CONFIDENTIALITY

HIV/AIDS and the Law Certificate Course
Lecture: 24 August 2010
Agnieszka Wlodarski
Outline

1. The concepts
2. The legal and policy framework
3. Discussion
1. The concepts

Privacy and Confidentiality

The scope and definition of the right to privacy

Constitution – section 14:

“Everyone has a right to privacy, which includes the right not to have –
(a) their person or home searched;
(b) their property searched;
(c) theirs possessions seized; or
(d) the privacy of their communications infringed.”
1. The concepts

+ South African Law Reform Commission:

“Privacy is a valuable and advanced aspect of personality. Sociologists and psychologists agree that a person has a fundamental need for privacy. Privacy is also at the core of our democratic values. An individual therefore has an interest in protection of his or her privacy.”

+ Bernstein v Bester, Ackerman J:

“. . . The inner sanctum of a person, such as his family life, sexual preferences and home environment.”

+ NM and Others v Smith and Others, O’Regan J:

“. . . privacy, liberty and dignity as the key constitutional rights which construct our understanding of what it means to be a human being.”
Confidentiality – is an aspect of privacy

+ As a result of a special relationship between two parties the information disclosed between them can be rendered confidential.
+ In certain instances the law recognises the confidential relationship between parties and protects the information shared between them under the right to privacy.
+ Why? The nature of the relationship between the parties is one of trust and there is an expectation of confidentiality.
+ For example the following relationships: doctor and patient relationship; attorney client; police and informant.
Difference between right to privacy and confidentiality:

+ **The right to privacy** – can be invoked directly to prevent anyone, including the State, from getting access to personal information & be held legally accountable if access is gained improperly.

+ **Confidentiality** – only binds certain individuals and in terms of the NHA has become a binding statutory principle (developed from an ethical principle).
Medical confidentiality and HIV disclosure

The Doctor/ health care professional (HCP)-patient relationship
A duty to keep secret and confidential information obtained as a result of such a relationship.

Case: *Jansen van Vuuren NO v Kruger* - on appeal

Facts:
Mr M applies for life insurance and requires various tests including an HIV test.
Consults Dr K, his general med practitioner, the HIV test result is that Mr M is HIV+. Mr M specifically asks Dr K to keep this confidential and Dr K promises to do so.
The next day Dr K discloses this on golf course to Mr M’s previous dentist and also another general practitioner whose wife is in business with Mr M and the news spreads and Mr M eventually finds out that the news has spread.
He sues both the Laboratory, after being told that the Laboratory Service was responsible for the leak (case later dropped against it) and Dr K – owed him a duty of confidentiality and that it was a term of the agreement established the doctor-patient relationship; in breach of his professional duties ‘wrongfully and unlawfully’ disclosed the results to 3rd parties.
Findings:

- Dr K did not obtain consent to disclose & said he had wanted to warn the dentist – ito “retrospective exposure”.
- Justifiable non-consensual disclosure? No. Dr K did not have duty to transfer the information nor the dentist and other GP reciprocal duty to receive this information.
- Patient has a right to expect compliance by HCP with ethical duties. Also express undertaking by Dr K.
- Therefore the communication to the other two was unreasonable and therefore unjustifiable and wrongful.
- Looked at specific merits of case – award of R5000 was made.
2. The legal and policy framework

**Legislation**
- National Health Act 61 of 2003
- Promotion of Access to Information Act 2 of 2000

Keep an eye on:
- Protection of Personal Information Bill [6 of 2010]
- Protection from Harassment Bill [1 of 2010]

**Policy**
- Health Professionals Council of South Africa – Ethical Guidelines for Good Practice with Regard to HIV (2007)
- SAMA Guidelines on HIV Disclosure
Section 14. Confidentiality

(1) All information concerning a user, including information relating to his or her health status, treatment or stay in a health establishment, is confidential.

(2) Subject to section 15, no person may disclose any information contemplated in subsection (1) unless-
   (a) the user consents to that disclosure in writing;
   (b) a court order or any law requires that disclosure; or
   (c) non-disclosure of the information represents a serious threat to public health.

Section 15. Access to health records

(1) A health worker or any health care provider that has access to the health records of a user may disclose such personal information to any other person, health care provider or health establishment as is necessary for any legitimate purpose within the ordinary course and scope of his or her duties where such access or disclosure is in the interests of the user.

(2) For the purpose of this section, “personal information” means personal information as defined in section 1 of the Promotion of Access to Information Act, 2000 (Act No. 2 of 2000).

16. Access to health records by health care provider

(1) A health care provider may examine a user’s health records for the purposes of-
   (a) treatment with the authorisation of the user; and
   (b) study, teaching or research with the authorisation of the user, head of the health establishment concerned and the relevant health research ethics committee.

(2) If the study, teaching or research contemplated in subsection (1)(b) reflects or obtains no information as to the identity of the user concerned, it is not necessary to obtain the authorisations contemplated in that subsection.
Promotion of Access to Information
Act 2 of 2000

Definitions
"personal information"
means information about an identifiable individual, including, but not limited to--

a) information relating to the race, gender, sex, pregnancy, marital status, national, ethnic or social origin, colour, sexual orientation, age, physical or mental health, well-being, disability, religion, conscience, belief, culture, language and birth of the individual;

b) information relating to the education or the medical, criminal or employment history of the individual or information relating to financial transactions in which the individual has been involved;

Relevant sections dealing with health records:

+ For public bodies: Section 30
+ For private bodies: Section 61
Clause 5. Confidentiality

- **Ethics, the South African Constitution (Act 108 of 1996) and the law** recognise the importance of maintaining the confidentiality of the HIV status of a patient.
- The test results of HIV positive patients should be treated with the **highest possible level of confidentiality**.
- **Confidentiality regarding a patient’s HIV status extends to other health care practitioners.** Other health care professionals may not be informed of a patient’s HIV status without that patient’s consent unless the disclosure is clinically indicated.
- The **decision to divulge information** relating to the HIV status of a patient must always be **done in consultation with the patient**.
- The report of HIV test results by a laboratory, as is the case with all laboratory test results, **should be considered confidential information**. A breach of confidentiality is more likely to occur in the ward, hospital or health care practitioner’s reception area than in the laboratory. It is, therefore, essential that health care institutions, pathologists and health care practitioners formulate a clear policy as to how such laboratory results will be communicated and how confidentiality of the results will be maintained.
Discussion

+ How can privacy be violated in the context of HIV?
  + Unauthorised blood tests
  + Imputation of HIV infection
  + Non-consensual HIV disclosure ** (*Jansen van Vuuren* and *NM* cases)
**Case:** NM and others v Charlene Smith, Patricia De Lille and New Africa Books (Pty) Ltd

**Facts:**

The three women had originally instituted legal action against the defendants after they had published their full names and HIV status without their consent in the biography of De Lille, written by Smith and published by New Africa Books.

The women argued that the disclosure of their names and HIV status in the book was an invasion of their rights to privacy, dignity, psychological integrity and mental and intellectual well-being. They asked the Court to grant them the following relief:

+ An order directing the defendants to issue a private apology to each plaintiff;
+ An order directing the defendants to cause the offending passages to be excised or removed from all unsold copies of the book; and
+ An order directing the defendants to pay damages of R200 000,00 to each plaintiff.
Findings in the Court a quo:

In his judgment Judge Schwartzman refers to previous case law which confirmed that the right to privacy entitles an individual to decide when and under what circumstances private facts may be made public.

He also acknowledged that “because of the ignorance and prejudices of large sections of our population, an unauthorized disclosure [of HIV status] can result in social and economic ostracism” and “can even lead to mental and physical assault.”

Nevertheless, he held that Patricia De Lille and journalist Charlene Smith could not be held liable for the disclosure of the three women’s HIV status. Instead, he said that only the publisher, New Africa Books, was liable for damages and that they should pay the plaintiffs R15 000,00 each in damages. He also ordered the publishers to delete any reference to the women’s names from all unsold copies of the book “ and gave the AIDS Law Project the right “any time after 30 June 2005 on 72 hours notice to inspect all copies of the book in the [publisher's] possession.

** A settlement offer was made in the amount of R35 000 for each of the plaintiffs as well as the deletion of the names, a private apology and the costs of the suit.
Findings in Constitutional Court:

Madala J, with whom Moseneke DCJ, Mokgoro J, Skweyiya J, Van der Westhuizen J and Yacoob J concurred, set aside the High Court decision.

Madala J held that:

- The respondents were aware that the applicants had not given their express consent but had gone ahead and published their names, violating their privacy and dignity rights.
- The use of pseudonyms instead of the applicants’ real names would not have rendered the book any less authentic and nowhere could it be shown that the public interest demanded otherwise.
- Ms Smith and Ms de Lille were liable for damages together with the publishers due to their infringement of the applicants’ rights to privacy and dignity from the moment of the publication of the book.
- He awarded R35 000 in damages to be paid by the three respondents to each of the applicants.
In a dissenting judgment, O’Regan J held that the right to privacy protects citizens from the publication of private medical information without consent and that this right had to be balanced with the right to freedom of expression. On the facts of the case, the publication of the applicants’ names and HIV status was neither intentional nor negligent. Ms Smith assumed that consent was generally given because the applicants’ names and HIV status were published in the Strauss Report, a reputable publication, with no disclaimer regarding their consent to the contrary. The respondents did not entertain the possibility that either the University or Professor Strauss would have sent a report to Ms de Lille, a Member of Parliament, in circumstances where the applicants’ consent was limited and was not noted as such. The media has an obligation to act in an objectively appropriate fashion when publishing material that may infringe on a person’s right to privacy. However, to hold that the respondents were under a further duty to contact either the University or the applicants to ensure that they had in fact consented to the original publication of their names would impose a significant burden on freedom of expression.

O’Regan J, however, found that the failure by New Africa Books to take steps to withdraw copies of the book once the lack of consent became clear, was unlawful, and that an appeal lodged by New Africa Books must fail. O’Regan J would have dismissed the appeal of the applicants.
+ In a separate concurring judgment Sachs J added that . . . if the slightest doubt existed, there was no need to publish the actual names of the applicants and that publishers should refrain from circulating information identifying the HIV status of named individuals unless they had the clearest possible proof of consent to publication.

+ Langa CJ wrote a judgment agreeing in part and dissenting in part with the judgment of Madala J. He found that the respondents did not act intentionally. He agreed with O’Regan J that the common law must be developed with regard to media defendants, and would develop it to replace the current requirement of intention with that of negligence. Langa CJ held that the first and third respondents would qualify as media defendants and as the Strauss Report cannot be regarded as a public document, they had acted negligently. Agreeing with Madala J’s assessment of damages, he held that the applicants were attempting to vindicate constitutional rights and should get all their costs.
Effects of disclosure of HIV status:

- Individual is at risk of further human rights violations.
- Mental and emotional stress.
- Discrimination in workplace and community, stigma and being ostracised from society or their families.
- Violence, abandonment, emotional abuse.
- Psychological effects – depression etc.

Sufficient protection in terms of the right to privacy?

- Litigation is an available avenue to adjudicate on the right to privacy, however, it can often be a disincentive due to the potential personal cost (emotional etc) to the litigant.
**Implications of disclosure – practical considerations in a health care setting**

+ HPCSA G/D– provides steps before disclosure can take place.
+ Allows for discretion of the HCPs, however, the HCP must take full responsibility for disclosure.
+ The steps to be taken before disclosure can take place are listed in section 9 of the G/D.
+ However, it DOES NOT look at:
  + factors influencing the decision to notify, (SAMA Guidelines provide slightly more here);
  + how the disclosure should be done by a HCP (manner) and the urgency;
  + What to do about the risk / possibility of violence ensuing – HPCSA mention it but fail to make recommendations, while SAMA suggests not to notify if there is a risk of harm.
+ When can one put off notification? A promise? (SAMA Requires action on substantial information and not mere suspicion – highlighting a risk assessment is required.)
Potential liability in respect of notification

- Non compliance with ethical rule – disciplinary measures or legally actionable.
- If consent provided, and in order to be a defence against unlawfulness, then the actions must be within the ambit of the consent given.
- No legal clarity from SAMA and HPCSA G/Ds whether notification of a partner is an acceptable limitation of the right to privacy and SAMA states that ‘in the absence of case law in this regard, no guarantees can be provided on how courts and/or the HPCSA will view disclosures.’
- What about partner suing HCP for not disclosing and thereby warning them of the risk of exposure – is there a duty there? (If yes then it would be a justifiable limitation of the patient’s privacy, if not then no.)
- While notification may in certain circumstances be a justifiable limitation – is there a legal duty to undertake the notification?
  - As a general rule a person does not act wrongfully if they fail to act positively to prevent harm to another, however, a person can be held liable for an omission if he were under a legal duty to act.
  - In terms of Hippocratic oath - act in best interests of the patient. What about SA context of the public health care system?
  - The patient and partner must take control of their own situation, including using preventative measures etc.
  - No such duty as such a general duty would undermine patient confidentiality.
  - Rather utilise public health interventions and encourage testing etc of couples.
Considerations:

+ Balancing of the individual’s right to privacy (resulting in non-consensual disclosure & breach of trust) vs partner’s right to bodily integrity (resulting in non-disclosure & disease) or public health
+ Privacy and confidentiality are not absolute
+ Merits of each case considered
+ What about other non-health role players – claims handlers, data capturers?
+ HPCSA ethical rulings
+ Some general principles:
  + In context of health care what falls within private sphere of patient:
    + Age; mental state; measures to take to avoid unwanted publicity or visitors; state of physical health.
  + Disclosure to one person does not mean patient wants to disclose to others thus within boundaries of the consent given.
  + Spouses are not entitled to information, or children etc. Without patients prior knowledge or consent.
  + Famous does not mean everything is/ or should be in the public light; disclosures to other HCP unjustifiable – expectation of privacy of all taking care of patient:
Case: Tshabala-Msimang and Another v Makhanya and Others

Facts:

Application by the former Minister of Health against a Sunday newspaper which allegedly obtained unauthorised possession of confidential medical records and publicised the contents. (Protection as afforded by section 14 of the NHA)

Included allegations of alcohol abuse while the former Minister of Health was a patient in hospital prior to operations

Infringement of right to privacy and dignity and application of section 17 of NHA – dealing with the protection of health records and control measures for unauthorised access, commits and offence and would be liable to a fine and/or imprisonment.

Vs the freedom of the press and public interest.
+ **Findings:**
  + The private information contained in the health records of a user was worthy protecting as an aspect of human autonomy and dignity (Ito CRSA and NHA). This included the right to control the dissemination of information.
  + The right to privacy therefore entitled her not to have her private medical information disclosed to the public without her consent and she was entitled to their return as they were not entitled to their access to these records or to keep them.
  + The acquisition of private facts through a wrongful act of intrusion and subsequent disclosure constituted an infringement of the right to privacy. But justifiable in the public interest (to the extent it is reasonable and necessary).
  + Reconciliation two sets of competing constitutional rights, the rights to freedom of expression and to receive and impart information and ideas (of the respondents and the public) and the Former Minister’s rights including her right to dignity.
  + In appropriate circumstances the public had the right to information about public figures even where it had been unlawfully obtained (section 16 – freedom of the press)
Sources and further reading

+ Stefanie Roehrs *Privacy, HIV/ AIDS and Public Health Interventions* SALJ 126 (2) 2009

+ Carstens and Pearmain *Foundational Principles of South African Medical Law* LexisNexis

+ Open Society Foundation of South Africa *A Best Practice Guide to HIV Disclosure*