

MEDICINE AND THE LAW

Disclosing details about the medical treatment of a deceased public figure in a book: Who should have consented to the disclosures in *Mandela's Last Days*?

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A recently published book by the head of Nelson Mandela's medical team made personal disclosures about his treatment of the late president in his final years up until his death. The author claimed that he had written the book at the request of family members. This was contested by some family members and the executors of Mandela's estate, and the book was subsequently withdrawn by the publishers. The Mandela book case raises ethical and legal questions about who should consent to publication of medical information about public figures after their death. The ethical rules of conduct of the Health Professions Council of South Africa (HPCSA) state that confidential information about a deceased person should only be divulged 'with the written consent of his or her next of kin or the executor of his or her estate'. 'Next of kin' is not defined, however, and problems arise when family members and the executors are divided about giving such written consent. It is recommended that in such cases the specific order of priority for consent by relatives in the National Health Act be followed. However, conduct that is unethical under the rules of the HPCSA may not necessarily be actionable under the law. For instance, the law 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. This means that the next of kin or executors of the estates of deceased persons may not bring actions for damages on behalf of such persons for breaches of confidentiality arising after their deaths. The next of kin may, however, sue in their personal capacity if they can show that the disclosures were an unlawful invasion of their own privacy. Conversely, if the privacy of interests of the next of kin are not harmed where there has been publication without their consent, they will not be able to sue for damages.

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The recently published book titled *Mandela's Last Days* by the head of the late former President Mandela's medical team^[1] made personal disclosures about the medical treatment received by Mandela during the final years leading up to his death. It also mentioned how the family and Mandela's colleagues reacted to the unfolding drama surrounding his death. The author claimed that he was requested by the family to write the book.^[2] He also claimed that a family member had read the contents of the book, and that the family had approved its publication.^[3] It was reported in the press that the publication of the book was criticised by Mandela's widow Graca Machel, the executors of his estate, the Nelson Mandela Foundation and his grandson, Mandla Mandela.^[2] As a result, the book was withdrawn from bookshops by its publishers out of respect for the family.^[2] Graca Machel and the executors of Mandela's estate had threatened to take legal action and stated that they intended laying a complaint with the Health Professions Council of South Africa (HPCSA) and the author's previous employers, the South African National Defence Force. The latter had already distanced itself from the publication.^[3]

The controversy surrounding which family members consented to the publication of the Mandela book raises questions about publication of medical information about a deceased public figure. These include: (i) when is it ethical to publish such information; (ii) which family members or next of kin must consent to publication of such information; (iii) when is it legal to publish such information; (iv) whether it makes a difference if the deceased is a public figure; and (v) whether family members have

legal standing to prevent or claim damages for such publication on behalf of the deceased.

When is it ethical to publish information about a deceased patient's medical treatment?

Rule 13(2)(c) of the Ethical Rules of Conduct of the HPCSA^[4] state 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.^[5]

Where a doctor has made disclosures about a deceased person's medical treatment in breach of rule 13(2)(c), the deceased person's next of kin or the executor of his or her estate may file a complaint with the HPCSA, and disciplinary action can be taken against the medical practitioner concerned for unethical conduct.^[6] This is the route that Mandela's widow and executors were threatening to take.^[3] Problems arise, however, if some family members give written consent and others do not, and actively oppose the publication. Rule 13(2)(c), however, does not provide a definition of 'next of kin'. The dictionary (I consulted the *Oxford Advanced Learner's Dictionary of Current English*^[7]) does not take the matter much further, as it simply defines a person's 'next of kin' as his or her 'nearest relatives'. This does not answer the question of which next-of-kin relatives take precedence over the others or whether they must all agree.

Meaning of 'next of kin'

Where there is a disagreement between family members regarding the granting of written consent for the publication of a deceased patient's records, the question arises as to whose wishes should prevail as next of kin. Should it be the surviving spouse or partner, or the children of the deceased? As mentioned, there is no definition of the term 'next of kin' in the ethical rules of the HPCSA, and the dictionary definition is vague,^[7] so it is necessary to look elsewhere.

The National Health Act^[8] describes the order of persons who can give consent on behalf of incompetent live patients (section 7(1)(b)). It is submitted that this could be used as a guide for determining which next-of-kin relatives should have the right to give written consent for the publication of personal medical information on a deceased person. This is because people who are authorised to give consent to treatment may also decide who has access to information about such treatment. The Act states that a 'user' must consent to disclosures in writing (section 14(2)(a)), while the definition of 'user' in the Act includes the order of listed persons who make decisions on behalf of mentally incompetent patients (section 1). In terms of the Act, the specific order of precedence is 'a spouse or partner, a parent, a grandparent, an adult child or a brother or sister of the person' (section 7(1)(b)).

If the National Health Act^[8] list of precedence regarding relatives who can give consent to medical treatment were to be followed in the Mandela book case, his widow, Graca Machel, would be the person who would legally have the authority to grant the necessary written consent. His widow would take precedence over his adult children and his ex-wife Winnie Madikizela-Mandela. While the latter is the mother of some of Mandela's children, she would no longer be regarded as a next of kin because she is divorced from him. The other categories, apart from his children, are not relevant to a person of Mandela's age at his death. The executors, the Nelson Mandela Foundation, and Mandela's grandson Mandla Mandela, head of the Mandela clan, were all reported to support the request of Graca Machel that the book be withdrawn.^[2]

When is it legal to publish information about a deceased patient's medical treatment?

Everyone has a constitutional^[9] and common-law right to privacy^[10] concerning their health status. The right is not unlimited, however, and may be infringed where the person concerned consents, where there is a statutory duty to make disclosure (e.g. in the case of child abuse),^[11] where it is reasonable for the media to make the disclosure,^[12] where the disclosure is true and in the public interest,^[13] or where the disclosure is privileged.^[12] The defences to an action for invasion of privacy are similar to those for defamation.^[6] The defences of truth and public interest^[13] are particularly relevant to disclosures concerning the health status of public figures.

Who is a public figure?

Public figures are people who have by their personality, status or conduct exposed themselves and their families to such a degree of publicity as to justify public disclosures of certain aspects of their private lives.^[13] Such persons include politicians, actors, entertainers, sportsmen and sportswomen, war heroes, and others who are regarded as having a limited right to privacy. This is because, as they have sought or consented to publicity, their personalities and affairs have already become public knowledge. In such instances the media has a duty to inform the public about them if their private life and that of their family interfere with their ability to carry out their public or professional duties properly or if they make statements

that are false and blatantly contradict their actions in their personal life.^[13]

President Mandela was a world-famous public figure, and as such was at the centre of much publicity. However, he was entitled to have his private life respected should he wish it – unless his private life contradicted what he stood for as a statesman. The same applies to his immediate family. His and his family's wishes for privacy concerning his medical condition during his last years, after he had retired from political life, should have been respected. It is difficult to think of exceptions that would have been in the public interest and could have justified disclosures about Mandela's medical condition as it impacted on him and his family. An unlikely scenario would have been if he had died immediately before the last general election, and the family had conspired with the ruling party to give the impression that he was still alive in order to use his name to garner support. In such circumstances the disclosures about his medical treatment and the role of the family in a cover up would have been justified. However, such an event did not happen. Disclosures about public figures and their families will be lawful if they are true and in the public interest.^[13]

Truth and the public interest

Generally a disclosure about a person's health status may not be unlawful if the statement is true and in the public interest.^[13] Truth does not mean that the disclosure has to be true in all respects, provided it is substantially true in the sense that the material facts are true.^[14] Truth alone will not be a defence to a public disclosure concerning a person's health status or how it impacted on his or her family – it must be linked to public benefit or interest for the defence to succeed.^[14] While all the medical information in the Mandela book and the role of his family in his final years may be true, they therefore should not have been published unless it was also in the public interest.

Public interest refers to 'material in which the public has an interest' – not 'what the public finds interesting'.^[12] It is a difficult concept to define. In the words of one judge: 'Public interest is a mysterious concept. Like a battered piece of string charged with elasticity, impossible to measure or weigh.'^[13] Public interest may include information about the private lives of public figures and their families, but only if such information is relevant to how they or their families conduct themselves in public.^[13] For instance, if a politician were to say that all members of parliament should send their children to state rather than private schools, when he himself sends his child to a private school, it would be justifiable to expose such hypocritical behaviour. In the Mandela book case it can be argued that although his last years leading up to his death would be found interesting by the public, it is not necessarily 'material in which the public has an interest'.

Do the family have standing to sue on behalf of the deceased for invasion of privacy?

Conduct that is unethical under the rules of the HPCSA may not necessarily be actionable under the law. For instance, there is no general protection for the personality rights of deceased persons,^[15] although there is some protection in criminal law against interfering with a corpse (e.g. having sexual intercourse with a corpse).^[16] Consequently, if a doctor intentionally discloses private information about a deceased patient – 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.^[15] The next of kin or executor of a deceased person may not sue a doctor who breaches the confidentiality rule regarding medical treatment of the deceased after the latter's death.^[15]

This is because the right to sue for a 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.^[15] As mentioned above, the deceased person's next of kin or the executor of his or her estate could, however, file a complaint with the HPCSA in the Mandela case.^[3]

The next of kin may also sue in their personal capacity for disclosures about a deceased patient's last years if they can show that the disclosures were an unlawful invasion of their own privacy.^[10] An invasion of privacy occurs when a person's private life is exposed to publicity^[17] or when a person's private life is portrayed in a false light.^[18] For instance, if personal information about how certain family members reacted during the period leading up to the death of the patient is disclosed or falsely represented in a publication, the family members might have an action for invasion of privacy. An exception might be where the deceased person is a public figure and the information about the family members is true and in the public interest.^[13] The deceased person's next of kin will also not be able to sue if their privacy interests have not been harmed – even where there has been unethical publication without their consent.

Conclusion

Medical practitioners must be very careful about making disclosures about the medical condition and its impact on the family of their deceased patients – particularly where there is likely to be a dispute between family members. Practitioners should ensure that they obtain written consent from the relevant next of kin. They should attempt to get consensus about the disclosures from the family and executors. However, if they cannot achieve this, they should ensure

that the nearest relatives give consent. In order to determine who the nearest relatives are, they can be guided by the provisions of the National Health Act^[8] dealing with the order of persons who can give consent on behalf of incompetent patients (section 7(1)(c)).

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4. South Africa. Rule 13(2)(c) of the Ethical Rules of Conduct for Practitioners registered under the Health Professions Act, 1974. Government Notice R717 of 4 August 2006, as amended by Government Notice R68 of 2 February 2009.
5. Cf. *Khumalo v. Holomisa* 2002 (5) SA 401 (CC).
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9. South Africa. Section 14 of the Constitution of the Republic of South Africa, 1996.
10. *O'Keeffe v Argus Printing and Publishing Co Ltd* 1954 (3) SA 254 (C).
11. South Africa. Section 110 of the Children's Amendment Act, 2007 (Act 41 of 2007).
12. *National Media Ltd v Bogoshi* 1998 (4) SA 1196 (SCA).
13. *Tshabalala-Msimang and Medi-Clinic Ltd v Makhanya* 2008 3 BCLR 338 (W).
14. Cf. *Johnson v Rand Daily Mail* 1928 AD 190.
15. Cf. *Spendiff v East London Despatch Ltd* 1929 EDL 113.
16. South Africa. Section 14 of the Criminal Law (Sexual Offences and Related Matters) Amendment Act, 2007 (Act No. 32 of 2007).
17. *Mhlongo v Bailey* 1958 (1) SA 370 (W).
18. *Kidson v SA Associated Newspapers Ltd* 1957 (3) SA 461 (W).

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