

Afrobarometer Paper No. 21

EXAMINING HIV/AIDS IN SOUTHERN AFRICA THROUGH THE EYES OF ORDINARY SOUTHERN AFRICANS

by Alan Whiteside, Robert Mattes, Samantha Willan, and Ryann Manning

A comparative series of national public attitude surveys on democracy, markets and civil society in Africa.



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AFROBAROMETER WORKING PAPERS

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Abstract

This paper marries public opinion survey data from the Afrobarometer with epidemiological data about the HIV/AIDS epidemic in seven Southern African countries. We use this data to examine the degree to which people are aware of the pandemic, and are willing to speak about it. We also use it to examine whether it yields any palpable consequences of the disease in terms of public health. In turn, we also ask whether data on public awareness of AIDS deaths and individual health status corroborate, broadly, existing epidemiological data on HIV/AIDS. Finally, we examine the degree to which HIV/AIDS affects southern Africans' political participation, and expectations for government action.

Substantively, we find that nationally representative survey data supports the epidemiological data in many ways, providing an independent corroboration of expected levels of AIDS illness and death across the region. The epidemiological data tell us that people in all seven of these countries are growing ill and dying from AIDS in large numbers. The Afrobarometer surveys tell us that large numbers of the people, in all seven countries, say they know someone who has died of AIDS and are willing to speak about it. Epidemiological estimates of AIDS deaths and popular experiences of AIDS deaths are closely correlated. Many people in these countries tell us that they are frequently ill, although the data do not disclose the nature of their illness. Epidemiological estimates of AIDS illnesses closely mirror the frequency with which people tell us that they are seriously ill.

In political terms, the Afrobarometer tells us some surprising things. Even where HIV/AIDS has reached severe levels and people are dying in large and rising numbers, and even where people recognise those deaths as the result of HIV infection, very few of them place HIV/AIDS high on the agenda for government intervention. Rather, the epidemic is superseded in most countries by demands for government action to create jobs, expand the economy, and improve crime and security, or is masked by demands for overall improvements in health-related services. Perhaps Southern Africans perceive HIV/AIDS as a problem for families and communities, and not for governments. Or perhaps – and perhaps more likely – they are engaging in rational prioritisation. Faced with grinding poverty and widespread unemployment, people may be more concerned with getting a chance to earn an income, feed their families, protect themselves from crime and insecurity, and obtain basic health care, than with being saved from a largely invisible killer.

Introduction

Throughout the cities, villages and kraals of Southern Africa, young people are falling ill and dying in unprecedented numbers. They leave behind families who have to deal not only with their grief but also with the economic burden of replacing lost incomes and caring for orphaned children. How do ordinary people experience and understand the HIV/AIDS pandemic? Epidemiological data about the nature and scope of HIV and AIDS in Southern Africa are rather limited, and we know even less about how citizens respond to and cope with the pandemic. Though it might appear that we could simply infer people's experiences from the objective, epidemiological data, things are not so straightforward. People's perceptions and experiences often differ in important ways from what the objective data might lead us to expect.

This paper combines two sets of data to address these questions. First, we discuss the quality of available epidemiological data and use the best data to describe the nature of the HIV/AIDS pandemic across seven Southern African countries. Second, we turn to an original and unique set of data found in Afrobarometer attitude surveys of nationally representative samples of citizens in those same seven countries, which were conducted between September 1999 and August 2000.

The Afrobarometer survey responses give us valuable information about how ordinary people experience the pandemic and, paired with epidemiological data, enable us to address a number of key topics. First, we examine data on people's awareness and contact with the epidemic. To what degree do Southern Africans recognize the increasing amount of death around them to be the result of AIDS? To what degree are they willing to talk about it openly, or is acknowledgement or debate suppressed by social stigma attached to the disease? Second, we examine the extent to which the Afrobarometer data – which are based on random, nationally representative samples – correlate with, and thus corroborate the epidemiological data. Third, we examine the political consequences of the epidemic. How do people conceive of or frame the political issues surrounding HIV/AIDS? Does the epidemic feature in their political priorities for government action? Does contact with AIDS deaths, or the severe illness induced by AIDS, affect people's priorities or political attitudes and behaviors?

Epidemiological Data

In order to understand the HIV/AIDS pandemic, one must proceed from the fact that it is complex, multi-faceted and influenced by many medical, social, economic, and cultural factors. Though it has much in common with other infectious diseases, it also presents a relatively unique challenge, because of the lengthy incubation period between HIV infection and the onset of illness, the factors that impact susceptibility and vulnerability to HIV/AIDS, and the rapidity and extent of the epidemic's spread. As a result of the complexity of this epidemic, there is a great deal of misinformation that needs to be clarified before we move on to analyse public attitudes about HIV/AIDS.

Epidemic Curves

As shown in Figure 1, epidemics generally follow an 'S'-shaped curve. They start slowly and gradually. If, however, they reach a critical mass of infection, the growth of new infections accelerates and the epidemic spreads through a population until all those who are exposed and susceptible to infection have been infected. The epidemic then reaches a final phase, where the 'S' flattens off at the top, and the number of those alive and infected passes its peak. In most cases, the curve begins to decline for some combination of two reasons: because people are recovering from the disease, or because the number of deaths has surpassed the number of new cases, thereby decreasing the total number currently infected.

What sets the HIV/AIDS epidemic apart from other epidemics is the presence of two curves. The *HIV Curve* precedes the *AIDS Curve* by about five to eight years, reflecting the incubation period between infection and onset of illness. This is why HIV is such a lethal epidemic compared to, say, cholera. With a disease such as cholera, victims fall ill quickly. This alerts the general population and public health professionals who then take precautions to halt the spread. In the case of HIV, however, the epidemic silently creeps through the population and it is only later – when the HIV pool has risen to a considerable level – that the true impact of the epidemic is felt in terms of AIDS deaths. By then, the epidemic is in full swing and – since there is no known cure – the only way people leave the pool of infections is by dying.

Figure 1 illustrates this point. The vertical axis represents the number of cases and the horizontal axis represents time. At T_1 , when the level of HIV is at A_1 , the number of AIDS cases will be much lower (B₁). AIDS cases will only reach A_2 (i.e., the same level as A_1) at T_2 , some time later. Meanwhile, HIV prevalence may rise even higher.





Incidence and Prevalence

When using HIV/AIDS epidemiological data, it is also vital to grasp the important concepts of incidence and prevalence. *Incidence* is the number of new infections over a given period of time. The *incidence rate* is the number per specified unit of population (this can be per 1000, per 10,000 or per million for rare diseases). *Prevalence* is the absolute number of people infected.

The *prevalence rate* is the proportion of the population that exhibits the disease at a particular time (or averaged over a period of time). An example is given in Table 1.

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Year	Population	Incidence	Incidence Rate	Prevalence	Prevalence Rate
		(Actual)	(Per 1000)		(Percent) ¹
1	9 750	0	0	0	0
2	10 000	50	5	50	0.5
3	10 500	50	4.8	100	1.0
4	11 000	150	13.6	250	2.3
5	12 000	750	62.5	1 000	8.3

 Table 1. Incidence and Prevalence

Incidence and prevalence are key statistics for tracking the course of an epidemic. Incidence data would be the most helpful to measure the spread of the epidemic and the impact of prevention efforts. Prevalence data may obscure changes in infection rates (and thus risk behaviour) because high incidence may occur even when prevalence has levelled off if newly infected people are simply replacing those dying of AIDS. Unfortunately, a "pure" measure of HIV incidence is very difficult to obtain. Until recently, tests only showed whether or not a person was infected, not when the infection occurred. A new generation of tests allows time of infection to be measured, but these are more expensive and more complicated. Even when such information has been gathered it is not widely available. However, we can relatively easily measure the proportion of a given population that tests HIV-positive at a given point in time (i.e., prevalence).

HIV Data

Until recently, the only way to test for HIV was to take a blood sample. Universal testing of entire populations in this way is neither feasible nor justifiable, and consequently, official HIV epidemiological data have been based on sample surveys of specific sub-groups. In the past, these included blood donors, intravenous drug users, people with tuberculosis or sexually transmitted diseases, and women attending antenatal clinics (ANCs), all of whom are accessible through medical or other facilities where blood is being drawn. In recent years new methods of HIV testing using saliva have enabled more extensive population-based sampling.

Today, the most consistent and long-running HIV surveillance data come from surveys of women attending ANCs. Epidemiologists need samples broadly representative of the general population that they can draw on at regular intervals (usually every year or two). ANC attendees provide one of the best available sample populations because they are sexually active adults and blood is routinely taken from women attending these clinics for a number of standard tests which makes the inclusion of an HIV test relatively easy. Most ANC surveys are done on an anonymous, unlinked basis that means women cannot be linked to a sample and thus informed consent is not needed.

However, the ANC sample data has several biases and is not statistically representative of the entire population. First of all, the subjects are (obviously) all women, and thus the data is only directly representative of infection rates among women, not those among men. Second, the data are not representative of all women. The results cover only those of childbearing age who have become pregnant, which means – among other things – that they are fertile and having unprotected sex. Third, they are not representative of all pregnant women, but only cover those who attend state or public clinics. This means that in places like Botswana and South Africa, where there is a relatively well-developed private health care system, middle class women are

under-represented since they are more likely to use private healthcare. And in poorer countries with more limited health infrastructure, the very poor and those from remote areas are also likely to be under-represented because they have minimal access to state clinics.

Yet even if every pregnant woman attended a state clinic, the sample would still present a skewed picture of HIV prevalence among women of childbearing age. The precise *direction* of the skew, however, is difficult to determine. On one hand, younger women are more sexually active and more likely to become pregnant, and thus likely to be over-represented. On the other hand, HIV-positive women are likely to be under-represented because HIV infection reduces fertility and their likelihood of going to antenatal clinics. But perhaps the greatest concern is that the sampled ANC clinics are not necessarily randomly selected and thus not representative of all clinics or all clinic attendees nationally. Sentinel sites have been selected for many historical reasons (e.g., they have been used in the past) or reasons of access and competence (e.g., staff are better trained to keep records).

Despite these shortcomings, however, available studies suggest that the ANC data provide a good indication of prevalence in the general adult population. For instance, UNAIDS has compared population-based data and ANC sample data for areas for which both are available. They conclude that "sentinel surveillance in pregnant women yields remarkably robust estimates for HIV prevalence in the general population of reproductive age," which UNAIDS defines as those aged 15-49.²

The next step, then, is to use epidemiological modelling techniques to adjust the raw ANC statistics in order to estimate other population statistics, such as the percentage of all adult men who are infected, or the percentage of children who will be born HIV-positive. These models incorporate information on how we expect HIV infection among ANC attendees to differ from that of other population groups – such as the expected differences in prevalence between ANC attendees and younger and older women, men, and children – as well as known transmission rates between infected mothers and newborn children. This information, in turn, is based on other sources of HIV prevalence data, particularly population-based testing of certain communities or groups, such as employees of a given company or members of the military, and on medical understandings of the virus.

Admittedly, the only way we could "know" HIV prevalence in a population for certain is by testing everyone (or a representative sample of everyone), but this is not possible or ethically desirable. Thus, in the absence of broad population testing, careful modelling based on ANC data can produce estimates of HIV infections, AIDS illnesses, deaths, rates of orphaning, and population changes which are believed to be very close to actual rates in the population.³

Based on these adjustments to official ANC clinic data, UNAIDS calculates an estimated adult prevalence rate (the percentage of adults between 15and 49 infected) for nearly every country in the world, and also disaggregates prevalence by urban and rural distinctions and particular population groups.⁴ However, it should be noted that there are cross-national inconsistencies created by the fact that each country carries out its own antenatal surveys with differing sample sizes, weighting procedures, and intervals between surveys.

What Available Data Tell Us

Let us examine several sources of HIV prevalence data, and draw out some lessons and conclusions about the HIV epidemics in the seven countries that we consider in this paper. Table 2 lists recent UNAIDS estimates of adult (aged 15-49) prevalence in these seven countries, and

Figure 2 graphs these data. The UNAIDS data shows that HIV prevalence rates in 2001 range from 38.8 percent in Botswana to 15 percent in Malawi. It also shows that prevalence is still rising steeply in several countries, particularly Lesotho and Zimbabwe, but may have begun to level out in the other countries. Again, it is important to stress that a levelling-out of a country's HIV epidemic does not necessarily mean a decline in new cases, but may be caused by a rise in AIDS deaths. Furthermore, because of the lag between HIV and AIDS shown in Figure 1, AIDS illness and deaths will continue to rise even after HIV prevalence stabilises or declines.

	Lesotho	Malawi	Namibia	South Africa	Zambia	Zimbabwe	Botswana				
1997	8.4	14.9	19.9	12.9	19.1	25.8	25.1				
1999	23.6	16.0	19.5	19.9	20.0	25.1	35.8				
2001	31.0	15.0	22.5	20.1	21.5	33.7	38.8				

Table 2: HIV Prevalence Among Adults Aged 15-49 in Seven Southern African Countries⁵

Figure 2: Adult Prevalence



Simply examining cross-national differences in HIV rates at any given point, however, misses much of the story. Current and recent prevalence rates are useful for tallying countries' current and future AIDS burden, but to really understand these epidemics it is essential that we consider the trends in HIV prevalence over time. Unfortunately, many countries did not begin monitoring the epidemic until recently and data for early years is extremely scarce. Based on epidemiological modelling and that scarce data, however, Figure 3 illustrates projected ANC prevalence from 1980 to 2005.⁶



Figure 3: National Trends in HIV Prevalence: Projected ANC Prevalence, 1980-2005

From this graph, we learn much more about each country's epidemic. First, we can see that these seven countries are at different stages of their epidemics. South Africa's epidemic began in the late 1980s, and Botswana's a few years earlier, but the epidemics in countries to the north began even earlier, in the early 1980s. In addition, we see that the seven countries have differently-shaped epidemics. For instance, the Zambian epidemic rises steadily through the 1980s and early 1990s, while Botswana's epidemic begins later but rises much more rapidly and to a higher overall level. These differences, and not just overall prevalence rate, affect how people experience the epidemic. For instance, in a country with an "older" epidemic – such as Zimbabwe, Zambia, or Malawi – people have had a longer time to become aware of HIV/AIDS, and to experience the epidemic first-hand. In a country like Lesotho or South Africa, however, where the epidemic began quite recently but has grown very rapidly, people may not yet have developed the same level of awareness around HIV/AIDS even if the overall prevalence rates have matched or even surpassed those of the other countries. This concept of the "speed" of the epidemic again relates back to Figure 1 and the lag between HIV infection and AIDS-related illness and death. If the HIV epidemic curve is very steep, then the apparent gap in severity between visible AIDS illness and invisible HIV prevalence at a given point in time will be very wide. For instance, in Botswana in the mid-1990s, the ANC prevalence had already topped 30 percent, but the level of illness and death was determined by the prevalence 5-8 years earlier, at the beginning of the decade, which was below 5 percent. Such disparities can contribute to ignorance and denial in countries with fast-moving epidemics.

Thus, based on a combination of current prevalence rates and the "age" of the epidemic in each country, we can distinguish between the "mature" but less severe epidemics of Zambia, Zimbabwe, and Malawi, and the more recent but very fast-moving epidemics of South Africa, Lesotho, and Namibia. Botswana seems to be a bit of an exception: it falls between these two groups in terms of when the epidemic began, but has surpassed all other countries in terms of overall prevalence. Finally, a cautionary note is necessary regarding the Zimbabwean data, as the most recent estimates (see Table 2) suggest that prevalence in that country is rising more rapidly than previously thought. This type of aggregate, country-level data provides a basic measure of the epidemic. It is useful for cross-country comparisons and the identification of trends over time. But for a more complex understanding of the epidemic we must look at results from sero-prevalence studies on a country-by-country basis that are disaggregated by geographic area, age, or other factors. For example, results from Botswana's ANC surveys are broken down by the geographic location of the sentinel clinics, shown in Table 3. This shows the variation in HIV prevalence from one geographic area (site) to another within this one country, a pattern that is found in all seven countries.

	1992	1993	1994	1995	1996	1997	1998	1999	2000
Francistown	23.7	34.2	29.7	39.6	43.1	42.9	43.0	42.7	44.4
Gaborone	14.9	19.2	27.8	28.7	31.4	34.0	39.1	37.1	36.2
Ghantsi		9.5		18.9			22.3		26.4
Kanye			16.0		21.8		24.67		40.7
(Southern)									
Molepolole		13.7		18.9			37.2		30.4
(Kweneng									
East)									
Selebi Phikwe			27.0		33.1		49.89		50.3
Tutume			23.1		30.0		37.45		35.4

Table 3: Botswana HIV Prevalence by Sentinel Surveillance Site Over Time

Figure 4 provides data on South Africa's ANC surveys by age group, and illustrates a pattern common across all countries in the region: that HIV/AIDS disproportionately affects young adults. In South Africa, the highest HIV prevalence rates among ANC attendees in 2001 were in women aged 20-29. Population based surveys show HIV prevalence among men usually peaks at an older age, in their mid- to late-30s.





AIDS Case Data

The problems with HIV data pale in comparison to the difficulties in collecting data about the actual number of people sick with AIDS illnesses or who have died from them. In most countries we have no idea of the total number of deaths each year, let alone the number of deaths caused by HIV/AIDS. People often do not register deaths and/or central authorities do not collect or collate the data. South Africa has one of the best registration systems for vital statistics (births and deaths) in the region, but even there it is estimated that only 80 percent of deaths are recorded, and we still do not know the precise cause of death. Nonetheless, it is evident that the number of deaths has been increasing within each age group over the past seven years (see Figure 5).



Figure 5: Estimated Increase in Adult Death Rates (South African Men and Women)

From Rob Dorrington, et al, The Impact of HIV/AIDS on Adult Mortality in South Africa, Technical Report, Burden of Disease Research Unit (Pretoria: Medical Research Council of South Africa, September 2001), p. 29. http://www.mrc.ac.za/bod/index.htm (July 31, 2002)

We used the Spectrum AIDS Impact Model from the Spectrum Policy Modelling System⁷ to calculate estimates of the number of AIDS cases and AIDS deaths over time in each of the countries we discuss. These estimates, listed in Table 4, are used in the analysis later in the paper.

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	Botswana	Lesotho	Malawi	Namibia	S. Africa	Zambia	Zimbabwe
AIDS Deaths							
1998	19491	7681	60930	6713	89985	90509	142426
1999	23220	10847	68480	8871	135997	95047	150099
2000	26466	14538	74842	11205	193599	98431	155034
2001	29061	18600	80088	13558	262037	100710	158263
Current AIDS	Cases						
1999	87508	32381	297700	28950	352610	626170	876929

364763

Table 4: AIDS Deaths and Cases – Spectrum AIDS Impact Model

46864

2000

112855

39947

Attitudinal Data: The Afrobarometer

For attitudinal data relevant to the HIV/AIDS pandemic, we turn to the Afrobarometer. The Afrobarometer is a systematic survey of ordinary Africans' views toward democracy, economics and civil society, conducted in countries that have introduced a degree of democratic and economic reform. Because the instrument asks a standard set of questions, countries can be systematically compared. While the first round of the Afrobarometer was based on surveys in 12 countries, this paper focuses on responses to a specific set of questions on HIV/AIDS that were included in seven Southern African surveys (Botswana, Lesotho, Malawi, Namibia, South Africa, Zambia and Zimbabwe).⁸ Each survey was based on a random, stratified, nationally representative sample and conducted between July 1999 and July 2000. Trained enumerators conducted face to face interviews in local languages with a total of 9368 respondents in the seven countries. With sample sizes of approximately 1200 in each country, responses based on the national sample are subject to a margin of sampling error of +/- 3 percentage points at a 95 percent level of confidence (South Africa had a sample size of 2200 and a margin of error of +/- 2.2 percentage points).⁹

What Can Attitudinal Data Add To Our Understanding of the Pandemic?

The epidemiological data just reviewed illustrate the extensive spread and severe scope of the HIV/AIDS pandemic in Southern Africa. Given this picture, we would expect relevant attitudinal indicators to produce evidence of widespread contact with the disease (for instance, through individual illness and personal exposure to AIDS-related deaths). Moreover, because Afrobarometer studies are based on nationally representative samples, we can also use these responses to corroborate the accuracy of the epidemiological data (given the data's weaknesses as outlined above). Finally, given the picture of the pandemic provided by the epidemiological data, we would also expect to find rapidly rising public demands for the region's governments to confront HIV/AIDS.

Yet the perceptions and experiences of ordinary people may depart in dramatic ways from what we expect given the objective data, even if those data accurately represent the realities of the epidemic. The relatively long time lag between HIV infection and AIDS-related illness and death, during which the epidemic is largely invisible, is only one of several reasons why citizens may not accurately recognize and appraise the nature and extent of the disease. Even in countries where AIDS-related deaths have reached high and very visible levels, the pattern of death may be sufficiently geographically scattered to mask the national scope of the epidemic. National mortality data reflect deaths across an entire country – one in Ixopo, two in Umtata, two in Cape Town, ten in Johannesburg, etc. – but an individual is unlikely to be personally exposed to deaths elsewhere in the country, even if he or she is fully aware of the deaths in his or her immediate area. As seen in Table 3, the severity of the epidemic can vary greatly across geographic areas within one country. In addition, social stigma around HIV/AIDS may prevent a full and candid appraisal of the extent and causes of illness and death. Such stigma and community taboos may disrupt the social flow of information about the disease. It is not clear, for instance, whether the ubiquitous reference to local elites and national leaders who "died after a long illness" sends a coded signal that these were AIDS deaths, or rather serves to confuse people.

Even where people are accurately aware of the increasing death rate, social and religious beliefs may lead them to conceive of or frame the epidemic as a consequence of personal morality or as fate, rather than as a "public problem" that the government should address. Although we might expect people to clamor for government intervention to slow the spread of HIV and mitigate the impacts of the disease, they may in fact perceive HIV/AIDS as a problem for communities, households, and individuals to address, rather than an area for government involvement.

Perhaps most importantly, the lack of certainty about HIV data and AIDS cases (due to time lags between infection and illness and death, differing national epidemic curves, and problems with obtaining accurate data) has provided hesitant governments and politicians with an excuse for obfuscation, misdirection and inaction. They can question the validity of the HIV data and contest the severity of the epidemic, or they can accept the data but question its usefulness because they contest the link between HIV and AIDS. Probably the most notorious example of this latter approach is South African president Thabo Mbeki, who has personally and repeatedly questioned the link between HIV and AIDS, and whose government has often echoed its leader's doubts. South African officials have also argued that there are no observable increases in mortality to "corroborate" the HIV epidemic, and then doubted the results of a study by its own Medical Research Council that found evidence of such an increase¹⁰.

The rest of this paper examines Afrobarometer data that enable us to address many of these issues around public perceptions of and experiences with HIV/AIDS. First, we examine data on people's awareness and contact with the epidemic. To what degree do Southern Africans recognize the increasing numbers of deaths around them to be the result of AIDS? To what degree are they willing to talk about it openly, or is acknowledgement or debate suppressed by social stigma attached to the disease? Second, we examine the extent to which the Afrobarometer data – which are based on random, nationally representative samples – correlate with, and thus corroborate the epidemiological data. Third, we examine the political consequences of the epidemic. How do people conceive of or frame the political issues surrounding HIV/AIDS? Does the epidemic feature in their political priorities for government action? Does contact with AIDS deaths, or the severe illness induced by AIDS, affect people's priorities or political attitudes and behaviors?

Contact with AIDS

To what extent have people experienced AIDS personally through the death of someone close to them? The Afrobarometer helps answer this with a question that asks respondents: "Do you know of a close friend or relative who has died of AIDS?" This is an admittedly imperfect proxy for actual contact with the AIDS epidemic. It is certainly possible that people may have had close friends or relatives die of the disease and not known it, or known of someone who died of the disease and simply refuse to admit it (two types of "false negative" responses). It is also possible that respondents may misinterpret the reasons for some deaths: they may falsely assume, for example, that someone who died from tuberculosis had developed AIDS (a type of "false positive" response). Or, alternatively, the same death may be reported by two or more respondents, and we would interpret it as two separate death cases; however, given the scattered pattern of primary sampling units, and of households within sampling units, such occurrences should be relatively infrequent.

In some countries we find high levels of reported contact with and knowledge of AIDSrelated mortality. In 1999, roughly two-thirds of Zimbabweans (68 percent), Zambians (65 percent) and Malawians (65 percent) said they knew of at least one "close friend or relative" who had died of AIDS. Namibia (40 percent) and Botswana (31 percent) have lower numbers of people who say they have lost someone close to them to AIDS. At the other end of the spectrum, relatively low numbers of South Africans (16 percent) and Basotho (11 percent) say they know of someone.

	Botswana	Malawi	Namibia	Zambia	Zimbabwe	Lesotho	South Africa
Yes	31	65	40	65	68	11	16
No	59	33	52	31	25	81	80
Will not say	3	1	4	2	5	1	3
Don't know	4	1	3	2	3	5	2

Table 5: Awareness of AIDS Death

"Do you know of a close friend or relative who has died of AIDS?" (percent)

We will shortly examine whether these cross-national variations are consistent with what the data on AIDS deaths tell us. For now, we turn to examine other demographic differences in contact with AIDS deaths. It is generally assumed that since women tend to be primary care givers, they carry the bulk of the mental, physical and financial strain of the epidemic. While this may be true, there is no evidence that they are more likely to encounter the death of a close friend or relative due to AIDS. Across the seven-country sample, female respondents are slightly more likely to report contact with an AIDS death (40 percent) than males (39 percent). However, this is not statistically significant, meaning that the difference between men and women in the sample is so small that we would not have any confidence to infer that it is true among the general population.¹¹ Younger people are slightly more likely to encounter AIDS deaths,¹² as are respondents with higher levels of formal education.¹³ There are larger differences by racial category, with 42 percent of black respondents knowing someone who had died, compared to just 16 and 9 percent of white and coloured respondents respectively, as well as 3 percent of Asians.¹⁴ However, even within South Africa, 20 percent of black South Africans have been personally exposed to AIDS deaths, compared to only 6 percent of whites, 4 percent of coloured respondents, and 2 percent of Asians.¹⁵ Overall, racial categories and national citizenship are the most important "predictors" of whether or not one has had contact with an AIDS death.¹

v	Black	White	Coloured	Asian
Yes	42	16	9	3
No	51	82	89	96
Will not say	2	1	1	0
Don't know	3	1	<1	1

Table 6:	Awareness	of AIDS	Deaths	by	Race
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Do you know of a close friend or relative who has died of AIDS? (percent)

Stigmatization and Reported Contact

As noted above, closely associated with the question of contact with AIDS deaths is the issue of whether people in Southern Africa are willing to talk about HIV/AIDS openly. The first thing to note is that in every country, at least 95 percent of the respondents offered a response to the question. While a structured survey is clearly not equivalent to a normal free flowing conversation, we would not expect to find as high levels of reported contact as we did if social stigma made ordinary Africans reluctant to speak about the disease. Only in Zimbabwe did as many as 5 percent refuse to answer the question.

It is particularly fascinating that Zambians and Malawians are so willing to admit personal or family experience with AIDS even though they are the most highly religious countries discussed in this paper. Eighty-two percent of Zambians and 65 percent of Malawians attend meetings of religious groups (excluding formal church or mosque services), higher than any of the other five countries, and much higher than their participation in other types of community organizations.¹⁷ If there is any significant pocket of hesitance to speak about the disease, it appears to be amongst older respondents. Almost one in ten Basotho and Batswana (9 percent) over the age of 65 refused to answer the question, as did 18 percent of Zambians, 14 percent of Malawians, and 7 percent of Zimbabweans over the age of 75.

Second, beyond looking at the absolute numbers of those providing a response, we wondered whether political and societal pressures that limit people's perceived freedom to speak might affect levels of reported contact. Thus, we examine whether those people who feel less able to speak their minds freely are also less likely to report contact with AIDS deaths. Three facets of the Afrobarometer survey are relevant here. One question asked respondents whether they agree or disagree with the statement: "In this country, you must be very careful of what you say and do with regard to politics." Interviewers were also asked to indicate whether they felt anyone influenced the respondent during the interview, as well as to rate the overall honesty of the respondent. Perhaps surprisingly, we find little evidence that those respondents who feel less free to speak their minds, who were influenced during the interview, or who were rated as less honest by the interviewer, were less likely to report a death or more likely to refuse to answer.¹⁸

The absolute levels of reported contact, the relatively infrequent rate at which people refused to answer or equivocated in their response, and the lack of any impact of perceived freedom of speech all suggest that social stigmatization of HIV/AIDS may not be as great as believed, or have as strong an impact as expected on people's response to formalized, impersonal questions on HIV/AIDS. One factor that probably facilitated more candid responses was that we did not ask for specific names, but merely whether or not they knew of *some* close friend or relative who died of AIDS. Regardless, ordinary Southern African citizens seem to be much more willing to acknowledge the presence of AIDS than their leaders.

Measures of Ill Health

Given the objective epidemiological data on HIV reviewed earlier, one would expect to see growing levels of actual illness across the region, illness that would presumably place severe pressure on national health systems. Although HIV/AIDS is not *solely* a health problem, it certainly is a major health problem for societies and countries throughout Africa. However, beyond HIV infection data from ante-natal clinics (and a few other small studies) and AIDS deaths data (based on limited official mortality records, projections by a number of epidemiological models, and the South African Medical Research Council's 2001 report on adult mortality¹⁹) we have little hard data on the extent of the impact of HIV/AIDS on public health.

The Afrobarometer provides us with a useful indicator of public health, which may help to fill this gap. As a measure of physical health, it asked respondents: "In the last month, how much of the time has your physical health reduced the amount of work you would normally do inside or outside your home?" Certainly this measures a whole range of ordinary, non-HIV/AIDS related sicknesses. However, the potential social, economic and political impacts of AIDS on society stem not so much from the peculiar nature of the sickness itself, but from the fact that it makes people very ill (and ultimately kills them). Thus, to the extent that our chief interest is sickness (and subsequent mortality) a simple measure of sickness is useful to track the sociopolitical impact of the disease. A breakdown of responses by age will also enable us to identify unusually high levels of sickness among younger cohorts, a strong indication of AIDS prevalence.

The extreme physical consequences of the types of disease brought on by immune deficiency not only make a person ill and lead to early death, but are also likely to lead to high levels of anxiety and depression among the sick. In general, levels of stress and anxiety tend to

increase when one is ill. However, if people know or suspect they are ill with HIV/AIDS, the resulting stress and depression is likely to be even greater. They may face discrimination in the workplace, at school, in the community, or even at home. They must worry about the possibility of infecting their partner, and women face the stress of possibly infecting their newborn children. Eventually, most people face permanent physical disability and the inability to earn an income for themselves or their family, or to provide for the future of their spouses and children after their death.

Moreover, the nature of the pandemic may raise levels of stress and mental illness even among those not infected. People may worry about contracting the disease from their partners. As the epidemic progresses, increasing mortality, especially among the young, puts significant strains on the community's emotional and psychological coping mechanisms. As a measure of mental health, the Afrobarometer surveys asked respondents: "In the last month, how much of the time have you felt so worried or anxious that you felt tired, worn out, or exhausted?"

The responses to these questions reveal important cross-national variations in physical and mental illness in Southern Africa. Basotho are by far the most likely to report frequent mental or physical illness. Four in ten (42 percent) said that in the previous month their physical health had "often" reduced the amount of work they did, inside or outside the home. One half (51 percent) said that worry or anxiety had "often" made them feel tired, worn out or exhausted in the previous month. In contrast, less than one in ten Namibians (9 and 8 percent respectively) and South Africa (7 and 12 percent) said this happened frequently. Approximately one-third of Zimbabweans were frequently prevented by physical illness from working (31 percent) or worn out by worry (36 percent). The figures are around one-fifth for Zambians and Malawians. South Africans and Namibians appear to be the healthiest in these surveys, but even here, approximately one in ten are frequently ill or anxious. Interestingly, ill health cuts across the racial divide in South Africa, with 15 percent of Asians, 7 percent of black and coloured respondents, and 6 percent of white respondents saying they are sick enough to miss work on a frequent basis.

	Botswana	Malawi	Namibia	Zambia	Zimbabwe	Lesotho	South Africa			
Often	15	16	9	19	31	42	7			
Sometimes	29	27	37	38	27	12	25			
Rarely	19	21	16	14	18	13	18			
Never	36	36	36	28	23	33	49			

Table 7: Physical Health

"In the last month, how much of the time has your physical health reduced the amount of work you would normally do inside or outside your home?" (percent)

	Botswana	Malawi	Namibia	Zambia	Zimbabwe	Lesotho	South Afric
Often	15	20	8	22	36	51	12
Sometimes	34	25	36	42	29	14	32
Rarely	19	25	17	12	17	13	19
Never	32	30	37	22	16	21	37

Table 8: Mental Health

"In the last month, how much of the time have you felt so worried or anxious that you have felt tired, worn out, or exhausted?" (percent)

Confirming the logical connection between physical illness and mental stress, we find a very strong correlation between physical and mental health on the individual level.²⁰ Of those respondents who said they frequently missed work due to physical problems, 71 percent also said

they were frequently stressed or anxious. More than one in ten (13 percent) of *all* respondents interviewed across Southern Africa were *both* frequently sick and frequently depressed. It is this group that is likely to contain the highest proportion of fully developed AIDS cases. The degree to which there is empirical support for this assertion is discussed in the next section.

Corroborating Attitudinal and Epidemiological Data

Given what we think we know about the pandemic, do these responses on contact with AIDS deaths and severe illness make sense? Or, to put it another way, do they corroborate, broadly speaking, the epidemiological data on AIDS prevalence and AIDS deaths? We first examine the data on awareness of AIDS deaths. If both sets of data were valid and reliable reflections of the underlying reality of HIV/AIDS, we would expect to see the highest levels of reported contact with AIDS deaths in those countries that the epidemiological data claim have suffered the most deaths. Figure 6 plots the total percentage in each country who say they know someone who has died of AIDS (on the Y, or vertical axis) against epidemiological data estimating the cumulative number of AIDS deaths from the beginning of the epidemic up to one year prior to the date of the survey (on the X or horizontal axis).

It bears repeating that the AIDS death data is modeled data, based on statistically adjusted extrapolations of the ANC HIV prevalence data as discussed above (see Table 4). In spite of this limitation, we find a strong relationship between the two types of data. As estimated national levels of AIDS deaths rise, the proportions of actual people who have had contact with an AIDS related death rise in predictable ways.²¹

But in addition to the simple number of cumulative deaths, the extent of public contact with AIDS deaths also appears to be a function of where each country is on the epidemic curve. As explained earlier, it is important to look not only at absolute levels of HIV prevalence and AIDS deaths, but also at how advanced or recent the epidemic may be in a given country. To recap, Zambia, Zimbabwe and Malawi have mature epidemics that began early, Botswana is in the middle and South Africa, Namibia and Lesotho have relatively young epidemics (see Figure 3). In a mature epidemic, such as that of Zambia, Malawi or Zimbabwe, people are more likely to have seen or heard about death, and to have seen and heard about it repeatedly. In a more recent epidemic, such as Lesotho or South Africa, the high HIV prevalence level may have just begun to turn into high numbers of deaths. Thus, citizens in these countries may be less able to recognize an AIDS related death.

An inspection of the regression line drawn through the country points on the graph in Figure 6 represents the "expected" rate of contact with an AIDS death given a specific level of cumulative deaths. We see that countries with a more "mature" epidemic are above the line, meaning that they tend to "over-report" to varying degrees (Zambia, Zimbabwe, and especially Malawi). This could be because where AIDS deaths have become a prominent feature of society there is a tendency for people to assume people have died from AIDS regardless of whether they have. Where AIDS is a more recent phenomenon, people may tend to "underreport" because people are less likely to realize why people are dying (Botswana, South Africa, and especially Lesotho). Namibia is the only country that does not conform to this pattern: it falls above the line but has a more recent epidemic.

Figure 6: Awareness of AIDS Deaths by Cumulative Number of AIDS Deaths



cumulaltive # of deaths 1998 (99 for Lesotho / RSA) per 1,000 pop -- lov

To what extent do the survey responses about physical and mental illness reflect AIDSrelated illness? Are people more likely to report levels of severe illness in those countries with the highest levels of current estimated AIDS cases? In order to test this, we created a composite measure of the proportions of people in each country who both often miss work due to illness and suffer from anxiety. We then correlated this measure with the estimated number of current AIDS cases per 1000 people, as of the year of the Afrobarometer survey (see Table 4 and Figure 8).²² We find that our combined illness measure fits very closely with the AIDS case data for five countries (Malawi, Namibia, South Africa, Zambia and Zimbabwe). For these five countries, reported serious illness increases consistently with rising levels of estimated AIDS cases.²³

There are two outliers in this graph, however: Botswana and Lesotho. Botswana's position indicates that levels of severe illness in that country are much lower than we would expect given the estimated number of current AIDS cases. This may be due to the fact that Botswana is a relatively wealthy country (compared to the others) with a good public health system, and the Debswana mining company – the country's largest employer – offers relatively comprehensive and high-quality health coverage to its employees. Lesotho fits even less well than Botswana. Here, there are far greater levels of severe illness than would be expected given its current level of AIDS cases. This suggests that the country's relatively high levels of reported illness reflect many other sources than AIDS: as Tables 7 and 8 indicate, 42 percent of Basotho are often physically ill, and 51 percent say that they are often worried or anxious. We wondered if the timing of the survey influenced the responses, but it was conducted in April and May -- late summer and early autumn -- so the weather presumably did not cause higher than usual levels of illness. We believe that the reasons for this response are complex. First, due to labour migration to South Africa, the resident population is not a normally distributed population, but is largely female and disproportionately old. This accounts for some of the disparity, but Basotho are much sicker than anyone else in the region within each age category. Second, those who stay may be

those who are unable to migrate because of poor health, thus creating a disproportionately unhealthy resident population. Finally, the very high levels of illness in Lesotho are also a function of extremely high levels of unemployment (76 percent) and consequent poverty in the resident population.²⁴ In fact, once we statistically "control" for levels of poverty, the relationship between current AIDS cases and severe illness increases considerably.²⁵





current # of AIDS cases 1999 (00 for SA / Lesotho) per 1,000 pop

Another way to cross-corroborate the Afrobarometer measure of severe illness and the epidemiological data is to test whether measured levels of severe illness predict the numbers of subsequent AIDS deaths in the year following the survey. Figure 8 displays the relationship between the Afrobarometer measure of severe physical and mental illness (as of national survey dates in 1999 and 2000) and *subsequent* AIDS death figures per 1000 people. The results mirror those of the previous test. Reported levels of severe illness are an almost perfect predictor of subsequent AIDS deaths in five countries.²⁶ However, the estimated number of AIDS deaths in Botswana in 2000 was far higher than would have been expected on the basis of self-reported health in that country in 1999. On the other extreme, Lesotho's AIDS deaths in 2001 were far lower than its very high levels of illness would have predicted, again suggesting that the relatively high levels of illness in Lesotho stem – at least for now - from sources other than AIDS. Once again, once the role of poverty is statistically removed, severe illness becomes an even stronger predictor of subsequent AIDS deaths.²⁷

Figure 8: Subsequent AIDS Deaths by Severe Illness



% people who are both often sick and depressed

Taken together, the previous three figures suggest that both the epidemiological HIV/AIDS data (even with all its shortcomings) and relevant attitudinal data from the Afrobarometer independently reflect the common underlying phenomenon of the HIV/AIDS pandemic. Where epidemiological data suggest the disease is most advanced, survey respondents are also most likely to indicate that someone they know has died of AIDS or (with some exceptions) report higher levels of severe illness.

A second way to assess the usefulness of the attitudinal data is to see whether it disaggregates in ways that correspond to known aspects of the disease. We know for example, that transmission and infection rates are highest among young adults. This is a result of a number of factors, including higher social mobility, higher levels of sexual activity, and more frequent partner change. Young women are often at particular risk of contracting HIV, one of the reasons being that many of them are sexually involved with older men, who may have multiple partners and who generally have greater power in the relationship, making it difficult for the women to negotiate the use of condoms. The uneven distribution of HIV by age was illustrated in Figure 5.

This profile is in fact reflected in the Afrobarometer responses (see Table 9). In most countries, the most widespread exposure to AIDS-related deaths occurs amongst those aged 25 to 44 (with it generally highest amongst those aged 35 to 44). In Namibia and South Africa, the highest levels of exposure to AIDS deaths occur at even younger ages: 25 to 34 in Namibia, and 18 to 24 in South Africa. It is perhaps surprising that the highest levels of awareness in Malawi, Zambia and Zimbabwe are actually among the oldest age groups, but this is in a context of very high levels of awareness across the board. Moreover, because the epidemics in these countries are older than in other countries, older individuals have had a long time to watch children, grandchildren and neighbors die of this disease.

	18-24	25-34	35-44	45-54	55-64	65-74	75-99	Total
Botswana	22	38	40	31	29	25	22	31
Malawi	59	66	75	70	67	83	57	65
Namibia	42	45	41	40	29	35	31	40
Zambia	55	66	72	66	73	64	75	65
Zimbabwe	58	67	77	73	67	77	63	68
Lesotho	11	13	11	10	5	11	8	11
South Africa	19	18	17	10	9	9	4	16

Table 9: Awareness of AIDS Deaths, by Country and by Age

Percent of respondents who said they knew someone who died of AIDS in the last year

The Afrobarometer data on severe illness also show some disproportionate levels of illness among younger Southern Africans (see Table 10). The data show unlikely peaks in illness among younger respondents – who should, in the absence of AIDS, be healthier than older respondents – in Malawi, Zimbabwe, Lesotho and (to a lesser extent) South Africa. These "bulges" provide support for the patterns of illness suggested by the HIV/AIDS epidemiological data. In the other four countries, reported levels of illness increase progressively with age, as would be expected even in the absence of AIDS. This does not, however, mean that young people in these countries are not more ill than they would have been without the AIDS epidemic. To determine that, we would need to have a distribution of illness by age in a "no-AIDS" control scenario, and such data is simply not available to us at this time.

			~ 0					
	18-24	25-34	35-44	45-54	55-64	65-74	75-99	Total
Botswana	5	7	9	14	15	21	31	10
Malawi	6	6	10	7	9	17	14	8
Namibia	2	4	2	5	4	9	7	4
Zambia	8	11	15	16	18	24	23	13
Zimbabwe	13	26	22	22	30	38	56	24
Lesotho	19	30	36	33	45	47	49	34
South	1	4	3	7	14	16	13	5
Africa								

Table 10: Severe Illness, by Country and by Age

Percent of respondents who reported being frequently both physically and mentally ill

Political Consequences of HIV/AIDS

AIDS and the Public Agenda

Thus far, we have seen that Afrobarometer data offers independent evidence corroborating the picture of the pandemic that has been painted by epidemiological data. But what about the pandemic's political impact? Given the epidemiological data reviewed early in this paper, we might expect that AIDS would soon – or already would have – come to dominate the national political agenda in almost every country in the region; that mass publics would be clamouring for governments to redirect large proportions of national resources to health care and other anti-AIDS interventions. Yet we might as easily expect to find that while large proportions of people know someone who had died of AIDS, the overall scope of the epidemic was not yet sufficiently evident to lead people to perceive it as a national crisis requiring government intervention. Or we might expect that conservative social and religious values would lead people to see AIDS illness and deaths as consequences of fate or personal (im)morality, or that people might perceive HIV/AIDS as a problem for communities, households and individuals, rather than for government intervention. It is also possible that the social environment which people confront on a daily basis is already so desperate that AIDS is simply one more problem, and one that must take a lower priority than simply finding work, food and security.

In order to understand how people understand and politically prioritise AIDS, we turn to an open-ended question in the Afrobarometer survey that asked people "What are the most important problems facing this country that government should address?" Interviewers offered respondents no response alternatives; answers were completely spontaneous, and people could provide us up to three answers, which interviewers transcribed verbatim. The tables below offer an after-the-fact aggregation of responses into broad categories. These tables provide us a concise description of citizens' priorities for government action, or what we have called "the people's agenda."

Given the extent of infection, illness, and death illustrated by the epidemiological and survey data, we might expect to find widespread popular demand on governments to confront HIV/AIDS. As displayed in Table 11, however, the data do not bear this out. In fact, "HIV/AIDS" features prominently on the public agenda of only three Southern African countries. One-quarter of Batswana (24 percent) and just over one in ten Namibians (14 percent) and South Africans (13 percent) cite this problem as one of the top three facing the country. AIDS was the second most frequently cited problem in Botswana, and the fifth most frequently cited in Namibia and South Africa. In contrast, just one in twenty Zimbabweans (4 percent), one in fifty Malawians (2 percent), and less than one in one hundred Basotho (less than 1 percent) mention HIV or AIDS as one of the most pressing problems that government should address. Absolutely *no* Zambians used the words "HIV" or "AIDS" to describe the most important national problems. In general, issues such as job creation, the national economy, and crime and security received far higher attention from Afrobarometer respondents than did the HIV/AIDS epidemic.

The lack of prioritisation of HIV/AIDS by Southern Africans is itself surprising. Perhaps more surprising, however, is that the public prioritisation of HIV/AIDS for government action does not vary in any systematic way with the actual extent of the epidemic. At the aggregate level, both the proportion of people who know someone who has died of AIDS²⁸ and the number of cumulative deaths²⁹ are poor predictors of the proportions of people who cite AIDS as a national political priority.

Botswana	Zimbabwe	Zambia	Malawi	Lesotho	Namibia	South Africa
Job Creation	Economy	Health	Economy	Job Creation	Job Creation	Job Creation
58%	74%	41%	48%	63%	54%	76%
AIDS	Job Creation	Job Creation	Health	Crime /	Education	Crime /
24%	37%	32%	29%	Security	46%	Security
				28%		60%
Education	Health	Education	Crime /		General	
20%	18%	31%	Security	Food	Services	Housing
		F · /	28%	20%	21%	25%
Poverty /		Farming /	Food		II.a.l4h	Education
		Agriculture	F000		Health 190/	
1 / 70		20%	20%		10 70	1 3 70
Health		Economy	Transportation		AIDS	AIDS
15%		20%	16%		14%	13%
					, .	/ ·
Farming /		Transportation	Water			Health
Agriculture		18%	16%			12%
14%						
		Poverty /	Farming /			Poverty/
Crime /		Destitution	Agriculture			Destitution
Security		14%	13%			11%
12%			Education			
			12%			
			Poverty /			
			Destitution			
			11%			
			Job Creation			
			11%			
			General			
			Services			
			10%			
1						

Table 11: Most Important Problems (problems mentioned by at least 10 percent)

"What are the most important problems facing this country that government should address?"

Southern Africans simply do not list HIV/AIDS as a political priority for their governments. On its own, this might have been seen to indicate the presence of social stigma, but we have already presented evidence to rule this out. To further investigate this surprising finding, we consider the possible impact of other factors. First, it could be that people see the responsibility for HIV/AIDS as lying with individuals and communities, rather than governments. Second, it could be that people's living conditions are already so desperate that government action against AIDS is seen as a lower priority than action to address more immediate needs by creating jobs and holding down prices so that people can live decently. Thus, it simply becomes a question of priorities. There is some support for this argument: as individual levels of poverty increase, people become less likely to cite AIDS as an important problem.³⁰

Third, these figures may reflect the role of leadership on the part of both elected officials and civil society. In Botswana, for example, public exposure to AIDS deaths is relatively low, yet citizens have placed the epidemic as the second priority for the government. Though Botswana's HIV/AIDS epidemic is relatively young, the government has been open about the epidemic and has in some sense "claimed" it as an appropriate issue for government intervention. In addition a great deal of international donor funding for HIV/AIDS education and prevention programs has poured into Botswana over the years. Debswana Diamond Company has embarked on a comprehensive campaign to address HIV/AIDS, including awareness and education campaigns, and, more recently, treatment.

In South Africa, a great deal of time and money has been spent on awareness and prevention campaigns. South Africa also hosted the XIII International AIDS Conference in 2000, which increased the public visibility of the epidemic. The prolonged public visibility created by President Thabo Mbeki's controversial remarks about the link between HIV and AIDS may have also, paradoxically, raised awareness of the epidemic in recent years. In fact, an examination of successive nationally representative surveys conducted by IDASA since1994 demonstrates that public awareness of HIV/AIDS as a key issue has increased steadily, moving from less than 1 percent in 1994. In fact, the July-August 2000 survey was the first time that more than 10 percent of South Africans nationally cited the problem (though this level had already been achieved among respondents in KwaZulu-Natal, where the epidemic is much more advanced, by early 1999). It is also important to note that the 2000 survey was conducted just after the XIII International AIDS Conference in Durban.

Finally, the lack of public emphasis on AIDS as a national problem could reflect the way people "name and frame" political issues. Looking at Table 12, we can see that "health" or "health care" is mentioned by large proportions of respondents in several countries, especially Zambia (41 percent, which made it the most often mentioned problem), Malawi (29 percent), Zimbabwe (18 percent) and Namibia (18 percent). These percentages are much higher than the percentage of respondents who mentioned HIV/AIDS as a problem.

	Botswana	Zimbabwe	Zambia	Malawi	Lesotho	Namibia	South Africa
Health	15	18	41	29	8	18	12
HIV/AIDS	24	4	0	2	<1	14	13

Table 12: Spontaneous Mention of HIV/AIDS vs. Health as an Important National Problem

Does this emphasis on health actually signify a (silent) prioritization of HIV/AIDS? Are people thinking of HIV/AIDS when they say "health?" Support for this hypothesis can be found in the strong relationship between the proportion of people who have had contact with an AIDS death and the proportions that cite "health" as an issue (see Figure 9).³¹ Similarly, the number of cumulative AIDS deaths in a country is also associated with higher levels of prioritization of "health" as an area of government attention.³² This suggests that people conceive of the political consequence of the pandemic as a national health crisis, rather than as an HIV/AIDS crisis *per se*. People seem to say that HIV/AIDS should be addressed primarily as a health problem. If this is a correct interpretation of the citizens' sentiments, it is somewhat unfortunate because it ignores the multi-faceted nature of the pandemic. To simply address AIDS as a health crisis is to neglect all the other aspects such as its impact on households, the economy, employment, gender relations, governance, democracy, and poverty.

Figure 9: Exposure to AIDS Deaths and Citing Health as a National Priority



% Know Someone Who Has Died of AIDS

Finally, while people may not spontaneously think of AIDS as a key national problem, they may still be able to offer meaningful opinions on it when prompted. A question placed on the questionnaire only in South Africa about government performance in fighting AIDS indicates that even though South Africans are only beginning to prioritize it as a national problem, they are not satisfied with government performance on the issue. In July-August 2000, just 39 percent of respondents said that government was handling this issue "well" or "very well," while 57 percent rated its performance as "not very well," or "not at all well."

AIDS and Political Participation

A final potential political impact of the HIV/AIDS data that we can test with Afrobarometer data concerns political participation and citizenship. There are strong reasons to believe that HIV/AIDS may have a negative impact on the democratization process in Southern Africa by reducing levels of popular participation in the political process. This can happen in several ways.³³ First, accumulating deaths will simply reduce the total pool of citizens available to vote, interact with representative institutions, or participate in civil society organizations. Second, increasing AIDS illnesses and increasing burdens of caring for infected people may also progressively decrease the relative proportion of the existing population able to participate in political life. Third, the peculiar psychological effects of HIV infection may reduce the importance that people attach to political participation and democracy. Fourth, besides reducing citizens' ability or motivation to participate, HIV/AIDS may also reduce the capacity of the grass roots organizations that mobilize, channel and structure public participation between elections. Finally, the epidemic is likely to have important effects on the "civility" of society by increasing criminal activity and decreasing popular compliance with citizen obligations and duties. Loneliness and depression are characteristics of people infected and ill with AIDS. Thus political violence and non-compliance are as likely to result from frustration and aggression as hopelessness and apathy.³⁴

We test these propositions by examining the linkages of severe illness with various forms of political participation or predispositions to participation. Although we clearly recognize that our indicators of severe illness (an additive index of mental and physical health) taps much more than simply AIDS-related sickness, we have presented evidence that this measure co-varies predictably with the extent of current AIDS cases and subsequent AIDS deaths. If we find that severe illness (whatever its nature) decreases political participation and citizenship, we will be able to make some important projections about future trends in public participation as AIDS increases the extent of illness in society.

What we find is surprising. The broadest generalization we can make is that greater levels of illness are not generally associated with declining levels of participation or declining confidence to participate. It is true that healthier respondents are more likely to possess a sense of political efficacy and competence, but the relationship is modest at best, and falls considerably once we control for individual levels of poverty (which itself is highly associated with illness).³⁵ However, illness does not significantly decrease people's interest in politics,³⁶ or their trust in other people (a factor often identified as a crucial component of public participation).³⁷ Nor does ill-health decrease levels of participation in community organization,³⁸ in non-voting forms of political participation,³⁹ or the rate at which people contact elected leaders.⁴⁰ Thus, the least healthy Africans appear as likely to participate in political procedures and civil society as the most healthy. Sickness does not appear to de-motivate or demobilize citizens. Apparently, the sources of individual political participation lie somewhere other than in personal health status.

However, we wondered whether healthy societies differed from sick societies in terms of overall levels of political participation. We find aggregate-level evidence that suggests that public health is related to *some* forms of political participation. First of all, the most healthy societies in Southern Africa are also those with the highest aggregate levels of interpersonal trust.⁴¹ Although there are good arguments that low levels of social trust are a key social-cultural factor responsible for the spread of HIV/AIDS,⁴² it is also likely that increasing levels of disease and illness in a society corrode interpersonal trust.

Figure 10: Interpersonal Trust and Severe Illness



% people who are both often sick and depressed

Second, the healthiest societies also tend to have the fewest number of citizens who avoid citizenship duties such as paying taxes or rates and services (or at least admit to doing so).⁴³

Figure 11: Compliance and Severe Illness



% people who are both often sick and depressed

And third, the healthiest societies also tend to have the highest rates of participation in local community groups.⁴⁴



Figure 12: Attendance in Community Group Meetings and Severe Illness

% people who are both often sick and depressed

So, individual health status does not appear to be related to levels of individual political participation, but national public health status is associated with overall levels of public participation in a country. In other words, whether or not an individual is healthy makes little difference to whether or not they participate in local civic affairs, but whether the larger society is healthy seems to play an important role in structuring public participation. Why is this? Part of the reason may be that pervasive illness demobilizes – or in the case of AIDS, eventually kills – critical proportions of those people who organize and channel the participation of others, such as those who work in community organizations. Another possibility is that being HIV-positive or even ill from AIDS may spur certain forms of participation at an individual level – such as AIDS treatment activism or membership in a people-living-with-AIDS support group – while the overall burden of illness in a society stunts participation.

On the whole, we believe that HIV/AIDS has long-term systemic consequences throughout all aspects of society, including implications for public participation. The weakness of the impact evident in this analysis may be due to the fact that the epidemic is still new. Even at its most advanced level, in East Africa and the United States, the HIV/AIDS epidemic is probably only 20 years old; in the countries we are discussing, it is no more than 15 years old. Much of the impact of HIV/AIDS and the resultant morbidity and morality is yet to come, though we accept that societies are able to adapt to significant challenges and we may find such an adaptation in the case of HIV/AIDS.

Implications

This paper represents a first attempt to marry data from the Afrobarometer surveys to epidemiological data about the HIV/AIDS epidemic. It is the work of authors from several fields of expertise, bringing together multiple perspectives to better understand what is driving this epidemic, ordinary people's daily experience of it, and its impact on us. We found great value in considering the epidemic from the perspective of representative samples of Southern Africans. It enables us to get beyond the usual picture of the epidemic presented by "AIDS experts" and unpack how "ordinary" individuals are experiencing this epidemic and what that means for their political priorities, their public participation, and their expectations for government action.

Substantively, we found that the Afrobarometer survey data supports the epidemiological data in many ways, providing an independent corroboration of expected levels of AIDS illness and death across the region. The epidemiological data tell us that people in all seven of these countries are growing ill and dying from AIDS in large numbers; the Afrobarometer surveys tell us that large numbers of the people in all seven countries say that they themselves know someone who has died of AIDS. Many people in these countries tell us they are frequently ill; though we do not ask people about the cause of their illness, the rates of ill health closely mirror rates of HIV/AIDS in all but two countries.

In political terms, the Afrobarometer tells us some surprising things: that even where HIV/AIDS has reached severe levels and people are dying in large and rising numbers, and even where people recognize those deaths as the result of HIV infection, very few of them place HIV/AIDS high on the agenda for government intervention. Rather, the epidemic is superseded in most countries by demands for government action to create jobs, expand the economy, and improve crime and security, or is masked by demands for overall improvements in health-related services. Perhaps Southern Africans perceive HIV/AIDS as a problem for families and communities, and not for governments. Or perhaps – and perhaps more likely – they are engaging in rational prioritisation. Faced with grinding poverty and widespread unemployment, people may be more concerned with getting a chance to earn an income, feed their families, protect themselves from crime and insecurity, and obtain basic health care, than with being saved from a largely invisible killer. What governments and people alike must realise, however, is that AIDS will only serve to worsen poverty and insecurity and to slow economic growth, as well as to burden already-weak public health services and severely increase the burden of illness in these societies.

Between July 2002 and July 2003, Round II of the Afrobarometer will revisit all of these issues, in addition to asking an expanded set of items about HIV/AIDS, this time in 15 countries. The issues discussed in this paper and will surely be revisited. Hopefully, this will form but one part of a growing effort by all social scientists to direct their respective talents toward understanding the social, economic and political consequences that the AIDS pandemic holds for all of us in Africa.

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Endnotes

² Joint United Nations Programme on HIV/AIDS (UNAIDS), *Report On the Global HIV/AIDS Epidemic-June 2000* (Geneva: United Nations, 2000), p. 117.

³ An illustrative product of this modelling produced from the ASSA2000 model (currently available only for South Africa) can be found at: <u>http://www.assa.org.za/ downloads/aids/ summarystats.htm</u>.

⁴ See Table 2 and the country-specific epidemiological fact sheets on the UNAIDS website: http://www.unaids.org.

⁵ UNAIDS, *Report on the Global HIV/AIDS Epidemic* (New York: United Nations, June 1998), pp. 64-65; UNAIDS, *Report on the Global HIV/AIDS Epidemic* (New York: United Nations, June 2000), p. 124; UNAIDS, *Report on the Global HIV/AIDS Epidemic* (New York: United Nations, July 2002), p. 190.

⁶ This graph is taken from The POLICY Project, *HIV/AIDS in Southern Africa: Background, Projections, Impacts, and Interventions*, October 2001, <u>http://www.policyproject.com/pubs/countryreports/SoAf10-01.pdf</u>. It has been modified to include only those seven countries discussed in this paper, and projections only through 2005. The colours and formatting of the graph have also been modified. The source data was not changed at all.

⁷ Spectrum Policy Modelling System, Version 1.63, Prepared by the POLICY Project, available from the Futures Group International at: <u>http://www.futuresgroup.com/WhatWeDo.cfm?page=Software&ID=Spectrum</u>. Each country's epidemic was modelled using prevalence data from The Futures Group and the "medium speed" AIDS Impact Model (AIM) scenarios. These are not meant to be definitive, exact numbers but rather to give a sense of the relative severity of each country's epidemic.

⁸ Ghana, Nigeria, Mali, Uganda and Tanzania are the other countries that comprised the Afrobarometer during the first round. However, the questionnaires used in those countries did not contain the full set of questions covered in this analysis.

⁹ Actual sample sizes for each country are as follows: Botswana = 1200, Lesotho = 1177, Malawi = 1208, Namibia = 1183, South Africa = 2200, Zambia = 1200, and Zimbabwe = 1200. Fieldwork was conducted by national research institutions affiliated with the Afrobarometer project. Samples were designed using a common multi-stage, stratified, area-cluster approach. Random selection methods were used at each stage, with probability proportional to population size where appropriate. Sampling frames were constructed in the first stages from the most up-to-date census figures or projections available, and thereafter from census maps, systematic walk patterns, and project-generated lists of household members. With the exception of South Africa, each country sample was self-weighted and sufficiently representative of national characteristics on key socio-economic indicators (gender, age, region) that post-weighting was not necessary. For more on the Afrobarometer, see www.afrobarometer.org.

¹⁰ Rob Dorrington, et al., *The Impact of HIV/AIDS on Adult Mortality in South Africa*, Technical Report, Burden of Disease Research Unit (Pretoria: Medical Research Council of South Africa, September 2001).

¹¹ Pearson's r = -.01, probability = .420, n = 9524. At the country level, women are significantly more likely to have contact with AIDS deaths only in Botswana: 35 percent of women vs. 29 percent of men

¹ HIV prevalence rates are cited as a percentage of a specific segment of the population (e.g., children below the age of five, adults aged 15 to 65, antenatal clinic attendees, blood donors, men with STDs, or the "at risk" population, which is generally taken to mean 15- to 49-year-olds who are sexually active). HIV is the only disease where prevalence is given as a percentage rather than a rate because the usual diseases do not infect sufficiently large proportions to make percentages meaningful measures of prevalence.

(Pearson's r = -.07, probability = .025). Gender also makes a difference in Malawi, but in the *opposite* direction: 62 percent of women versus 69 percent of men report contact (Pearson's = .07, probability = .010). There are no significant differences in the other five countries.

¹² Pearson's r = -.07, probability = .000, n = 7383.

¹³ Pearson's r = .07, probability = .000, n = 7383.

 14 Eta = .18; Chi square significance = .000. Beside 320 interviews with white respondents in South Africa, an additional 125 were scattered across Namibia, Botswana, Zambia and Zimbabwe. Interviews with 220 "coloureds" were conducted in South Africa, and another 60 were done mostly in Namibia, although there were a handful each in Malawi, Zimbabwe and Zambia. Finally 100 interviews with Asians were conducted in South Africa, and just 8 more in Namibia, Botswana and Zimbabwe.

¹⁵ Eta = .19; Chi square significance = .000,

¹⁶ A multivariate regression analysis indicates that a set of demographic variables measuring rural / urban location, gender, age, education, employment status, and level of poverty account for just 5 percent of the variance in contact with AIDS deaths. However, once a series of dummy variables for race (with "black" being the excluded category) and country (with South Africa as the excluded variable) are added to the model, it explains 25 percent of variation in exposure to AIDS death. For complete results of the analysis, contact the authors.

¹⁷ Robert Mattes, Yul Derek Davids, Cherrel Africa and Michael Bratton, *Public Opinion and the Consolidation of Democracy in Southern Africa*, Afrobarometer Working Papers No. 7, Michigan State University, July 2000.

¹⁸ Only in Malawi is there a significant relationship (that is, a probability of .001 or smaller) between reporting contact with an AIDS death and perceived freedom of speech (Pearson's r = 24, probability = .001, n= 1181). This suggests that if anything, Malawi's high levels of reported contacts with AIDS deaths are underestimated. And only in Zimbabwe is there a significant relationship between freedom of speech and refusal, though curiously refusal increases with perceived freedom of speech (Pearson's r = .14, probability = .001, n = 1124). Otherwise there is no significant relationship between willingness to answer the question and responses to indicators of freedom of speech across the entire sample or within any country sample.

¹⁹ Dorrington et al., *The Impact of HIV/AIDS on Adult Mortality*.

²⁰ Pearson's r = .60, probability = .000, n = 9267.

²¹ Pearson's r product moment correlation = .67; Kendall's Tau B rank order correlation = .52. Data drawn from Spectrum.

²² Current AIDS cases were calculated as the total number of cumulative AIDS cases as of the year of the survey minus the total number of cumulative AIDS deaths as of the year prior to the survey. Data drawn from the Spectrum model, as outlined in Table 4 and Endnote 7.

²³ For these five countries, the Pearson's product moment correlation = .98 and the Kendall's Tau B rank order coefficient = .84. Removing only Lesotho, the six country aggregate correlations are still quite strong: Pearson's r = .70 and Kendall's Tau B = .41. For all seven countries, the aggregate relationship is quite weak: Pearson's r = .31 and Kendall's Tau B = .29.

²⁴ An average 58 percent of Basotho say they "often" or "sometimes" go without key necessities of life, such as food, home safety, medical treatment, cash, water, and home heating fuel. This is the highest figure

across the seven countries examined in this paper. See Robert Mattes, Michael Bratton and Yul Derek Davids, *Democracy, Poverty and SurvivaliIn Southern Africa*, Afrobarometer Working Papers, Michigan State University, forthcoming.

²⁵ For all seven countries, the value of Pearson's r increases from .31 to .53 once the impact of poverty is statistically removed.

²⁶ For five countries, Pearson's r product moment correlation = .98 and Kendall's Tau B = .84. Removing only Lesotho, the six county correlations are Pearson r = .59 and Kendall's Tau B -= .60. For all seven countries, Pearson's r = .25 and Kendall's Tau B = .41.

²⁷ Across all seven countries, the value of Pearson's r increases from .25 to .58.

²⁸ Pearson's r = -.38, Kendall's Tau B = .00.

²⁹ Pearson's r = -.15 and Kendall's Tau B = -.10

- ³⁰ Pearson's r = -.15, sig. = .000, n = 8736.
- ³¹ Pearson's r = .78 and Kendall's Tau B = .68

³² Pearson's r = .47 and Kendall's Tau B = .39

³³ For a fuller discussion of these various mechanisms, see Robert Mattes, *AIDS and Democracy: What Are the Linkages*? Discussion Paper for Workshop on "Democracy and AIDS in Southern Africa: Setting the Research Agenda" (Cape Town, 22-23 April 2002).

³⁴ Robert Schell, "Halfway to the Holocaust: The Economic, Demographic and Social Implications of the AIDS Pandemic to the Year 2010 in the Southern African Region," In *HIV/AIDS: A Threat to the African Renaissance?* Konrad Adenauer Stiftung Occasional Papers (Parktown: Kondrad Adenauer Stiftung: June 2000), pp. 19-20.

³⁵ Pearson's r = -.13, probability = .000, n = 7412. Controlling for levels of poverty, Pearson's r = -.07, probability = .000, n = 7408.

- ³⁶ Pearson's r = .00, not significant at .95 level, n = 7412.
- ³⁷ Pearson's r = -.02, not significant at .95 level, n = 7412.
- ³⁸ Pearson's r = .10, probability = .000, n = 4944.
- ³⁹ Pearson's r = .07, probability = .000, n = 4944.
- ⁴⁰ Pearson's r = .08, probability = .000, n = 4944.

⁴¹ Pearson's r = -.71. Controlling for national levels of poverty, Pearson's r = -.83.

⁴² This has been extensively discussed in work by Alan Whiteside and Tony Barnett. For the most recent statement, see Barnett and Whiteside, *AIDS in the Twenty-First Century: Disease and Globalisation* (Palgrave, Basingstoke, 2002).

⁴³ Pearson's r = -.49. Controlling for national levels of poverty, Pearson's r = -.25.

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⁴⁴ Pearson's r = -.64. Controlling for national levels of poverty, Pearson's r = -.81. The same general finding emerges with regard to severe illness and attendance at meetings of community service / welfare groups: Pearson's r = -.41, but once we control for levels of poverty, Pearson's r = -.59.

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