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HIV/AIDS, TO DISCLOSE OR NOT TO DISCLOSE: THAT IS THE QUESTION

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1 Introduction

An estimated 22.5 million people (including 2.3 million children) were living with HIV/AIDS in Sub-Saharan Africa at the end of 2009. It is furthermore estimated that approximately 1.3 million Africans died of AIDS in 2009.[1] According to the South African National HIV Survey of 2008, it is estimated that 10.9% of South Africans older than two years are living with HIV/AIDS, and among those between the ages of 15 and 49 years the estimated HIV prevalence is 16.9%.[2] These figures remain staggering and it therefore comes as no surprise that the impact and effect of HIV/AIDS are no longer limited to mortality rates and illnesses but are actually widespread and influence all aspects of our everyday lives. The health care sector, households, schools, workplaces and the economy - all of these are experiencing distinct challenges due to the high HIV/AIDS prevalence rate, and appropriate action must therefore be taken to deal with these challenges in their different contexts.

Yet, despite the high prevalence rate of HIV/AIDS and the global challenges this pandemic poses for all a person's HIV status remains a private affair, primarily due to the way in which it is generally transmitted and the lack of a cure; "... HIV is a condition related to sex, death and disease – topics that allude to the most existential aspects of life and are therefore perceived as highly intimate".[3] This was confirmed *in NM v Smith,* where it was held that—

> ... an individual's HIV status deserves protection against indiscriminate disclosure due to the nature and negative social context the disease has, as well as the potential intolerance and discrimination that result from its disclosure.[4]

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1 Avert Date unknown http://bit.ly/XQn7tr; UNAIDS 2010 http://bit.ly/13Ipzu8.

2 Avert Date unknown http://bit.ly/16pKTCh.

3 Roehrs 2009 *SALJ* 369; Maile 2004 *Africa Education Review* 113-127.

4 *NM v Smith* 2007 5 SA 250 (CC) para 42; Roehrs 2009 *SALJ* 369.

Ethical problems in the management of the disclosure of a person's HIV status have certainly also increased.[5] Numerous examples exist where people have suffered discrimination, were treated unfairly, were denied employment or access to particular services and/or institutions based only on their HIV-status.[6]

This article provides a comprehensive summary of the position regarding HIV/AIDS and disclosure in South Africa.[7] The primary aim of the article is to consider and comment on the practical manifestations and considerations of HIV/AIDS and disclosure that different role players in the economy, criminal justice system and the health care industry in South Africa are confronted with. The consensual and non-consensual disclosure of a person's HIV/AIDS status and related information in different contexts will consequently be discussed to illustrate the diversity of approaches utilised under different circumstances and the underlying considerations in each instance. Reference will therefore be made to relevant legislation, case law, and academic literature as well as ethical guidelines and protocols like the Code of Good Practice of the *Employment Equity Act* 55 of 1998, the Health Professions Council of South Africa's ethical rules and the ethical guidelines of the South African Medical Association.

It will become evident from this discussion of the disclosure of HIV/AIDS status in different contexts that there is often no simple answer or single approach to be followed. Whether a person him- or herself should disclose their status or whether a health care worker or employer/another employee should disclose this information is largely determined by the particular circumstances of each and every situation.

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5 Maile 2004 *Africa Education Review* 113-127.

6 Maile 2004 *Africa Education Review* 113-127; *Hoffmann v South African Airways* 2001 1 SA 1 (CC); *Allpass v Mooikloof Estates (Pty) Ltd t/a Mooikloof Equestrian Centre* 2011 2 SA 638 (LC); *Irvin and Johnson Limited v Trawler and Line Fishing Union and Others* 2003 24 ILJ 565 (LC); *Joy Mining Machinery a division of Harnischfeger (South Africa) (Pty) Limited v National Union of Metal Workers of South Africa (NUMSA)* 2002 ZALC 7; *NM v Smith* 2007 5 SA 250 (CC); *Jansen van Vuuren v Kruger* 1993 4 SA 842 (AD).

7 This is not a legal comparative study. It is rather a comprehensive exposition on the South African experience of HIV/AIDS disclosure in different contexts.

Some general principles based on the constitutional rights to privacy,[8] human dignity[9] and the right to bodily and psychological integrity[10] can however be extracted from the case studies and discussion below.

2 Disclosure and the larger economy

In a 2006 study on the status of HIV/AIDS reporting, De Bruyn submitted that HIV/AIDS is most prevalent amongst the economically active groups in South Africa and that this could ultimately change the demographic, social and economic landscape of the country.[11] It was furthermore submitted that the high prevalence of HIV/AIDS in South Africa had already had a systematic economic impact in the work place, as companies were already experiencing a lack of productivity due to staff absenteeism as a result of AIDS-related illnesses and the need to grant compassionate leave. Employees attending the funerals of relatives, friends and colleagues who had died of AIDS was also said to be contributing to the negative economic impact of HIV/AIDS at the workplace.[12] In addition, companies were incurring additional costs from having to provide anti-retroviral drugs to their employees, increased recruitment and training costs in the case of an HIV-positive employee dying or being incapacitated, general healthcare costs, increased death and disability benefits expenses, and the cost of in-house HIV/AIDS management programmes.[13]

In the light of these exorbitant expenses and the negative economic impact of HIV/AIDS on companies, it is quite comprehensible that investors and shareholders would expect companies to voluntarily disclose information about the HIV/AIDS prevalence rate amongst their employees.[14] While some companies listed on the JSE

8 Section 14 *Constitution of the Republic of South Africa*, 1996.
9 Section 10 *Constitution of the Republic of South Africa*, 1996.
10 Section 12(2) *Constitution of the Republic of South Africa*, 1996.
11 Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 2.
12 Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 2.
13 Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 2.
14 Mandatory disclosure refers to those aspects and items of information that are required by statutes, stock exchanges or prescribers of accounting standards. The disclosure is accomplished through company annual reports. Voluntary disclosure, on the other hand, is disclosure in excess

Securities Exchange do include such information in their annual reports on the impact of HIV/AIDS on their operations, no accounting standard/pronouncement exists to guide companies in this regard.[15] However, both the King Report II[16] and the Global Reporting Initiative (GRI)[17] encourage companies to understand the social and economic impact that HIV/AIDS has on its business activities, to adopt an appropriate strategy to deal with it, and to devise plans and policies to address and manage the impact. It is also suggested that companies should regularly monitor their performance with regard to HIV/AIDS and report back to all stakeholders.[18] The JSE Securities Exchange and the South African Institute of Chartered Accountants (SAICA) also advocate a more formal approach to HIV/AIDS reporting by companies.[19]

The GRI, in a document entitled *Reporting Guidance on HIV/AIDS: A Resource Document*,[20] identifies four areas that need to be addressed when reporting on HIV/AIDS:

- Good governance, including HIV/AIDS policy, strategies for managing the risk, as well as the monitoring and reporting of these and related issues;
- Measuring, monitoring and evaluation, including HIV/AIDS-related costs and losses and future costs and losses due to HIV/AIDS;
- Workplace conditions and HIV/AIDS management, including stakeholder involvement in policy formulation, workplace-related programmes and interventions, as well as the budgets for these programmes; and
- The depth, quality, and sustainability of programmes that aim to prevent further infections and support those employees already infected.[21]

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of the requirements and represents free choices on the part of company management to provide accounting and other information deemed relevant to the decision needs of users of the annual reports (Myburgh 2001 *Meditari Accountancy Research* 199-216; Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 5). Also see De Bruyn 2008 *Meditari Accountancy Research* 59-78.

15 Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 2.

16 Institute of Directors *King Report II*.

17 The GRI is is a non-profit organisation that works towards a sustainable global economy by providing sustainability reporting guidance. See www.globalreporting.org.

18 Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 6.

19 Also see De Bruyn 2008 *Meditari Accountancy Research* 59-78.

20 GRI *Reporting Guidance on HIV/AIDS: A Resource Document* 10-16, accessible at http://bit.ly/ZwyIxe.

At present, approximately 72% of JSE-listed companies voluntarily disclose some information on HIV/AIDS, while 28% of the companies do not report on the impact of HIV/AIDS on their operations at all. A mere 11.41% of the companies report financial information related to the impact of HIV/AIDS on their operations.[22] This result shows that companies in South Africa are generally not very willing to report about the impact of HIV/AIDS on their financial operations.[23] Many reasons may exist for this lack of disclosure but Mokoaleli-Mokoteli and Ojah highlight the following three as the main reasons for non-disclosure:

a) Firms are not obliged to disclose HIV/AIDS-related information and therefore prefer not to disclose additional information;
b) No standard or guideline on how HIV/AIDS should be reported for financial reporting purposes exists; and
c) Some firms may not want to disclose this sensitive information for all (including their competitors) to read.[24]

Although it is evident that many companies in South Africa do not currently report on the systemic and economic effects of HIV/AIDS on their business, the need definitely exists, especially amongst shareholders, for such reporting in terms of standard financial reporting guidelines. The disclosure of HIV/AIDS-related information by JSE-listed companies would not only assist in providing a picture of the impact of HIV/AIDS on the demographic, social and economic landscape of the country but it would also allow for companies to determine the systematic economic impact of HIV/AIDS in the workplace and the positive role that company-specific HIV management programmes and interventions could play in this regard.

21 Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 6.
22 Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 15.
23 Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 20.
24 Mokoaleli-Mokoteli and Ojah 2010 *African Finance Journal* 20.

3 Disclosure and the workplace

But whether or not to disclose your HIV/AIDS status at the workplace/to your employer is certainly a thorny issue. The *Code of Good Practice on Key Aspects of HIV/AIDS and Employment* (hereafter the "Code of Good Practice")[25] issued by the minister of labour in terms of the *Employment Equity Act* unequivocally states that no employer may require an employee or an applicant for employment to undertake an HIV test in order to ascertain the employee's HIV status.[26] Employers can, however, approach the Labour Court in terms of sections 7 and 50(4) of the Act to obtain authorisation for such testing. But this will be granted only if existing legislation permits or requires such testing or if the testing is justifiable in the light of medical facts, employment conditions, social policy, the fair distribution of employee benefits or the inherent requirements of the particular job/position.[27] (It should be noted, however, that these provisions do not prohibit cases of permissible testing in the workplace where an employer provides HIV testing, counselling and treatment to employees as part of a healthcare service plan, or in the event of an occupational accident carrying a risk of exposure to blood or bodily fluids or for the purposes of applying for compensation following an occupational accident.)[28] Employees are furthermore under no obligation to disclose their HIV status to their employers or to other employees and where such information has been disclosed, the express consent of the particular individual must be obtained before this information may also be disclosed to others.[29]

In an interesting case concerning pre-employment testing, the Constitutional Court had to decide whether an HIV-testing employment policy of the South African Airways was justified in terms of the Code of Good Practice and the *Employment Equity Act*. The appellant in the case of *Hoffmann v South African Airways* 2001 SA 1

25 The Code of Good Practice is accessible at http://bit.ly/X8P9Do.
26 Clause 7.1 of the Code of Good Practice.
27 Section 7(1) *Employment Equity Act* 55 of 1998.
28 Clause 7.1 of the Code of Good Practice; See *Irvin and Johnson Limited v Trawler and Line Fishing Union* 2003 24 ILJ 565 (LC); *Joy Mining Machinery a division of Harnischfeger (South Africa) (Pty) Limited v National Union of Metal Workers of South Africa (NUMSA)* 2002 ZALC 7.
29 Clause 7.2 of the Code of Good Practice.

(CC) applied for a position as a cabin attendant at South African Airways, and at the end of a four-stage selection procedure he was one of only twelve remaining suitable candidates identified by the SAA for appointment. However, the appointment was subject to undergoing a pre-employment medical examination which included a blood test for HIV/AIDS. While the medical examination found the appellant to be clinically fit and suitable for employment, the blood test showed that the appellant was HIV positive. SAA consequently informed the appellant that he could not be employed as a cabin attendant because of his HIV-positive status.

SAA defended its decision and employment policy, contending that no person who is HIV positive can work as a cabin attendant since the SAA flight crew must be fit to travel world-wide and must be fit to be vaccinated against various ailments, including yellow fever, a vaccination to which HIV-positive people do not react too well, and consequently cannot receive. Without the vaccination, HIV-positive cabin crew members would be at risk of contracting yellow fever and they would pose a risk of transmitting it to others, including the passengers. In addition, it was argued that HIV-positive persons are also at risk of contracting opportunistic diseases and that this also posed the risk of transmitting the diseases to others, including passengers.

The High Court[30] agreed with the decision made by the SAA and found that the employment practice of the SAA was based on considerations of medical safety and operational grounds that did not exclude persons with HIV from employment in all positions within SAA, but only from cabin-crew positions. It was also found that the employment practice was aimed at achieving a worthy and important societal goal.[31] The Constitutional Court found, however, based on the medical evidence, that an asymptomatic HIV-positive person could indeed perform the work of a cabin attendant competently and that any hazards to which an immunocompetent cabin attendant might be exposed to could be managed by counselling, monitoring, vaccination and the administration of the appropriate antibiotic prophylaxis if

30 *Hoffmann v South African Airways* 2000 2 SA 628 (W).
31 *Hoffmann v South African Airways* 2000 2 SA 628 (W) para 28.

necessary.[32] The risks to passengers and other third parties arising from the employment of an asymptomatic HIV-positive cabin crew member was therefore inconsequential, and well-established universal precautions could be utilised to minimise any possible risk.[33] The fact that the SAA was testing only individuals who applied for positions at SAA and not those who were already in their employ was also questioned. This, the court found, was irreconcilable with the stated purpose of SAA's employment practice.[34] The Constitutional Court found in favour of the appellant, stating that the refusal by SAA to employ the appellant as a cabin attendant because he was HIV positive violated his right to equality guaranteed by section 9 of the *Constitution*.[35]

In another case, *Allpass v Mooikloof Estates (Pty) Ltd t/a Mooikloof Equestrian Centre*[36] a horse-riding instructor and stable manager was dismissed by Mooikloof Estates for being HIV positive and not having disclosed this during the pre-employment interview. Although the applicant had been asked about his health during the pre-employment interview he had not divulged his HIV-status, even though he had been living with HIV for some 17 years at that stage.[37] It was only a few days after the applicant's appointment, when he was asked to complete a personal particulars form — which included questions on his health, allergies and chronic medication — that the applicant's HIV status became known to his employer. The respondent, Mooikloof Equestrian Centre, argued that the applicant had not been honest in his pre-employment interview and that the particular position for which the applicant applied required long working hours including nights and weekends, thus generally requiring good health and well-being. Although the respondent agreed that the applicant was under no duty to disclose his status, the respondent contended that it was dishonest for someone with HIV to claim good health, not because it implied that the person was unhealthy, but because it was a

32 *Hoffmann v South African Airways* 2001 1 SA 1 (CC) para 15.
33 *Hoffmann v South African Airways* 2001 1 SA 1 (CC) para 15.
34 *Hoffmann v South African Airways* 2001 1 SA 1 (CC) para 31.
35 *Hoffmann v South African Airways* 2001 1 SA 1 (CC) para 41.
36 *Allpass v Mooikloof Estates (Pty) Ltd t/a Mooikloof Equestrian Centre* 2011 2 SA 638 (LC).
37 *Allpass v Mooikloof Estates (Pty) Ltd t/a Mooikloof Equestrian Centre* 2011 2 SA 638 (LC) para 6.

realistic factor impacting on that person's health and potentially also on his/her job.[38]

However, both the applicant and his medical expert contended that the applicant was in excellent health, as he consistently adhered to a proper treatment regime, his CD4 count was at all times exceptionally low and his viral load was at such a low level as to be indetectable. It was also submitted that the applicant was able to perform his duties at all material times.[39] The court agreed with this and found that the respondent's primary concern was indeed the applicant's HIV status and that it was the sole reason for his dismissal. Based on the evidence, it was clear that the applicant had no medical or physical impediment preventing him from performing his duties and it was also evident that the applicant had acquitted himself well in a strenuous and demanding job.[40] The applicant's good health and ability to perform his duties at all material times were consequently the decisive considerations in this judgement.

It is evident from the discussion above that pre-employment HIV testing and the mandatory disclosure of an employee's HIV status will be warranted only in exceptional circumstances where existing legislation allows for it, or where it is justifiable in the light of medical facts, employment conditions, social policy, the fair distribution of employee benefits, or the inherent requirements of the particular job/position. This thorough protection of HIV positive individuals' right to privacy in the workplace is indeed necessary, as unfair discrimination against HIV-infected employees is rife, and further stigmatisation — that HIV-infected persons are a risk at the workplace in particular and for communities at large — should be avoided as far as possible.[41]

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38 *Allpass v Mooikloof Estates (Pty) Ltd t/a Mooikloof Equestrian Centre* 2011 2 SA 638 (LC) para 19.

39 *Allpass v Mooikloof Estates (Pty) Ltd t/a Mooikloof Equestrian Centre* 2011 2 SA 638 (LC) para 6.

40 *Allpass v Mooikloof Estates (Pty) Ltd t/a Mooikloof Equestrian Centre* 2011 2 SA 638 (LC) para 54.

41 SALRC *Pre-employment HIV-testing* 2.49.

4 Non-consensual disclosure by a health practitioner

Yet, before an HIV-infected person is confronted with the question of disclosure in the workplace, the very first relationship where this private and intimate information is shared is the relationship between the patient and his/her healthcare worker. This relationship between a medical practitioner and a patient is a unique and intimate relationship that requires the utmost respect for the patient's rights to privacy and dignity.

In the landmark case of *Jansen van Vuuren v Kruger*[42] a medical practitioner had disclosed the HIV status of his patient — after an explicit request by the patient to keep the information confidential — to other health practitioners during the course of a game of golf. The patient/plaintiff instituted proceedings claiming that the medical practitioner owed him a duty of confidentiality in regard of their doctor-patient relationship and regarding any knowledge of the plaintiff's medical and physical condition. The plaintiff argued that he had suffered an invasion of privacy and had been injured in his rights of personality. The medical practitioner, however, argued that the disclosure had been made on a privileged occasion, that it was the truth, and made in the public interest, and that it was objectively reasonable in the public interest in the light of the *boni mores*. The medical practitioner contended that he had a social and moral duty to make the disclosure to the other health practitioners and that they had a reciprocal social and moral right to receive the information and apply due diligence when again dealing with or treating the plaintiff.[43]

In this case it was highlighted that a sense of the importance of maintaining confidentiality about the information acquired in a medical practitioner's professional capacity even predated Hippocrates and should always be honoured at all costs.[44] This is important not only to protect the privacy of patients but it is also the only

42 *Jansen van Vuuren v Kruger* 1993 4 SA 842 (AD). Also see Van Wyk 1994 *THRHR* 141.
43 *Jansen van Vuuren v Kruger* 1993 4 SA 842 (AD) 38.
44 *Jansen van Vuuren v Kruger* 1993 4 SA 842 (AD) 11 – 12.

way of securing public health, as doctors would otherwise be discredited.[45] This duty of medical practitioners to respect the confidence of their patients is furthermore not merely an ethical duty but it is also a legal duty recognised by South African common law.[46] This was reiterated in the case of *NM v Smith*.[47]

The applicants in the case of *NM v Smith* claimed that their rights to privacy, dignity and psychological integrity had been violated as their names and the fact that they were HIV positive had been disclosed, without their prior consent, in the biography of Ms Patricia de Lille, a publication that had been authored by Ms Charlene Smith. The applicants' details were included in the book in a chapter discussing Ms de Lille's work in campaigning for the rights of people living with HIV/AIDS. The applicants' details were relevant to the discussion as they were involved in a clinical trial that was the source of some complaints as well as an ethical enquiry in which Ms de Lille gave her assistance and support. Ms Smith, the author of the biography, made use of an external report, that had been e-mailed to Ms de Lille as well as two other journalists, and that detailed the information on the clinical trial, the complaints, and the ethical enquiry into the trial.

The external report did not contain the informed consent forms of the applicants and it was furthermore not marked as confidential. Had the informed consent forms of the applicants been attached to the report it would, however, have become clear that the consent forms signed by the applicants did not permit full public disclosure of their identity and the fact that they were living with HIV/AIDS. The consent forms permitted only limited disclosure for the purposes of the University's investigation into the clinical trial and the complaints received. While the respondents admitted publication of the applicants' names and their HIV status they denied that the publication was intentional or negligent and pleaded that the HIV status of the applicants was no longer private at the time of the publication of the book. They also argued that it was reasonable for any reader of the external report to assume that

45 *Jansen van Vuuren v Kruger* 1993 4 SA 842 (AD) 13 – 14.
46 *Jansen van Vuuren v Kruger* 1993 4 SA 842 (AD) 14.
47 *NM v Smith* 2007 5 SA 250 (CC). Also see Neethling 2008 *SALJ* 36-46; Scott 2007 *Stell L R* 483-494.

the necessary consent had been obtained since nothing in the report indicated that it was confidential. The applicants, however, argued that their rights of personality, privacy, dignity and psychological integrity had been violated as a result of the disclosure, and that they had suffered damages.

Justice Madala from the Constitutional Court held that the lack of respect for private medical information and its subsequent disclosure might result in fear, jeopardising an individual's right to make certain fundamental choices that he/she has a right to make.[48] Especially with regard to the disclosure of an individual's HIV/AIDS status, the court held that confidentiality was important as it would encourage individuals to seek treatment and divulge information encouraging disclosure of HIV, and that it might also result in the improvement of public health policies on HIV/AIDS.[49] Medical information was furthermore not only private and confidential while in the hands of health care personnel. People continued to have a direct interest to control information about themselves and to keep it confidential. Thus, although the applicants had given their consent to take part in the clinical trial and in the consequent enquiry that was held, they certainly had not given consent for their names to be published in a book having a wide circulation throughout South Africa.[50]

The doctor-patient relationship is possibly one of the most important relationships that can come into being between any two people. The relationship is based on trust, morality and respect, and it is vital to the quality of the care provided as well as to the outcomes and relative success of the specific medical intervention and treatment.[51] This duty of medical practitioners to respect the confidentiality of their patients is both an ethical and a legal duty and extends even beyond the limits of the relationship between patient and medical practitioner. It was evident from the judgment in the case of *NM v Smith* that it can never be assumed that others are allowed access to private medical information once it has left the hands of authorised physicians and other personnel involved in the facilitation of medical care.

48 *NM v Smith* 2007 5 SA 250 (CC) para 41.
49 *NM v Smith* 2007 5 SA 250 (CC) para 42.
50 *NM v Smith* 2007 5 SA 250 (CC) para 39.
51 Le Roux-Kemp *Law, Power and the Doctor-Patient Relationship*.

It can consequently be concluded that the confidentiality of medical information obtained by a medical practitioner in his/her professional capacity is one of the cornerstones of health care and — especially with regard to the disclosure of HIV and related information — this fundamental aspect of medical care and relationships even extends beyond the boundaries of the health care milieu.

5 Non-consensual disclosure: Unauthorised blood tests

In terms of rule 9.4 of the Health Professions Council of South Africa's ethical rules, informed consent is a prerequisite for testing a person for HIV. Even where healthcare practitioners are expected to record diagnostic information for patients on medical insurance forms or in accordance with the rules of a medical scheme, the patient must give informed consent for such information to be placed on the account.

This general principle was reiterated in *C v Minister of Correctional Services,*[52] but it was completely disregarded in the case of *VRM v Health Professions Council of South Africa.*[53] In the latter case a woman, six months pregnant, consulted with the medical practitioner whom she wanted to deliver her baby. During this consultation a blood sample was taken. At a follow-up consultation the patient and her husband enquired about the blood test and the account they had received for it as the account made mention of HIV Elisa and they wanted to know whether the blood test had anything to do with HIV/AIDS. The medical practitioner denied that the blood test was for HIV and offered to take it up with the pathologists who conducted the test and had sent the account. However, after the patient's baby was stillborn the medical practitioner informed her that the blood test taken during the first consultation was indeed for HIV testing and that she was HIV positive. The medical practitioner also stated that her baby had been HIV positive and that it was the reason for the baby's stillbirth.

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52 *C v Minister of Correctional Services* 1996 4 SA 292 (T). Also see Knobel 1997 *THRHR* 533-536.

53 *VRM v Health Professions Council of South Africa* 2002 ZAGPHC 4.

In this case the conduct of the medical practitioner was questioned as illegal and unethical, it was alleged that he had performed an unauthorised HIV test on both the patient and the baby, that he had not provided the requisite counselling before and after the HIV test, he had not disclosed the outcome of the test as soon as it became known to him, and he had not advised, acted and provided treatment to reduce the risk of mother-to-child HIV transmission. It was also asked if the medical practitioner had the requisite consent from the patient to inform her husband of her HIV-positive status.[54] The medical practitioner, however, defended his conduct on the grounds that the patient's right to security in and control over her body in terms of section 12(2)(b) of the *Constitution* had violated because there were no counselling facilities at the specific hospital and that he had exercised his discretion in not informing the patient of her status immediately upon the outcome of the test since he thought it was in her best interests, from a psychological point of view, not to do so.[55]

In a most unsatisfactory and shocking judgement the High Court found that it was "…difficult to understand in what respect [the patient's] constitutional rights were violated".[56] The court held that there were, in any event, very few choices/options available to the patient, as she had been six months pregnant already, that the hospital lacked counselling facilities and "...the fact that she was informed later instead of sooner was really of no moment at that stage".[57] The court went on to say that "...the difference between informed consent and consent is marginal" and had very little import in the case at hand.[58] Justice H Daniels surprisingly found "...no room for the contention that [the medical practitioner] arrived at a decision in a paternalistic and capricious manner".[59]

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54 *VRM v Health Professions Council of South Africa* 2002 ZAGPHC 4 para 24. Also see part 6 of this article.
55 *VRM v Health Professions Council of South Africa* 2002 ZAGPHC 4 9.
56 *VRM v Health Professions Council of South Africa* 2002 ZAGPHC 4 13.
57 *VRM v Health Professions Council of South Africa* 2002 ZAGPHC 4 14.
58 *VRM v Health Professions Council of South Africa* 2002 ZAGPHC 4 15.
59 *VRM v Health Professions Council of South Africa* 2002 ZAGPHC 4 16.

It is submitted that the judgement in the case of *VRM v Health Professions Council of South Africa* is wide of the mark and that no situation or circumstance can ever warrant the use of unauthorised HIV blood tests without a patient or individual's informed consent. To act otherwise would be a serious infringement of a patient's constitutional rights, especially the right to psychological and bodily integrity.[60]

6 Non-consensual disclosure: by a health practitioner to an intimate partner and/or family member

Of particular concern for healthcare practitioners — and this issue too was raised in the case of *VRM v Health Professions Council of South Africa* discussed above — is whether or not to disclose the HIV-status of a patient to that patient's spouse/partner. The ethical conflict between the healthcare practitioner's duty to respect the patient's right to privacy and confidentiality weighs heavily in such circumstances against the general duty of all healthcare practitioners to inform individuals of possible health risks. While UNAIDS, the Canadian Advisory Committee and the American Medical Association have made provision for partner notification - first with the source patient's informed consent and in limited circumstances[61] without such consent – no comparable partner notification programmes or guidelines exist in South Africa.[62]

Instead, rule 9 of the Health Professions Council of South Africa's ethical rules provides for situations where an HIV-infected patient refuses to inform his/her intimate partner of his or her status.[63] In such situations it is recommended that health care workers use their discretion on whether or not to divulge the information to the patient's intimate partner. The possible risk of HIV infection to the intimate partner, as well as the risks to the patient of disclosing his or her status, must be

60 Section 12(2) *Constitution of the Republic of South Africa*, 1996.

61 Partner notification without the source client/patient's consent will be permissible where the source client fails to apply appropriate behavioural changes (eg practising safe sex), the partner of the patient is clearly identified, and that partner is at a real risk of HIV transmission or has little or no reasonable suspicion of the risk; Roehrs 2009 *SALJ* 377.

62 For a discussion of whether or not such a partner-notification programme should be introduced in South Africa, see Roehrs 2009 *SALJ* 386-388.

63 HPCSA *Booklet 12*.

taken into consideration. It is furthermore emphasised in the guidelines that the decision is to be made with great care and that consideration is to be given to the rights of all of the parties concerned. The guidelines include recommendations to guide the health care worker through the decision-making process, as well as the procedure to be followed before the disclosure of the information to the intimate partner.

The pre-disclosure procedure (in terms of the HPCSA guidelines) basically entails that the patient is counselled and that the importance of disclosure to the intimate partner is emphasised, as well as the behavioural changes the patient is required to make. Support must be offered to the patient throughout the disclosure process and only if the patient continues to refuse to disclose his or her status to the intimate partner himself or herself is the healthcare practitioner allowed to disclose the HIV status of the patient to the intimate partner without the patient's consent. However, the patient must be informed by the healthcare practitioner of this action, it must be explained to the patient that it is the healthcare practitioner's ethical duty to divulge the information, and the patient must also be counselled on the possible adverse consequences of the disclosure.[64]

The South African Medical Association (SAMA), however, provides for stricter guidelines re the disclosure of a patient's HIV/AIDS status to an intimate partner, and it is evident from these stricter SAMA provisions that the primary duty of the healthcare practitioner lies with the patient and not the patient's intimate partner(s). In terms of the SAMA guidelines the healthcare practitioner may breach the confidentiality of a patient only if the partner of that patient is clearly identified, there is a real risk that the partner will be infected, and there is no other way to protect the partner other than to disclose the patient's HIV/AIDS status.[65] Where the patient reasonably believes that the disclosure of his/her HIV/AIDS status entails a

64 Roehrs 2009 *SALJ* 379-380.
65 Roehrs 2009 *SALJ* 380.

risk of harm, the healthcare practitioner's primary duty will be to protect the patient and not disclose his/her HIV/AIDS status at all.[66]

Yet, irrespective of whether the HPCSA or SAMA guidelines are followed, it is clear that if the healthcare worker ultimately decides to make the disclosure against the patient's wishes, the healthcare worker must do so after explaining the situation to the patient, and the healthcare worker must then also accept full responsibility for the decision made and the action taken.[67]

With regard to the disclosure of the HIV/AIDS status of a deceased to his/her intimate partner McQuoid-Mason argues that such a disclosure can be regarded as being *in the public interest*, that there is a legal duty on medical practitioners to warn the intimate 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 incur any loss or damage as a result of being unaware of their HIV status.[68]

It is unclear to date whether or not a healthcare practitioner's general ethical duty to protect others from harm and inform them of possible health risks will be a justifiable limitation of his/her patient's right to privacy and confidentiality in terms of the patient's HIV/AIDS status. Roehrs argues that various factors will have to be taken into consideration, including whether there is a legal duty on the healthcare practitioner to act, whether there is a special relationship between the healthcare practitioner and the particular patient's intimate partner, what the *boni mores* of the community warrants in such a situation, what the particular patient's responsibilities are towards their intimate partner(s), and whether these responsibilities may be conferred upon healthcare practitioners by their patients.[69]

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66 Roehrs 2009 *SALJ* 380.

67 For a comprehensive comparison between the HPCSA and SAMA guidelines, see Roehrs 2009 *SALJ* 380.

68 McQuoid-Mason 2007b *SAMJ* 920-923.

69 Roehrs 2009 *SALJ* 380-385.

7 Disclosure and compulsory HIV-testing

Chapter 5 of the *Criminal Law (Sexual Offences and Related Matters) Amendment Act* 32 of 2007 came into operation on 21 March 2008 and provides for the compulsory HIV testing of alleged sex offenders. (In the United States, California, Colorado and Texas have similar legislative measures, compelling the HIV testing of rape suspects.)[70] Sections 30 and 28 of the *Sexual Offences and Related Matters Act* make provision for the victim of a sexual offence (or any interested person on behalf of such a victim, who obtained the required consent from the victim) to apply to a magistrate for an order that the alleged offender be tested for HIV and that the results thereof be disclosed to the victim or the interested person, as well as the alleged offender.[71] This application must be brought within 90 days after the alleged commission of the offence concerned, and may be made before or after an arrest has been effected.[72]

It is furthermore a requirement for this application to confirm that the alleged offence was reported to the police within 72 hours after the alleged commission of the offence or that it was reported at a designated health establishment within the same time limit.[73] The application must be handed to the investigating officer of the particular case, and the investigating officer must, as soon as is reasonably practicable, submit the application to a magistrate of the district in which the sexual offence is alleged to have been committed.[74]

The magistrate will then, as soon as is reasonably practicable, consider the application and may call for additional evidence as he/she deems fit, including evidence by or on behalf of the alleged offender.[75] If the magistrate is satisfied that there is *prima facie* evidence that a sexual offence was committed against the victim

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70 Bedward 1990 *U Ill L Rev* 347. Also see *The Penal Code of California*: a 1524; *Colorado Revised Statutes: Criminal Code - aa* 18-3-415; *Texas Code of Criminal Procedure: a* 21.31.

71 Section 30(1)(a)(i) *Criminal Law (Sexual Offences and Related Matters) Amendment Act* 32 of 2007 (hereafter "*Sexual Offences and Related Matters Act*").

72 Section 30(3) *Sexual Offences and Related Matters Act*.

73 Sections 28(a) and 30(2)(a)(ii) *Sexual Offences and Related Matters Act*.

74 Section 30(4) *Sexual Offences and Related Matters Act*.

75 Sections 31(1) and 31(2)(a) *Sexual Offences and Related Matters Act*

by the alleged offender, that the victim may have been exposed to the body fluids of the alleged offender, and that no more than 90 calendar days have elapsed from the date on which it is alleged that the offence in question took place, the magistrate must order that the alleged offender undergo an HIV test and that the results of this test be disclosed in the prescribed manner to the victim or interested person acting on behalf of the victim, as well as to the alleged offender.[76]

An alleged offender who fails or refuses to comply or avoids complying with an order to undergo a compulsory HIV test is guilty of an offence and is liable on conviction to a fine or imprisonment for a period not exceeding three years.[77] Any person who, with malicious intent, lays a charge with the SAPS in respect of an alleged sexual offence and makes an application in terms of section 30(1) with the intention of ascertaining the HIV status of any person is also guilty of an offence and is liable on conviction to a fine or imprisonment for a period not exceeding three years.[78]

In terms of section 32 of the Act, an investigating officer may also apply for the compulsory HIV-testing of an alleged offender and in this instance the type of crime that the offender allegedly committed is not confined to a sexual offence. Instead it includes any offence in which the HIV status of the offender may be relevant for the purposes of investigation or prosecution. If the magistrate in such an instance is satisfied that there is *prima facie* evidence that a sexual offence or other kind of offence has been committed by the offender and that an HIV test would appear to be necessary for the purposes of investigating or prosecuting the offence, the magistrate must order that the alleged offender undergo the HIV test.[79]

The fact that an order for the HIV testing of an alleged offender has been granted in terms of sections 31 and 32 of the Act may be communicated only to the victim and/or interested person(s), the alleged offender, the investigating officer, the

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76 Section 31(3) *Sexual Offences and Related Matters Act*.
77 Section 38(2) *Sexual Offences and Related Matters Act*.
78 Section 38(1)(a) *Sexual Offences and Related Matters Act.* The institution of a prosecution for this offence must be authorised in writing by the relevant Director of Public Prosecutions in terms of s 38(1)(c).
79 Section 32(3) *Sexual Offences and Related Matters Act*.

prosecutor where applicable, the persons who are required to execute the order, and any person who needs to know the test results for the purposes of any criminal of civil proceeding.[80] A sealed record of the test results must be handed to the victim and/or interested person(s), as well as to the alleged offender.[81] The test results may furthermore be used only in connection with the alleged offence under investigation.[82] Any person who with malicious intent or gross negligence discloses the results of any HIV test in contravention of section 37 of the Act (as set out above) is guilty of an offence and liable to a fine or imprisonment for a period that may not exceed three years.[83]

Although the high prevalence of both sexual violence and HIV/AIDS in South Africa certainly warrants the protection of the victims of sexual crimes and the enabling provisions dealing with the compulsory HIV-testing and disclosure of alleged sex offenders in the *Criminal Law (Sexual Offences and Related Matters) Amendment Act* 32 of 2007, it remains doubtful if these litigious provisions of the Act are justifiable.[84] The transmission of HIV/AIDS from the perpetrator to the victim of a sex crime is usually prevented by the use of post-exposure prophylaxis (PEP). PEP is a 28-day regimen of antiretroviral drugs which may prevent the transmission of HIV/AIDS and is given to victims up to 72 hours after the sexual violence had occurred. It is highly unlikely, however, that the procedures provided for in the *Criminal Law (Sexual Offences and Related Matters) Amendment Act* 32 of 2007 will be concluded within the 72-hour period within which the PEP regimen must be started. Also, if the perpetrator is in the window period of his/her HIV infection, in other words the first 3 to 6 weeks, or sometimes up to 12 weeks after the initial infection, during which period HIV antibody tests cannot detect the antibodies to the virus in the blood, the compulsory HIV test provided for in the Act will also be of no

80 Sections 36, 37 *Sexual Offences and Related Matters Act*.
81 Section 33 *Sexual Offences and Related Matters Act*.
82 Section 34 *Sexual Offences and Related Matters Act*.
83 Section 38(1)(b) *Sexual Offences and Related Matters Act.* The written authorisation of the relevant Director of Public Prosecutions is required for the institution of a prosecution for this particular offence.
84 Roehrs 2009 *SALJ* 390.

value to the victim, as the test result will be negative despite the perpetrator's positive status.[85]

Thus, victims of sex crimes should always use PEP as soon as possible after an attack and should definitely not wait for the outcome of the legal procedures described above.[86] The serious infringement of these mandatory provisions on a suspect's rights to be presumed innocent and the right to privacy and confidentiality is certainly debatable in the light of the uncertain value that the test results may hold for the victims of sex crime.[87]

8 Disclosure of the HIV-status of a healthcare worker[88]

The question of whether or not mandatory HIV testing should be implemented for all healthcare workers was raised in a 2008-2009 cross-sectional survey amongst members of the Association of Surgeons of South Africa.[89] It was submitted that all healthcare workers should know their status for the purpose of de-stigmatising the illness and promoting safer practices overall. A substantial majority of the surgeons were against such mandatory testing. They perceived it as discriminatory if only surgeons and none of the other health professions were to subject themselves to such mandatory testing, and they also submitted that it would undermine surgeon autonomy.[90] However, calls for such compulsory and/or routine testing are on the increase amongst some of the health professions, while others argue that strict and standard precautionary measures should always be employed to prevent HIV-infection of their patients by healthcare workers. It is submitted by those who argue for strict and standard precautionary measures instead of mandatory and routine follow-up testing that the standard precautionary measures will in actual fact preclude the requirement of mandatory and/or routine testing, as it will ensure that

85 Roehrs 2009 *SALJ* 395.
86 Roehrs 2009 *SALJ* 394.
87 Roehrs 2009 *SALJ* 396.
88 For research on the disclosure of the HIV/AIDS status of educators and other officials in education, see Maile 2003 *SAJE* 78-83; Maile 2003 *Acta Academia* 185-204.
89 Szabo *et al* 2009 *SAMJ* 110-113.
90 Szabo *et al* 2009 *SAMJ* 110-113.

the safest possible practices will always be employed, thereby limiting any risk of infection and contamination.[91]

Various guidelines and policy documents pronouncing on the management of HIV-infected practitioners exists. The 1991 guidelines issued by the Centres for Disease Control and Prevention (CDC) focus specifically on the prevention of the transmission of HIV and the hepatitis B virus from healthcare workers to patients. These guidelines, however, have been criticised on the grounds that they discriminate against practitioners without really contributing to and serving the best interests of patients.[92] The guidelines issued by the Health Professions Council of South Africa (HPCSA) for the management of patients infected with HIV or AIDS also provide for the management of infected practitioners. These guidelines contain recommendations with regard to such a practitioner's continuation in practice, the disclosure of his/her status, and the need to seek medical treatment and counselling. With regard to the disclosure of such a practitioner's status, the guidelines place no duty or obligation on the practitioner to disclose.[93] Similarly, the guidelines of the South African Medical Association also place no obligation on HIV-positive practitioners to disclose their status to patients, employers or co-workers. It is only recommended for HIV-infected practitioners to consider modifying their practice so as not to place patients at risk.[94]

It is argued that a patient's knowledge of a practitioner's HIV-status would not be in the patient's best interest as it might deter patients from undergoing certain necessary treatments which they believe might put them at risk, or it might deter patients from consulting HIV-infected practitioners simply because the practitioner is HIV-positive and not because of any doubt of the practitioner's skills and expertise.[95] The possibility also exists for patients to disseminate the information of a

91 Falk-Kessler, Barnowski and Salvant 1994 *Am J Occup Ther* 27-37; McQuoid-Mason 2007a *SAMJ* 416-420; Szabo *et al* 2009 *SAMJ* 110-113; Consten et al 1995 *AIDS* 585-588.
92 Szabo *et al* 2009 *SAMJ* 110-113.
93 Szabo *et al* 2009 *SAMJ* 110-113.
94 Szabo *et al* 2009 *SAMJ* 110-113.
95 Szabo *et al* 2009 *SAMJ* 110-113.

practitioner's HIV-status to others, as patients are not bound by ethical codes with regard to confidentiality.[96]

If, however, a practitioner's HIV-status is paramount to the diagnostic procedures and treatment options recommended in a particular instance, and it the practitioner's status might represent a risk, cost or consequence to the patient, it must be disclosed in terms of section 6(b) and 6(c) of the *National Health Act* 61 of 2003.[97]

9 Disclosure, confidentiality and home-based care for HIV-infected patients

With more than 33.3 million people living with HIV/AIDS worldwide and 16.6 million deaths due to AIDS-related illnesses recorded in 2009, home-based care for HIV/AIDS patients has become necessary in order to cope with the great demands placed on the healthcare sector, specifically with regard to hospitalisation and the continuity of care for patients.[98] The policy with regard to the confidentiality of an HIV diagnosis remains, however, and the term "chronic illnesses" is now a generic label used in public health documents to conceal HIV/AIDS as the primary source of such chronic conditions of poor health.[99] Yet maintaining the confidentiality of HIV patients and keeping pertinent information with regard to the illness from primary caregivers is controversial.[100]

While the right to privacy and confidentiality of HIV/AIDS patients is central, it is submitted that it also marginalises caregivers, who assume the bulk of the responsibility for the patient's wellbeing and are expected to adhere to standard precautions to prevent HIV infection.[101] The extension of the healer-patient relationship (discussed in part 4 above) to include caregivers and home-based care rather requires shared responsibility and confidentiality, together with the health

96 Szabo *et al* 2009 *SAMJ* 110-113.
97 Szabo *et al* 2009 *SAMJ* 110-113.
98 Avert Date unknown http://bit.ly/13IroqU; Makoae and Jubber 2008 *SAHARA J* 36-46.
99 Makoae and Jubber 2008 *SAHARA J* 37
100 Makoae and Jubber 2008 *SAHARA J* 37.
101 Makoae and Jubber 2008 *SAHARA J* 37.

care worker. Such a principle of shared responsibility and confidentiality, it is argued, also has the potential of de-stigmatising HIV/AIDS in those "… resource-poor contexts where families and communities shoulder most of the care responsibility".[102] Moreover, the notion of shared responsibility and confidentiality coincides with the African Ubuntu philosophy that provides the basis of social cohesion in African culture.[103] In terms of the Ubuntu philosophy human relationships are based on interdependence, trust, openness, and shared responsibility, reflecting a cultural value of communality and sharing.[104]

But while such shared responsibility and confidentiality may be in the best interests of the patient when it comes to the continuity and quality of home-based care, public health experts agreed at the 2001 Health Summit that HIV and AIDS should not be made a notifiable disease.[105] It was generally agreed that the stigma was too severe and that the compulsory disclosure of an individual's status was not conducive of effective public health practice and management.[106]

10 Disclosing the HIV/AIDS status of deceased patients

According to the ethical rules of the Health Professions Council of South Africa (HPCSA), the confidential information about a deceased patient (including his or her HIV-status) may be disclosed only if the written consent of that deceased person's next-of-kin is obtained, or if the written permission of the executor of the deceased person's estate is obtained.[107] Deviation from this general principle will be allowed only if the deceased's personal information must be disclosed in terms of a statute or

102 Makoae and Jubber 2008 *SAHARA J* 38.
103 Makoae and Jubber 2008 *SAHARA J* 38.
104 Makoae and Jubber 2008 *SAHARA J* 38.
105 Healthcare practitioners diagnosing a notifiable disease have an obligation to inform the local health authorities. The purpose of defining certain diseases as notifiable diseases is to actively control the spread of the disease by locating and contacting infected individuals and possibly submitting them to coercive measures and/or passively enabling the accurate surveillance of the spread of the notifiable disease (Roehrs 2009 *SALJ* 375; *Jansen van Vuuren v Kruger* 1993 4 SA 842 (AD)).
106 Roehrs 2009 *SALJ* 375.
107 McQuoid-Mason 2007b *SAMJ* 920-923; HPCSA *Booklet 14* Rule 12.

a court order, or if the disclosure is justified in the public interest.[108] It is therefore evident that in terms of the law there is no special protection for the deceased's right to privacy and confidentiality.[109]

However, medical practitioners continue indirectly to protect the confidentiality of the deceased when completing the compulsory BI 1663 form (the death certificate) in terms of the *Births and Deaths Registration Act* 51 of 1992.[110] The first page of the BI 1663 form is for the purposes of registering the death with the Department of Home Affairs and issuing a burial order, and the second page is required for medico-legal and statistical purposes.[111] This second page contains the demographic details of the deceased as well as the cause of death.[112] While the second page of the BI 1663 form is supposed to be sealed and attached to the first, the notion of confidentiality with regard to the deceased's cause of death is an illusion, as home affairs officials and funeral undertakers have to check the serial numbers, surnames, first names and demographic information of the deceased with the information contained on the first page.[113] It is for this reason that many medical practitioners are wary of indicating the cause of death due to AIDS-related illnesses.[114]

It is submitted by McQuoid-Mason that such practices are unethical, as rule 12 of the HPCSA recognises that a statute may require disclosure with regard to a deceased person's health status to be made. Also, the law imposes a duty upon medical practitioners to provide the correct information on the BI 1663 form (irrespective of the confidentiality concerns) and failure to do so is a criminal offence liable on conviction to a fine or imprisonment of 5 years or both.[115]

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108 McQuoid-Mason 2007b *SAMJ* 920-923; *Spendiff v East London Despatch Ltd* 1929 EDL 113.
109 McQuoid-Mason 2007b *SAMJ* 920-923.
110 McQuoid-Mason 2007b *SAMJ* 920-923.
111 It is said that the purpose of the BI 1663 form is to improve statistics on the cause of death, and this information is used to allow for the proper monitoring and development of health policies (McQuoid-Mason 2007b *SAMJ* 920-923).
112 McQuoid-Mason 2007b *SAMJ* 920-923.
113 McQuoid-Mason 2007b *SAMJ* 920-923.
114 McQuoid-Mason 2007b *SAMJ* 920-923.
115 McQuoid-Mason 2007b *SAMJ* 920-923; s 31 *Births and Deaths Registration Act* 51 of 1992.

11 Disclosure and the HIV status of minors

Should a minor/child be told the truth about his/her HIV status? Can minors be forced to undergo HIV testing, or when is a minor old enough to be told that he/she is HIV positive? While it has already been established that the disclosure of an adult's HIV status is a contentious issue, the disclosure of the status of a minor is even more complex and multilayered. It is said that the disclosure of a child's status is multilayered as it includes the disclosure of the information to the child, the parents of the child and other siblings or family members, as well as the anticipation of the child's own disclosure of this information to friends, family and the community.[116] Moreover, while the disclosure of the HIV status of an adult has received considerable attention in research and guidance documents, there are no guidelines on the paediatric disclosure of HIV/AIDS in South Africa.[117]

Although the early disclosure of a child's HIV status holds therapeutic value – in that the child will understand the risks and will generally cooperate in the treatment – it is advised that very young children under the age of 5 years or children with a developmental delay, or with poor intellectual capabilities, and/or children with severe emotional disturbances not be informed of their status. Such children should rather be assessed periodically and the information should be disclosed only if their circumstances change for the better.[118] The American Academy of Paediatrics furthermore emphasises the role of counselling before and after the disclosure, that the disclosure is individualised in order to meet the specific child's needs, and that the information provided must correspond with the specific child's cognitive ability, developmental stage, clinical status and social circumstances.[119] Moodley *et al* also warn that when and how a parent discloses to a child can affect the provision of care for the child and may influence the child's psychosocial adjustment and development.[120]

116 Naeem-Sheik and Gray 2005 *South African Journal of HIV Medicine* 46.
117 Moodley *et al* 2006 *SAMJ* 201.
118 Naeem-Sheik and Gray 2005 *South African Journal of HIV Medicine* 46.
119 Naeem-Sheik and Gray 2005 *South African Journal of HIV Medicine* 48.
120 Moodley *et al* 2006 *SAMJ* 201.

Section 130(1) of the *Children's Act* 38 of 2005 provides that no child may be tested for HIV unless it is in the best interest of the child and consent was given in terms of section 130(2) of the Act or if the test is necessary to establish if a healthcare worker (or any other person) may have contracted HIV due to contact with any substance from the child's body that may transmit HIV.

Section 130(2)(a) of the Act states that consent for an HIV test on a child may be given by the child only if the child is 12 years of age or older or under the age of 12 years but is of sufficient maturity to understand the benefits, risks and social implications of such a test.[121] Where the child is under the age of 12 and is not of sufficient maturity to understand the benefits, risks and social implications of the test the following persons may give consent on behalf of the child: the child's parent or caregiver,[122] the provincial head of social development,[123] a designated child protection organisation arranging the placement of the child,[124] and the superintendent or person in charge of a hospital if the child has no parent or caregiver and there is no designated child protection organisation arranging for the placement of the child.[125] The children's court may give consent on behalf of the child only if the consent by the roleplayers referred to above and in section 130(2)(a) to (d) of the Act is unreasonably withheld or the child or the parent or the caregiver of the child is incapable of giving consent.[126]

The Act furthermore provides for required counselling before and after testing,[127] as well as for the confidentiality of the information on the HIV/AIDS status of children.[128] Section 133 prohibits anybody from disclosing the HIV status of a child without the consent given by the child if the child is 12 years of age or older or is under the age of 12 years and is of sufficient maturity to understand the benefits,

121 Also see s 10 of the *Children's Act* 38 of 2005 re child participation.
122 Section 130(2)(b) *Children's Act* 38 of 2005.
123 Section130(2)(c) *Children's Act* 38 of 2005.
124 Section 130(2)(d) *Children's Act* 38 of 2005.
125 Section 130(2)(e) *Children's Act* 38 of 2005.
126 Section 130(2)(f) *Children's Act* 38 of 2005.
127 Section 132 *Children's Act* 38 of 2005.
128 Section 133 *Children's Act* 38 of 2005.

risks and social implications of such disclosure.[129] Consent on behalf of the child by the parent or caregiver, a designated child protection organisation arranging the placement of the child, the superintendent or person in charge of a hospital and the children's court is provided for *mutatis mutandis* as in section 130 of the Act.[130] However, disclosure of a child's HIV/AIDS status is permitted in those instances where it falls within the scope of a particular person's powers and duties in terms of the *Children's Act* or any other law that warrants the disclosure,[131] or when it is necessary for the purpose of carrying out the provisions of the *Children's Act*,[132] or for the purpose of legal proceedings,[133] or in terms of a court order.[134]

With regard to the treatment of minors specifically for HIV/AIDS the *Children's Act* is silent. It is interesting to note, however, that section 39(4)(b) of the now repealed *Child Care Act* 74 of 1983 did make specific provision for consent and the treatment of minors with HIV/AIDS. In terms of the *Child Care Act* a minor (a person under the age of 18 years) generally required the consent of a parent or caregiver in order to undergo medical treatment. Section 39(4)(b) of the *Child Care Act* provided that children over the age of 14 years but still under 18 years could consent to medical treatment without the assistance of a parent or guardian/caregiver.

Paediatric disclosure of HIV status is becoming increasingly important, due not only to the prevalence of HIV in South Africa but also to the scale-up of HIV treatment services in many parts of South Africa.[135] The current provisions of the *Children's Act* and *Child Care Act* discussed above also do not give due regard to the ethical conflicts that may exist between the autonomy of the consent giver vs the autonomy of the child, or the autonomy of the consent giver and the obligation to tell the truth, or the beneficence of knowing vs non maleficence.[136] Greater attention should

129 Section 133(2)(a) *Children's Act* 38 of 2005.
130 Section 133(2)(b) to (d) *Children's Act* 38 of 2005.
131 Section 133(1)(a) *Children's Act* 38 of 2005.
132 Section 133(1)(b) *Children's Act* 38 of 2005.
133 Section 133(1)(c) *Children's Act* 38 of 2005.
134 Section 133(1)(d) *Children's Act* 38 of 2005.
135 Moodley *et al* 2006 *SAMJ* 202.
136 Pfaff 2004 *SA Family Practice* 36-37.

therefore be given to issues of the HIV testing and disclosure of infected minors, as this may contribute to the improved quality of long-term care.[137]

12 Disclosure of school learners' HIV status

The impact of HIV/AIDS on children and the stigma associated therewith directly jeopardise a child's right *inter alia* to education.[138] Research indicates that HIV-positive learners are isolated and are often the target of other children's humiliation and bullying.[139] In the case of *Perreira v Buccleuch Montessori Pre-school and Primary (Pty) Ltd;*[140] for example, it was alleged that a child was denied access to the school because of his HIV status. However, the disclosure of the HIV status of teachers is just as problematic, as it is said that teachers living with AIDS are also seriously discriminated against by school managers, teaching colleagues and the students.[141]

There are two guidance documents that address the disclosure of HIV/AIDS in the context of education. First, Statement 1998:10 by the Department of Education states that all information pertaining to the medical condition of a learner, student or educator with HIV/AIDS must be kept confidential and that disclosure to third parties can be authorised only with the individual's informed consent.[142] The National Policy on HIV/AIDS for learners and educators in public schools and students and educators in further education and training institutions[143] also prohibits the mandatory testing of learners, students or educators and dismisses the notion of routine testing as there is said to be no medical justification for such programmes.[144]

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137 Moodley *et al* 2006 *SAMJ* 201.
138 Maile 2003 *Acta Academia* 186.
139 Maile 2003 *Acta Academia* 186.
140 *Perreira v Buccleuch Montessori Pre-school and Primary (Pty) Ltd* 2003 ZAGPHC 1.
141 Maile 2003 *SAJE* 78.
142 Referred to in Maile 2003 *SAJE* 80. Also see para 6 of the National Policy on HIV/AIDS for Learners and Educators in Public Schools, and Students and Educators in Further Education and Training Institutions (Gen N 1926 in GG 20372 of 10 August 1999).
143 Gen N 1926 in GG 20372 of 10 August 1999. Also see the SALC *Working Paper 58;* SALC *Discussion Paper 73*; SALC *Third Interim Report*.
144 Gen N 1926 in GG 20372 of 10 August 1999 para 4.3.

13 Conclusion

The non-consensual or inappropriate disclosure of another person's HIV/AIDS status may put the infected individual at great risk of human rights violations, including rejection, ostracism, unfair discrimination, the disruption of family relations, violence, sexual abuse or abandonment.[145] It may also affect the individual's employment, whether he/she may become a member of a medical aid scheme, life insurance, bonds and the general quality of life. Respect for a person's right to privacy and confidentiality (in the latter instance where information was disclosed in a special relationship between parties) therefore remains – irrespective of the particular context – the most important consideration in the treatment and management of HIV/AIDS. Not only does the preservation of confidentiality protect the privacy of the patient, but it also secures public health in general, as health practitioners will largely be discredited when patients trust and confidentiality is breached.[146] It is only with due regard to the privacy and autonomy of those infected or suffering from HIV/AIDS that we will be able to encourage those individuals to seek treatment and to disclose their HIV status themselves.

It is also due to the lack of standardised guidelines on the modalities of managing HIV disclosure in different contexts that patients' rights to privacy, autonomy and confidentiality should be used as the primary parameter in the disclosure of HIV/AIDS statuses.[147] The right to privacy in South Africa is protected as an independent personality right in section 14 of the *Constitution*. Privacy is also included within the concept *dignitas*, and is closely intertwined with the right to bodily and psychological integrity.[148] Privacy is, moreover, closely related to the concept of identity and it has been held that the right to privacy is not based on a notion of the unencumbered self but actually on the notion of what is necessary to have one's own autonomous identity.[149] The *Consumer Protection Act* 68 of 2008

145 Roehrs 2009 *SALJ* 372; Maile 2003 *SAJE* 78.
146 SALRC *Pre-employment HIV-testing* 2.40.1.2; *Jansen van Vuuren v Kruger* 1993 4 SA 842 (AD) 850B-D; *X v Y* 1988 2 All ER 648 (QB) 653a-b.
147 Adedimeji 2010 *SAHARA J* 18.
148 SALRC *Pre-employment HIV-testing* 5.10.3; Roehrs 2009 *SALJ* 361.
149 SALRC *Pre-employment HIV-testing* 5.10.4.

furthermore protects individuals' right to privacy in the context of consumer markets and consumer rights. It is said to present the most comprehensive set of consumer rights relating to privacy and within the context of consumer markets, which certainly apply to healthcare providers as well.[150]

It is submitted that the question of whether or not to disclose the HIV/AIDS status of a person in different contexts should be addressed through a rights-based approach and with specific consideration of the individual's rights to privacy, dignity, and bodily and psychological integrity. It is only by means of such a rights-based approach that the aspirations for public health and human rights in the context of HIV/AIDS can truly be realised. [151]

150 Jacobs, Stoop and Van Niekerk 2010 *PELJ* 320.
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List of abbreviations

Am J Occup Ther	American Journal of Occupational Therapy
CDC	Centres for Disease Control and Prevention
HPCSA	Health Professions Council of South Africa
PELJ	Potchefstroom Electronic Law Journal
PEP	post-exposure prophylaxis
SAHARA J	Journal of Social Aspects of HIV/AIDS Research Alliance
SAJE	South African Journal of Education
SALJ	South African Law Journal

SALC	South African Law Commission
SAMJ	South African Medical Journal
Stell L R	Stellenbosch Law Review
THRHR	Tydskrif vir Hedendaagse Romeins-Hollandse Reg
U Ill L Rev	University of Illinois Law Review