

# **Through a Glass, Darkly<sup>1</sup>:**

## **Data and Uncertainty in the AIDS Debate**

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<sup>1</sup> Corinthians Chapter 13

In their 2002 “Report on the global HIV/AIDS epidemic” UNAIDS<sup>i</sup> estimated that 40 million people globally were living with HIV and a further 20 million had died. The majority of new infections occur in young adults, with young woman particularly vulnerable. It is estimated that one-third of those who have contracted HIV/AIDS are aged between 15 and 24. It is truly a global epidemic. At the moment the fastest growing epidemic is in Eastern Europe, fuelled by drug use. At the end of 2001 it was estimated that there were one million people living with HIV there with 25 percent of those infections occurring in the 2001 calendar year. Asia and the Pacific have an estimated 7.1 million people living with HIV/AIDS. The Middle East and North America are experiencing a slow but marked spread with 440 000 people now living with HIV/AIDS. In Latin America and the Caribbean there are an estimated 1.8 million adults and children infected with the HIV virus.

It is Sub-Saharan Africa that bears the brunt of the epidemic. Just over 70% of those infected with HIV are found here. AIDS deaths in 2001 alone, totaled 2.3 million. UNAIDS estimates that with the 3.5 million new HIV infections in sub-Saharan Africa in the past year 28.5 million Africans now live with the virus. Even here the picture is by no means uniform. There are variations between regions, countries, and provinces and district within countries.

In this article we will examine some of the available data on the epidemic and discuss how it is presented and the implications of this. We will use data from five African countries to illustrate our discussion, these are Botswana, Nigeria, South Africa, Swaziland and Zimbabwe. We will then go on to look at the impact of AIDS, and assess what actual evidence there is for this. We will show that we rely on very few data points to estimate the scale and scope of the epidemic and these data must be treated with caution. From the outset, we shall argue that the unreliability of data is not only a contingent curiosity of the current international debate about AIDS, but indeed a problem with significant moral dimensions and ramifications.

We must stress that we are not questioning the HIV causes AIDS hypothesis. We believe there is an AIDS epidemic in Africa, and it will have far reaching consequences. We believe that the HI virus causes AIDS. We argue AIDS is the most serious threat facing Africa at present; it will reverse the limited development gains of the past two decades and will push parts of the continent into political and economic crisis.

However we show that **seeing** and **believing** this requires imagination and perception. Thus, although, as this article will show, there is a problem with sufficient data about the AIDS pandemic, that is not an excuse for continued denial and obfuscation, as occur in the statements and policies of some African countries, South Africa in particular. The problems with the data are no indication that the crisis of AIDS in Africa is not extremely serious. To the contrary, we shall argue that the problems with the data require, on ethical grounds, that a much more imaginative effort to acquire and corroborate sufficient data is called for – an effort which policy makers in developing countries ought to fully support.

## **The moral dimension of the phenomenon of unreliable data**

The reliability of data has become one of the most controversial issues in the debate about AIDS in Africa.

The denial that has characterized so much of the response from the political leadership<sup>2</sup> in South Africa and

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<sup>2</sup> For the way this denial has been phrased, cf. Thabo Mbeki: Reciting comfortable catechisms on AIDS is not good enough. *The Sunday Times*, 23 April 2000: 25. In this article, Mbeki asks a number of questions about the apparent differences between the way AIDS presents in Africa, and in other Western countries, and claims that “we will not, ourselves, condemn our own people to death by giving up the search for specific and targeted responses to the specifically African incidence of AIDS”. He claims that this search for “targeted responses” has been viewed as a “criminal abandonment of the fight against HIV-AIDS”. He continues: “Some elements of this orchestrated campaign of condemnation worry me very deeply. It is suggested, for instance, that there are some scientists who are ‘dangerous and discredited’ with whom nobody, including ourselves, should communicate or interact. In an earlier period in human history, these would be heretics that would be burnt at the stake!” He then continues to sing the praises of these discredited scientists. The people he is referring to, are dissident scientists like Duesberg and Rasnick who, for many years, have denied the causal relationship between HIV and AIDS, claiming that the HI virus is, in fact, harmless (cf. Duesberg, P. & Rasnick, D. 1997. The drug-AIDS Hypothesis. *Continuum*, 4(5)). What exactly the reason for Mbeki’s sympathy with these dissidents is, is not entirely clear. However, he did give a rather sinister hint as to his motive in this regard in a widely reported address to the University of Fort Hare in 2001 (cf. Forrest, D. & Streek, B. Mbeki in bizarre Aids outburst. *Mail & Guardian* 26 October to 1 November 2001: 4-5). We quote Mbeki’s words from this latter report: “Thus does it happen that others who consider themselves to be our leaders take to the streets carrying their placards, to demand that because we are germ carriers, and human beings of a lower order that cannot subject its [sic] passions to reason, we must perforce adopt strange opinions, to save a depraved and diseased people from perishing from self-inflicted disease...Convinced that we are but natural-born promiscuous carriers of germs, unique in the world, they proclaim that our continent is doomed to an inevitable mortal end because of our unconquerable devotion to the sin of lust”. From these words it seems that his and other members of the governing party’s denial

other African countries to the AIDS pandemic is, in an important sense, the outcome of both the explicit and implicit challenge of the reliability of data on the pandemic.

There are two moral problems that must be pointed out in this regard. The *first* is that scientists have a moral responsibility to provide the most reliable data that is possible. Science is not only an intellectual enterprise. As a practice that is not value free, it also has a moral dimension. Accuracy and reliability are fundamental values that accompany the practice of science from its inception in our culture, and the moment the perception is created that regard for truth and accuracy is devalued, science is bound to lose both credibility and support in our society. In addition, it must be noted that so much of the policy decisions of modern societies rely on accurate scientific knowledge. Responsible policy formation in modern societies without the continual input of reliable scientific knowledge has become almost inconceivable.

This is, also, and in particular, true of the formation of a responsible policy to manage HIV/AIDS, which brings us to the *second* moral problem that must be pointed out, viz. the responsibility of leadership in disease-riddled societies to rise to their task of responsible disease management. Responding to reasonably reliable scientific data, the government of Uganda has, for example, launched a comprehensive, co-ordinated national strategy over the past few years, and has, in the process, attained considerable success. The HIV prevalence in pregnant women in the urban areas of Uganda has, for example, consistently come down over the past eight years from a peak of 29.5% in 1992 to 11.25% in 2000<sup>ii</sup>. The fact, however, is that such a national strategy is sorely lacking most African countries. There probably are many reasons for this phenomenon, but one of them undoubtedly is denial based on the questioning of reliable data on the pandemic. This article will show that data about the AIDS pandemic is far from completely reliable. This fact oils the fire of denial in Africa. The irony is that inaccuracy of data, as will be shown, is hardly a reason

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springs, not only from scepticism about accepted scientific facts, but also from concerns about what these facts imply about continued racism as well as the sexual mores of African people.

for complacency based on the perception that scientists over-estimate the seriousness of the crisis. In fact, as will be shown, inaccuracy of data more often implies an under-estimation of the crisis!

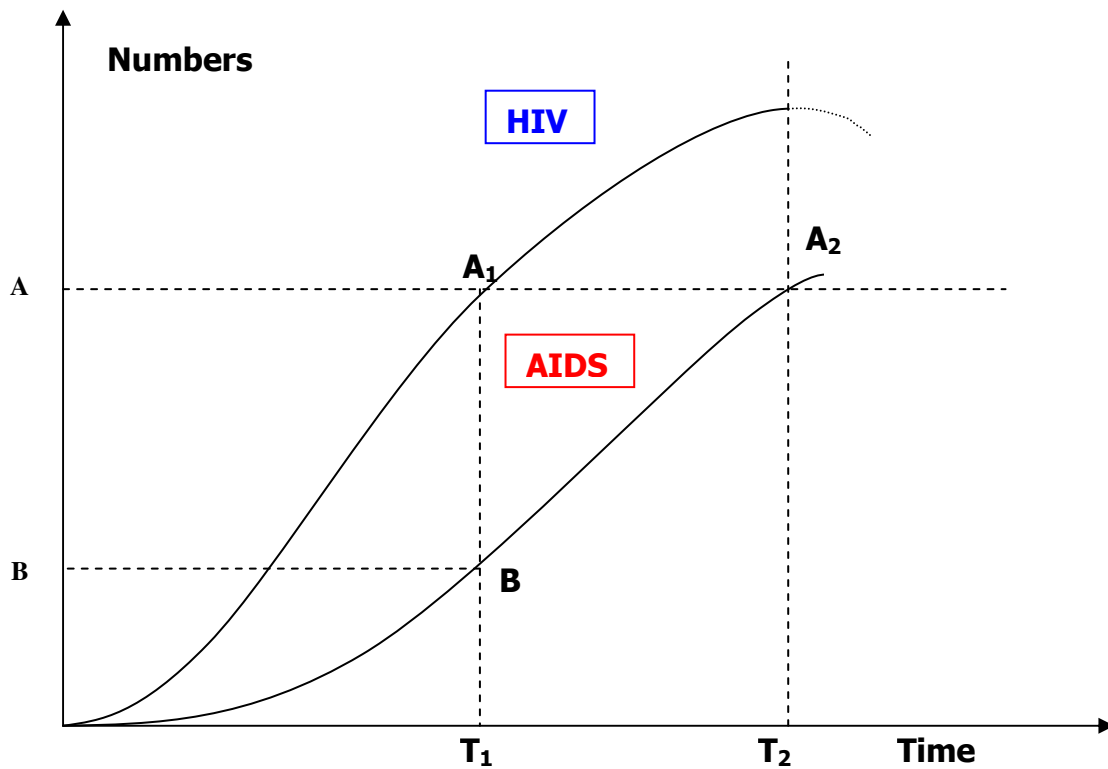
Denial is the main reason why so many millions suffer – in many instances (e.g. where programs could have been launched to prevent vertical transmission from mother to child) unnecessarily. As the numbers of the infected grow, the drain on Africa's meagre resources increases and the social catastrophe widens in scope. There is therefore both an urgent moral duty on scientists to try and minimize the margin of error as regards AIDS statistics, but also on the national leadership in societies where the AIDS epidemic is out of control (as is the case in most of Africa) to act responsibly on the basis of this data. This problematic is a clear indication of how science and morality are seamlessly linked and ought to be conjointly theorized and practiced.

## **Understanding the epidemic**

### *Epidemic Curves*

Epidemics usually follow an 'S' curve as shown in Figure 1. They start slowly and gradually and if a critical mass of infected people is reached then the growth of new infections accelerates. The epidemic then spreads through the population until all those who are susceptible to infection and are exposed have been infected. In the final phase of an epidemic – where the 'S' flattens off at the top - people are either getting better or deaths outnumber new cases so that the total number alive and infected passes its peak and begins to decline.

**Figure 1: The Two Epidemic Curves**



What sets HIV and AIDS apart from other epidemics is there are two curves, as shown in the figure. The HIV curve precedes that of AIDS by about seven to ten years, reflecting the incubation period between infection and onset of illness. This is why HIV is such a lethal epidemic compared to, say, cholera. In the latter case, victims of the disease die quickly which puts the general population and public health professionals on their guard. They take precautions to halt the spread. In the case of HIV, however, the epidemic is silently creeping through the population and it is only later – when the HIV pool has risen to a considerable level – that the true impact of the epidemic is felt in terms of AIDS deaths. By then, the epidemic is in full swing and the only way people leave the pool of infections is by dying, since there is no cure yet. Figure 1 illustrates this point clearly. The vertical axis represents numbers and the horizontal axis time. At  $T_1$ , when the level of HIV is at  $A_1$ , the number of AIDS cases will be very much lower at  $B_1$ . The AIDS cases will only reach  $A_2$  (i.e. the same level as  $A_1$ ) at  $T_2$ . A considerable amount of time will have elapsed and HIV will have risen even higher though it may be levelling off.

## ***Incidence and Prevalence***

Incidence and prevalence are two important concepts to grasp when looking at HIV/AIDS data. *Incidence* is the number of new infections over a given period of time. The *incidence rate* is the number per specified unit of population (this can be per 1 000, per 10 000 or per million for rare diseases). *Prevalence* is the absolute number of people infected. The *prevalence rate* is the percentage of the population which exhibits the disease at a particular time (or averaged over a period of time). The incidence and prevalence are key statistics for tracking the course of an epidemic. With HIV, prevalence rates are given as a percentage of a specific segment of the population, e.g. children below the age of five, adults aged between 15 and 65, ante-natal clinic attenders, blood donors, men with STDs, or the “at risk” population which is generally taken to mean 15 to 49 year olds who are sexually active. HIV is unique in that it is the only disease where prevalence is given as a percentage rather than a rate.

Unfortunately we do not have HIV incidence figures because we don’t know when people were actually infected – but only the date on which we *discover* they are infected. The data, which would be most helpful in measuring the spread of the epidemic and impact of prevention efforts, are simply not available.

Moreover, high incidence may occur even when prevalence has levelled off, because newly infected people are replacing those dying.

## **Data Sources**

### ***HIV Data***

Epidemiological data are drawn from official sources. The HIV data are taken from surveys of specific groups. In the early years of the epidemic they included blood donors, STD clinic attenders, people with TB and women attending ante-natal clinics. Until recently the only way to test for HIV was through blood, this meant that whatever population was used for surveys, blood samples had to be taken, which immediately created a bias, and was expensive. New methods of testing using saliva have been developed in the last few

years but have not yet been extensively used. Our most consistent data come from ante-natal clinic surveys. The reason for this was that epidemiologists needed a sample which was broadly representative of the general population, and which they could draw on at regular intervals, usually every year or two. Ante-natal clinic attenders provide a good sample because they are sexually active, adult and blood is routinely taken from women attending these clinics for a number of standard tests. Most ANC surveys are done on an anonymous, unlinked basis – women cannot be linked to the samples. This means that informed consent is not necessarily required.

It is the ANC prevalence data that is quoted most frequently. UNAIDS produces an estimated adult prevalence rate (the percentage of adults between 15- 49 infected). The UNAIDS data provides the most easily accessible public domain information. In addition to the national data they provide reports for each country and as Table 2 shows figures are given for urban and rural areas. (See the epidemiological fact sheets on the UNAIDS website: [www.unaids.org](http://www.unaids.org)). UNAIDS bases its data on the HIV database maintained by the United States Bureau of Census where data from different sources, including national reports, scientific publications and international conferences are compiled.

**Table 2: HIV Prevalence amongst pregnant woman in selected countries in percent**

Country	Area	1989	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
Botswana	Major Urban Areas		6.0	8.0	19.3	26.8	27.8	34.1	37.8	38.5	43.0	39.9	43.9	44.9
	Outside Major Urban Areas		4.1		10.1	17.8	19.4	29.9	31.6	33.7	30.0	31.7	35.4	34.8
Nigeria	Major Urban Areas	1.0		3.2	0.7		4.0	1				4		4.2
	Outside Major Urban Areas	0.0	0.2		0.5		2.9	2.3				4.3		5.3
South Africa	Major Urban Areas		0.6	0.9	1.8	3.0	6.0	9.0	11.8	14.9	19.2	21	24.3	
	Outside Major Urban Areas		0.4	1.2	1.1	2.2	6.7	8.3	15.8	18.1	21.3	23	22.9	
Swaziland	Major Urban Areas				4.3	21.9	15.5	19.1	26.3		30.3		32.3	
	Outside Major Urban Areas				4.1		16.7		26.5		31.5		34.5	

Zimbabwe	Major Urban Areas	10.0	18.7	17.1		25.8	36.1	31.0	30.4	30			31.1	
	Outside Major Urban Areas		16	18.5	0.0	21.3	24.3	39.5	41.6	28.7	31	22.3	33.2	

Source: UNAIDS – Epidemiological Fact Sheets by country, 2002 Update

Fortunately in most cases there are more complete data sets and we give the data for Botswana, South Africa, Swaziland and Zimbabwe below. We have been unable to locate additional data for Nigeria.

The data for Botswana, shown on Table 3, are given by site of clinic. Until recently there was no attempt to calculate the national average. This meant Botswana could not be compared to other countries.

**Table 3: Botswana's HIV Prevalence by site**

	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
<b>Francistown</b>	23.7	34.2	29.7	39.6	43.1	42.9	43.0	42.7	44.4	44.9
<b>Gaborone</b>	14.9	19.2	27.8	28.7	31.4	34.0	39.1	37.1	36.2	39.1
<b>Ghantsi</b>		9.5		18.9			22.3		26.4	26.4
<b>Kanye (Southern)</b>			16.0		21.8		24.67		40.7	34.0
<b>Molepolole (Kweneng East)</b>		13.7		18.9			37.2		30.4	32.4
<b>Selebi Phikwe</b>			27.0		33.1		49.89		50.3	55.8
<b>Tutume</b>			23.1		30.0		37.45		35.4	50.9

*Source: Botswana 2000 and 2001 (crude prevalence rates for pregnant women attending the above sites) HIV Sero-Prevalence Sentinel Survey amongst pregnant woman and men with sexually transmitted diseases.*

Data from South Africa is shown on Table 4 by province. What is significant here is the national trend. In 1998 it was estimated 22.8 percent of those surveyed were infected, in 1999 22.4 percent, in 2000 24.6 percent and in 2001 24.8 percent. Simple mathematics in calculating the weighted average indicates the 1999 national figure must have been miscalculated. This was remarked on in the South African Medical Journal in 2000. Four independent researchers: Dorrington, Bradshaw, Bourne and Abdool Karim argued that the officially stated decline in HIV prevalence from 1998 to 1999 (from 22.8 to 22.4 percent) was incorrect<sup>iii</sup>. An examination of the 1999 results showed that prevalence fell only in Mpumalanga, a province with a mere 7 percent of South Africa's population. Otherwise rates of infection showed little or no change in three provinces and rose in the remaining five. Dorrington et al (2000) concluded therefore, using population weighted methods, that national prevalence should not have fallen. Rather a small increase was to be expected. Government officials and a respondent from the South African Medical Research Council argued that the data were accurate, and castigated Dorrington et al for their pessimism, failure to approach the Department of Health before writing with 'whatever suggestions they might have', and not 'joining in an active partnership against HIV/AIDS'<sup>iv</sup>.

**Table 4: South African HIV Prevalence by province**

	1994	1995	1996	1997	1998	1999	2000	2001
<b>KwaZulu-Natal</b>	14.4	18.2	19.9	26.8	32.5	32.5	36.2	33.5
<b>Mpumalanga</b>	12.1	18.3	15.8	22.6	30	27.3	29.7	29.2
<b>Free State</b>	9.2	11	17.5	19.6	22.8	27.9	27.9	30.1
<b>North-West Province</b>	6.7	8.3	25.1	18.1	21.3	23	22.9	25.2
<b>Gauteng</b>	6.4	12	15.5	17.1	22.5	23.9	29.4	29.8

<b>Eastern Cape</b>	4.5	6	8.1	12.6	15.9	18	20.2	21.7
<b>Northern Cape</b>	1.83	5.3	6.6	8.6	9.9	10.1	11.2	15.9
<b>Limpopo</b>	3	4.9	7.9	8.2	11.5	11.4	13.2	14.5
<b>Western Cape</b>	1.2	1.7	3.09	6.3	5.2	7.1	8.7	8.6
<b>South Africa</b>	<b>7.6</b>	<b>10.4</b>	<b>14.2</b>	<b>16</b>	<b>22.8</b>	<b>22.4</b>	<b>24.5</b>	<b>24.8</b>

*Source: National HIV and Syphilis Sero-Prevalence Survey of woman attending Public Antenatal Clinics in South Africa 2000 and 2001*

However, survey results can be wrong as well as miscalculated. The official Swazi data are given in Table 5 below. This shows data for every second year. What is not generally known, is that the second survey, carried out in 1993, recorded ANC prevalence of 21.9 percent. It was evident that either the first or second survey results were wrong but it was not until the third and fourth surveys had been carried out that we could see which was the rogue data – that from 1993. Unfortunately these data (which were excluded from all subsequent official documentation) were used by one of the authors of this paper in preparing a report on the potential impact of AIDS in Swaziland<sup>v</sup>.

**Table 5: Swaziland: HIV Prevalence in ANC clients 1992 –2000**

	<b>1992</b>	<b>1994</b>	<b>1996</b>	<b>1998</b>	<b>2000</b>
Sample Size	726	2,343	2,468	1,659	2,316
<b>National HIV prevalence, %</b>	<b>3.9</b>	<b>16.1</b>	<b>26.0</b>	<b>31.6</b>	<b>34.2</b>
(CI 95%)	(2.5; 5.3)	(14.5; 17.5)	(24.2; 27.8)	(29.3; 33.9)	(32.3; 36.2)

<b>Age Groups (yrs)</b>	<20	-	18.4	24.7	25.2	25.9
	20-24	-	18.8	33.1	38.4	42.5
	25-29	-	14.3	28.0	38.0	40.7
	30-39	-	10.3	23.7	23.7	25.4
<b>Woman aged 15-24yrs</b>		-	<b>18.4</b>	<b>29.8</b>	<b>32.9</b>	<b>35.4</b>

*Source: 7<sup>th</sup> HIV Sentinel Serosurveillance Report Year 2000*

Data also have political sensitivity. In the case of Zimbabwe a good survey was carried out among women attending ANC clinics in late 2000<sup>vi</sup>. The report was not made available until early 2002 and even now it has not been publicly released and is hard to obtain. The report shows HIV prevalence of 35% compared to 29% in 1997 the date of the last survey. This document is as important for what it does not say as what it does. There is little attempt to compare with earlier data, thus we learn that 27.8% of women aged 15 – 19 were HIV positive in 2000, but have no idea of the infection level by age in earlier years. It is stated that: ‘The HIV/AIDS epidemic in Zimbabwe is severe’, but there is no attempt to provide figures (apart from the 35%). Why is this? In part it must be because the data show prevention efforts have not worked and there are political problems of having an epidemic of this scale.

The problem with ANC data is that there are biases: younger women will be over- represented as they are more sexually active and likely to fall pregnant; and HIV positive women will be under-represented as HIV infection reduces fertility. An obvious drawback to the present method of sampling is that it applies solely to women attending the state ante-natal clinics. It does not cover those who do not visit government facilities because they are too poor or do not have access to such services. In Southern Africa this group is probably small, but in Nigeria it may be large. It also does not pick up better-off women who attend private doctors an

issue in South Africa and Botswana with their well-developed private health sector. Nonetheless, once the raw data from the state ante-natal clinics are available, it is possible to estimate the percentage of all women, men and adults who are infected, as well as the percentage of children who will be born HIV positive. This is done using a model which adjusts for: the degree to which ante-natal clinic attendance figures are unrepresentative due to the adverse impact of HIV on fertility of women; the fact that there are young and old members of both sexes who are not (or not as) sexually active; the lower prevalence in men; and the number of children expected to be infected through mother-to-child transmission. The raw data can then be turned into more representative numbers, using various computer models, some of which are in the public domain, and accessible through the Internet.<sup>3vii</sup>

Aside from the obvious problems with HIV data and the representativeness, they are subject to misinterpretation and political spin. The data from Zimbabwe is just one example. The significance of 1998/99 South African data has been alluded to above. Sometimes of course the interpretation is simply wrong. To return to the Swaziland data, the 1998 survey found that 31,6 per cent of women attending the clinics at the time of the survey were infected.<sup>viii</sup> The antenatal surveillance report then estimated that HIV prevalence among the *adult* Swazi population, those aged between 15 and 49, was 23 per cent. However it gave the number of infected people in the country as 293,100. The total population in Swaziland in 1997 was about 978 200. This would give an adult prevalence of nearly 60 percent – assuming half the population was adult. Clearly the interpretation of the data left something to be desired.

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<sup>3</sup> There are two reasonably easily useable models - the first a locally developed one from the Actuarial Association of South Africa [www.assa.co.za](http://www.assa.co.za) The second one developed in the USA by The Futures Group International available from [www.tfgi.com](http://www.tfgi.com)

## *AIDS Case Data*

In the early years of the epidemic, AIDS case data were what hit the headlines. But in Africa, most AIDS cases are not officially recorded. In many countries one of the principal stumbling blocks to cases being reported is that most people are not seen by the formal medical services. Even if they are cases may not be recorded. There are a number of reasons for this: reporting may be very slow, it takes time for data to flow into a central point and be collated; data may be inaccurate because of the unwillingness of medical staff to report cases due to the stigma associated with AIDS or medical aid societies and insurance companies paying out more for other diseases; AIDS may not be the condition diagnosed, instead the patient may be recorded as having TB or meningitis; health professionals may feel that it is pointless to report cases as there are always problems with collecting and collating the data.

## **Impact**

This epidemic is only 20 years old. The curve of HIV infection is followed by the curve of AIDS illness and death. Impact flows from the excess illness and deaths in a society caused by this disease. In the countries we are using as examples HIV prevalence rates appear to still be rising. This means that the full extent of the HIV epidemic is not apparent and it will take even longer for the AIDS cases to emerge. The full impact of this disease is going to take decades to become apparent. AIDS is a long wave, intergenerational disaster. For example orphaned girl children both have a higher likelihood of infection thus potentially perpetuating the epidemic for a further generation. They are also more likely to be withdrawn from school. This means their children will have higher mortality rates as female education is correlated with infant and child mortality rates. Thus AIDS impacts over three generations.

We have a fairly clear idea of the current scale of the HIV epidemic in some countries, as our examples of Botswana, South Africa and Swaziland show. From this we can make reasonable assessments of potential

morbidity and mortality using modelling techniques. Demographic impacts can be estimated but others are speculative.

### **What do we know about impact?**

There are a few literature reviews, some region specific<sup>ix</sup> and some global<sup>x, xi</sup>. What is particularly significant, and evident from these reviews, is how little original research there has been! The reviews tend to refer to the same studies again and again. Indeed, there is a general problem that reports of “impact” are sometimes no more than recycled anecdotes, a game of “Chinese whispers”.

As might be expected (and this is no criticism of researchers who are operating with limited funds and time) impact studies usually focus on one geographical area, one company or one community. The problem is that these results are then applied without discrimination to whole populations or nations. An example is the study done for the Zimbabwe Farmers Union in one communal and small farm area. This found that any adult death had an adverse effect on output, but that in the case of AIDS this effect was worse. An adult death resulted in a 45 per cent decline in marketed output of maize, but where the cause of death was identified as AIDS there was a 61 per cent loss.<sup>xii</sup> The study is good, 56 key informants and a survey of 544 households, well analysed and clearly written up. The problem is that others then applied the findings simplistically to the whole country. On the basis of this one study in one area, another “study” reported that there would be a decline in agricultural output not just in Zimbabwe as a whole, but more generally across Africa, and that this could be ascribed to AIDS. This tendency is particularly worrying from an ethical perspective. If one adopts a utilitarian approach to ethical decision-making, as will mostly be done in this article, concerns about the greater good for the most people involved are paramount. This kind of approach, however, requires much responsibility when making claims about the position and/or needs of “the majority”. Simple and indefensible extrapolations of findings to larger groups of people as has been described, are indefensible from both a scientific and ethical perspective.

Impact is hard to see, but it will occur, and by the time it is visible it will be too late to take many of the actions that are needed. However the one exception is in regard to the demographic effects of the epidemic.

## **The Demographic Impact of AIDS**

Unusual levels of death alter population dynamics. Demography looks at populations and their dynamics. It is concerned with the numbers, growth rates and structure of populations. It measures and predicts size and growth rates, structure by gender and age, and key indicators like birth, death and fertility rates, life expectancy and infant and child mortality.

Demographers derive raw data from two main sources<sup>4</sup>: the census and vital registration statistics. Most countries conduct censuses every ten years. The purpose of a census is "the total process of collecting, compiling, evaluating and publishing or otherwise disseminating demographic, economic and social data pertaining at a specific time to all persons in a country or a well delimited part of a country"<sup>xiii</sup>. The United Nations sets out what should be collected – and this includes data on age, sex, place of birth, citizenship, household and family structure, marital status, number of children and child deaths, literacy and educational qualifications, urban and rural domicile and economic status.

Vital registration is information about births, deaths and marriages. In many countries it is compulsory to register these events. But in poorer countries these data may not be recorded or collected. An exception is South Africa and we will draw on these data later.

There are three main problems in looking at demographic impact. The first concerns the difference between an event and a process. The impact of AIDS is felt as a process: a person begins to feel unwell and so,

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<sup>4</sup> For some countries, a third source of data is available, the Demographic and Health Surveys conducted by Macro International Inc. of Calverton, Maryland, USA. These surveys have been carried out and repeated in a number of countries.

perhaps, does not grow as much food, the family has less to sell and can't afford to send children to school. When the person dies household composition changes. The demographer records the death and its effect on household composition and dependency ratios. But the impact of the events leading up to the death and flowing from it are unrecorded. Demography is one of the most "counting" of the social sciences<sup>xiv</sup>, and because of this it may insulate its exponents and readers of its reports from the underlying human processes.

Secondly demographic indicators look at nations, provinces or areas. The impact of the disease may be very concentrated – cases will tend to cluster in households and among specific groups. A large-scale perspective, which concerns itself with averages, will not pick up small-scale impacts. This will only happen if the data are reanalysed in ways specific to the exploration of impact issues.

The third problem concerns the frequency with which demographic changes are measured. A census is carried out every 10 years and analysis and reporting of the results may take several years. In the absence of vital registration, trends and changes have to be calculated on the basis of the census data alone.<sup>5</sup>

International compilations of data rely on national statistical agencies, central banks and so on. The impact of a new and evolving disease will not be picked up and reflected in most national official data and has even less chance of appearing in international data sets.

## **Mortality**

The most direct demographic consequence of AIDS is an increase in mortality<sup>xv</sup>. In the absence of effective treatment the period from infection to illness is between 7 and 10 years<sup>xvi</sup>. UNAIDS states: "someone who has just been infected with HIV can expect to live nine years on average before falling seriously ill and to

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<sup>5</sup> The limitations of demographic information are clear from the 2000 World Development Indicators (World Bank, 2000). These include a mass of figures in numerous tables and graphs. It provides a table showing what primary data are available and when they were produced – no comment is made on their accuracy or reliability. Thus we learn that the latest population census data from Botswana was 1991, and the most recent Demographic and Health Survey available to the Bank was 1988. Cameroon had a census in 1987 and a DHS in 1998; Nepal a census in 1991 and DHS in 1996; and in India the last census was in 1991 but a national family health survey was carried out in 1992-93.

survive up to a year beyond that, even in the absence of anti-retroviral therapy”<sup>xvii</sup>. Even with recent price decreases and the withdrawal from litigation in South Africa by the multi-national pharmaceutical corporations, available anti-retroviral therapy is unlikely to make a difference to life expectancy in the poor world. These drugs are too expensive and need a fairly sophisticated delivery infrastructure. This not to say that access is impossible. Elites in many countries are accessing some form of treatment. For others there is a lottery of buying drugs when they can afford them and stopping when they can't. As prices fall, the number of people accessing treatment will increase. However even at \$350 per year for the drugs – the price offered by the Indian company CIPLA to NGOs in Africa in early 2001 - the cost of providing ARV treatment remains beyond the reach of most. The bleak conclusion is that demographic impacts are seemingly unstoppable.

In countries where HIV is primarily spread through sexual transmission, the peak age of infection is 20 to 40 years and the peak ages of AIDS death are seven to 10 years later. Thus, AIDS increases mortality in adult age groups that would otherwise typically have the *lowest* mortality rates. Mother to child transmission which is estimated to occur in about 30 percent of births to infected mothers (in the absence of interventions) accounts for increased infant and child mortality.

What evidence is there that the AIDS epidemic is causing increased mortality? To know the answer we need to measure mortality accurately. A metanalysis found mortality rates in African adults and children has risen in the mid-1990s<sup>xviii</sup>. However the data were limited, reporting slow and therefore mortality reflected the state of the HIV epidemic a decade previously. For most poor countries we are never going to have really up to date information about the demographics of HIV/AIDS. We will always be working with history.

Data are however available for some specific sites and cohorts. AIDS has been identified as the major cause of deaths of adults aged 15 to 44 in Abidjan, Cote d'Ivoire, and of adults aged 15 to 59 in Tanzania<sup>xix, xx</sup>.

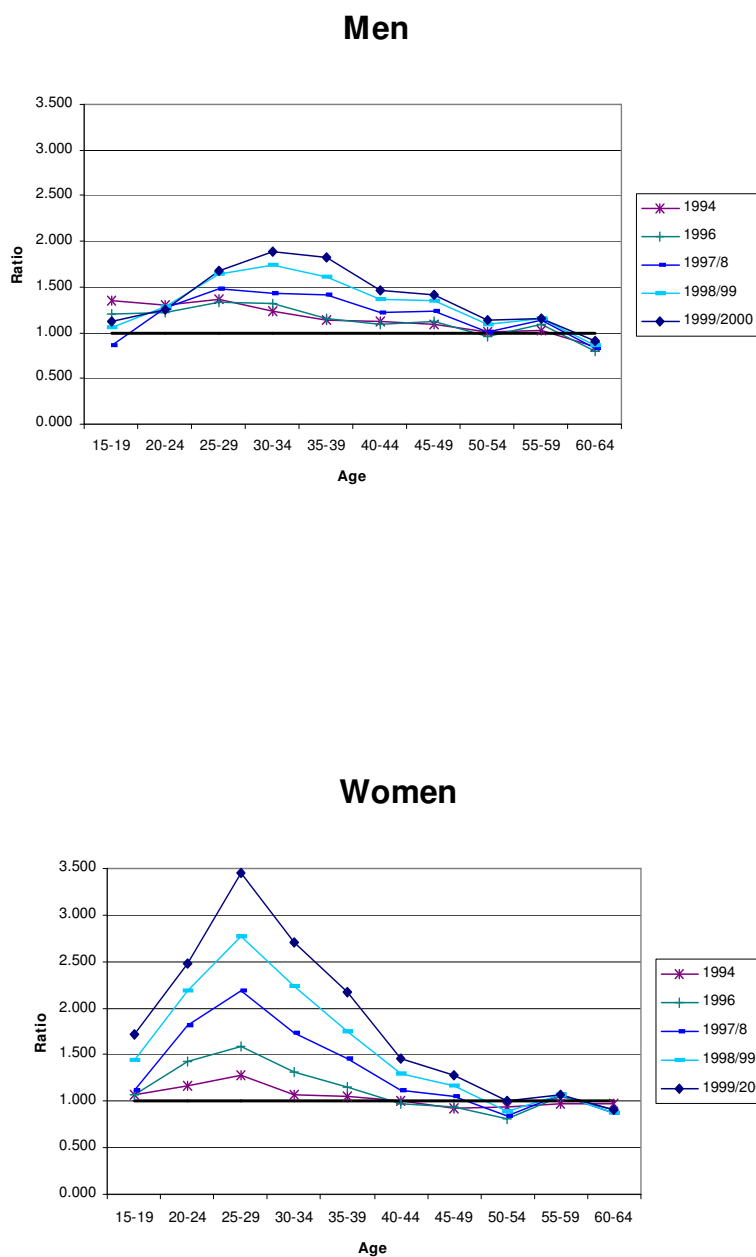
More recent information on excess mortality for sub-national locations comes from Uganda. In Rakai, a team of researchers followed a cohort of 19,983 adults aged 15 - 59 at 10 monthly intervals over four surveys. HIV prevalence in this cohort was 16.1 percent. Mortality in HIV positive people was 132.6 per 1000 person years while in HIV negative people it was only 6.7<sup>xxi</sup>. In other words HIV positive people were 18 times more likely to die than their peers who were not infected.

### **South African Mortality Data**

There is one location in which the system of vital registration system is good enough to estimate mortality and this is South Africa. Mortality data has been collected for years in South Africa. Until recently these were not processed or released. One of the few good things to come out of the messy debate over the causes (and even existence of AIDS) that dominated South Africa in 2000 and 2001 was analysis and release of these data. One of the contentions of the 'dissident' group of scientists was there was no evidence of increased mortality in South Africa. The Medical Research Council and Actuarial Society of South Africa collected and analysed mortality data from the Department of Home Affairs' Population register. They estimated that coverage of adult deaths (over age 14) improved from 54 percent in 1990 to 89 percent in the 12 month period to the end of June 2000. The government is clearly succeeding in establishing a system to give accurate information on adult deaths.

After much delay the MRC report was finally released in November 2001..<sup>xxii</sup> This shows that there is a changing pattern of adult mortality, as is shown for men and women respectively on Figure 2. Mortality of young adult women has increased rapidly in the last few years with the mortality rate in the 25-29 year age range in 1999/2000 being some 3.5 times higher than in 1985. Mortality of young men start from a higher base, but it too has increased, in the 30-39 year age range in 1999/2000 it was nearly twice 1985 rate.<sup>xxiii</sup>

**Figure 2: Estimated increase in adult death rates relative to the 1985 death rates.**



*Source: The impact of HIV/AIDS on adult mortality in South Africa, MRC technical report*

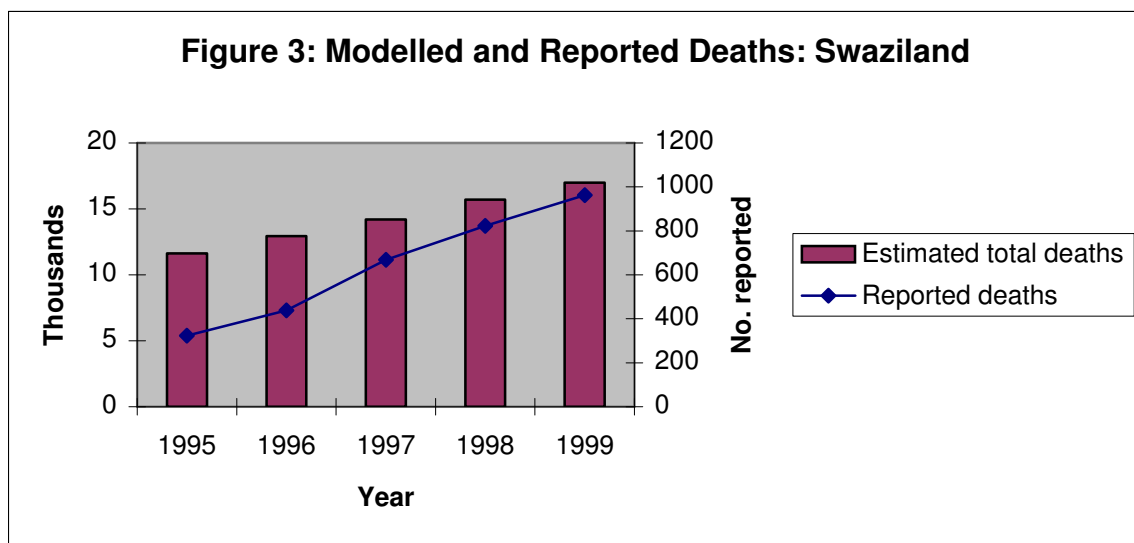
The South African data proves conclusively that there is increased mortality in the country. In the absence of any other plausible explanation AIDS is implicated. In 2000 of the adult deaths aged 15 -49 some 40 percent were due to HIV/AIDS. It is estimated that AIDS accounted for about 25% of all deaths, making it the single biggest cause of death. Most worrying is that, without treatment, the number of AIDS deaths can be expected to grow, in the next 10 years, to more than twice the number of deaths due to all other causes.

The fact that this data proves conclusively that South African mortality rates are rising sharply because of AIDS, ought to be more than an ample incentive for the South African government to explore all possible and ethically justifiable interventions to try and curb the pandemic. We have earlier noted the possibilities in terms of a cure, a vaccine and ARV treatments for mother-to-child transmissions – the issue which currently consumes the news and public debate in South Africa. The one area that remains is the issue of motivating people to change their sexual behaviour. It is in this respect that, in particular, the South African government is currently seriously undermining its moral responsibility. Whereas, on the one hand, it is widely known that policy interventions are generally not guaranteed to change people's behaviour, *morally* speaking that can not serve as an excuse *to refrain from trying*, as is currently happening in South Africa. South Africans have, up till now, not once heard their President, their Minister of Health, or any other cabinet minister publicly denounce the irresponsible sexual practices that are the main cause of the pandemic. No official appeal or call has been made by such leaders that people should refrain from promiscuity, or use condoms and keep their sexual relations closed. This call ought to be made, even if not for purely moral reasons concerning sexuality, then at least for reasons of national survival or economics. To refrain from such an appeal, given the extent of the pandemic in South Africa and the undeniable increase in mortality, as shown above, is immoral negligence on the part of the South African government, and posterity will judge them harshly for it.

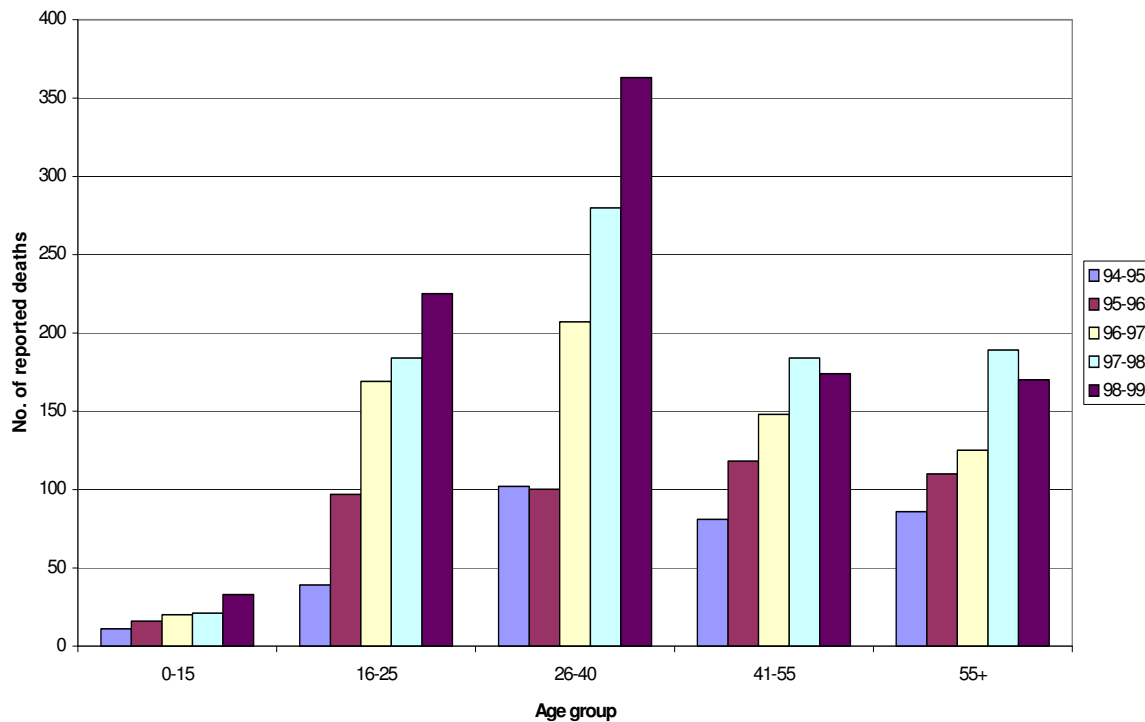
### **The Swazi Mortality Notices**

Given the problems with official data an obvious question is: are there alternative data sources? These are important if policy makers and politicians are to be convinced of the seriousness of the epidemic. In addition if such data can be found this will allow these people to acknowledge the reality of what they may well know through anecdote. We carried out a study in Swaziland (which had an ANC prevalence of 34.2 percent in 2000<sup>xxiv</sup>) using death notices from the local paper<sup>xxv</sup>.

Many people place bereavement notices in the local press. Increasingly, these notices include a photograph and some biographical details. The study reviewed death notices in the Swazi Times from July 1<sup>st</sup> 1994 to 30<sup>th</sup> June 1999. The total number of deaths rose substantially during the period and track the trajectory of deaths predicted from models (The Futures Group personal communication from John Stover). This is shown in Figure 3. When the data are analysed by age (Figure 4) it is apparent that the majority of deaths are in the 26 to 40 year olds. This is also the age group with the largest increase. While this method of analysis has biases it has the advantage of being consistent and illustrating the magnitude of an existing problem.



**Figure 4: Reported Deaths by Age: Swaziland**



Source: Whiteside et al, 2000

## Measuring AIDS Impact on Human Progress: Life Expectancy and Infant and Child Mortality Data

In the last part of this article we ask what evidence of impact is available from international data sets. The main sources of internationally comparative data are the multilateral agencies such as the World Bank and United Nations Development Programme. The most basic and popular measures of human progress and development are life expectancy and infant and child mortality. In Japan the life expectancy of a citizen born in 1999 was 80.8 years. By contrast a Sierra Leone born in the same year had a life expectancy of just 38.3 years. For every 1000 Japanese babies born in that year four would die before their first birthday, in Sierra Leone 182 babies would not survive to age one.<sup>xxvi</sup> Without any other information it is clear where most people would prefer to live. These indicators in turn feed into the UNDP's Human Development Index or HDI which was introduced in 1990 to look beyond financial measures to assess development and progress

toward it. It is constructed from three indices: life expectancy which is a proxy indicator for longevity; educational attainment which is measured by literacy and enrolment rates; and standard of living which is measured by real GDP per capita

So what information do we have about the impact of AIDS on life expectancy and infant and child mortality? The UNDP's Human Development Report and World Bank's World Development Report produce data purporting to show what has happened up to the present. However although the multilateral agencies should start from the same epidemic data their results and interpretation are different. In some cases the difference is significant. For example UNDP puts Botswana's 1998 child mortality at 48 per thousand, the World Bank at 105. It is not clear whether and/or how AIDS impact is considered in these official figures. UNDP did not put AIDS into its population calculations before its 1997 report and up to 1999 did not do so for all countries.<sup>6</sup> The impact of AIDS on life expectancy, HDI and ranking for our selected countries is shown in Table 6.

**Table 6. Life Expectancy and Place in the HDI<sup>xxvii</sup>**

	1996 Report (1993 data)		1997 Report (1994 data)		1999 Report (1997 data)		2001 Report (1999 data)	
	Life Expect.	HDI (Rank)	Life Expect.	HDI (Rank)	Life Expect.	HDI (Rank)	Life Expect.	HDI (Rank)
Botswana	65.	0.741 (71)	52.3	0.673 (97)	47.4	0.678 (97)	41.9	0.577 (114)

<sup>6</sup> The 1998 UNDP report has the following statement. "The 1996 revision incorporates the demographic impact of HIV/AIDS in the population estimates and projections for developing countries where HIV seroprevalence had reached 2% in 1994 or where the absolute number of infected adults was large: Benin, Botswana, Brazil, Burkina Faso, Burundi, Cameroon, the Central African Republic, Chad, the Congo, Côte d'Ivoire, Democratic Republic of the Congo, Eritrea, Guinea-Bissau, Haiti, India, Kenya, Lesotho, Malawi, Mozambique, Namibia, Rwanda, Sierra Leone, the United Republic of Tanzania, Thailand, Togo, Uganda, Zambia and Zimbabwe". Page 127 The 1999 report added Cambodia, Ethiopia, Gabon, Liberia, Nigeria and South Africa. The note has been dropped from the 2000 report so we must assume no new countries have been added. This means that in Swaziland with HIV prevalence at over 30% the life expectancy is recorded at over 60 years! UN data may be imperfect but so are those provided by the World Bank. Up to 1998, the World Development Report contained a mass of statistics in its World Development Indicators. In 1998, the report changed and many statistics were left out, as indeed are a number of countries. The result, comparisons can no longer be made between countries. Instead, the user of this data is required to purchase the new document, 'World Development Indicators' (in 2000, this cost \$60.00). However even the new, 'comprehensive' publication's user guide states, 'Selected indicators for 58 other economies – small economies with populations of between 30,000 and 1 million, smaller economies if they are members of the World Bank, and larger economies for which data are not regularly reported are – shown in Table 1.6'. *In other words detailed data on 58 countries are omitted.* It is perhaps not surprising that countries like Afghanistan, Liberia, and Somalia do not have data. It is a source of concern, however, that the only data available for places like Bahrain, Swaziland and Fiji, are gross national product, life expectancy, adult illiteracy and carbon dioxide emissions. (all 'where available'.)

Nigeria	50.6	0.400 (137)	51.0	0.393 (141)	50.1	0.391 (142)	51.5	0.455 (136)
South Africa	63.2	0.649 (100)	63.7	0.716 (90)	54.7	0.717 (89)	53.9	0.701 (94)
Swaziland	57.8	0.586 (110)	58.3	0.582 (114)	60.2	0.597 (115)	47	0.583 (113)
Zimbabwe	53.4	0.534 (124)	49.0	0.513 (129)	44.1	0.507 (130)	42.9	0.554 (117)

Also badly affected are mortality rates for infants and children under 5. In the absence of interventions an infected mother has about a 30 percent chance of transmitting HIV to her infant. Most infected children will not reach their fifth birthdays. In addition some mothers of uninfected children will die of AIDS and evidence is that orphans have higher mortality rates. The economic and social stress associated with having AIDS in a household further reduces life chances of infants and young children. This indicator will take time to show the effect of AIDS, but it is starting to become apparent in the UNDP data.

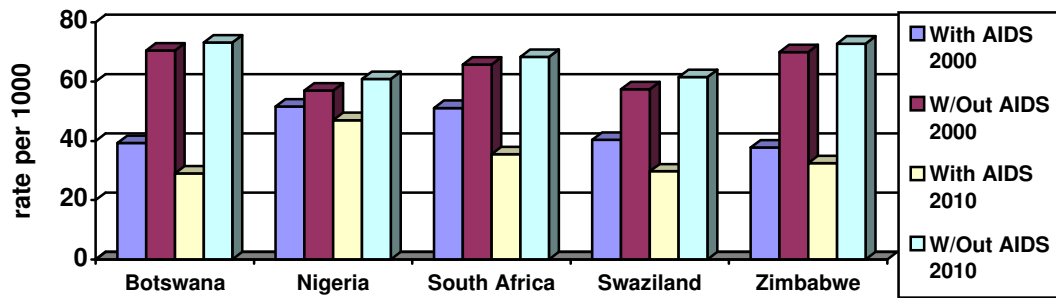
**Table 7. Infant and Child Mortality<sup>xxviii</sup>**

	UNDP 1996		UNDP 1997		UNDP 1999		UNDP 2001	
	Infant Mortality	Child Mortality	Infant Mortality	Child Mortality	Infant Mortality	Child Mortality	Infant Mortality	Child Mortality
Botswana	42	54	55	52	39	49	46	59
Nigeria	84	91	82	191	112	187	112	187
South Africa	52	68	51	67	49	65	54	69
Swaziland	74	107	72	107	66	94	62	90
Zimbabwe	67	81	70	74	53	80	60	90

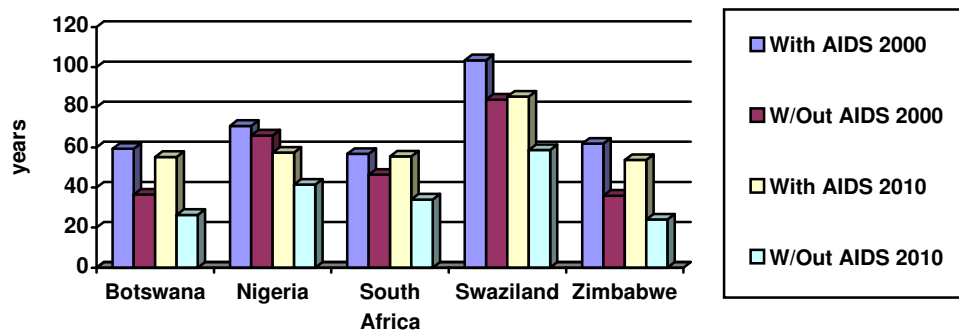
These indicators are imperfect in many ways: they are based on information provided by national governments with all the biases this entails; they reflect events rather than processes; but most important is that they are outdated. They show what happened a few years ago, not what is going to happen and given the nature of the HIV/AIDS epidemic this is inevitable, the number of adult illnesses and deaths will rise dramatically and there will be an increase in infant and child mortality – although this is less inevitable.

In order to look into the future we need models and fortunately these are available from the US Bureau of the Census and Figure 5 shows modelled life expectancies for 2000 and 2010 and modelled infant and child mortalities for the same years for our selected countries. This picture is devastating.

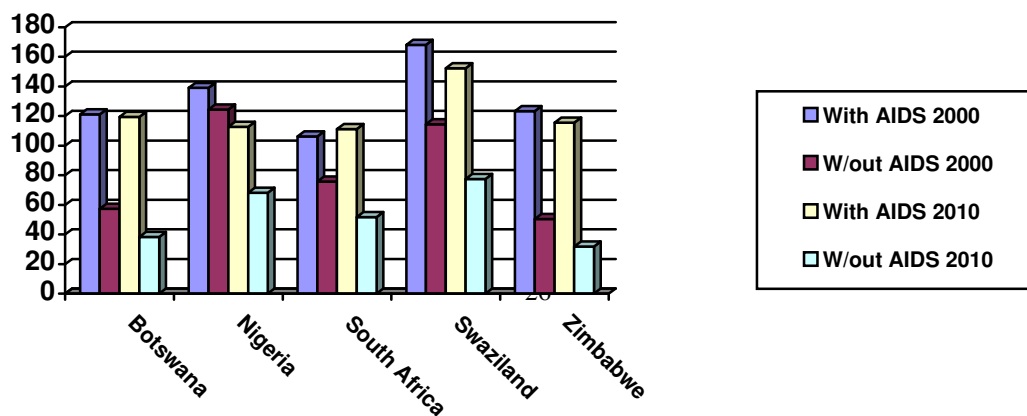
**Figure 5: Life expectancy 2000 and 2010**



**Figure 6: Infant Mortality for 2000 and 2010**



**Figure 7: Child Mortality for 2000 and 2010**



## Conclusion

This article makes two main arguments, the first is that we are somewhat cavalier with our data about the scale and scope of the epidemic. We do not make it clear that we are working from limited data sources and what the implications of such limitations are. We suggest that people working in this field have allowed the urgency around the epidemic and need to respond to lead us to accept data of lower quality and certainty than we would otherwise have done so. In addition our presentation of the data has not been as critical as it might have been.

However set against that is the need to convey the impact this disease will have. Here we have UN figures but these reflect the situation in the past not the present or the future. In addition in South Africa there has an analysis that provides a harbinger of what is to come, and our work in Swaziland shows that non-standard data sources can be mined for useful information. If we want to look ahead then the modelling done by the US Bureau of the Census provides a sobering window into the future. In the absence of cheap, effective and deliverable treatments adult deaths are inevitable but child deaths are not. We know that there are cheap and effective treatments can greatly reduce mother to child transmission rates and it would be criminal if these were not made available as rapidly as possible.

People working in policy and planning in this field face a reality that is unique. There is a lot we don't know about the epidemiology of HIV/AIDS, but we know enough to predict potentially devastating development, social, economic and possibly political impacts. Our problem is to convince leaders at all levels that this is what we are facing; to show that there are things that can be done; and to persuade them to put responses in place. All this has to be done with imperfect data and where there are no precedents!

There therefore is an urgent need for more research that will hopefully yield more reliable data. Insufficient data has two consequences that are of moral import in the current crisis surrounding HIV/AIDS in the developing world. The first is that the scientific assessment of the scope and impact of the pandemic is

thwarted. Given the extent to which scientific advances have benefited mankind over the past century, particularly in the area of medicine, this is a consequence that is lamentable. Science is no infallible royal route to happiness and riches for all; some of the morally most problematic events of the past century (Hiroshima, Auschwitz and Chernobyl) occurred because of an irresponsible application of scientific knowledge. Yet, these hardly measure up to what we know science can produce if applied responsibly. There is little excuse for haphazard knowledge when we are dealing with a problem as calamitous as AIDS. The real extent and scope of what we are dealing with, must be known. This is important in order to enable policy makers, planners and health care managers to make well-informed, rational decisions about the use of resources and preferential areas of action.

There is also a second consequence of insufficient data, which, in turn, suggests a further reason why more research is a dire moral requirement. As has often been referred to in this article, in Africa (specifically) we are dealing with policy makers on the level of national governments (particularly in South Africa) that seem to be in perpetual denial about the scope and seriousness of the pandemic. These people could easily abuse the findings of this article, interpreting it as oil to the fire of their state of denial. If data is, scientifically judged, insufficient, why take seriously what accredited scientists tell us about the pandemic? If such denial is part of the social and political context in which the pandemic has to be managed, there is an additional moral responsibility on scientists to attain as much reliable data as possible. Of course, the moral responsibility is not only on the scientists, but also on those who question their findings. An argument in support of denial has no moral standing if it does not suggest and enable imaginative and credible efforts to yield data that will settle the current disputes beyond reasonable doubt.

Enough research that will yield sufficient data is furthermore of the utmost importance, not only to counter the denials by African leaders, but also, and probably more importantly, to enable policy makers, once they face up to the real problem, to make informed policy decisions. There are so many things that, as yet, we still do not know about the pandemic. Some have already been suggested in this article. To these can be added

the question as to whether the health care infrastructures in Africa are able to administer anti-retroviral drugs effectively and safely country-wide with adequate monitoring. It is, in addition, not really known whether preventing a maternal transmission of the HI virus does indeed save a life in the long term. It should (and can) be firmly established that lives saved from HIV will not in any case be taken by other ailments such as measles or diarrhoea in early childhood. And if this were the case what are the policy implications? It is also a question whether more children's lives will not be saved by improving maternal education and literacy than by anti-retroviral treatment.<sup>7</sup> The fact is: informed policy decisions have to be made which imply choices that must be motivated by sound scientific data. Of course, as has been forcefully argued by Karl Popper<sup>xxix</sup> and others, certainty is not and cannot always be an achievement of science. Most of our theories are never certain, and only corroborated, pending further evidence. But that does not mean that all efforts to establish the things that can be established, must not be pursued. The need for more research and more reliable data is therefore beyond question.

It is a commonplace to nowadays argue that science is not value-free, and that scientists must accept the moral responsibility for and the moral consequences of their work. The HIV/AIDS pandemic has created an almost unprecedented opportunity for this. Almost all scientific work done on this epidemic creates the opportunity for applications that will hopefully benefit mankind – if only in the sense of influencing policies that are required by the most rational and optimal use of resources. In that sense the pandemic also creates a unique opportunity for scientists and policy makers to co-operate in a concerted effort to fight the plague of HIV/AIDS. Wherever this opportunity is not utilised to the full, moral blame is in order.

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<sup>i</sup> UNAIDS. Report on the global HIV/AIDS epidemic 2002", Geneva July 2002

<sup>ii</sup> UNAIDS AIDS Epidemic Update December 2001: 17

<sup>iii</sup> Dorrington, Rob; Bradshaw, Debbie; Bourne, Dawn; Karim, Salim Abdool. HIV surveillance results - little grounds for optimism yet. South African Medical Journal, May 2000. Volume 90 No 5 p452-453

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<sup>7</sup> Cf. S. Benatar, AA van Niekerk, WA Landman & T Fleischer: Laying down Aids gauntlet: there are some things that must be accepted so that HIV/Aids can be defeated. *The Sunday Independent*, 7 April 2002, page 7.

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