

SHORT REPORT

RECOMMENDATIONS FOR COMPLETING DEATH NOTIFICATION FORMS IN HIV-POSITIVE PATIENTS

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Death notification is a valuable tool for providing data on the HIV pandemic in South Africa, if it is done correctly. This article addresses common misconceptions regarding practical, legal, and ethical aspects of death notification form (BI-1663) completion in order to improve reporting and, ultimately, national statistics and policy-making.

INTRODUCTION

In order to plan effective health interventions in a country and in turn to monitor their impact, sets of uniformly and routinely collected health data are required. One important example of this type of data is the national cause of death statistics. These are compiled by Statistics South Africa from analysis of cause of death information completed on the death notification form BI-1663. These statistics give us an overview of the main underlying causes of mortality in our population overall, and in specific demographic categories (e.g. gender, age, etc.).¹

Unfortunately, these statistics have poor accuracy, and this severely limits their value for the abovementioned purposes. This lack of accuracy can be attributed to errors made by health professionals in recording causes of death. Several studies performed recently in this country have shown very high rates of major (i.e. influencing the coding of the underlying cause of death) and minor errors in completed death notification forms.^{2,3}

WHAT DO OUR CAUSE OF DEATH STATISTICS SAY ABOUT HIV?

The realm of HIV/AIDS statistical reporting has been fraught with challenges (whether ethical, political, or practical) since the beginning of the epidemic, and cause of death statistics have suffered just as much in this regard. According to the findings from the statistical report on causes of death in 2005, the top ranking cause was tuberculosis, followed by influenza and pneumonia, and intestinal infectious diseases. Certain disorders involving the immune mechanism were ranked 7th, while HIV disease was ranked 9th – classified as the underlying cause of death in only 14 532 deaths, or a

mere 2.5% of the total.¹ Does this mean that very few people in the country die of HIV/AIDS, or does it mean that very few deaths due to HIV are recorded as such on the death notification form?

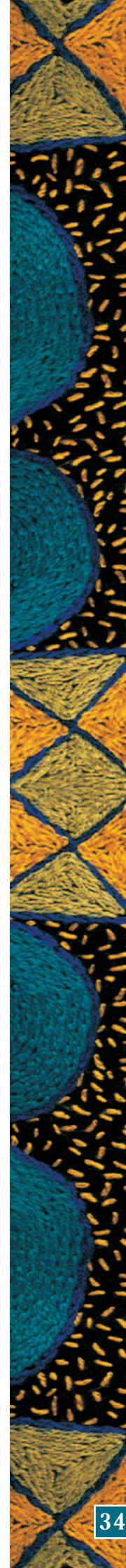
Groenewald *et al.*³ in 2005 compared the trend in age-specific death rates for nine AIDS-related conditions (including tuberculosis and respiratory diseases) with age-specific death rates for HIV as predicted by the Actuarial Society of South Africa model (ASSA 2000), and observed a high level of correlation, concluding that these diseases account for the 'missing' HIV cause of death statistics, and showing that only about 40% of deaths due to HIV are recorded as such. Nojilana *et al.*⁴ recently reviewed death notification forms completed at an academic hospital, and observed a similar percentage of HIV deaths as being officially reported on the death notification form.

There is much anecdotal evidence suggesting reasons for non-completion of HIV as cause of death on the BI-1663 form, including confidentiality issues and confusion as to whether or not it is 'legal' to write 'HIV' on the form. Furthermore, there are a significant number of instances on forms where a convenient euphemism (e.g. 'RVD', 'ELISA+', 'immunocompromised', etc.) is recorded in lieu of 'HIV'. It is of utmost importance for these issues to be addressed and the correct information supplied to medical practitioners countrywide if an improvement in the quality and accuracy of cause of death data is to be seen.

PRACTICAL POINTS TO CONSIDER WHEN NOTIFYING CAUSE OF DEATH⁵

Relating to opportunistic infections:

- Always specify the causative organism responsible for an infectious process, e.g. pneumonia, meningitis,



gastroenteritis. If the specific organism has not been cultured, specify the class of organism (e.g. viral, bacterial, protozoal, fungal, etc.) or record as 'organism unknown/unspecified'.

- When recording tuberculosis as a cause of death, avoid abbreviations such as 'PTB'. Always record the anatomical area affected by the organism, e.g. lung, kidney, etc.

Relating to HIV infection:

When recording HIV/AIDS as underlying cause of death, it must be stated as one of the following:

- Acquired immune deficiency syndrome/AIDS (acquired immunosuppression is also acceptable)
- Human immunodeficiency virus/HIV infection
- B24 (ICD-10 code for HIV – see below)
- If the diagnosis is based on clinical findings and not on laboratory diagnosis, the above can be prefixed by 'probable', 'clinical findings consistent with', '?', etc.

The following are not acceptable:

- Immunosuppression
- Immunocompromised
- Retroviral disease/RVD.

The above is necessary because the coders working at Statistics South Africa can only code what they see. They are not permitted to assume that you are referring to HIV infection when you use a euphemism such as 'RVD'. Immunosuppression/compromised is therefore coded under 'certain disorders involving the immune mechanism', and RVD under 'viral diseases unspecified' instead of under 'HIV disease', thus affecting the statistics (personal communication with coding staff at Statistics South Africa Data Processing Centre).

LEGAL AND ETHICAL ASPECTS

The widespread confusion on the ethical and legal aspects of death notification form completion has been fuelled by *inter alia* the widely publicised disciplinary hearing involving a prominent state pathologist. This arose from a complaint laid against him by the family of the deceased for writing 'AIDS' as cause of death. The charges were subsequently dropped as there was no evidence that any legal or ethical boundaries had been transgressed.^{6,7}

The law requires you to complete the BI-1663 accurately, as it is an official document, and failure to do so in essence constitutes a criminal offence.⁸ The HPCSA guidelines on confidentiality address the issue of disclosure of health information after a patient's death, and refer back to the law, stating that it is a legal requirement for the health care practitioner to complete the death notification form

'honestly and accurately'.⁹ It is therefore illegal as well as unethical to omit HIV as cause of death in a patient who died of pathology resulting from this infection. However, the HPCSA also cautions health care practitioners to 'consider whether the disclosure of information may cause distress to, or be of benefit to, the patient's partner or family'.⁹

Although the second page of the BI-1663 form is required to be sealed in an envelope and attached to the first page before being handed to the family,¹⁰ there are no systems in place to ensure this confidentiality. It is therefore conceivable that the family may see the cause of death written on the second page. If the cause of death is stated as HIV, this could cause the family distress if they were not privy to this information beforehand.

In such cases, where the practitioner feels that writing 'HIV' on the death notification form is not appropriate in light of the confidentiality situation, they may record 'B24' as cause of death. B24 is the ICD-10 code representing 'Unspecified HIV disease'. It will be understood perfectly by the coders, and not by anyone else who may happen to glance at the second page of the BI-1663. It therefore satisfies legal and ethical requirements for death notification form completion, protects the family from distress, and facilitates accurate statistical analysis.

CONCLUSION

If the above guidelines are followed when completing the BI-1663, great steps can be taken to improve mortality statistics in the country, providing policy makers with a clearer picture of the epidemic, and, in so doing, improve the interventions aimed at curbing its spread.

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