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An Ethical Dilemma in Clinical Practice: Confidentiality, HIV Positive Status and Disclosure to Third Parties

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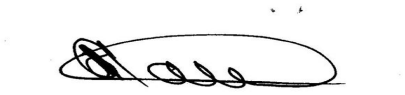
Supervisor: Donna Knapp van Bogaert

Johannesburg, 2011

DECLARATION

I, Dr Pardon Maluleke student number 0501853E am a student registered for MSc Med Bioethics and Health Law in the year 2011 I hereby declare the following:

- I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong.
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- I have not submitted this work to any other university or institution for degree or other purposes**.**
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Signature:
Date: 31 August 2011

DEDICATION

This research report is dedicated to my daughter, Lorna Tlangelani and my son Noah Smangaliso. I hope this piece of work will inspire you to a life of scientific inquiry**.**

ABSTRACT

Keeping information a patient has given in confidence to his or her doctor is a fundamental value in each individual doctor-patient relationship. However, when a medical professional is faced with disclosing confidential information in the face of competing public interests (or other ethically compelling reasons) he or she faces an ethical dilemma. In the context of the HIV/AIDS epidemic in South Africa, the dilemma to keep medical confidences or to disclose information to identifiable third parties is frequently faced by doctors and other healthcare professionals. This research report highlights the duty of medical confidentiality identifying its importance both as an 'absolute' principle in healthcare practice as well as suggesting that there are contexts in which it should be considered as a relative duty. In keeping, this format of this research report will present current data concerning the HIV/AIDS epidemic, interrogate the idea of medical confidentiality, explore some professional guidelines associated with HIV/AIDS disclosure, as well as raise some ethical–legal considerations concerning healthcare professionals and the problem of disclosure of their patient's HIV positive status to identifiable third parties.

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TABLE OF CONTENTS

Chapter 1. The Burden of HIV/AIDS

Preface

1.1 International burden of HIV/AIDS

1.2 HIV/AIDS in Africa

1.3 HIV/AIDS in South Africa

1.4 HIV/AIDS: Social and economic effects in Sub-Saharan Africa and South Africa

Chapter 2. Medical Confidentiality as an Absolute Duty

Preface

2.1 Medical confidentiality

2.2 The absolute duty of medical confidentiality

Chapter 3. Medical Confidentiality as a Relative Duty

Chapter 4. Professional Guidelines and Ethical-Legal Considerations Concerning Medical Confidentiality

Chapter 5. The HIV/AIDS Epidemic and Medical Confidentiality: Discussion and Concluding Remarks

References

Chapter 1. The Burden of HIV/AIDS

Preface

Detected first by the Centers for Disease Control (CDC) in the United States of America (USA) in 1980, HIV has subsequently spread all over the world (AVERT 2000). This pandemic has diverse consequences and impacts in different continents. The worst affected nations are the developing regions of the world especially the African continent, in particular Sub-Saharan Africa. South Africa is unfortunately amongst the nations most affected by the scourge of HIV/AIDS. The pandemic has varying effects on different levels of the society e.g. the economic impact at macro national level; family impact viz. destruction of core family structures and increase in the number of orphans; as well as the emotional impact viz. the sadness of those infected and affected by HIV/AIDS.

1.1 International burden of HIV/AIDS

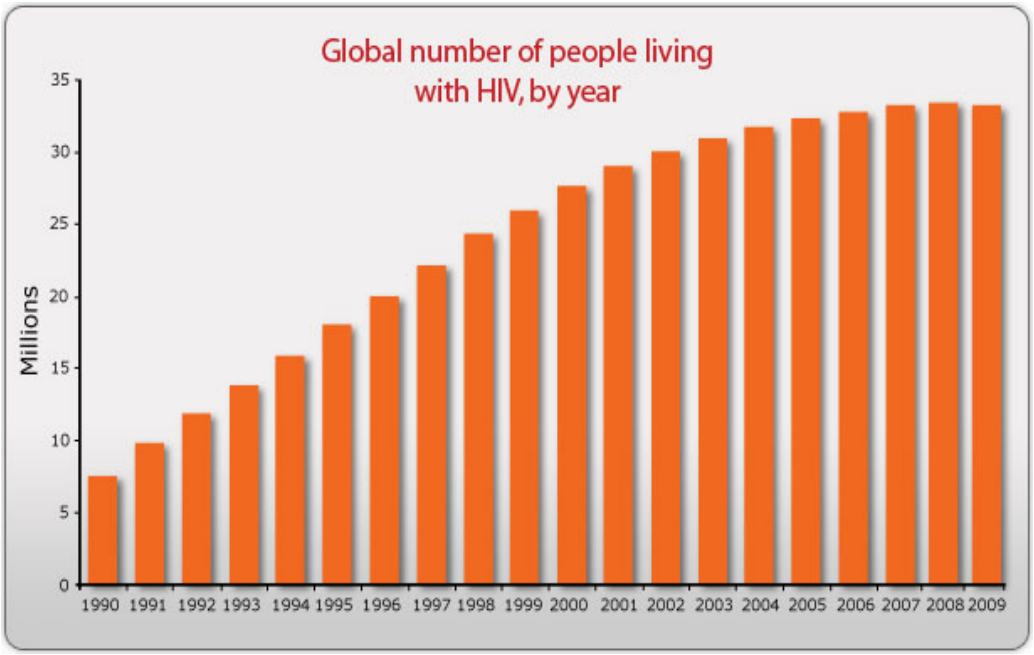
HIV/AIDS has resulted in a large number of deaths throughout the world. It continues to have a considerable impact on the lives of nations and societies worldwide at different spheres of peoples' lives. An estimated number of 33.3 million people were living with HIV/AIDS in 2009. Globally, a large proportion of these individuals

were women. New infections of HIV/AIDS were estimated to be 2.6 million worldwide in the year 2009 and 1.8 million deaths were attributable to the epidemic in the year same year (AVERT 2009).

The statistics presented below are credited to the UNAIDS/WHO, and were released in November 2009 by the AVERT organisation (2009). The graph below shows globally, the growth of the epidemic between 1990 and 2009 by the number of people living with HIV per year (Avert 2009)

(Graph 1) Global number of people living with HIV, by year.

(Reference: Avert Organization 2009.)



1.2 Regional burden of HIV/AIDS

The effects of HIV/AIDS are more pronounced in Sub-Saharan Africa. The estimated number of infections was 22.5 million in 2009, including both children and adults (AVERT 2009). Of major concern is the high number of children who are born with the infection estimated to be 2.3 million worldwide. An estimated 1.3 million people have succumbed to HIV/AIDS in Sub-Saharan Africa, which constitutes almost 72 percent of the total deaths reported globally. It has been established that HIV/AIDS is the leading cause of death in Sub-Saharan Africa, resulting in a global

estimate of 16.6 million children orphaned by the disease (UN/WHO 2009). During the year 2009 alone, 1.3 million people died of HIV and AIDS related causes in Sub-Saharan Africa (ibid). It is also estimated that two-thirds of people living with HIV/AIDS are found in the Sub-Saharan African region, which represents only 10 per cent of the world's total population (AVERT 2009).

Table 1 (below) shows the statistics for HIV and AIDS at the end of 2009. As shown, the problem of HIV/AIDS is most worrisome in the Sub-Saharan region.

(Table 1) Regional statistics for HIV and AIDS end of 2009

(Reference: UNAIDS Global HIV/AIDS Statistics 2009)

Region	**Adults and Children Living with HIV/AIDS***	**Adults and Children Newly Infected**	**Adult Infection Rate (percent)**	**Deaths of Adults and Children***
Sub-Saharan Africa	***22.5 million***	***1.8***	***5 percent***	***1.3 million***
East Asia	770,000	82,000	<0.1 percent	36,000
South and South-East Asia	4.1 million	270,000	0.3 percent	260,000

Oceania	57,000	4,500	0.3 percent	1,400
Eastern Europe and Central Asia	1.4 million	130,000	0.8 percent	76,000
Western and Central Europe	820,000	31,000	0.2 percent	85,000
North Africa and Middle East	460,000	75,000	0.2 percent	24,000
North America	1.5 million	70,000	0.5 percent	26,000
Caribbean	240,000	17,000	1 percent	12,000
Central and South America	1.4 million	92,000	0.5 percent	58,000
Global Total	**33.3 million**	**2.6 million**	**0.8 percent**	**1.8 million**

As Table 1 clearly demonstrates, the numbers of new infections, the figures indicating new infections in adults and children and number of deaths offer a bleak picture for our region.

1.3 Changes in life expectancy due to HIV/AIDS

HIV/AIDS has had a crippling effect on the life expectancy of African people. Below, Table 2 shows the average life expectancy in eleven African Countries (age in years) before HIV/AIDS and the projected value for the year 2010. It was expected that by the year 2010 the life expectancies of people living in African countries would drop due to the impact of HIV/AIDS, which it has. Amongst the worst affected countries are those in Sub Saharan Africa including Botswana, Lesotho, Malawi, Namibia, South Africa, Swaziland and Zimbabwe.

(Table 2) Predictions of life expectancy in Sub-Saharan Africa due to HIV/AIDS deaths (2004)

(Reference:

Country	**Before AIDS**	**2010**
Angola	41.3	35.0
Botswana	74.4	26.7
Lesotho	67.2	36.5
Malawi	69.4	36.9
Mozambique	42.5	27.1
Namibia	68.8	33.8
Rwanda	54.7	38.7
South Africa	***68.5***	***36.5***
Swaziland	74.6	33.0
Zambia	68.6	34.4
Zimbabwe	71.4	34.6

1.4 Effects of HIV/AIDS in South Africa

According to the Department of Health's 2009 *National Prevalence and Syphilis Antenatal Sero-prevalence Survey in South Africa* published in 2010, over a 8 year period starting in 2001 until 2009, Kwazulu Natal had the highest prevalence rate of HIV when compared to the other eight provinces. The National prevalence rate was 29.4 percent in 2009 whilst that of Kwazulu Natal was higher at 39.5 percent. The other provinces that recorded high prevalence rates are Mpumalanga at 34.7 percent, Free State at 30.1 percent and the North West at 30 percent. The Northern Cape at 17.2 percent and the Western Cape at 16.9 percent had the lowest prevalence rates.

This survey was based on data collected from antenatal clinics. The purpose of these surveys is to estimate HIV prevalence rates amongst pregnant women in South Africa. The highest prevalence rate was amongst the age group between the ages 30-34 with a prevalence rate of between 41.5 percent in women attending antenatal clinics country wide, and lowest on women between the ages 45-49 average of 23.9 percent.

The South African Government and Statistics Report titled *Mortality and Causes of Death in South Africa* (2008), indicated that there was an increase in the number of people dying in 1997-2006 in the age group 25-49 with 17.3 percent suspected to be due to HIV/AIDS.

Another study, the South African National HIV Survey (2008) is a household survey that involved a sampling proportional cross section of the society. The study included all social, geographical, and racial groups. The results showed that 10.9 percent of all South Africans were living with HIV in 2008. In 2002 and 2005 the figure was 11.4 percent and 10.8 percent respectively. The prevalence was found to be higher for the age group 15-49 years with an estimated rate of 16.9 percent in 2008, and at 2.5 percent for the age group 2-14 year. The study also showed a higher prevalence in women (13.6 percent) when compared to males (7.9 percent).

Comparing the prevalence rates of HIV by provinces, Kwazulu Natal showed a high prevalence rate (15.8 percent) followed by the following provinces Mpumalanga (15.4 percent), Free State (12.6 percent) and North West (11.3 percent). Just like in the

previous study, Northern Cape (5.9 percent) and Western Cape (3.8 percent) showed the lowest prevalence rates (Avert 2000; 2009).

1.5 HIV/AIDS: Social and economic effects in Sub-Saharan Africa and South Africa

As in most developing nations, African healthcare sectors are already overburdened with other healthcare challenges that bedevil all nations of the same status. HIV/AIDS puts an added pressure on the already overburdened healthcare sector in various ways.

Some overlapping, but key ways, in which HIV/ AIDS effect and affects the healthcare sector are identified in the United Nations AIDS (UNAIDS) and The World Health Organization's (WHO) 2004 report:

- *By the devoting financial, human and infrastructural resources to care for those who are sick with HIV/AIDS related conditions;*

- *The provision of hospitalisation for the debilitated with HIV/AIDS;*[1]
- *Compromise of the overall quality of care provided because of staff and other shortages;*
- *The diversion of healthcare resources to HIV/AIDS programmes; and*
- *The placing of added pressures on healthcare professionals* (UNAIDS WHO 2004).

There is also an impact on the family structures themselves. As parents die, many children become orphans. This is mainly because of the age group in which HIV thrives best - the age group of people in their reproductive years. This has a devastating effect on the family as perceived as the fundamental unit of society as it results in a breakdown of family structures. Cumulatively, and separately, all of the examples above have a resultant negative impact on the broader society. As more resources within families are diverted towards taking care of the sick, they are forced to cut back on other essential expenditures. This alone exacerbates the level of poverty in many communities.

[1] For example, a study carried by the Swaziland Human Development in 2001 found that 50 percent of the beds in the health care centers are occupied by HIV/AIDS patients.

Although considered illegal in many countries, children are sometimes forced to join the workforce at a very early age to provide for their siblings and are instantly compelled to become heads of households, as such lose their "childhood". The educational level of these children is obviously compromised as they are forced out of school for various reasons such as early death, for work in order to provide for their siblings, and an overall inability to pay for their school fees. The low level of education reached in many communities further compromises HIV/AIDS prevention programmes. As Peter Piot (2002), the Director of UNAIDS said,

> *Without education, AIDS will continue its rampant spread. With AIDS out of control, education will be out of reach.*

The situation is worsened in cases where teachers are lost due HIV/AIDS. HIV/AIDS mostly affects the economic active members of the communities i.e. those between the age of 15 and 49. Corporate Organisations are also losing many resources due to early retirements and work-related programmes (ibid).

What follows are some of the real stories from Africa emphasising the impact HIV/AIDS on different aspects of our lives. These stories have been adapted from the AVERT website (2000).

"She then led me to the kitchen and showed me empty buckets of food and said they had nothing to eat that day just like other days ...

I used to stay with the children, but now it is a problem. I have to work in the fields. Last year I had more money to hire labour so the crops got weeded more often. This year I had to do it myself- Angelina, Zimbabwe.

The first problem with this family is that no one is working. There is no food and no clothes, her mum is not working and there is no father ...

"Her brother is sixteen, he is also not in school, and he is looking after someone else's cattle for little money. The last born girl has been taken by another pensioner who is not a relative, they see her on holidays." - Nosipho, South Africa.

> *If there is a shortage of money the girl child stays behind and the boy child goes to school. Even if a girl is more intelligent ...*
>
> *Some of the schools have lost teachers due to this disease. Eventually after a year or two, they are replaced with another teacher. But they are not the same as the ones who have died. They cannot teach or do the work as well as the one affected by AIDS. And also the learners, the learners used to know their teachers very well.* - School principal, Namibia.

This chapter has overviewed some of the ways in which HIV/AIDS has effected and affected the lives of many millions of people. While statistics reflect empirical data, it is important to remember that behind each number is or was a person. Because HIV/AIDS involves human to human transmission, the ways in which it is transferred is an issue.

The ways of transmitting HIV/AIDS are mainly through the use of infected needles (in intravenous drug use or poor infection-control practices), contaminated blood (as in blood transfusions for Haemophilia), mother to child transmission, homosexual transmission, and heterosexual transmission. In Africa, the

majority of HIV transmission occurs between mother-to-child transmission and heterosexual contact. The manner in which HIV is transmitted ensures that individuals at risk for acquiring HIV are the same individuals whose human actions contributed to their own risk of HIV infection, mainly through intimate sexual contact.

Chapter 2: Medical Confidentiality

Preface

In this chapter because of the context in which I discuss confidentiality, the following definition of a *confidential situation* will be used:

> *A situation is confidential when information revealing that harmful acts*[2] *have been or possibly will be performed is consciously or voluntarily passed from an individual patient (assumed to be rational and competent) to another person (a doctor,*[3] *assumed to be rational and competent) in the understanding that the information given will not be further disclosed without the patient's open and voluntary consent*.

Beauchamp and Childress (1994) believe confidentiality is "present when one person discloses information to another, whether through words or an examination, and the person to whom the information is disclosed pledges not to divulge that information to a third party without the confider's permission." When this type of situation occurs within a healthcare setting, it

[2] A 'harmful act' may be considered as one that is biological, physical, or psychological.
[3] In this research report, I will use the terms 'doctor' and 'healthcare professional' interchangeably.

represents medical (or healthcare professional) confidentiality. Confidential information derives from the right to privacy or the control over the use of personal information (Knapp van Bogaert and Ogunbanjo 2009: 45).

Confidentiality *per se* is directly related to the control over further disclosure of that information for example, the storage, security and use of personal information already stored (Weston 1970:6). In 1982, Marc Siegler, an ethicist, wrote that confidentiality is a "decrepit concept" because in the age of informatics, many people can access information gleaned from patient records. Considering the technical advances in electronic communication, Siegler (1982) thinks that by now we might consider confidentiality as just an ancient relic.

On the other hand, it has been argued that medical confidentiality must be kept absolute under all times and circumstances. However, other ethicists have argued that while it once was a fundamental duty in healthcare practice, now it is not considered 'carved in stone' (Adler 1991: 196-198). By this is meant that confidentiality is a *prima facie* duty rather than an absolute one. So information cannot be released – including patient records

unless there is a serious and overriding ethical reason to disclose (Keys and Waithe 1993: 86-87; Moodley 2000: 308).

The main ethical dilemma around medical confidentiality concerns the assessment of whether more harm is done by breaching confidentiality or by respecting it. By their very nature, moral dilemmas exist in two forms: (1) some evidence indicates that x is morally right, and some evidence indicates that x is morally wrong, but evidence on both sides is inconclusive; (2) an agent believes on moral grounds, he or she both ought and ought not to perform act x. (Beauchamp and Childress: 1994). Medical dilemmas around medical confidentiality and disclosure, as do all moral dilemmas, arise from any of the two above-mentioned forms. Here it is important to note that the purpose of this research report is not just to present arguments for or against a particular position. Rather, the purpose of this research report is to present each of the opposing positions in a fair and comprehensive manner. This allows the reader to make a conscious judgment which he or she reflects and acts upon.

Now we will turn to a discussion about medical confidentiality from an absolutist view.

2.1 Absolute medical confidentiality

Some people view confidentiality as an absolute commitment in healthcare practice, even if the ideas of absolute principles are debated (Anscombe 1981: 28). When confidentiality is looked on like an interpersonal communications strategy, then it is easy to see the importance of confidentiality in a doctor-patient relationship (Morton and Landesman 1987: 22-23). This is because of course, it is not only vitally important as part of an ethical relationship, but also because practically speaking, no patient would go to a doctor who spread to others the intimate details of his or her life that were given to the doctor in confidence (Knapp van Bogaert and Ogunbanjo 2005; Anon 1990: 1-4).

There are two distinct approaches that justify the ethical duty of medical confidentiality that centre around the doctor-patient relationship. Mclean and Jenkins (1994: 669-674) believe there are two perspectives to consider concerning the doctor-patient relationship. The first perspective looks at the relationship from the patient's point of view. They argue that the "patient's perspective on confidentiality emphasises the idea of respect for persons as moral ends in themselves" (ibid: 670).

2.2 Kant and duty: A patient's perspective

The idea that each individual should be treated as an end in his or her self is an idea rooted in deontology, also called Kantism. Immanuel Kant ([1785] 1993: 196) developed a theory based on a person's duty to do act in accordance with the moral law within him or her, that which he calls a "good will". 'A will is good simply because of its willing' explains LaFollette (2007:34). Kant believed that each adult human is a rational being so he or she has intrinsic value. Because humans are of intrinsic value, they should be treated with dignity and respect. The idea of "respect for persons" comes from Kant. Kant's theory is called deontological because it is based on duty. For him, being moral is not about the consequences of our actions, it is about our intentions or doing what is right because it is right. And it is our duty to do what is right (ibid: 37). He developed categorical imperatives.

Categorical imperatives are not the same as hypothetical imperatives. A hypothetical imperative for example, could say "If I break medical confidentiality then I will have a bad professional reputation". Since I consider my professional reputation to be in my personal interest (if it was known that I don't keep patient confidences then I will lose patients) I will never break patient

confidentiality. Categorical imperatives are not like that (Singer 1999). Kant could create a maxim which would ground a categorical imperative. For example, we could say "One ought to not ever break medical confidentiality." Categorical imperatives tell us that we should do what is right because it is right (Kant [1785]1993: 30). Acting right, for Kant, is separated from and not dependent on any of our desires or beliefs or interests (La Folette 2007).

In a doctor-patient relationship, mutual trust is what makes it unique; an individual patient trusts that the information he or she confides to his or her doctor will be kept in confidence. Healthcare professionals have a moral obligation to be faithful and worthy of this trust (Pellegrino 2002: 384). If we place Kant's idea of duty and respect for persons in the context of this relationship (considering it as a moral enterprise) then each individual doctor because he or she respects the individual patient should be bound to keep absolute confidentiality.

The other perspective focuses on the autonomy of the doctor. This perspective appeals to the very nature of the consequences of the doctor's actions (consequentialist in nature). It argues that the doctor's autonomy will be in danger if he or she was to

divulge the confidential information given to him or her by a patient.

In relation to the doctor-patient relationship, Gillon (1985) mentioned that there are two conditions that are necessary to create a moral duty of confidentiality:

> *... one person (doctor) must undertake – that is explicitly or implicitly – not to disclose to another's secrets and that the other person (the patient) must disclose to the first person information that he considers to be secret.*

It is important to keep in mind that confidentiality in medical practice involves a relationship, but the idea of privacy does not. In cases of respecting medical confidentiality, the ethical weight of confidentiality should be the primary focus as opposed to only the consequences of breaching it (Boyd 1992: 176). As long as the healthcare professional keeps his or her focus only on private information (information of direct patient interest) it will concern only the individual patient. If the focus is kept solely on the individual patient then it could be argued that any disclosure of this information would be an untoward act on the part of the doctor (Dunstan and Shinebourne 1989).

Doctors are taught that the best interests of their individual patients should be their only concern (Kalavathy, et al. 2000 148-163). In this patient-centred approach, a healthcare professional e.g. keeps information confidential, attends to only the patient's needs, and does not allow outside forces to interfere with the solemn duty to act only in the best interests of his or her individual patient.

This is how doctors ethically justify not becoming involved in dual loyalty problems - when a doctor is torn between the duty to act in the best interests of his or her patient and simultaneous duty to a third party (usually the state) or others (PHR 2000). If a healthcare professional's loyalty rests only and absolutely with his or her patient then situations of dual loyalty cannot exist. Dual loyalty cannot exist because the doctor's focus is completely and absolutely confined only on his or her patient. So, we can see that the focus on the patient's best interests (including confidentiality, privacy and other issues) is not only ethically justifiable but in situations such as that of dual loyalty, may be considered ethically mandatory as well (van Bogaert 2010).

Absolute medical confidentiality is fortified by the idea that breaching it will irrevocably cause direct harm to the patient. Such harms may be e.g. causing him or her to undergo investigations, restrictions, and confessions, perhaps even with poor outcomes (Keys and Waithe 1993: 81-98). In addition, the socially embedded idea of doctors treating confidentiality as a primary virtue in healthcare professional-patient practice is in itself harmed because the idea of fidelity / trust is tarnished. In a doctor-patient relationship, when trust is diminished or broken it reduces the very concept of what is ethically implied in a 'doctor-patient relationship' (Kimberly, Serovich and Greene 1995; Pheby 1982: 12-28; Melden 1977).

Moreover, if breaching confidentiality is looked at in the context of harm to others, the idea of potential and actual harm should be considered. This is because the healthcare professional must make a judgment based upon his or her idea of the probability of harm to others (Pheby 1982: 12-18). The general disclosure of medical information in "the public's best interest" has raised the question whether medical information should merely be disclosed in the public's best interest or whether it is not in the public's best interest to withhold medical information. According to McLean

and Mason (2003: 35), the public's best interest, similar to a judgment of the probability of harm depends on the doctor's values and his or her subjective balance of best interest / harm to others.

Another way of looking at absolute medical confidentiality is to consider it as a conflict of rights and their co-relative responsibilities. These are both present in situations involving confidentiality. Confidentiality is an agreement bound by the principle of fairness (Rawls 1971: 342-350). Because of this, it gives the patient the right to expect good judgment on the part of the doctor. The doctor, though, has the right to hear information that is true and to abide by the absoluteness of confidentiality - to keep that which is known to him/ her as sacred (Thompson 1979: 59).

In keeping confidentiality it also can be said that others who were placed in harm's way or those who are or could be harmed also have rights. Such rights could be fulfilled by a healthcare professional if he or she divulged confidential information. It would make sense that these actual or potential victims have a right to justice and protection (McLean and Mason 2003: 76-77).

However to meet the rights of others, at least in the sense of actual or potential victim's rights, then the patient must involuntarily forfeit his or her right to medical confidentiality which the doctor will violate against the patient's will (Patel 2008). Of course, the forfeiture of the patient's right can only occur after the content of the information is given.

To avoid the risk of losing the right to medical confidentiality, patients would have to confide falsely or not at all (Gruskin, et al. 2007: 5-8). For example, if a patient knows he or she is HIV positive and does not trust that medical confidentiality will be kept, then the patient might refuse an HIV test, request that only his or her HIV symptoms be treated and so forth (Dunbar and Rehm 1992: 180-185). If this is enacted, then the idea of absolute medical confidentiality is completely changed (Odunsi 2007: 297). It is changed because the doctor no longer can believe that he or she is being told the truth as there is no longer the element of mutual trust. Thus, the institution of confidentiality as conceived in an ethical doctor-patient relationship is destroyed.

We can see that healthcare professionals appear to be under the *prima facie* obligation to respect the right to confidentiality, but

also to abide by the right of potential victims to be protected. In cases involving moral conflict, one right must be necessarily overridden (Khuse and Singer 2000). While understanding that infringing certain rights for the sake of others may be justifiable, in the context of the doctor-patient relationship, it can also leave a shadow of negative feelings such as regret, shame or guilt (Melden 1977: 47-48; Morris: 1981: 44). In professional healthcare practice, it is discouraging to think that the relationship of trust between doctor and a patient could unexpectedly turn into a situation of infringement of rights adversity and guilt. As Kottow (1997: 118) notes,

> *It appears contradictory to offer confidentiality as an enticement to sincerity only to subsequently breach it because the information is so terrible it cannot remain unknown. Confidence is understood as an unconditional offer, otherwise it would not be accepted, and it appears profoundly unfair to disown the initial conditions once the act of confiding has occurred.*

Looking at it this way, we can see that there are arguments supporting absolute confidentiality in a doctor-patient

relationship so it would hold that medical confidentiality should keep an absolutist position. This is because a doctor receives information from his or her patient which is intimate and which is given to him or her on the grounds of trust. In the establishment of a doctor-patient relationship, the moral boundary takes for granted that disclosure of information will not be transmitted to third parties (Stewart and Reppucci 1994: 110). If confidentiality is not kept apart from other considerations in medical practice, it, like the doctor-patient relationship, runs the risk of becoming less sacred.

Should one decide to introduce exception clauses, it would only be fair to explain this before any other discussions take place. This is because fairness requires that patients are fully informed of what to expect from their doctor (Jenkins et al. 2005). At the same time, there is something unsettling in the side effect of a patient feeling it is too dangerous to assume that his or her doctor would keep their confidences. The important thing to note in the above discussion is that we are discussing a doctor-patient relationship which involves two individuals in a bond of trust. Yet, when the ratio shifts, then a different stance is promoted.

This can be argued in different ways, For example, UNAIDS (2004) make a point that due to insufficient resources and personnel, disclosure of HIV status to sexual partners and other family members may take place without patient consent. The report (ibid) goes on further to mention that another contributing factor to the epidemic might be that healthcare professionals do not understand their duties with regard to HIV/AIDS confidentiality and disclosure. However the Nuffield Council on Bioethics (2007) points out that cautious consideration should be taken because protecting others from harm should not be done at the expense of the patient whether this is done in what the healthcare professional considers as the interest of the patient.

Here, John Stuart Mill's *Harm Principle* (Jackson 2010) makes it clear as Mill stated that ... his own good, either physical or moral, is not a sufficient warrant ... ' [to externally impose interventions that promote an individual's good health.] The framework for the "stewardship model" (Nuffield Council 2007) concurs that 'a greater more explicit justification is needed to infringe upon individual liberties' than those of the interests of third parties.

Many ideas raised in this chapter support keeping medical confidentiality absolute in an individual doctor-patient relationship. In the following chapter, I will look at some of the arguments which are against this position - exceptions to medical confidentiality.

Chapter 3. *Exceptions to medical confidentiality*

In the previous chapter, the importance of absolute medical confidentiality was outlined. We can all agree that respecting medical confidentiality builds trust between an individual doctor and his or her individual patient, enhances the confidence on the part of the patient towards a doctor, and ensures that the patient and doctor interact in good faith. The result overall, is a patient's loyalty (Herbert 1996). The above-mentioned points shape the foundation of the doctor-patient relationship. However, are there times when the idea of absolute medical confidentiality should be broken? This is the topic of this chapter.

3.1 *Limiting medical confidentiality*

Is it argued that in certain instances the principle of medical confidentiality may be limited, and such justifications for limiting medical confidentiality are, in the main, based on public health principles.

With the advent of the HIV/AIDS epidemic, including its complexities and dynamics, it seems only right to revisit the duty of confidentiality. In this chapter, exceptions to medical

confidentiality will be outlined in the context of the HIV/AIDS epidemic. In other words, we will discuss confidentiality in the context of a public health crisis, one in which the keeping of absolute confidentiality may present a discernable risk to others: the spread and transmission of a deadly infectious disease (Boyd 1992; Dunstan and Shinebourne 1989; Girardi, et al. 1998).

Elsayed (2007) argues that very little attention has been paid to confidentiality in public health, the domain under which HIV/AIDS epidemiologically falls. There is an acknowledgement that public health ethics share some characteristics with clinical medicine and research ethics. If that is the case, then public health ethics should be conducted in line with the following common medical ethical principles: respect for autonomy (viz. confidentiality of information), beneficence, nonmaleficence and justice (Gruskin, Ferguson and O'Mally 2007).

For example, it is argued that from a public health point of view, it is essential that epidemiologists keep accurate data and information of illness. This will not only assist in determining the burden of disease but assist in coming with appropriate health intervention measures (Hayter 1997: 1162-1166; Pickett and

Hanlon 1990). Elsayed (2007) identifies that for a public health code to be ethical, the following conditions must be fulfilled: political acceptance, it must address population concerns, adhere to the confidentiality principle (exceptions can be made provided they are clearly stated in the code), and be just and equitable.

Confidentiality does not only create a moral duty but also legal imperative on the part of the healthcare professional. The corresponding moral right of the patient is therefore a "right to confidentiality". Yet, the right to confidentiality usually causes conflicts of moral principles / duties between the duty of autonomy of the patient and the duty to protect others (as an example the right of life of the third parties who are in danger of contracting the disease) on the part of the healthcare professional (Dunstan and Shinebourne 1999; Adler 1991: 196-198).

In practice and faced with the HIV/AIDS epidemic, the ethical dilemma although seemingly clear becomes more complex. For a doctor, the duty to keep fidelity (as in keeping a patient's information confidential) is in conflict with his or her duty to do no harm or as little harm as is possible to other people (Odunsi 2007: 297-306). There are arguments which hold that indeed this

duty is not absolute, and there may be situations that require limiting of confidentiality or breaching of patient confidentiality in order to protect identifiable third parties (Keys and Waithe 1993).

The idea of doing no harm or as little harm as is possible to others has direct relevance towards the upholding and promoting of sound public health practices (Odunsi 2007; Andrain 1998). In the context of the HIV epidemic, this would mean to try to ensure there is no further spread of the epidemic (Stewart and Reppucci 1994: 107-120). Breaching confidentiality therefore, is protected because the harm given in confidence is very dangerous and the only way that the consequences can be changed is by the doctor's disclosure (Walters 1978: 169-170). In cases involving infectious diseases such as HIV, a healthcare professional might be compelled to disclose confidential information in order to prevent others from being harmed. Gillon (1987) however emphasises the fact the justification to limit confidentiality should be based non-maleficence and justice, never on paternalistic and beneficence as ethical justifications. This is because both paternalism and beneficence may misguidedly preclude a patient from being actively involved in his or her own health care, which includes information and information sharing. When balancing the four

principles of biomedical ethics (respect for autonomy, non-maleficence, beneficence and justice) Gillon considers that doing no harm or as little harm as possible to one's patient as well as justice as fairness should trump the other principles (ibid).

3.2 Disclosing confidential information

One of the problems is found in the way in which disclosure of confidential information can expand. For example, first an individual finds out that they are HIV positive and must make a decision whether or not share their status with others.[4] Let us assume that the patient makes the decision to confide in his or her doctor. The healthcare professional (believing it to be the right or legally required thing to do) then discloses the patient's HIV status to another person or an identifiable third party. We will place this scenario in a country which has HIV/AIDS listed as a notifiable condition, and can assume that this information is reported to a national HIV/AIDS registry. That national registry then discloses such information to others (UNAIDS, 2004). The point is that unless there are safeguards regarding the patient-identifiable information confided, it is possible that confidential

[4] This has bearing on the doctor-patient relationship as the patient must make the decision that he or she trusts the doctor and the idea of medical confidentiality enough to disclose the information.

information may be leaked to others such as insurance companies and employers. To avert such happenings recommendations are made to healthcare professionals that during mandated HIV pre- and post-test counselling, patients should be told of the need to disclose their HIV status to their partner(s) and how they should protect their partners in this regard.

The first line of action should be to persuade the patient to consent to the doctor disclosing or to self-disclose this confidential information. Patients should be encouraged to be responsible in terms of their behaviour so as to prevent others from becoming infected. Moreover, patients should be made aware that penalties may result in cases of irresponsible (negligent or culpable) conduct (Patel 2008). If the patient is unwilling or afraid to disclose, the doctor may offer, with the patient's consent, to speak with e.g. the patient and his or her partner as a matter of seeking good healthcare (Morton and Landsman 1987: 22-23). If the patient is still unwilling to disclose, the doctor may choose to disclose the patient's HIV status only if all the following conditions are met:

- The sexual partner should be a known and identified person and

- The sexual partner should be at risk of being infected (UNAIDS 2004).

From a public health perspective, disclosure of confidential information concerning a patient's HIV status is ethically permissible if the following conditions have been satisfied:

> *The doctor has failed in attempts to get his or her patient to disclose; Harm is likely to occur and is serious, imminent and foreseeable; There is an identifiable third party at risk; The disease is preventable; and The harm from failing to disclose should outweigh the harm of disclosure* (Stewart and Reppucci 1994; Giradi et al. 1988: 1-27; Thompson 1979: 57-64).

This chapter has shown that the principle of confidentiality cannot be viewed as absolute as there are professional public healthcare considerations that may justify limiting the principle of confidentiality.

There are certain professional codes of ethics that affirm the significance of confidentiality e.g. The Hippocratic Oath; the Declaration of Geneva; and the World Medical Association's International Code of Ethics. These are internationally recognised ethical guidelines that seek to direct healthcare professionals on

confidentiality and disclosure. As we will see, some of them conflict. This is the topic of the next chapter.

Chapter 4. Professional guidelines concerning medical confidentiality

In this chapter I will identify and discuss professional guidelines that seek to provide guidance to healthcare professionals on HIV/AIDS confidentiality and disclosure. I will also try to identify any shortcomings in the guidelines.

4.1 International guidelines on confidentiality and disclosure third parties

Different professional organizations in the world have different views regarding the breach of confidentiality of an HIV positive patient to an identifiable third party.

In Canada (CAHIV: 1989), the preamble to the guidelines states another part of the Hippocratic Oath:

> *"whatever one has heard in the course of medical practice must never be spread abroad*. "

In this Canadian guideline (ibid) it is considered professional misconduct

> *... to give information concerning a patient's condition or any other professional services performed for a patient to anyone other than the*

patient without the consent of the patient unless required to do so by law ....

In line with the above, the American Medical Association (AMA) Code of Ethics (2008-2009) states that a physician "shall safeguard patient confidences within the constraints of the law". The AMA however does allow for exceptions. In their 150th edition of the AMA's Code of Medical Ethics (AMA: 62) they state:

> *…exceptions to confidentiality are appropriate when necessary to protect the public health or when necessary to protect individuals who are endangered by persons infected with HIV. If a physician knows that a seropositive individual is endangering a third party , the physician should, within the constraints of the law, (1) attempt to persuade the infected patient to cease endangering the third party; (2) if persuasion fails, notify authorities; and (3) if the authorities take no action, notify the endangered third party* (Schneider and Levinson 2005).

The World Medical Association's (WMA) Declaration of Geneva[5] claimed "absolute secrecy" on the part of the doctors. It read:

> *I will respect the secrets which are confided in me, even after the patient has died.*

Their new WMA declaration reads as follows, a physician shall

> *... respect a patient's right to confidentiality. It is ethical to disclose confidential information when the patient consents to it or when there is a real and imminent threat of harm to the patient or to others and this threat can be only removed by a breach of confidentiality.*

The strength of the declaration is that it gives its members some kind of a leeway to discuss disclosure of information, secondly it provides conditions under which a physician can disclose information, and lastly it gives discretion to physicians to make decisions on type of information to be disclosed (WMA 2006)

A contradiction is however noted in the sense that World Medical Association's 1983 International Code of Medical Ethics still expects absolute secrecy from the physicians writing "…preserve

[5] *Adopted by the 3rd General Assembly of the World Medical Association, London, England, October 1949and amended by the 22nd World Medical Assembly, Sydney, Australia, August 1968and the 35th World Medical Assembly, Venice, Italy, October 1983and the 57th WMA General Assembly, Pilanesberg, South Africa, October 2006(WMA 2010).*

absolute confidentiality on all he knows about his patient even after the patient has died" (NIH 2006).

There are other medical associations worldwide which have HIV/AIDS specific guidelines that are unclear or not helpful. For example, the American Psychiatric Association (APA) supports disclosure as a last resort. They advise healthcare professionals to first try to change the behaviour of the patient or persuade the patient to disclose him or herself (Schneider and Levinson 2005).
It is only once the efforts have failed that the psychiatrist can consider disclosing to third parties (APA 2009). The American Psychiatric Association's Practice Guideline for the Treatment of Patients with HIV/AIDS (ibid: 370) states,

> *... if a patient refuses to change behaviour that places others at risk for HIV infection or not inform individuals at ongoing risk, or if the psychiatrist has good reason to believe that the patient has failed to or is unable to cease such behaviours or to inform those at risk, it is ethically permissible for the psychiatrist to notify identifiable individuals at risk or to arrange for public health authorities to do so.*

However in the United Kingdom, the guidelines are not very definitive. In 2000, the following was noted from a report by a disgruntled practitioner (Pinching, Higgs, and Boyd 2000):

> *How far should a doctor go in attempting to protect others from a HIV risk from his patient? Many clinicians are very uncomfortable with knowing that an HIV positive patient is continuing to have unsafe sex with a person whom the patient is unwilling to inform. After attempting to influence the patient's behaviour or willingness to discuss his HIV status, the clinician may be left with either feeling unable to act further because of confidentiality, or feeling obliged to breach confidentiality to protect the third party. The General Medical Council guidance allows either, so long as the clinician is able to justify his actions. Each case has to be judged on its particulars.*

The American Medical Association's (AMA) Council on Ethical and Judiciary Affairs states that "a physician who knows that a seropositive individual is endangering a third party should attempt to persuade the infected patient to cease endangering

the third party; if persuasion fails, the healthcare professional should notify the authorities and if the authorities take no action, notify the people at risk (third parties).

The disparity in the application of the principle of confidentiality is once more underlined in debate between the British Medical Association (BMA) and general practitioners. A general practitioner stated that consultants treating patients who are living with HIV/AIDS are overprotective. Some of the reasons advanced by the general practitioners are that:

- It is a normal medical practice to share information amongst healthcare professionals;
- It is in the best interest of the patients leading to best medical care;
- It is in the best interest of the general practitioner and associated staff by reducing the risk of acquiring the diseases; and
- It is in the best interest of the general public by reducing the spread of the disease (Gillon 1987).

The BMA (2009) on the other hand believes that

> *... the traditional confidentiality of the doctor-patient relationship must be held in the case of*

patients suffering from AIDS and HIV seropositive patients.

There are other professional ethic codes that acknowledge that under certain circumstances, a healthcare professional is justified in limiting the principle of confidentiality either for public health considerations or in order to protect identifiable third parties. For example in the United Kingdom (UK), a 1993 publication of the *Professional Conduct: Fitness to Practice* provided circumstances under which doctors were permitted to disclose information and included the following 1) when information is shared with other doctors, nurses or health professionals participating in the care for the patient; 2) when on medical grounds it is undesirable [or impossible] to seek the patients' consent; and 3) when information regarding the patient health may be sometimes be given in confidence to a close relative.

In the United States of America (USA), the American Public Health Association (APHA) code of ethics states that "public institutions should protect the confidentiality of information that can bring harm to an individual or community if made public". This allows for confidential collection and use of valuable data to curb the

spread of disease. It however suggests exceptions provided that it "must be justified on the basis of the likelihood of significant harm to the individual or others" (APHA 2002). In the same country, the *Health Insurance Portability and Accountability Act* of 1996 (HIPAA) was passed to protect confidentiality of health information amongst the array of stakeholders involved in the provision of healthcare. HIPAA makes exception for collection and sharing of information for public health activities of reporting, case finding, partner notification or contact tracing (CDC HIPAA 2006).

Collection of such information not only contributes to care of an individual but the achievement of systemic goals. Whilst HIPAA recognises the importance of data collection for public health purposes, it still emphasises the importance of legal privacy. To this end it requires that all identifiable health information be legally protected, whilst non-identifiable health information requires no legal protection and disclosures are strictly limited (ibid).

Other countries also have professional ethics codes and legislation. Mason and McCall Smith (2005) note that "Medical

confidentiality in France and Belgium is absolute and is protected in the criminal code." The Medical Council of New Zealand holds that confidentiality is a fundamental principle in the doctor-patient relationship, it however allows for disclosure of information in instances where harm to a patient or another individual could be prevented by breaking that confidence. The *New Zealand Health Privacy Code* 1994 makes provision for disclosure to prevent or lessen serious and imminent threat to 1) public health or public safety and 2) the life or health of the individual concerned or another individual. HIV/AIDS meets both of the conditions stated above (NZMC 2006). The *New Zealand Health Privacy Code of 1994* allows for limiting or breaching the principle of confidentiality. The two conditions mentioned in the New Zealand Health Privacy Code of 1994 would allow for HIV/AIDS disclosure to identifiable third parties.

Considerations such as these lead Maclean and Maher (Gwyn Tovey,1991-2009) to conclude that

> … [codes, declarations, guidelines] *render the principle of confidentiality almost meaningless*.

4.2 South African national guidelines on confidentiality and disclosure to third parties

In the previous section I focused my attention on international professional ethical guidelines and some legislation that seek to provide guidance to healthcare professionals on HIV/AIDS confidentiality and disclosure. In this section I will discuss some South African guidelines on confidentiality and disclosure to third parties.

The *South African Medical Association* (SAMA) provides the following guidelines relating to the management of patient information and behaviour of medical practitioners including HIV/AIDS:

- Managing confidentiality between health care workers on the HIV status of a patient.

This guideline provides for the use of a doctor's discretion and defines the circumstances under which patients' information may be disclosed with or without consent.

- Managing confidentiality and sexual partners.

Here again the guidelines allows for doctors' discretion and circumstances under which breach of the doctor's duty of confidentiality could be justified (SAMA 2009).

The Human Rights and Ethical Guidelines on HIV states that any person's HIV status may only be made known to a person or group only if that patient consents to disclosure of their HIV status. [6]

The *Health Professional Council of South Africa* (HPCSA) exists as the statutory body responsible for the behaviour and conduct of healthcare professionals in South Africa. The HPCSA provides the following ethical-legal procedures regarding the management of patient information including HIV/AIDS:

According to the HPCSA, the results of HIV positive patients should be treated with the highest possible level of confidentiality. The mode of transmission of clinical data to those medical colleagues and health care workers directly involved, or who will probably become involved with the care of the patient, will dictate the extent of disclosure of such information.

[6] Ethical and legal aspects of a fully conversant informed consent include full disclosure of all necessary information needed to make a decision, understanding of information given, mental and legal capacity to consent or refuse consent and voluntariness or participation without coercion.

The HPCSA emphasizes the upholding of the principle of professional secrecy in respect to patient information. The decision whether to divulge the information to third parties must therefore take place in consultation with the patient. One way of reading this is to say that a doctor should not, unless bound by law, divulge patient information without his or her patient's consent.

The HPCSA (2006) provides the following steps to be followed "the healthcare provider must offer the patient counsel on the importance of disclosure/safe sex and offer support to make disclosure. If the patient still refuses to disclose, the healthcare provider must "counsel on ethical obligation to disclose and ask for consent to disclose. The patients' attention should be drawn to the possibility of violence/adverse consequences to not disclosing."

The HPCSA guidelines also tell us that if the patient's consent cannot be obtained, then the health care professional should use his or her discretion whether or not to divulge the information to other parties. Such a decision, they point out, must be made

"with the greatest care, after explanation to the patient and with acceptance of full responsibility at all times."

Traditionally straightforward practices such as confidentiality have been subjected too much review and investigation. Such articles, documents and guidelines have proved unable to provide a united or unambiguous guideline for action (Thompson 1979: 598-59; Pheby 1982: 12).

Chapter 5. Ethical-Legal considerations concerning medical confidentiality

Preface

The ways in which the law as a normative enterprise relates to HIV/AIDS, confidentiality, and disclosure to identifiable third parties will be overviewed in this section. The law on HIV testing seeks to protect the HIV positive individuals from abuse by the public including healthcare professionals and employers. Legislation concerning the treatment of HIV positive individuals came about because of actual cases or fears concerning the breaches of privacy of HIV positive patients, discrimination by healthcare workers and others, dismissals/exclusion from the workplace and protection of the sexual partners of HIV positive patients.

In this chapter, some of the ethico-legal issues will be discussed. It is also important from ethical-legal point of view to identity any contradictions between the ethical guidelines and any legal framework.

5.1 The legal basis of confidentiality

The legal basis of the duty to maintain confidentiality arises from both statute and common law (Mae, 2004). Statutes make it an offence to disclose confidential information. On the other side from a common law point of view, "the duty developed from cases studies where healthcare professionals faced legal action from their patients for disclosing private information without their consent or legal justification. Under common law, the duty is based on the following areas: contract law (implied or express contractual duty between the patient and the doctor), equity (the patient relies in good faith that information shared with the doctor will be kept confidential) and torts (duty of care in the law of negligence, not to cause foreseeable harm to another person that may result in damage" (ibid: 56).

MacFarlane and Reid (Paul Mae,2004) identified three circumstances under which limiting of the principle of confidentiality may be legally justifiable:

(a) Where legal statutes make provision for such a disclosure;

(b) Where there is an overriding public duty to disclose; and

(c) information is sought through a court order.

5.2 Legislative framework on confidentiality and disclosure

Within the South African context, the following provides a legal framework for confidentiality and disclosure:

The South African Constitution Act 108 of 1996:

The Constitution of the Republic of South Africa of 1996 makes provision for the protection of unfair discrimination of any of its citizens. In Section 10 it state that 'everyone has inherent dignity and the right to have their dignity respected and protected'. In the context of the HIV/AIDS epidemic, no persons, health care professional, family member, hospital, colleague or any institution may disrespect and insult another person based on their health status.

This Constitutional provision is further strengthened by the *Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000.* Section 2 of the Act encourages all citizens to prevent, prohibit and eliminate unfair discrimination, hate speech and harassment. Understanding that HIV infected persons are often

the brunt of stigmatization and abuse makes this Act particularly relevant.[7]

Section 14 of the Constitution affords 'everyone the right to privacy, which includes the right not to have the privacy of their communications infringed'. Concerning Section 14, no one is obliged to reveal their HIV status and that no one may volunteer this information on behalf of another person. An employer or healthcare professional may not coerce you to reveal your status. Section 27 of the Constitution is probably one of the most recognized rights regarding health care. It states that 'everyone has the right to have access to health care services, sufficient food and water and social security'. Thus, no government hospital or healthcare worker or professional may refuse a citizen health care services and no health institution, whether private or public hospital, may refuse emergency medical treatment. This also affords people living with HIV/AIDS a right to reproductive care. This means that people living with HIV/AIDS also have a right to be informed about reproductive care in order to make their own informed reproductive choices.

[7] The Domestic Violence Act 166 of 1998 recognizes many forms of abuse; these include physical abuse, sexual abuse, and emotional, verbal and psychological abuse which add even more emphasis on an individual's right to be treated at all times under all health and other conditions with dignity.

Section 24 of the Act (ibid) states *'… everyone has the right to an environment that is not harmful to their health or well-being …'* In the context of HIV/AIDS, an interpretation of this could be read as meaning that people suffering from HIV/AIDS related opportunistic infections e.g. TB, MDR-TB or XDR-TB, particularly the latter who require placement in isolation units, still have a right to an adequate living environment. By an adequate environment, one could consider a unit which is open to sunlight, clean with space enough to exercise or relax and is not devoid of other human contact.

Section 26 states that, 'everyone has the right to have access to adequate housing'. Concerning this right, there has been a tendency or even unspoken procedure for banks and other loan companies to refuse home loans or housing subsidies because it is known to them that a client has HIV or AIDS. The category of a 'high risk client' is then applied and the applicant is unable to secure a housing loan. This is discriminatory and unconstitutional (ibid). In addition, since everyone has a right to 'sufficient food and water', this also implies that they are entitled to social security, especially when they are too ill and that 'they are unable to support themselves and their dependants' (ibid).

The South African Law Commission researched and published reports dealing with law reform and HIV/AIDS from 1997 that included amongst others the following that are relevant to this section: The development of a National Policy on HIV testing (1997), the removal of uncertainty regarding AIDS as a notifiable disease (1997), and the Employment Equity Act (1998). The Law Commissions Recommendations (2000; 2001) also discuss public pressure to create an HIV specific criminal offence for nondisclosure to sexual partners. In this regard, the *South African Portfolio on Community Health* endorsed the Commission's recommendations for compulsory testing of alleged sex offenders.

Other South African legislative frameworks include the following: *National Health Act of 2003* emphasizes the issue of protecting confidential information of the patients. *The Medical Schemes Act of 1998* promotes constitutional obligations of confidentiality within the medical aid industry, to ensure proper handling of member information between healthcare providers and healthcare funders. *The Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000* aims to protect individuals from unfair discrimination including those living with HIV/AIDS.

There is also Draft *Regulation R485* that focuses on amongst other issues on immediate named horizontal notification of HIV status of individuals. Immediate named horizontal notification refers to notification of family members and care giver in case of AIDS diagnosis; and notification to "people responsible for preparation of the body" in case of AIDS related death. The horizontal named reporting contradicts confidentiality and does not include notification to partners and therefore has other limitations.

The introduction of the *Criminal Law (Sexual Offences) Amendment Bill of 2007* seeks to protect partners of HIV positive people. It states in Section 5(1)*: A person ("A" who engages in intimate contact with another person ("B") and who intentionally does not disclose to B that he or she has HIV/AIDS is guilty of an offence of criminal non-disclosure of HIV or AIDS.*

5.3 Workplace related perspectives

The focus of this section is primarily on South African legislation that seeks to protect people living with HIV/AIDS in their workplace.

The Labour Relations Act Number 66 of 1995 is probably the most easily recognizable statute that protects people living with HIV/AIDS. Whilst it prohibits unfair discrimination in the workplace, it does make provision for exceptions in situations that are related to the inherent requirements of the job. Insofar as employers may want to force the employees to go for an HIV test. Section 7(2) of the *Employment Equity Act of 1998* prohibits such unless if authorised by the Labour Court. Currie and De Waal in their publication 'The Bill of Rights Handbook' (2008) cite the case of *Irvin v Johnson 2002.* In this case, it was declared that anonymous and voluntary medical testing does not fall within the ambit of Section 7.2 of the *Employment Equity Act.*

Section 23 of *The Labour Relations Act Number 66 of 1995*, states that 'everyone has the right to fair labour practices'. This prohibits prejudice against an employee or a person seeking employment because of his or her past, present or anticipated health condition is prohibited (see: *Labour Relations Act 1995, Chapter 8*). This means that a persons past or present HIV status or any inferences about the course of the health of people living with HIV/AIDS may not be used to justify discrimination, unfair dismissal or the imposition of unfair labour practices.

From all of the legislation cited, it is clear that South Africa has legislation in place to guard against human rights abuses. We also see different views on HIV/ AIDS as the epidemic continues. Now I will turn to a case report which was presented to the South African court for legal judgment.

Jansen Van Vuuren v Kruger 1993 (4) SA 842: is an example of case wherein a healthcare professional disclosed the status of one of his patient's while playing golf with to his colleagues. In this case, the patient had specifically requested his doctor not to disclose his HIV status. The court ruled that the disclosure was unreasonable, unjustified and wrongful as the patient posed no risk to the colleagues of the healthcare provider. At the trial, Mrs. Christie, the Head of the AIDS Centre at the South African Institute for Medical Research (SAIMR) said,

> *… For one thing, there is widespread ignorance and subsequent fear of the disease. The public is afraid of AIDS and the media has also helped to reinforce existing fear through sensationalist and sometimes inaccurate coverage on the topic. This is largely*

> *detrimental to society because it is well-documented psychological facts that fear arousal is not conducive to learning or promoting behavioural change. In fact, fear elicits denial so that people tend to block out what they hear or see. Another difficulty in promoting socially responsible behaviour is that AIDS deals with so many taboo subjects, including: sex, blood, death, promiscuity, prostitution, abortion, homosexuality, drug use, et cetera. These taboos makes AIDS an uncomfortable subject to deal with and creates impediments in the learning process. …* (Christie, 1993)

Despite the fact that there is a strong legal framework and ethical guidelines, people living with HIV/AIDS are still being discriminated against, there is fear and therefore lack of disclosure to identifiable third parties, fear of people living with HIV and stigmatization. On the other hand, although there are similarities in some guidelines, there are also clear differences amongst them. This creates some ambiguity for healthcare providers and they find themselves having to make different ethical decisions that are risky to themselves and their patients.

5.4 International Law and Human Rights

This section briefly explores the relevance of international law and human rights on HIV/AIDS confidentiality and disclosure. Such arguments should guide and promote responses that are based on public health principles, however bearing in mind that "what makes public health sense does not automatically become a human rights obligation in international law"(Fidler, 1999:210)

Human rights are defined "as a set of universal entitlements that individuals enjoy irrespective of their sex, nationality, religion, culture or other status, that are inherent to human beings and that are proclaimed and protected by international law"(WHO c 2000)

Due to the genocide and other war crimes of Nazi Germany, a human right movement emanated that resulted in the drafting of the 1948 *Universal Declaration of Human Rights* that reiterates that "human rights should be protected by the rule of law" (UN 1948). Such international laws were also identified to be relevant to as comprehensive framework to which the public health practitioners can anchor the response to the challenges of HIV/AIDS and other health issues (Mann, 1996). Such approaches

support public health practices that seek to promote public health goals, as well as connecting with other stakeholders or social movements that promote the rights of individuals.

Under the auspices of UNAIDS and the office of the High Commissioner, the *International Guidelines on HIV/AIDS and Human Rights* was developed with input from different stakeholders and social movements in 1996. The guidelines do allow that states may impose limitations on individuals' freedom and talk specifically about limiting patients' rights and allowing health care professionals to inform their partners of the HIV status of the patients. However strict legal processes are required for such limitation to prevent discrimination against people living with HIV/AIDS' (UN SG 1996; 1997)

It can be argued that there has been more emphasis on protecting civil and political rights of people living with HIV/IDS and as such polices failed to engage on a full range of social, political and cultural factors that underlie the vulnerability of to HIV and the response to the pandemic (Kirby, 1996: 1217-1218). To circumvent the above, Heyward and Altaman (2005: 156) suggest a more human rights approach should be adopted in developing policies to ensure that health care practitioners are more

comfortable in dealing with the issues of confidentiality and disclosure.

From the perspective of human rights we can see that there is much activity towards the protection of individuals who have HIV/AIDS from discrimination and injustice.

Chapter 6. The HIV/AIDS Epidemic and Medical Confidentiality: Discussion and Concluding Remarks

In chapter one of the report I highlighted the impact that HIV/AIDS has had on the population of the world, and the African continent is the worst affected continent in the world, especially the Sub-Saharan region (South Africa included). I also discussed the socio-economic impacts that the epidemic had on healthcare systems and individuals. I noted that in the year 2009, almost 33.3 million people were living with HIV/AIDS worldwide, with 50 percent of those being women. During the same year, new infections of the disease were around 2.6 million, and that 1.8 million people died due to HIV/AIDS related conditions. The chapter also highlighted how the number of people living with HIV/AIDS has increased from around 7 million in year 1990 to around 33.3 million in 2009. I showed that the African continent is the worst affected continent in the world, with almost two thirds of people living with HIV/AIDS found in the region. I also highlighted the socio-economic impacts that the disease has within the Africa continent particularly in the healthcare section. Other social effects such as the increase of orphans, family reductions of essential services to take care of the sick, increased

child labour, educational demise due to drop-outs and finally, increased levels of poverty. The resultant effects of these factors exacerbate the levels of the disease and create a vicious cycle of despair.

Chapter 2, *Absolute medical confidentiality* and Chapter 3, *Exceptions to medical confidentiality* set out the pros and cons concerning confidentiality in healthcare practice. These chapters identified the direct relevance of confidentiality to my topic of HIV and disclosure of confidential information to identifiable third parties.

Concerning absolute medical confidentiality, I highlighted the fact that the reasons for the upholding of the principle mainly appeal to the importance of the idea that the doctor-patient relationship is based upon its intrinsic morality; that if medical confidentiality is removed, then the practice of medicine as well as healthcare will be damaged. I advanced the argument providing views that limiting the principle of confidentiality will have a negative effect on the relationship between the patient and the doctors as this enhances trust in the relationship necessary for the transfer of confidential information between the two parties.

Another argument I provided to advance the upholding of the principle is the dual interpretation of the doctor-patient relationship. I argued that the doctor-patient relationship can be looked at either from the patient or doctor's perspective, and both support the upholding of the principle of confidentiality. The doctor's perspective of the relationship is grounded on the philosophical principle of the professional autonomy whilst the patient's perspective demands that people be respected as rational agents in line with Kant's theory of respect for persons. I also supported the argument of absolute medical confidentiality through the example of dual loyalty, noting that if a doctor focuses his or her attention on only his or her patient, then situations of dual loyalty (and maintaining confidentiality) can be averted. The motivations are therefore to maintain trust/fidelity and avoid direct harm to the patients.

I identified that whilst public health interests may be used as a justification to limit confidentiality they may also be used as arguments to uphold confidentiality (Brooks, 2006). They do so because if confidentiality is not encouraged and maintained, then patients will not present themselves when they are ill and these could create serious health problems in terms of communicable

disease and the spread thereof. To further enhance the arguments for absolute confidentiality, I pointed out that the use of 'the public best interest' as a justification for limiting the principle of confidentiality is not strong enough as it depends on the doctor's values, and becomes subjective. Another justification highlighted was the principle of fairness, in the sense that the patients have a right to expect good judgement on the part of the doctor and the doctor have a right to hear information that is true, and abide by the absoluteness of confidentiality.

The real dilemma for healthcare professionals is the *prima facie* obligation to respect the right to confidentiality and also abide by the right of potential victims to be protected. On the other hand, as I identified, overriding of rights in the doctor patient relationship has negative effect on the delivery of healthcare. In the final analysis if exceptions are to be made, such clauses be discussed with patients' first and patients to be fully informed of such clauses.

Having discussed some justifications advanced for upholding of the absolute confidentiality principle, I the focused on possible exceptions for limiting the confidentiality principle. The section

explored mainly the circumstances under which limiting medical confidentiality might be both morally and legally justifiable. In the main the justification for limiting the principle of confidentiality are based on public health interests. This is despite and against earlier assertion that the use of public best interest as a justification for limiting the principle of confidentiality is not strong enough as it depends on the doctor's values, and becomes very subjective. On the other hand, I suggested that to allow the doctors to balance the best of interest of the individual versus harm to others might be an acknowledgement on itself that public health interest may be strong reason for limiting the principle of confidentiality.

Whilst there are there are arguments that very little attention has previously been paid to the ethical codes that governs the discipline, it is however noted and true that public health shares some characteristics with clinical and research practice, as such the following *prima facie* principles should apply: autonomy, beneficence, non maleficence and justice. It is interesting to note that all these principles featured very prominently as justification for upholding the principle of confidentiality in the previous section. If it were to be accepted that *prima facie* principles apply

to the public health field as it applies to other disciplines, the use of public interests as justification for exceptions to the principle will have no weight.

I highlighted the some of the characteristics that are required for a public health code: politically acceptance, meeting population concern, adhering to the confidentiality principle, and justice and equality. Although there is an overlap of between these characteristics with the *prima facie* principles applicable in medical ethics, it should be noted that public health is somehow unique and does not completely share the same characteristics with clinical and research ethics. Therefore to some extent public interest do carry weight as a justification for limiting medical confidentiality.

Having accepted the value of public health as possible reason for limiting the confidentiality principle, I highlight some of the arguments used as justifications. I pointed out that from an epidemiological point of view there is a need to collect accurate information and information on illness. Accurate collection of information will require sharing of confidentiality of information and as such involve invasion of privacy rights discussed in the

previous section. Of course it is noted that from a public health point "right to confidentiality" creates a conflict of moral principles/duties between respect for persons (in an individualist perspective) and that of the public's good (in a social perspective).

In Chapter 4 I looked at *Professional Guidelines and Ethical-Legal Considerations Concerning Medical Confidentiality.*

In examining some of these guidelines and codes, I noted inconsistency or lack of guidance provided by many of the documents. The purpose and objectives of these codes are amongst others to provide its members with codes of conduct related to medical practice including medical confidentiality. For example the most recognizable international code of conduct in the medical practice worldwide is the Hippocratic Oath. I highlighted how its wording to a certain extent some leeway in its interpretation of the following statement "…of that which ought not to be spoken about". I showed that there are professional codes in different countries which also make for exceptions for medical limiting confidentiality in their codes. Overall, I showed that there are both similarities and differences in interpretation of the duty of confidentiality. In the South African context, I identified various codes and guidelines relating to medical

confidentiality particularly focusing on HIV/AIDS. I again showed similarities as well as differences in their understanding.

I pointed out that there are general recommendations in place for providers on disclosure: that healthcare professional should emphasise disclosure during counselling, such as persuading the patient to consent to disclosure or to self discipline, and to accept responsible behaviour. I identified that if a patient remains unwilling to consent that a healthcare professional should try to speak to both parties. However, if a patient remains unwilling to disclose, a doctor may choose to disclose the patient's HIV status to known and identified parties who are at risk of being infected. As I identified, the weakness of the above-mentioned is that there is no obligation on the side of healthcare provider to disclose to identifiable third parties. Nonetheless as I identified, healthcare professionals must still make judgement concerning a determination on the likelihood, seriousness and imminence of harm to identifiable third parties.

In Chapter 5, I looked at some issues arising from *Ethical-Legal considerations concerning medical confidentiality.* In that chapter, I paid attention to the rationale of some international and

national legislation regarding the privacy, the principle of confidentiality and HIV/AIDS. I pointed out in the chapter that the objectives of the legal framework are mainly to: protect HIV patients against breaches of privacy by healthcare workers, deal with possible discrimination of HIV patients by healthcare workers, possible discrimination/exclusion from the workplace, and protection of sexual partners HIV positive patients.

I explained that the legal basis emanate from both statute and common law. The most relevant aspects of common law to confidentiality issues are contract law between patient and the doctor (explicit or implicit), equity (good faith from healthcare practitioners) and torts emanating from law of negligence. However, I noted that it may be legally justifiable to disclose confidential information if a legal statute makes provision for that, if there is an overriding public duty to do so or if ordered by a court order. To deal with the challenges of HIV/AIDS and confidentiality in South Africa, a legal framework has been developed to protect people living with HIV/AIDS. I highlighted the importance of many South African laws bearing on HIV/AIDS and confidentiality. In terms of the workplace, I explored the *South African Labour Relation Act of 1998* that protects

employees against unfair discrimination of any kind including health related matters as well as other relevant Acts and their sections such as *Section 7(2) of the Employment Equity Act of 1998 .*

In the last part of Chapter 5, I briefly presented an overview of the interaction between law and human rights. I pointed out that based on the *Universal Declaration of Human Rights of 1948*; human rights should be protected by rule, as this will enhance the response to the challenges of HIV/IADS and other health issues. Those promoting public health must take into consideration social movements that seek to promote the rights of individuals. The *International Guidelines on HIV/AIDS and Human Rights* provides for limiting individual rights in order to inform a partner of the other's HIV status.

In this research report I have tried to show ways in which the effects and the affects of the HIV/AIDS pandemic are found at different societal levels i.e. governmental, community and family. Social stigmatization and lack of full disclosure has been identified as among the factors contributing to the spread of the pandemic (UNAIDS, 2004). I have suggested that this may be attributed

firstly to the moral dilemmas and conflicts emanating from the recognition of the duty of confidentiality and the breach of this duty by the disclosure of confidential information to identifiable third parties. I have also illustrated that there is often vague or contradictory direction provided by available professional guidelines on HIV disclosure. The above may result in poor or inadequate pre- and post-test counselling of HIV positive patients in both general medical practice or in other healthcare settings. In addition, because patients are aware that if they disclose their HIV status to their doctor, it is conceivable that this information will be transmitted to identifiable third parties and this may lead to poor or non-disclosure on the part of patients (Adler 1991: 197). As such, the lives of identifiable third parties are put at risk.

In this research report I have shown that keeping medical confidentiality remains vital for doctors to hold because 'it facilitates a patient to divulge all information relevant to his or her health'. Moreover, it also improves patient adherence to treatments such as HAART. The benefits of absolute medical confidentiality are assured and strengthen the bond of trust between a patient and his or her doctor. Yet, at the same time, there is the fear on the part of patients that disclosure of

confidential information will occur which may result in injustice and victimization. This then remains the dilemma faced by doctors and other healthcare professionals in the face of the HIV/AIDS pandemic: Should my duty to my patient override my duty to identifiable third parties / society?

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