Gauging the epidemic

> *'Of what use are statistics if we do not know what to make of them? What we wanted at that time was not so much an accumulation of facts, as to teach the men who are to govern the country the use of statistical facts.'*[1] *(Florence Nightingale)*

Facts don't 'speak for themselves'. The English nurse Florence Nightingale understood this when, during the Crimean War 150 years ago, she set about collecting mortality statistics of soldiers admitted to the field hospital of Scutari. Viewed from one obvious angle, the statistics reflected casualties of battle – a regrettable 'fact of war'. Nightingale saw a more complex picture. Once analyzed, her data enabled her to show that injured soldiers were seven times more likely to die from typhus and cholera contracted in hospitals than from wounds sustained out on the battlefield. Wretched sanitary conditions in military hospitals were claiming more lives than bullets and shrapnel (Scott, 2005). A simple tally of the dead would have hidden this vital fact; analysis brought it to light. Facts don't disclose their value themselves, and the important ones don't automatically eclipse the dross.

Until very late, warnings that a serious HIV/AIDS epidemic was incubating in South Africa were either ignored, disputed or dismissed. It's not hard to see why. HIV spreads with stealth, and for many years hides its presence from casual observation. An epidemic becomes 'obvious' long after it has become a fact of life and death. In our case, this was happening in a society wrenching itself free of apartheid and in a period when the future seemed there for the making. Seeing this gathering shadow of the epidemic for what it was implied a betrayal of hope, a kind of blasphemy. History could not be that cruel and cynical.

But it was. By the time voters went to the polls for the country's second-ever democratic election in 1999, at least 3 million and possibly as many as 4 million South Africans were living with HIV.[1] Forecasts of what lay ahead had been flying thick and fast. Uniformly grim, they were of varying quality, however. While many were being assembled with the best available data and the requisite rigour, a few were slipshod, even sensationalist. So it was perhaps inevitable that doubt would resurface when, to some, the anticipated doom seemed indiscernible from 'routine' wretchedness. Steadily, that doubt morphed into disbelief. Battlelines were being drawn between science and heresy, realism and denial, reason and flakiness. The middle-ground became no-man's-land. Questioning the accuracy of statistics invited the label of 'denialism', defending the robustness of an estimate drew allegations of manipulation and deceit.

Were it not for the institutional location of some of the participants, this would have been a brief skirmish.[2] Although in some respects still incomplete, the evidence-based understandings of South Africa's epidemic pointed to one, indisputable conclusion: an extraordinary disaster was under way. South African dissidents' grasp of HIV/AIDS epidemiology was un-

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1 The ASSA 2002 model estimates 3.2 million South Africans were living with HIV in 1999; for reasons discussed below, this is probably the most accurate estimate available and incorporates data and research findings that were not available at the time. Using a more rudimentary model and less nuanced assumptions, UNAIDS/WHO (2000) estimated there were 4.2 million South Africans with HIV at the end of 1999.

2 Amar Hamoudi (2000), for example, set out to examine two questions that flowed from the claim that AIDS was a misnomer for various poverty-related conditions. Firstly, had mortality trends in the hardest-hit countries changed significantly compared with trends in other countries on the continent? And, secondly, could such discrepancies be attributed to factors other than AIDS – e.g. to malnutrition, parasitic diseases, illness due to poor sanitation, and unnatural causes such as violence or accidents? Focusing on southern Africa, Hamoudi found no statistically significant differences in log life expectancy for southern Africa compared with the rest of Africa in 1980. Fifteen years later, however, significant differences were evident (thus answering the first question). Yet, differences in incidence of malnutrition and access to sanitation were found not to be statistically significant between southern Africa and the rest of continent, while malaria had a comparatively less-severe presence in most southern African countries compared with the tropical regions of the continent. In addition, most of the burden of mortality caused by malnutrition, diarrhoea and parasitic diseases (such as malaria) is borne by infants and young children, yet significantly higher *adult* mortality was being observed in countries with severe AIDS epidemics. He concluded that the rising mortality rates seen in southern Africa could not be explained without factoring in the AIDS epidemics.

sure, their familiarity with key research findings cursory, and their handling of technical data often adventurous. But this was not only a battle about the substance and quality of knowledge; it was also about how knowledge is inflected with power, prejudice, memory and hope (see Introduction). And, as such, it also forced science off its remote perch.

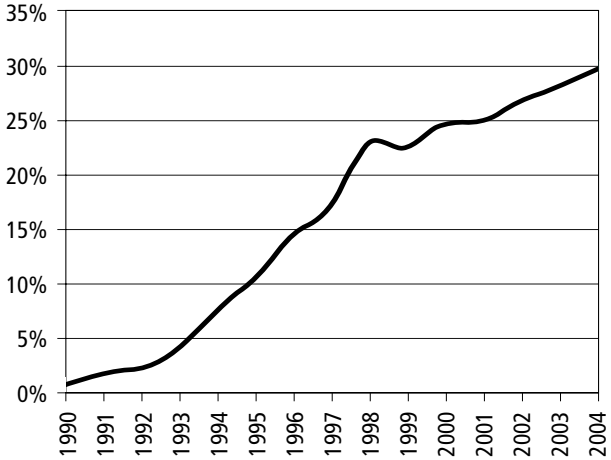
Delayed images

HIV prevalence data indicate the total number of people infected with HIV at a particular point in time – and these are usually expressed as a percentage of the adult (15 to 49 year-old) population. As such, prevalence data can provide a good picture of the overall *trend* of an epidemic but a less satisfactory picture of recent developments, since they do not distinguish between people who acquired the virus very recently and those who were infected several years earlier. Some of the people testing positive at any given point would have been infected quite recently, others would have become infected at various, earlier points. So, HIV *prevalence* estimates point to HIV *incidence* trends – the rates of new infections – from several years earlier. It's a delayed picture of incidence.

In South Africa, the steep rise in HIV prevalence through most of the 1990s was an echo of exceptionally high incidence rates; very large numbers of people were becoming infected each year – more than 600 000 when incidence peaked in the late 1990s, according to the ASSA 2002 projections (Dorrington et al., 2004). AIDS deaths, though, were nowhere near peaking in the late 1990s. This is because people do not develop AIDS-related symptoms until several years after first HIV infection; even without antiretroviral treatment, some can survive for a decade or more.[3] Estimates of average survival time from sero-conversion vary; Statistics SA fixes it at between 9 and 11.5 years, depending on the age group (10.5 years for people aged 25-34 years and 11.5 years for those aged 15-24 years), while UNAIDS assumes a median survival time of 9 years.[ii]

It is once people with HIV become chronically ill and die in large numbers that the epidemic's impact begins to register more visibly in society. In South Africa, where the epidemic has lagged behind those in East Africa and in other southern African countries, that phase only began in the late 1990s. The epidemic's chain of effects is delayed in South Africa. The impact experienced half way through the 2000s is the after-shock of new infection trends that occurred as far back as a decade ago, when HIV incidence had not yet reached its zenith and when HIV prevalence was still rising steeply (see Figure).

HIV prevalence among antenatal clinic attendees in South Africa: 1990-2004



Source: Department of Health, South Africa

Limits of certainty

No AIDS epidemic on the continent has been as carefully and insistently probed as South Africa's. This is due partly to the controversies swirling around it, but mostly due to the quality of the available data and to the efforts invested in deciphering the information. One may therefore expect to see a fairly snug consensus in various estimations of the extent of South Africa's epidemic. But that's not so. The estimates vary – and sometimes by wide margins, or so it seems. This

3 This 'incubation period' varies, and the relative weight of the factors affecting it is not known with certainty. However, there are strong indications that the period is shorter in sub-Saharan Africa than in Europe and North America, possibly due to 'the poorer health status of the general population, more virulent strain[s] of HIV, and repeated re-infections' (Stover, 1997).

has encouraged a healthy tendency to interrogate HIV and AIDS estimates, and to examine more closely their respective strengths and weaknesses (see box above). Unfortunately, it has also triggered ham-fisted reflexes to dismiss the plausibility of all HIV and AIDS estimates, and even to discount the existence of the epidemic.

As with any unfolding epidemic, there have been inaccurate statements about HIV and AIDS trends and the epidemic's scale, with projections of future trends perhaps the biggest culprit. Derived from limited data and incomplete, sometimes inaccurate, understandings of epidemic trends and patterns, early estimates sometimes overshot the mark. Indeed several epidemiologists involved in generating UNAIDS/WHO estimates have admitted that the focus on point estimates may have led readers to infer an unwarranted level of certainty about the estimates (Walker et al., 2004) – a diplomatic way of saying they had inadvertently oversold the precision of earlier estimates.[iii] Similar acknowledgements would apply also to estimates produced in the past by USAID and others.[iv]

Globally, and especially in sub-Saharan Africa, AIDS advocacy efforts have tended toward portents of doom, even when the epidemiological basis for some claims has been ambiguous, even questionable. This has prompted some observers to warn of 'a danger that advocacy is getting in the way of objective assessments of the level and trends of the AIDS epidemic in Africa' (Bennell, 2003).[v] Often, the publicized versions of findings would not draw sufficient attention to caveats that tempered interpretations of the data. News media in particular have been guilty of such omissions, opting for sensationalism over rigour. Estimates couched in colourless qualifications make for mealy sound-bytes and dull headlines; vital, though sometimes remote, details found in annexes and footnotes tend not to intrude on most media accounts of the epidemic.

Overall, the tendency has been to highlight 'point estimates',[4] despite their shortcomings, rather than to publicize the ranges or boundaries within which the actual number very probably lies. Even when padded with qualifications, 'point estimates' make an unmerited showing of accuracy when they declare, say, life expectancy to be 66.7 years or that the number of people living with HIV is 4.34 million. After all, the very notion of a *precise* estimate is oxymoronic. Better to present projections and estimates in ways that more plainly acknowledge the uncertainty that surrounds them. The fact that they are pointillist pictures of reality, not draughtsman's drawings, does not diminish their value.[5] Even if we cannot say with certainty that there are 5 million or 5.6 million or 6.5 million South Africans living with HIV, it matters that we can confidently state that, say, between 4.5 and 5.6 million South Africans are living with the virus.[6]

So, part of the problem has been the *manner* of presentation. But the difficulties extend further. Various estimates and projections are also the products of different models and methodologies which extrapolate different sets of data (of varying quality sometimes), and that apply different assumptions about the many variables that are in play. There's nothing sinister or mischievous about this. The discrepancies are easily explained, and some even dissolve once the data is studied carefully.

Data feuds

There is no practical way to determine exactly how many people have been infected with a virus like HIV. Scientists gather pertinent data, refine various assumptions about the manner and pace of HIV transmission and develop mathematical models that can approximate how many people have HIV or have died

4 There's nothing mysterious about this reflex. The paradoxically more accurate *ranges* of estimates are clumsy to work with. They clutter sentences, muffle the drama and can be wide enough to resemble guesswork more than science. Last, though not least, they lend themselves to lousy headlines.

5 A better metaphor might be the pixel imagery of digital technology. The 'pixel densities' of HIV and AIDS estimates and projections have been improving steadily, providing clearer images of situations and trends, but not yet achieving the crisp precision of highly-detailed and -accurate information. These images are invaluable when viewed at a certain distance but they tend to shed their informative power at closer range.

6 In December 2003, UNAIDS and WHO grasped this nettle by laying more emphasis on the ranges of estimates, rather than on the specific point estimates (in other words, South Africa has between, say, 4 and 6 million people living with HIV, as opposed to strictly highlighting the mid-point – 5 million – in that range). UNAIDS calculates country estimates every two years (UNAIDS/WHO, 2004).

of AIDS, and more. Various such models are being used to gauge South Africa's epidemic, each applying slightly different parameters and assumptions.

In heterosexual HIV/AIDS epidemics like South Africa's, the most commonly-used data for such calculations are gathered at a sample of antenatal clinics, where blood samples of pregnant women are anonymously tested for HIV. Unlike other countries in Africa, South Africa's system captures data from a random sample of all antenatal clinics – in urban, peri-urban and rural areas. By definition, though, the data only reflect HIV prevalence among women who have had unprotected sex; the data do not provide *direct* evidence of prevalence among men, nor among women younger and older than child-bearing ages, nor among women who are not having unprotected sex. However, when modulated with various assumptions, the data offer a basis for estimating such prevalence, which the Department of Health does annually. Still, there are many potential sources of error. The assumptions may be inaccurate, they may vary between parts of the country or they may change as the epidemic matures.[7] These assumptions include estimations of different infection rates between men and women, in urban and rural areas, and in various age groups, as well as fertility rates, and more (Walker et al., 2004; Ward et al., 2004).[8] HIV/AIDS estimates therefore are presented within 'plausibility bounds' or 'ranges of uncertainty'. In general, the more steps or assumptions have to be introduced to achieve a calculation, the less precise that estimate is likely to be. Estimates of the number of children orphaned by AIDS, for example, involve several other layers of estimates and assumptions, which can diminish their precision (Grassly et al., 2004).[9]

Household surveys that include testing for HIV, on the other hand, can provide countrywide data on HIV prevalence for both sexes and for various age groups, and can include samples from remote rural areas. But they're not the last word, either. If a significant share of respondents refuse to be tested, or they only answer certain questions, or they are absent at the time of the survey, a potential bias is introduced into the survey data. This has been a recurrent issue in household serosurveys carried out in sub-Saharan African countries recently, where non-response rates of 24-44% have been reported. Of course, the estimates can be adjusted if the salient characteristics of non-responders are known. But they're usually not. The surveys cannot measure the possible association between a person's absence or refusal to participate, and that person's HIV status. It might be that a person's refusal to participate or his/her absence from the household is correlated with a stronger likelihood of HIV infection. (For example, migrant or mobile workers are believed to face higher risks of infection, and are also more likely not to be home when the surveys are carried out.) There is a strong likelihood, therefore, that high non-response rates in household-based surveys could

7 For detailed discussion of the methodologies and assumptions used to achieve HIV/AIDS estimates, and the uncertainty surrounding them, see Grassly NC et al. (2004). Uncertainty in estimates of HIV/AIDS: the estimation and application of plausibility bounds. *Sexually Transmitted Infections*, 80(Supplement I):i31-i38; Walker N et al. (2004) 'The quality of estimates of HIV: What do we really know about the HIV pandemic?' Lancet, 363(9427). 26 June; and Ward H, Walker N, Ghys PD (2004). Methods and tools for HIV/AIDS estimates and projections. *Sexually Transmitted Infections*, 80(Supplement 1). August.

8 It's now clear, for example, that fertility rates in South Africa are lower than in the rest of sub-Saharan Africa. In Kenya, meanwhile, the assumed ratio of HIV-positive women to men was initially misjudged. When a national household survey reported lower HIV prevalence than shown in other estimates, a review of antenatal clinic-based HIV data concluded that adult HIV prevalence in Kenya had been *overestimated* in previous years. The hitch? Earlier estimates had assumed too small a ratio of females with HIV to males with HIV. In Kenya, the ratio was found to be almost 2:1 – larger than in most other countries in sub-Saharan Africa, where the average ratio was 1.3:1. In other words, the numbers of males with HIV had been overestimated, yielding a too-high estimate of adult HIV prevalence.

9 Depending on the methodology, those assumptions would vary in detail, but could include an estimate of the total population, an estimate of the total number of children living (which implies an assumption regarding fertility rates), male/female HIV infection ratios, adult HIV prevalence, adult survival rates with and without antiretroviral treatment (the former possibly also implying estimates of antiretroviral treatment coverage and adherence), adult AIDS mortality rates, infant and child mortality rates (including AIDS-related mortality), and more.

lead to *underestimation* of HIV prevalence. Elsewhere in Africa, many household-based surveys have returned HIV estimates lower that those generated from antenatal clinic data.[10]

So there's no golden mean, at least not yet (Ward et al., 2004). On the whole, estimates based on antenatal clinic data are a useful gauge of HIV infections *trends* among 15 to 49 year olds, while national household surveys can reveal more about the nature of the epidemic and can flesh out other important details including, possibly, incidence trends, if conducted in a comparable fashion at regular intervals. Considered in tandem, the various data can yield more accurate estimates of HIV infection levels and rates (and of other estimates, such as AIDS deaths). The bottom-line is that all HIV-related estimates – whether they are based on a national survey or on sentinel surveillance data – need to be assessed critically, and their assumptions and data need to be reviewed consistently.

Why it matters

To some, questioning the accuracy of HIV and AIDS estimates is an unaffordable luxury, a reckless distraction. Whether or not 6 million or 4 million people are living with HIV, and whether or not 500 000 or 250 000 are dying of AIDS each year, a catastrophe is under way. This is so. At the levels of social justice and morality, it should not matter whether 2.5 million or 5 million South Africans are living with HIV. There is a manifest obligation to control an epidemic of such scale, to aid those whose lives it threatens, and to limit the ruin it can bring on households, institutions and society.

But there are also very practical reasons why it does matter. In an epidemic as severe as South Africa's – and even the lowest estimations describe a grievous epidemic – proper planning requires as precise an understanding as possible of the status and likely trends of HIV and AIDS. The less precise our knowledge of the epidemic, the more our responses become a gamble and the more we rely on luck – and that's an unaffordable luxury. The successful design and adaptation of prevention efforts require at least an accurate sense of the epidemic's scale, trends and likely evolution in different age groups, among males and females respectively, and in various parts of a country. Potentially effective remedial steps require a fairly faithful estimation of the scale and the nature of that impact, and who is bearing its brunt. This need is obvious in the health sector, for example, where the complicated logistics of a sustained treatment programme require reasonably accurate information about how many people are living with HIV, how many are in need of treatment, and where they are. It's also necessary to be able to anticipate and meet the demand for resources (diagnostic services, hospital beds, duration of admission, health staff). The ramifications spill a lot wider, too. Remedial strategies, particularly those that imply long-term institutional demands and fiscal commitments, are ill-served by shabby estimates. This affects a multitude of institutions and programmes, not least those tasked with economic matters, as well as fiscal issues (via skewed pressures on budget lines, increased take-up of state grants, shrinking savings, pressure on revenue systems, etc.) and economic strategies (via labour market changes, consumer demand trends, investment trends, productivity effects, etc.). Severe, long-standing epidemics can knock demographic patterns off kilter. Male-female ratios, for example, can shift dramatically enough to entrench or alter some social behaviour patterns, migration patterns can change in ways that require adjusting housing and infrastructure strategies or health service logistics, etc.

10 'Many' but not all. Household HIV surveys have been conducted in Botswana, Kenya, Mali, Niger, South Africa, Tanzania, Uganda, Zambia and Zimbabwe, among others. In mainland Tanzania, a 2003-2004 survey of more than 13 000 adult men and women found 7% of adults were infected with HIV, compared with the UNAIDS' end-2003 prevalence estimate was higher, at 8.8%. See 'About 7% of adult Tanzanians HIV-positive, new survey shows', *Kaiser Daily HIV/AIDS Report*, 11 April 2005, available at http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=29246. An earlier household survey in Kenya found 6.7% of Kenyans were living with HIV, lower than UNAIDS' 8.0% estimate for end-2001. In Botswana, meanwhile, a population-based survey in 2004 returned much lower HIV prevalence estimates than antenatal clinic data suggested (National AIDS Coordinating Agency Botswana, 2005). How-ever, the refusal rate was so high (44% of participants refused to be tested for HIV) that the prevalence findings probably were heavily skewed. Interestingly, in Uganda, a 2004 population-based survey (where the refusal rate was very low and the likely bias therefore more limited) found HIV prevalence was *higher* than indicated in estimates derived from HIV test data gathered at antenatal clinics: 7%, compared with the Ministry of Health's 2003 national HIV prevalence estimate of 6.2% (Ministry of Health Uganda, 2005; UNAIDS/WHO, 2005).

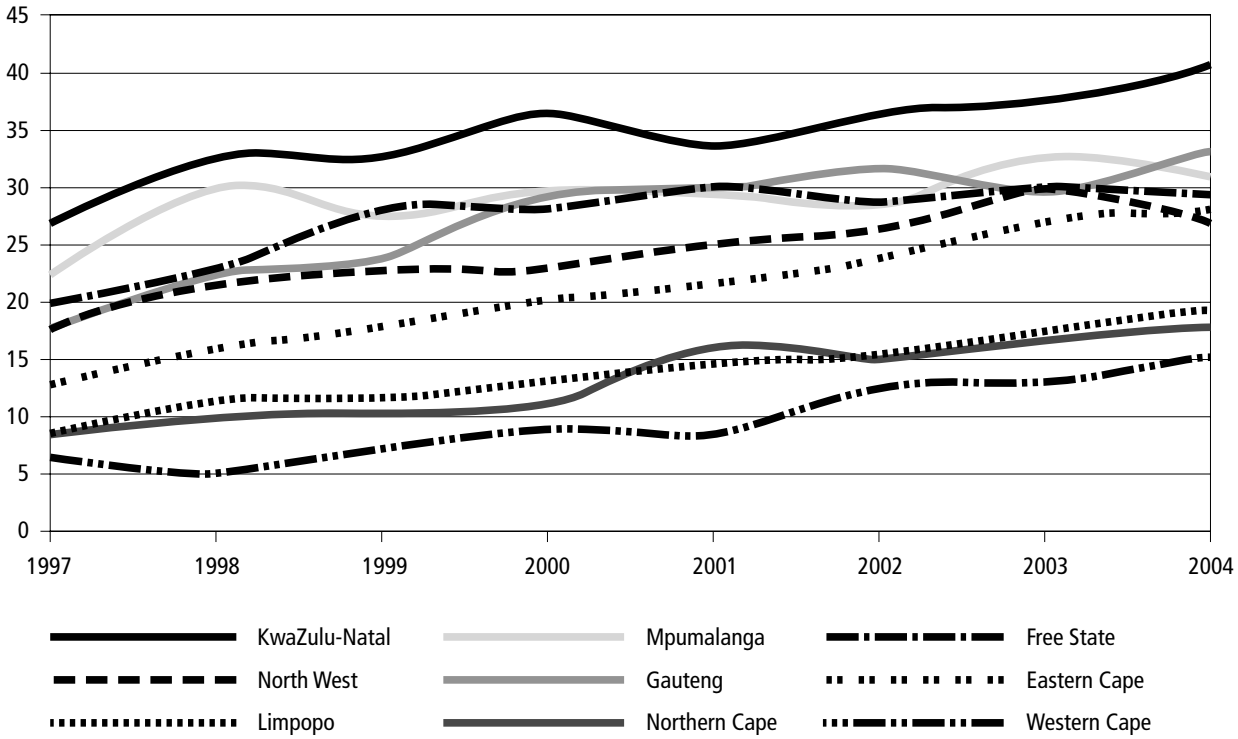
So what do we confidently know about South Africa's epidemic and its likely impact?

Infection patterns and trends

Each year, the Department of Health routinely tests approximately 16 000 pregnant women for HIV, the results of which provide the most regular sources of data on HIV infection in the country. The most recent survey indicated that 29.5% [range 28.5-30.5%][vi] of women attending antenatal clinics were HIV positive in 2004 – which translated to an estimated 3.3 million [range 3.1-3.6 million] women overall. Leaving aside any further extrapolations, the data confirmed that HIV infection was rife in this sub-group of the South African population (i.e. pregnant women attending antenatal clinics). Prevalence peaked among women aged 25-34 years – more than one in three of whom was estimated to be living with HIV. Among women aged 20-24 years almost one in three was infected.

As the Figure below shows, HIV prevalence was highest among pregnant women in KwaZulu-Natal (40.7% in 2004), but remained exceptionally high also in Mpumalanga (30.8%), the Free State (29.5%), North West (26.7%), Gauteng (33.1%) and the Eastern Cape (28%). The most significant increases since 2000 have occurred in the Eastern Cape, KwaZulu-Natal, Limpopo, the Northern Cape, North West and the Western Cape (Department of Health, 2002, 2003 & 2004).[11]

HIV prevalence among antenatal clinic attendees in South Africa by province: 1997-2004



Source: Department of Health

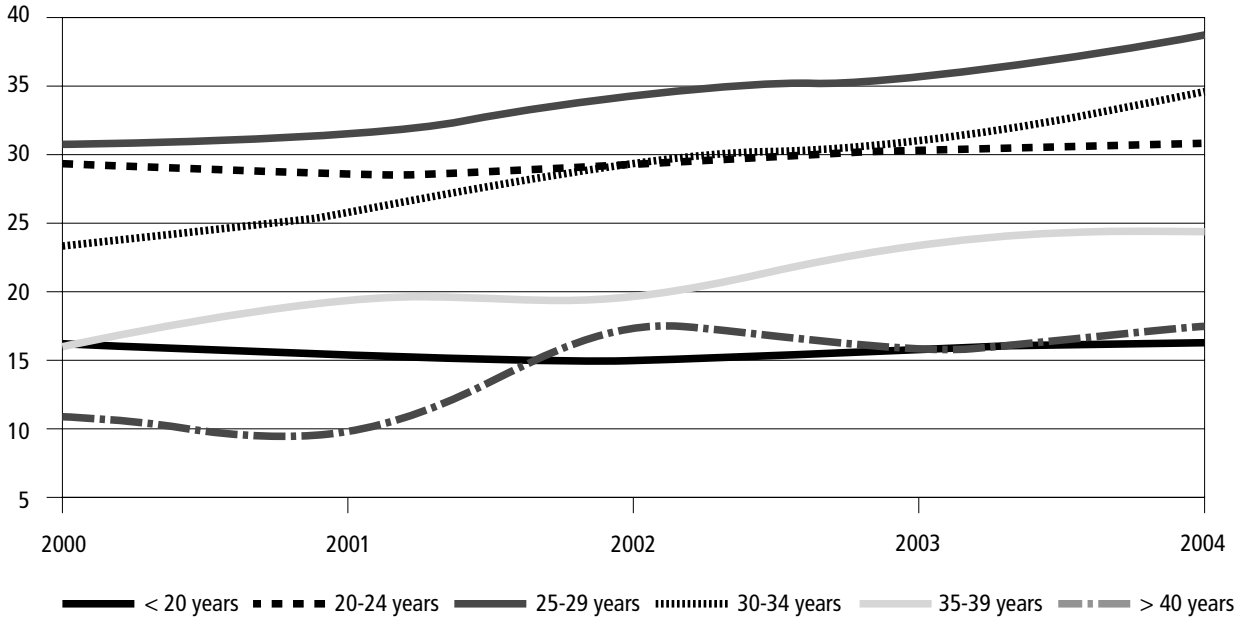
The data underscored two dominant features of South Africa's epidemic: the astonishing speed at which it has evolved (national adult HIV prevalence of less than 1% in 1990 rocketed to almost 25% within 10 years; see Figure above) and its extraordinary scale. Between 3 million and 3.6 million women and between 2.6 million and 3.1 million men, as well as more than 100 000 babies were living with HIV in 2004. Fully 76% of the people living with HIV were 15-34 years of age (Department of Health, 2005).

11 For the ranges around these estimates, please refer to Department of Health (2005:8). Depending on the province, the ranges vary from 4% to more than 7% around these point estimates. The ranges are narrowest for KwaZulu-Natal and Gauteng.

There were no glimmers in the gloom. Among pregnant women in their late teens (15-19 years), HIV infection levels were just over 16%, belying the Department of Health's earlier claims that the possible 'beginnings of a decline in HIV rates among women below 20 years' were visible.[12] HIV prevalence levels among 20- to 24-year-old pregnant women stayed steady and high in 2000-2004, hovering between 28% and 31% (Department of Health, 2002, 2003 & 2004). Beware, though. This doesn't necessarily refute other indications (from household surveys, for example) that more young South Africans are protecting themselves against HIV and AIDS. The Department of Health data reflect HIV prevalence among women who are pregnant – and who, by definition, are sexually active and have had unprotected sex. The data do not tell us how representative these women are in their respective age groups; it might be that large numbers of young women are not having sex or are having protected sex. We're not sure. Indeed, the biggest discrepancies between antenatal clinic-based estimates and those derived from household surveys is found among 15 to 24 year olds (see Figure below). Overestimation of HIV prevalence in this age group is a common bias in antenatal studies.

What was particularly striking in the latest data, however, was the pronounced rise in HIV prevalence among *older* women, all the way up to 40 years and beyond.[13] This is unusual. It confirmed that women face extremely high odds of being infected with HIV when they forego protected sex (because they're in steady relations or marriages and trusttheir partners, or because they wish to become pregnant, or because power imbalances deprive them of the ability to insist on safer sex).

HIV prevalence by age group among antenatal clinic attendees in South Africa by province: 2000-2004



Source: Based on Department of Health data, 2000-2004.

12 Department of Health (2002:12). HIV prevalence among 15-19 year-old pregnant women dipped from 16.1% in 2000 to 14.8% in 2002, then climbed back to 15.8% and 16.1% in 2003 and 2004, respectively. Declining prevalence in this age group might have indicated that prevention efforts were starting to bring positive results among young women. This is because HIV prevalence in the 15-19 year age group sometimes is regarded as a proxy for HIV *incidence* (the number of new infections), since people in this age group are likely to have been infected quite recently. Many epidemiologists, however, are reluctant to draw such inferences, and argue that the 15-24 year cohort offers a more reliable indication of possible incidence trends. If average age at first sex is very early – i.e. close to 15 or 16 years – then the 15-19 year age group could provide a tantalizing glimpse of possible incidence trends. But when average age at first sex is closer to 19 years, the 15-24 year age group data becomes more suggestive of incidence trends.

13 The Department of Health data also point to an important gap in prevention campaigning. The sharpest rises in HIV prevalence among pregnant women in recent years have been among women aged 25-40 years. This suggests that, whatever behaviour changes are being achieved among young women (15-24 years of age), once women are married or in long-term relationships, protected sex becomes more infrequent, and the odds of being infected increase. Prevention strategies that target young people in the main therefore are inadequate.

How well do the Department of Health estimates compare with others?

South Africa's antenatal clinic network probably is the most extensive and geographically representative such system on the continent. Still, the data it provides can suffer significant biases and shortcomings. Sexual behaviour patterns vary and in some places a large percentage of young women are either not sexually active or are very rarely having sex. Extrapolations from the antenatal clinic data have to adjust for such variances; the catch is that sexual behaviour data provide relatively patchy pictures of reality. In addition, the data do not reflect infection levels among women using private health-care services (and thus introduce possible distortions of race and class). On the other hand, antenatal clinic-based data could also underestimate actual prevalence; since HIV is known to lower fertility, it is possible that significant numbers of HIV-infected women are unable to conceive and therefore do not pass through this HIV surveillance system.

As a rule of thumb, though, estimates based on antenatal clinic data seem to overshoot the mark, as comparisons with population-based surveys – such as the HSRC study – have suggested. Such weaknesses, as we shall see, have been addressed most concertedly in the ASSA 2002 model, which incorporates an extensive set of updated variables.[vii]

Released in December 2002, the 2002 *Nelson Mandela/HSRC Study of HIV/AIDS* (HSRC, 2002) was the country's first nationally representative household HIV survey. It arrived at several surprising findings that seemed to alter the picture of South Africa's epidemic. In particular, it cast sharper light on the geographical, gender and racial patterns of the epidemic.

HIV prevalence among white and coloured South Africans was estimated at 6.2% and 6.6%, respectively. The 5-6% prevalence estimate for children baffled observers, and revived suspicion that significant numbers of HIV infections could be occurring through unsafe medical practices.[14] (Subsequent research has discounted that explanation, though; see below.) Also surprising was the finding that the worst-affected provinces were the Free State, Gauteng and Mpumalanga (where prevalence was estimated at 14-15%), and not KwaZulu-Natal (11.7%).[15] Adult prevalence in the Western Cape was found to be surprisingly high at 10.7%, outstripping that found in the Eastern Cape, Limpopo and Northern Cape provinces (where it ranged from 6.6% to 9.8%).

In other respects, the survey findings were in line with those of earlier studies. The age and sex distribution of HIV infection, for example, matched the patterns revealed in other studies. Thus women were more at risk (17.7% prevalence) than men (12.8%). Young women in particular were found to be considerably more prone to HIV infection than young men; among 15 to 24 year olds, HIV prevalence was twice as high among women. As elsewhere in sub-Saharan Africa, HIV prevalence was found to be higher in urban than in rural areas, but the finding that it was highest in urban informal settlements (an average of 21% but as high as 28% in some locations) highlighted some of the socio-economic dimensions of the epidemic. The two provinces with the highest HIV prevalence – Gauteng and the Free State – also had the highest proportion of persons living in urban informal areas.[viii] Prevalence was considerably lower in tribal areas (12.4%) and on farms (11.3%).

Much was being made, though, of the apparent contrast with other sets of HIV estimates. Adult (15-49 years) HIV prevalence was pegged at 15.6% (13.9%-17.5% approximate range), almost one-quarter lower than the 20.1% estimate UNAIDS had arrived at for 2001,[16] and much lower than the 24.8% (range 23.6%-26.1%) of pregnant women who tested positive in the Department of Health's 2001 antenatal sero-prevalence

14 The HSRC study authors tried to determine what proportion of the children (aged 2-14 years) were likely to have been infected through mother-to-child transmission. They discovered that only 6.1% of the 86 HIV-positive children had a biological mother who had died and a similar percentage (7%) had a biological father who had died. MTCT therefore seemed to be a minor factor in these infections (Garbus, 2003).

15 The KwaZulu-Natal finding was especially perplexing. It has been suggested that the province's antenatal clinics sampled in the annual sero-survey of the Department of Health were highly unrepresentative, since they were clustered mostly along major transport routes (where HIV prevalence is likely to be especially high), and therefore might have led to gross overestimation of HIV prevalence in KwaZulu-Natal. Whether or not that is the case is unclear, though. A recent study done in the Vulindlela district of the KwaZulu-Natal Midlands, where the antenatal clinics are not included in the Department of Health's annual seroprevalence surveys, found very high HIV prevalence of 43%. See 'South African HIV prevalence steadily rising; researchers investigate why some communities are harder hit', *Aidsmap*, 17 June 2005.

16 The confidence interval for the HSRC survey estimate was 13.9%-17.5%, meaning that actual prevalence could lie anywhere within that range (HSRC, 2002:5); UNAIDS did not publish ranges for its end-2001 country estimates (see UNAIDS, 2002). It is vital that these perimeters are borne in mind when considering the accuracy of estimates.

survey. But viewed from other angles, the discrepancies appeared less harsh.[17]

One might expect estimates drawn from household surveys data to trump those arrived at by extrapolating from antenatal clinic data. But, as noted earlier, household-based surveys are not without shortcomings – and the HSRC study was no exception. Most significant was the fact that fewer than two thirds of the respondents identified for the survey agreed to take an HIV test,[ix] a participation rate low enough to introduce considerable potential for bias in the results. The estimates could be adjusted to correct for bias if the salient characteristics of non-responders were known. But they're not. The survey therefore could not measure the possible association between a person's absence or refusal to participate, and that person's HIV status. Some who declined to participate may have known or suspected they were HIV positive, while others who did not take part because they were not home may have belonged to potentially 'high-risk groups' such as military personnel, prison inmates and hospital patients (Bennett, 2003). It is quite possible, therefore, that the study underestimated HIV prevalence. In addition, the small sample size widened the bands of uncertainty around the estimates. According to Bennett (2003), ignoring any other possible source of bias, the small sample size (8 428 respondents) stretched the confidence intervals in some instances. The HIV prevalence for whites and coloured people, for example, could be half or one-and-a-half times as high as the 6.2% and 6.6% respective estimates – i.e. it could lie anywhere between 3% and 9%. Similarly, the 5.6% prevalence estimate for children aged 2-14 years was based on only 86 HIV-positive tests.[18] (More recent HSRC research suggests that the prevalence levels found in this age group were aberrations.) While the HSRC study revealed important details in the epidemic, it was by no means the last word. Antenatal clinic-based estimates might be too high, while those derived from household surveys might be too low; but taken together, they offer the basis for a much more detailed picture of the epidemic.

Comparing the estimates – who gets it right?

Statistics SA, using a different methodology, estimated that 3.83 million South Africans were living with HIV in 2004 (Stats SA, 2004), while the HSRC arrived at a figure of 4.6 million and the ASSA 2002 model calculated 4.93 million for 2004 – all considerably lower than the Department of Health's range of 5.7-6.2 million for the same year. Such variance seems to undermine confidence in any single set of estimates. But the discrepancies are actually less dramatic than they seem.

The Statistics SA estimate was for 15-49 year-olds only (Dorrington et al., 2004), while the others apply to the entire population. Using the ASSA 2002 calculations as a guide, approximately 500 000 people younger than 15 years and older than 49 years most probably were living with HIV in 2004. Add that, and it brings the Statistics SA estimate to 4.33 million – well within the range of the HSRC estimate, and much closer to the ASSA 2002 figure. Statistics SA also applies more conservative assumptions (it assumes, for example, a slower progression in the epidemic), which means that its estimate will tend to be lower than the others. By the same token, if male/female infection ratios are brought in line with newer research findings, the Department of Health estimates would be lower. The Nelson Mandela/HSRC study (2002) indicated that males were 74% as likely to be infected than were females, whereas the Department Health still worked with a ratio of 85%. Make the adjustment and the Department's estimate of the total

17 The HSRC survey indicated that 11.4% (10%-12.7% range) of South Africans (of all ages) were living with HIV at the end of 2002. Extrapolate the end-2001 UNAIDS numbers to the entire population and one arrives at HIV prevalence in the total population of just over 11% – roughly the same as in the HSRC survey. The ASSA 2002 model put prevalence lower, at under 10% in 2002 (Dorrington et al., 2004).

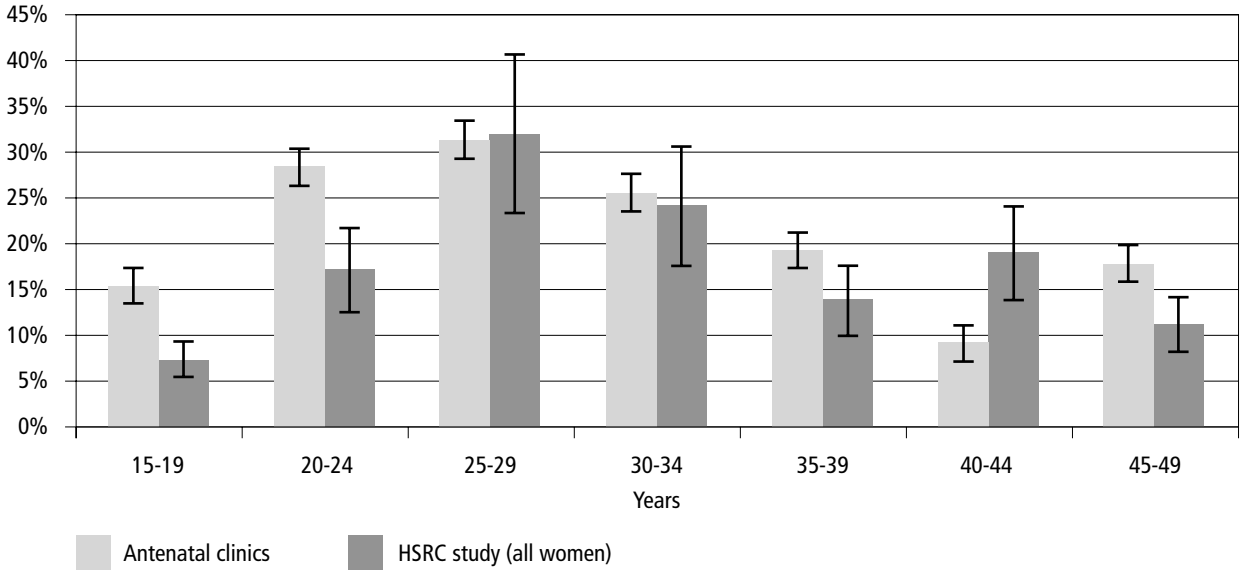
18 According to Dorrington, the 5.6% estimate would translate into about 700 000 children aged 2-14 living with HIV/AIDS and roughly 4 000 deaths of children aged 10-14 annually. The evidence for deaths on such a scale in that age group lacks, however: 'Extrapolating from the cause of death data captured by Statistics South Africa and adjusting for underreporting of deaths, we only have some 350 to 400 deaths due to AIDS and potentially AIDS-related conditions per annum' (Bennett, 2003:3). A subsequent study was conducted in the Free State province to examine the unusually high rates of infections found among children (Shisano et al., 2005). It found high HIV prevalence among children aged 2-9 years (the age group studied). The overwhelming majority of infected children (98.6%) had HIV-positive mothers, making mother-to-child transmission the dominant mode of the HIV transmission. Among the 1.4% HIV-infected children with HIV-negative mothers, it was found that having been breastfed by a non-biological mother was highly associated with the child's HIV status. Finally, the study noted the potential for nosocomial HIV transmission in public health facilities in the Free State provinces.

number of South Africans living with HIV in 2004 becomes more than 400 000 lower than the 5.7-6.2 million range it calculated.[19]

required, because we don't yet know exactly how to weigh the comparative influence of the various factors driving the South African epidemic. But the accuracy of such modelled incidence

other sexually transmitted infections, and more. Given the refinements and updated assumptions incorporated into the ASSA 2002 model, the latter currently probably provides the most accurate picture of South Africa's epidemic.[21] For 2005, ASSA estimates that about 5.17 million South Africans were HIV positive.

Comparison of antenatal data and Nelson Mandela/HSRC study data, HIV prevalence % (2001)



Sources: Department of Health (2002), HSRC (2002).

Other, potentially more accurate estimates of incidence are available, including the ASSA 2002 model[20] and a recent model used by the HSRC. There's still some intelligent guesswork

is being enhanced by incorporating new information on key variables, such as behaviour change (drawn from population-based surveys and site-specific studies) or the prevalence of

Fuzzy pictures

AIDS advocacy has shown a strong penchant for pitching 'with AIDS/without AIDS' scenarios deep into the future. It's easy to see why. The exercises conjure gripping illustrations of the havoc the epidemic could unleash. But these scenarios should be used with circumspection.

The variables that conspire over 20 or 50 years – and the relationships between them – are complex, contingent and inter-related. At the heart of 'AIDS/no-AIDS' scenarios is the fiction that a single factor (in this case an AIDS epidemic) can discretely be introduced into or removed from an equation without triggering a series of other effects – that all else indeed does 'stay equal', as the *ceteris paribus* principle requires. There's

19 For its part, the Nelson Mandela/HSRC survey did not include data for persons younger than 2 years, thus missing as many as 100 000 or more babies and infants that were HIV infected.

20 For a summary of the model's methodology and innovations, see http://www.assa.org.za.

21 There's a further, intuitive reason for siding with the ASSA estimates. The various generations of models have been developed to provide the health and life insurance industry with the most accurate projections of HIV and AIDS possible. Those estimates are used to assess risk, design medical schemes and insurance policies, and set premiums. Underestimating the epidemic's scale and pace implies an accumulation of unforeseen costs and obligations that could threaten profits. Overestimating the epidemic can lead to overpricing medical schemes and life policies, thus undercutting competitiveness and potentially eating into market share. So the stakes are high.

also a philosophical hitch. A 'with-AIDS' scenario is an extrapolation of data that describe observed reality. As such, it can be tested against observable reality as that unfolds. A 'no-AIDS' scenario, on the other hand, is a *counterfactual*, a fiction which defies empirical validation or refutation. It is not a prediction of what-could-be, but a prediction of what-could-never-be. We can, once 2050 arrives, measure the total population or calculate average life expectancy and retrospectively pass judgement on how accurate a projection done in 2005 was. We cannot, however, test the accuracy of the counterfactual (the 'no-AIDS' scenario) – because that reality never happened.

The upshot? 'AIDS/no-AIDS' projections have considerable suggestive value. They can alert us to the power and extent of factors that are changing our world. But they do so as suggestive pictures of likely trends, not as detailed predictions of specific outcomes.

Dead-wrong

Still, the apparently contrasting estimates and the torrent of gloomy forecasts primed a backlash. If experts couldn't agree on how many people were living with HIV and dying of AIDS, then how much store could one put in any of their estimates? Perhaps the epidemic was being exaggerated. More sinister currents were being divined, too. Some in the ruling African National Congress (ANC) and government felt attracted to the notion that HIV/AIDS estimates were being manipulated for aims that had nothing to do with the health and lives of South Africans. By early 2000 it had become clear that powerful political figures shared such views, and that President Thabo Mbeki was willing to carry the torch for AIDS dissidents or (as they would come to be called) 'denialists' in South Africa.

Just how seriously President Mbeki was invested in this enterprise was underlined when he ordered a re-examination of South Africa's social policy spending priorities in August 2001. The cue was a 1995 WHO data set, which the president had apparently tracked down on the internet and which indicated that AIDS was the cause of just 2.2% of deaths in South Africa. In a letter to the health minister, Manto Tshabalala-Msimang, President Mbeki predicted that the move would 'provoke a howl of displeasure and concerted propaganda campaign from those who have convinced themselves that HIV/AIDS is the single biggest cause of death' in the country.[x] He had earlier referred to the data when interviewed on BBC World television's Hardtalk programme, when he claimed that accidents and violence – not AIDS – were the primary cause of death in South Africa:[xi]

> TM: Do you know what the largest single cause of death in South Africa is? The largest single cause of death as we sit here is what in the medical statistics is called external causes and that is violence in the society. For instance I've seen figures that say that if you take the male age cohort from 16 to 45 years, 54% of the people who die in that age cohort die from external causes.
>
> TS: Violence isn't going to threaten the lives of seven million South Africans ...
>
> TM: I'm saying that the majority of the people in the country are dying from that and you cannot say to me I must ignore that and not take into account the fact that the majority of the people in that particular age cohort, which is a working population, is dying from the violence that is so terrible in this society. The government must respond to that.

It was a puzzling statement. In the mid-1990s already, the government had grown incredulous of crime and violence statistics – so much so that it instituted a temporary moratorium on the public release of crime statistics. Now data from that period were being enlisted in an attempt to disprove the scale of the AIDS epidemic. The WHO statistics would crop up again in the 'Castro Hlongwane' pamphlet (see below), where the author(s) declared them 'the truth about the health of our people' (Anon, 2002).[xii]

Deploying 1995 cause-of-death estimates in discussions about the impact of AIDS in 2001/2002 was dead wrong. Given median survival time of 8-11 years after first infection, most deaths attributable to AIDS in 1995 would have stemmed from HIV infections acquired during the very early stages of

South Africa's epidemic – in the mid- to late-1980s. Even in 1990, HIV prevalence among pregnant women attending antenatal clinics was still less than 1%. In seriously-affected countries elsewhere on the continent, mortality trends have shown a steep rise in adult mortality starting roughly 4-5 years after HIV spread has become widespread in the general population.[xiii] In South Africa's case, this meant sharp increases in mortality would have started occurring only in the late 1990s – as modelling indicated and the *Mortality and causes of death in South Africa* report (Statistics SA, 2005) would confirm.

Suspicions and doubt, however, had given way to outright incredulity that was being broadcast with rare fervour. Locally and internationally, the reactions were reproachful, and the exchanges grew increasingly exuberant and florid. As two opposing and mutually dismissive camps took shape, the prospects of dignified dialogue between them all but dissolved. In the manner of a medieval religious dispute, those subscribing to orthodox interpretations of the epidemic presented themselves as guardians of established verity, while sceptics struck the pose of free-thinking rebels. The former entered the fray armed with the ostensible authority of science, which the latter rubbished as the handmaiden of pharmaceutical commerce and a vessel of racist prejudice. The battle-lines snaked through Parliament, the ANC, the Cabinet, and civil society, where the Treatment Action Campaign (TAC) was burgeoning and maturing into a formidable force, capable of commanding global media attention, marshalling grassroots militancy and forging tactical alliances with motley other players.

Research institutions, too, were being drawn into the fray. When, in September 2001, the Medical Research Council (MRC) produced estimates attributing 25% of all deaths (and 40% of deaths among *adults*) during 1999/2000 to AIDS, the release of the document was unexpectedly delayed, possibly due to pressure from within government. The report was leaked to the media, which shared with the public the MRC's conclusion that AIDS had become the leading cause of death in South Africa.[xiv] A clear shift in age distribution of deaths towards young adults was demonstrated. After taking into account population growth and more comprehensive death registration, the pattern appeared consistent with a serious heterosexual HIV/AIDS epidemic (Dorrington et al., 2001). Later, after analyzing more up-to-date data, the MRC found a real increase of more than 40% in the number of adult deaths on the population register between 1998 and 2003.[22] Among women aged 20-49 years, the real increase exceeded 150% (MRC, 2005).

Government spokespersons declared the findings 'alarmist' and 'inaccurate', a view apparently echoed in the President's Office. The Cabinet promptly commissioned Statistics South Africa (which was critical of the MRC's methodology) to undertake a study on AIDS-related mortality. The expectation, President Mbeki later explained, was that the data would provide 'for the first time, a picture of the causes of death'.[xv]

The 'Castro Hlongwane' pamphlet, circulated in top ANC structures in early 2002 (see above), poured more oil on the water by dismissing 'the claim' that AIDS was the biggest killer in the country and declaring the provision of antiretroviral treatment to be odds with the need to address 'the real health concerns of the millions of our people' (Anon, 2002). Scornful reaction led to the document's withdrawal from official circulation inside the ANC, but the episode had highlighted the fact that powerful figures in the ANC (and government) believed the epidemic was a hoax or, at least, massively exaggerated.[23]

Seeing ≠ believing

The alchemy of conspiracy theory, historicized indignation and Afro-nationalist pride evident in the 'Castro Hlongwane' pamphlet has continued to resonate. Reacting to media coverage of debates about the accuracy of AIDS mortality estimates, for instance, ANC Youth League spokesman Khulekani Ntshangase

22 The 40% figure was arrived at by adjusting the observed 68% increase for population growth (approximately 12%) and for improved registration of deaths and of persons included on the population register (less than 10%); see MRC (2005:4).

23 Powerful enough, for example, to prevent health minister Manto Tshabala-Msimang from enabling members of the ANC's health secretariat to attend the ANC national executive committee meeting at which the pamphlet was to be discussed, according to Lodge (2004). This 'denialist' tendency appears to have left a mark on popular consciousness about the epidemic; almost one quarter (23.3%) of respondents aged 15 years and older in the Nelson Mandela/HSRC survey (2002), for example, said they were unsure whether HIV causes AIDS. Meanwhile, other sceptics, including writer Rian Malan, whose questioning 2001 article in *Rolling Stone* magazine had received wide airing, also seemed to be shambling towards the miasma of AIDS 'denialism'. See, for example, Rian Malan (2003). Apocalypse When? *noseweek* no 52. December. A copy is posted at http://www.aliveandwell.org/html/africa/related_africa_not_dying.html.

brushed aside AIDS statistics in an article that also featured a thuggish attempt to equate the Treatment Action Campaign with the vigilante group Pagad:[24]

> Today, South Africa is the 'HIV and AIDS capital of the world'. We are told that the biggest killer in this country is HIV and AIDS. But every honest person knows that the overwhelming majority of our people die from accidents and violence. The second biggest killer is TB, pushing HIV/AIDS into the third place. The government has consistently explained this and yet some sections of the media and those in business use all means possible to divert the attention.

A few months later, President Mbeki told the *Washington Post*, in an interview, that 'Personally, I don't know anybody who has died of AIDS.' Asked whether he knew anyone with HIV, answered, 'I really honestly don't'.[xvi] Such utterances, and the dissidents' claims generally, seem morbidly distant from the realities ordinary South Africans have been experiencing and community health workers, hospital staff, school administrators, prison officials and cemetery supervisors have been relaying. Almost one third (31%) of the respondents in the 2004 Afrobarometer survey reported losing a close friend or relative to AIDS – almost twice as many as the 18% in 2002 and the 16% in 2000 (Afrobarometer, 2005a). Localized research has been unearthing the same trends. Conducted in rural northern KwaZulu-Natal in 2000, one such study found 'a sudden and massive shift in adult mortality', due largely to AIDS. Adult mortality was so high that the probability of dying between the ages of 15 and 60 years was 58% for women and 75% for men. AIDS deaths in 2000 would have been roughly in line with HIV prevalence in the area five years previously; in other words, while the epidemic was still growing there (Hosegood et al., 2004).[25] Meanwhile 'natural' deaths in South Africa's prisons reportedly quadrupled between 1995 and 2002. An increase in the number of inmates could explain only part of that trend. According to the Inspecting Judge of Prisons, the natural death rate among prisoners had risen from 1.65 per 1 000 in 1995 to 7.75 per 1 000 prisoners in 2002 (various media reports, September 2003).

As late as February 2004, though, President Mbeki was still insisting that 'We do not know what [kills] South Africans'. Asked, during a nationally televised interview, whether he felt irritated when people expected him to 'expatiate on HIV/AIDS', Mbeki replied:[xvii]

> South Africa does not have, up to today, does not have a proper record of mortality statistics. We don't have it. Doesn't exist. We don't know the causes, what are the things that kill South Africans? Now, not from mathematical models or extrapolations, but from Home Affairs. Home Affairs receives notices of death by law.

The reasoning seemed sound, and sat squarely within the empiricist tradition. If AIDS was killing people then it seemed obvious that one should be able to record and tally those deaths, which is what Statistics SA had been ordered to do in 2001:

> We have collected all of these notices of death from Home Affairs from 1996 to June 2003, altogether two and a half million. We have given them to people to say: Now, can you please work on this, sort out all of these things systematically, to say: in 1996 so many people died and this is what killed them [...] So, when that process is done ... for the very, very first time you will get a picture based on actually what has been recorded by the medical profession in this country in terms of causes of mortality. For the first time. So, you will see the numbers and all of these things will be checked ...[xviii]

Implicit in that reply – and in most of the skepticist forays around HIV and AIDS in South Africa – is the notion that truth

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24 Khulekani Ntshangase, 'Pagad and TAC two sides of the same coin', *The Sowetan*, 22 April 2003. Pagad was a violent and socially conservative vigilante group, with its stronghold in Cape Town. According to Ntshangase, 'both Pagad and TAC come from Cape Town and are formed for the single mission, to mobilise people against the African National Congress [...] They also get funding from the same source and employ the same strategy and tactic [...] Pagad was destroyed so will be TAC!'. See a copy of the article at http://www.tac.org.za/newsletter/2003/ns22_04_2003.htm#Strange.

25 The study ascribed patients' deaths to AIDS when the medical notes reported immuno-compromised, retroviral disease, Kaposi's sarcoma, or Cryptococcus meningitis. As well, patients with suspected HIV and those referred to HIV counselling were classified as dying from AIDS if they presented with an AIDS disease pattern. For more detail on the methodology and explanations of ostensible anomalies in the findings, please refer to the document.

resides in facts that can be surveyed, gathered and tallied.[xix] Reality, in other words, is constituted strictly by objective, observable phenomena which can be apprehended with absolute precision. And the only meaningful statements about reality therefore are those that report empirical observations.[26] These are errant notions. We don't know – and cannot know – with 100% certainty how many people live in South Africa at any given point, for example. No statistician would stake her reputation on there being exactly 44.8 million people in living in South Africa at the time of the 2001 census; she would be much more confident that the number lay within a 95% confidence interval which, in the case of Census 2001, meant that there was a 95% chance that between 44.4 million and 49.2 million people were living in the country when the census was conducted.[xx] And even that approximation can only be arrived at by invoking a series of assumptions. As you read this sentence, XXX million South Africans are living with HIV. But it is impossible, practically, to know exactly which figure should replace those 'X's. Even if every South African were to agree to an HIV test and a massive HIV census were undertaken, at least two variables would prevent us from simply counting our way to the 'truth': while the exercise lasts, YY thousands of South Africans will have died (some of them of AIDS), and ZZ thousands of South Africans will have become infected with HIV. The strictly empirical data would have to be extrapolated, using various assumptions, if this gargantuan effort is to yield a relatively accurate *estimate* of the number of people living with HIV at the time of the exercise.

In the case of AIDS-related deaths, recorded reality provides only a partial picture which needs to filled out by tracking trends in the numbers and patterns of deaths and their causes, and by using supplementary methods, such as mathematical modeling (MRC, 2004). A small percentage of people living with HIV in South Africa are aware of their sero-status. Unless documentary evidence of the deceased's HIV status is available to the certifying official, the death certificate typically ascribes the death to the immediate illnesses and conditions (and not the possible underlying HIV infection). In addition, there is much anecdotal evidence that both social stigma and the risk of forfeiting funeral and/or life insurance payouts disinclines disclosure of HIV status on death certificates (Groenewald, 2005). With respect to AIDS deaths, routine official death statistics therefore serve as a *guide* to the actual state of affairs.[xxi] Stepping outside and 'counting' facts does not guarantee a firm grasp of 'truth'.

Body count

In early 2004-2005, South Africans were presented with several accounts of the epidemic's death toll – one the result of a literal tallying exercise, others the result of extrapolation.

In one, based largely on Statistics SA death registration data, researchers pinpointed conditions that were associated with marked increases in mortality. When an increase in deaths matched the age patterns typical of an AIDS epidemic, a proportion of those deaths was treated as misclassified AIDS-related deaths.[27] The researchers concluded that the substantial increase in deaths observed between 1996 and 2000-2001 (the mortality rate had increased by more than 30%) was largely AIDS-related, and that the actual number of deaths due to underlying HIV infection was *more than double* that reported on the death certificates (Groenewald et al., 2005).[28]

Another study, using death notification, census and household survey data, highlighted three ominous developments. After factoring in population growth and improved registration of deaths, the authors found a *real* increase of more than

26 The empiricist tradition insists that authentic information about the world must be acquired by *a posteriori* means, i.e. that nothing can be thought without first being observed. Empiricism functioned as an invaluable corrective to the speculative indulgences of methaphysics. Its principles were later extended and applied in logical positivism, a philosophical trend that achieved ascendancy in the first decades of the 20th century, before losing influence. Despite appearing to be self-evidently 'true', the approach suffers several weaknesses. The most obvious problem is that descriptions of reality – i.e. the language of expression – require agreement on certain basic concepts which cannot always and entirely be derived from observed reality. Reality, in other words, is necessarily also constituted by *a priori* concepts and formulations. Scientific knowledge therefore is not merely the product of recording and analyzing that which is observable, but requires hypotheses and assumptions that guide and structure those enquiries.

27 The 2005 *AIDS* article attributed about 80% of adult AIDS-related deaths in males and 70% in females to TB and lower respiratory infections. In children under 5 years, 85% of AIDS-related deaths were attributed to lower respiratory infections, diarrhoea and malnutrition.

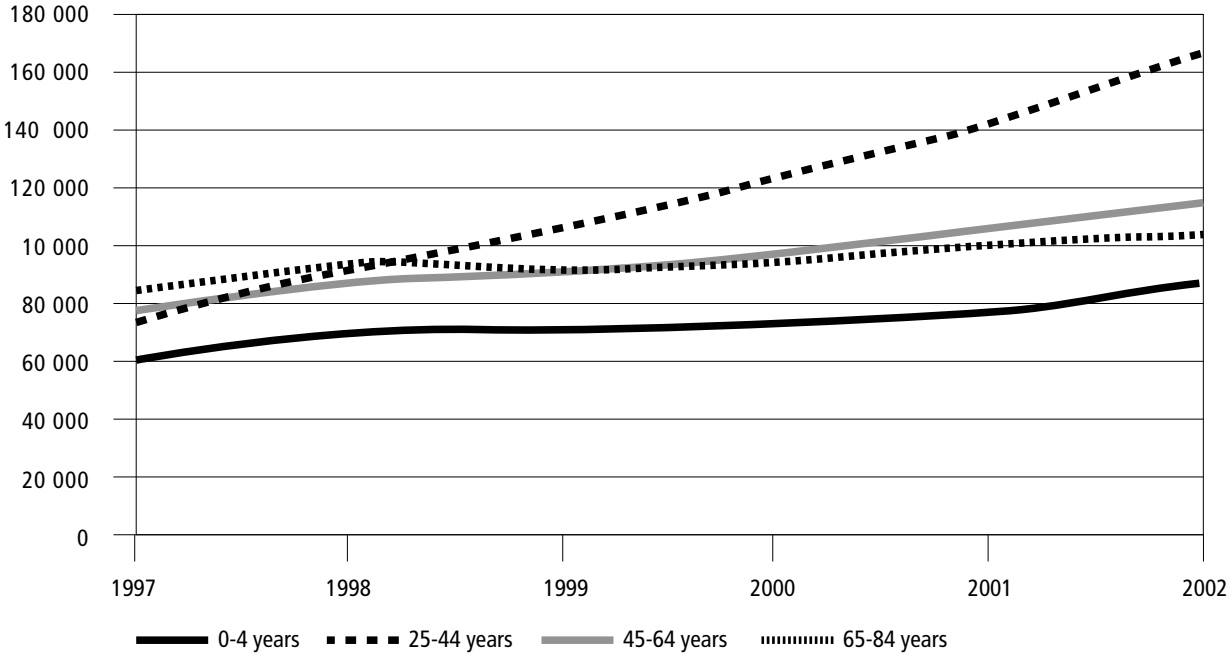
28 This seemed to yield a figure quite close to the projections of some models – as close as 93%, according to the authors. But when compared with the data in the later Statistics SA report (released in February 2005), the authors' conclusion seemed a little generous. Total deaths in 2001 were 451 936 (not 556 585 as estimated by the MRC researchers). Even if AIDS were responsible for 25% of deaths in 2001, the number of AIDS-related deaths in that year would be 78 000 less than estimated by the authors of the *AIDS* article. However, this does not alter the overall trend findings.

40% in the total number of deaths between 1998 and 2003.[29] In addition, the age distribution of deaths was shifting significantly toward younger people. For women aged 20-49 years, there was a real increase in mortality of more than 150%. And, finally, the causes of death profile was rapidly changing (with large increases in deaths due to HIV, TB, pneumonia and diarrhoea – all indicator conditions of AIDS) (Bradshaw et al., 2004a). Changes in the age distribution of total deaths and the unusually steep rise in total deaths shown in both studies matched the anticipated effects of a severe epidemic.

Then came the long-awaited *Mortality and causes of death in South Africa*, 1997-2003 report from Statistics SA (2005), a harrowing compendium of data that left no room for doubt that South Africa lay in the grip of an eviscerating scourge.

From 1998 to 2000, the total number of deaths rose by 13%, and from 2000 to 2002, it climbed a further 30% – in other words, a rising trend.[30] Based on information from nearly 2.9 million death notification certificates, the report showed that in 1997 some 870 people died per day, compared with 1 370 in 2002 – a 57.5% increase.[xxii] The bulk of that increase occurred among people 15 years of age and older, among whom deaths increased by 62% in that period, with women accounting for a steadily larger proportion of deaths. In five years (1997-2002), the number of deaths among South Africans aged 25-44 years more than doubled, as the Figure below illustrates. Having accounted for less than one quarter (23%) of all deaths in 1997, that proportion grew to 30% in 2000, and reached almost 34% in 2002. In other words, more than onethird of all deaths were among people who, generally speaking, should have been in the prime of their lives (Stats SA, 2005).[31] An extraordinary phenomenon was under way.

Total number of deaths by age group and year of death, 1997-2002



Source: Statistics SA (2005). Based on data in Figure 3.3.

29 The number of adult deaths on the population register rose by 68% in the six-year period. Population growth was approximately 12% while improvements in the registration of persons on the population register and of deaths was unlikely to exceed 10%, which leaves a real increase of over 40% (Bradshaw et al., 2004a).

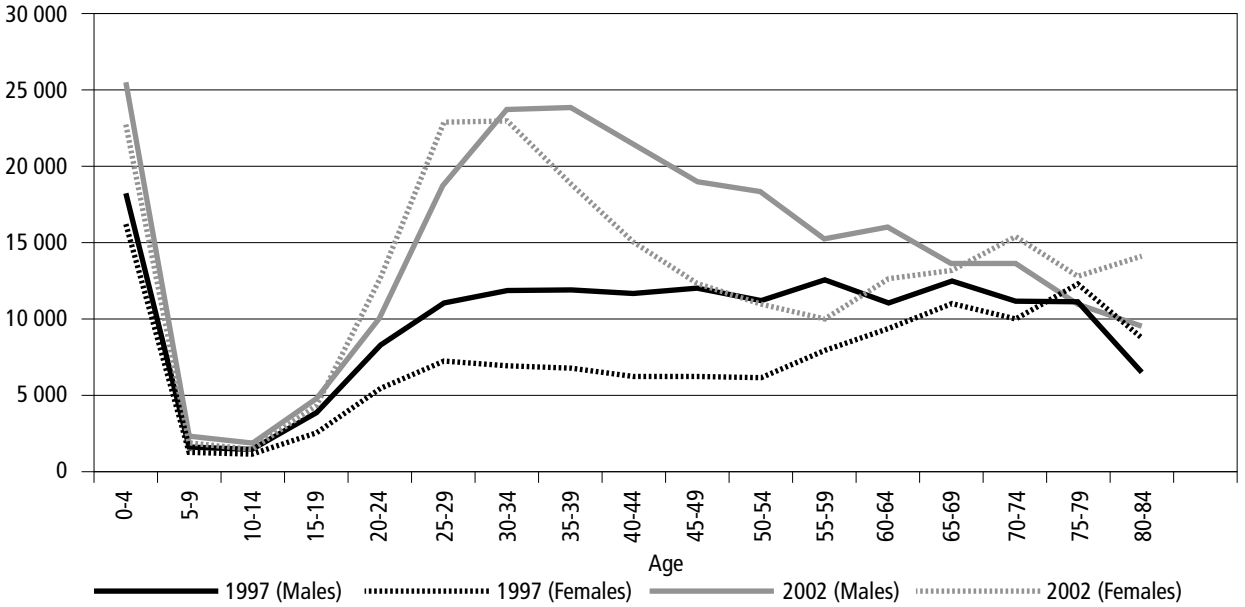
30 The data compiled in the 2005 Statistics SA study suggested that other estimates of total deaths had been erring on the high side: ASSA 2002 'change' model (540 000 deaths in 2000), HSRC (550 000 deaths) and Stats SA 2004 mid-year population report (460 000 deaths), compared with the Statistics SA study's tally of 414 000 deaths in the same year. Were one to assume 10% under-reporting, then the two Statistics SA reports were more or less in agreement, though. Note that the report listed two figures, one drawn from the Population Register (366 121 for 2000) and the other described as 'valid forms received' (413 969 for 2000). The discrepancy is explained by the fact that people lacking ID numbers are not recorded in the Population Register, and neither are their deaths (Statistics SA, 2005:4).

31 The proportion of total deaths occurring in the 25-44 year age group increased as follows: 23.2% (1997), 25% (1998), 27.7% (1999), 29.9% (2000), 31.7 (2001), 33.6% (2002).

As projected by various models and now tabulated by the Statistics SA report (2005), South Africa was experiencing an extraordinarily steep increase in the annual number of deaths. Could an increase in non-natural deaths (trauma, accidents, suicide, etc.) be responsible for the observed trends? No. On the contrary, they're associated with a steadily shrinking proportion of deaths. We know that political violence claimed a rapidly-decreasing number of lives from 1994 onward (the toll fell from 2 476 people in that year to 470 people in 1997, for example).[32] 'Non-natural causes', according to the Statistics SA report, declined in absolute number in 1997-2002, and accounted for an ever-shrinking share of total deaths (down from 17% in 1997 to 11% in 2001) and of deaths among 15-24 year olds (declining from roughly 55% in 1997 to 38% in 2001).[xxiii]

Could more complete death registration records provide an explanation? More comprehensive capturing of mortality data contributed, although mainly up to around 1999, after which many of the improvements in the system had been introduced and death registration was 90% complete. Those improvements probably accounted for a small part of the increase in total deaths observed over the study period. What about the increase in the total population? Population growth (which has been running at approximately 12% and appears to be slowing) accounts for a part of the increase in total deaths, but it cannot explain shifts in the distribution of deaths between various age groups.

Distribution of male and female deaths, 1997 & 2002

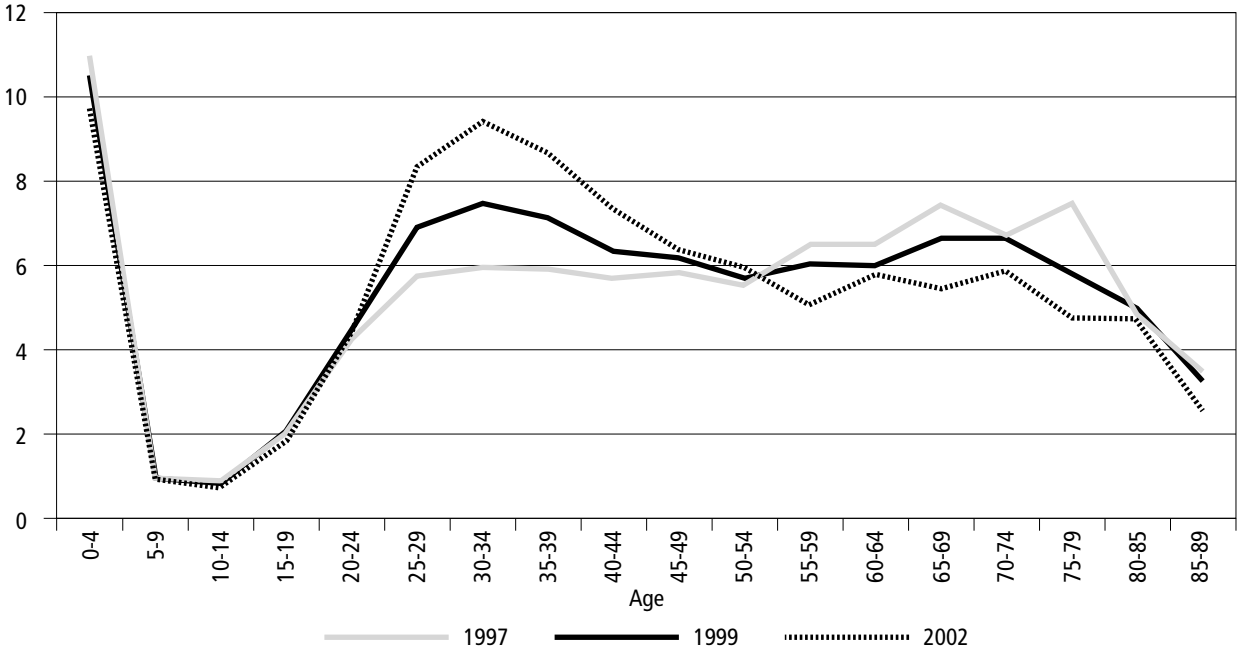


Source: Statistics SA (2005). Based on data in Table 3.4.

Take a look at the graph on the next page. It shows that, in 1997, a similar number of males – between 10 900 and 12 600 – died in each age cohort from 25-29 years all the way to 70-74 years. By 2002, that pattern had disappeared. Deaths were now peaking sharply among males aged 30-44 years. Go back to 1997 and it's clear that roughly similar numbers of women were dying from 25-29 years up to 55-59 years, with deaths then increasing markedly among older women. By 2002, that distribution of deaths had tilted dramatically. Most women were now dying between the ages of 25 and 39 years – three times as many as five years earlier. Deaths in those age cohorts accounted for 15.1% of all female deaths in 1997; in 2002, they comprised 27.7% (Stats SA, 2005:13-16). South Africans were dying in patterns closely matching those predicted by HIV and AIDS models. And those deaths attributable to AIDS reflected HIV infection rates in the early 1990s, when the epidemic was commencing its exponential growth.

32 Political violence had contributed significantly to this category of deaths until 1994 when the number of deaths attributable to political violence began falling. As tallied by the SA Institute for Race Relations, deaths from political violence (including the so-called TBVC states – Transkei, Bophuthatswana, Venda and Ciskei) fell from 3 794 in 1993, to 2 476 in 1994, 1 044 in 1995, 683 in 1996 and 470 in 1997. See South African Institute of Race Relations (1998). *South African Survey 1997/98*, SAIRR, Johannesburg, p 51.

Percentage distribution of deaths by age and year of death, selected years



Source: Statistics SA (2005). Based on Tables 3.5 & 3.7

But how many of the observed deaths could confidently be attributed to HIV infection? The 2005 Statistics SA report proceeded literally, only counting those deaths explicitly declared HIV-related on the death notification form by an official (usually a medical officer or doctor, although in some rural areas certificates are sometimes completed by headmen). In most cases, such classification would have occurred only when explicit proof (such as documentation) of the deceased's HIV-positive status was at-hand, thus 'misclassifying' those deaths where HIV featured among the underlying causes. The report found that only 9 479 deaths in 2001 were associated with HIV diseases, about 2.1% of all deaths in that year.[xxiv] The study commentary delicately described this as 'most likely' an underestimation and noted the need for modelling exercises to yield a more accurate figure.

A closer look at the data shows that a significant and ever-larger share of deaths were officially attributed to conditions associated with AIDS. Tuberculosis was the leading underlying *natural* cause of death from 1997-2002, accounting for 6.9% of deaths in 1997 but 11.3% in 2001. Influenza and pneumonia ranked second in 2001, when they comprised almost twice as big a share of deaths (7%) compared to 1997 (3.6%). 'Certain disorders of the immune mechanism' ranked ninth in 2001, and were deemed responsible for 2.6% of deaths. Among adults aged 15-49 years, such patterns were especially vivid. Taken together, tuberculosis, HIV, influenza and pneumonia and 'certain immune disorders' were associated with just over 20% of deaths in 1997 but 32% in 2001 (Statistics, 2005).

A baneful reality

Six months after the release of Statistics SA's *Mortality and causes of death in South Africa, 1997-2003* report, neither President Mbeki nor his government had offered substantive comment on its findings. That despite the earlier claims that the report would put to rest the speculation about what killing South Africans. There's nothing curious about this silence.

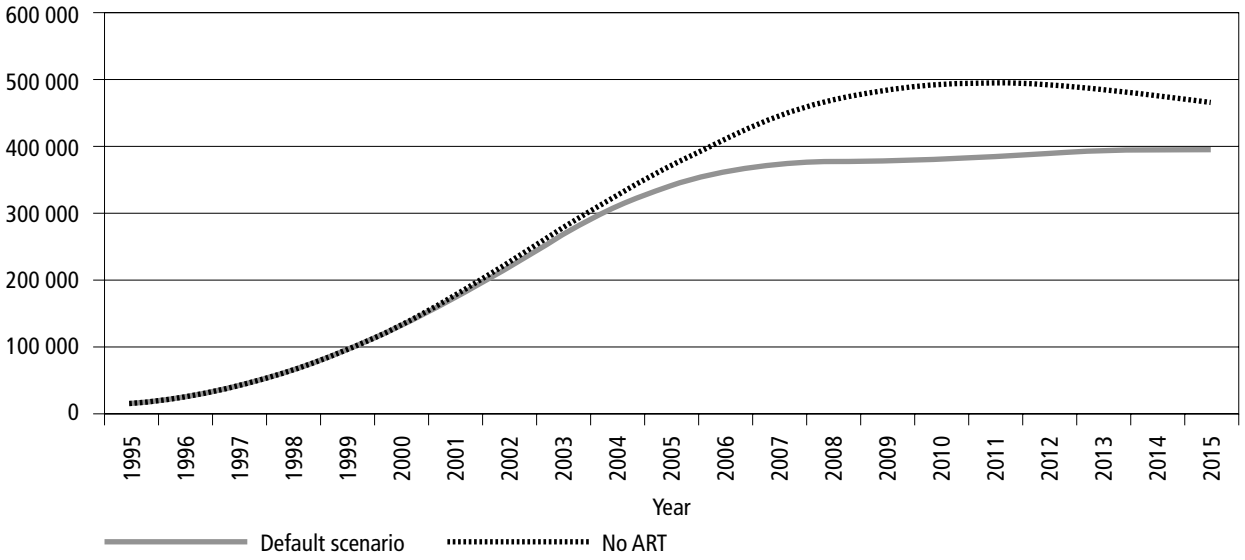
The report shows an astonishing rise in deaths, with diseases and afflictions commonly associated with poverty and deprivation prominent among the main killers – tuberculosis, HIV/AIDS, diarrhoea, malnutrition, etc. – all this occurring in a period marked by economic growth and increased service provision. There's not much room for grandstanding amid figures showing that just under 10% of 1-4 year-olds who die are killed by malnutrition, or that the toll taken by tuberculosis (whatever the underlying cause) among 15-24 year-olds doubled in just five years. In effect the report paints political denialism into a corner. Read its litany of scourges literally, and it indicts government's ability to safeguard people's most elementary right, their right to live. Or analyze the data and discover that it traces the passage of a ruinously severe AIDS epidemic.

There is no disputing this grizzly fact: South Africans are dying in unprecedented numbers, at exceptional rates and at unusually young ages. Statistics SA's *Mid-year population estimates* (2004) showed total annual deaths increasing by 44% in 1995-2000 and 39% in 2000-2005, while ASSA 2002's best-case projections showed that toll growing by 39% in each of those periods. According to the *Mortality and causes of death in South Africa, 1997-2003* report (Statistics SA, 2005), the total number of adult deaths (people aged 15 years and older) increased by 62% in 1997-2002. Adjusting for the misclassification of underlying causes of deaths,[xxv] the MRC's National Burden of Disease Study 2000 projected a total number of deaths in 2004 of 700 000 – well in line with an extrapolation from Statistics SA's mortality and causes of death in South Africa, 1997-2003 data.[33]

When it comes to assigning causes to deaths, the various studies don't vary by large margins either. Like the MRC, Statistics SA has attributed about one third of total deaths in 2000 to AIDS. In 2005, it estimates, that share will have swollen to just over one half – which is more or less midway between ASSA 2002's 45% and the HSRC's forecasted 58%.[xxvi] No matter the data set one selects, by 2005 AIDS will have killed at least 1.8 million South Africans and possibly as many as 2.5 million since the epidemic began.[34] AIDS has become the single largest cause of death in South Africa.

This, unfortunately, is just the beginning. Even if prevention efforts grow stronger and more effective, AIDS deaths will keep increasing at least until 2010 and very likely well beyond then. The ASSA 2002 model estimates that some 900 South Africans will have died each day of an AIDS-related illness during 2005, and suggests that this death toll would keep rising at least until 2014.[35] A massively expanded antiretroviral programme can force this trend onto a slightly lower path, but the toll will still be horribly severe (see Figure). Even with a national antiretroviral treatment programme, approximately 400 000 people will die of AIDS each year until at least 2015, according to ASSA 2002 projections. We're left with this cruel fact: when South Africans should have been striding clear of a wretched past, we are again slipping into the shadow of a baneful and murderous reality.

Projected number of AIDS deaths with and without national antiretroviral therapy programme, ASSA2002



33 Total registered deaths increased by 8.4% in 1999-2000, 9.2% in 2000-2001 and 10.4% in 2001-2002, reaching 499 268 in 2002 (Statistics SA, 2005). Working from the Statistics SA tally for 2002 (the most recent year for which it provided complete data), and assuming that officially registered deaths comprised 90% of actual total deaths (as estimated by both Statistics SA and the MRC) and that the officially registered deaths increased by 11% in 2002-2003 and the same proportion again in 2003-2004, one arrives at a 2004 total deaths figure of 683 000 – which compares very well with the MRC's modeled 700 000 figure.

34 The 2.6 million estimate is the HSRC's (2003), and the 1.8 million one is Statistics SA's (2004). The ASSA 2002 model projects that between 1.9 million and 2.2 million South Africans will have died of AIDS by 2005.

35 ASSA provides 'change' and 'no-change' projections. The 'change' projections assume no ARV therapy is available; mother-to-child transmission programmes reach 90% coverage by 2006 and are 50% effective; prevalence of other sexually transmitted infections declines by 15% by 2006; condom use doubles by 2006; and the number of new sexual partners declines by 15% by 2006.

Chapter endnotes

i Quoted in Cook ET (1913). *The Life of Florence Nightingale*. London, Macmillan, volume 2, p.396; and cited by Macdonald J & Richardson AM (2004). This passionate study: A dialogue with Florence Nightingale. *Journal of Statistics Education*, 12(1).

ii Stats SA (2004); UNAIDS estimate from personal communication with UNAIDS Secretariat, Geneva.

iii Walker N, Grassly NC, Garnett GP, Stanecki KA, Ghys PD (2004) 'The quality of estimates of HIV: What do we really know about the HIV pandemic?' *Lancet*, 363(9427). 26 June.

iv USAID in 2001, for example, projected that, by 2003, South Africa (as well as Botswana and Zimbabwe) would be experiencing negative population growth. They're not. See Roy Anderson's keynote address at the March 2003 'Scientific Meeting on Empirical Evidence for the Demographic and Socioeconomic Impacts of HIV/AIDS', held in Durban, South Africa.

v http://www.eldis.org/fulltext/BennellHIVAfrica.pdf. See also Hein Marais (2004). 'The quicksand of quick fixes: the vexing temptation to make AIDS manageable'. *Isandla Development Communique* 1(6). Available at http://www.isandla.org.za/newsletter/news6.htm

vi With a confidence interval of 95%, this mean there is a 95% probability that the actual number lies within that range.

vii A full description of the methodology and assumptions can be found at http://www.assa.org.za.

viii Note, however, that the correlation between HIV infection levels and poverty is more complicated than this might suggest. Earlier studies suggested that HIV prevalence levels among more poorly skilled and paid workers were higher than among their better-skilled counterparts, but the differences between the levels were comparatively small (Abt Associates, 2001).

ix Of the 13 518 individuals who were selected and contacted for the survey, 9,963 (73.7%) agreed to be interviewed and 8 840 (65.4%) agreed to provide a specimen for an HIV test (HSRC, 2002:11). According to the HSRC, the total sample size was limited by financial constraints, and a 65% response rate is generally considered adequate for this type of survey. The latter claim, though, does not address the potential bias introduced by a non-participation rate of 35%.

x See 'President uses 1995 data to bolster claim that HIV/AIDS is not SA's leading killer', *Business Day*, 10 September 2001.

xi President Mbeki was interviewed by Tim Sebastian on the BBC World programme Hard Talk on 6 August 2001. The full text is available at http://www.info.gov.za/speeches/2001/010813145p1001.htm (accessed 7 April 2005).

xii The table ranked deaths by cause. Top of the list, as reported by Anon (2002), were deaths caused by 'external causes' (accidents, violence, etc.; 20% of all deaths), followed by 'diseases of the circulatory system' (17.5%), 'signs, symptoms and other ill-defined conditions' (13.6%), 'malignant neoplasms' (9.9%), 'TB' (5.3%), 'bronchitis, emphysema, asthma and other respiratory' (4.6%) and 'pneumonia' (4.3%). 'HIV disease' was deemed to account for 2.2% of deaths in 1995.

xiii Paper presented at March 2003 Durban SA conference 'Scientific Meeting on Empirical Evidence for the Demographic and Socioeconomic Impacts of HIV/AIDS': Timaeus I and Bradshaw D and Jasseh M (2003) Adult Mortality and sub-Saharan Africa: Evidence from the Demographic and Health Surveys.

xiv The leak so incensed government that it reportedly demanded that the MRC institute a forensic enquiry to identify its source. MRC President Dr Malegapuru Makgoba seemed to be referring to this when he later remarked that 'the so-called forensic investigation of scientists and the erroneous notion that "MRC employees are government employees" continue to erode the confidence and the autonomy of the MRC'; see 'Dr Makgoba-a passion for excellence', *MRC News*, August 2002, Vol 33 No 4, p 6. Available at http://www.mrc.ac.za/mrcnews/aug2002/makgoba.htm.

xv The comment was made during an interview screened on SABC2 television on 8 February 2004. The full text is available at http://www.info.gov.za/speeches/2004/04021809461003.htm.

xvi The quote appeared in the 24 September 2003 edition of the *Washington Post*. The Government Communication and Information System (GCIS) later 'clarified' President Mbeki's remarks, saying they were in reply to a question whether 'he knew of anyone in his family or amongst his close associates who had died of AIDS or was infected by HIV'. See Govt clarifies Mbeki's statement on HIV/AIDS, *IRIN*, 30 September 2003; available at http://www.aegis.com/news/irin/2003/IR030935.html.

xvii The interview, conducted by Redi Direko and John Perlman, was screened on SABC2 television on 8 February 2004. The full text is available at http://www.info.gov.za/speeches/2004/04021809461003.htm.

xviii *Ibid*.

xix Accordingly, Rian Malan's 2001 thrust at AIDS 'orthodoxy' was subtitled 'In search of the truth'; see Malan R (2001). AIDS in Africa: In search of the truth. *Rolling Stone*. 22 November.

xx For more, see The South African Cities Network (2004). *The State of South African Cities 2004 (executive summary)*, South African Cities Network. Johannesburg, p 14. Available at: http://www.sacities.net/2004/may30_nation.stm [accessed 22 May 2005].

xxi Estimations of AIDS mortality, as Charles Simkins (2001) has reminded, have to be derived from trends in total mortality. Or, according to Groewald et al. (2005): 'If death registration were complete, the effects of a severe epidemic would be reflected in a change in both the overall number and age distribution of total deaths, regardless of any misclassification of or protocol defining a death from HIV or AIDS'.

xxii Reported in *SouthScan*. Funding boosted as AIDS devastation becomes clearer. Vol 20 No 4. 25 February 2005.

xxiii See Figures 4.4-4.6 in Statistics SA (2005:25-26).

xxiv Note that multiple causes of death can be listed on the death notification forms. About half the reported deaths in each year of the study were attributed to one cause only.

xxv 'Due to inadequacies in the medical certification of the cause of death as a result of both insufficient detail provided by medical doctors and the certification by traditional headmen in some rural areas, it was necessary to make adjustments for misclassification of underlying causes' (Bradshaw et al., 2004b:139).

xxvi The figures are drawn from Statistics SA's *Mid-year population estimates, South Africa 2004*. Statistical release P0302, Table 8, page 16.