AN INVESTIGATION INTO THE LOW RATE OF REPORTING OF CONFIRMED AIDS-RELATED DEATHS BY PRIVATE MEDICAL PRACTITIONERS: THE IMPLEMENTATION OF BI-1663 IN MAFIKENG

Dr. Molosi, L. D.

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AN INVESTIGATION INTO THE LOW RATE OF REPORTING OF CONFIRMED AIDS-RELATED DEATHS BY PRIVATE MEDICAL PRACTITIONERS: THE IMPLEMENTATION OF BI-1663 IN MAFIKENG

by

Dr Letlhogonolo Daniel Molosi

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DECLARATION

I, Letlhogonolo Daniel Molosi, do hereby declare that this mini dissertation for the degree of Masters in Business Administration at the North West University has not been previously submitted by me for a degree at this or another university, and that it is my original work in design and execution, and further that all material contained herein has been duly acknowledged.

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Signed

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DEDICATION

This work is dedicated to my ten-year old daughter Oarabile and three-year old son Phenyo, whom it is my sincere wish that it shall inspire them to strive for excellence in whatever career path they will choose in future.

ABSTRACT

The aim of this study was to investigate experiences and perceptions of private medical practitioners about the implementation of the current death notification form (BI-1663) in cases of confirmed Aids-related deaths. The study focussed on reporting patterns by private medical practitioners of the deceased's underlying causes of death in BI-1663. The study also focussed on the reasons advanced for the reporting patterns described above.

The research method employed in this study was cross-sectional surveys. Self-administered questionnaires were used to gather the data and the target population was all private medical practitioners practising within the Mafikeng / Mmabatho area of the North West Province of South Africa. A response rate of eighty-two and half percent (82,50%) was achieved. The data were presented in the form of frequency tables and pie charts and descriptive statistics was used to analyse it.

The findings of this study revealed that the majority of private medical practitioners either omitted information that HIV/AIDS was an underlying cause of death or reported another condition in BI-1663 during notification of confirmed AIDS related deaths. 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 relatives 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 directly to Public Health Officials. The study also recommends that the Department of Health should provide formal training to the medical practitioners with respect to death certification in order to enable them to certify causes of deaths in a manner that is useful for epidemiological analysis and public policy.

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1. AIDS: Acquired Immune Deficiency Syndrome.
2. ASSA: Actuarial Society of South Africa.
3. DoH: Department of Health.
4. DoHA: Department of Home Affairs.
5. HCPSA: Health Professions Council of South Africa.
6. HIV: Human Immunodeficiency Virus.
7. HSRC: Human Sciences Research Council.
8. HST: Health Systems Trust.
9. MDPB: Medical and Dental Professions Board.
10. MRCSA: Medical Research Council of South Africa.
11. SAMA: South African Medical Association.
12. SAMJ: South African Medical Journal.
13. SSA: Statistics South Africa.
14. USAID: United States Agency for International Development.
15. UN: United Nations.
16. UNAIDS: The Joint United Nations programme on HIV/AIDS.
17. WHO: World Health Organisation.
18. WMA: World Medical Association.

CHAPTER 1

THE ORIENTATION

1.1 Background.

Current media reports state that the whole world is experiencing a serious and escalating epidemic of Human Immunodeficiency Virus (HIV)/Acquired Immunodeficiency Syndrome (AIDS) that maims and kills significant numbers of people yearly, threatening the welfare and well being of societies. The media reports further state that South Africa has the world's highest single HIV/AIDS caseload. According to the United Nations (UN) estimates, more than 5 million of South Africa's 45 million people are infected with HIV (Alert.org, 2005).

Dorrington *et al*. (2001) state that while reliable empirical data on the epidemic in South Africa is hard to come by, information obtained from a series of annual antenatal surveys conducted by the Department of Health (DoH) indicate that South Africa experienced a very rapid spread of HIV during the last decade. The authors further state that the prevalence rate of the disease escalated from less than 1% in 1990 during the first year of the surveys up to nearly 25% in 2000. They argue that while model projections of the impact of HIV/AIDS have an important role to play in providing planning information, accuracy of these projections are however based on certain assumptions. 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 (Dorrington *et al.*, ibid).

Having recognised the importance of mortality and causes deaths 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) (SSA, 2005). 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 assertions made by Baker *et al.* (1999: 118) when they state: "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" 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 (Baker *et al.*, ibid).

Beaglehole *et al.* (1993: 19) state: "Internationally agreed classification procedures, which are given in the *International statistical classification of diseases and related health problems* (WHO, 1992) and revised at regular intervals to take into account the emergence of new diseases and changes in criteria for established diseases, are used for coding causes of death". Meanwhile Bradshaw *et al.* (2005: 497) state that the World Health Organisation (WHO) defines the underlying cause of death as: "The disease or injury which initiated the train of morbid events leading directly to death". The International Classification of Diseases (ICD-10) provides rules for the determination of the underlying cause of death, the authors stated further. In the case of AIDS, the ICD-10 classifies a person as having died of HIV as an underlying cause when HIV is present, and the person dies from a subsequent co-morbidity mediated by HIV infection (codes B20 through B24) (Bradshaw *et al.*, ibid).

It was in pursuit of the collection of reliable cause-specific mortality statistics that the DoH initiated collaborative efforts with the main stakeholders, the DoHA and SSA, and embarked on a Joint Vital Registration Infrastructure Initiative in 1995 (DoH, 2001). The report states that this process culminated in the promulgation of the new death notification form (BI-1663) in the Government Gazette No: 19006, Registration Number: 6216, Volume 397, Notice Number 897 on July 3, 1998. The existing death notification form (BI-12) changed from a single page form to a new two-page form (BI-1663), the report further states. The first page of the BI-1663 confirms death, while the second page presents demographic and the health data of the deceased that enables authorities to establish the health status of the nation and the burden of diseases (ibid). Manuals on how to complete the new death notification form were distributed and the DoH, the DoHA and SSA participated in the training of provincial personnel prior to implementation (ibid). Copies of the new form were distributed to health care practitioners and the implementation of the new death notification form (BI-1663) took place in September 1998 (ibid).

According to Dorrington *et al.* (2001), subsequent to the processes referred to in the preceding discussion, 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 when compared with projections from the Actuarial Society of South Africa (ASSA) 600 model. Despite efforts aimed at improving the quality of information generated by death certificates, cause of death statistics significantly underestimated the number of AIDS deaths (Dorrington *et al.*, ibid). 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 (ibid). These observations appeared to reinforce Erlich's statements (2005) that medical practitioners were generally poor at accurate cause of death certification to the degree required for epidemiological analysis and public policy.

Following the analysis of death notification forms submitted to the DoHA for the period between 1997 and 2003, Lehohla (2005) also noted the poor quality of information that was supplied by medical practitioners. The author stated that the factors which limited the accuracy and completeness of the data obtained from death notification forms included 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 focussing 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 (Lehohla, ibid).

The Health Systems Trust (HST) (2001) states that doctors were against the new death certificate requirements because they said they compromised patient confidentiality in AIDS related deaths. The report further states that 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 (HST, ibid)

The concerns raised by doctors seemed not to be without just cause when one evaluated them against the DoH's stated policy directives with respect to the correct procedures that should be followed when completing BI-1663. These policy directives are contained in the document entitled: '*Training Manual For The Death Notification Form (BI-1663)*'. The manual states that after completing page 2 of the form, the form should be folded, sealed in an envelope to ensure confidentiality and be attached to page 1 of the form that contains information for the registration of death (DoH, 2001). Once sealed, the document should be **handed to the informant or person in charge of the funeral** (my emphasis) for purposes of arranging for a burial order and registration of the death, the report further states. While it is the responsibility of the next of kin/informant to ensure that a death is registered with the Regional DoH, **it is the responsibility of the health professional to maintain confidentiality** (my emphasis) the manual asserts (ibid). Evaluations of anecdotal reports of medical practitioners' concerns about the risks of possible breach of confidential medical information contained in Part 2 of the BI-1663 were made with this official policy in mind.

Observations of actual omissions and misclassifications of underlying causes of deaths in BI-1663 where HIV/AIDS was suspected to have contributed to the cause of death that were demonstrated by Lehohla (2005) seemed to lend credence to anecdotal reports of doctors' concerns with page 2 of the BI-1663. The aim of this study therefore was to document empirical data to corroborate or refute these practices and find the reasons behind them. The findings of this study will contribute solutions to the problems that, despite introduction of a comprehensive death notification form (BI-1663), continue to obstruct collection of South Africa's credible AIDS mortality statistics.

Notification of deaths is an integral part of Epidemiology. Kartzenellenbogen *et al.* (1997: 5) define Epidemiology as: "The study of the distribution and determinants of health related conditions and events in populations, and the application of this study to the control of health problems". This study therefore, entails a scientific evaluation of the performance of the epidemiological arm of the South African public health system with respect to AIDS mortality statistics.

1.2 The statement of the problem.

HIV/AIDS is a serious epidemic that is responsible for the deaths of many South Africans daily. The AIDS mortality statistics that are currently used for planning and assessing the impact of interventions consist of estimates that are based on model projections of limited empirical data. Despite the country's recent introduction of an improved death notification form (BI-1663) whose primary objective was to assist authorities gather credible cause-specific mortality data, the collection of valid and reliable AIDS mortality data in South Africa remains a problem. This study investigated the practices of non-reporting and misreporting of underlying causes of death in the death notification form (BI-1663) by private medical practitioners during registration of confirmed AIDS-related deaths as factors that contribute to this problem. The reasons advanced for practices described above were also examined.

1.3 The objectives of the study.

In keeping with the problem statement stated above, the study aimed to achieve the following objectives:

- To document private medical practitioners' reporting patterns of the deceased's underlying causes of deaths in cases of confirmed AIDS related deaths in the current death notification form (BI-1663).
- To document the reasons that influenced private medical practitioners' reports of the deceased's underlying causes of deaths in cases of confirmed Aids related deaths in the current death notification form (BI-1663).

1.4 The central research questions.

In order to achieve the objectives outlined above, the study was guided by the following research questions:

- What official training, if any, did medical practitioners receive prior to implementation of the current death notification forms (B1-1663)?
- When reporting confirmed AIDS-related deaths, to what extent did medical practitioners routinely disclose, withhold or misreport medical information in the current death notification forms (BI-1663) that HIV/AIDS was an underlying cause of death?
- What were the reasons that influenced medical practitioners to report the deceased's confirmed underlying HIV/AIDS information in death notification forms (BI-1663) in the manners described above?

1.5 The rationale for the study.

The study sought to highlight deliberate lack of reporting and misreporting of the deceased's confirmed underlying HIVAIDS information in the death notifications forms (BI-1663) as well as the reasons behind those practices as reported by medical practitioners themselves. By presenting this empirical evidence, the study sought to highlight weaknesses with implementation of BI-1663 that did not adequately address medical practitioners' ethical concerns of unauthorised access to the deceased's confidential medical information by unintended non-state parties. These weaknesses constituted a significant limiting factor to the country's efforts to collect valid and reliable AIDS mortality data.

1.6 The significance of the study.

It is hoped that the findings of this study will have the following practical applications:

- Assist policy makers to strengthen the country's death registration systems in a manner that will enable health care practitioners to readily disclose information that HIV/AIDS was an underlying cause of death during registration of confirmed AIDS-related deaths.
- Facilitate uninhibited disclosures of all other confidential underlying causes of deaths by health care practitioners and thereby contribute to the overall credibility of the country's cause-specific mortality statistics.

1.7 The scope of the study.

Lack of reporting of AIDS related deaths is a very wide topic that can be studied from various perspectives. The bias of the studies depends on a need to justify particular stakeholders' choice of actions with respect to the epidemic, ranging from such factors as the scientific community, the medical profession, politicians, financiers, economists and social activists. This study was conducted from a perspective that emphasized structures and processes within the public health system that contributed to under-reporting of the size of the AIDS epidemic in South Africa, to the exclusion of other motives.

With this perspective in mind, the study limited itself to the following parameters:

- Participants were restricted to medical practitioners, both general practitioners and specialists who were currently registered with the Health Professions Council of South (HPCSA) to practise clinical medicine in the private health sector of the Mafikeng / Mmabatho geographic area of North West Province of South Africa and were personally involved in the registration of deaths.

- The study investigated experiences, practices and perceptions of medical practitioners relating to actual cases where the HIV/AIDS status of the deceased was confirmed by appropriate laboratory tests.
- The study investigated causes of deaths that, notwithstanding mere confirmation of the HIV/AIDS status of the deceased at the time of death, the

doctors registering them believed that HIV/AIDS was indeed an underlying cause of death as described by the WHO.

The study was structured in the form of cross-sectional surveys that examined a number of factors that were thought to influence practices and perceptions by medical practitioners with respect to implementation of BI-1663 for confirmed AIDS-related deaths. This was done in order to establish trends and patterns that may become subjects of more intensive studies at a later stage.

1.8 The organisation of the study.

The study was divided into the following chapters:

- Chapter 1: Orientation.
- Chapter 2: Literature Review and Theoretical Paradigms.
- Chapter 3: Methodology and Research Design.
- Chapter 4: Results and Analysis.
- Chapter 5: Discussions, Conclusions and Recommendations.

CHAPTER 2

LITERATURE REVIEW AND THEORETICAL PARADIGMS

2.1 LITERATURE REVIEW.

2.1.1 Introduction.

Annan (2004) states that the Acquired Immunodeficiency Syndrome (AIDS) epidemic is one of the greatest challenges facing our generation. The author further states that AIDS is a new type of global emergency and unprecedented threat to human development that requires sustained action and commitment over the long term. The epidemic's dynamics need to be explored in human development terms, focusing analysis and policy recommendations on people rather than the virus (Annan, ibid).

2.1.2 Trends in the global HIV infection.

It is estimated that in 2003, approximately 4.8 million people became newly infected with Human Immunodeficiency Virus (HIV), more than in any one year before, according to a report by the Joint United Nations Programme on HIV/AIDS / World Health Organisation (UNAIDS/WHO) (2004). The report further states that, having killed 2.9 million in 2003 and over 20 million since the first cases of AIDS were identified in 1981, as at the time of publication 37.8 million people were living with the HIV. The epidemic leaves virtually no country in the world unaffected and it erases decades of health, economic and social progress (UNAIDS/WHO, ibid). It reduces life expectancy by decades, slows economic growth and deepens poverty, as well as contributes to and exacerbates chronic food shortages in the hardest hit countries (ibid).

2.1.3 HIV infection trends in Sub-Saharan Africa.

Sub-Saharan Africa has just over 10% of the world's population, but there are close to two-thirds of the people living with HIV (approximately 25 million), and an estimated 3 million people in the region becoming newly infected in 2003 alone, while 2.2 million died of AIDS (UNAIDS/WHO, 2004). The disturbing aspect about the pattern of spread of HIV/AIDS in Sub-Saharan Africa is that many African countries experience generalised epidemics, the report further states. This means that HIV spreads throughout the general population, rather than being confined to populations at higher risk, such as sex workers and their clients, men who have sex with men and injecting drug users, as in other regions of the world (ibid).

Although massive challenges exist in determining the exact prevalence levels of the disease and all figures are based on available data, an accurate picture of the epidemic is nonetheless vital for directing national responses (ibid). Dorrington *et al*. (2004) states that while uncertainty about the estimates are inevitable, this does not mean that they can be ignored because planning in all sectors must take the impact of HIV/AID into account.

2.1.4 Impact of HIV/AIDS on societies.

All sectors of society will be negatively impacted by the HIV/AIDS epidemic according to information gathered from the press release of the Population Division of the Department of Economic and Social Affairs of the United Nations (UN) that took place in New York on September 6, 2004 (UNAIDS/WHO, 2004). The following are some of the key impacts reflected in the report:

- HIV/AIDS has a devastating demographic impact, having already killed over 20 million people. Between 1980 when the epidemic started emerging and 2025, HIV/AIDS will cause about 100 million excess deaths, out of 500 million total deaths in Sub-Saharan Africa.
- The burdens of HIV/AIDS on families and households are staggering. During the long period of illness, the loss of income and the cost of caring for family members may impoverish the household. Adult deaths, especially of parents, often cause the break-up of households, with children being sent to live with relatives or even becoming homeless.
- HIV/AIDS threatens the viability of health-care systems. Treating AIDS and related opportunistic infections is placing heavy burdens on the health systems of developing countries.
- HIV/AIDS affects business enterprises as well. Ill workers are less productive, as are those workers who must care for ill family members. The costs of replacing experienced workers and paying health and death benefits is becoming a serious financial drain on businesses.

- HIV/AIDS weakens the economy and has begun to stall economic development. Where HIV prevalence is high, experienced workers are lost, and funds for investment may be diverted to pay for health care and support of afflicted families. Lower investment in human capital and the health and education of the next generation will undermine prospects for development for many years to come (ibid: 39).

The course of the HIV/AIDS epidemic is by no means pre-determined, instead the eventual course of the disease depends on how individuals, communities, nations and the world respond to the HIV/AIDS threat currently and in the future, the report further states.

2.1.5 National responses to the HIV/AIDS epidemic to date.

Until the 2000's the response to AIDS lacked an essential element: political recognition and commitment at the highest global and national levels (UNAIDS/WHO, 2001). Given the societal root causes, the breadth of impact of HIV and the continuing stigma it attracts, a purely medical or public health response is insufficient, the report further states. Political leadership at the highest levels is needed to mobilize an effective multi-sectoral response (ibid).

The Health Systems Trust (HST) (2005) states that in the second half of 2004, the number of people on antiretroviral (ARV) therapy in developing and transitional countries increased dramatically from 440 000 to an estimated 700 000. The report further states that this figure represents about 12% of the approximately 5.8 million people currently needing treatment in developing and transitional countries. This also includes people receiving ARV therapy supported by the Global Fund to Fight AIDS, Tuberculosis and Malaria, the United States Presidents Emergency Plan for AIDS Relief, the World Bank and other partners (HST, ibid). In sub-Saharan Africa, the number of people on treatment doubled from 150 000 to 310 000 in just six months, with the number of people receiving treatment in Botswana, Kenya, South Africa, Uganda and Zambia increasing by more than 10 000 in each country (ibid). Notwithstanding these developments, overall national responses to the HIV/AIDS epidemic were found to be insufficient according to the report published during the press release of the Population Division of the Department of Economic and Social Development of the UN that took place in New York on May 26, 2005 (UN, 2005). Amongst other deficiencies, the report cites continuing risky behaviour by people despite governments' comprehensive HIV/AIDS prevention strategies, poor quality of condoms as well as supply shortages, poor access to life-saving antiretroviral treatment in many countries and insufficient number of countries that have adopted legal measures to prohibit AIDS-related discrimination and stigma.

2.1.6 HIV infection trends in South Africa.

Dorrignton *et al.* (2001) state that the situation with respect to the exact size of the epidemic in South Africa is, not unlike in the rest of the world, uncertain. The authors further state that while reliable data on the epidemic in South Africa is hard to come by with the main source of information being the series of annual antenatal sero-prevalence surveys conducted by the DoH, these nonetheless show that the country has experienced a rapid spread of HIV during the last decade. The rise is marked by the prevalence of the disease at less than 1% in 1990 during the first year of surveys that rose to nearly 25% by 2000 (Dorrington *et al.*, ibid).

Uncertainty about the exact size of the epidemic in South Africa can be further appreciated when one considers the wide margins between different estimates that are published by different bodies in South Africa about the number of people thought infected by HIV as at the end of 2004. Dorrington *et al.* (ibid: 20) published the following figures:

- Statistics South Africa (SSA): 3,8 million.
- Actuarial Society of South (ASSA): 5.0 million.
- The Joint United Nations Programme on HIV/AIDS (UNAIDS): 5,6 million.
- Human Sciences Research Council (HSRC): 4,6 million.
- Department of Health (DoH): 5,6 million.

2.1.7 The response of the South African government to the epidemic.

Given estimates that differ very widely with respect to the size of HIV/AIDS in South Africa, it is perhaps not surprising that debates surrounding the country's approach to the epidemic have been marred by disagreements and controversies often conducted in the public arena. The National Aids Treatment and Advocacy Project (Natap) (2005) cites the reports made by Alexandra Zavist whereby he stated that President Thabo Mbeki's government has been criticised for its sluggish response to the crisis. The Centre for Disease Control (CDC) (2005) also states that the South African President has previously questioned the association of HIV infection and AIDS. The report further states that National Minister of Health is said to have made numerous controversial statements relating to HIV/AIDS medical treatment.

Presenting the other side of the debate, the United States Agency for International Development (USAID) (2003) argues that in contrast to misconceptions regarding the political will to address the HIV/AIDS epidemic, the South African Government has committed significant financial and institutional resources to combat the epidemic. The report further argues that the South African approach has come to be accepted in many respects as the best in the world. Meanwhile, the Aids Foundation of South Africa (2005) states that the South African government's response to the epidemic is grounded in the HIV/AIDS and Sexually Transmitted Diseases (STD) Strategic Plan for the period 2000 – 2005, the purpose of which is to provide a broad national framework around four priority areas. These priority areas include prevention, treatment, care and support, research, monitoring and evaluation as well as human and legal rights, the report explains further.

2.1.8 The role of reliable mortality statistics in public policy planning, implementation and monitoring.

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 (SSA, 2005). Baker *et al.* (1999: 118) state: "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". 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, the authors further state. Lehohla (2005) argues that despite the importance of reliable mortality statistics in policy formulation, planning, implementation and monitoring, the systematic collection of data on mortality in South Africa is a recent phenomenon.

2.1.9 Reform of South Africa's death notification system.

In its efforts to strengthen the collection of reliable mortality data for the South African population, the DoH initiated collaborative efforts with the main stakeholders, namely, the DoHA and SSA (DoH, 2001). The Department embarked on the Joint Vital Registration Infrastructure Initiative in 1995, the report further states. At the provincial level, Provincial Steering Committees comprising representatives from Health, Home Affairs, the SSA, Forensics and Welfare spearheaded process (ibid). Additional stakeholders such as representatives from Local Government, Traditional Leaders, Undertakers, and the Private Sector participated actively, the report asserts.

The process described in the preceding paragraph culminated with the DoH promulgating the new death notification form (BI-1663) in the Government Gazette No: 19006, Registration Number: 6216, Volume 397, Notice Number 897 on 3rd July 1998 (DoH, 2001). The death notification form (BI- 12) changed from a single page form to a two- page form (BI-1663), the report further stated. Having implemented the new death notification form (BI-1663), the DoH stated:

> The use of incomplete mortality data to describe the health status has been unavoidable in the past. It is crucial that this inadequacy is addressed to obtain an accurate picture of health 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 (ibid: 2).

The first page was designed for the purpose of reflecting information required for registering the death, while the second page was used for demographic and health data of the deceased (DoH, 2001). The form was specifically designed to become confidential, thus enabling the health data obtained in this manner to be used to establish the health status of the nation and the burden of diseases, with group fields created for disease trend analysis, the report further stated. The form was implemented in September 1998 and manuals on how to complete the new death notification form produced and distributed (ibid). The DoH, the DoHA and SSA participated in the training of provincial personnel prior to implementation and the distribution of copies of the new forms to general practitioners, the report further stated.

The *Training manual for the death notification form (BI – 1663)* published by the DoH states that the processes that need to be followed when completing the new death notification form are:

1. Completion of the notification/Register of Death/Stillbirth Form as soon as possible by the members of the institution where the death/stillbirth occurred in order to obtain a burial order. A burial order will only be issued once the form is completed and no corpse can be buried without this order.
2. After completion, page 2 of the form should be folded and sealed in an envelope to ensure confidentiality and attached to page 1.

3. The document should thereafter be handed to the informant or person in charge of the funeral for purposes of arranging for a burial order and registration of the death.
4. The Regional Home Affairs office will check that the correct information is recorded on both pages of the form and, if necessary, fill in any missing particulars before issuing a burial order.
5. After registration of the death and microfilming of the form by Home Affairs, the form will be forwarded to the National Health authorities who will then collate the data, perform analyses and produce reports on deaths and stillbirths occurring in the country. These reports will be made available to the public.
6. It is the responsibility of the health professional to maintain confidentiality.
7. It is the responsibility of the next of kin/informant to ensure that a death is registered with the Regional Department of Home Affairs (DoH, 1999: 3).

The directives above need to be evaluated against the guidelines that were published by the South African Medical Association (SAMA) (2002: 25) advising medical practitioners on the correct manner of completing the new death notification form (BI-1663) which state:

> New regulations on death certificates have been passed in 1998.
> The new death certificate has two pages, which are detachable.
> The first page is used so that the burial can be authorised by Home Affairs. On this page the cause of death can only be indicated as "natural" or "unnatural". This is the page the family sees. Please detach this page from the second one before handing it to the undertaker and/or family. The second page is confidential and is

> used by the state (Home Affairs) to collect data. On this the medical cause of death, which may include reference to HIV status must be indicated. The second page is sent to (or in many cases collected from the hospital by) the Department of Home Affairs. This page may not be given to the undertaker, the family or any insurer or other interested party.

Comparison of the two documents indicates conflicting procedural differences on how page 2 of the BI-1663 that contains the deceased's confidential medical information should be submitted to the DoHA. These differences leave the exercise of this vital step of the death notification process open to confusion on the part of medical practitioners. This confusion present a very serious legal and ethical dilemma for medical practitioners particularly when one considers prescriptions under point 6 and 7 of the *Training manual for the death notification form (BI – 1663)* published by the DoH.

Notwithstanding the contradictory guidelines with respect to completion of the new death notification form (BI-1663), subsequent evaluation of restructuring of the death notification form exercise revealed 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 when compared with projections from the Actuarial Society of South Africa (ASSA) 600 model (Dorrington *et al.*, 2001).

2.1.10 South African AIDS mortality statistics.

The suitability of the current death notification form (BI-1663) in gathering reliable data was put to the test when SSA was given the task to analyse the information collected through the DoHA on causes of deaths for the period 1997 until 2003 (SSA, 2005). The researcher was prompted in particular by the findings of a report released by SSA that documented empirical information of incompletely filled death notification forms. He was convinced that the problems of non-reporting or misreporting of AIDS-related deaths by medical practitioners required a scientific study, focussing specifically on the problems around the implementation of the death notification form (BI-1663).

The SSA report revealed that the annual number of registered deaths had risen by a massive 57% between 1997 and 2002, with the figure among those aged 25-49 years standing at 116% (Avert.org, 2005). While part of the overall increase was due to population growth and more complete reporting of deaths, that did not however explain the substantial rise in the proportion of deaths occurring among persons aged 25 to 49 years, the report stated. The report further stated that it was important to also note that shortly before the SSA report was released, the Medical Research Council of South Africa (MRCSA) had published an article which claimed that the majority of deaths due to HIV were misclassified, as a result of doctors not recording HIV as the underlying cause of death. This happened for a number of reasons including the following the fact that medical practitioners did not know the HIV status of the deceased, or in those instances where they knew the status, because of their desire to conceal the deceased's HIV infection in order to spare stigmatisation of relatives or to avoid invalidating insurance claims the report further stated (ibid).

The MRCSA had analysed a 12% sample of death certificate data from 2000-2001 and compared them to all the data from 1996, the report stated. When they looked at deaths for which HIV was a reported cause, the rates (deaths per thousand) had increased according to distinctive age-specific patterns with greatest increases in the age groups 0-4 and 25-49 years, the report further stated. Death rates among teenagers and older people remained more or less unchanged (ibid).

The report stated that the researchers observed that nine other causes of death had increased substantially according to the same distinct age pattern as HIV. They then estimated how much of the increases were likely to be caused by HIV, concluding that 61% of deaths related to HIV had been wrongly attributed to other causes in 2000-2001, the report further stated. In adults, tuberculosis accounted for 43% of misclassified deaths, lower respiratory accounting for another 32%, whereas among infants, most of the excess deaths had been classified as lower respiratory diseases or diarrhoeal diseases (ibid).

Following analysis of the death notification forms submitted for the period between 1997 and 2002, Lehohla (2005: 2) also corroborated observations discussed in the preceding paragraph when he stated that some of the factors that were thought to limit the accuracy and completeness of data obtained from the death notification forms included:

- Content errors and omissions that data from the death notification forms were subjected to.
- The causes of deaths may have been misreported on the forms when an incorrect cause of death was given or when the underlying cause was not detailed.

The author further stated that in spite of the fact that the report did not focus specifically on HIV/AIDS *per se*, and while no adjustments were made for misclassification of underlying causes of deaths, the findings nevertheless provided indirect evidence that HIV may be contributing to the increase in the level of mortality for prime-aged adults. This conclusion was based on the increasing number of deaths due to associated diseases (Lehohla, ibid)

The theme of the social stigma related to AIDS as an important factor behind medical practitioners' certification of AIDS related deaths was highlighted by Avert.org, (2005). According to the report, *The Lancet* stated that the South African Government's reluctance to bring the crisis into the open tacitly perpetuated the social stigma associated with HIV/AIDS and prevented many from speaking about the causes of illness and deaths of loved ones. This reluctance led doctors to record controversial diagnoses on death certificates the report further said. In many societies people living HIV / AIDS were often seen as shameful (Avert.org, ibid). This is because the disease is associated with certain behaviours such as homosexuality, perversion or a result of personal irresponsibility that brings shame upon the family and community, the report further states (ibid).

The reports concerning misclassifying of AIDS-related deaths need to be read against the Health Systems Trust (HST) (2005) report which highlighted medical practitioners' concerns with the death notification form (BI-1663). The report states that doctors felt that that the new death requirements compromised patient confidentiality. It further states that doctors said while AIDS was not a notifiable disease, they were asked to say whether a person died of the disease or not. This requirement made them vulnerable to being charged by the Health Professions Council of South Africa (HPCSA) (HST, ibid)

Controversies around the extent of the country's AIDS mortality is perhaps aptly demonstrated by the wide margins of estimates of the number of people thought to have died due to AIDS by the middle of 2004 that are advanced by various stakeholders as published by Dorrington *et al.* (2004: 21):

- SSA: 1,5 million.
- ASSA: 1,2 million.
- UNAIDS: 2,3 million.
- HSRC: 2,1 million.

2.1.11 Patient Confidentiality After Death.

Confidentiality is one of the most articulated ethical obligations to patients, but it is also one subject to most breaches on behalf of the state, according to a report by Physicians for Human Rights (2005). This, the report states, is paradoxical since the duty to keep patient information confidential is usually asserted in absolute terms. The

Declaration of Geneva and the International Code of Medical Ethics states that the duty of patient confidentiality exists unequivocally and lists no exceptions, the report further states. Despite this, the duty of confidentiality for health professionals is replete with exceptions designed to serve a range of accepted social purpose, including prevention and control of epidemics, protection of third parties, especially from harm, the evaluation of claims of social benefits, as well as the collection of statistical data about population health (Physicians for Human Rights, ibid). The Medical and Dental Professions Board (MDBP) of the Health Professions Council of South Africa (HPCSA) (2002: 12) lays down the following guidelines for health care professionals in South Africa in respect of maintaining confidentiality of the deceased's medical information:

> You still have an obligation to keep personal information confidential after a patient dies... There are a number of circumstances in which you may be asked to disclose, or wish to use information about patients who have died-
>
> a. To assist in connection with an inquest or fatal accident inquiry. In these circumstances you should provide relevant information;
> b. As part of any clinical audit or for education or research. The publication of properly anonymised case studies would be unlikely to be improper in these contexts;
> c. On death certificates, the law requires you to complete death certificates honestly and fully;
> d. To obtain information relating to public health surveillance. Anonymised information should be used, unless identifiable data is essential to the study.

The disclosure of confidential patient information after death to the state is a legal duty imposed upon health care practitioners via the Births and Deaths Registrations Act No 51 of 1992. However, the administrative nature of the current death notification system is such that there seems to be confusion among medical practitioners on 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.

The anomaly stated in the preceding discussion obtains against the background of the fact that the HPCSA, a body that regulates professional conduct by medical practitioners, holds patient confidentiality in very high regard, unjustified breaches of which carry disciplinary sanctions. According to Dhai *et al.* (2001: 126), the HPCSA sanctions include (1) caution or a reprimand, or caution and reprimand, (2) a suspension from practice, and (3) a removal from the role of practitioner. The authors state that unjustified breaches of the rule of medical confidentiality by a doctor could also result in civil action before ordinary courts for damages. They further state that civil liability may include breach of the doctor patient contract as well as defamation (invasion of the patient privacy). 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.

2.1.12 Conclusion.

In conclusion, it is not to be totally unexpected that when evaluating the risks of possible breaches of the deceased's confidential information to unintended third parties against the risks of non-disclosure of statistical information to public health authorities, medical practitioners may find the option of non-disclosure more attractive. While arguably, this risk exists for disclosures of other confidential information during notification of deaths, the situation with HIV /AIDS has potentially far reaching negative consequences for both the health care professional as well as for the emotional and financial well-being of the relatives. These factors make the condition particularly appropriate for highlighting the serious weaknesses that are inherent in implementation of the current death notification form (BI-1663) based on current official policy. It is important to correct these apparent weaknesses in order to enable the Public Health System to collect reliable AIDS mortality statistics necessary for public planning across all sectors of society.

2.2 THEORETICAL PARADIGMS

2.2.1 Introduction.

The problem of low rates of reporting of AIDS-related deaths by medical practitioners to Public Health Authorities is a subject matter of the discipline of Epidemiology. Katzenellenbogen *et al.* (1997: 5) define Epidemiology as: "The study of the distribution and determinants of health related conditions and events in populations, and the application of this study to the control of health problems". The authors further state that Epidemiology forms the research arm of the public health system which provides the scientific basis for making public health policies. The main reasons behind the introduction of the new death notification form (BI-1663) in Septembers1998, was to enable the South African public health system to gather accurate and reliable cause-specific mortality data, necessary for public policy formulation, implementation and review.

2.2.2 Scientific theories underlying Epidemiology.

Weed (2001) states that there are two types of theories that are relevant to the practice of Epidemiology, namely, scientific theories and ethical theories. The author further states that scientific theories explain why disease occurs and how it manifest itself in cells, tissues, individual organisms and in diverse social groups that inhabit the globe. Causal theories are central to these theories (Weed, ibid).

On the other hand, ethical theories guide epidemiological practitioners in making good, justified decisions about when and under what conditions public health interventions should be undertaken, the author asserts.

2.2.2.1 Theories of Ethics.

The World Health Organisation (WHO) (2005:1) states “From its outset, the AIDS epidemic has raised many ethical challenges for public health officials, clinicians and the general public, reaching from macro-level policy to micro-level clinical decisions”. Meanwhile, Beaglehole *et al.* (1993: 30) state: “The practice of Epidemiology requires adherence to the basic principles of bio-medical ethics and carries special obligations to the individuals and communities, not only those participating in the studies but also others whose health may be protected or improved by application of the results”. Katzenellenbogen *et al.* (1997: 27) identify and describe the two most important ethical theories that are relevant for epidemiological studies as follows:

2.2.2.1.1 *Utilitarian theory*, whereby the most important underlying value for judging whether an action is ethically right or wrong is the amount of ‘good’ it produces, the approach prioritising the greatest benefit to the greatest number of people as the main criterion for judging the action.

2.2.2.1.2 *Deontological theory* that holds that actions are to be judged on the basis of certain values irrespective of the consequences for the general good they produce.

Despite differences between proponents of the two theories, the authors argue that there is agreement on the moral value of particular actions. According to the authors agreement is reached via ethical reviews, court judgements, popular debates and in other ways, the end result of which is the distilling of three main ethical principles against which almost any proposals of medical and health research can be reviewed based on the following principles:

1. The principle of respect for persons which is the main principle underlying the process of obtaining informed consent for medical procedures or research. It has two components, namely:
    - The principle of autonomy, which refers to the notion that competent persons have the right to self-determination. It means that other people including health and medical practitioners have an obligation to provide information that allows individuals to make autonomous decisions.
    - The principle of maximization of autonomy and protection of incompetent people. The principle includes people with intellectual disabilities (permanent incompetence) or persons under the influence of alcohol or medication for surgery (temporal incompetence) and persons with reduced autonomy (such as children, prisoners and refugees)
2. The principle of beneficence which has two components, namely:
    - The principle of non-malevolence, i.e., the obligation not to do harm.

    - The principle of beneficence, i.e., the obligation to prevent harm, to remove harm and to do good.

3. The principle of justice, the general notion that people receive what is due to them, and therefore includes:

    - The right of persons to demand certain things, such as researchers.
    - The duty of other persons to provide these (Katzenellenbogen *et al.*, ibid: 27 – 31).

Insight into of the concept 'ethics' would be incomplete without an understanding of a related concept 'professionalism'. *The Charter on Medical Professionalism* (*The Charter*), a document that was authored by leaders from the American Board of Internal Medicine Foundation, American College of Physicians – American Society of Internal Medicine Foundation and the European Federation of Internal Medicine (Annals of Internal Medicine, 2002: 2) defines 'Professionalism' as: "The basis of medicine's contract with society that demands placing the interest of patients above those of the physician, setting and maintaining standards of competence and integrity, and providing expert advice to society on matters of health". The report further states that *The Charter* notes that the medical profession everywhere is confronted by many challenges that increasingly make it difficult for physicians to meet their responsibilities to patients and society. Despite these, certain themes emerge that form the basis of *The Charter* in the form of the following three fundamental principles and a set of definitive professional responsibilities:

- *The principle of primacy of the patient* (based on dedication to serving the interests of the patient),
- *The principle of patient autonomy* (physicians must be honest with their patients and empower them to make informed decisions about their treatment) and,
- *The principle of social justice* (physicians must promote justice in the health care system) (ibid: 2-3).

Quinn and Smith (1987: 3) state: "Although the term 'profession' is sometimes used in purely descriptive way, a careful analysis of the nature of a profession will show that the idea of a profession carries with it some important ethical implication". Meanwhile, the World Medical Association (WMA) (2003) states that there is an overlap between ethics and professionalism. The report states that anyone who is interested in medical ethics needs to be aware of developments in medical professionalism. The rationale behind assertions made by these statements can be appreciated when one considers the fact that among one of the professional responsibilities that *The Charter* holds in high regard is the commitment to patient confidentiality (Annals of Internal Medicine, 2002). In asserting this responsibility, *The Charter* states: "Earning the trust and confidence of patients requires that appropriate confidentiality safeguards be applied to disclosures of patient information," (ibid: 2). It is precisely these safeguards which, given the administrative nature of the current death notification system, appear to be particularly lacking to the extent that they might be compelling medical practitioners to withhold the confirmed HIV status of the deceased.

It follows from the discussion on bioethics and medical professionalism that when notifying deaths, medical practitioners are often confronted with challenges caused by conflicting legal and ethical responsibilities. Lack of reporting of deceased's HIV/AIDS information by medical practitioners in death notification forms seems to be driven by these conflicting responsibilities that interacts in an unbalanced manner based on perceptions of inadequate safeguards against unauthorised breaches of the deceased's confidential medical information by non-state parties. This results in the ethical responsibilities of medical practitioners to their patients superseding their legal responsibilities to the state to the detriment of the gathering of reliable AIDS mortality statistics.

2.2.2.2 Theories of Disease Causation.

Mulhall (1996) makes a distinction between two conceptual frameworks historically associated with epidemiology, namely *positivism* and *naturalism/interpretism.* The author cites emergence of the third conceptual frame-work called *critical theory* and makes a call for a new approach that incorporates aspects of all three as follows:

1. *Positivism*, is a philosophy based upon positive facts and observable phenomenon which makes specific claims about reality that are objective, empirical and generalisable and from which hypotheses are generated, while;
2. *Naturalism/interpretism*, opines that the social world cannot be broken into a series of objects that can be validly and accurately measured and that things should be studied as they are since they have different meanings to different people, i.e., meaning does not have a fixed entity but may change depending on context (time and place).

3. The third view, namely, the *critical theory*, moves beyond notions of objectivity and measurability encompassed in positivism, and the naturalistic school of thought, where understanding is based on an interpretation of social interactions, to the belief developed through Hegelian philosophy that knowledge evolves through the human ability to act rationally to achieve greater knowledge and emancipation.
4. The fourth view: A new paradigm of disease causation should be developed that will among others:

- Acknowledge the social production of disease, re-examine ideas surrounding classifications of diseases based upon technical biological criteria only to include social origins of diseases.
- Reconsider the unit of analysis that are based on reductionist approaches but to include political and economical factors in disease causation.
- Consider the taxonomic collectives with which epidemiologists use not possessing any functional reality, i.e., the groups under study not being an accurate reflection of the true state of affairs.
- Reconsider the almost total reliance on quantitative methods which although often consist of large samples the data produced is often superficial and highly categorised as opposed to qualitative methods which may study only a few cases but study them in depth (Mulhall, ibid: 147 – 149).

While this study was not primarily concerned with the debates around disease causation of HIV/AIDS, the topic under consideration nonetheless made it imperative that diseases causation should be explored, albeit in brief. The sections of this discussion that appeared to be somewhat relevant for the topic under consideration were found in the calls for a fourth paradigm of disease causation theories that seeks to redefine the methods that are used to measure diseases to become more inclusive. In particular the call to acknowledge external factors that impact upon disease causation found resonance with how the HIV/AIDS manifest and spreads. Such inclusive an approaches help to explain some of the difficulties that are encountered during notification AIDS-related deaths. It is therefore not totally inconceivable that epidemiological information associated with the condition might be influenced by external factors as political and economical influences.

2.2.2.3 Other theories thought to be relevant to Epidemiology.

According to Weed (2001), there are other theories that while not being core to the practice of Epidemiology nonetheless matter to the discipline. These include theories of health, theories of acquisition and discovery of knowledge, theories of society and social processes, theories of medicine, behavioural theories, theories of religion, law, economic and politics, theories of history, theories of physics, chemistry and other physical sciences as well as theories of chaos and complexity (Weed, ibid). Given the constraints imposed by the scope of this research and the stated extent of their relevance to Epidemiology, these theories are not discussed.

2.3 Summary of Literature Review and Theoretical Paradigms.

The discussion on literature review outlined the complex problems caused by HIV/AIDS across all sectors of societies. The centrality of accurate death certificates in the gathering of reliable AIDS mortality statistics necessary for public policy was discussed. The discussion highlighted reporting patterns of HIV/AIDS deaths by medical practitioners that were unsatisfactory for epidemiological and public policy purposes. Various anecdotal reports identified different factors centred on the implementation of the death notification form (BI-1663) which were thought to contribute to this problem.

The discussion on theoretical paradigms highlighted Theories of Ethics and Theories of Disease Causation as the most important theories that are relevant to Epidemiology. Under Theories of Ethics, various principles that define Ethics Theories were discussed. The requirement to always act ethically and professionally towards their patients and third parties by medical practitioners was also discussed. The ethical and legal dilemmas faced by medical practitioners during notifications of deaths with respect HIV/AIDS were identified. Meanwhile, the discussion on Theories of Disease Causation explained the three conceptual frameworks that have historically defined these theories. A call for a fourth paradigm was also discussed. External influences that often impact on definition of diseases were also noted.

The discussion in the following chapter focuses on the research methods that were employed in order to enable the study to arrive at its findings.

CHAPTER 3

METHODOLOGY, RESEARCH DESIGN, DATA COLLECTING TOOLS AND TECHNIQUES

3.1 Introduction.

This study investigated experiences and perceptions of medical practitioners personally involved in the administrative processes of registration of deaths. It focussed on the use of the current death notification form (BI-1663) by private medical practitioners in the Mafikeng / Mmabatho geographic areas of the North West Province of South Africa. The main objectives of the study was the collection of empirical evidence of non-reporting and or misreporting in BI-1663 of underlying causes of deaths in cases of Acquired Immune Deficiency Syndrome (AIDS)-related deaths by medical practitioners and the reasons behind such practices.

3.2 The research methodology.

Bless and Higson-Smith (2000) state that a research project stands or falls on the quality of the facts on which it is based. The authors further state that good results depend on an excellent research design, a representative sample, and analysis of correct data collected using appropriate and accurate data measuring instruments. They also state that every research project requires a research design that is carefully tailored to the exact needs of the problem in order to enable the researcher to logically exclude all reasonable explanations other than the one he or she wishes to demonstrate.

The methodology used in the collection of data for this study was qualitative research methodology of the descriptive type. Qualifying words or descriptions were used to describe the phenomenon under consideration based on perceptions and experiences of participants. Bless and Higson-Smith (ibid) assert that unlike numbers that are used in quantitative research, language as used in qualitative research provides a far more sensitive and meaningful way of recording human experience.

3.3 The research design.

3.3.1 The unit of analysis and research focus.

The unit of analysis from whom research data were obtained was individual private medical practitioners practising in the Mafikeng / Mmabatho geographic area of the North West Province of South Africa. The primary focus of the study was their actions with respect to disclosure of the deceased's underlying Human Immune-deficiency Virus (HIV) status in BI-1663 during notification of confirmed AIDS related deaths.

A secondary focus was placed on the attitudes and beliefs of medical practitioners as underlying reasons behind their choice of actions. 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 and loyalty to the deceased in their scope of practice.

3.3.2 Research time dimension.

The nature of the problem under investigation made it imperative that the phenomenon would be adequately understood if the period over which all the data was collected was at the same time. Cross-sectional surveys were therefore chosen as the most appropriate design for the study. In this regard Bless and Higson-Smith (2000: 66) state: "The immediate nature of cross-sectional designs as well as the relative ease of data collection makes these designs the most common choice for social scientists".

3.3.3 The target population.

All private 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. These included general and specialist medical practitioners, resident and visiting doctors practising in the private health sector. An all-inclusive list containing the names of such medical practitioners was obtained from Victoria Private Hospital.

3.3.4 The sample design.

The sample design used in the study was purposive sampling of the 'expert' subtype. All fully registered medical practitioners within the target population formed part of the sample. All of them were incorporated in the sample because their total number within the identified geographic area was relatively small. Consequently all of them had an equal chance of being involved in the registration of AIDS-related deaths.

Medical interns doing locum work were specifically excluded from the sample because, in terms of the country's laws governing medial training, they carry out most of their duties under direct supervision of their seniors. It was therefore considered possible that their professed actions may not necessarily be true reflections of their own desires and intentions but those of their seniors under whom they practised.

3.4 Data collection.

3.4.1 Data collection tools.

A self-administered questionnaire was used to survey medical practitioners' actions with respect to disclosure of confirmed HIV status information of deceased individuals in the current death notification forms. The questionnaire was also used to survey the reasons behind the doctors' actions and to explore possible solutions to the problems identified with implementation of BI-1663 in cases of confirmed AIDS related deaths.

3.4.2 Data collection procedures.

The researcher delivered copies of the questionnaire to all medical practitioners by hand mail, explained the purpose of the study and assured the participants that their participation in the study was completely voluntary and anonymous. 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.

3.4.3 Ethical considerations with respect to data collection.

While copies of the questionnaire were distributed to all medical practitioners in the Mafikeng / Mmabatho area, their right to refuse to participate in the study was stated upfront. Anonymity of their participation was outlined as described in the preceding discussion both verbally and by way of a covering letter accompanying each questionnaire.

3.5 Data analysis.

The data obtained from completed copies of the questionnaire were computed into frequency distribution tables to indicate the number of responses as well as percentage scores per each categorical variable contained in the questionnaires. Pie charts also were used to illustrate the demographic profile of participants. Microsoft Excel, version Microsoft Office 2000 Professional was used to summarise the data into tables and graphs. Text was used to describe the patterns that emerge from the data presented in frequency distribution tables and graphs.

CHAPTER 4

RESULTS AND ANALYSIS

4.1 Introduction.

This chapter presents the results of cross-sectional surveys of the experiences and perceptions of private medical practitioners in Mafikeng when notifying confirmed Human Immunodeficiency Virus (HIV) / Acquired Immunodeficiency Syndrome (AIDS)-related deaths using the current death notification form (BI-1663) conducted during the month of November 2005.

Copies of the self-administered questionnaire were sent to forty (40) private 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 82,50%. Two questionnaires were incorrectly completed and therefore excluded from the study. The final analysis was based on responses of thirty-one (31) participants.

The demographic profile of participants is presented first in frequency tables and pie charts. This is followed by the presentation of the participants' responses in the form of scores to the various questions contained in the questionnaire in frequency tables. These scores constitute empirical accounts of Mafikeng / Mmabatho private medical practitioners' personal experiences and opinions about the implementation of the current death notification form (BI-1663) with respect to notification of confirmed AIDS related deaths.

4.2 The demographic profile of participants.

Table 4.2.1: Frequency distribution of participants by occupational category.

(Pr = Practitioner)

Occupational Category	**General Pr**	**Specialist Pr**	**Total**
Frequency	22	9	31

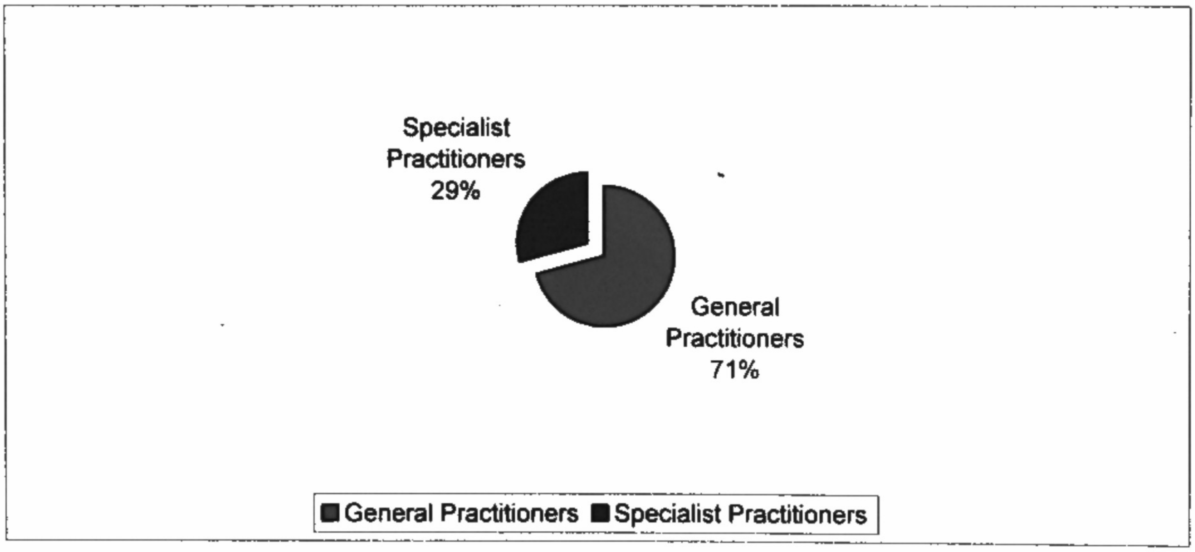


Figure 4.2.1: Percentage distribution of participants by occupational category.

According to the information presented in Table 4.2.1, the majority of the participants were general practitioners. They constituted 71% of the sample size as illustrated in Figure 4.2.1. This finding was to be expected given the fact that general practitioners outnumber specialist practitioners within the geographic area under consideration.

Table 4.2.2: Frequency distribution of participants by gender.

Gender	Male	Female
Frequency	26	5

According to data presented in Table 4.2.2, the majority of the participants were male (26/31), a situation that was also not unexpected given the gender inequalities that are still prevalent within the medical profession in South Africa.

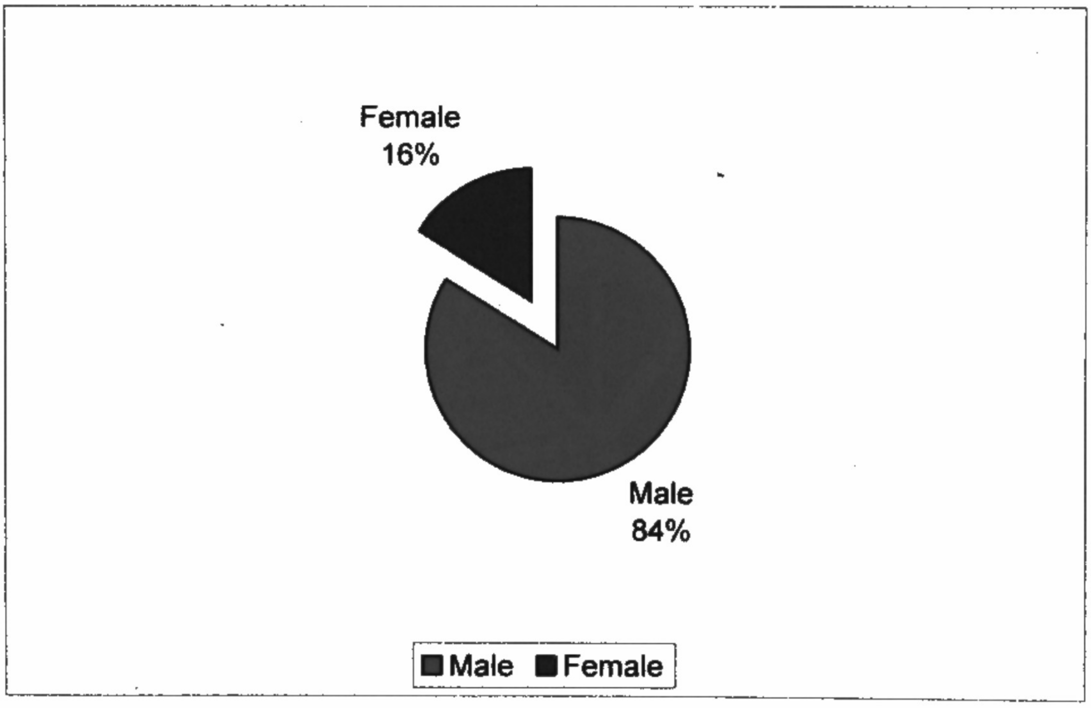


Figure 4.2.2: Percentage distribution of participants by gender.

The gender distribution of participants presented in the preceding discussion is illustrated by way of a pie chart in Figure 4.2.2.

Table 4.2.3: Frequency distribution of participants by age.

Age	26– 30yrs	36 – 40yrs	41 – 45yrs	46 – 50yrs	> 50 yrs	Total
Frequency	3	11	8	5	4	31

The data presented in Table 4.2.3 reveal that the majority of the participants were in the age brackets 36 – 40 years (11/31) and 46 –50 years (8/31) respectively. Only 3 participants were in the age bracket (26 –30 years) and the remainder were distributed almost equally between the other age brackets, five (5/31) in the 46 –50 years and four (4/31) in the >50 years age brackets respectively.

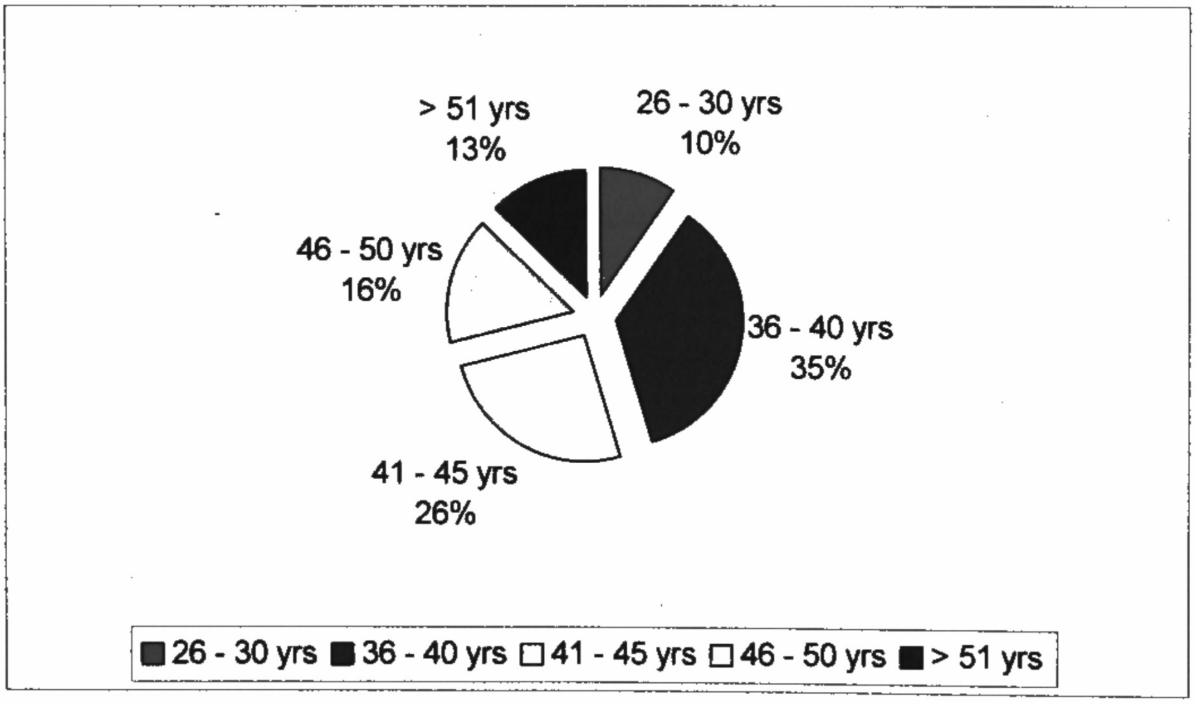


Figure 4.2.3: Percentage distribution of participants by age.

The age profile of the participants, represented by way of a pie chart in Figure 4.2.3, was found to be consistent with the age distribution of medical practitioners within the geographic area under study.

4.3 The participants' responses to questions in the questionnaire.

Table 4.3.1: 'Formal training' received with respect to correct procedures to be followed when implementing current death notification forms (BI-1663).

	Attended workshop / seminar/ conference	Read training manual on own	Did not receive any formal training	Other	Total
General Pr	0	4	18	0	22
Specialist Pr	1	1	7	0	9
Totals	1 3,23%	5 16,13%	25 80,65%	0 0%	31 100%

According to results presented in Table 4.3.1, 80,65% (25/31) of the participants responded that they did not receive any type of 'formal' training on correct procedures to be followed during death notification processes using the current death notification forms (BI-1663). 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 a training.

Only one participants (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.

Table 4.3.2: Frequency of notifications of confirmed HIV/AIDS related deaths during ordinary scope of practice.

	Very often	Often	Sometimes	Never	Total
General Pr	11	7	4	0	22
Specialist Pr	2	2	5	0	9
Total	13 41,94%	9 29.03%	9 29,03%	0 0%	31 100%

According to the information presented in Table 4.3.2, 41,94% (13/31) 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 4.3.3: Practices with respect to 'not completing' (omitting) confirmed underlying HIV/AIDS information in death notification forms (BI-1663).

	Almost always	Occasionally	Never	Total
General Pr	8	8	6	22
Specialist Pr	3	3	3	9
Total	11 35,48%	11 35,48%	9 29,03%	31 100%

The data presented in Table 4.3.3 show that the number of participants who stated that they 'never' left information about underlying cause of death as required in the death notification forms (BI-1663) when notifying confirmed AIDS related deaths is 29,03% (9/31), while those that stated that they left it out 'almost always' constitute 35,48% (11/31). The rest, 35,48% (11/31) stated that they left it out 'occasionally'.

These results show that up to 70,07% of the participants omitted information that HIV/AIDS was an underlying cause of death when completing the current death notification forms (BI-1663) during notification of confirmed AIDS related deaths, with only 29,03% stating that they 'never' leave out such information.

Table 4.3.4: Practices with respect to 'disclosure' of confirmed underlying HIV/AIDS information in death notification forms (BI-1663).

	Almost always	Occasionally	Never	Total
General Pr	1	4	17	22
Specialist Pr	2	3	4	9
Total	3 9,68%	7 22,58%	21 67,74%	31 100%

According to the data presented in Table 4.3.4, 67,74% (21/31) of the participants responded that they 'never disclosed' information that HIV/AIDS was an underlying cause of death in death notification forms (BI-1663) when notifying confirmed AIDS related deaths, while only 9,68% (3/31) responded that they disclosed 'almost always' and the rest, 22,58% (7/31) responded that they disclosed 'occasionally'.

Table 4.3.5: Practices with respect to completing 'another' underlying cause of death (misreporting) in death notification forms (BI-1663) despite underlying HIV/AIDS information being confirmed

	Almost always	Occasionally	Never	Total
General Pr	7	6	9	22
Specialist Pr	4	1	4	9
Total	11 35,48%	7 22,58%	13 41,94%	31 100%

The data presented in Table 4.3.5, reveal 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.

Table 4.3.6: Perceived influence of the need to protect the deceased's insurance benefits on decision to withhold information confirmed underlying HIV/AIDS information in BI-1663 Forms.

	Almost always	Occasionally	Never	Total
General Pr	15	4	3	22
Specialist Pr	3	3	3	9
Total	18 58,06%	7 22,58%	6 19,35%	31 100%

According to the data presented in Table 4.3.6, 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. Fifty-eight percent (18/31) of the participants responded that this need influenced them 'almost always', and the rest, 22,58%, (7/31) responded that this need influenced them 'occasionally'.

Table 4.3.7: Perceived influence of the need to protect the deceased's funeral benefits influence on decision withhold confirmed underlying HIV/AIDS information in death notification forms (BI-1663).

	Almost always	Occasionally	Never	Total
General Pr	12	8	2	22
Specialist Pr	3	2	4	9
Total	15 48,39%	10 32,26%	6 19,35%	31 100%

The data presented in Table 4.3.7 show that 48,39% (15/31) of the participants responded that the need to protect the deceased's funeral benefits 'almost always' influenced them to withhold information in death notification forms (BI-1663) that HIV/AIDS was an underlying cause of death when notifying confirmed AIDS related deaths, while 32,26% (10/31) of participants responded that they were influenced 'occasionally' and only 19,35% (6/31) responded that they were 'never' influenced by this need.

Table 4.3.8: Perceived influence of the need to protect the deceased's confidential medical information from the next of kin on decision to withhold confirmed underlying HIV/AIDS information in death notification forms (BI-1663).

	Almost always	Occasionally	Never	Total
General Pr	10	9	3	22
Specialist Pr	2	5	2	9
Total	12 38,71%	14 45,16%	5 16,13%	31 100%

The data presented in Table 4.3.8, reveal that 16,13% (5/31) of the participants responded that the need to protect the deceased's confidential medical information from the next of kin 'never' influenced them to withhold confirmed underlying HIV/AIDS information in the BI-1663, 38,71% (12/31) responded that they were 'almost always' influenced by this need and the rest, 45,16% (14/31) 'occasionally'.

Table 4.3.9: Perceived influence of the need to protect deceased's confidential medical information from the state (Public Health Officials) on decision to withhold information confirmed underlying HIV/AIDS information in BI-1663 Forms.

	Almost always	Occasionally	Never	Total
General Pr	3	9	10	22
Specialist Pr	2	1	6	9
Total	5 16,13%	10 32,26%	16 51,61%	31 100%

The information presented in Table 4.3.9, show that 16,13% (5/31) of the participants responded that the need to protect the deceased's confidential medical information from the state (Public Health Officials) 'almost always' influenced them to withhold information that HIV was an underlying cause of death in BI-1663, compared to 51,61% (16/31) that responded that they were 'never' influenced. The rest of the participants responded that they were 'occasionally' influenced.

Table 4.3.10: Practices with respect to 'sealing' part 2 of the death notification form (BI-1663) that contains the deceased's confidential medical information prior to handing it to the informant.

	Almost always	**Occasionally**	**Never**	**Other**	**Total**
General Pr	5	8	9	0	22
Specialist Pr	0	2	5	2	9
Total	5 16,13%	10 32,26%	14 45,16%	2 6,45%	31 100%

The data presented in Table 4.3.10 show that 16,13% (5/31) of the participants responded that they 'sealed' Part 2 of the death notification form (BI-1663) that contains the deceased confidential medical information prior to handing it to the person notifying death (informant) 'almost always' compared to 45,16% (14/31) of participants who responded that they 'never' sealed the form and 32,26% (10/31) who responded that they sealed it 'occasionally'.

Table 4.3.11: Opinions about the extent to which 'unauthorised' access by 'non-state' parties to the deceased's confidential medical information is effectively eliminated by 'sealing' Part 2 of BI-1663 prior to handing it to the informant.

	Strongly agree	Agree	Strongly disagree	Disagree	Indifferent	Total
General Pr	2	5	5	7	3	22
Specialist Pr	0	3	0	4	2	9
Total	2 6,45%	8 25,81%	5 16,13%	11 35,48%	5 16,13%	31 100%

The data presented in table 4.3.11 reveal that 35,48% (11/31) of the participants responded that they disagreed that 'unauthorised' access by 'non-state' third parties to the deceased's confidential medical information was effectively eliminated by sealing Part 2 of the BI-1663 that contains the deceased's confidential medical information prior to handing it to the informant and a further 16,13% (5/31) that responded that they 'disagreed strongly'. While 16,13% (5/31) of participants responded that they were 'indifferent' to this practice, only a minority of participants at 6,45% (2/31) responded that they ''strongly agreed' and another at 25,81% (8/31) responded that they 'agreed'.

Table 4.3.12: Opinions about the extent to which the use of a 'direct method' that did not make use of a third party (informant) to 'transfer' confidential medical information could encourage medical practitioners to disclose more readily to the state the deceased's confirmed underlying HIV/AIDS information.

[illegible]	Strongly agree	Agree	Strongly disagree	Disagree	Indifferent	Total
General Pr	16	4	0	0	2	22
Specialist Pr	5	3	0	1	0	9
Total	21 67,74%	7 22,58%	0 0%	1 3,23%	2 6,45%	31 100%

The data presented in Table 4.3.12 indicate that 67,74% (21/31) of the participants responded that they 'strongly agreed' that the use of a 'direct' method that did not make use of a third party (informant) to 'transfer' confidential medical information can encourage them to disclose more readily to the state the deceased's underlying HIV/AIDS information during notification of confirmed AIDS related deaths. A further 22,58% (7/31) of participants responded that they 'agreed' to the suggestion, according to the same data. While 3.23% (1/31) of participants responded that they 'disagreed' with the suggestion, none (0%) of them responded that they 'strongly disagreed'. Only 6,45% (2/31) of participants responded that they were 'indifferent' to this suggestion, however, no reasons were advanced for these responses.

4.4 Conclusion.

In conclusion, the findings presented in this chapter indicated highly variable patterns of accounts of participants' training with respect to implementation of the current death notification form (BI-1663). The findings also revealed highly variable accounts of practices, opinions and external influences by private medical practitioners with respect to reporting of the deceased's underlying causes of death information in the death notification forms in cases of confirmed AIDS related deaths. These findings form the basis for the discussions, conclusions and recommendations that are presented in the next and final chapter.

CHAPTER 5

DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction.

This study was undertaken because of the perceived problem of low rates of reporting of confirmed Human Immune-deficiency Virus (HIV) / Acquired Immune-deficiency Syndrome (AIDS)-related deaths by medical practitioners that leads to unreliable AIDS mortality statistics in South Africa. The problem continues to confront the authorities exist despite recent efforts by the Department of Health (DoH) to strength the country's death registration systems through amongst others the introduction of a new death notification form (BI-1663). This chapter presents the discussion of the findings of the analysis of the results of surveys of experiences and perceptions of Mafikeng private medical practitioners with respect to implementation of BI-1663 for the registration of confirmed AIDS-related deaths. The discussion is guided by the findings from literature review and theoretical paradigms that provided a contextual framework for the study. Conclusions and recommendations emanating from this discussion are presented next, followed by a presentation of limitations of the study last.

5.2 Discussion.

The HIVAIDS epidemic is one of the greatest challenges facing our generation (Annan, 2004). The epidemic presents an unprecedented threat to human development that requires sustained action and commitment over the long term (ibid).

While the exact size of the epidemic in South Africa is unknown, estimates published by various stakeholders suggest that the numbers of people infected with the HIV and those dying from AIDS continue to rise (Dorrington *et al*., 2001). According to Statistics South Africa (SSA) (2005), the level of mortality is one of the indicators of the level of human development hence its inclusion in the construction of human development indices.

The introduction of a new death notification form (BI-1663) by the DoH in 1998 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 was collected using the new death notification forms for the period between 1997 and 2003, revealed many instances of content omissions and misreporting of underlying causes of death were individuals had died form conditions associated with AIDS (Lehohla, 2005).

While various explanations could be advanced for the apparent failure of the new death notification form (BI-1663) to generate accurate AIDS mortality statistics, the explanations advanced in this study are centred around four main themes, namely:

- Inadequate formal training received by medical practitioners with respect to death certification prior to implementation of BI-1663 is a contributing factor behind low rates of reporting of confirmed AIDS related deaths.
- Social discrimination and invalidation of insurance and funeral policies of people who die due to AIDS-related conditions influence medical

practitioners to withhold the deceased's confirmed HIV/AIDS information in death notification forms (BI-1663).

- Medical practitioners deliberately omit and misreport the deceased's confirmed underlying HIV/AIDS information in BI-1663 during notification of AIDS-related deaths.
- The current protection measures recommended by the DoH against unauthorised access to the deceased's confidential medical information contained in part 2 of BI-1663 by non-state parties are inadequate.

These themes form the basis upon which recommendations on how the implementation of the death notification form (BI-1663) can be modified in a manner that enables the country's public health system to collect valid and reliable cause-specific mortality data generally and AIDS-related mortality data in particular.

5.2.1 Formal training received by medical practitioners with respect to death certification prior to the implementation of the death notification form (BI-1663).

When asked to indicate the type of formal training they had received with respect to correct procedures to be followed when they completed the new death notification form (BI-1663), up to 80,65% (25/31) of the medical practitioners surveyed responded that they had not received any formal training and only one medical practitioner (3,23%), a specialist, responded that he had attended formal training conducted in a form of workshop / seminar / conference according to results presented in Table 4.3.1. Five participants (16,13%), according to the information presented in the same Table, responded that they had read the training manual on their own.

Contrary to assertions made by the DoH that prior to the implementation of the current death notification form various stake-holders were actively involved, the private sector included, (DoH, 2001), 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. The seriousness of this finding can perhaps be succinctly illustrated by referring to comments made by one medical practitioner (3,23%) surveyed, who responded to the question as follows: "The forms were just dumped on us", while another (3,23%) said: "I was not even aware of the existence of such training".

The findings referred to in the preceding discussion seem to corroborate Erlich's (2005: 198) 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** (my 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.

5.2.2 Social discrimination and invalidation of insurance and funeral policies of people associated with the disease influence medical practitioners to withhold the deceased's confirmed HIV/AIDS information in the death notification forms (BI-1663).

Dorrington *et al.* (2001) states that the majority of deaths due to HIV are misclassified because doctors did not record HIV as the underlying cause of death. Some of the reasons advanced are 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, the author further states. This was done in order to spare stigmatisation of relatives, or to avoid invalidating insurance claims (Dorrington *et al.,* ibid). The purpose of this study was to interrogate veracity of the latter reports where the medical practitioners concerned knew the deceased's underlying HIV/AIDS status.

Only six participants (19,35%) indicated the need to protect the deceased's insurance benefits and funeral benefits influenced 'never' influenced them to withhold the deceased's confirmed underlying HIV/AIDS information when completing BI-1663 according to the data presented in Table 4.3.6 and Table 4.3.7 respectively. Similar patterns emerge with respect to the perceived need to protect the deceased's confidential medical information from the next of kin. According to the information presented in Table 4.3.8, only five participants (16,13%) indicated that this need 'never' influenced them. These findings seem to corroborate themes centred on fears of social discrimination and invalidation of insurance and funeral policies of the deceased as some of the contributing factors behind non-reporting or misreporting of confirmed AIDS related deaths by medical practitioners as advanced by Dorrington *et al.* (2001).

The high number or participants who responded that the perceived need to protect the deceased's HIV/AIDS information form Public Health Authorities influenced them was unexpected because such practices go against the very intentions of the official death registration system that is legislated in terms of the Births and Deaths Registrations Act. According to the data presented in Table 4.3.9, only sixteen participants (51,61%) responded that they were 'never' influenced by this need. While the questionnaire did not specifically request participants to state the reasons behind their responses to this question, some of the reasons may well have to do with inadequate training received by medical practitioners generally with respect to death certification. It is not inconceivable that some of the reasons behind these practices may be related to the negative media coverage that the South African government's response to HIV/AIDS has experienced. *The Lancet* (Avert.org, 2005) states that the stigma associated with HIV/AIDS was tacitly perpetuated by the government's reluctance to bring the crisis into the open. The report further states that the government's stance on HIV/AIDS prevented many people from speaking about the causes of illness and deaths of loved ones. This also led to doctors to record controversial diagnoses on death certificates (Avert.org, ibid). While thought provoking, these comments were not specifically tested in this survey.

Notwithstanding failure to advance precise reasons behind perceived the 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 by them. Dhai *et al.* (2001: 126) states:

> The Births and Deaths Registrations Act provides that any person who fails to furnish information required by the Act or who makes a false statement…shall be guilty of an offence, and on conviction, liable to a fine or to imprisonment for a period not exceeding 5 years, or to both.

Katzenellenbogen *et al.* (1997: 27) state that ethical reasoning takes place whenever there is a moral justification for a particular action. Notwithstanding the existence of these ethical imperatives which medical practitioners could, if charged with non-compliance of the legal prescripts of death certification, argue the moral justification of their non-compliance, the extent to which they were aware and prepared to face the possible legal consequences of those decisions, including specifically possible imprisonment of up to five years, was not specifically tested.

It is worth noting the fact though, that by highlighting the rationale behind the legal prescripts of the Births and Deaths Registrations Act to the medical practitioners, it is possible to influence their ethical reasoning in a manner that favours the interest of the broader society more than those of individual patients and thereby facilitate disclosure of the deceased's underlying HIV information in line with Utilitarian Theories of Ethics. Such outcomes are possible through, amongst others, undertaking of formal training of medical practitioners in death certification.

5.2.3 Medical practitioners deliberately omit or misreport the deceased's confirmed underlying HIV/AIDS information in death notification forms.

According to the findings of the study presented in Table 4.3.4, 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. Logically, non-disclosures of the deceased's HIV/AIDS information in the death notification forms can only be expressed in the form of either omissions or misreporting. When all medical practitioners were asked to indicate the extent to which they 'left out' the section that required them to complete information that HIV/AIDS was an underlying cause of death in cases of confirmed AIDS related deaths, their responses were almost evenly divided between those who said they 'almost always' reported, 'occasionally' reported and 'never' reported according to data presented in Table 4.3.3. The reporting patterns with respect to misreporting were similar according to the data presented in Table 4.3.5.

The findings presented in the preceding discussion corroborate anecdotal reports of content omissions and or misreporting of underlying causes of deaths and suggests 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.

Beaglehole *et al*. (1993: 30) state: "The practice of epidemiology requires adherence to the basic principles of bio-medical ethics and carries special obligations to the individuals and communities whose health may be protected or improved by application of the results. The World Health Organisation (WHO) (2005) states that from its outset, HIV/AIDS raises many ethical challenges for public health officials, clinicians and the general public. It follows therefore that in deciding whether to disclose or not to disclose the deceased's HIV status in the death notification form during registration of confirmed AIDS-related deaths, medical practitioners make moral choices informed by certain ethical values. Katzellebogen *et al*. (1997: 27 - 31) state that irrespective of which ethical values influence their actions, there is however agreement that the principle of respect for persons, the principle of beneficence and the principle of justice are the three principles against which the actions of medically related researchers should be judged.

5.2.4 Current protection measures against unauthorised access of the deceased's confidential medical information contained in Part 2 of the death notification form (BI 1663) by non-state parties are inadequate.

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. 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 (DoH, 2001). 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 informant to ensure that the death is registered at the DoHA (ibid)

According to the data presented in Table 4.3.10, only a minority (16,13%) of the medical practitioners surveyed responded that they sealed the form 'almost always', while a majority (45,16%) of them responded that they 'never' sealed the form. Ten participants (32,26%) responded that they sealed the form 'occasionally' while the remainder (6,45%) responded 'other', stating that they handed the completed form to the nurse assistant who in turn gave it to the informant. Whether such practitioners handed the completed Part 2 of the death notification form to the nurse assistant in a sealed or unsealed form was not explained further.

It is vital to highlight nonetheless, that given the high number of medical practitioners surveyed who responded that they did not disclose the deceased's confirmed HIV/AIDS information in the death notification forms as was discussed in section 5.1.3 of this document, it was not entirely surprising to discover that only a minority of medical practitioners reported that they sealed the form 'almost always'. Similarly, the majority of the participants disagreed that unauthorised access of the deceased's confidential medical information by non-state third parties was effectively eliminated by sealing Part 2 of the death notification prior to handing it over to the informant, according to the data presented in Table 4.3.11.

Lastly, the participants were asked to indicate the extent to which they thought the use of a 'direct method' that did not make use of a third party (informant) to transfer the deceased's confidential medical information to the state could encourage them to readily disclose the deceased's confirmed underlying HIV/AIDS information in death notification forms. This question was intended to gauge support for an alternative method of implementing the death notification form. Twenty-one medical practitioners (67,74%) responded that they 'strongly agreed' with the proposed remedy, and a further seven (22,58%) responded that they 'agreed', according to the data presented in Table 4.3.12. Only one participant (3,23%) responded that he 'disagreed' with the proposed remedy. This participant argued that the only viable long-term solution to the problem of stigmatisation associated with the disease, as well as fears of civil and criminal prosecutions of medical practitioners for unauthorised disclosures of deceased's HIV/AIDS information would be to make the condition a notifiable disease. While two participants (6,45%) responded that they were indifferent to the suggestion, no participant responded that he or she disagreed, according to the same data (Table 4.3.12).

5.3 Conclusion.

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 Organisation, medical practitioners find 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 a conditions that is 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.

5.4 The recommendations.

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

- The DoH should facilitate more intensive formal training of medical practitioners with respect to death certification in order to enable them 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.

5.5 The study limitations.

5.5.1 Measuring reports of behaviours / practices.

Since this study investigated experiences and perceptions of medical practitioners as reported by them, it has to be remembered that responses to the questionnaires assess reports of behaviour and not the behaviour itself. Katzenellenbogen *et al.* (1997: 197) states: "Reports of behaviour are subject to a number of influences that can potentially distort them". These influences include the following:

- **Social desirability.**

People may be reluctant to divulge information about themselves which portrays them in bad light and may say they engage in behaviour which are socially desirable, even when it is not the case. This tendency may also be observed in the reporting of attitudes and beliefs and may be stronger if the interviewer fails to convince the respondent that strict confidentiality may not be maintained (Katzenellenbogen *et al.*, ibid). While each questionnaire was accompanied by a letter stating that confidentiality of the participants' responses would be guaranteed by way of the use of a messenger who would collect all questionnaires and submit them for analysis without reference to their names, this limitation needs to be borne in mind.

- **Recall**

People may forget details of their behaviours, particularly those of minimal psychological significance to them. Some questions may require attention to detail which respondents have neither the ability nor motivation to recall (ibid). It was in pursuit of gauging the extent to which the problem of recall would constitute a significant limiting factor for this study that the medical practitioners surveyed were asked to indicate the frequency at which they were involved with notification of confirmed AIDS-related deaths within their ordinary scope of practice. In terms of the findings of this survey presented in Table 4.3.2, thirty-one participants (41,94%) responded that they were 'very often' involved with this function within their day to day scope of practice, nine (29,03%) responded 'often' and the remainder, nine (29,03%) responded that they were involved 'occasionally'.

5.5.2 Geographic location.

It is possible that since this study was confined to private medical practitioners that practiced their profession within the geographic area of Mafikeng, their experiences and perceptions about implementation of the death notification form with respect to notification of confirmed AIDS-related deaths could well differ with those of medical practitioners throughout other geographic regions of the country. It is therefore suggested that similar investigations should be undertaken in other geographic locations of South Africa in order to interrogate the findings presented in this study.

BIBLIOGRAPHY

1. Annals of Internal Medicine. 2002.

   http://www.annals.org/cgi/reprint/136/3/243.pdf

   (Accessed 2005)

2. Annan, K. 2004. 2004 Global Report on HIV/AIDS http://www.unaids.org/

   (Accessed 2005).

3. Aids Foundation of South Africa. 2005. http://www.aids.org.za/hiv.htm

   (Accessed 2005)

4. Alert.org. 2005. http://www.alert.org (Accessed 2005)

5. Avert.org. 2005. http://www.avert.gorg (Accessed 2005)

6. Baker, D., Kjellstrom, T., Calderon, R. & Pastides, H. 1999. Environmental Epidemiology, A Textbook on Study Methods and Public Health Applications. Geneva: World Health Organisation.

7. Beaglehole, R., Bonnita, R., & Kjellstrom, T. 1993. Basic Epidemiology. Geneva: World Health Organisation.

8. Bless, C. & Higson-Smith, C. 2000. Fundamentals of Social Research Methods. Lansdowne: Juta Publishers.

9. Bradshaw, D., Nana, N., Groenewald, P., Joubert, J., Laubsher, R., Nojilana, B., Norman, R., Pieterse, D. & Schneider, M. 2005. ***Provincial mortality in South Africa, 2000 – priority-setting for now and a benchmark for the future.*** South African Medical Journal 95: 496 – 503

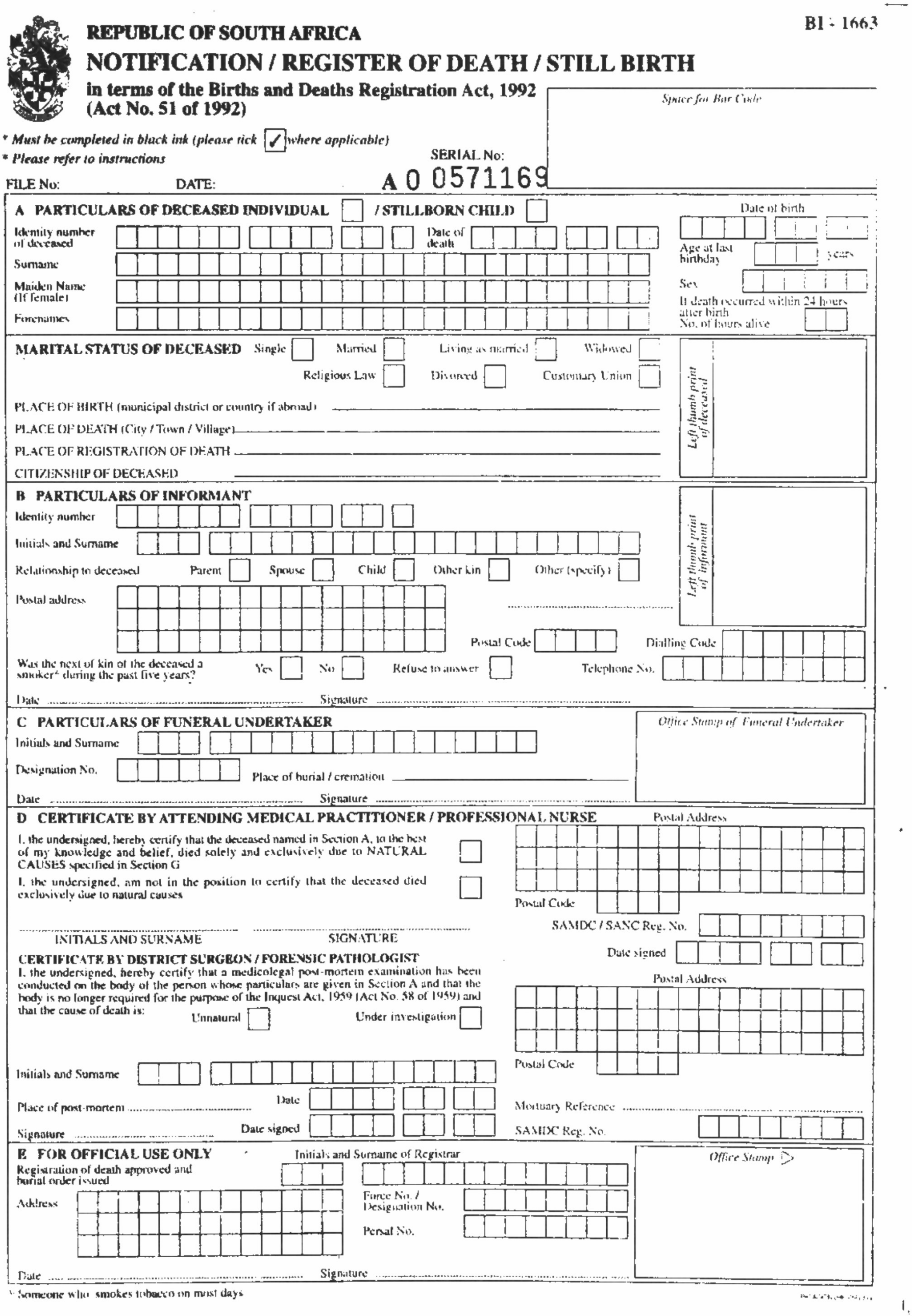
10. Centres for Disease Control and Prevention. 2005. http://www.cdc.gov/

    (Accessed 2005)

11. Dhai, A., Dada, M. A., Kirk, G. M. & McQuid-Mason, D. J. 2001. ***Confidentiality – A dying wish?*** South African Medical Journal 91: 123- 126
12. Department of Health. 1999, 2001. http://www.doh.gov.za/search/index.html (Accessed 2005)
13. Dorrington, R., Bourne, D., Bradshaw, D., Laubsher, R. & Timaeus, I. M. 2001. The impact of HIV/AIDS on adult mortality in South Africa. Cape Town: Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa, website http://www.mrc.ac.za/bod (Accessed 2005)
14. Dorrington, R., Bradshaw, D., Johnson, L. & Budlender, D. 2004. The Demographic Impact of HIV/AIDS in South Africa: National Indicators for 2004. Cape Town: Centre for Actuarial Research, South African Medical Research Council and Actuarial Society of South Africa, website http://www.commerce.uct.ac.za/care/ (Accessed 2005)
15. Ehrlich, R. *Mbewu ducks AIDS deaths*. South African Medical Journal 2005; 95: 198
16. Health Professions Council of South Africa. 2002. Booklet 14 Guidelines for Good Practice in Medicine, Dentistry and Medical Sciences, Confidentiality: Protecting and Providing Information HPCSA: Pretoria
17. Health Systems Trust. 2001. http://www.hst.org.za (Accessed 2005)
18. Health Systems Trust 2005. http://www.hst.org.za (Accessed 2005)
19. Katzenellenbogen, J. M., Joubert, G. & Karim, A. S. S. 1997. Epidemiology: A Manual for South Africa. Cape Town: Oxford University Press.

20. **Lehohla, P. 2005. Mortality and Causes of Death in South Africa, 1997 – 2003, Findings from death notification form website** http://www.statssa.org.za **(Accessed 2005)**
21. Mulhall, A. 1996. Epidemiology Nursing and Healthcare. London: Macmillan Press.
22. National Aids and Treatment Advocacy Project. 2005. http://natap.org (Accessed 2005)
23. Physicians for Human Rights. 2005. www.phrusa.org/healthrights/dl_2.html#d (Accessed 2005)
24. Quinn, C. A. & Smith, M. D. 1987. The Professional Commitment: Issues and Ethics in Nursing. London: W. B. Sanders Company Press.
25. SAMA. 2005. http://www.samedical.org (Accessed 2005)
26. SSA. 2005. Website. www.statssa.org.za (Accessed 2005)
27. UN. 2005. http://www.un.org (Accessed 2005)
28. UNAIDS/WHO. 2004 Global Report on Aids. Website http://www.unaids.org/ (Accessed 2005)
29. UNAIDS/WHO. 2001 Global Report on Aids. http://www.unaids.org (Accessed 2005)
30. USAID. 2003. http://www.usaid.gov/ (Accessed 2005)
31. Weed, D. L. 2001. *Theory and Practice of Epidemiology*, Annals of the New York Academy of Sciences, 954: 52-62.
32. WHO. 2005. Ethical issues raised by the HIV/AIDS epidemic http://www.who.int/ethics/topics/hiv_aids/en/print.html (Accessed 2005)
33. World Medical Association .2003. http://www.wma.net/e/ethicsunit/professionalism.htm (Accessed 2005)

Appendix 1: Part 1 of the death notification form (BI –1663)



BI - 1663

REPUBLIC OF SOUTH AFRICA

NOTIFICATION / REGISTER OF DEATH / STILL BIRTH

in terms of the Births and Deaths Registration Act, 1992 (Act No. 51 of 1992)

Space for Bar Code

** Must be completed in black ink (please tick* ☑ *where applicable)*

** Please refer to instructions*

SERIAL No: A 0 0571169

FILE No: DATE:

A PARTICULARS OF DECEASED INDIVIDUAL ☐ **/ STILLBORN CHILD** ☐

Identity number of deceased

Date of death

Date of birth

Age at last birthday years

Surname

Sex

Maiden Name (If female)

If death occurred within 24 hours after birth No. of hours alive

Forenames

MARITAL STATUS OF DECEASED Single ☐ Married ☐ Living as married ☐ Widowed ☐ Religious Law ☐ Divorced ☐ Customary Union ☐

Left thumb print of deceased

PLACE OF BIRTH (municipal district or country if abroad) ____

PLACE OF DEATH (City / Town / Village) ____

PLACE OF REGISTRATION OF DEATH ____

CITIZENSHIP OF DECEASED ____

B PARTICULARS OF INFORMANT

Identity number

Left thumb print of informant

Initials and Surname

Relationship to deceased Parent ☐ Spouse ☐ Child ☐ Other kin ☐ Other (specify) ☐

Postal address ....

Postal Code

Dialling Code

Was the next of kin of the deceased a smoker* during the past five years? Yes ☐ No ☐ Refuse to answer ☐

Telephone No.

Date .... Signature ....

C PARTICULARS OF FUNERAL UNDERTAKER

Office Stamp of Funeral Undertaker

Initials and Surname

Designation No.

Place of burial / cremation ____

Date .... Signature ....

D CERTIFICATE BY ATTENDING MEDICAL PRACTITIONER / PROFESSIONAL NURSE

Postal Address

I, the undersigned, hereby certify that the deceased named in Section A, to the best of my knowledge and belief, died solely and exclusively due to NATURAL CAUSES specified in Section G ☐

I, the undersigned, am not in the position to certify that the deceased died exclusively due to natural causes ☐

Postal Code

SAMDC / SANC Reg. No.

....

INITIALS AND SURNAME SIGNATURE

Date signed

CERTIFICATE BY DISTRICT SURGEON / FORENSIC PATHOLOGIST

I, the undersigned, hereby certify that a medicolegal post-mortem examination has been conducted on the body of the person whose particulars are given in Section A and that the body is no longer required for the purpose of the Inquest Act, 1959 (Act No. 58 of 1959) and that the cause of death is: Unnatural ☐ Under investigation ☐

Postal Address

Postal Code

Initials and Surname

Place of post-mortem .... Date

Mortuary Reference ....

Signature .... Date signed

SAMDC Reg. No.

E FOR OFFICIAL USE ONLY

Initials and Surname of Registrar

Office Stamp

Registration of death approved and burial order issued

Address

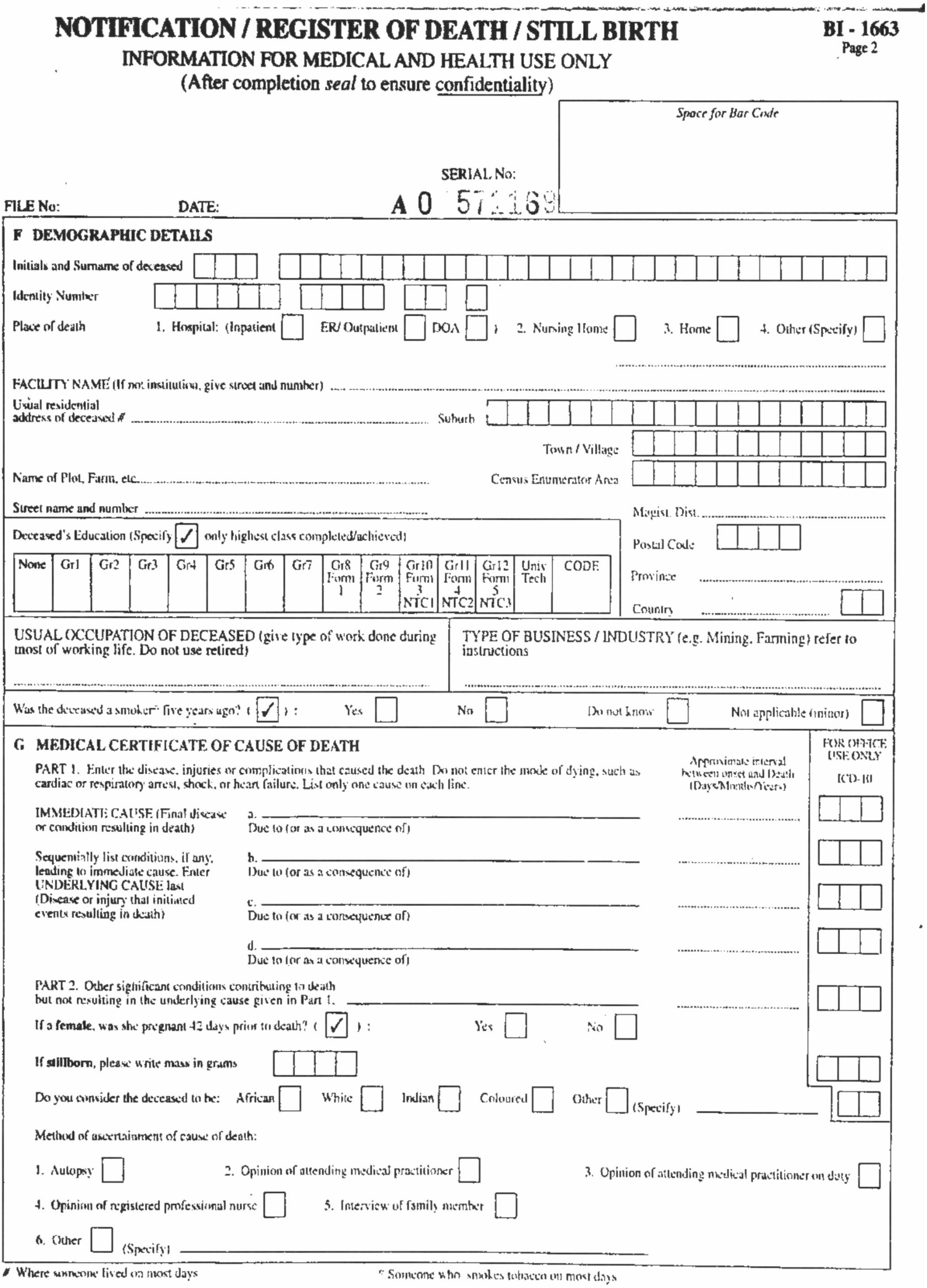
Force No. / Designation No.

Persal No.

Date .... Signature ....

* Someone who smokes tobacco on most days

Appendix 2: Part 2 of the death notification form (BI –1663)



NOTIFICATION / REGISTER OF DEATH / STILL BIRTH

BI - 1663
Page 2

INFORMATION FOR MEDICAL AND HEALTH USE ONLY
(After completion *seal* to ensure confidentiality)

Space for Bar Code

SERIAL No: A 0 57[illegible]169

FILE No: DATE:

F DEMOGRAPHIC DETAILS

Initials and Surname of deceased ☐☐☐ ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Identity Number ☐☐☐☐☐☐ ☐☐☐☐ ☐☐ ☐

Place of death 1. Hospital: (Inpatient ☐ ER/ Outpatient ☐ DOA ☐) 2. Nursing Home ☐ 3. Home ☐ 4. Other (Specify) ☐ ....

FACILITY NAME (If not institution, give street and number) ....

Usual residential address of deceased # .... Suburb ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

Town / Village ☐☐☐☐☐☐☐☐☐☐☐☐

Name of Plot, Farm, etc.. Census Enumerator Area ☐☐☐☐☐☐☐☐☐☐☐☐

Street name and number .... Magist. Dist. ....

Deceased's Education (Specify (☑) only highest class completed/achieved)

None	Gr1	Gr2	Gr3	Gr4	Gr5	Gr6	Gr7	Gr8 Form 1	Gr9 Form 2	Gr10 Form 3 NTC1	Gr11 Form 4 NTC2	Gr12 Form 5 NTC3	Univ Tech	CODE

Postal Code ☐☐☐☐

Province ....

Country .... ☐☐

USUAL OCCUPATION OF DECEASED (give type of work done during most of working life. Do not use retired)
....

TYPE OF BUSINESS / INDUSTRY (e.g. Mining, Farming) refer to instructions
....

Was the deceased a smoker* five years ago? (☑) : Yes ☐ No ☐ Do not know ☐ Not applicable (minor) ☐

G MEDICAL CERTIFICATE OF CAUSE OF DEATH

PART 1. Enter the disease, injuries or complications that caused the death. Do not enter the mode of dying, such as cardiac or respiratory arrest, shock, or heart failure. List only one cause on each line.

Approximate interval between onset and Death (Days/Months/Years)

FOR OFFICE USE ONLY
ICD-10

IMMEDIATE CAUSE (Final disease or condition resulting in death)
a. ________________________ .... ☐☐☐
Due to (or as a consequence of)

Sequentially list conditions, if any, leading to immediate cause. Enter UNDERLYING CAUSE last (Disease or injury that initiated events resulting in death)
b. ________________________ .... ☐☐☐
Due to (or as a consequence of)
c. ________________________ .... ☐☐☐
Due to (or as a consequence of)
d. ________________________ .... ☐☐☐
Due to (or as a consequence of)

PART 2. Other significant conditions contributing to death but not resulting in the underlying cause given in Part 1. ________________________ .... ☐☐☐

If a **female**, was she pregnant 42 days prior to death? (☑) : Yes ☐ No ☐

If **stillborn**, please write mass in grams ☐☐☐☐ ☐☐☐

Do you consider the deceased to be: African ☐ White ☐ Indian ☐ Coloured ☐ Other ☐ (Specify) ________________ ☐☐

Method of ascertainment of cause of death:

1. Autopsy ☐ 2. Opinion of attending medical practitioner ☐ 3. Opinion of attending medical practitioner on duty ☐

4. Opinion of registered professional nurse ☐ 5. Interview of family member ☐

6. Other ☐ (Specify) ________________________

Where someone lived on most days

* Someone who smokes tobacco on most days

Appendix 3: Covering letter to the questionnaire

Researcher: Dr L D Molosi, MB ChB (Medunsa), DOH (Pret)

Dear Respondent,

Thank you for taking time to answer the following questions. The purpose of this study, conducted in part fulfilment of MBA requirements, is to investigate the problems surrounding implementation of the current death notification form (BI-1663) with respect to official notification of confirmed AIDS related deaths. Specifically experiences and perceptions of medical practitioners with respect to disclosure of the deceased's confirmed HIV status information in the current death notification form (BI-1663) shall be investigated.

It is hoped that the results of this study shall assist policy makers to strengthen the current death notification systems in a manner that enables medical practitioners to disclose more readily the HIV information of individuals who died from confirmed AIDS related causes when completing death notification forms and thereby enable the state (Public Health Officials) to collect **valid and reliable AIDS mortality statistics** needed for public policy formulation, implementation and monitoring.

Please note that your participation in the study is voluntary and anonymous, and that the laboratory messenger will collect the questionnaire within one week of delivery.

Yours Truly

____

Dr L D Molosi

Appendix 4: Questionnaire.

Perceptions and experiences of medical practitioners of the current death notification form (BI-1663) with respect to official notification of confirmed AIDS related deaths.

SECTION 1: Profile of respondents

Mark either with X or √ where applicable.

1. Age
   a. 26 – 30 ______
   b. 31 – 35 ______
   c. 36 – 40 ______
   d. 41 – 45 ______
   e. 46 – 50 ______
   f. 51 – and above ______

2. Gender
   a. Male ______
   b. Female ______

3. Type of Practice
   a. Private health sector. _______
   b. Public health sector. _______
   c. Private – public health sectors. _______

4. Occupation / profession
   a. Medical officer (General) _______
   b. Medical officer (Specialist) _______
   c. Dentist _______

5. Education Level
   a. First degree ________
   b. Second degree or diploma ________
   c. Specialist degree ________

SECTION 2: Perceptions and experiences of medical practitioners about the current death notification form (BI 1663) when notifying confirmed AIDS related deaths.

Mark with either X or √ where applicable.

1. What form of 'formal training', if any, did you receive regarding correct procedures to be followed when completing the current death notification form (BI-1663)? (Select one answer only)
   a. I attended a workshop/seminar/conference. _________
   b. I read the official training manual on my own. _________
   c. I did not receive any formal training. _________
   d. Other. _________

   Explain briefly:____

   ____

   ____

2. How often, in your ordinary scope of practice, are you involved with notification of deaths where it was known by you or confirmed to you that HIV/AIDS was an 'underlying cause' to the immediate cause of death? (Select one answer only)

   a. Very often _____

   b. Often _____

   c. Occasionally _____

   d. Never _____

3. When notifying confirmed AIDS related deaths using the current death notification forms (BI-1663), how do you complete the section requiring medical information about the 'underlying cause of death'? (Select one answer only for each sub-question)

   a. I leave out information about 'underlying cause of death'.

   Almost always _____

   Occasionally _____

   Never _____

   b. I always disclose that HIV/AIDS was an 'underlying cause of death'

   Almost always _____

   Occasionally _____

   Never _____

   c. I state another 'underlying cause of death'.

   Almost always _____

   Occasionally _____

   Never _____

4. Do any of the following factors ever influence your decision to withhold information that HIV/AIDS was 'an underlying cause of death' in the death notification form (BI-1663), when notifying confirmed AIDS related deaths? (Select one answer only for each sub-question)

   a. The need to protect insurance benefits of the deceased?

      Almost always _______

      Occasionally _______

      Never _______

   b. The need to protect funeral benefits of the deceased?

      Almost always ______

      Occasionally ______

      Never ______

   c. The need to protect the confidentiality of the deceased's medical information from the next of kin?

      Almost always ______

      Occasionally ______

      Never ______

   d. The need to protect the confidentiality of the deceased's medical information from the state (Public Health Officials)

      Almost always ______

      Occasionally ______

      Never ______

5. **After completing the death notification form do you routinely seal part 2 of the form that contains deceased's confidential medical information before handing the form to the person notifying death (informant)?** (Select one answer only)

   a. Almost always ______

   b. Occasionally ______

   c. Never ______

   d. Other ______

   Explain briefly:____

   ____

   ____

6. By sealing the part of the death notification form (BI-1663) that contains deceased's confidential medical information prior to handing it to the informant, do you agree that 'unauthorized' access by 'non-state' third parties of the deceased's confidential medical information is effectively eliminated?

   a. I strongly agree _____

   b. I agree _____

   c. I strongly disagree _____

   d. I disagree _____

   e. Indifferent _____

   Explain briefly:____

   ____

   ____

7. If you were to report to the state the confirmed HIV/AIDS status of the deceased via a 'direct method' that does not make use of a third party (informant) to 'transfer' this confidential medical information to the death registration offices, would you feel more confident to disclose the HIV/AIDS status of the deceased in the forms? (Select one answer only)

a. I strongly agree ______

b. I agree ______

c. I strongly disagree ______

d. I disagree ______

e. Indifferent ______

Explain briefly:____

____

____