



To Disclose Or Not To Disclose: The Moral Complexities of Hiv Status Disclosure In Southern Africa

Christopher A. B. Zigira

University Of Swaziland

Private Bag 4

Kwaluseni

Email: Zigira@Uniswacc.Uniswa.Sz

Abstract

Residual mass ignorance and various degrees of denial that still surround HIV/AIDS and the associated stigma make it difficult for people either suffering or suspected to be suffering from the opportunistic infections related with HIV to go for testing and when they do to accept and disclose their status and seek the necessary psychosocial and medical support. Consequently there are people, some of whom are in lifelong marital relationship, who have (either due to lack of testing or disclosure of their seropositivity) passed on the virus to their partners and unwittingly to some of their children and thereby contributed to the geometric progression in the onward march of HIV pandemic. As a result, there has been close to a tenfold increase in the rate of infection in Swaziland, within the most productive segment of population, from 3.9 percent in 1992 to 38.6 percent in 2003, predominantly due to lack of testing and disclosure of one's HIV-status, which factor (in combination with other variables) has exacerbated the problem of HIV/AIDS. This paper examines the moral complexities of HIV seropositive status disclosure and argues that personal voluntary disclosure is essential in the fight against the spread of HIV infections.

Introduction

On the 4th of February 1989, a baby was born HIV positive. Two years later the child had developed full-blown AIDS and medical doctors suggested that he had only nine months to live. But this child lived up to twelve years. Adopted by Gail Johnson, in 1991, the child became the famous Nkosi Johnson who fought against all odds to be "the voice of a generation orphaned by HIV/AIDS", a generation which through no fault of their own have been and will be born with the virus that causes AIDS in their blood stream, or if they are born virus-free may lose their parents to the virus and grow

up in a society which is ill-prepared to receive, love and care for them. Many of us might have heard of and seen a frail Nkosi Johnson, on the small screen, who made a famous speech at the World AIDS Conference in Durban (July 2000) and later at the International AIDS Conference held in Atlanta, Georgia (October 2000). At the Durban Conference, he haltingly made a moving appeal for love, care and compassion. In his own words: "Care for us and accept us, we are all human beings. We are normal. We have hands. We have feet. We can walk, we can talk, we have needs just like everyone else – do not be afraid of us – we are all the same" (UNDP News, 4 June 2001). And he urged governments to provide treatment for expecting mothers with the virus so that their babies may be born without the virus.

In spite of Nkosi Johnson's plea, four years ago, it is estimated that over 60 000 babies per annum are born with the virus in their blood and in all probability destined to die before the age of 5, and it is practical logic that many thousands of HIV negative children are bound to live as orphans after their parents have fallen victim to the virus. Let us tarry and remind ourselves that the life of Nkosi Johnson was a life filled with stigma, sickness, pain and suffering, which included brain-damage, loss of consciousness and untimely death at the age of 12. Besides, he was an orphan (whose biological mother died in April 1997 of the virus that she contracted during a rape ordeal). He had experienced extreme prejudice while "living with a disease which many of his fellow citizens were still too scared to talk about". (*Southern Cross*, June 2002).

But why, in spite of public testimonies by people like Nkosi Johnson, has the virus continued to spread? Let us remind ourselves of the recent statistics. According to the UNAIDS 2004 Report on Global AIDS Epidemic, 39.4 million people were living with the virus and that 2.3 million had died of AIDS in 2003 (UNAIDS Fact sheet, 2004). According to the UN Integrated Regional Information Network (IRIN), HIV/AIDS was exacting a devastating toll in Southern Africa (IRIN, 22 December 2004). Similarly, the UNAIDS Report (2004) further showed that "Women (were) increasingly affected by HIV and make nearly half of the 37.2 million people living with HIV-worldwide. In sub-Saharan Africa, almost 60 percent of adults living with HIV were women" (UNAIDS, 2004). In Botswana, Lesotho and

Swaziland, the ante-natal clinics surveillance of mothers showed an infection rate in excess of 30 percent.

The statistics for Swaziland make a sober reading. The USAID Country profile on HIV/AIDS notes that “the Swaziland HIV/AIDS prevalence rate of 38.6 percent is the second in the world... The epidemic has affected the small kingdom in dramatic ways. Approximately 50 000 children have lost one or both parents as a result of AIDS, and 60 percent of hospital admissions are due to HIV/AIDS - related illnesses. The majority of deaths occur among young people aged 15-49, the nation’s most productive segment” (USAID, 2004). The estimated number of adults (15-49) living with HIV, at the end of 2003 was 200 000 person (in a population of 1 110 000 which gives a yield of 18 percent of the national population) and an estimated number of 1700 deaths (*Swazi News*, 18 December 2004).

The high incidence of HIV infection in sub-Saharan Africa prompted the United States Secretary of State, Collin Powell, during his visit to Africa, in May 2001, to use the analogy of war, when he said: “There is no war that is more serious, there is no war that is causing more death and destruction, there is no war on the face of the earth right now that is more serious, that is more grave, than the war we see...in the Sub-Saharan Africa against HIV/AIDS” (cited by Dobriansky, 22 June 2001). Nonetheless every country in Sub-Saharan Africa and Southern Africa in particular, has launched programmes aimed at stemming the spread of the virus that causes AIDS. In Swaziland, His Majesty King Mswati III declared HIV/AIDS a national disaster and a number of agencies (NERCHA, TASK, SHAPE, SNAP, FLAS, PSI, Red Cross, SASO, SWANASO) are actively engaged in prevention education, information and promoting awareness of the HIV epidemic throughout the country. There are also other interested civil organizations like the churches¹, non-governmental organizations, which have joined the parastatal agencies in the enormous task of sensitizing the young people towards behavioural change. No doubt most of the population living in Swaziland and other SADC countries will have heard about HIV/AIDS but as the saying goes “Things will get worse before they can get better” and behavioural change (while the key factor in controlling the spread of AIDS) will not be realized more quickly than has been the case unless the moral dilemma surrounding HIV status disclosure has

been resolved. The key to behavioural change, it would appear to me, lies in HIV testing and disclosure but this has thus far been constrained by residual denial, stigma and secrecy.

Consider the following scenarios. Allow me to begin with an imaginary Ligugu, a happily married man, to a faithful wife. He has been employed for ten years by Anglo-American or Debswana mining conglomerate, but his loving wife stays in the peri-urban area of Manzini, or Maseru. During his stay at the mining compound, Ligugu cohabits with a female companion. However, it has been rumoured that the “comfort woman” has recently lost a close male buddy to HIV. On his death, she was counselled and advised to take an HIV test and she tested positive. She however did not disclose her status to Ligugu. During the Christmas and New Year festive season, the mining industry closes for two weeks. Ligugu did a lot of shopping for the home-coming. The spirit of Christmas hangs in the air. However, lest we lose the plot, the mining industry carried out a comprehensive survey of HIV prevalence amongst its employes, using the Saliva Test, on anonymous basis, and found (on basis of the numbered test-tubes) that Ligugu was one of the employees who were HIV positive. The tragedy is that the company cannot disclose the results. Moreover, Ligugu does not look sick and so when he finally came home, he was the ‘Father Christmas’ in all respects. The celebrations began. However, it is not all rosy. It is a complex situation in which only two parties (the company and companion) hold vital information which could have been useful in the prevention of the virus to Ligugu’s wife.

Or look at the case of Ogaba, a progressive high school teacher. Through the help of a business magnate, Ogaba has risen from being a poorly paid teacher to a businessman. He has had a thriving business in form of an hotel dubbed “Half-London”. Business has been lucrative and he has married two wives to match his new social status. Besides the hotel, he has gradually bought a fleet of long distance kombis and is an agent of an international franchise. Consequently, his life has been fast and hectic but he has begun to suffer from frequent bouts of fever and coughs. He has received the best treatment available without any noticeable change in his health condition. His doctor has finally persuaded him to take an HIV test and the test has confirmed he is HIV positive. He has consulted his

lawyers and drawn a will and has decided to go on a retreat at Bali island, in Indonesia. While there, he has arranged for himself the company of a female consort with whom he had intimate sexual relationship. He has however not disclosed his seropositive status to the wives nor his new companion. In the meantime, a sociogram of HIV infection is in the making.

The sociogram of HIV-infection is a network of all persons who have had sexual relationship with a common denominator of an infected person. Often the radius of the sociogram extends through some of those persons and the network widens. Recently, the *Times of Swaziland* (12 December 2004) carried an interesting story of a "Lawyer Scouting for a Holiday Mate". The lawyer, whether real or fictitious, invited eligible women to tender for a dream Christmas holiday. The applicants were to send SMS and a closing date was given. They had to meet a number of criteria: explain their interest, list all previous male friends with whom they were intimately involved, and noted that any one who had "previously slept with him stood a better chance". Although we might never know who won the dream holiday, the story exposes ignorance and a degree of reckless behaviour by the man. It is possible, the story was a prank by a phantom lawyer or a desperate attempt by a genuine seeker but the historical era in which we live today would require far more prudence than was reported.

VOLUNTARY COUNSELLING AND TESTING

In an address to the CSIS Task Force and the Washington Ambassadorial Corps, on 30 November, 2004, Ambassador L.C. Lekoa of Botswana reported that Botswana had, since January 2004 introduced routine HIV testing at antenatal clinics and STD clinics but that they were not compulsory. Anyone who chose to be tested was counselled before testing, tested and counselled after testing. According to him, "The people of Botswana have embraced routine HIV testing. Substantial increases in HIV testing, particularly by pregnant women were observed at various government sites nationwide. Between April and June 2004, a total of 11783 people were tested for HIV at public facilities. 3627 were male and 8156 female. A total of 5473 tested HIV positive, 1757 were male and 3716 female" (Lekoa, 2004). The benefits of routine testing in Botswana had been enhanced enrolment for access to HIV treatment and psychological support. However, it can be argued

that while testing shows that people are overcoming stigma, there was no evidence available to show that all the people who were found to be HIV positive had disclosed their status (although it must be noted that disclosure was not the focus of the Ambassador's address).

Similarly, the call for voluntary counselling and HIV testing in Swaziland has been loud although counseling the response has been lukewarm in spite of some high profile public testing by some religious and cabinet ministers. Even then their results remain confidential with exception of a handful results which were made public through the media. However, James Hall (2002) has documented the stories of twenty-three people living with HIV/AIDS in Swaziland. An analysis of their testimony shows that they had all tested positive for the virus but only 40 percent had declared their status either publicly or partially to some confidants. Sixty percent had not disclosed their seropositive status yet some of them had known their status for the last three years. This has unfortunately been the pattern even amongst those who had eventually declared publicly; some of them had lived with the secret for up to four years and the disclosure had been gradual: from a trusted aunt, mother, spouse to family elders, church leaders and finally to the media. The dominant thinking has however been that "in Swaziland, it is a taboo to acknowledge that you are HIV positive" (*IRIN News*, 23 December 2004).

REASONS FOR NON-DISCLOSURE

There are a number of reasons why people choose not to disclose their status. The most crucial factor for non-disclosure of a person's HIV status is the right to privacy which is universally recognized as a human right. The right to privacy means that only the person who has tested positive for the virus (not his counsellors nor his doctor) has a right to disclose the result but the person often goes through various stages of shock, confusion, depression and denial which impede disclosure. However, as has been indicated elsewhere above, the period of learning to cope and accept the positive result can go on for up to four years or more, and in the meantime (unless the person adopts a positive life style), the virus continues to spread thereby undermining the rights of others. There lies the crux of the matter. Medical ethics do not allow a doctor to divulge a patient's HIV status yet this is against the greater public good. Counsellors,

doctors and a few friends who are privy to the information are in a moral dilemma, and there are no easy solutions. What can the society or government do to ensure that an HIV positive person protects the lives of others?

The question brings to mind the story of Stephen Kelly, 33, of Provanmill, Glasgow, Scotland who tested HIV positive while in prison for drug abuse. When he was released after six months, he had sexual union with his girl friend on a number of occasions despite his knowing that he carried the virus. When the girl friend fell sick later, she sued him for culpable and reckless conduct. "The police investigating the case were able to seize evidence of blood samples from a confidential clinic to use in the prosecution". The judge, Lord Mackay, jailed Kelly for five years for "total disregard of life", the *Severe* consequences of his action, and noted that the girl friend "has suffered several years of serious illness and her life expectancy has been seriously reduced" (*Guardian Unlimited*, 19 March 2001). Thus the right to privacy has been and continues to be the powder keg in the spread of HIV. However the verdict in the case against Kelly seems to suggest that the state could abridge the right to privacy on grounds of morality, public health and welfare of the community.²

The next important factor in the non-disclosure has been the stigma, shock and confusion associated with finding out that one is seropositive for HIV. It is a well documented fact the world-over that there is absence of HIV-status disclosure due to the stigma associated with the infection. At the heart of the stigma lies shame and fear. In some communities and churches in particular, HIV infection is seen as punishment for immoral and permissive behaviour for which the HIV persons and their families ought be ashamed. Hence the shame and fear of disclosure. Fear is based on the likely negative response from the family, friends and the community due to the very nature of the mode of HIV transmission. As Mataure P, et al (2000:1-2) have reported: "The vast majority of HIV transmission in Swaziland occurs during sexual intercourse between men and women. Most of the rest is from mother to child during pregnancy, child-birth or breast-feeding. A few cases are the result of sex between men or sexual abuse of children. Transmission can also occur through injection of recreation drugs such as heroine which is growing rapidly in Southern Africa. Transmission through

transfusion of contaminated blood still occurs where such blood is not screened, but this is rare in Swaziland where the blood is strictly monitored”³. As a result, a person who tests HIV Positive experiences a great deal of internalized guilt and shame, and there is fear of refection and loss of benefits.

Some people also fear discrimination, isolation and violence. For instance, Gugu Dlamini of kwaZulu Natal, came out and publicly declared that she was HIV positive, on television, in December 1998, and was later beaten to death in her hometown of kwaMashu, Durban (Kalebbo, 1999). Hall (2002:33-42) has reported a similar incident. Lindiwe Simelane, 25, had a boyfriend who died of some unexplained cause. She got another boy friend, conceived and bore a child who died within the first year. She was counselled and took HIV test and was found positive. She disclosed her status to the boy friend and he “went away and saw other girls” (Hall, 2002:40). Lindiwe then disclosed her status to the church elders and the church isolated her. Seeing that the church had not provided her any support, she left and joined the ‘Hope Crusade Church’ where she felt welcome, comfortable and supported, and has since joined Swaziland AIDS Support Organization (SASO) where she works as a counsellor. However stigma and violence have not been limited to Southern Africa. When Samuel Williams, one of the first Sierra Leoneans to publicly declare that he was HIV positive in 1996, “his house was ransacked, his personal possessions set alight and he was forced to seek refuge, with his HIV-positive wife and live in a hospital cubicle” (IRIN News, 10 December 2004). Thus for people living with the virus, it is no longer death that they are afraid of but “what people are saying about us, how we contracted the virus” (*Loc.cit*). Moreover, there is the double jeopardy for Africans who contract the virus through gay lifestyle since in some countries, homosexuality is proscribed. However, the recent high profile public disclosure by Prince Mangosuthu Buthelezi that he had lost his son, Prince Nelisuzulu, and his daughter, Princess Mandisi Sibukakonke, to AIDS (*Drum*, 26 August 2004) might help to de-stigmatise people living with HIV/AIDS in KZN province⁴.

There is also the well founded fear that a person who discloses the HIV-positive status may be discriminated against with regard to employment, housing and access to social services. For instance the Umbutfo Swaziland Defence Forces (USDF) has recently unveiled a

policy that “rejects HIV positive recruits”, although the army acknowledged that there were HIV-positive officers within its ranks. The rationale, according to the army spokesman, was that: “The army was experiencing a rise in HIV/AIDS –related illnesses and deaths, and this has adverse effects on its overall mission and preparedness, and may eventually lead to insecurity in the country” (*The Swazi Observer*, 15 December 2004). The policy document went on to argue that “Military training is designed to mould individuals into tough soldiers who can endure extremely stressful conditions during the tour of duty. The high level of HIV/AIDS in the military can undermine its effectiveness. The most potent way to avert the devastating impact of HIV/AIDS is to act before the epidemic spins out of control” (*IRIN News*, 24 December 2004). Given that there is an unemployment rate of 40 percent, the question of disclosure therefore becomes a weighty matter.

There is also the issue of gender inequality. UNAIDS 2004 Report has shown that “In Sub-Saharan Africa, three quarters of all 15 to 24 year-olds living with HIV are female” and it highlighted the fact that “women were often the subject of sexual violence, meaning that the promotion of abstinence and being faithful was meaningless in preventing the spread of HIV”. The main explanation of the feminization of the human immune deficiency virus is attributable to the subordinate status assigned to women and lack of women’s empowerment. Due to lack of economic and social empowerment, a significant number of women are not able to negotiate safe sex and take control of their reproductive health. In the context of Swaziland, culture and lack of economic empowerment have meant that women are unable to demand that their male partners use condoms and practice faithfulness. There are also some conservative traditional practices which emphasize procreation and primacy of children in marriage, and give social acceptance of men having multiple partners like the traditional polygynous relationships. Even outside the polygynous marital relationships, men have admitted having multiple sexual partners. For example, in a 1998 survey, “one in five men reported having non-regular sexual partnerships (with partners other than their regular wife or partner) in the preceding 12 months. For women, the figure was one in sixteen. This means that... over a lifetime, men are more likely to have periods when they have casual sex with different women, whereas women are likely to be faithful to the partner they are

with" (Mataure, et al, 2000:5). The story of 'Honey' Dlamini, 38, illustrates the point of multiple partners. 'Hanni' completed Form 5 and trained at Manzini Industrial Training Centre as a builder, and was very popular with girls. Hence his nickname of 'Honey'. In 1991, he had a bout of flu, developed lymph nodes at the back of his neck and was advised by his doctor to go for counselling and testing. He went to TASC (The AIDS Information Support Centre) for counselling, took the test and was HIV-positive. In spite of his HIV-status, he kept the information to himself and maintained active sexual relationship with the several girl-friends until April 1995 when he disclosed his status after attending a conference for people living with HIV/AIDS in Cape Town. Although he declared his status, he had not yet developed full-blown AIDS. He even got married in 1992, and had a male child in 1993, without ever telling his wife that he was HIV-positive. See Hall (2002:7-12). This story confirms the contention that faithful women often get HIV infection from their adventurous partners. In a non-marital situation, "women and girls are more likely to be coerced into sex or raped often by someone older who has already been infected with HIV" (Lekoa, 2004). There have also been reports of "rape of virgins by some HIV-positive men who believe that this will cure them of AIDS" (*The Swazi Observer*, 14 December 2004).

Closely related to the gender factor is the issue of migrant workers. Rural poverty has often led to periodic migration of unaccompanied bread-winners, both men and women, from rural areas to cities in search of work within Swaziland and across the border in South Africa. However migration leads to higher risk of HIV infection as men and women often engage in casual sex either to relieve loneliness or as a means of income. Hence the practice of short term sexual relationships (comically referred to as 'serial monogamy') by mobile working people is another sure source of the spread of HIV unless they remain faithful to their partners or practice safe sex. Moreover, this kind of situation is not helped by the economic hardships which a significant number of families experience. Lack of economic security often deprives women of the choice of when and with whom to have sexual relationship. Poverty may pressurize some women into "high risk 'transactional' sex – sex in exchange for money or goods or .. the illusion of material security" (Lekoa, 2004). As one mother put it, "I would sell my body if it meant I was able to get food for my children" (*Guardian Unlimited*, 23 November 2004).

Lastly, there is the 'informed ignorance' and reckless behaviour which is often associated with youth and a number of old men who enter their "teenage" late. A close reading of the enquiries to "Auntie Clara", a regular column in the *Sunday Times*, shows that most of the youth enquire on relationships. For instance, one young woman, 23, one time was asking Auntie Clara to help her decide which of the two men in her life was the father of her child, and without doubt 'Clara' decried the young lady's inappropriate sexual behaviour in the era of HIV, and then went on to advise her to go for HIV and DNA tests. This is yet another example of multiple partners and unprotected sex with the likelihood of an HIV infection. There is also the interesting if surreal story of a young South African who boasts of punishing his landlord who secretly dated his wife by making the landlord's daughter (a graduate nurse) pregnant (*Frank Talk Magazine*, Nov-December, 2004: 22-26).

In the context of Swaziland, there is an interesting testimony by Nomsa, an HIV positive woman who disclosed her status to the husband and he deserted the wife and children, and went to live with his girl-friend in Mbabane (Hall, 2002:81). In all these cases, we find there is non-disclosure due to ignorance and reluctance to confront reality of the HIV-positive result. As one man put it, "I told my wife I have HIV but not the chicks I sleep with" (*In Vivo*, January 2004).

MORAL COMPLEXITIES OF DISCLOSURE

HIV thrives on secrecy. Hall's *Life Stories* (2002) on Swaziland and various studies elsewhere (FHI, 2000; *Shop Talk*, 1998; *Business Day*, 2004) have shown that people who test HIV-positive are reluctant to disclose their status to their partners and friends. Studies have also shown that "an individual with one sexual partner was 3.2 times more likely to disclose his or her status than a person with multiple sexual partners" (*Shop Talk*, 1998). We have already seen in the discussion heretofore the social, psychological, economic and practical considerations that contribute to non-disclosure. In addition, some HIV positive persons may rationalize that their partners are responsible for protecting themselves. Nonetheless, disclosure and enlisting community or family support is one of the effective ways of preventing the spread of HIV. However, it must be

contended that disclosure has to be personal. It is a personal responsibility. This method of personal disclosure has the advantages of respect for the right to privacy and it respects the confidentiality between a physician and a patient. In fact it has been suggested that such confidentiality should be extended to include postmortem, autopsy reports as part of decedent's medical records. The American Medical Association (AMA) has, for instance, advised that "it is unethical for a physician to make public disclosure of an individual patient's HIV status independent of legal requirements", except where there is need "to notify endangered third parties (e.g. sexual and needle-sharing partners). This includes reporting to organ or tissue procurement agencies if any parts of the decedent's body were taken for use in transplantation" (AMA, E5.057, June 1994).

It is possible that an HIV positive person will gradually overcome fear, confusion, denial, stigma and reach the stage of acceptance and disclosure to very close confidants and later to friends and the community so that s(he) can receive community support. It is important to bear in mind that medical information is personal and largely protected by the right to privacy yet the HIV status ought to be disclosed for the sake of "the other person" and for public good. The danger of secrecy and non-disclosure is the harm caused to the other persons. It is in this context that the story of Patricia becomes relevant. Patricia is living with HIV/AIDS at Hope House in Manzini. When her husband who was a long distance truck driver tested HIV positive, "he never bothered telling his wife. By that time he was extremely thin and died of AIDS" (*Swazi Observer*, 13 December 2004). When Patricia fell ill, she was found to be HIV positive and has been cared for by the Hope House which provides love, care and compassion to terminally ill persons.

According to Noerina Kaleeba, a Ugandan woman who has been living with HIV since 1987 (when the husband died of AIDS), disclosure of one's HIV positive status is based on the "responsibility to let others live". In her own words: "I have a right to live, and I also have a responsibility to let others live... Whether the results of an HIV test are positive or negative, we must conduct ourselves in a manner that avoids either becoming infected or spreading the infection" (in Reid E, 1995). People who know they are HIV positive have a moral obligation to prevent the spread of HIV infection.

Moreover, it must be realized that disclosure to all potential and real partners is a giant step towards behavioral change but it is a process which has to be planned. The unfortunate thing is that there is no roadmap and no protocol to guide the process. Each person, and family, will deal with the moral complexities of disclosure by working out a roadmap which will guide the process and identify the challenges and strengths of the communication patterns in the family, who needs to know, and the benefits of disclosing to them. In the words of Nelson Mandela, "let us give publicity to HIV/AIDS and not hide it, because that is the only way to make it appear like normal illness" (*The independent*, 7 January 2005). It is however important that we do not adopt the scholarship agencies approach which requires applicants for overseas scholarships to take an HIV test without adequate counselling and preparation. Here we have the testimony of a Swazi female, university graduate with B.Sc in Agriculture who applied for a postgraduate scholarship to go for training in economic management. The Ministry of Agriculture and Cooperatives required her to take a blood test but the doctor was obliged not to tell the applicant the results of the test. When the results came out, the doctor reported to the Ministry which in turn informed the applicant that her application was unsuccessful, without giving reasons. Out of curiosity, the Cooperative Officer chose to take the test again and found she was HIV positive, and went for counselling. However, the doctor advised her that she did not have to take the antiretroviral drugs provided she kept on a balanced diet (Hall, 2002:79-82). The trouble with the scholarship agency approach is the absence of counselling before testing. Quite often a number of applicants have suffered from shock and severe depression yet there is no one else who knows so as to provide emotional support.

The value of disclosure is the great potential it has for behavioral change. When Philly Lutaya, a popular musician in Uganda, came from Sweden to Makerere University to address the students on 13 April 1989, there was no lecture theatre large enough to accommodate the audience. It was decided to hold an open air forum. But when he publicly disclosed that he was living with HIV/AIDS, his music fans were shocked and initially accused him of telling lies. Within months, Lutaya was no more⁵. The youth took notice. His battle with AIDS had been documented in a film: "Born in

Africa". When it was screened in 1990, on Uganda Television, people stayed indoors and "wept before the TV screens" (*East African*, 15 November 2000). The stark reality of AIDS had hit them because of their love of the Philly Lutaya music. His death awakened those who were still in the denial stage and it shaped the country's perception of HIV/AIDS. As if that was not enough, AIDS touched the University community. The academic staff and students were no exception. I particularly remember a colleague in the Faculty of Veterinary Medicine, in his 30s, who lost a wife to some unexplained cause. He was left with a healthy five-year old son to look after. After some months, when he fell sick and tested HIV positive, he could not cope with the results. He collected some chemicals from the faculty lab, brewed a cup of coffee after supper, took the coffee and retired to bed. He was found dead in the morning. His son was left an orphan who grew up to learn the circumstances that led to his parents' death later. However, when we took his body for burial at his home, the family members disclosed the cause of his death, and that disclosure helped some of his friends and neighbours to appreciate the nature of the war that had to be fought. And we also lost a number of students to the opportunistic infections that are associated with the Acquired Immune Deficiency Syndrome. Parents who had invested heavily in their children's education and were looking forward to the fruits of their children's labour had their hopes and children buried together. The traditional pattern of children burying their aged parents has changed to parents burying their youthful offsprings.

Disclosure is morally justified mainly to protect the lives of others. As Noerina Kaleeba has testified, disclosure means that "no one who is not HIV positive is going to have sex with them" (Reid, 1995). Disclosure of a person's HIV-status is therefore a selfless act which protects the lives of others. There is double protection for those who are still negative and the HIV positive person is protected from contracting other sub-types of the virus⁶. Disclosure is very important and conforms to the Christian ethic of love. Love for your neighbour means that you do no harm to your neighbour. It is out of selfless love that disclosure becomes imperative. The 2004 World AIDS day focused on the plight of women and girls, and in Swaziland the theme was expanded into "Women and Girls: Care for them, love them and protect them from HIV/AIDS". It was a poignant message that responded to the UNAIDS 2004 Report on the Global

Epidemic which had highlighted the vulnerability of women and girls. The moral challenge of HIV/AIDS is that we should love ourselves enough to protect ourselves and love our neighbours enough to protect them. One sure way of protecting our neighbour is by disclosing our HIV status to them so as to ensure that we do no harm to them.

In this context, it is important to realize that the AIDS epidemic has put our moral values of what is right and wrong on the line. It has posed questions that did not arise in Biblical times or in Church tradition. Therefore the prescriptive ethics which advocates that we apply the positive and negative rules to a situation before we can decide the right course of action cannot be applied without stigmatizing those living with HIV/AIDS. The new situation demands a new pragmatic way of doing Christian ethics by anchoring our decisions on "love". As Joseph Fletcher (1997:43) has argued, "Christianly speaking, ... the norm of measure by which any thought or action is to be judged a success or failure, i.e. right or wrong is love"⁷. In other words, the fundamental principle around which all decision making hinges is that of love. This principle offers a practical "method of solving complex problems. It claims to correct the legalism and artificiality which have in the past disfigured much Christian thinking about conduct. It endorses the modern... disinclination to treat any external rules as unbreakable" (Parker J.1, 2002).

When we read John 13:34, we find that Jesus himself gave his followers a new commandment. "Love one another; as I have loved you". In this era of HIV/AIDS, love is the main duty laid before the HIV positive person, his/her family and friends. The HIV positive persons have a duty, out of love, to protect others and, it must be emphasized, this is possible through disclosure. But the love commandment demands reciprocity. This means that friends, partners and the community also have a duty to love, care and support people living with HIV/AIDS. It is through love and caring that stigma can be overcome. However, no one is expected to risk life or limb for our neighbour but to render that which is justified by the neighbour's need (*Catholic Encyclopedia*, ix, 2003).

However, given the non-discriminatory credentials of HIV/AIDS, it is important to find creative ways of changing the social conditions

that deny women the ability to control practices which increase their vulnerability to HIV by creating open space for both men and women, equally, to speak, disclose and protect lives. Disclosure will however mean that those living in marital relationships will no longer be merely oriented to reproduction. Rather there is need for fostering a new relationship which is compatible with mutual respect, mutual support, and mutual understanding.

Conclusion

The University of Swaziland students have organized a number of AIDS Awareness campaigns, talks and peer counseling. No doubt they will have succeeded in raising awareness of HIV issues. However, in spite of the high rate of infection that has been reported in the country, one cannot help sensing an attitude of “it cannot happen to me” amongst students. Consequently, there has been no noticeable change in behaviour. Besides, the negative attitudes to seropositive persons persist, and so there is only a small number of people that has tested and rarely do they disclose. Moreover some of the religious beliefs act as a barrier to HIV prevention due to some religious communities’ resistance to “speak about sex” on grounds that it promotes immorality or that it should be restricted to married couples (Women in Higher Education and Science, 2001). In this context, the Christian and other religious bodies in Swaziland have not yet done enough in crating awareness among their own members about HIV/AIDS yet the fight against the spread of HIV requires a multisectoral approach. Nonetheless, and in spite of the moral complexities of HIV testing and disclosure, the values of disclosure are compelling. These values include:

- Better protection of self and others
- Promotion of acceptance and responsibility
- Helps to reduce stress that is associated with keeping everything secret
- Helps in reducing social stigma
- Helps in obtaining community support and medical services.
-

In contrast, the major consequence of non-disclosure is the high risk of spreading the infection. Therefore it is essential to encourage people to take the advantage of the voluntary counselling and

testing to establish their HIV status and to encourage those whose results show that they are HIV positive to consider an informed full disclosure to interested third parties. Disclosure of a positive result is not an easy thing but it is the right thing to do.

End Notes

¹ During the World Aids Day, in December 2004, the University of Swaziland Community was addressed by speakers from the Seventh Day Church (International).

² See the UN's International Covenant on Civil and Political Rights (ICCPR), 1966: Article 4(1).

³ The authors did not mention the danger inherent in the dental health care and treatment which has been found to be another avenue for the spread of HIV since most of the dental care/surgery requires use of sharp instruments which are nonetheless used on a number of clients without proper sterilization. If one of the clients is HIV positive, it is evident that without sterilization, the dentist unwittingly infects other clients. The absence of safeguards in dental clinics in Swaziland is evident and the Medical Council has to take action.

⁴ Buthelezi bravely tackled the stigma surrounding HIV/AIDS. In his words, "I reach out to all other people who died of HIV/AIDS. My son.. died of HIV/AIDS" (Drum, 26 August 2004). And when Nelson Mandela lost his son, Makgatho, 54, a lawyer by profession, he broke the silence and said, "I hope that as time goes on, we realise it is important for us talk about people who die of AIDS" (Independent, 7 January 2005).

⁵ Lutaya came back to Uganda in December 1989 to launch his album "alone and Frightened". After the launch he fell ill, was admitted to Nsambya hospital where he died on 15 December 1989.

⁶ Medical science has revealed that there are two main types of the virus but that there are variations even within one type.

⁷ Fletcher makes six propositions to guide Christian action:

1. Love is always good
2. Love is the only norm
3. Love and justice are the same
4. Love is not liking

LIST OF ABBREVIATIONS

AIDS	:	Acquired Immune Deficiency Syndrome
FLAS	:	Family Life Association of Swaziland
HIV	:	Human Immunodeficiency Virus
IRIN	:	Integrated Regional Information Network
NERCHA :		National Emergency Response Committee on HIV/AIDS
PSI	:	Population Services International
SASO	:	Swaziland Services International
SHAPE :		Schools HIV/AIDS Population Education
SNAP	:	Swaziland National AIDS Programme
SWANASO	:	Swaziland Network of AIDS Services Organisations
TASC	:	The AIDS Information Support Centre.

BIBLIOGRAPHY

Acton Institute for Study of Religion and Society, Action Commentary (18 July 2001).

'A Face of HIV/AIDS: Nkosi Johnson', The African American Registry (4 February 2004).

'African Ignorance Fuels AIDS Spread', The New Vision (Kampala: 2 December 2004).

Canadian HIV/AIDS Policy and Law Newsletter Volume 2(4), July 1996.

Cooley, John, 'HIV/AIDS in Law Enforcement', The FBI Law Enforcement Bulletin (February 2000).

'Co-Wives Fight in Church', The Monitor (Kampala: 28 December 2004)

Christopher A. B. Zigira

'Danny Glover Pays Tribute to Young AIDS Activist', UNDP News (4 June 2001)

Dobriansky, P. J. 'US Role in Global AIDS Struggle': An Address to the Conference on "The Fight Against AIDS", New York: 22 June 2001.

Drum No. 625, 26 August 2004.

Family Health International (FHI), 'Health Services Raise Ethical Questions', Network Volume 21 Number 2, 2002.

Fletcher, Joseph. Situation Ethics: The New Morality (Westminster: John Knox Press, 1997).

Gruskin S & Tarantola, D, Human Rights and HIV/AIDS (HIV InSite, UCSF: April 2004)

Hall, James. Life Stories: Testimonies of Hope from People with HIV/AIDS (Mbabane:UNICEF, 2002).

'HIV Infection Hits Record Numbers', Guardian Unlimited, 23 November 2004.

'HIV Man Jailed for Knowingly Infecting Lover', Guardian Unlimited, 19 March 2001.

Health Systems Trust News 9January 2001 and 30 April 2003.

The Independent, 7 January 2005.

Information and Privacy Commissioner, HIV/AIDS: A Need for Privacy (Ontario IPC, October 1990.

Integrated Regional Information Network (IRIN), Swaziland: County Profile, 2002

Integrated Regional Information Plus News, 24 September 2001.

Integrated Regional Information Ness, 10 December 2004

International Community of Women (ICW) Living with HIV/AIDS, "Young Woman's Dialogue: Swaziland", ICW: 18 November 2004.

International Covenant on Civil and Political Rights, N.Y:UN, 1966.

International Planned Parenthood Foundation (IPPF), "Swaziland: County Profile' (UN Population Information Network (POPIN), 2004)

Kahn, Tamar, 'Denial Ignorance Continue to Define SA's Response to HIV/AIDS', Business Day (1 December 2004).

Kalebbo, G. D. 'AIDS Patients Come Out Against Stigma' (Lusaka: Panos Institute, 17-30 September 1999).

Kaleeba, N. 'I Can See Light at the End of the Tunnel', in Reid E; HIV/AIDS: The Global Inter-Connection (New York UNDP, 1995).

Kanya, Mary M, 'Feminization of HIV/AIDS in African Countries'. A Paper Presented at the Fifth Annual African Women's and Children's Health Symposium at the University of the District of Columbia (11 November 2004).

Lekoa, L. C. 'Reaching Out with Anti-AIDS Strategies for Women and Girls'. A paper presented to the CSIS Task Force and the Washington Ambassadorial Corps on 30 November 2004.

Miles, Gillian, 'A Hero at Age Eleven, Dead at Twelve', Southern Cross on line, June 2002.

The Monitor, Kampala: 27 December 2004.

The New Vision, Kampala: 21 December 2004

Nyanzi Peter, 'Health Defends HIV Drug', The Monitor (Kampala: 20 December 2004).

'One Baby, Two Dads', The New Vision, Kampala; 20 December 2004.

Onyango-Obbo, C. 'Malaria Kills Us, But AIDS Makes Us Equal', The East African (Nairobi: 15 November 2000).

Parker, J. I. 'Situation Ethics' @ <http://www.the-highway.com/articleJan02.lhtml>.

Raquel, Silverio. 'To Disclose or Not to Disclose; The Dilemma Facing Families Living with HIV/AIDS' (Gay Men's Health Crisis, 2003).

Reid, Elizabeth (ed). HIV/AIDS: The Global Inter-Connection (New York: UNDP, 1995).

Shernoff, Michael, 'Physicians Living with HIV/AIDS', Journal of International Association of Physicians in AIDS Care Volume 2 No 11, November 1996.

Seeds of Light, March 2003

Shop Talk Volume 2 Issue 24, 6 March 1998

Southern Anglican, Volume 2, September 2004

Strans, Tamara. 'The Moral Calculus of AIDS' (10 April 2001) @ <http://www.alternet.org/story/10706>

Sunday Vision. Kampala; 19 December 2004

The Swazi Observer, 13, 21 December 2004

Times of Swaziland, 14, 21 December 2004

UNAIDS, Report on Global AIDS Epidemic (December 2004).

UNAIDS, Swaziland: County Profile: HIV/AIDS (Washington: Global Health and Development Strategies, January 2004).

'Virgins' Club Formed', The New Vision, Kampala: 21 December 2004.

'Women in Higher Education and Science; African Universities Responding to HIV/AIDS. Report on a Workshop Held in Nairobi, Kenya, 3-5 December 2001.

To Disclose Or Not To Disclose: The Moral.....

Zuma, Jacob. Address to the Moral Regeneration Movement:
National Consultative Meeting, on 23 November 2001.
