
Mandatory partner notification versus the right
to confidentiality in HIV and AIDS:
Balancing competing rights

Catherine C. Makoni

**A dissertation submitted in partial fulfillment of the requirements of the Masters degree in women's law,
Southern and Eastern Africa Regional Centre for Women's Law, University of Zimbabwe, 2004**

DEDICATION

For my mother, my distant inspiration.

For my daughter, may the sun always light your way by day and the moon by night.

Contents

Dedication	2
Acknowledgements	4
Acronyms	5
Preface	6
1 Introduction	8
2 Methodology	11
3 Law and literature review	14
4 Theory versus reality: The findings	22
5 Balancing competing rights – A discussion	27
6: Confidentiality and disclosure in South Africa, a comparative look at their experiences	30
Bibliography	34
Websites	35
Table of Statutes	35
International instruments	35
Table of Cases	35
Appendix 1 General Research Questions	36
Appendix 2 Questions for Women and Men Living with HIV AND AIDS	37

Acknowledgements

I would like to acknowledge with thanks the assistance I received from my supervisor, Professor Julie Stewart in guiding me through my research. Her patience and forbearance were a Godsend during those times when the deadlines came too soon! She graciously called them the challenges of multi-tasking.

I would also like to acknowledge with gratitude the financial support received from Norad, without which I would not have been able to go on this programme.

To my family, especially my sister Joyce, for taking over some of my gender roles, freeing me to work on this programme.

To my partner and friend, the words of encouragement and your presence during those late night working sessions were always appreciated, though this appreciation was not always articulated.

Acronyms

AIDS	acquired immune deficiency syndrome
ARV	anti-retroviral
ASO	AIDS service organization
CEDAW	Convention on the Elimination of all forms of Discrimination Against Women
GAIA	Global AIDS Interfaith Alliance
HIV	human immunodeficiency virus
NGO	non-governmental organization
PLWHA	people living with HIV and AIDS
PMTCT	prevention of mother to child transmission
PPTCT	prevention of parent to child transmission
PSI-Z	Population Services International Zimbabwe
SAfAIDS	Southern Africa HIV/AIDS Information Dissemination Service
STI	sexually transmitted infection
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNIFEM	United Nations Development Fund for Women
VCT	voluntary counselling and testing
WAG	Women's Action Group
WASN	Women and AIDS Support Network
WCC	World Council of Churches
ZAN	Zimbabwe AIDS Network

Preface

Maria was a 25-year-old woman when she came to the Women's Action Group where I was working as a legal officer. She had travelled 275 kilometres by bus from the city of Gweru because she had heard that she could receive free legal assistance. Her husband of one and a half years had recently died and his relatives were evicting her from the matrimonial home. This was her story:

'I met Tom, almost two years ago. I was nearly twenty-three and he was thirty-five years old. He was a friend of the people I was working for as a domestic worker. When he asked me out, I was flattered and I agreed. We started seeing each other on Sundays – my day off. He asked me to keep our relationship a secret because it might upset his friends and cause problems for me. I agreed. It made sense. I was, after all, just a domestic worker and he was a sergeant with the Air Force at a nearby air base in Gweru. He assured me that he was serious about our relationship and wanted to marry me.

'Three months later he asked me to elope, which I did. I was two months pregnant at that time. He made arrangements to pay *lobola* and he paid *lobola*. I was now officially his wife. I remember asking him about his wife at that time because he had three children. He told me his wife had run away to her natal home after a misunderstanding, four years back, taking their children with him. That since then he had been living by himself, and that is why he wanted us to have a family of our own. This was about August 1998. In September when I was three months pregnant, I had a miscarriage. In December while I was doing some cleaning, I came across a death certificate. It was his wife's death certificate. It told me that his wife had died in January 1997 and that she had immune-suppression. I did not know what this disease was. What angered me more was that my husband had lied to me. I confronted him. He admitted to lying. He said that he had been afraid that if I knew that his wife had died, I would refuse to marry him, since I was so young. He said he did it because he loved me and was afraid to lose me. I forgave him because I thought it showed that he really loved me and would have gone to any lengths to marry me.

'Then in January 1999, Tom fell sick. He had a fever. We thought it was malaria but he did not respond to malaria medication. After two weeks he recovered. Only to immediately fall sick again. He had continuous diarrhea for a month and would vomit. He said it was his relatives bewitching him because he was the most successful person in the family. I believed him. Three months later in May or June he contracted tuberculosis but was treated and recovered. However he then contracted meningitis. By this time he had lost a lot of weight and I had begun to worry because I had heard that a person with AIDS loses a lot of weight. My fears were confirmed when after he was hospitalized, the doctor wrote a prescription which cost a lot of money. I approached his brothers who said that it was pointless spending so much money on Tom.

'It was only a matter of time before Tom died because AIDS has no cure. So even if the meningitis were cured, the next time it would be something else. They said they had learnt from the experience with Tom's first wife when she became sick. That was when I really realized my husband had AIDS. I asked the doctor what immune-suppression was and he told me that it had something to do with AIDS. I asked for a test. Two weeks later the results came back, I was HIV positive. At the same time my husband was discharged. The hospital saw no point in keeping him when there were no drugs. They told me I could buy the drugs and take care of him at home. This was October. I looked after him until he died in December 1999. During this time his relatives would come and visit and go back to their homes. They would be angry if they came and found the house dirty although they never offered to assist. I had to feed him and clean him myself, sometimes with help from my family.

‘After his funeral, his relatives said I should leave together with my relatives who had come for the funeral. They told me that I had no child and had only been married for a short time and therefore did not deserve anything from the estate. I tried to tell them that when he married me I was pregnant as they all knew. It was not my fault that I had lost the child. I told them when Tom met me I did not have AIDS. They participated in the marriage ceremony, yet did not tell me that Tom’s wife had died of AIDS or that he was infected. When I was looking after Tom, they recognized me as his wife, yet now that he was dead, I was suddenly not a real wife because I had only been married a short time! I told them it was their relative who had done this to me...

‘I just want a place to live and support until I die. I want to be compensated for this infection and if they want me to leave, they should pay me for the year I spent looking after him. I did it when no one else would. It was difficult and it was painful... He didn’t tell me he was HIV positive, his doctor did not tell me when I was pregnant and lost the child. His relatives did not tell me. No one told me and now they want me to leave when my life has been destroyed.’

1 Introduction

HIV and AIDS in Zimbabwe: the facts

- Zimbabwe has a population of 11.2 million people (Central Statistics Office).
- Between a quarter and a third of all adults are infected with HIV (UNAIDS).
- Zimbabwe has the highest estimated tuberculosis incidence in the world – more than 500 cases for every 100,000 people every year (Centres for Disease Control-Global Aids Programme – CDC-GAP).
- In the past decade, life expectancy declined by almost a quarter of a century, from 63 to 39 years (CDC-GAP).
- 60,000 children become orphans from AIDS daily in Zimbabwe (Global AIDS Interfaith Alliance – GAIA).
- In five years Zimbabwe is expected to have an orphan population of 1.1 million (CDC-GAP).

Women and AIDS: the facts

- In Africa, about 12 women for every 10 men live with HIV (UNAIDS).
- The highest incidence of HIV is among African girls and young women in the 15–24 age range. Their HIV infection rate is about six times that of boys and men in the same age group (Commission on the Status of Women, 2001).

‘In the context of HIV and AIDS, special attention should be given to the human rights of women. This is justified by the reproductive role of women, and a subordinate role in some societies, which makes them particularly vulnerable to HIV infection, as well as affecting their access both to knowledge about AIDS and the steps they may take to protect themselves’ (United Nations Centre for Human Rights, Human Rights Newsletter Volume 2 No. 3:2).

Maria’s story and several others like it that I came across in my professional and personal life first opened my eyes to women’s special vulnerability to HIV and AIDS. Since the HIV/AIDS pandemic first exploded, it has been thoroughly investigated and a lot has been written on the subject of women’s vulnerability to HIV. It has now emerged that women are more vulnerable to HIV than men. It is estimated that women between the ages of 20–29 have the highest prevalence of HIV infection. Some of the risk factors include:

- Women have a higher risk of HIV infection during unprotected sex. Biologically, the risk of HIV infection during unprotected vaginal intercourse is two to four times higher for women than men.
- Women have a higher surface area of vaginal and cervical skin that is exposed to their partner’s secretions during sexual intercourse. The skin in the vagina can also tear easily, especially during dry or forced sex, making it easy for the virus to enter the body.
- Semen infected with HIV is more infectious than vaginal fluids. Semen is left in the vagina making it easier for HIV to infect women. Semen also carries live cells which are necessary for HIV transmission and has a high concentration of HIV.
- Sexually transmitted infections that cause sores inside the vagina make it easy for the virus to enter the body.
- Women’s risk of HIV infection depends on the extent to which they can make decisions about their lives, their bodies and their relationships. Women are not always able to decide when and whether to have sex, engage in certain sexual practices and use contraception.
- Men often control whether safe sex is practised and the barrier methods that are used. There are few preventive methods that women have control over. The female condom is not widely or cheaply available and other barrier methods like microbicides are still being researched (Matlin and Spence, 2000).

Quite apart from the biologically determined factors, socially determined factors like women's subordinate position in society have resulted in the epidemic assuming a female identity. The AIDS epidemic has become largely 'female, young and poor' (Beyrer, 1998) as Maria's story shows.

However, for a long time, HIV has been viewed as a health problem, properly the domain of trained medical personnel. This point is best captured by the following comment:

'Law and medicine, together with theology, can claim the longest history of professionalism. In a sense, they compete for the control of social behaviour, which may also account for the frequently uneasy relationship between the professions. The lawyer is often regarded as an interloper in the field of medical practice, a person without the necessary knowledge to decide questions of treatment or ethics' (Law and Medicine Acta Juridica, Bennett et al., 1988).

I was aware of this perception and respondents repeatedly raised the point during my research. They felt that the law had no role to play in HIV and AIDS issues. However as contemporary knowledge has now shown, HIV and AIDS impact on every aspect of people's lives, therefore responses need to be just as multifaceted. Law is but one of those facets. The law certainly cannot provide all the answers but the point is made that it is one area which has been neglected and which might have a role to play in prevention efforts.

A lot has been written about the rights of people living with HIV/AIDS. That the rights of people living with HIV/AIDS need to be respected and promoted is beyond question. Just as it is beyond question that rights come with responsibilities and one of the greatest responsibilities of a person living with HIV is to ensure that the virus does not spread to the next person.

Justification

'20 years ago HIV/AIDS was a western gay man's disease. Today it is the number one disease for African women' (Catholic nun in Kelly, 1999).

My concern in this research was that the issue of the rights of people living with HIV was being explored and promoted to the exclusion of their responsibilities. In the light of women's vulnerability to HIV infection as exemplified by Maria's story, I felt that there was need to explore the complexities in this relationship so that, if possible, a balance could be achieved.

Because in my experience and through anecdotal evidence, it appeared a lot of women were being infected by their partners and spouses, I felt that it was important to investigate what the law provided with regard to the responsibilities of partners to each other. I knew that the Sexual Offences Act, Chapter 9:21 in section 15, criminalizes willful transmission of HIV regardless of the relationship between the parties. One of the problems with this Act was that this provision made the assumption that there was knowledge of one's partner's status. I was also aware that the National Aids Policy had given the guiding principle that legislative provisions be put in place to enable non-consensual disclosure of a person's status to his or her partners or spouses. Given that the country's blueprint on HIV and AIDS management had given this recommendation, it was intriguing that nothing appeared to be happening on the ground. In fact it appeared that instead of promoting voluntary disclosure of one's status, the norm among a majority of relevant organizations was to promote confidentiality. Given that research has now shown marriage to be a risk factor for women,¹ it was worrying that organizations working on HIV/AIDS did not appear to be keen on promoting disclosure between spouses or partners as a way of preventing the spread of HIV. I felt there was need to investigate the apparent dichotomy between policy and practice.

¹ Jackson, 2002 at 111 states that "the bitter truth is that marriage is probably the relationship through which the majority of women in southern Africa become infected". See also Kelly *et al.*, 2003,54.

Objectives

Given the above observations, it appeared there was resistance to the enactment of legislation which would enable disclosure of a person's status to his or her partner or spouse. It was thus the objective of this research to determine what, if any, were the causes of this resistance and what measures needed to be put in place to ensure a balance between one partner's right to confidentiality and another's right to life-saving information. Further suggestions would then be made as to what form such legislation or policy framework would take.

Assumptions

These objectives were premised on several assumptions about the problem. These were:

- 1 While a person may know or with reasonable cause suspect that he or she is HIV positive, men are usually reluctant to disclose their status to their sexual partners, resulting in the partners being exposed to infection.

This assumption was influenced by my experiences with women who had been infected with the virus by their spouses or who believed, with reasonable cause, that they had got the infection from their husbands. This research sought to establish exactly why people, but especially men, do not disclose their status to their spouses or other sexual partners even where the latter are at risk.

- 2 The second assumption was that while guiding principle number 3 in the National AIDS Policy indicates a realization among people working with HIV and AIDS that voluntary partner notification does not always work and therefore that there is need to make disclosure mandatory, there was perceived or apparent reluctance among policy or lawmakers as well as non-governmental organizations working in the area of HIV and AIDS to effect the necessary legislative reform.

This assumption arose from the fact that the National Aids Policy was the product of a broad-based consultative process involving the national interdisciplinary and intersectoral task force (NITF) and seven expert groups on HIV and AIDS policy. In addition organizations and individuals made their submissions to the task force. I concluded that the recommendation made in the policy, vis à vis legislative reform to enable disclosure, was based on realities on the ground. It was therefore baffling that almost five years after policy formulation in 1999, this recommendation had not been taken up. This merited investigation.

- 3 The third assumption was that the apparent ambivalence on the part of non-governmental organizations, AIDS service organizations and policy makers was a result of the unresolved conflict between a person's right to confidentiality and another's right to life-saving information. The belief was that since these players did not know how to deal with the problem, they decided to simply not deal with it all.
- 4 The fourth assumption was that perhaps people were not promoting mandatory disclosure because this would lead to stigmatization and discrimination of people living with HIV. I felt that perhaps there was another reason for not encouraging disclosure, which would merit investigation. Fear of stigma and discrimination appeared to be reasonable grounds.
- 5 The final assumption was that for as long as men do not disclose their status to women and for as long as marriage remained a risk factor for women, then women as sexual partners who are unable to negotiate safe sex would continue to be exposed to infection by their HIV positive partners. It was my assumption that the lack of an appropriate legislative framework contributes to the disempowerment of women, which in turn contributes to women's vulnerability to HIV and AIDS.

It emerged during the early stages of the research that respondents were generally not in favour of legislating mandatory disclosure even while acknowledging the limitations of voluntary disclosure. It was then necessary to explore the reasons why those who disclosed did so and to use this to revisit and reformulate my assumptions.

To this end the role of access to treatment as an incentive for disclosure was explored and a new assumption was formulated that perhaps if treatment were made available in the form of anti-retrovirals, people would have a reason to come forward. The approach was then to try and decide what role the law could play in facilitating disclosure.

Research questions

Research questions were formulated to match the assumptions: These were:

- Do people (particularly men) who are HIV positive disclose their status to their partners? If not, why not?
- Is there need for mandatory disclosure of a person's HIV status to his or her partner? If yes, why has no legislative reform been effected?
- Is there a conflict between the right to confidentiality and the right to information?
- What is the effect of this apparent conflict? Can this conflict be resolved? How?
- Could mandatory disclosure lead to stigmatization and discrimination against people living with HIV and AIDS? In what way?
- Is the lack of a legislative mechanism contributing to women's vulnerability to HIV? How?

These questions were a guide to some of the issues that needed investigating. More specific questions were developed to enable the researcher to interrogate more fully the various actors targeted in the research. Furthermore, the 'next question' technique was employed which enabled the exploration of some issues which were relevant to the study but which had not been covered during its conceptualization.

2 Methodology

One of the objectives of conducting this research was to ascertain women's experiences and views on the issue of confidentiality and disclosure. Drawing from my experience working as a legal officer for the Women's Action Group, I felt that I had a fairly good grasp of the reality on the ground but this needed to be proved. One of the issues that I sought to investigate was what I believed to be the gap between policy and practice. The National AIDS Policy provided one thing, while the practice on the ground was something else. Further I sought to investigate what I viewed as the gap between women's real needs in terms of HIV information and the programmes organizations had put in place to address what they perceived to be women's problems.

Because of the nature of the problem I was investigating, I felt that I had to start with an investigation of women's lived realities. I wanted to find out what their experiences of confidentiality and disclosure were. Having ascertained this, I then investigated the attitudes and programmes of organizations dealing with HIV and AIDS. This was meant to compare and contrast what the organizations were doing 'for women' and what women wanted. Were the programmes and policies reflective of and responsive to the needs of women?

Because the research is informed to a large extent by the National AIDS Policy, it was necessary to investigate whether the policy was being translated into reality and what impediments there were to its use – mapping the gap between policy and practice.

Because a deeper understanding of the problem was required, especially as the research was to an extent problematizing men's role in HIV transmission, it became necessary to attempt to investigate the issue of non-disclosure, not from the woman's point of view but from the man's – investigating his fears and his needs in so far as disclosure was concerned. The findings section deals with the findings in this regard.

Charting the course

As already discussed, I had what I thought was a fair idea of the issues in so far as the conflict between confidentiality and disclosure was concerned. My experiences had created the strong belief that the position taken by staff of non-governmental organizations and AIDS service organizations on the implications of confidentiality for women was different from the position taken by women on the ground. From this I was able to identify the actors I needed to talk to get the information I needed. The following were identified as some of the actors:

- Women and men living with HIV and AIDS;
- Health service providers (doctors, nurses, other caregivers), non-governmental organizations and AIDS service organizations;
- Government (Ministry of Health and Child Welfare);
- Legislators;
- Churches.

Further, the assumption that the resistance to the legislation that would enable disclosure was at the level of non-governmental organizations meant that I had to investigate the opinions and attitudes of people in these organizations. Because there are so many of these organizations, the decision was made to talk to the Zimbabwe AIDS Network (ZAN) which is the umbrella body of most of the organizations working in the area of HIV and AIDS. The aim was to seek assistance in ascertaining which organizations would be most useful to talk to, given the topic, and to get contact details. Assistance received went beyond identification of organizations to talk to. The staff set up appointments for me and generally introduced the research. This assisted in that when the time for the actual interviews arrived, the ice had to some extent already been broken.

Zimbabwe AIDS Network also assisted by giving background information on the organizations I intended to visit, including how I could benefit from talking to the different organizations. A lot of relevant literature was also furnished for the research.

Geographical setting

The deliberate decision was made to confine the research to organizations and people within Harare and the Norton area which is a mainly residential area about 40 kilometres from Harare. This decision was made partly on the basis of ease of access to respondents and also because a sizeable number of organizations working in the area of HIV and AIDS are either located in Harare or have offices in Harare.

Data collection: the methods

The main methods used for collecting the relevant data were:

- Interviews with key informants and general public;
- Group discussions;
- Library, documentary research;
- Internet search.

Key informant interviews

Key informants in this research were officers in non-governmental organizations, doctors, nurses, caregivers, the church, legislators and women and men living with HIV and AIDS.

Interviews with key informants were meant to form the core of my data collection process. Different interview guides were prepared for the different respondents. For instance from non-governmental organizations, I sought to ascertain: whether they knew about the provision in the AIDS policy that I was researching; what their views were with regard to the issue of confidentiality; whether they perceived any conflict and how this ought to be resolved. I also wanted to find out what, if anything, was being done to enable disclosure.

From the nurses, doctors and other caregivers, I wanted to find out what they perceived to be the problems associated with the issues of confidentiality and disclosure between partners, if any, and how they were dealing with them.

I had the idea that the church as a semi-autonomous social field as well as one of the actors in the area of HIV and AIDS, had to be investigated to ascertain what it was doing on this, if anything, and to solicit its views on what needed to be done. One issue that clearly emerged was that just as there are many non-governmental organizations working in the area, there also many churches. Some of the churches are quite active, like the Catholic church, while other churches are not. Each church has its own ideology and this influences the message it sends out.

Women and men living with HIV were interviewed for their very grounded experiences of the issues. The interviews, especially with women living with HIV and AIDS, were at once a rewarding and depressing experience. A friend and colleague took the opportunity presented by the research to tell me that she was living with HIV. The fact that she is a lawyer added another dimension to the in-depth interview that I held with her. We were able to analyze some of the issues from both a legal and personal perspective. She was also able to give insights on how some of my proposals would translate into reality. One of the challenges faced in interviewing women living with HIV was how to approach what I felt to be a sensitive topic. In the initial phases of the interview I was hesitant to ask some of the questions for fear that I would either cause offence or invoke painful memories. It was especially difficult with my friend. Some of the questions I could not bring myself to ask because I felt close to breaking down. However, she had resolved to talk to me, so she took the interview guide and proceeded to deal with the questions, in addition to bringing up some other issues she felt were relevant.

The other women I spoke to also surprised me with their candour and their willingness to deal openly and fully with the questions that I was asking. This soon made me realize that the only limitations that would be placed in the interview would be the ones I set myself. That is how open and cooperative they were.

Another problem encountered related to trying to interview doctors. I had to work around their schedules and because they were busy, I did not get as much time as I needed to delve into the issues.

Other challenges faced in trying to arrange interviews with key informants was their unavailability. The Minister of Health and his Permanent Secretary are a case in point. In December they were not in their offices and in January I was told that the Permanent Secretary was not taking any new appointments for an indefinite period since she was busy, and that the Minister would only be free in about March. I was told to leave my questions and covering letter and he would get back to me. I am still waiting!

Group discussions

Group discussions were held with students from the University of Zimbabwe and other young adults who were attending a workshop organized by Shape, Zimbabwe Trust. This is a University of Zimbabwe based organization working to address gender and HIV issues among university students and other young adults. The ages of the participants ranged from 19 to 31 years. The majority of these participants were unmarried; out of the 22 participants only two were married. This was an important group for me because it allowed me to understand the issues from the perspective of the youth who were not yet married and who were, perhaps, not yet as sexually active. Apart from eliciting their responses for my research, I felt the discussion presented me with an opportunity to do some activist research, that is by sharing with the group some of the legal and gender related aspects of HIV. I did this by responding to the impromptu question and answer session that followed the discussion.

I was attending the same workshop and spoke to the organizers to find out if I could be allocated time to talk to the participants. Where I had thought that I would be allocated time after the main activities, I was pleasantly surprised when I was offered the slot that had been set aside for a discussion on gender and HIV. The rationale of the organizers was that my topic appeared important to them and one they could benefit from, in addition to being on HIV and AIDS. The challenge was how to moderate the discussion while taking notes. I finally solved the problem by asking the facilitator for the session and workshop organizer to assist by noting the points as they were raised.

Internet search

The wonders of modern technology! The internet was a veritable mine of information. It was of great assistance in providing information on the HIV and AIDS situation and responses in other countries. The one challenge faced was with regard to accessing the facility, not having an internet facility of my own. I had to make arrangements with friends to access their facilities after hours. It was difficult in that I could not spend as much time as I needed at any one time to work on my search. However, over time, I managed to collect all necessary information. The other problem related to the e-mails seeking information which I sent out but which had not been responded to by the time I was writing up this research.

A lot is happening in the area of HIV and keeping abreast of developments has been a challenge. When I started working on this dissertation, the issue of access to treatment did not appear to be on the agenda. By the time the first draft was due for submission, concrete measures were being taken to make anti-retrovirals available in selected health centres throughout the country! Some of the articles in this regard are attached to this report.

3 Law and literature review

A lot has been written about the rights of people living with HIV. In addition, a lot of human rights instruments have been put in place to protect their rights. Rightly so, because during the early years of the pandemic when knowledge of the virus was still scant there was a lot of panic and there were kneejerk reactions. There were calls for the quarantining of people found to be HIV positive, some people were stoned to death, others shunned, international travel in some countries was proscribed and scholarships denied (Dyk, 2003) Fear of contracting the virus influenced many of these responses.

It was therefore imperative that adequate provisions were made to protect the rights of people living with HIV and to promote their protection. According to Mann *et al.* (1999):

‘... more broadly, the evolving HIV/AIDS pandemic has shown a consistent pattern through which discrimination, marginalization, stigmatization and, more generally, a lack of respect for the human rights and dignity of individuals and groups heighten their vulnerability to becoming exposed to HIV’ (page 17).

This paradigm shift was evidenced by the explosion of literature on the rights of people living with HIV while international bodies responded by passing conventions, declarations, resolutions and recommendations. Below is an analysis of some of the literature and law on the issue.

International framework

The Convention on the Elimination of all Forms of Discrimination (CEDAW)

The Convention on the Elimination of all forms of Discrimination Against Women (CEDAW) came into being on 18 December 1979 and entered into force on 3 September 1981. This was before the AIDS era. In the formulation of Article 12, which deals with women and health, AIDS was not within the brief of the drafters and therefore was not covered.

However the CEDAW committee in its general recommendation 24 of 1999 highlights the issue of HIV and AIDS and recommends that programmes to combat HIV and AIDS give special attention to the factors relating to women’s reproductive role and subordinate social position which make them vulnerable to HIV. It further emphasizes the need for state parties to implement a comprehensive national strategy to promote women’s health throughout their life span.

It is interesting but not surprising to note that on the issue of confidentiality, the committee requires that:

‘all health services [are] to be consistent with the human rights of women, including the rights to autonomy, privacy, confidentiality, informed consent and choice’.

Insistence on confidentiality is premised on the oft-quoted argument that lack of confidentiality:

'may deter women from seeking advice and treatment and thereby adversely affect their health and wellbeing.'

This is the main argument that has been advanced by a number of writers on the issue of confidentiality in HIV/AIDS. It is also the argument advanced by those non-governmental organizations interviewed who were not in support of legislating for compulsory disclosure.

CEDAW committee general recommendation 15 of 1990

Avoidance of Discrimination against Women in National Strategies for the Prevention and Control of AIDS.

This recommends that:

'States parties intensify efforts in disseminating information to increase public awareness of the risk of HIV infection and AIDS, especially in women and children, and its effects on them.' (Recommendation 15,1990)

However experience has shown that to a large extent, women have been the targets of HIV and AIDS prevention efforts. Due to gender role expectations, they are 'forced' to attend community workshops where AIDS is discussed. 'Forced' because in most communities, especially in the rural areas, not participating in community activities can attract censure and sanction. To say therefore that they always attend these activities voluntarily would not be an accurate reflection of the reality. When they go for antenatal care, they receive information. When they take sick children to the clinic, nurses and others take the opportunity to address them. The prevention of mother to child transmission programme was targeted specifically at women. It is only now that some of the gender-related problems of this initiative have been exposed that the programme is being renamed. It has now been re coined the prevention of *parent* to child transmission programme. This recognizes the crucial role men play in transmission of HIV as well underlining the role they can play in the prevention of transmission to their children. It is an acknowledgement of the fact that HIV is not a women's issue. It is everyone's responsibility, men included. Finally, as observed elsewhere, support groups draw mainly from women. However, as pointed out by Beyrer (1998), it is largely male sexual behaviour which has to be addressed. Targeting women with information about condom use when they lack the power to insist on use, is ineffective. Insisting that women do not have sexual relations with men when it is the medium of exchange which guarantees them access to resources can be problematic, especially when women see no other option of securing resources.

What this has shown is the need to target men in prevention efforts, hence the slogans now emerging: 'Men make a difference' and 'Real men care'. More important, perhaps, is the need for appropriate information which responds to the real needs of women. One such need is for openness between spouses and sexual partners.

Recommendation on ethical issues in health care and social settings – Council of Europe, 1989

Although this recommendation has application in Europe, it is relevant to this research in that it provides insights into how the conflict between confidentiality and partner notification has been dealt with elsewhere: Appendix to recommendation R (89) 14 states that:

'B - confidentiality

In relation to partner notification,

ensure that as a general rule, there is no partner notification without the consent of the patient and consider procedures of consultation in accordance with national codes of medical ethics where a patient refuses to cooperate in the notification of an unsuspecting third party known to the health care worker.'

While the recommendation starts from the premise that full respect of confidentiality is necessary, it does not stress confidentiality at any cost as appears to be the case in Zimbabwe, where no guidelines exist as to the

action to be taken in the event that the patient refuses to cooperate in the notification of his partner.

The recommendation states the further need to draw the attention of health care staff to the importance of assisting patients in understanding their responsibility towards partners. This research showed that while counsellors do talk about disclosure, it does not appear to be something that they have clear guidelines on, besides the one principle that disclosure is voluntary. For instance, one counsellor specializing in post-test counselling, when presented with the scenario where a person insists on continuing with behaviour liable to place his partner at risk despite counselling, did not know what else she could do or how she could handle such a scenario. 'It was just not part of her brief.' Service delivery in Zimbabwe as far as counselling is concerned could benefit from guidelines such as these.

Declaration of the Paris AIDS Summit – WHO, 1994

This was a declaration made by 42 states in Paris on 1 December 1994. Among other things, it recognizes that although the pandemic affects everyone without distinction, it is the women, children and the youth who are becoming infected at an increasing rate. It makes the important acknowledgement that obstacles to effective information, prevention, care and support include cultural, legal, economic and political obstacles. It therefore calls on states to protect and promote the rights of individuals, in particular those living with or most vulnerable to HIV and AIDS through the 'legal social environment'. A number of organizations are concerned with mitigating the social impact of HIV and AIDS. They are concerned with issues of nutrition, home-based care and treatment of opportunistic infections, among other things. For instance an organization working in the area of women's reproductive health rights which addresses strategic gender needs, like the Women's Action Group, was heavily involved in the home-based care initiative, without critiquing the implications of this initiative for women, who have to bear the brunt of the care work burden, even while sick themselves.

In the Protocol to the African Charter on Human and People's Rights on the Rights of Women in Africa, adopted by the Conference of Heads of State and Government in Mozambique in July 2003, it was agreed in Article 14 (1) that states parties shall ensure the right to health of women, including sexual and reproductive health, and this includes:

'The right to self protection and to be protected against sexually transmitted infections including HIV/AIDS.

The right to be informed of one's health status and of the health status of one's partner, particularly if affected with sexually transmitted infections including HIV/AIDS, in accordance with internationally recognized standards and best practices.'

This clause is recognition of the special vulnerability of women to infection by their sexual partners. This vulnerability is invoked by Chris Beyrer in his work, *War in the blood* (Beyrer, 1998). The observations he makes are of women in South East Asia but they could have been made of African women. He paints the following picture:

'Imagine yourself a young married woman ... You have only one sex partner, he is your sexual life. Your risks are his risks. You may or may not know what they are, you may or may not be able to ask. Reducing the number of sex partners means not having sex with him, and thus not at all. This is not an option for many women no matter what their husband's behaviour entails. It would mean giving up having children, an option very few women can accept particularly among the rural poor...Condoms again represent your husband's risks. Using them acknowledges that he has risks, has other partners. To speak of these issues is to suggest infidelity. This can be frightening. It can be deadly.'

It is a grim picture that he paints, but it is perhaps the picture that African heads of states and governments had in their minds when they signed the protocol on the rights of women in Africa. In the book, *The body of Christ has AIDS*, the authors acknowledge that it is unrealistic and even harmful to suggest that the only real solution

to the HIV/AIDS pandemic lies in the being faithful to one partner sexual ethic. For most women this may prove to be the occasion of their infection (Kelly *et al.*, 2003:54).

Although at international and regional level the government has committed itself to the protection and promotion of women's health and reproductive health rights, this has not been reflected in national laws, nor has the national policy framework been fully implemented.

National framework

The Constitution of Zimbabwe

One of the major problems with the Zimbabwean constitution is that it does not provide for social, cultural and economic rights. It does provide for the right to life (section 12). However, the way this right has been interpreted, has been to guarantee the right of an individual not to be arbitrarily deprived of his life at the hands of the state. It has not been interpreted to protect life in the private sphere, that is between a husband and his wife. The criticism made against such an approach is that it neglects women's experiences and women's realities (Tsanga, 2001).

The right to information is protected by the constitution in section 20 under right to freedom of expression. The constitution talks of '...the freedom to hold opinions and to receive and impart ideas and information without interference...'. One could argue that this provision can be interpreted to mean that people are entitled to information about their spouses or partners' status, particularly if they are infected with sexually transmitted infections or HIV as contemplated in the Protocol to the African Charter. However the cases that have been brought before the courts challenging violations of this provision indicate that it is protection in the public domain that is guaranteed. For instance, cases have involved the right to protest as a constitutional issue, challenges to the monopoly of the then Posts and Telecommunications Corporation, which saw the entrance of other players into the telecommunications business.²

Section 20 contains the further proviso that:

'2) Nothing contained in or done under the authority of any law shall be held to be in contravention of subsection (1) to the extent that the law in question makes provision for:

(b) preventing disclosure of information received in confidence.'

From the foregoing provisions, it would appear that confidentiality of health information and information relating to HIV status can be deemed to be protected by the constitution. The one certain way of discovering whether this would be the right interpretation of this provision is to bring a constitutional case on the issue, to oblige the court to give an interpretation.

Given the current political environment, it is unlikely that the drive for constitutional law reform will take place in the near future, which would have been the other available option to effect the necessary reform. This would have enabled the incorporation of social, cultural and economic rights, which are the rights that have the most impact on women's lives.

What may be possible at this point is to bring cases which seek a re-interpretation of the right to life or extend its interpretation to include positive obligations on the state to provide treatment to people infected with the virus.

² See *T.S Masiyiwa Holdings (Pvt) Ltd. and Another v The Minister of Information and Another* 1996 (2) ZLR 754 and *Retrofit (Pvt) Ltd v Minister of Information* 1995 (2) ZLR 422 for an example of how the court is likely to decide about the application of the section.

The National AIDS Policy

The National Aids Policy, which came into being in 1999 following extensive consultation, is meant to promote and guide responses to HIV and AIDS in Zimbabwe. It is quite clear in its articulation of the rights and responsibilities of all people, including people living with HIV or AIDS.

It states from the onset that human rights and dignity of all people irrespective of their HIV status should be respected. It acknowledges the special vulnerability of people living with HIV or AIDS but recognizes that rights come with responsibilities. In section 3 which lays down the policy's human rights framework, the policy states that, 'discrimination should be avoided as far as *is consistent with the rights of society and those who are uninfected*' (emphasis mine). This is an important point to consider. It emphasizes that a person's rights are guaranteed only in so far as their exercise and enjoyment does not lead to the abuse of the next person's rights.

On confidentiality, the policy states at 3.1 that:

'confidentiality is important because of the risk of stigma and discrimination in respect of HIV/AIDS. It underlines privacy in health matters as a fundamental human right and a core principle in medical ethics.'

The policy recognizes however that there are instances where information can be disclosed to a third party under the Public Health Act, Chapter 15:09. In terms of this Act, sexually transmitted infections, among other diseases, are notifiable and yet HIV, which in sub-Saharan Africa and in Zimbabwe in particular, is a sexually transmitted infection, largely transmitted through heterosexual intercourse, is excluded.

It is beyond the scope of this work to delve into the public health debate on the need to exclude HIV from the scope of illnesses and diseases that are notifiable. Suffice it to say that one of the major arguments that has been advanced and which is reflected in the National AIDS Policy is that, with other diseases, notification was a viable option because appropriate treatment and other public health interventions could be applied. Not so with HIV. At present, access to treatment is beyond the reach of many. A single anti-retroviral drug reportedly cost, at the time of this study, Z\$265,000 per month (*Sunday Mail*, 7 March 2004). If one needs a combination of three drugs, then the cost becomes prohibitive and is beyond the reach of the majority of the 1.8 million Zimbabweans living with HIV.

The situation should change following a commitment from the World Health Organization (WHO) that starting from March 2004, cheaper generic drugs manufactured locally should become available at some of the country's hospitals. This follows WHO's commitment to place three million people worldwide on anti-retrovirals by 2005.

If the drugs become available, then the argument could be put forward that notification in terms of the Public Health Act should be possible, because medical intervention is possible.

On legislating disclosure, the policy notes that during the policy development process, repeated calls were made for the creation of a legal framework for disclosure of one's status to be made by health professionals, under certain specific conditions, to those who have critical reasons to know, even where consent has been denied. This led to the formulation of the policy's guiding principle 3, which states that:

'Confidentiality regarding a person's HIV status should be respected. Legal provisions should be made to enable health professionals to disclose a client's or patient's HIV status to those who have critical reasons to know.'

This appears to be a clear provision, especially when read with the rest of section 3. Spouses, partners and caregivers are included as those who have critical reasons to know.

Given this provision in the policy document and given that Zimbabwe has ratified, signed or acceded to several international and regional instruments, including those discussed above, it is baffling that no action has been taken to create the necessary legislative framework.

The law

The only laws enacted that are meant to impact on the HIV/AIDS issue are the Sexual Offences Act, chapter 9.21 which came into effect in 2001 and Statutory Instrument 202 of 1998 (Labour relations HIV and AIDS) Regulations under the Labour Relations Act, chapter 28.01.

Section 15 of the Sexual Offences Act, chapter 9.21, criminalizes willful transmission of HIV by a person who actually knows that he or she is infected and who does anything to expose another person to HIV infection. While a full discussion of this provision of this Act is beyond the scope of this work, it is important to make the point raised by Jill Makarati of the Ministry of Justice, Division of Policy and Law, that the enactment of this provision can be interpreted to mean that an uninfected person or partner has a right to life which needs to be protected by law. The significance, according to her, lies in the right to life being interpreted as between individuals and not the usual state versus individual scenario. This is an important observation, especially if taken in the light of calls that are being made, both globally and locally, for the re-interpretation of rights, so that they are relevant to the risks women face. Such calls have included making domestic violence a torture issue, in other words it threatens the right to life and the right to freedom from torture and inhuman and degrading treatment (Tsanga, 2001).

The other piece of legislation, Statutory Instrument 202 of 1998 (Labour Relations HIV and AIDS) Regulations, was introduced under the Labour Relations Act (28.01). It was enacted to deal with rights and responsibilities of both employers and employees with regard to the prevention and management of HIV and AIDS in the workplace. It regulates issues like pre-employment testing, compulsory testing within the work environment, stigmatization and discrimination on the grounds of HIV or AIDS, among other things. It is thus not specifically relevant to this work, although it serves to demonstrate some of the legislative mechanisms put in place by government. This begs the question if other situations have had laws drafted to cover them – why not this one?

The answer appears to lie in a combination of factors evidenced in the wide range of literature on the subject. For many of the writers, the rights of the individual are paramount and, in the HIV context, the rights of the person living with HIV are paramount. According to Mann *et al.* (1999:5):

'promoting health requires explicit and concrete efforts to promote and protect human rights and dignity.'

On page 17 they proceed to state that more broadly the evolving HIV/AIDS pandemic has shown a consistent pattern through which discrimination, marginalization, stigmatization and, more generally, a lack of respect for human rights and dignity of individuals and groups, heighten the vulnerability to becoming exposed to HIV.

This and similar interpretations of human rights have led to a practice whereby when people talk of rights, it is the rights of people living with HIV and AIDS that are discussed, not their responsibilities, nor the rights of the uninfected. Part of the answer might also lie in what is perceived to be the complexity of the issue. Confidentiality is a long-standing principle. According to McQuard Mason (1988:94):

'abdication of this responsibility (confidentiality) chills the physician–patient transaction, discouraging candour and permitting extra-clinical threats or incentives to distort diagnosis and therapy.'

So it is deemed to be vital that the popular voluntary counselling and testing run by the New Start Centres of Population Services International, Zimbabwe and other non-governmental organizations is founded on confidentiality. So vital do people believe it to be to their work, that breach of the duty earns an employee in one organization a straight dismissal. This has been described as a western position and it is the position held by a number of donor agencies. Given this scenario, it is therefore perhaps not surprising that local non-governmental organizations, dependant on donor funding, would rather not fall foul of their donors by promoting anything contrary. To do so might mean withdrawal of funding.

However, there is ample evidence to show that the right to confidentiality is not absolute and never has been. According to Mason (1986):

‘legally the doctrine of medical confidentiality is founded on the law of contract and of equity – the duty of confidence is certainly not absolute. In fact, that some qualification exists has long been recognized.’

This proposition is certainly correct and in the case of *Attorney-General v Foster* (1963) 2 QB 477, Lord Riddell at page 331 states that while confidence is very important, *‘we must recognize also that (it) must be modified to meet the inevitable changes that occur in the necessities of various generations.’* He states further that important principles lie in the ‘right to know of the person informed and the degree of public risk’.

It can be argued that there is no greater right to know than that of a spouse or sexual partner. Knowing may mean the difference between life and death. As Helen Jackson puts it (2002:205):

‘...the benefits and costs of keeping strict confidentiality, need weighing against each other, taking into account the needs of individual clients or patients, spouses or other sexual partners, carers and family in general.’

The benefit of maintaining confidentiality versus the cost of maintaining confidentiality is what this research is grappling with. From the evidence on the ground and given the realities of HIV transmission, it would appear that the costs are far greater than the benefits.

Jackson exhorts health staff and counsellors to be as open and honest as possible about the limits of confidentiality (Jackson, 2002). Talking to some counsellors, however, one does not get the sense that they are capable of articulating as openly as possible the issues of confidentiality and disclosure. One respondent gave an account of how she had to break the news that a man was HIV positive to him. After having tackled what she perceived to be the hard part – telling him the result, they started discussing the implications. She recalled.

‘ I asked him who he wanted to tell the news, he said his mother. I asked him whether he had considered telling his wife, to which he responded, “sister munoda kuti ndife ndisinawo mwana here? (sister, do you want me to die without a child?)”’.

Telling his wife would have meant the possibility that she would not want to have children with him.

The respondent said she was then unable to deal with this response by the client. Nor could she do anything about the unsuspecting spouse at home. She concluded by saying that this case made her decide to leave counselling, and up to this day, it keeps coming back to her. She keeps wondering what happened to the couple, to the woman.

Jackson further presents the very compelling argument that in the context of sub-Saharan Africa, confidentiality needs to be redefined to incorporate social, cultural and traditional beliefs. She observes how in many African countries health and welfare problems are viewed as family problems needing family solutions. She attributes this partly to the interpretation of ill health and other problems as having social and spiritual causes that may involve the whole family. She further makes the point that the extended family has also been the only reliable source of social welfare and security in the past. She quotes the late Peter Sibanda, National Aids Coordinator, Zinatha who said:

‘If you do not inform the family that a patient has AIDS, you are taking away the family’s authority and making it impossible for them to be fully involved. It puts all the responsibility on the patient, which is not how disease is traditionally handled in our culture. It is isolating and frightening for the patient to carry the burden alone.’ (Sibanda, 1992)

This statement could not be more correct. Evidence from the researcher’s own experience bears testimony to the role of the family in times of crisis – be it illness or death or even in times of joy. Graduation ceremonies, for

instance, are occasions for the whole clan to rejoice because it is the whole clan that would have been edified. Just as funerals involve the whole family – because the loss is regarded as the loss to the whole extended family.

Jackson further points to some of the problems associated with the overemphasis on individual confidentiality with respect to HIV and AIDS as being that it reinforces the general stigma attached to AIDS in society by keeping the problem hidden, and it may therefore impede prevention efforts.

It also reinforces the feeling that having HIV/AIDS is a shameful condition that people are likely to want to hide from their families even though they would not keep other medical conditions secret.

There is a contradiction in the way in one breath people will proclaim how HIV is just like any other disease, yet in the next breath demand that it is treated differently from all the other conditions. If it can be managed with drugs just like diabetes or hypertension – conditions which need management for life – why then should people not be encouraged to be open about it. She goes further to note that it undermines the family's capacity to play its traditional support role and that a regular sexual partner or spouse is at risk and needs to know. Partners may or may not be infected.

Some people interviewed were of the view that where the parties are regular sexual partners, then the woman might already be infected. There is therefore no need to limit the right to confidentiality because it would not assist anyone. The counter argument can be raised: what if she is not yet infected? Do we then sacrifice her at the altar of expedience?

There are also other categories of people who have a critical need to know. Carers are people with the need to know – they need to take appropriate safety precautions in handling blood and other body fluids. Care work involves risk. Their right to know and thereby take necessary precautions cannot be denied. As it is the nurses interviewed reported how they told each other the status of certain patients routinely. This was supported by the Director of the Women and AIDS Support Network who said that this disclosure among health careworkers makes a mockery of the whole concept of confidentiality because in the end it is usually only the wife or family who do not know, while everyone else involved in the care of the patient knows.

The health information manager for the Women's Action Group, herself a former nurse, recalled how nurses would disclose among themselves, especially when, as sometimes happened, a male patient developed an interest in one of the nurses. She recalled how the nurses would warn each other about a person's medical history. Given this reality it would appear that the law is out of touch with the reality on the ground. It would be my argument that maintaining the status quo is behaving like the proverbial ostrich, hiding its head in the sand. The reality is that people identified a need in terms of information and they are taking action as they see fit. The law needs to respond to or correspond with the reality on the ground and come in to regulate disclosure.

Jackson concludes her discussion by saying that the openness approach normalizes AIDS by treating it similarly to other social, health and welfare issues and as it reinforces community awareness of AIDS, it should contribute to HIV prevention (Jackson, 2002).

The arguments that Jackson makes are not only credible but are also borne out by the reality on the ground. Where there is more openness about an issue, there is more awareness.

The church has also realized the need for a balanced approach to rights and responsibilities in HIV and AIDS. In *Facing AIDS: The challenges and the church's response* (World Council of Churches) the authors make it clear that an important aspect of equality of human beings involves striking the proper balance between the rights of one individual and those of another individual or of the community (WCC, 2001).

With regard to confidentiality, the World Council of Churches states that every attempt must be made to help the client disclose the information voluntarily to his or her partner. Only when this fails may the doctor or counsellor consider overriding the principles of confidentiality but always on a need-to-know basis. This approach, while commendable, makes the assumption that there are adequate human resources to enable effective

counselling. This might not be the case in countries like Zimbabwe where counselling and testing centres have largely been donor-driven initiatives, with the limitations of reach that this entails. The health system as it currently stands is characterized by severe shortages of personnel. With so few doctors, a doctor spends on average two to three minutes with a patient (researcher's personal recollection of experiences with her gynaecologist). There is hardly time for a patient to ask questions let alone for the doctor to explain issues at any length.

The World Council of Churches further notes that the relationship between rights and responsibilities is complex, and that the latter are often not discussed:

'out of fear that such discussion might compromise the principle of inalienability of human rights – the conviction that individuals remain entitled to such rights even if they fail to comply with their responsibilities' (page 72).

It is clear that the World Council of Churches realizes the need to address this relationship in a manner that is not arbitrary and that represents the least harm to the parties involved. As a world body its position is clear. The reality on the ground in terms of the local churches' response is anything but clear as the findings will show.

4 Theory versus reality

Confidentiality and disclosure

One of the issues under investigation was what was happening in terms of disclosure. Were people disclosing? If so, who was disclosing and why?

The research sought to investigate whether men were disclosing their status to their partners and, if not, their explanations for not doing so. In so far as the organizations were concerned, what were their views on confidentiality and disclosure? Which did they deem more important?

Of the 49 people interviewed in the different organizations and as individuals, a majority conceded that maintaining confidentiality between spouses was problematic. Two people, one from the Catholic church and one lawyer stated that openness had to be confined to spouses. They were of the view that those people who were not married assumed the risk of infection by engaging in non-marital sexual relations.

From the various interviews and discussions held, it was made clear that men generally did not disclose their status to their partners. One respondent working with an organization offering post-test counselling and support went on to say that although no thorough research had been done into how many men disclose, in her experience, women formed the majority of the people who disclosed their status to their partners or spouses. This view was supported by five of the six women interviewed at Tsungirirayi AIDS Support Group in Norton. They all stated that they had not known that their husbands were infected. Four of them stated that they would have done things differently had they known (insisted on safer sex methods or abstained). While two felt that knowing would not have changed anything because they did not feel able to demand condom use nor was leaving an option since they were orphans.

Betty, aged 35, narrated how she and her husband were diagnosed in 1997 at the instance of a relative of her husband who was employed at a hospital. This followed her husband's chronic illnesses. She did not receive any pre-test or post-test counselling. She narrated how her husband consistently refused to use condoms to prevent re-infection. She recounted to the group how he would be ill for some time, but the minute he was well enough, he would demand unprotected sex. She quietly concluded:

'It was as if he wanted me to die with him.'

For Beauty Kadzima, aged 31, disclosure should cover not just HIV but also sexually transmitted infections. She had been repeatedly infected by sexually transmitted infections by her husband. Every time he visited their

rural home where she lived most of the time, or she visited him in town, which was about once in three months, he would leave her with a sexually transmitted infection. Or she would leave town with a sexually transmitted infection. He also steadfastly refused to use condoms nor did he advise her of the infections. She however knew that he knew of the infections because she would find hospital cards to show that he was receiving or had received treatment. Describing how bad these repeated infections were, she narrated how at first the clinic staff used to ask her to bring her husband so that they could be treated together, in the end, they just treated her whenever she went to the clinic. She also felt unable to either refuse intercourse or to insist on condom use because he would threaten to divorce her. In that event, she would have nowhere to go. In March 2003, she was diagnosed HIV positive. At the time of the interview in November 2003, her husband was seriously ill and confined to bed. She was nursing him.

For Betty Chitowo, aged 40, Jestina Dziva, aged 42, and Spiwe Magumira, aged 45, the issue was one of disclosure not just of HIV status or sexually transmitted infections but also of any other opportunistic infections that are AIDS related. Their husbands died of HIV-related tuberculosis (TB). They had not considered themselves to be at risk. Before their husbands' deaths and their subsequent diagnoses, they had only had peripheral awareness of HIV. Jestina said it was only after they started attending the support group and learning about the various opportunistic infections that a person with HIV may be susceptible to, that she was able to look back and make the connection that her husband's various illnesses were HIV related. All the women, except Betty (who had been tested together with her husband), agreed that they had not known what lay behind their husbands' tuberculosis-related deaths (their husbands all succumbed to tuberculosis).

For all these women, information was not imparted and they were all infected. Perhaps knowing would not have changed anything given all the other dynamics at play. However, the information would have been laid before them to enable them to make informed decisions, even where they might perceive their options to be limited.

Twenty-two university students who were engaged in a discussion on the issue also felt that disclosure of one's HIV status was of vital importance. This group was composed of ten men and twelve women. All except four of them were still at university. These four were either awaiting their results in order to graduate or had recently completed their studies. The students were drawn from the University of Zimbabwe and the Midlands State University. Only two of the participants were in marital relationships, the rest were single. Their ages ranged from 20 to 32 years. Apart from legislating disclosure, they also pointed to the need to destigmatize sexual activity because it was this association with sex which caused the shroud of silence around HIV and AIDS. They also believed that access to treatment and other support mechanisms were necessary to promote disclosure. An issue which they felt extremely strongly about and which was dealt with at length, was the issue of premarital counselling and testing which they felt should be made mandatory.

Who is disclosing and why ?

An overwhelming majority of respondents stated that women made up the majority of people who disclose their status and different explanations were advanced for this phenomenon.

A colleague who is HIV positive and who was interviewed for this research gave an account of her experiences with infection, diagnosis and disclosure. On disclosure she said that for her, it was 'confronting rather than disclosure'. She said,

'...for me it was a matter of confronting him with a demand for answers. I wanted an explanation from him as to why I was positive. I knew I had gotten it from him. He is the only man I have ever had sexual intercourse with. I was angry. He just said sorry...'

According to officers in a number of the organizations visited, there are several reasons for disclosure and these include the fact that women are the usual recipients of HIV and AIDS information, so it is usually they who

respond to the information or try to change their behaviour. Further, women are the ones likely to be tested when they go for antenatal care or when they take children to hospital. The prevention of parent-to-child transmission programmes originally targeted women and largely still do. They were even previously called prevention of mother-to-child transmission programmes, leaving the man out of the HIV transmission equation and perpetuating the myth of women as vectors of disease. Women also constitute the majority of members of AIDS support groups. At Tsungirirayi Centre in Norton, there were three groups that met on Tuesdays, Thursdays and Saturdays. There were only two men who were members of the Thursday and Saturday groups, out of the nearly fifty women who attended support group meetings. Of these two, one was a youth who worked at the centre as a volunteer.

As the HIV problem has worsened, women have increasingly taken on the burden of care work due to their socially assigned roles as carers. They are over represented in home-based care work and this is usually done with the least support, either in terms of information or in terms of material resources.

According to Regis Mtutu, the Director of Padare – Men’s Forum on Gender, women have more and better platforms for sharing than men do. For instance, the church environment is conducive to sharing. Most religions, including Christianity and Islam, promote values like honesty, virtue, charity, love, forgiveness, submission, and so on. A lot of women attend church. For many, if not most, it represents a social life and a break from work. It is one of the few places women can go which are accepted by society. It is therefore largely women who hear and learn about the different virtues and values. It is women who are exhorted to conform and, because so few men go to church, it becomes a female environment. They have a space to share their experiences and get emotional and psychological support. The phrase ‘female environment’ is used advisedly because as a semi-autonomous social field, the church is an important institution for reinforcing women’s subordinate positions in the patriarchal order. Hence Christian teachings that call for perseverance in the face of adversity have been used to encourage women to persevere in abusive relationships, even unto death. These and other teachings are increasingly coming under scrutiny as the AIDS pandemic unfolds.

According to the women at Tsungirirayi, they came forward in order to access assistance. They cited the following as some the reasons they disclosed: to access support from the family (emotional and material); to access National AIDS Council funds; and to access school fees under the basic educational assistance module (BEAM) and other assistance programmes run by non-governmental organizations. They also disclosed in order to access information on living positively and to get support from being around people who know and understand their problem, rather than suffering alone. In addition, some disclosed to save themselves from making difficult explanations as to why, in a society where breast-feeding is a virtue, they were not breast-feeding. For others, disclosure was part of a strategy to show that normal people can get infected and live with the infection. It would also take a burden off their shoulders because then they would not have to be worrying about who would find out, since it would be out in the open.

For others, disclosure was used to bring up issues of condoms and negotiate their use, as a means of avoiding re-infection. A project coordinator with the same organization stated that she regularly tells people that she is positive as a strategy to get people to come forward and access assistance. She reported that this strategy works because after a workshop she finds herself swamped by people wanting to disclose their status, wanting information on how she has coped with the infection and what they can do to prolong their lives.

According to Elizabeth Dangaiso of the Women’s Action Group, disclosure is usually made when there is a benefit from such disclosure and she cited some of the reasons given above as being some of the factors influencing disclosure by people generally but women in particular.

According to a report by the Musasa Project, 90 per cent of women who participated in their research on HIV and violence said that they would inform their partners if they had a sexually transmitted infection. Reasons given for disclosure included: for treatment purposes; to confirm that he is the source of the infection; to inform him; as well as to ask him the source (Musasa Project, 2003).

This confirms some of the reasons given by the respondents in this study as to why they would advise their husbands or partners of their status. These reasons clearly show women's subordinate position as being a major factor in their vulnerability to HIV. They do not have the means to sustain themselves. They have to ask the person who is responsible for their infection for assistance. They cannot demand condom use even when their partner is being unfaithful and there is an infection to prove it, it still has to be 'negotiated'!

The other side of disclosure – findings on the negative consequences of disclosure

According to Musasa Project in its research, 'Domestic violence and HIV/AIDS: two linked epidemics', 10 per cent of women interviewed said they would not inform their partners if they had a sexually transmitted infection. Reasons given included: he would accuse her and suspect that she was unfaithful; he would be violent, abusive and beat her; and he would reject her and dump her. Again issues arose of where a woman would go and how she would support herself and her children in a society that is critical of divorced or unmarried women and where little support is available for women in difficult circumstances.

Mary Sandasi of the Women and AIDS Support Network (WASN), while being fully in support of disclosure, stated that in her experience disclosure by women had sometimes resulted in violence, with women being accused of having infected their partners simply by virtue of having been diagnosed first. A counsellor with a post-test counselling facility stated that some husbands had taken their wives off their medical aid schemes or denied their wives access to the medical aid card which would enable her to access treatment. Others have been denied nutritious food or money to access essential medicines. As Noeline Heyzer, Executive Director of Unifem, said in a statement released on the eve of the twelve days of activism against gender violence, on the Unifem website as well as in local press:

'...violence against women is both a cause and a consequence of HIV infection among women ... When a woman discloses that she is seropositive, she may be attacked or ostracized because of the stigma that is brought on the family' (Herald, 25 November 2003).

However, despite the very real problems discussed which women face, they still disclose their status. Mostly they have no choice and some of the reasons for this have been discussed.

Men and disclosure

'For men opening up is like crying – you are not allowed to' (male respondent).

In the very early stages of the research, it emerged that there would be limitations to the 'follow the woman' and 'taking the woman as a starting point' methodology. The research had to explore not only what was happening with women, but also what was happening with men. The burning questions sought to be answered were: were men disclosing their status? If not, why not? Unproblematic cases also had to be explored. For those who were disclosing, why were they seemingly going against the grain? What lessons could be drawn from their experiences?

As alluded to earlier, most respondents firmly believed that men do not disclose their status and some women had learnt this fact the hard way. What was not clear, however, was why this was so. A number of guesses were hazarded as to why men do not ordinarily disclose their status to their partners. According to a male programme officer with Population Services International – Zimbabwe, which runs the New Start voluntary counselling and testing centres:

'Men do not disclose because it is a sign of weakness. For men, disclosure is an admission of the need for help which is seen as an admission of weakness – a lack of self-sufficiency.'

He further stated that men will only disclose:

'when they are forced by circumstances and they are vulnerable. For example, when they need care.'

According to Regis Mtutu of Padare, the reason why men do not disclose has to do with socialization. He stated that men are socialized to take their place in the public arena and they are comfortable in the public sphere. The problem becomes that disclosure is something that requires the ability to navigate private spaces. He further said that the way society has defined strength and coping as the hallmarks of masculinity is problematic. To admit to a weakness in such a system can leave someone 'with the feeling of having his manhood or masculinity compromised'. This observation perhaps explains why Betty's husband would always insist on having sexual intercourse with his wife even when he could barely stand. He was possibly affirming his masculinity.

Mtutu goes on further to state that women have more platforms for talking than men do. Churches and social gatherings are predominantly female domains. He said that at Padare they are trying to create spaces for men to participate effectively in the management of HIV and AIDS.

Christopher Ngwenya of the HIV/AIDS Truth Society, an organization formed to promote status openness among professionals believes that:

'Men do not disclose – it's a macho thing, disclosing his status is an admission of weakness, a chink in his armour'.

His organization's goals are based on the premise that destigmatization can only be achieved through openness.

The women interviewed had slightly different perspectives on the issue. According to an HIV/AIDS counsellor, men did not disclose because our culture condones promiscuity, therefore men felt no need to be accountable for their actions which would follow with disclosure. She also felt that for some men, admission of HIV status was an admission of promiscuity and they would not want to be held responsible for bringing the virus into the home. For others it was a case of being in denial about a harsh reality and trying to live as normal a life as possible. This perhaps would explain the remarks from the man who felt that disclosing to his wife would mean saying goodbye to any prospects of having a child and he simply could not imagine living or dying without fathering a child.

As stated earlier, there is no clear-cut explanation for men's non-disclosure. This points to the fact that the issue of HIV and men has not been explored as fully as the issue of women and HIV, otherwise there would be ready knowledge on the issue. What the foregoing also points to is the need to redefine the concepts of masculinity in our society and the need to create space for men to disclose (Men and HIV/AIDS conference report, 2003).

Legislating disclosure: what role should the law play?

'Confidentiality between couples is problematic because the risk that the one will infect the other is very real. To this extent, there is definite need to legislate partner notification. There will always be instances where, despite going through counselling, someone will not disclose their status voluntarily. At present there is nothing that can be done by service providers in such instances. The law should then come in so that that person's spouse is protected' (Elizabeth Dangaiso, WAG).

The above view was shared by a large number of the respondents. The nurses that were interviewed as well as the HIV/AIDS counsellors strongly felt that the law had to come in to provide a framework or law on disclosure and that this should be done to protect them from possible consequences of non-consensual disclosure to third parties.

Mary Sandasi of the Women and AIDS Support Network, did not see the law playing any role in enabling disclosure, she said:

'I do not think that legislation helps – how would it be enforced? Right now we have the Sexual Offences Act meant to prevent the willful transmission of HIV/AIDS but I do not think it has ever been used. So what is the use of such legislation? For us the answer lies in empowering women and girls, hence the programmes we are running – empowerment and self-assertiveness.'

According to the Member of Parliament, Blessing Chebundo, who is the chairperson of the parliamentary committee on health, confidentiality had no place in a relationship between a couple, therefore there was need to put legislation in place to enable disclosure to happen. He however pointed out that as parliament, they were not experts in the various fields they had to work in. They therefore waited for input from people working in the various fields before taking up the issues. While this might certainly be true of some issues, on issues such as AIDS, one would think that the problems are self-evident so that the MPs do not need wait to be told about them. The women interviewed who were living with HIV all agreed that there is need to legislate for disclosure, although they were not clear as to the form such legislation would take.

Not surprisingly, some of the officers of Population Services International – Zimbabwe, while personally believing that legislation was relevant to solving the issue of the conflict between confidentiality and disclosure, were quick to point out that those were just their personal views and not the organizational policy. The official policy was that confidentiality was the cornerstone of their programmes and it should not be tampered with. Breaching this tenet, was liable to get one dismissed.

Despite holding views that the law had a role to play in enabling disclosure, none of the respondents were clear on what this role would be. As to why nothing had been done to ensure that such legislation became a reality, the respondents did not have clear responses. The responses ranged from ‘we just haven’t thought about it’, to ‘it’s not really our area of focus as an organization’. This was despite having mission statements that purported to promote and protect women’s sexual and reproductive health rights. For others, their mission was the promotion of women’s human rights. It was interesting to note that despite working in the area of women, human rights, AIDS, and women’s sexual and reproductive health rights, almost none of the non-governmental organizations knew of the provisions of the National AIDS Policy dealing with confidentiality and disclosure.

5 ‘Your right to swing your fist ends where my nose begins’ – balancing competing rights: A discussion

The captivating title of this chapter was taken from a comment made by one respondent on the issue of balancing competing rights between confidentiality and disclosure. It captures the essence of the argument that rights come with responsibilities. A person should exercise and enjoy his rights, as long as he does not in so doing infringe on the rights of the next person. This seems to be a clear enough concept and in ordinary human rights discourse, it appears to be an accepted principle. Not so with HIV and AIDS.

As the research findings show, a lot of people believe this issue to be complex and most would rather not tackle it at all. Then there are those who do not see it as a grey area, who believe that either the one or the other must go. In *HIV/AIDS care and counselling*, the author believes that:

‘...confidentiality in the counselling context is non-negotiable. A counsellor may under no circumstances disclose the HIV status or any other information to anybody without the express permission of the client even where client refuses to be responsible (Dyk, 2001).

This view is shared by some organizations in Zimbabwe.

The research has shown that while the issue of disclosure has its positive and negative sides, an overwhelming majority of respondents are more in support of disclosure than confidentiality between sexual partners and others with a critical need to know. Respondents from within non-governmental organizations, the church and medical practices and among counsellors and ordinary men and women were in support of some framework being put in place to make either voluntary or non-voluntary disclosure possible.

A number of respondents within non-governmental organizations, who supported non-consensual disclosure to spouses and caregivers, were quick to point out that the sentiments expressed were in a personal capacity and did not reflect their organizations’ positions on the issue. Some organizations did not have a policy or position

on the issue. It had just not been considered. While for others the disparity between organizational policy on disclosure and confidentiality and the personal views of key members of staff of those organizations was interesting to note. It was therefore understandable that two of the respondents only agreed to be interviewed on condition of anonymity. For them to come out in the open as espousing different views from their organizations' would have been foolhardy. This disparity cries out for analysis. The scenario simplified is as follows: the programme officer who is the person on the ground is aware of the realities of people's lives. He is aware of the impact or lack thereof of organization policies and programmes, after all he has hands-on experience trying to implement them. He notices some limitations in the programmes but does not take the necessary steps to ensure that policies or programmes are reviewed and adjusted accordingly. Perhaps the programme officer advises the programme manager. He is reminded of the organizational policy or of the funders' policy. The result? Things are done without any meaningful impact assessment. Programmes are not designed to meet the real needs of the people, hence their relevance or impact is minimal.

This is what appears to be happening with the non-governmental organizations which agreed that non-disclosure between partners is untenable, yet confessed to doing nothing about it because they 'just never thought about it'. If it goes to the root of an organization's goals and objectives, how come the relevant people do not think about it? It points to a lack of critical thinking within organizations and the furthering of donor-driven agendas. This research acknowledges the limitation that no donors were spoken to for their perspective on the issue under discussion, which would have given the discussion more depth. Nonetheless, there seems to be some validity, given the evidence on the ground, for the assertion that non-governmental organizations either are not engaging in critical analysis of their programmes or they do not believe they have the space to do so given the conditionalities that come attached to funding.

Whatever the reason, guiding principle 3 in the National Aids Policy remains a recommendation on paper which no one has bothered to take up in a meaningful way. While this is happening, many more women continue to be infected by their spouses. There is therefore need to revisit the issue with a view to translating the principle into reality. Several suggestions have been made and these will be considered in turn.

Disclosure methodologies

Legislating mandatory partner notification

There were varied responses to this issue. The women who were interviewed who are living with HIV expressed their support. For the respondents who were not in support of legislating disclosure, the reasons for this non-support did not appear to have been thought through. One organization did not see how effective the law would be. They believed that because the Sexual Offences Act has presented some challenges in implementation, so too would any legislation proposing mandatory partner notification. But should the issue not be learning from the lessons of the Sexual Offences Act and ensuring that any challenges are addressed effectively during the drafting process?

An important point was raised that given that relatively few people are being tested, if disclosure were to be made mandatory, the effect of such a provision would be to punish people for getting tested, while those who have not been tested would not be punished. According to statistics furnished by the New Start Centre, in the five years (1999–2003) that the centres have been in operation a total of 227,303 people have been tested in their 18 centres. This is out of a population of eleven million (CSO, 2002). If relatively so few people are being tested, then the concern expressed above is a very real one. Suggestions for addressing this concern included compulsory pre-marital counselling and testing, among others. These issues will have to be seriously considered before any legislation can come into effect.

Incentives to disclose

An investigation of the non-problematic cases – those who disclosed – showed that in most of the cases, disclosure was done in order for some benefit or perceived benefit to be acquired. Going further, the question can be asked, what is it that they most wanted to access? Mainly it was treatment, psychological support, emotional support, material resources (assistance with fees, food, for example) and information on positive living. Yet for others disclosure was part of the process of coming to terms with the diagnosis: the need for answers. But how have other countries dealt with the issue?

Treatment

While there is evidence from the research that people will come forward if they can access treatment and other assistance, the issue has so far not received as much attention as it should. HIV positive people in Zimbabwe generally cannot access anti-retrovirals (ARVs). It is only in the recent past that the issue of anti-retrovirals has become topical. According to the World Health Organization, steps are underway to ensure better accessibility of anti-retrovirals worldwide, and Zimbabwe is just one of the countries where this initiative is taking root.

Anti-retrovirals – what are they?

Anti-retroviral drugs are drugs that act by blocking the action of enzymes that are important for the replication and functioning of HIV. The ultimate purpose of anti-retroviral therapy (ART) is to reduce the HIV viral load as much as possible and for as long as possible. This means that less damage will be inflicted on the immune system and the onset of AIDS is delayed (Dyk, 2001). For optimum viral suppression, triple therapy is recommended. This includes taking a combination of three types of drugs. However this is very expensive and few people can afford the therapy.

At the time of this research, a month's supply for a single drug was about Z\$265,000. A person needs a combination of three drugs, not just once a month, but every day and every month for the rest of their lives. If a person stops taking the anti-retroviral therapy, then resistance may develop and the virus will start multiplying again. This is why the issue of accessibility and affordability is so vital in HIV management. With therapy, the viral load can be reduced to undetectable levels within the body and the person can live as normal a life as possible. Without access to treatment, the virus takes its natural course and within a few years a person will be dead, with all the attendant problems and negative impacts. Anti-retrovirals are not a cure for HIV, the virus cannot be eliminated totally from the body. They are a management agent aimed at keeping the infected person as healthy as possible.

The WHO has made a pledge to put three million people on anti-retrovirals by 2005 (UNAIDS). In Zimbabwe, plans are underway to introduce anti-retrovirals at different hospitals around the country. However, although the cost was then Z\$265,000 for a month's supply of the triple therapy, this was beyond the reach of many of the people infected. There is therefore still a very real need to lobby government to make anti-retrovirals available free of charge or at minimal cost to the needy. Any other course will mean that the poor infected die, while the rich infected live.

One suggestion that has been made is to use the money from the AIDS levy to procure the necessary drugs. Another suggestion, which is already being implemented, is to facilitate the manufacture of generic brands of the necessary drugs. The law should create an enabling framework for this to happen, for example revisiting the Patents and Trademarks Act. One local pharmaceutical company, Varichem, has already started production (*Sunday Mail*, 7 March 2003). Local organizations need to be more organized around this issue. At present it appears the access to treatment initiative is only just starting. As treatment becomes more accessible, people will come forward to try and access it and in so doing there will be more openness about the issue. As HIV becomes more manageable it will become like other conditions which need lifelong management, like diabetes and hypertension, for example. As this happens, the stigma attached to the disease should fall away.

Psycho-social support

Respondents in the study also reported disclosing because they wanted to access emotional, psychological and other support. In terms of provision of support to those who will have disclosed, the answer for most organizations is support groups. However apart from Padare – Man’s Forum on Gender and to a limited extent the Moving-on Post-test Club, no organization has made a deliberate effort to identify the psychological needs of men who have been diagnosed. If they want to disclose their status without the necessary environment or support, they might find it difficult to do so. The result is that they cannot access the necessary information to effect behaviour change and to start living positively.

6 Confidentiality and disclosure in South Africa – a comparative look at their experiences

This discussion can perhaps be enriched by a comparative look at what is happening in South Africa in terms of confidentiality, disclosure, access to treatment and generally creating an environment that enables openness around HIV and AIDS. Judging by newspaper articles and other publications, South Africa has had many people coming out about their HIV status, arguably more than Zimbabwe. The people who have come out have included ordinary men and women, entertainers, a judge of the Supreme Court, Edwin Cameron and leading AIDS activists like Zachie Achmat of the Treatment Action Campaign. So much about the practice but what is the legal position with regards to these issues?

Charter of Rights on AIDS and HIV

The Charter of Rights on AIDS and HIV was drafted in 1991 and developed through a wide consultation process in 1992. It was launched in November 1992 at a conference of over 300 people drawn from non-governmental organizations, religious leaders, political leaders, artists, international organizations and leaders and individuals. The charter is the ‘Bill of Rights of People living with HIV/AIDS’ (AIDS Law Project, 2001).

In section two on confidentiality and privacy, it states that people with HIV and AIDS have the right to confidentiality and privacy regarding their health and HIV status. Further, that information regarding status must not be disclosed without that person’s consent, *‘except when required by law or in cases of clear threat to and disregard of an identifiable individual’s life interests’* (section 2.2). The charter therefore recognizes the need for the right to confidentiality to be limited where its exercise will result in the abuse of someone else’s rights.

The AIDS Law Project has also given clear guidelines on confidentiality and disclosure. Efforts were made to contact the AIDS Law Project during the research to ascertain what their experience of this issue has been but there was no response to the e-mail sent to the organization. It has therefore not been possible to establish how they have translated in practice or whether occasion to use them has ever arisen. The guidelines are given as follows:

‘A health care worker may only tell your sexual partner about your HIV status when:

- 1 The sexual partner is clearly known and identifiable.*
- 2 The sexual partner is at risk of being infected with HIV by you, and you have refused to inform the partner of your HIV status or you have refused to have safer sex.*
- 3 You have been counselled on the need to inform your sexual partner or have safer sex.*
- 4 The health care worker has told you of your duty to protect your sexual partners.*
- 5 The health care worker has warned that if you do not inform your sexual partner or have safer sex, then the health care worker will have to breach confidentiality’ (AIDS Law Project, 2001:125).*

Besides the AIDS Law Project, the Health Professions Council of South Africa, which is a body set up to control the training, registration and conduct of doctors, dentists, psychologists and other health professionals

who practice in South Africa, has also published guidelines on confidentiality and disclosure in HIV. As a general principle, they state that:

'the results of HIV positive patients should be treated at the highest possible level of confidentiality.'

However it recognizes that some situations arise whereby there may be need to disclose a person's status to third parties. In that event, the Health Professions Council of South Africa recommends the following steps, which are not unlike those given by the AIDS Law Project:

- 1 *Counselling the patient on the importance of disclosing to his or her sexual partner and taking other measures to prevent transmission of HIV;*
- 2 *Providing support to the patient to make this disclosure;*
- 3 *Where the patient still refuses to disclose his or her HIV status or refuses to consider other measures to prevent infection, counselling to patient on the health care worker's ethical obligation to disclose such information and requesting consent to do so; and finally*
- 4 *Disclosing such information.*

While recognizing the complexity of some situations that can arise, it cautions that health care professionals should be prepared to assume full responsibility in the event of a civil suit because the law does not quite cover the scenario meant to be catered for in the guidelines. This is in itself problematic because it does not provide protection should a medical practitioner exercise her discretion and disclose to a patient's partner.

The legal position

The legal position on confidentiality of HIV status was settled in the matter of *Jansen van Vuuren and Another v Kruger* 1993 (4) SA 842 (A) (the McGeary Case). McGeary wanted to apply for a life assurance policy. The insurance company told him he had to have an HIV test. He went to his doctor and asked for a test. It came back positive and McGeary was so advised. The next day his doctor played golf with another doctor and a dentist, they discussed AIDS and McGeary's doctor told the other doctor and dentist that McGeary had tested positive. Within days the news of McGeary's HIV status had spread through his small community. McGeary sued his doctor for breaching his duty of confidentiality. McGeary died of an AIDS-related illness during trial but lawyers for his estate pursued the claim.

The then Appellate Division held that Dr Kruger (McGeary's doctor) had a duty to respect McGeary's confidentiality, which duty he had breached. Damages were awarded in the sum of R5000.

While this case involved breach of confidentiality where the people told did not have a right or need to know, the situation involving a spouse or sexual partner is not as clear-cut, hence the guidelines that the various bodies and organizations have drawn up. This case also shows that a civil suit is a real possibility when someone feels that his or her confidence has been breached. It therefore underlines the need for legislative protection for medical personnel in instances where their discretion has been exercised for the benefit of a third party who has a critical need to know. Legislative intervention would also need to clarify persons deemed to have a critical need to know, so as to exclude instances of gossip as in the McGeary case.

Other initiatives to promote disclosure

Access to treatment campaigns have largely been more successful in South Africa. Dr Peter Piot of UNAIDS stated in a recent interview that South Africa will soon have the world's largest anti-retroviral distribution programme. The political and budgetary commitment having already been made (*Mail and Guardian*, March 2004).

Beyond the access to treatment enabling more people to come forward, there are also several initiatives by non-governmental organizations like the Disclosure and Acceptance Campaign, the National Association of People Living with HIV/AIDS, as well as the Beyond Awareness Campaign. The latter published a book, *Living openly: HIV positive South Africans tell their stories*. These campaigns have seen people disclosing their status at individual and societal or community levels. Leadership by example has seen AIDS activists coming out about their status. The openness campaign is aimed at destigmatization through status openness. It is meant to show that HIV can and does affect anyone regardless of social, economic or political status.

Such an approach has not been taken in Zimbabwe. There has been little leadership from HIV/AIDS activists with regard to openness. The relatively few people who have come out about their status have been people with low social status – people who have disclosed because they need assistance of one form or the other. The one organization formed specifically around openness and which issued a challenge to activists to come out and reveal their status whether positive or negative, the HIV/AIDS Truth Society (HATS), appears to be regarded with derision by the more established non-governmental organizations. A lot still needs to be done and lessons can be drawn from a country such as South Africa.

AIDS activists and AIDS service organizations need to revisit their strategies with a view to devising interventions that meet the needs of their target groups.

Recommendations

Research into the issue of men and HIV and AIDS

There appears to be dearth of information on the issue of men and HIV and AIDS. There is therefore need to build up a body of knowledge. As Ingeborg Breines puts it, ‘perhaps it is time that we started thinking of being male as a risk factor’. This is because men’s life expectancy is lower than that of women, men have more accidents, they fill up prisons and top criminal statistics. With the advent of HIV the risk has become not just a risk for themselves but for those they associate with – women (Breines and Connell *et al.*, 2000).

Creation of male spaces

For a long time responses have been geared at finding ways of assisting women in dealing with the HIV pandemic. Responses need to acknowledge the fact that as men are part of the problem, they should be part of the solution. Male spaces need to be created to enable men to access assistance and to play a useful role in mitigating the impact of HIV. In Mufakose where Padare is working with men on the issue of HIV and AIDS, men are already actively involved in volunteer home-based care work. They are also involved in support groups. Initiatives like Padare’s should be strengthened so that they gain ground. If men become more involved, society in general, and women in particular, can only benefit. One question that needs to be asked is: where are men to be found? Is it at ‘boozers’ – soccer clubs? Or is it at sports clubs in town? This is one of the strategies used by Padare. It only needs to be spread further – Padare is just one organization.

Promotion of voluntary disclosure

Deliberate efforts need to be made to promote disclosure and openness around HIV, AIDS and sexuality. Innovative ways of promoting disclosure and openness need to be explored. In this regard lessons from South Africa and Uganda will be useful. Leadership by political, business and non-governmental organization leaders needs to be cultivated. At present the issue of openness and disclosure has no public prominence, yet it is of fundamental importance when talking of destigmatization. Organizations like Population Services International can begin by including information on disclosure in their pamphlets. For example, in their pamphlet, *What to expect from counselling and testing*, in the section which deals with what happens after being tested, the pamphlet should address the issue of disclosure, in addition to talking about abstinence, faithfulness and condom use. This is because the issue of disclosure is central to the post-test concerns of people. The individual does not live

in a vacuum; addressing this issue is an acknowledgement of this fact. Alternatively, or in addition, the issue of disclosure can be dealt with fully in a separate pamphlet. The issues to be addressed in such a pamphlet include the guidelines for disclosure previously described. Initiatives like that of the HIV/ AIDS Truth Society should be supported and strengthened, and their interventions given more support in terms of direction. For instance, the breakfast meetings they hold may not be the most efficient way of dealing with the issue but at least they have identified a certain class in society that is left out of prevention efforts – the professional class. There should be a drive to involve politicians and business leaders in the fight against HIV and AIDS. Indications from the region are pointing to this as the way forward. Already the president of Malawi has taken an HIV test and disclosed to the nation, the president of Lesotho recently had an HIV test done (*Mail and Guardian*, 12–19 March 2004).

Coordination of efforts

There is need for the efforts of the various players in the area of HIV and AIDS to be better coordinated. One suggestion that has been made is for the creation of a ministry responsible for the HIV/AIDS response. This will be an acknowledgement that the issue is not just a health issue. It cuts across all sectors and all disciplines. The response needs to be just as multisectoral. This will enable a holistic approach to the problem of HIV. Secondly, there can be control of the quality of messages and programmes on HIV. At present, conflicting messages are being sent out by the various players – abstinence, condom use, the dangers of using condoms, marriage as the answer to AIDS, and faithfulness have all been promoted by the different players. It tends to create confusion among the recipients of the information, and if a couple is receiving these mixed messages, the consequences could be dire. Networks and umbrella bodies like the Zimbabwe AIDS Network should play an active role in the coordination of the efforts of member organizations. Perhaps regulation of the various organizations should be seriously explored to weed out opportunists and ensure greater accountability in the sector. Finally, a mechanism of ensuring that research bodies can feed their knowledge to implementing bodies should be developed so that interventions by the latter are based on empirical knowledge and are thus responsive to the real needs of the people. At present it does not appear that there is a quick uptake of research findings by implementing organizations, since some of the issues, which these organizations were ignorant of, had been covered extensively in research.

Legislative guidelines for non-consensual disclosure

There is need to legislate for non-consensual disclosure of a person's HIV status to those who have a critical need to know. Such legislation would be recognition of the fact that voluntary disclosure, while ideal, does not always happen. It would be recognition of the difficulties faced by medical practitioners and other service providers in real-life situations and their need for protection as they try to deal with the dilemmas they face around the issue of HIV and AIDS.

Suggested legislative guidelines

The test results of HIV positive patients shall be treated with confidentiality.

However, where it appears to the doctor, nurse, counsellor or other medical professional in a position of authority, that there is risk of the patient infecting or exposing other persons to risk of infection, then it shall be lawful for the medical professional to disclose a patient's status to a third party. Before any disclosure can be made in terms of this section, the medical professional, shall:

- Counsel the patient on the importance of disclosing his or her HIV status to his or her sexual partner and taking measures to prevent transmission of HIV.
- Provide the necessary support to enable patients to make disclosure, including referral to specialist organizations.

- Advise patients of the medical professional's ethical obligation to disclose such information to a known sexual partner,
- Disclose such information.

Any disclosure of confidential information made in terms of this section shall not be deemed to be a breach of a doctor, nurse or other medical professional's duty of confidentiality.

Bibliography

Beyrer C., *War in the blood: Sex, politics and AIDS in Southeast Asia*, Zed Books, London, 1998.

Commonwealth Secretariat, *Gender mainstreaming in HIV and AIDS: Taking a multisectoral approach*, London, 2002.

Dyk A., *HIV/AIDS, Care and counselling: A multidisciplinary approach*, second edition, Pearson Education, South Africa, 2001.

Feldman R *et al.*, *Positive women: Voices and choices*, Zimbabwe report, International Community of Women Living with HIV and AIDS, Zimbabwe, 2002.

Hellum A., *Women's human rights and legal pluralism in Africa: Mixed norms and identities in infertility management in Zimbabwe*, Mond Books, Harare, 1999.

Jackson H., *AIDS Africa: A continent in crisis*, Safaids, Harare, 2002.

Kaleeba N., *We miss you all; AIDS in the family*, Women and AIDS Support Network, Harare, 1991.

Kelly T. (Fr), *The body of Christ has AIDS: Opportunities and challenges for the church*, Catholic Fund for Overseas Development, Harare, 2003.

Matlin T. and N. Spence, 'The AIDS pandemic and its gender implications', paper presented to the UN expert group meeting on gender and HIV/AIDS, Windhoek, Namibia, 2000.

Midlands AIDS Service Organization, *Stories of courage: Living openly with HIV/AIDS*, MASO, Gweru, 1998.

Musasa Project, *Domestic violence and HIV/AIDS: Two linked epidemics*, Musasa Project, Harare, 2003.

Population Reference Bureau, *Conveying concerns: Media coverage of women and HIV/AIDS*, Population Reference Bureau, Washington, 2002.

Staib A., 'Women's human rights and reproductive autonomy: The argument of development illustrated through adolescents girls' right to choose protection from procreation and sexually transmitted diseases', in *Studies in Women's Law* no 46, Oslo, 2001.

UNESCO, *Males, masculinities and violence: A culture of peace perspective*, Paris, 2000.

Weis-Bentzon *et al.*, *Pursuing grounded theory in law: South-North experiences in developing women's law*, Mond Books and Tano-Aschehoug, Harare, and Oslo, 1998.

World Council of Churches, *Facing AIDS. The challenge, the church's response*, 2001.

World Health Organization, *Legislative Responses to AIDS*, 1988.

Websites – Internet resources

www.alp.org.za – The AIDS Law Project

www.cdc.gov/zimbabwe – Centres for Disease Control

www.thegaia.org/resources/facts.htm – Global AIDS Interfaith Alliance

www.genderandaids.org – Gender and AIDS Organization

www.unifem.undp.org – United Nations Development Fund for Women

www.unaids.org – Joint United Nations Programme on HIV/AIDS

Table of statutes

The Constitution of Zimbabwe
The Sexual Offences Act, Chapter 9:21
The Public Health Act, Chapter 15:09
The Labour Relations Act, Chapter 28:01
Statutory Instrument 202 of 1998
The National Aids Policy, 1999

International instruments

The Convention on the Elimination of all forms of Discrimination Against Women (The CEDAW)
CEDAW Committee General Recommendation 15 of 1990 (Avoidance of discrimination against women in National Strategies for the Prevention and Control of AIDS)
Recommendation on Ethical Issues in Health Care and Social Settings – Council of Europe, 1989.
Declaration of the Paris AIDS Summit (WHO, 1994)
Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (AU, 2003)

Table of cases

Attorney-General v Foster [1963] 2 QB 477
Jansen van Vuuren and Another NO v Kruger 1993 (4) SA 842 (A)
Retrofit (Pvt.) Ltd. v Minister of Information 1995 (2) ZLR 422
TS Masiyiwa Holdings (Pvt.) Ltd. v The Minister of Information and Another 1996 (2) ZLR 754 (S)

Appendix 1

RESEARCH QUESTIONS – GENERAL

1. Do people (men) disclose their HIV positive status to their partners?
2. Under what circumstances is such disclosure done?
3. Who disclose more – men or women?
4. How can this be explained?
5. If they do not ordinarily disclose, what are the reasons usually advanced for not doing so?
By men?
By women?
6. Do you think there is need to legislate mandatory disclosure to one's spouse or partner?
7. If not, why not?
8. If yes, why do you think no legislation has been enacted to make this possible?
9. Is your organization doing anything in this regard?
10. What do you understand by the duty of or right to confidentiality?
11. Is this right absolute?
12. If there are exceptions, what are these?
13. Is there a conflict between the right to confidentiality and the right to information?
14. If yes, what are the implications of such a conflict?
15. Can it be resolved? How?
16. Does mandatory disclosure lead to stigmatization of people living with HIV and AIDS? In what way?
17. Does the lack of legislative mechanisms contribute to women's vulnerability to HIV?
18. Do medical personnel disclose a person's HIV status to their relatives?
19. If they do, under what circumstances is this done?
20. Who is told and why?
21. What role can the law play to enable disclosure – guidelines for enabling disclosure to partner by other persons, for example, counsellor, medical personnel and so on? Or any other role, for example, incentives by way of treatment, and so on.

Appendix 2

QUESTIONS FOR WOMEN and MEN LIVING WITH HIV

1. Do you know how you got infected? How did it happen?
2. Did you know or suspect that your partner was infected?
3. How did you get to know about his status?/ Why did you suspect your partner was infected?
4. When or at what point in your relationship did you know?
5. If you had known his or her status would this knowledge have changed anything in your relationship? What would you have done differently?
6. For those who knew, did knowing change anything? What did you do differently? If you did not do anything differently, why not?
7. Do you think that spouses or partners should be made to disclose their status to each other? Or should the law enable doctors or nurses to advise a person's spouse or partner?
8. If not, why not?
9. If yes, why?
10. How did you find out about *your* status?
11. When did you find out?
12. Did you disclose to your partner?
13. At what point did you disclose or how long after knowing or suspecting?
14. What motivated you to disclose?
15. Who did you disclose to first?
16. What was their response?
17. What was your partner's response?
18. Did you get any assistance in making the decision to disclose? Who gave you this help? What kind of help was it?
19. What, if anything, would you have done differently? Why?
20. What role do you think the law can play to enable disclosure? For example, policy relating to access to treatment for people living with HIV?
21. What can be done, generally, to enable disclosure?