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Difficulties in attributing deaths to HIV/AIDS

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Background

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There are many questions about HIV/AIDS that we in South Africa cannot answer at present.

- **We do not know how many people in South Africa are infected with the virus.**
- **We do not know how many of those who are infected have symptoms of full-blown AIDS.**
- **We also do not know how many people have died from the disease.**

- We do not have sufficient information about the life circumstances and living conditions that place certain groups of people at greater risk than others of being infected with the disease.
- We do not know how effective education campaigns have been in raising awareness.
- We do not know the extent to which awareness translates into actual behavioural change.

There is a wide range of reasons, which explains our present lack of knowledge.

- HIV/AIDS is not a notifiable disease. Therefore it is difficult to trace the disease to its sources of origin.
- Incomplete registration of deaths in the country, particularly in rural areas.
- Death certificates are often poorly completed.
- Unnatural causes of deaths cannot be fully recorded at present.
- The present rate of capture of natural causes of death is slow.
- Present estimations of the extent of the epidemic are based on sero-prevalence tests in pregnant women. This is not necessarily a representative sample of the population.

The only recourse we have at present regarding the extent of the epidemic is through demographic modelling.

This type of model has its own built-in risks.

- Demographic modelling may be based on incomplete and possibly inaccurate or unrepresentative data.
- Each model is based on certain underlying assumptions, which are sometimes difficult to test.
- It is an indirect method of estimation.
- It may over- or under-estimate the extent of a phenomenon such as probability of transmission.
- Modelling cannot identify risk factors associated with the epidemic.
- Models depend on the data, which are available to the modeller, and at present, this base of data, from both sero-prevalence testing of pregnant women and from deaths records, is insufficient.

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The MRC report on deaths caused by HIV/AIDS

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Issue

Lack of accurate and reliable empirical data

The MRC findings:

- **Do not flow from empirical evidence;**
- **Is the outcome of a theoretical model;**
- **Deciding whether the excess deaths are due to HIV/AIDS is difficult in the absence of accurate information as to the cause of death;**

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Model assumptions

The MRC report assumes:

- **The completeness of registration of deaths was about 89% in 2000 from a base of 57% in 1993. But Stats SA's calculations suggest that these estimates of completeness may be high.**
- **That there is uniform recording of deaths-registration in both urban and non-urban areas. But, evidence suggests that underreporting occurs mainly in rural areas**

Model assumptions (contd.)

- That completeness in death registration fluctuates. For example, in 1990, registration of adult deaths was estimated at 60%, increasing to 61% in 1991. But the following year – 1992 – it dropped to 57%. Two years later, in 1994, this had shot up to 73%.
- The MRC report further estimates by 1996, 85% completeness and by 1999/2000, 89% completeness in deaths-registration.

Are the assumptions of completeness of recorded deaths correct?

Lower level of completeness of recorded deaths leaves room for apportioning any observed increase in mortality to

- improvement in registration, and to
- genuine increase.

The MRC report has not furnished any empirical evidence to support the assumption of near-completeness in the registration of deaths.

The probability of transmission assumption

- Probabilities of transmission of HIV are not known with precision.
- Recently published research (*Lancet*, 2001), on probabilities of transmission in Uganda, suggests an overall value of .0011 (lower than the values used in the MRC model). This value would reduce or increase, based on the presence of other co-factors such as STDs or genital ulcers.
- In an exercise using the MRC model but with a different probability of transmission matrix (with the .0011 as the central value), the accumulated AIDS deaths by 2010 would vary by between 1 million to 2 million deaths.

Projecting mortality from 1985

Underlying the MRC model are mortality estimates that are based on the 1985 reported deaths and projected to 2000.

- **For 1985, the completeness of mortality (which was very low then) is estimated using different assumptions and combination of methods.**
- **An annual percentage decline is assumed for each life table value.**
- **Such a life table value then forms the basis of the 'normal mortality'.**
- **However, all of these life table values have not been unverified nor substantiated.**

Underplaying the role of unnatural deaths

The MRC may be underplaying the role of unnatural deaths in young adults.

They cite data from the Institute of Race Relations, suggesting that number of deaths due to political violence (only part of the picture) had decreased over time (since 1993).

The 1996 causes of death data base shows that the number of deaths due to unnatural causes has been increasing over time; from 42 114 (19,7% of all registered deaths) in 1994, to 54 937 (20,5%) in 1995 to 61 303 (18,7%) in 1996.

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Problems with verifying causes of unnatural deaths

- The 1996 full causes of death data set shows that about 69 000 deaths were recorded for males and females in the age group 15 to 49. Of these, about 45 000 (or 65%) died of unnatural causes.
- Act 51 of 1992, section 17, part 2, remains on our statute books.
- The Act states that causes of unnatural deaths need not be completed on death certificates.
- This proviso makes it difficult to distinguish whether death is due to violence, accidents or other causes.

MRC conclusion is not supported

The MRC report states:
"It is estimated that about 40% of the adult deaths that occurred in the year 2000 are due to HIV/AIDS and that over half the deaths in the ages 15 to 49 are due to AIDS. When this is combined with the excess deaths in childhood, it is estimated that AIDS accounted for 25% of all deaths in the year 2000 and has become the single biggest cause of death."

This statement cannot be uncritically accepted.

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The way forward

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Stats SA believes that at present it is difficult to model the HIV/AIDS epidemic adequately or accurately.

- **The country requires much better empirical data for modelling.**
- **The way in which to obtain the data is through a repeated, possibly annual, series of household surveys, which are representative of the population as a whole.**

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Empirical research

Stats SA would like to propose that such empirical studies be undertaken in the country which link life circumstances and living conditions of households, and attitudes and behavioural practices within them, to the prevalence of the disease.

Empirical research (contd.)

The only way in which such a study can be undertaken is through bringing the household survey expertise of Stats SA together with the expertise of other bodies. For example, nurses in the Department of Health could draw blood or saliva samples from selected households for testing, the MRC could give conceptual and methodological inputs, and the expertise of the SAIMR or other bodies could be used for blood or saliva testing.

Empirical research (contd.)

- After wide consultation with relevant stakeholders, a questionnaire could be developed, which covers living conditions and life circumstances of South Africans, with particular emphasis on those circumstances that may place certain people at higher risk than others regarding contracting the disease.
- The survey could also ask questions on knowledge, attitudes and behavioural practices in relation to the transmission of the disease.

Empirical research (contd.)

- This questionnaire could be administered to a representative selection of households throughout the country. The size of the sample would depend on funds available, but it should be a large one (at least 60 000 households), since larger samples are required to measure the extent of less common phenomena.
- Following on questionnaire administration, a sample of blood could be drawn from members of the household, or a sample of saliva extracted.
- This sample could be sent for HIV/AIDS testing.
- The data from the results of the tests could be linked to the questionnaire information.

Ethical issues

There are certain issues that would need to be addressed before such a study could be undertaken:

- Setting ethical standards, for example, having the issue of the ethics of this type of research debated through an ethics committee.
- Testing methodology, for example, whether to embark on confidential, or anonymous testing, as against giving people information and counselling about their status. The blood testing among pregnant women is done anonymously.

Ethical issues (contd.)

- Ensuring ongoing confidentially, for example throughout the linking process of questionnaire completion and the results of blood or saliva testing.
- Having a very safe testing procedure, and allaying people's fears about contracting a disease through the testing procedure.
- Embarking on an educational and publicity campaign around the survey.

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