

A Strebhel, A Cloete, L Simbayi, D Ntseane, K Nthomang, M
Segwabe & O Phorano

Social Aspects of HIV/AIDS and Health (SAHA)

August 2009

Four-country report on
formative research into
the development of a HIV
behavioural risk reduction
intervention for PLWHA
Botswana, Lesotho, South
Africa and Swaziland

HSRC



HSRC
Human Sciences
Research Council

TABLE OF CONTENTS

INTRODUCTION	2
Prevention interventions with PLWHA	3
Support groups for PLWHA.....	4
Interventions in clinical care settings.....	5
Aims and objectives	6
METHODOLOGY	6
South Africa	7
Botswana	7
Swaziland.....	7
Lesotho	8
Data analysis	8
RESULTS	8
Challenges facing PLWHA.....	8
Stigma	9
Disclosure.....	10
Risky behavior	13
Socio-economic issues.....	13
Myths, traditional practices and beliefs	14
Some considerations for possible risk reduction interventions.....	15
Available services	16
CONCLUSION.....	17
REFERENCES	18

ACKNOWLEDGMENTS

This report was prepared in collaboration with:

M.M. Kosene¹; B. Makhakhane¹; D. Braimoh²

¹ Department of Adult Education, National University of Lesotho

² Institute of Extra Mural Studies, National University of Lesotho

Mthembu, P.³; Mkhonta, N.R.³

³ University of Swaziland, Swaziland

This project was funded by the UK Department for International Development (DFID), the Canadian International Development Agency (CIDA) and the Directorate General for International Cooperation (DGIS) of the Netherlands Ministry of Foreign Affairs through the Social Aspects of HIV/AIDS Research Alliance.

INTRODUCTION

This research project was part of a multi-country study which was conducted in eight sub-Saharan African countries including four in the Southern Africa Development Community (SADC) region, namely South Africa, Botswana, Lesotho and Swaziland from 2005 to 2007. The main goal of the overall project was to develop and/or adapt behavioural and supportive interventions to assist people living with HIV/AIDS (PLWHA) reduce their risk of re-infection or infecting others.

To date, HIV prevention efforts in most countries have focused primarily on encouraging people, including those not at risk, to engage in safe sex practices. This has meant that people who know they are HIV positive have been largely ignored regarding prevention efforts in the sub-Saharan HIV epidemic. Although southern Africa has made some significant strides over the past few years to reduce the spread of HIV infection through several national prevention programmes, such as the syndromic management of sexually transmitted diseases (STDs) and HIV/AIDS voluntary counselling and testing (VCT) in health facilities, the rates of HIV infection in these countries continue to be unacceptably high.

The main prevention strategies employed in national HIV and AIDS campaigns typically involve abstinence, being faithful and using condoms (the so-called ABC approach). Increasingly it has been recognized that, in order to be successful, HIV prevention efforts also have to target PLWHA. Several recent population-based surveys in sub-Saharan countries with high HIV prevalence, such as Botswana, Kenya, South Africa, Zambia and Zimbabwe, have shown that the number of PLWHA is growing as anti-retroviral (ARV) drugs become available. Considering the predictions of continuing increases in the population of PLWHA who know their HIV status globally and particularly in sub-Saharan African countries, due to the wider availability and access to ARV treatment since 2005 which has mainly been supported by both the USA President's Emergency Plan for AIDS Relief (PEPFAR) and The Global Fund to Fight AIDS, Tuberculosis and Malaria, a shift towards the implementation and scaling up of behavioural and social support interventions for PLWHA who know their HIV status is needed. In addition to this, as the numbers of people who undergo VCT in order to determine their HIV status in sub-Saharan Africa increases, we can expect substantial increases in the number of PLWHA who

know they are infected. Therefore, the need to direct prevention interventions towards PLWHA becomes a public health imperative. Indeed increased access to ARV treatment in developing countries provides a historic opportunity to impact the AIDS epidemic, by integrating HIV prevention intervention into expanding treatment programmes for PLWHA (Global HIV Prevention Working Group, 2004).

Nonetheless in southern African countries, HIV risk reduction interventions for PLWHA remain scarce. Acknowledgement of the need for new and innovative strategies to curb the further spread of HIV has led to the evaluation and revision of current national HIV prevention campaigns. Even though curbing the further spread of HIV is important, by means of focusing on reducing unprotected sex acts and high risk behaviours among PLWHA, other factors like psychological adjustment and coping are central to HIV management; and if not adequately addressed, this could contribute immensely to high-risk behaviour. Equally important is the need to base HIV prevention efforts for PLWHA on empirical evidence. To date, the bulk of the available evidence-based HIV prevention interventions for PLWHA have been designed and implemented in the United States of America (USA) and in other developed countries (Kalichman, 2005).

Prevention interventions with PLWHA

In a publication released by Insite¹, Colfax (2004) asserts that there has been increasing emphasis in the USA's public health care system on addressing the HIV transmission behaviours of HIV-positive persons. This can be related to the use of newer and more effective treatments of HIV/AIDS that are becoming increasingly available to HIV-positive people. Moreover according to Colfax (2004), where ARV therapy is readily available, decreasing HIV morbidity has been paralleled by increasing HIV infection rates, suggesting that prevention programmes targeting only HIV-negative persons may be inadequate to curb the epidemic,. Addressing the HIV prevention needs of PLWHA becomes even more of a priority in the light of studies illustrating that a significant minority of people living with HIV are still engaging in risky behaviour (see: Clearly, 1991; Crepaz & Marks, 2002; Hankins et al., 1997; Kalichman, 1999, 2000; Marks et al., 1991; Robins et al., 1994). Indeed, the 2002 national population-based survey in South Africa (Shisana & Simbayi, 2002) showed risk behaviour to be a very common occurrence among PLWHA in South Africa who

¹ HIV insite is a project of the University of California San Francisco Centre for HIV Information

were aware of their HIV status. While the 2005 survey noted a significant improvement, nearly one third of PLWHA who were aware of their HIV status were still engaging in risky behaviour (Shisana et al., 2005a). Interestingly, similar results to the 2005 survey were obtained in a study that was conducted among South African educators (Shisana et al., 2005b).

Support groups for PLWHA

According to the University of California at Los Angeles's Centre for HIV Identification, Prevention and Treatment Services (CHIPTS) (2003), since the beginning of the AIDS epidemic, many interventions designed for PLWHA were implemented within existing structured group programmes, for instance in support groups for PLWHA. A 1996 study found that the primary purpose of the support group was grounded on avoidance of drug use and adjusting to HIV. Little time was spent on discussing safer sex practices to prevent transmission of HIV (Greenberg et al., 1996).

Other studies also illustrated that in support groups for PLWHA there was a lack of addressing or changing risky behaviour of PLWHA (Blanch et al., 2002; Coates et al., 1989; Lechner et al., 2003; Perry et al., 1991). However, it was found that some support groups also produced changes in risk behaviours, and in the context of this study, these findings illustrated that a focus on coping or mental health was related to decreased risk behaviours (Kelly et al., 1993).

At the time when this study was started in 2005 there had been only a handful of behavioural interventions specifically designed for HIV-positive individuals that have been tested, shown to be effective and published in peer-reviewed journals (Fogarty et al., 2001, Kalichman et al., 2001). Group-level interventions for HIV-positive individuals located in a community setting include Healthy Relationships developed by Kalichman et al. (2003), which is a behavioural intervention grounded in social cognitive theory. It was tested and found successful with gay and bisexual men as well as heterosexual men and women. Healthy Relationships was among the first interventions to demonstrate successful HIV transmission risk reduction resulting from a behavioural intervention tailored for HIV positive persons. Healthy Relationships has been compiled in a user-friendly package, and is now being implemented in several American states (Kalichman, 2005; Metsch et al., 2005).

Another study by Margolin et al. (2003) incorporated prevention efforts into the structure of existing substance abuse treatment, in what is essentially a harm reduction intervention. Since effectiveness of the intervention was demonstrated, the harm reduction intervention and the materials necessary to implement it have been compiled into a user-friendly package called Holistic Harm Reduction Program (HHRP). Kalichman (2005) reported on a third intervention called Teens Linked to Care (TLC) by Rotheram-Borus et al. (2001a, 2001b). The intervention consisted of 31 sessions and three modules designed to decrease HIV transmission behaviours, and help HIV positive youth maintain health care regimens and improve their quality of life. Since the effectiveness of TLC was demonstrated and tested prior to highly active antiretroviral therapy (HAART), the intervention was restructured and is now called CLEAR: Choosing Life: Empowerment, Action and Results Intervention for Youth Living with HIV.

Interventions in clinical care settings

While an increasing amount of work has been done on testing group-based interventions, individual interventions in clinical care settings have been a relatively new area of research for which limited outcome data are as yet available. Kalichman (2005) has reported on a few such interventions currently being implemented and tested in clinical care settings as follows. The first one, called The Healthy Living Project (Rotheram-Borus et al., 2003), is a multi-site intervention conducted in a number of states in the US. It involves HIV-positive individuals from across risk groups, recruited at clinical care sites. Another intervention called The Partnership for Health, asks healthcare providers to deliver an HIV prevention intervention to HIV-positive patients (see Kalichman, 2005). Providers briefly address HIV risk-reduction behaviours during each clinic visit. A third intervention, the MD 4 Life project, enlists clinical care providers to deliver an HIV risk reduction intervention for HIV positive persons (Lightfoot et al., 2004). Patients complete a 20-minute computer-assisted HIV risk behaviour assessment during each clinical care visit (approximately every three months for two years) while waiting to see the clinician. The Methadone Maintenance Programmes are another clinical care setting intervention.

A further individual-level intervention for HIV positive persons in a clinical care setting was conducted by Fisher et al. (2004; Fisher, 2005), called Options for Health. This

intervention is implemented by HIV care clinicians on an ongoing basis over the course of clinical care among PLWHA. Analysis of Options for Health 18-month follow-up data showed that this brief, theoretically-based intervention had a highly significant impact in reducing unprotected vaginal, anal, and oral sexual contacts among PLWHA over the follow-up period. These results provide substantial empirical support for the use of this approach on an ongoing basis in the HIV clinical care setting, linking HIV treatment and care, as a feasible and effective means of assisting HIV-positive patients to reduce HIV transmission risk behaviors (Fisher et al., 2004; Fisher, 2005; Fisher & Cornman, 2003).

Aims and objectives

The first phase of the broader research project involved both qualitative formative methods, as well as a quantitative baseline study. The main aim of the qualitative part of the study, reported on below, was to identify issues for consideration in creating or culturally adapting intervention models for behaviour change for use among PLWHA who are aware of their status. This report will provide a summary of some of the findings that were found in the reports on the studies that were conducted in each of the four SADC countries, namely Botswana, Lesotho, Swaziland and South Africa. In particular, it highlights some of the similarities and differences in the results across the countries involved.

METHODOLOGY

A preliminary set of consultations between the four countries focused on conceptualising the research methodology for this formative phase of the project, as well as developing the tools for the study. As a result of this process, it was decided that there would be two main forms of data gathering: key informant interviews and focus group discussions with PLWHA involved in community support group structures. In addition, generic interview guides were developed during the consultation, for adaptation as necessary in the specific context of each country. Thus, while the implementation of the research design differed somewhat across the four countries, depending on local contextual factors, the model of key informant individual interviews together with focus groups with PLWHA was broadly followed. Issues explored in both the individual and group interviews included the challenges facing PLWHA, as well as their experiences of the value of and need for support

groups, and the nature of available services for PLWHA. Particulars of the methods used in each country are provided below.

South Africa

Fourteen key informants were interviewed, seven of whom were affiliated to support groups for PLWHA and others, and the other seven represented NGOs, activist groups, government departments and training services. In addition, eight focus group discussions were held with existing support group structures that were situated at either ARV roll out sites or organisations that provided services to PLWHA. Access to these support groups was obtained through some of the key informant participants. Inclusion criteria for this sample were that participants should be HIV positive 18 years or above. They were sampled to include a mix of African, Coloured and White participants, of both sexes, and some with same-sex partners. Three mixed sex and five single sex groups participated in the focus group discussions. The total number of participants for these focus groups was 83. The focus groups were conducted in Xhosa, English or Afrikaans. All sessions were audio-tape recorded, and facilitators kept session notes. All participants in this study did so voluntarily and anonymously, and signed consent forms beforehand. Fieldwork was conducted in the Cape Town Metropole in the Western Cape Province. Ethical approval was obtained through the Human Sciences Research Council's Research Ethics Committee.

Botswana

Data were collected using face-to-face interviews with 17 key informants. These included primary health care providers such as doctors, nurses, VCT counsellors and social workers; as well as five AIDS advocates and support group programme managers. Focus groups were held with men, women and mixed groups (i.e. both men and women). Six focus group discussions were conducted, with a total of 60 participants. Almost all respondents were members of or closely associated with a support group for PLWHA. The focus groups were conducted in Setswana in both Gaborone and Gabane (a small village in the outskirts of Gaborone). Ethical approval was obtained from the Health Research Development Committee, in the Ministry of Health.

Swaziland

Four focus group discussions were conducted, one in each region (Hhohho, Lubombo, Manzini and Shiselweni). All respondents were screened by the leaders of

the support groups before their participation in the study to certify that only PLWHA were involved. The focus groups ranged in size from 7-13 participants. There were 24 females and 7 males. Convenience sampling was used to select the participants for the study. The interviews were conducted in siSwati and audio-tape recorded.

Lesotho

For key informants, questionnaires were distributed among 10 organisations that have programmes or projects combating HIV/AIDS. These were key organisations which were identified as having well established programmes/projects. The focus group participants were sampled from several support groups in Maseru communities. There were 55 participants, all of whom were PLWHA, who were randomly chosen as representatives of their groups, and who participated in seven sessions conducted in Sesotho.

Data analysis

All the audio-recorded interviews were transcribed verbatim, and translated into English where necessary. Thematic content analysis was used to analyse and interpret the data.

RESULTS

The reporting of findings will focus on those issues which were common to the four country reports, and will highlight some points which were mentioned by respondents in a specific country. The qualitative results of both the key informant interviews as well as the community focus group discussions are reported together. In line with the aims of the broader research project, namely challenges facing PLWHA, their responses to the possible risk reduction interventions, as well as services available to PLWHA in the four countries, are presented.

Challenges facing PLWHA

The main challenges identified by participants in both the key informant individual interviews, as well as the focus groups with PLWHA, related to stigma; disclosure; risky behaviour; socio-economic issues; and myths, traditional practices and beliefs, as discussed below.

Stigma

The first major issue that was mentioned in all four country case studies was that of the stigma associated with being HIV-positive. Respondents across the four countries mentioned this as one of the main issues which affect PLWHA. The source of this stigma varied somewhat – in two countries (Lesotho and Swaziland) a person's family was considered to be the major source of stigma, while in South Africa and Botswana, the greater community were perceived to be the main offenders. However, fear of this stigma was equally strong and pervasive in all four countries. Respondents mentioned the fear of losing their jobs, of being evicted by their families, or of being divorced, or walked out on, by their partner or spouse:

The problem that we are facing as a person living with this virus, there's a stigma and a discrimination, because people, if you say 'I am HIV-positive', they are going to chase you away [South African focus group]

Although it was mentioned in all four countries that this stigma seemed to be lessening in towns, the stigma faced by PLWHA in rural areas was still severe, as reported in the Swaziland study:

In the rural areas, they do not want to live with you once they discover that you are HIV positive, while others do not want to eat with you.

This extended in many cases to stigma against the person's family members or children, and included labeling and name-calling, refusal to allow the PLWHA to share cooking or eating utensils, or simply refusing them access to buildings, homes, or jobs. As one respondent in a Botswana focus group put it:

We are afraid to disclose because they laugh at us and discriminate against us and once they know about your status they do not want to share household utensils with you.

It also led to accusations of promiscuity or adultery against the PLWHA – the assumption being that only people who sleep around, or who cheat on their partners, were infected with HIV. Thus, in Swaziland, a respondent stated that people in the community believed that:

A person with HIV/AIDS is promiscuous and is engaged in prostitution... People believe that HIV/AIDS people are sex maniacs.

It was mentioned in all four country reports that this stigma seemed to be particularly directed towards women; and that the implication of being promiscuous or sleeping around seemed to be more damaging for women than for men:

Stigma is still prevalent in our township, and as a result it is very detrimental to our communities, more particularly for women [South African key informant]

Generally, the stigma was attributed to a lack of education and understanding on the part of the broader community regarding methods of transmission of HIV. Many in the community also seemed to be of the opinion that HIV was something that only “immoral” people are infected with, so that people who have it must “deserve it” somehow. As noted above, the idea seemed to be that one only got HIV through being promiscuous:

The idea that HIV and AIDS is a punishment from God I think runs through all religions, and that you're being punished for leading a promiscuous life or immoral life or whatever, so that is also a dominant theme in the Muslim community [South African focus group].

Disclosure

This fear of being stigmatised had a number of negative spin-offs, especially regarding lifestyle choices for PLWHA. For example, most PLWHA were reported as being very reluctant to disclose their HIV-positive status to their family members, partners, friends or associates:

Disclosure is difficult because relatives might desert the HIV-positive person. Discrimination is common especially in rural areas. [Swaziland report]

Almost all the patients I see every day (about 5-7) are afraid to disclose They say they fear stigma and discrimination from other people. It looks like stigma and discrimination is very common in Botswana and this is a major challenge for PLWHA. [Botswana key informant]

Thus, those who faced extensive stigma were unlikely to disclose their status openly; while those who were less worried about being stigmatised by those around them would be more likely to disclose. The fear of disclosure was also often more strongly felt by women, especially if they were financially dependent on the person to whom they planned to disclose (e.g. a husband/partner, family members). They feared being divorced or thrown out of the house, thereby losing their financial security:

As women we do not have money and are dependent on men. If you tell him you have HIV, he is gone and you will never find him ... you lose a source of livelihood. Also disclosure leads to conflicts in the family [Botswana focus group]

A number of women also mentioned a fear of physical abuse from their spouses or other male relatives. For example, in a South African focus group, one woman stated:

I was scared to tell him [boyfriend], I was just thinking, how am I going to tell him, because he likes to beat me, he is vicious, I thought if I can tell my boyfriend that I am HIV-positive, I have AIDS, he might kill me

In the South African report, it was moreover noted that the fear of disclosing one's HIV-positive status was higher for those who were also lesbian, gay, bisexual, or transgendered (LGBT). This is because they had often not disclosed their sexual orientation yet to their families, and felt that they would need to disclose both aspects at the same time (i.e. their sexuality and their HIV-positive status). This was sometimes referred to as the “double whammy” of disclosure:

90% of the men here haven't even told their family members they were gay, never mind that they are positive ... wow, you haven't even told your family that you are gay, or your friends, so how can you open up and tell them that you're positive?
[South African key informant]

Although disclosure for LGBT was mentioned as a potential issue in some of the other country reports, it generally seemed to be believed that there were not enough LGBT in these countries for this to be considered a problem. However, for those in South Africa, the combined stigma of being HIV-positive and LGBT (both generally

considered to be “dirty” or “immoral”) made disclosure especially difficult for this group.

In all four countries, the fear of stigma meant that many people were reluctant to be tested at all; and they preferred not to know their HIV status, rather than face the stigma of being confirmed as HIV-positive. This seemed to be especially true for men in all four countries, who would refuse to get tested until they began to show symptoms of HIV, or fell ill. Women, on the other hand, were more likely to go for testing earlier, especially if their partners, husbands or children tested positive, and did not necessarily wait until they became symptomatic themselves:

When I found out that I am HIV-positive, I told my partner, my husband that I'm HIV-positive, then he said he is fine, he won't go for a test ... and now he's not here, he's in Joburg with my children [South African focus group]

Interestingly, however, in the South African study, there was also a sentiment among some focus group participants that stigma and discrimination were decreasing, and that attitudes were shifting toward greater acceptance of PLWHA in local communities:

I think it [acceptance of PLWHA] is getting better ... according to my feelings it is really improving ... stigma and discrimination in the workplace is going down

The fear of stigma meant that many PLWHA did not feel able to follow positive living suggestions for fear that others would discover their status. For example, a number of women believed that they could not be seen to be giving their children formula feed instead of breast milk:

Because people in the location know that if you give your baby [name of formula feed brand] you are HIV positive [South African focus group]

PLWHA also often refused to access services, for fear of their community discovering that they were HIV-positive. For example, there was sometimes low anti-retroviral treatment (ART) adherence, with PLWHA refusing to take their medication on a daily basis, as this could lead others to the conclusion that they were HIV-positive. Many were also reluctant to visit Voluntary Counselling and Testing (VCT) centres, or to

attend support groups, as members of the community would assume that they were HIV-positive. As a respondent in a Swaziland focus group put it:

The support group offices have a stigma attached to the infrastructure.

Risky behavior

A number of issues were raised regarding risk factors related to HIV infection. The fear of stigma, and lack of belief in the reality of HIV, also occasionally led PLWHA to continue (or begin) to engage in risky behaviour, including alcohol abuse, unprotected sex, and poor nutrition and health choices. Many people did not feel able to moderate their lifestyles, again for fear of having others discover that they were HIV-positive, which for women could also result in gender-based violence. In some cases, PLWHA continued to have unprotected sex with their partners, even though they were aware of the risk of infecting their partner, rather than begin using condoms, and have their partner discover their HIV-positive status:

The challenge is that if a man is positive and a woman is negative you may find that male partners will try and force the other partner to have unprotected sex and if they don't agree with them they try by all means to force them in a way they could so that they can infect them. That is what we normally experience [Botswana key informant].

The Botswana study also noted that it was most difficult to negotiate condom use when the positive partner had not disclosed their status. Some respondents also mentioned that it was difficult to try and cut down on the number of sexual partners they had, as they were used to being able to have multiple partners:

It's hard to change our habit and difficult to impose limits because one is used to have sex with anybody [Swaziland Focus Group].

Socio-economic issues

However, stigma was not the only reason for PLWHA continuing to engage in risky behaviour. In some cases, the person's socio-economic context played a big role in their ability to follow positive-living guidelines, as reported from Swaziland:

The poverty that prevails in the general population undermined the need for change.

For many, poverty and unemployment meant they were unable to afford good nutrition and exercise, or formula feed for babies (in the case of new mothers). It was therefore noted in all four-country reports that the socio-economic context of PLWHA needed to be taken into account when planning risk reduction interventions. For some people, their HIV-positive status may be a secondary issue, with poverty, unemployment or even gender violence as their primary concern:

People come because they are HIV-positive, they come to the support group, but many times the HIV status is almost secondary in the support group, it's like a whole lot of other issues that come out about poverty and about unemployment, about domestic violence, about child support, just everything else but the HIV status [South African key informant]

Myths, traditional practices and beliefs

Myths, and traditional or cultural beliefs and practices, also often played a big role in people continuing to engage in risky behaviours. For example, there were numerous myths relating to condoms reported in all four countries, although these were only explained in detail in the Swaziland report. These myths included that condoms contained worms; that the lubricant on condoms actually contained the HI-virus and could therefore infect you; that condoms were a ploy by white people to kill black people; that condoms made a man lose his erection; that the time taken to put on a condom would lead to a woman losing interest and then refusing to have sex; and that using condoms was the same as having an abortion because it was “wasting” sperm. Condom use was frowned upon by many churches and religious groups. It was also not a viable option for women who wanted (or were expected to have) babies. Many men and women also believed that using condoms lessened the pleasure of sex, and were unwilling to begin using them. Thus, many men and women were still unwilling to use condoms, even after having tested positive for HIV.

A number of traditional practices were also thought to be harmful to many people, and to increase the likelihood of HIV spreading. These included the tradition of polygamy (one man having multiple wives or girlfriends, and often having unprotected sex with all of them); the *umhlanga* ceremony (or reed dance); wife inheritance (where a family member “inherits” the wife of a male relative who passes away); the adopting of younger sisters-in-law (for example, if the first wife is unable to bear children); *coitus interruptus* (where the man withdraws prior to ejaculation).

Although the practices may have positive roots, there were those who now abused the process, making them risky for those involved:

Polygamy was good before but now it is dangerous. Sometimes you find that a man has many wives and he cannot satisfy them all. These women will go out to seek sexual satisfaction, thus catch HIV and spread it.

This practice [the reed dance], whose intention is the preservation and appreciation of female youth, has been abused in the recent years by men who exploit the innocence of the girls by promising material gifts in exchange for sex. [Swaziland focus groups]

People in a number of cases also believed that having unprotected sex with virgins could cure them of HIV. Some other traditional practices have become risky for those participating due to the spread of HIV. For example, a number of cultural ceremonies involved cutting with blades (e.g. the circumcision ritual during initiation for Xhosa boys in South Africa). These blades were often used on multiple people without being sterilised. If any of the participants were HIV-positive, others could also become infected.

Traditional practices, a lack of education surrounding HIV and its transmission, and a strong belief in witchcraft seemed to be most prominent in Swaziland:

According to Swazi culture, the cause of the virus is witchcraft. Swazis believe that they have been bewitched. We believe that if someone has the virus he has been bewitched [Swaziland key informant]

Thus, the stigma attached to being HIV-positive was strongest here, and people were more afraid to disclose their status than in the other countries. The King's role in addressing or reducing stigma was also seen as important. Until the King announced that HIV was everybody's business ("HIV/AIDS indzaba yethu sonkhe"), HIV/AIDS was generally not spoken about; and people were unwilling to provide services to those who were HIV-positive because of the extent of the stigma involved.

Some considerations for possible risk reduction interventions

Respondents were asked about the possible value of group as well as individual risk reduction interventions for PLWHA. Most answered that support groups would be

most effective, but maintained that these groups should remain small, as too many people would mean members would be uncomfortable discussing personal issues. In these groups, PLWHA would be able to share their experiences with each other, and thus learn new or different ways of managing their lives after learning their HIV-positive status. Also, the groups could be used to spread information about positive living; to debunk myths, stigma and ignorance relating to HIV and its transmission; and to teach group members about problem-solving skills for issues that they were likely to face. However, some respondents, especially in the South African study, believed that individual interventions would be more effective, as PLWHA would be reluctant to disclose their status to too many people simultaneously. Issues were also raised about people becoming dependent on groups, and only attending for the benefits that they might receive (eg. food parcels). It was generally agreed that the groups should be facilitated by members of the community who were openly living with HIV/AIDS, as they would provide positive role-models for PLWHA who were still coming to terms with their status. But some respondents believed that other factors would be more important in choosing facilitators, such as socio-economic class, age, marital status or gender.

Available services

As reported by participants, the services currently available to people attending VCT or support group centres were fairly common across all four countries. These included medical services (ART; treatment for other illnesses/infections, such as STIs and TB; medication for preventing mother-to-child transmission – PMTCT; and home-based care); education or training (treatment literacy, nutrition, positive living, stress-management techniques, income-generation techniques or skills, financial management etc); psycho-social care (individual or family counseling, and support groups); and other benefits (including food parcels, free condoms). However, in Swaziland, many of these services could only become available once the King made his declaration. Prior to this, very few people were willing to attend VCT or support group centres for fear of stigma or discrimination. However, the King's declaration made it more permissible to speak about HIV/AIDS, meaning that groups were able to set up neighbourhood care points and soup kitchens (for orphans and vulnerable children and their families), form support groups, publicly provide VCT and ART, and grow community vegetable gardens. It has also contributed to lowering the stigma somewhat, leading to increased family and community acceptance of PLWHA.

CONCLUSION

This multi-country formative study provided valuable information for consideration in developing interventions for PLWHA in sub-Saharan Africa. When asked about the issues which were most relevant to PLWHA, the answers from respondents in all four countries were quite similar. Thus, the single greatest challenge facing PLWHA was stigma from their families and communities. This then led to PLWHA being too afraid to disclose their HIV-positive status, because of the potential repercussions due to the stigma; and continuing (or beginning) to engage in risky behaviour, despite being aware of their HIV-positive status. The role of traditional practices and beliefs played a big part in many people not feeling able to adopt positive living practices, as did their socio-economic status. When asked about how the risk reduction interventions should be structured, most answered that support groups, facilitated by community members who were openly living with HIV would be most effective. Some believed individual interventions would be most important, and that the age, gender, language, ethnicity and socio-economic status of facilitators would be important. The services currently available to PLWHA in all four countries were fairly uniform, and ranged from medical and psycho-social care, to education or training programmes.

On the basis of these findings, the research project decided to select the Healthy Relationships model of group intervention, which deals with disclosure issues including stigma and behaviour risk reduction in small group settings for people already in support groups (as outlined above), for testing and adaptation in SADC. Options for Health for individual behaviour risk reduction was also selected for testing and adaptation, as it was considered optimal for people not yet in support groups.

REFERENCES

- Blanch, J. et al. (2002). .Assessment of the efficacy of a cognitive-behavioural group psychotherapy program for HIV-infected patients referred to a consultation psychiatry department. *Psychotherapy and Psychosomatics*, 71, 77-84.
- CHIPTS (2003).CHIPTS Projects. Retrieved from: <http://chipts.ucla.edu/projects/chipts/index.html>.
- Cleary, P.D. et al. (1991). Behaviour changes after notification of HIV infection. *American Journal of Public Health*, 81, 1586-1590.
- Coates, T. et al. (1989). Stress reduction training changed number of sexual partners but not immune function in men with HIV. *American Journal of Public Health*, 72, 885-886.
- Colfax, G. (2004). *Integrating HIV prevention into the care of people with HIV*. HIV InSite Knowledge Base Chapter. AIDS Research Office, San Francisco
- Crepaz, N. & Marks G. (2002). Towards an understanding of sexual risk behavior in people living with HIV: a review of social, psychological, and medical findings. *AIDS*, 16, 135-149.
- Fisher, J. D. & Cornman, D. (2003). *OPTIONS/OPCIONES Project. Clinician-Initiated Prevention Intervention for HIV Positives*. Centre for Health/HIV Intervention and Prevention, Department of Psychology. University of Connecticut, USA.
- Fisher, J. D., Cornman, D. H., Osborn, C.Y., Amico, K. R., Fisher, W.A., & Friedland, G.H. (2004). Clinician-initiated HIV-risk reduction intervention for HIV+ persons: Formative research, acceptability, and fidelity of the Options Project. *Journal of Acquired Immune Deficiency Syndromes*, 37 (Supplement 2), S78-S87.
- Fisher, J. D. (2005, April). *HIV risk behaviour change interventions for seropositives: Initial ideas on theory and practice*. Plenary delivered at the AIDS IMPACT Conference held in Cape Town, South Africa.
- Fogarty, L.A. et al. (2001). Long-term effectiveness of a peer-based intervention to promote condom and contraceptive use among HIV-positive and at-risk women. *Public Health Reports*, 116, S103-S119.
- Global HIV Prevention Working Group (2004). HIV prevention in the era of expanded treatment access. Available at: <http://www.kff.org/hiv/aids/upload/HIV-Prevention-in-the-Era-of-Expanded-Treatment-Access.pdf>. Accessed December 22, 2006.
- Greenberg, B. et al. (1996). A community support group for HIV-seropositive drug users: Is attendance associated with reductions in risk behaviour? *AIDS Care*, 8(5), 529-540.

- Hankins, C. et al. (1995). Prior risk factors for HIV infection and current risk behaviours among incarcerated men and women in medium-security correctional institutions - Montreal. *Canadian Journal of Infectious Diseases*, 6(Suppl B), 31B.
- Kalichman, S.C. (1999). Psychological and social correlates of high-risk sexual behaviour among men and women living with HIV/AIDS. *AIDS Care*, 11, 415-427.
- Kalichman, S.C. (2000). HIV transmission risk behaviour of men and women living with HIV/AIDS. Prevalence, predictions and emerging clinical interventions. *Clinical Psychology: Science and Practice*, 7, 32-47.
- Kalichman, S. C. (2005). Positive prevention reducing HIV transmission among people living with HIV/AIDS. Kluwer Academic/Plenum Publishers. New York, Boston, Dordrecht, London, Moscow.
- Kalichman, S.C. et al. (2001). Effectiveness of an intervention to reduce HIV transmission risks in HIV positive persons. *American Journal of Preventive Medicine*, 21, 84-92.
- Kelly, J. A. et al. (1993). Factors associated with severity of depression and high-risk behaviour among persons diagnosed with human immunodeficiency virus (HIV) infection. *Health Psychology*, 12, 215-219.
- Lechner, S.C. et al. (2003). Cognitive-behavioural interventions improve quality of life in women with AIDS. *Journal of Psychosomatic Research*, 54, 253-261.
- Lightfoot, M. et al. (2004). *Prevention for positives in medical care settings*. Unpublished manuscript, University of California, Los Angeles.
- Margolin, A. et al. (2003). A randomized clinical trial of a manual-guided risk reduction intervention for HIV-positive injecting drug users. *Health Psychology*, 22(2), 223-228.
- Marks, G. et al. (1991). Self-disclosure of HIV - infection to sexual partners. *American Journal of Public Health*, 81[10], 1321-1322.
- Metsch, L., Gooden, L., & Purcell, D. (2005). Interventions in community settings. In S. C. Kalichman (Ed.), *Positive prevention: Sourcebook for HIV prevention with people living with HIV/AIDS* (pp.193–218). New York: Kluwer.
- Perry, S. et al. (1991). Effectiveness of psychoeducational interventions in reducing emotional distress after human immunodeficiency virus antibody testing. *Archives of General Psychiatry*, 8, 143-147.
- Robins, A.G. et al. (1994). Psychosocial factors associated with risky sexual behaviour among HIV-seropositive gay men. *AIDS Education and Prevention*, 6, 483-492.
- Rotheram-Borus, M. et al. (2001a). Efficacy of a prevention intervention for youths living with HIV. *American Journal of Public Health*, 91, 400-5.

- Rotheram-Borus, M et al. (2001b). An intervention for parents with AIDS and their adolescent children. *American Journal of Public Health*, 91, 1294-1302.
- Rotheram-Borus, M.J. et al. (2003). Four-year behavioral outcomes of an intervention for parents living with HIV and their adolescent children. *AIDS*, 17(8), 1217-25.
- Shisana, O. & Simbayi, L.C. (2002). *Nelson Mandela/HSRC Study of HIV/AIDS: South African National HIV Prevalence, Behavioural Risks and Mass Media Household Survey 2002*. Cape Town: Human Sciences Research Council.
- Shisana, O. et al. (2005a). *South African National HIV prevalence, HIV incidence, behaviour and communication survey, 2005*. Cape Town: HSRC.
- Shisana, O. et al. (2005b). (Eds). *The Health of our educators: A focus on HIV/AIDS in South African public schools*. [Report on Factors Determining Educator Supply and Demand in South African Schools funded and prepared for the Education Labour Relations Council]. Cape Town: HSRC.