# Twenty-five Years of HIV/AIDS South Africa's Policy Challenges

# Anokhi Parikh and Alan Whiteside

South Africa is one of the few countries in sub-Saharan Africa where HIV prevalence is still rising.<sup>1</sup> The trend is distressing and peculiar, given that South Africa is well-resourced compared to its African counterparts, and that AIDS was identified as an issue in the early 1990s by the African National Congress (ANC).

South Africa's rising HIV prevalence begs the question: why has South Africa been unable to stem the spread of the disease? We are not certain of the reasons for this failure. It is appropriate to take stock of what we have learned about the epidemic and grapple with the policy challenges. This paper discusses the key policy challenges that South Africa faces with regards to HIV/AIDS. To articulate these challenges means understanding the context and nature of the epidemic in the country. The second part of this paper, therefore, provides such a background and offers rationale for a strong response by highlighting the severity of the disease's impact. Part three sets out the four key policy challenges identified: political leadership and will; stigma and discrimination; the human resource crisis in the health sector; and vulnerability and poverty. Part four concludes with policy recommendations.

## HIV/AIDS IN SOUTH AFRICA

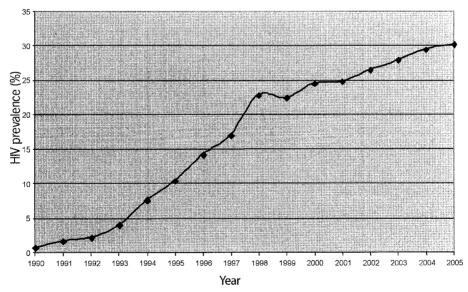
The first two AIDS deaths were recorded in South Africa just over 25 years ago this year, in 1982. However, it was not until 1990 that HIV was seen in the broader population. In a tragic coincidence of history, it

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was in 1994—the year of South Africa's transition to democracy—that the primarily heterosexual epidemic began to escalate rapidly. The current national prevalence rate is 10.8 percent,<sup>2</sup> and an estimated 5.1 million people are living with HIV. Annual HIV prevalence statistics are derived using sero-prevalence surveys of women attending antenatal clinics. Figure One shows the dramatic rise of HIV prevalence among ANC attendees from 1990 to 2005. While the prevalence is higher for women attending ANC clinics than the whole population (the sample only captures sexually active women), this figure provides a clear picture of the overall trend in prevalence. However, it masks the considerable heterogeneity of the epidemic within South Africa. Prevalence varies by province, with the eastern province of KwaZulu-Natal at 40.7 percent and the Western Cape at 15.4 percent. The epidemic also disproportionately affects women: infection rates among younger women are particularly worrisome, with those aged 25 to 29 being the hardest hit.<sup>3</sup>

# FIGURE ONE HIV prevalence among antenatal clinic attendees in South Africa: 1990–2005<sup>4</sup>



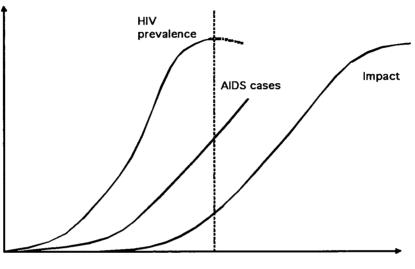
While the epidemic has already severely affected South African society, it is important to note that AIDS will impact the country as a longwave event for decades to come. We visualize the epidemic as having waves over time, as shown in Figure Two. First comes the wave of infection, followed by a wave of illness, then a wave of AIDS-related mortality and, with it, a wave of orphaning.<sup>5</sup> The impact of the epidemic is thus an echo of the infections: those infected today form the wave of mortality and impact in the future. This means that the bulk of the mortality—and therefore most

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of the policy and public health challenges—is yet to come. Twenty-five years after the first two reported cases of AIDS, South Africa is only beginning to feel the long-wave effects of the disease.

## FIGURE TWO Epidemic Curves: AIDS as a Long-Wave Event<sup>6</sup>

Numbers



Time

### **Demographic Impacts**

HIV/AIDS is an exceptional disease; it strikes primarily the young adult and economically active population. Figure Three shows mortality in the South African population by age, as recorded through vital registra-

tion from 1997 and 2004. The increase in recorded deaths, especially among those aged 25 to 50, is remarkable and demonstrates the demographic impact of the epidemic. By striking the working-age population, AIDS impacts the household's ability to generate income, contribute to society and the economy, and care for children, consequently straining the extended family. AIDSrelated deaths also bring increased

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expenses, such as funeral and medical costs, that further impoverish poor households.<sup>7</sup>

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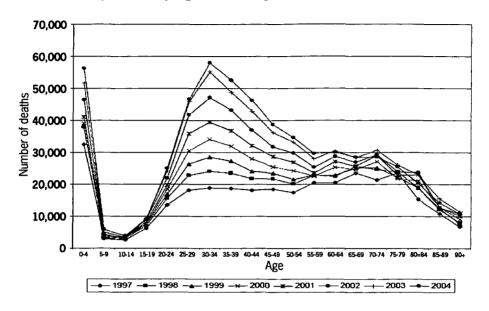


FIGURE THREE Distribution of Deaths by Age in South Africa 1997–2004<sup>8</sup>

The consequences of this mortality impact the young and the elderly. There are a staggering 1.2 million orphans<sup>9</sup> living in South Africa today.<sup>10</sup> This figure is expected to peak in 2015 at approximately 2.3 million,<sup>11</sup> the vast majority orphaned by AIDS. This issue has received significant international attention, with speculation that orphaning could have dire consequences for society in the future. For instance, orphaning could result in negative impacts on school enrollment and long run health outcomes, as indeed some studies have shown,<sup>12</sup> and will have long run consequences for society and the economy. Moreover, one cannot overstate the psychological trauma of losing a parent, and the impact this may have on a child's future well-being and on social cohesion.

Related to the issue of orphaning is the impact on the elderly. South Africa'a apartheid planning required that men migrate to work in factories and mines in white urban areas for long periods of time. The fractured society that resulted from this forced migration often meant that grandparents took care of many children. AIDS has intensified this trend and grandparents increasingly form the basis of support structures for children once their parents are gone. Chazan has shown that the elderly are taking care of large numbers of children with diminishing sources of income, relying heavily on old-age pensions.<sup>13</sup> The story of one informal female trader from the Warwick Junction trading area of Durban illustrates this dynamic clearly. Between December 2002 and December 2005, the woman, in her 50s, absorbed two orphans into her family, which increased from 15 to 19 members; lost four young adults (two of whom were her children); cared for six seriously ill people; and became the only income earner. HIV/AIDS is thus changing the composition of households and family dynamics in ways that will have long-term implications for South African society.

## Economic Impacts

What do these individual and household-level effects mean for the national economy? At the macroeconomic level, some models have predicted that AIDS will cripple the economy,<sup>14</sup> which would be crushed due to the loss of human capital and the decline in intergenerational transfer of knowledge. Other models, with different assumptions, have shown minimal impact.<sup>15</sup> Indeed, observed growth seems to show negligible macroeconomic impact; South Africa's recent growth rates have been robust and high. However, the lack of observable macroeconomic impact may be because the bulk of the impact is yet to come.

Some impacts could be mitigated by antiretroviral therapy, allowing HIV-positive people to live longer, healthier lives. Unfortunately, as discussed in the next section, South Africa got off to an exceptionally slow start with respect to delivering such treatment. Today, despite having one of the world's largest public sector treatment programs, South Africa's coverage is woefully inadequate, reaching only 21 percent of those in need.<sup>16</sup> Scaling up antiretroviral rollout sustainably and quickly is a major challenge with which South Africa is grappling. Although the amount of money being made available by the National Treasury is increasing each year, with a real increase of 36 percent between 2004 and 2005,<sup>17</sup> the capacity constraints, lack of leadership, and stigma regarding HIV have prohibited rapid scaling up. South Africa's slow antiretroviral therapy roll out and inadequate prevention policies make the need for aggressive AIDS policies abundantly clear.

## POLICY CHALLENGES FOR THE FUTURE

Combating the epidemic requires successful prevention of infection, universal access to treatment, and minimization of the epidemic's impact on the families of those affected and the broader society. In South Africa, the major cross-cutting policy challenges that have affected prevention, treatment, and management have been:

- A lack of political leadership and will;
- Stigma and discrimination against the infected;
- A human resource crisis in the health sector;
- A failure to understand HIV/AIDS in the context of gender inequalities and poverty.

## Lack of Political Will and Leadership

The ANC's initial response to the AIDS epidemic was encouraging. In 1990, a time when few African countries were openly confronting the disease, anti-apartheid activist and ANC leader Chris Hani stated: "We cannot allow the AIDS epidemic to ruin the realization of our dreams."<sup>18</sup> In 1992, a meeting was called to unite South Africans against AIDS, and in October 1994, the cabinet adopted the National AIDS Plan. The response then quickly went from being thoroughly inadequate to terribly damaging. In the Mandela years, AIDS was hardly mentioned. The reasons for this are complex and have to do with the inability to understand a disease that was still largely invisible, as well as the new government's prioritization of the enormous task of transition.

In 1999, just as the impacts of the epidemic were beginning to be felt, President Thabo Mbeki publicly questioned whether HIV caused AIDS and supported the "denialist" position that AIDS was caused by poverty, malnutrition, and antiretroviral therapy.<sup>19</sup> Furthermore, in a television interview, he stated that he would not take an HIV test as it would be "confirming a particular paradigm."<sup>20</sup> The controversy of his denialist claim forced him to withdraw from the debate in 2000, but the damage had already been done; he had undermined prevention and delayed the availability of treatment. Many found comfort in the president's view that AIDS symptoms were caused by poverty, and thus did not see the need to change behavior. The resultant stigma linked to the infection meant that those who were ill did not come forward for testing or treatment.

Carrying the torch of poor leadership, Health Minister Manto Tshabalala-Msimang resisted the delivery of antiretroviral therapy on grounds that the drugs were "toxic."<sup>21</sup> A mass civil disobedience by civil society organizations under the leadership of the Treatment Action Campaign compelled the government to provide antiretroviral therapy at some public sector hospitals in 2004, although the delivery has been slow. Since then, the minister has failed to espouse a clear message on antiretroviral therapy and has consistently supported the use of nutritional supplements, garlic, lemon, and olive oil over "poisonous" antiretrovirals.<sup>22</sup> As contrary as they are to scientific evidence, these statements have led to both a disbelief in the disease as well as a reluctance of AIDS patients to access antiretroviral therapy.<sup>23</sup> The messages surrounding AIDS treatment have been confusing. Thus, antiretrovirals are currently perceived as another "alternative therapy" for HIV/AIDS, alongside traditional medicine and nutritional supplements. This is one of the main reasons that antiretroviral therapy has not had the desired effects of reducing stigma, increasing testing levels and decreasing

increasing testing levels, and decreasing HIV incidence in South Africa.<sup>24</sup>

Mixed messages have not been limited to treatment. Misinformation around HIV transmission has been inserted into the public domain by poThe messages surrounding AIDS treatment have been confusing.

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litical leaders. In 2006, former Deputy President Jacob Zuma admitted to having unprotected sex with an HIV-positive woman, despite knowing her status. His claims that HIV was not transmitted easily from a woman to a man, and that his chances of contracting the virus were minimized by his showering after sex, caused fury and dismay amongst HIV/AIDS activists and organizations. The National AIDS helpline was reportedly flooded by queries regarding the validity of his claim.<sup>25</sup>

These mixed messages from people in positions of political power have negative implications for behavior change, prevention, treatment uptake, and efforts aimed at reducing stigma. Moreover, these events have compromised the public policy agenda, distracting from more productive discussions around the epidemic in the public arena.<sup>26</sup> One of the biggest challenges for future HIV/AIDS policy is the development and dissemination of clear, coherent, and evidence-based messages on prevention and treatment from South Africa's leadership.

## Stigma and Discrimination

As stated by Barnett and Whiteside, "HIV/AIDS mixes sex, death, fear and disease," making it a highly stigmatized illness.<sup>27</sup> Stigma lies at the heart of HIV transmission: it limits testing, prevents the uptake of treatment, and results in the discrimination of those infected. Indeed, AIDS is still rarely mentioned as the cause of death, even when young adults are being buried after periods of illness. Despite a framework of antidiscriminatory laws, stigma in South Africa has remained a barrier to testing, prevention, and treatment. Mitigating the impact of stigma is a key policy challenge today. Campbell, et al. found that stigma is rife in South African communities and directly affects the ways in which HIV/AIDS is managed. HIV-positive persons were uncomfortable disclosing their status to family members for fear of rejection. Family members often "hid away sick relatives, depriving them of health care or support."<sup>28</sup> Stigma affected the uptake of voluntary counseling and testing, as youth were scared of being seen entering a counseling office in their communities.

The provision of free antiretroviral therapy was expected to increase testing levels by giving people incentives to know their own status. However, the stigma is so severe that it has prevented people from accessing therapy at all, or resulted in their seeking treatment only in the late stage of illness.<sup>29</sup> Stigma also pervades the health sector and was cited as one of the main reasons why even health care workers did not seek treatment.<sup>30</sup>

Dr. Peter Piot, Executive Director of the Joint United Nations Program on HIV/AIDS (UNAIDS), has suggested that treating HIV/AIDS like a manageable, normal illness and "normalizing" the disease could contribute positively to the ways in which people respond to those infected and help minimize stigma.<sup>31</sup> Several experts feel that moving away from thinking of AIDS as an exceptional disease to thinking of it as just another chronic, manageable illness (like diabetes) would reduce stigma. This is certainly a way forward.

## Health Sector Human Resources

As in most parts of Africa, South Africa is facing an acute shortage of health personnel. With aid money on the rise, the supply of health care professionals is the dominant constraint in scaling up treatment programs and providing care for the infected, both crucial to reducing the impact of the disease. Nearly 30 percent of health professional posts in the public sector were vacant in 2006.<sup>32</sup> The number of doctors, nurses, and pharmacists registered to work in the public sector has been decreasing over the years,<sup>33</sup> and attrition rates among nurses are high, at 6.2 to 9.9 percent.<sup>34</sup> Moreover, HIV/AIDS-related mortality is itself responsible for some of the decline in supply of health professionals. A study by Shisana, et al. found that between 1997 and 2001, HIV prevalence among health care workers was 15.7 percent, and that 13 percent of deaths among health workers could be attributed to HIV/AIDS.<sup>35</sup>

Contributing to this shortage is the migration of health workers. Between 1990 and 2000, there was a 559 percent increase in nurses earning qualifications verified for overseas employment, and between 1998 and 2000, 58.3 percent of health personnel interviewed declared an intention to migrate to the West, predominantly to the United Kingdom.<sup>36</sup> Poor salaries, inefficient management practices, and high workloads were cited as the main reasons for the desire to migrate.<sup>37</sup> While not all those with the intention to migrate actually manage to do so, the statistics point to the need to address issues of human resources in the health sector.

There have been successful efforts at addressing human resource crisis, as in Malawi. The government launched an "Essential Health Package" initiative in 2004 using donor assistance to increase incentives for retention, increase training capacity, and provide technical assistance to improve management capacity.<sup>38</sup> Though this is a rather recent initiative, there are signs of early success, indicating that the human resource crisis in other parts of Africa is clearly surmountable.<sup>39</sup>

The health sector crisis within South Africa is undermining the country's ability to roll out antiretroviral therapy and provide care to those infected. A goal of universal access to treatment will require that South Africa tackle this issue head on. Raising salaries, improving systems of management, and tackling stigma in the workplace should help alleviate the crisis.

## HIV/AIDS in the Context of Gender Inequality and Poverty

Responding to HIV/AIDS as a health issue is important but not sufficient. This is because the transmission of HIV is linked inextricably with gender inequality and poverty. A successful AIDS policy should be cognizant of this reality.40 Nowhere are the links between gender, poverty, and transmission more apparent than in informal urban settlements, where prevalence rates are twice as high and incidence is approximately four times as high as in formal urban settlements.<sup>41</sup> Hunter's study from one such settlement has shown how "women's exchange of sex for money in a variety of locations is intricately associated with gendered economic inequalities."42 In the context of approximately 40 percent unemployment and the feminization of poverty, women are increasingly reliant on transactional sex in exchange for basic necessities, commodities, accommodation, and protection. Moreover, studies have shown that large income differences between men and women fuel sexual activity across an age gap,43 a significant avenue for the spread of the disease. This is supported by data showing that 23.9 percent of women aged 20 to 24 were infected with HIV, as opposed to only six percent of men in this age group.44 Although this may not be the only reason why prevalence rates are higher in informal settlements, this example brings to the forefront the complexity and interconnectedness of sex, risk, and livelihood.

Current prevention policies focus on behaviour change and condom use. Driven by the government, donors, and a range of nongovernmental organizations, educational and awareness-building programs have had some success. However, they fail to address the reasons why some people have risky sex, or how they are able or unable to negotiate safe sex. Indeed, prevention programs have assumed the ability of women to negotiate safe sex. This is particularly problematic in the absence of female-controlled methods of prevention. Colvin estimates that 60 to 80 percent of African women in South Africa had just one partner but were infected because they were unable to negotiate safe sex and were infected by their partner.<sup>45</sup> For HIV prevention programs to truly be successful, there needs to be a radical restructuring of women's ability to both negotiate safe sex and to make a living.

### CONCLUSION

To summarize, a number of policy recommendations have been brought out so far. These include:

- A strong, clear, and coherent message from political leadership matched with a political will to tackle the epidemic;
- A shift towards "normalizing" the disease in order to reduce stigma;
- Addressing the human resource crisis by increasing health care workers' salaries, improving human resource management systems, addressing stigma within the health sector, providing treatment for infected health care workers, and creating mechanisms and institutions to train more health professionals;
- Tackling gender inequalities and developing female-controlled methods of prevention. (The recent microbicide trials have been promising and, if they indeed are publicly available soon, may make a dent in infection rates.)

Concrete AIDS-specific interventions—providing political leadership, addressing stigma, and responding to the human resource crisis in the health sector—will have an impact on the spread and management of the disease. However, it is also important to remember that socio-economic, political, historical, and cultural realities both shape and are shaped by the epidemic. While most HIV/AIDS policies have focused mainly on prevention through behavior change, providing treatment, and impact-mitigation, addressing HIV/AIDS at the root of the problem requires addressing the vulnerabilities and impoverishment of people in their socio-economic reality. As Hein Marais notes: When it comes to the epidemic's mangling consequences, policy responses are more likely to make a genuine difference if AIDS is made to take its place in the dock alongside the other culprits, which often include agricultural, trade, and macroeconomic policies....The over-privileging of AIDS lets decision-makers off the hook by endorsing fashionable courses of action that can fail to go to the heart of the matter. <sup>46</sup>

This is perhaps our biggest challenge, and one in which all the players in the development arena must take initiative.

Since a policy recommendation of "all-economic-policies-mustchange-to-incorporate-the-poor" is simultaneously grandiose and meaningless, we support a more manageable policy—that of a basic income grant. In the context of high unemployment and jobless growth, South Africans are increasingly relying on social grants to survive, but not all who need these grants can access them. This initiative was first discussed in 2003. Feasibility studies showed that the grant was fiscally affordable and could be financed through taxes without placing an undue burden on current tax structures,<sup>47</sup> although concerns about administrative costs and sustainability remain. A basic income grant for all may relieve many of the economic pressures that render people vulnerable to both transmission and the impact of the disease. Perhaps then we will be able to turn the epidemic around.

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