Whither the AIDS epidemic — or lies, damned lies and statistics?

The current HIV/AIDS pandemic is the worst plague ever to afflict humanity, and unfortunately it is at its most severe in southern Africa. Approximately 5 million people are currently infected in South Africa, and therein lies the rub, for our estimates are always based on data that contain uncertainties. While the impact on health is undeniably profound, the uncertainties around the statistics create debate.

Our main source of data on the epidemic is the annual report of the Department of Health on HIV prevalence in a sample of pregnant women attending antenatal clinics in the public sector. This needs to be extrapolated to the general population, and to do this a series of assumptions (that may differ between different researchers) are needed. Even the population of South Africa is uncertain. While the official population in the 2001 census is 44 819 778, this figure is of questionable accuracy. There was an undercount of about 1 in 6 of the population, so assumptions and statistical models were required to arrive at the final estimate.

In an endeavour to obtain the critically important empirical information on the prevalence of HIV in South Africa, the Human Sciences Research Council (HSRC) conducted a survey on the general population of South Africa. However, as with all sample surveys, there are still uncertainties which are quite large when stratified by age and gender. The HSRC will be doing a similar survey again next year.

In 2001 a group from the University of Cape Town and the Medical Research Council produced a report indicating that HIV/AIDS had become the leading cause of death in South Africa. It was based on empirical data and demonstrated that total mortality had risen dramatically in recent years, particularly among young adults (and especially young females). By a process of elimination, it was concluded that HIV/AIDS was the major cause of the changing pattern, but the proportion of AIDS deaths needed to be estimated indirectly from the model, leaving some uncertainty about the statistics. This was done using the AIDS and demographic model of the Actuarial Society of South Africa (ASSA).

Official mortality statistics for South Africa are several years out of date. The latest full published report which has causes of death is for 1996, and a report on a sample of deaths is available for 1997 to 2001. Again the data are not conclusive. A person who is sick with AIDS will often die from an opportunistic coinfection such as pneumonia or tuberculosis, and the HIV status may not be reflected on the death certificate. Death certificates explicitly recording HIV as the underlying condition are very much in the minority.

Both the MRC/UCT and the HSRC groups have produced reports on future projections of the HIV/AIDS epidemic in South Africa. While they have utilised different models and have different numerical estimates, the broad sweep of the natural course of the epidemic is remarkably similar. The course of the epidemic can best be described as a series of waves, each with a different time component. The first wave of the epidemic, that of incidence or new cases, peaked around 1998 and has since declined. The second wave of the epidemic, that of prevalence or the numbers infected with HIV, is peaking around now, and will drop even if there are no interventions. The third wave of the epidemic is that of deaths, now the dominant phase, which will peak around 2009, and finally the wave of children orphaned by AIDS will peak in around 2015 at several millions (the precise figure depends on the definition adopted).

It is important to understand the natural course of epidemics and understand the interplay between incidence, deaths and prevalence. It should be noted that the HIV/AIDS epidemic, like any epidemic, will become self-limiting and start to decline, even without intervention. The level at which it stabilises will be influenced by the effectiveness of interventions. Too much emphasis on causality should not be placed on the link between behavioural change and the stabilising of the prevalence; and in the future, on the introduction of antiretroviral therapy. Paradoxically a successful ART programme would initially lead to a rise in the numbers of those who are HIV-positive, compared with what would otherwise be the case, as death is delayed. Most importantly the numbers of orphans will be drastically reduced as the lives of their parents are extended, and many people will have a longer, healthier life.

In order to reduce our future uncertainties regarding the course of the epidemic, we will need to develop new surveillance tools and data sets as the ART programme is rolled out, such as direct measurement of years of life saved, and more and regular population-based seroprevalence surveys. Given the health crisis this country faces, there is a specific obligation that whatever statistical systems are developed the data need to be rapidly available, at the finest level compatible with confidentiality, and be subject to critical evaluation and analysis by all.

David Bourne
School of Public Health and Family Medicine
University of Cape Town, and
Burden of Disease Research Unit
Medical Research Council

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