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What do South Africa's AIDS statistics mean? A TAC briefing paper

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On 21 July 2006, the Department of Health released the annual HIV and syphillis antenatal survey2. What does this survey show? Is it of any use? Is it true that the number of people with HIV is finally stablising? What do we really know about the the prevalence of HIV and the number of AIDS deaths?

TAC has been asked these and many similar questions. They are good questions and so this analysis will try to provide useful answers. But to do so, we really need to explain HIV/AIDS statistics in South Africa generally.

Contrary to popular belief the quality of South Africa's HIV/AIDS statistics are actually very good. From the available statistics we can estimate approximately how many people are infected with HIV and the minimum number of people who have died of AIDS. We also learn from the statistics who is most at risk of being infected, how serious prevalence rates in different provinces are, at what ages people are dying of AIDS and which opportunistic infections kill the most people.

For example, we are sure that three out of every ten women who attend public antenatal clinics3 are HIV-positive. We know with great confidence that at least one in ten of all people in South Africa is HIV-positive. We know with similar confidence that up until 2003 several hundred thousand people died of AIDS. We are also sure that relatively few people had HIV in 1990 but that the epidemic exploded over the next decade and that mortality from the epidemic has increased steadily, such that many more people died of AIDS in 2003 than 2002 and many more people died of AIDS in 2002 than 2001 and so on. We are sure that in 1997 most adults in South Africa died when they were over 60. This has changed. By 2000 most adults were dying in their 20s, 30s and 40s.

We know with some confidence that most people who are infected live in informal settlements. This suggests that housing and related living conditions are a big factor in HIV transmission. We also know with confidence that significantly more women are infected than men. This can probably be explained by both biology and social conditions. We are virtually certain that black Africans are disproportionately infected, although the epidemic has reached epidemic proportions among other population groups too. This too is very likely due to social conditions.

There are three key sources of information for estimating the extent of the HIV epidemic: (1) the annual antenatal clinic surveys conducted by the Department of Health, (2) the mortality data published by Stats South Africa and also in 2001 by the Medical Research Council and (3) the household surveys published by the HSRC in 2002 and 2005, which will be repeated in 2008. All three sources are very useful and by and large sound4. All the above statistics are derived from these three sources.

There are also numerous other small-scale studies that show us the effects of HIV in some hospitals, various corporations, on teachers, nurses, prisoners, migrant workers and miners, just to mention a few. But here we will only consider the three main sources because they are the ones that provide information about large numbers of people

across the whole country.

The mortality data tells us approximately how many people die each year and at what ages they're dying. They tell us something about the cause of death as well. When a person dies, a doctor has to indicate the underlying cause of death on a death certificate. These certificates show that there have been massive increases in deaths due to TB, pneumonia and diarrhea. We know that these are diseases typically, but not always, associated with HIV. Unfortunately, doctors for various reasons do not usually indicate HIV or AIDS as the underlying cause. There are two main reasons for this: many people die of AIDS without ever being tested for HIV, so doctors often do not know if a person had HIV, let alone if he/she died because of it, or the doctor decides to protect the patient's family from possible stigma by not writing HIV or AIDS as the underlying cause of death. Nevertheless, we know that AIDS is the only cause that can explain the massive increase in the number of deaths since 1997. By taking into account population growth and allowing for improved death registration, we can estimate a plausible minimum number of deaths due to HIV from 1998 to 2003. I did this and calculated at least 600,000 AIDS deaths, but probably there were substantially more.5

One of the most important things we learn from the mortality data is the ages at which people are dying. For most diseases, it is either the very young or the old who suffer disproportionately. But HIV is sexually transmitted and it is therefore young adults who are dying disproportionately of AIDS. This is reflected in the mortality data. The age pattern of mortality in South Africa is so starkly obvious that it leaves us with no reasonable doubts about the seriousness of the epidemic.

It must also be understood that the Stats SA mortality data is not merely a statistical sample used to project the total number of deaths; it is a direct calculation based on all the death certificates. The only problem is that some adult deaths and a large number of infant ones are not registered. Nevertheless, the mortality data is sufficiently complete to be extremely informative and useful.

Unlike the number of deaths we cannot count, not even approximately, all people with HIV in South Africa. That would require testing every person in the country for HIV at roughly the same time, an impossible task. So instead of testing everyone, the HSRC household surveys estimate the likely number of people with HIV by testing a large representative sample of people. The survey was conducted in 2002 and again in 2005. Because the 2002 survey was the first one and had some teething problems it produced some anomalies, but the 2005 survey resolved these and gives a credible estimate of the number of people with HIV, i.e. about 10.8% of all people over the age of two years. From this study we learn the prevalence by province and the racial and gender compositions of the epidemic. It also found that people in informal settlements are most at risk of HIV. The HSRC survey is vital because none of the other two sources can easily tell us the current size of the HIV epidemic. The HSRC also interviewed the survey participants so that we now have a lot of useful information on attitudes towards sex, health-care and HIV.

Of the three sources of data, the annual antenatal surveys, which have been repeated every year since 1990, is the longest running. It has the advantage of having been repeated many times and has given consistent results on almost every occasion6. Each year, a large representative sample (about 16,000) of pregnant women is tested for HIV. From this, the percentage of pregnant women attending public antenatal clinics --i.e. the vast majority of pregnant women in the country-- with HIV is known with a high degree of confidence. The surveys also tell us one critical thing the HSRC survey cannot yet tell us: the growth rate of the HIV epidemic. Actually this estimate of the rate of growth is not very accurate, because the downside of the antenatal surveys is that pregnant women are not representative of the whole population. There are approximately 1.1 million pregnancies in South Africa a year, so the surveys tell us what is happening to less than 1 in 45 people. Nevertheless, they have shown a more or less steady rise in the prevalence of pregnant women from 0.7% in 1990 to just over 30% in 2005, the latest year for which we have data.

When the latest survey was released, the Department of Health stated:

?The prevalence profile continues to confirm the ... projections of numerous groups whose models suggest that South Africa will begin to see a decline in the prevalence profile. The studies conducted over the years have begun to show that intervention programmes, which emphasise prevention, have a very important role in moderating HIV prevalence and the epidemiology of HIV infections in general.?

It is hard to understand what precisely is meant by this, but it appears the department is implying that the epidemic has now stabilised and that this stablisation demonstrates the success of the country's prevention programmes. Unfortunately, there is little evidence to support these claims.

It might be true that the epidemic is stabilising and we will soon see a decline in antenatal prevalence, though there is far too little evidence available to make such a bold statement. It is highly unlikely that if the HIV epidemic has reached this stage, it has anything to do with South Africa's pitifully low-profile prevention programmes. Also, while it might seem unintuitive, a decline in prevalence may not be a good thing: infected people are living ? if the number of people with HIV is declining, it could be because they are dying of AIDS instead of getting treated.

The antenatal HIV prevalence grew faster in the early years of the epidemic than it has in recent years. From 1993 to 1997 it grew 13 percentage points. From 2001 to 2005 it grew less than six percentage points. Nevertheless, it has continued to grow. The growth from 2004 to 2005 was from 29.5% to 30.2%, less than 1%. Possibly the epidemic has begun to plateau. However consider this: from 2000 to 2001 it grew by only 0.3% percentage points, even less than the growth from 2004 to 2005. The Department of Health claimed the epidemic had stabilised but then the next year prevalence shot up again. So we need to be very careful before claiming that prevalence is stabilising. It might very well be, but more data is needed. We at least need to wait for this year's survey to be produced.

Now assuming that prevalence is stabilising, what could the causes of that be? Three possibilities come to mind: (1) the number of people dying of AIDS has now increased to the point where it matches, more or less, the number of new infections, (2) the epidemic slows down because there are more people with HIV than at the start of the epidemic and those with HIV are more likely to have sex with people already infected and consequently less likely to have sex with those who do not have it ? and (3) people practice safer sex or reduce their partners. Of these three possible causes, only the first has clear evidence to support it.

But what is the measure of success when it comes to HIV prevention? Is it really decreased prevalence? No, it is decreased new infections, known as incidence. Until recently the prevalence found by the antenatal survey gave us a very good picture of incidence. However, the relatively new confounding factors of increased deaths due to AIDS (which decreases prevalence) and increased numbers of people getting access to antiretrovirals (which counters decreased prevalence) make it more difficult to understand the meaning of changes in prevalence as measured by the antenatal surveys.

We can get an idea of what's happening to incidence by examining the percentage of pregnant women under 20 years old with HIV or the changes in prevalence levels across age-groups and years. The evidence from this is disturbing: prevalence among the under 20 group has remained at approximately 15-16% for a number of years, which suggests no success at reducing incidence in this group. But we really need to find a way of measuring incidence much more directly. It is incidence that will tell us if our HIV prevention programmes might be working.[7]

How do we find out incidence? The most obvious way, but impractical unfortunately, is that we could sample thousands of HIV-negative people and measure how many of them become infected over a given period. This is expensive and presents ethical problems.[8] An easier method would be to make use of a relatively new HIV testing technology which can tell whether someone was recently infected. This test should be incorporated into both the HSRC and antenatal surveys. Indeed, the HSRC did use such a test in the 2005 survey.[9] However, because it was then a new, poorly understood technology the study estimated an unrealistically high incidence. The technology is becoming better understood though and future surveys should produce more accurate results.

There's one more important use of the antenatal survey. Neither Stats SA mortality data nor the HSRC survey data are

ideal for estimating the number of infants with HIV. As mentioned already, the mortality data under-records child deaths and the HSRC survey only includes children over two years. Using the antenatal survey prevalence we can estimate how many newborn infants will be put at risk of contracting HIV.

But estimating exactly how many newborn infants contract HIV is difficult. We can estimate the mother-to-child transmission rate but we do not easily know how many HIV-positive mothers abort their pregnancies or die before giving birth, nor are we sure how many mother-child pairs go through the mother-to-child transmission prevention programme[10]. Calculating such a statistic can however be done. It is one of the uses of modelling the HIV epidemic using computers.

There's a widespread myth that South Africa's AIDS statistics are mysteriously calculated by computer models. None of the statistics given above were calculated by computers models. However, there are very important uses of these models. For example, they provide more detailed statistics than the above ones and they give us an idea of what is likely to happen in the future. If used correctly, they help clarify problems with the raw data by correcting, for example, underreporting. Models are used by many institutions that need a detailed understanding of the HIV epidemic, including the Department of Health.

The most widely used computer model is produced by the Actuarial Society of South Africa (ASSA). The latest version is called ASSA2003. Is there anything mysterious about it? Not really. For sure, it is complicated. You need a sophisticated mathematical background to understand how it works but the principles behind it are straightforward. Furthermore, ASSA2003 is in the public domain; anyone may download, examine, criticise, and use it. This is how science should be.

ASSA2003 estimates useful information such as the number of children born with HIV, life-expectancy, more precise estimates of the number of deaths than the one given above, how HIV effects the population size, as well as how these statistics are likely to change in the future and much more.

The model takes into account factors that influence the HIV/AIDS statistics, for example fertility rate, number of people on treatment, average time from HIV to AIDS and from AIDS to death etc. These factors (which the ASSA researchers call parameters) are not guessed or made up by the computer; they are estimated based on real-world research.[11] Understanding the effect of the parameters on each other is complex, but this is where computers are useful; they can accurately model the complex mathematical relationships between these parameters. The model is also calibrated. This means that when it is run it produces, very closely, the observed numbers of deaths, prevalence and other known statistics. This gives us greater confidence in its outputs.

Examples of some of the outputs of ASSA2003 are: In 2005 over 320,000 people died of AIDS (about 890 people a day) and that by the end of the year 1.4 million people had died since the beginning of the South African epidemic. Also in 2005, about 65,000 infants were infected. Life expectancy is approximately 51 years down from nearly 62 in the early 1990s.

ASSA2003 estimates that life-expectancy will be 50 in 2010 and that cumulatively nearly 3.3 million people will have died of AIDS by the end of that year. But scientists cannot foretell the future; they can only estimate what will happen if all current trends continue. We, however, can change the future by changing trends. It should be the aim of every politician, activist, health worker and person with HIV/AIDS to disprove the future predictions of ASSA2003, not by writing pseudo-scientific attacks on the model in the popular press, but by taking action to change the course of the epidemic.

Together, the mortality data, antenatal surverys, household surveys and the ASSA2003 model provide a detailed and accurate picture of the HIV epidemic. They are all valuable tools for implementing policy. They demonstrate beyond reasonable doubt that there is a massive HIV epidemic that has now become a massive AIDS epidemic, and that there is much to be done if we are to save millions among us from avoidable premature deaths.

Further reading

- Actuarial Society of South Africa. 2005. ASSA2003 Summary Statistics.
  Old broken link: http://www.assa.org.za/scripts/file_build.asp?id=100000547&pageid=100000...
  Because the site hosting the ASSA2003 file has frequently changed the link or is often down, we have made the file available locally on the TAC website:
  ASSA2003 Summary Spreadsheet

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Footnotes

1 Thank you to Rob Dorrington, David Bourne and Zackie Achmat for reviewing this paper in draft. The author takes full responsibility for all opinions expressed and any errors.

2 Known as the National HIV and Syphilis Antenatal Sero-prevalence Survey in South Africa for 2005.

3 That is, the vast majority of pregnant women.

4 This is not to say that they are free of biases and problems.

5 I used 1997 as a baseline and calculated all additional deaths in 1998 to 2003 as due to AIDS, less 20% for improved registration of deaths and population growth. This is very much a minimum estimate because it does not take into account decreased non-natural deaths and it probably overestimates the under-registration of deaths and population growth. It also assumes that there were no AIDS deaths in 1997, which is definitely not the case.

6 There was an unexplained prevalence blip in 1998 but otherwise the results have been reasonable.

7 I say might because a decline in incidence could also be caused by the second of the three reasons given above. People might also practice safer sex because they have seen firsthand the effects of AIDS and not because of prevention programmes.

8 One would have to counsel the participants in such a study to have safer sex. This would render the sample unrepresentative of the general population.

9 Apparently the latest antenatal survey also used this technique, but it was not reported on.

10 It is unacceptable that we do not know how many women participate in the mother-to-child transmission prevention programme. This is a consequence of the Department of Health's poor monitoring and evaluation of the HIV/AIDS operational plan.

11 Where the ASSA researchers do not know realistic values for a parameter, they run the model with a whole range of values for this parameter to see its influence on the statistics. This is called sensitivity testing. Such sensitivity tests have demonstrated that the ASSA2003 model is quite robust.

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