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THE RIGHT TO KNOW AND THE RIGHT NOT TO TELL:

THE ETHICS OF DISCLOSURE OF HIV STATUS

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A research report submitted to the Faculty of Health Sciences, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Science in Medicine in the branch of Bioethics and Health Law, Steve Biko Centre for Bioethics

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Declaration:

I, Mary O'Grady, declare that this research report, The Right to Know and the Right Not to Tell: The Ethics of Disclosure of HIV Status, is submitted for assessment for the MSc Med (Bioethics & Health Law) course and is my own unaided work except where I have explicitly indicated otherwise. I have followed the required conventions in referencing the thoughts and ideas of others. It is being submitted for the degree of MSc Med (Bioethics & Health Law) in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree of examination at this or any other university.

Signature: **Date: 5 August 2009**

Dedication

This research report is dedicated to my parents and to all those continuing to fight against injustice in the world.

"Without a social justice component, medical ethics risks becoming yet another strategy for managing inequality."

Paul Farmer, 2005

Abstract

Disclosure of HIV status has been considered an important public health issue for some 20 years. Yet the ethical issues surrounding the disclosure of positive HIV status have not been examined comprehensively. This report examines the ethics behind the disclosure of HIV-positive status primarily or individuals to their sex partners, and for health care practitioners to a patient's sex partner when the patient is unwilling to disclose. Relevant rights and ethical principles are analysed, including the rights to: self-preservation; privacy and confidentiality; and the bioethical principles of respect for autonomy, beneficence, non-maleficence, and justice. Historic and contemporary individual rights that people living with HIV (PLHIV) have regarding disclosure are emphasised, especially in adverse circumstances, where ethics can support non-disclosure based on the right to self-preservation. Rights declarations and current disclosure guidelines for health care practitioners from several international and South Africa medical organisations also are reviewed. Of key importance to disclosure decisions are the specific situations of individuals in climates rife with stigma toward, and discrimination against, PLHIV, existing more or less worldwide. The potential negative impacts of disclosure are the basis for disclosure decisions of PLHIV. Research study results show that the negative impacts of disclosure can be severe for individuals, ranging from divorce or abandonment to community ostracism and even to murder. Relevant current theories of social justice related to HIV disclosure also are discussed. A conclusion is reached that, by decreasing stigma and discrimination against PLHIV and protecting individual rights related to HIV disclosure, prevention behaviours will be practised more widely, including 'positive prevention' by PLHIV and higher rates of disclosure. The eventual result will be the long-term public health goal of decreased spread of HIV.

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Acronyms

AIDS	acquired immune deficiency syndrome
ART	antiretroviral therapy
ASTHO	U.S. Association of State and Territorial Health Officials
CDC	U.S. Centers for Disease Control and Prevention
HIV	human immunodeficiency virus
HPCSA	Health Professions Council of South Africa
IPV	intimate partner violence
MSM	men who have sex with men
NGO	non-governmental organisation
PLHIV	person(s) living with HIV or AIDS
PMTCT	prevention of mother-to-child transmission of HIV
SAMA	South African Medical Association
STI	sexually transmitted infection
UDHR	Universal Declaration of Human Rights
UK	United Kingdom
UN	United Nations
USA	United States of America
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization
WMA	World Medical Association

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Preface

The purpose of this examination of the ethics behind the disclosure of HIV status is to illuminate the options and justifications for disclosure or non-disclosure based on ethical principles and individual human rights. Expanding the ethical understanding of the disclosure of positive HIV status within adverse environments is important for public health practitioners and ethicists as disclosure remains low in some communities, especially in sub-Saharan Africa. Only by understanding why this is the case can public health practitioners, legal professionals, and others working on the response to the HIV epidemic globally have greater effect in protecting the rights of PLHIV and achieving the goals of increased positive disclosure and decreased spread of HIV. Moreover, it is important for the wider global community to understand that legalising HIV disclosure, which is under review by a number of legislatures in 2008, will not result in decreased spread of the HIV epidemic. Rather, the ongoing stigma toward, and discrimination against, PLHIV will rise if disclosure of positive status is legally mandated, potentially resulting in even fewer people going voluntarily for HIV testing. When the majority of PLHIV in some countries do not even know they are infected with the virus, criminalising transmission will not open the floodgates to greater disclosure. What is needed to stanch the spread of the epidemic is more understanding of and action toward social justice and the protection of the rights of the individuals and groups marginalised by society based on their HIV status, with women at the forefront. The dictum pronounced by Warren and Brandeis more than 100 years ago still applies, "…the protection of society must come mainly through a recognition of the rights of the individual."

Chapter 1: Introduction

One of the most difficult issues patients have to grapple with after testing positive for HIV is whether or not they should disclose their HIV status and, if so, to whom, when, and how. Self-disclosure of HIV status has drawn the attention of researchers for 15 years or more (Klitzman and Bayer 2003: 232). The issues surrounding disclosure of one's own positive HIV status are complex. They are complicated by the stigma toward and discrimination against people living with HIV (PLHIV), which may be growing in 2008 (Kershaw 2008: 1). The goal of this research report is to examine the ethical issues surrounding the disclosure positive HIV status for individuals, especially to their sex partners, and the ethical issues surrounding possible disclosure of positive HIV status of their patients by health care practitioners to their patients' sex partners.

Health care providers also have to address disclosure of the HIV status of their patients who test positive for the virus. Ethically, they have to deal with issues of confidentiality surrounding information about their patients, whether the latter test positive or negative for HIV. In some areas, including twenty-three of the 50 states in the USA, notification of the patient's sex partners is mandated by law (Galletly and Pinkerton 2006: 1). In such cases, health care providers must decide how such notification can be carried out effectively, and without provoking violence or other discriminatory actions against the HIV-positive patient (or themselves), when patients refuse to disclose themselves to their sex partner(s) (Gielen *et al.* 2000: 115-116). It is in the health care provider's best interest that a patient who is living with HIV disclose his or her HIV status to all his or her sex partners without intervention by a third party, relieving the provider of the ethical and legal burden of the disclosure where it is mandated. However, not only is such disclosure a legal and logistical

burden for some health care providers, it is an ethical one for all health care providers, as potential future disclosure-related legislation is under debate. Among other factors, this report will describe how partner notification by health care providers may not advance public health interests, one of its primary purposes.

Stigma toward, and discrimination against, PLHIV is practically universal around the world (Brown 2007: 1). These ongoing conditions greatly complicate the disclosure of HIV-positive status and the ethical decision-making by everyone surrounding disclosure. Stigmatization towards HIV includes both the internal and external stigmatisation many PLHIV feel (Cameron 2005: 53). According to Justice Edwin Cameron of South Africa's Supreme Court of Appeal, who is openly living with HIV,

> "The disfiguring sense of shame that emanates from the internal world of some with HIV or AIDS…colludes with external stigma, overcoming efforts to deal with the disease rationally, keeping those with AIDS or HIV in involuntarily imposed self-isolation, casting a pall of contamination and silence over the disease" (ibid.: 70).

Discrimination against PLHIV is intense in many environments, including those in sub-Saharan Africa. In South Africa, five people, all of them women, have been killed after they disclosed their HIV status publicly or interpersonally or spoke out about HIV (Associated Press 1998: 1; Carroll 2003: 1; Human Rights Watch 2007: 1). Clearly, disclosure of HIV status can be extremely dangerous. It can result in bodily injury and/or the loss of one's home, one's job, one's children, even one's life.

Examining the ethical underpinnings surrounding the disclosure of HIV status is important as disclosure remains controversial within medical ethics. The goal should be to give

appropriate and comprehensive guidance to individuals who must make decisions about disclosing their own HIV-positive status. This paper will not focus on the legality of disclosure or non-disclosure, by oneself or by health professionals. Rather, it aims to help foster greater understanding of the hurdles HIV-positive individuals face in their decision-making surrounding disclosure, to help provide some insights to PLHIV as well as to health care practitioners and ethicists. Ideally, a better understanding of the hostile environment in which PLHIV live and the hurdles they face regarding disclosure will help more people, communities, and nations be able to make further progress toward providing a safer and more secure environment societally for PLHIV. In turn, a safer and more open environment will empower more PLHIV to disclose their status. Benefits of HIV disclosure do exist. But in hostile environments, which are practically universal, the demands of self-preservation and personal protection can be far more important to a PLHIV, especially a woman, than sharing HIV status. Telling her partner her positive HIV status so he can take protective action can instead result in violent action against her.

For the HIV epidemic to be halted, more PLHIV will have to help protect their sexual partners who are not infected from infection through safe sex practices (Maman and Medley 2004: 1). Yet this paper will point out that disclosure of positive HIV status does not necessarily result in the practice of safer sex. To prevent more HIV infections, more pregnant women who are living with HIV will have to protect their foetuses and babies from infection. However, this paper will point out that to do so, more women will have to disclose within community environments in which such disclosure will expose them to danger, a risk some are unwilling to take. To prevent more HIV infections, more PLHIV will have to disclose to their family members when they become seriously ill. But this

paper also will describe why such disclosure remains so difficult for some PLHIV in sub-Saharan Africa even when the health of family members is put at risk.

Initiating condom use or even discussing safe sex practices with a partner, especially in countries where condom use with a regular sex partner is uncommon, can promote distrust rather than security. For more than ten years many authors have documented how initiating a discussion about safe sex ca be a dangerous step—especially for women—to take in African countries (Sasman 2008: 1). Their male partners think it means they have been having sex with other men. Consequently, it is easy to understand that in environments where sexual inequality, domestic violence, and HIV prevalence rates are high, disclosure of positive HIV status to a sex partner, especially by a woman in sub-Saharan Africa, can be fraught with negative consequences. These consequences can include violence, abandonment, emotional and psychological abuse, as well as murder (Mathews *et al.* 1999: 1128; De Cock *et al.* 2002: 10; Maman *et al.* 2003: 379).

People living with HIV can receive treatment for their infection via antiretroviral therapy (ART) only if they are willing to disclose their status to health-care practitioners, community health workers, or counsellors. Yet these health workers are, in many cases, members of the same communities in which PLHIV live (Norman *et al.* 2005: 10). By disclosing their HIV-positive status to someone who lives in their community, if the health worker unethically passes the information on to another community member, PLHIV risk losing confidentiality, privacy, friendships, community support, and sometimes familial support due to the high level of stigma toward and discrimination against them common in communities in Africa. Communities practising stigma toward and discrimination against PLHIV can include health workers themselves. In some health care facilities, privacy and

confidentiality are not respected, and unauthorised shared knowledge of the positive HIV status of patients is common (Gielen *et al.* 2000: 113).

This research report will outline situations where HIV disclosure is ethical and wise. However, it will focus centrally on situations in which HIV disclosure would be unwise when self-preservation is at stake. Saving one's own life cannot be considered an unethical act. This report will outline the views of several prominent philosophers on the importance of self-preservation and individual rights, important rights declarations, and current guidelines for health care providers related to HIV disclosure. Not only is there a "right to know" in some situations regarding the disclosure of HIV status, there also is a right for individuals not to tell in other situations. It is up to each and every individual adult to determine her or his own situation and a rationale for disclosure of HIV status or not (Hayford 2000: 2).

This research report also includes the results from multiple studies focusing on HIV disclosure that have been performed in Africa, Asia, Eastern Europe, Western Europe, Latin America and the Caribbean and the United States (USA). The study results show that disclosure of positive HIV status in hostile environments can reap grave consequences for individuals as well as for families. Consequently, recognising the conditions existing in such environments toward PLHIV, and the ethics surrounding disclosure of one's positive HIV status in these negative atmospheres, are essential in guiding disclosure determinations in the midst of the current global HIV pandemic.

Much needs to be done to lessen the hostility toward PLHIV in view of the extensive stigma toward and discrimination against them worldwide, and especially in sub-Saharan

Africa. Only through greater insights into the conditions surrounding the complicated decisions about disclosure can public health, development and policy professionals design individual, community and structural interventions to help facilitate greater openness and support of PLHIV resulting in higher levels of disclosure (Serovich and Mosack 2003: 71).

It was hoped in the 1980s and early 1990s in public health circles that by increasing the rates of disclosure of HIV status, more people would practise prevention behaviours, and thus greater disclosure would have an eventual impact in decreasing the spread of HIV. A consequentialist approach of the greatest benefit for populations as a whole was the priority public health concern (Gostin and Hodge 1998: 67). According to Kang *et al*.,

> "HIV-stigma has compromised the psychological and physical health of persons living with the illness since the earliest days of the HIV pandemic. Generally, stigmatised groups are 'pejoratively regarded by the broader society and are devalued, shunned or otherwise lessened in their life chances'"(2005: 145).

Thus PLHIV have suffered enormously from the stigmatised lives they have had to lead if their HIV status has become known. This predicament continues to exist in 2008 even in developed countries such as the USA (Moody 2008: 1). It is not unique to resource-limited settings such as sub-Saharan Africa. Consequently, there has been good reason for many PLHIV to keep their positive status secret. According to Hayford writing for the Test Postive Aware Network,

> " Each person should be allowed to decide if and when it is safe to disclose his or her HIV status. We must not scorn those who choose to remain silent in order to keep food on their tables and a roof over their heads. Sometimes, silence equals life" (2000: 2).

In considering the balance between public health and individual rights regarding HIV disclosure amidst hostile conditions, reviewing the competing interests becomes a complex exercise even when it involves only two people. Yet the objective for many public health ethicists in making the relevant ethical determinations is to balance the respective interests of PLHIV and their sex partners in such a way that societal health is maximised (Gostin and Hodge 1998: 67). Obviously, this approach to the ethics involved in disclosure determinations is, again, a utilitarian or consequentialist approach.

This report, however, will present ethical theories and approaches and study results debating the present societal situation regarding HIV disclosure in many countries from an individual rights-based approach. It will describe the ethical dilemma of trying to determine the appropriate balance of the rights of one individual against another within a largely unequal and unhealthy environment. Such an environment is the existing environment surrounding HIV in sub-Saharan Africa and elsewhere (Farmer 2005: 177). Thus this report will take an applied ethics approach to the issue, rather than one based on public health theory or utilitarian ethics. Importantly, this report also will highlight that only by decreasing stigma and discrimination toward PLHIV, will disclosure of positive HIV status become more common. The end result will be progress toward the public health goal of decreasing the spread of HIV infection. Thus, by protecting individual rights, this author believes it is indeed possible to meet a public health objective.

Methodology

The research method used for this report was non-empirical, involving a literature review related to ethics, rights, human rights, social justice, the HIV epidemic, stigma and discrimination against PLHIV, and a summary of the history of HIV disclosure and current

guidelines for disclosure of HIV positive status by several international and South African health agencies and a few cases of relevant law. The method entailed taking a rights-based approach to HIV disclosure as a moral problem. Relevant issues have been identified and the questions as to how these issues relate to human dignity and individual rights are described, referencing relevant developments in rights theory from the 1600s to the present. The facts surrounding HIV disclosure are outlined and examples provided from published research study results. The groups and individuals who have a stake in HIV disclosure and the outcomes, and their needs and obligations, are described. The options for disclosure of HIV status, especially to sex partners, are summarised, including the reasons for and against it. A review of the issues related to individual rights, privacy and confidentiality and the bioethical principles related to disclosure has been undertaken. The main focus is on the disclosure options that will produce the least harm to an individual PLHIV, examining possible individual circumstances based on the present epidemic environment. A conclusion on whether individuals should always disclose positive HIV status is reached, including recommendations. Books, journal articles (electronic and hard copy) and related publications have been used as textual and statistical sources. A 'snowball' approach has been taken, i.e., reviewing references in the most important related publications, to expand the information sources, ethical concepts and recent research study results. Books and information search engines have been used through the Wits Library's electronic catalogue. Google Scholar and other search engines such as ProQuest, ScienceDigest, etc., have been used to include journal articles and other relevant source materials. The author's collection of HIV-related publications also has been used for sources where relevant.

The rationale behind this research report is that focused and pro-active attention to the real environment surrounding HIV and disclosure is urgent, especially in southern Africa where

HIV prevalence rates are the highest in the world and continue to grow in some countries (UNAIDS 2007: 12, 16, 18, 20). Chapter 2 of the report examines human rights and ethics related to disclosing positive HIV status, providing the background against which to examine the "right to know" HIV status and the right not to tell, in African and other communities around the world. Chapter 3 examines the "right to know" the HIV status of others, especially sex partners, and the issues surrounding health care practitioners' disclosure of a patient's HIV-positive status to the patient's sex partner(s) when the patient is unwilling to disclose. Chapter 4 discusses the complexities involved in individual disclosure and professional ethical decision-making. Chapter 5 centres on the right not to tell others about positive HIV status and the right of health care practitioners not to inform sex partners about a patient's positive status. Included are guideline excerpts from the World Health Organization (WHO), the World Medical Association (WMA), the South African Medical Association (SAMA), the Health Professions Council of South Africa (HPCSA), which revised its ethical guidelines in 2007 based on issues this report examines, the U.S. Centers for Disease Control and Prevention (CDC), and the U.S. Association of State and Territorial Health Officials (ASTHO). The conclusion brings the argument to a close on the ethics of disclosing HIV-positive status when the potential for social abandonment, community ostracism or death can be the result. The conclusion identifies the need for more service provision, societal changes, and more equitable social norms and support before PLHIV can be expected to be more open about their HIV status than they are now. The report ends suggesting that, once there is more openness about HIV and societal support for PLHIV, disclosure of positive HIV status will increase and should start having an impact on the transmission of HIV, its public health objective.

Chapter 2: Rights Theory

This chapter will focus on upholding the right to life and other human rights. It will emphasise self-preservation as a bona fide human right. It will illustrate why some philosophers believe the right to life and self-preservation is the fundamental human right. It will examine this right in accordance with the disclosure of positive HIV status. The chapter also will examine the ethical principle of respect for autonomy, its historical foundation, and its relationship to the disclosure of HIV status. Finally, excerpts from the Universal Declaration of Human Rights (1948) will be used to illustrate the rights of PLHIV generally and as related to the disclosure of HIV status.

The fundamental right all human beings have is the right to life. Brazier and Harris (2003: 172) contend that:

> "Society's interest is in upholding the concept that all human life is sacred and that it should be preserved if at all possible. It is well established that in the ultimate the right of the individual is paramount."

The right to life, or the right to survive, is partly based on Thomas Hobbes's *Elements of Law*, first published in 1651 (ix). Hobbes wrote, "It is therefore a right of nature: that every man may preserve his own life and limbs, with all the power he hath" (Tuck 1989: 60). According to Hobbes and what is referred to as his general theory of action, in the words of Richard Tuck, "we always act in such a way as to secure what we take to be good for us" (*ibid.*). Thus acting on behalf of our own self-preservation is, obviously, in our best interest, and it is good.

Philosopher John Locke's theory of personal identity also serves as an influential foundation for discussions of ideas of identity, according to Nicholas Jolley (1999: 101). Locke's *Two Treatises of Government*, published in 1691, 40 years after Hobbes's important work introducing the concept of an individual's rights, stated:

> "Every one as he is bound to preserve himself, and not to quit his Station willfully; so by the like reason when his own Preservation comes not in competition, ought he, as much as he can, to preserve the rest of Mankind, and may not unless it be to do Justice on an Offender, take away, or impair the life, or what tends to the Preservation of Life, the Liberty, Health, Limb or Goods of another" (Locke: 271).

Importantly, Locke has expanded on the right first identified by Hobbes, that of the right of an individual to self-preservation. He has added to the right to life the rights individuals have to liberty, health, bodily protection, and personal property. Locke has formulated the premise that these are fundamental rights each person has, and one person should not take these rights away from another. In this statement Locke secured what later came to be referred to by Thomas Jefferson in the American *Declaration of Independence* as the "inalienable" rights of each and every human being (1776). These are rights each person has that cannot be taken away. What also is germane is that in the case of competition from another person for any of these rights, the individual's duty is to preserve his or her own rights ahead of the rights of another. Locke has not advised the altruistic or Christian principle of 'turning the other cheek' by stating that the rights of others are more important than one's own. Nor has he stated that the rights of a large group are more important than the rights of one individual, which would be a consequentalist or utilitarian approach to rights. Rather, Locke has pointed out the duty each person has to protect his or her own

individual rights, and the rights of other individuals when they are not in competition with one's own rights.

The importance of the rights of individuals is also derived from philosopher Immanuel Kant's 'formula of autonomy' described in his work, *The Moral Law: Groundwork of the Metaphysics of Morals,* published in 1785. Kant defined the principle of autonomy as "every man's freedom of action," because every rational being is "an end in himself" (Paton 1991: 93). In other words, every rational human being has the inherent right to make decisions for himself or herself. Kant wrote that these decisions deserve ultimate respect, although he also asserted they are subject to the law (*ibid.*). A few quotes from the *Groundwork* are illuminating in regard to the importance placed by Kant on respect for oneself, including:

> "Act in such a way that you always treat humanity, whether in your own person or in the person of any other, never simply as a means but always at the same time as an end" (Paton 1991: 32).

Even more specifically focusing on the self, Kant stated,

> "We have an imperfect, but *positive*, duty to further the ends of nature in ourselves and in others—that is, to seek our own perfection and the happiness of others."

The above passage becomes more complicated when one's duty toward seeking one's own perfection is in conflict with the happiness of another or others, which sets it apart from Locke's theory. However, Kant did not write that the happiness of another or others as a group is more important than seeking one's own perfection or happiness (Metz 2005: 377). In fact, he also addressed the subject of happiness regarding one's health, or good health, or as he put it, "the good fortune supposed to attach to soundness of health" (Paton 1991:

65). Kant was referring to gout, a common illness in his time, as HIV infection did not exist during his lifetime. Yet while writing about making the personal choice either to forego what would relieve one's ill health symptoms or perhaps exacerbate them, Kant noted the intrinsic importance of furthering one's happiness in regard to one's health:

> "But in this case also, when the universal inclination towards happiness has failed to determine his will, when good health, at least for him, has not entered into his calculations as so necessary, what remains over, here as in other cases, is a law— the law of furthering his happiness, not from inclination, but from duty; and in this for the first time his conduct has a real moral worth" (*ibid.*).

Kant emphasised that furthering one's happiness is a duty, and it has a moral component. He also emphasized the importance of duty over other reasons for making choices, as he had outlined earlier in the *Groundwork:*

> "If a rational agent is truly an end in himself, he must be the author of the laws which he is bound to obey, and it is this which gives him his supreme value" (Paton 1991: 34).

In this passage, Kant impresses again upon his readers that the choices humans make must be their own individual choices, based on their dignity and their agency as rational human beings. Thus, according to Kant, human beings have the right to make free and informed decisions (Metz 2005: 378). Further, the passages included above highlight the notion of maintaining respect for the decisions of a rational human being, since human beings have supreme value. The principle of autonomy, which Kant was espousing, has been a long-held philosophical principle, as will be shown. It is the right of an individual to make decisions about his or her own person or health. Moreover, the principle of autonomy has

become a central one in medical ethics, the ethical field now commonly referred to as bioethics.

Integral to Kant's theory is that each rational being is the end in himself or herself, rather than the means to an end. This idea is one of the differences between Kant's theory, with its extensive focus on the individual, and that of 'Utilitarianism,' promoted by John Stuart Mill—even though Mill believed in individual sovereignty except in cases of preventing harm to others (Vincent 2006: 20). Yet it is important to refine what has been called the "harm principle" of Mill by reviewing what he wrote in his treatise, *On Liberty,* which was published in 1859 (1991: 72):

> "Acts, of whatever kind, which, without justifiable cause, do harm to others, may be, and in the most important cases absolutely require to be, controlled by the unfavourable sentiments, and, when needful, by the active interference of mankind."

Mill did not state that the harm principle is absolute in and of itself. Thus the question relevant to the disclosure of HIV status in the context of this passage seems to be whether it might be considered justifiable not to disclose information concerning one's status if potentially more harm might come to oneself by doing so than the potential for inflicting harm on another. No studies have shown that disclosing one's positive HIV status to a sex partner automatically results in the other person's taking specific action to protect his or her own health, or even investigating his or her own HIV status as this paper will show later. Clearly, it is important to be aware of the potential harm to oneself, or to one's patient, that can result from disclosure of an individual's HIV-positive status within a violent relationship or in an environment fraught with stigma toward, and discrimination against, PLHIV.

Mill also wrote in *On Liberty* concerning the "harm principle:"

> "That principle is, that the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number, is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others" (*ibid.*: 30).

In these statements, Mill recognised the importance of self-protection as a rationale for action. Yet he also focused on the need to prevent harm to others. Therein Mill's "harm principle" presents a justification for limiting personal autonomy and lays an ethical foundation for recognising the need to maintain public health (Bayer 2003: 133). But in analysing what Mill has stated to relate most closely in the case of HIV infection to someone who would actively try to infect others with the virus. Decisions about the disclosure of one's own HIV status, or indeed that of a patient, are generally made within more complex circumstances and are less dramatic—and clear cut—than those of someone actively trying to infect others. Within more complex circumstances, one needs to think about the potential harm one could bring upon oneself in regard to HIV disclosure unless a positive outcome of disclosure is certain. Moreover, health care providers also need to consider the potential harm that could come to a patient related to disclosure, which can outweigh the possible benefit of disclosure to a third party, depending on a variety of circumstances. Indeed, according to the Nuffield Council on Bioethics in the United Kingdom, Mill's harm principle does not provide "a satisfactory answer to all the questions that arise in the context of public health. Nor does it commit us to the wider theoretical framework in which it was set out, or to claim that harm to third parties is always a

sufficient legitimization of coercion" (2007: 16). In other words, the Nuffield Council has stated that harm to a third party is a necessary, but not automatically a sufficient reason for a coercive individual intervention (*ibid.*). The Council went on to state, "…interventions in personal life, even when they are intended to reduce health risks to others, carry a significant ethical cost" (*ibid.*: 17).

Though Mill went on to write that one's "own good" is not a sufficient reason to harm others, one wonders whether even Mill would conclude it is essential for a person to disclose his or her HIV status to his or her sex partner if significant harm, even death, might come to him or her by doing so. This question is central when the person who must make a decision about disclosure is involved in a previously violent relationship. It is also relevant when it is the sex partner who passed on his or her own HIV infection to the person who has to make a decision about disclosure. In both cases, the decision about disclosure of positive HIV status must be made by individuals who already have been harmed by the very person some believe it is their obligation not to harm. These are indeed complicated situations personally, potentially physically, and ethically. In environments of secrecy about HIV status, the sex partner could have passed on his or her HIV infection despite being aware of the potential for onward transmission if unprotected sex (without a condom) was practised. Much research has shown that such situations are not unusual (Olley, Seedat, Stein 2004: 1)**.**

It is impossible to know what Mill would have decided in individual HIV disclosure situations. However, some may remain steadfast in their belief that, of course, a sex partner always should be told about his or her sex partner's HIV-positive status, and any

dangerous circumstances surrounding the disclosure simply do not matter. Yet, according to philosopher and historian Isaiah Berlin, Mill was:

> "acutely aware of the many-sidedness of the truth and of the irreducible complexity of life, which rules out the very possibility of any simple solution, or the idea of a final answer to any concrete problem" (1991: 148).

Berlin also wrote of Mill's "distrust of simple models and of cut and dried formulae to cover complex, contradictory, and changing situations" (*ibid*.: 149). Such a cogent description of Mill's understanding of the complexity of life seems relevant to the idea that one must always disclose one's HIV-positive status to a sex partner, or, that a health provider must always disclose a patient's positive HIV status to a patient's sex partner if s/he is unwilling to disclose it, despite the possibility of serious harm coming to the patient. Such an attitude seems to defy not only the individual's right to life and survival, but even human reason, the range of individual circumstances existing across society, and also that the primary professional responsibility of a health care provider is to his or her patient (HPCSA 2007: 2).

Mill also wrote in *On Liberty* (*ibid.* 31), "Over himself, over his own body and mind, the individual is sovereign." This statement emphasizes Mill's belief in the importance of decisions about one's own bodily integrity. Mill also manifested the central importance of individual liberty and integrity when he wrote about an individual (*ibid.*: 91),

> "He is the person most interested in his well-being: the interest which any other person, except in cases of strong personal attachment, can have in it, is trifling, compared with that which he himself has; the interest which society has in him individually (except as to his conduct to others)

> is fractional, and altogether indirect: while, with respect to his own feelings and circumstances, the most ordinary man or woman has means of knowledge immeasurably surpassing those that can be possessed by anyone else."

Mill seems to leave the door open for speculation in regard to special circumstances surrounding individual responsibility to others when one's own life might be at stake when he also wrote in *On Liberty,*

> "Whoever fails in the consideration generally due to the interests and feelings of others, *not being compelled by some more imperative duty, or justified by allowable self-preference,* is a subject of moral disapprobation for that failure…" (*ibid*:. 96) (italics added for emphasis).

One also needs to think about autonomy in regard to HIV disclosure as a fundamental bioethical principle practised in the present day and not just what has been written about it by a number of philosophers. For example, it is an ethical requirement for health providers to procure 'informed consent' from their patients prior to providing medical treatment to them as competent individuals. Yet the principle underlying informed consent is respect for the individual patient's autonomy. The ethical principle of patient autonomy was elaborated by Beauchamp and Childress in 1979 in their landmark book, *Principles of Biomedical Ethics* (Widdows *et al.* 2003: 102). As Beauchamp and Childress pointed out in their book, this principle originated in ancient Greece regarding self-governance of the Greek city states thousands of years ago (1994: 120). They also noted that "principles in ethics are deeply embedded in the concrete world of human social conduct" (Beauchamp and Childress 1994: 94).

According to Beauchamp and Childress, "To respect an autonomous agent is, at a minimum, to acknowledge that person's right to hold views, to make choices, and to take actions based on personal values and beliefs" (2001: 63). Surely, a belief that sharing one's HIV status with one's sex partner might put one at risk of bodily harm, potentially losing one's home, or make life in one's home environment emotionally or physically intolerable falls into the realm of respect for personal autonomy. Moreover, Beauchamp and Childress later went on to write about autonomy, "As a positive obligation, this principle requires respectful treatment in disclosing information and fostering autonomous decision-making" (2001: 64). And, further,

> "…it is also questionable whether many physicians have developed skills to determine the information that is in their patients' best interests. The assumption that they have such expertise would rest on empirical studies, but available data cast doubt on it. The weighing of risks in the context of a person's subjective beliefs, fears and hopes is not an expert skill, and information provided to patients and subjects sometimes needs to be freed from the entrenched values and goals of medical professionals" (2001: 82).

What Beauchamp and Childress are addressing in this passage is that what may seem to be the 'right thing to do' to some physicians nowadays was the 'right thing to do' for physicians in the past. But what seemed to be right in the past can encounter a different moral standard and ethical decision-making dilemma in view of compelling circumstances in the present day, especially in the face of an epidemic of a new and different type of disease. Importantly, Beauchamp and Childress also point out that physicians may not be the best judges of patients' best interests at all. They go on to imply that this is especially true as physicians have not been trained in skills for the probing of psychological

information to make such determinations. Moreover, the in-depth ethical training that helps anyone to understand what it is like to walk in the shoes of another and also to be able to weigh the options of another person is not part of physician training. Thus what seems to be right or wrong, ethical or unethical as an action related to a specific patient's possible choices is not the expertise of physicians. Finally, to try to make such a determination for someone else who is competent denies that person respect for his or her own individual autonomy and decision-making.

According to Rachels, fundamental to Utilitarianism, which is based on the amount of happiness for the greatest number of people, is the proposition that "each person's happiness counts the same" (2002: 102). Yet taking a Utilitarian approach in making a decision about HIV disclosure is problematic in situations where the rights of individuals are not really equal and may not be equally protected. Such an imbalance is very common especially in regard to the inferior legal as well as socioeconomic rights of women in many, if not most, countries. Moreover, how can happiness for the greatest number be determined in cases where the 'happiness' of one individual is potentially pitted against another in the case of individual HIV disclosure to a sex partner? Again the fundamental question arises: is one's responsibility toward another greater than one's duty or responsibility to oneself? Some examples have been given showing that some philosophers do not believe so.

Much has been written on individual rights since Hobbes, Locke, Jefferson and Mill addressed this topic in their writings. It also is important to look at the most famous and thus germane international human rights declaration. Article 3 of the Universal Declaration of Human Rights (UDHR), adopted on 10 December 1948 without dissent by the General Assembly of the United Nations (UN) (1948: 2), states: "Everyone has the right to life,

liberty and security of person." The following additional articles from the UDHR are all relevant to the rights of the individual that can be jeopardised by disclosure of one's HIV status:

"Article 5

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment."

"Article 7

All are equal before the law and are entitled without any discrimination to equal protection of the law. All are entitled to equal protection against any discrimination in violation of this Declaration and against any incitement to such discrimination."

"Article 12

No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attacks."

"Article 16

(1) Men and women of full age, without any limitation due to race, nationality or religion, have the right to marry and found a family. They are entitled to equal rights as to marriage, during marriage and at its dissolution.

(3) The family is the natural and fundamental group unit of society and is entitled to protection by society and the state."

"Article 23

(1) Everyone has the right to work, to free choice of

employment, to just and favourable conditions of work and to protection against unemployment."

"Article 25

(1) Everyone has the right to a standard of living adequate for the health and well-being of himself and his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

(2) Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection" (UN 1948: 2-6).

Article 5 of the UDHR highlights that no persons should be treated cruelly or degraded—even if they are living with an infectious disease such as HIV. Article 7 states that all people should be protected under the law equally free from any discrimination. But many PLHIV suffer discrimination on a daily basis (Mabunda 2006: 28). Certainly, Article 12 identifies at least three examples of the violation of rights many PLHIV must contend with after their HIV status becomes known. The first is violations of their right to privacy. The second is attacks upon their honour and reputation, particularly in the case of women, but not limited to women. Finally, the third is protection of the law against interference or attacks.

Article 16 of the UDHR lays out that every adult man and woman has a right to marry and to found a family. It does not restrict this right to those who are not living with an

infectious disease. In addition, both spouses are entitled to equal rights in marriage, even at its dissolution. This is the case whether or not one has become infected with HIV during the marriage—or knowledge of HIV infection arises during the marriage. Nonetheless, such circumstances have been used as evidence of adultery and therefore grounds for divorce by husbands in some countries, including Kenya and Uganda, and evidence of sexually transmitted infections (STIs) has been used as grounds for divorce in some countries for many years (Mutungi 2006: 8; Kiapi Matsamura 2004: 1; *Parkes v Parkes* 1916: 702). Article 16 also guarantees protection of families by the State. Thus a husband, according to the UDHR, cannot throw his wife (and their children, if they have any) out of their house after he learns of her HIV infection. Yet this potential personal and familial disaster remains a relatively common fear of African women after learning of their own HIV infection (Norman *et al.* 2005: 6; Paxton 2002: 561). Abandonment after HIV disclosure is also a common fear of women in the USA (Sowell *et al.* 2003: 3; Kass and Gielen 1998: 96). Article 23 supports the right of everyone, including PLHIV, to employment, as do laws in some countries, including South Africa (*Hoffman v South African Airways* 2001:2). Consequently, PLHIV should not lose their jobs based on their HIV infection status. However, this potential result continues to be a common concern of many PLHIV in regard to decisions about disclosure to employers, and remains ill-advised in most circumstances (Buckley and Gluckman 2002: 27).

The rights spelled out in Article 25 of the UDHR regarding economic well-being are not fully enforced anywhere in the world even in 2008, 60 years after the UDHR was adopted by all the member countries in the UN. Nevertheless, they guarantee an adequate standard of living especially in the event of sickness, with mothers and children entitled to special care and assistance. Thus Article 25 guarantees special rights to PLHIV which,

unfortunately, few enjoy. This is true especially in developing countries, where nations also are bound by the limits of distributive justice. Nonetheless, few developing countries seem to work actively toward ensuring greater numbers of their citizens gain access to more of their basic human rights as laid out in the UDHR than they have already. As a global society, humanity still aspires to recognition and enforcement of the rights guaranteed in the UDHR. Yet no one living with HIV should be discriminated against based on their infection status. Nor should anyone be discriminated against based on whether or not they have disclosed their status to one person, to their family members, to their community or their nation, or to no one. According to South Africa's Constitutional Court in *Bernstein v Bester* 1996, "the right to privacy is recognized as an independent personality right, which the courts have included with the concept of dignitas" (SA 789). The next chapter will focus on the individual "right to know" and the complications surrounding this right amidst the current response to the HIV pandemic on societal, community and interpersonal levels.

Chapter 3: The "Right to Know" HIV Status

This chapter examines the "right to know" the HIV status of others. It specifically focuses on the right to know the HIV status of a sex partner. The chapter also examines the issues surrounding health care providers' disclosure of a patient's HIV-positive status to the patient's sex partner(s) when the patient is unwilling to disclose. It focuses on the common public health thinking of the necessity of disclosure primarily to stem the spread of epidemic disease. Yet it also focuses on how decisions about disclosure always have to be personal ones, based on the complicated factors that have to be weighed before reaching a decision about disclosure.

In regard to disclosure of HIV status to sex partners if one is living with HIV, the simple and basic ethical approach would be that, of course, everyone should disclose their HIV status to their sex partners as soon as they learn they are infected with the virus. Otherwise, they are jeopardising their partner's health through potential transmission of a life-threatening viral infection to an uninfected person, or potentially re-infecting their partner with a different strain of HIV. Such a stance on HIV disclosure was indeed the common moral and legal stance in the 1980s, and even the early 1990s, when the necessity for disclosure seemed to be considered absolute by many health professionals in developed countries (Marks, Richardson, Maldonado 1991: 1321). It was thought that by convincing more PLHIV to disclose their status, HIV transmission would be reduced. However, since then recognition has grown of how common the lack of HIV disclosure is to sex partners, in particular. Consequently, there is a greater need for health professionals to understand why such decisions and subsequent actions are so complex. If they were not complex and did not involve risk, there would be no reason not to disclose. If disclosure were easy, most

people would proceed to tell everyone soon after learning of their HIV infection. But disclosure of HIV status clearly is difficult, and the reasons why need to be explored.

The interest by researchers in why HIV disclosure is so fraught with anxiety has grown over the last ten or more years. Recently, it has been recognized more widely in the public health community that the assumption that a greater degree of disclosure of HIV-positive status by individuals to their sex partners would result in decreased sexual transmission of HIV may be incorrect. In fact, the effectiveness of disclosure of HIV status as an HIV prevention measure is not known (Pinkerton and Galletly 2007: 1). Consequently, disclosure of HIV status to sex partners may not be an important public health focus for preventing the spread of the epidemic. Rather, HIV disclosure seems to be more of an issue relating to the individual's 'right to know' relevant information about the health status and potential disease infectiousness of a current or potential sex partner. Knowing such information about sex partners can help individuals maintain their own health and potentially prevent their exposure to a chronic, even deadly, disease.

In theory, everyone has a right to know information to help them protect their own health. Certainly, one would think that if someone is directly asked about their HIV status by a potential sex partner, the individual should disclose whatever his or her status is honestly. Yet the difficulties in claiming and enforcing the 'right to know' regarding an individual's HIV status are many. The difficulties include, but are not limited to the ethical dilemma related to HIV disclosure when an individual knows his or her status within a highly stigmatised and discriminatory environment. Thus relaying one's HIV-positive status in such an environment can be quite risky physically and emotionally. What is more, without mandatory testing on a global basis, which many would consider unethical as well as

undoable, how can everyone be expected to know their HIV status? Should each person who tests positive for HIV have to wear some sort of emblem or mark showing he or she is a PLHIV so all their potential sex partners would know?

Why should someone who is living with HIV have to disclose his or her status when people with other infectious diseases, such as tuberculosis (TB), which is more infectious than HIV, walk around town and cough, with some not even knowing they are infected? In fact, many African PLHIV die from TB rather than from AIDS itself (World Health Organization 2005: 1; World Health Organization 2008: 1). Thus why should HIV be singled out? In fact this was the argument against legalising HIV disclosure put forward by three scholars in 2000 (Chalmers 2002: 3). Yet the ongoing and historic potential for criminality regarding HIV transmission, which is legislated in some areas, is receiving increased attention in 2008 internationally. Such legislation does support an individual's right to know HIV status. But it is nearly impossible to prove legally that intentional viral transmission occurred at a specific time through infection by a certain person (*ibid.*: 2). Thus situations related to disclosure of HIV status and any demand related to the 'right to know' face real complications ethically and legally for a number of reasons. Among them is that the lack of access to full knowledge of one's own health status is common to most people around the world and especially so in developing countries (Farmer 2005: 143). The right to know remains the ideal, but is mainly hypothetical and unenforceable at present, at least related to HIV.

In fact, most PLHIV in the world do not know they are infected with the virus. Even in Europe, an estimated 33% of PLHIV do not know they infected with the virus (Deutsche Welle 2008: 2). A recent survey of 3,500 gay men in five cities in the UK showed most of

the men infected with HIV had assumed they were HIV-negative (Medical Research Council 2008: 1). A study among men who have sex with men (MSM) in the state of Washington in the USA and published in 2008 also showed that asking a sex partner his HIV status in advance was not a workable approach, as more than 30% of individuals who used this as a protection method subsequently tested HIV-positive (Golden *et al.* 2008: 1). It seems ironic to consider that someone might demand the 'right to know' or calmly ask about someone's HIV status before having sex with the person, but be given the wrong information for the right reason.

It is important to examine what some of the benefits of HIV disclosure encompass. Both UNAIDS and the World Health Organization (WHO) encourage 'beneficial disclosure,' of HIV status. Such disclosure entails voluntariness, respect for the autonomy and dignity of affected individuals, confidentiality as appropriate, and " leads to beneficial results for the individual, his/her sexual and drug-injecting partners, and family; [it] leads to greater openness in the community about HIV/AIDS; and [it] meets ethical imperatives so as to maximize good for both the uninfected and the infected" (UNAIDS/WHO 2000: 6). Indeed, disclosure of one's positive HIV status leads to access to ART when a person meets the criteria where this is available to the public, or the person can pay the extremely high costs to receive it through private health care.

Based on research performed in 2007 and 2008 by this writer, however, 'beneficial disclosure' defined by UNAIDS/WHO in 2001 remains aspirational more or less worldwide except in individual relationships that are unusually personally supportive. There is greater openness in one community in South Africa, Vulindlela, about HIV in 2008 than there was in 2000. But the openness has resulted from the introduction of, and

common accessibility to, ART in the community where HIV prevalence was more than 42% in the adult population in 2003 (Cullinan 2007: 1). The community is not representative of other rural communities in South Africa or even in its province, KwaZulu-Natal. It is primarily a rural research site for HIV prevention studies with funding from the US government. Thus the greater openness about HIV in Vulindlela, South Africa, is not indicative of a general trend of decreased stigma and discrimination in other communities in South Africa or in other countries. It is, though, an example of what all communities should be striving to move towards in regard to greater openness about HIV.

Beneficial disclosure may have seemed like a good approach for a trend that might occur in the near future to some health professionals in 2001, or at least a potential target worth addressing at the time by developing guidelines. For the most part, though, there is acknowledgment by at least some members of the HIV/AIDS community internationally that aspirational guidelines do not necessarily advance openness, or diminish stigma and discrimination. What is needed is more action on the ground by communities and nations to decrease hurdles to HIV openness, and lessen the stigma and discrimination faced by PLHIV just about everywhere, as well as legislation put in place to protect individual rights where it does not yet exist. Greater enforcement of legislation is needed where it already exists, such as in South Africa, which has a supportive Constitution and existing laws on employment equity, national health and children. There also has been greater awareness among some international HIV/AIDS activists lately that human rights challenges related to HIV seem to be growing in some countries rather than diminishing as time goes on (Gonsalves 2008: 1).

Thus in regard to 'beneficial disclosure' of HIV status, one must examine the ongoing lack of environments and of many relationships that seem supportive of beneficial disclosure in 2009. Rationally, there seems to be little, if any, justification to jeopardise a person's life or domestic security to share health information a spouse or sex partner may already know about themselves, or who may do nothing as a result to protect his or her health status in the future. On the other hand, the spouse or partner, or a third party may inflict injury on the other person in a variety of ways as a result of discovering the person's HIV-positive status. In cases where there is a real threat of harm, cautioning against disclosure seems to be the wiser act by a health professional. Choosing not to disclose seems to be the rational and personally justifiable option for an individual in potentially life-threatening circumstances if s/he proceeds with disclosure. Nonetheless, making a decision not to disclose is a difficult one because many people feel torn about not practicing what might be viewed as individual justice toward a sex partner. Yet some research has shown that some people do not feel a sense of justice at all toward their sex partners, including some married women and men about their spouses, even when violence or other subjugation is not a threat (Nsabagasani and Yoder 2007: xv, 37). Some even claim to be protecting their sex partners or spouses through a lack of disclosure, which does not seem justifiable.

Disclosure decisions where there is no potential for abuse would seem to be more straightforward to make than many find them to be. Thus there is a need for further research to pinpoint what the difficulties are for different groups of people. Certainly, more research should be done on this topic in sub-Saharan Africa. While some research has been done with specific groups such as injecting drug users, the vast majority of research on HIV disclosure has focused on MSM. It has been useful in illuminating aspects of disclosure related to this population group. But it is not necessarily useful regarding the

situation of women, who have received some disclosure research attention, but far too little to date. Such research, if it is spread more broadly across various other population groups, also might aid the development of approaches, tools, and interventions that will help decrease stigma toward, and discrimination against, all PLHIV and help society to be more supportive of them.

The information available on disclosure to PLHIV is also too limited. It mostly says it is good to disclose and what some of the benefits can be, but it generally does not suggest to people how to disclose. Thus it does not really foster disclosure in a helpful way. For example, discussing one's HIV-positive status in a gay, public bathhouse before having sex with someone certainly seems like the appropriate and wise thing to do, to protect oneself and potentially one's partner from unwanted infection. But such specific messages are rare, as MSM still receive too little attention from HIV prevention programmes (Roehr 2008: 2). Using a condom with a sex partner when the person's HIV status is unknown obviously is the right thing to do whether one is living with HIV oneself or not. But some young people believe that if a person seems trustworthy, s/he is not living with HIV. Too little attention has been directed toward the need for disclosure discussions and furthering the understanding of HIV transmission and the progression of disease.

Discussing one's HIV-positive status in a private setting, where the only injury suffered afterward might be a refusal to have sex by a first-time partner also seems like the wise and just thing to do. But, again, this topic has not been addressed by many HIV programmes. Discussing HIV status with a potential longer-term lover if one is living with HIV also is the right and ethical thing to do, despite the possibility of ending a budding and potentially emotionally rewarding relationship. Such an outcome obviously would be more painful if

one never saw someone again with whom one had hoped to develop a relationship. Obviously, disclosure under these circumstances would be a greater emotional challenge to a PLHIV than disclosing to someone with whom a person has not fostered any hopes. This potential disclosure situation, too, has fallen outside the purview of prevention programming. Recent research studies have shown the need to address all of these disclosure-related situations to provide better understanding of the personal ethics surrounding disclosure that currently exist. Accordingly, recent innovative programmes focusing on the major historic gap in prevention and care programming for PLHIV, i.e., 'positive prevention' also have identified the need to help PLHIV understand why they should disclose their status and help them identify appropriate opportunities to do so (Rosenberg *et al.* 2007: 1-27).

Regarding disclosure, Klitzman and Bayer found that for most men and women living with HIV in New York City, one of the hardest decisions they faced regarding their status was whether to reveal the truth about it, to lie, or to speak about it "in code" both to their sex partners and to others (2003: 228). However, their study participants also said that using "code," such as saying a previous lover died of AIDS, or using supposed signs of infection, such as leaving HIV pill bottles around their homes or apartments, was not always deciphered correctly by sex partners (*ibid.* 244). Moreover, Klitzman had found in previous research with gay men that, even when some men living with HIV were asked outright about their HIV status by a potential sex partner, they would not admit to it or would simply lie about it (1999: 44, 48). The stigma of living with HIV seems to know no bounds of race, gender, socioeconomic status, nationality, or sexual preference in the USA or elsewhere (Crepaz and Marks 2003: 384).

When men and women have decided to disclose their HIV status, Klitzman and Bayer found it was done for varying reasons depending upon who was the recipient of the revelation (2003: 233). To sex partners, it was done out of a sense of moral responsibility and a concern for a partner's health. To parents, it was done for support and because of a feeling they had a right to know. To friends, it was done for support *(ibid.*).

Non-disclosure to sex partners was decided based on the fear of rejection and also a need to maintain secrecy about one's HIV status. Non-disclosure also was found to be more common among individuals with a greater number of sex partners (Marks *et al.* 1991: 1321; Holt *et al.* 1998:50; Simbayi *et al.* 2007: 2). Some individuals decided not to disclose to family members, particularly parents, out of a sense of shame, or to avoid rejection or future dependence. Others wanted to protect their families from emotional distress (Klitzman and Bayer 2003: 233). However, Klitzman and Bayer also found that such decisions about disclosure "shifted over time," based on greater individual understanding of the epidemic, the importance of who the sex partner was, and various other contextual reasons (*ibid.* 235).

The length of time since testing HIV-positive also was found to have an impact on disclosure decisions (Crepaz and Marks 2003: 382). When one has been living with awareness of a disease for a long time, it becomes easier to come to terms with it, according to many people. Also, when one is living in an environment where there are some tangible benefits to disclosure, to access ART, to gain some necessary support when one becomes ill with AIDS, or to obtain the social service or disability benefits available in some countries, making such a decision is much easier than when the costs seemed to outweigh the benefits.

Finally, it is important to recognise that one person's decision to disclose in a seemingly supportive relationship or familial circumstance does not make another's non-disclosure decision under entirely different circumstances unreasonable or unethical. Disclosure decisions are by their very nature personal ones. This paper will go on to show that this is the case even for health care practitioners based on several current guidelines regarding HIV disclosure. Even South Africa's Department of Social Development recognises the personal nature of disclosure decision-making and the stress related to it as they advise people who test positive for HIV: "Do not feel you have to rush into coping and telling people" (n.d.: 8). The Department gives such advice even though it states that a spouse or partner should be made aware of the HIV status of a PLHIV and that safe sex should be practised (*ibid.*). But the Department does not advise when the spouse or partner should be told, such as immediately, or soon. Rather, it recognises that disclosure decisions are extremely stressful to make and that professional advice is wise to obtain in cases of anger or fear after learning one's positive status (*ibid*.). Thus, in a way, the Department tries to address situations where fear is based on reality, by hoping that professional assistance will either help with disclosure or help someone recognise situations where non-disclosure seems to be the wiser thing to do. The next chapter will examine a number of the barriers to disclosure of positive HIV status and why these barriers remain significant hurdles to disclosure of HIV-positive status even more than 25 years after the HIV epidemic was first identified.

Chapter 4: Current Barriers to HIV Disclosure

This chapter is central to the stance taken in this research report that disclosure of positive HIV status is never easy. The complexities involved should (and do) guide personal and professional ethical decision-making. This chapter will explain why the barriers to disclosure can indeed be too high and too dangerous for many people to want to try to overcome when their disclosure of HIV-positive status may mean the loss of their lives or their future security.

"AIDS is stigma disgrace discrimination hatred hardship abandonment isolation exclusion prohibition persecution poverty privation" (Cameron 2005: 42). These words were written by Edwin Cameron in his book, *Witness to Aids.* They describe the manifestations of both internal and external stigma toward PLHIV many, if not all, of them feel or have felt at one point or another after they have tested positive for HIV. These words and feelings highlight the intensity of the societal, interpersonal, and individual responses to HIV/AIDS and the very deep negativity accompanying this disease. They connote the enormous difficulty most people face in deciding whether or not to share their HIV status with another person. They also introduce the variety of possible negative reactions that may occur after disclosure, or in some environments ordinarily do occur.

The stigma facing PLHIV remains pervasive worldwide. According to Valdiserri (2002: 342), in the USA, "stigma needs to be recognized as a continuing impediment to HIV prevention and care programs." While efforts over the last ten years have increased to try to lessen the stigma toward HIV/AIDS, the results of a survey performed in nine countries, including Brazil, China, France, India, Mexico, Russia, South Africa, UK and USA, and

released in November 2007, found that nearly half of the people surveyed said they felt uncomfortable walking next to an HIV-infected person (Brown 2007: 1). This worrisome finding points out that seemingly little progress has been made in reducing the level of stigma toward PLHIV in most countries, including those where ART to treat HIV/AIDS is widely available. The survey results also emphasise the seriousness of the social stigma toward HIV. Many of the respondents felt they would not even want to be seen with someone who is infected with the virus, even though some may know HIV transmission is not possible through such casual interactions.

Disclosing one's HIV status in a highly stigmatised society could risk one's life. If disclosed publicly, it most certainly would risk one's liberty, as it would invite discrimination and free movement socially. It also could risk one's security of person either from a specific individual, such as one's sex partner, or from members of the community if one's positive status were to become widely known in an environment where HIV is highly stigmatised. This was the case for Gugu Dlamini, a woman who was murdered based on her HIV status in 1998 in KwaMancinza, South Africa (Associated Press 1998: 1). According to Justice Edwin Cameron, Gugu's attackers

> "…accused her of shaming her community by announcing her HIV status. She died in hospital—her body broken not by the HIV she faced with such conspicuous courage, but by the injuries her neighbours inflicted on her. She left a thirteen-year-old daughter" (Cameron 2005: 54).

In South Africa, HIV/AIDS-related stigma continues to be very common, both socially and culturally, according to Kalichman and Simbayi (2003: 442). Edwin Cameron calls it "stubbornly intransigent" (2005: 66). Women living with HIV/AIDS in South Africa in

particular tend to be more stigmatised than men living with the virus, as observed by Sigxaxhe and Mathews (1) at the XIII International AIDS Conference held in Durban in 2000 and many others since then. A higher degree of stigma toward women living with HIV also exists in Zambia, as noted in 2005 by Campbell *et al.* (2). It is likely that the same research result regarding stigma toward women who are PLHIV could be found in a number of other African countries. Many authors have noted that women are generally blamed for bringing AIDS into families as they tend to be diagnosed with HIV before their partners, when they are tested for the virus during pregnancy. Such stigmatised environments, as noted by Valdiserri (2002: 342), make it extremely difficult for HIV/AIDS prevention and care programmes to operate effectively. Moreover, trying to stop the spread of the epidemic in such an environment, especially in the country with the estimated highest number of people living with HIV of any country in the world—South Africa, according to UNAIDS in 2007 (16)—requires measures well beyond standard infectious disease interventions. The lack of South African governmental leadership for many years until very recently, and the too limited support for an intensified response to the world's largest epidemic also have played important roles in maintaining a stigmatised atmosphere.

South Africa only introduced ART in 2003 after substantial criticism of the lack of governmental action by the country's civil society sector. The criticism has received publicity worldwide for at least eight years. Such a late response highlights the lack of political support for the type of comprehensive response that is needed amidst a major epidemic (Omarjee 2007: 1). These contentious conditions underline the degree of difficulty anyone living with HIV in South Africa must face in deciding whether or not to share his or her HIV status with anyone, especially publicly. Indeed, even sharing one's

status with health professionals to access ART in this type of stigmatised environment takes courage. Stigma toward PLHIV does not necessarily stop at the clinic door even in health-care settings in Africa (Stegling 2004: 240; Norman *et al.* 2005: 10; UNAIDS 2006: 199; Human Rights Watch 2007: 3).

One also should keep in mind that in South Africa a climate of stigma and discrimination is historic. Apartheid, with its "divide and rule" segregation strategy, reigned in the country for more than 40 years, starting in 1948 and ending in 1994 (Government of South Africa 2006/2007: 2). Apartheid was perpetrated by the white minority against the black majority. Ironically, the same or similar situation exists relative to the proportion of racial groups currently estimated to be infected with HIV: the majority of individuals infected with the virus in South Africa are black. The transmission of HIV is not limited to human beings of a specific colour. Nonetheless, the epidemic represents to some blacks in South Africa, according to Kalichman and Simbayi, yet one more opportunity of discriminating against them in a country where most still labour under greater economic disadvantages than the white minority (2003: 446).

Historically, black women in South Africa are the country's most powerless group (Petros *et al.* 2006: 72). The HIV epidemic is seen by some of them as one more threat to the long-needed rise in their social status and even to their very survival. In a qualitative research study conducted in Durban, South Africa, all 11 women living with HIV who were interviewed "experienced either physical abuse (hitting, punching, slapping, etc.) and or/psychological abuse (social stigma name calling, discrimination) related to disclosure of their HIV status" (Finney and Njoko 2000: 1). In addition, violence against women in South Africa appears to be so common and was so accepted in 1999 that approximately

44% of the men who were interviewed in Cape Town municipalities admitted they abused their female partners (Vetten 2005: 2). Rape Crisis estimates that some 2,800 women are raped each day in South Africa (Hennop 2006: 1). South Africa's Medical Research Council found in a study conducted in 2005 that a woman was killed every six hours by an intimate partner, which is the highest rate ever reported anywhere in the world: 8.8 per 100,000 females older than 14 (Kapp 2006: 719). In such a climate of violence, it is understandable that any South African woman would think long and hard before providing the type of information to her sex partner, such as disclosure of positive HIV status, which might invite violence. For women involved in relationships where violence already has occurred, it seems undeniable that they would have great qualms about provoking further violence from their partners. Research results from a study of HIV disclosure performed by Wong *et al.* in two communities in South Africa, Soweto and Vulindlela, released in February 2009 showed that HIV disclosure, especially to sex partners, is still a cause for serious concern by PLHIV, as 36% of the study participants had not disclosed their positive status to their sex partners (Wong, *et al.* 2009: 216). The study also reported that the sex partners of those who disclosed were more likely to *decrease* their social support for the HIV-positive individual, with spouses decreasing support by 25%, and boy/girlfriends by 11% (*ibid.*: 219). These outcomes show that disclosure to sex partners can have a negative impact, even if it does not result in rejection, abandonment, or violence. Wong *et al.* also noted, "Because decreases in social support may have tangible effects on quality of life and disease trajectory, further research is needed to specify the reasons why these individuals received less support" (*ibid.*).

Little has been accomplished to lessen stigma toward HIV over the last ten years, despite recognition that it is a serious problem in making progress against the epidemic (Sarangi

n.d.: 1; Valdiserri 2002: 241-242; Kalichmann and Simbayi 2004: 572; Kalichman *et al.*: 2005: 135; Renniel and Behets 2006: 1; Bartlett 2007: 1; Kershaw 2008: 1). Moreover, testing more people will not necessarily mean an increase in prevention behaviours. The counselling focus on prevention for those who are potentially HIV-negative, as well as those who test HIV-positive, has been lessened by the major health authorities. The new HIV testing guidelines, referred to as provider-initiated testing and counselling, or 'routine testing,' may result in earlier and possibly better treatment for more people living with HIV, which would indeed be a very positive outcome. Yet the possible prevention outcome from the HIV counselling and testing intervention has been decreased or even minimised over the last two years by the two most important health agencies in the world. Nonetheless, the HIV prevention outcome on the individual, dyadic (couples), and eventually the societal levels is one of the primary reasons for the support of health agencies and professionals for disclosure of HIV status (Varga *et al.* 2005: 952). The international policies and current practices on HIV testing and HIV disclosure do not seem to be in good harmony with each other.

Studies in a number of countries have found that disclosure of HIV status is one of the most difficult decisions anyone who tests HIV positive has to make, whether or not the individuals live in a country where violence in common (Blais 2006: 37). A study performed by Holt *et al.* (1998: 49) in the UK found that immediately after diagnosis, "individuals were more likely to adopt a policy of non-disclosure and this provided them with an opportunity to come to terms with their diagnosis before having to contend with the reactions of others." Clearly, being told one is HIV-positive and thus is living with a terminal or, if lucky, chronically manageable disease, must be a shock. Each individual has

to digest this information in his or her own way even if s/he had an inkling this might be the case—unless the person is so ill already that such news is not a surprise.

In many clinics where HIV testing is available in African countries, some individuals only come for a test after they already are gravely ill, according to Chimwaza and Watkins (2004: 799). Even in such cases, however, the home caregiver for the individual, who is generally a family member, and more often than not a woman or girl, frequently is not informed of the person's real diagnosis while s/he is in a hospital or at a clinic testing site because of the stigma attached (*ibid*.). An example Chimwaza and Watkins cited in their study in rural Malawi shows that many healthcare professionals in Africa are very aware of the extensive stigma toward, and discrimination against, HIV existing in communities across the continent, even in the home setting (*ibid.*). Some of the ill individuals in question in the interviewing of healthcare staff for the study were on their deathbeds, or already had died. These tragic circumstances pinpointed how deep and widespread stigma toward HIV really is in many communities across sub-Saharan Africa.

Stigma toward HIV, however, is not limited to sub-Saharan Africa, as indicated earlier. In a study in the USA of mostly African-American women living with HIV in the rural South, the "women's fear that others in their community might learn of their HIV infection was second only to having the disease itself" (Sowell *et al.* 2003: 32). Of the more than 300 women who participated in the study, only 65% of them had disclosed their status to all their sexual partners. Only 3% of them had told all their close friends. Obviously, disclosure of HIV status was a very serious issue to these women as well (*ibid.*: 37). What is more, a small group of these women had decided not to disclose to anyone, even though by not disclosing to their sex partners, they were putting any uninfected partners at risk of

HIV infection. Such an action is punishable by imprisonment in the states in which they lived in the USA, where laws relating to HIV disclosure to sex partners vary by state (*ibid.*: 42). Whether or not each of these women had clearly thought through all the potential consequences of non-disclosure is unknown. However, that they were afraid of the potential consequences of disclosure of their HIV status to their sex partners seems palpable.

A study conducted by Gielen *et al.* in the USA of mostly African-American women living with HIV for an average of nearly six years in an impoverished inner city section of Baltimore found that younger women─76% of those under 30─were at the greatest risk of being abused since learning their HIV status (2000: 117). If their sex partners' status was HIV-negative or unknown, though, their likelihood of experiencing abuse was twice as high as that of women without a main sex partner, or whose financial resources were greater (*ibid.*: 118). Thus the low socio-economic status of women living with HIV in Baltimore seems to put them at the same risk of partner abuse that women living with HIV in southern Africa, and South Africa in particular, also face (Physicians for Human Rights 2007: 2, 3).

Yet whether or not women experience physical violence based on disclosure, "notification of a positive HIV test result can profoundly affect a woman's psychological and physical well-being," according to Gielen *et al.* (2000: 111). An HIV-positive test result can cause them to "experience feelings of isolation and shame" (*ibid.*). Such knowledge, even if unshared, will only worsen how a woman feels about herself when she is already in an inferior socio-economic and highly vulnerable position, no matter where she lives.

Based on their revelation, men, too, suffer stigma and discrimination after disclosing their HIV-positive status, whether or not many undergo violence afterward. Several African-American men who were part of a study conducted by Gaskins in the rural southern USA suffered negative reactions from family members whom they had told they were living with HIV (2006: 5). One man's sister "betrayed him by telling her husband and son" (*ibid.*). Most of the 20 men interviewed for the study wanted to warn other people to be careful about with whom they shared their HIV status and to choose the individuals very carefully. One man advised,

> "Pray about it. Think long and hard about who this person is you are going to tell. The last thing, be prepared if the person goes out and tells it. You have to handle it if they do" (*ibid.*: 6).

Many of the respondents who tested positive in a research study performed in Uganda focusing on HIV voluntary counselling and testing (VCT) and disclosure also were afraid of being talked about in their village (Nsabagasani and Yoder 2006: 35). They expected to experience hostility from any members of their community who learned they were living with HIV (*ibid*.). Yet the men who tested HIV-positive who were not "severely sick" did not tell their wives about their results. They claimed they did so to avoid rumors, blame, and disruption of their familial relationships. Some of them even said that women have "weak hearts" and might collapse after hearing the news. Ironically, some of these same men disclosed their positive status to others who were not their sex partners, including their parents, siblings, other relatives and close friends (*ibid*.).

In addition to the concerns PLHIV have about their potential ostracism by their family members, friends, and communities through their own disclosure or shared knowledge of

their status without their permission, they concurrently live with other major stressors related to their HIV infection. These include the uncertainties about the disease itself and their own individual rate of disease progression, as well as consequent anxieties about their future health and their future in general (Holt *et al.* 1998: 49). According to a study by Holt *et al.*, they also worried about how their interpersonal relationships would change based on their disease. Further insecurity, especially about their financial future, also plagued them (*ibid.*). Such anxieties and thoughts, however, will not be theirs alone. They will be shared by anyone to whom they reveal their HIV status, such as lovers, family members, friends, church members, and even employers, if they feel the need to share information about their status widely or have the desire to disclose it publicly.

Despite the worries associated with disclosure, a presentation made by Visser at the XVI International AIDS Conference, held in Toronto, Canada, in August 2006, concluded that even in South Africa where violence, including gender violence, is common, most women living with HIV (58% according to the study of nearly 300 women) do disclose their status to their sex partners (1). The women in the study also disclosed relatively soon, within three months after learning of their infection (*ibid.*). Yet whether disclosure by women living with HIV in South Africa to their sex partners is really as common as this study suggests needs further exploration. The results of another study performed by Olley *et al.* in South Africa and published in 2004 showed that 78% of the people living with HIV participating in their study had not disclosed their status to their sex partners (1). At the time of the study, the knowledge of the participants of their HIV infection averaged more than seven months (*ibid.*). Also, Simpson and Forsyth's study of 11 pregnant women in New Haven, Connecticut, USA, who were mandatorily tested for HIV during their pregnancy according to Connecticut state law between 1999 and 2005, produced different

results from both of these studies (2007: 39). When the participants were asked whether their diagnosis had changed their relationship with their spouse, children, or extended families, "some responses were positive and uplifting but the majority of responses were troubled and filled with disappointment and anger" (*ibid*.). At the time of the birth of their babies, nine of the 11 women were managing on their own with no or minimal support from their spouses or sex partners. The results obtained by Simpson and Forsyth speak for themselves:

> "Many of the women were victims of verbal and physical abuse and controlling partners. One woman had been badly beaten and scalded by the father of her baby. Another study subject was later shot dead by the father of her babies. It was not determined what role, if any, the women's HIV infection played in the abandonment and/or abuse" (*ibid.*: 38).

While the abuse of these women in the USA and even murder of one of them cannot be attributed directly to disclosure of their HIV status, the study results are chilling. Such potential HIV disclosure results would almost certainly give any physician or other health care practitioner much to ponder in determining whether to proceed with partner notification in a setting with any potential for violence such as this one. What is also important to remember and what does not seem to be adequately addressed in the HIV disclosure guidelines for health care practitioners of several international and national medical bodies is the result of a study by Zierler *et al.* It also is supported by results from other studies, including one by Vlahov *et al.* (1998: 54). The study results state, "Apart from the risk of serious injury, physical assault victimization may have dire consequences for HIV-infected persons. Physical assault may directly affect immune function as well as disrupt other bodily systems" (Zierler *et al.* 2000: 208). Surely, the risk of worsening a patient's physical condition and disease progression needs to be taken into account when

health care practitioners make a decision about partner notification related to HIV infection. Also germane is consideration of the potential emotional deterioration that can follow psychological abuse by a spouse or sex partner, which can result in deleterious physical symptoms over time.

To illustrate the impact of psychological abuse, a study by Coker *et al.* in South Carolina, USA, found that psychological "intimate partner violence" (IPV) "was as strongly associated with the majority of adverse health outcomes as was physical IPV" (2000: 1). Among the subsequent physical manifestations of psychological abuse by their partners, more than 13.6% of 1,152 women had experienced included: disability preventing work, arthritis, chronic pain, migraine and other frequent headaches, stammering, sexually transmitted infections (STIs), chronic pelvic pain, stomach ulcers, spastic colon, and frequent indigestion, diarrhea, or constipation (*ibid*.). Yet none of these women had suffered physical abuse. While most of these physical symptoms can be individually debilitating, it is especially worrisome that some are the same side effects many people experience at various times while taking ART (Johnson *et al.* 2007: 1). Thus, if a woman is already taking ART, from which side effects are common even though it is a life-preserving medication, health care practitioners considering disclosing a woman's HIV status to a sex partner must take into account the possible concurrent physical after-effects of psychological abuse she could suffer from her partner. Consequently, it is not only the potential resulting physical violence that health care practitioners must take into consideration regarding HIV disclosure determinations about their patients to third parties. They also must review the overall potential negative health consequences for their patient resulting from their disclosure. Moreover, negative health consequences can grow over time depending on the presence and the level of psychological abuse a patient suffers.

Perhaps worse in some cases is the increased potential PLHIV who are aware of their status have for severe depression (Gross 2008: 1). According to Meel, based on his forensic pathology work in South Africa, with additional support for his findings from previously published research and other publications (including Beauchamp and Childress 1994: 414), "HIV infection is associated with an increased risk of suicidal behavior" (2003: 8). Also, "Suicidal acts seem to be more frequent in AIDS patients than in the general population" (*ibid.*). Obviously, health care practitioners should consider the potential multifarious effects their disclosure of a patient's HIV-positive status can have on the individual.

What these worrisome findings give rise to is a reminder of the basic ethical principle upon which every physician has been trained: "Primum non nocere," or "First do no harm" (Medical Dictionary 1998: 1), or, "at least do no harm" (Szasz 2004: 1). This statement is commonly attributed to the Greek physician Hippocrates, known at the "Father of Medicine," although this attribution is not without controversy (Hippocrates trans. 1923: 1). This classical medical tenet has been historically important over some 2,400 years. It has been in active use in medical teaching in the USA and the UK for more than 150 years since the publication of Hooker's *Physician and Patient: A Practical view of the Mutual Duties, Relations and Interests of the Medical Profession and the Community* (Yale Medical School n.d.: 4; Herranz 2002: 4). It underscores that in the treatment of a patient, first and foremost the physician should not make the patient any worse than s/he already is. Disclosing a patient's HIV status to his or her sex partner(s) will indeed make the patient worse if there are negative emotional or psychological and/or physical repercussions affecting the patient from third-party disclosure.

Some study results also highlight that, ironically, there is not necessarily greater acceptance of HIV-positive status in the gay community than in any other. This seems to be the situation according to what can be discerned from the results of research studies on disclosure. Such a lack of acceptance seems ironic, despite HIV infection being more common in the gay community than in any others in a number of countries, including the USA, Canada, and the UK (UNAIDS 2007: 33-34). Consequently, the widespread nature of HIV infection as well as the availability of ART, as mentioned previously, do not necessarily seem to lessen stigma toward the disease. While some have speculated otherwise, this is the case even in communities where the HIV epidemic has taken a great toll historically.

Indeed, ideas vary among gay PLHIV about whether they have a moral responsibility to disclose their positive status to their sex partners. Thus, there is still no clarity in the gay community surrounding HIV infection. Not disclosing one's HIV-positive status to a sex partner simply to be able to enjoy sexually "getting off" instead of facing potential rejection is a morally assailable stance by anyone, including members of the gay community (Klitzman 1999: 45). The core issue is there seems to be no common understanding across the gay community about whose responsibility safe sex really is, despite significant concern within the community about the HIV epidemic for 25 years. Part of this problem, and indeed the public health challenge, lie in the lack of enough specific, intensive and targeted HIV prevention programming using appropriate and resonant messages. This situation has occurred in the USA even in 2008 in targeting prevention programming to the gay community, which both historically and currently has been the population group with the highest number of HIV infections in the country (Roehr

2008: 1-2). But it also seems to stem partly from the lack of widespread recognition and acceptance of the need for taking personal responsibility for sexual behaviour by each and every person in the gay community. This is not to say that members of the "straight," i.e., heterosexual, community accept more personal responsibility for their sexual behaviour than gays. But the important findings by Klitzman and Bayer focusing mainly on gay men may provide the consideration of possible gender differences in regard to the acceptance of personal responsibility for sexual behaviour and one's actions when a person believes s/he is in an equal position to take personal responsibility. For example, one study in the USA in the mid-1990s found that 90% of female PLHIV eventually revealed their HIV-positive status to their sex partners (Klitzman *et al.* 2004: 629). Specific research would have to be performed to confirm any attitudinal gender differences or disprove the possibility of different behaviours toward HIV disclosure depending upon gender, however.

Many authors, though, have highlighted the need for greater understanding of HIV disclosure decisions in all target groups to be able to provide individuals with better counselling on disclosure. Counselling is needed by many PLHIV to help them learn better skills to aid them in making disclosure decisions and in the process of disclosure itself. Given how prominent and worrying these decisions are, apparently, to nearly all people who test positive for HIV, there is a need to focus more attention on disclosure decisions and the ethics surrounding disclosure. Such counselling, though, also should include discussion surrounding the potential negative results of disclosure of HIV-positive status.

'Fully informed' counselling to PLHIV, which seems like it would be a logical ethical step in counselling provision, a form of psychosocial treatment given to PLHIV, is not widespread (Maman *et al.* 2003: 380). That is, some patients are advised by counsellors,

physicians, or nurses to disclose their status to other health professionals (Sankar and Jones 2005: 2379). Some are advised to disclose their status to their sex partners (Gluckman 2002: 27; Olufs 2002: 3). And, some PLHIV are counselled to disclose to their family members, including their children (Murphy *et al.* 2003: 207; Nostlinger *et al.* 2004: 641). But, during such counselling, PLHIV are not necessarily informed about what the negative ramifications of such disclosure can be in individual circumstances. Rather, the emphasis tends to be put on the benefits of disclosure without delving into the individual's relationships and any specific personal circumstances they should consider before making disclosure decisions to various members of their interpersonal network, including their sex partners.

In fact, the trend toward providing good and comprehensive counselling as a key component of HIV testing was reversed by the Centers for Disease Control and Prevention (CDC) in the United States in 2006 and the World Health Organization (WHO) in Geneva in 2007, as mentioned earlier (WHO/UNAIDS 2006: 34; CDC 2006: 8). As these two agencies have a major role to play in health policy globally, their policies carry a great deal of weight internationally. The HIV testing guidelines, referred to by some routine testing, were revised by both agencies to result in a greater number of individuals undergoing testing due partly to a reduction in counselling both before and afterward as part of testing requirements and because health care providers now suggest HIV testing to their patients. Yet these international guidelines conflict with the very fact that in a highly stigmatised epidemic, individuals need more counselling rather than less (Siyayinqoba – Beat It 2005 (26): 1). Consequently, there is still a great lack of understanding across the public health community of what the real needs of PLHIV are, including support regarding disclosure and other decision-making that will have an impact on their future.

This chapter has described the significant hurdles facing most PLHIV in disclosing their HIV infection because of the high degree of stigma toward, and discrimination against, them. Research results, some of which have been summarised here, have shown the negative atmosphere surrounding HIV and thus around PLHIV to be common worldwide. Some PLHIV are able to overcome the barriers to disclosure because they are lucky enough to be living in unusually supportive environments. But this is not the situation many, if not most, PLHIV face where they live. Thus this chapter has outlined what the various barriers are across communities, both in developing and developed countries. Such barriers include political environments hostile to HIV in some countries, which breed discrimination. The chapter also explains that so far public health experts have not been able to discover how to change these negative environments and lessen the stigma toward, and discrimination against, PLHIV. Part of the problem is that not enough interventions have been tried to date to discover what works and what does not in decreasing stigma and discrimination. Even locations where ART has been available for more than ten years continue to be difficult environments for PLHIV, which has surprised some public health experts. Thus the threat of physical violence, emotional and psychological abuse, and community ostracism for PLHIV continues to be substantial hurdles in increasing the rates of disclosure of HIV-positive status. Disclosure must be regarded as a personal action or non-action individuals take within the larger environment. Consequently, in determining the ethics around disclosure, it is essential to think back to Paul Farmer's admonition in 2005 that medical ethics must consider social justice in fostering truly ethical determinations and behaviours. The following chapter will look into the right not to tell positive HIV status for individuals and by health care practitioners about their patients.

Chapter 5: The Right Not to Tell Positive HIV Status

This chapter centres on the right not to tell others about one's positive HIV status, and the right of health care practitioners not to tell the positive status of a patient to third parties. It focuses on this right in relation to sex partners. The chapter examines relevant historic legal texts related to the right to privacy and protection against invasions of privacy. It also elaborates on research study findings about individuals who have disclosed their HIV-positive status in Africa and the USA, as well as individuals who have chosen not to disclose. The chapter examines a number of relevant guidelines for health care practitioners about disclosure of a patient's positive status. The right not to tell appears to be gaining ground in the guidelines of some health care agencies, especially in South Africa.

A number of ethical questions arise surrounding the disclosure of HIV status. The importance of autonomous decision-making regarding disclosure already has been discussed in this report. While respect for a patient's autonomy, and indeed one's respect for one's own freedom to make personal decisions remain central, there are other bioethical principles relevant to disclosure. One of them is privacy. What many of the examples of stigma toward PLHIV described in this report, and the rights delineated in the UDHR (most explicitly Article 12) support is the fundamental right of each and every person to his or her privacy.

Focusing on the right to privacy for the *Harvard Law Review* in the USA in 1890, Warren and Brandeis wrote:

> "In very early times…the "right to life" served only to protect the subject

> from battery in its various forms;…Gradually the scope of these legal rights broadened; and now the right to life has come to mean the right to enjoy life,--the right to be let alone" (1).

They went on to write:

> "The protection against actual bodily injury was extended to prohibit mere attempts to do such injury; that is, the putting another in fear of such injury" (*ibid.).*

Thus Warren and Brandeis not only focused on harm resulting from physical injury, but also the importance of protecting people from the threat of injury. This statement thus relates to assault and the fear of assault. It encompasses the concern of Warren and Brandeis that individual privacy extends across a number of realms: physical as well as emotional. Regarding law, they wrote:

> "The design of the law must be to protect those persons whose affairs the community has no legitimate concern, from being dragged into an undesirable publicity and to protect all persons, whatsoever; their position or station, from having matters which they may properly prefer to keep private, made public against their will. It is the unwarranted invasion of individual privacy which is reprehended, and to be, so far as possible, prevented" (*ibid.*: 9).

In the passage above, Warren and Brandeis concentrated on a subject such as the public disclosure of HIV status, stating that individuals should be protected from having their private information made known to the community. One might believe that someone's HIV status is a matter of public health concern to a community. This attitude has aroused controversy over the last ten years regarding HIV, and it has been discussed in this paper. In considering such an attitude, Warren and Brandeis sagely wrote at the end of their paper

on the right to privacy more than 100 years ago, "Still, the protection of society must come mainly through a recognition of the rights of the individual" (*ibid.*: 11).

Elaborating on the right to privacy, Fried wrote in 1968, "…privacy is…the *control* we have over information about ourselves." Also, "The person who enjoys privacy is able to grant or deny access to others." He went on to write, "Most obviously, privacy in its dimension of control over information is an aspect of personal liberty" (276). In *Privacy: A Moral Analysis*, Fried includes:

> "The rights of privacy are among those basic entitlements which men must respect in each other; and mutual respect is the minimal precondition for love and friendship (277)."
>
> "…this most complete form of privacy is perhaps also the most basic, as it is necessary not only to our freedom to define our relations to others but also to our freedom to define ourselves. To be deprived of this control not only over what we do but over who we are is the ultimate assault on liberty, personality and self-respect (278)." And, "There can be no trust where there is no possibility of error. More specifically, a man cannot know that he is trusted unless he has a right to act without constant surveillance so that he knows he can betray the trust. Privacy confers that essential right. And since, as I have argued, trust in its fullest sense is reciprocal, the man who cannot be trusted cannot himself trust or learn to trust. Without privacy and the possibility of error which it protects that aspect of his humanity is denied to him" (*ibid.*).

What is especially relevant about Fried's views is they support an individual's basic right to privacy. Yet they also address the need to be able to maintain this basic right even in one's most intimate relationships and in actions within intimate relationships. Thus his views are illuminating and relevant in regard to the issue of disclosure of HIV status and how disclosure falls within the overall parameter of the fundamental right to privacy. That is not to suggest that it is ethical to keep whatever information one has about oneself from others if it will harm them. Rather, one has a right to consider one's own dignity, self-worth, value to society and safety in the equation of the need for others to know one's HIV status and one's right not to tell. Clearly, the circumstances involved in maintaining privacy, whether in regard to personal information about oneself, or in actions surrounding revelations of private information, are central to ethical decision-making. Preventing potential harm to another has to be considered, but it is not more important than considering what harm might come to oneself through the loss of privacy.

Surely, if there is significant risk of some type, or multiple types, of harm coming to an individual by disclosing specific information about himself or herself, the question as to whether or not it is wise to do so needs great consideration. Likewise, whether harm may come to another individual by disclosing the information also deserves extensive deliberation. Weighing the potential dangers involved and whom they may affect requires extensive knowledge of the environment and the individuals who are involved. They may include family members and members of the surrounding community for whom disclosure of HIV-positive status of another family or community members may be a significant cause for concern. This is the case in African communities where HIV disclosure has ramifications for one's spouse or partner, one's children, and indeed one's extended family in some settings (Kalichman and Simbayi 2004: 578; Varga *et al.* 2005: 956, 959).

These considerations are not to be trifled with when one's life, livelihood, and all social interactions, as well as perhaps the same factors for several others, or possibly many other family members, are at stake.

Weighing one's individual ethical considerations and internal comfort level against the potential community ramifications surely enters into HIV disclosure decisions. Such decision making has been articulated by many researchers referenced here. The potential ramifications also encompass whether or not to share the knowledge of one's HIV-positive status with one's most intimate partner. Yet the weighing of potential outcomes occurs even when there is internal realisation that one's sex partner has the need to know more than anyone else. In many countries in Africa and even in the USA, where ART has been far more readily available since 1996 than in Africa so far, many individuals have decided it is simply too risky to share their HIV-positive status with anyone, including their sex partners (Mabunda 2006: 27; Stein *et al.* 1998: 253). These individuals have decided that the cost-benefit ratio most seem to use when making such disclosure decisions is simply against them (Sowell *et al.* 2003: 11; Klitzman and Bayer 2003: 253). Even in the USA where one would think that the availability of ART for more than ten years would have lessened discrimination based on HIV-positive status, there is evidence from various sources of interpersonal violence perpetrated by sex partners toward PLHIV and discrimination against them in health care settings. A primary care-based study by Zierler *et al.* in 2000 found that 20.5% of HIV-positive women, 11.5% of men who have sex with men (MSM), and 7.5% of other men had experienced physical harm after their diagnosis, with half of them attributing the violence directly to their HIV status (208; Mills 2002: 331). Indeed, Zierler *et al.* also noted, as mentioned previously in this paper, that physical

assault can affect immune system function and disrupt other bodily systems, thus potentially resulting in dire consequences for a PLHIV (*ibid.*).

Given the prevalence of violence related to HIV in a number of countries around the world, it seems obvious that maintaining privacy in regard to HIV-positive status would be paramount to most people. One's health status in general should be kept private, and others should honour this principle. The WHO has laid out eight regulations specifically regarding privacy of information and in regard to treatment of individuals, which include those set out below.

> "(a) All information must be kept confidential, even after death.
>
> (b) Information can only be disclosed if the patient gives explicit consent, or if the law specifically provides. Consent may be presumed where disclosure is to other health care providers involved in that patient's treatment.
>
> (c) All identifiable patient data must be protected.
>
> (d) Patients have the right of access to their medical files and so forth which pertain to diagnosis, treatment and care.
>
> (h) Patients admitted to health care establishments have the right to expect physical facilities which ensure privacy, particularly when health care providers are offering them personal care or carrying out examinations or treatment" (Davies 1996: 31-32).

The WHO regulations emphasise the importance of maintaining patient privacy and the confidentiality of all health information that can be traced to a specific patient. Certainly, when such information involves a life-threatening STI, the importance of maintaining

confidentiality for the patient can only be underscored. Yet in cases where public interest seems to trump private interest based on the danger of death or serious harm, such as through highly infectious epidemic disease, such as multi-drug resistant (MDR) and extremely drug-resistant (XDR) TB, disclosure of confidential patient information can be warranted (Brazier and Harris 2003: 175; Gruskin and Loff, 2002: 1; Abbo and Volandes 2006: 33). Obviously, though, situations where breaching confidentiality is warranted have to be unusual, and the disease must pose very serious harm to public health and to the public in general. An English Court of Appeal found in the case of W *v* Egdell concerning a mental health review of a patient in 1988:

> "(a) Disclosure should be limited to those regarded as vitally in need of the information…
>
> (b) The risk, if the material is not disclosed, must be real rather than fanciful...
>
> (c) Rather more specifically this real threat needs to be of physical, as opposed to some other form of, harm" (Harbour 1998: 67; Brazier and Harris 2003: 40).

Thus the English Court seemed to say that where a disclosure decision is not clear and a breach is not essential to protect physical health, err on the side of caution. Further, legal guidance published in South Africa in 2008 states:

> "Disclosure of an individual's HIV status, particularly within the South African context, is deserving of protection against indiscriminate disclosure due to the nature and negative social consequences of the disease as well as the potential intolerance and discrimination that may result from such disclosure" (Joubert, Faris, Harms 2008: 48)

The World Medical Association (WMA) attempted to strike a balance between patient privacy rights and the rights of their sex and drug-injecting partners in its *Statement on HIV/AIDS and the Medical Profession* policy, released in 2006 (2):

> "Fear of stigma and discrimination is a driving force behind the spread of HIV/AIDS. The social and economic repercussions of being identified as infected can be devastating and can include violence, rejection by family and community members, loss of housing and loss of employment, to name only a few….Lack of confidence in protection of personal medical information regarding HIV status is a threat to public health globally and a core factor in the continued spread of HIV/AIDS. At the same time, in certain circumstances, the right to privacy must be balanced with the right of partners (sexual and injecting drug) of persons with HIV/AIDS to be informed of their potential infection. Failure to inform partners not only violates their rights but also leads to the same health problems of avoidable transmission and delay in treatment."

The WMA's policy advises physicians to counsel their patients to disclose their status to their sex and injecting-drug partners themselves. But in cases where the patients have refused and physicians know the identity of their partner(s), the physicians should take disclosure action based on their moral and legal obligations. However, the WMA also advises that such action should be taken only after informing the patient, discerning how to protect the patient's identity, and taking "appropriate measures" to ensure the patient's safety, especially in the case of a "female patient vulnerable to domestic violence" (2006: 3). The policy goes on to state that physicians must gain understanding of the medical, psychological, social and ethical considerations involved in partner notification before

undertaking it in specific situations. The policy also states that national medical associations should work with governments to ensure physicians who carry out their ethical obligation of patient notification, when necessary, are legally protected (WMA 2006: 3). How to protect the patient's identity in the case of spousal notification seems to present a serious hurdle. Also germane is that the legal systems of most developing countries are not equipped to protect physicians from a lawsuit brought against them by the sex partner of one of their patients (Human Rights Watch 2007: 1).

The *Revised HIV/AIDS Ethical Guidelines* of the South African Medical Association (SAMA) are very direct in regard to the need for "the highest possible level of confidentiality" for patients who test positive for HIV (1995: 4). But they also recommend partner notification in special circumstances. In regard to disclosure by a physician of a patient's HIV status to his or her sex partner(s), the guidelines state that a physician may divulge information only if the three conditions set out below are met.

> "1. An identifiable third party is at risk.
>
> 2. The patient, after appropriate counselling, does not personally inform the third party.
>
> 3. The doctor has informed the patient that he/she intends breaking confidentiality under the circumstances" (*ibid.* 3).

The *Ethical Guidelines for Good Practice with Regard to HIV* published by the Health Professions Council of South Africa (HPCSA) in 2007 are the most explicit and the most sensitive to the reality of the complexity of disclosure in South Africa. They specify that "the primary responsibility of health care practitioners is to their patients" (HPCSA 2007:2). Regarding disclosure, they state:

> "If the patient refuses consent, the health care practitioner should use his or her discretion when deciding whether or not to divulge the information to the patient's sexual partner, taking into account the possible risk of HIV infection to the sexual partner and the risks to the patient (e.g. through violence) that may follow such disclosure" (*ibid.*: 5).

They go on to say:

> "If the health care practitioner *decides* to make the disclosure against the patient's wishes, the practitioner must do so after explaining the situation and taking full responsibility at all times" (*ibid.*).

The guidelines spell out seven steps the practitioner must take as part of such disclosure. The most relevant is that the health care practitioner must:

> "After disclosure, 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" (*ibid*.).

Finally, they state:

> "Health care practitioners must recognize the major ethical dilemma when confronted with a person who is HIV positive and who refuses, despite counselling, to inform his/her partners" (*ibid.*: 6).

The HPCSA guidelines on HIV disclosure clearly recognise the widespread prevalence of violence in South Africa, including violence after HIV disclosure, which is to their credit. Yet by laying all responsibility for such potential violence on the health care practitioner, they make the practitioner responsible for any deleterious result of his or her disclosure of the HIV positive status of the patient. Thus the practitioner is responsible for any violent actions happening to the patient after the practitioner discloses the patient's status. Further,

the HPCSA makes it the practitioner's responsibility to help the patient in the case of any negative result.

It is significant to consider the following circumstances potentially resulting from the health care practitioner's disclosure: What if abandonment of the patient is the result of the practitioner's disclosure of the patient's HIV status to a partner? What if permanent physical damage to the patient results from violence occurring after the health care practitioner's disclosure and the patient is no longer able to work? These may seem to be extreme consequences resulting from HIV disclosure, but such consequences have occurred in South Africa. It is hard to imagine any health care practitioner who would be willing to accept any and all responsibility for a patient's livelihood, shelter, or medical needs resulting from violence following the practitioner's disclosure.

The HPCSA guidelines seem to recognise there are potentially serious problems related to health care practitioner disclosure of HIV status in an environment as violent as that of South Africa. However, the guidelines obviously do not provide any protection for practitioners who disclose a patient's HIV status. Rather, they seem to serve as a caution about the real responsibility for HIV disclosure to third parties. Indeed, they leave practitioners who decide to disclose a patient's HIV status entirely on their own to cope with the consequences. The guidelines seem to take one step forward re: recognition of the great complexity and danger of HIV disclosure to a third party in the South African environment. But they also seem to take two steps backward in the lack of any protection for a practitioner who decides to proceed with disclosure of a patient's positive status to a third party. They do not state or even imply that the ethical thing for health practitioners to do in South Africa is to inform a patient's sex partner of his or her HIV-positive status if

the patient is unwilling to do so. Instead, they state that such disclosure may indeed harm the patient. Importantly, they do not limit the time period in which resulting harm could occur. As such, they recognise the ethical principle of non-maleficence, without directly stating or suggesting that practitioner disclosure would be a non-maleficent act. Yet as they focus on the results of the disclosure, rather than on rights theory, they take a consequentalist approach to the ethics involved.

In the USA, the legal duties and responsibilities of health care practitioners regarding disclosure to sex partners if a patient is unwilling to disclose vary from state to state, as mentioned previously (Nathanson 2002: 1). Even the CDC guidelines for health care practitioners, *Guidance for HIV Partner Counseling and Referral Services*, rely on patient provision of the name of a sex partner to a health care practitioner for such an action to be carried out (*ibid*.). Obviously, the practitioner would otherwise not have knowledge of their patients' sex partners in many cases. However, the Association of State and Territorial Health Officials (ASTHO) in the USA does not specifically state in its disclosure guidelines that the ethical and/or legal duty is for a practitioner to disclose a patient's HIV status to the sex partner if the patient is unwilling to do so (*ibid*.). Rather, the ASTHO guidelines recommend that "a health care provider may invoke his or her 'privilege to disclose' when that provider knows of an identifiable at-risk partner who has been named by the HIV-infected person" (*ibid.*). Obviously, the ASTHO leaves the HIV disclosure decision and action regarding a potentially at-risk third party to the discretion of the health care practitioner. Thus the ASTHO guidelines are cognisant of the ethical quandary such HIV disclosure decisions can present to health care practitioners.

The range of guidelines quoted here is somewhat broad. Yet a health care practitioner should only inform a spouse or sex partner of a patient's positive HIV status if the patient has been counselled long and intensively enough to determine that most likely the person's spouse or sex partner is not already knowingly living with HIV. The practitioner also should have determined the patient's sex partner does not know s/he is at significant risk of becoming infected with HIV. And, the practitioner should have determined the partner will not harm the patient afterward in any way. Also, it should be very clear to the practitioner that such a disclosure action should only be taken when the patient has no plans at all in the future to disclose his or her positive status to the spouse of partner. The practitioner should keep the identity of the patient confidential, although this can be impossible and it remains one of the problems with partner notification.

It may seem that specific determinations about safety and security surrounding disclosure to an HIV-positive patient's partner or spouse would be very difficult to make. There may be a very strong reason for a patient's unwillingness to disclose, such as a threat of violence, abandonment, or psychological abuse, or even all three. Given the prevalence of violence in South Africa, it seems as though it would be quite difficult for a health care practitioner to determine that a South African woman, for example, would not be at any risk of violence, abandonment, or psychological abuse if her spouse/partner were to be informed of her HIV-positive status by a third party. Unless the health care practitioner has in-depth personal knowledge of the spouse or partner, which would be uncommon, making a decision to proceed with such disclosure in South Africa seems very dangerous. Even if the HPCSA were more supportive of taking such an action, it seems questionable ethically in the present environment. Even if a physician knows the spouse or sex partner of the patient, exactly what the introduction of the topic of potential infection with a life-

threatening disease would do to an intimate relationship cannot be known in advance by anyone. It might be thought that the reaction could be gauged through extensive knowledge of both individuals involved, as well as extensive knowledge of their relationship. But how many people, health care practitioners or not, are really in a position to make supposedly well-informed judgments about the intimate relationships of others and indeed the future outcomes of these relationships?

In the current global environment where stigma toward, and discrimination against, PLHIV are very common, the need for intense inner debate by PLHIV about whether to disclose their status, whom to tell, when to tell, and what effect it might have on their future is not just understandable. It is essential. One cannot make these decisions for others when it would be undeniably difficult for each person to make them for ourselves. One cannot decipher for others what their interpersonal relationships consist of with each and every lover, family member, or friend they have. One cannot predict what all the reactions by others will be toward individuals who reveal their positive HIV status (Sokol 2005: 3). Many people might not even be able to predict their own reaction to a lover, family member, friend, or colleague who would suddenly reveal his or her HIV-positive status. Thus one cannot make judgments for others about exactly whom they should tell, why they should tell specific individuals, and what the necessary circumstances should be surrounding such revelations.

However, it is possible to provide some guidance to others for making such crucially important decisions—which potentially can change their lives for the better or, in more extreme situations, result in their deaths. Indeed, UNAIDS, the World Health Organization (WHO) and many government programmes and non-governmental organisations (NGOs)

do provide guidance to individuals on how, when, and why they should reveal their HIV status when it would be beneficial, or at least not result in harm to them (UNAIDS 2000: 12; Khomanani n.d.: 2, 4).

Yet what if such disclosure may result in death? What if there is already a history of violence in a relationship between sex partners? What if a woman who has just learned her positive status is totally dependent on her partner for any income she requires to feed herself and her family? What if she is pregnant? What if the person's partner is the only sex partner she has ever had and thus, in all likelihood, she has been infected with HIV by that partner? What if the person who has just learned her status is only 16, has had several sex partners, lives in an environment where HIV is highly stigmatised, and knows she would be risking her safety by disclosing to all or perhaps any of her partners? What if she knows her partner would tell others in the community about her status if she were to tell him, resulting in ostracism? What if she lives in an area where ART is not yet available and thus would not be available to her partner either and disclosure to her partner would result in no perceivable health benefit for either of them, but would jeopardise her physical health or future security? What if she makes her living as a sex worker with no other feasible economic support options available locally? Should she tell all her clients she is living with HIV (although she could insist on condom use)? Should a woman who has just been raped tell the man who has raped her that she is living with HIV and then wait to see if he kills her? This is exactly what happened to Lorna Mlosana, a 21-year-old woman in Khayelitsha, South Africa, on 15 December 2003 when she was raped by two men who then killed her after she revealed her HIV-positive status to them (Carroll 2003: 1).

While a few of these situations may seem overly dramatic, they are real-life situations in the stigmatising environments where women who test positive for HIV in sub-Saharan Africa live (Colebunders *et al.* 2001: 625; Schuklenk and Kleinsmidt 2007: 1182). If they were truly equal to their male sex partners and had socio-economic options, many women might not have become infected with HIV in the first place—around the world (Farmer 2005: 166). Are many women in developing-world settings truly autonomous? Are they really "independent, free and self-directing," according to the *Webster's Dictionary* definition of autonomy (1959: 148)? Have they been educated enough to be autonomous? More significantly, have they been educated enough to be autonomous about their reproductive health decisions, including their virginity? Are they aware, which many Africans seem not to be, of the importance of using a condom if one has multiple sex partners? Are they knowledgeable about the importance of using a condom with anyone who has not tested negative for HIV recently (or was tested during 'the window period,' when a person's HIV antibodies may not have developed yet) even if this person seems trustworthy? Are they in a position even to suggest using a condom to their sex partner(s)? Are they in a position to say "no" to sex? Even if some women in developing countries are in a position to make these determinations rationally, do they really feel they are in the position and have the proper support to do so successfully in their relationships?

These questions relate to the essential currency of gender power relations in a very unequal environment more or less worldwide (Farmer 2005: 231). They are relevant to how such power relations play out ethically regarding HIV status in a climate of socio-economic disparity and gender violence (Abdool Karim 2005: 258, 275; Varga *et al.* 2005: 959; Orza 2006: 5). Recognition is growing of the developing-country conditions combining the social, cultural, and legal constraints on women that inhibit them from controlling their

lives, their basic human rights, and those of their children, which medical anthropologists call "structural violence" (Tuller 2007: 2; Farmer 2005: 230). Yet far too little is being done so far to address and rectify these conditions socially, economically and legally. What is more, if one examines the environments in which disclosure of HIV status seems to be expected by many health care practitioners of PLHIV, in these real life settings, ethics and ethical relationships are nowhere to be found.

How can a woman be expected to tell her partner, who is the sole support of herself and her children, that she is infected with a life-threatening and dreaded disease? He may blame her for the infection, as many do, cast her out, and refuse to support their children when he─himself─may have been the source of the HIV infection. Is it really 'ethical' to have to tell one's sex partner about one's own HIV infection if it endangers one's life and livelihood? And, if children are involved, such disclosure may endanger the future livelihoods of several individuals? According to Hobbes and Locke, self-preservation is more important in life and death circumstances than preventing harm to someone else. This author believes most people would agree with them, especially if disclosing one's HIV status could end in one's own death.

Relevant to the argument against disclosure of HIV status by a health care practitioner to a sex partner, if it has potential to do harm to the physician's patient, is that the physician's primary responsibility is the patient, not the patient's sex partner (Levinson *et al.* 1999: 1; Project of the ABIM Foundation *et al.* 2002: 244-245; Friedenberg 2000: 11; Beach *et al.* 2005: 1; HPCSA 2007: 2). This is a key concept related to patient care encompassing a variety of principles. What is most relevant here is the principle of confidentiality as well as primary loyalty to the practitioner's patient's needs. The long-held principle of

confidentiality in health care goes back to Hippocrates, as already noted, in his statement translated from his original Oath in Ancient Greek:

> "Whatever, in connection with my professional practice or not, in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret" (Hippocrates, trans. Adams 1849: 1).

Hippocrates did not modify the Oath by saying that divulging information is acceptable if it will save another person from infectious disease, in his other work, *Epidemics* (trans. Jones 1923). The human immunodeficiency virus (HIV) did not exist in 400 B.C. In his time, Hippocrates obviously did not have full knowledge of what can cause various infectious diseases. Yet he did note some characteristics about epidemics: their seasonality, i.e., weather conditions in relation to some infectious disease occurrences; other possible causes; the variety of symptoms they manifest; disease progression; the importance of the body ridding itself of the infection through body fluid expectoration or urination for improvement in some individuals; and, the possible causes of death when it occurred (trans. Adams 1849: 1-26). Importantly, Hippocrates noted the need for confidentiality of specific patient information that should not be shared with others. It is arguably likely he would have felt that patient information related to an STI requires protection of patient confidentiality. Indeed, it is hard to imagine what other types of illnesses he would have found the need to keep confidential more than the presence of an STI.

While this report has asked many questions, what is not in question is that medical knowledge has progressed vastly over the past 2,400 years since the time of Hippocrates. Yet the point is that some aspects of the ethical practice of medicine that Hippocrates held sacred so long ago are still held sacred today. Patient privacy and confidentiality are two of

them. Non-maleficence, or the Hippocratic tenet "first do no harm," is a third (Beauchamp and Childress 1994: 189). Beneficence or what Hippocrates referred to as "benefit of the sick" in the Oath is a fourth (trans. Adams 1849: 1). In a discussion of the bioethical principle of beneficence, Kass and Gielen (1998: 92) have defined it as the following:

> "…beneficence means that persons have the responsibility to do good for others, to prevent harm to others, or, at the very least, to avoid directly harming others. Beneficence also requires the balancing of harms and benefits that might result from a given policy to determine whether or not, on balance, the policy is beneficial."

In 1998 Kass and Gielen examined beneficence specifically in regard to the policy of contact tracing of the sex partners of women living with HIV in the USA. They questioned the beneficence of such a policy when its enforcement involved potential risks to such women, as well as possible benefits to their sex partners and society, if further infection could be prevented through the introduction and enforcement of such a policy (*ibid.*: 102). Yet even in a country with substantial health resources available such as the USA, they questioned the real value of contact tracing to reach the intended goal of HIV prevention. They wrote that, even in the USA, health resources were not infinite and, in their view, were actually "limited" (*ibid.*). They also emphasised that contact tracing had been useful as a disease control mechanism for gonorrhea in the USA, but not for syphilis. Both of these diseases are STIs. Yet syphilis is the more serious STI with greater similarity to HIV, another STI, including its lengthy latency period and its eventual cause of death without treatment. Obviously, a policy of contact tracing of sex partners over many years for a PLHIV, perhaps decades, as in the case of someone who has contracted syphilis, would involve very substantial human and financial resources. One wonders whether contact tracing in regard to HIV is even possible in most settings where the epidemic is rampant.

Gostin and Hodge (1998: 9-88) also examined the policy of partner notification related to HIV and other STIs in the USA in 1998 in regard to privacy and disclosure. They focused on a number of issues. Among them was that it has not been proven that partner notification by health care practitioners is actually a cost-effective HIV prevention policy related to public health and the common consequentialist goal of decreasing new infections (*ibid.*). Secondly, confidentiality is critically important as an ethical issue in partner notification programmes and, in fact, confidentiality cannot be assured in the implementation of such programmes (*ibid.*). Thirdly, partner notification may cause "more harm than good, especially as experienced by STD (STI)-positive women and other disadvantaged persons who may suffer mental and physical harm, societal discrimination, and personal economic ruin" as the index patients upon whom the implementation of the policy will be based (*ibid.*: 82). Fourthly, the degree of positive behavioural impact of partner notification on the individuals at risk of HIV infection is not clear (*ibid.*: 76; Pinkerton and Galletly 2007: 1). Finally, implementing partner notification as a public health strategy may have a harmful impact on the number of people presenting for HIV and other STI testing because of their fear of such notification (Gostin and Hodge 1998: 82).

According to a physician in Botswana who treats many PLHIV, she would not disclose a patient's HIV status to a sex partner. She said she would consider it to be an invasion of the patient's privacy. Further, she said she did not know any physician in Botswana who would do so for the same reason (Cavric 2008: personal communication). The physician has been treating patients in the country's capital for some 20 years, including PLHIV, and she has a wide network of medical colleagues in the country. Moreover, according to a

Physicians for Human Rights report in 2007, nearly one in three men and women in Botswana believed that testing positive for HIV and disclosing their status to their partner would result in the break-up of their marriage or relationship (2). Surely, the views of these individuals reflect the real environment in the country, and they deserve professional and personal respect.

A policy, and even the very idea, that notification of a patient's sex partner in South Africa, or in other countries in southern Africa, should be a decision and action taken by a patient's health care practitioner when the patient does not disclose himself or herself seems open to question in the present hostile environment. At the very least, taking such an action remains controversial. Moreover, the current HPCSA guidelines on disclosure do not suggest that there would be much support from the health care community for such a policy if it were developed for practitioners in South Africa in the near future.

Proof that partner notification actually works to prevent HIV transmission in South Africa or elsewhere does not exist. Such a fact already has been pointed out by a number of legal and public health scholars and mentioned above. Also, partner notification runs against the bioethical principle of non-maleficence if any harm should come to the patient related to the physician's disclosure of his or her HIV status. There is no way of assuring this will not be the case, as previously discussed, either through abuse by the patient's partner or from other members of the community if confidentiality is not maintained (Sokol 2005: 5). Indeed, there is no way to assure confidentiality. Berg even proposed in regard to such disclosure in the USA in 2006, "Whether the societal balance of disclosure versus confidentiality is correctly decided on a system level may need to be re-evaluated" (25). Berg was focusing not only on the benefit or 'good' related to disclosure to one individual

such as the patient's sex partner, but also on whether disclosure is a 'good' regarding public health in general.

Some professionals, such as Frieden *et al.,* have written in support of partner notification specifically regarding the HIV epidemic in the USA for public health purposes. They have stated that it is more important to protect the public rather than individual patient rights (Frieden *et al.* 2005: 2399-2400). Yet at the same time they admitted that the more standard HIV prevention approaches such as using condoms for safe sex, lowering one's number of sex partners, using clean needles, accessing voluntary HIV counselling and testing, and linking to psychosocial care still are not practised widely enough to make a difference in the continuing epidemic—despite the ability of these strategies to prevent HIV infections.

What has been recognised over the last several years since HIV treatment has become more widely available, including in some developing countries, is that enough emphasis and resources have not been mobilised by public health systems on the importance of preventing HIV transmission. Much greater efforts are needed in 2009 and beyond toward instilling better understanding and much wider implementation of interventions that will change the relevant individual behaviours and cultural and societal norms that inhibit HIV prevention attitudes and practices. Such interventions need to be implemented as widely as possible both to be effective and to be taken over by communities and nations as their own sustainable initiatives to protect their populations from further epidemic spread.

Finally, in examining disclosure of HIV status against the bioethical principle of justice, the notion of contact tracing for public health purposes related to HIV epidemics in

developing countries becomes particularly questionable. The issue of justice relates to the use of limited health resources, according to the definition by Beauchamp and Childress of it as "…a group of norms for distributing benefits, risks and costs fairly" (2001: 12). But attempting contact tracing in a country with already seriously limited health resources, especially human resources, seems as if it should be relegated to the very back burner of potentially useful interventions regarding HIV prevention. Four public health and legal scholars, as noted above, questioned the cost-effectiveness of partner notification in 1998 in the USA, partly based on that country's limited resources available for health. Moreover, bioethical experts Beauchamp and Childress also questioned the efficacy of partner notification as a public health strategy in regard to syphilis and AIDS in 1994 because of the latency period that occurs in both diseases (1994: 429).

A systematic review of partner notification performed in the USA found 1% to 8% of people exposed to HIV who subsequently tested HIV-positive were identified through partner notification (Hogben *et al.* 2007: S89). The figure of 8% is a relatively high percentage of former sex partners testing HIV-positive in the USA, where 0.47% of the total population is estimated to be HIV-infected (CDC 2008). Whether the lower percentages in the 1% to 8% range validate the level of resources used for partner notification, as the total expenditure involved is not known, is open to conjecture. The systematic review did not show that partner notification "was also effective in changing behavior or reducing HIV transmission" (Hogben *et al., ibid.*). By contrast with the USA, South Africa had an estimated 17% of adults living with HIV in 2007, with 39% of pregnant women in KwaZulu Natal testing HIV-positive in 2006 (WHO 2008: 5, 7). The potential usefulness and the level of resources required for partner notification in African

countries with high HIV-prevalence rates do not support its implementation, in addition to the ethical difficulties that would be involved.

Of special relevance is that in many African countries, including South Africa, having multiple concurrent sex partners is common and continues to fuel the HIV epidemic (SADC 2006: 5). Yet the number of sex partners one has, as well as their identities, is highly confidential in African countries. This circumstance makes contact tracing in regard to HIV exposure in Africa potentially even more complicated than it might be in other settings. Thus the resources involved in trying to find the sex partners of all individuals testing positive for HIV in high-prevalence countries, when funds for health care are already very limited, could be both prohibitive and culturally unacceptable.

One could also question whether a policy of partner notification is actually discriminatory toward individuals who test HIV-positive and do not disclose to their partners who are married or living with a sex partner. Obviously, it would be much easier for a health care practitioner to locate one partner to give such notification—the spouse or live-in partner—than it would be to locate one or more sex partners of someone who is not living with a sex partner.

Justice, however, also needs to be considered regarding HIV disclosure in its normal frame of reference. Justice is "…the constant and perpetual disposition of legal matters or disputes to render every man his due," using the definition in *Black's Law Dictionary* (Gibson 2006: 24). This approach to justice takes into account the need to balance the rights of the health care practitioner's patient with the rights of the person his or her patient may have infected with HIV, or could infect in the future. Certainly, it seems that it would

be just for a sex partner to learn of his or her possible exposure to HIV infection and take future precautions against it, and be tested for HIV and potentially gain access to ART, if needed. This fundamental juxtaposition of rights and the decision about the potential disclosure required currently falls onto the shoulders of the health care practitioner when the patient will not disclose his or her HIV status to his or her partner. Such a predicament for a physician would be considered an ethical quandary (Bayer and Toomey 1992: 1163).

As previously summarised herein, for health care providers considering partner notification or disclosure to a patient's sex partner, clearly the determination must be made on an individual basis involving a multiplicity of factors. Indeed, it is not a casual decision. However, the health care provider needs to keep in mind that it will be a causal action that will have significant effects. It is not neutral. It will have an impact, either for the most part, positive, or for the most part, negative, in the future. In addition to the ethical responsibilities involved in health care practitioners making such determinations, moral and legal responsibilities exist. In fact, the HPCSA guidelines impose the full weight and all potential ramifications of disclosure by health care practitioners solely on their shoulders, as well as potentially into their pocketbooks. Weighing both their responsibilities and the potential impacts of their actions needs to be done very carefully by health care practitioners to achieve a just outcome even when their available resources might seem unlimited.

Where there is no cause for concern about potential harm to the physician's patient and the resources are available to the physician to pursue it, notification appears to be justified ethically. However, it is difficult to foresee a situation where there would be no concern about potential harm occurring from notification, and the patient himself or herself would

not already have agreed to undertake partner disclosure or be able to be convinced of this necessity. If a minor is involved, though, the situation clearly becomes more complicated. But even so, caution should be taken by the physician in deliberating all the possible ramifications of a decision to undertake partner notification to be as comprehensive as can be imagined. If a patient's fear is so prominent to the physician as s/he deliberates whether or not to disclose the patient's HIV-positive status to his or her sex partner, there must be one or more reasons for it, assuming the patient is competent.

Also what is important for health care practitioners to remember regarding disclosure is the need for balancing non-maleficence toward one's patient with beneficence to a patient's sex partner (or injecting drug use partner). A number of the issues involved in a physician's deliberation about the options and the consequent determination have been mentioned previously in this report. Yet it needs to be reiterated that physicians should look at the whole picture, as they know it, in regard to the patient. They need to do so very carefully to be in a position to make a just and equitable decision about whether to follow up with partner notification in the case of HIV infection, as well as to protect their own position if they choose the disclosure route. Making the ultimate determination involves weighing conflicting ethical responsibilities (Klitzman 2006: 26).

Clearly, more direct HIV prevention interventions are called for than contact tracing in countries with high HIV prevalence rates. The interventions include, but are not limited to: instilling the essentiality of condom use if one has multiple concurrent sexual partnerships; regular HIV counselling and testing if one is sexually active; and, widespread access to prevention of mother-to-child transmission (PMTCT) programmes. It seems to be time to question whether a policy of patient notification would really be useful in South Africa and

other countries with high HIV prevalence rates for the reasons mentioned above, and because of the need for greater coverage and uptake of interventions that are proven to prevent HIV transmission amidst limited human and financial health resources.

As implied herein, health care practitioners must consider their ethical responsibilities about a specific patient living within a specific environment to make an adequate determination about the potential outcomes of any decision they make regarding disclosure of HIV status. Obviously the same approach holds true for PLHIV themselves, and should be central in their decision-making about whether to tell, whom to tell and when to tell. One also needs to bear in mind that the resources of many PLHIV are extremely limited, while at the same time they are facing the ultimate limitation: the number of years they will live. To quote from Edwin Cameron in his thoughtful and incisive book, *Witness to AIDS:*

> "…millions of South Africans living with HIV or AIDS…have no jobs, or their jobs would be at risk if they spoke about their HIV. They not only lack community support, but face grave danger if they do so. And, most importantly, they do not have access to proper medical care and treatment. For them, in a still hostile climate, the choices are strictly limited. Their right to invoke confidentiality remains of critical importance to them" (2005: 62).

Until the hostile climate toward HIV and PLHIV changes in sub-Saharan Africa, it seems illogical and unjust to deny these people their right to life by ethically demanding they disclose their HIV status when doing so could put their lives at stake. Moreover, to consider the legality of demanding disclosure of HIV status in such an environment, the statement of two of the foremost legal scholars again comes to mind: "…the protection of society must come mainly through the recognition of the rights of the individual" (Warren

and Brandeis 1890: 11). South Africa's Constitutional Court also has focused on the right to privacy in the following relevant quote from the *Bernstein v Bester* decision in 1996:

> "A very high level of protection is given to the individual's intimate personal sphere of life and the maintenance of its basic preconditions and there is a final untouchable sphere of human freedom that is beyond interference from any public authority. So much so that, in respect to the intimate core of privacy, no justifiable limitation thereof can take place" (*Bernstein v Bester*: 793-794).

This chapter has examined the rights to privacy, beneficence, non-maleficence, and justice in regard to HIV disclosure by PLHIV as well as health care practitioners. It has emphasised that social justice regarding PLHIV in sub-Saharan Africa has to be kept foremost in mind by individuals and health care practitioners. Indeed, the individual situations of PLHIV in a resource-limited environment have central relevance to decisions around disclosure. Moreover, disclosure decisions must be made within the existing highly stigmatised environment toward PLHIV, with women on the bottom rung of the socio-economic ladder in sub-Saharan Africa. The extent of domestic violence and violence toward women, especially in South Africa, is central to the disclosure decisions of female PLHIV. Abandonment runs a close second in concerns female PLHIV have about disclosure based on their low socio-economic status and extremely limited opportunities. The chapter also has examined a number of guidelines for health care practitioners related to the disclosure of HIV status. Among the guidelines included, the recent HPCSA guidelines stand out. They recognise the fundamental importance of the South African environment to decisions of health care practitioners about partner notification. Thus they support the real difficulty anyone encounters when making disclosure decisions in a highly

stigmatised and indeed violent environment. By citing various examples, the chapter asserts that individual circumstances do play a role in ethical decision-making, and they must. Not only should the ethical rights of PLHIV be considered within the overall framework of human rights, but they need to be considered holistically in regard to individuals, looking at the whole picture that is relevant to disclosure decisions about HIV-positive status.

This work has shown that the right to life and thus self-preservation is a basic human right. Indeed, it is the most basic. If anyone considers himself or herself to be in a position to flout this right of another, taking full responsibility for doing so is a necessity. Such responsibility is supported by the HPCSA professional guidelines regarding HIV disclosure. Thus the right not to tell one's HIV positive status if one's life might be at stake in doing so seems to be a basic right that should be assured. Assuring greater protection or perceiving the ownership of a more fundamental right for a sex partner, which some espouse, does not seem equitable or just. Making a decision that will potentially result in life or death circumstances is thus a decision that should be left to the individuals involved. Medical ethics supports autonomous decision-making currently and going back to the time of Hippocrates. Autonomy should not be discarded in regard to HIV disclosure decisions, despite the wish to protect as many as possible from infection. The concluding chapter reviews a number of the arguments made previously in the report. It also discusses a few of the next steps that are necessary to help the environment surrounding HIV to become less hostile and more open and supportive of PLHIV and individual decisions surrounding disclosure. It also aims to provide further understanding of what some of the present needs of PLHIV, which continue to be unacknowledged, overlooked, or misunderstood by the health care community and even some ethicists.

Chapter 6: Conclusion

This chapter brings the argument to a close regarding the ethics surrounding disclosing HIV-positive status in environments where the individual rights of PLHIV are being challenged on a daily basis. When such disclosure can result in social abandonment and community ostracism, and indeed physical violence or even death, it seems unjust to demand that PLHIV disclose their HIV status. Surely, saving one's own life cannot be considered unethical. Various societal changes are needed, as well as more equitable social norms, before PLHIV can be expected to be more open about their HIV status than they are now. In environments of significant inequity, social rights and social justice have to be perceived as part of ethical decision-making (De Negri Filho 2008: 97).

It must be kept in mind that philosophical discussions of ethics and moral principles by contemporary philosophers focus on the moral obligations of individuals when they do not have to sacrifice anything of comparable value to provide support to another individual (Singer 1973: 229). Moreover, the right to life is recognized as a natural or 'foundational right' and is more weighty than other rights (Cooney 1998: 877). Thus the duty to self and the obligations to others have to be weighed rationally when deciding whether or not to disclose to a previously violent partner, or to a community member in a largely hostile environment. In some cases, one's life or security may hang in the balance. In these cases, the scales of justice, as well as the principle of respect for autonomy, seem clearly weighted in favour of self-preservation and protection of the individual rights and dignity of PLHIV.

Where disclosure of HIV-positive status poses no personal danger or potential loss of future security, the ethical choice is indeed disclosure. However, PLHIV should be allowed time to reach this determination, which some guidelines suggest. Clearly, there are benefits to disclosure; most importantly, to be able to access life-saving ART. Yet the availability of ART, as outlined previously, has not led to a decrease in stigma toward, and discrimination against, PLHIV. Hence, attention must be focused on learning how to decrease stigma and discrimination surrounding HIV for a variety of reasons, including building the potential for greater disclosure of positive status by PLHIV. People cannot be expected to put their own lives at stake in hostile environments simply to help others to recognise their health risks. This is too much to ask of people who have very little, all of which they may lose through such an action. Moreover, there is enough information circulating in sub-Saharan Africa about HIV/AIDS to ensure that a lack of awareness of the epidemic generally is not the main barrier to practising preventive behaviours (Cohen *et al.* 2008: 1244; Kibombo, Neema and Ahmed 2007: 2, 6, 7).

Keeping private information confidential and practising beneficence, non-maleficence, and justice are not ethical principles that should be regarded as unique to health care providers. Everyone should be practising these principles or virtues in their daily lives while simultaneously respecting the dignity of other human beings and their autonomy to make their own decisions. Yet the ethics surrounding the issue of disclosure of HIV status in environments that are quite hostile to PLHIV are complex, as this report has described. Many of the individual rights of PLHIV are challenged at present in these environments, including countries across sub-Saharan Africa. Such atmospheres of intense stigma toward, and discrimination against, PLHIV breed fear and anger in people who are not infected with HIV against people who are infected. Such antipathy also magnifies the inner turmoil,

feelings of disgrace, and sense of otherness from society that PLHIV feel. People living with HIV in hostile environments are well aware of the potential for social abandonment if they disclose their status simply because such abandonment has happened to many others.

Because of the present widespread stigma toward, and discrimination against, PLHIV, this report has addressed how central these hostile conditions are to PLHIV in making decisions about disclosure. To some PLHIV in developed countries the importance of disclosure impacts seems to diminish over time, especially as these people become ill and need support and care from others (Klitzman *et al.* 2004: 629). Yet as previously discussed, many Africans do not disclose even when they are on their deathbeds because of the atmosphere of shame and hostility surrounding HIV that continues to be the norm in sub-Saharan Africa. In Botswana, according to Edwin Cameron, people do not disclose:

> "…because they fear they will be identified as having AIDS. So they postpone it for as long as possible. They fall sick first. Even then they delay. They eventually go and stand in the clinic's queues. But mostly they do so only when they are approaching the point of death" (2002: 67).

The continuing stigma and discrimination surrounding this life-threatening disease must be curtailed with far greater efforts across society to increase an understanding of the need to embrace those who are ill, rather than make them believe they are outcasts (Gluckman 2002: 27; Parsons *et al.* 2004: 459; Kang *et al.* 2005: 145; Serovich *et al.* 2006: 1; Kumar *et al.* 2007: 89). Changing the negative atmosphere surrounding HIV will enable more PLHIV to receive better treatment in general, including life-saving medical treatment. Moreover, countries must work harder collectively and individually in health care and across society to prevent more people from becoming infected with the virus in the first

place. People infected with HIV need much more psychosocial support and access to a range of social services. Unfortunately, these services are not common in sub-Saharan Africa to date.

To change the environment surrounding HIV especially for women, significant progress also will be needed on gender equality. The legislation and enforcement of better policies to decrease the various vulnerabilities that place so many, particularly women, at increased risk of HIV infection need special attention in nearly every country, especially in sub-Saharan Africa. While gains have been made in decreasing HIV prevalence rates through government leadership and increasing HIV prevention interventions in a few countries, most notably Uganda in the late 1980s and early 1990s, the gains have been reversed in some countries for a variety of reasons, including Uganda (Stoneburner and Low-Beer 2004: 714). The reverses seem to be partly due to the lack of sustained attention societally, and in the upper echelons of government, on the need for HIV prevention to be practised and fostered as a social norm, as well as common access to prevention methods and services (UN 2005: 3). Another key factor regarding a growth in HIV prevalence rates in countries that were making strides ten years ago, including some developed countries, is that younger people over the last several years have not witnessed the deaths of so many of their community members since ART has become more widely available (Kershaw 2008: 3). Further, some young people feel that the availability of ART has made becoming infected with HIV a less serious condition (*ibid.*). Yet as discussed previously, the availability of ART does not seem to have had an impact on stigma and discrimination (*ibid.*; UNAIDS and WHO 2005: 9, 10). Thus disclosure rates appear not to have been affected by ART, nor possibly by the greater accessibility of HIV counselling and testing

interventions in sub-Saharan Africa. In consequence, stigma and discrimination really stand out as significant ongoing hurdles to wider disclosure of HIV status.

Whether someone lives in an environment of intense stigma toward and discrimination against PLHIV or not, each individual PLHIV must decide whether or not to disclose his or her HIV-positive status, and if so, to whom, when, where, and how. Personal ethics are at play as well as each person's interpersonal, familial, and social relationships, and the economic, cultural, political and geographic environment in which the individual lives (Parsons *et al.* 2004: 459; Sullivan 2005: 43). Others can be helped to disclose positive HIV status, or health care practitioners can disclose for them when this is deemed necessary and without risking harm to them. But, one cannot force PLHIV to disclose. Indeed, society must work harder to make the overall environment more receptive to and supportive of positive disclosure. Doing so will help to even the balance from disclosure decisions currently being too profoundly influenced by an external environment riddled with fear to one of compassion and support.

People living with HIV desperately need conducive conditions in which to live full, happy, and productive lives in spite of their illness. Until the external environment surrounding HIV changes, there is no reason to expect that the internal environments of those living with HIV─intensely felt stigma and discrimination─will change in any substantial way. In the meantime, harder work is essential both to prevent, as well as protect, PLHIV from further suffering beyond that caused by the disease itself.

Disclosure to sex partners by PLHIV is seen by many as essential and the only ethically correct thing to do. This paper has delved into situations where disclosure of HIV status to

a sex partner can, however, endanger someone's life and thus may not be the essential ethical choice balanced against the person's right to survive. Thus to this author, the ethics surrounding disclosure of positive HIV status vary depending on an individual's situation within the larger contextual environment. Nonetheless, disclosure of positive HIV status can result in significant benefits. Disclosure of HIV status has the potential to improve personal well-being when assistance, including emotional support, is provided by others (*ibid.*: 45). Disclosure to sex partners living with HIV helps them protect themselves from re-infection with HIV or secondary STIs, which will make their own HIV infection status worse (Crepaz and Marks 2003: 379). Disclosing positive HIV status to health providers enables access to HIV treatment, which will make the difference between life and death when a PLHIV has reached the point of requiring ART for survival (Sankar and Jones 2005: 2378). Some health professionals believe that ART can extend the life spans of PLHIV perhaps even to a normal length (Janssen *et al.* 2001: 2-3). Disclosure of positive HIV status to health care practitioners also will help them to provide the best possible care. Even disclosing one's status after one already is seriously ill with AIDS is helpful for partners and family members to be able to protect themselves from infection in personal care situations of late-stage AIDS illness, and for children to help them prepare for a parent's eventual death (Myer *et al.* 2006: 2).

Yet despite the benefits of disclosure of positive HIV status, such disclosure may not be as important a public health intervention for preventing HIV infection on the population level as many have believed, as reflected earlier (Marks *et al.* 1991: 1321; Ciccarone *et al.* 2003: 2). Simoni and Pantaleone have shown through their research among PLHIV in the USA that "…although information about a partner's HIV serostatus may play a role in one's choices about safer sex, disclosure alone does not automatically lead to safer sex in the

way one might presume" (2004: 117). The same results also were found in a study by Hart *et al.* (2005: 155). What is more important for PLHIV to do ethically than to disclose their positive HIV status to sex partners is to discuss the absolute need for safer sex, assuming this will not result in harm, whether or not they choose to disclose their status (Crepaz and Marks 2003: 379). Obviously, PLHIV should always use condoms with their sex partners if condoms are accessible (Chalmers 2002: 6). Indeed, condom use is the most important point for communication and action, if needed, by PLHIV with their sex partners who are HIV-negative. However, the consistent and proper use of condoms with sex partners who are living with HIV also is essential. Condom use when one's own HIV status may be in question, or with partners whose status is unknown, also should be the norm.

The reasons why many women are not in a position even to broach the subject of safer sex with their spouses and partners, whether they are living with HIV or not, have already been explored in this report. Continuing gender inequity, especially in sub-Saharan Africa where more women than men are infected with HIV, has to be taken very seriously regarding the danger of disclosure of positive HIV status (UNAIDS 2007: 8; Schuklenk and Kleinsmidt 2007: 1192). Such gender inequity and its overriding impact on the HIV epidemic, women's vulnerability, and fears related to disclosure and gender-based violence are crucial motivations for bolstering the need further to open up the societal and interpersonal dialogue about HIV in general. To start to address this situation, it is essential to challenge and indeed to overcome the serious stigma and discrimination surrounding the disease. While some health professionals working in the field recognise that "we know little about how to reduce stigma and violence," it is imperative to start trying to do so more than we have done to date (Mills 2002: 1).

When the HIV stigma and discrimination paradigm changes, disclosure about positive HIV status will become easier. When the environment becomes less hostile to PLHIV, the ethics behind making disclosure decisions will become more clear to all those involved, especially PLHIV. Indeed, when the attitude toward and environment around PLHIV become more open and supportive, more lives will be saved. At that point more PLHIV will go for HIV counselling and testing, especially men, and will likely practise more health-seeking behaviours rather than risk behaviours. More individuals who need it will access ART. Thus more people living with the virus will be better able to become more productive, live longer, and hopefully enjoy happier lives. But more lives will not be saved, and the choices about disclosure will not become ethically easier to make based on greater openness about disclosure, but about HIV itself.

End Note

The recent study by Wong *et al.,* cited on page 46, is very important and the first of its kind in South Africa. Most participants in the study eventually disclosed their positive HIV status to someone, which some other studies in African countries did not document. However, the average length of time it took those who disclosed to a sex partner was 16 months. Moreover, 36% of the study participants did not disclose their positive status to their sex partners, which emphasises the continuing difficulty surrounding disclosure to sex partners in South Africa. In fact, 13% of the participants reported they never disclosed their HIV-positive status to anyone, which is consistent with some other research results in the USA, where most of the research on disclosure has been conducted. The study also reported that the sex partners of those who disclosed were more likely to decrease their social support for the HIV-positive individual, with spouses decreasing support by 25%, and boy/girlfriends by 11%. These outcomes show that disclosure to sex partners can have a negative impact, even if it does not result in rejection, abandonment, or violence. The researchers made several points that already were reflected in my research report based on other research studies and my previous recommendations. Among them include the following quotes from the Sowetan and Vulindlela study researchers: “HIV interventions that are encouraging disclosure must recognize the potential stigmatizing cost of disclosure and help prepare HIV-positive individuals to cope with any negative consequences.” The researchers also noted, “The decision to disclose one’s HIV diagnosis is a difficult and often stressful process because the potential costs of disclosure, such as social stigma and burden on others, must be weighed against potential benefits, such as social support and reduced risky sexual behavior.” The researchers’ final sentence also echoes two points made in my research report, “As the HIV epidemic continues to rise in the South Africa population, it will become all the more important to develop effective interventions to

assist HIV-positive individuals in disease disclosure decisions and sexual risk reduction." It is important to note that the researchers did not suggest future interventions to help all HIV-positive individuals to disclose, but to help them make their disclosure decisions, emphasising that these are decisions have to be made by the individuals themselves. Also, the individuals who did not disclose in the Sowetan and Vulindlelan study were younger than those who did, had lower socioeconomic assets, and had not known their positive status for as long as those who disclosed. The latter two of these issues were included in my report as common reasons for non-disclosure in many settings. The results from the study support that non-disclosure of positive HIV status to sex partners can be relatively high, with more than 1 in 3 individuals not disclosing. Importantly, the study results provide new information about the disclosure situation in two communities in South Africa, while its findings are largely consistent with similar findings by other researchers in other countries, as cited in my report.

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