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Low rate of reporting of confirmed AIDS-related deaths using BI-1663 forms by private medical practitioners in the Mafikeng, North West Province

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The aim of the study was to investigate the experiences and perceptions of medical practitioners about the implementation of the current death notification form (BI-1663) in cases of confirmed AIDS-related deaths. The study focused on reporting patterns by private medical practitioners of the deceased's underlying causes of death in BI-1663, together with reasons advanced for the reporting patterns. Using self-administered questionnaires, data were collected from 31 medical practitioners in the Mafikeng area of the North West Province. The findings revealed that the majority of medical practitioners either did not disclose, did omit or mis-report information that HIV/AIDS-related disease was the underlying cause of death in BI-1663 during notification of confirmed AIDS-related death. Reasons advanced for the phenomenon were fears of unauthorised breach of the deceased's confidential information by unintended parties that often led to invalidation of the deceased's insurance and funeral benefits, as well as stigmatisation and social discrimination of the relatives of the deceased. The study recommends that third parties (informants) should be relieved of the duties of conveying the deceased's confidential medical information to the state during death notification processes. Medical practitioners themselves should submit part 2 of BI-1663 that contains the deceased's confidential information to the state during to the medical practitioners with respect to death certification to enable them to certify causes of death in a manner that is useful for epidemiological analysis and public policy.

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Background

That the epidemic of human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS) is the world's biggest challenge is now no news.^{1,2} It is, however, alarming that South Africa has the world's highest single HIV/AIDS caseload, with more than five million of South Africa's 45 million people infected with HIV.^{1,3} South Africa is currently experiencing one of the most severe AIDS epidemics in the world. At the end of 2007, there were approximately 5.7 million people living with HIV in South Africa, and almost 1,000 AIDS deaths occurring every day.⁴

Considering the magnitude of the epidemic, it is extremely important for South Africa to monitor AIDS mortality in order to provide reliable information necessary for planning and to be able to assess the impact of interventions.⁵

Having recognised the importance of mortality and death statistics, the government of post-apartheid South Africa prioritised the collection of mortality data and gave Statistics South Africa (SSA) the legal mandate to publish vital statistics based on deaths reported to the Department of Home Affairs (DoHA).⁶ The rationale behind the need to invest resources in measures that guarantee the credibility of a country's mortality record system can be appreciated when one considers the assertions made by Baker, Kjellstrom, Calderon and Pastides⁷ that "The basis for a mortality system is that all deaths are medically certified by cause and registered on a registry that is accessible to appropriate parties". The authors further argue that a review of reliable death certificates can provide an easy and rapid means of surveillance efforts and can be a useful adjunct to other methods of surveillance for AIDS. It was in pursuit of the collection of reliable cause-specific mortality statistics that the DoHA initiated collaborative efforts with its main stakeholders and embarked on a Joint Vital Registration Infrastructure Initiative in 1995⁵ which culminated in the promulgation of the new death notification form (BI-1663) in 1998,⁸ the subject of this study.

Despite efforts aimed at improving the quality of information generated by death certificates, cause of death statistics significantly underestimated the number of AIDS deaths.⁵ Due to the stigma associated with HIV and AIDS, details completed on the death certificate tended to focus on opportunistic infections or the mechanism of dying rather than providing the underlying cause. These observations appeared to reinforce Erlich's (2005) statements that medical practitioners were generally poor at documenting the accurate cause of death certification to the degree required for epidemiological analysis and public policy.⁹

Following the analysis of death notification forms submitted to the DoHA for the period between 1997 and 2003, Lehohla (2005)

noted the poor quality of information that was supplied by medical practitioners, attributing it to content errors, omissions as well a misreporting of the causes of deaths. He further stated that despite these limitations and while analysis of death notification forms was not focusing on HIV and AIDS *per se*, the findings did provide indirect evidence that HIV may be contributing to the increase in the level of mortality for prime-aged adults. These conclusions were based on the increasing number of reported deaths due to associated diseases such as tuberculosis, influenza and pneumonia for the period under study.¹⁰

The Health Systems Trust¹¹ states that doctors were against the new death certificate requirements as it compromised patient confidentiality in AIDS-related deaths. The doctors felt that the new requirements meant that if a death was caused by tuberculosis, which resulted from a weakened immune system caused by AIDS, they had to reveal such facts. These certificates were forwarded to the DoHA where they became public documents open to inspection.¹¹ The concerns raised by doctors seemed not to be without just cause when they are evaluated against the DoHA's stated policy directives which place the burden of confidentiality of the cause of death on the health professional.

Literature review and problem definition

Accurate mortality statistics are needed for public policy formulation, planning and monitoring as well as implementation of health programmes aimed at improving the health status of the population.^{6,7,10} The form BI-1663, which came into effect in September 1998, was meant to achieve the objective of achieving accurate mortality statistics in South Africa: "The introduction of the newly revised death notification is a positive move towards the long-term aim of providing accurate and complete information on all deaths that occur in South Africa."12 However, a closer inspection of the procedures for completing the form showed some contradictions between what the DoHA requires and those of the South African Medical Association (SAMA).¹³ While SAMA regarded the completion, conveying and registering of the cause of death as the absolute responsibility of the medical practitioner, the directive from the DoHA allowed the next of kin or the funeral undertaker a role in the process of conveying and registering the confidential page regarding the actual cause of death. Both SAMA and DoHA are in agreement as to the need for the medical practitioner to maintain confidentiality of information, with SAMA specifically prohibiting the undertaker, family or insurer or other interested party from handling the affected page.13 These differences place medical practitioners in a very serious legal and ethical dilemma. It is strongly suspected that this might be partly responsible for the under-reporting and variances in the total number of all deaths registered in the country, in spite of the new death notification form (BI-1663).7

Even though confidentiality is one of the most articulated ethical obligations to patients (see the Declaration of Geneva, 1948,¹⁴ and World Medical Association, 1949¹⁵), it is also subject to most breaches on behalf of the state, for reasons such as the prevention and control of epidemics, protection of third parties and health research.¹⁶ While the disclosure of confidential patient information after death to the state is a legal duty imposed upon healthcare practitioners via the Births and Deaths Registrations Act No 51 of 1992, the administrative nature of the current death notification system is such that there seems to be confusion among medical

practitioners as to who is responsible for transferring the deceased's confidential medical information to the relevant public health authorities. Such confusion makes possibilities of breaches of this confidential information to non-state third parties during transit very likely. Such breaches, it must be noted are regarded as unjustified and may carry disciplinary sanctions including caution or reprimand, suspension or removal from the roll or civil action.¹⁷ The severity of these sanctions is understandable when one notes the fact that in terms of the Health Act, No 63 of 1977, HIV/AIDS is not classified as a notifiable disease.

Aim of this study

The aim of this study, therefore, was to provide empirical evidence regarding reporting, non-reporting or mis-reporting of underlying causes of death in the death notification forms (BI-1663) by medical practitioners during registration of confirmed AIDS-related deaths. The findings of this study will contribute solutions to the problems that, despite the introduction of a comprehensive death notification form (BI-1663), the collection of South Africa's credible AIDS mortality statistics continue to be compromised.

Methodology

This study investigated experiences and perceptions of medical practitioners personally involved in the administrative processes of registration of deaths. It focused on the use of the current death notification form (BI-1663) by medical practitioners in the Mafikeng/ Mmabatho geographic areas of the North West Province of South Africa. The main objectives of the study were the collection of empirical evidence of non-reporting and or misreporting in BI-1663 of underlying causes of deaths in cases of AIDS-related deaths by medical practitioners and the reasons behind such practices. A secondary focus was to understand the attitudes and beliefs of medical practitioners as underlying reasons behind their choices of actions, when confronted with potential dilemmas. The attitudes and beliefs were themselves considered important because they were thought to constitute indirect reflection of how medical practitioners, through their actions, effectively dealt with the legal and ethical dilemmas of choice between loyalty to the state, their medical profession and loyalty to the deceased, in their scope of practice.

The target population

All medical practitioners practising within the geographic areas of Mafikeng/Mmabatho in the North West Province of South Africa constituted the target population for the study. An all-inclusive list of 40 names of such medical practitioners was obtained from the Department of Health. The sample consisted of all fully registered medical practitioners practising in Mafikeng/Mmabatho and their environs. The list excluded all medical interns.

The instrument and data collection

A seven-page self-administered questionnaire was developed, consisting of two sections. The first section requests biographical data. The second section consists of seven items measuring respondents' participation in the formal training of the completion of form BI-1663, their experiences with notification of deaths involving an HIV/AIDS patient, reasons influencing the decision to declare or withhold the underlying cause of death, the processes for sealing and conveying the part containing the deceased's confidential medical information and whether using a 'direct method' would

make them more at ease to disclose the HIV/AIDS status of the deceased. Each of these was anchored on a fixed response scale, with space for further explanations. There was a covering letter which explained the purpose of the study, guaranteed voluntary participation and anonymity. The instrument was pilot-tested on a group of five medical doctors and found to have both high face and content validity. The instrument received the approval of the ethics committee of North West University, under whose aegis the study was conducted in 2005.

The researcher delivered copies of the questionnaire to all medical practitioners by hand mail. In order to further encourage participation the researcher asked medical practitioners to hand over all copies of the questionnaire, whether completed or not completed, within one week of their receipt to the laboratory messenger who would in turn deliver them to the researcher and thereby guarantee participants' anonymity.

Results

Copies of the self-administered questionnaire were sent to 40 medical practitioners, both general practitioners and specialist practitioners. Thirty-three questionnaires were completed and returned within one week of distribution, yielding a response rate of 82.5%. Two questionnaires were incorrectly completed and therefore excluded from the study. The final analysis was based on responses of 31 participants.

The demographic profile of participants

The majority (84%) of the participants were male, a situation that was also not unexpected given the gender inequalities that are still prevalent within the medical profession in South Africa. While 35% are in the age group 36-40, 55% are above 45 and only about 10% are below 30 years.

Formal training in completing death notification forms (BI-1663)

Respondents were asked to indicate the nature of training they had received on the completion of the death notification form (BI-1663). The responses are given in Table 1.

Table	1: '	Formal	training'	in	completing	death	notification	form	(BI-	1663))
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	N	%
Attended workshop/seminar/conference	1	3.23
Read training manual on own	5	16.13
Did not receive any formal training	25	80.65
Other	0	0
Total	31	100.0

According to results presented in Table 1, 80.65% (25/31) of the participants responded that they had not received any type of 'formal' training on correct procedures to be followed during death notification processes using the current death notification form (BI-1663). Only one participant (3.23%) responded that he had attended some 'formal training' in the form of a workshop/seminar/ conference. The remainder of participants (16.13%) responded that they had read the training manual on their own. It is important to highlight here also the comments of 6.45% (2/31) of participants who responded that they were not even aware of the existence of such training.

Frequency of notifications of confirmed HIV/AIDS-related deaths during ordinary scope of practice

Table 2 shows that 13 (41.94%) of the participants responded that they were 'very often' involved with notification of confirmed AIDS-related deaths, while 29.03% (9/31) responded that they were 'often' involved and only 29.03% (9/31) responded that they were involved 'occasionally'.

Table 2: Frequency of notifications of confirmed HIV/AIDS-related deaths during ordinary scope of practice

	N	%
Very often	13	41.94
Often	9	29.03
Sometimes	9	29.03
Never	0	0.0
Total	31	100.0%

Practices with respect to completing the confirmation of the underlying HIV/AIDS information in death notification form (BI-1663)

Table 3 presents data on the prevailing practices regarding the completion of the form BI-1663, for confirming the cause of death.

Table 3: Medical practitioners' handling of the HIV/AIDS information in the death notification form (BI-1663)

	Almost always	Occasionally	Never
Disclosed	3 (9.68)	7 (22.58)	21 (67.74)
Omitted	11 (35.48)	11 (35.48)	9 (29.03)
Misreported	11 (35.48)	7 (22.58)	13 (41.94)

About 68% of the respondents had 'never' disclosed the information that HIV/AIDS was an underlying cause of death in the death notification form (BI-1663) when notifying confirmed AIDS-related deaths; only 9.68% (3/31) responded that they disclosed 'almost always' and the rest, 22.58% (7/31), responded that they disclosed 'occasionally'.

Similarly, about 71% 'almost always' or 'occasionally' omitted information about the underlying cause of death as required in the death notification form (BI-1663) when notifying confirmed AIDS-related deaths. Only about a third 'never' omitted such information.

Finally, Table 3 also revealed that 35.48% (11/31) of the participants responded that they 'almost always' stated another (misreported) underlying cause of death in the BI-1663 when they notified confirmed AIDS-related deaths, while 22.58% (7/31) of the participants responded that they did so 'occasionally' and only 41.94% (13/31) of participants responded that they 'never' misreport the information.

Underlying motives for withholding information confirming underlying HIV/AIDS information in BI-1663 form

One of the objectives of the study is to understand the motives of the medical practitioners in complying or not complying with the requirements of form BI-1663. This was tested against four reasons often advanced in contemporary discussions and the literature. Table 4 presents the results.

Table 4: Underlying motives for withholding information confirming underlying HIV/AIDS information in BI-1663 form

	Almost always	Occasionally	Never
To protect the deceased's insurance benefits	18 (58.06)	7 (22.58)	6(19.35)
To protect the deceased's funeral benefits	15 (48.39)	10 (32.26)	6(19.35)
To protect the deceased's confidential information from the next of kin	12 (38.71)	14 (45.16)	5(16.13)
To protect the deceased's confidential medical information from the state (public health officials)	5 (16.13)	10 (32.26)	16(51.61)

From Table 4, only 19.35% (6/31) of the participants responded that the need to protect the deceased's insurance benefits 'never' influenced them to withhold information in the BI-1663 that HIV/AIDS was an underlying cause of death when notifying confirmed AIDS-related deaths. On the other hand, about 80% of the participants had 'almost always' or 'occasionally' withheld information confirming underlying HIV/AIDS as the cause of death in order to protect their clients' insurance benefits. The same pattern applies to funeral benefits or the next of kin.

However, with regard to the need to protect the deceased's confidential medical information from the state (public health officials), there is an even split, with about 52% of the respondents 'never' so influenced by such considerations, while about 48% are 'almost always' and 'occasionally' influenced by the need to protect the deceased's confidential information from the state.

Attitudes to the 'sealing' of part 2 of form BI-1663 containing the deceased's confidential medical information

Part 2 of the death notification form contains such information to ensure confidentiality. The training manual published by the DoH states that after completing part 2 of the death notification form, health practitioners should fold and seal the form in order to ensure confidentiality and thereafter hand it over to the informant or person in charge of the funeral for purposes of arranging a burial order.³ The manual further states that while it is the responsibility of the health professional to maintain confidentiality throughout the process, it remains the responsibility of the dead person's next of kin to ensure that the death is registered at the DoHA.

Survey results showed that less than 20% (16.13%) 'almost always' sealed part 2, in contrast to 77.42% who either 'occasionally' or 'never' sealed it. This is not surprising because the medical practitioners in question either failed to disclose (32%), omitted (71%) or mis-reported (58%) the true cause of death, as reported in Table 4.

When asked if a 'direct method' that did not make use of a third party (informant) to transfer the deceased's confidential medical information to the state would be a preferred option and which would encourage honest disclosure, an overwhelming majority (90.32%) agreed and strongly agreed, with only 6.45% being 'indifferent'.

Discussion

The introduction of a the new death notification form (BI-1663) by the DoH in 1998⁶ was a positive intervention aimed at strengthening the epidemiological arm of the public health system with respect to the collection of valid and reliable useful cause-specific mortality data that could easily identify the extent of AIDS mortality. Subsequent

review of the quality of the data that were collected using the new death notification form for the period between 1997 and 2003, revealed many instances of content omissions and misreporting of underlying causes of death where individuals had died from conditions associated with AIDS.⁸ The following discussion is centred around four emerging themes: importance of training; influence of social discrimination; mis-reporting and confidentiality of medical information.

Contrary to assertions made by the DoHA that prior to the implementation of the current death notification form various stake-holders were actively involved, the private sector included,³ the findings of this study suggest that formal training received by a majority of private medical practitioners surveyed in Mafikeng/ Mmabatho with respect to death certification prior to the introduction of the new revised death notification form (BI-1663) was inadequate, if at all carried out. The seriousness of this finding can perhaps be succinctly illustrated by referring to comments made by one medical practitioner surveyed, who responded to the question as follows: "The forms were just dumped on us", while another said: "I was not even aware of the existence of such training".

The findings corroborate Erlich's⁹ observations that: "Contrary to what is asserted in the press release, medical practitioners are generally poor at accurate cause of death certification to the degree required for epidemiological analysis and public policy. **They have little training if any in such certification** (our emphasis). There is a large international literature showing this in relation to many conditions, let alone one attended by as high degree of fear and stigma as AIDS."

Hence, there is a need to train and retrain medical practitioners in fulfilling this important national requirement.

Dorrington et al state that the majority of deaths due to HIV are mis-classified because doctors did not record HIV as the underlying cause of death.5 This is because either doctors claimed that they did not know the HIV status of the deceased or, in instances where they knew the status, because of their desire to conceal the deceased's HIV infection. This was done in order to spare stigmatisation of relatives, or to avoid invalidating insurance claims.3 This trend is confirmed by the findings of this study. Only six participants (19.35%) indicated that the need to protect the deceased's insurance benefits and funeral benefits had 'never' influenced them to withhold the deceased's confirmed underlying HIV/AIDS information when completing BI-1663, while the rest (80%) of the medical practitioners are 'almost always' or 'occasionally' influenced by such considerations. Similar patterns emerge with respect to the perceived need to protect the deceased's confidential medical information from the next of kin. That as many as 48% of the respondents were influenced by the need to protect the deceased's HIV/AIDS information from public health authorities is disconcerting and negates the very intentions of the official death registration system legislated in terms of the Births and Deaths Registrations Act. This may be due to the South African government's initial reluctance to bring the crisis into the open, fuelling confusion about the causes of the disease, thus preventing many people, including medical practitioners from speaking about the real causes of illness and deaths of loved ones.⁴

Notwithstanding failure to advance precise reasons behind the perceived need to withhold the deceased's underlying HIV/AIDS information from public health authorities by medical practitioners surveyed, such a finding, nonetheless, indicates a serious

contravention of the Births and Deaths Registrations Act, which may carry a fine or imprisonment not exceeding five years or both.¹⁷

According to the findings of the study, 67.74% of medical practitioners surveyed responded that they 'never' disclosed information that HIV/AIDS was an underlying cause of death during registration of confirmed AIDS-related death using the current death notification form (BI-1663). Only 9.68% responded that they 'almost always' disclosed the deceased's confirmed underlying HIV/AIDS information in the death notification forms. These findings corroborate anecdotal reports of content omissions and or misreporting of underlying causes of deaths and suggest that such practices are conscious and deliberate on the part of medical practitioners registering confirmed AIDS-related deaths. Lehohla (2005) suspected this practice during analysis of death notification forms submitted by them to the DoHA for the period between 1997 and 2003, for individuals who were certified to have died from conditions known to be associated with HIV/AIDS.¹⁰

Closely linked with inconsistent disclosure practices of the deceased's confirmed underlying HIV/AIDS information as reported by medical practitioners, were the practices with respect to 'sealing' part 2 of the death notification form that contains such information to ensure confidentiality. This is an area where there is a discrepancy between the expectations of the DoHA and SAMA as to the role of the medical practitioner in protecting the confidentiality of information. The findings show that only a minority (16.13%) of the medical practitioners surveyed responded that they sealed the form 'almost always', while as many as 45.16% of them responded that they 'never' sealed the form and 32.26% responded that they sealed the form 'occasionally' while the remainder (6.45%) reported handing the completed form to the nurse assistant who in turn gave it to the informant. This was to be expected since the majority (68%) of the medical practitioners 'never' disclosed information that HIV/AIDS was an underlying cause of death during registration of confirmed AIDSrelated death using the current death notification form (BI-1663). Hence, the medical practitioners surveyed overwhelmingly support (90.32%) sending the confidential information regarding the cause of death 'directly' to DoHA, as a way of encouraging them to readily disclose the deceased's confirmed underlying HIV/AIDS information in death notification forms. The use of a third party (next of kin or the funeral undertaker) to convey this vital information is, therefore, shunned by most of the medical respondents.

Recommendations

When implemented by policy makers, the following recommendations will enable medical practitioners to disclose more readily the deceased's underlying HIV/AIDS information when notifying confirmed AIDS-related deaths:

- The DoHA should facilitate more intensive formal training of medical practitioners with respect to death certification in order to enable them to certify causes of death in a manner that is useful for epidemiological analysis and public policy.
- Part 2 of the death notification form (BI-1663) that contains the deceased's confidential medical information should be submitted directly by the medical practitioner notifying death. A third party (informant) that is not accountable to the death registration system should not be used to carry out this function.

 More in-depth studies should be undertaken to document experiences and perceptions of medical practitioners in other geographic areas of South Africa as well as nationally.

Limitations

This study is limited by geographical location, which may mean that the experiences and perceptions of medical practitioners in the Mafikeng/Mmabatho areas may differ from those of their counterparts in other parts of the country. Therefore, future studies should embrace a wider geographic area consisting of rural and urban populations.

Conclusions

The findings of this study suggest that while introduction of the revised death notification form (BI-1663) by post-apartheid South Africa was a positive development towards collection of credible cause-specific mortality statistics in the country in line with recommendations of the World Health Organization, medical practitioners find the implementation of BI-1663 in cases of confirmed AIDS-related deaths challenging for the following reasons:

- Inadequate formal training received by them with respect to death certification prior to implementation of the death notification form (BI-1663).
- Perceived lack of sufficient measures aimed at preventing unauthorised access to the deceased's confidential medical information by unintended non-state parties that is inherent in implementation of BI-1663 for conditions that are often associated with denial of insurance and funeral benefits as well as social stigmatisation of relatives.

These challenges manifest by way of omissions and misreporting of the deceased's HIV/AIDS information in death notification forms by medical practitioners. The obstacles identified in this study contribute to the problem of the low rate of reporting of confirmed AIDS-related deaths in the country and, therefore, need urgent policy intervention.

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