



A best practice guide to HIV disclosure



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FOREWORD

The first case of HIV in South Africa was detected nearly 25 years ago in 1985. Since then, HIV has grown to pandemic proportions and in 2009 it was estimated that over five million South Africans were living with HIV. Sadly, there have already been an estimated 2.5 million deaths due to HIV in South Africa.

This makes HIV and AIDS one of the greatest challenges that faces the government and people of the democratic South Africa. Fortunately, we now have an ambitious National Strategic Plan on HIV, AIDS and Sexually Transmitted Infections (2007–2011) that aims to reduce the number of new infections by 50% by the end of 2011 and to give access to treatment to 80% of people who need it. I would encourage every reader of this publication to know and understand this Strategic Plan.

However, HIV is not just a virus. It is also a disease of society and human relationships. It brings out both the best and the worst in how people treat each other. Tragically up to now, it has been more of the latter than the former. HIV has become an epidemic of stigma, unfair discrimination and even extreme violence against people known or suspected to have HIV. Our history is becoming full of untold stories of people who have had to face the cruelty of others simply because of

the fact that they live with the virus that is now treatable and manageable.

It is strange to think that in 2009 we still do not know the names of those political leaders, famous South African sports people or church leaders who live with HIV. In fact many people still think that they do not know anybody with HIV – despite the fact that nearly one in ten of us are infected. Only a few names are known: Zackie Achmat, Edwin Cameron, Nkosi Johnson and a few other brave people.

This is tragic because it helps a person to disclose their HIV status to a lover, a family member or a friend. It helps when it is possible to be open about HIV infection at school or in prison. It helps because although HIV is a treatable medical condition, with which people who have access to treatment can now live to old age, it is still a virus that frightens us and which requires people to make major changes to their lives, particularly their sex lives.

In these circumstances it is always easier to be able to share fears and challenges and get reassurance from people we love or trust.

It is important to promote openness about HIV, but it is equally important to protect human rights. It is important to recommend that each person has knowledge of their own HIV status. But it is also important to assure each person that the result of an HIV test is confidential and that decisions about

disclosure will be decisions that they themselves must make – rather than somebody else, be it a doctor, prison warder or employer.

Ending the stigma around HIV and fighting human rights violations is the best formula to promote openness.

In the context of these ongoing challenges, the publication of this manual on the law and best practices around disclosure is timely and important. I hope that it is widely used in workplaces, prisons and health facilities and that it informs and guides people to a better understanding of issues around privacy and HIV.

The objective of this publication is not to make HIV an epidemic of secrecy and to hinder disclosure, but to create as quickly as possible and in as many settings as possible a social environment where trust and understanding lay the foundation for openness and acceptance.

Mark Heywood

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Executive Director: AIDS Law Project

ABOUT THE CONTRIBUTORS AND THEIR ORGANISATIONS

Chapter 1

Ntombizozuko Dyani is a Law Lecturer at the School of Law, University of the Witwatersrand. She teaches constitutional law, human rights law and public international law. Her research interest is in constitutional law and international law, specifically law of armed conflict in Africa and the rights of women during armed conflict. She also has an interest in women's rights and children's rights in general.

Chapter 2

Dan Pretorius is a former trade unionist attorney and trainer working for the AIDS Law Project (ALP) and sitting part-time as a CCMA commissioner.

The **AIDS Law Project** is a human rights organisation that seeks to influence, develop and use the law to address the human rights implications of HIV and AIDS in South Africa, regionally and internationally, through policy processes, litigation, research and certain types of training. Developing content and a better understanding of the duties of the public and private sectors regarding the right of people to health care is a key ALP objective.

Chapter 3

Sasha Gear is a Senior Researcher at the Centre for the Study of Violence (CSVR) where she coordinates work on sexual violence in prison, conducts studies and works with prison staff on the issue, incorporating a broader concern with sexual health in prisons.

The Centre for the Study of Violence is an NGO that works to prevent violence, heal its effects and build sustainable peace and reconciliation in South Africa and internationally. It does this via a multidisciplinary approach and wide-ranging activities including research, policy formation, community interventions, service delivery, education and training, and the provision of consultancy services.

Chapter 4

Pierre Brouard is a Clinical Psychologist and has worked in the field of HIV and AIDS for over 20 years. Currently employed as the Deputy Director of the Centre for the Study of AIDS at the University of Pretoria, he has always been passionate about fairness and equity and this has informed his approach to HIV and AIDS.

The Centre for the Study of AIDS was established in 1999 and is a self-funded, stand alone, centre of excellence. Using the University of Pretoria as its base, the Centre aims to create new and innovative ways to address HIV and AIDS, human rights and development in Southern Africa, through the lens of social theory.



Chapter 1

**Constitutional values
and state obligations
regarding HIV and AIDS
and disclosure in South
Africa**

Ntombizozuko Dyani



The chapter in brief

The South African Constitution commits all institutions to human dignity, the achievement of equality and the advancement of human rights and freedoms. This chapter discusses these constitutional values and the state's obligations in relation to HIV and AIDS disclosure. It examines the state's legislative and policy efforts to date, including The National Health Act, The Medical Schemes Act, The Labour Relations Act, the Employment Equity Act, The Promotion of Equality and Prevention of Unfair Discrimination Act, The HIV and AIDS and Sexually Transmitted Infections (STI) and the National Strategic Plan 2007–2011.

The state should continue its efforts to combat discrimination and stigma around disclosure, as these social factors inhibit prevention of the disease. It should do this by:

- expediting the National Stigma Framework
- including HIV and AIDS as a specific ground for discrimination in PEPUDA
- distributing guidelines for health workers around disclosure.

The judiciary has played a crucial role in developing jurisprudence around HIV and AIDS, and should continue to do so.



Focus of this chapter and definition of disclosure

The South African Constitution of 1996 was adopted to be the foundation of the new democratic society. The Constitution expressly commits all state and private institutions to human dignity, the achievement of equality and the advancement of human rights and freedoms. This chapter discusses these constitutional values and the state's obligations in relation to HIV and AIDS disclosure. The chapter also makes some recommendations on the state's obligations in relation to HIV and AIDS disclosure.

Disclosure of a person's HIV and AIDS status can take place in three ways:

- an individual finds out about his or her HIV status and decides whether or not to disclose
- a health worker finds out someone's HIV status and decides to disclose such status
- a third party (public or private institution such as employers and schools) finds out someone's HIV status and decides to disclose such status.

Disclosure is discussed in the context of all state and private institutions and third parties who have a legal obligation towards a person living with HIV and AIDS.

An overview of the constitutional values that inform the state's obligations

Constitutional values inform and give substance to all the provisions of the Constitution.¹ The values are seen as interpretive guidelines that favour a certain way of understanding the Constitution. In the context of HIV and AIDS disclosure, the constitutional values prefer the interpretation of the provisions of the Constitution that promote human dignity, equality and freedom. This section discusses the values of equality and human dignity as they relate to disclosure issues, as well as the right to privacy.

Equality confers equal rights on people living with HIV and AIDS and those who are not

Everyone is equal before the law and has the right to equal protection and benefit of the law.² The Constitution defines equality to include 'the full and equal enjoyment of all rights and freedoms'.³ This means that a person living with HIV and AIDS has the same rights as a person who is not.

The goal is to build a country free of unfair discrimination

The Constitution does not assume that there is already equality in South Africa. It recognises that South Africans come out of a time in the past where the political and legal systems were based on inequality and unfair discrimination.⁴ Section 9 (3) of the Constitution provides that neither the state nor any person may unfairly discriminate directly or indirectly against anyone on one or more grounds, including race, gender, sex, pregnancy, marital status, conscience, belief, culture, language and birth.⁵ The Constitutional Court has also said that:

The goal is to develop a concept of unfair discrimination which affords each human being equal treatment on the basis of equal worth and freedom.

That goal cannot be achieved by insisting upon identical treatment in all circumstances before that goal is achieved. Each case, therefore, will require a careful and thorough understanding of the impact of the discriminatory action upon the particular people concerned to determine whether its overall impact is one which furthers the constitutional goal of equality or not.⁶

Everyone has inherent human dignity, including people living with HIV and AIDS

Section 10 of the Constitution states that everyone has inherent dignity and the right to have their dignity respected and protected. The state is required to respect and promote this right.

In addition to being a right in itself, dignity is used as an interpreting tool for the rights to privacy and equality. When a person's right to privacy is infringed (by disclosing one's HIV status without consent), the person's right to dignity is violated. Further, when one's right to equality has been infringed (for example, when unfairly discriminating against an employee living with HIV and AIDS for having disclosed his or her status), this also impacts on the person's right to dignity.

Involuntary disclosure of a person's HIV status is an affront to human dignity

Under our constitutional law a person living with HIV and AIDS's dignity is not impaired simply because of the disease. Other factors contribute to the impairment of such a person's human dignity, including unfair discrimination against and stigmatisation of a person who has disclosed that he or she is living with HIV and AIDS.

The Constitutional Court has reaffirmed that there is nothing shameful about suffering from HIV and AIDS because it is a disease like any other. However the social construction and stigma associated with the disease make fear, ignorance and discrimination the key factors hindering progress around its prevention. It is however, an affront to the person living with HIV and AIDS's dignity for another person to disclose details about a person's HIV status or any other private medical information without their consent.⁷ In other words, the fact that a person is HIV positive does not compromise their right to human dignity; what compromises this right is when another person, public or private institution discloses someone's HIV status to a third party without their consent.

Everyone has a right to privacy of their person, their property and to make certain decisions

Privacy in itself is not a value but is valued for the contribution that it makes to the freedom of choice.⁸ Therefore, the value of freedom (such as freedom of choice) goes hand in hand with privacy. Privacy is defined as the right of an individual to restrict availability by others to certain attributes of their person. This refers not only to physical places such as the human body, the home or private property, but also to certain kinds of decisions.⁹

In other words,

- The right to privacy leads to the freedom to choose whether or not to disclose one's HIV and AIDS status and how to disclose.
- The right to privacy also means that a person has the right to control information about themselves, such as one's HIV status, by keeping it confidential.¹⁰

The role of the legislature, the executive and the judiciary in protecting unwanted disclosure of a person's HIV status

The Constitution provides that the state must respect, protect, promote and fulfill the rights in the Bill of Rights. The Bill of Rights binds the legislature, the executive, and the judiciary. The state obligations also extend to any other institution which exercises a public power or performs a public function.¹¹

This section deals with the obligations of the three pillars to each contribute to the creation of a society that is based on equality, freedom and human dignity. The section looks at some laws, policies and court judgments that deal with HIV and disclosure, and their often negative consequences.

The legislature must make laws that prohibit unwanted disclosure and the effects of disclosure

In fulfilling one of its obligations, the legislature is required to make laws to prohibit the disclosure of a person's HIV and AIDS status without their informed consent. The legislature must also legislate against unfair discrimination. The laws discussed below, expressly or generally, are designed to ensure compliance with the state's constitutional obligations.

Laws in the health sector

The National Health Act of 2003

The National Health Act addresses the issue of medical confidentiality without expressly mentioning HIV and AIDS.

The Medical Schemes Act of 1998

Another legislative measure that has an impact on HIV and AIDS is the Medical Schemes Act. It is designed to ensure compliance with the constitutional obligations which include confidentiality of a person's medical records and other related matters.

Laws in the labour sector

Labour Relations Act 66 of 1995

The Labour Relations Act prohibits unfair dismissal of an employee on any listed grounds, although it does not include HIV and AIDS specifically. The Labour Relations Act also prohibits the employer from disclosing an employee's personal information (including HIV status) without the employee's written consent.

Employment Equity Act of 1998

The Employment Equity Act expressly protects against unfair discrimination on the basis of HIV status in the workplace. Furthermore, the Act prohibits employment related HIV testing unless authorised by the Labour Court. By removing the power over HIV testing from the employer to the Labour Court, the legislature has created the space for the Labour Court to develop standards for testing that are consistent with the constitutional values described above.

A Code of Good Practice on HIV and AIDS and Employment has been added to both the Labour Relations Act and the Employment Equity Act. This is a general guide on how employers, employees and trade unions should respond to HIV and AIDS in the workplace. The Code encourages all employers to develop a workplace HIV and AIDS programme. In addition, the Code prohibits unlawful disclosure of one's HIV status without written consent.

Laws on Equality

The Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (PEPUDA)

The Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000 (PEPUDA) came into being following an instruction in the Constitution to introduce new laws to enforce equality.¹² Although HIV and AIDS is not expressly listed under the seventeen grounds for non-discrimination in PEPUDA, discrimination is prohibited generally on any other ground where it perpetuates systematic disadvantage, undermines human dignity or adversely affects the equal enjoyment of a person's rights and freedoms in a serious manner that is comparable to discrimination on one of the listed grounds.¹³ HIV and AIDS is therefore protected as one of the 'other grounds'.

PEPUDA has taken a step further to ensure that people living with HIV and AIDS are protected from unfair discrimination by recognising that the HIV and AIDS status, whether real or perceived, leads to discrimination. PEPUDA states that the Minister of Justice must consider adding HIV and AIDS to the list of prohibited grounds.¹⁴ In the meantime, the courts can still decide on a case by case basis whether the rights of people living with HIV and AIDS have been infringed.

The executive must develop policies that prohibit unwanted disclosure and its negative effects, and implement laws and court judgments

The executive branch of government plays an important role with regard to issues of HIV and AIDS disclosure since it is constitutionally mandated to develop policies and to also implement the law, including the decisions of the courts. This section looks at some of the policies that the executive has created.

The Department of Health

Policy on HIV and AIDS and Sexual Transmitted Diseases in the Workplace, November 2000

The Department of Health has developed a policy on HIV and AIDS and Sexual Transmitted Diseases in the Workplace, in which it is stated that employees have the right to confidentiality with regard to their HIV and AIDS status.

This policy also prohibits unlawful disclosure by the employer without written consent from the employee. It also requires that employees should be informed and educated about HIV and AIDS, including the means of preventing transmission, the need for counselling and care, and the social impact of infection on those who are infected and affected by the disease.

The Department of Education

Policy on HIV and AIDS for Learners and Educators in Public Schools and Students and Educators in Further Education and Training Institutions, August 1999

The Department of Education has also developed a policy on HIV and AIDS for Learners and Educators in Public Schools and Students and Educators in Further Education and Training Institutions.¹⁵ This policy encourages voluntary disclosure of one's status and prohibits mandatory disclosure. It also requires a holistic programme for life skills and HIV and AIDS education.

The policy requires that the educators be educated about HIV and AIDS, including disclosure, so that they can also inform the students about the disease. Part of this education is the fact that people living with HIV and AIDS need to be treated the same way as those people who are HIV and AIDS free. In this way, the Department seeks to condemn unfair discrimination and stigmatisation of people living with HIV and AIDS as undesirable and unlawful.

National policy

The HIV and AIDS and Sexually Transmitted Infections (STI) National Strategic Plan 2007–2011 (the NSP)

The HIV & AIDS and STI National Strategic Plan grew out of the previous National Strategic Plan (2000–2005). When all the stakeholders assessed the implementation of this latter policy, they observed that, amongst others, stigma and discrimination remain unacceptably high and this has been a deterrent to the use of some of the services.¹⁶

One of the priority areas of the NSP is that of human rights and access to justice; it outlines goals and objectives to promote these rights and address discrimination. One of its goals is to ensure public knowledge of and adherence to legal and policy provisions including:

- developing and distributing guidelines for health workers on human rights and confidentiality
- ensuring adherence to existing legislation and policy relating to HIV and AIDS, particularly in employment and education
- conducting a national analysis of the implementation of HIV and AIDS programmes in workplaces
- finalising and implementing a national agreement on a framework for HIV and AIDS policy and programmes in the workplace; developing and distributing a national

guideline of rights of children in schools to access to information, prevention, treatment, care and support, and

- developing and distributing guidelines for health workers on human rights and confidentiality and disclosure. Further to the Priority Area on Human Rights, the NSP has objectives requiring the promotion of openness and disclosure and involvement of people living with HIV and AIDS in programmes in Priority Area on Prevention and Priority Area on Treatment.

The policies and aspirations expressed in the NSP are commendable; however, more could be done to ensure that these policies become law. For example, the NSP highlights the problems relating to stigma and discrimination in its situational analysis. However, there is no mention of stigma in any of the goals outlined in the rest of the NSP. Stigma and discrimination are the important issues that need to be dealt with before reaching any other goal, because of the impact they have on people living with HIV and AIDS.

The National Stigma Framework

One assumes that the National Stigma Framework, which is still in a draft format, will fill in some of the gaps of the NSP.¹⁷ This framework attempts to be a guideline for the implementation of HIV and AIDS related stigma–reduction interventions by the government and its partners.

The judiciary must interpret the law in accordance with the constitutional values of equality, dignity and freedom

The judiciary, in interpreting the law in terms of the constitutional values, has played a crucial role in relation to HIV and AIDS disclosure. It has decided a number of cases addressing HIV and AIDS related issues directly.¹⁸ In most of these cases, the judiciary has produced an emerging body of jurisprudence in which constitutional values of dignity, equality, freedom, unfair discrimination limitation of rights and privacy and confidentiality have been explained.

Disclosure and the right to privacy

An example of one's right to privacy in the context of HIV and AIDS disclosures is the Constitutional Court case of *NM and Others v Smith and Others (Freedom of Expression Institute as amicus curiae)*,¹⁹ where the names of three HIV positive women were disclosed without their consent in a biography of Patricia De Lille. Because of the disclosure of their status, the applicants testified that their circumstances changed for the worse: the first applicant had her shack burned down by her boyfriend who had since left her and broken off that relationship; the second applicant had withdrawn from society for fear of being ostracised by her family; and the third applicant had not told members of her family about her condition, which depressed her.

The Court made the following findings:

- There are special circumstances which justify the protection of confidentiality, bearing in mind that the disclosure of the condition has serious personal and social circumstances for the HIV positive person.
- Private and confidential medical information contains highly sensitive and personal information about individuals. The personal and intimate nature of an individual's health information, unlike other forms of

documentation, reflects delicate decisions and choices relating to issues pertaining to bodily and psychological integrity and personal autonomy.²⁰

- The Court stated that individuals value the privacy of confidential medical information because of the vast number of people who could have access to the information and the potential harmful effects that may result from disclosure.
- The lack of respect for private medical information and its subsequent disclosure may result in fear, thus jeopardising an individual's right to make certain fundamental choices that he or she has a right to make. There is therefore a strong privacy interest in maintaining confidentiality.²¹
- The Court rejected the idea that once someone discloses their HIV and AIDS status, others can freely disclose such status without the discloser's consent. In other words, the Court's view is that an individual does not automatically consent to or expect the release of information to others outside the administration of health care.²²

Disclosure, equality and unfair discrimination

People living with HIV and AIDS suffer unfair discrimination in the hands of private and public institutions, especially in the workplace. *Hoffmann v South African Airways* is an example of a case where the principle of equality was enunciated.²³ In this case, the applicant sued when he was denied employment by South African Airways because of his HIV status. The Court found that people who are living with HIV constitute a minority, and that society has responded to their plight with intense prejudice. It noted that people living with HIV have been subjected to systematic disadvantage and discrimination, and have been stigmatised and marginalised.²⁴ The Court made the following observations:

- At the heart of the prohibition of unfair discrimination is the recognition that under our Constitution all human beings, regardless of their position in society, must be accorded equal dignity; that that dignity is impaired when a person is unfairly discriminated against.
- The determining factor regarding the unfairness of the discrimination is its impact on the person discriminated against.²⁵
- In addressing the question of the impact of discrimination against people living with HIV, the Court noted that

people living with HIV and AIDS are denied employment opportunities because of their HIV positive status without regard to their ability to perform the duties of the position from which they have been excluded.

- The Court then made an important remark that society's response to people living with HIV and AIDS has forced many not to reveal their HIV status for fear of prejudice. The effect of this is that it has deprived many of their ability to come forward for counseling, testing, early education and treatment. Instead, most remain beyond the reach of health services and pose a risk to the community at large. It is within this context that people living with HIV and AIDS are one of the most vulnerable groups in South African society. ²⁶

Recommendations on how the state can ensure that its constitutional obligations are met regarding HIV and AIDS disclosure

This section recommends that the state develop a general policy informing all South Africans about stigma; that it enacts legislation dealing with HIV and AIDS specifically or includes it in existing legislation; that the National Stigma Framework be expedited and guidelines for health workers around disclosure be distributed, and that the courts use their full powers to ensure the state meets its obligations.

A general policy informing all South Africans about stigma and discrimination is needed

- Stigma and discrimination are two of the problems that the NSP states still need to be tackled. While the NSP is committed to ending stigma by creating knowledge and competence about HIV and AIDS especially within communities, the state needs to develop a policy that

will educate the public, specifically tackling the issues of stigma and discrimination. Educating the public should be an ongoing project.

Legislation needs to tackle stigma and discrimination directly in PEPUDA

- This also links to the state's failure to enact legislation to include HIV and AIDS as one of the grounds of unfair discrimination under PEPUDA. The state should expedite its consideration of the inclusion of HIV and AIDS as one of the listed grounds of discrimination under PEPUDA.

Policies for health workers are needed and the National Stigma Framework needs to be expedited

- The Department of Health and its partners are urged to develop a final draft of the National Stigma Framework so that policies can be developed on how to combat the stigmatisation of people living with HIV and AIDS. This is important in reaching the ultimate goal of reducing new infections and to also encourage voluntary disclosure without fearing stigma and discrimination.
- The NSP acknowledges that one of the interventions still needed regarding HIV and AIDS is to develop and

distribute guidelines for health workers on human rights and confidentiality and disclosure. Therefore, policies to train health care personnel on how to handle sensitive medical information both in verbal, print and electronic formats are required.

The courts should oblige the state to pass laws promptly

- The judiciary could do more to address HIV and AIDS disclosure. For example, courts can grant mandatory orders that require the state to pass laws promptly, by a predetermined date, for instance, on HIV and AIDS stigmatisation and unfairness. Courts can even give a suspended order until such time that the legislature develops the relevant laws.²⁷

Endnotes

- 1 *Minister of Home Affairs v National Institute for Crime Prevention and the Re-Integration of Offenders (NICRO) and Others* 2005 (3) SA 280 (CC) para 21.
- 2 Section 9 of the Constitution.
- 3 Section 9(2) of the Constitution.
- 4 Ian Currie and Johan De Waal *The Bill of Rights Handbook* (2005) 231.
- 5 Section 9(3) of the Constitution.
- 6 *President of the Republic of South Africa v Hugo* 1997 (4) SA 1 (CC) para 41.
- 7 *NM v Smith* para 2007 (5) SA 250 (CC) 48.
- 8 *Bernstein and Others v Bester NO and Others* 1996 (2) SA 751 (CC).
- 9 *Case v Minister of Safety and Security* 1996 (3) SA 617 (CC) para 91.
- 10 *S v A* 1971 2 SA 294 (T).
- 11 Section 239 of the Constitution.
- 12 Section 9(3) of the Constitution states that 'National Legislation must be enacted to prevent or prohibit unfair discrimination'.
- 13 Section 1 of PEPUDA.
- 14 Section 34 (1)(a) of PEPUDA.
- 15 *Government Gazette* 410 No 20372, Notice 1926 of 1999, 10 August 1999.
- 16 Broad Framework for HIV & AIDS and STI Strategic Plan for South Africa, 2007–2011, November 2006.
- 17 Department of Health, Draft of 5 May 2008.
- 18 Examples are *Hoffmann v South African Airways* 2001 (1) SA 1 (CC); *NM V Smith and Jansen van Vuuren v Kruger* 1993 (4) SA 842 (A).
- 19 *Ibid.*
- 20 Para 40.
- 21 Para 41.
- 22 Para 44.

- 23 2001 (1) SA 1 (CC).
- 24 Para 28.
- 25 Para 27.
- 26 *Hoffmann v South African Airways* para 28.
- 27 For example in the case of *Minister of Home Affairs v Fourie (Doctors for Life International and Others, Amici Curiae) Lesbian and Gay Equality Project and Others v Minister of Home Affairs* 2006 (1) SA 524 (CC), the Constitutional Court held that declarations of invalidity of certain provisions of the Marriage Act 25 of 1961 and the common law were suspended for 12 months from the date of the judgment to allow the legislature to correct the defects. If the legislature did not correct the defect within the prescribed period, the order was to kick in.



Chapter 2

**Disclosure in the
workplace: Some
best practice
recommendations**

Dan Pretorius



The chapter in brief

Disclosure of a person's HIV positive status in the workplace is at present mostly a risky and potentially damaging act for the employee. But it need not be: in a safe, confidential and supportive work environment, disclosure of HIV status could provide concrete benefits to employees, such as access to medical care. This chapter examines current laws and policies relating to HIV and disclosure and concludes that they are insufficient, in the sense that there is no compulsory obligation on employers to run workplace programmes promoting anti-discrimination and anti-stigmatisation of employees with HIV and AIDS.

The following recommendations are made that would create a conducive environment for disclosure in the workplace:

- Ongoing participative workplace programmes should be promoted
- Disclosure procedures must be clearly set out
- There is a need to amend and update existing legislation to promote confidentiality and protections against involuntary disclosure in workplaces.

The chapter recommends actual wording for some of the clauses that should go into any HIV and AIDS workplace policy.



Focus of this chapter and definition of disclosure

This chapter covers:

- Voluntary disclosure of their own HIV status by employees (including managers) to their employers, or to other employees in the workplace
- Legal protections against involuntary or forced disclosure in the workplace
- Voluntary and/or negligent disclosure by employees or managers concerning the HIV status of other employees, who are living with HIV, in the workplace.

Disclosure in this chapter refers to the passing on of private and confidential medical information relating to oneself or to another person. This includes verbal and written disclosure.

An overview of HIV and AIDS generally in the workplace

At present, the majority of employees avoid disclosing their HIV or AIDS status, as they fear discrimination, stigma or another form of victimisation. This section points out some of the benefits that employees could receive if the working environment was conducive to disclosure.

HIV and AIDS affects many areas of the infected person's life, including their working life. Many employees who have disclosed their HIV status have found themselves the victims of stigma and discrimination; some have even been dismissed, burdening them additionally with joblessness and being without an income. It is no wonder that employees are reluctant to test for or to disclose their positive status.

Yet disclosure need not have detrimental consequences for employees. Positive consequences can follow when employers encourage employees to test for HIV and then offer employees' assistance to manage their HIV status, just like managing other chronic illnesses.

Disclosure of HIV status can bring employees peace of mind if they feel safe and supported in their workplace. But employees can only feel sufficiently safe to test and disclose their status to their employer or co-employees if there is a clear and demonstrated commitment by the employer and their co-employees to human rights for HIV positive workers. For this to happen, employers need clear policies on HIV and AIDS in the workplace that ensure non-discrimination and protect confidentiality. They also need workplace programmes that offer concrete benefits to HIV positive employees, such as information, care, support and access to treatment.

However, this is not the case in the majority of workplaces in South Africa. Recent research shows that in 75 percent of those workplaces that already have the best of the available HIV and AIDS workplace policies and programmes in place (such as mines and financial services companies), employees who disclose their HIV status still experience stigma and discrimination. Given this lack of sufficient support by employers and the prevailing climate of stigma amongst employees and managers, the majority of employees living with HIV currently avoid HIV disclosure in the workplace if possible.

Current legislation relating to HIV disclosure in the workplace in South Africa

This section gives an overview of the legislation currently in place.

The Constitution of South Africa of 1996

The Constitution provides for everyone's right to fair labour practices, as well as rights to equality, human dignity and not to be subjected to unfair discrimination. Although HIV status is not specifically listed as a ground for unfair discrimination in the Constitution, it has already been held to be an analogous ground in a 2000 Constitutional Court case involving an applicant for employment as a cabin attendant (*Hoffman v South African Airways*). This case is discussed in Chapter 1 of this volume.

The Labour Relations Act of 1995

The Labour Relations Act does not mention HIV and AIDS specifically. It does, however, deal with privacy, stating

that employees have a right to privacy with regard to their personal and private information, including any personal medical information.²⁸ Employers are not required to disclose information that is confidential and which, if disclosed, may cause substantial harm to an employee or that is private personal information relating to an employee, unless that employee consents to the disclosure of that information. HIV and AIDS has also been established as an analogous ground for automatically unfair dismissal linked to unfair discrimination.

The Employment Equity Act of 1998

The Employment Equity Act (EEA) deals with HIV and AIDS, specifically in relation to unfair discrimination. It does not, however, deal with disclosure.

The Act provides that no employer may ask an employee to take an HIV test to find out their HIV status. This also applies to applicants for jobs. If an employer feels that an HIV negative status is an 'inherent requirement' of a job, they would have to prove this to the Labour Court in an application for permission to require an employee to test for HIV. Without this application, confidentiality is absolutely protected.²⁹

An employee is under no obligation to disclose his or her HIV status to an employer, any other employee or anyone associated with the organisation.

The Act makes provision for every workplace over 50 people to have workplace policies and programmes relating to employment equity, and to report on progress to the Department of Labour at regular intervals.

However the more detailed employment equity provisions in the EEA and regulations tend to focus on race and gender discrimination, and not on discrimination linked to HIV and AIDS. Whether employers' reports adequately cover HIV and AIDS issues could depend on how an employer reads the details in the regulations and Codes. Likewise, because of the sparse, intermittent and mainly non-specific references about employers' obligations to address HIV issues in the EEA regulations, these can easily be ignored or misinterpreted by unwilling employers.

Current policies relating to HIV disclosure in the workplace in South Africa

This section deals with the Codes attached to legislation on how to deal with HIV and AIDS issues as well as the National Strategic Plan on HIV and AIDS and STIs. It points out that these are meant as guidelines, and do not carry the same force as legislation.

National Strategic Plan on HIV and AIDS and STIs 2007–2011

No current tripartite agreement on HIV and AIDS in the workplace exists yet, although this is under discussion in the National Economic Development and Labour Advisory Council (Nedlac). The current National Strategic Plan on HIV and AIDS and STIs, 2007–2011 (NSP) which covers employers, government, labour and communities, contains provisions applying to workplaces and calls on all employers to have workplace policies on HIV and AIDS by 2011. The current Nedlac discussions are about how to give substance to these obligations, as well as how to meet other NSP targets.

Workplace policies and programmes are currently only being implemented in larger workplaces in the private sector (primarily in the larger mines and financial services companies, and partly in larger transport and manufacturing companies). The public sector is consulting broadly on a comprehensive overhaul of their workplace policies and programmes in order to try to meet the ambitious NSP targets. In 2009, we have not reached half of the 2007–2011 of the NSP targets.

Code of Good Practice on the Integration of Employment Equity into Human Resource Policies and Practices

The Code of Good Practice on the Integration of Employment Equity into Human Resource Policies and Practices deals specifically with disclosure and confidentiality issues. The Code:

- prohibits disclosure of HIV status unless the employee gives written permission
- prohibits collection and retention of information on employees' HIV status unless this is for an identifiable employment purpose
- directs employers to keep this information secure and only accessible to those who must use it

- provides that a written record must be kept of such access, with employees being given the right to access and correct such information.³⁰

Code of Good Practice on Key Aspects of HIV/AIDS and Employment

This Code summarises all the relevant workplace laws impacting on workers living with HIV. However, it dates to December 2000, which pre-dates free public health access to antiretroviral treatment for managing HIV. The NSP directs that this Code, although still relevant in many respects, should be updated to cover developments since 2000.

According to this Code, an employee may choose to disclose their HIV status, either to a limited number of employees (such as an HR manager, a supervisor or an occupational health worker) or to the entire workforce. If so, they must expressly consent in writing to such disclosure.³¹

The Code also addresses the need for adequate workplace policy and programmes on HIV and AIDS. However it also states that these are not obligatory. It can however be strongly argued that the creation of a national tripartite code means that any employer who does not stick to the Code must show very good reasons if challenged on any departure from the provisions of the Code.

Data protection guidelines

While South Africa awaits the passing of the proposed Protection of Personal Information Bill (a process begun in 2000), international data protection standards and especially the International Labour Organisation (ILO) Code of Practice on the Protection of Workers' Personal Data, 1997 provide guidance on the following areas for data protection, especially with regard to sensitive information, such as employees' HIV status, suggesting that in the workplace:

- employees must know the reason for processing any data
- data which identifies employees individually may only be kept until the purpose for which it was collected is discharged
- personal data must not be kept longer than necessary
- systems must ensure data is only available for its original and agreed purpose
- employees must give clear and unambiguous consent for use of their personal and health information
- employees have the right to access copies and correct any such information
- employers must keep records of who accesses such data and discipline anyone who does not respect privacy, and

- employers must provide training on data access and appropriate storage, for example, personal health information should be stored only by personnel bound by the rules of medical secrecy.

So far these guidelines on securing personal information in workplaces are partly covered in section 17 of the Department of Labour's August 2005 Code of Good Practice on the Integration of Employment Equity into Human Resource Policies and Practices.

The impact of current policies and practices on workplaces

Since workplace policies and programmes are not obligatory for companies, very few small and medium-sized companies have them in place. The Department of Labour and trade unions have not been effective in persuading all employers to have such policies and programmes in place and to report on progress regularly. HIV related stigma and discrimination inside the workplace following on disclosure and sometimes leaking into the surrounding community is a reality and prevents many employees from disclosing their status, accessing legal protections and any prevention, care and treatment services that are available through their employers. This section gives actual examples of breaches of confidentiality and their consequences.

Breaches of confidentiality in the workplace have serious consequences for the employee

Union representatives report a lack of confidentiality regarding HIV and AIDS in workplaces. Examples they give of resulting problems for employees who have disclosed their status in the workplace include:

- dismissals
- limited or no assistance in claiming compensation for occupationally acquired diseases
- occupational doctors misleading HIV positive workers about treatment in order to make them leave the workplace instead of continuing to work after accessing treatment
- doctors disclosing the HIV status of employees to managers without their consent.

Employees who test positive need ongoing and pro-active support from managers

Some employees disclose their status to their employers soon after being diagnosed HIV positive and before they have

considered the possible consequences (particularly if they have not had the legally mandatory pre- and post-test counselling). This may be because they are shocked and stressed and mistakenly still believe that HIV is an early-onset terminal illness, instead of a chronic, manageable disease, such as diabetes, asthma or hypertension.

Currently few managers take active steps to dispel such misconceptions and to make sure that all supervisors under their control provide timely and adequate support or better, pre-empt such fearful reactions by providing enough information and support for such workers to respond more positively after learning of their HIV positive status. Such information should include:

- how HIV is and is not transmitted
- safer sex methods
- symptoms
- access to treatment
- social grants for families
- support through counselling, and
- legal support if evicted, unfairly treated, dismissed or discriminated against, or for future planning, such as making a will.

Ongoing programmes at general medical facilities increase uptake for testing

Where employees fear a breach of confidentiality, they may be reluctant to use HIV related on-site services. The uptake of medical and counselling services offered by employers at sites specifically designated for HIV, as opposed to more general medical facilities, may be low.

Employees may also be reluctant to participate in once-off events, such as HIV voluntary counselling and testing days, as opposed to more gradually taking part in ongoing programmes and services where there is no assurance of confidentiality and support.

Outsourcing HIV management to specialised professional health care management providers can reduce some of these problems, but unions and employees will continue to be concerned about the consequences of disclosure of employees' HIV status in the light of such providers' commercial relationship with employers.

Examples of breaches of confidentiality

- Senior management asked nurses at the on-site workplace clinic to give names of those who had volunteered for testing and counselling.
- A provincial government employee who disclosed her status publicly in the supportive atmosphere of a World AIDS Day event was later verbally harassed in hurtful and abusive terms and isolated by her colleagues.
- A mechanic employed by a small company was dismissed for incapacity despite producing a doctor's certificate saying he had started antiretroviral treatment and was fit to work.
- A metal worker disclosed his HIV status to his supervisor and a co-worker, expecting them to maintain confidentiality. But he discovered that everyone in the workplace knew his status and when this information reached the surrounding community, relatives started pressuring his girlfriend to leave him.

Recommendations on disclosure procedures and obligations in the workplace

This section contains some practical and implementable recommendations to improve voluntary disclosure in a supportive and safe environment.

Ongoing participative workplace programmes should be promoted

- Employers should provide on-site educational and awareness programmes, for both management personnel and staff, in order to reduce HIV discrimination and stigma.
- Any workplace HIV and AIDS programme should encourage workers living openly with HIV to conduct and participate in education, prevention, and awareness programmes by providing paid time off and ensuring that workers who are open about their HIV status are not unfairly discriminated against or stigmatised.

- The employer should promote the development of support groups for workers living with HIV, including by giving space and paid time off for them to meet.
- Employers should use workplace HIV and AIDS policies and programmes to promote knowledge about voluntary counselling and training, where and how to access treatment (and provide information directed at HIV positive employees publicising the benefits and effectiveness of medical treatment), and where and how to access support services, such as temporary disability grants.
- Employers should ensure that any workplace programmes should be ongoing, to build trust and confidence.
- Workplace HIV and AIDS programmes should start from consultation with all groups in the workplace, using trade unions or other employee representatives where these exist. A joint committee on HIV can be established, getting expert evidence and referring to the legislative guidelines, drafting a policy and consulting on it, then finalising, circulating and implementing it. People in the workplace living with HIV should be equal partners in all phases of planning and implementation.
- Workplace HIV and AIDS programmes should set clear targets with indicators, allocate persons/mechanisms for monitoring, evaluate and update policy on an annual

basis, and consult with experts to ensure that the policy takes account of rapid advances in medical science and legal practice. No programme can succeed without the allocation of adequate funds and persons to carry out the programmes.

Clauses that should be part of HIV and AIDS workplace policies

Employers should establish a respect for human rights as a foundation for any interactions involving HIV and AIDS, linking this to workers' rights to privacy and dignity in terms of the Constitution.

Workplaces should use HIV policies and programmes to guarantee non-disclosure and confidentiality.

Only once these protections are in place, known to all supervisors at every level and signed off by the Chief Executive Officer, may employees feel safe enough to disclose their status more easily. These lay the basis for an atmosphere which will encourage openness, acceptance and support for employers and employees who disclose their HIV status.

Recommended clauses to achieve the above should include:

- The parties (employer and employees) will work together to end unfair discrimination and stigmatisation against

people on the basis of real or perceived HIV status, and to ensure that employees with HIV are able to continue working for as long as they are able to do so.

- The parties will ensure that no employee or job applicant with HIV experiences unfair discrimination in recruitment procedures, advertising and selection criteria, appointments, the appointments process, job placement, job classification, job grading, wages and terms of employment, employment benefits, accommodation, employee assistance programmes, job assignments, training and development, performance evaluation, promotion, transfer, demotion and termination of services.
- A manager, supervisor or other employee who discriminates, harasses or otherwise mistreats an employee with HIV shall face normal disciplinary procedures.
- Co-employees are expected to continue working relationships with employees living with HIV and AIDS. Employees who refuse to work with such fellow employees must be counselled and provided with adequate access to information on transmission of the disease. Following such education and counselling, if an employee continues to refuse to work with an infected employee, that employee may be subject to disciplinary action.

Disclosure procedures must be clearly set out

Better practice disclosure clauses in workplace programmes should at least include clauses such as:

- All disclosure of private and personal information in the workplace should be voluntary and confidential.
- No actual or prospective employee may be required to declare their HIV status.
- If any employee chooses to disclose their HIV status to their employer, this information may not be disclosed to anyone else without their express written consent.
- Any information disclosed to an employer about an employee's HIV status should be kept secure. Employers should keep a written record of the express written consent from the employee to any disclosure, a record of the names of those to whom this information has been revealed and for what purpose.
- Employees should be allowed to check the accuracy of any medical information relating to them, and to rectify and update it.
- If any employee volunteers to be tested, the test results will be kept only in medical files accessible to medical

personnel only and fully confidential. If this information is held in the workplace, the employer will ensure that such files are not marked or flagged to indicate HIV status.

- Trustees and administrators of retirement, provident and medical scheme funds may not disclose the identity of an employee living with HIV and AIDS to the employer, any employees or to the union without the employee's written permission.

There is a need for amended and updated legislation to enforce confidentiality and protections against involuntary disclosure in workplaces

- The Department of Labour should further clarify that employers are compelled to report on their HIV and AIDS workplace plans and policies, including provisions to secure confidentiality of private and personal information.
- The revised Code of Good Practice on HIV and AIDS in workplaces should make it compulsory for all workplaces to have an HIV and AIDS workplace policy and programmes, clearly covering provisions related to the disclosure of an employee's HIV status.

- More recognition by smaller employers of the need to report on their employment equity plans, also in relation to HIV, will add impetus to the achievement of the goals of the National Strategic Plan on HIV and AIDS and STIs, 2007–2011 through more and better-implemented workplace policies and programmes.

Endnotes

28 Section 16(5)(d).

29 Section 50(4), read with section 7 of the Employment Equity Act as amended.

30 Section 17.3.

31 Sections 7.1 and 7.2.



Chapter 3

Disclosure in
prison settings
and criminal law:
Some best practice
recommendations

Sasha Gear



The chapter in brief

Prisons (now referred to as ‘correctional centres’) are total institutions, and as such pose particular challenges for inmates and prison staff regarding disclosure of HIV. For inmates, an initial issue they have to deal with may be who to disclose to. They may not only have a family or partner(s) outside to consider in their disclosure decisions, but also other inmates with whom they live in very close proximity and have different kinds of relationship, including sexual ones. Disclosing an HIV positive status may also mean that they face discrimination, stigma and even victimisation as a result.

Because inmates are largely shut off from outside society, correctional services’ officers play a fundamental role in ensuring that they have access to health care services and information, and in protecting the confidentiality of prisoners’ disclosures. In addition, they are crucial in protecting inmates from stigmatisation or discrimination. Also important is the attitude of correctional service workers towards their own HIV testing and status.

Although the Department of Correctional Services has adopted a ‘Framework for the Implementation of Comprehensive HIV and AIDS Programmes and

Services for Offenders and Personnel 2007–2011’, and subsequently, additional guidelines, these need much fleshing out before they can be effectively implemented and monitored in prison settings.

Some practical recommendations around disclosure in prison settings include:

- Staff need training to deal with disclosure such as on the importance of confidentiality; in understanding and engaging with homophobia, discrimination, stigmatisation and victimisation in prison.
- Health workers who examine prisoners on arrival must use this opportunity to educate and provide support for disclosure and other HIV related services.
- Prison staff should be trained to detect health problems early and to act swiftly to ensure that inmates are linked with the necessary services.
- All staff need to observe confidentiality, including security staff and doctors. Staff members who do not should be disciplined and these offences should be clearly stated in disciplinary codes.



Focus of this chapter and definition of disclosure

This chapter focuses on the implications of a prison setting on prisoners' disclosure of their HIV positive status, in relation to:

- Inmates disclosing to regular prison staff and prison health care workers
- Disclosure of inmates' statuses by health care workers to other health care workers in other prisons and the community (in cases of inmate release or transfer)

- Inmates' disclosure to family, friends, partners and children's care givers outside of prison
- Inadvertent disclosures that occur in prisons where daily movements are scrutinised by fellow inmates and staff.

An overview of HIV and AIDS in prisons

This section deals with the unique characteristics of prisons, which provide the setting for challenges faced by prisoners in disclosing their HIV positive status. It stresses the importance of the attitude that prison staff have towards prisoners accessing health care and health care information, towards HIV disclosure and confidentiality, and towards preventing discrimination and stigmatisation as a result of disclosure.

South African prisons – like most others globally – hold particular and critical challenges regarding the HIV pandemic. Inmate populations tend to have higher rates of HIV infection than the broader population. High levels of incarceration combined with continuous movement of people between prisons and the ‘outside’, make HIV and AIDS as much an issue of public health as of prison health. Annually an estimated 360 000 people move through the prison system.

Prison environments, which are ‘total institutions’ and more closed than outside society, are characterised by unhealthy, overcrowded and under-resourced conditions, which complicate the task of health care. But prisoners do have a

right to health care. They are also entitled to be treated with dignity and exercise all their other basic human rights, save those that are necessarily restricted by their incarcerations. The health care of inmates should be in accordance with that available outside of prison and in this regard, the state – through the Department of Correctional Services (DCS) – is entrusted with and obliged to see to the safety and care of prisoners.

Prison conditions tend to lead to rapid deterioration in a person's health status, which for many is already compromised on arrival in prison due to HIV and other factors. It is therefore imperative that inmates are able to access treatment speedily. Building the support for inmates to test for and disclose their HIV status – as part of a holistic approach to HIV and AIDS – is a vital ingredient in receiving effective treatment. Measures to ensure that others do not get infected (primarily through sexual intercourse) can also be put in place.

Correctional officers are crucial to ensuring prisoners have access to health care services

A key difference between prison life and life outside is that inmates have far fewer potential avenues of support and information than the rest of us. In addition, they face constraints in accessing those avenues of support they are

entitled to (for example, needing to be unlocked and escorted to see a health worker). Correctional officers play a role that exercises enormous power: they are the face of the Department (which is mandated with prisoners' safe care) and inmates are dependent on them to be linked to services, assistance and information.

The other side of this is that prisoners have been removed from existing networks of outside support. Once inside, they may be transferred between sections and prisons, meaning they have to learn new ropes and re-develop in-prison networks. Again, this underscores the importance that prison staff inform inmates about available services and connect them to these, as well as be alert to potential difficulties and problems.

Health care workers in prisons play an important role in advocating their patients' health

As security-focused institutions, prisons go against the culture of health care, and health workers may find themselves in tricky situations where medical concerns and ethics conflict with security prerogatives. But because of the shut-off nature of prisons, health care workers represent an important source of care and information for inmates: their role in advocating for their patients' health carries greater weight than in the general population.

Staff attitudes and perceptions regarding HIV and AIDS are a fundamental factor for disclosure. Recent research among prison staff has found that many officials would literally rather die than reveal their HIV positive status or take anti-retroviral medications, and that many do die. Apart from the devastating effects these attitudes and fears have on individuals and Departmental staffing, they surely impact on officials' dealings with inmates. Particularly in relation to HIV and AIDS, the pivotal role that correctional officers play in the lives of inmates, and in mediating inmates' access to disclosure-related and treatment support makes this serious cause for worry.

Special efforts need to be made to create a healthy and trusting context conducive to HIV disclosure and holistic health care because prison environments do not automatically lend themselves to this. Quite the contrary – critical issues like confidentiality are seriously undermined in prison. The communal nature of the living circumstances and of accessing services (where, for example, inmates regularly hear each others' requests and complaints made to staff members) makes this so.

The fact of being in prison adds complexity to disclosure decisions and consequences

Inmates may not only have a family or partner(s) outside to consider in their disclosure decisions. Since they live in very close proximity to and have varying relationships with other inmates, they may consider disclosing their status to a wider group.

Adding complexity to decisions about who to disclose to are issues around inmates' separation from family and friends in circumstances that have often created tension and conflict in these relationships. In addition, the time that inmates are able to spend with visitors is severely limited and happens where there are lots of other people around. And the hardship of dealing with negative responses to disclosure can be compounded by the experience of being in prison, which is where the inmate must sit with possible rejection and obstacles in accessing support.

Inmates may be abused and stigmatised as a result of their disclosure

Key to disclosure considerations in any setting is fear of stigmatisation. It is conceivable that the danger is heightened

in prison because inmates have so little control over whom they associate with.

Among women, fears of violence, abuse or removal of financial support (often from partners) may be altered and complicated in prison. While their separation may somewhat protect them from physical abuse, imprisonment could add burdens which cause those who are mothers, for example, to fear for the well-being of children outside. If they are mothers who have young children with them, children will sometimes be required to leave the prison before them. A child's HIV positive status may increase the already difficult arrangements that need to be made for the child and may demand disclosure to those taking over the child's care.

Another potential consideration in relation to male prisoners (who make up 98% of South Africa's prison population) is the impact on decisions to get tested and/or disclose of the brutal understandings of masculinity, which are prevalent in prison and forbid male vulnerability.

Current procedures and practices relating to HIV disclosure in prisons in South Africa

This section considers fairly recent policy that provides a framework and guidelines for tackling HIV and AIDS in relation to prisoners and staff. It also deals with the circumstances in which courts can order an HIV test.

The Framework for the Implementation of Comprehensive HIV and AIDS Programmes and Services for Offenders and Personnel

In 2007 the Department adopted the 'Framework for the Implementation of Comprehensive HIV and AIDS Programmes and Services for Offenders and Personnel 2007–2011'. It outlines the Department's plan for the (staggered) implementation of an HIV and AIDS strategy, and although it is under review, for now it remains the guiding policy. The policy aims, among other things, to promote voluntary disclosure of HIV status, encourage peer education and establish support

groups. Slightly more detailed guidelines and obligations are provided in the 'DCS Minimum Service Level Standards for HIV and AIDS Programmes for Offenders'.

The Minimum Standards state that:

- VCT must be done in facilities where confidentiality can be ensured.
- If offenders want to disclose their status they should receive counselling first to ensure they will be able to cope with the effects of disclosure.
- Disclosure must be managed with regard to whom and when this will be done.
- Care must be taken that the offender is not taken advantage of and used in all and every event as a person living with AIDS (sic). This provision apparently aims to prevent inmates being used in exploitative ways by the Department to tell their story at public relations or awareness events.
- Staff are also required to keep registers of all testing requested, conducted, related counselling, referrals and disclosures.

These standards make all personnel involved in implementing HIV and AIDS programmes for prisoners responsible for meeting these standards and set particular measures (such as that information and educational material must continuously be available to inmates and displayed in accessible areas). It specifies that the principle of confidentiality must always be adhered to.

The courts may direct an inmate to take an HIV test

While inmates can never be forced to have an HIV test by virtue of being prisoners, certain circumstances in criminal law now make an HIV test compulsory. This however, requires an application and court process, and if granted, disclosure is permitted to specific people only. If one is alleged to have committed a sexual offence, the victim (or someone on behalf of the victim) may – within 90 days of the alleged offence – apply to a magistrate to have the alleged offender tested for HIV and the results disclosed to them (Sexual Offences Act, 2007). This law could affect inmates incarcerated for (alleged) sexual offences or inmates alleged to have committed sexual offences in prison.

The impact of current policies and practices on prison populations

The 'Framework for the Implementation of Comprehensive HIV and AIDS Programmes and Services for Offenders and Personnel 2007–2011' is only a framework, and needs more detail to be really useful on a practical level. Because of the gaps in policy and implementation, issues that discourage disclosure (such as discrimination and stigma) are regularly not addressed. This section outlines some of the policy gaps, which may provide a more favourable environment for disclosure.

The current policy framework requires more substance

It is difficult to get a good sense of the impact of HIV and AIDS policies in prison partially because the policy is relatively new, has not yet been close to fully implemented or evaluated, and because parts of it have been overridden by other decisions. For example, when referring to 'offenders', the Framework ignores awaiting trial prisoners, while actual practice reportedly does not. Nevertheless un-sentenced inmates are particularly

disadvantaged in relation to inmate services in general, and HIV and AIDS prevention and treatment assistance is no exception. The inferior conditions in which un-sentenced inmates are housed – often for long periods of time – remains an issue of grave concern.

The policy merely sets out the parameters for more detailed policy formulation and programme development and its implementation requires that it be substantially fleshed out.

Staff shortages contribute to the limited reach of HIV and AIDS programmes

The capacity of different correctional centres varies considerably, with, for example, some especially hard hit by professional staff shortages. Thirty-five percent of professional nurse posts are currently vacant. There is also uneven use of HIV and AIDS service partnerships with NGOs and support groups, so while some correctional centres are accessing additional support through civil society, others are not.

The shortage of capacity and serious overcrowding contributes to low numbers of offenders being reached by health promotion initiatives, which has seen inmates resorting to legal action in a desperate bid to access anti-retroviral treatment. High numbers of health-related deaths soon after admission highlight the gravity of the situation.

Gaps in policy need to be filled to create a conducive environment for disclosure

Fear of stigmatisation and discrimination and the broader adverse situation of responses to HIV and AIDS in prison militate against disclosure and require attention in order to establish an environment that is conducive to disclosure.

Important gaps in existing policy inhibit the realisation of a supportive disclosure environment, simultaneously undermining inmates' rights. The policy fails to address the peculiarities of the correctional centre environment. Staff do not have guidance on how they should approach barriers that result from the prison context.

There is no acknowledgement of the obstacles inmates experience in accessing health care, and their reliance on third parties (usually correctional officers) to access all other support services.

The policy is silent on the difficulties of maintaining discretion and confidentiality inside prison. Anecdotal reports from several health staff provide conflicting accounts of confidentiality within

The realisation of the policy is still a long way off and this means that while HIV disclosure should be a gateway to support and treatment, inmates may in fact see little benefit to getting tested or disclosing.

the prison system: some maintain that confidentiality is not compromised because there's no telling the reason that an inmate is accessing health services or why he or she is receiving a high-protein diet, while others argue that there's no such thing as confidentiality in prison and HIV positive inmates are quickly identified through visits to health care workers and special food.

The role of correctional officers as mediators of inmates' access to health services is not addressed by the policy and no guidelines are provided for managing confidential issues they may encounter in performing this role.

The policy does not deal with disclosure to inmates' families or partners outside prison or how staff might encourage this and assist, given the additional burdens that inmates may face by virtue of being incarcerated. The logistics of disclosure to families can also present challenges. Anecdotal accounts suggest that in many prisons staff can manage this in a private setting, providing support in the form of a health care or social worker, or both.

Less directly related to disclosure but equally pertinent is that the policy is silent on male on male intercourse and sexual violence which together represent key modes of HIV transmission in prison. Lack of acknowledgement of these issues contributes to ongoing discomfort with them. This hinders disclosure, and health promotion and

violence prevention generally. Sex and sexual violence inside correctional centres pose important questions regarding disclosure as staff may become aware of certain inmates being at risk of contracting HIV.

The policy also does not address how HIV positive inmates are to be linked to support when transferred between prisons or following release. The current practice is apparently for health professionals to prepare a report and referring letter to be enclosed in a sealed envelope and given to the transferring officer. However, initial investigations point to breaches and confusion with this system.

A grave broader concern that also impacts on HIV and AIDS is that the Department completely ignores mental health issues.

Some best practice recommendations on disclosure in the prison environment

This section contains some practical and implementable recommendations to promote voluntary disclosure in a supportive and confidential environment.

Willingness by an inmate to disclose their HIV positive status largely depends on the status of care and support in the prison. This means ensuring that inmates' health and human rights are protected, and that they are provided with relevant prevention and treatment programmes. This requires the full commitment of Departmental leadership, both in word and in deed.

The current typical lack of direct interest in the programmes presented to officials of the Department, and centre managers' unwillingness to undergo VCT, work against disclosure. In order to bring about a truly supportive and respectful environment that encourages disclosure and better understanding of the disease on the part of both staff and inmates, management needs to take a dedicated and energetic lead. Some other practical recommendations follow:

Assessments, training, policy and practice around confidentiality and sexual issues should encourage a safe environment for disclosure

- Health assessments done when inmates are admitted to correctional centres are the ideal opportunity to establish HIV and AIDS support, to encourage disclosure, and to inform inmates of their rights, including that of confidentiality. (This is in addition to the importance of the assessment for ensuring that inmates get immediate medical treatment where necessary). HIV clinicians provide a checklist of HIV and AIDS related actions on admission which could be used to help ensure that initial health assessments are used optimally.
- Staff training, policies and codes of conduct should address the issues of confidentiality, discrimination and homophobia, and the occurrence of sex and sexual violence in prison. Ignorance surrounding these factors and the lack of related policy contribute to discomfort, myth and stigma, which discourages disclosure and feeds risky and abusive practices. Correctional officers have a critical role in protecting inmates' rights to confidentiality.
- Staff need to be trained to pick up on warning signs such as deteriorating health or fear, and to proactively engage

with inmates to promote disclosure and prevent abuses and risky behaviours.

- Because of the lack of privacy in prisons, inadvertent disclosure to non-medical staff and other inmates may occur. Staff need to be vigilant regarding any victimisation or stigmatisation that may follow.
- Any inappropriate disclosures or threats to confidentiality by staff members need to be addressed through disciplinary measures.
- Any staff member who unreasonably prevents an inmate from accessing services or unreasonably delays such access must be disciplined. The nature and consequences of such infringements must be clearly stated in policy.

Inmates must be supported before and after making a disclosure

- Clear procedures for the logistical support of inmates to disclose to families, sexual partners and friends need to be in place. Inmates should be offered a private setting to disclose in the presence of a health care worker.
- Staff working in women's prisons need to be equipped to support women in the additional disclosure issues they face around, for example, abusive partners, accessing

antenatal treatment, and arrangements for HIV positive children in prison and moving out of prison and away from their mothers.

- The sustained involvement of NGOs and CBOs, for example, in HIV disclosure-related services should be fostered, as should working with inmate groupings to build support groups and peer education.

Confidentiality should extend to security staff, medical records and doctors

- The safety of health workers should not be jeopardised for the sake of confidentiality. The presence of security staff may be necessary during health consultations, in which case security staff must be bound by confidentiality requirements.
- A prisoners' medical records should always be forwarded in a sealed envelope, and not labelled in a manner that discloses HIV status, to health services in other sites where inmates are transferred or given to the inmate in person if released.
- The same ethical standards and principles that govern the forced disclosure of medical information must be applied in prison.

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Chapter 4

**Disclosure by health
care practitioners
of a patient's HIV
positive status:
Some best practice
recommendations**

Pierre Brouard



The chapter in brief

Do doctors and other health professionals have the right to disclose a patient's HIV status to another health worker, or a partner who may be at risk of infection? Do they in fact have a duty to do so? If so, in what situations? What are the possible risks to the doctor or to the patient of disclosing? What are the possible consequences of not disclosing?

This chapter discusses the prevailing approach to HIV and AIDS in South Africa – a human rights approach – which considers the individual patient's right to privacy, dignity and confidentiality as paramount. It balances this against the competing public health goal of disclosing a patient's HIV status to at risk partners in order to prevent their possible infection and to stem the spread of the disease.

The author examines the laws that are relevant to doctors when they are faced with a disclosure dilemma, and also the remedies that an individual may use if they feel their rights have been offended. In addition to national legislation, several professional institutions have developed guidelines about best practice relating to disclosure. These include the Health Professionals Council of South Africa Guidelines. The *HIV/AIDS and the Law Manual* published by the AIDS Law Project also contains recommendations. Both stress the practitioner's duty

not to disclose a person's HIV status without their consent, and that even in a forced disclosure situation, the patient should be aware of the event.

The chapter makes several best practice recommendations. Doctors should:

- Have an understanding of the ethical issues around disclosure
- Build open and trusting relationships with patients, including telling patients from the outset that there may be limits to confidentiality
- Identify partners who may be at risk and try to counsel partners together
- Encourage voluntary disclosure and provide support to the patient
- Encourage resistant patients to disclose to their at-risk partner
- Only disclose when all the risks to the patient and the partners have been fully considered and thought through, as well as the doctor's own ethical position.



Focus of this chapter and definition of disclosure

Although the definition of health care professional is broad – it includes nurses, dentists, radiologists and physiotherapists for example – in practice, it is mainly medical doctors who test for HIV and who are involved in disclosure issues and dilemmas. This chapter is therefore aimed at the medical doctor, but may in certain cases apply to other health care professionals.

This chapter focuses on:

- disclosure by a health care professional of the HIV status of their patient to other health care providers or allied health professionals
- disclosure to sexual partners (mainly where the sexual partner is a known regular partner of the patient)
- disclosure to employers (sick certificates)
- disclosure to family members and life insurers (death certificates).

Disclosure in this chapter means the passing on of private and confidential information obtained or revealed in a medical setting to a health care professional, or to another person. This disclosure may be written or verbal.

An overview of HIV and AIDS generally in the medical field

This section looks at the approach that the government has taken to HIV and AIDS generally, namely a human rights approach in which privacy, dignity and non-discrimination are protected.

A human rights approach to HIV and AIDS – rationale and criticism

Since the first evidence of AIDS emerged in 1981, the epidemic has been characterised by prejudice, stigma (negative attitudes), discrimination (observable acts of harm or neglect or avoidance) and ‘othering’ of those living with HIV. These phenomena were often also experienced by anyone associated with a person living with HIV, such as a partner, friends, health care workers and people working in the field. Partly as a result of this, a human rights approach was adopted in addressing HIV and AIDS, the rationale being that when rights are protected, individuals will be more likely to come forward for testing, treatment and care, and they would also be more amenable to prevention messages.

This approach has entailed the development of specific laws and policies to protect the rights of those both living with, or affected by, HIV. It has also provided a context for re-examining whether some practices in medical settings provide suitable protection for people living with HIV. While some have criticised this ‘AIDS exceptionalism,’ others argue that the standards around patient rights (such as dignity, privacy, confidentiality, autonomy, informed consent) have in fact revitalised practice in medical settings in general, and reminded practitioners about the oaths they have taken to care for their patients in the best possible way.

Examining the tension between a human rights approach and public health goals

The human rights approach has not been universally accepted. Critics of the human rights approach have also argued that an over emphasis on privacy, consent and autonomy in medical settings undermines public health goals, which are to promote health and prevent illness. They argue that limiting the health care professional’s right to reveal the HIV status of a patient to another professional, a sexual partner, a family member or caregiver prevents them from passing on important information which could contribute to lessening the spread of HIV, or at least empower others to take the necessary precautions.

In fact, while it may be possible to achieve these aims through, at best, voluntary disclosure, and at worst, forced disclosure, there is no guarantee that these aims will be achieved. In addition, as long as stigma and discrimination persist, forced disclosure may be harmful and even dangerous for some individuals. It is also important to note that stigma and discrimination are not limited to community settings but are features of every aspect of life in South Africa today: in workplaces, in faith communities, in educational institutions and, worryingly, health settings. It is also clear that the social and psychological mechanisms that drive stigma and discrimination are complex and multi-factorial, and are not amenable to simple, public-health driven, solutions. Botswana and Lesotho experience the same stigma and discrimination, despite various forms of routine testing being in place for some time, and an aggressive ARV programme in Botswana.

Inadvertent, unwanted or even voluntary disclosure often has negative consequences

The current position in many clinics and hospitals, both public and private, is that unwanted disclosure, whether in the form of patient charts, intra-professional communication, informal conversations with families and caregivers, HIV-specific waiting or treatment areas, and inappropriate storage or privacy of

files, is commonplace and a daily occurrence. This is not always malevolent, and the consequences are not always negative, but in some cases they are. Disclosure of this kind reflects an insufficient understanding, not only of privacy and confidentiality laws and policies, but also of the consequences of disclosure, stigma and discrimination.

In addition, the culture of medicine – where patients are often disempowered in encounters with health professionals and may feel pressured into premature disclosure or are too afraid to protest when a non-consensual disclosure has taken place – militates against the rights, autonomy and dignity of many patients. Health professionals have not always had the necessary training to deal with complex social issues, and often have an unrealistic expectation of the outcome of disclosure, assuming that it will lead inevitably to a reduction in risk at an individual level and a lowering of prevalence at a population level. In fact, behaviour change does not necessarily, or easily accompany a positive HIV diagnosis.

Women face consequences of disclosure such as violence and abandonment

More women than men test for HIV in South Africa. This is partly because women are more likely to seek help for medical problems than men and to be proactive about preventing illness, but also because women are more exposed to testing

for HIV in antenatal care settings. In theory women can refuse to test at antenatal clinics, but in practice, because of concerns for their unborn babies, and because they can access prevention of mother to child transmission (PMTCT) services, very few do so.

Men sometimes encourage their female partners to test for HIV, to use the result as a proxy for their own HIV status. If the woman tests negative, the man assumes he is negative too. What this all means is that more women than men are placed in the position of having to make a decision about disclosure. With the levels of gender-based violence in South Africa, this constitutes an unfair demand on women. In a study done on disclosure by women in 17 African countries, women gave as their reasons for not disclosing to others their fear of accusations of infidelity, abandonment, discrimination and violence. Up to 15% reported a violent reaction from a partner following disclosure.

Current procedures and practices relating to HIV disclosure in medical settings in South Africa

Although there are legal, policy and guideline frameworks in place around disclosure in South Africa, the way it has been interpreted for doctors is still somewhat ambiguous. The distinction between the right and the duty to disclose is not well defined. Doctors are then placed in the position of having to make difficult ethical decisions using their own judgement. Too many of these decisions are conducted in an ad hoc and inconsistent manner. As a result, the unintended consequences may be that both they and their patients are placed in awkward positions and other parties may also be at risk. Where disclosures have happened after death there may be unintended consequences for family members, and challenges to death benefits linked to life insurance.

This section looks at current laws, policies, guidelines and case law in South Africa.

Laws that are relevant to disclosure, and possible remedies for individuals

This section gives a brief description of legislation around HIV and AIDS with provisions specifically related to disclosure. It describes what individuals or other parties can do if they feel the law has been contravened.

The Bill of Rights of the South African Constitution

Section 9 of the Bill of Rights states that everyone in South Africa has the right to equality. This means that no person, or the state, may unfairly discriminate against another person on 16 listed grounds, including disability. Section 10 asserts that everyone has inherent dignity and has the right to have this protected. Section 14 states that everyone has the right to privacy, which includes the right not to have the privacy of their communications infringed. This means your personal information is confidential and no one has the right to disclose personal information without your consent.

The law, however, does not protect the confidentiality of deceased persons. Generally when people die their constitutional and common law personality rights – including the right to privacy and confidentiality – die with them.

- This means that the next-of-kin or executors of the estates of a deceased person may not bring court actions for damages on the deceased's behalf for breaches of confidentiality arising after their death.

The Promotion of Equality and Prevention of Unfair Discrimination Act of 2000

This Act prohibits unfair discrimination on any grounds, including the 16 grounds listed in the 1996 Constitution. Ordinary people who allege that they have been discriminated against on the ground of their HIV status (even though not explicitly listed as a ground in the Act) may approach the Equality Courts for a remedy. These courts are easy to access, as they do not have many of the legal formalities of other courts that people often find alienating or difficult to follow. This is particularly relevant where disclosure by a medical practitioner has led to other disclosures in the community.

- The complainant can bring a civil claim to the court but they would need to be able to prove that there was a pattern of harmful discrimination for this claim to be successful.

The Births and Deaths Registration Act of 1952

Disclosures in death certificates: This Act requires medical practitioners to complete a death certificate form, which consists of two pages. The first page is for the registration of the death by the Department of Home Affairs and the issuing of a burial order. The second page contains demographic details about the deceased and the medical cause of death, required for medico-legal and statistical purposes. This page must be sealed and attached to the first for transmission to the Department of Home Affairs. In practice officials and undertakers review the second page to check if the details conform to those on the first. As things currently stand, doctors are obliged to state the true cause of death and to complete these forms accurately.

- It has been suggested that the details on the second page could be recorded anonymously, given concerns about the confidentiality of the certificates, but this has not yet been formally adopted as practice.

Disclosures as a result of a court order are legally binding and refusal to disclose will result in a conviction of contempt of court.

- In this situation the legally required disclosure will not be viewed as unethical, as the courts will have weighed up the possible damage to public interest or to the patient.

Disclosures in the public interest may occur if the deceased occupied a position in society where revelation of their HIV status would make a difference, for example in combating the epidemic.

- This would not be regarded as unethical in terms of the Health Professionals Council of South Africa (HPCSA) guidelines (see below for more information on the guidelines) but even if the disclosure was not found to be in the public interest, the disclosure would still not be illegal. The next-of-kin could approach the Health Professionals Council of South Africa for a remedy though.

Disclosures without the written consent of the deceased's next-of-kin or the executor are not illegal, but they may be unethical.

- The parties concerned may approach the HPCSA on the grounds that they regard the disclosure as unethical.

Disclosures to insurance companies are legal if the deceased person had given consent prior to death. Even if this consent was not given, insurance companies may request it in terms of the Promotion of Access to Information Act or a court order, if the company could show it was furthering or protecting a right, for example needing to show if the deceased had breached a condition of the insurance policy. Some people argue that even if these steps were not followed, the doctor's actions would not be illegal but they may be unethical.

- If next-of-kin or the executor feel the action is illegal, they can approach the HPCSA for a remedy.

The National Health Act of 2003

This Act prohibits disclosure without consent and thus protects a patient's personal information. All information, including information relating to a person's health status, treatment or their stay in a health care facility, is confidential (section 14(1)). No person may disclose any information relating to a person's health status, treatment or stay in a health care facility, unless:

- the person gives written permission to do so
- a court order or a law requires the disclosure, or
- non-disclosure of the information represents a serious threat to public health (section 14(2)).

South African guidelines relating to HIV and AIDS and disclosure

This section examines how professional bodies, NGOs involved in HIV and AIDS and government currently deal with disclosure issues. All stress the relationship of trust between the patient and the doctor.

Health Professionals Council of South Africa Guidelines

The HPCSA has developed Guidelines for good practice in the health care professions. These guidelines deal specifically with HIV in a section called Ethical Guidelines for Good Practice with Regard to HIV. The guidelines form an integral part of the standards of professional conduct against which a complaint of professional misconduct will be evaluated. The guidelines were widely consulted and are based on international best practice.

Practice as a health care professional is based on mutual trust between patients and the health care practitioners

The guidelines note that the health care professional's primary responsibility is to their patient, but that they must also consider other health care professionals who are involved in the management of the same patient. This may mean

A health care practitioner means someone registered with the Council.

The HSCSA Guidelines refers to ‘health care practitioners’, which only includes those professionals who are registered with the Council. Pharmacists, nurses, chiropractors, homoeopaths, dental technicians and health care institutions (like hospitals and clinics) are not registered with HPCSA.

informing another health care worker of the patient's status, with the patient's consent. Test results, reports of results by a laboratory, records of diagnostic information for patients on medical insurance for the purposes of processing claims, or in line with the rules of the medical scheme, are also confidential. The patient must give informed consent for such information to be disclosed.

Confidential information about a deceased patient should only be divulged with the written consent of their next-of-kin or the executor of the estate – except where this information must be disclosed in terms of a statute or court order, or the disclosure is justified in the public interest.

Disclosure to sexual partners may be made after all considerations have been taken into account

Health care practitioners should encourage their HIV positive patients to disclose their status to their sexual partners, so

as to encourage them to undergo VCT and access treatment if necessary. If the patient refuses to consent, the health care practitioner may, after carefully weighing up all the factors, use their discretion when deciding whether to divulge the information to the patient's sexual partner. Disclosure by the health care practitioner without the patient's consent must still involve the patient: The health care practitioner must counsel the patient on the health care practitioner's ethical obligation to disclose such information. After disclosure, the health care practitioner must follow up with the patient and the patient's partner to see if disclosure has resulted in adverse consequences or violence for the patient, and, if so, intervene to assist the patient appropriately.

The guidelines are not clear on whether doctors have an ethical duty to inform at-risk sexual partners about a deceased's person's HIV status even if the patient did not consent to this, on the grounds of 'public interest'. It is unclear whether failure to inform could result in legal action by the dependents of the deceased.

The health practitioner must respect the wishes of the patient with regard to sick certificates. The patient can ask that confidential information be left off the certificate and it is acceptable and legal for the doctor to respect this wish.

Guidelines of the South African Medical Association and South African Nursing Council

South African Medical Association (SAMA) is a voluntary association of doctors and other health care workers. Their guidelines recommend that a patient's medical information should be kept confidential. The South African Nursing Council (SANC) has ethical guidelines that state that nurses must respect a patient's right to confidentiality.

HIV/AIDS and the Law – a resource manual

This manual was published by the AIDS Law Project (ALP) and the AIDS Legal Network (3rd edition). It sets out guidelines around disclosure based on the HPCSA guidelines and the writer's interpretation of these and the law.

Disclosure by a health care worker to another health care worker should be done with the patient's consent

The manual states that a health care worker must ask for the patient's consent to disclose the patient's HIV status to another health care worker. If the patient refuses consent, the health

care worker should explain to them that they may not receive the correct treatment. The guidelines seem to suggest that if consent is refused, and the health care worker still believes it is important, they can disclose, but must accept responsibility for the consequences.

Disclosure by a health care worker to a patient's partner must follow certain processes

The health care worker may not reveal a patient's HIV status to a sexual partner. The exceptions are if the sexual partner is clearly known and specific, and at risk and the patient has refused to inform the partner and has refused to have safer sex. The patient must also have been counselled on disclosure and safer sex, as well as the health care worker's duties to protect others.

Health care workers may not disclose to other people, unless ordered by a court of law

The manual goes on to say that health care workers may not tell family members or care givers about a patient's HIV status unless forced to do so by a court.

The National Patients' Rights Charter

The Charter sets out the rights and duties of patients who attend government clinics and hospitals. While it is not a legally binding document, the Charter establishes guidelines based on existing laws and policies. Among the rights listed are the entitlement to take part in making decisions about treatment, to confidentiality and privacy about medical treatment, and informed consent to medical treatment. Among the duties of patients are respecting other patients and health care workers and providing the doctor or nurse with correct information about their health.

National Policy on Testing for HIV

The National Policy on Testing for HIV, published in August 2000, has this to say on disclosure:

- In a situation such as a needle stick injury experienced by a health care worker where the patient's HIV status is unknown, and a blood sample is available, an HIV test may be conducted with or without informed consent, provided privacy is respected. The result may be disclosed to the health care worker concerned but must otherwise remain confidential and may only be disclosed to the patient with their informed consent.

- Information regarding the result of an HIV test must remain fully confidential and may be disclosed in the absence of an overriding legal or ethical duty only with the individual's fully informed consent.

When a doctor should not have disclosed his patient's HIV status

Jansen van Vuuren and Another v Kruger is the only case to date that has specifically tested the issue of disclosure of a patient's HIV status by a health care practitioner without the patient's consent in South Africa. In this case, a medical doctor disclosed his patient's HIV positive status to other medical practitioners in the community, while playing golf with them, even though the patient had asked him not to tell anyone. The news of the patient's HIV status soon spread throughout the community, causing the patient stress and embarrassment.

The Appellate Division of the Supreme Court (now the Supreme Court of Appeal) decided that a doctor may not disclose the HIV status of a patient to other doctors without the consent of the patient unless there is a clear legal duty to do this. The case established the norm of confidentiality of HIV results, especially because the health care professionals to whom the primary doctor had disclosed were either not treating the patient at the time (one was a dentist) or had no interest or relationship with him.

Some best practice recommendations on disclosure to third parties who are at risk

The recommendations in this section are limited to situations in medical settings where disclosure to a third party who may be at risk from sexual transmission is necessary.



Doctors need to familiarise themselves with ethical and other issues around disclosure

- Start by familiarising yourself with the most recent legal, policy and guideline frameworks for HIV disclosure. This may involve reading the latest literature, attending conferences and seminars and through collegial discussion on ethical issues.

The suggestions here are aimed at doctors, who are mostly involved in disclosure situations, but may be applied to other health care workers if they are faced with the issue of whether to disclose confidential information.

- Interrogate your own beliefs and attitudes and also know the epidemiological and psycho-social aspects of HIV and AIDS so that you have a thorough understanding of who is getting infected; which communities are more affected; the gender dimensions of testing, prevalence and disease burden; the social circumstances in which patients live; the nature of responses to HIV in the communities from which patients are drawn; the dynamics of stigma and discrimination; and an appreciation of the power dynamics in medical settings and encounters.
- Have to hand lists of resources, including counsellors, social workers and support groups. This is desirable so that when you have reached the limits of your own expertise on psycho-social matters you can refer appropriately.
- Be aware that knowing your HIV status does not necessarily result in people changing their risky sexual behaviour.



Doctors should build a communicative, open and trustworthy relationship with the patient

- You should strive to build a relationship of honesty and open communication with your patients and to create a climate of acceptance and trust, based on conveying your genuine desire for the patient's best interests.
- At the first consultation, you may want to tell the patient that there may be limits to confidentiality and to spell out what these are right away. This might make it easier to deal with issues of disclosure if they need to be raised later.
- Always keep the patient informed about their condition, by explaining very clearly and carefully how HIV transmission can be prevented, so that the patient can understand risks to their sexual partners and other health care providers.
- Start from the position that most patients need to be empowered to take charge of their health and should be given the support and resources to do so. If patients feel that they own their health and are responsible for it, they will already be in the right frame of mind to think about the issues surrounding HIV disclosure.



Doctors should try to identify if there is an at-risk partner and develop a relationship with both partners together

- Establish whether there is a spouse or partner who may be at risk. If not, then further discussion on this specific issue is not necessary, but you can refer the patient to a counsellor to discuss disclosure to family and friends, for support.
- Where possible, try to see individuals with their partners when they test and beyond so that the HIV status of both parties is openly declared and the treatment plan is contextualised within the relationship system.
- If the patient states that they will not disclose because they always practise safer sex, or that their partner already knows that they are HIV positive, or that they are not in a relationship, you should make a reasonable effort to interrogate this politely.



Practical ways to encourage voluntary disclosure

- If there is an identified third party at risk, explore with the patient the dynamics of disclosure. This should not be approached from the perspective that disclosure is problematic or contentious, but rather from the point of view that it is inevitable and desirable. A question here could be: ‘Have you thought about telling anyone of your HIV result?’ or ‘How do you feel about telling other people about your HIV result?’
- Invite the patient to explore the possible outcomes of a disclosure. A question here could be: ‘What would happen if your partner found out that you were HIV positive?’
- Ask the patient if they feel willing and ready to make the disclosure. If the answer is ‘yes’ then explore possible outcomes of the disclosure, the timing of the disclosure, the method of the disclosure and offer support and referral to counsellors.
- Invite the patient to return for a follow up and suggest that they bring the partner so that support, testing and treatment can be discussed with them.



Practical ways to move patients from a position of involuntary disclosure

- If there is an identified third party at risk and the patient indicates that they cannot make the disclosure, explore the reasons for this. A question here could be: ‘What are you afraid of if you disclose to your partner?’
- Offer to support the patient through the disclosure so that they can be assisted to overcome the challenges they have articulated, rather than just accepting that the disclosure is impossible.
- If the patient still declines to make the disclosure, offer counselling and suggest that they take time to think about it until the next consultation. At that consultation review the patient’s decision. If they still insist that the disclosure is impossible, and you believe that serious harm could come to them from the disclosure, let the matter rest but revisit it at regular intervals.



Some considerations and risks if doctors do decide to disclose

- If, in your opinion and after counselling has been offered and the patient has been given time to consider all the options, there are still good reasons to warn the third party, explain this and your reasons to the patient, including what your ethical codes say. This will be easier if you have made it clear from the outset of your relationship with the patient that confidentiality may have to be breached in very specific circumstances.
- Be clear in your own mind what your reasons are and whether the disclosure will achieve the aims you intend. Distinguish in your own mind between your right to disclose in terms of your ethical guidelines and your duty to disclose (there is no absolute duty to disclose). It is advised that you talk your decision through with another senior practitioner to clarify your motives and plan.
- Invite the patient again to disclose voluntarily.
- If they still refuse, and you still believe that the disclosure is necessary, inform the patient that you will be making the disclosure and revisit the possible consequences of the disclosure.

- Plan the disclosure to the third person: when, how, why and what should be the key considerations here. After making the disclosure to the third party, invite them to discuss testing, treatment and care options.
- After the disclosure, invite the patient to return to discuss the outcomes and refer for support if necessary. If possible, see the parties together.
- Forced disclosure should be an extremely rare event. Other risks involved in forced disclosure are:
 - the patient may never return, leaving the doctor in doubt about their future health
 - the patient may have given false details because they feared a forced disclosure
 - the patient's confidence in the doctor may be irreparably damaged
 - the patient may tell others of the disclosure, affecting the reputation of, and trust in, the particular medical setting.

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