THE IMPACT OF HIV/AIDS ON ADULT MORTALITY IN SOUTH AFRICA Technical Report

Burden of Disease Research Unit Medical Research Council By Rob Dorrington, David Bourne, Debbie Bradshaw, Ria Laubscher Ian M. Timaeus

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PREFACE

by Professor Malegepuru William Makgoba President of the MRC South Africa July 2001

In 1982, in Oxford, Dr Harold Jaffe, a senior investigator from the Centers for Disease Control (CDC) in Atlanta presented a cluster of cases of homosexual men who were engaged in risky sexual behaviour, who had all the features of Acquired Immune Deficiency Syndrome (AIDS). At this stage the Human Immunodeficiency Virus (HIV) had not been isolated or identified yet but AIDS, as a syndrome, had been described a year earlier by the CDC. At this meeting I remarked that "This syndrome may be more common in Africa than it is appreciated". I made this premature, but predictive, remark for the following reasons: as a medical student at King Edward Hospital in the years 1973 to 1976 I had seen several young, male patients with Kaposi's Sarcoma and I knew homosexual behaviour was being practised within African communities but always denied or suppressed. In rural Sekhukhune, for example, we always heard of the practice of 'matanyola' (sexual practice between men) and we also heard of men who engaged in this practice, particularly in prisons. In KwaZulu-Natal I also came to know of 'isitabane', a Zulu word for homosexual practice.

However, when AIDS was first wrongly linked to homosexual practice many Africans promoted the notion that homosexual practices were 'unAfrican', thus sowing the seeds for denial to justify why AIDS would not be prevalent in their communities. This denial predictably became the first African public

response to AIDS and swept across the continent as country after country became engulfed in the HIV/AIDS epidemic. Today, despite many documented cases of homosexual practice in Africa, this denial continues. The AIDS denial was later compounded by stigmatisation, chauvinism, the distortion of scientific information and ignorance.

In 1985, actor Rock Hudson died of AIDS. Much later Freddie Mercury of Queen and Rudolf Nureyev (the Russian ballet dancer) also died of AIDS. In the 1990s, tennis player, Arthur Ashe died of AIDS after a transfusion of HIV-infected blood. Noerine Kaleeba, Director of the AIDS Support Organisation in Uganda lost her husband Chris through AIDS; former Zambian President, Kenneth Kaunda lost his son through AIDS and Fela Kuti, world-renowned Nigerian musician and political activist died from AIDS. At the same time, many thousands of nameless people were dying from AIDS through heterosexual transmission. One name, Nkosi Johnson, became well known through his brave campaign after he became infected through mother-to-child transmission. I point out this history to illustrate that HIV/ AIDS knows no boundaries of class, status, race or sexual preference. Both the powerful and powerless in every society are caught up in this vicious epidemic and it is now estimated that 36 million have been infected worldwide.

A virus named HIV has been identified and fully characterised by its unique sequence. HIV has fulfilled all of Koch's postulates[the standard criteria for disease causation] as the sole cause of AIDS. It is vitally important to recognise that diagnosis and classification of a disease in medicine is based on the exponential summation of discriminating characteristics from four components:

medical history, clinical signs, laboratory investigations and response to treatment. At each level there should be a discriminating feature that, when taken in context and in toto with the others, allows us to arrive at a probable diagnosis. This, too, is the case with AIDS. From this report, it has become clear that statistical modelling of epidemiological and mortality data adds a fifth component to the art of diagnosis.

The data presented in this report make the following salient points:

- i) the pattern of mortality from natural causes in South Africa has shifted from the old to the young over the last decade particularly for young women - this is a unique phenomenon in biology;
- ii) there is a differential mortality pattern between women and men;
- iii) this shift in mortality pattern fits several AIDS models;
- iv) the future burden and impact of the epidemic is broadly predictable from the models with reasonable confidence over the next decade;

v) the differential patterns of mortality and prevalence will allow for differential intervention strategies in the different parts of the country.

This report is a chilling reminder of how powerful stereotypes across society have colluded in creating the most explosive epidemic in the history of our country. Comprehensive, powerful and rigorous as these data are, they can be seized upon positively by individuals, government and society to intervene at many levels such that no South African person, family or community has to live under the cloud of this vicious and unrelenting epidemic.

I sincerely hope that information in this report will be used to promote the culture of 'Breaking the Silence' around this silent killer of our nation. As Africa faces the challenges of its renewal or renaissance, there is no greater potential barrier to the attainment of this vision than the spectre of the HIV/AIDS epidemic.

Executive Summary

South Africa is experiencing an HIV/AIDS epidemic of shattering dimensions. The main source of information about the epidemic is the antenatal clinic HIV seroprevalence surveys conducted by the Department of Health. Reliable statistics on HIV/ AIDS deaths in South Africa are not available despite government's extensive, and largely successful, efforts to improve the national vital registration system. The most recent official death statistics available are those for 1996. By 1996 the proportion of deaths due to AIDS was too low to tell us much about the shape of things to come. Even if the numbers of AIDS deaths were substantial, vital registration statistics may well be an unreliable source of cause of death information because the true cause of death of someone who died of AIDS can be expected to be frequently misreported.

Demographic projections of the epidemic indicate that HIV/ AIDS will cause a rapid change in the age and sex pattern of deaths. A system to rapidly monitor the age pattern has been developed by the Medical Research Council. Details of registered deaths are obtained directly from the Population Register maintained by the Department of Home Affairs.

Standard indirect techniques have been adapted for estimating the extent of under-reporting of deaths to allow for different levels of completeness at different ages which can be expected in South Africa, in order to estimate the extent of under-registration in both the routine vital statistics reported by Stats SA as well as the data obtained from Home Affairs. The coverage of adult death registration appears to have improved from 54% of deaths occurring in 1990 being reported to 89% of adult deaths (in those older than 15 years) occurring in the 12- month period to the end of June 2000 being reported. This is a clear sign of the success of the extensive efforts on the

part of Government to improve vital registration. While this system provides good information on adults, deaths among children are under-represented as a relatively high proportion of children are not recorded on the Population Register.

The data show that there has been a steady increase in adult mortality during the 1990s. The 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 (see graph [in PDF version on-line]). The mortality of young men has also increased, however, the pattern suggested that this may be a combination of a rise during the early 1990s in injury-related deaths, that typically occur among men in their twenties, that began to fall in the late 1990s, and a more recent increase in deaths due to AIDS in a slightly older age group. Mortality in the 30-39 year age range in 1999/2000 was nearly two times higher than in 1985 (see graph), but obviously this is off a much higher base.

The pattern in the empirical data is largely consistent with that predicted by models of the AIDS epidemic, in particular the ASSA600 model developed by the Actuarial Society of South Africa, suggesting that it is reasonable to interpret an increase in young, adult mortality as being essentially a consequence of HIV/ AIDS. We looked at alternative explanations for these patterns and found none of them plausible. In addition, we cite evidence from a number of sources in support of our interpretation.

While there is inevitably some degree of uncertainty because of the assumptions underlying both the model and the interpretation of the empirical data, we estimate that about 40% of the adult deaths aged 15- 49 that occurred in the year 2000 were due to HIV/ AIDS and that about 20% of all adult deaths in that year were due to AIDS. When this is combined with the excess deaths in childhood, it is estimated that AIDS accounted for about 25% of all deaths in the year 2000 and has become the single biggest cause of death. The projections show that, without treatment to prevent AIDS, the number of AIDS deaths can be expected to grow, within the next 10 years, to more than double the number of deaths due to all other causes, resulting in 5 to 7 million cumulative AIDS deaths in South Africa by 2010.

This study has demonstrated the value of supplementing the routine vital statistics with rapid mortality surveillance, making use of administrative data from the Population Register. The system needs to be formalized as rapidly as possible with the data being released routinely to inform research and policy. Further work to improve models and data is needed to develop the surveillance tool to meet the needs of provinces and local government and for assessment of the impact of interventions. Although there is an impressive consistency between the pattern of total deaths by age projected by the ASSA600 model and those captured on the Population Register, the discrepancies suggest that the model can be improved in a number of ways. Among these it is suggested that no allowance be made for a reduction in

adult mortality since 1985 when estimating the non- AIDS mortality. In addition, the results suggest that the estimates of prevalence based on the early antenatal clinic survey data probably exaggerated the prevalence in those years. Various other recommendations are made including extending this work to the provincial level. It is also important to develop a mechanism to monitor the impact of the AIDS epidemic on the mortality of children.

The rapid change in the empirical death rates confirms predictions of the profound impact of AIDS on mortality. These shocking results need to galvanise efforts to minimize the devastation of the epidemic.

<u>Introduction</u>

The HIV/ AIDS epidemic in South Africa continues to grow at a rapid rate. UNAIDS estimates that in 2000, 19.9 % of adults were infected, up from 12.9 % two years previously. According to UN figures with an estimated total of 4.2 million infected (and some put the figure higher than this), South Africa is said to have more people living with HIV than any other country.

Reliable empirical data on the epidemic in South Africa are hard to come by. The main source of information is the series of annual antenatal seroprevalence surveys conducted by the Department of Health (DoH). These show that South Africa has experienced a very rapid spread of HIV during the last decade. In 1990, the first year of the survey, prevalence was less than 1% and by 2000 its level was nearly 25%. This yearly survey, covering all the regions of the country, is conducted on a sample of the routine bloods taken from pregnant women who attend the public health sector for antenatal care. The majority of pregnant women (over 80%) make use of public antenatal care. This group of women makes an ideal sentinel group for monitoring the epidemic as they have recently had unprotected sex. In 1998 the protocol for this survey was revised to standardise procedures and sampling methodology across all the provinces. It was also changed to allow women to choose whether or not to be tested, however, it is thought that very few refuse. Not only does this change make it difficult to compare the figures of more recent years with earlier years, it also makes the recent data more difficult to interpret. Despite the observed anomalies in the provincial level results, this survey provides reasonably consistent data that form a foundation for surveillance of the epidemic.

Various projections of the demographic impact of HIV, based on the antenatal survey results, suggest that the disease will have a considerable impact on mortality in South Africa. While the projections differ somewhat, they suggest that between 2000 and 2010, somewhere between four and seven million South Africans will die from AIDS. This number of AIDS deaths will be considerably larger than that from any other single cause of death and will be

almost double the number of deaths from all other causes combined over that period. Model projections of the impact of HIV/AIDS have an important role to play in providing planning information. However, their accuracy depends on the many assumptions that are made in the model. Considering the magnitude of the epidemic, it is extremely important for South Africa to monitor AIDS mortality so as to provide reliable information for planning and to be able to assess the impact of interventions.

Routine mortality statistics are compiled by Statistics South Africa (Stats SA) from the vital registration system. The statistics are based on the medical certification of the cause of death, required by law, at the time of registration of the death with the Department of Home Affairs (DHA). However, the statistics are problematic, as death registration is known to have been incomplete and to suffer from misclassification of cause of death. After 1994, the Government initiated extensive efforts to improve death registration and statistics. These involved significant interdepartmental collaboration, the introduction of a new death certificate, dissemination of manuals on how to complete the death certificate and classify the cause of death, and the establishment of a task teams in each province to improve registration. Comparison with projections from the ASSA600 model (of the Actuarial Society of South Africa) suggest that the percentage of all deaths registered improved from a low of slightly more than 50% in 1990 to 78% in 1995 and over 80% in 1996.

Despite improved registration, delays continue to occur in the production of full cause of death statistics. The most recent detailed statistics are for 1996. Furthermore, cause of death statistics significantly underestimate the number of AIDS deaths. Due to the stigma associated with HIV and AIDS, details completed on the certificate tend to focus on opportunistic infections or the mechanism of death rather than providing the underlying cause. Thus, the routine official death statistics fail to provide timely or accurate information on the extent of AIDS deaths and, at best, give underestimated numbers some time later.

The Department of Home Affairs maintains the national population register on computer. It comprises administrative details of all persons who have been issued with a South African identity document. A unique identity (ID) number is allocated to each individual on the register. Death details are also included on the population register. This database provides information on the age and sex of dead individuals who were on the Population Register. Since many children are not registered, this data source does not provide adequate statistics on children.

This study investigates the trends in reported deaths up until 1996 based on the statistics from Stats SA and compares the results for adults with more recent data obtained from the population register. After adjusting for the under-reporting of deaths, the trend in the age pattern and the broad cause of death profiles are considered to assess the impact of HIV/AIDS on

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