://www.dvlp.ucl.ac.be/colloques/chairafri_sidaafrique> (Accessed: 2 August 2005).

published in an English (to be published in 2007) and a French (published in late 2006)¹¹⁵ volume.

In 2004, Phillips argued that HIV/AIDS requires both a comparative analysis to other South African epidemics and an examination of its unique and distinctive features.¹¹⁶ He stated that one of the relative failures of South African historiography is the lack of historical narratives of South African epidemics. Thus, he stressed the importance of both the 'prehistory of HIV/AIDS' and 'AIDS as history.' In 2005, there were further examples of historical HIV/AIDS research in South Africa.¹¹⁷

Finally, in 2006 John Iliffe published a history of HIV/AIDS in Africa.¹¹⁸ Iliffe argued that in order to better understand the devastating epidemic in Africa one needs to look at historical sequence. He argued that the spread of HIV and the responses to it were determined by the unique characteristics of the virus: the fact that the virus is mildly infectious, slow acting, incurable, and fatal. He established western equatorial Africa (Cameroon and the DRC) as the likely source of HIV in Africa, and he outlined migration routes. He claimed that the continental spread of the disease was the result of Africa's huge demographic growth, urbanisation, and social change in the later 20th century. He made the critical point that "HIV/AIDS was not one epidemic but four: first the virus, then disease, next death, and finally societal

¹¹⁵ P. Denis et C. Becker, éd., *L'épidémie du sida en Afrique subsaharienne. Regards historiens* (Louvain-la-Neuve et Paris: Academia Bruylant et Karthala, 2006).

¹¹⁶ H. Phillips, "HIV/AIDS in the Context of South Africa's Epidemic History," in *AIDS in South Africa: The Social Expression of the Pandemic*, eds. K. D. Kauffman and D. L. Lindauer (New York: Palgrave Macmillan, 2004).

¹¹⁷ For example, Fassin's analysis of HIV/AIDS in post-Apartheid South Africa (D. Fassin, *The Body as Memory. Experience and Politics of AIDS in Post-Apartheid South Africa* (Berkeley: University of California Press, 2005), and Denis's historical exploration of Zulu children's experience of HIV/AIDS (P. Denis, "Are Zulu Children Allowed to Ask Questions? Silence, Death, and Memory in the Time of AIDS," in *Being Zulu: Contesting Identities Past and Present*, eds. B. Carton, J. Laband and J. Sithole (Pietermaritzburg: University of KwaZulu-Natal Press, 2006). Oppenheimer and Bayer are presently conducting an oral history of doctors working with HIV/AIDS patients in South Africa (R. Bayer and G. Oppenheimer. Personal communication with the author. St John's, 7 February 2005).

¹¹⁸ J. Iliffe, *The African AIDS Epidemic: A History* (Oxford: James Curry, 2006).

decomposition, each superimposed upon its predecessor.”¹¹⁹ Iliffe’s work is a major contribution to the field of the history of HIV/AIDS in Africa.

Historical Research of HIV/AIDS Training

While there are a growing number of international HIV/AIDS training guidelines,¹²⁰ there are distinctly few historical analyses of training. Examples of African research dealing with HIV/AIDS counselling programs include the HIV/AIDS training of para-professionals,¹²¹ various education and counselling approaches adopted,¹²² and the attitudes of health care workers towards HIV/AIDS.¹²³ This dissertation thus aims to fill a significant historiographical lacuna in the realm of the social history of medicine and disease in southern Africa, in order to improve our understanding of history and society. Training organisations produce much work (for example, programs, evaluations, and reports), but most of this output is not widely circulated.¹²⁴ Training organisations have found it difficult to provide an historical critique of what training has worked and why it has worked. These organisations often needed to respond to external demands from clients and health care services without having the necessary time to document, evaluate, and reflect on best practices. This has resulted in ahistorical and decontextualised planning and assessment of training programs.

¹¹⁹ Iliffe, 5.

¹²⁰ For example, see organisations like UNAIDS <<http://www.unaids.org>>, Centre for Disease Control (CDC) <<http://www.cdc.gov>>, International Training and Education Centre on HIV <<http://www.go2itech.com>>, Centre for Aids Research <<http://www.sph.emory.edu>>, World Health Organisation (WHO) <<http://www.w3.whosea.org>>, World Bank <<http://www.worldbank.org>>, The Synergy Project <<http://www.synergyaids.com>>, and IntraHealth International <<http://www.intrah.org>>.

¹²¹ M. L. Ego and M. Moran, “HIV/AIDS Counselling Program: A Rural Ghana Experience,” *Health Transition Review*, 3 (1993): 1-8.

¹²² K. Awusabo-Asare, “HIV/AIDS Education and Counselling: Experiences from Ghana,” *Health Transition Review*, 5 (1995): 229-236.

¹²³ K. Awusabo-Asare and C. Marfo, “Attitudes to and Management of HIV/AIDS among Health Care Workers in Ghana: the Case of the Cape Coast District,” *Health Transition Review*, 7 (1997): 271-280.

¹²⁴ Delius and Walker, 11.

When HIV/AIDS training has been addressed, it has been part of historical analyses of issues like NGOs,¹²⁵ education,¹²⁶ life skills and peer education,¹²⁷ awareness programs,¹²⁸ and counselling.¹²⁹ One of the primary reasons for this is the neglect of training in the health care system. Moreover, training moves hastily from the planning phase, to delivery, to cursory participant assessment, and so on. Finally, historians have not researched health care training, perhaps because it is seen, erroneously, as a medical issue. Grundlingh's historical analysis of HIV/AIDS education¹³⁰ and James' historical analysis of life skills and peer education¹³¹ stand out as examples of research in which HIV/AIDS training has been addressed as part of historical analyses.

Summary

Research in the HIV/AIDS field is strongly weighted in favour of the biomedical sciences. Only recently have the social sciences begun to contribute to the field. Much of the international historical research is focussed on the epidemic in the USA and Europe. While there were a few publications of some aspects of the history of HIV/AIDS in 1987 and 1989, it is only since 1992 that there has been a concerted effort to produce historical HIV/AIDS research in Africa. Recent historical

¹²⁵ N. Schaay, "The History and Development of NGO-Based HIV/AIDS Work in South Africa," The South African STDs/HIV/AIDS Review Report, 1997.

¹²⁶ L. Grundlingh, "Neither Health nor Education? An Historical Analysis of HIV/AIDS Education in South Africa, 1980s-1990s," Development Studies Seminar, RAU, South Africa, 24 May 2002, <<http://general.rau.ac.za/sociology/Grundlingh2.PDF>> (Accessed: 1 August 2005).

¹²⁷ D. James, "To Take the Information Down to the People: Life Skills and HIV/AIDS Peer Educators in the Durban Area," *African Studies*, 61, no. 1 (2002): 169-191.

¹²⁸ M. Hunter, "The Ambiguity of HIV 'Awareness' and the Power Behind Forgetting: Historicizing and Spatializing Inequality in Mandeni, KwaZulu-Natal," conference paper, AIDS in Context Conference, University of the Witwatersrand, South Africa, 4-7 April 2001.

¹²⁹ School of Psychology, University of Natal (Pietermaritzburg), "Evaluation of HIV/AIDS Counselling in South Africa," November 1999.

¹³⁰ L. Grundlingh, "Neither Health nor Education? An Historical Analysis of HIV/AIDS Education in South Africa, 1980s-1990s," Development Studies Seminar, RAU, South Africa, 24 May 2002, <<http://general.rau.ac.za/sociology/Grundlingh2.PDF>> (Accessed: 1 August 2005).

¹³¹ D. James, 169.

HIV/AIDS research in Africa is producing important findings and effects. The failure to see HIV/AIDS in historical context is finally being addressed: different aspects of the epidemic are now being investigated by historians, for example, the origin of HIV, the spread of the disease, and the impact of the epidemic. Yet, the progress of historians remains sluggish.¹³²

Certain observations stem from the historical analysis and literature review. One, historiographically, research of the history of HIV/AIDS in Africa has taken the form of biomedical investigations of the first AIDS cases, cultural history, political history, social history, and oral history. There is a noticeable lack of Marxist historiography in HIV/AIDS research in Africa. Marxist historiography is implicit in some of the class analyses of HIV/AIDS in social historical studies. Two, while historical examination of HIV/AIDS in Africa is now established, significant historical research lacunae remain. This is most evident in the lack of comprehensive HIV/AIDS histories of specific countries, regional and continental research that highlights and integrates pertinent HIV/AIDS themes, and critical historiographical analyses of how HIV/AIDS is addressed in Africa. Three, the social and historical research of HIV/AIDS in Africa led to the examination, and, at times, re-examination of issues like colonial and post-colonial health policies and practices, previous epidemics, traditional medicine, cultural practices, and gender. Some of these issues continue to be contested in the origin of AIDS debate, between advocates of the natural transfer theories and the iatrogenic theories. Four, the constraints of medical classification systems have shaped the history of HIV/AIDS, especially the search for earlier AIDS cases before 1981. Five, the main research trends have been the early

¹³² As can be witnessed in the suggested topic – HIV/AIDS: Are Historians in Denial? – in the call for papers for the upcoming history conference, “Transformations, Renewals and Reconfigurations in Southern African Historical Studies – Only Skin Deep?,” The Southern African Historical Society, Biennial Conference, University of Johannesburg, June 24-27, 2007.

documentation of the disease by biomedical scientists, followed by the examination of the social contributors and impact of the disease by social scientists. While there was a comprehensive response by historians to HIV/AIDS in Europe and the USA, African historians have been slow to address the epidemic. This is particularly true of South African historians, with the exception of Grundlingh, Schneider, Phillips, and Campbell.

This dissertation draws on the work of researchers like Berridge who have highlighted the need for the historical examination of HIV/AIDS in terms of both the 'pre-history of AIDS' and 'AIDS as history,' and the historians doing HIV/AIDS research in Africa like Becker, Denis, Fassin, and Rémy. In terms of South African historians, this dissertation is informed by the work of Grundlingh, Schneider, and Phillips. Moreover, this dissertation is informed by the recent conference and publication initiatives to draw together and analyse the material from diverse sources: here the work of biomedical and social scientists is vital. The field is probably still too young to make any conclusive statements, but there is an increasing awareness of how HIV/AIDS is investigated and interpreted historically. This study highlights that the conversation is not over, and that it aims to fill the historiographical gaps. Important initiatives in health care, advocacy, prevention, education, and management have not been documented, and continue to go undocumented. This study attempts the historical documentation of the HIV/AIDS narrative as experienced by health care workers and trainers in the Western Cape between 1989 and 2004. Finally, this dissertation notes that training organisations find themselves between competing views and resulting demands – for example, government and health care workers, community and NGOs – and thus they are in key positions to contribute to the ongoing HIV/AIDS narrative.

Methodology

The research is based on qualitative historical research methods. Data was collected from primary sources, secondary sources, and oral history. A qualitative historical analysis was utilised to provide the appropriate access, analysis, and interpretation of the diverse research material. This method provides the flexible approach needed to create a better understanding of the social phenomena under investigation.

As the period covered in this study is 1989-2004, this is a study in contemporary history. This approach to history has certain strengths and limitations. Some of the strengths include a possible increase in self-knowledge for the groups under examination and better records for future historians. These records can inform future choices and provide in-depth analyses for both formal and informal policy making.¹³³ The major criticism levelled against contemporary history is the researcher's lack of historical distance, without which, it is argued, a reasonably definitive account of history cannot be written.¹³⁴ It has been argued that a "history of the present" is flawed because it lacks a thorough examination of archival material and it could be distorted by contemporary politics.¹³⁵ This study was based on the need to document the early responses to the epidemic in the Western Cape because much of this information remains undocumented and thus there is the risk of such information being lost for future historians. The issues of the lack of adequate

¹³³ Centre for the History of Science, Technology, and Medicine, "Contemporary History and Its Uses," 2005,

<<http://www.ls.manchester.ac.uk/chstm/research/hstmbroadthemes/contemporary/+difficulties+of+contemporary+history&hl=en&ct=clnk&cd=11>> (Accessed: 15 January 2007).

¹³⁴ L. Veysey, "Ways of Writing Contemporary History," *Reviews in American History*, 1, no. 1 (1973): 151-157.

¹³⁵ A. D. Kahn, "AIDS and Contemporary History - AIDS: The Winter War," *New England Journal of Medicine*, 330, no. 14 (1994): 1025-1026.

distance to the material and the possible distortions of contemporary politics were acknowledged and commented on throughout the relevant parts of the dissertation.

Other problems associated with this research methodology include researcher bias, lengthy data collection and interpretation periods, and weak internal validity due to the lack of control over external variables. These potential problems were kept in mind, and methods were used to counter such problems, for example, a structured research plan,¹³⁶ and systematic research design, data collection, interpretation, and communication.¹³⁷

Purposive sampling methods were used in this research. This method involves the selection of informants based on important research characteristics like where informants live and work, their unique occupational experience, and their specific cultural knowledge. Informants were selected with the assistance of key training and health care personnel. In determining sample size, the concept of *redundancy* or *saturation* was utilised in this study. The boundaries of the phenomenon being investigated were considered exhausted when no new data emerged.¹³⁸

With regards to *participants*, data from various organisations that were involved in the HIV/AIDS training of health care workers was used.¹³⁹ This included government training organisations (for example, the Aids Training, Information, and Counselling Centre (ATICC)), non-government organisations (NGOs), government

¹³⁶ NIH, "Qualitative Methods in Health Research," Office of Behavioral and Social Sciences Research, National Institute of Health, 2000.

¹³⁷ N. Mays and C. Pope, "Qualitative Research: Rigour and Qualitative Research," *British Medical Journal*, 311 (1995): 109-112.

¹³⁸ R. Bayer and G. M. Oppenheimer, *AIDS Doctors: Voices from Within* (Oxford: Oxford University Press, 2000).

¹³⁹ These organizations include: Aids Training, Information, and Counselling Centre (ATICC) (this organization has trained the majority of health care workers in the province); Lifeline/Childline HIV/AIDS Program; Department of Health – Western Cape; Somerset Hospital – HIV/AIDS Unit; Red Cross Society; Student Health Services (University of Cape Town); Primary Health Care Department – 6th Year Medical Student HIV/AIDS Training (University of Cape Town); Department of Psychology (University of Cape Town); Philipi Trust HIV/AIDS Training; Helderburg HIV/AIDS Training; FAMSA; Leadership South HIV/AIDS Training Program; Irving & Johnstone Pty. (Ltd.); and Rape Crisis Centre.

departments (for example, health and education), professional associations and societies (for example, the Health Professions Council of South Africa (HPCSA)), and university departments involved in HIV/AIDS training (for example, medical, psychology, and education). Participants in the study include training directors, managers, trainers, health care workers, counsellors, course participants, students, program administrators, primary health care clinic staff, and consultants.

The *data gathering methods* included interviews, feedback forms, training material, and documents. A brief description of these methods follows:

- *Interviews:* Training directors, managers, and trainers; course participants; health care workers; counsellors; and supervisors. Information was also gathered from focus groups in which specific issues were discussed, and supervision sessions of health care workers and trainers in which patient cases and organisational issues were discussed.
- *Feedback & evaluation forms:* Various training courses and programs.
- *Training material:* Review of training material from various HIV/AIDS training organisations and universities.
- *Documents:* Review of: (1) national planning documents (for example, the National HIV/AIDS Strategy for Technikon and Universities in South Africa); (2) relevant training documents (for example, the University of KwaZulu-Natal's Evaluation of HIV/AIDS Counselling in South Africa); and (3) international Best Practice codes for HIV/AIDS management.

All participants in the interviews, focus groups, and supervision are anonymous given the medico-legal issues of client confidentiality and because

participants did not wish to be identified, especially when managers and national and local responses were being criticised. This issue of anonymity could lead to limitations in interpretation, and this was dealt with by ensuring that no crude generalisations were included in the study. Finally, this dissertation examines HIV/AIDS from the perspective of the social and cultural history of disease and medicine. This perspective highlights the biological, political, social and cultural factors involved in the ecology of disease.¹⁴⁰ Disease is seen as both a biological event and a metaphor reflecting social and cultural beliefs across time, and thus our ideas about what constitutes a disease differs across culture and history. In this dissertation, three main issues are highlighted with regards to HIV/AIDS. One, the social construction of HIV/AIDS differs across time and place. Two, the transmission, prevention, and management of HIV/AIDS are informed by the political and social history of South Africa and the Western Cape (for example, Apartheid and health care, HIV/AIDS and race, and HIV/AIDS and gender). Three, this study also highlighted how government and health leaders made policies and cultural assumptions about “silenced voices” or people “without knowledge.” Health care workers complained of being kept out of the national and provincial HIV/AIDS discourses and being treated as “not knowing.” This illuminates the issue of Foucault’s concept of power/knowledge,¹⁴¹ which could be used as a point of departure for further related HIV/AIDS research.

¹⁴⁰ C. E. Rosenberg, “Introduction. Framing Disease: Illness, Society, and History,” in *Framing Disease: Studies in Cultural History*, eds. C. E. Rosenberg and J. Golden (NY: Rutgers University Press, 1992), xiii-xxvi.

¹⁴¹ M. Foucault, *The Archaeology of Knowledge* (New York: Harper and Row, 1972).

CHAPTER THREE: “I thought HIV/AIDS training would be like other health training, simple and predictable” – Historical changes in HIV/AIDS training content, methodology, and organisational issues, 1989-2004.

This chapter examines the historical shifts in content, methodology, and organisational issues in HIV/AIDS training organisations in the Western Cape between 1989 and 2004. The discussion begins with an historical overview of HIV/AIDS training in the Western Cape. This is followed by an examination of the shifts in training *content*, that is, the accessing of material, the development of courses, the experiences of training organisations and trainers, and the feedback from course participants. The next section focuses on the changes in training *methodology*, and highlights examples of different methodologies and the feedback from trainers and participants about the methodologies utilised. The final section focuses on the shifts in *organisational issues*, and outlines organisational structures and roles, recruitment, and capacity development. Organised temporally, these shifts accord with the following four periods: 1989-1994: The Early Days, 1995-1998: The Growing Epidemic, 1998 onwards: The Questioning of Orthodoxy, and 1999-2003: The Generalised Epidemic.

These four periods are not strictly delineated and certain issues exist across periods. These periods are used to organise the data into some of the significant issues experienced by HIV/AIDS training organisations and health care workers in the period under study. Before examining the historical changes in HIV/AIDS training organisations, a brief history is provided of the three principal training organisations under study.

History of HIV/AIDS Training in the Western Cape

This overview provides an historical context in which HIV/AIDS organisations emerged and developed their work. An overview of the AIDS Training, Information, and Counselling Centre (ATICC) is provided first because this organisation was the main provider of HIV/AIDS training to health care workers, and it provided strategic leadership to other HIV/AIDS organisations in the province in the period under study. The history of two other important HIV/AIDS training organisations in the province, Lifeline (Western Cape) and the Department of Family Medicine/Primary Health Care, the University of the Cape Town (UCT), are provided. As noted in the previous chapter, ten other training organisations were examined in this study.¹

ATICC (Western Cape)

HIV/AIDS training organisations and programs stemmed from a national health initiative begun in the late 1980s.² The goal of this initiative was to establish an HIV/AIDS training centre in each of the major cities countrywide to provide training and education to health care workers and the public.³ On 26 July 1989, ATICC (Western Cape) was established. It was the first HIV/AIDS training organisation in the province, and its budget came from the National Department of Health. Three

¹ These organizations include: Aids Training, Information, and Counselling Centre (ATICC) (this organization has trained the majority of health care workers in the province); Lifeline/Childline HIV/AIDS Program; Department of Health – Western Cape; Somerset Hospital – HIV/AIDS Unit; Red Cross Society; Student Health Services (University of Cape Town); Primary Health Care Department – 6th Year Medical Student HIV/AIDS Training (University of Cape Town); Department of Psychology (University of Cape Town); Philipi Trust HIV/AIDS Training; Helderburg HIV/AIDS Training; FAMSA; Leadership South HIV/AIDS Training Program; Irving & Johnstone Pty. (Ltd.); and Rape Crisis Centre.

² C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 17 May 2004.

³ L. Grundlingh, "Neither Health nor Education? An Historical Analysis of HIV/AIDS Education in South Africa, 1980s-1990s," Development Studies Seminar, RAU, South Africa, 24 May 2002, <<http://general.rau.ac.za/sociology/Grundlingh2.PDF>>.

training officers were employed to develop and deliver the HIV/AIDS training, with Ms. Trish van der Velde as manager.

On 14 August 1989, ATICC delivered its first HIV/AIDS training course. Thirty-six participants, drawn predominantly from hospitals and clinics, attended this course.⁴ The goal of this training was to provide basic HIV/AIDS awareness to health care workers treating patients with AIDS. Between August 1989 and April 2004, ATICC trained 14,648 health care workers, counsellors, educators, human resource personnel, politicians, and administrators.⁵ Of the 14,648 persons trained, 11,034 (75%) attended the HIV/AIDS information course. The remainder of the training courses included counselling, medical management, train-the-trainer, master training, advanced counselling, and clinic based counselling courses. ATICC played a leading role in the introduction of new programs like the Prevention of Mother-to-Child Transmission (PMTCT) program (1998), the Voluntary Counselling and Testing (VCT) program (2000), and the roll out of the antiretroviral (ARV) program (2003).⁶ By 2004, ATICC still provided the majority of HIV/AIDS training in the Western Cape, and its training and counselling procedures had become models for most other provincial HIV/AIDS training initiatives that followed.

Lifeline (Western Cape)

In November 1968, Reverend Peter Storey established Lifeline (Western Cape), and the goal was to establish a telephone service to assist people in emotional

⁴ These 36 participants were comprised of nurses, doctors, and health inspectors (10 from the City Health Department, 10 from the Regional Services Council Health Department, 10 from Day Hospitals, and 10 others). C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 25 May 2004.

⁵ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 25 May 2004.

⁶ Certain training organisations, like ATICC and Lifeline, were successful at positioning themselves at the centre of these initiatives by ensuring that they were part of all strategic program development, training, and assessment.

distress.⁷ In 1995, Lifeline/Childline was created as a response to child abuse. In 1997, Lifeline opened an office in Khayelitsha, and its goal was to train Xhosa-speaking Lifeline counsellors.

In October 1997, the Department of Health requested that Lifeline recommend six Lifeline counsellors for the HIV/AIDS Lay Counsellor Program.⁸ In 1998, four of these lay counsellors were selected for the PMTCT Program. They received specialised training in HIV/AIDS and PMTCT from ATICC. In October 1998, these counsellors started work at Michael Mapongwana and Site B – the two hospitals in Khayelitsha selected for the program. Their brief was to provide information and education to pregnant women of the benefits of HIV counselling and testing, and the reduction in risk of HIV transmission to unborn babies through the use of azidothymidine (AZT). In 2000, Lifeline partnered *Médecins Sans Frontières* (MSF) in the leading ARV program in Khayelitsha.

In 1998, Lifeline provided further training to its HIV/AIDS counsellors. One person who had completed the master training course at ATICC, senior counsellors, and external trainers provided this training. By 2004, there were 57 government-funded posts for Lifeline HIV/AIDS counsellors.⁹ A psychologist provided ongoing training and capacity development through weekly supervision. By 2004, an increasing amount of Lifeline's work was HIV/AIDS-related, and the organisation found itself at the forefront of counselling and support initiatives on the provincial PMTCT and ARV programs.

⁷ See <<http://www.lifelinewc.org.za/history>> (Accessed: 6 October 2004).

⁸ S. Schute, "Transmitting Hope in Khayelitsha," *ChildrenFIRST*, 31 (June/July 2000).

⁹ See <<http://www.lifelinewc.org.za>> (Accessed: 6 October 2004).

Department of Family Medicine/Primary Health Care, UCT

In 1993, Dr. Judith van Heerden from the Department of Family Medicine/Primary Health Care (UCT) approached ATICC to help design HIV/AIDS training for the final year medical students.¹⁰ ATICC, in consultation with Dr. Gordon Isaacs from the Department of Social Work (UCT), designed the HIV/AIDS course. The goal of the course was to introduce final-year students to the essential issues in HIV/AIDS treatment and management, with a particular focus on the social determinants and emotional needs of the patient and the family.¹¹ In March 1993, Dr. Isaacs and Trish van der Velde (Manager, ATICC) facilitated the first course. This course consisted of a five-day workshop, three hours each day, in which issues like attitude formation towards disease and HIV/AIDS, death and grief, sexuality, pre- and post-test counselling, and crisis counselling were explored. These topics were in keeping with the departmental goals of providing “multi-disciplinary community-based teaching with a strong focus on primary care training.”¹²

Between 1993 and the end of 2004, approximately 2,000 medical students received this HIV/AIDS training.¹³ Feedback from participants was positive, with consistent commentary on the importance of being introduced to the wider social aspects of HIV/AIDS, and the counselling and management skills that were gained.¹⁴ This HIV/AIDS training played an important part in educating medical students in relevant concepts in the social sciences and the humanities. Long-term feedback showed that this input played a constructive role in the delivery of primary health care

¹⁰ B. Schweitzer (Family Medicine/Primary Health Care Course Co-ordinator, UCT). Private communication with author. Cape Town, 11 October 2004.

¹¹ Family Medicine/Primary Health (UCT), 6th Year Manual, 2001, 4.

¹² Family Medicine/Primary Health (UCT), Departmental Profile, 1999, 1. See <<http://web.uct.ac.za/depts/dri/resrep/resrep99/phcare99>> (Accessed: 21 March 2005).

¹³ B. Schweitzer (Family Medicine/Primary Health Care Course Co-ordinator, UCT). Private communication with author. Cape Town, 11 October 2004.

¹⁴ Medical Students, UCT. Feedback forms to author. Cape Town, 1993-2003.

management after graduation. Moreover, according to Dr. Beverley Schweitzer (course co-ordinator), the course introduced students to the importance of some of the wider medico-legal issues like informed consent, that is, knowledge that they were able to transfer to other medical situations.¹⁵

Changes in Content

The discussion now moves to the findings in changes in content, methodology, and organisational issues. In terms of the shifts in training *content*, the first period (1989-1994: The Early Days) was characterised by the establishment of HIV/AIDS awareness and information courses. The content of ATICC's first training courses was a combination of medical facts and basic counselling skills, and aimed primarily at preparing health care workers for HIV/AIDS counselling and testing. Local specialists like Dr. Frank Spracklen and Dr. Jane Pierce provided the medical information for courses.¹⁶ In 1990, Dr. Steve Millar, from the Johannesburg General Hospital, provided a series of evening lectures for doctors and nurses. Between 1989 and the end of 1993, ATICC had visits from various international experts who provided medical and treatment updates.

Counselling and testing models were based on models provided by American organisations like the San Francisco AIDS Foundation (SFAF)¹⁷ and the Centre for Disease Control (CDC),¹⁸ and British organisations like the Terrence Higgins Trust.¹⁹ The reasons for this include the fact that most counselling models in the early 1980s

¹⁵ B. Schweitzer (Family Medicine/Primary Health Care Course Co-ordinator, UCT). Private communication with author. Cape Town, 11 October 2004.

¹⁶ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 7 October 2004.

¹⁷ In 1982, the San Francisco AIDS Foundation (SFAF) was founded. Its purpose was to collect and disseminate important information to gay men who were suffering from what was considered, at the time, to be a rare cancer. The SFAF was one of the first AIDS specific voluntary organisations, together with the AIDS Project Los Angeles (APLA), and the Gay Men's Health Crisis (GMHC) in New York. See <<http://www.sfaf.org/aboutsfaf>> (Accessed: 6 April 2004).

¹⁸ See <<http://cdc.gov>> (Accessed: 24 March 2005).

¹⁹ See <<http://www.tht.org.uk>> (Accessed: 24 March 2005).

were European or American, thus illustrating the importance of European and American thought on the development of psychology and counselling. When the need for HIV/AIDS counselling became evident, these counselling models were adopted for HIV/AIDS counselling. Also, some of the first persons in Cape Town who were trained in HIV/AIDS counselling received their training in either America or the UK.²⁰ Thus, European and American models were transplanted into the new HIV/AIDS training organisations in the Western Cape.

Examples of these sources are evident in books by Miller and Bor,²¹ Dilley,²² Miller,²³ and Egan,²⁴ which were used to guide the establishment of training content. These books provided overviews on the clinical aspects of HIV/AIDS, counselling, testing, psychological and social support, and staff stress. These books were based on the HIV/AIDS experiences of health care workers in the USA and the UK, and they were used to set up counselling, testing, and treatment training input. ATICC had the benefit of providing both counselling and training services, and thus the counselling and testing issues confronted in the ATICC outpatient clinic were used to inform training content. One of the benefits was that this resulted in training content that was informed by clinical practise. One of the negative aspects of ATICC having its own counselling and testing clinic was that trainers were unable, at times, to understand the unique and complex issues confronted by health care workers working in under-resourced community clinics.²⁵

Both trainers and participants reported that training during this period was difficult and often frustrating because of government, public, and professional

²⁰ G. Taylor (ATICC Training Manager). Interview by author. Cape Town, 21 March 1996.

²¹ R. Miller and R. Bor, *AIDS. A Guide to Counselling* (London: Science Press, 1989).

²² J. W. Dilley, *Face to Face: A Guide to AIDS Counselling* (San Francisco: Ten Speed Press, 1989).

²³ D. Miller, *Living with AIDS and HIV* (London: Macmillan Press, 1987).

²⁴ G. E. Egan, *The Skilled Helper: A Problem Management Approach to Helping* (California: Brooks/Cole, 1990).

²⁵ ATICC Course Participants. Interviews by author. Cape Town, 20-24 June 1994.

disbelief and inaction.²⁶ Health care workers claimed that they did not see the many HIV-positive patients that were reported by surveys and epidemiological studies to exist in their communities. Trainers stated that it was difficult to convince health care workers that HIV/AIDS was a problem, and that stigma and denial were important reasons for keeping these patients out of clinics. Furthermore, getting health care workers to understand that their own denial contributed to the fear and silence proved difficult for trainers and administrators.²⁷ Trainers argued that health care workers had a limited and purely medical understanding of HIV/AIDS. Health care workers challenged much of the training content, especially the statistical and social content. Many participants denied that any HIV-positive persons lived in their communities. The fact that people with HIV can be relatively asymptomatic for years made the task of convincing course participants of the threat of HIV/AIDS even more difficult: "Unlike all other diseases, we couldn't see this disease."²⁸

Health care workers complained that their managers forced them to attend training courses.²⁹ Trainers complained of the apathy and aggression with which their training was met.³⁰ The historical context in which this training occurred is important in understanding these responses and experiences. One, the slow response of the government to HIV/AIDS in the country meant that health care workers were not prepared for the epidemic and the associated training. This point is examined further in chapter four. Two, the training of health care workers in the Western Cape up to 1994 was sporadic and not taken seriously by health care workers.³¹ One of the reasons for this was that some health care workers did not accept the legitimacy of the

²⁶ ATICC Trainers and Participants. Interviews and course discussions. Cape Town, 1993-1996.

²⁷ ATICC Trainers. Strategic planning by author. Cape Town, 8 December 1995.

²⁸ ATICC Participants. Course feedback and discussions. Cape Town, 1993-1994.

²⁹ ATICC Participants. Course feedback and discussions. Cape Town, 1993-1994.

³⁰ ATICC Trainers. Interview by author. Cape Town, 24 February 1994.

³¹ Health Care Worker. Interview by author. Cape Town, April 1994.

government and ignored the health care training that it provided. This was also true for health care workers who supported the National Party (NP).³² Three, many health care workers did not have a social understanding of the disease and some blamed the NP government for manufacturing the disease, or at least managing the disease in racist ways.³³ These health care workers did not see the need for HIV/AIDS training.³⁴ Other health care workers commented on the perceived neglect of the NP government of Black and Coloured communities: "This government doesn't care if we get sick. And no money is given to our communities. So why are we now learning about this AIDS?"³⁵ The apathy of participants is seen in one example provided by a trainer who reported that during a training session in 1993 over half of the trainees had put their heads down on their hands and slept through or ignored the training.³⁶ Trainers observed that those health care workers involved with the early HIV/AIDS outpatient clinics were more likely to give positive course feedback, while those not involved with HIV/AIDS cases tended to complain about the courses and the irrelevant training content.³⁷

In terms of the shifts in training *content*, the second period (1995-1998: The Growing Epidemic) was characterised by increased training. In 1995, trainers stated that the number of reported HIV-positive persons attending clinics and hospitals began to increase significantly.³⁸ These reports were based on the higher number of patients who requested HIV tests and presented with HIV/AIDS symptoms at primary health care clinics. Historically this change in clinic attendance and the attitude of health care workers towards HIV/AIDS is important because it highlights how health

³² Health Care Worker. Interview by author. Cape Town, June 1994.

³³ Health Care Worker. Interview by author. Cape Town, December 1993.

³⁴ Health Care Worker. Course feedback. Cape Town, 7 December 1993.

³⁵ Health Care Worker. Course feedback. Cape Town, 17 February 1994.

³⁶ ATICC Trainer. Interview by author. Cape Town, 24 March 1994.

³⁷ Health Care Workers. Focus group by author. Cape Town, 6 April 1995.

³⁸ Health Care Workers. Focus group by author. Cape Town, 21 April 1995.

care workers responded to the increased demand for services and treatment from patients, and the promise of better health care from the newly elected government in 1994.

Health care workers reported that they felt overwhelmed by the increasing number of patients and the lack of resources within the healthcare system for adequate treatment.³⁹ In particular, they felt overwhelmed in terms of basic testing and counselling skills and the unforeseen ethical complications. For example, the issues of confidentiality, and partners and family members at risk to HIV infection raised many ethical and patient management problems for health care workers. Health care workers increasingly recognised the importance of HIV/AIDS training, and more courses were requested and presented.⁴⁰

The content of the courses incorporated the topics mentioned above in the first period with more specific input on high incidence prevention, treatment, and care. There was an emerging HIV/AIDS literature in South Africa that was utilised by training organisations in the Western Cape.⁴¹ These publications were used because there were increasing reports from health care workers that the training models, particularly the counselling models that ATICC was using, were not entirely relevant in provincial primary health care clinics. These models were not working for reasons of class, race, and gender.⁴² The preferred South African publications were more cognisant of these social issues in the way that they dealt with issues like counselling and therapy,⁴³ counselling families,⁴⁴ pre- and post-test counselling,⁴⁵ and the training

³⁹ Health Care Workers. Focus group by author. Cape Town, 21 April 1995.

⁴⁰ ATICC Trainers. Strategic planning by author. Cape Town, 6 December 1996.

⁴¹ For example, (1) *AIDS Bulletin* – a quarterly HIV/AIDS newsletter first published in August 1992 by the Medical Research Council (MRC), and (2) *AIDS Scan* – a journal circulated to doctors and other key health workers. It was first published in 1995, and is sponsored by Sanlam.

⁴² Trainers and Health Care Workers. Interviews by author. Cape Town, 1995.

⁴³ G. Lindegger, "Boundaries of HIV/AIDS Counselling: Where Does Counselling End and Therapy Begin?," *AIDS Bulletin*, 3 (1994): 22-23.

⁴⁴ G. Isaacs, "Counselling Persons with AIDS & their Families," *Medical Sex Journal*, 1 (1990): 19-20.

of counsellors.⁴⁶ These publications were produced nationally, with many stemming from KwaZulu-Natal, which had a significantly higher HIV/AIDS prevalence than the Western Cape. Training organisations valued these publications because their South African focus made them pertinent to the work in which health care workers in the Western Cape were engaged.

A few comments shall be made on the use of technology in the HIV/AIDS training of health care workers. In 1996, training organisations turned to the World Wide Web to provide content.⁴⁷ Examples of web pages used included the Terrence Higgins Trust, and the CDC. The UNAIDS website, in particular, provided important information on HIV/AIDS counselling, testing, and medical facts.⁴⁸ This was the beginning of internet-based HIV/AIDS training resources, but its use in the Western Cape was inconsistent and limited. The reasons for this were lack of resources, lack of knowledge, discomfort with technology, and complaints that the information was not specifically relevant to South Africa and the Western Cape.⁴⁹

Following training assessments and requests from health care workers, ATICC introduced an advanced counselling course for health care workers in 1996.⁵⁰ External training consultants were hired to assist in the planning, writing, and delivery of the course. Health care workers with more HIV/AIDS experience requested input on topics like breaking bad news to patients, crisis counselling, confidentiality, couple counselling, gender, home-based care, and managing the dying patient and the family.

⁴⁵ V. Tallis, "Pre- and Post-Test Counselling," *AIDS Bulletin*, 3 (1994): 1-2.

⁴⁶ G. Wood, "Improving the Quality of Counselling Through the Standardisation of Counsellor Training," *AIDS Bulletin*, (1994): 11.

⁴⁷ ATICC Trainers. Strategic planning by author. Cape Town, 6 December 1996.

⁴⁸ The Joint United Nations Programme on HIV/AIDS (UNAIDS) was constituted on 13 July 1995, and launched in January 1996, as the main advocate for global action on the epidemic. Its goal is stated as "it leads, strengthens and supports an expanded response aimed at preventing transmission of HIV, providing care and support, reducing the vulnerability of individuals and communities to HIV/AIDS, and alleviating the impact of the epidemic." See:

<<http://www.unaids.org/en/about+unaids/what+is+unaids.asp>> (Accessed: 24 March 2005).

⁴⁹ ATICC Trainers. Strategic planning by author. Cape Town, 6 December 1996.

⁵⁰ ATICC Training Manager. Interview by author. Cape Town, November 1999.

Participants received these courses enthusiastically, with a subsequent increase in demand for such training. In terms of social history, it is important to note the shift in attitude and levels of engagement with HIV/AIDS of health care workers. These shifts highlight the increased acceptance of HIV/AIDS (both in medical and social terms) and the increased trust of health care workers of HIV/AIDS training organisations and their provincial government partners. Counselling was increasingly regarded as an important tool for health care workers. In fact, HIV/AIDS played a significant role in legitimising the importance of counselling in health practise.⁵¹

Trainers reported that training during this period was more challenging and interesting than before.⁵² The increased enthusiasm of participants made the writing of material and the presentation of courses more enjoyable. For example, trainers stated that there was a dynamic interaction between the experiences of the health care workers and the ever-changing material presented by the trainers, and that this resulted in significant learning for participants and trainers. Moreover, health care workers acknowledged the experience brought in by both the trainers and other participants. Health care workers reported that they did not feel that their own institutions provided the necessary HIV/AIDS leadership and support, and, to a degree, training organisations filled this gap. While there were still health care workers who challenged some of the information, feedback from course participants was generally more positive.

In terms of the shifts in training *content*, the third period (1998 Onwards: The Questioning of Orthodoxy) was characterised by an unexpected challenge to HIV/AIDS training. The controversial “Does HIV Cause AIDS?” debate that was

⁵¹ J. Parle, “States of Mind: Mental Illness and the Quest for Mental Health in Natal and Zululand, 1868-1918,” Unpublished dissertation, University of KwaZulu-Natal, 2004, 415. Private communication with author. St John’s, 25 June 2004.

⁵² ATICC Trainers. Supervision by author. Cape Town, June 1995.

resurrected by President Thabo Mbeki and his advisors had an interesting effect on the belief structures of the South African public and the international health community, as well as on training organisations. Trainers stated that training content was compromised by the government's stance.⁵³ This issue played an important part in the social history under investigation, and a full analysis of the issue is provided in the chapter four, as well as further references in the remaining chapters. In terms of analysing the shifts in content, trainers claimed that they had to return to the dissemination of the basic HIV/AIDS information and awareness of the first training courses in the early 1990s.

Trainers reported frustration at having to once again convince health care workers of the scale and impact of the epidemic.⁵⁴ The topics that were challenged most frequently by participants were virology, epidemiology, and ethics. Trainers found it difficult to balance the needs of those health care workers who challenged the government's stance with those who accepted it.⁵⁵ Courses had a combination of both groups, as well as a third group of confused participants. Trainers reported that pitching training courses at the right level to promote participant interest, involvement, and learning was difficult. Training organisations were forced to rework their training content. Training organisations played an important advocacy role during this period in that they continued to provide information while the epidemic grew amidst confused public health messages.

As in the early 1990s, participant feedback was mixed, with complaints from participants who accepted the government position and support from those who challenged this position. As before, those who accepted the scale and impact of the epidemic were usually those health care workers with more experience working in

⁵³ ATICC Trainers. Supervision by author. Cape Town, February 2000.

⁵⁴ ATICC Trainers. Supervision by author. Cape Town, October 1999.

⁵⁵ ATICC Trainers. Supervision by author. Cape Town, October 1999.

higher incidence areas. Some participants reported feeling duped by training organisations in that previous training, according to government's stance, was based on false facts.⁵⁶ Many participants expressed the same frustration and disinterest in HIV/AIDS training as in the early years.

In terms of the shifts in training *content*, the fourth period (1999-2003: The Generalised Epidemic) was characterised by a return to earlier (pre-1998) HIV/AIDS training and support issues. As the epidemic grew and the government's inaction and nonconformity continued, health care workers reported increasing numbers of persons attending hospitals and primary health care clinics for HIV/AIDS testing, counselling and treatment.⁵⁷ Intensifying demands were being made on health care workers and the health care system, and health care workers turned to training organisations to provide specialised training and support.

The most noticeable shift at the beginning of this period (1999-2000) was the return to the training content of pre-1998 when the government questioned the HIV-AIDS link. Thus, the progression of the epidemic and the resulting clinical needs of patients outweighed the confusion created by the government's position. The progression of the epidemic, as well as national and international criticism largely silenced the government.⁵⁸ This issue is further explored in chapter four.

In response to the increased demand for training and the massive number of training applicants, specialised training courses were devised. Courses included advanced counselling courses, master training for peer educators, peer counsellor and educator training for prevention programs like the prevention of mother-to-child transmission (PMTCT), and Voluntary Counselling and Testing (VCT). Basic information and awareness played a much smaller part in training, and this content

⁵⁶ Health Care Workers. Focus group by author. Cape Town, February 2000.

⁵⁷ Health Care Workers. Focus group by author. Cape Town, February 2000.

⁵⁸ HIV/AIDS Counsellor. Interview by author. Cape Town, April 2001.

was usually reserved for the increasing number of courses being provided for health care workers from outlying, rural health districts in the province that had lower prevalence rates. The fact that participants reported increased stress levels led to more training input on stress management strategies, peer support, and organisational development and support.

Training organisations stressed the importance of multisectoral responses in the prevention, treatment, and management of HIV/AIDS. Training content reflected this shift through the inclusion of topics like home-based care, economics, poverty reduction, and gender violence. This content was well received in that health care workers reported relief at finally having the complexity of their everyday experience with HIV/AIDS validated.⁵⁹ Trainers reported better responses and participation from participants.⁶⁰ Courses were easier to present because it was widely accepted that HIV does cause AIDS and thus the important prevention and treatment issues could be addressed. Compared to the previous period characterised the government's questioning of orthodoxy, participants reported more satisfaction with course design and content, and feedback included acknowledgement of the support and guidance provided by training organisations.

By 2000, training organisations were well established, and thus able to focus on important current and upcoming issues.⁶¹ For example, training organisations prepared for the government plan to provide ARVs in the public sector. The government announced their ARV plan after a special Cabinet meeting on 8 August

⁵⁹ Health Care Workers. Training feedback forms. Cape Town, 1999-2003.

⁶⁰ Trainers. Interviews by author. Cape Town, February 2001.

⁶¹ ATICC Trainer. Interview by author. Cape Town, December 2000.

2003.⁶² Training organisations played an important role in sensitising and training health care workers to implement and manage this program.

Before examining the shifts in training methodology, an historical example of content across the four periods is provided. The issue is the presentation of national and regional HIV/AIDS statistics to health workers receiving HIV/AIDS training. In South Africa, the collection of HIV/AIDS statistics is controversial. Since 1991, the *Annual National HIV Survey of Women Attending Antenatal Clinics* has provided data in terms of national, provincial, and age group percentages. These figures have been questioned by various international and local sources. For example, in 2000, UNAIDS claimed that the antenatal surveys represent a significant underestimation.⁶³ In 2002, the Nelson Mandela Foundation/ HSRC Study on HIV/AIDS argued that the antenatal survey is not representative of HIV prevalence nationally.⁶⁴ The government attacked the former study with its higher prevalence rates as being alarmist, and commended the second study because it gave cause for false hope with its lower figures.⁶⁵

This diversity of opinion concerning HIV/AIDS prevalence created confusion for the South African public, and made it difficult for training organisations to present accurate national and regional statistics. Most organisations chose to present the results from the antenatal survey because despite its flaws this data is continuous from 1991 to the present.⁶⁶ Even though statistics are updated in training courses, many training participants continued to question their validity and reliability based on their own lack of, or very close, association with HIV/AIDS. The former group regarded

⁶² South African Government, "Report of the Joint Health and Treasury Task Team, Statement on Special Cabinet Meeting: Enhanced Programme against HIV and AIDS," 8 August 2003, <<http://www.gov.za/speeches/8aug03>> (Accessed: 31 March 2004).

⁶³ UNAIDS, *Aids Epidemic Update* (Geneva: WHO, December 2000).

⁶⁴ Nelson Mandela/HSRC Study on HIV/AIDS, Press Briefing, 2002. See <<http://www.cadre.org.za>> and <<http://www.comminit.com>> (Accessed: 28 March 2005).

⁶⁵ Department of Health, South Africa, "Government Statement on the Nelson Mandela/HSRC Study on HIV/AIDS," 5 December 2002, <<http://www.doh.gov.za/docs/pr/2002/pr1205>> (Accessed: 21 January 2004).

⁶⁶ Trainers. Feedback to author. Cape Town, 2003.

the estimates as an underestimation, while the latter group regarded the estimates as an overestimation of HIV prevalence. The resulting views had a profound influence on whether or not the presented statistics were seen as accurate, and how trainees responded to the rest of the training. It was common for trainers to present examples of participants who had argued about the statistics, typically presented at the beginning of a course, and who then either left the training or stopped listening to further training input.⁶⁷

ATICC reported that it was more useful to present the statistics in a low-key manner and rely on participants' personal and work experience to discuss incidence and changing trends in the epidemic.⁶⁸ In this way, the official statistics simply backed up or challenged professional and personal experience. In 2002, UCT and ATICC claimed that it was more useful to use the *UNAIDS/WHO Classification of Epidemic States* when dealing with statistics.⁶⁹ This classification system uses three states to describe an epidemic, that is, low-level, concentrated and generalised. *Low-level* refers to an HIV infection that has not spread to a significant degree in any sub-population despite its presence over a period of time. *Concentrated* refers to an HIV infection that has spread rapidly and widely in a particular sub-population but is not established in the general population. *Generalised* refers to the state when HIV is firmly established in the population as a whole.

This brief history of the methods and presentation of HIV/AIDS statistics illustrates the difficulties in presenting statistics to health care workers. There were vast differences in how health care workers understood the HIV/AIDS statistics: these differences stemmed from important historical, political, educational, and cultural

⁶⁷ Trainers. Feedback to author. Cape Town, 2003.

⁶⁸ Trainers. Feedback to author. Cape Town, 2003.

⁶⁹ WHO/UNAIDS Report, "Improved Methods and Assumptions for Estimation of the HIV/AIDS Epidemic and its Impact: Recommendations of the UNAIDS Reference Group on Estimates, Modelling and Projections," *AIDS*, 16 (2002): W1-W14.

factors. In the above example, participants responded more positively to the concept of classifiable states than fixed numbers. The difficulties in presenting statistics continue, particularly in terms of reliability, validity, availability, and government support thereof. This was especially true when working with participants from low-incidence areas. By 2004 most health care workers were working in high-incidence areas and the reality of their daily contact with HIV/AIDS was enough to convince them of the enormity of the epidemic, despite their lack of familiarity and understanding of the HIV/AIDS statistics.

Changes in Methodology

Significant shifts in training *methodology* were observed over the four periods under review: there was a shift from traditional teaching methodology to more adult-based learning methodology. This section examines the reasons for this shift, and the resulting methodology that was more culture-, gender-, and language-sensitive.

In terms of the shifts in training *methodology*, the first period (1989-1994: The Early Days) was characterised by traditional training methodology. This training methodology was largely a continuation of the traditional and didactic training that was prevalent in provincial health training at the time.⁷⁰ The assumption of this methodology was that trainers provided specific information to health care workers: that is, it utilised the traditional “talk-and-chalk” method of educating children in school classrooms, in which trainers “gave” and participants “received” information.

Participants were also exposed to another training methodology at this first period: the lecture format. Training organisations utilised guest speakers for specialised input like medical facts, epidemiology, virology, and counselling. These

⁷⁰ A. Du Plooy (EAP Manager, Cape Town City Council). Interview by author. Cape Town, 1997.

guest speakers were doctors, university lecturers, and other health care professionals. Input was presented in lecture format with time at the end for questions. Few handouts were given to participants who were expected to take their own notes. Group discussions were seldom used because it was assumed that due to limited exposure to HIV/AIDS there was not much participant expertise. Presentations were given using the white board, slides, and overhead transparencies. These presentation aids reinforced the lecture format with the trainers as teachers and the health care workers as students. Participants were thus exposed to traditional and lecture format methodology in the same course.

Feedback was mixed in that many participants did not have the educational background to follow presentations given in the lecture format.⁷¹ Follow-up interviews showed that the main reason for this was the inferior high school and university education, especially those of Black and Coloured participants.⁷² Thus, the impact of Apartheid education was witnessed in adult learning in HIV/AIDS training programs. The traditional methodology worked well for more factual input like medical information, virology, epidemiology, and counselling models. Trainers reported that this methodology was not useful for complex training issues like ethics, home-based care, and pre- and post-test counselling.⁷³ Some trainers reported frustration with the training methodology, which they described as “boring and ineffective,” while other trainers expressed satisfaction.⁷⁴ Course feedback showed a contradiction between what methodology participants reported enjoying and what methodology was effective in practise.⁷⁵ Participants generally requested the “teaching” methodology: they reported that this was more familiar and thus

⁷¹ Health Care Workers. Training feedback forms. Cape Town, 1990-1994.

⁷² Health Care Workers. Interviews by author. Cape Town, April 2005.

⁷³ ATICC Trainers. Interviews by author. Cape Town, January 1994.

⁷⁴ ATICC Trainers. Interviews by author. Cape Town, January 1994.

⁷⁵ ATICC Participants. Training feedback forms. Cape Town, 1990-1994.

comfortable for them.⁷⁶ Follow-up feedback showed that despite the comfort of participants, this methodology did not contribute to sustainable learning.⁷⁷

Younger and recently qualified health care workers complained that the traditional methodology resulted in exhaustion and loss of concentration.⁷⁸ The first ATICC courses covered three full days with between six and eight lectures per day. Follow-up surveys confirmed the ineffectiveness of some of the training in that little factual information had been retained six months after training.⁷⁹ These dissatisfied participants requested more time to share their work and personal HIV/AIDS experiences, especially those experiences that dealt with issues like counselling, occupational exposure, confidentiality, partner notification, and care. Trainers stated that they felt trapped between the request for more discussion and the need to fill the training courses with as much information as possible.⁸⁰ Trainers understood that their brief for these early courses was to provide HIV/AIDS awareness and information to health care workers.

In terms of the shifts in training *methodology*, the second period (1995-1998: The Growing Epidemic) was characterised by many changes. The socio-economic historical changes after the 1994 elections played an important part in educational changes in the country. Some of these changes included the shift to skills-based education, less authoritarian approaches to learning, and the revision of teaching material particularly in subjects like history. During this period, training organisations witnessed a shift from traditional training methods to adult-based learning. Moreover, the increase in the reported number of HIV-positive persons attending clinics meant that health care workers brought more experience and expertise to training courses.

⁷⁶ This method was referred to as “spoon feeding” by some trainers.

⁷⁷ Health Care Workers. Interviews by author. Cape Town, April 2005.

⁷⁸ ATICC Participants. Training feedback forms. Cape Town, 1990-1994.

⁷⁹ ATICC Trainers. Training survey by author. Cape Town, September 1994.

⁸⁰ ATICC and UCT Trainers and Training Managers. Interviews by author. Cape Town, March 1995.

Participants with more HIV/AIDS experience and better secondary and tertiary education argued that the traditional training methods were cumbersome and unsuccessful.⁸¹

Trainers realised that the training methodology needed to be adjusted in order to meet the changing national education guidelines and the needs of health care workers.⁸² In response, trainers lengthened courses and included group discussions, which resulted in courses being comprised of a combination of traditional training methods for topics like medical information, virology, epidemiology, ethics, and counselling models, and more adult-based learning methods for topics like counselling, support, and care issues. Trainers stated that it was difficult to facilitate discussions because participants always seemed to need more time for discussion.⁸³ Some trainers managed this request by continuously reworking training material in order to promote more discussion, and leaving more time for questions and discussions. Some trainers were not that successful, primarily because of their strict adherence to training briefs and time constraints, which resulted in incomplete discussions.⁸⁴

Trainers and participants reported that group discussions were useful.⁸⁵ In 1995, much of the information that arose from group discussions was new and had not been communicated or documented by researchers or organisations. This information was important because of its local relevance: it had emerged from specific historical communities and contexts. It is important to note that the fact that local experience was generating community-based information was difficult for some trainers to accept

⁸¹ ATICC and UCT Trainers and Training Managers. Interviews by author. Cape Town, March 1995.

⁸² ATICC Trainers. Supervision by author. Cape Town, November 1994.

⁸³ ATICC Trainers. Training survey by author. Cape Town, September 1994.

⁸⁴ Health Care Workers. Training evaluation by author. Cape Town, December 1994.

⁸⁵ Trainers. Supervision by author. Cape Town, June 1997.

because it posed a challenge to their assumed HIV/AIDS expertise.⁸⁶ Trainers who were able to work with this shift by being more innovative in their training methodology were successful in providing pertinent, and at times, ground-breaking, training. For example, Lifeline utilised local clinic- and NGO-expertise in their training of lay counsellors for the PMTCT program in Khayelitsha. This training initiative was the first of its kind in South Africa. The trainers who were unable to make this methodological shift from expert to facilitator were criticised in participant feedback forms for providing repetitive training.⁸⁷ Some of these trainers stepped down as trainers, while other left the HIV/AIDS field.

In terms of the shifts in training *methodology*, the third period (1998 Onwards: The Questioning of Orthodoxy) was characterised by a split in methodology. This split occurred despite the methodological shift from traditional to adult-based learning in the previous period. For those participants who became confused by the government's reluctance to state that HIV caused AIDS, a return to more traditional methodology was witnessed. For those trainees who continued to work with high numbers of HIV-positive persons, there were continued advances towards more adult-based learning.

In 1998, trainers objected to facilitating courses in which both pro- and anti-dissident positions were expressed within the same training group.⁸⁸ Trainers argued that this created significant methodological problems because they were working in two methodologies simultaneously while providing input on one topic. This led to clumsy presentation of training material and arguments amongst participants that left

⁸⁶ ATICC Trainers. Supervision by author. Cape Town, November 1994.

⁸⁷ Health Care Workers (ATICC) and Medical Students (UCT). Training feedback forms. Cape Town, 1993-1995.

⁸⁸ Lifeline and UCT Trainers and Clinic-based Counsellors. Supervision by author. Cape Town, December 1998.

both trainers and participants frustrated.⁸⁹ In 1999, training organisations, in consultation with HIV/AIDS advisors, sought solutions to this problem. It was decided that trainers would do more regular training assessments, planning, and re-writing of material. In December 1999, trainers reported that these measures were not successful.⁹⁰ Trainers stated that they were stuck in a no-win situation. Despite the many organisational meetings that were held during this time to discuss the problem, few solutions were found because it was difficult to know the make-up of the training group in terms of the participants' views about the relationship between HIV and AIDS until the training had started. Thus, trainers had to prepare for both views with the ensuing arguments, confusion, and frustration.

Health care workers complained that the training did not meet their clinical and counselling needs.⁹¹ Pro-dissident trainees argued that the key questions, like the relationship between HIV and AIDS, were glossed over, while the anti-dissident trainees argued that too much time was spent on issues that were already well-established, and not enough time was spent on issues like prevention, treatment, support, and care. Pro-dissident participants wanted more time to discuss the relationship between HIV and AIDS, but this frustrated anti-dissident participants and trainers. Anti-dissident participants wanted to discuss cases and clinic issues, but pro-dissidents participants argued that all this was irrelevant until the basic causal factors had been established.

In terms of the shifts in training *methodology*, the fourth period (1999-2003: The Generalised Epidemic) was characterised by a return to the principles of adult-based learning. While there were still a few participants who supported the dissidents,

⁸⁹ Philipi Trust, ATICC, University of Cape Town Student Health Services, and Helderberg HIV/AIDS Unit Trainers. Interviews by author. Cape Town, January 1998-June 1999.

⁹⁰ Philipi Trust, ATICC, University of Cape Town Student Health Services, and Helderberg HIV/AIDS Unit Trainers. Interviews by author. Cape Town, January 1998-June 1999.

⁹¹ Health Care Workers. Feedback forms and supervision by author. Cape Town, December 1999.

their numbers were no longer large enough to have a significant impact on training.⁹² By 2000, trainers reported that HIV/AIDS training had returned to the more dynamic stage that it had been between 1995 and 1998.

Historically, by 2000, the epidemic was established and thus evident in the public and private sectors.⁹³ The government's position had masked this fact in 1999, but the increasing numbers of HIV/AIDS patients who presented at primary health clinics in 2000 and 2001 highlighted the need for more relevant training input on prevention, treatment and support. In 2000, health care workers demanded training methodologies that reflected their work: the high number of HIV-positive persons seen in primary health care clinics, the resource-limited environments in which health care workers lived and worked, and the urgency and complexity of clinical caseloads.⁹⁴ This resulted in methodological innovations that better reflected historical, cultural, social, and gender experiences of the health care workers in the Western Cape.

In 2000, training organisations discussed adult-based learning more directly: this was the beginning of HIV/AIDS training that was run almost exclusively according to these principles.⁹⁵ The exceptions, as already mentioned, were topics like medical information, virology, epidemiology, and ethics. These topics were more factual and required the establishment of basic awareness before the complexities of these issues could be discussed. Examples of the adult-learning principles that training organisations used are: immediacy, self-direction, experience, and motivation.⁹⁶ The principle of *immediacy* states that adults pursue subjects that have immediate relevance to their job or personal life. The principle of *self-direction* holds that adults

⁹² Lifeline and ATICC Trainers. Focus groups by author. Cape Town, May 2001.

⁹³ F. Fouche (HIV/AIDS Doctor). ATICC HIV/AIDS training. Cape Town, 2000.

⁹⁴ Health Care Workers. Feedback forms and supervision by author. Cape Town, December 1999.

⁹⁵ Lifeline and ATICC Trainers. Focus groups by author. Cape Town May 2001.

⁹⁶ M. Knowles, *The Adult Learner: A Neglected Species* (Houston: Gulf Publishing, 1984).

identify their own learning needs and pace themselves in the acquisition of new information and skills. The principle of *experience* states that experience provides the most important basis for learning activities. Finally, the principle of *motivation* holds that adults are internally motivated to learn rather than dependent on external motivation or discipline. Trainers used these principles to guide their methodological planning and the delivery of training.

In 2000, trainers reported relief at being able to utilise one methodology rather than two, as in 1998 when the government questioned the link between HIV and AIDS.⁹⁷ In 2001, feedback showed that adult-based learning methodology was successful, particularly its ability to create new opportunities for learning.⁹⁸ Trainers reported that the material was covered in more depth than before and that peer learning had become an important method of information acquisition. By 2004, the key features of HIV/AIDS training were small and large group discussions, participant presentations, and ongoing communication between participants after the conclusion of the course. There was also a new focus on training in rural areas and the utilisation of local skill bases in the provision of training. This led to the successful implementation of community-based train-the-trainer programs and capacity development initiatives. Presentations were group run, and thus there was less reliance on training aids like white boards, slides, and overhead transparencies. Role-play, group discussion, and problem-based tasks characterised presentations. By 2004, internet-based training were still poorly utilised due to the lack of knowledge and resources.⁹⁹

⁹⁷ Trainers. Supervision by author. Cape Town, July 2000.

⁹⁸ Health Care Workers. Feedback forms. Cape Town, May 2001.

⁹⁹ ATICC, Lifeline, and UCT Trainers. Feedback to author. Cape Town, April 2004.

During this fourth period, feedback from participants regarding the training methodology was generally positive.¹⁰⁰ Participants reported that training was more relevant to the issues that they confronted on a daily basis at work, and that they felt they had more input into what was discussed on training courses and how it was discussed. Follow-up feedback highlighted the success of adult based learning methodology, as well as the ongoing communication with, and support of, health care workers after having attended training courses. One participant summed it up as follows: “Many years ago we used to sit and sleep on these courses, but now we do the talking and the teaching.”¹⁰¹ By 2004, training methodology was still a combination of traditional and adult-based learning, but with a significantly larger emphasis on the latter. This methodological shift experienced in HIV/AIDS training mirrored the significant wider shifts in education in South Africa. During this final period, trainers described their work as facilitation.

Changes in Organisational Issues

In terms of shifts in *organisational issues*, HIV/AIDS training organisations reported unexpected and difficult organisational issues. Initially, organisational issues were overlooked as a consequence of the narrow focus on the delivery of training to health care workers. The management of issues like staff recruitment, performance appraisal, capacity development, organisational development, and stress management were later recognised to be vital to the success of HIV/AIDS training organisations. This section outlines the historical development of HIV/AIDS organisations in the period under review.

¹⁰⁰ Health Care Workers. Feedback Forms, ATICC, Lifeline, Philipi, and UCT. Cape Town, 1999-2004.

¹⁰¹ Health Care Workers. Feedback forms. Cape Town, May 2001.

In terms of the shifts in *organisational issues*, the first period (1989-1994: The Early Days) was characterised by limited organisational structures and development. Most of the first trainers ended up in HIV/AIDS training by default or because it seemed like a new challenge.¹⁰² Almost all of these trainers entered the field in the late 1980s or early 1990s with no HIV/AIDS experience: some had training experience in health or human resources within government organisations or NGOs. For example, ATICC's first two trainers had human resources and Hospice experience.¹⁰³ These first trainers had little support, few resources, and almost no national comparative training data.¹⁰⁴ They wrote training material in isolation and developed courses from scratch. During this period human resource practises were either inherited from the previous training organisation or rudimentary.¹⁰⁵ Those organisations that were linked to universities and government organisations benefited from the host organisation's human resources infrastructure. For example, in 1989, ATICC had selection and recruitment, salary and benefits, and disciplinary procedures in place because of its association with the Cape Town City Council. Organisations without these links had to begin developing human resource structures, often without the required knowledge and resources. When organisational problems did arise in these organisations they were often managed by hiring external human resource experts at great expense. Legal problems arose from inconsistent and inadequate employment practices in areas like grievances, discipline, and promotion.¹⁰⁶

¹⁰² ATICC Trainers. Interviews by author. Cape Town, March 1993.

¹⁰³ ATICC Trainers. Interviews by author. Cape Town, March 1993.

¹⁰⁴ It is important to note that similar and important processes of HIV/AIDS training development were taking place independently in other national areas, for example, KwaZulu-Natal and Gauteng.

¹⁰⁵ Managers. Interviews by author. Cape Town, August 1995.

¹⁰⁶ T. van der Velde (ATICC Manager). Private communication with author. Cape Town, 1995.

Organisational culture influences the way in which an organisation functions.¹⁰⁷ The organisational culture is defined by the beliefs of how work should be structured and managed, and how people should be rewarded and managed. The early HIV/AIDS training organisations had a *role* culture, which is bureaucratic and controlled by procedures and specific job descriptions. Training organisations were hierarchical in structure, with one manager who was responsible for all of the organisational and human resource functions. Management styles were usually closed and authoritarian. The reasons for these organisational structures and management styles in early HIV/AIDS organisations are important.

First, historically, in the late 1980s health training organisations were strongly linked with the government health department, which controlled all funding, training, and interventions. Organisational structures were bureaucratic and leadership was authoritarian. The training organisations adopted these organisational structures and management styles, either because of familiarity or because the health department still played an important role in managing the training organisation. The latter was the case in the establishment and management of ATICC, where the provincial Department of Health exerted control in funding and management issues. Second, in the late 1980s, the government organisational culture was bureaucratic and authoritarian because this was the organisational structure of Apartheid-based organisations in which centralised control and absolute power were essential to the maintenance of the system. Third, organisational structures in the business world were also bureaucratic and authoritarian, and alternative organisational and management models were only introduced internationally at the beginning of the 1990s. Thus, it is

¹⁰⁷ C. B. Handy, *Understanding Organisations* (Harmondsworth: Penguin Books, 1976).

understandable from an historical point of view that HIV/AIDS training organisations were organised bureaucratically.

In 1991, a national evaluation of the ATICCs by the Human Sciences Research Council (HSRC) highlighted various problems. Some of the problems linked to organisational issues were work overload, staff shortages, inadequate qualifications, lack of clinical psychologists and social workers, and the lack of funds for training.¹⁰⁸ In 1994, a similar survey of regional HIV/AIDS initiatives by the National Coordinating Committee of South Africa (NACOSA)¹⁰⁹ reported that these problems remained.¹¹⁰ Finally, it should be noted that ATICC was established in 1989 and developed over the next five years: ATICC's development was thus strongly influenced by the country's transition to democracy in 1994 (these issues are further examined in the remaining chapters of the dissertation).

In terms of the shifts in *organisational issues*, the second period (1995-1998: The Growing Epidemic) was characterised by similar patterns to the first period. By the mid-1990s, other HIV/AIDS training initiatives followed in the Western Cape. For example, in 1993, the training of 6th year medical students in primary health care at the University of Cape Town was established. Later, in 1997, Lifeline established the training of HIV/AIDS lay counsellors in Khayelitsha. The above-mentioned issues regarding organisational structure and management style for the period 1989-1994 were applicable to these new organisations. The newer and smaller training organisations had rudimentary organisational structures, and they were typically run by one manager who performed all of the human resource functions. This situation

¹⁰⁸ L. Grundlingh, "Neither Health nor Education? An Historical Analysis of HIV/AIDS Education in South Africa, 1980s-1990s," Development Studies Seminar, RAU, South Africa, 24 May 2002, <<http://general.rau.ac.za/sociology/Grundlingh2.PDF>>.

¹⁰⁹ NACOSA was formed in 1992, and its HIV/AIDS plan marked the beginning of the national coordinated public policy.

¹¹⁰ AIDS Bulletin, "NACOSA: Update on Regions," *AIDS Bulletin*, 3, no. 2 (1994): 10-12.

resulted in many human resource problems that were beyond the skills and experience of the manager. Important decisions were often made in isolation with no input from internal or external sources.

In 1995, the increase in the number of reported HIV/AIDS infections led to a greater demand for training.¹¹¹ Organisations managed the increased demand for training by implementing more frequent planning sessions.¹¹² By late 1995, this planning resulted in more training sessions and the recruitment of additional part-time and full-time trainers. Despite these changes, trainers reported that they were still extended beyond their resources. Newer organisations fared worse: they found themselves in the difficult position of not being able to finance new trainers because they were recently established and had limited funding.¹¹³ Thus, their trainers were forced into unrealistic training schedules without adequate resources or support. Many trainers in these smaller organisations reported symptoms of burnout and some trainers resigned.

Trainers reported that participants, while becoming more experienced in HIV/AIDS management, were also becoming more demanding.¹¹⁴ Health care workers found themselves with more HIV/AIDS cases, and given the wider socio-economic factors involved in the epidemic and lack of national leadership, they reported more frustration and stress. This frustration was brought into training sessions, and trainers found themselves providing not only training, but also support and even counselling to participants.¹¹⁵ These additional roles placed an extra burden on trainers, which had a negative impact on their work and their perception of their

¹¹¹ Trainers. Interview by author. Cape Town, March 1999.

¹¹² C. Jacobs (ATICC Manager). Interview by author. Cape Town, March 2001.

¹¹³ Managers. Interviews by author. Cape Town, 1995-1997.

¹¹⁴ ATICC, Philipi Trust, University of Cape Town Student Health Services, and Helderberg HIV/AIDS Unit Trainers. Interviews by author. Cape Town, January 1998-June 1999.

¹¹⁵ ATICC Trainers. Interviews by author. Cape Town, 1999.

work. ATICC implemented a weekly support group facilitated by a psychologist in order to assist trainers with these problems.¹¹⁶ Trainers reported that strong leadership from training managers and directors played an important role in the provision of strategic direction and support, not only to staff, but also to course participants. This strategic leadership influenced training content and methodology, and ultimately changed prevention and treatment practises.¹¹⁷

In terms of the shifts in *organisational issues*, the third period (1998 onwards: The Questioning of Orthodoxy) was characterised by organisational growth and frustration for HIV/AIDS training organisations. The government's questioning of the link between HIV and AIDS created problems for training organisations and trainers.¹¹⁸ These organisations were at the receiving end of much of the increasing public and professional confusion and anger. Health care workers brought their frustration and confusion into HIV/AIDS training. In 1998, trainers stated that they found the daily management and facilitation of courses more difficult than before.¹¹⁹ For example, participants were arguing with each other, blaming the government for their questioning stance, and accusing training organisations of misleading participants with false information in previous training courses. While trainers constantly evaluated and reworked training content and methodology, they reported increased frustration, anger, and disillusionment.¹²⁰

¹¹⁶ C. Jacobs (ATICC Manager). Interview by author. Cape Town, March 2001.

¹¹⁷ In 1995, the AIDS, Training, Information, and Counselling Centre (ATICC) agreed to take on 4 of the 5 Provincial Key HIV/AIDS Strategies. ATICC managed the following strategies: Syndromic Management of STIs, Media/Condom Distribution, Lifeskills, and Counselling. ATICC made changes to their training content and methodology in order to incorporate these into their courses. This initiative was successful in orienting health care workers to the key provincial strategies.

¹¹⁸ ATICC, Philipi Trust, University of Cape Town Student Health Services, and Helderberg HIV/AIDS Unit Trainers. Interviews by author. Cape Town, January 1998-June 1999.

¹¹⁹ ATICC, Philipi Trust, University of Cape Town Student Health Services, and Helderberg HIV/AIDS Unit Trainers. Interviews by author. Cape Town, January 1998-June 1999.

¹²⁰ Trainers. Interview by author. Cape Town, February 1999.

In 1998, after nine years of staff stability, there was a sudden turnover of staff in ATICC.¹²¹ One manager described the early days as pioneering days when people stayed in their jobs because they felt a commitment to fighting the epidemic.¹²² The reasons for the resignation of HIV/AIDS trainers were that many felt that the field had become too complicated and politicised; there were too many players; there was no clear career development; and health care workers found HIV/AIDS work more exhausting than other areas of health work. Historically, important underlying factors for these perceptions were the rapidly growing epidemic and the confusing government messages. Moreover, organisationally, training organisations were experiencing the expected developmental problems given their growth with its associated human resources problems.

In 1998, some directors and managers were sensitive to the organisational reasons for trainers leaving the field, and they made changes to ensure staff continuity.¹²³ These changes included the establishment of greater diversity in job descriptions, increased networking and involvement in external task groups and committees, advanced skills development, career path development, and management training. Other initiatives included coaching, 'caring for the carer' initiatives through interventions like staff support groups focussing on psychosocial and occupational stress, and regular and ongoing strategic planning.

In terms of the shifts in *organisational issues*, the fourth period (1999-2003: The Generalised Epidemic) was characterised by the growth of training. In 1999, trainers stated that the expectations and demands from government, the health sector,

¹²¹ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, May 2004.

¹²² C. Jacobs (ATICC Manager). Private communication with author. Cape Town, May 2004

¹²³ Directors and Managers. Interviews by author. Cape Town, 1999.

and the public were increasing.¹²⁴ Training organisations were expected to be actively involved in a wide range of issues. For example, they needed to be involved in, or at least be aware of, issues like multisectoral HIV/AIDS responses with its focus on capacity and human resource development, care and support, children, conflict, education, democracy and governance, and economic development and micro finance.¹²⁵ This increase in involvement led to staff specialisation, a high rate of reworking and turnover of material, and ongoing discussions about the presentation of material. From 1998 onwards, training organisations began promoting and providing training for specific prevention and treatment strategies, for example, the Prevention of Mother-to-Child Transmission (PMTCT) program (1998), the Voluntary Counselling and Testing (VCT) program (2000), and the roll out of the ARV program (2003).¹²⁶

From an organisational development point of view, training organisations were now coming of age. They were no longer small and uncomplicated organisations but growing and increasingly complex organisations. Management styles were more open and participative. Staff was more involved in decision making, while trainers entered management positions. Historically, these changes mirrored the organisational development in the corporate sector in the late 1990s. Also, these changes mirrored the shifts towards organisational democratisation as a result of the political democratisation of the country. The need for increased capacity development, training

¹²⁴ ATICC, Philipi Trust, University of Cape Town Student Health Services, and Helderberg HIV/AIDS Unit Trainers. Interviews by author. Cape Town, January 1998-June 1999.

¹²⁵ UNAIDS, "Multisectoral Responses to HIV/AIDS: A Compendium of Promising Practices from Africa," USAID-PVO Steering Committee on Multisectoral Approaches to HIV/AIDS, April 2003.

¹²⁶ As mentioned, certain training organisations, like ATICC and Lifeline, were successful at positioning themselves at the heart of these initiatives by ensuring that they are part of all strategic program development, training, and assessment.

specialisation, and ongoing recruitment was well established. By 2004, most organisations were employing at least double the number of trainers than in 1993.¹²⁷

The final point deals with the recruitment of trainers. From the mid-1990s, there was an enthusiastic response to advertised posts for HIV/AIDS trainers. Organisations realised the importance of offering first language training, and they made an effort to recruit and develop suitable Xhosa, Afrikaans and English trainers.¹²⁸ This change in recruitment strategy made a significant difference to the training content and methodology, and organisational make-up. In 1999, training organisations piloted parallel courses in three languages, with different content and methodology depending on the target-training group. This resulted in more complex and relevant training and organisational structures, as attested to by training assessments and organisational evaluations.¹²⁹ Following these pilot courses in 1999, health care workers consistently requested more first language training from trainers drawn from their, or similar, communities. This issue is examined in detail in chapter six.

By the end of 2003 training organisations were complex and evolving structures. Trainers were no longer simply presenters of HIV/AIDS awareness and education programs: they had multiple and challenging organisational roles. The successful trainers were those who were involved in wider socio-economic issues like community networking, advocacy, and other development work. Acknowledging this shift and helping trainers develop these skills was an important function of management. By 2004, human resource structures were well established, and this

¹²⁷ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, May 2004.

¹²⁸ Lifeline, ATICC, Helderberg, and UCT Training Managers and Directors. Interviews by author. Cape Town, June 2000-May 2001.

¹²⁹ Health Care Workers. Feedback forms. Cape Town, 1998-2003.

aided training organisations to function in the rapidly changing field of HIV/AIDS management.

Conclusion

This analysis highlighted four main periods in the shift in content, methodology, and organisational issues in HIV/AIDS training organisations. From 1989 to 2004, training organisations moved from the provision of basic HIV/AIDS information with traditional classroom methods to specialised program and skills development with innovative adult-learning methods.

The formation of HIV/AIDS training organisations and the delivery of the first training courses characterised the first period (1989-1994: The Early Days). The training *content* consisted of basic HIV/AIDS information and awareness. The traditional classroom training *methodology* was a carry over from previous education and health training models. The *organisational* structures were basic and hierarchically organised, and usually inherited from supporting organisations like the provincial health department.

Increased health care worker experience and expertise, growth of training and training organisations, and more community-specific training characterised the second period (1995-1998: The Growing Epidemic). The training *content* included more advanced prevention, treatment, and care input, largely as a result of the increasing numbers of HIV-positive persons presenting at clinics and the increasing experience of health care workers. Training *methodology* began to shift towards adult-based learning principles, and this resulted in more relevant peer- and community-based learning. The *organisational* structures of training organisations became larger and more complex.

Participant and trainer confusion and frustration characterised the third period (1998 Onwards: The Questioning of Orthodoxy). The training *content* was split between the pro- and anti-dissident views. There was a return to basic information, especially in the areas of virology and epidemiology, for those who supported the government stance, while there was more specialised and locally relevant information for those who opposed the government stance. There was also a split in training *methodology*: a return to tradition methodology for the pro-dissident supporters, and a continuation of more adult-based learning for anti-dissident supporters. Staff frustration and resignations dominated the *organisational issues*. The importance of staff support and capacity development was highlighted during this period.

With the fading of the dissident debate and the significant increase in persons attending primary health clinics, organisations focussed on training health care workers for specialised interventions and programs in the fourth period (1999-2003: The Generalised Epidemic). The training *content* was specialised and linked to specific programs, and it reflected local and international HIV/AIDS prevention and treatment priorities. The training *methodology* moved closer towards the principles of adult-based learning. The new training demands resulted in innovative methodological solutions, which were a combination of traditional and adult-based learning, depending on the content. In terms of *organisational issues*, training organisations were larger, more complex, and evolving structures.

The remaining four chapters examine the changes in content, methodology, and organisational development in terms of the contributing historical factors. A deeper historical analysis links these changes to the wider political, socio-economic, cultural, and gendered changes in the period under review. The contributing historical factors are grouped as follows in the remaining chapters:

- Political factors (Chapter Four)
- Socio-economic factors (Chapter Five)
- Cultural factors (Chapter Six)
- Gender factors (Chapter Seven).

CHAPTER FOUR: “If we can beat Apartheid, we can beat AIDS” – State politics and the history of HIV/AIDS training, 1989-2004.

This chapter provides an historical overview of government responses to HIV/AIDS in South Africa: that is, the responses of the National Party (1980s-1994), as well as the African National Congress under the leadership of Nelson Mandela (1994-1999) and Thabo Mbeki (1999-2004). The influence of the historical and political factors on the attitudes and responses of health care workers and trainers to HIV/AIDS training and programs is discussed. The next two sections explore the role of provincial political factors and HIV/AIDS leadership in the HIV/AIDS training of health care workers and the delivery of services in the Western Cape. This chapter seeks to contribute to the social history of medicine by examining the HIV/AIDS training of health care workers. The sources utilised in this chapter are largely oral, contextualised with secondary sources. Health care workers and trainers were interviewed in order to analyse the underlying political factors that influenced the changes in HIV/AIDS training, content, and organisational issues in the period under review.

The Apartheid Government and HIV/AIDS: c.1982-1994

Historically, governments have been slow to respond to HIV/AIDS. In Africa, the reasons for this include the fear of withdrawal of foreign investment, misunderstanding of the origin and transmission of HIV/AIDS, poverty, and cultural and sexual taboos.¹ Goliber argued that in southern Africa the pervasive governmental silence around HIV/AIDS was a result of governments regarding HIV/AIDS as a

¹ C. Akukwe and M. Foote, “HIV/AIDS in Africa: Time to Stop the Killing Fields,” *Constituency for Africa*, 6, no. 15 (2001).

problem of Central and West Africa only.² This perception was partly true, and supported by the Joint United Nations Programme on HIV/AIDS (UNAIDS)/World Health Organisation's (WHO) observation that in the early 1980s, HIV/AIDS was "found in a geographic band stretching from West Africa across to the Indian Ocean . . . by 1987, the epidemic begun gradually to move south."³ Thus, the slow response of governments was a combination of the reasons cited above for African countries and the geographical spread of the disease from central to southern Africa. This was true for South Africa as well as its neighbouring countries: Botswana, Namibia, Angola, Zimbabwe, and Mozambique.

The National Party's (NP)⁴ response is now analysed. In 1982, health officials recorded the first two AIDS deaths in South Africa.⁵ Based on transmission patterns in the USA and on the two South African cases, HIV/AIDS was associated with homosexuality. In 1983, Dr. Slabbert (Director General of the Health Department) stated: "Homosexuality is not accepted by the majority of the population and certainly not by the Afrikaans speaking population. To advocate that homosexuals use the condom is therefore very difficult."⁶ Also, Dr. Coogan (Medical health Officer of Cape Town) stated that the city's residents should not fear HIV/AIDS because only homosexuals contracted the disease and there were very few homosexuals in the city.⁷

² T. Goliber, "Africa's Political Response to HIV/AIDS," *Population Reference Bureau*, 2002, <<http://www.prb.org/aidsresponseafrica>> (Accessed: 30 March 2005).

³ UNAIDS/WHO, *A History of the HIV/AIDS Epidemic with Emphasis on Africa* (Geneva: UNAIDS, WHO, UN/POP/MORT/2003/2).

⁴ National Party (NP): In 1914, Afrikaner nationalists founded the National Party. In 1924, the party first came to power with J. M. B. Hertzog as Prime Minister. In 1948, the NP defeated J. C. Smuts' United Party to assume power again, a position that it held until the first democratic elections in 1994, when it was defeated by the African National Congress (ANC).

⁵ A. Thom and K. Cullinan, "Responses to HIV/AIDS," Centre for the Study of AIDS, Pretoria, 28 November 2004, <<http://www.health-e.org.za/news/article.php?uid=20031154>> (Accessed: 29 June 2006).

⁶ L. Grundlingh, "HIV/AIDS in South Africa: A Case of Failed Responses because of Stigmatisation, Discrimination and Morality, 1983-1994," *New Contree*, 46 (1999): 55-81.

⁷ Grundlingh, "Stigmatisation," 11.

In 1985, the government established an AIDS advisory group.⁸ In the absence of any treatment options, Drs. Sher and Sifris contacted the government to set up an AIDS clinic, and they were granted permission to do this in 1986. They established the first AIDS clinic at the Johannesburg General Hospital, which initially operated once a week.⁹ Government messages were scant and misinformed, for example, in 1988, Dr. van Niekerk (Minister of Health Population Development) stated that “Promiscuity is the greatest danger, whether one likes it or not,” while Dr. Barnard (Spokesperson of the Progressive Federal Party) suggested that HIV-positive persons be isolated.¹⁰ In December 1988, the government’s stereotyping yielded to the realities of the disease.¹¹ On 26 July 1989, the AIDS Training, Information, and Counselling Centre (ATICC, Western Cape) opened: that is, the first HIV/AIDS training organisation in the province.¹²

1990 was a pivotal year in that the government changed its view from one of stigmatisation to the need for urgent action.¹³ The government focused on ensuring safe blood supplies, began the antenatal HIV surveillance program, and established the network of ATICCs across the country.¹⁴ The government responded to pressure from health officials and gay advocacy groups.¹⁵ The reasons for this include the fact that between 1987 and 1990 heterosexual prevalence increased fourfold and exceeded the total number of people with AIDS.¹⁶

⁸ Thom and Cullinan, “Responses.”

⁹ A. Thom and K. Cullinan, “Virus Veterans,” Centre for the Study of AIDS, Pretoria, 28 November 2004, < <http://www.csa.za.org/article/articleview/335/1/1>> (Accessed: 29 June 2006).

¹⁰ Thom and Cullinan, “Responses.”

¹¹ L. Grundlingh, “Government Responses to HIV/AIDS in South Africa as Reported in the Media, 1983-1994,” *South African Historical Journal*, 45 (2001): 124-153.

¹² C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 17 May 2004.

¹³ Grundlingh, “Government,” 128.

¹⁴ A. Whiteside and J. Van Niftrik, “AIDS in South Africa: Government and ANC Responses,” *AIDS Analysis Africa*, 3, no. 4 (1995): 1 & 9

¹⁵ Whiteside and Van Niftrik, 9.

¹⁶ Grundlingh, “Government,” 128.

The period 1990-1994 saw significant shifts in the government's responses to HIV/AIDS. At the beginning of 1991 the government launched its first full-scale national strategy, and Dr. Venter (Minister of Health) argued that the different parts of society – for example, government, corporate sector, trade unions, and community leaders – needed to be mobilised to combat the disease.¹⁷ In November 1991, the government's Department of National Health and Population Development met with the Health Secretariat of the African National Congress to discuss HIV/AIDS. These discussions and the national conference, *South Africa United against AIDS*, in October 1992, led to the formation of the *National AIDS Convention of South Africa* (NACOSA) with the aim of preventing the spread of HIV/AIDS.¹⁸ Representatives of NACOSA included the NP, ANC,¹⁹ NGOs, and organized industry and labour representatives.²⁰ In 1994, Cabinet endorsed this strategy and South Africa had a National AIDS Plan.²¹

There is little significant historical research of the government's response to HIV/AIDS between 1982 and 1994, especially until 1990. This shows the historiographical fissure in South Africa, particularly in the social history of medicine and disease. As referred to above, Louis Grundlingh's research of the University of Johannesburg is the exception to this. He has provided historical analyses of: how stigmatisation, discrimination, and morality contributed to the government's failed response to HIV/AIDS from 1983-1994,²² the attitudes and responses of the government, the medical profession, and the public regarding HIV/AIDS between

¹⁷ Grundlingh, "Government," 131.

¹⁸ V. van der Vliet, "South Africa Divided against AIDS: A Crisis of Leadership," in *AIDS in South Africa: The Social Expression of the Pandemic*, eds. K. D. Kauffman and D. L. Lindauer (New York: Palgrave Macmillan, 2004), 48.

¹⁹ Including later ANC health ministers, Dr. Manto Tshabalala-Msimang and Dr. Nkosazana Zuma.

²⁰ C. Ijsselmuiden et al., "AIDS in Africa," *AIDS Society*, 4, no. 2 (1993): 10-11.

²¹ A. Butler, "South Africa's HIV/AIDS Policy, 1994-2004: How can it be Explained?," *African Affairs*, 104, no. 417 (2005): 591-614.

²² L. Grundlingh, "HIV/AIDS in South Africa: A Case of Failed Responses because of Stigmatisation, Discrimination and Morality, 1983-1994," *New Contree*, 46 (1999): 55-81.

1983 and 1988,²³ and the media's reports of the government's responses to HIV/AIDS from 1983-1994.²⁴ The last study is especially valuable because it provides insight into the policies of the government up to 1994 as documented in the media.

Attention is now turned to the responses of health care workers in this period. The government's perception of the factors effecting HIV/AIDS had a marked effect on what the public and professional sectors thought about disease. ATICC's first courses emphasized the medical components and thus the organisation helped establish the medical discourse that continued to dominate HIV/AIDS training throughout the period under study: HIV/AIDS was seen as unconnected to socio-economic conditions.²⁵ Trainers reported that the medical aspects of the disease received precedence in the planning and content of HIV/AIDS courses.²⁶ An historical analysis showed the medical bias in HIV/AIDS training content. For example, an ATICC trainer stated how guest speakers, who were mostly doctors, emphasized medical information: "We did this because this is what we learnt from America and because there was no-one else. But, this did add to the impression that doctors were the gatekeepers of the disease. This excluded many other important health care professionals for many years."²⁷ This quote shows the significance given to doctors and the medical aspects of HIV/AIDS in training courses. This, in turn, contributed to the perception that HIV/AIDS was primarily a medical issue. Historically, it should be noted that in the USA in the 1980s there were important contributions from the humanities and the social sciences, especially in the areas of the spread, management, and treatment of the disease (see chapter two for details). These contributions were

²³ L. Grundlingh, "Early Responses, Attitudes and Behaviour regarding HIV/AIDS in South Africa, 1983-1988," *Journal of Contemporary History*, 26, no. 1 (2001): 86-103.

²⁴ L. Grundlingh, "Government Responses to HIV/AIDS in South Africa as Reported in the Media, 1983-1994," *South African Historical Journal*, 45 (2001): 124-153.

²⁵ ATICC Training Participants. Interview by author. Cape Town, 25 November 1993.

²⁶ ATICC Trainers. Focus group by author. Cape Town, 8 December 1993.

²⁷ ATICC Trainers. Focus group by author. Cape Town, 8 December 1993.

not incorporated into the first training courses in 1989. Arguably, this is the usual route of understanding: first the medical narratives, and then the expanded understanding of the social issues.

In 1993, health care workers reported that the dismantling of Apartheid created more optimism with regards to health care and HIV/AIDS prevention and management.²⁸ This confidence in the transition to democracy led to the belief that the government would confront and manage HIV/AIDS more actively. For example, a participant stated: "We live in a time of change. Comrade Hani is right:²⁹ we must not let AIDS stop us from building our country. If we can beat Apartheid, we can beat AIDS."³⁰ Even though the links between the responses of government and HIV/AIDS were still not well understood, trainers and health care workers expressed confidence that the new government would at least address the disease, and do this equitably: "AIDS is smaller than Apartheid."³¹

By the end of 1993, trainers and health care workers expected that the government would be involved in the prevention and management of HIV/AIDS, and moreover they believed that there were important government initiatives that could be built on. For example, a senior trainer stated: "We [training organisations] are ready to implement the suggestions of NACOSA. We use this plan to help us prepare services and programs, especially in the area of HIV/AIDS counselling."³² Its mandate was to develop a national strategy on HIV/AIDS, and its goals included the

²⁸ ATICC Health Care Workers. Feedback to author. Cape Town, 14 December 1993.

²⁹ This refers to Chris Hani's words in May 1991: "We have a noble task ahead of us – reconstruction of our country. We cannot afford to allow the AIDS epidemic to ruin the realisation of our dreams." Cited in Van der Vliet, "AIDS," 130.

³⁰ Health Care Worker. Training feedback to author. Cape Town, 28 June 1995.

³¹ Health Care Worker. Training feedback to author. Cape Town, 24 February 1995.

³² Trainer. Focus group by author. Cape Town, 28 February 1995.

prevention of HIV transmission, the reduction of the personal and social impact of HIV/AIDS, and the mobilisation of local, provincial, and international resources.³³

Some commentators have argued that the NP failed to respond appropriately to HIV/AIDS in the crucial early phases of the disease.³⁴ This view highlighted the fact that from the first diagnosis of HIV/AIDS in South Africa in 1982 (see chapter six for a discussion of the history of transmission of HIV/AIDS in South Africa) to the first HIV/AIDS training in the Western Cape in 1989 there were few significant government interventions. Yet, the NP's response was no worse than other countries in the early phase of the epidemic. While the historical documentation of the government's early response to HIV/AIDS is incomplete, conjecture is possible as to the response. It is argued that discrimination played a significant part. In the early 1980s, most of the HIV/AIDS cases in South Africa were confined to the gay community, with the first Black diagnosis in 1987, and the limited government intervention was partly a result of the discrimination against gays and Blacks in the government.³⁵ Fassin argued that South Africa and Namibia's Apartheid structures and homophobia resulted in unique and extreme forms of inequality, most notably in health care services, which led to problematic HIV/AIDS responses by the Apartheid governments and the democratic governments that followed them.³⁶ Thus, while South Africa's neighbours were also slow to react to HIV/AIDS and did not respond in any consistent or proactive way either, South Africa and Namibia's HIV/AIDS responses were uniquely hampered by a particular kind of inequality.³⁷ Ijsselmuiden

³³ Department of Health, South Africa, "HIV /AIDS Strategic Plan for South Africa," January 2000, <<http://www.doh.gov.za/aids/doc/aids-plan>> (Accessed: 21 June 2004).

³⁴ Whiteside and Van Niftrik, 1 & 9.

³⁵ Van der Vliet, "South Africa Divided," 50.

³⁶ D. Fassin, "Une crise épidémiologique dans les sociétés de post-apartheid. Le sida en Afrique du sud et en Namibie," *Afrique contemporaine*, 195 (2000): 105-115.

³⁷ H. Schneider and D. Fassin, "Denial and Defiance: A Socio-Political Analysis of AIDS in South Africa," *AIDS*, 16, supplement 4 (2002): S45-S51.

et al. argued that political and social polarization between Blacks and Whites was responsible for the view that HIV/AIDS was only found in other races “which only diminishes the personal and collective sense of susceptibility and the volition and aptitude to act.”³⁸ This racially delineated nature of the epidemic encouraged racism and inaction: the politics of the epidemic would undoubtedly have been different if all South Africans had been equally infected.³⁹ Shisana and Zungu-Diwayi argued that conservative Christian ethics and racism informed the government’s limited reaction to HIV/AIDS before 1990.⁴⁰ As evidence of this hypothesis, they showed that HIV/AIDS was associated with gays and Blacks, and that sex education – the most important preventative measure – was largely ignored because HIV/AIDS was associated with the gay community, condoms, and promiscuity.

A major area of criticism of the NP’s government was its limited funding of early HIV/AIDS prevention campaigns.⁴¹ Condom distribution was the corner stone of the prevention campaign in the USA, yet the issue of condoms was controversial in South Africa in the 1980s because it was argued by government members that condom distribution campaigns encouraged promiscuity.⁴² By the end of 1988, the government made condoms available to the public at no cost. By 1990, major problems had been identified, including: inexperience with the supply of condoms and the resistance from large sectors of society against condom use. One of the reasons for the resistance is the historical suspicion that Blacks had for condoms following the government’s previous attempts at family planning. Moultrie argued that from as early as 1910, White South Africans feared being swamped by the increasing Black

³⁸ Ijsselmuiden et al., 10.

³⁹ V. van der Vliet, “AIDS: Losing “The New Struggle”?,” *Daedalus*, 130, no. 1, (2001): 151-184.

⁴⁰ O. Shisana and N. Zungu-Diwayi, “Government’s Changing Response to HIV/AIDS,” *Development Update*, 4, no. 3 (2003): 165-187.

⁴¹ Whiteside and Van Niftrik, 9.

⁴² Grundlingh, “Government,” 137.

population.⁴³ The call for family planning programmes targeting Blacks grew louder in the 1960s. In 1974, the government launched the National Family Planning Program, which it argued stemmed from demands from Black women for contraception.⁴⁴ This program contributed to the mistrust of Blacks to institutionalised attempts at fertility.⁴⁵ Thus, Blacks associated the early HIV/AIDS prevention campaigns with the family planning program.⁴⁶

Linked to this, the NP government lacked the political legitimacy to suggest and implement successful health prevention strategies, especially given the political unrest of the mid 1980s and early 1990s. In 1990, Dr. Ivan Toms (present Director of City Health Services, Cape Town) argued that there was “no possibility that the present government could, even if it [had] the inclination, run an effective campaign to limit the spread of HIV infection. It has no credibility or legitimacy whatsoever among Blacks.”⁴⁷ In 1994, Nelson Mandela⁴⁸ stated that the NP “government does not have the credibility to convince the majority of Black South Africans to change their sexual behaviour.”⁴⁹

Van der Vliet criticised the NP government for not consulting political and trade union leaders at the time in order to address HIV/AIDS policy directly.⁵⁰ By keeping HIV/AIDS an isolated medical issue and not linking the disease to the conditions under which people lived in Apartheid, the government was unprepared for

⁴³ T. Moultrie, “Racism and Reproduction: The Institutional Effects of Apartheid on the South African Fertility Decline,” conference paper, XXIV IUSSP General Population Conference, Salvador, Brazil, 18-24 August 2001.

⁴⁴ Moultrie, 19.

⁴⁵ A. Seedat, *Crippling a Nation: Health Under Apartheid South Africa* (London: International Defence and Aid Fund for Southern Africa, 1984), 12.

⁴⁶ Whiteside and Van Niftrik, 1.

⁴⁷ Cited in Van der Vliet, “South Africa Divided,” 52.

⁴⁸ Nelson Rolihlahla Mandela (b.1918): joined the African National Congress (ANC) in 1944; imprisoned from 1964 to 1990; released from prison on 11 February 1990; and served as South Africa’s first democratically elected president between 1994 and 1999.

⁴⁹ Shisana and Zungu-Diwayi, 169.

⁵⁰ Van der Vliet, “South Africa Divided,” 49.

the HIV/AIDS epidemic, and thus delayed any meaningful response. Finally it should be noted that the government was also pre-occupied with various political crises during this time, for example, the state of emergency that was declared in 1986.

Crewe offered a different view to the above critics. Her argument highlighted the two phases of the NP's response to HIV/AIDS: one, the government's limited response between 1982 and 1989, and, two, the proactive government response between 1989 and 1994. This argument is significant because it outlines the two different phases, and provides a more nuanced understanding of historical, political and socio-economic factors underlying the NP's responses to HIV/AIDS. Crewe argued that South Africa was in a relatively strong position with regards to HIV/AIDS in 1990 because the social, cultural, and economic boycotts of the Apartheid government had essentially insulated South African society from spiralling transmission patterns.⁵¹ In 1994, with an infection rate below 5%, South Africa was ready for the epidemic – it had a comprehensive and well-informed plan that was realistic and easy to implement within two years.⁵² She argued that the National AIDS Plan recognised the issues related to the social, economic, and discriminatory realities of the disease: "It highlighted the need for legal reform and legislation and research, all underpinned by prevention strategies and planning for care. The plan was imbued with the notion of effective AIDS prevention being closely aligned to human rights."⁵³ While South Africa was insulated, it is important to remember the historical significance of migrant labour in South Africa from countries like Malawi, Mozambique, Botswana, and Zimbabwe. The migrant labour system is a strong

⁵¹ K. D. Kauffman, "Why is South Africa the HIV Capital of the World?," in *AIDS and South Africa: The Social Expression of the Disease*, eds. K. D. Kauffman and D. L. Lindauer (New York: Palgrave Macmillan, 2004), 28.

⁵² M. Crewe, "South Africa: Touched by the Vengeance of AIDS," *South African Journal of International Affairs*, 7, no. 2 (2000): 23-39.

⁵³ Crewe, 25.

candidate in the early spread of HIV/AIDS in South Africa (see chapter five for a detailed discussion of migrant labour and HIV/AIDS in South Africa).⁵⁴

Significantly, this period was characterised by the transition to democracy. While the initial training courses stressed the medical aspects of the disease to the neglect of political and other factors, significant government initiatives like the National AIDS Plan were begun. The political transition to democracy created expectations in health care workers and trainers of positive government HIV/AIDS intervention. The ANC government's HIV/AIDS response from 1994, including the fact that the National AIDS Plan was neither consulted nor implemented, will be explored chronologically in the subsequent sections of this article. Finally, the historiographical lacunae in HIV/AIDS studies in the period 1982 to 1990 are noted.

Mandela's Government: c.1994-1999

There are different views regarding how successful Mandela's government was in responding to HIV/AIDS. Shisana and Zungu-Diwayi argued that Mandela's government was proactive in the fight against HIV/AIDS.⁵⁵ They provided examples of what they argue were significant responses. For example, in 1992 Mandela opened the *South Africa United against AIDS Conference*, where he warned that a failure to deal with HIV/AIDS would affect many future generations. On 18 August 1994, in his 'first 100 days speech' he stressed the social and economic implications of the epidemic and the urgent need for a response from all sectors of South African society. Mandela partially implemented programs based on the NACOSA plan and the Reconstruction and Development Plan (RDP). Finally, a National AIDS Control

⁵⁴ H. Phillips, "HIV/AIDS in the Context of South Africa's Epidemic History," in *AIDS and South Africa: The Social Expression of the Disease*, eds. K. D. Kauffman and D. L. Lindauer (New York: Palgrave Macmillan, 2004), 32.

⁵⁵ Shisana and Zungu-Diwayi, 171.

Programme was established within the Department of Health, with the appointment of Dr. Olive Shisana as the Director of HIV/AIDS. Thus, Shisana's pro-government analysis is understandable given her close association with the ANC government and its HIV/AIDS initiatives. Shisana and Zungu-Diwayi did concede that while the government was proactive, it was not successful in its fight against HIV/AIDS: they argued that the reasons for the failure lie in the "massive administrative changes which South Africa underwent in the first five years of the transition."⁵⁶ They highlighted the changes in personnel structures, lack of delivery structures, and limited HIV/AIDS management skills. This argument fails to account for the government's silence and inconsistent responses to the epidemic.

In 1994, the complexities of the political transformation process made the co-ordination and management of the HIV/AIDS difficult. The combination of the rapidly increasing epidemic and the institutional demands on the new government contributed to the problems of national HIV/AIDS management. Marais argued that the ANC government inherited a rapidly worsening epidemic.⁵⁷ The ANC government acknowledged the problem but it was slow to address HIV/AIDS in any significant way. Kauffman held that in 1994 the ANC had more pressing issues that the new government had to address, for example, the inequities in poverty, education, and health.⁵⁸

Crewe countered these explanations, as outlined above, by stating that in 1994, despite the massive institutional changes, Mandela's government had a basic infrastructure through which to implement the NACOSA plan.⁵⁹ As examples she cited the AIDS centres, the HIV clinics in hospitals, NGOs, researchers, and health

⁵⁶ Shisana and Zungu-Diwayi, 171.

⁵⁷ H. Marais, *To the Edge: AIDS Review 2000* (Pretoria: Centre for the Studies of AIDS, University of Pretoria, 2000).

⁵⁸ Kauffman, "HIV Capital," 28.

⁵⁹ Crewe, "Vengeance," 24.

care workers that had significant experience and expertise. Crewe concluded that the ANC government “completely ignored the voice and expertise of local scientists and AIDS NGOs.”⁶⁰ According to Schneider, “all are in agreement that the National AIDS Plan was not implemented as expected and has turned out to be not much more than ‘a neat book on the shelf.’”⁶¹ Health care workers and trainers shared the perspective that the government’s neglect of the fledgling national initiatives in its first years of power had a negative effect on the management of the epidemic.⁶² The government’s uncertain position was exemplified by ensuing HIV/AIDS controversies. These government controversies play an important role in the social history of HIV/AIDS.

Government’s HIV/AIDS Controversies

In 1995, the government was criticised for its management of *Sarafina II*.⁶³ This was the musical commissioned by the Department of Health at an initial cost of R14.27 million, and in August 1995 the contract was awarded to the playwright Mbongeni Ngema.⁶⁴ The goal of the musical was to provide HIV/AIDS preventative education to children and adolescents. By January 1996, numerous questions were raised about the musical.⁶⁵

The public’s response centred on the mismanagement of the government allocated funds, the lack of a proper tender process, the lack of adequate educational

⁶⁰ Crewe, “Vengeance,” 24.

⁶¹ H. Schneider, “The Politics Behind AIDS: The Case of South Africa,” conference paper, 12th World AIDS Conference, Geneva, Switzerland, 1998, 7.

⁶² Health Care Workers and Trainers. Focus groups by author. Cape Town, 8-12 April 1996.

⁶³ A. Carlsson, “Controversy Between Politics and Science when South Africa Handles the AIDS Epidemic,” *Axess*, 1 (2004).

⁶⁴ Mbongeni Ngema (b.1955): A South African playwright, musician, choreographer, and director. His award-winning plays include: *Woza Albert!* (1981), *Asinamali!* (1984), *Sarafina* (1987), *Township Fever!* (1990), and *Magic at 4 am!* (1993). Source: D. Killam and R. Rowe, eds., *The Companion to African Literature* (Oxford: James Currey, 2000).

⁶⁵ National Progressive Primary Health Care Network, “The Sarafina II Controversy,” *PHILA Legislative Update*, 3 June 1996, < <http://www.healthlink.org.za/pphc/Phila/sarafina> > (Accessed: 6 April 2005).

HIV/AIDS content, and the inaccessibility of the play to the general population.⁶⁶ This led to a public investigation of the musical, and on 11 September 1996, Selby Baqwa (the National Public Protector) submitted his findings.⁶⁷ Baqwa stated that the musical was an unauthorised expenditure, which meant that the Department of Health had spent money that it did not have. Moreover, the Public Prosecutor argued that the musical's content was questionable, and that the mismanagement of the initiative was unjustifiable. In 1996, the PHILA Legislative Update argued that the government's inability to manage *Sarafina II* "could adversely impact future international donor funding for the Department of Health, the RDP, and the entire Government of National Unity."⁶⁸ While this view might have been overstated, *Sarafina II* did have a lasting negative effect on HIV/AIDS management in South Africa.

Sarafina II affected health care workers and training organisations negatively. Between 1995 and 1996 not a single health care worker or trainer supported *Sarafina II*. Those who saw the musical were critical of the contents: "I saw this play in Jo'burg. Hey, there was *lekker* singing and dancing, but I couldn't see the AIDS messages."⁶⁹ Others commented on the abuse of resources, for example, "I don't know what to say. What we could have done in this province with only one or two of those millions. Imagine how our AIDS patients feel."⁷⁰ Others commented on how the process and contents affected patients: "We waited so long for this government, and this is the first thing they do with AIDS. We cry with our patients."⁷¹ In 1995 and 1996 health care workers stressed the negative social and personal impact of *Sarafina*

⁶⁶ Centre for the Study of AIDS (CSA), "Responses to HIV/AIDS," 28 November 2004, <<http://www.csa.za.org/article/view/333/1/1>> (Accessed: 21 September 2005).

⁶⁷ Public Prosecutor, "Investigation Concerning the *Sarafina II* Donor," Report in terms of Section 8(2) of the Public Protector Act 23 of 1994, Report No 2 (Special Report), 11 September 1996. (ISBN0-621-17645-1, RP 35/1977).

⁶⁸ National Progressive Primary Health Care Network.

⁶⁹ Primary Health Care Clinic HIV/AIDS Counsellor. Interview by author. Cape Town, 8 May 1997.

⁷⁰ Health Care Worker. Training discussion with author. Cape Town, 14 August 1996.

⁷¹ Nurse. Training discussion with author. Cape Town, 14 August 1996.

II on people who were HIV-positive. For example, health care workers stated that HIV/AIDS persons reported increased public discrimination as a result of the play because the public associated HIV/AIDS persons with the failures of the play.⁷² Finally, HIV/AIDS persons told health care workers that they felt particularly let down by the “Sarafina II joke.”⁷³

On 3 February 1997, at the *World Economic Forum Session on AIDS* in Switzerland, Mandela made a speech about HIV/AIDS which was one of the few times that he mentioned the disease during his Presidency. He stated:

Conscious of our own need to put the effort to combat AIDS on a higher plane, South Africa's National AIDS Programme has made the call for “A New Struggle.” The vision which fuelled our struggle for freedom; the deployment of energies and resources; the unity and commitment to common goals - all these are needed if we are to bring AIDS under control.⁷⁴

The media and health care workers took up Mandela’s call for “A New Struggle,” and the phrase “HIV/AIDS – the new Apartheid” was used in training discussions from this point onwards.⁷⁵ The other action taken by the government in 1997 was the establishment of the Inter-ministerial Committee. Yet, both the speech and the committee were over-shadowed by the next government controversy.

In 1997, Thabo Mbeki (then Deputy President) and Dr. Nkosasana Zuma (then-Health Minister) personally endorsed the drug Virodene as a purported cure for HIV/AIDS.⁷⁶ This endorsement was based on preliminary and uncontrolled research conducted by cryogenic researchers Olga and Jacques Visser. The drug proved

⁷² Health Care Worker. Interview by author. Cape Town, 6 August 1997.

⁷³ Health Care Worker. Interview by author. Cape Town, 6 August 1997.

⁷⁴ Nelson Mandela, “Speech at the World Economic Forum,” ANC Documents, 3 February 1997, <<http://www.anc.org.za/ancdocs/history/mandela/1997/sp970203.html>> (Accessed: 4 July 2006).

⁷⁵ Trainers. Interview by author. Cape Town, 17 February 1999.

⁷⁶ Virodene - dimethylformamide (DMF) - is an industrial solvent used in cryopreservation (that is, preserving body tissues by lowering the body temperature). There is no evidence that Virodene inhibits HIV's protease enzyme. See: <<http://www.aidsmap.com/en/docs>> (Accessed: 8 April 2005).

severely toxic to the liver, taken orally or through skin exposure.⁷⁷ The Medicines Control Council (MCC) criticised the government's role and management of this issue and refused testing of the drug. In response the government called for the abolishment of the MCC. Mbeki stated that "to confirm its determined stance against Virodene, and contrary to previous practice, the MCC has, with powers to decide who shall live or die, also denied dying AIDS sufferers the possibility of "mercy treatment" to which they are morally entitled."⁷⁸ Also in 1997, the government made the controversial decision to make AIDS a notifiable disease.

By 1998, the government's actions were raised by health care workers in every HIV/AIDS training session.⁷⁹ For example, "There is only one person making all the decisions. Zuma has shown that she does not have the expertise to do this . . . Our HIV/AIDS experts have all been excluded by the government."⁸⁰ Health care workers reported that patients also raised these issues.⁸¹ In 1998, the government fired the AIDS Advisory Committee. In October 1998, Mbeki launched the *Partnership against AIDS* program to mobilise all South Africans against the disease. This created more frustration for health care workers and trainers because the initiative was made "in the void of any logical and progressive input from the government."⁸²

The most noticeable consequence of these controversies on HIV/AIDS health care workers and trainers was the increased pessimism about the government's ability to respond to the epidemic. By 1998, health care workers had abandoned their pre-1994 election optimism regarding HIV/AIDS and they stated that they had no choice

⁷⁷ Aidsmap, "Virodene P058," 1 August 2003, <<http://www.aidsmap.com/en/docs>> (Accessed: 8 April 2005).

⁷⁸ Thabo Mbeki, "ANC has No Financial Stake in Virodene," *ANC Today*, March 1998, <<http://www.anc.org.za/ancdocs/history/mbeki/1998/virodene>> (Accessed: 8 April 2005).

⁷⁹ Trainers. Interview by author. Cape Town, 25 November 1998.

⁸⁰ Doctor. Interview by author. Cape Town, 24 March 2000.

⁸¹ Health Care Workers. Interview by author. Cape Town, 24 March 2000.

⁸² Health Care Workers. Interview by author. Cape Town, 24 March 2000.

but to take responsibility for the epidemic because the government had proved itself inept.⁸³ This had the interesting effect of health care workers networking more with each other, sharing community resources, and relying more on training organisations like ATICC, Lifeline, Leadership South, and FAMSA for support and guidance.

“Why does the Old Man stay so quiet?”⁸⁴ – Mandela’s Response

The absence of Mandela’s criticism of these issues raised doubts about his commitment to HIV/AIDS treatment and management.⁸⁵ Mandela’s inaction became even more confusing after 1999 when, no longer the president, he became active in the HIV/AIDS debate. In March 2003, Mandela stated his regret at not having done more in providing HIV/AIDS leadership while he was the president. In discussing his presidential response to HIV/AIDS Mandela said, “I could have done more.”⁸⁶ In this interview, Mandela claimed that he was advised not to talk about HIV/AIDS because it could endanger his election campaign. Those frustrated with Mandela included his friend and personal physician, Dr. Nthato Motlana, who stated: “I get so angry. I go to Mandela - I had breakfast with him this morning - and I give him hell . . . The response by the previous apartheid government was a national disgrace. The response by my government - and I’m a very loyal member of the ANC, have been since the age of 18 - has also been disgraceful.”⁸⁷

Between 1994 and 1999, health care workers were perplexed by Mandela’s seeming reluctance to address the HIV/AIDS problem. Focus groups in 1998 showed

⁸³ Health Care Workers. Focus groups by author. Cape Town, 4 December 1998.

⁸⁴ Health Care Worker. Supervision by author. Cape Town, 18 February 1999.

⁸⁵ M. Schoofs, “AIDS: The Agony of Africa,” *The Village Voice*, 22-28 December 1999, <<http://www.pulitzer.org/year/2000/international-reporting/works/AIDS7>> (Accessed: 7 August 2006).

⁸⁶ BBC, “Madiba: I Could Have Done More,” Interview with Nelson Mandela, 2 March 2003, <<http://www.news24.com>> (Accessed: 8 April 2004).

⁸⁷ M. Schoofs, “AIDS: The Agony of Africa,” *The Village Voice*, 22-28 December 1999, <<http://www.pulitzer.org/year/2000/international-reporting/works/AIDS7>> (Accessed: 7 August 2006).

that the majority of health care workers questioned Mandela's position. Health care workers commented on their need for his leadership in the area of HIV/AIDS: "We need his guidance. Why does the Old Man stay so quiet? We need his wisdom."⁸⁸ Some health care workers raised the issue of ANC members being HIV-positive: "Maybe Madiba can't talk about AIDS because there are too many of his friends that has AIDS. Or maybe he is bossed around by the younger ANC. Maybe he is no longer the lion."⁸⁹

Such responses from health care workers and trainers were common. Health care workers argued that Mandela had provided leadership on so many crucial issues and his silence on HIV/AIDS was considered confirmation of its unimportance. A few health care workers expressed their understanding of the government's difficult task of transforming South Africa amidst so many pressing issues like housing, unemployment, and education. For example, "Our government has too many things to do. AIDS is just one of the many things that Apartheid has left. Where does our government start?"⁹⁰ Generally, in 2004, the government inaction and controversies, and the lack of political HIV/AIDS leadership had shifted the narrative from optimism to pessimism. Trainers and health care workers no longer believed that the government was capable of providing the necessary leadership. This pessimism led to more initiatives that were driven by primary health clinics, faith-based organisations, and NGOs.

Mbeki's Government: c.1999-2004

This section examines the HIV/AIDS responses and controversies associated with President Thabo Mbeki's government. In 1999, in the first year of his

⁸⁸ Nurse. Interview by author. Cape Town, 15 September 1998.

⁸⁹ Trainer. Interview by author. Cape Town, 24 September 1998.

⁹⁰ Nurse. Interview by author. Cape Town, 24 September 1998.

presidency, Mbeki questioned the link between HIV and AIDS. Later that year, Mbeki claimed that it was irresponsible for the government to provide HIV-positive persons with Azidothymidine (AZT)⁹¹ because of its alleged toxicity. In 2000, Mbeki contacted AIDS-dissidents for their views on the link between HIV and AIDS. In 2001, Mbeki used 1995 HIV/AIDS statistics to argue that prevalence rates in the country were lower than what the antenatal and UNAIDS surveys claimed them to be. In 2003, Mbeki denied that he knew anyone affected by the disease. Of these scandals, the one that received the most attention was Mbeki's association with the *dissident* view. This issue shall be examined because of the national and international attention that it drew to Mbeki and HIV/AIDS in South Africa and the effects that it had on training organisations and health care workers.

In October 1999, Mbeki told the National Council of Provinces that AZT was toxic.⁹² This conclusion was based on personal Internet research, where he read the views of AIDS-dissident Peter Duesberg (Professor of Molecular and Cell Biology at the University of California, Berkeley).⁹³ Duesberg claims that AIDS diseases are the result of the long-term use of recreational drugs and/or AZT.⁹⁴ Mbeki's scepticism of the orthodox view led him to question the 'science of AIDS' by arguing that poverty and antiretroviral drugs are the cause of AIDS.⁹⁵ In early 2000, Mbeki established the *Presidential International Panel of Scientists on HIV/AIDS in Africa* to investigate these issues. The inclusion of international and vocal AIDS-dissidents like Peter Duesberg and David Rasnick (Visiting Scientist, Department of Molecular and Cell Biology at the University of California, Berkeley) on this panel resulted in harsh

⁹¹ Chemical name: Azidothymidine, generic name: Zidovudine, acronym: AZT, and brand name: Retrovir ®.

⁹² Van der Vliet, "South Africa Divided," 58.

⁹³ M. Schoofs, "Flirting with Pseudoscience," *The Village Voice*, 15 March 2000, <<http://www.thebody.com/schoofs/mbeki>> (Accessed: 11 April 2005).

⁹⁴ See <<http://www.duesberg.com>> (Accessed: 12 April 2005).

⁹⁵ P. Sidley, "Clouding the AIDS Issue," *British Medical Journal*, 320, no. 7240 (2000): 1016.

criticism from scientific and various other quarters. For example, Mamphela Ramphele (Managing Director at the World Bank) stated that: "It's irresponsibility that borders on criminality."⁹⁶

In April 2000, Mbeki sent letters to world leaders, including US President Bill Clinton and Britain's Prime Minister Tony Blair, requesting that they revisit the orthodox views of HIV/AIDS (there was no response to these letters).⁹⁷ In April 2002, Mbeki formally distanced himself from the dissidents, but the government's views remained confusing.⁹⁸ At the end of Mbeki's association with the dissidents, he had spent R2.5 million and had a 134-page document of recommendations, produced by the *Presidential International Panel of Scientists on HIV/AIDS in Africa*, that was split between the views of dissident and orthodox scientists.⁹⁹

Mbeki's association with the dissents and the government's continuing confusion is the source of ongoing speculation. Some of the hypotheses that have been forwarded include Mbeki's misunderstanding of texts and research,¹⁰⁰ a weak presidency,¹⁰¹ the reduction of HIV/AIDS to an imaginary disease to lessen responsibility,¹⁰² and the utilisation of the dissident debate as a political strategy of distraction.¹⁰³ More recently, Lodge argued that Mbeki's response to the HIV/AIDS debate is the result of his acceptance of Western prejudice and bias towards Africa,

⁹⁶ Treatment Action Campaign, "Treatment Action News," (17 July 2000), <<http://www.tac.org.za/newsletter/2000>> (Accessed: 11 April 2005).

⁹⁷ Van der Vliet, "South Africa Divided," 59.

⁹⁸ Van der Vliet, "South Africa Divided," 77.

⁹⁹ See: Presidential AIDS Advisory Panel Report, "A synthesis report of the deliberations by the panel of experts invited by the President of South Africa, the Honourable Mr Thabo Mbeki," March 2001, <<http://www.gov.co.za/aids>> (Accessed: 18 April 2005).

¹⁰⁰ S. Seepe, "A Response to Mzamane's "The Politics of Health in the New South Africa," *African Review of Books* (May 2003), <<http://www.africanreviewofbooks.com/Newitems/mzamaneresp>> (Accessed: 13 April 2005).

¹⁰¹ Tom Lodge argued that the weak presidency is a result of the president's lack of clear vision, his inability to admit mistakes, and his advisors being either too misinformed or timid to properly advise or challenge him. Also, see, for example, T. Susman, "AIDS Battle in South Africa: Mbeki's Stance Becoming an Embarrassment," *Newsday (New York)*, 22 May 2000.

¹⁰² M. Mbali, Review of *AIDS: Crisis and Resistance*, by Alan Whiteside and Mark Heywood. Second Wolpe Lecture, Centre for Civil Society, 2003.

¹⁰³ Helen Suzman cited in "The Pall of Politics," *Mail & Guardian (Johannesburg)*, 8 August 2003.

opposition to established bodies of knowledge, and desire for an African rebirth.¹⁰⁴ Moreover, Lodge argued that the ANC is an organisation with a revolutionary self-image, and therefore it prefers criticism of dominant players like international technological and scientific business.

The hypersensitivity and antagonism of Mbeki, Dr. Manto Tshabalala-Msimang (Minister of Health),¹⁰⁵ and other government officials to criticism were marked. At times, Mbeki tried to demonise and marginalize his critics.¹⁰⁶ For example, in 2000, Mbeki, while delivering the Oliver Tambo Memorial Lecture, attacked Tony Leon obliquely by referring to him as “the White politician” - an arrogant racist who saw Africans as “pagan, savage, superstitious and unscientific.”¹⁰⁷ Posel argued that lurking beneath such raw antagonism is the grandiose vision of renewal, the “African renaissance.”¹⁰⁸ This point is illustrated in Mbeki’s description of the Treatment Action Campaign:

We must free ourselves of the 'friends' who populate our ranks, originating from the world of the rich, who come to us, perhaps dressed in jeans and T-shirts, as advisers and consultants, while we end up as the voice that gives popular legitimacy to decisions we neither made, nor intended to make, which our 'friends' made for us, taking advantage of an admission that perhaps we are not sufficiently educated.¹⁰⁹

It has been argued that HIV/AIDS revealed the undemocratic side of the government by highlighting the government’s reluctance to accept AIDS plans (for example, like NACOSA), negotiate HIV/AIDS with civil society (for example, TAC, trade unions, and opposition), and accept court decisions (for example, the implementation of the

¹⁰⁴ T. Lodge, *Politics in South Africa: From Mandela to Mbeki* (Oxford: James Curry, 2003).

¹⁰⁵ Dr. Manto Tshabalala-Msimang: Co-ordinator of ANC Health Plan on Women’s Health (1991-1994), Member of Parliament (since 1994), Minister of Health (since 17 June 1999). Her term in office has been controversial in terms of her views on HIV/AIDS, her support of the dissidents, and her position on antiretroviral treatment.

¹⁰⁶ Carlsson, “Controversy.”

¹⁰⁷ P. Hawthorne, “The Legacy that Won’t Die,” *Time (Europe)*, 156, no. 9, 28 August 2000.

¹⁰⁸ D. Posel, “Getting the Nation Talking about Sex: Reflections on the Politics of Sexuality and ‘Nation-Building’ in Post-Apartheid South Africa,” *MS* (2003).

¹⁰⁹ “The Pall of Politics,” *Mail & Guardian (Johannesburg)*, 8 August 2003.

PMTCT program).¹¹⁰ While Mbeki's other presidential achievements, especially his economic achievements, have been applauded, van der Vliet argued that these achievements have been overshadowed by his response to HIV/AIDS.¹¹¹ Kauffman held that "the leadership of the ANC probably has done more to confuse the public by its inaction."¹¹² Finally, Carlsson argued that because the government addressed HIV/AIDS autocratically and unsuccessfully, some of its moral authority was undermined.¹¹³

Yet, a political economy of HIV/AIDS does not go far enough in explaining South Africa's (not only the President's) widespread suspicion of science and orthodoxy.¹¹⁴ Fassin and Schneider held that a political anthropology helps explain two important reactions to the HIV/AIDS epidemic: first, the racialisation of the HIV/AIDS debate in South Africa (for example, the government habitually accusing HIV/AIDS critics of racism),¹¹⁵ and, second, the belief that there is a conspiracy against Africans (for example, orchestrated by conservative Whites or international pharmaceutical companies). Fassin and Schneider argued that these views stem from the deeply embedded effects of living in an Apartheid state. They concluded that understanding that the resulting suspicion and denial are historically rooted in South Africans assists in the prevention and treatment of the HIV/AIDS epidemic.

¹¹⁰ M. Mbali, "HIV/AIDS Policy-Making in Post-Apartheid South Africa," in *State of the Nation: South Africa 2003-2004*, eds. J. Daniel, A. Habib, and R Southall (Cape Town: HSRC Press, 2003).

¹¹¹ Van der Vliet, "South Africa Divided," 88.

¹¹² Kauffman, "HIV Capital," 24.

¹¹³ Carlsson, "Controversy."

¹¹⁴ D. Fassin and H. Schneider, "The Politics of AIDS in South Africa: Beyond the Controversies," *British Journal of Medicine*, 326 (2001): 495-497.

¹¹⁵ Mbali, "Review."

The Response of Trainers and Health Care Workers

In 1999, when Mbeki invited scholars to debate the HIV-AIDS link in South Africa, many people became confused after having slowly begun to accept the realities of HIV/AIDS. From 1999 onwards, there were numerous training examples of direct challenges from participants in response to previously accepted and well-utilised material.¹¹⁶ Many participants no longer believed the HIV/AIDS information delivered by trainers. The questioning of orthodoxy was particularly evident in training content like virology, epidemiology, statistics, and treatment strategies. Nurses questioned the time that HIV/AIDS took away from their other duties. For example, “What if the President is right? Then we are wasting our time with all this HIV/AIDS stuff. We should be doing ‘real’ nursing again, not all this counselling and problems with confidentiality.”¹¹⁷ Some health care workers raised doubts more characteristic of the early years of training (1989-1993) regarding the veracity of the disease: “You know, I have always thought that there was something wrong with this AIDS story. How can a virus stay in your body so long without you getting sick?”¹¹⁸ These shifts were alarming and frustrating for trainers who felt that all their education was being undone by Mbeki’s views.¹¹⁹ Health care workers also questioned the antenatal statistics and the reliability of HIV tests: “The President’s experts say that the HIV tests are unreliable. Why are we using them? These statistics were wrong. We don’t see those high numbers of AIDS patients that the surveys say. My manager says I must still do these tests but I don’t believe the results anymore.”¹²⁰ Finally, some health workers showed appreciation for Mbeki’s view of poverty and the racist attitudes of foreign leaders and organisations towards Africa. For example, “Mbeki is

¹¹⁶ Health Care Workers. Training feedback to author. Cape Town, 18 May 1999.

¹¹⁷ Nurse. Training feedback to author. Cape Town, 18 May 1999.

¹¹⁸ Counsellor. Training feedback to author. Cape Town, 18 May 1999.

¹¹⁹ Trainers. Interview by author. Cape Town, 7 April 2001.

¹²⁰ Nurse. Focus groups by author. Cape Town, 6 March 2001.

not only talking about AIDS – he is talking about the racist attitudes of the world towards Blacks. One can't separate AIDS from politics. So I understand Mbeki. He is telling the world to shut-up; let us make our own decisions.”¹²¹

There were also many reports from health care workers who stated that patients were openly declaring that they were no longer going to use condoms because, even in the unlikely event of contracting HIV, they would not develop AIDS.¹²² The government's negative impact on the beliefs and behaviour of patients resulted in anger in health care workers. For example, “I don't know what he [Mbeki] is doing. My patients don't care about if HIV causes AIDS. They have AIDS! What they want is treatment. What I want is a President who doesn't confuse my patients. My counselling is much longer now because they are confused.”¹²³ Health care workers argued that not only did Mbeki's views affect patients, but his views questioned the basic premise of their work: “Mbeki should visit our AIDS clinic, and maybe do my job for a day. Hey, he will not then speak the rubbish that he speaks every day. If I see him I am going to tell him that Apartheid never existed – we'll see if he likes that.”¹²⁴ Generally, health care workers and NGOs claimed that Mbeki's stance had a long-lasting negative impact on clinic attendance, treatment, and the safer sex campaign.

The following example from Khayelitsha illustrates how the government's stance impacted on safer sex beliefs and practices.¹²⁵ Since 1997, a group of HIV counsellors walked home from the day clinic along a certain route that brought them into contact with the same group of teenagers. Often they would stop to talk to the teenagers, which was a good opportunity for sex education. The teenagers invariably

¹²¹ Nurse. Focus groups by author. Cape Town, 6 March 2001.

¹²² Leadership South and Lifeline Counsellors. Interviews by author. Cape Town, 8 December 1999.

¹²³ Nurse. Focus groups by author. Cape Town, 6 March 2001.

¹²⁴ Nurse. Focus groups by author. Cape Town, 6 March 2001.

¹²⁵ Lifeline Counsellors. Private communication with author. Khayelitsha, 9 June 2000.

told them that there was no such thing as AIDS, and hence they did not have to practise safer sex. Over the year the banter continued, and there was no change in what the teenagers believed. In October 1998, then-Deputy President Mbeki delivered the government's *HIV Address to the Nation*. President Nelson Mandela was scheduled to give this address and at the last moment Mbeki delivered the address on behalf of Mandela. The message of this address was: "The danger is real . . . [and] we can only win against HIV/AIDS if we join hands to save the nation."¹²⁶ A few days after the address the counsellors were walking home and were stopped by the visibly agitated teenagers. They said, "You were right, Mma, AIDS does exist – Thabo Mbeki said so!"¹²⁷ This report from HIV/AIDS counsellors in Khayelitsha may appear unrepresentative, but numerous health care workers provided similar examples of how patients were affected by the HIV/AIDS announcements of the president and the government.¹²⁸ Without follow-up research it is difficult to know whether the effects of these announcements on patients were sustained.

From 1999 onwards, what was clear to trainers was that health care workers were confused by the government's inconsistent public health messages, and concerned about the government's lack of action.¹²⁹ The government justified its slow response by arguing that the link between HIV/AIDS had to be clarified before prevention, treatment, support, and care issues were implemented. Health care workers reported that they became less interested in the theoretical debates, and that they were only interested in what the government could do for clinic patients on a day-to-day basis.¹³⁰ Linked to this, health care workers expressed concern over what

¹²⁶ Thabo Mbeki, "Partnership against Aids Declaration," 9 October 1998, <<http://www.gov.za/issues/hiv/aidsdeclaration98>> (Accessed: 17 April 2004).

¹²⁷ Lifeline Counsellor. Private communication with author. Khayelitsha, 9 June 2000.

¹²⁸ Health Care Workers. Training feedback to, and supervision by, the author. Cape Town, 1997-2001.

¹²⁹ Trainers. Focus groups by the author. Cape Town, 4 May 2000.

¹³⁰ Nurse. Supervision by the author. Cape Town, 13 December 2000.

they described as the government's lack of responsibility to health care workers: they felt that they were carrying the HIV/AIDS burden for the government with limited acknowledgement and support from the government. As a health care worker reported: "The government likes talking; we like working. Their talking does nothing for the woman who saw me yesterday. She was beaten up so badly she could hardly speak. She thinks that her husband is HIV-positive and she asked if he would wear a condom. He beat her up with beer bottles. Then, he tied her to a post and set his dog on her."¹³¹

One of the significant negative effects of the government's stance and inaction on health care workers was the breakdown of trust in the government. This was especially evident in health care workers' views that the government did not keep its promises and that even if programs were delivered there was no adequate follow-through and support. One nurse claimed: "They'll [the government] drop the ARV program on us with much noise, and then they'll disappear. We'll [health care workers] have to carry the ARV program; I mean the cost and the personnel issues."¹³² This break of trust in the government in the government's ability to respond proactively to HIV/AIDS is one of the main features of the period under review.

A positive effect of the government's controversial stance and inaction was that health care workers felt less reliant on the government's HIV/AIDS response and leadership.¹³³ In the early 1990s, health care workers continually requested more government involvement. By the end of the decade, this request had been replaced with conversations about what health care workers had to do in response to the HIV/AIDS epidemic. Health care workers took the initiative in mobilising community

¹³¹ Health Care Worker. Interview by author. Nyanga, 21 July 2000.

¹³² Nurse. Private communication with the author. Cape Town, 21 November 2003.

¹³³ Nurses. Training with the author. Cape Town, 20 February 2001.

resources in order to assist with issues like home-based care, feeding schemes, and caring for orphans.¹³⁴ For example, in 2000, health care workers stated: “We have started organising our own clinics, and we get help from anyone who wants to help. We have support groups, sewing groups, feeding groups, education sessions, counselling, and a referral network. We started all of these things on our own.”¹³⁵ Health care workers, especially nurses, took responsibility for the increasing HIV/AIDS demands: “We need to do the proper education and treatment. I call my colleagues who work in other communities and we do things for our patients. I help patients find help in the community. We have many people who want to help, but it’s not easy because we don’t have money.”¹³⁶ Lost confidence in the government forced health care workers to take ownership of certain prevention, support, care, and human resource issues.

Mbeki’s government entered the debate by championing the dissent view of HIV/AIDS. This response was markedly different from the Mandela government’s silence and inconsistent responses. The Mbeki period was characterised by the government’s confusing public health messages and its failure to enact legislation that assisted HIV/AIDS treatment.¹³⁷ The dissident debate polarised government rhetoric, on the one hand, and health worker praxis, on the other hand. Health care workers focussed more on what was needed for patients, while politicians questioned the HIV-AIDS link and downplayed treatment options like AZT. This polarisation had interesting effects on the political allegiances of health care workers in the Western Cape, a province with a complex political history.

¹³⁴ Counsellors. Training feedback to the author. Cape Town, 4 February 2000.

¹³⁵ Nurse. Interview by author. Khayelitsha, 7 July 2000.

¹³⁶ South Peninsula Counsellor. Interview by author. Cape Town, 20 July 2000.

¹³⁷ Kauffman, “HIV Capital.”

Provincial Politics

The unique political conditions of the Western Cape had significant effects on HIV/AIDS. Despite the overwhelming national electoral victory of the ANC in 1994, the province remained under the leadership of the National Party (NP).¹³⁸ In 1999, the Democratic Party (DP) received the most provincial votes. In 2000, the DP merged with the New National Party to form the Democratic Alliance.¹³⁹ In 2004, the ANC won the provincial election. These political changes in the province had important consequences for how HIV/AIDS initiatives were perceived and managed.

Between 1994 and 1998, there were few provincially led HIV/AIDS initiatives. The provincial government supported ATICC, and in 1995 they worked together on the *Syndromic Management of Sexually Transmitted Diseases (STDs)* program for the province. In October 1998, the national government announced that it would finance AZT for pregnant women.¹⁴⁰ In December 1998, Dr Zuma (Minister of Health) retracted this statement and claimed that South Africa could not afford to finance AZT. Health care workers and trainers had keenly anticipated the rollout of AZT, and people were angry after hearing the government's policy shift.¹⁴¹ Despite this announcement, the Western Cape Provincial Department of Health decided to pursue the funding of AZT for pregnant HIV-positive women. ANC doctors motivated this decision even though there was the threat of reprisals from national ANC comrades.¹⁴² The New National Party supported this provincial ANC-driven initiative because it saw it as an opportunity to oppose the national ANC government

¹³⁸ In 1997, the National Party (NP) changed its name to the New National Party (NNP).

¹³⁹ In 2001, the New National Party (NNP) left the Democratic Alliance to form an alliance with the African National Congress (ANC).

¹⁴⁰ M. Schoofs, "Problem Pregnancy: Doctors Regard AZT as an AIDS Vaccine for Babies. But South Africa says it's too Expensive," 9 December 1998, <<http://www.thebody.com/schoofs/azt>> (Accessed: 14 October 2004).

¹⁴¹ Health Care Workers and Trainers. Training discussions with author. Cape Town, 26 February 1999.

¹⁴² S. Schute, "Transmitting Hope in Khayelitsha," *ChildrenFIRST*, 31 (2002).

and to be seen taking HIV/AIDS leadership in the province. The provincial Prevention-Mother-to-Child-Transmission (PMTCT) program was thus established under the auspices of the provincial Department of Health. In 2000, the Democratic Alliance supported the extension of the PMTCT program to more clinics.¹⁴³ In 2000, *Médecins Sans Frontières (MSF)* started the first provincial pilot project with triple therapy to AIDS patients in Khayelitsha. Thus, HIV/AIDS policy development, treatment, and care continued in what was one of the wealthier provinces. The continuation of health care delivery was in sharp contrast to failing health care services in poorer provinces, for example, the Northern Cape and the Eastern Cape.

Health care workers who supported the NNP openly dismissed the national HIV/AIDS policies of the ANC with the traditional, and often racist, arguments, while quietly endorsing the role of the provincial ANC Health Desk.¹⁴⁴ Black health care workers who supported the ANC reported ambivalence with regards to the national HIV/AIDS policies of the ANC.¹⁴⁵ Publicly, these health care workers agreed or remained silent when the national ANC HIV/AIDS policies were discussed; privately they expressed their confusion with what they considered the government's double standards. Some health care workers felt betrayed by the ANC's HIV/AIDS policies. One health care worker stated: "We supported them in the old days when it was difficult for us; now they have forgotten their people."¹⁴⁶

One of the unexpected results of this provincial political questioning was that health care workers united, despite their political affiliations, in the delivery of health services to HIV/AIDS patients. A health care worker put it as follows: "My colleagues and me are tired of all this politics. Our patients are humans, like us, and

¹⁴³ Van der Vliet, "South Africa Divided," 65.

¹⁴⁴ Health Care Workers. Focus group by author. Cape Town, 4 May 2000.

¹⁴⁵ Health Care Workers. Focus group by author. Cape Town, 4 May 2000.

¹⁴⁶ Health Care Worker. Interview by author. Khayelitsha, Cape Town, 7 July 2000.

we need to help them. This politics helps no-one.”¹⁴⁷ These sentiments translated into productive interventions across racial and class lines. For example, nurses and counsellors were assisting each other by contributing specific cultural and language education and prevention material to clinic and community interventions. Ironically, the government’s stance united many health care workers around the issue of HIV/AIDS. Training organisations played a significant role in facilitating this communication and collaboration.

Despite the confusion created by the shifting political alliances and leadership in the Western Cape, trainers and health care workers were able to press forward with relevant training. Moreover, they helped to create and support groundbreaking program initiatives like the PMTCT and ARV programs. Training organisations challenged the national ANC HIV/AIDS discourse, while supporting the provincial ANC HIV/AIDS initiatives. The support of training organisations and health care workers seemed less determined by politics than by pragmatism: they supported HIV/AIDS initiatives, less than political rhetoric. In a way, politics served HIV/AIDS pragmatism.

The Role of HIV/AIDS Leadership

Despite the shift towards more health care worker responsibility and ownership of HIV/AIDS initiatives, they reported that they felt limited in their ability to influence national and international HIV/AIDS legislation. For example:

There are two levels of care concerning HIV/AIDS in this province. First, there is what the politicians say and what we say in meetings with the province. Then there is the level of grass-roots care, which is carried out almost in isolation, almost completely uninformed by the bureaucracy, by committed nurses

¹⁴⁷ South Peninsula Health Care Worker. Interview by author. Cape Town, 7 July 2000.

and doctors. This grass-roots level is where all the important work is being done. We talk to the bureaucrats to keep them happy and hopefully to get money.¹⁴⁸

If health care workers received little political leadership, other groups and individuals were vital in providing support and examples of clear political HIV/AIDS messages and treatment options.

One group that played an important role in providing strong and clear messages in opposition to the government was the *Treatment Action Campaign (TAC)*. TAC was launched on 10 December 1998. Its objective was to "campaign for greater access to treatment for all South Africans, by raising public awareness and understanding about issues surrounding the availability, affordability and use of HIV treatments."¹⁴⁹ Initially TAC worked with the government, but the relationship began to sour in 1999 because of Mbeki's association with the dissident view of HIV/AIDS. In 2000, TAC became increasingly frustrated with the new Minister of Health, Dr. Tshabalala-Msimang. TAC argued that she did not prioritise the amendment of the *Medicines and Related Substances Control Amendment Act* that would allow government to shop around for cheaper medication for HIV/AIDS patients.¹⁵⁰ In August 2001, TAC sued the government, demanding that AZT be made more widely available. On 14 December 2001, Judge Botha judged in favour of TAC, arguing that, "a countrywide MTCT prevention program is an ineluctable obligation of the state."¹⁵¹ The government took their appeal to the Constitutional Court. TAC, with the consequential support of groups like the Congress of South African Trade Unions (COSATU), continued to pursue its objectives of targeting pharmaceutical companies

¹⁴⁸ Doctor. Interview by author. Cape Town, 19 June 2000.

¹⁴⁹ Treatment Action Campaign, "About TAC," <<http://www.tac.org.za>> (Accessed: 2 August 2004).

¹⁵⁰ PlusNews, "South Africa: Special Report on a Decade of Democracy – HIV/AIDS," *IRIN*, 9 April 2004, <<http://www.plusnews.org/pnprint.asp?ReportID=3252>> (Accessed: 10 April 2004).

¹⁵¹ Cited in Van der Vliet, "South Africa Divided," 69.

to lower the costs of all HIV/AIDS medications and maintaining pressure on the government to fulfil its HIV/AIDS obligations.

Health care workers were aware of, and supported, TAC.¹⁵² Trainers reported that, from 1999 onwards, participants increasingly asked questions about TAC and its objectives, and used TAC as a reference point for treatment and policy guidelines. A trainer reported: “Participants were interested in the legal actions and civil disobedience campaigns of TAC. It reminded people of the struggle against Apartheid, thereby activating support for TAC and its causes. Important issues like cheaper medication and MTCT became public and understood.”¹⁵³ In addition, the individual leadership of persons associated with TAC – for example, Zachie Achmat, Judge Edwin Cameron, and Mark Haywood (Spokesperson of the TAC, and Director of the AIDS Law Project from the Centre for Applied Legal Studies (CALS) at the University of the Witwatersrand) – provided the support and direction to health care workers and training organisations that the government did not provide.

Health care workers reported that TAC helped them to better understand HIV/AIDS treatment issues. For example, “My clinic uses suggestions from the TAC to help guide practice. We don’t always have the resources but at least we have guidance on what should be happening, what we should be doing.”¹⁵⁴ Health care workers also argued that TAC was closer to the issues raised by patients: “I call TAC for advice because what they say is close to what my patients are saying in the clinics. TAC is in tune with the people and their needs.”¹⁵⁵ TAC provided the leadership that health care workers argued was absent from the government: “TAC is a practical and

¹⁵² ATICC Trainers. Supervision by author. Cape Town, 7 April 2000.

¹⁵³ Primary Health Care Clinic Trainer. Private communication with author. Cape Town, 19 August 2003.

¹⁵⁴ Primary Health Care Clinic Doctor. Interview by author. Cape Town, 26 June 2000.

¹⁵⁵ Health Care Worker. Interview by author. Cape Town, 6 February 2001.

moral example of HIV/AIDS management.”¹⁵⁶ As the last quote illustrates, health care workers argued that TAC’s influence went beyond clinical practice into areas like ethics, politics, and advocacy.

Zackie Achmat’s example also made an impression on health care workers and trainers. They saw him as a pragmatist who was doing relevant work in the field: “Zackie doesn’t want to wear a tie in Pretoria; he will fight the lazy government. When I get down at work, I just think of what he is doing and it gives me hope to keep going.”¹⁵⁷ Others were inspired by his activism that was a reminder of the civil opposition during Apartheid: “TAC should be running the Department of Health. They know more about HIV/AIDS than all of them in government. Zackie Achmat reminds us of our past and that we did not sit quietly during Apartheid and listen to stupidity. Why should we now?”¹⁵⁸

Thus, the role models for health care workers were not politicians, but activists like Zackie Achmat. Interestingly, this mirrors the important leadership role of civil society during Apartheid. Pieterse and van Donk argued, “South Africa possesses a large and diverse range of civil society organisations that could play a vital role in the realisation of socio-economic rights.”¹⁵⁹ They provided an analysis of TAC’s role in HIV/AIDS prevention and treatment, and highlighted the organisation’s success in its various HIV/AIDS campaigns. Its successes include: its ability to rouse the media, its development of interconnected campaigns with specific objectives and target groups, its dynamic relationship with the government in providing opposition and co-operation, and its vast strategic local and international network. Pieterse and van Donk concluded that TAC’s lessons are worth considering because “social dialogue

¹⁵⁶ Counsellor. Interview by author. Cape Town, 6 February 2001.

¹⁵⁷ Primary Health Care Counsellor. Interview by author. Cape Town, 29 June 2000.

¹⁵⁸ Primary Health Care Doctor. Interview by author. Cape Town, 29 June 2000.

¹⁵⁹ E. Pieterse and M. van Donk, “Realising Socio-Economic Rights: The Role of the State and Civil Society,” *EMR Review*, 3, no. 3 (2002).

and contestation will become ever more important as growing unemployment and income inequality sharpen the many social cleavages.”¹⁶⁰ Thus, TAC’s model may be useful for future civil society advocacy campaigns. Health care workers reported that they were prepared to fight HIV/AIDS and that they appreciated the example of civil society campaigns like TAC: what they had not expected was the lack of leadership and support of the new democratic government.¹⁶¹

Another example of a public figure to which HIV/AIDS health care workers and trainers turned for guidance is Desmond Tutu. In December 1996, on World AIDS Day, Archbishop Tutu stated: “We in the church believe that sex should only take place within marriage. However, for those of you who do practise sex outside of marriage, I encourage you to take the right precautions and practise safer sex. Please use condoms.”¹⁶²

The effect of these words on HIV/AIDS health care workers was significant. Within days, trainers reported that they had received many telephone calls from health care workers about this statement.¹⁶³ It appeared that there was a need to discuss Tutu’s words, especially for those health care workers who were religious and felt confused by the message “please use a condom.” In training courses in 1997, Tutu’s message was raised often, and health care workers encouraged further discussion. A minority of health care workers were discouraged by his words. For example, responses included: “It is shameful that a man in his [Tutu’s] position can say things like this and get away with it. He is corrupting our youth. Encouraging them to have more sex.”¹⁶⁴ Other health care workers commented on his integrity and the fact that

¹⁶⁰ Pieterse and van Donk, 2.

¹⁶¹ Health Care Workers. Focus group by author. Cape Town, 16 October 2001.

¹⁶² Cited in <<http://www.cnn.com/WORLD/9611/aids.special/aids.africa>> (Accessed: 12 October 2004).

¹⁶³ Trainer. Supervision by author. Cape Town, 5 December 1996.

¹⁶⁴ Nurse. Training by author. Cape Town, 18 March 1997.

his message encompassed the realities of sexual politics in South Africa: "He [Tutu] is a clever man, and his words have made me think. Also, he has integrity. What I like about his message is that he is admitting that some people want to have lots of sex or some have no choice when they have sex, and then they should try and use condoms."¹⁶⁵ There were many reports from health care workers regarding the positive effects of Tutu's words on patients. For example, "I had a young man who came to the clinic last week and said that he now wears condoms every time he has sex because he felt that the Archbishop was talking to him. He doesn't feel judged; he felt encouraged by the message."¹⁶⁶

Tutu's message influenced health care workers from different religions. Christian and Muslim health care workers reported that they were relieved that someone of religious and political influence had finally acknowledged the lack of control that many women had in negotiating sex.¹⁶⁷ They applauded his realism, courage, and concern in asking people to protect themselves. Health care workers reported positive shifts in perception and sexual behaviour in their patients as a result of Tutu's words.¹⁶⁸

The COSATU president Willie Madisha also provided guidance to health care workers. In September 2000, COSATU strongly condemned the government's confusing HIV/AIDS policies: "The current public debate on the causal link between HIV and AIDS is irrefutable, and any other approach is unscientific and unfortunately, likely to confuse people."¹⁶⁹ Within one week of Madisha's

¹⁶⁵ Counsellor. Training by author. Cape Town, 18 March 1997.

¹⁶⁶ Trainers. Focus group by author. Cape Town, 19 June 1997.

¹⁶⁷ Trainers. Focus group by author. Cape Town, 19 June 1997.

¹⁶⁸ Health Care Workers. Focus groups by author. Cape Town, 17-21 May 1999.

¹⁶⁹ CNN, "South African Unions Slam Mbeki Over Economy, AIDS," *CNN*, 18 September 2000, <<http://www.cnn.com/2000/WORLD/africa/09/18/s.africa.aids>> (Accessed: 9 June 2004).

pronouncement, health care workers commented.¹⁷⁰ They reported that it was important to hear a powerful government ally say what they felt too uncertain or afraid to say. Health care workers reported that Madisha's message was clear and echoed their experience in the primary health clinics.¹⁷¹

Finally, persons living with AIDS (PLWAs) were another group that played an important role in the HIV/AIDS training of health care workers. They play an interesting role as a special category of civil society, mainly because they are infected with HIV and they are well organised and active.¹⁷² Training organisations identified PLWAs to attend training courses and to present input on courses. PLWAs also played an important advocacy role in opposing the government's actions, thereby becoming sources of information and role models for health care workers, trainers, and the public.

Training organisations found themselves in leadership and activist roles. This was, at times, difficult because some organisations were provincially and nationally funded. Trainers felt strongly about the negative impact of the government's stance and they actively supported activism. A trainer reported: "We never expected our training roles to become this complicated. When I started training in 1993, HIV/AIDS was a health issue. Every month saw another dimension being added. Then, with our government's apathy and *kak*, we found ourselves in the position of providing political education on our courses."¹⁷³

Training organisations were looked to for guidance in the political HIV/AIDS debate. Training organisations reported that it was difficult to remain silent in

¹⁷⁰ Health Care Workers. Supervision and training sessions with author. Cape Town, 20, 21, 22, and 25 September 2000.

¹⁷¹ Health Care Workers. Supervision and training sessions with author. Cape Town, 20, 21, 22, and 25 September 2000.

¹⁷² J. Putzel. Private communication with author. St. John's, 5 August 2004.

¹⁷³ Trainer. Private communication with author. Cape Town, 12 August 2003.

response to the government's actions. Training organisations found themselves in leadership positions, the kind of HIV/AIDS leadership that health care workers wanted from government. Also, trainers reported that participants educated them politically.¹⁷⁴ Some health care workers had important links with civil society during Apartheid, and they used their knowledge and skills in HIV/AIDS management. A cross-pollination of political ideas and experiences went across racial, cultural, and political lines.

Conclusion

From the first South African diagnosis of HIV/AIDS in 1982 to 1989, the NP failed to respond to the disease in any significant way. The few government initiatives were delineated according to race and sexuality. HIV/AIDS was not regarded as a threat (especially to heterosexual Whites) and the public perception was that the disease was not a threat. The NP's HIV/AIDS campaigns were unsuccessful because of homophobia, racism, and Black fears of oppressive family planning measures. The NP's lack of political legitimacy hampered their HIV/AIDS efforts. The narrative of this period was that HIV/AIDS was a medical condition, isolated from political, social, and economic conditions. Towards the end of 1988, the NP government started acknowledging the realities of the disease. With ATICC's establishment in 1989, health care workers and administrators in the Western Cape were provided with training for the first time. This brought a large group of people in contact with HIV/AIDS; who in turn educated, counselled, and treated patients and families.

Between 1990 and 1994, under the NP, the HIV/AIDS narrative shifted from one of recognition of the disease to that of expectation. One of the important driving

¹⁷⁴ Trainers. Feedback to author. Cape Town, 5 April 2002.

forces was the political shift towards democracy. Health care workers and trainers argued that they now felt they had agency, and training was characterised by many debates and suggestions regarding how the new government should respond to HIV/AIDS. This period saw a significant shift in the NP's position to HIV/AIDS. In 1990 the government turned its attention to safe blood supplies and the antenatal surveillance program. HIV/AIDS was now a public narrative with various perspectives and arguments. In the Western Cape, ATICC stood at the centre of these debates. The most important political initiative during this period was the establishment of NACOSA in 1992 and the subsequent National AIDS Plan in 1994. There was an energy and excitement in the HIV/AIDS narrative during this time. Between 1990 and 1994, the NP had established a basic infrastructure from which to launch a successful HIV/AIDS campaign.

Mandela's response to HIV/AIDS during his presidency (1994-1999) was perplexing and limited. The sense of expectation was replaced with confusion and frustration. The narrative of this period was characterised by Mandela's silence on HIV/AIDS, the government controversies involving Sarafina II, Virodene, and the Aids Advisory Committee. Health care workers and trainers stated that their previous optimism was replaced with pessimism and the realisation that there would be little leadership from the government. The result of this for some health care workers was a sense of pragmatism: that is, having to do it themselves.

During 1994 to 2004, Mbeki created a national and international stir by questioning the link between HIV and AIDS. The results of Mbeki's stance were a split between government and civil society initiatives, a split in regional and national

HIV/AIDS programs,¹⁷⁵ an almost exclusive focus by the international community on the polemic raised by the president,¹⁷⁶ and distraction from the central prevention and treatment issues, for example, the implementation of the ARV program.¹⁷⁷ In the absence of clear and consistent messages from the government, training organisations and health care workers turned to leaders in civil society and religion for leadership. The rift between health care workers and civil society, on the one hand, and the government, on the other hand, continued to dominate HIV/AIDS narratives provincially and nationally.

¹⁷⁵ C. Campbell and Y. Mzaidume, "How Can HIV be Prevented in South Africa? A Social Perspective," *British Journal of Medicine*, 324 (26 January 2002): 229-232.

¹⁷⁶ Fassin and Schneider, 495-497.

¹⁷⁷ Kauffman, "HIV Capital," 28.

CHAPTER FIVE: “Tonight the gangsters will shoot outside my house – this HIV-thing can wait” – Changing socio-economic factors in the history of HIV/AIDS training, 1989-2004.

This chapter provides a contemporary historical examination of the socio-economic factors that influenced the HIV/AIDS training of health care workers between 1989 and 2004. Health care workers and trainers lived and worked in specific historical and socio-economic contexts, which influenced their attitudes and responses to HIV/AIDS training and programs. The discussion begins with an examination of the socio-economic factors involved in the changes over time of health care workers' attitudes towards HIV/AIDS in the areas of social and professional exposure, occupational exposure, and the impact of HIV/AIDS on patients. The next section examines how these socio-economic factors changed, and thus impacted on training organisations and health care workers. The final section examines how the training organisations exercised agency in both challenging and perpetuating certain of the socio-economic conditions. The increased number of patients and the personal exposure to patients resulted in greater awareness in health care workers of the symptoms of the disease. More significantly, this resulted in not only a greater awareness of the symptoms, but an understanding of the socio-economic factors that cause and spread the disease. The sources utilised in this chapter are largely oral, contextualised with secondary sources. Health care workers and trainers were interviewed in order to analyse the underlying socio-economic factors that influenced the changes in HIV/AIDS training, content, and organisational issues in the period under review.

Fassin and Schneider identified three socio-economic factors that are important HIV/AIDS risk factors in South Africa.¹ First, social and economic inequalities are important predictors in HIV transmission. A low socio-economic status is associated with unsafe sex, reduced access to health information, prevention, and treatment, and less concern about one's health because of present and past experiences. Second, mobility increases the risk of HIV/AIDS. This is a complex historical issue in South Africa because of the many forms of mobility like forced removal under Apartheid, labour migration, and trade route migration (this issue is examined in chapter six). Moreover, the last decade has witnessed an increase in refugees from other African countries and urbanisation. Third, sexual violence increases HIV transmission (this issue is addressed in chapter seven). Understanding these socio-economic factors is vital to the prevention and management of the pandemic and to understanding its history.

Socio-economic factors are also important in understanding why information on HIV prevention is not used. Hallman found that socio-economic disadvantage significantly increased unsafe sexual behaviour.² Specifically, low socio-economic status increased a woman's chance of exchanging sex for money or goods and experiencing coerced sex, and a woman and man's chance to have multiple sexual partners. Low socio-economic status decreased the female and male age of sexual debut, and condom use. In explaining the reasons for this, Hallman argued that young people living in underprivileged environments, even if they have sound information and communication skills, are still more vulnerable to high-risk situations: "Many poor young people in South Africa live in densely populated and informally structured

¹ D. Fassin and H. Schneider, "The Politics of AIDS in South Africa: Beyond the Controversies," *British Journal of Medicine*, 326 (2001): 495.

² K. Hallman, "Socio-Economic Disadvantage and Unsafe Sexual Behaviours among Young Women and Men in South Africa," Policy Research Division Working Paper, No. 190, Population Council, New York, 2004.

communities characterised by a severe lack of livelihood opportunities, and safe recreation options, and high levels of crime and abuse.”³ In other words, people’s knowledge and actions are maintained by their historical and socio-economic realities. The socio-economic factors related to the HIV/AIDS training of health care workers are now discussed.

Attitudes towards HIV/AIDS

Social and Professional Exposure

Following the training trends in Europe and the USA in the 1980s, the Aids, Training, Information, and Counselling Centre (ATICC) held that the success of HIV/AIDS prevention was determined, in part, by the familiarity of health care workers with HIV/AIDS issues. Thus, ATICC aimed at making health care workers more familiar with the medical and social aspects of HIV/AIDS.⁴ In the first training course in August 1989, trainers argued that one of the main strategies was to encourage participants to greater exposure to HIV/AIDS patients and issues. Trainers hoped that this exposure would advance compassion for those living with HIV/AIDS, which would in turn encourage safer sex practises in patients. Knowing someone with HIV/AIDS is an important factor in changing high-risk sexual behaviour.⁵ A study in Khayelitsha found that condom use was increased among individuals who knew someone living with HIV/AIDS.⁶ Thus, starting with the first training course in 1989,

³ Hallman, 26.

⁴ T.van der Velde (ATICC Manager). Private communication with author. Cape Town, 28 November 1995.

⁵ A. Harrison, J. Smit, and L. Myer, “Prevention of HIV/AIDS in South Africa: A Review of Behaviour Change Interventions, Evidence and Options for the Future,” *South African Journal of Science*, 96 (2000): 285-290.

⁶ K. Ijumba et al., “Sexual Risk Behaviours are Influenced by Knowing Someone with HIV/AIDS,” *South African Medical Journal*, 94, no. 7 (2004): 522-523.

ATICC encouraged health care workers to increase their exposure to people living with HIV/AIDS.

When the first HIV/AIDS training started in 1989, few health care workers had personal or professional exposure to HIV/AIDS.⁷ Socially, HIV-positive persons did not know that they were HIV-positive because of limited testing resources and the stigma and discrimination associated with the disease. Professionally, few health care workers were involved with HIV-positive persons. The few HIV-positive patients who had been identified in the health care system were managed in the specialist HIV/AIDS units at Groote Schuur and Somerset Hospitals.⁸ This pattern of specialist treatment sites continued until 1995, when health care workers reported increased HIV/AIDS cases at primary health care clinics.⁹ Notably, while the *National HIV Antenatal Prevalence Surveys* between 1991 and 1995 showed significant increases in the national prevalence rate (1.4% to 10.4%), the increase in the provincial prevalence rate for the Western Cape seems insignificant (0.4% to 1.7%).¹⁰ As argued in chapter three, the collection of HIV/AIDS data in South Africa is controversial, and especially between 1991 and 1995 doctors and other health care professionals in the Western Cape argued that the provincial prevalence rates were probably an underestimation. This view was based on the increasing number of HIV/AIDS patients presenting at primary health care clinics.¹¹

By 1995, trainers reported that every training group of twenty participants had between five to ten health care workers who had professional and personal exposure

⁷ Health Care Workers. Training feedback to author. Cape Town, 2 August 1995.

⁸ The doctors who established these specialist HIV/AIDS clinics and provided much of the early leadership were, for example, people like Frank Spracklen, Gary Maartens, and Robin Wood. In 1989, ATICC formed links with these doctors and their clinics, which was an important factor in considering ATICC's central position in the provincial HIV/AIDS response.

⁹ ATICC Trainers. Interview by author. Cape Town, 23 March 1995.

¹⁰ See: <<http://www.doh.gov.za/docs/reports>> (Accessed: 12 April 2005).

¹¹ ATICC Trainers. Interview by author. Cape Town, 12 December 1995.

(an HIV-positive family member or friend) to HIV/AIDS.¹² Between 1995 and 2000, this number had risen to fifteen to twenty.¹³ By the end of 2000, all health care workers who had received HIV/AIDS training had been exposed to HIV-positive persons either professionally and personally.¹⁴ This was due to the training initiatives aimed at increasing professional exposure to HIV/AIDS, as well as the increasing number of HIV/AIDS people reporting at the community clinics. In 2000, the *National HIV Antenatal Prevalence Survey* reported a national prevalence of 24.5%, with 8.7% for the Western Cape. By 2004, this pattern of professional and personal exposure of health care workers to HIV/AIDS was well established.¹⁵ This shift in professional and personal HIV/AIDS exposure had important implications for the quality of training participation, attitudes towards HIV-positive persons, and the prevention and management of the epidemic. Thus, the historical analysis of health care workers' attitudes to HIV/AIDS between 1989 and 2004 shows that the increased numbers of patients and personal and professional exposure to HIV/AIDS had an important role in exposing health care workers to the symptoms and the wider political, socio-economic, cultural, and gender factors of the disease. The pivotal years are 1994-1995, when the government adopted the primary health care model in which more health care workers were exposed to HIV/AIDS persons.

Having outlined the shifts in professional and personal exposure, the discussion now turns to an analysis of the important factors in these shifts. In 2001, in a review of the history of HIV/AIDS training in the Western Cape, trainers from various organisations argued that the principle was simple and predictable: greater personal and professional exposure to HIV-positive persons resulted in more

¹² ATICC Trainers. Interview by author. Cape Town, 12 December 1995.

¹³ ATICC Trainers. Interview by author. Cape Town, 18 November 1999.

¹⁴ ATICC Trainers. Interview by author. Cape Town, 5 December 2000.

¹⁵ ATICC, Lifeline, Leadership South, and Philippi Trust Trainers. Feedback to author. Cape Town, 19-30 April 2004.

constructive involvement in training courses.¹⁶ These trainers argued that personal and professional exposure were more important variables than trainees' education in assessing the quality of course participation and subsequent learning. In fact, they argued that higher education often served as a hindrance to constructive participation and learning. This problem was evident in training courses with nurses and doctors who often had set ways of approaching disease prevention and treatment.¹⁷ Training courses that were held exclusively for doctors and nurses were notoriously difficult and challenging for trainers to manage.¹⁸

The rigidity in response to HIV/AIDS information and training was more noticeable before 1995, when there were less HIV/AIDS patients presenting at clinics. Health care workers argued that the increased number of patients and availability of training from 1994-1995 resulted in more information and experience that changed previous treatment ideas and methods.¹⁹ These trainers also stated that the public response to the government HIV/AIDS controversies (as discussed in chapter four), and the lack of resources for HIV/AIDS patients, especially between 1994 and 1999, resulted in significant attitudinal changes in health care workers. Most notably, health care workers became more involved in HIV/AIDS issues and sided with the patients in terms of their frustrations regarding lack of treatment, care, and support programs.

Trainers reported that the only health care workers who did not have significant HIV/AIDS exposure were those persons working in rural areas with lower

¹⁶ ATICC, UCT Medical School, Lifeline, and Philipi Trust Trainers. Interviews by author. Cape Town, 5-23 February 2001.

¹⁷ ATICC, UCT Medical School, Lifeline, and Philipi Trust Trainers. Interviews by author. Cape Town, 5-23 February 2001.

¹⁸ ATICC and UCT Student Health Clinic Trainers. Interviews by author. Cape Town, September 1999.

¹⁹ ATICC, UCT Medical School, Lifeline, and Philipi Trust Trainers. Interviews by author. Cape Town, 5-23 February 2001.

HIV/AIDS prevalence rates.²⁰ Similar patterns were observed for medical students participating in HIV/AIDS training in the period under review. In 1994, the few medical students who had prior experience in primary health clinics with higher numbers of HIV/AIDS patients found it easier to engage in the mandatory HIV/AIDS training.²¹ Those medical students who did not have student clinical or personal exposure to HIV/AIDS consistently raised, and justified, issues like stigma and testing; issues that were biomedically isolated in the face of the wider political, social and economic factors.²² By 2004, all medical students who attended the HIV/AIDS training had seen an HIV/AIDS patient, and some had friends or family members who were HIV-positive.²³ More generally, by 2004, it was the exception to observe negative attitudes from doctors and nurses to HIV/AIDS training material.²⁴

The discussion now moves to the issue of training content and methodology. The social exposure of health care workers to HIV-positive persons became important to organisations in the choice of training content and methodology. In 1995, trainers reported that up to this point training was characterised by intractable course participants.²⁵ The trainers argued that the lack of social exposure of the health care worker to HIV/AIDS was one important variable in such responses. Other variables included HIV/AIDS knowledge, cultural and religious beliefs, and exposure to other sexually transmitted diseases.

In 1995, trainers reported that these variables led to moralistic views in the training room, which in turn hindered the trainer's ability to deliver the HIV/AIDS

²⁰ ATICC, UCT Medical School, Lifeline, and Philipi Trust Trainers. Interviews by author. Cape Town, 5-23 February 2001.

²¹ T. van der Velde (ATICC Manager). Private communication with author. Cape Town, 28 November 1995.

²² UCT Medical Students. Training by author. Cape Town, 1995-2001.

²³ B. Schweitzer (UCT Medical School). Private communication with author. Cape Town, 11 October 2004.

²⁴ ATICC, UCT Medical School, Lifeline, and Philipi Trust Trainers. Interviews by author. Cape Town, 5-23 February 2001.

²⁵ ATICC Trainers. Focus group by author. Cape Town, 8 November 1995.

input.²⁶ For example, some training participants claimed that HIV-positive persons: should be physically isolated from the rest of society in order to curb the spread of the epidemic (as had been done in Cuba²⁷), and, were being punished by God because of their 'promiscuity' (a very popular word in training courses in the early 1990s)²⁸ and thus did not deserve treatment and care. Also, some participants argued that HIV/AIDS was not a threat to anyone in a 'stable' relationship or marriage.²⁹ These attitudes changed over time, mostly due to the exposure of health care workers to HIV-positive persons. In 1996, feedback from trainers, participants, and counselling supervisors suggested that exposure of health care workers to HIV-positive persons had tempered some of these problematic attitudes.³⁰ These attitudes were also influenced by other social changes in broader society like increased media exposure and education campaigns.

²⁶ ATICC Trainers. Focus group by author. Cape Town, 8 November 1995.

²⁷ This refers to Cuba's controversial yet seemingly successful HIV/AIDS prevention measures in which HIV-positive persons are placed in semi-isolation. This prevention initiative has an interesting history. This strategy was developed in 1986, after Cuban health officials noticed that soldiers returning from Angola in the early 1980s were suffering from a then-unknown immuno-deficient disease. 59 HIV-positive persons were identified and quarantined in a hospice 16 km outside of Havana, known as *Sanitarium Santiago de las Vegas*. By 2003, there were fourteen of these hospices across Cuba. The HIV-positive person is required to spend six months in the hospice, where they receive free medication and HIV/AIDS education. Once they are considered low risk, they are permitted to return to society. Despite its success, this program has been criticised for the removal of civil liberties, and the fact that this program is not replicable in other countries, due to politico-socio-economic factors. See: G. Marx, "AIDS strategy praised, criticized: Cuba is trying to manage HIV through isolation, treatment and outreach. Some call it extreme; others commend the results," *Chicago Tribune*, 26 October 2003, <<http://www.aegis.com/news/ct/2003/CT031006>> (Accessed: 13 April 2005). In South Africa, the issue of quarantine was raised recently, in September 2006, in relation to the lethal TB strain (XDR TB) in KwaZulu-Natal. Its relevance to HIV/AIDS patients is that it is estimated that over half of all adult South Africans have latent TB and three-quarters of all TB patients in KwaZulu-Natal are also HIV/AIDS positive. The related practical and medico-legal issues, amongst others, are significant. See: B. Beresford, "Call to Isolate TB Victims," *Mail and Guardian (South Africa)*, 8 September 2006.

²⁸ The view that HIV/AIDS is a punishment for 'sinful' behaviour appears to be a common historical response to epidemics, especially those infections that are sexually transmitted, for example, syphilis. See, for example, L. M. Kopelman, "If HIV/AIDS is Punishment, Who is Bad?," in *Ethics and AIDS: The Challenge to Our Thinking*, eds. A. A. van Niekerk and L. M. Kopelman (Cape Town: David Philip, 2005), 208-218; S. Sontag, *AIDS as Metaphor* (Harmondsworth: Penguin, 1989); and S. Hunter, *Who Cares? AIDS in Africa* (New York: Palgrave, Macmillan, 2003).

²⁹ Health Care Workers. Training feedback to author. Cape Town, August 1989-December 1994.

³⁰ Trainers and Health Care Workers. Supervision and focus groups by author. Cape Town, 1996.

In 1997, trainers implemented initiatives to deal with the moralistic attitudes of health care workers. Trainers argued that changing the training methodology helped to expose participants to the complexities of HIV/AIDS.³¹ Some of these initiatives included HIV-positive persons as facilitators on training courses, identifying family members who felt comfortable talking about the care and loss of an HIV-positive person, and insisting that participants have basic professional HIV/AIDS experience as an entry-level training requirement. Another initiative was the inclusion of practical training, under professional supervision, with HIV-positive persons as part of the course. The first observation regarding these initiatives is that training organisations became more sophisticated in terms of content and method. This was due to the increasing demand from health care workers for more training and more relevant training that began in 1995 (as discussed in chapter three). The second observation is that the public debate around the government's HIV/AIDS responses (for example, Sarafina II and Virodene) resulted in a more nuanced public and professional understanding of HIV/AIDS issues. In 1997, ATICC trainers argued that: "We are doing a good job, I think, in providing useful training to health care workers. Our training is well matched to the other important social and historical issues that South Africans have to deal with. We are often told that we are providing education on many other important issues outside of HIV/AIDS."³² This comment – which was confirmed by other participant feedback at the time – highlighted the dynamic state of HIV/AIDS training prior to the public and professional confusion that erupted in 1998 with Mbeki's dissident views of HIV/AIDS.

Between 1989 and 2004, ATICC played an important role in encouraging direct contact and interaction between health care workers and HIV-positive persons

³¹ ATICC Trainers. Supervision by author. Cape Town, 30 January 1997.

³² ATICC Trainers. Supervision by author. Cape Town, 30 January 1997.

and those persons directly affected by the disease. As has been stated, there were other broader social factors that encouraged or even forced health care workers to confront HIV/AIDS more directly, yet training organisations helped to challenge the stigma and discrimination associated with HIV/AIDS. By 2004 much of the learning and exchange of information was reciprocal. In 1989, ATICC encouraged health care workers to engage in greater exposure to HIV-positive persons; in 2004, ATICC and other training organisations were learning about the complexities of the disease and the socio-economic factors that influenced HIV/AIDS from the training participants.³³ A trainer concluded: “Nurses and counsellors now tell us that we don’t know enough about HIV/AIDS. They tell us to leave our training rooms and spend a day with them in the clinic. Last month I did this and they are right. They know much more than we do these days.”³⁴ Thus, by 2004, the complexities of issues like poverty, social and family instability, migrant labour, sexually transmitted infections, gender, violence against women, and the sexual patterns between older men and younger women were well established in HIV/AIDS training, and, to a large extent, accepted by the health care workers.

A final point highlights the impact of high HIV/AIDS incidence areas on the visibility and exposure of health care workers to HIV-positive persons. Even though it is well known that HIV/AIDS is not limited to any specific economic group, it did accelerate in certain high incidence areas in the Western Cape. By the end of the 1990s, areas like Khayelitsha, Gugulethu, Mitchell’s Plein, Nyanga, and Helderberg were identified as high-incidence areas.³⁵ The reasons for the acceleration of HIV/AIDS in areas are linked to socio-economic factors like the disruption of family

³³ ATICC, Lifeline, UCT Medical School, Philipi Trust, and Leadership South Trainers. Feedback to author. Cape Town, 19-30 April 2004.

³⁴ ATICC, Lifeline, UCT Medical School, Philipi Trust, and Leadership South Trainers. Feedback to author. Cape Town, 19-30 April 2004.

³⁵ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 22 May 2001.

and community life by Apartheid, lack of access to health care and education, unemployment, the mobility of people, the low status of women in relationships, resistance to condom usage, and sexually transmitted infections.³⁶ In 2001, trainers observed that health care workers living and working in these areas brought relevant experience to training courses, and remained better informed than participants from low-incidence areas where there was less social and professional exposure to HIV/AIDS.³⁷

Occupational Exposure

In 1989, one of the main concerns of participants was the fear of occupational exposure to HIV/AIDS.³⁸ In the next few years after 1989, health care workers often raised this concern, and they appeared more concerned with contracting the virus than treating patients.³⁹ This is predictable reaction to unknown and new viruses: similar reactions of health care workers to HIV/AIDS were reported in the USA in the 1980s.⁴⁰

In the early 1990s, the fear of occupational exposure was high and health care workers were generally misinformed.⁴¹ For example, a trainer stated: "Remember, in those days [early 1990s] everyone was terrified of AIDS. Health care workers were worried that if an infected person sneezed on them, they might contract the virus."⁴² In 1992, the Medical Association of South Africa (MASA) published *Guidelines for*

³⁶ C. Sunter and A. Whiteside, *AIDS: The Challenge for South Africa* (Tafelberg: Human and Rousseau, 2000).

³⁷ Primary Health Care Trainers. Focus group by author. Cape Town, 20 June 2001.

³⁸ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 7 October 2004.

³⁹ Trainer. Focus group by author. Cape Town, 26 August 1996.

⁴⁰ R. Bayer and G. M. Oppenheimer, *AIDS Doctors: Voices from the Epidemic* (New York: Oxford University Press, 2000).

⁴¹ Trainer. Focus group by author. Cape Town, 26 August 1996.

⁴² C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 7 October 2004.

the Management of HIV/AIDS.⁴³ MASA made three recommendations regarding occupational exposure. One, the adoption of universal precautions is the best way for health care workers to protect themselves. Two, the HIV status of patients should not be routinely determined before surgery, except in procedures that are considered to be exceptionally high risk. Three, universal precaution must be taken in high-risk situations. These guidelines followed international recommendations and earlier suggestions that were available to health care workers in South Africa.⁴⁴ These recommendations did provide guidance to health care workers, yet they were also the source of many debates.

From 1993 onwards, health care workers argued that these guidelines were good in theory, but not in practice.⁴⁵ They maintained that these guidelines were not specific enough to the wide range of clinical situations that they encountered in primary health care clinics. Moreover, health care workers in the province had significantly different levels of information about the prevention and management of occupational exposure.⁴⁶ Following the publication of these guidelines in 1992, training organisations found themselves caught between what should be done (guidelines) and what was being done (practice). For example, while MASA called for universal precautions to be taken, medical students complained that there were often not the necessary gloves for them to wear during surgery. In 1994, a female medical student commented: "This problem is particularly bad for women. I have small hands, and the gloves that are available are all large. I feel that I have no control

⁴³ Medical Association of South Africa (MASA), "Guidelines for the Management of HIV/AIDS," December 1992.

⁴⁴ For example, see M. Bailey, "What is the Risk of AIDS to Health Care Workers," *AIDS Watch*, 14 (1991): 5-6.

⁴⁵ Health Care Workers. Training feedback to author. Cape Town, June 1993 - December 1998.

⁴⁶ ATICC Trainers. Supervision by author. Cape Town, 26 October 1995.

over my fingers in these gloves, and when I complained about this, the consultant told me to put on more layers of gloves.”⁴⁷

In 1994, there were reported cases of health care workers who had been exposed to blood from HIV positive patients.⁴⁸ Health care workers claimed that they did not know their legal rights and they did not receive counselling after being exposed to the virus: this despite the fact that national and local guidelines for post-exposure counselling did exist.⁴⁹ In July 1994, the South African Medical and Dental Council (SAMDC) published *The Management of Patients with HIV Infection or AIDS*.⁵⁰ These guidelines included an addendum, which outlined universal precautions for health care workers. These guidelines were also debated in HIV/AIDS training.

In 1994, health care workers argued that not only were these guidelines limited in terms of their clinical application but also they did not address what to do if health care workers were exposed to HIV.⁵¹ A doctor commented: “These guidelines are typical of bureaucratic doctors who haven’t laid eyes on a patient for years. What they suggest is idealistic and impractical. I have had two colleagues, one medical student and one nurse, who have been exposed to HIV and we have no guidelines on how to treat them. So, we make it up as we go.”⁵² In 1994, due to the concerns and reported cases of occupational exposure, there was increased coverage of this issue in the South African medical press. For example, McKerrow provided detailed

⁴⁷ UCT Medical Student. Interview by author. Cape Town, 27 June 1994.

⁴⁸ Health Care Workers and Medical Students. Training feedback to author. Cape Town, 21 October 1994.

⁴⁹ For example, D. White, “Counselling Health Care Workers After Exposure to Blood from an HIV-Positive Patient,” *Continuing Medical Education*, 10, no. 2 (1992): 181-187.

⁵⁰ SAMDC, “The Management of Patients with HIV Infection or AIDS,” Interim National South African Medical and Dental Council, July 1994.

⁵¹ Health Care Workers. Training discussion with author. Cape Town, 2 November 1994.

⁵² Doctor. Interview by author. Cape Town, 14 March 1995.

information on recommended procedures following a needle-stick injury.⁵³ These kinds of specific clinical guidelines were quickly circulated by training organisations and utilised by health care workers, universities, and corporate organisations.

From 1994 onwards, despite the SAMDC guidelines, health care workers complained of management's lack of knowledge and inconsistent applications of these recommendations in hospitals and clinics.⁵⁴ For example, medical students reported that because they did so much of the blood work for patients, they were at higher risk for HIV exposure. The UCT Medical School did not have a policy in place for medical students exposed to HIV until 1999.⁵⁵ Before this, anxious or uninterested doctors managed at-risk medical students. A student reported:

We were all worried because it was said that a [medical] student ahead of us had contracted the virus from a needle-stick injury. I had a needle-stick injury and was told to report it to my consultant. He called me into his office and then told me that he was supposed to counsel me, but because I was a medical student there was nothing that he could tell me that I didn't already know. I was furious when I left his office because he had completely missed the point. I was scared to death of being HIV-positive. I didn't need information; I needed support.⁵⁶

This report was typical of what many health care workers were saying in the mid-1990s, whether they were working in primary health care clinics, hospitals, or occupational health. Doctors countered these complaints by arguing that they were restricted by socio-economic factors like budget cuts and limited resources in clinics in poorer areas.⁵⁷ By 1995, due to the increased number of HIV-positive persons attending primary health care clinics, the reports of occupational exposure increased.⁵⁸

Training organisations assisted in establishing and communicating guidelines for HIV

⁵³ For example, N. K. McKerrow, "Needlestick Injuries," *Positive Outlook*, 3, no. 1 (1995): 19.

⁵⁴ Health Care Workers. Training discussions with author. Cape Town, 25 February 1994.

⁵⁵ Dr. J. van Heerden (UCT). Private communication with author. Cape Town, 15 October 1999.

⁵⁶ UCT Medical Student. Interview by author. Cape Town, 26 June 1996.

⁵⁷ Doctors. Training discussion with author. Cape Town, 9 October 1996.

⁵⁸ Doctor (HIV/AIDS Clinic, Somerset Hospital). Private communication with author. Cape Town, 5 December 1995.

post-exposure prophylaxis and the management of potentially exposed health care workers.

In 1997, health care workers argued that the SAMDC was slow to provide practical guidelines for universal precautions and needle-stick injuries.⁵⁹ This resulted in training organisations having to fill in the gaps by providing the information and support to health care workers. In 1999, training organisations reported that health care workers phoned and came in to see trainers to help them with information, counselling, and support regarding occupational exposure.⁶⁰ Between 1999 and 2003, this pattern continued. By 2004, the issue of occupational exposure was raised less by health care workers in HIV/AIDS training.⁶¹ The reasons for this change over the period under study were the increased availability of exposure management guidelines, access to AZT, the practise of universal precaution, and the support of training organisations.⁶²

Between 1989 and 2004, the issue of occupational exposure changed from one of heightened fear, the lack of treatment guidelines, and unsafe precautions to greater comfort, clear management guidelines, and increased practise of universal precautions for health care workers. Important socio-economic factors related to issues of occupational exposure included the lack of clear employment codes, budgetary cuts in health care, and limited resources in community clinics. Training organisations responded to the concerns of health care workers regarding occupational exposure by remaining informed of the latest developments relating to this issue. Training organisations surrounded themselves with medical, psychological, and legal experts. Capacity building and increased knowledge resulted from these actions and

⁵⁹ Health Care Workers. Supervision by author. Cape Town, 29 May 1997.

⁶⁰ ATICC Training Manager. Interview by author. Cape Town, 18 May 1999.

⁶¹ Primary Health Clinic Trainers. Feedback to author. Cape Town, 20 July 2004.

⁶² Primary Health Clinic Trainers. Feedback to author. Cape Town, 20 July 2004.

discussions. Overviews of the medical management of occupational exposure to HIV continue to be published with the advances in medication and international treatment guidelines.⁶³

The Impact of HIV/AIDS on Patients

In 1989, HIV/AIDS training was medically based, and the underlying political, social, and economic factors in the spread and management of the disease were largely ignored. Between 1990 and 1992, this pattern continued. In 1993, health care workers raised the socio-economic issues in the distribution of HIV/AIDS in the province and the varying access to, and quality of, hospitals and clinics.⁶⁴ In 1996, health care workers began reporting a curious pattern: socio-economically disadvantaged patients were often not worried about their HIV-positive diagnosis because they had too many other worries, many of them stemming from poverty.⁶⁵ For example, "My patient says that AIDS will take a long time to kill her; she needs food for her family tonight."⁶⁶ In 1996, the author observed this pattern in HIV/AIDS counselling at Somerset Hospital and in private practice. The issues of illness, disability, and work were raised: "My wife was fired because she is positive, and the *miesies* doesn't want her near the children. I am too sick to work. My daughter is also sick, and my son is hungry."⁶⁷ Also, patients raised the issue of the socio-economic issues of the areas in which they resided and how this minimised the immediate problems associated with the disease: "Tonight the gangsters will shoot outside my

⁶³ For example, G. Maartens, "Occupational Post-Exposure HIV Prophylaxis," *South African Medical Journal*, 94, no. 8 (2004): 626-627.

⁶⁴ Trainers. Interview by author. Cape Town, 27 July 1995.

⁶⁵ Health Care Workers. Supervision by author. Cape Town, 21 November 1996.

⁶⁶ Health Care Worker. Supervision by author. Cape Town, 18 July 1996.

⁶⁷ Patient. HIV/AIDS Counselling. Cape Town, 19 June 1996.

house – this HIV-thing can wait.”⁶⁸ Some health care workers found these reports difficult to understand because it seemed impossible that HIV-positive persons could have any greater concerns than a life-threatening disease. This highlights the earlier examination of the one-dimensional medical understanding of HIV/AIDS that failed to grasp the wider historical, political, socio-economic, cultural, and gender factors that influenced HIV/AIDS.

In 1997, trainers focussed more on these wider underlying issues impacting on HIV/AIDS.⁶⁹ This was in response to the increasing disillusionment of health care workers and trainers with the government’s silence and controversies (see chapter four). There was a growing gap between what patients were raising in response to the disease and the government’s relative inactivity. The socio-economic factors were important issues for patients and for health care workers: HIV/AIDS became a mechanism through which they could address certain of these historical issues. In 1999, Mbeki’s response to HIV/AIDS had the unexpected impact of raising health care workers’ awareness of issues like poverty in the transmission of HIV.⁷⁰ Health care workers’ narratives focussed more specifically on the issue of poverty and the links between HIV/AIDS and transmission and varying levels of treatment and care. Surprisingly, despite their general criticism of Mbeki (see chapter four), health care workers continued to echo Mbeki’s focus on poverty and HIV/AIDS, largely because of government pressure: this was the foremost government narrative of this period. This pattern continued through the period 1999 to 2004. By 2004, health care workers accepted the fact that HIV-positive persons could have more immediate concerns than a disease that might kill them in ten to fifteen years’ time.⁷¹ The significant socio-

⁶⁸ Patient. HIV/AIDS Counselling. Cape Town, 8 November 1995.

⁶⁹ ATICC Trainers. Supervision by author. Cape Town, 20 November 1997.

⁷⁰ Health Care Workers. Private communication with author. Cape Town, 25 June 2004.

⁷¹ Health Care Workers. Private communication with author. Cape Town, 25 June 2004.

economic factors that impacted on patients and health care workers resulted in health care workers accepting the fact that they had to be informal “social workers who deal with hunger, domestic violence, rape, money grants, unemployment, and child abuse.”⁷² This reflects research, for example, Lehmann and Zulu, who in their analysis of nurses’ experiences of HIV/AIDS in Cape Town clinics, stated: “The picture which emerged from our engagement with frontline staff is a bleak one . . . A recurring theme in interviews and focus-group discussions was the fact that nurses increasingly find themselves engaged in extra-ordinary (non-clinical) activities in the absence of other kinds of support services.”⁷³

HIV/AIDS Programs and Health Care Workers

This section provides an historical examination of the socio-economic factors involved in doing HIV/AIDS work from the perspective of training organisations and health care workers and how these issues changed in the period under review. The issues examined include stigma, working conditions, salaries, the responses of other health care workers, and the expectations and responses of patients and other community organisations.

The first issue examined is the stigma associated with doing HIV/AIDS work. In 1989, health care workers reported that most colleagues were apathetic regarding HIV/AIDS.⁷⁴ Few health care workers saw the disease as a threat, and hospital and clinic staff was unmotivated to attend HIV/AIDS training and education. This pattern continued until 1993. In 1993, health care workers reported that colleagues and patients shunned them because they worked with HIV/AIDS. The narrative had

⁷² Health Care Workers. Private communication with author. Cape Town, 25 June 2004.

⁷³ U. Lehmann and J. Zulu, “How Nurses in Cape Town Clinics Experience the HIV Epidemic,” *AIDS Bulletin*, 14, no. 1 (2005).

⁷⁴ Health Care Workers. Supervision by author. Cape Town, 15 September 1994.

shifted from apathy to stigma. In discussing HIV/AIDS work in the early 1990s, a nurse stated: "Those were the funny days. I couldn't even sit in the tearoom with my colleagues. They wouldn't touch anything I'd touched in case they got AIDS, or else they wanted all the juicy gossip of my HIV-positive patients. Just like on TV. And remember I am HIV negative; I was just doing my work."⁷⁵ Such collegial responses to health care workers doing HIV/AIDS work resulted in professional conflict and isolation.⁷⁶ It became a case of those health care workers doing HIV/AIDS work and those who wanted nothing to do with the issue. Due to the lack of exposure and HIV/AIDS patients only being seen in specialist clinics, this split continued between 1990 and 1994. In 1994, nurses argued that while the work was interesting, this professional split was difficult to manage.⁷⁷ This is particularly important given that nurses, for example, did not feel supported by the government or the health department, and then they felt isolated at work too.

In 1995, interviews showed that some nurses asked for reassignment to non-HIV/AIDS work, became more stressed and ill, and left nursing.⁷⁸ Between 1995 and 1998 more health care workers were exposed to the disease and its impact. In 1998, health care workers stated that there had been a significant reduction in work discrimination and stigma.⁷⁹ The reasons cited for this change in attitude included greater numbers of HIV/AIDS patients presenting at the primary health care clinics, greater professional knowledge of the socio-economic impact of HIV/AIDS on communities in which health care workers worked and lived, and increased media coverage of the epidemic.

⁷⁵ Primary Health Care Nurse. Interview by author. Cape Town, 24 November 1998.

⁷⁶ Health Care Workers. Private communication with author. Cape Town, 19 November 2004.

⁷⁷ Nurses. Training discussions and feedback to author. Cape Town, 14 December 1993.

⁷⁸ Nurses. Interviews by author. Cape Town, June-November 1997.

⁷⁹ Health Care Workers. Supervision by author. Cape Town, January-December 1998.

In 1999, health care workers claimed that as a result of Mbeki's questioning of the HIV-AIDS link, colleagues accused them of wasting time and money on HIV/AIDS work that was unnecessary.⁸⁰ For example, comments from health care workers included: "My colleagues sabotage my work because they think Mbeki is right. The clerks don't bring my files, and my patients are sent to the wrong place."⁸¹ There was also a noticeable questioning and reduction in job satisfaction: "I hate my work. Before I enjoyed it, now it is difficult. Everyone tries to make my job difficult. Last week a nurse told me I should pack up and leave because AIDS doesn't exist."⁸²

In 2000, despite Mbeki's pronouncements, HIV/AIDS became a visible public epidemic, and communities increasingly recognised the significance of the HIV/AIDS prevention and treatment provided by health care workers in local clinics.⁸³ This was an important shift because the socio-economic realities of the epidemic overwhelmed the political narrative. In 2001, health care workers commented on the shift in perception: they reported that they were requested to speak to other clinic and hospital staff, schools, and other community events.⁸⁴ They were invited into existing institutional structures: for example, they were taken into the confidence of church ministers and traditional healers. A nurse stated: "My minister asks me for advice on HIV/AIDS problems in the church. Sometimes, he even asks me for advice on other family problems. I have been moved to the second row in the church, behind the minister's family."⁸⁵ Their work gave them a voice in community matters. HIV/AIDS work had elevated some health care workers to important community positions. An HIV/AIDS lay counsellor stated: "Now I am an important somebody. People respect

⁸⁰ Health Care Workers. Supervision by author. Cape Town, June-December 1999.

⁸¹ Health Care Workers. Supervision by author. Cape Town, June-December 1999.

⁸² Health Care Workers. Supervision by author. Cape Town, June-December 1999.

⁸³ Health Care Workers. Supervision by author. Cape Town, 7 December 2000.

⁸⁴ Lifeline and Leadership South Counsellors. Supervision by author. Cape Town, January-May 2001.

⁸⁵ Primary Health Care Nurse. Supervision by author. Cape Town, 15 June 2001.

me because I do a good job. I help people and they don't forget that. Two years ago I was a maid for Mrs A. and I didn't like being a servant. I like working in my community. Now I walk down the street, straight up."⁸⁶

By the end of 2000, training organisations had recognised this shift in social prestige in that health care workers were increasingly used to provide training input and develop strategic partnerships with community clinics. By 2004, health care workers reported that their HIV/AIDS jobs were more satisfying (despite the ongoing problems with government support and resources), and provided them with greater social prestige in their communities.⁸⁷ Notably, this social prestige did not make any significant difference to the many other socio-economic problems those health care workers from poorer communities brought with them, for example, poverty, debt, violence, and disempowerment. Thus, by 2004, HIV/AIDS was regarded as regular work and health care workers were rarely stigmatised. The reasons for this conspicuous transformation of professional attitude towards HIV/AIDS work are rooted in the historical context of the growing epidemic, the increased response from NGOs and government to the epidemic, the government's questioning of the HIV-AIDS link in 1999, and the socio-economic impact of the disease on patients and health care workers.

The second issue is the historical examination of how the working conditions of HIV/AIDS health care workers changed in the period under review. In 1989, there were few health care workers doing HIV/AIDS work, and they worked in specific specialist clinics. HIV/AIDS was regarded as a relatively rare disease, and health care workers had few complaints about their working conditions: instead, they commented

⁸⁶ Health Care Workers. Focus group by author. Cape Town, 25 April 2000.

⁸⁷ Health Care Workers. Feedback to author. Cape Town, 23 April 2003.

on the excitement of working in specialist teams.⁸⁸ Between 1990 and 1994, even though the number of HIV/AIDS patients was increasing, the numbers were still small enough to be managed by the specialist clinics. In other words, HIV/AIDS at this point in history was not seen at the primary health care level.

In 1994, the increased numbers and focus on primary health care by the new government resulted in a change of provincial policy regarding HIV/AIDS: it was now decided that primary health care clinics would manage the disease. Between 1994 and 1998, the first complaints emerged from health care workers regarding their working condition. Most of the complaints focussed on the lack of adequate space for treatment, support, and care.⁸⁹ In 1998, with the higher numbers of those people infected as well as the increased training of HIV/AIDS health care workers detailed and consistent complaints were presented.⁹⁰ These complaints included the lack of adequate space, the lack of resources, and the negative attitude of managers, supervisors and colleagues to HIV/AIDS work. In 1998, with the increase in the number of HIV/AIDS health care workers trained, they reported the stress of adverse working conditions and the high expectations of patients.⁹¹ For example, lay counsellors reported that they worked beyond their designated eight-hour day in trying to accommodate patients for HIV/AIDS counselling, education, and management.⁹² This was particularly true in "HIV/AIDS-friendly" primary health care clinics, where there were numerous examples of patients bringing HIV-positive family and friends from the Transkei in order to see a counsellor and doctor.⁹³ There were also examples of people coming from Zimbabwe and Mozambique to clinics in

⁸⁸ Nurses. Interviews by author. Cape Town, June-November 1997.

⁸⁹ Nurses. Interviews by author. Cape Town, June-November 1997.

⁹⁰ Trainers and Supervisors. Feedback to author. Cape Town, 11 October 2002.

⁹¹ Health Care Workers. Supervision by author. Cape Town, June-December 1998.

⁹² Lifeline and Leadership South Lay Counsellors. Interviews by author. Cape Town, February-July 2000.

⁹³ Health Care Workers. Training discussions with author. Cape Town, 25 January 2000.

the Western Cape. Patients were prepared to wait for what were regarded as better HIV/AIDS services, and there are examples of patients queuing from as early as 3:00 a.m.⁹⁴ In the busier clinics, HIV/AIDS counsellors reported seeing up to 19 patients a day.⁹⁵

In 2000, health care workers reported that there was scant regard for official clinic hours and personal privacy.⁹⁶ Patients arrived at counsellors' homes after hours and on weekends requesting assistance. A counsellor stated: "Some patients come and see me at 11 p.m. because this is when we can have a little privacy, they say. If I don't speak to them then, maybe I'll never see them again at the clinic. I have two small children who wake up when they [the patients] knock on my door. Then I have to call a neighbour to look after my children, and I can speak to the patient."⁹⁷ In 2001, trainers reported that they found such issues difficult to deal with because health care workers and patients did not follow the Western pattern of seeing a doctor or counsellor at their office at a specified time.⁹⁸ This pattern reflected customary relationships and interactions with traditional healers, as well as the problems of appropriate space and privacy at the primary health care clinics. The issue of traditional healers in HIV/AIDS management is examined in chapter six.

An important issue relating to the working conditions of HIV/AIDS health care workers was office space. Before 1998, health care workers were generally integrated into the existing clinic structures. For example, clinic space was given for one afternoon a week. In 1999, with the start of the Prevention of Mother-to-Child

⁹⁴ Lifeline and Leadership South Lay Counsellors. Interviews by author. Cape Town, February-July 2000.

⁹⁵ The efficacy of the counselling was seriously questioned by clinical supervisors of HIV/AIDS counsellors, given that professional psychologists regard 5-8 patients a day as the maximum number of patients to be seen in order to maintain the quality of counselling.

⁹⁶ Health Care Workers. Supervision by author. Cape Town, 27 July 2000.

⁹⁷ Lifeline and Leadership South Lay Counsellors. Interviews by author. Cape Town, February-July 2000.

⁹⁸ Trainers. Focus group by author. Cape Town, 19 November 2001.

Transmission (PMTCT) program many more HIV/AIDS health care workers were trained (see chapter three), health care workers reported the lack of adequate office space. They argued that this was a result of other medical staff in the hospitals and clinics not taking the issue of HIV/AIDS seriously.⁹⁹ Health care workers argued that this problem was illustrated in the designation of office space. HIV/AIDS counsellors were either not given their own offices or they were given inappropriate spaces. Health care workers had to continually negotiate with the sister-in-charge for a space in which to counsel. They were given spaces like the nurses' tearoom, where nurses walked in to boil the kettle in the middle of counselling sessions.¹⁰⁰ An HIV/AIDS counsellor reported:

I do not have a room at my clinic. The sister [nurse] told me to use the toilet. So I did. That was the only place where I get some privacy. I asked another patient to stand outside the door and stop anyone from coming in while I spoke to my patient for 10 minutes. Then I would let people use the toilet for 10 minutes before I asked my next patient in . . . I am tired of this counselling; they [the nurses] make me feel like a dog.¹⁰¹

In 2000, training organisations did confront many of these problems and they were told by nurses in management positions that while they appreciated the frustrations of the HIV/AIDS counsellors, nurses were also affected by the lack of adequate clinic space.¹⁰² Also, nurses in primary health care clinics were angry that they were expected to accept the increase in staff, usually working in the HIV/AIDS field, without any planning or support from the provincial government.¹⁰³ Doctors were generally given preference with office allocation while other HIV/AIDS health care workers had to make do with what space remained. In 2000, some HIV/AIDS

⁹⁹ Health Care Workers. Focus group by author. Cape Town, 5 April 1999.

¹⁰⁰ Lifeline Counsellor. Supervision by author. Cape Town, 18 August 2000.

¹⁰¹ Leadership South Health Care Workers. Focus group by author. Cape Town, 26 April 1999.

¹⁰² ATICC, Lifeline, and Leadership South Trainers. Interviews by author. Cape Town, 4-29 September 2000.

¹⁰³ Primary Health Care Nurses. Interviews by author. Cape Town, 24 November 2000.

counsellors in primary health care sites decided to ask for donations of railway storage containers that were then used as offices.¹⁰⁴ In 2001, other counsellors set up their offices in the grounds outside of the clinic, which raised important privacy and confidentiality issues.¹⁰⁵ The historical socio-economic problems linked to inadequate resources in areas of displaced peoples and informal settlements in the Western Cape affected not only health care, but also many other areas like education and recreational spaces.¹⁰⁶

The third issue examined is the salaries of HIV/AIDS counsellors and educators. This examination begins in 1998 because this was year that the first HIV/AIDS lay counsellors and educators were employed for the new PMTCT program in the province. From the beginning, the salary and employment conditions became controversial issues when HIV/AIDS counsellors and educators were trained for the program.¹⁰⁷ In 1998, Lifeline, in partnership with the Department of Health, took on the AIDS lay counsellor program as part of a job creation project.¹⁰⁸ The goal of the program was the recruitment of unemployed people from informal settlements as HIV/AIDS counsellors and educators. These people were trained (ATICC) and managed (Lifeline and Leadership South) to provide counselling and support to HIV/AIDS persons in clinics and hospitals. In 1998, Lifeline and the Department of Health employed these people at a salary of R2 000 with no additional benefits. Dissatisfaction with this salary was immediate: "This is not enough. We work many hours, and even on weekends the patients are knocking on my door at home. We do

¹⁰⁴ Health Care Workers. Supervision by author. Cape Town, 17 April 2000.

¹⁰⁵ Health Care Workers. Supervision by author. Cape Town, 21 June 2001.

¹⁰⁶ Health Care Workers. Supervision by author. Cape Town, 9 November 2000.

¹⁰⁷ HIV/AIDS Counsellors and Educators. Training and supervision by author. Cape Town, 11-15 May 1998.

¹⁰⁸ Lifeline/Childline (Western Cape), "The HIV and AIDS Project: Purpose of the Project," October 2004, <<http://www.lifelinewc.org.za/hivaidspurpose>> (Accessed: 11 October 2004).

too much work for too little money.”¹⁰⁹ In 2000, after receiving complaints from counsellors and feedback from the clinical supervisor, Lifeline decided to top up the salary, and pay for liability insurance, uniforms, ongoing training, and transport.¹¹⁰ These measures put Lifeline lay counsellors in a better position than the lay counsellors employed by other organisations. Nevertheless, the salaries were still low, especially given the counsellors’ work volume, working conditions, and extensive responsibility and stress associated with their jobs.

The fourth issue is the historical examination of the responses of other health care workers to the problems of stigma, working conditions, and salaries. Before 1994, there was little response from other health care workers to HIV/AIDS (as discussed above). In 1994, HIV/AIDS had a wider impact on clinic and hospital staff in terms of the higher numbers and the subsequent pressure places on the already meagre resources. Between 1994 and 1998 this pattern intensified. In 1998, doctors and nurses working in primary health clinics downplayed these problems, mainly because it seemed that they were relieved to have someone who could do this kind of work instead of having to do it themselves.¹¹¹ Up to 2001, the provincial government did not respond meaningfully to these issues that were identified and discussed by training organisations.¹¹² In 2001, the provincial government requested that the managing organisations compile a list of the complaints.¹¹³ Health care workers received no feedback after these lists had been submitted.

From 1989 to 2004, training organisations provided much of the education, capacity development, and support that the health care workers and lay counsellors

¹⁰⁹ Leadership South Counsellors (PMTCT Program). Supervision by author. Cape Town, 22 March 1999.

¹¹⁰ S. Kilroe (Ex-Director, Lifeline/Childline). Interview by author. Cape Town, 15 May 2000.

¹¹¹ Health Care Workers. Training discussion with author. Cape Town, 3 November 1998.

¹¹² ATICC and Lifeline Trainers. Interviews by author. Cape Town, 12-16 March 2001.

¹¹³ Lifeline and Leadership South Managers. Interviews by author. Cape Town, 18-22 June 2001.

required. This was done through technical updates, ongoing training, and mentoring programs. Training organisations reported that the fact that they had assumed these responsibilities created problems for them because it placed extra demands on their human and financial resources.¹¹⁴ Training organisations had to fund the support and development of the health care workers and lay counsellors because the provincial government claimed that they were funding the salaries of the lay counsellors and they did not see the importance of supporting and developing lay counsellors.¹¹⁵ In 2002, training organisations and health care workers argued that the provincial government was more interested in showcasing the number of HIV/AIDS counsellors and educators trained and placed rather than the quality and development of their work.¹¹⁶ By 2004, few of these issues had been solved.

The fifth, and final, issue examined is the expectations and responses of the wider community to the problems that were raised by HIV/AIDS health workers. From 1989, health care workers experienced difficulties assimilating into HIV/AIDS prevention, treatment, and support programs.¹¹⁷ Between 1989 and 1995, these complaints continued but, because of the relatively low number of HIV/AIDS health care workers, these complaints were not taken seriously by the Department of Health.¹¹⁸ In 1995, health care workers reported that other health care workers and patients confused them with community social workers.¹¹⁹ For example, “My patients call me ‘social worker.’ They ask me to help them with bus money, pensions, and

¹¹⁴ Leadership South, Lifeline, and ATICC Training Managers. Interviews by author. Cape Town, 3-7 December 2001.

¹¹⁵ The lack of provincial government support of the lay counsellor project was controversial. Some organisations like Lifeline and Leadership South took it upon themselves, from 1998 onwards, to recruit and fund professional supervision, support, and capacity development for the lay counsellors whom they had employed.

¹¹⁶ Trainers. Feedback to author. Cape Town, October 2002.

¹¹⁷ ATICC, Lifeline, and Leadership South Trainers. Feedback to author. Cape Town, 18-29 March 2002.

¹¹⁸ ATICC, Lifeline, and Leadership South Trainers. Feedback to author. Cape Town, 18-29 March 2002.

¹¹⁹ Health Care Workers. Training discussion with author. Cape Town, 17 July 1995.

debt. They think I have money in my pockets to give them, or that I can get them this money from somewhere. I'm not doing too much counselling these days."¹²⁰ This meant that patients expected the HIV/AIDS counsellors to work beyond their areas of expertise and training.

In 1998, this proved especially problematic for lay HIV/AIDS counsellors.¹²¹ They were trained to do only HIV/AIDS pre- and post-test counselling and limited ongoing HIV/AIDS counselling. From 1998 onwards, HIV/AIDS health care workers were asked by colleagues (mostly doctors and nurses) and patients to assist with social issues like bereavement, domestic and sexual violence, crisis counselling, and development issues like poverty, hunger, and transport money.¹²² In 2000, an HIV/AIDS counsellor related one of many such examples:

On Monday I saw a woman who wouldn't talk to me. She just cried and cried. I sat with her for one hour before she talked. She then told me that she had caught her husband having sex with their three-year old daughter. She took the girl to Red Cross who told her that the girl is HIV-positive. When she got home she told her husband and he beat his wife unconscious. When she woke up, she realised that she had been raped. Her husband is a gangster, and he drinks and takes drugs. This woman has no support because her family lives in A. I think she is depressed and wants to die. I don't know what to do for her, God help her.¹²³

This case is important not only for the frequency with which such cases were reported by health care workers but also for the complex socio-economic, cultural, gender, and psychological issues involved. The stress of working outside of their areas of competency was immense. Many of these lay counsellors had not completed their formal education, and some had only a few years of basic education. In 2002, lay counsellors reported that they did not have the skills to handle these requests from colleagues and patients, yet they felt that they should not send patients away

¹²⁰ Health Care Workers. Supervision by author. Cape Town, 20 April 1998.

¹²¹ Health Care Workers. Supervision by author. Cape Town, 20 April 1998.

¹²² Health Care Workers. Interview by author. Cape Town, 23 February 2001.

¹²³ Lifeline and Leadership South Lay Counsellors. Interviews by author. Cape Town, February-July 2000.

unassisted.¹²⁴ It is important to note that the legal issues involved in lay counsellors working outside of their training and competencies were disconcerting, and largely ignored by the provincial health department, management, and other health care professionals.¹²⁵ By 2004, these factors contributed to low staff morale and high levels of stress and staff turnover.

Health care workers argued that the way in which local organisations were included in HIV/AIDS programs was important to the success of the program.¹²⁶ In 1997, training organisations, in consultation with the Department of Health, stressed the importance of training local health care workers and lay counsellors and educators for PMTCT (1998) and Voluntary Counselling and Testing (VCT) (2000) programs.¹²⁷ Local community organisations and leaders were contacted to assist with the recruitment and selection of local health care workers and lay counsellors and educators. This strategy did encourage the assistance of local communities, yet the problem of not being involved enough in the implementation and management of these HIV/AIDS programs remained.

Training organisations played a dual, and mostly uncomfortable, role. On the one hand, they were trying to assist local communities by taking cognisance of the relevant socio-economic issues by recruiting and selecting community members.¹²⁸ On the other hand, community health care workers regarded training organisations as being too closely aligned to the White researchers and foreign funding organisations.¹²⁹ This was a problem for community health care workers because they felt that program agendas were forced on them without adequate consultation.

¹²⁴ Lifeline and Leadership South Lay Counsellors. Feedback to author. Cape Town, 8-19 April 2002.

¹²⁵ Training Managers and Health Care Workers. Focus groups by author. Cape Town, January 1998-May 2001.

¹²⁶ Health Care Workers. Training discussion with author. Cape Town, 20 August 1996.

¹²⁷ ATICC and Lifeline Trainers. Interviews by author. Cape Town, 15-30 January 2001.

¹²⁸ ATICC and Lifeline Trainers. Interviews by author. Cape Town, 15-30 January 2001.

¹²⁹ Health Care Workers. Supervision by author. Cape Town, 22 March 2001.

Notably, in 2001 some health care workers from poorer areas argued that foreign researchers wanted only to conduct HIV/AIDS experiments on Blacks.¹³⁰ Such views resulted in mistrust, opposition, and procrastination from community organisations, leaders, and health care workers to outside HIV/AIDS initiatives.

Most of these problems were historical in the sense of the limited health infrastructure in Black townships, and the socio-economic conditions in which many people found themselves. That is, health care workers felt limited in terms of what they were able to do because of the restricted health infrastructures, while patients did not always see HIV/AIDS as a threat because of the more immediate socio-economic concerns like hunger, unemployment, and crime.¹³¹

The role of Apartheid in creating these conditions was verbalised by patients,¹³² health care workers,¹³³ and trainers.¹³⁴ For example, an HIV/AIDS counsellor who attended the opening of the *Galeshewe Urban Renewal Program* on 2 February 2002 stated that she agreed with Deputy Minister Botha that Black townships were not planned to develop dignity or provide adequate health care facilities.¹³⁵ One of the interesting effects of this historical understanding was that health care workers and trainers had realistic expectations of what initiatives were possible within given infrastructures. In terms of program planning and delivery this understanding was important because it contributed to more effective HIV/AIDS

¹³⁰ Health Care Workers. Supervision by author. Cape Town, 20 April 2001.

¹³¹ Health Care Workers. Supervision by author. Cape Town, 14 June 2003.

¹³² Patients, Somerset Hospital. HIV/AIDS counselling. Cape Town, 1 November 2000.

¹³³ Lifeline Health Care Workers. Supervision by author. Cape Town, 23 March 2001.

¹³⁴ ATICC Trainers. Focus group by author. Cape Town, 25 January 2001.

¹³⁵ ATICC Counsellor. Training feedback to author. Cape Town, 25 April 2002.

Note: On 2 February 2002, Deputy Minister Botha said the following: "Black townships, such as Galeshewe in Kimberly, Khayelitsha in Cape Town, KwaMashu in Durban, Mdantsane in East London, were designed as labour "reservoirs" to support the economies of these urban centres. They even had names like NY (Native Yard) in Cape Town and NU (Native Unit) in Mdantsane. There was no provision for any significant economic activity in these townships, no recreational facilities, recreation was synonymous with beer-halls and no quality health care facilities or programmes." <<http://www.dplg.gov.za/speeches/2feb02.htm+health+infrastructure+in+black+townships,+cape+tow n&hl=en>> (Accessed: 20 April 2005).

initiatives.¹³⁶ By 2004, there were few positive changes in the working conditions of health care workers.

The Historical Role of Training Organisations

The final section deals with the historical role that training organisations played in the recognition of socio-economic factors in the HIV/AIDS epidemic. In 1989, health care workers saw training organisations as the experts or they felt pressurised into attendance of training (see chapter three). Yet, as the first cases were seen in clinics, factors like social and occupational exposure, and the social interaction between health care workers, communities, patients, clinics, and provincial management were identified through training discussions and feedback forms. Training organisations were uniquely placed to receive regular feedback from the various interacting agencies. After 1994, with the new government's focus on primary health care, health care workers stated that they had little support from provincial departments, and therefore they discussed HIV/AIDS and the associated socio-economic problems with training organisations.¹³⁷ Because of this continuous exchange between health care workers and training organisations, significant socio-economic factors linked to HIV/AIDS were identified before they were researched and discussed academically. The important role of information generated by action research conducted by health care workers and trainers is thus highlighted.

A more controversial point deals with the role of training organisations in supporting certain socio-economic factors. In 1999, training organisations were responsible for supporting stances opposed to the government's inaction and confusing public health messages. The adoption of a political position meant that

¹³⁶ Primary Health Care Trainers. Feedback to author. Cape Town, 29 April 2003.

¹³⁷ Health Care Worker. Focus group by author. Cape Town, 29 May 2001.

training organisations encouraged certain social expectations and responses to the role of government in the prevention and treatment of HIV/AIDS. In 2000, a doctor commented on her social naivety before receiving HIV/AIDS training: “I realised that I knew little about social aspects of AIDS. Now I am a supporter of TAC [Treatment Action Campaign], and I am involved in real HIV/AIDS issues in my clinic. Training made me an activist.”¹³⁸

This response highlights one of the many ways in which training organisations increased social awareness during the 1990s. Notably, this took place during a time of massive political, social, and economic changes, and thus training organisations were part of the larger national social changes that people were experiencing. Health care workers were challenged and encouraged (especially through peer learning, supervision, and peer support groups) to see socio-economic factors in the HIV/AIDS epidemic in new ways.¹³⁹ By 2004, training organisations were responsible for moulding new social attitudes, behaviours, and community responses to HIV/AIDS by recognising and including the socio-economic factors in HIV/AIDS in training.

The negative side of training organisations’ role in shaping social attitudes and behaviour of health care workers is seen in some of the mistakes made in training content and methodology. As discussed in chapter three, initially training organisations presented American and British counselling models that were later undermined by local social, cultural, and gender HIV/AIDS experiences. In presenting inappropriate counselling models, training organisations contributed to racial stereotyping that implied the superiority of Western models. In 1996, health care workers reported that they felt inadequate because they were not meeting the

¹³⁸ Primary Health Care Doctor. Interview by author. Cape Town, 21 April 2000.

¹³⁹ Health Care Workers. Supervision by author. Cape Town, 11 May 2001.

Western standards presented by the training organisations.¹⁴⁰ In 1998, a nurse commented:

Those counselling models are hard for us Xhosa to understand. My people don't talk like that. I tried these models, but they don't work. I tried harder because they [trainers] told us that this is the only way to do it. I made many clients angry. One man said: "Sis, take off your White face." That helped me see that I needed to change the model to help my people talk about this terrible thing [HIV/AIDS].¹⁴¹

Moreover, HIV/AIDS educators in clinics adopted the initial "talk-and-chalk"¹⁴² methodology of training organisations. In 1999, these educators reported that they were met with silence from patients, and they argued that their education was of no effect.¹⁴³ Unlearning these traditional teaching methods proved difficult. By 2004, HIV/AIDS educators were generally more aware of the socio-economic factors of the clinics in which they worked, and they reported greater confidence in using content and methodology that suited the specific target group of patients.¹⁴⁴

Conclusion

In 1989, with the first provincial HIV/AIDS training course, trainers and health care workers' understanding of the interaction between the socio-economic factors and HIV/AIDS was limited. HIV/AIDS was seen as a medical illness, and high prevalence rates were not linked to poverty and inequality. Initially the issue of HIV transmission challenged health care workers to consider the link between HIV/AIDS and socio-economic factors. In 1989, health care workers who saw HIV/AIDS patients were concerned with contracting HIV: these fears were particularly strong until 1992 when the first guideline for the management of

¹⁴⁰ Health Care Workers. Supervision by author. Cape Town, 16 September 1996.

¹⁴¹ Primary Health Care Nurse. Interview by author. Cape Town, 8 October 1998.

¹⁴² "Talk-and-chalk": The traditional method of educating children in school classrooms, in which teachers "gave" and pupils "received" information.

¹⁴³ HIV/AIDS Educator. Focus group by author. Cape Town, 3 June 1999.

¹⁴⁴ HIV/AIDS Educator. Private communication with author. Cape Town, 28 May 2004.

HIV/AIDS was published. With the changing political dispensation in the early 1990s, the socio-economic factors in the interactions between health care workers, the patients, and the clinics highlighted the need for local, relevant, and updated training models. Between 1992 and 1994, health care workers reported increased social and professional exposure. By 1994, training organisations, by paying closer attention to the relationship between the socio-economic factors and HIV/AIDS, recognised the Apartheid hangover in health care infrastructure and other community issues.

In 1994, the new government implemented primary health care services, which resulted in more health care workers being exposed to HIV/AIDS persons in primary health clinics. By 1995, through greater awareness of the socio-economic factors in HIV/AIDS and the lack of a consistent political response, training organisations, at times unconsciously, became active in more global development issues through their attempts to grapple with the complexities of HIV/AIDS transmission, prevention, and treatment. As a result, the organisational structures and limitations of national and provincial health care were recognised and important questions were raised about the impact of these structures on the future of the epidemic.

Between 1995 and 1997, trainers and health care workers discussed socio-economic factors, and yet it was the implementation of the lay education and counselling program in 1998 that highlighted important socio-economic issues for patients and health care workers. Now health care workers had to deal with the rapidly worsening epidemic and the problems associated with being employed exclusively in the HIV/AIDS field. Ironically, Mbeki's questioning of the link between HIV and AIDS in 1999 had the effect of raising health care workers' awareness of poverty and inequality in the transmission and management of

HIV/AIDS. Between 2000 and 2004 the importance of socio-economic factors in the spread and management of HIV/AIDS was well established. Also, by 2004, HIV/AIDS was regarded as regular work and health care workers were rarely stigmatised. This shift is rooted in the historical context of the growing epidemic, the increased response from NGOs and government to the epidemic, the government's questioning of the HIV-AIDS link in 1999, and the socio-economic impact of the disease on patients and health care workers. Finally, the historical analysis of the socio-economic factors in the history of HIV/AIDS training between 1989 and 2004 showed that training organisations played an important role in educating health care workers, and vice versa, by establishing a socio-economic narrative in the HIV/AIDS training and management of the disease.

CHAPTER SIX: “It’s hard to explain this to a White person. I am a nurse, but I also believe in my Ancestors” – Cultural factors in the history of HIV/AIDS training content, methodology, and organisational issues, 1989-2004.

This chapter provides an historical examination of the cultural factors underlying the delivery of HIV/AIDS training to health care workers in this period. Cultural factors were evident in the ways that health care workers and trainers understood and discussed the origin and transmission of HIV, the role of traditional healers in the treatment of HIV-positive persons, the provision of sex education, and the training of first language trainers. Viewed historically, these cultural factors were important in terms of the political, economic and social changes within South Africa in the period under review. Training organisations and health care workers were increasingly exposed to important cultural factors that were previously ignored in HIV/AIDS training, treatment, and care. The sources utilised in this chapter are largely oral, contextualised with secondary sources. Health care workers and trainers were interviewed in order to analyse the underlying cultural factors that influenced the changes in HIV/AIDS training, content, and organisational issues in the period under review.

Ideas Surrounding the Origins of HIV

This historical analysis of the origin of AIDS raises the issue that HIV/AIDS is a socially and culturally marked disease, that is, HIV/AIDS, because it is predominantly transmitted sexually, has various and complex social and cultural

dimensions.¹ As a result of these social and cultural dimensions social critics have attempted to expose the narratives and subtexts of HIV/AIDS.² Treichler argued that HIV/AIDS is constructed through language and in particular through the discourses of medicine and science: that is, an “epidemic of signification.”³ She held that we should pay particular attention to how language creates rather than simply reflects the meanings of illness. Thus, biomedical definitions of HIV/AIDS are based “on *prior* social constructions routinely produced within the discourses of biomedical science.”⁴ Treichler concluded that this is an important issue because: “Such an approach illuminates the construction of AIDS as a complex narrative and raises questions not so much about truth as about power and representation.”⁵ For the historian, this raises important historiographical questions. That is, it highlights how diseases are investigated, constructed, and reported, and the implications of this for the social history of medicine. The speculation about the origin of HIV in South Africa illustrates the ways in which HIV/AIDS is discussed, and how it opens windows into social history. There remains much to be written about the construction of HIV/AIDS in Africa, and here historians have an important contribution to make.

From the first HIV/AIDS training course in 1989, it was common to hear participants echoing the larger community, that is, HIV/AIDS, if it did exist, existed

¹ T. I. Spector, “The Molecular Aesthetics of Disease: The Relationship of AIDS to the Scientific Imagination,” *International Journal for Philosophy of Chemistry*, 9, no. 1 (2001): 51-71.

² For example, A. M. Brandt, “AIDS and Metaphor: Toward the Social Meaning of Epidemic Disease,” in *In the Time of Plague*, ed. A. Mack (New York: New York University Press, 1991), 91-110; S. L. Gilman, *Picturing Health and Illness* (Baltimore: Johns Hopkins University Press, 1995); S. Sontag, *AIDS and Its Metaphors* (New York: Farrar, Straus, and Giroux, 1989); P. A. Treichler, “Biomedical Discourses: An Epidemic of Signification,” in *AIDS: Cultural Analysis and Cultural Activism*, ed. D. Crimp (Cambridge: The MIT Press, 1988), 87-108; P. A. Treichler, “AIDS, HIV, and the Cultural Construction of Reality,” in *The Time of AIDS*, eds. G. Herdt and S. Lindenbaum (Newbury Park: Sage Publications, 1992), 65-97; P. A. Treichler, *How to Have Theory in an Epidemic* (Durham: Duke University Press, 1993); and J. Williamson, “Every Virus Tells a Story: The Meanings of HIV and AIDS,” in *Taking Liberties*, eds. E. Carter and S. Watney, (London: Serpent's Tail, 1989), 69-80.

³ P.A. Treichler, “Biomedical Discourses: An Epidemic of Signification,” in *AIDS: Cultural Analysis and Cultural Activism*, ed. D. Crimp (Cambridge: MIT Press, 1988), 87-108.

⁴ Treichler, “Biomedical,” 48.

⁵ Treichler, “Biomedical,” 48.

only in other cultural or religious groups.⁶ These allegations, on the back of the larger political and social strife and changes in South Africa in the late 1980s and early 1990s, created a climate in which many conspiratorial, bemusing, and alarming HIV/AIDS genesis theories proliferated. Many of these theories had strong racial determinants. In 1994, a focus group highlighted the various examples of origin theories reported by health care workers. Theories by some Black health care workers included the allegedly sinister role of America, colonialists, and the National Party. For example, "I heard that P.W. [Botha]⁷ made this virus because he was angry he was no longer President. He has a laboratory in George where he made AIDS. He wants to kill all the Blacks and the Whites that rejected him."⁸ Theories that evoked more traditional racial divides between Afrikaners and Black were also prevalent: "You know those oranges that have the red spots in them? [blood oranges].⁹ Yes, the Boers injected AIDS blood into the oranges so that all us Coloureds and Blacks would die. You can't buy those AIDS oranges in the White shops, only in our shops."¹⁰ White theories focussed on reputed Black promiscuity and the key players in the changing political dispensation: "It is all the Black ANC freedom fighters who have brought this terrible disease with them. They were all living in other African countries with nothing to do all day except drink and have sex. Now these people run our

⁶ ATICC Trainers. Interviews by author. Cape Town, January 1995 and March 2001.

⁷ P. W. Botha, Prime Minister of South Africa, 1978-1984, and President, 1984-1989.

⁸ Health Care Worker. Focus group by author. Cape Town, March 1994.

⁹ In 1993, rumours emerged that oranges with dark red pigmentation, resembling blood, contained HIV-positive blood. *Outspan International* reported that these rumours coincided with the marketing of the rare blood oranges. This version of the "poisoning or infecting of blacks by whites through food" myth is not new to Africa. For example, (1) In 1946, it was rumoured that government meat in Bulawayo was contaminated in order to make black men sterile, and (2) Bantu Holomisa's pre-1994 election speeches that warned blacks not to eat ink-laced porridge because the invisible ink would show up under ultraviolet light and disqualify ANC voters in the first democratic election. See R. H. Kaschula, "Myth and Reality in the New South Africa: Contemporary Oral Literature," *LitNet* (2004), <<http://www.litnet.co.za/seminarroom/myth>> (Accessed: 2 May 2004).

¹⁰ Health Care Worker. Focus group by author. Cape Town, March 1994.

country.”¹¹ Health care workers in training also reported that race played an important role in the various beliefs about the origin of HIV/AIDS.¹²

Responses like these are not new in the history of international and South African epidemics. Phillips cited examples like the Germans blaming Jews for the Black Death in 1349; Russians blaming Poles for the spread of cholera in 1830; Whites blaming ‘dirty Malays’ for the spread of smallpox in 1840, 1858, and 1882; Africans blaming the ‘Spanish’ influenza epidemic of 1918 on Whites who wanted to exterminate Africans.¹³ The English-speaking White government blamed the ‘Spanish’ influenza on the German’s gas warfare, while Afrikaners blamed it on the “irresponsible members of the Native Labour Corps.”¹⁴ Referring to HIV/AIDS, Grundlingh referred to this process as the “plague mentality” in which the socially marginalized, ethnic minorities, and the poor are blamed,¹⁵ the “outsiders,”¹⁶ while Crewe argued that it is psychologically reassuring to blame others for the origin of the disease because blame is projected onto external sources of transmission.¹⁷

In the first HIV/AIDS training courses in 1989 and 1990, a significant part of the training at the AIDS Training, Information and Counselling Centre (ATICC)¹⁸ was spent debating the origins of HIV.¹⁹ Trainers at ATICC reported that participants wanted to understand the origin of HIV before they discussed other training input. In 1990, this question was being asked and debated in the general population, in political

¹¹ Health Care Worker. Focus group by author. Cape Town, March 1994.

¹² Health Care Workers. Training feedback to author. Cape Town, 1993-1995.

¹³ H. Phillips, “HIV/AIDS in the Context of South Africa’s Epidemic History,” in *AIDS and South Africa: The Social Expression of a Pandemic*, eds. K. D. Kauffman and D. L. Lindauer (New York: Palgrave Macmillan, 2004), 33-34.

¹⁴ Phillips, 33.

¹⁵ L. Grundlingh, “HIV/AIDS in South Africa: a Case of Failed Responses because of Stigmatisation, Discrimination and Morality, 1983-94,” *New Contree* 46 (1999): 55.

¹⁶ S. Cross and A. Whiteside, *Facing up to AIDS. The Socio-Economic Impact in Southern Africa* (New York: St. Martin’s Press, 1993), 15.

¹⁷ M. Crewe, *AIDS in South Africa: The Myth and the Reality* (London: Penguin, 1992), 14.

¹⁸ A government established organisation (1989) with the goal of providing HIV/AIDS training and education to health care workers and the public.

¹⁹ Aids Training, Information and Counselling Centre (ATICC) Trainers. Interviews by author. Cape Town, January 1995 and March 2001.

rhetoric, and scientific investigations. Trainers noted that while questions concerning the origins of HIV were frequently asked, the answers given by scientific consensus and trainers were shifting.²⁰

In South Africa, most of the early explanations of the origin of HIV evoked homophobic and racist stereotypes (see chapter four for discussion).²¹ Grundlingh has examined the discourse surrounding HIV/AIDS and homosexuality by the Dutch Reformed Church in the 1980s.²² For example, in 1983, Reverend van der Colf stated that: "Homosexuals has chosen to leave behind normal life and therefore he has to accept the consequences [sic]."²³ In 1987, Reverend Gous claimed: "The Word of God warns against this devious form of sexuality. AIDS proves the biblical prescriptions. For the sake of mankind homosexual practices should be abandoned."²⁴ This response of some ministers of religion to HIV/AIDS in South Africa mirrored the American response of blaming the gay community for HIV/AIDS partly because the first reported HIV cases were also in the gay community.²⁵ That is, in the early 1980s HIV/AIDS was associated with gay men in the USA, Europe, and Australia.²⁶ Brandt argued that the media was largely responsible for generating this confusion about the disease.²⁷ The American media fostered the widespread link between HIV/AIDS and homosexuality, for example, in popularising the term "gay plague."²⁸

²⁰ ATICC Trainers. Interviews by author. Cape Town, January 1995 and March 2001.

²¹ Phillips, 34.

²² Grundlingh, "Stigmatisation," 63.

²³ Grundlingh, "Stigmatisation," 63.

²⁴ Grundlingh, "Stigmatisation," 63.

²⁵ These examples are by no means illustrative of all ministers of religion in South Africa in response to HIV/AIDS. For example, the Anglican Church in Cape Town responded in positive and proactive ways to the early epidemic.

²⁶ Joint United Nations Programme on HIV/AIDS (UNAIDS)/World Health Organisation (WHO). *A History of the HIV/AIDS Epidemic with Emphasis on Africa*. Geneva: UNAIDS, WHO, UN/POP/MORT/2003/2, 2003.

²⁷ A. M. Brandt, "AIDS in Historical Perspective: Four Lessons from the History of Sexually Transmitted Diseases," *American Journal of Public Health*, 78 (1988): 367-371.

²⁸ I. Emke, "Agents and Structures: Journalists and the Constraints on AIDS Coverage," *Canadian Journal of Communication*, 25, no. 3 (2000).

In South Africa in the 1980s, there were probably two separate clades or subtypes of HIV-1: one brought in from America or Europe, the other from central Africa. Clade B, which is dominant in North America and Europe, was found predominantly in the South African White, gay community with travel links to Europe and the USA. The first reported cases in the early 1980s were confined to this part of the gay community.²⁹ In 1983, the South African government tried to reassure South Africans by saying that the disease only affected homosexuals.³⁰ In 1984, the government refused to give R20 000 to a proposed AIDS education program in the gay community: the reason, according to Dr. Dennis Sifris, one of the pioneering HIV/AIDS doctors in South Africa, was that the government supported the legislation that made homosexuality illegal.³¹ Prevalence rates in the gay community peaked in 1987, and then declined, largely as a result of non-governmental education and behaviour change resulting from people at risk and people living with HIV/AIDS educating each other (as discussed in chapter five).³²

Clade C, which is dominant in southern Africa, was spread heterosexually. Phillips argued that Clade C was most likely brought to the Witwatersrand by migrant mineworkers from Malawi.³³ This hypothesis stems from the fact that, in 1986, the first heterosexual cases were reported in 130 Malawian miners on the Rand. Between 1988 and 1992, the South African mining industry repatriated approximately 13,000

²⁹ V. van der Vliet, "South Africa Divided against AIDS: A Crisis of Leadership," in *AIDS and South Africa: The Social Expression of a Pandemic*, K. D. Kauffman KD and D. L. Lindauer (New York: Palgrave Macmillan, 2004).

³⁰ A. Thom and K. Cullinan, "Responses to HIV/AIDS," Centre for the Study of AIDS, Pretoria, 28 November 2004, <<http://www.health-e.org.za/news/article.php?uid=20031154>> (Accessed: 29 June 2006).

³¹ A. Thom and K. Cullinan, "Virus Veterans," Centre for the Study of AIDS, Pretoria, 28 November 2004, <<http://www.csa.za.org/article/articleview/335/1/1>> (Accessed: 29 June 2006).

³² Van der Vliet.

³³ Phillips, 32.

Malawians on the grounds that 200 Malawians had tested HIV-positive up to 1992.³⁴ Chirwa questioned the official reasons for this repatriation: he argued that it had little to do with HIV/AIDS and that the “South African mining industry was going through a period of crisis which necessitated massive retrenchment of workers, especially foreigners.”³⁵ He held that HIV/AIDS was used as a smokescreen for underlying socio-economic problems. These Malawian miners remain the favoured protagonists in the introduction and spread of HIV in South Africa, yet more historical research is required to better understand this issue.

South Africa’s well-established system of migrant labour probably played an important part in this initial establishment and entrenchment of the virus.³⁶ Historians of epidemics have highlighted the importance of political, social, and economic factors in understanding the spread of diseases,³⁷ yet it is not within the scope of this dissertation to provide a detailed analysis of migration.³⁸ Historical analyses of the

³⁴ W. J. Chirwa, “Aliens and AIDS in Southern Africa: The Malawi-South Africa Debate,” *African Affairs*, 97 (1998): 53-79.

³⁵ Chirwa, 54.

³⁶ See, for example: J. Crush, “HIV/AIDS and Cross-Border Migration in Southern Africa,” conference paper, National Consultation on Migration and HIV/AIDS, Pretoria, 1999; and C. Campbell, “Migrancy, Masculinity and HIV: The Psycho-Social Context of HIV-Transmission on the South African Gold Mines,” *Social Science and Medicine*, 45, no. 2 (1997): 273-283.

³⁷ For example, for HIV/AIDS: (1) S. Epstein, *Impure Science: AIDS, Activism, and the Politics of Knowledge* (California: University of California, 1996), (2) R. Bayer and G. Oppenheimer, *AIDS Doctors. Voices from the Epidemic* (New York: Oxford University Press, 2000), and (3) P. Baldwin, *Disease and Democracy: The Industrialised World Faces AIDS* (California: University of California, 2005). For Influenza: (1) A. Crosby, *America’s Forgotten Pandemic: The Influenza of 1918* (Cambridge: Cambridge University Press, 1989). For the Plague: (1) A. G. Carmichael, *Plague and Poor in Early Renaissance Florence* (Cambridge: Cambridge University Press, 1986), (2) C. Cipolla, *Fighting the Plague in 17th Century Italy* (Wisconsin: University of Wisconsin Press, 1981), (3) P. Slack, *The Impact of the Plague in Tudor and Stuart England* (London: Routledge & Kegan Paul, 1985), and (4) A. L. Martin, *Plague?: Jesuit Accounts of Epidemic Disease in the Sixteenth Century* (Missouri: Sixteenth Century Journal Publishers, 1994).

³⁸ Migration is a significant contributor to the spread of HIV/AIDS and other sexually transmitted infections (STIs), and it underscores the fact that sexually transmitted diseases are not only the result of individual behaviour but influenced by the political, social, and economic organisation of a society (M. Lurie, “Migration and AIDS in Southern Africa: A Review,” *South African Journal of Science*, 96, no. 6 (2000): 343-347). Brummer argued that in southern Africa migration is related to civil war (for example, Angola), economic migration (for example, to South Africa), and internal rural-urban migration in various countries (D. Brummer, *Labour Migration and HIV/AIDS in Southern Africa*, International Organisation for Migration, Regional Office for Southern Africa, Pretoria, 2002, 7). The most significant cross border migration in South Africa in the 1990s was the increase in people from other parts of Africa (as far as West Africa) who came to South Africa for reasons of employment and

issue of migration and HIV/AIDS in southern Africa are essential: in terms of both the initial and present-day spread of the disease.

By the early 1990s many other views about the introduction and spread of HIV were in existence, levelled largely by White and Black politicians and the press at various targets. Certain White accusations focussed on the supposed perils of public desegregation, non-racial sport, and the role of domestic workers in the spread of the virus.³⁹ The strength of these misguided fears is evident in the 1990 decision by the director of the Highveld Blood Services to ban the blood of Blacks and Coloureds because it was more likely to be HIV-positive.⁴⁰ This issue re-emerged fourteen years later.⁴¹

Certain African views about the spread of HIV/AIDS centred on the beliefs that the disease was an attempt by the Apartheid government and its supporters to check African liberation by reducing the African population through death and the

for the selling and buying of goods. Exactly how these people have contributed to the introduction of new strains of HIV and the spread of HIV/AIDS in South Africa remains unclear (D. A. McDonald, et al., "Guess Who's Coming to Dinner: Migration from Lesotho, Mozambique and Zimbabwe to South Africa," *International Migration Review*, 34, no. 3 (2000): 812-840).

³⁹ Van der Vliet, 50-51.

⁴⁰ Phillips, 34.

⁴¹ In December 2004, the South African National Blood Service (SANBS) was questioned about two issues: that President Mbeki's donated blood was destroyed, and the organisation's method of racial profiling for risk management of HIV transmission through transfusion. Regarding the first issue, in an interview with the *Mail and Guardian* on 16 December 2004, Professor Anthon Heyns (CEO of the SANBS) stated that the President's blood was discarded because the SANBS staff did not regard this as a real donation, but as a publicity stunt (E. Hollemans, "No Such Thing as Zero-risk Blood," *Mail and Guardian*, 16 December, 2004,

http://www.mg.co.za/articlePage.aspx?articleid=193804&area=/ten_questions/) (Accessed: 2 May 2005). Regarding the issue of racial profiling, Heyns argued that, "the average risk of a Black South African being HIV-positive was 100 percent greater than a White South African and, depending on the specific group, could be about 150 percent higher" (H. H. Bauer, "Demographic Characteristics of HIV: III. Why Does HIV Discriminate by Race?," *Journal of Scientific Exploration*, 20, no. 2 (2006): 255-288). This raises the controversial point that there are few viable alternatives to the racial profiling of blood, and if the SANBS drops this method of screening, they become liable for transmitting HIV through blood transfusions. The Human Rights Commission accused the SANBS of racism (PlusNews, "South Africa: Race Back on the Blood Testing Debate Table," *IRIN*, 14 April 2005, <http://www.irinnews.org>) (Accessed: 2 May 2005). These issues illustrate the complexity of race in South Africa, and how race continues to emerge in the prevention and management of HIV/AIDS.

discouragement of sex.⁴² These beliefs were characterised by the acronyms like “Afrikaner Invention to Deprive Us of Sex”⁴³ or “American Invention to Discourage Sex.”⁴⁴ There is clear parody in these acronyms, but health care workers did state that some patients reportedly believed these views.⁴⁵ In 1995, trainers reported that health care workers claimed that the Apartheid and American governments used HIV/AIDS to lower Black birth rates.⁴⁶ In 1999, another sensational claim of using HIV/AIDS to target Blacks was made by Willie Nortje and Andries van Heerden.⁴⁷

Nortje and van Heerden were two Apartheid-era security officers who asked the Truth and Reconciliation Commission (TRC) for amnesty for their part in the alleged attempted spread of HIV/AIDS in 1990. According to the journalist Jacques Pauw, this plan was reconstructed from separate affidavits signed by Nortje and Van Heerden for the Institute for Democracy in South Africa (IDASA).⁴⁸ Shell and Qaga argued that in 1990 four *askaris* (ANC operatives who became state informers) were diagnosed HIV-positive.⁴⁹ Nortje claimed that Eugene de Kock had instructed these *askaris* to work in the Chelsea and Little Roseneath Hotels in Hillbrow, where they were to spread HIV among Black sex workers.⁵⁰ De Kock denied these allegations to the TRC, when he stated, “It is known that the most regular clients of Black

⁴² A. Whiteside and J. Van Niftrik, “AIDS in South Africa: Government and ANC Responses,” *AIDS Analysis Africa*, 3, no. 4 (1995), 1 & 9.

⁴³ Van der Vliet, 50.

⁴⁴ O. Shisana and N. Zungu-Diwayi, “Government’s Changing Response to HIV/AIDS,” *Development Update*, 4, no. 3 (2003): 165-187.

⁴⁵ ATICC Trainers. Supervision by author. Cape Town, July 1995.

⁴⁶ ATICC Trainers. Supervision by author. Cape Town, July 1995.

⁴⁷ According to a statement issued by the Truth and Reconciliation Commission (TRC) on 14 July 1998, Willie Nortje was an amnesty applicant for the bombing of Cosatu House on 7 May 1988, while Andries van Heerden was an amnesty applicant for the bombing of cinemas that showed “Cry Freedom,” the film about Donald Woods and Steve Biko, <http://www.info.gov.za/speeches/1998/98715_0w6159810188> (Accessed: 2 May 2005).

⁴⁸ J. Pauw, *Into the Heart of Darkness: Confessions of Apartheid’s Assassins* (Johannesburg: Jonathan Bell, 1997), 77.

⁴⁹ R. Shell and P. S. Qaga, “Trojan Horses: HIV/AIDS and the Military Bases in Southern Africa,” conference paper, Demographic Association of Southern Africa (DEMSA) Conference, University of the Western Cape, South Africa, 24-27 September 2002, <<http://science.uwc.ac.za/stats/DEMSA>> (Accessed: 2 May 2005).

⁵⁰ Shisana and Zungu-Diwayi, 168.

prostitutes are White men. I wouldn't have achieved anything by infecting prostitutes."⁵¹

The truth of these allegations has not been established.⁵² Shell (researcher-historian) and Qaga (researcher) argued that, for the sake of illustration, an AIDS component model seeded with four HIV-positive *askaris* and four sex workers in 1985 in a free population of one million people suggests that there could be 365 788 associated deaths by 2021 if these allegations were true.⁵³ It is important to note, from the perspective of this dissertation, that while the veracity of the story continues to be debated, the story highlights the power of social and cultural dynamics to shape people's belief about the origin and spread of HIV/AIDS in South Africa.

In 1997, trainers noted that health care workers no longer raised the issue of race in relation to the origin of HIV/AIDS.⁵⁴ They argued that the increasing number of patients at the primary health care clinics resulted in a less racially delineated view of the disease. This point is central to the argument in this chapter. That is, HIV/AIDS did affect everyone, despite their race or class. Trainers claimed that this was a significant shift because health care workers were no more likely to focus on the issues of prevention and management. Between 1997 and 2000, race was not raised as an issue in training. In 2000, the issue of race was resurrected with Thabo Mbeki's questioning of the HIV-AIDS link, which is another central tenet in the argument in this chapter. At the International AIDS Conference in Durban, Mbeki's speech that focussed on poverty not on HIV/AIDS, fuelled suspicion that he saw poverty, not HIV, as the primary source of AIDS.⁵⁵ Many health care workers were confused by

⁵¹ Shell and Qaga, 21.

⁵² Shell and Qaga, 21.

⁵³ Shell and Qaga, 21.

⁵⁴ Trainers. Supervision by author. Cape Town, 20 February 1997.

⁵⁵ G. Pembrey, "HIV/AIDS in South Africa," *Avert*, 21 July 2006, <<http://www.avert.org/aidssouthafrica.htm>> (Accessed: 2 August 2006).

this message and some agreed with Mbeki that the source of AIDS was poverty that historically was caused by colonialism (see chapter four for discussion).⁵⁶ This view was short-lived for health care workers. Between 2000 and 2004, the debate amongst trainers and health care workers about poverty and AIDS diminished: the reasons for this included the strong opposition to Mbeki's views especially from the medical fraternity, and the fact that health care workers had to get on with the work of managing patients. The discussion now turns to case studies that are integral to the chief argument.

The History of Cultural Factors in the Transmission of HIV

Dry Sex

Dry sex refers to the practice where men insist that their female sexual partners "dry" their vaginas before having sexual intercourse.⁵⁷ The practise has been identified in South Africa, Zimbabwe, the Democratic Republic of Congo, Malawi, Zambia, Kenya, Senegal, Cameroon, Nigeria, Saudi Arabia, Indonesia, Malaysia, Haiti, and Costa Rica.⁵⁸ Women use drying agents like soap, wool, coffee grind, tea bags, household detergents, scouring agents, antiseptics, leaves, and herbal remedies.⁵⁹ Mothers, grandmothers, and peers teach this practice to young women at the time of first menstruation.⁶⁰ The main reasons for dry sex are threefold. One, certain men enjoy "tight" sex, which is sex with more friction, despite the reported

⁵⁶ Health Care Workers. Training feedback to author. Cape Town, 27 November 2000.

⁵⁷ PATH (Program for Appropriate Technology in Health), "Vaginal Douching: Unnecessary and Potentially Harmful?," *Outlook*, 15, no. 4 (1997): 6-7.

⁵⁸ K. Kun, "Vaginal Drying Agents and HIV Transmission," *International Family Planning Perspectives*, 24, no. 2 (1998): 93-94.

⁵⁹ S. Lachman, *A Knowledge Base of Heterosexual HIV/AIDS as a Global Problem in the 21st Century: a Guide for Medical Practitioners and Health Care Workers* (Houghton: Pharmaceutical Society of South Africa, 1999), and S. Ray, N. Gumbo, and M. Mbizvo, "Local Voices: What Some Harare Men Say About Preparation for Sex," *Reproductive Health Matters*, 7 (1996): 34-45.

⁶⁰ N. Morar, G. Ramjee, and S. A. Karim, "Vaginal Insertion and Douching Practices Among Sex Workers in KwaZulu-Natal," *Women's Health Project*, 25 (1998): 26.

discomfort and pain to the woman. Two, based on certain cultural associations of vaginal fluid being “unclean” and a barrier to fertility, certain men want dry sex in order to ensure “cleanliness.”⁶¹ Three, certain men believe that if a woman’s vagina is lubricated or “wet” it means that the woman has just had sex with another man and is thus being unfaithful.

While health care workers (White and Black) in Southern Africa were aware of this practice, most were not aware of its long history and prevalence.⁶² There is no data for the prevalence of dry sex for the general population, but in 2003 a study in KwaZulu-Natal found that the prevalence rate among sex workers was 94%.⁶³ No equivalent data exists for the Western Cape, and thus no generalisations can be made about the prevalence in certain cultures. Researchers warned that dry sex could promote HIV-1 because the practise promoted lesions by damaging vaginal mucosa. Women who practise dry sex have been found to have vaginal inflammation resembling a chemical burn or allergic reaction.⁶⁴ Moreover, it was unlikely that men who were insisting on dry sex would permit the use a condom because of condom lubrication.⁶⁵

The issue of dry sex was not raised nationally or provincially before 1999. In 1999, a year after the issue of dry sex was raised in the *Lancet*, Western Cape training organisations addressed the issue in training courses. The delay in the response from

⁶¹ L. van der Poll, “Formulating an Appropriate Legal Response to Dry Sex and Virginitly Testing within the Discourse on Sexuality and Human Rights in Africa,” conference paper, IASSCS International Conference: Sex and Secrecy, University of the Witwatersrand, South Africa, 22-25 June 2003.

⁶² B. E. Beksinka et al., “The Practice and Prevalence of Dry Sex Among Men and Women in South Africa: A Risk Factor for Sexually Transmitted Infections?,” *Sexually Transmitted Infections (London)*, 75, no. 3 (1999): 178-180.

⁶³ N. S. Morar et al., “Vaginal Douching and Vaginal Substance Use Among Sex Workers in KwaZulu-Natal, South Africa,” *South African Journal of Science*, 99, no. 7/8 (2003): 371.

⁶⁴ K. Kun, “Vaginal Drying Agents and HIV Transmission,” *International Family Planning Perspectives*, 24, no. 2 (1998): 93-94.

⁶⁵ D. Civic and D. Wilson, “Dry Sex in Zimbabwe and Implications for Condom Use,” *Social Science and Medicine*, 42, no. 1 (1996): 91-98.

training organisations was due to the disagreements between provincial public health officials and NGO training organisations as to the appropriateness of this topic in the training of health care workers in the province.⁶⁶ Initially ATICC attempted to raise general awareness among health care workers in order to better equip them to identify and manage HIV/AIDS education and counselling.

In 2000, trainers reported that the topic of dry sex was met with silence from Black women and men and shock from the other participants.⁶⁷ This response led to a reassessment of the issue in training organisations. A trainer stated: “We had to do something. We knew dry sex existed, but it was deeply enshrouded in secrecy. Protected by silence and hostility . . . We knew that we were dealing with something important, both culturally and in terms of women’s rights.”⁶⁸ In 2000, ATICC trainers decided to change their approach because of the lack of response from health care workers to this topic: rather than simply providing information, trainers attempted small group discussions without plenary group feedback in order to learn more about the practise and the prohibitions against its public discussion.⁶⁹ Thus, this methodology was chosen in order to promote more open discussion of the issue. Trainers also identified more experienced Black women and men in the health care system who were willing to discuss the issue in training sessions and primary health care clinics. Finally, trainers used focus groups in training and clinics to gain access to the issue. In 2001, trainers reported that these various methods proved successful in that participants started discussing the issue.⁷⁰ This led to more detailed and relevant discussions, which allowed participants to develop their own ideas and strategies for dealing with dry sex in day hospitals and clinics. Many older female and a few male

⁶⁶ Trainers. Interview by author. Cape Town, November 2000.

⁶⁷ Health Care Workers. Interview by author. Cape Town, November 2000.

⁶⁸ ATICC Trainers. Interview by author. Cape Town, October 2000.

⁶⁹ ATICC Trainers. Interview by author. Cape Town, October 2000.

⁷⁰ Trainers. Supervision by author. Cape Town, June 2001.

health care workers included a discussion of dry sex in their HIV/AIDS education and pre- and post-test counselling. By the end of 2001 both female and male patients reported examples of successful education and behaviour change interventions.⁷¹

Between 2001 and 2004, health care workers argued that the increased exposure to the issue of dry sex in training encouraged them to discuss the practice with patients.⁷² For example, “Before we did not talk about this. Not with Whites, not with men. Our mothers told us to keep it secret. Now we feel stronger to talk about it, and it’s helping the patients. This is a terrible something, and our patients need education and to talk about it.”⁷³ Health care workers also reported the transfer of knowledge to patients: “I now have young girls telling me about dry sex. They feel that they have no choice in doing dry sex. Their boyfriends force them to do it. If the girls don’t do it their boyfriends look for sex somewhere else. There are too many girls who want to make sure their boyfriends stay with them.”⁷⁴ This example shows how dry sex thus becomes a way of ensuring the continuity of a relationship. Many women reported to health care workers that dry sex was seen as a guarantee of commitment. For example, “I spoke to six girls this week about dry sex, and they all say the same. ‘Sis [sister], if my boyfriend doesn’t wear the condom it means that I am the ‘original’ girlfriend.’* Dry sex means no condom, and then the girl thinks she is the ‘original.’ I feel sorry for these girls because they do not have a choice.”⁷⁵

After 2001, the discussion of dry sex in training decreased. Trainers argued that the main reason for this was not the unimportance of dry sex but rather the

⁷¹ Lifeline, Khayelitsha HIV/AIDS Project Counsellors. Supervision by author. Cape Town, June 2001.

⁷² Lifeline, Khayelitsha HIV/AIDS Project Counsellors. Supervision by author. Cape Town, June 2001.

⁷³ Health Care Workers. Interview by author. Cape Town, November 2001.

⁷⁴ Health Care Workers. Interview by author. Cape Town, November 2001.

* *Original girlfriend* refers to the term used by male patients, in discussing multiple sex partners, for the long-term, stable girlfriend. This is in contrast to *sponses*, which refers to casual girlfriends. See Chapter Seven for a detailed discussion of this issue.

⁷⁵ Primary Health Care Counsellors. Supervision by author. Cape Town, 19 January 2001.

urgency of other local and national HIV/AIDS issues like the increased number of HIV/AIDS persons presenting at community clinics and the government's lack of delivery of antiretrovirals.⁷⁶ It is important to note that the role of dry sex in the transmission of HIV remains controversial,⁷⁷ with studies suggesting a range from borderline significance to significance.⁷⁸ In 2004, trainers reported that the cultural and gender dynamics of dry sex became better understood, and even though the issue remained controversial it exposed health care workers and trainers to cultural issues that were previously concealed.⁷⁹ Another silenced issue, male circumcision amongst Xhosas, was also important in the HIV/AIDS training narrative in the Western Cape.

Male Circumcision

In 1986, Dr. Aaron Fink first suggested male circumcision as a method of HIV prevention.⁸⁰ Research suggests that the foreskin provides a "vulnerable portal of entry to HIV and other pathogens."⁸¹ Since 1986, there have been over forty studies that have found that male circumcision provides significant protection against HIV.⁸² More specifically, circumcised males were found to be eight times less at risk to HIV infection than uncircumcised males.⁸³ These findings led to a call by clinicians and international public health researchers for "consideration of male circumcision as a possible addition to our limited armamentarium of HIV prevention strategies in

⁷⁶ Trainers. Feedback to author. Cape Town, May 2005.

⁷⁷ M. Garenne and N. Lydié, *Gender and AIDS* (Paris: Centre Francais sur la Population et le Developpement, 2002).

⁷⁸ A. Baleta, "Concern Voiced Over "Dry Sex" Practices in South Africa," *Lancet*, 352, no. 9136 (1998): 1292.

⁷⁹ Trainers. Feedback to author. Cape Town, February 2004.

⁸⁰ A. Fink, "A Possible Explanation for Heterosexual Male Infection with AIDS," *New England Journal of Medicine*, 314 (1986): 1167.

⁸¹ D. T. Halperin and R. C. Bailey, "Male Circumcision and HIV Infection: 10 Years and Counting," *Lancet*, 354 (1999): 1813-1815.

⁸² R. C. Bailey, "Male Circumcision to Reduce HIV Acquisition – Not Quite Yet," *The AIDS Reader*, 15, no. 3 (2005): 130-135.

⁸³ Halperin and Bailey, 1814.

regions where the epidemic is driven primarily by heterosexual behaviour.”⁸⁴ This suggestion was made cautiously – avoiding any suggestions of mass prophylactic male circumcision – mainly because of the fierce opposition in response to these findings. The debate about the role of male circumcision in HIV prevention remains controversial.⁸⁵

Before 1995, there was little discussion of male circumcision in HIV/AIDS training in the Western Cape because few health care workers were aware of the debate. In 1995, health care workers in the province first raised the issue of male circumcision in response to young Xhosa men undergoing *ukwaluka*, ritual circumcision performed as a rite of passage into manhood.⁸⁶ This issue was raised because health care workers were concerned that the young men undergoing circumcision were at risk to increased infection because of the reported use of one blade or knife used to perform serial cuts. For example, in 1995, a doctor stated: “We hear they [the circumcisers] use old rusty blades on the boys. And these blades are unsterilised. What happens if one boy has AIDS and the blade is then used to cut the next boy? We worry that circumcision is spreading AIDS.”⁸⁷ The frustrations of female health care workers were evident in statements like: “The man uses a blunt knife and that old knife is used for all the boys standing in line. But as women we cannot say we are worried because this is a man’s thing – we have no say in what happens to our boys. But we are also nurses and we know that our boys are at risk to HIV and general infection.”⁸⁸ These concerns of some health care workers show the

⁸⁴ Bailey, 130.

⁸⁵ In November 2005, a study in Johannesburg found that male circumcision might reduce the incidence of HIV in men by 60% in sexual intercourse with women. See: B. Auvert et al., “Randomized, Controlled Intervention Trial of Male Circumcision for Reduction of HIV Infection Risk: The ANRS 1265 Trial,” *PLoS Medicine*, 2, no. 11 (2005).

⁸⁶ Health Care Workers. Training feedback to author. Cape Town, 7 November 1995.

⁸⁷ Health Care Workers. Training feedback to author. Cape Town, 12 April 1996.

⁸⁸ Health Care Workers. Training feedback to author. Cape Town, 12 April 1996.

fear of HIV infection from cultural practises like male circumcision. Moreover, these concerns highlight the issues of female exclusion and the ensuing disempowerment felt by female health care workers to such cultural practises.

In 1996, training organisations reported their helplessness in the face of these complex historical, cultural, and gendered practises.⁸⁹ Between 1996 and 1998 the narrative of health care workers was dominated by the same themes. In 1998, training organisations took a more definite stand on the issue of male circumcision, by introducing discussions on the topic. This initiative was in response to the research that suggested the possible health benefits of male circumcision, for example, the research by Moses, Bailey, and Ronald.⁹⁰ In 2000, trainers reported that health care workers did not respond as expected: health care workers were not generally interested in this research, but more interested in the risks of HIV infection during the procedure of male circumcision (as noted above).⁹¹ Trainers argued that the reasons for this response included the fact that there is a strong history of the practise in the Western Cape (with Xhosa, Muslim, and Christian support), and thus the high incidence of male circumcision makes the practise less controversial. For example, in 1998, a counsellor stated: “We are doing circumcision anyway, so if it helps that’s good.”⁹²

In 2000, one related issue that health workers did discuss was the artist Peet Pienaar’s proposal to undergo public circumcision in a booth (and have a live internet feed) as part of the exhibition *Man and Masculinity*, at the AVA gallery in Cape Town in October 2000. On 9 July 2000, the *Sunday Times* reported that two fellow artists, Thembinkosi Goniwe and Zwelethu Mthethwa, objected to Pienaar’s work

⁸⁹ Trainers. Supervision by author. Cape Town, 5 December 1996.

⁹⁰ S. Moses, R. Bailey, and A. R. Ronald, “Male Circumcision: Assessment of Health Benefits and Risks,” *Sexually Transmitted Infections*, 74 (1998): 368-373.

⁹¹ Trainers. Supervision by author. Cape Town, 6 July 2000.

⁹² Health Care Workers. Supervision by author. Cape Town, 28 September 2000.

because it was disrespectful towards Black culture.⁹³ Pienaar and Goniwe reached a compromise: it was decided that Pienaar would have the circumcision performed elsewhere before the start of the show, and that the foreskin would be exhibited. In August 2000, health care workers raised this issue in training.⁹⁴ There were heated debates that centred on artistic freedom, cultural respect, health risks of a non-sterile environment, ethics, liability, and gender issues. By debating this issue, health care workers expressed the historical and cultural complexities in South Africa that the proposed exhibition raised. Jeremy Mulvey (Curator of the Exhibition) commented that the “strength of the piece for us seems to be offered as a charged and confrontational metaphor for the continued tensions between Black and White culture, particularly amongst men, beyond apartheid.”⁹⁵

Between 2000 and 2004 health care workers spoke less frequently about male circumcision in HIV/AIDS training.⁹⁶ This was due to the contradictory research that continued to emerge, training organisations argued that health care workers did not respond to the issue in training, and the fact that male circumcision was culturally established in the Western Cape and thus questioned less by health care workers. The next section focuses on the history of cultural factors in the treatment of HIV/AIDS.

The History of Traditional Healers in the Treatment of HIV/AIDS

An important issue raised in HIV/AIDS training in the province in the period under review was the role of traditional healers in HIV/AIDS prevention and treatment. This issue proved difficult in that there were polarised views in HIV/AIDS

⁹³ S. Williamson, “Cultural Apartheid? Circumcision Proposal Provokes Questions,” July 2000, <<http://www.artthrob.co.za>> (Accessed: 17 May 2005).

⁹⁴ Health Care Workers. Training feedback to author. Cape Town, 23 August 2000.

⁹⁵ S. Williamson, “Cultural Apartheid? Circumcision Proposal Provokes Questions,” July 2000, <<http://www.artthrob.co.za>> (Accessed: 17 May 2005).

⁹⁶ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 16 July 2004.

health care and training about the role of traditional medicine and patients' needs to attend either or both primary health care clinics and traditional healers.

The first national initiative took place in November 1992: the training of 27,000 traditional healers in HIV/AIDS treatment and management.⁹⁷ This project was initiated jointly by the AIDS Control and Prevention (AIDSCAP) project, United States Agency for International Development (USAID), Family Health International (FHI), AIDS Communication (AIDSCOM), and the Academy for Educational Development (AED). The goal of the project was to train 30 traditional healers who would in turn train a second group of trainers and so on. Seven months after the first training, eighteen trainers reported having trained 630 second-generation traditional healers.⁹⁸ Furthermore, 90% of the traditional healers showed correct retention of information regarding the prevention and treatment of HIV/AIDS and STDs. Despite this national initiative, trainers and many health care workers in the Western Cape did not regard traditional healers as important to HIV/AIDS treatment strategies. This situation began to change with the democratic elections in 1994.

In November 1995, the South African government took the initiative to legitimise African traditional medicine when the National Health Minister called on provincial governments to conduct public hearings on the viability of traditional health care.⁹⁹ The government proposed a statutory council for African traditional healers, which aimed to "enable traditional doctors to play a much greater role in the public health sector while regulating their training and practice."¹⁰⁰ The Western Cape

⁹⁷ E. Green, *AIDS and STDs in Africa: Bridging the Gap between Traditional Healers and Modern Medicine* (Oxford: Westview Press, 1994).

⁹⁸ E. Green, B. Zokwe, and J. Dupree, "The Experience of an AIDS Prevention Programme Focused on South African Traditional Healers," *Social Science and Medicine*, 40 (1995): 503.

⁹⁹ E. Pretorius, "Traditional Healers," 1999, <<http://www.hst.org.za>> (Accessed: 6 May 2005).

¹⁰⁰ ANC (Western Cape), "Towards Equity in Health for the People of the Western Cape," 1995, <<http://www.anc.org.za/ancdocs/policy/wc-health.html+ANC,+traditional+healers,+1994>> (Accessed: 4 May 2005).

Provincial Health Plan (1995) – which was based on the Primary Health Care Approach of the World Health Organisation (WHO) – prioritised Tuberculosis (TB), HIV/AIDS, Malnutrition, and Communicable Diseases (for example, measles), and highlighted the importance of extensive community and role-player consultation and the “maximisation of the role of traditional and complementary healers.”¹⁰¹ In May and June 1997, public hearings were held, which resulted in a report that was compiled by the National Council of Provinces. According to a national survey in 1998, there were approximately 350,000 traditional healers in South Africa.¹⁰² Thus, the traditional healer-population ratio was 1:116 as opposed to the 1:1,500 doctor-population ratio. Given these ratios and the crucial historical and cultural links to traditional healers in Africa, it is not surprising that an estimated 80 percent of rural South Africans in KwaZulu-Natal province, for example, seek treatment from traditional healers.¹⁰³ There was no related data for the Western Cape. In April 2003, the government published the *Traditional Health Practitioners Bill*.¹⁰⁴ This legislation aimed to establish the *Interim Traditional Health Practitioners Council of South Africa*, which would provide for “a regulatory framework to ensure the efficacy, safety, and quality of traditional health care services . . . [and] control over the registration, training, and practice of Traditional Health Practitioners.”¹⁰⁵ In terms of HIV/AIDS, the Bill states that any person who claims to be able to treat this disease (and other terminal illnesses like cancer) will be guilty of an offence.¹⁰⁶

¹⁰¹ ANC (Western Cape), “Towards Equity in Health for the People of the Western Cape,” 1995, <<http://www.anc.org.za/ancdocs/policy/wc-health.html+ANC,+traditional+healers,+1994>> (Accessed: 4 May 2005).

¹⁰² ANC, “Traditional Healers to be Legitimised, Regulated,” *ANC Daily News Briefing*, 13 November 1998, <<http://www.anc.org.za/anc/newsbrief/1998/news1113>> (Accessed: 1 March 2004).

¹⁰³ PlusNews, “South Africa: Linking Traditional and Formal HIV/AIDS Treatment,” *IRIN*, 4 June 2004, <<http://www.irinnews.org>> (Accessed: 8 June 2004).

¹⁰⁴ Government Gazette, “Traditional Health Practitioners Bill,” No. 24704, Vol. 454, 11 April 2003. Notice 979 of 2003. <<http://www.info.gov.za/gazette/bills/2003/24704>> (Accessed: 5 May 2005).

¹⁰⁵ Government Gazette, Preamble.

¹⁰⁶ Government Gazette, Section 44 (1)(g)(i).

This Bill proved controversial with White doctors.¹⁰⁷ The debate was characterised by views like Bateman who stated that: “Western medical practitioners are hopping mad at the looming prospect of traditional healers and pharmacists, and other health care workers, being legally empowered to diagnose and treat patients and even write sick notes.”¹⁰⁸ Phillip Kubukeli (Advisory Director of the Western Cape Traditional Healers Association) responded that traditional primary health care was “inherited from our forefathers and proved to be working long before Dutch settler medicine came into South Africa.”¹⁰⁹ These views simplified a complex debate, and it is not the aim of this chapter to discuss this debate but rather the social history behind and stemming from this debate. Finally, by 2004, while the government had acknowledged traditional healers and started the process of their regulation, much research is still needed into the role of traditional healers in managing HIV/AIDS patients.¹¹⁰

The specific responses of trainers and health care workers to the issue of traditional healers and HIV/AIDS are now explored. Between 1989 and 1994, there was little discussion of the role of traditional healers in the HIV/AIDS management and treatment. One of the reasons for this was that the early training courses were heavily weighted in favour of biomedical information (as discussed in chapter three), with little input on other treatment approaches. Another reason was that the role of the traditional healer in Western health care in South Africa has a long and complex history.¹¹¹ Trainers argued that between 1989 and 1994, training organisations largely

¹⁰⁷ C. Bateman, “Legal Bone Throwing has Doctors Hopping Mad,” *South African Medical Journal*, 93, no. 12 (2003): 882-883.

¹⁰⁸ Bateman, 882.

¹⁰⁹ Bateman, 883.

¹¹⁰ M. Richter, “Traditional Medicines and Traditional Healers in South Africa,” discussion paper prepared for the Treatment Action Campaign and AIDS Law Project, May 2004, 24.

¹¹¹ R. King, *Collaboration with Traditional Healers in HIV/AIDS Prevention and Care in Sub-Saharan Africa - A Literature Review* (Geneva: UNAIDS/00.29E, September 2000).

accepted the negative views implied in such descriptions as *witch doctors* and *bone throwers*, largely because of the “historical bias in favour of Eurocentric medicine in training.”¹¹²

The earliest significant discussions of traditional healers in HIV/AIDS training courses were documented in 1995 because as has been noted above there were few national initiatives and patients did not raise the issue with health care workers.¹¹³ Trainers reported that traditional healers were regarded with suspicion by the some trainers and administrators (race and class did determine some of these responses).¹¹⁴ One of the reasons for this included the lack of information that many health care workers had about traditional healers (the view of traditional healers as *witch doctors* and *bone throwers*, as discussed above). Another reason was the data that emerged in 1995 in provincial primary health care clinics that traditional healers used medication to purge HIV/AIDS patients.¹¹⁵ Diarrhoea and vomiting are particularly dangerous to sick AIDS patients because it leaves them dehydrated and susceptible to rapid death.¹¹⁶ One trainer commented: “These traditional doctors give our patients funny things to eat that make them vomit or have diarrhoea. Then the patient comes to us when they are almost dead, and there’s nothing we can do for them.”¹¹⁷ Trainers held strong views about the role of traditional healers in HIV/AIDS treatment and management: “Why should we present any information on traditional healers when they give them [HIV/AIDS patients] nothing but false hope . . . Traditional healers are

¹¹² Trainers. Supervision by author. Cape Town, 29 June 1999.

¹¹³ ATICC Trainers. Focus group by author. Cape Town, 24 May 1995.

¹¹⁴ ATICC Trainers. Focus group by author. Cape Town, 24 May 1995.

¹¹⁵ Health Care Workers. Training feedback to author. Cape Town, 13 November 1995.

¹¹⁶ Treatment Action Campaign, “Traditional Healers and Public Health,” *Equal Treatment*, 15 May 2005, <<http://www.tac.org.za/ET/EqualTreatmentMay2005Issue15>> (Accessed: 9 May 2005).

¹¹⁷ Health Care Workers. Training feedback to author. Cape Town, 13 November 1995.

out of their depth with HIV/AIDS, and it is our ethical obligation to say so to course participants.”¹¹⁸

In 1996, trainers used reports like these from health care workers to warn others against the practice of purging but also to question the legitimacy of traditional healers. This pattern of opposition to traditional healers continued from 1996 to 1999. In 1999, Black health care workers raised an important historical and cultural issue: they stated that these warnings from trainers in 1996 were part of the reason that they did not divulge their traditional beliefs in training.¹¹⁹ Linked to this, these health care workers claimed that they did not report their interactions with patients regarding the consultation of traditional healers for HIV/AIDS related problems. This resulted in a gap between the beliefs and experiences of Black health care workers and what they discussed with colleagues at work and on training courses.¹²⁰ Thus, communication between training organisations and health care workers was hampered.

In 1997, in response to the developing public debate about the role of traditional healers, health care workers raised the issue of traditional beliefs and HIV-related behaviour: that is, are people, especially Xhosa patients, who have traditional beliefs about illness more or less likely to protect themselves and others from HIV/AIDS?¹²¹ Black and White health care workers argued that traditional beliefs might interfere with HIV prevention, counselling, and management. These discussions reinforced the need for culturally appropriate AIDS education for people who hold traditional beliefs about HIV/AIDS.¹²²

¹¹⁸ ATICC Trainer. Supervision by author. Cape Town, 6 November 1996.

¹¹⁹ Health Care Workers. Interview by author. Cape Town, 9 August 1999.

¹²⁰ Health Care Workers. Interview by author. Cape Town, 9 August 1999.

¹²¹ Health Care Workers. Training feedback to author. Cape Town, January-July 1997.

¹²² These views were confirmed in a 2004 study conducted in Cape Town that examined the associations between the belief that HIV/AIDS is the result of spirit forces, and AIDS-related knowledge and stigmas. The researchers concluded that people who believed that spirits caused HIV/AIDS were significantly more likely to be generally misinformed about the pandemic, and to support the expulsion of people living with AIDS. See: S. C. Kalichman and L. C. Simbayi,

In 1999, after specific discussions to make health care workers feel more comfortable discussing their views on traditional healers, training organisations invited Black health care workers to give training input on the issue.¹²³ Trainers had observed that in large training group discussions, Black health care workers were silent on the issue because they felt ridiculed and vulnerable in these conversations.¹²⁴ A nurse reported: “We feel stupid when they [trainers] talk about traditional healers. It’s hard to explain this to a White person. I am a nurse, but I also believe in my Ancestors. White medicine doesn’t know everything. So when they speak about it, we keep it quiet because it is easier.”¹²⁵ These health care workers were not only referring to the question of aetiology and treatment of HIV/AIDS, but also to the degree of support that patients reported receiving from traditional healers. In 1999, Black health care workers, especially those from rural and impoverished areas, were angry that only the negative stories about traditional healers were reported.¹²⁶ For example, the often cited example in HIV/AIDS circles of a traditional healer in Cape Town who reportedly enslaved his HIV/AIDS patients by getting them to work in his house and yard for months. In contrast to the negative stories that circulated regarding traditional healers, in 1999, a health care worker stated:

HIV/AIDS patients like going to the traditional healer because he/she can tell the patient why they got infected: who has cursed you. Clinic doctors can’t do this. Patients also feel comfortable with traditional healers. It is hard to trust many of these White doctors that have no time for you. Traditional healers give you explanations, they have time for you, and they are supportive. This is what my HIV/AIDS patients need.¹²⁷

“Traditional Beliefs about the Cause of AIDS and AIDS-related Stigma in South Africa,” *AIDS Care*, 16, no. 5 (2004): 572-580.

¹²³ Trainers. Interview by author. Cape Town, 9 August 1999.

¹²⁴ Health Care Workers. Supervision by author. Cape Town, 25 June 1999.

¹²⁵ Health Care Workers. Supervision by author. Cape Town, 25 June 1999.

¹²⁶ Health Care Workers. Interview by author. Cape Town, 9 August 1999.

¹²⁷ Health Care Workers. Supervision by author. Cape Town, 25 June 1999.

Many Black health care workers reported that they privately told HIV/AIDS patients to continue seeing their traditional healers as well as attend the clinic.¹²⁸

By 2000, some health care workers became adept at identifying reliable traditional healers in the community, and referring patients to them at the request of patients. In 2001, anecdotal reports from health care workers suggested that patients, especially those from rural areas, maintained contact with traditional healers and clinics.¹²⁹ This two-tiered treatment of HIV/AIDS patients was not discussed in clinics. Health care workers claimed that the reason for this was that managers did not want to acknowledge the fact that traditional healers were treating HIV/AIDS patients: traditional healers were “a blind-spot for managers.”¹³⁰ Between 2001 and 2004, there was no further progress on the issue of the role of traditional healers and HIV/AIDS treatment and management. Trainers argued that in the Western Cape, Provincial Health funded much of the HIV/AIDS training and that they exerted pressure on training organisations to present Western medical models.¹³¹ Trainers also believed that the historical and cultural roots of the issue were too complex for a simple and quick solution.

Finally, it is worth noting the only example in the province of attempted collaboration between a training organisation and traditional healers. In 1998, Lifeline/Childline (Western Cape) attempted to familiarise itself, and collaborate, with local traditional healers.¹³² The reason that it occurred at this time was the formation of the lay counsellor project (as discussed in chapter three), which resulted in many more HIV/AIDS counsellors working in community clinics and engaging the

¹²⁸ Health Care Workers. Supervision by author. Cape Town, 14 September 1999.

¹²⁹ Health Care Workers. Supervision by author. Cape Town, 5 April 2001.

¹³⁰ Health Care Workers. Supervision by author. Cape Town, 5 April 2001.

¹³¹ Trainers. Private communication with author. Cape Town, 13 July 2004.

¹³² S. Kilroe (Ex-Director, Lifeline/Childline, Western Cape). Private communication with author. Cape Town, 20 July 2004.

treatments utilised by HIV/AIDS patients. Lifeline/Childline employed the most HIV/AIDS lay counsellors and educators in the region, and it encouraged these counsellors and educators working in primary health care clinics to attend meetings between traditional healers and NGOs.¹³³ These meetings were preliminary attempts at finding common ground in the treatment of HIV/AIDS in the province.

In 1999, health care workers reported that while they were encouraged by these attempts, the historical turf wars, cultural differences, and obstinacy evident on both sides of the debate frustrated them.¹³⁴ They argued that the political battles of these meetings had little to do with their everyday interaction with HIV/AIDS patients in the clinics. In 2000, this Lifeline initiative broke down due to disagreements regarding project management and resources.

Traditional healers have an important role to play in the building and maintenance of the health care system and national response to HIV/AIDS in South Africa.¹³⁵ This was an important point and one that was downplayed by the medical fraternity in the province. Traditional healers, given their historical importance in cultural medicine and how often they are consulted, could play an important role in the prevention and management of HIV/AIDS. However, according to King, there is limited research examining the impact of traditional healers in HIV management.¹³⁶ Hence, while the importance of traditional healers in the management of HIV/AIDS was recognised by some health care workers (from a historical and cultural perspective), other health care workers questioned their efficacy (from a medical perspective). Following the issue of traditional healers and HIV/AIDS management,

¹³³ S. Kilroe (Ex-Director, Lifeline/Childline, Western Cape). Private communication with author. Cape Town, 20 July 2004.

¹³⁴ Health Care Workers. Supervision by author. Cape Town, 26 July 1999.

¹³⁵ M. Richter, "Traditional Medicines and Traditional Healers in South Africa," discussion paper prepared for the Treatment Action Campaign and AIDS Law Project, May 2004.

¹³⁶ R. King, *Collaboration with Traditional Healers in HIV/AIDS Prevention and Care in Sub-Saharan Africa - A Literature Review* (Geneva: UNAIDS/00.29E, September 2000).

the discussion now turns to the provision of sex education to health care workers and patients because it raised significant cultural issues for HIV/AIDS training organisations.

The History of Cultural Factors in the Provision of Sex Education

Many health care workers and other commentators in the period under review argued that Africans were unable to speak openly and frankly about sex.¹³⁷ This notion played an important part in the HIV/AIDS debate. The inability to discuss sex was used to account for, among others, the spread of the disease, the government's inaction, and the lack of consistent sex education for children and adults in the country.¹³⁸

Between 1989 and 1994, this issue was raised in terms of all patients: that is, there was not a racial delineation of the issue. This was probably due to the low number of patients presenting at clinics and hospitals. In 1990, after the first HIV/AIDS training courses, the importance of providing basic sex education to health care workers was recognised.¹³⁹ The goal of this sex education was to normalise and familiarise health care workers with the various names for sexual organs and acts. This was done because trainers soon realised that health care workers were limited in their ability to discuss sex, even amongst peers. For example, even experienced nurses

¹³⁷ In the public domain, the following statements were made: (1) In 2001, Dr. Malegapuru Makgoba (then President of the Medical Research Council) stated: "Sex is regarded as a taboo in Africa – you don't speak openly about it." Furthermore, he argued that research into specific cultural beliefs and sexual practices of Africans is almost nonexistent, and that research needs to focus on the sexual mythologies, taboos, and ignorance of many Black men and women. See: A. Mozes, "African Aids Epidemic Fuelled by Sexual Ignorance," 18 May 2001, <http://hivandhepatitis.com/hiv_and_aids/public/051801a> (Accessed: 16 June 2004), and (2) In 2003, Nelson Mandela, in a BBC interview, said: "They [Africans] don't want to talk about it [sex]." He went on to say that Africans are very conservative about sexual matters. See: News24, "Madiba: I Could Have Done More," *news24.com*, 2 March 2003, <http://www.news24.com/News24/South_Africa/Aids_Focus> (Accessed: 19 May 2004). Many health care workers and other commentators in the period under review stated that Africans are unable to speak openly and frankly about sex.

¹³⁸ Health Care Worker. Focus group by author. Cape Town, 29 June 1999.

¹³⁹ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 16 July 2004.

and doctors reported discomfort when talking about sex to patients and in training. By 1994, training organisations had developed and utilised creative content and methodology to challenge sexual knowledge and narratives.¹⁴⁰ For example, small group activities were devised that allowed participants to verbalise the various names for *penis* and *vagina* that they had ever heard. Such activities were good icebreakers and allowed participants to have fun, while discussing sexual issues in novel and useful ways as well as learning about social, cultural, and gender dynamics and differences.

In 1994, health care workers reported that Black patients, in particular, were reluctant to discuss their sexual behaviour in pre- and post-test counselling.¹⁴¹ This was likely due to the increased number of HIV/AIDS patients that were seen in the provincial shift towards primary health care, and the more open debates regarding culture and health care that emerged with the elections in 1994. The supposed reluctance of Blacks to discuss sex caused heated debates amongst health care workers.¹⁴² Once again, cultural determinants contributed to popular opinion, in that Coloured and White health care workers supported the assumption, while Black health care workers challenged these assumptions. On the one side Coloured and White health care workers argued that there was a cultural difference: "These Blacks don't know how to talk about sex. It's in their culture. We're not good at it, but at least we do it. I see these Black children in the clinics and they know nothing about sex."¹⁴³ On the other side Black health care workers argued that all patients had problems talking about sex, or that if there was a difference, it reflected urban and rural differences. For example, "None of us are good at talking about sex [but] there is

¹⁴⁰ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 16 July 2004.

¹⁴¹ Health Care Workers. Supervision by author. Cape Town, 3 October 1995.

¹⁴² ATICC Trainer. Supervision by author. Cape Town, 8 June 2001.

¹⁴³ Nurse. Focus group by author. Cape Town, 22 June 1998.

a big difference between Blacks that live in the city and those from the Transkei. They are too shy to talk about sex in the Transkei.”¹⁴⁴

Between 1994 and 1997, this debate continued and in the process became more complex. ATICC attempted to raise the awareness of health care workers to the diversity of people presenting for HIV/AIDS education and counselling in primary health clinics. It was hoped that this would show that a simple racial delineation failed to highlight the complex socio-economic and gender issues involved in HIV/AIDS transmission and management.¹⁴⁵ ATICC also feared that one of the effects of this debate was that attention was diverted away from the important shortcomings in national policies and research.

In 1998, focus groups and interviews with health care workers showed that they were still experiencing problems: “It’s so hard to use these words [for anatomy] with patients – I get too embarrassed. When I get embarrassed, they get embarrassed, and then I can’t talk about sex any more. So we don’t talk about transmission.”¹⁴⁶ This comment was typical of recently qualified and younger health care workers. More experienced health care workers provided positive feedback regarding the sex education conducted by training organisations: “I have been a doctor for 17 years, and this training has shown me how poorly I manage my sexual conversations with patients. I have never allowed patients to open up; I have bombarded them with medical terminology. And, probably silenced them with this terminology.”¹⁴⁷ Not only did health care workers learn different words and narratives, they learnt about the many ways in which sex is negotiated between people. This was the anthropology of

¹⁴⁴ Nurse. Focus group by author. Cape Town, 22 June 1998.

¹⁴⁵ Trainer. Supervision by author. Cape Town, 23 July 1997.

¹⁴⁶ Nurse. Focus group by author. Cape Town, 22 June 1998.

¹⁴⁷ Doctor. Focus group by author. Cape Town, 22 June 1998.

sexual contact that was influenced by factors like culture, gender, economics, and class.

Also in 1998, health care workers discussed their own limits in sexual knowledge. For example, a nurse stated: "No wonder I don't know how to talk to patients about sex; I don't know much about sex. I'm a married woman with children. I thought I did, but I don't."¹⁴⁸ HIV/AIDS introduced the complexities of sexual politics to many health care workers: "I thought we all did it the same way. There are many women that have no choice. Their partners beat them, he rapes them, hurts them. This sex is a complicated thing."¹⁴⁹ In 1998, trainers attempted to encourage health care workers to look at sex through the eyes of others, thus challenging their own cultural and gendered beliefs about sex.¹⁵⁰ Because of the important role of religion in beliefs about sex and sexuality, trainers assisted health care workers in deconstructing their beliefs and replacing them with more tolerance and relativity.

In 1999, some Black health care workers stated that they felt responsible for the spread of HIV/AIDS because they were seen as being unable to speak openly about sex.¹⁵¹ A nurse commented: "Everyone sees Africa as full of sex-crazed Blacks. We deserve this AIDS, because everyone thinks we're responsible for how it started. And how it gets spread around people. It is hard to talk about sex and AIDS as a Black person because we feel responsible. And AIDS is a very big responsibility."¹⁵² Some Black health care workers expressed embarrassment about HIV/AIDS, as if it were their fault and burden. Trainers observed that, ironically, this embarrassment resulted in a greater reluctance to talk about HIV/AIDS and sex.¹⁵³ Some researchers

¹⁴⁸ Nurse. Focus group by author. Cape Town, 22 June 1998.

¹⁴⁹ Nurse. Focus group by author. Cape Town, 22 June 1998.

¹⁵⁰ ATICC Trainers. Supervision by author. Cape Town, 20 November 1998.

¹⁵¹ Health Care Workers. Focus group by author. Cape Town, 22 June 1998.

¹⁵² Nurse. Focus group by author. Cape Town, 22 June 1998.

¹⁵³ Trainers. Supervision by author. Cape Town, 20 October 1999.

have argued that the fact that Africans feel responsible for HIV/AIDS is partly a result of the West's ongoing racist attitude towards the African continent.¹⁵⁴ Health care workers verbalised these historical constructs surrounding disease and Africans being responsible for the origin and spread of disease (see chapter four).

In 2000, health care workers claimed that HIV/AIDS training played an important part in allowing them to conduct fruitful conversations about sex with patients.¹⁵⁵ In addition, they argued that training enabled them to engage their children, family, and community organisations more constructively about the importance of speaking about sex. This included challenging and engaging established Christian and Muslim views and structures. For example, "I asked my minister about why he never talks about AIDS and sex. He was quiet, and this is a man who blows a lot of hot air. Two weeks later he asked me to educate him and the two deacons about these things. Last month he gave a sermon on AIDS. It was beautiful, and the people are still speaking about it."¹⁵⁶ Health care workers were also asked to provide education about HIV/AIDS and the prevention of sexual diseases: "The Imam asked my husband if I could talk to the women's group about STDs and AIDS. I gave the Imam some literature, and he now includes it when he talks to couples about their marriage. More needs to be done but this is a good start."¹⁵⁷ Between 2000 and 2004, trainers argued that they felt sex education for health care workers was well established, and the simplistic arguments surrounding race and the ability to talk about sex were replaced with a more complex understanding of the underlying socio-economic, cultural, and gender factors.¹⁵⁸

¹⁵⁴ For example, S. Hunter, *Who Cares? AIDS in Africa* (New York: Palgrave, Macmillan, 2003), and R. C. Chirimuuta and R. J. Chirimuuta, *AIDS, Africa and Racism* (Derbyshire: Brentby House, 1987).

¹⁵⁵ Health Care Workers. Supervision by author. Cape Town, 6 May 1998.

¹⁵⁶ Health Care Workers. Supervision by author. Cape Town, 6 May 1998.

¹⁵⁷ Health Care Workers. Supervision by author. Cape Town, 6 May 1998.

¹⁵⁸ Trainers. Feedback to author. Cape Town, 29 September 2004.

By 2004, it was clear that training organisations had played an important role in the sex education of health care workers and, by association, the public.¹⁵⁹ A trainer claimed: “This is the *stone-in-the-water* scenario. The first ripple was us trainers educating ourselves. The next ripple was the education of the health care workers. Then, they educated patients, who educated family and friends, and so on and so on.”¹⁶⁰ Training organisations maintained their focus on the sex education of health care workers all through the period of this study. In so doing, they challenged and contributed to the re-writing of the traditional and dominant pre-AIDS sexual discourse. One of their more lasting contributions to the management of HIV/AIDS was the creation of a new sexual language that encompassed cultural relativity, acceptance, and openness; that is, a democratisation of sexual narratives. Finally, the discussion shifts to the cultural factors in the training of first language trainers and counsellors.

The Training of First Language Trainers and Counsellors

The final section deals with the cultural issues raised in the selection and capacity development of HIV/AIDS trainers (as raised in chapter three). The discussion begins with a discussion of the first HIV/AIDS training course delivered in the Western Cape in 1989. This training course was conducted in English (a reflection of the previous provincial health care training and the language of the first trainers in ATICC), which remained the predominant language of training until the 1994 when there was strong pressure from health care workers and trainers for a revision of the language policy in training.¹⁶¹ There were calls from trainers, participants, and consultants to recruit and train Xhosa and Afrikaans trainers, and to develop and

¹⁵⁹ Trainers. Feedback to author. Cape Town, 29 September 2004.

¹⁶⁰ Trainers. Feedback to author. Cape Town, 29 September 2004.

¹⁶¹ Trainer. Interview by author. Cape Town, 23 August 1999.

facilitate training in these languages too.¹⁶² These calls for change were part of the larger political and cultural changes that took place at the time, including the national emphasis on the recognition of the country's eleven official languages and regional languages. Also, in 1995, HIV/AIDS training was in the process of being extended to community clinics and rural parts of the province that were principally Afrikaans and Xhosa. Finally, in 1995, there was an increase in the number of Xhosa-speaking patients who had moved to Cape Town from the Eastern Cape who were presenting at the primary health care clinics. The post-Apartheid language policy of encouraging English and the other regional languages in politics, business, and education legitimised what training organisations were planning to do.¹⁶³

In 1996, trainers reported that they missed important information because of language and cultural barriers.¹⁶⁴ These gaps in information were reported in training areas like counselling models, cultural practises, and sex education. In 1996, a trainer stated: "It is hard discussing STDs when you can't speak the language of the course participants. I feel that something isn't connecting, isn't illuminating. And that means that information is getting lost between trainer and participant. That is not adequate training."¹⁶⁵

In 1996, in response to the above-mentioned problems, ATICC initiated a drive to recruit suitable Xhosa, Afrikaans, and English trainers.¹⁶⁶ There was a huge response to advertised posts.¹⁶⁷ Those persons selected were trained to develop courses in their first language and initially deliver one-hour input. Between 1996 and 1999, there was capacity development and training of these persons. In 1999, their

¹⁶² C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 16 July 2004.

¹⁶³ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 16 July 2004.

¹⁶⁴ Trainers. Interview by author. Cape Town, 20 June 1996.

¹⁶⁵ Trainers. Interview by author. Cape Town, 24 June 1996.

¹⁶⁶ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 16 July 2004.

¹⁶⁷ C. Jacobs (ATICC Manager). Private communication with author. Cape Town, 16 July 2004.

input was extended to the facilitation of complete first language courses. In 2000, trainers reported that these initiatives had made a significant difference to both the content and methodology employed by training organisations.¹⁶⁸

Between 2000 and 2004, more intensive and specialised courses were offered to trainers and counsellors (see chapter three). During this period training and counselling groups were representative of the general population.¹⁶⁹ By 2004, most training organisations offered standardised training in English, Xhosa, and Afrikaans. The content and methodology differed slightly from one course to the other depending on the target-training group. This resulted in more complex and interesting training, as attested to by training assessments and participant feedback.¹⁷⁰ Finally, health care workers requested more first language training from trainers drawn from their own, or similar, cultures and communities. As discussed above, social critics have argued that language creates rather than simply reflects the meaning of illness and disease, and that the HIV/AIDS narrative is a complex construction that says more about power and representation than about truth. By training health care workers in English, Afrikaans, and Xhosa, training organisations assisted in highlighting the cultural determinants in HIV/AIDS narrative: there was thus a challenge to the English and largely medical-based narrative of the preceding years. As expected, the inclusion of other training languages led to a more complex, localised, and representative HIV/AIDS narrative.

¹⁶⁸ Trainers. Supervision by author. Cape Town, 5 December 2000.

¹⁶⁹ Trainers and Health Care Workers. Private communication with author. Cape Town, 30 July 2004.

¹⁷⁰ ATICC and Lifeline Health Care Workers. Training feedback to author. Cape Town, April 1995-May 2003.

Conclusion

In the first training course in 1989, the cultural factors in HIV/AIDS were not well articulated by researchers and training organisations, and thus these factors were not included in the training content. Trainers presented HIV/AIDS as a medical problem. Culture was initially present when health care workers discussed the origin of HIV/AIDS: health care workers claimed that HIV/AIDS existed in other race groups, which is a common initial response in the history of epidemics. These claims resulted in many conspiratorial theories of the origin of the disease. This speculation is relevant to historians because it highlighted the way in which diseases are investigated, constructed, and reported.

Between 1989 and 1994, there were few references to cultural factors in the spread and management of the disease. In this period there were brief references to traditional healers in HIV/AIDS training, mainly because of the relatively few HIV/AIDS persons presenting at the specialised AIDS clinics and the medical focus of the early courses. In 1992, the first national HIV/AIDS training initiative of traditional healers took place. In the build-up to the transformation of government between 1990 and 1994, cultural issues gained more prominence in HIV/AIDS training because of the changing political narrative around race. The narrative of this period was characterised by an increasing awareness of cultural factors in HIV/AIDS in training. Notably, race was used to explain certain responses to HIV/AIDS, for example, that Black health care workers were more reluctant to discuss sex in training than were other participants.

The 1994 election had a significant impact on HIV/AIDS training in that cultural issues now gained importance. Firstly, the ANC government implemented the program of primary health care, and health care workers were now exposed to many

more patients seeking HIV/AIDS counselling and care. Secondly, in 1995 the government actively started advocating issues like the legitimisation of traditional healers. Trainers and health care workers raised the issue of male circumcision in HIV/AIDS training in response to the spread of HIV through traditional circumcision rites. Health care workers also discussed the reports from patients regarding their treatment by traditional healers, for example, the use of purging. Health care workers started to speak differently about culture now: there was an increasing openness about cultural differences and similarities in the HIV/AIDS narrative.

Between 1995 and 2000, cultural issues like male circumcision, sex education, and dry sex were prominent in HIV/AIDS training. Training organisations played an important role in creating a dialogue about these cultural issues, as well as assisting health care workers to explore ways of dealing practically with these issues. In response to the shifts in the social and cultural consciousness as a result of the 1994 elections, training organisations explored and included cultural issues into training material and discussion. What training material was presented and how it was presented was now interpreted through a cultural lens. The HIV/AIDS narrative of this period was one of more active engagement of these cultural issues by trainers and health care workers.

In 2000, Mbeki questioned the link between HIV and AIDS, and some of the previously discussed cultural issues like the link between poverty and AIDS re-emerged. Some health care workers were frustrated by the confusion that this caused while others agreed with Mbeki's views. While Mbeki's views did sidetrack the debate on cultural issues, it also highlighted the importance of South Africa's history and the impact of racial inequality. The HIV/AIDS narrative of this period was characterised by ongoing debates concerning issues like dry sex, traditional healers,

and male circumcision. At the same time, some health care workers and trainers took up the racial issues inherent in Mbeki's views.

Between 2000 and 2004, some cultural issues were discussed to completion, for example, the establishment of comprehensive HIV/AIDS training for first language trainers. Also, the issue of the origin of HIV/AIDS no longer had a racial delineation: health care workers now spoke about the disease more in terms of gender than culture (see chapter seven). While there was still a public debate about race and HIV/AIDS in South Africa, health care workers argued that HIV/AIDS was universal. Very few health care workers focussed on the racial aspects of the disease. Some issues like dry sex and male circumcision remained unresolved in the HIV/AIDS training debates, and they largely disappeared from the central narrative. Finally, it is noted that the history of the early spread of HIV/AIDS in South Africa remains incomplete and anecdotal, and much historical research is required in this area.

CHAPTER SEVEN: “Simply put: women can die!” – Gender factors in the history of HIV/AIDS training, 1989-2004.

This chapter examines the changing dimension of gender¹ in the HIV/AIDS training of health care workers in the sixteen years under review. An overview of relevant international and national gender issues is provided before examining specific historical issues related to gender that training organisations and health care workers encountered in the Western Cape. Specific issues include the biological factors in HIV transmission, violence against women, disclosure, condom usage, and the prevention-of-mother-to-child-transmission (PMTCT) program. The next section addresses the role of men in the spread and management of HIV/AIDS. The historical responses of training organisations and health care workers to these issues are provided. This chapter seeks to contribute to the social history of medicine by examining gender issues in the HIV/AIDS training of health care workers. The sources utilised in this chapter are largely oral and secondary sources. Health care workers and trainers were interviewed in order to analyse the underlying gender factors that influenced the changes in HIV/AIDS training, content, and organisational issues in the period under review.

Before beginning with the overview of the gender research it should be noted that while training in the early 1990s focused on men who have sex with men (MSM), the focus by the mid-1990s was almost exclusively heterosexual sex. This reflects the shifting HIV transmission patterns in sub-Saharan Africa from predominantly

¹ “The word [gender] denoted a rejection of the biological determinism implicit in the use of such terms as “sex” or “sexual difference,”” and, gender is “a way of denoting “cultural constructions – the entirely social creation of ideas about appropriate roles for women and men.” See: J. W. Scott, “Gender: A Useful Category of Historical Analysis,” *The American Historical Review*, 91, no. 5 (1986): 1053-1075.

homosexual transmission in the 1980s to heterosexual transmission in the 1990s.² This focus on heterosexual transmission is not without criticism. Gay and lesbian advocacy groups have argued that this bias leaves gay men and lesbians at greater risk of contracting HIV.³ The discussion now begins with an historical overview of gender in HIV/AIDS research in order to introduce the important concepts in this field.

Historical Overview of Gender in HIV/AIDS Research

In the late 1980s, researchers made the link between HIV/AIDS and gender. In 1988, Caraël et al. examined the patterns of heterosexual transmission patterns in Central Africa,⁴ while in 1989 Hunt explored the role of migration and gender in the spread of HIV/AIDS in Africa.⁵ In 1990, Kisekka argued, based on data collected in Uganda between 1981 and 1988, that gender was an important variable in understanding HIV/AIDS, particularly in the areas of women's reproductive rights, women in high-risk professions, and the acceptability of the condom.⁶ In 1990, gender was showcased in the World AIDS Day theme of *Women and HIV/AIDS*. Other emerging research on gender and HIV/AIDS in the early 1990s included: women and

² UNAIDS/WHO, *AIDS Epidemic Update: December 2004* (Geneva: UNAIDS/04.45E, 2004).

³ In 2004, Evert Knoesen (Director of the Lesbian and Gay Equality Project) stated: "The South African government has done absolutely nothing around safer sex education specifically for gay and lesbian people. The entire onus has been shifted to NGOs, and that sector is not capable of coping with such an unfair burden." PlusNews, "Gays Neglected in HIV/AIDS Campaigns," *IRIN*, 16 September 2004, <<http://www.irinnews.org>> (Accessed: 16 September 2004).

⁴ M. Caraël et al., "Immunodeficiency Virus Transmission among Heterosexual Couples in Central Africa," *AIDS*, 2 (1988): 201-205.

⁵ C. Hunt, "Migrant Labour and Sexually Transmitted Disease: AIDS in Africa," *Journal of Health and Social Behaviour*, 30, no. 4 (1989): 353-373.

⁶ M. N. Kisekka, "AIDS in Uganda as a Gender Issue," *Women and Therapy*, 10, no. 3 (1990): 35-53.

HIV/AIDS in Zimbabwe,⁷ gender and sex workers in Ghana,⁸ changing gender relations in Kenya,⁹ and HIV/AIDS and gender in Zaire.¹⁰

Between 1989 and 1995, HIV/AIDS prevention strategies in Africa centred on the promotion of condom use, reduction of numbers of sexual partners, and treatment of STDS.¹¹ The problem with these initiatives was their failure to address the political, socio-economic, cultural, and gender factors between women and men. In 1995, the World Health Organisation (WHO) reported the risks of HIV infection and the two primary modes of sexual intercourse with regards to gender.¹² The following modes of sexual intercourse refer to unprotected penile-vaginal intercourse. One, from infected female to uninfected male, the risk of HIV infection is 1:1,000 (to uninfected male with a sexually transmitted infection (STI), 1:250). Two, from infected male to uninfected female, the risk of HIV infection is 1:100 (to uninfected female with an STI, 1:25). This research suggested that women were ten times more at risk for contracting HIV than men for the same sexual act, which had important implications for training organisations in the prevention of HIV/AIDS. In 1995, de Bruyn et al. noted that despite the acknowledgment of the importance of gender and HIV/AIDS, women continued to bear the burden of the epidemic and be highly vulnerable to HIV infection.¹³

⁷ M. T. Basset and M. Mhloyi, "Women and AIDS in Zimbabwe: The Making of an Epidemic," *International Journal of Health Services*, 21, no. 1 (1991): 143-156.

⁸ R. Neequay, J. E. Neequaye, and R. J. Biggar, "Factors that Influence the Spread of AIDS in Ghana: Knowledge of AIDS, Sexual Behaviour, Prostitution, and Traditional Medical Practices," *Journal of Acquired Immune Deficiency Syndromes*, 9, no. 4 (1991): 914-919.

⁹ D. Bulow, "Bigger Than Men? Gender Relations and Their Changing Meaning in Kipsigis Society, Kenya," *Africa*, 62, no. 4 (1992): 523-546.

¹⁰ B. G. Schoepf, "Sex, Gender and Society in Zaire," in *Sexual Behaviour and Networking: Anthropological and Sociocultural Studies on the Transmission of HIV*, ed. T. Dyson (Liege, Editions Derouaux-Ordina, 1992), 353-375.

¹¹ L. L. Heise and C. Elias, "Transforming AIDS Prevention to Meet Women's Needs: a Focus on Developing Countries," *Social Science and Medicine*, 40, no. 7 (1995): 931-943.

¹² WHO, cited in "Database," *AIDS Analysis Africa*, 5, no. 6 (April/May 1995): 12.

¹³ M. De Bruyn et al., *Facing the Challenges of HIV, AIDS, STDs: A Gender-based Response* (Amsterdam: The Royal Tropical Institute, 1995).

In 1995, Preston-Whyte argued that gender inequality decreased women's ability to negotiate safe sex practices.¹⁴ This includes the ability to agree or disagree to sex, the nature of sex, and the use of condoms. Even though some women in Africa are becoming increasingly independent economically, this autonomy is associated with increased risk to HIV infection because of the delay in marriage and the increased number of sexual partners.¹⁵ Lowered self-esteem in women as a result of gender inequality is important in that self-esteem is a major risk factor in HIV transmission because it is correlated with increased unsafe sexual activity.¹⁶ There is an increase in multiple sexual partners for women because of their low status, their lack of economic opportunities, and violence. These factors are important in commercial sex, both informally in young schoolgirls and formally in casual professional sex workers.

In 1999, Carpenter et al. found that for women, biological susceptibility to HIV is high in the age group 13-24.¹⁷ Glynn et al. argued that behavioural factors do not fully explain the discrepancy in HIV prevalence between men and women.¹⁸ Some of the characteristics of this age group include the higher prevalence of herpes simplex virus type 2 infection,¹⁹ the lower levels of oestrogen which result in higher rate of anovulatory cycles, less vaginal lubrication,²⁰ disturbed vaginal flora,²¹ and the

¹⁴ E. M. Preston-Whyte, "Bring Us the Female Condom: HIV Intervention, Gender and Political Empowerment in Two South African Communities," *Health Transition Review*, 5 (1995): 209-222.

¹⁵ Garenne and Lydié, 13.

¹⁶ Garenne and Lydié, 13.

¹⁷ L. M. Carpenter et al., "Rates of HIV-1 Transmission within Marriage in Rural Uganda in Relation to the HIV Sero-status of the Partners," *AIDS*, 13 (1999): 1083-1089.

¹⁸ J. R. Glynn et al., "Why Do Young Women Have a Much Higher Prevalence of HIV Than Young Men? A Study in Kisumu, Kenya and Ndola, Zambia," *AIDS*, Supplement 4 (2001): S51-S60.

¹⁹ Glyn, S51.

²⁰ Carpenter et al., 1085.

²¹ N. Sewankambo et al., "HIV-1 Infection Associated with Abnormal Vaginal Flora Morphology and Bacterial Vaginosis," *Lancet*, 350, no. 9077 (1997): 546-550.

high concentration of the virus in semen.²² This biological susceptibility is important in sub-Saharan Africa where young women have an increased chance of sexual activity, sexual violence, and sex with older men.

In 2001, a study of violence against women in three South African provinces showed that between 19-28% of women had been physically abused by a current or ex-partner.²³ A 2001 survey in Cape Town showed that 41% of men reported physically abusing a female partner in the ten years before the study.²⁴ A Medical Research Council of South Africa (MRC) study showed that 15% of men claimed to have raped or attempted to rape their female partners.²⁵ These surveys are probably an underestimate because women fear recriminations, feel ashamed, see it as a private matter, do not regard it as abuse, or do not want to expose their partners. Jewkes stated: "Gender violence data are highly vulnerable to extraneous factors which influence levels of reporting."²⁶

The causes of gender violence are multifaceted. Important factors include: the woman's personal experience of abuse of women in her family, the dynamics of her relationship with her partner, the social context in which the relationship takes place, and individual and community beliefs about the abuse of women.²⁷ Alcohol abuse also plays an important role in that it adds to conflict in relationships, intensifies poverty, and contributes towards belligerence and violence.²⁸ Thus, some communities are historically more at risk to gender violence and thus HIV/AIDS.

²² National Institute of Allergies and Infectious Diseases (NIAID), *HIV Infection in Women* (Maryland: NIAID, 2001).

²³ R. Jewkes, "Violence against Women: An Emerging Health Problem," *MRC News*, 32, no. 3 (2001).

²⁴ Jewkes, 1.

²⁵ Jewkes, 1.

²⁶ Jewkes, 2.

²⁷ Jewkes, 2.

²⁸ Jewkes, 2.

In 2002, research showed that women, particularly young women and girls, are at greater risk than men to HIV infection and the impact of AIDS and higher mortality rates for men.²⁹ These patterns are the product of epidemiological, biological, social, behavioural, and gender factors. Demographic data suggests that the age and sex differences in infection and mortality rates are complex. Two patterns that emerged are earlier infection and lower mortality rates for women, and later infection. In 2002, Maman et al. showed that rape and violence against women are potential risk factors in HIV transmission.³⁰ Rape perpetrated against young women is particularly dangerous because of their biological susceptibility to the physical trauma and increased exposure.

Violence against women has an impact on the spread of HIV and the prevention and treatment of HIV/AIDS. For example, South Africa has gained notoriety for the rape of virgins, often infant girls, in the belief that this prevents HIV, immunises one against HIV, or cures AIDS.³¹ This myth has created a huge crisis for young girls who are the targets of older men searching for “safe” sexual partners.³² While this fact is important, there are other important historical factors underlying this behaviour. For example, Stones and Earl-Taylor argued that many men in South Africa have, and do, not recognise that the legal age of consent is sixteen.³³ They held that this attitude has created a massive problem for law enforcement agencies, the courts, and welfare organizations, and that it is “symptomatic of a patriarchal culture

²⁹ M. Garenne and N. Lydié, *Gender and AIDS* (Paris, France: Centre Francais sur la Population et le Developpement, 2002).

³⁰ S. Maman et al., “The Intersections of HIV and Violence: Directions for Future Research and Interventions,” *Social Science and Medicine*, 50, no. 4 (2000): 459-478.

³¹ C. Stones and M. Earl-Taylor, “Letter from Grahamstown: HIV/AIDS, the so-called “Virgin Cure” and Child Rape in South Africa,” 13 December 2004, <http://www.gig.org/Features/gig_GD_Letter_16.php> (Accessed: 1 June 2005).

³² J. Walsh, *Fact Sheet on Gender and HIV/AIDS* (Geneva: United Nations, 2001).

³³ Stones and Earl-Taylor, 2.

of sexual entitlement and control in which rape is socially condoned.”³⁴ Another important factor in understanding the prevalence of child rape is the fact that police officers are poorly trained, under-funded, under-staffed, and under-resourced.³⁵ Leclerc-Madlala argued that the closer examination of cultural schemas is critical to better understanding belief-behaviour linkages in the context of rape and AIDS.³⁶ It is also important to highlight the examination of gendered schemas in this context. It should be noted that some researchers claimed to have seen few cases where the perpetrators believed in the virgin myth, and thus they have challenged the relationship between child rape and myths about HIV/AIDS.³⁷

Leclerc-Madlala argued that underlying the abuse of women is the “irresponsible, aggressive, and indeed, criminal ways in which men are enacting their sexuality and manhood.”³⁸ Moreover, South Africa has the highest rate of rape in the world (outside of warring countries); the highest reported cases of child abuse (particularly against young girls); and it is known as the “Baby Rape Capital of the World.”³⁹ In South Africa, 3% of women report having been raped, this is likely a significant underestimate because of the underreporting of rape.⁴⁰

In 2002, Garenne and Lydié argued that older women in Africa, acting as caregivers for sick persons in the community, carry the main psychosocial and physical burdens of AIDS care.⁴¹ While exposure to HIV/AIDS while caring for a

³⁴ Stones and Earl-Taylor, 2.

³⁵ South African Police Services (SAPS) Training Participants. Training by author. Cape Town, 12 March 1997.

³⁶ S. Leclerc-Madlala, “On the Virgin Cleansing Myth: Gendered Bodies, AIDS and Ethnomedicine,” *African Journal of AIDS Research*, 1 (2002): 87-95

³⁷ M. Rotchford Galloway, “Rape in Schools a ‘Substantial Public Health Problem’ in South Africa,” *AIDS Bulletin*, 11, no. 1 (2002).

³⁸ Leclerc-Madlala, “Myth,” 2.

³⁹ S. Leclerc-Madlala, “And the Word was Made Flesh: Gender Power and Socialisation for Sexual Communication,” Paper presented at the *Getting the HIV/AIDS Word Out to Youth Symposium*, Centre for the Book, Cape Town, 22-23 March 2002.

⁴⁰ Garenne and Lydié, 14.

⁴¹ Garenne and Lydié, 14.

person is rarely a condition of infection, carers are at greater risk for other infections like tuberculosis. These women have less control and access to resources than men, thus limiting their ability to cope effectively.

In 2004, a study showed that vulnerability to HIV transmission is not only a factor for young and older women but also unborn girls.⁴² An investigation of 3,231 mother and child pairs showed that girls in the womb might be more vulnerable to HIV infection than boys. Specifically, this study suggested that HIV transmission before 36 to 38 weeks of pregnancy is twice as likely to occur in girls as in boys. The reasons for this include possible underlying genetic or immunological differences between the sexes. The above studies show the importance of understanding the underlying gender factors in the spread of HIV/AIDS. Moreover, these studies stressed the importance of gender-based HIV/AIDS responses that focus on social expectations, gender roles, cultural beliefs, and gender inequalities.

In 2004, the University of Witwatersrand's Reproductive Health Research Unit's (RHRU) national survey of youth and HIV/AIDS found that there is little negotiation of sex in South Africa, and a large percentage of women claimed that their first sexual experience was coerced.⁴³ Specifically, the survey found that 31% of women reported that their first sexual experience was coerced. Women reported that they needed to be submissive to men in order to please men or limit aggression; while men reported that respect from women is only gained through dominance and violence. Leclerc-Madlala noted that many of the young men that she interviewed in KwaZulu-Natal held the view that "If you hit a woman, she will respect you."⁴⁴

⁴² European Collaborative Study, "Are Girls at More Risk of Intrauterine-Acquired HIV Infection than Boys?," *AIDS*, 18 (2004): 344-347.

⁴³ K. Ndaki, "Risky Business – SA Youth and HIV/AIDS," *AIDS Bulletin*, 13, no. 2 (2004): 52-53.

⁴⁴ Leclerc-Madlala, "Myth," 2.

In 2004, van der Vliet noted, "It is one of the ironies of South Africa that a country with one of the most gender-sensitive constitutions, including a Commission on Gender Equality, should also experience very high levels of violence against women."⁴⁵ The ANC's women's groups have been active with regards to rape, violence against women, and the virgin myth. The ANC Women's League and the ANC Women's Caucus have met with little success on these issues because of the tensions within the ANC regarding HIV/AIDS policies. For example, on 14 November 2001, the Parliamentary Joint Standing Committee on the Improvement of the Quality of Life of Women (largely dominated by the ANC's Women's League) called for antiretrovirals (ARVs) for rape victims and the prevention of mother-to-child-transmission; this was a call in opposition to the government's HIV/AIDS policies.⁴⁶ Even though there are laws to protect women against violence, there is a big gap between policy and the everyday experiences of women at home and at the police stations.⁴⁷ Also, Hallman noted that socio-economic factors significantly limit the impact of interventions.⁴⁸ That is, low socio-economic status has greater negative effects on female than on male sexual behaviours and experiences. Finally, in 2004, a study conducted in a Western Cape township found that women who had been sexually assaulted were more likely to have multiple male sexual partners, higher

⁴⁵ V. van der Vliet, "South Africa Divided against AIDS: A Crisis of Leadership," in *AIDS in South Africa: The Social Expression of the Pandemic*, eds. K. D. Kauffman and D. L. Lindauer (New York: Palgrave Macmillan, 2004), 68.

⁴⁶ Van der Vliet, "Divided," 68.

⁴⁷ PlusNews, "Gender Equality Needed in National HIV/AIDS Policy," *IRIN*, 8 November 2004, <<http://www.irinnews.org>> (Accessed: 10 November 2004).

⁴⁸ K. Hallman, "Socio-Economic Disadvantage and Unsafe Sexual Behaviours among Young Women and Men in South Africa," *Policy Research Division Working Paper*, No. 190 (New York: Population Council, 2004).

rates of unprotected sex, more STIs, and engaged in survival sex.⁴⁹ The historical context of gender issues in women's health and HIV/AIDS is thus established.

This body of literature illustrates the importance of gender in the HIV/AIDS debate. How gender contributes to the spread of HIV/AIDS is particularly significant, as illustrated in the literature that highlights many women's lack of control over when and how sex occurs. Also, this literature established women's increased biological vulnerability to the virus, and showed how women's low socio-economic status is linked to an increase in multiple sexual partners. The vital link between socio-economic and gender factors is thus established in the HIV/AIDS debate. The discussion now turns to case studies that illustrate these arguments.

The History of Specific Gender Issues Raised in HIV/AIDS Training

The specific gender issues faced by training organisations and health care workers in the Western Cape are now discussed in order to show the relevant areas as well the shifting narratives of trainers and health care workers in the period 1989-2004. These issues include the biological factors in transmission, violence against women and children, disclosure to partners, condom usage, and the PMTCT program.

Biological Factors in Transmission

Between 1989 and 1995 there was little understanding of the differences in the HIV transmission factors for men and women. As noted above, in 1995 the WHO stated that women are ten times more at risk to HIV infection than men (1:10 versus 1:100, respectively). At the end of 1995 it was observed that training organisations

⁴⁹ S. C. Kalichman and L. C. Simbayi, "Sexual Assault History and Risks for Sexually Transmitted Infections Among Women in an African Township in Cape Town, South Africa," *AIDS Care*, 16, no. 6 (2004): 681-689.

were slow to accept and share this information.⁵⁰ There were two main reasons for this. One, as this was the beginning of the exploration of gender and HIV/AIDS trainers did not yet fully understand the implications of gender for HIV transmission. Two, for those trainers who had more experience in these issues, they feared that by concentrating on the biological differences in transmission they would be reinforcing the misperception that women were responsible for the spread of the disease. Recent research highlighted the danger of creating the perception that HIV/AIDS is a woman's illness and her fault.⁵¹

In 1995, health care workers countered the fear of reinforcing misperception by arguing that there are biological differences in transmission and that it was the responsibility of training organisations to share this information with health care workers. A trainer reported: "Doctors tell us "facts are facts." While the biological differences [in transmission] are true, this medical perspective does not appreciate what dangerous gender inequality messages we are reinforcing."⁵² Trainers expressed another fear regarding the information about biological susceptibility: men might misinterpret their lower risk for transmission and thus be dissuaded from practising safer sex. In 1995, this fear was proved correct in the first training course that presented this information about biological susceptibility.⁵³ Male participants immediately commented on this information by stating that men no longer needed to wear condoms. Trainers challenged this response, especially the part that ignored the significant risk to women if men stopped using condoms. Some male health care

⁵⁰ ATICC Strategic Planning. Conducted by author. Cape Town, 8 December 1995.

⁵¹ T. Shefer, "Gendered Representations of HIV/AIDS and the Reproduction of Hegemonic Discourses on Femininity in Media Images," Draft paper, International Workshop on Gender and Visuality, September 2004, <<http://www.uwc.ac.za/arts/gendervisuality/TamaraShefer.doc>> (Accessed: 11 October 2006).

⁵² Trainer. Focus group by author. Cape Town, 20 February 1996.

⁵³ Trainer. Focus group by author. Cape Town, 20 February 1996.

workers did not seem to grasp this point and focussed only on the fact that men had a lower risk of infection than women.⁵⁴

This reaction was echoed in other training and supervisory contexts. For example, in 1996, male medical students seized upon the biological susceptibility of women as proof of the futility of condom usage. A student argued: "It doesn't matter if I wear a condom. This information says that my risk is almost nil. And there is no risk to my girlfriends because I am HIV-negative. As long as I remain negative, I don't have to wear condoms."⁵⁵ Such lack of gendered understanding was common among medical students and health care workers. Female students argued that the biological susceptibility reinforced the importance of safer sex for both women and men. Female students also understood that men might use this information to blame women for the spread of HIV. The issue of biological susceptibility created a useful context for debate, and students were educated about sexuality and gender. What began as a conversation about transmission ended in complex discussions about gender relations and agency. These examples illustrate the importance of trainers taking controversial gender issues and grappling with the details and implications of these issues with health care workers and students.

In 1996, trainers stated that they required outside assistance and motivation (for example, training consultants) in order to properly understand and present this kind of information.⁵⁶ Moreover, presenting this kind of information required more time and resources. Health care workers reacted to this issue in different ways. Some health care workers flatly denied the information because they said that it did not make sense or it did not reflect their experiences.⁵⁷ Other health care workers reported

⁵⁴ Trainer. Focus group by author. Cape Town, 20 February 1996.

⁵⁵ UCT Medical Student. HIV/AIDS training feedback to author. Cape Town, 12 April 1996.

⁵⁶ Trainer. Focus group by author. Cape Town, 20 February 1996.

⁵⁷ Trainers. Focus group by author. Cape Town, 27 February 1996.

mixed results in the relaying of the information to patients concerning biological susceptibility. Women often believed the information, while many men did not. As one trainer stated: "This reflected women's vulnerability and men's comfort in gender relations."⁵⁸

In 1997 health care workers reported that the conversations about biological susceptibility were useful.⁵⁹ These conversations provided them with the opportunity to explore gender issues that were linked to wider cultural, political, and social issues. Other conversations followed that dealt with issues like violence, the negotiation of sex, power, and blaming women for STIs and HIV/AIDS. A female nurse stated: "I understand that a woman's body is different and that they can get these things [STIs] easier [than men]. Men must change the way they treat us. It's not only the sex, but also the attitudes that are important in AIDS."⁶⁰ Health care workers were increasingly talking about attitudes to gender roles and exploring ways of addressing this issue.

By 1998, health care workers reported that some male patients did not understand the information regarding biological susceptibility. For example, a counsellor stated: "One man told me that now he can have sex 100 times without a condom before he can get AIDS. He asked me if he should wear a condom on the 100th time before not using a condom for the next 100 times."⁶¹ Training organisations, clinical supervisors, and peer support groups played an important part in providing ongoing opportunities for health care workers to discuss such responses from patients. Responses and solutions to counselling issues were discussed with health care workers before they saw the patient again.

⁵⁸ Trainer. Focus group by author. Cape Town, 27 February 1996.

⁵⁹ Health Care Workers. ATICC training feedback forms to author. Cape Town, 1997

⁶⁰ Trainer. Interview by author. Cape Town, 28 January 1997.

⁶¹ Health Care Workers. ATICC training feedback forms to author. Cape Town, 1998.

In 1999 the discussions on biological susceptibility encouraged some female patients to be more open and assertive about their sexual health. Patients engaged in conversations that they did not previously feel they had the right to hold. A nurse recounted the counselling case of a woman from the Transkei who was angry when she was told that her risk for HIV was greater than her boyfriend: "She knows he has other girlfriends. She went home and told him 'no condoms, no sex.' He was cross and said she must leave, but he came back the next week with a condom. My patient said the new information about her risk as a woman was important enough to tell her boyfriend 'no more.'"⁶² There were also many reports from health care workers of men who had changed their sexual behaviour. For example, a nurse reported the case of a man who requested monthly HIV tests tested for HIV because he had one 'original' girlfriend and ten 'spares': "He uses a condom with his 'original' girlfriend but not with his 'spares.' After our counselling he told me: "Sister, you have opened my eyes like the sun in the morning. I must use a condom every time. He took a whole envelope of condoms and comes back every week now for more."⁶³

In 2001, trainers abandoned the numbers (1:10 for women and 1:100 for men) and replaced them with the risk information without the numbers.⁶⁴ That is, training organisations began to simply state that there was a difference in biological vulnerability without reporting the statistics. In 2003, trainers and health care workers reported that these changes worked better in that the information was less confusing and thus more easily grasped and better utilised.⁶⁵ Specifically, training content had to be adapted to the varying levels of education and understanding of health care workers.

⁶² Nurse. Focus group by author. Cape Town, 15 February 1999.

⁶³ Health Care Workers. ATICC training feedback forms to author. Cape Town, 1999.

⁶⁴ Trainers. Provincial technical update by author. Cape Town, 21 February 2001.

⁶⁵ Trainers. Feedback to author. Cape Town, 25 March 2003.

In 2004, trainers reported that the time and effort in educating health care workers were justified because there was a marked increase in biological (transmission) and gender knowledge (complexities of risk and sexual politics) for trainers, health care workers, and patients.⁶⁶ Notably, the biological differences in transmission provided the opportunity for debates and learning. Trainers, health care workers, and patients were educated about biological transmission and gender issues, as well as the wider political, social, economic, and cultural factors. The extent to which HIV transmission is more efficient from female to male or male to female is still being debated.⁶⁷ Other important gender issues were identified and explored in HIV/AIDS training.

Violence against Women

Between 1989 and 1994, the reports of violence against women and children increased dramatically in primary health care clinics.⁶⁸ One of the reasons for this was that HIV/AIDS counselling services were made available, and women now had a place to talk about the violence. Another reason was the increased media coverage given to these issues. Training organisations, trainers, and health care workers were unprepared for increased reports of violence, and the breadth and depth of disclosure.⁶⁹

Two main themes were evident with regards to the disclosure of violence by female patients: the first deals with the increased reporting of violence, and the second deals with the effect of this on health care workers and trainers. In the early 1990s, training organisations avoided topics like violence because it was assumed to be

⁶⁶ Trainer. Interview by author. Cape Town, 28 January 1997.

⁶⁷ Garenne and Lydié, 8.

⁶⁸ Health Care Workers and Trainers. Focus group by author. Cape Town, 20 November 1996.

⁶⁹ Health Care Workers and Trainers. Focus group by author. Cape Town, 20 November 1996.

irrelevant to the discussion of HIV/AIDS. By 1994, trainers reported that participants increasingly reported rape, domestic violence, child sexual abuse, and baby rape.⁷⁰ This is a germane example of how what health care workers heard influenced training content: the information went from patients to health care workers to trainers. While training organisations provided input to health care workers on the issue, the sociological and political aspects of sexual violence were reported from patients to health care workers to trainers. This had the effect of creating a more multifaceted narrative about sexual violence, and health care workers reported that their understanding and response was more nuanced.⁷¹ Despite this deeper understanding of health care workers regarding gender, these issues were not seen as part of HIV transmission.

In 1996, trainers reported that not only were health care workers discussing violence against women more, they appeared to be psychologically traumatised by this content.⁷² Health care workers reported symptoms that are characteristic of trauma. These responses were physical (for example, fatigue), emotional (for example, irritability and grief), cognitive (for example, decreased attention and poor memory) and behavioural (for example, insomnia). Between 1996 and 1999, psychological investigations showed that the content of violence reported in HIV counselling and training were strongly associated with these symptoms.⁷³ An example of a 1996 case report included: "I am so tired; I don't want to work any more. It is not the number of patients [per day] I see – I work in a well-organised clinic – but what these women tell me. I just can't hear about any more domestic violence or child

⁷⁰ Health Care Workers and Trainers. Focus group by author. Cape Town, 20 November 1996.

⁷¹ Health Care Workers. Supervision by author. Cape Town, 11 April 1995.

⁷² Health Care Workers and Trainers. Focus group by author. Cape Town, 20 November 1996.

⁷³ HIV/AIDS Psychology Supervisors. Focus groups by author. Cape Town, 1996-1999.

rape.”⁷⁴ Health care workers reported ongoing exposure to traumatic clinical material.⁷⁵ These reports were numerous and more intense depending on the area in which the clinic was situated. In 1996, it was reported that health care workers took more sick leave, reported more conflict with colleagues and burnt-out, and they were more likely to leave the field of health care.⁷⁶ Many health care workers reported guilt at needing time off when there was such a demand for their services. Trainers and clinic managers became alarmed at how quickly HIV/AIDS health care workers developed burnout symptoms. A trainer reported her concern about how much gender violence health care workers internalised in HIV/AIDS counselling and testing: “We knew we had to do something to help the nurses, doctors, and counsellors. We recognised the post-traumatic stress symptoms of listening to these horror stories all day long. That is when we requested assistance from psychologists.”⁷⁷

In 1997, in the work place and in supervision, health care workers showed signs of an acute stress reaction associated with the repeated exposure to intensely traumatic stories.⁷⁸ This was particularly marked for health care workers who had experienced their own previous trauma (sexual and other). In 1997, training organisations recognised the importance of proper selection and training of health care workers. This recognition was limited by the fact that training organisations did not have much input into who was selected and trained for HIV/AIDS work. Training organisations were more successful in changing training material to include crisis and grief counselling skills, and stress management skills. In 1999, trainers also organised

⁷⁴ Health Care Worker. Focus group by author. Cape Town, 26 March 1996.

⁷⁵ For example, a health worker stated: “On Monday I had three clients in a row who spoke about sexual abuse of their little boys and girls, and being raped by their men. This was after seeing a 9-year old girl who was raped by a gang – ten boys raped her again and again. This is enough – my head is too full.” Health Care Worker. Focus group by author. Cape Town, 26 March 1996.

⁷⁶ HIV/AIDS Psychology Supervisors. Focus groups by author. Cape Town, 1996-1999.

⁷⁷ Trainer. Focus group by author. Cape Town, 21 May 1996.

⁷⁸ HIV/AIDS Psychology Supervisors. Supervision by author. Cape Town, 11 August 1997.

individual and group debriefing for health care workers who were being traumatised by the patients' reports.⁷⁹

Not much was done for the patients themselves, mostly due to the lack of regional health care resources. Only in 1999, a pivotal year, did organisations like Rape Crisis begin to deal specifically with the trauma of violence and HIV/AIDS on women, trainers, and counsellors. In 2000, health care workers reported frustration with the lack of support that patients reported in communities.⁸⁰ In 2001, for example, patients claimed that police responded inappropriately to rape reports - they failed to offer medical and psychological treatment, and they insisted that a police report be completed before medical treatment was made available, which contradicted the government policy.⁸¹ Health care workers reported patient frustration at the lack of pledged service delivery. In April 2002, the government stated that it would provide post-exposure prophylaxis (PEP) as part of a larger response for rape survivors. Silence surrounded the launch of this program, and many nurses and police were unaware that the program existed.⁸² Moreover, in 2003, health care workers found themselves in the uncomfortable position of having to explain and justify this lack of service delivery.⁸³ In 2004, the government was still being criticised for the gap between its stated intention to provide drugs for rape survivors and the reality that rape survivors could not access these drugs or counselling services.⁸⁴ HIV/AIDS played a significant role in facilitating the disclosure of this largely hidden and unexpressed gendered violence. The movement of violence against women from the

⁷⁹ Trainers. Supervision by author. Cape Town, 19 July 1999.

⁸⁰ Health Care Workers. Supervision by author. Cape Town, 24 January 2000.

⁸¹ Health Care Workers. Focus group by author. Cape Town, 12 April 2001.

⁸² Human Rights Watch, "HIV-Prevention Program Fails Rape Survivors," *Human Rights News*, 4 March 2004, <<http://www.hrw.org/english/docs/2004/03/04/safric7930>> (Accessed: 29 September 2004).

⁸³ Health Care Workers. Private communication with author. Cape Town, 9 May 2003.

⁸⁴ Human Rights Watch, "HIV-Prevention Program Fails Rape Survivors," *Human Rights News*, 4 March 2004, <<http://www.hrw.org/english/docs/2004/03/04/safric7930>> (Accessed: 29 September 2004).

private to the public sphere had important implications for how female health care workers regarded themselves, both personally and systemically. Female health care workers began grappling with the assumptions of power and authority; that is, the issue of agency. The discussion now addresses the third issue raised by health care workers in HIV/AIDS training: women's HIV/AIDS disclosure to their partners.

Disclosure to Partners

An important aspect of gender violence as it relates specifically to HIV/AIDS was the disclosure of a patient's HIV status to partners. Following the international guidelines for HIV testing and disclosure, training organisations argued that testing was critical for receiving treatment and access to drugs to prevent the transmission of HIV from a woman to her child. As part of these reasons for HIV testing, it was argued that disclosure to one's partner was important in curbing HIV transmission. While testing and disclosure were important principles, they proved difficult to implement.

Between 1989 and 1995, the disclosure of a person's HIV status was not a central theme in HIV/AIDS counselling because it was held that people would unquestioningly disclose their status as suggested by counsellors in pre- and post-test counselling.⁸⁵ In 1995, there was a significant shift towards more HIV testing and disclosure after the release of the Provincial Key HIV/AIDS Strategies, when the Provincial Health Department instructed ATICC to encourage testing and disclosure in order to challenge discrimination and stigma.⁸⁶ Almost immediately health care workers reported their discontent with these new initiatives. The first problem raised by health care workers was that many of their patients, particularly women, were not

⁸⁵ Trainers. Focus group by author. Cape Town, 14 September 1995.

⁸⁶ T. van der Velde (ATICC Manager). Interview by author. Cape Town, 8 July 1996.

willing to disclose their HIV-positive status to partners. This fact was largely unknown before health care workers started focusing on the issue. In 1995, a nurse reported: "We say we must force our patients to tell their boyfriends and husbands, but no-one wants to. They say they will but they don't. Or they say they will and they never come back to the clinic. Why? They are scared. Telling means getting a beating. How can women trust us when we ask them to do this?"⁸⁷ This report shows that not only were health care workers frustrated with the gender-based obstacles to patient disclosure, they also felt that they were advocating a policy that placed women at greater risk to violence. The power of the stigma and discrimination associated with HIV/AIDS (as discussed in chapter six) were underestimated by training organisations and health care workers, and they continued to be problems in the management and treatment of HIV/AIDS.⁸⁸

The second problem related to the fact that health care workers argued that it was impossible for many women to initiate HIV testing because their male partners had to suggest it. Disclosure proved even more complex because while many men felt that they had the right to bring in their partners for testing and to know the HIV result, they did not feel that their partners had the right to know either that they were tested or the result. In 1996, for example, a counsellor reported a case in which a husband had brought in his wife for HIV testing. The husband refused to leave the room during the pre-test counselling and answered all the questions for his wife. The counsellor finally got him to leave the room: "It took a long time for the woman to speak: she is a quiet somebody. The counselling was 2 ½ hours long. She told me that her husband told her to come for testing. She said that he has many girlfriends and he told her to be

⁸⁷ Health Care Workers. Supervision by author. Cape Town, 9 November 1995.

⁸⁸ PlusNews, "Fear of Stigma Still Prevents Disclosure," *IRIN*, 13 July 2005, <<http://www.irinnews.org>> (Accessed: 14 June 2005).

tested because she thinks he wants to know if he is HIV-positive.”⁸⁹ This case is significant because it was one of many such reports. Moreover, it illustrates the gender imbalances reported by health care workers.⁹⁰ The link between disclosure and domestic violence soon became evident to health care workers.

In 1997, health care workers stated that they felt caught between the training guidelines and the potential violent consequences for their female patients: beaten and homeless patients turned up at the clinics, often angry with the health care worker for having encouraged disclosure.⁹¹ A doctor noted: “I understand the logic of testing and disclosure but traditional gender attitudes result in awful disempowering consequences. Seriously disempowered women are further disempowered by ongoing violence and being cut off from their only economic lifeline. We have to truthfully rethink this whole issue.”⁹² While these sentiments continued to be expressed and discussed, not much changed. If anything, the situation worsened with increased reports of gendered violence.⁹³

On 12 September 1998, the issue erupted with the death of Gugu Dlamini in KwaZulu-Natal. Dlamini announced her HIV-positive status on a local radio, and eleven days later her neighbours attacked her and stoned her to death. The reason cited for the stoning was that she had brought shame to her community by being HIV-

⁸⁹ Nurse. Supervision by author. Cape Town, 17 October 1996.

⁹⁰ This case ended predictably. Despite being reassured by the nurse that she would not be tested against her will, she requested testing because she said she feared another beating if she refused testing. The patient was HIV-positive and she felt compelled to tell her husband. He did beat her up and kicked her out of their home.

⁹¹ Counsellors. Focus group by author. Cape Town, 9-11 June 1997.

⁹² Doctor. Focus group by author. Cape Town, 9-11 June 1997.

⁹³ Health Care Workers. Focus group by author. Cape Town, 9-11 June 1997.

positive.⁹⁴ Dlamini had taken seriously the call of campaigners and educators to come forward with her HIV-positive status.⁹⁵

Her death had a powerful effect on trainers and health care workers in the Western Cape. Health care workers highlighted certain pertinent issues. Some commented on the risks of the principle of disclosure and women's safety: "This is exactly why I have been going on and on about the dangers of disclosure. Simply put: women can die!"⁹⁶ Gender and racial aspects were also raised. For example, "This disclosure thing is a White thing – it doesn't work in our community. As a woman one must know what you can and cannot say. One can only speak openly to God; otherwise one is in big trouble."⁹⁷ Health care workers' frustration with government and society's seeming apathy towards violence against women was evident in comments like: "To kill someone with your bare hands is incomprehensible. Your mother, your daughter, your sister, your aunt. Gugu Dlamini had to die for us to stop condoning this through our inaction."⁹⁸ One counsellor related a story that had a significant effect on the training group and trainers.⁹⁹ She reported that she knew someone whom she suspected was killed in Gugulethu because she was HIV-positive. The story soon spread amongst health care workers, and they claimed that the story had backed up their concerns with Dlamini's murder.¹⁰⁰ The apparent victim remained nameless; she was soon regarded as the "Gugu Dlamini of the Western Cape."¹⁰¹

⁹⁴ H. Phillips, "HIV/AIDS in the Context of South Africa's Epidemic History," in *AIDS in South Africa: The Social Expression of the Pandemic*, eds. K. D. Kauffman and D. L. Lindauer (New York: Palgrave Macmillan, 2004), 35.

⁹⁵ S. Leclerc-Madlala, "Enemy of the People: The HIV Epidemic in South Africa," *New Internationalist*, 313 (June 1999).

⁹⁶ Doctor. Training by author. Cape Town, 4 December 1998.

⁹⁷ Nurse. Supervision by author. Cape Town, 4 December 1998.

⁹⁸ Social Worker. Training by author. Cape Town, 20 January 1999.

⁹⁹ Counsellor. Training by author. Cape Town, 14 June 1999.

¹⁰⁰ Health Care Workers. Training by author. Cape Town, 14 June 1999.

¹⁰¹ The original story was as follows: "I haven't wanted to say anything before because I was scared, but Gugu Dlamini has given power to my heart. I think that one of my patients was also killed by her boyfriend. I gave her the HIV-positive result and she was scared to go home. At the end of the day she

In 1999, through training, focus groups, and supervision four other reports of alleged murder because of HIV disclosure emerged in the Western Cape. This chilling information was discussed amongst health care workers and trainers, and presented to the province. While there was no official response to the information (the reasons for which remain unclear), Dlamini's murder prompted training organisations to significantly revise the whole issue of disclosure. Her murder acted as a watershed event: that is, in 2000, trainers decided that while testing and disclosure are important to transmission and treatment, the message to health care workers and patients needed to incorporate the real threats to women.¹⁰² Firstly, trainers decided that women should be encouraged to decide on whether or not they wanted to be tested – with an appreciation of their domestic relationships. Secondly, health care workers should be trained to assess risk factors to women. Thirdly, health care workers should try to leave disclosure to the patient after having explored risk factors. Fourthly, health care workers should liaise with police stations regarding threats to women who chose to disclose. The main hindrance in the discussion of this issue was the weakened police force and rampant sexism in the health care system. Nevertheless, these new training guidelines did address the complexities of disclosure, the empowering of women, and the training and support of health care workers.

In 2001, health care workers argued that disclosure patterns were different depending on the education, cultural, gender, and social conditions of the patient.¹⁰³ While counsellors reported that counselling helped patients to be more discerning about disclosure, which encouraged more appropriate and safer disclosure, there was

was sitting outside the clinic waiting for me. 'He is going to kill me if I tell him,' was all she said. I sent her home, and then my sister told me that a young Sotho woman was killed in her street. My patient lived in that street and she was Sotho. I sent her to her death." Counsellor. Training by author. Cape Town, 14 June 1999.

¹⁰² Trainers (Various HIV/AIDS Organisations). Meeting. Cape Town, 5 July 2000.

¹⁰³ Health Care Workers. Focus group by author. Cape Town, 26 February 2001.

no data to prove this. Between 2001 and 2004, training organisations continued discussing the limitations of disclosure. In 2004, a study in Johannesburg found that the disclosure patterns of female patients in PMTCT programs depended on the household structure and social networks.¹⁰⁴ The maintenance of secrecy and involuntary or negative disclosure experiences were related to residing in extended families. Constructive experiences of disclosure were related to residing in nuclear families and having few social contacts. Women recanted and used lies to avoid public disclosure. The role of counselling was found to be important to the choice to disclose and the management of the psychosocial impact. Understanding women's disclosure patterns is important to "both HIV prevention and [the] mitigation of its impact."¹⁰⁵ A 2004 study of HIV-status disclosure revealed different disclosure patterns for different relationships.¹⁰⁶ By 2004, training organisations and health care workers were more circumspect with regards to testing and disclosure, and gender was at the centre of a new understanding and practises. The roles of the social context¹⁰⁷ and discrimination¹⁰⁸ in disclosure patterns were also highlighted. Thus, Dlamini's death was a watershed event that changed training organisations' approach to disclosure: the narrative shifted from the championing of disclosure to a greater

¹⁰⁴ C. A. Varga, "Psychosocial Consequences of Early Diagnosis of HIV Status in Vertically Exposed Infants in Johannesburg, South Africa," *Health Care for Women International*, 26, no. 5 (2005), 387-397.

¹⁰⁵ Varga et al., 397.

¹⁰⁶ S. C. Kalichman et al., "Stress, Social Support, and HIV-status Disclosure to Family and Friends among HIV-positive Men and Women," *Journal of Behavioural Medicine*, 26, no. 4 (2003): 315-332.

¹⁰⁷ Research in 2006 in Cape Town highlighted the importance of the social context that the HIV-positive person needs to negotiate. See: C. Almeleh, "A Qualitative Study into the Impact of HIV Disease Progression on Initial HIV-serostatus Disclosure to Significant Other," oral abstract presentation, XVI International AIDS Conference, Toronto, Canada, 14 August 2006, <<http://www.aids2006.org/PAG/PSession.aspx?SessionID=232>> (Accessed: 16 August 2006).

¹⁰⁸ Other research in 2006 in Cape Town highlighted the importance of stigma and discrimination in disclosure patterns. See: L. C. Simbayi et al., "HIV Status Disclosure to Sex Partners and Sexual Risk Behaviours among HIV Positive Men and Women in Cape Town, South Africa," poster presentation, XVI International AIDS Conference, Toronto, Canada, 16 August 2006, <<http://www.aids2006.org/PAG/PSession.aspx?SessionID=313>> (Accessed: 16 August 2006).

awareness of the limitations of disclosure. Gender issues were highlighted in this shifting narrative.

Finally, it has been noted that there are other marginalized groups of women who are at high risk for HIV/AIDS. Migrant women are at high risk for HIV/AIDS because they engage in sexual activities with multiple partners as a form of economic survival.¹⁰⁹ That is, women are forced into 'transactional sex' with many partners when they move to urban areas with no economic security. This research also found that condom use was lower amongst migrant women than non-migrant women; an important issue in the Western Cape with high numbers of migrant women, particularly from the Eastern Cape. Female street hawkers are also at high risk for HIV/AIDS.¹¹⁰ In the period under review, training organisations and health care workers did not address these high-risk female groups in any significant way.

Condom Usage

Gender proved to be a significant barrier to safer sex practices. The power structures that compound a woman's vulnerability to HIV challenge the notion that condoms can be used without reference to the social context.¹¹¹ Research showed that women find themselves in relationships in which they are unable to control the nature and safety of the sexual encounter.¹¹² The issue of violence against women was discussed above, and now the issues of gender and condom usage are examined.

¹⁰⁹ PlusNews, "Migrant Women at Much Higher Risk of HIV/AIDS," *IRIN*, 14 September 2004, <<http://www.irinnews.org>> (Accessed: 14 September 2004).

¹¹⁰ PlusNews, "Women Street Traders Falling through the Cracks," *IRIN*, 11 November 2004, <<http://www.irinnews.org>> (Accessed: 12 November 2004).

¹¹¹ C. Campbell, "Male Gender Roles and Sexuality: Implications for Women's AIDS Risk and Prevention," *Social Science and Medicine*, 41 (1995): 197-210.

¹¹² C. C. Da Cruz, "From Policy to Practice: the Anthropology of Condom Use," in *AIDS in South Africa: The Social Expression of the Pandemic*, eds. K. D. Kauffman and D. L. Lindauer (New York: Palgrave Macmillan, 2004), 145.

Between 1989 and 1995 the issue of condoms was regarded as important as a preventative measure, particularly for homosexual men who were in the high-risk category. Yet, in this period there was no government-endorsed condom campaign. In 1995, at the beginning of the condom distribution campaign in South Africa, health care workers argued that the successful use of condoms was hampered by gender factors. A nurse reported: "I believe condoms are good. We need to promote them. But just because I tell someone to use it doesn't mean this will happen. Women have no say about condoms. My patients listen to me but always say, "he will decide," "he doesn't like condoms, and "he gets angry and fights if I talk about condoms.""¹¹³ By the end of 1995, health care workers reported that the reasons for the low condom usage were the unavailability of condoms, male discomfort, cultural rationale, lack of relevant education, the desire for pregnancy, and the perceived masculine need for "skin-on-skin" contact.¹¹⁴ Later research in South Africa confirmed the observations of health care workers: the reasons for sexually active women not using a condom at last intercourse were relationship issues (29%), personal attitudes (28%), wanting to get pregnant or not perceiving a personal risk (18%), lack of health education (9%), and condoms not available (6%).¹¹⁵

In 1997, one clinic had a measure of success countering the male opposition to condom usage: the health care workers argued that they were tired of the male rationalisations of condoms being too difficult to use, too tight, too loose, or too unmanly.¹¹⁶ In order to increase condom use health care workers adopted the Kenyan initiative in which patients were told to tell their boyfriends and husbands that their penis felt bigger with a condom on, and that the women enjoyed sex more when he

¹¹³ Nurse. Focus group by author. Cape Town, 20 March 1995.

¹¹⁴ Health Care Workers. Supervision by author. Cape Town, 1995-2001.

¹¹⁵ I. Kleinschmidt et al., "Dual Protection in Sexually Active Women," *South African Medical Journal*, 93, no. 11 (2003): 854-857.

¹¹⁶ Counsellors. Focus group by author. Cape Town, 19 March 1997.

wore a condom. A counsellor reported: "We tried this. We told our female and male patients that previous patients said that condoms increased penis size, male potency, and female enjoyment. We had good results. Some of our old HIV-positive patients started using condoms for the first time."¹¹⁷ There was no follow-up on this intervention, and some health care workers and trainers had problems with the deceit involved. Others argued that this deceit was better for women than infection, stigma, and death.¹¹⁸

One motivator for the disuse of condoms is a stable relationship.¹¹⁹ Women who were aware that their partners had other girlfriends did not feel that they had the right to insist on condoms because this would result in conflict. Also, women cited the reasons of trust and love for not insisting on condom usage. In 1997, a nurse stated: "My patients are too scared to ask for condoms because the boyfriend then says that she must be hiding something. Men turn this around and then blame the women for having another boyfriend. Why else would she ask to use condoms?"¹²⁰ This case illustrates how women's desire for protection was turned into accusations of infidelity. These accusations were ironic given the fact that many of the male partners were HIV-positive from other relationships. By the late 1990s it became clear that training organisations and health care workers had to tackle the issue of multiple partners.¹²¹

Cruz examined the complexities of multiple sex partners and condom use. Stable relationships often begin with condom use or at least inconsistent condom use. As the relationship progresses, couples stop using condoms, a step that is perceived to

¹¹⁷ Counsellors. Focus group by author. Cape Town, 19 March 1997.

¹¹⁸ Health Care Workers. Supervision by author. Cape Town, 12 May 1998.

¹¹⁹ Da Cruz, 146.

¹²⁰ Counsellors. Focus group by author. Cape Town, 19 March 1997.

¹²¹ Trainers. Private communication with author. Cape Town, 23 May 2003.

prove commitment and trust.¹²² This becomes complicated when there are multiple sex partners. In 1997, health care workers stated that patients (across all races and classes) reported that many men had one “original” (long-term, stable) girlfriend and many “spares” (casual) girlfriends.¹²³ While many men used a condom with their “original” girlfriends, they used condoms inconsistently with their “spares.” This issue became an important topic of debate in HIV/AIDS training from 1997 onwards, and health care workers were confronted with different cultural and gender sexual interaction. Obviously the pattern of condom usage is variable, and health care workers reported many different forms of condom usage depending on subjective perceptions of risk and trust, and other influences like clinic education and the media.

In 1998, by focussing on gender issues, HIV/AIDS counselling highlighted previously hidden patterns of sexual interaction, and many health care workers found it difficult to accept these practices. For example, a counsellor reported: “If I’ve learnt one thing it’s this: people lie about sex all the time. Everyone is having more sex than I thought. Men have *originals* and many *spares*, and so do many women. I used to get shocked when I first started counselling, but now I have heard it all.”¹²⁴ Gender became a lens through which to explore the sexual interaction that put women more at risk to HIV/AIDS.

Between 1998 and 2001, training organisations included more gender specific input in their courses in order to expose the sexual politics of HIV/AIDS in relation to condom usage. Health care workers argued that they were being educated by their patients and training organisations, and this had the effect of equipping them to better respond to issues raised in HIV educating and counselling.¹²⁵ By 2001, health care

¹²² Da Cruz, 147.

¹²³ Health Care Workers. Supervision by author. Cape Town, 4 September 1997.

¹²⁴ Health Care Workers. Supervision by author. Cape Town, 12 May 1998.

¹²⁵ Health Care Workers. Supervision by author. Cape Town, 25 April 2001.

workers reported that patients' sexual behaviour shocked them less and while they did not agree with what their patients told them, they were better able to counsel and advise them about condom usage.¹²⁶ Between 2001 and 2004, health care workers reported that what they found difficult to accept was their inability to help women protect themselves despite the large and public condom distribution campaign.¹²⁷ By 2004, health care workers reported that they had more user-friendly distribution of the male condom but still the same frustrations with no, selective, or inconsistent condom use. Throughout the period under review, anecdotal evidence was presented that highlighted how many women were infected with HIV due to the inability to negotiate condom use. Condoms had little to do with good administrative intention and distribution, and everything to do with associated political, social, cultural, and gender factors.

The issue of female condoms is now examined. In 1998, the female condom was first piloted in South Africa at twenty-nine public sector sites.¹²⁸ By the end of 2002 the number of public sector sites was 200. The rationalisation of encouraging the use of the female condom included greater control a woman had over safer sex and privacy because the condom can be inserted up to eight hours before sex. One of the problems with female condoms is the cost: they are up to twenty-two times more expensive than male condoms.¹²⁹

In 1999, health care workers complained that despite all the marketing done by the Department of Health and training organisations, female condoms were difficult to access, and they were inconsistently available. For example: "One day we

¹²⁶ Health Care Workers. Supervision by author. Cape Town, 25 April 2001.

¹²⁷ Health Care Workers. Training feedback to author. Cape Town, 11 December 2003.

¹²⁸ Department of Health, South Africa, "Public Sector Condoms," 5 February 2002, <<http://www.doh.gov.za/docs/pr/2002>> (Accessed: 30 September 2004).

¹²⁹ UNAIDS, "The Female Condom: Fact Sheet," 2004, <<http://www.unaids.org/EN/other/functionality>> (Accessed: 13 June 2005).

have them, then no-one knows where to get more. Patients don't want to try something new, and then when we give them female condoms and they want more, we have to say that we are waiting for new stock. They don't try it again."¹³⁰ This meant that it was almost impossible for health care workers to carry through with the intervention because the female patients ended up not trusting the health care workers. In 2000, health care workers argued that the female condom was less enthusiastically received than was the male condom (for the reasons stated above).¹³¹ Third, in 2003, health care workers stated that the marketing of the female condom in the Western Cape had failed.¹³² The reasons cited for this were that the female condom was more cumbersome to use due its size, texture, and the difficulties associated with insertion.

In 2004, the issue of female condoms had "fallen off the map."¹³³ This was largely due to the unsuccessful attempts at implementation, patients' lack of trust in the product, and the government's focus on wider issues like the call for antiretrovirals. Finally, successful female condom usage has been associated with women's ability to mobilise around political issues, where they are more willing to speak out and act concerning sexuality and the negotiation of safe sex.¹³⁴ Historical research in this area is notably absent. The final issue, PMTCT program, is now examined in order to highlight the relevant gender factors.

Prevention-of-Mother-to-Child-Transmission (PMTCT) Program

In 1998, the PMTCT program was introduced in Khayelitsha. Counsellors and educators living in the area were selected and trained, and then placed in Site B and

¹³⁰ Counsellor. Supervision by author. Cape Town, 9 July 1999.

¹³¹ Health Care Workers. Focus group by author. Cape Town, 12 June 2000.

¹³² Health Care Workers. Interview by author. Cape Town, 24 March 2003.

¹³³ Trainers. Private communication with author. Cape Town, 23 May 2003.

¹³⁴ I. Susser, "Women, AIDS, and the Female Condom: Preventing HIV in Southern Africa," in *African Visions: Literary Images, Political Change, and Social Struggle in Contemporary Africa*, eds. C. Mwarira, S. Federici, and J. McLaren (Westport: Greenwood Press, 2000), 137-152.

Michael Maponyane clinics. Nurses and doctors working at these clinics were provided with specialised PMTCT training. The goal of the PMTCT program was to offer counselling and free Azidothymidine (AZT) for the last month of pregnancy to HIV-positive women living in the area. This intervention was based on research in the USA (1994) that showed that AZT administered to the mother during the second trimester and to the baby for six weeks after birth, reduced HIV transmission from infected mothers to their babies by 68%.¹³⁵ Owing to the high cost of this treatment regimen, shorter dosages of AZT were investigated. In 1998, a study was conducted in Thailand in which women received AZT for four weeks in the last trimester and the babies did not receive any treatment and were not breastfed.¹³⁶ Reduction rates were comparable to the USA study, and costs were reduced from \$900 to \$50. Thus, the treatment of pregnant women with AZT in developing countries became feasible. As discussed in chapter four, the Western Cape was the only province to defy the national government and begin AZT trials. After the program's implementation, it became clear that there were serious gender considerations and implications.

Within weeks after implementation, health care workers reported that women were afraid to attend the clinics because they were already known as the "AIDS clinics."¹³⁷ If a patient saw her neighbour at the clinic, she was immediately under suspicion for being HIV-positive. As the case of Gugu Dlamini showed, this posed a serious threat to women's safety. In 1999, a counsellor reported: "Two of my patients have been attacked; one kicked out of her home. Her husband's sister saw her come in to see me and told him that she had AIDS. There is no confidentiality in this

¹³⁵ E. M. Conner et al., "Reduction in Maternal-infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment," *New England Journal of Medicine*, 331 (1994): 1174-9.

¹³⁶ Morbidity and Mortality Weekly Report, "Administration of Zidovudine during Late Pregnancy and Delivery to Prevent Perinatal HIV Transmission-Thailand. 1996-1998," *MMWR*, 6 (1998): 151-154.

¹³⁷ Health Care Workers. Supervision by author. Cape Town, 23 November 1998.

program.”¹³⁸ This information was significant because no research had looked at the safety implications for women of a program that had such obvious medical benefits. In 1999, health care workers reported that the issue of patient confidentiality was a problem, and various components of the program challenged it.¹³⁹ One issue was that of bottle-feeding. Patients were told not to breastfeed (to diminish the risk of transmission) and to bottle-feed instead. For some Xhosa women, bottle-feeding was an uncommon practice, and patients reported that people within Khayelitsha regarded it with suspicion.¹⁴⁰ People, often correctly, associated bottle-feeding with an HIV-positive status. Patients had to hide the bottles at home and in public, and hide themselves and the baby while feeding: all of which heightened suspicion. In 1999, a nurse commented: “In Khayelitsha, bottle-feeding means you are HIV-positive. Women have no way to hide this.”¹⁴¹ This was an important issue as illustrated by the 2003 PMTCT study in Khayelitsha that found 63% of the women on the trial chose not to breastfeed because they feared infecting their child.¹⁴² Other issues that challenged confidentiality were women having to take the medication; not allowing any relatives or neighbours to wet-nurse (that is, a relatively common practice for some rural Xhosa women); and regular, scheduled visits to the clinic for follow-up. Another problem was the attitude of health care workers towards the program.

In 2000, some health care workers reported that they did not support the PMTCT program because of the stigma that they felt it brought to the community.¹⁴³ Others felt that women deserved their HIV-positive status and should not receive free

¹³⁸ Counsellor. Supervision by author. Cape Town, 12 August 1999.

¹³⁹ Nurse. Supervision by author. Cape Town, 3 August 1999.

¹⁴⁰ Counsellor. Supervision by author. Cape Town, 3 August 1999.

¹⁴¹ Counsellor. Supervision by author. Cape Town, 3 August 1999.

¹⁴² K. Hilderbrand, E. Goemaer, and D. Coetzee, “Formula Feeding is Safe for Infants on the Mother to Child Transmission Program in Cape Town,” *South African Medical Journal*, 93, no. 10 (2003): 779-781.

¹⁴³ Health Care Workers. Supervision by author. Cape Town, 21 November 2000.

medical treatment, counselling, and support.¹⁴⁴ Finally, some health care workers argued that the program, while admirable, was badly planned, implemented, and managed, which resulted in unrealistic case loads and little administrative or personal support.¹⁴⁵ These factors contributed towards health care workers asking difficult things of patients, for example, nurses insisting that known HIV-positive mothers breastfeed their babies, thus exposing the babies to infection or reinfection.¹⁴⁶ That is, “A patient’s baby was crying and wouldn’t stop. The mother didn’t want to bottle-feed because she was scared of the other patients in the waiting area. The nurse went up to her and forced her to breastfeed the baby to keep it quiet. The patient did it – and she knew her baby was negative.”¹⁴⁷ This case shows the frustrations of health care workers and how they put babies at risk for HIV transmission, even from within the program.

In 2000, a significant intervention was the implementation of support groups to help women deal with the stigma and practical problems associated with the PMTCT program.¹⁴⁸ This was in response to the problems highlighted by patients in the previous months. Health care workers reported that the first problem in setting up support groups was to ensure that confidentiality was properly understood and maintained. A counsellor stated: “Women need the support, but it is hard for them to trust that the other women in the group will keep everything confidential.”¹⁴⁹ There were various practical difficulties, for example, finding appropriate space in which to hold the support group, the long distances that patients had to walk to attend the support group, and finding financial support for travel costs and meals. Health care

¹⁴⁴ Health Care Workers. Supervision by author. Cape Town, 21 November 2000.

¹⁴⁵ Health Care Workers. Supervision by author. Cape Town, 21 November 2000.

¹⁴⁶ Health Care Workers. Supervision by author. Cape Town, 21 November 2000.

¹⁴⁷ Counsellor. Supervision by author. Cape Town, 28 March 2000.

¹⁴⁸ Hilderbrand et al., 780.

¹⁴⁹ Health Care Workers. Supervision by author. Cape Town, 14 July 2000.

workers often discussed the expectation of patients that there would be some kind of financial reward for attending support groups. That is one of the reasons why health care workers created income-generating projects for patients. In 2001, an educator stated: "The more food there is, the better the women attend. They like to be busy and be working. That is when they talk and help each other. If we can get them a little money from their work it is better for them."¹⁵⁰ Despite the problems, support groups were useful in helping patients share information resources, ensuring more compassionate treatment from clinic staff, and getting donations from NGOs.¹⁵¹ Moreover, support groups played an important role in reducing staff burnout, largely because health care workers reported that these interventions contributed to their feelings of usefulness in the program.¹⁵²

In 2001, training organisations, particularly ATICC and Lifeline, attempted to rectify some of these problems by addressing these issues in training and providing support to health care workers through supervision and ongoing training. These attempts had limited success mainly because of the dire lack of resources in primary health care clinics. What is noticeable about the PMTCT program all the way through to 2004 is the lack of specific gender sensitivity in planning, training and management. Women were subjected to ongoing violence because they were in the program that exposed their HIV-positive status. Women were also being punished for being treated. At the end of 2003, health care workers, in order to include male partners in the counselling, had made certain adjustments. This had mixed results, either exposing women to more violence or getting men tested and getting their support. Awareness of gender in the experiences of patients, health care workers and

¹⁵⁰ Health Care Worker. Focus group by author. Cape Town, 23 February 2001.

¹⁵¹ S. Nzama and T. Welz, "Setting Up and Sustaining Support Groups around a Prevention of Mother to Child Transmission (PMTCT) Program in Rural KwaZulu-Natal, South Africa," *MRC*, 2004, <<http://www.afroaidsinfo.org>> (Accessed: 21 September 2004).

¹⁵² Health Care Worker. Focus group by author. Cape Town, 23 February 2001.

training organisations was inconsistent in the PMTCT program. The discussion now turns to the central role that men play in the spread and management of the disease.

The Role of Men in the Spread and Management of HIV/AIDS

Between 1989 and 2004, there was a pervasive silence surrounding male sexuality and responsibility in the HIV/AIDS debate.¹⁵³ In 1998, a UNAIDS report argued “researchers and prevention workers are coming to the firm conclusion that the global epidemic is driven by men.”¹⁵⁴ The inclusion of men in the discussion of HIV/AIDS was boosted by the World AIDS Campaign of 2000, entitled *Men and AIDS: A Gendered Approach*. This campaign focussed on the cultural expectations and beliefs that increase men and women’s vulnerability to HIV/AIDS. In 2000, Bujra argued that HIV/AIDS campaigns are needed that not only changes men and women but also the relations between them.¹⁵⁵ In 2003, there was a call in South Africa to move the debate beyond “men drive the pandemic” to “how can men be engaged in containing HIV/AIDS.”¹⁵⁶ A 2003 study looked at the characteristics of men who are unlikely to allow their pregnant wives to take AZT to prevent the vertical transmission of HIV.¹⁵⁷ The survey of 586 men whose female partners were receiving prenatal care concluded that these men are more likely to be less educated than those men who support their wives taking AZT. The study concluded with a call for ongoing education of men. In 2004, research argued that HIV/AIDS strategies that

¹⁵³ Regional AIDS Initiative of Southern Africa of Voluntary Services Overseas (RAISA/VSO) & AIDS Conference, Pretoria, South Africa, February 2003.

¹⁵⁴ M. Foreman, ed., *Men: Taking Risks and Taking Responsibility?* (London: Panos Institute, 1999).

¹⁵⁵ J. Bujra, “Targeting Men for Change: Aids Discourse and Activism in Africa,” *Agenda*, 44 (2000): 6-23.

¹⁵⁶ M. Savage, “Africa’s Men Meet Challenge of Fighting HIV/AIDS,” *Alertnet*, 13 June 2003, <<http://www.alertnet.org/thefacts/reliefresources/aidsfeature>> (Accessed: 26 July 2004).

¹⁵⁷ N. Bukonda, “Uncovering the Characteristics of Men Who are Unlikely to Allow Their Pregnant Wives to take AZT to Prevent Vertical Transmission of HIV/AIDS,” *MRC*, 2003, <<http://www.afroaidsinfo.org>> (Accessed: 28 September 2004).

have focussed only on women have proved ineffectual.¹⁵⁸ In South Africa, the call for men to take more responsibility came from NGOs and health care workers, as well as the government who, for example, requested men to use condoms because it is a “sign of respect . . . not a sign of mistrust.”¹⁵⁹

The reasons for men’s active role in HIV/AIDS-related violence and unsafe sex are numerous. Marks, in examining the economic factors in the emergence and spread of HIV/AIDS, argued that an appreciation of the history of migrant labour, particularly in the mining industry, assists in explaining the exploitation, subordination, and control of men that intensified the social dislocation, violence, and sexual brutalisation of women.¹⁶⁰ Kaband, in discussing the absence of men in the HIV/AIDS struggle, stated: “Men have become spectators, irresponsible and indifferent.”¹⁶¹ Lindegger argued that men’s sense of loss of leadership in families and communities has left men feeling displaced and hopeless, and that this has contributed to men’s reduced motivation to practise safer sex.¹⁶²

The issue of men’s role in HIV transmission was barely raised in HIV/AIDS training before 1995.¹⁶³ The main reasons for this were the medical emphasis in HIV/AIDS training and the lack of focus on gender issues. Unfortunately, the WHO research mentioned earlier in this chapter (men being at a lower risk than women to infection in the same sexual act) did little to include men in the debate. In 1996, health care workers argued that male patients used inheritance and culture to justify unsafe

¹⁵⁸ PlusNews, “Frank Dialogue about Gender Key to Tackling HIV/AIDS,” *IRIN*, 16 November 2004, <<http://www.irinnews.org>> (Accessed: 18 November 2004).

¹⁵⁹ T. Mbeki, “Address on World AIDS Day,” 1 December 1999, <<http://www.anc.org.za/ancdocs/history/mbeki/1999/tw1201>> (Accessed: 4 October 2004).

¹⁶⁰ S. Marks, “An Epidemic Waiting to Happen? The Spread of HIV/AIDS in South Africa in Social and Historical Perspective,” *African Studies*, 61, no. 1 (2202): 13-26.

¹⁶¹ Kaband cited in Savage.

¹⁶² Lindegger cited in Savage.

¹⁶³ Trainer. Supervision by author. Cape Town, 11 May 2000.

sex and violence against women.¹⁶⁴ This observation was confirmed by research that showed that training organisations argued that men in rural settings used inheritance and culture to justify sexual practices that harm women.¹⁶⁵ In 1997, some male health care workers argued that culture justified gender differences in power. For example, a nurse on a training course commented: “My father’s father did it this way. You need to be the boss with your women otherwise they don’t respect you. (laughs) I know this is not right, but no-one tells me how to be a man in this new South Africa.”¹⁶⁶ Such responses entrenched the view that men were responsible for fuelling the epidemic, and unable to take responsibility for their role in HIV/AIDS.

Between 1998 and 2000, various discussions were held between trainers and health care workers: it was generally agreed that male trainers and health care workers needed to become more involved.¹⁶⁷ In 2000, trainers reported success in engaging male health care workers in specific issues like STIs, counselling men, and traditional gender assumptions.¹⁶⁸ Certain male trainers also modelled more appropriate gender behaviour in training and in health care meetings. ATICC encouraged initiatives that provided male health care workers with coaching from older male nurses. Other organisations like Lifeline and Leadership South actively recruited male counsellors drawn from local communities and chose male clinical supervisors. In 2000, the UNAIDS produced a document that highlighted the importance of striking a balance between the recognition that the behaviour of some men fuels the pandemic and inculcating all men.¹⁶⁹ The risk of generalising blame was the alienation of all men. In 2000, certain male health care workers commented on the fact that HIV/AIDS

¹⁶⁴ Health Care Workers. Supervision by author. Cape Town, 16 July 1996.

¹⁶⁵ RAISA/VSO.

¹⁶⁶ Health Care Workers. Supervision by author. Cape Town, 5 September 1997.

¹⁶⁷ Trainers. Supervision by author. Cape Town, 12 August 1998.

¹⁶⁸ Trainer. Supervision by author. Cape Town, 11 May 2000.

¹⁶⁹ UNAIDS, *Men and AIDS: A Gendered Approach* (Geneva: UNAIDS, 2000).

messages should acknowledge the men who were not contributing to violence against women and the spread of HIV/AIDS.

In 2001, health care workers reported that the training focus on men and HIV/AIDS in the three preceding years had been successful because there were significant attitudinal and behavioural changes in their male patients.¹⁷⁰ For example, “I’m different now. I’m proud to be a counsellor for HIV. I tell men they can be different, they can be better men.”¹⁷¹ The importance of positive male role models¹⁷² was evident in observations like: “I have a colleague who has single-handedly changed the hearts of hundreds of men. He is a trainer and he has taken his message into clinic waiting rooms, training rooms, and rural communities. He has managed to engage them, involve them. The health care workers are now out there addressing issues like violence, rape, condoms, etc.”¹⁷³ Between 2001 and 2004, the issue of men remained important in HIV/AIDS training, and while health care workers reported successes, the majority of the problems still involved the relative absence of men in the debate at the primary health care level. By 2004, male health care workers had made significant contributions to HIV/AIDS and gender through their attitudes and ability to challenge men and alter their sexual behaviour.

There was one corporate example that illustrates an attempt to engage men more actively in the HIV/AIDS debate. In 1999, Irving and Johnson (I&J) implemented the *5 in 6 Project* (established by Charles Maisel in 1993) as part of their gender and HIV/AIDS initiative. The project’s premise is based on a community survey that found that women claimed that five out of six men are good husbands,

¹⁷⁰ Counsellor. Supervision by author. Cape Town, 21 February 2001

¹⁷¹ Counsellor. Supervision by author. Cape Town, 21 February 2001.

¹⁷² This view was backed up by research that male politicians and other men play an important role in the public acknowledgement of HIV/AIDS and the promotion of men’s responsibility. For example, J. Bujra and C. Baylies, *AIDS, Sexuality and Gender in Africa: Collective Strategies and Struggles in Tanzania and Zambia* (London: Routledge, 2000).

¹⁷³ Trainer. Focus group by author. Cape Town, 17 May 2001.

brothers, sons, and uncles, and thus that these men should be acknowledged and encouraged to play a more active role in dealing with gender inequality within their communities. That is, the project attempts to enrol men who are not abusers and who oppose abuse to change the attitude and behaviour of men. Maisel claimed: "Our aim is simply to recognise the 5 in 6 men who have a positive influence in our society."¹⁷⁴ Workshops were held to assist men to understand power relations between men and women and to find positive solutions to difficult domestic situations.¹⁷⁵ Thus, the project is an awareness and prevention initiative that confronts men to end violence against women and children. Coordinating staff were positive about the results, for example: "We had wonderful feedback and the men were very positive about the whole project. It was obviously very powerful. Men said they wished to take it further into their communities."¹⁷⁶ Participants were also positive: "The project has changed my perception of women and made me realise my selfishness. Now the ball is in my court."¹⁷⁷

In September 2000, men from I&J were part of the *One City Many Cultures Festival* held in Cape Town.¹⁷⁸ As part of the festival, the 5 in 6 Project exhibited all 500,000 names of positive men that had been submitted by the people of Cape Town, and twelve photographs of men from I&J. In December 2000, the I&J collaboration with the 5 in 6 Project ended because "it was too large a project to continue."¹⁷⁹ There was no consistent follow-up in the I&J project and thus the success of the intervention in terms of domestic violence and HIV/AIDS remained unclear. Yet, this project is an

¹⁷⁴ C. Maisel, "Positive Men: The Silent Majority," *ChildrenFIRST*, 22 (December/January 1999).

¹⁷⁵ M. Jaffer, "Fighting Abuse with "Good" Men and Savings Clubs for Women," *Changemakers Journal*, (November 2001).

¹⁷⁶ D. van der Walt (Occupational Health Nurse, I&J). Private communication with author. Cape Town, 16 November 2004.

¹⁷⁷ C. Maisel, *The Secrets of Working with Men* (Cape Town: Open Book, 2000).

¹⁷⁸ Archdiocesan News, "Goodman/Badman Exhibition," *Archdiocesan News*, 18 (April/June 2000).

¹⁷⁹ D. van der Walt (Occupational Health Nurse, I&J). Private communication with author. Cape Town, 16 November 2004.

example of the attempts to engage men in positive ways in the HIV/AIDS debate and change destructive attitudes and behaviour. This case study highlights the relative success of such initiatives, yet the lack of commitment to this issue by organisational management remains. The debate about gender and HIV/AIDS has remained predominantly about women, and critical dialogue regarding men's role in the spread and management of the epidemic continues to be peripheral.

Conclusion

The link between gender and HIV/AIDS was made a year before the first HIV/AIDS training course in the Western Cape in 1989. The medical emphasis of the training content meant that gender was not addressed in the first HIV/AIDS training course. Between 1989 and 1994, patients increasingly reported rape, domestic violence, child sexual violence, and baby rape to health care workers as part of HIV/AIDS counselling and testing. The narrative of this period was characterised by the increased reports of violence against women, yet health care workers regarded these issues as unrelated to HIV/AIDS. Thus gender was not linked to HIV/AIDS transmission. Issues like disclosure to partners, condom distribution, and the role of men were seldom raised in this period.

1995 was an important year in that gender was highlighted in the HIV/AIDS narrative. First, the WHO study that showed women's biological susceptibility to HIV was a significant shifting point in how training organisations regarded gender in relation to HIV/AIDS. Gender was thus firmly linked to HIV transmission. Second, with the release of the Provincial Key HIV/AIDS Strategies, trainers encouraged HIV/AIDS testing and disclosure. One of the main results of this initiative was that

health care workers reported many women who were not willing to disclose their HIV/AIDS status for fear of physical abuse by their partners.

Between 1995 and 1998, trainers developed the issue of women's susceptibility to HIV/AIDS by making suggestions as to how health care workers could raise the issue with patients. Moreover, health care workers engaged gender issues like domestic violence, rape, and child sexual abuse. Trainers reported that health care workers were traumatised by exposure to this kind of information from patients. ATICC played an important role in establishing support and counselling for health care workers and patients who had been traumatised. The narrative during this period shifted from the identification of important gender issues to the practical management of the gender-HIV/AIDS link as presented by patients in primary health care clinics.

In 1998, the murder of Gugu Dlamini resulted in a revision of standard practice regarding notification of partners. The preceding years witnessed a growing awareness in trainers and health care workers of the dangers for women in contracting and communicating her HIV-status, but Dlamini's death was the turning point in HIV/AIDS management. Trainers and health care workers understood the particular complexities of being an HIV-positive woman. The previous reports of abuse were now consolidated and more general reports were replaced with specific incidents drawn from clinics in the Western Cape. Also in 1998, the PMTCT program started in Khayelitsha and this program raised particular gender issues faced by the mothers receiving AZT. Trainers played an important part in supporting health care workers and developing new treatment and care protocols. Finally, in 1998 the female condom was introduced. The narrative of this period was characterised by the in-depth

exploration of the particular risks and problems faced by women with HIV/AIDS. Gender was now centrally placed in the HIV/AIDS debate.

Between 1998 and 2001 health care workers continued to address the issues highlighted above. For example, they developed support and work groups for women attending the PMTCT program. In response to partner disclosure, trainers developed new guidelines for health care workers to assess risk and help women make individual decisions. During this period, training organisations focussed on the need for male trainers and health care workers to become more involved in the gender-HIV/AIDS debate. The narrative of this period was characterised by actions as opposed to the awareness in the period above.

Between 2001 and 2004, health care workers reported significant sexual behavioural change in male patients as a result of their gender-focused initiatives. Despite many reports of success, health care workers still generally complained about the lack of public awareness in the area of gender and HIV/AIDS. Most of the suggestions regarding gender initiatives during this period were raised by trainers, health care workers, and NGOs, with little input from government. The narrative by 2004 was one of limited success and much frustration.

An important area of HIV/AIDS and gender research that remains relatively unexplored is the issue of agency, in which the assumptions of power and authority are engaged.¹⁸⁰ Engaging gender means examining interpersonal and structural gender relations that place women at a disadvantage in terms of their choices and ability to act. Issues like the condom distribution campaign, the depiction of women as givers but not receivers of care, and the structural and interpersonal experiences of female health care workers present different kinds of challenges to the management of gender

¹⁸⁰ T. Marcus. Private communication with author. Cape Town, 1 November 2004.

relations. There have been calls for a stronger emphasis on gender-based power imbalances in the national HIV/AIDS policy and the proper enforcement of laws.¹⁸¹ How researchers, training organisations, and health care workers respond to these challenges over the forthcoming years is vital not only to the management of HIV/AIDS but also to gender structural power relations.

¹⁸¹ PlusNews, "Gender Equality Needed in National HIV/AIDS Policy," *IRIN*, 8 November 2004, <<http://www.irinnews.org>> (Accessed: 10 November 2004).

CHAPTER EIGHT: Conclusion and Discussion of Findings

The historical analysis of HIV/AIDS training in the Western Cape between 1989 and 2004 highlighted significant shifts in content and methodology, and the political, socio-economic, cultural, and gender factors contributing to these shifts. Moreover, this analysis illustrated the complex interaction between the various contributing factors that influenced HIV/AIDS training. Historically, this study covered HIV/AIDS training during monumental political, social and economic changes. Certain principal themes emerged from this historical analysis.

When the Aids Training, Information, and Counselling Centre (ATICC) delivered the first HIV/AIDS training in the Western Cape in August 1989, it was part of a limited set of national interventions managed by the National Party (NP) from the first diagnosis HIV-positive diagnosis in 1982 to 1989. At the time of the first training course, few people guessed (including the ATICC staff) how quickly the HIV/AIDS numbers and the demand for training would increase. Given the political climate in 1989, there was a certain amount of suspicion of ATICC'S mandate amongst health care workers. This suspicion was heightened by the fact that few health care workers outside of the specialist HIV/AIDS clinics had significant experience with HIV/AIDS patients and issues. Health care workers' main initial fear was that of occupational exposure to HIV/AIDS.

This analysis illustrated the medical emphasis of the first courses. The HIV/AIDS organising narrative was largely medical, with a primary emphasis on disease and disease management. Doctors provided the medical input, and the methodology resembled medical courses for doctors and nurses. This was a significant organising narrative because it remained the basis of all subsequent

HIV/AIDS training in the province despite the inclusion of other relevant factors (socio-economic, cultural, gender, and legal) in the spread and management of the disease. In terms of the spread of the disease, the narrative of 1989 focussed on two of these factors in isolating gays and Blacks as the high-risk groups. Even though this view reflected the predominant research trends of the 1980s, this discrimination and stigma against Blacks, to a greater degree, and gays, to a lesser degree, as the transmitters of HIV/AIDS lingered all the way to 2004.

In chapter four, this analysis highlighted the National Party's (NP) response to HIV/AIDS. Many arguments have been forwarded which blame the NP for not having responded adequately to the disease in the early years. While these arguments illustrate the racial and gender bias of the NP's response, especially in the period 1982 to 1989, such arguments fail to compare the NP's response to other regional or international governments' early responses to HIV/AIDS. With the exception of Musiveni's response to HIV/AIDS in Uganda, few examples exist of proactive government responses to the disease, especially in the early phases of the disease. This point is mentioned not as a justification of the NP's response to HIV/AIDS, but rather as an illustration of the dearth of critical and comparative historical analyses in this area. The limitations of ahistorical commentary on such issues are thus raised.

Between 1990 and 1994, there was significant collaboration on the issue of HIV/AIDS between the NP and the African National Congress (ANC) amidst the negotiations on political transition. This collaboration led to the formation of the National AIDS Convention of South Africa (NACOSA), which was represented by the ruling NP government, ANC, NGOs, and organized industry and labour representatives. This period was the only one in which there was a parallel process between the practical HIV/AIDS initiatives of training organisations and government.

That is, trainers and health care workers on the one hand, and government on the other hand, shared similar goals with regards to HIV/AIDS. Health care workers and trainers were motivated by the political shift: they saw their ideas reflected in the policies and practises of the proposed democratic government. In this period, trainers and health care workers were optimistic about the future of HIV/AIDS training and management. This optimism was largely determined by the political changes and collaboration between the NP and ANC.

The April 1994 general election was critical to the changing HIV/AIDS narrative. The ANC government effected two changes that had a lasting effect on HIV/AIDS management. One, after the April election, the ANC dominated Cabinet adopted the NACOSA strategy and established the South African National AIDS Plan. Given the relatively small number of HIV infections, this meant that the government was in a reasonably strong position to respond to the disease. Two, government adopted a health plan that was based on the Primary Health Care Approach of the World Health Organisation (WHO), which meant that HIV/AIDS persons now presented at the primary health care clinics instead of the few specialist clinics, thus exposing considerably more health care workers to the disease. HIV/AIDS had a wider impact on clinic and hospital staff in terms of the higher numbers and the subsequent pressure placed on the scant resources. There was a democratisation of the HIV/AIDS narrative: there was the expectation that all South Africans would receive adequate health care, including in the area of HIV/AIDS. Thus, 1994 was a watershed year in terms of the political, social, and economic issues that health care workers raised. The election legitimised these issues that had remained largely silenced in HIV/AIDS training before 1994.

As chapter five has shown, the increasing number of patients who presented at clinics influenced the attitudes of health care workers towards HIV/AIDS persons. Health care workers were compelled to engage with the more complex historical, political, socio-economic, cultural, and gender issues underlying the epidemic. In this sense, the clinical, counselling and support structures in clinics and hospitals provided the opportunity for rapid and significant learning for health care workers. Personal and professional exposure appears to have reduced discrimination and enhanced the responses of health care workers.

In 1998 many significant events that contributed to the changing HIV/AIDS narrative. One, the government controversies intensified around the Virodene issue when the government fired the AIDS Advisory Committee. Health care workers commented on the confusion that this action created, particularly given the three seemingly positive initiatives of the government in October 1998, namely: Mbeki's launch of the *Partnership against AIDS* program aimed at mobilising South Africans against the HIV/AIDS; Mbeki's delivery of the government's *HIV Address to the Nation*, in Mandela's absence; and the government's announcement that it would finance AZT for pregnant women. In December, the government's retraction of the offer of AZT on the grounds that it was too expensive and this increased the narrative of disillusionment amongst trainers and health care workers. Despite this announcement, the Western Cape Provincial Department of Health decided to pursue the funding of AZT for pregnant HIV-positive women: a decision headed by ANC doctors in the province. Two, the stoning of Gugu Dlamini in KwaZulu-Natal had important effects on trainers and health care workers in the Western Cape. The most significant effect was the increased awareness that led to the rewriting of disclosure policies for female patients in order to protect HIV-positive women from their male

partners. Dlamini's death highlighted gender in the HIV/AIDS narrative, and changed how health care workers regarded the sexual politics of the disease. Three, Lifeline initiated two important initiatives. In October 1998, it introduced the Prevention-of-Mother-to-Child-Transmission (PMTCT) program in Khayelitsha, and locally selected counsellors and educators were placed in Site B and the Michael Maponyane clinic. Moreover, Lifeline was the first NGO that attempted to familiarise itself, and collaborate, with local traditional healers. Lifeline's initiatives were important because resident counsellors and educators brought a new narrative from their community work: the narrative was patient-based, and highlighted the important socio-economic, cultural, and gender issues that effected people living with HIV/AIDS. Health care workers reported that there was an increased demand by patients for their assistance with social issues like bereavement, domestic and sexual violence, crisis counselling, and development issues like poverty, hunger, and transport money. Four, on 10 December 1998, the Treatment Action Campaign (TAC) was launched. TAC proved to be an important role model for trainers and health care workers, especially in the context of the lack of government leadership. Thus, in 1998, the narrative was characterised by further disillusionment with the government, on the one hand, and encouragement with the PMTCT program in Khayelitsha and the establishment of TAC at the end of the year.

As discussed in chapters three to seven, Mbeki's role in the government controversies under the Mandela government as well as his role in championing the dissident view of HIV/AIDS had significant effects on trainers, health care workers and trainers. Much of the research surrounding Mbeki's HIV/AIDS pronouncements has focussed on the international and national responses on the political and scientific level. Little research has focussed on the impact of these pronouncements on civil

society, in particular on persons affected by HIV/AIDS and health care workers. This study showed the negative impact of Mbeki's response to HIV/AIDS on how training was delivered, and the regression in knowledge and attitudes of health care workers and patients between 1999 and 2000. Health care workers were generally severe in their criticism of Mbeki, and they played an important part of the larger opposition to the ANC's HIV/AIDS management of the epidemic. Yet, there was another side to how health care workers responded: they also turned their attention away from the political narratives and focussed on managing HIV/AIDS patients. As chapter four has shown, by 2001, praxis was more important than politics. Finally, HIV/AIDS facilitated public debate in the midst of government silence.

In contrast to the President's nationally and internationally debated views, there were three important developments in term of provincial initiatives. These initiatives highlighted the significant differences between national responses and those in the Western Cape. One, when the ruling Democratic Alliance's support of the extension of the PMTCT program to more clinics in the Western Cape: there were no other comparable national initiatives at this time. Two, the international organisation *Médecins Sans Frontières* (MSF) started the first provincial pilot project with triple therapy to AIDS patients in Khayelitsha. This was an important precursor to the calls for the national antiretroviral (ARV) program in 2004. Three, the provincial government started the Voluntary Counselling and Testing (VCT) program, in which significantly more health care workers and lay educators and counsellors were trained. Moreover, patients were now actively encouraged to attend HIV counselling and testing. The narrative of this period had two voices: one, the ongoing frustrations with the national government, and two, the support and energy associated with provincial initiatives. In the absence of adequate national government responses, health care

workers and training organisations became important conduits of HIV/AIDS information reported by patients. Moreover, training organisations relied increasingly on health care workers to provide training input and develop strategic partnerships with community clinics.

Related to the above issue, the Western Cape was relatively unique in its response to HIV/AIDS. It had a comparatively good health infrastructure, which allowed for the establishment of HIV/AIDS clinics in the early 1990s. Also, ATICC was established in 1989 in the province and unlike other provinces, ATICC (Western Cape) created training and counselling services that were consistent and relevant over the ensuing years, and widely applied by health care workers and NGOs in the province. Finally, the Western Cape had ANC doctors who were willing to challenge the national HIV/AIDS initiatives after the 1994 elections. The best example of this is the defiance by these provincial doctors of the national ANC government's policy on the PMTCT program: the Western Cape implemented the first PMTCT program in the country. All of these factors illustrate the contextual difference of the Western Cape in comparison to the other provinces.

As considered in chapters four and five, this study highlighted the important role of NGOs in the response to HIV/AIDS. NGOs filled the gap created by the tardy and inconsistent responses of the NP and ANC governments. This research showed that NGOs are at the forefront of much of the innovative action research in the field, and that little of this experience is documented. The collaboration between academic researchers and NGOs would arguably thus produce important results. Without such collaboration, important information about attitudes and responses to HIV/AIDS has been, and is, being lost. One issue is the challenge to researchers to accept a participatory model of community-based intervention research. NGOs and training

organisations are significant new sources of information: they have opened up new historiographical questions regarding the social history of disease and how various sectors of society respond to and manage HIV/AIDS. The complexities of the underlying historical, political, socio-economic, cultural, and gender factors were thus illustrated. Thus, NGOs have articulated the complexities and interactions of these underlying factors. Presently, NGOs are at the centre of the government's roll-out of the ARV program.

In chapters three to seven, this study showed that HIV/AIDS training organisations are significant new sources of information. Little formal research captured the depth and breadth of the information to which training organisations had access. In the process of training, health care workers raised prevention, management, clinic, and patient issues. There was a dynamic exchange of information between patients, health care workers, and trainers. Fresh historiographical questions were opened up in this process. Training organisations became the spokesperson for the complex political, socio-economic, cultural, and gender issues that health care workers and patients confronted. A complex narrative developed in training organisations: a narrative that was often better informed about HIV/AIDS than government and researchers. A history of HIV/AIDS emerged from these narratives, but it was a history that was not documented due to the pressing and changing demands placed on training organisations. This, at times, resulted in ahistorical and decontextualised training. One of the challenges facing training organisations is the historical documentation of their work in order to contextualise their narratives and training.

In the province there was an increasing demand for HIV/AIDS training, especially in response to the recently established PMTCT and VCT programs. In

these programs, local people continued to be selected and trained as peer counsellors and educators, and they played an important part in developing community HIV/AIDS resources. The narrative of this period was influenced by the increased provincial response to HIV/AIDS: while health care workers and trainers continued to complain about the national government's insignificant responses, they no longer expected any national guidance or assistance. Health care workers and trainers showed increased competence and self-reliance.

The HIV/AIDS narrative by 2004 was almost exclusively focussed on provincial initiatives. The main national issue that health care workers and trainers debated was that of the roll-out of the ARV program. Patients in the PMTCT program showed the benefits of ARVs, and health care workers expressed excitement about the government's promise to deliver ARVs, but also caution at the government's commitment to this promise and its ability to deliver. As this analysis has illustrated, by 2004 trainers and health care workers had little confidence in government initiatives because there had been few adequate and sustainable government initiatives since the first HIV-positive diagnosis in 1982.

This study also highlighted how government and health leaders made policies and cultural assumptions about people "without knowledge." This finding corresponds to research that highlighted the problems of health policies and programs that are imposed from above without respect for the voices of patients and other users of the health system.¹ Such policies and programs usually face more resistance and are less successful. The fact that health care workers complained of treated as "not knowing" illuminates the issue of Foucault's concept of power/knowledge in which he showed how power is situated in a plethora of social institutions, practices, and

¹ For example, see M. Echenburg, "Historical Perspectives on HIV/AIDS: Lessons from South Africa and Senegal," in *The HIV/AIDS Epidemic in Sub-Saharan Africa in a Historical Perspective*, eds. P. Denis and C. Becker (Online edition, October 2006).

situations. There is little HIV/AIDS research that explores this issue, and thus this issue could be used as a point of departure for further related HIV/AIDS research.

Certain issues were absent from the HIV/AIDS training of health care workers in the period under review. As discussed above, while training organisations did engage, to varying degrees, the underlying political, socio-economic, cultural, and gender issues associated with HIV/AIDS, certain issues were absent. Most noticeably absent were the issues of intergenerational sex, foreigners and HIV/AIDS, AIDS orphans, HIV/AIDS carers, date rape, gang rituals that contributed to the spread of HIV/AIDS, younger women, domestic workers, and older people at risk to HIV/AIDS. These were all important provincial issues, and all of these areas require further historical research. On the national level, the Truth and Reconciliation Commission (TRC) was markedly absent in HIV/AIDS training. Besides some commentary by health care workers on the December 1998 findings that white health care workers in South Africa ignored international health standards in support of Apartheid policies and engaged in abuse of patients, little else of the TRC was discussed. The comments that were made highlighted the fact that patients continued to endure an under-resourced health care system and an unresponsive government.

This study is limited in that only one province, the Western Cape, was analysed, and thus the results are not representative of the whole country. There are regions with significantly higher prevalence rates, for example KwaZulu-Natal, which might show dissimilar shifts in HIV/AIDS training and the underlying factors that contributed to these shifts. Similar comparative historical analyses would be useful if conducted elsewhere in South Africa, and in other sub-Saharan countries with high incidence rates, for example, Botswana, Zimbabwe, or Swaziland. Analogous comparative historical analyses would also be valuable in countries elsewhere in

Africa and the rest of the developing and developed world with different incidence rates, that is, low, concentrated, and generalised epidemics.

While one of the strengths of this study is that all of the major HIV/AIDS training organisations in the Western Cape were included, a weakness is that ATICC made up a significant part of the data. The main reason for this is that ATICC was the first and remains the leading provider of HIV/AIDS training in the province. The size and selection of the sample may limit the generalisability of the results. Also, this study covered a large breadth of data, which may restrict the conclusions that can be drawn from the study. Finally, this study is hampered by the methodological problems of writing contemporary history as outlined in chapter two.

Historical analyses have important implications for HIV/AIDS practice and research. The high prevalence rates of HIV/AIDS in Southern Africa has forced training organisations to work as quickly and efficiently as possible in delivering training to health care workers. Most training organisations have managed to establish innovative, successful, and practical training courses, and the history of how this was achieved can be used to assist organisations nationally and internationally in designing, delivering, evaluating, and managing HIV/AIDS training. The findings of this study highlight the underlying historical factors influencing HIV/AIDS training, treatment, and care, which could guide other HIV/AIDS training. Moreover, the importance of historical methodology to HIV/AIDS research is highlighted: this is a central issue given the ahistorical and decontextualised nature of many HIV/AIDS studies. More broadly speaking, many significant areas of HIV/AIDS research await the attention of historians, for example, the origin of HIV in South Africa, the transmission of HIV in Africa, and in-depth historical analyses of local responses to HIV/AIDS. This study highlighted specific areas that require historical analyses:

among others, the role of gender in HIV/AIDS transmission and management; NGOs and HIV/AIDS; the complexities of cultural factors in determining attitudes towards and prevention of HIV/AIDS; and the role of globalisation in the spread and treatment of the disease.

The relationship between the HIV/AIDS training organisations and the provincial government is complex and largely unexplored. Further research is needed that investigates the sustainability of HIV/AIDS training organisations without the consistent support of central government. Related to this issue is the lack of historical research on the interaction between policy formation and training organisations. Further research is needed to examine the experiences and roles of health care workers and other professionals working in the field of HIV/AIDS. Also, it would be useful to conduct historical research of the experiences of those largely silent people working with or impacted by HIV/AIDS: for example, patients, family, home-based carers, lay educators and counsellors, and AIDS orphans. So, while the broader topics like transmission, education, and attitude formation have been examined historically, numerous specific areas like those mentioned above remain outside of historical study. The above suggestions are made with the view that it is the responsibility of historians to provide ideas, paradigms, and methodologies for understanding and responding to epidemics like HIV/AIDS.² As Berridge argued, the strength of the historical approach lies in “the historian’s sense of chronology; the historical sense of continuity as well as change; and, within the overall chronology, a synthetic and critical ability to interweave and assess different forms of source material and

² A. Whiteside and A. de Waal, “AIDS: A Darwinian Event?,” conference paper, The HIV/AIDS Epidemic in Sub-Saharan Africa in an Historical Perspective Conference, University of Louvain, Louvain-la-Neuve, Belgium, 11-13 March 2004, <<http://www.aids.soton.ac.uk/documents/DarwinianEventpresentation15thApril2004.ppt>> (Accessed: 4 February 2005).

different levels of interpretation.”³ This study highlights the importance of historical methodology and perspective in comprehensively examining a complex and dynamic issue like HIV/AIDS. Historians still have much to contribute to the understanding of this epidemic.

³ V. Berridge, “Introduction: AIDS and Contemporary History,” in *AIDS and Contemporary History*, eds. V. Berridge and P. Strong (Cambridge: Cambridge University Press, 1993), 12.

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