



MEDICINE AND THE LAW

Disclosing the HIV status of deceased persons – ethical and legal implications

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The ethical rules of the Health Professions Council of South Africa (HPCSA) provide that confidential information about a deceased patient should only be divulged 'with the written consent of his or her next-of-kin or the executor of his or her estate' – except where such information ought to be disclosed in terms of a statute or court order, or the disclosure is justified in the public interest. The law, however, does not protect the confidentiality of deceased persons, and generally when people die their constitutional and common law personality rights – including their right to privacy and confidentiality – die with them.^{3,4} This means that the next-of-kin or executors of the estates of deceased persons may not bring actions for damages on their behalf for breaches of confidentiality arising after their deaths.

The question to be answered is: When is it justified to disclose the HIV status of deceased persons who are found to be HIV positive or have died as a result of an AIDS-related illness? Ethically, the answers will depend upon whether there is a statutory duty to disclose or a court order requiring disclosure, the disclosure is justified in the public interest, or the disclosure is made with the written consent of the person's next-of-kin or the executor of his or her estate.¹ Legally, there is no protection for the personality rights of deceased persons – including protection against disclosures about their HIV status. In some instances, the law goes further and imposes a positive duty on medical practitioners to disclose the medical cause of a person's death.

In terms of the civil law, if a doctor were to intentionally disclose the HIV status of a deceased person – outside of a statutory or common law right to do so – there would be no action for damages in law because the person is deceased.³ In such cases, the deceased person's next-of-kin or the executor of his or her estate could file a complaint with the HPCSA, and disciplinary action could be taken against the medical

practitioner concerned for unethical conduct in terms of Rule 12,¹ but there would be no legal action for damages.

The following categories of disclosures concerning deceased persons will be considered: (i) disclosures in death certificates; (ii) disclosures as a result of a court order; (iii) disclosures in the public interest; (iv) disclosures without the written consent of the deceased's next-of-kin or the executor of his or her estate; (v) disclosures to endangered third parties; and (vi) disclosures to insurance companies.

Disclosures in death certificates

The Births and Deaths Registration Act⁵ requires medical practitioners to complete the BI 1663 'death certificate' form, which consists of two pages. The first page is for the registration of the death by the Department of Home Affairs and the issuing of a burial order. The second page contains demographic details about the deceased and the medical cause of death required for medico-legal and statistical purposes. This page must be sealed and attached to the first for transmission to the Department of Home Affairs office in the district where the deceased died.⁴

The purpose of the BI 1663 form is to improve statistics on the causes of death to allow proper monitoring and development of health policies. Such information is particularly relevant in respect of the HIV/AIDS pandemic. In practice, however, many practitioners are reluctant to indicate causes of death linked to AIDS-related illnesses because the confidentiality of the BI 1663 form is suspect. To protect confidentiality, the second page of the BI 1663 form is supposed to be sealed and attached to the first. Confidentiality, however, is an illusion because 'Home Affairs officials and funeral undertakers are required to check the serial numbers, surnames, first names and demographic information' to make sure that the information is the same on both pages.³ It has been suggested that the threat to confidentiality posed by the BI 1663 form can be overcome by amending the second page so that the information is recorded anonymously and by requiring the form to be forwarded directly to the Department of Home Affairs by the medical practitioner.⁴

Rule 12 of the HPCSA ethical rules recognises that a statute may require disclosures about a deceased person's health

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status to be made.¹ Therefore, it would not be unethical to disclose on a BI 1663 form that a person has died from an AIDS-related illness. The law imposes a positive duty on medical practitioners to provide the information required by the BI 1663 form, and those who fail to do so or who make false statements are guilty of a criminal offence and liable on conviction to a fine or imprisonment of 5 years or both.⁵ Whatever the shortcomings regarding confidentiality caused by the BI 1663 form, medical practitioners are obliged to complete it properly and to indicate the medical cause of death on the second page for statistical purposes.

Disclosures as a result of a court order

If a court orders a medical practitioner to make a disclosure about a deceased patient's HIV status and the doctor complies with the order, he or she will not be acting unethically in terms of Rule 12. Legally, failure to comply with such an order will result in a conviction for contempt of court. In deciding whether or not to order disclosure the court will weigh the possible damage to the public interest or individual members of the public against the possible damage to the patient.⁶

Disclosures in the public interest

Disclosures about a deceased person's HIV status made in the public interest would not be regarded as unethical under Rule 12. Matters in the public interest include aspects of the private lives of public figures that are relevant to their public lives, people catapulted into the public eye, and matters that 'are in the public domain such as politics, governance, administration of justice, administration of public or professional bodies, sport and the arts'.⁷ Given the high incidence of HIV infection in the country, the death of a public figure from an AIDS-related illness may be in the public interest and such disclosure will not be unethical.

Legally, even if the disclosure is not in the public interest, the next-of-kin of deceased persons or the executors of their estates may not bring a legal action against a medical practitioner who discloses the HIV status of such persons. This is because the latter's right to bring legal proceedings dies with them.³ However, the next-of-kin or executors may lodge a complaint about the ethical conduct of the practitioner concerned with the HPCSA.

Disclosures without the written consent of the deceased's next-of-kin or the executor of his or her estate

Except under the circumstances justified under Rule 12 or in terms of the law, disclosures about a deceased person's HIV status by a medical practitioner will be unethical if made without consent in writing by the next-of-kin or executor of the deceased's estate. Where such disclosure is made without

the requisite consent the next-of-kin or executor may lodge a complaint with the HPCSA.

In law, the next-of-kin or executor of deceased person may not institute legal proceedings against a doctor who breaches the confidentiality rule regarding the HIV status of the deceased after the latter's death. This is because legally the right to sue for breach of confidentiality or invasion of privacy vests in deceased persons during their lifetime and not in their next-of-kin or executors after their death.³

Disclosures to endangered third parties

There is no reference to endangered third parties in Rule 12 of the HPCSA rules on confidentiality,¹ but endangered spouses and sexual partners of HIV-positive patients are covered in Rule 10 of the HPCSA guidelines on HIV.⁸ Although Rule 10 refers to live patients, it can be argued that the same principles should apply to disclosures concerning the HIV status of deceased persons – except the requirement regarding the counselling of infected patients (in this case the deceased).

For example, if a patient known to be HIV positive dies, does the medical practitioner have an ethical duty to inform the spouse or sexual partner of the deceased about the dead person's HIV status – even though the patient did not give consent to such disclosure prior to death? The answer must be in the affirmative. Spouses or sexual partners of HIV-positive deceased persons should be encouraged to have their HIV status tested so that they can take prophylactic steps where necessary. It is also essential for them to know their status if they are likely to have future sexual relationships. Such disclosure may be regarded as being 'in the public interest' for the purposes of Rule 12.¹

It can also be argued that there is a legal duty on medical practitioners to warn the spouses or sexual partners of HIV-positive deceased persons and that failure to do so may result in legal action by the dependants of such spouses or sexual partners should they be breadwinners who have died as a result of being unaware of their HIV status.

Disclosures to insurance companies

In the past, life insurance company contracts have included exemption clauses that have absolved them from paying the beneficiaries of the insured person where the deceased has died of an AIDS-related illness. In cases where insured persons have given written consent in advance to insurance companies to have access to their medical records after their death, medical practitioners may comply with this request.^{9,10}

Where no consent has been given in advance by the deceased person regarding access to medical records, the insurance companies will have to rely on the provisions of the Promotion of Access to Information Act¹¹ or a court order to obtain the necessary information. The insurance company would have to



show that it was furthering or protecting a right,¹² because an unreasonable disclosure of personal information is prohibited.¹³ It can be argued that an insurance company is furthering or protecting a right in trying to determine whether or not a person died of an AIDS-related illness in breach of a condition in an insurance policy.

There is no legal liability on a medical practitioner who divulges confidential information about a deceased person to an insurance company in situations where the deceased has not given written consent in advance, or the next-of-kin of the deceased or executor of the estate have not consented, or the insurance company has not proceeded in terms of the Promotion of Access to Information Act or a court order. However, although the next-of-kin of the deceased or the executor of the estate may not sue the doctor for damages, such relatives or executor may lodge a complaint with the HPCSA against the medical practitioner for violating Rule 12 of the ethical rules of professional conduct.¹

Conclusion

Ethically, disclosures of the HIV status of deceased persons after their death may only be made in terms of a statute or a court order, in the public interest or with the written consent

of their next-of-kin or the executors of their estates. Legally, the right to confidentiality and privacy of dead persons dies with them, and neither their next-of-kin nor their executors may sue on behalf of their estates for breaches of confidentiality arising after their deaths. However, the next-of-kin or executors may lodge a complaint with the HPCSA if the breach of confidentiality is a violation of the professional rules of conduct.

1. Rule 12 of the Health Professions Council of South Africa. *Guidance for Good Practice in Health Professions: Confidentiality: Protecting and Providing Information Booklet 14*. Pretoria: HPCSA, 2002.
2. Section 14 of the Constitution of the Republic of South Africa Act No. 108 of 1996.
3. *Cf Spendiff v East London Despatch Ltd* 1929 EDL 113.
4. Dhai A, Dada MA, Kirk MA, McQuoid-Mason DJ. Confidentiality – a dying wish? *S Afr Med J* 2001; 91: 123-127.
5. Section 31 of the Births and Deaths Registration Act No. 51 of 1992.
6. *Cf Botha v Botha* 1972 (2) SA 559 (N).
7. McQuoid-Mason D. Disclosing the health status of public figures: Privacy versus public interest – when may doctors make disclosures? *S Afr Med J* 2007; 97: 598-600.
8. Health Professions Council of South Africa. *Guidance for Good Practice in Health Professions: Ethical Guidelines for Good Practice with Regard to HIV. Booklet 8*. Pretoria: HPCSA, 2006.
9. South African Medical Association. HIV/AIDS and Insurance. *Human Rights and Ethical Guidelines on HIV: A Manual for Medical Practitioners*. Pretoria: SAMA, 2001: 15.
10. South African Medical Association. Requests for Information. *Ethics and Human Rights Guidelines on HIV and AIDS*. Pretoria: SAMA, 2006: para 5.4.
11. Promotion of Access to Information Act No. 2 of 2000.
12. Section 32(1) of the Constitution of the Republic of South Africa Act No. 108 of 1996.
13. Sections 34 and 63 of the Promotion of Access to Information Act No. 2 of 2000.

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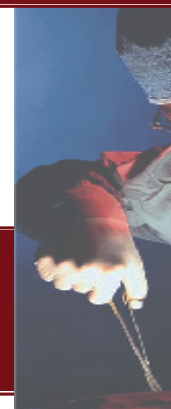
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