

Chapter 3

Barriers to sexual behaviour change after an HIV diagnosis in sub-Saharan Africa

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Abstract

This longitudinal, in-depth study of sexual behaviour of 96 HIV-positive individuals in a sub-Saharan country where HIV is heavily stigmatized, showed that even with counselling and free condoms, most people with HIV did not succeed in maintaining long-term, consistent condom use. Their condom use depended on fluctuations in their health status, and the anticipated or actual reaction of their social environment. People with HIV encountered the same barriers to safer sex as the community in general: women's lack of sexual decision-making power; men's dislike of condoms; denial of HIV, especially in men; and child-wish. In addition, HIV-positive people who did not disclose their HIV status feared that proposing to use condoms would raise partners' suspicions, and lead to social rejection and stigma. Results suggest that HIV testing and counselling programs will only achieve prevention of secondary HIV spread when they are preceded and supported by strong measures promoting acceptance and openness with regard to HIV.

HIV testing, with or without counselling, is promoted as a means to prevent the spread of HIV in developed and developing countries. The underlying assumption is that knowing their HIV status will enable individuals to take measures to reduce or eliminate HIV risk to others.

This study provided an opportunity to investigate this assumption. Between 1991 and 1993, 96 persons diagnosed HIV-positive at a counselling clinic in Bulawayo, Zimbabwe, were asked to participate in a program of continuing counselling and support. The study aimed to increase understanding and information about the medical, social, economic, and psychological problems of people with HIV in order to strengthen support services.

The study was conducted in collaboration with the Ministry of Health and the Matabeleland AIDS Council, a non-Government AIDS service organization located in Bulawayo which provides information, care and support in Matabeleland. A full report of the study can be found in Meursing (1997).

Context of the study

Zimbabwe has one of the most severe AIDS epidemics recorded. Between 1991 and 1993, seroprevalence among pregnant women in Bulawayo rose from 17 to 27 per cent, and it continued to rise in subsequent years. Because there is good transport infrastructure, seroprevalence in rural Zimbabwe is often not much lower than in urban areas. In 1995, seroprevalence figures in some urban and rural sites in Masvingo province exceeded 70 per cent of pregnant women. Heterosexual spread is the main risk factor, so that many children born to HIV-positive parents are born with the virus or face an uncertain future as orphans.

In recent years it has become clear that Botswana and South Africa are undergoing equally serious epidemics. A number of social, cultural and medical factors are believed to contribute to the rapid spread of HIV in Southern Africa, including (1) gender role expectations, specifically women's low social status, men's claim to have a right to free sexual expression, and a high value placed on fertility (Taylor and Stewart 1991; Bassett *et al.* 1992; Berer and Ray 1993; Njovana and Watts 1996; Ray, Gumbo and Mbizvo 1996); (2) migrant labour, poverty and women's economic dependence on men (Bassett and Mhloyi 1991); and (3) an epidemic of sexually transmitted disease.

In Zimbabwe from the late 1980s there has been a continuing AIDS information campaign which was highly ambivalent: while the Ministry of Health issued public warnings about HIV, other ministries and political and community leaders kept aloof. Until 1991, the Government actively suppressed information about the spread of HIV in the area.

HIV education was strongly prescriptive and biomedical in nature and was mainly communicated through the mass media and one-way lectures. Though in the early 1990s most adults in Zimbabwe knew the basic facts about HIV, behaviour change remained limited and HIV and STD incidence continued to rise (Ministry of Health 1994). HIV remained highly stigmatized, related to promiscuity and prostitution and difficult to acknowledge at a personal level. Condoms remained unpopular as men feared loss of sexual pleasure. Major barriers for condom use among married couples were difficulties in discussing sex, the association between condoms and promiscuity, and reduction of fertility (Mbizvo and Adamchak 1991; Jackson 1992).

Method

Fifty-eight women and 38 men diagnosed HIV-positive at an HIV counselling clinic attached to the outpatient department of a large tertiary hospital in Bulawayo were invited to take part in the study program, which consisted of continuing counselling, access to home-based care and free medical care at the hospital outpatient department. Each client was carefully counselled before and after testing, where possible with their spouse, sexual partner or close relative, and informed consent was obtained. Clients could choose to hold counselling sessions at their home, in the hospital, at the Matabeleland AIDS Council or at another convenient place.

Participants' ages ranged from 12 to 53 years. As usual in samples drawn from public health facilities, the great majority of patients had low socio-economic status. This group consisted of symptomatic teenage girls and adults, and asymptomatic women diagnosed because of a sick child.

Out of 96 clients 72 agreed to participate in the study program and did so for a period varying between two and 31 months, with an average of 15.5 months and between three and 26 contacts. There were 67 contacts with participants' social contacts: family members, sexual partners or service providers, for example, traditional healers or social workers. Twenty-four clients participated in pre-test and post-test counselling but refused further counselling.

Counsellors transcribed each counselling session or contact, thus creating a confidential and highly detailed record of clients' problems and coping strategies over time. The validity of the data was increased by the length and intensity of the contact between the patient and counsellor and in-depth knowledge of the patients' home situation. The study design also made it possible to triangulate information from patients with information obtained from their social environment and medical records.

Data were analysed by an iterative process of coding and condensation, which allowed the emergence and quantification of main themes from patients' narratives while simultaneously retaining the richness and originality of their accounts.

Results

Transcripts of counselling sessions showed that with continued counselling and access to free condoms, most study participants took some measures to prevent HIV spread, such as reducing the number of sexual partners, temporarily abstaining from sex or some-time condom use. Most married participants disclosed their HIV status to their spouses, which opened up the way for partner testing and co-operation to prevent infection. However, in non-marital relationships such disclosures remained rare.

Main motivations for condom use were to prevent the spread of infection, and to protect oneself against STD. Many participants were highly motivated to avoid STD as they were familiar with painful, persistent STD episodes. Nevertheless, long-term consistent condom use remained rare. Factors impeding consistent condom use were as follows.

Lack of hope, based on misinformation about HIV and fear of stigma

Many people with HIV and family members met the news of HIV infection with deep fatalism. This fatalism, which was difficult to dispel in counselling, was based on the belief that 'HIV equals AIDS and AIDS equals death', and on the expectation of universal social rejection. Many patients therefore experienced the prospect of disclosing their HIV status or introducing condom use as socially risky, with little to be gained.

Psychological avoidance

Very few study participants denied their HIV status completely, as most who denied their HIV status had dropped out of the study at pre-test or post-test counselling. However, participants' acceptance of their HIV status fluctuated over time with changes in their health status. Periods of illness strengthened patients' belief that the infection was real, and increased motivation for active coping strategies such as condom use. However, when symptoms improved many people pushed thoughts of their HIV status aside or even began to believe that they were cured, and motivation for condom use decreased. Such avoidance was fed by rumours in the community about available 'miracle cures'.

Lack of co-operation from the partner

Wives who informed their husbands or partners that they had been diagnosed HIV-positive rarely received full support in coping actively with the infection. Many men had built up a habit of ignoring or denying HIV, and continued this habit once they knew their wife or child was infected. Men's avoidance practices varied from refusing to be tested and refusing to discuss HIV, to aggression and abandonment of wife and children. Husbands' aggression was a main reason for women not to participate in the study, as aggressive husbands had the power to bar their wives from contact with counselling services and to limit wives' health-seeking options to health care providers unlikely to mention HIV, such as traditional healers or private doctors. Even in married couples who coped well together, husbands often remained reluctant to use condoms. As a consequence, condom use tended to decline over time or fluctuated with health problems in the family.

In non-marital relationships, women's ability to prevent the spread of infection was limited by their economic dependence on their partners. Mature single women often had continuing relationships with married or divorced men based on an exchange of comfort and pleasure for material support. While mutual trust and intimacy in these relationships often was not sufficient for full disclosure of HIV, these mature women usually made concerted

attempts to persuade their partners to use condoms, as they feared STDs. However, many men reacted to these proposals with scorn, denial or threats to end the relationship. Women's social and economic dependence on men meant that when partners were unco-operative, women were left with the choice of continuing the relationship without condoms, or breaking it off.

Fertility concerns

In relationships with hopes for marriage, disclosure of one's HIV status to a prospective marriage partner was particularly difficult. Young single women in premarital relationships feared that proposing condom use would endanger their marriage prospects, as society expects brides to be keen to prove their fertility and their compliant nature. None of the teenage girls and few women in their early twenties felt confident enough of their relationships to disclose their HIV status to their partners.

Men in premarital relationships had similar problems, but were more able to introduce condoms temporarily without much explanation.

Because of the incompatibility of desire for marriage and disclosure with or without condom use, several young men and women started new relationships during the study period without taking any steps to protect their partners from HIV.

The consequences of unprotected sex were unwanted pregnancies, new STD episodes, and serious risk of HIV to sexual partners.

Conclusions

The problems clients encounter in using condoms are similar to the barriers encountered by the community around them. In Zimbabwe, this includes women's lack of sexual decision-making power, men's dislike of condoms, high value placed on fertility, and community denial of HIV. In addition, people with HIV fear that proposing to use condoms will raise suspicions of their HIV status and thereby increase their already immense load of problems by social rejection and stigma. Options and problems in introducing condoms differed with sex and type of sexual relationship, premarital, extramarital, and marital.

HIV testing programs should therefore not assume that knowledge of HIV status automatically enables individuals to take measures to reduce or eliminate HIV risk to others. Though counselling and support strengthen motivation and intention to use condoms, where secrecy and stigma prevail and where condoms are little accepted, knowing one's HIV status may not be sufficient to achieve long-term consistent safe sexual behaviour. Once diagnosed, people with HIV continue to face the same barriers to safe sex as before diagnosis. In addition, they may fear that taking precautions will increase the risk of detection, stigma and rejection. Stigma reduces motivation to be tested and increases the likelihood that people will react to their HIV status by denial. Symptomatic individuals who practise denial are likely to avoid health and support services that may confront them with their HIV status, and may seek out health providers who will confirm their avoidance by giving a different diagnosis.

HIV education emphasizing the association between HIV and death promotes a view of HIV as a 'death sentence', increases denial and reduces the chance that people with HIV will feel 'empowered' to adopt active, positive coping strategies, including the use of condoms.

Programs for voluntary counselling and testing therefore need to go hand in hand with interventions that promote 'living positively with HIV' to the community as a whole, and address an existing community culture of stigma, denial and silence surrounding HIV.

Recommendations

Condom use should be seen as one element of 'positive living'. Hope and belief that active coping strategies will improve the quality and quantity of life of people with HIV and their families is crucial to engender motivation to cope actively with HIV. This necessitates unequivocal and widely publicized support, including personal messages, from Government and community leaders, for safe sexual behaviour and those infected and affected by HIV; reduction of stigma and avoidance by strong advocacy from Government, people-with-HIV groups, and public models of successful living with HIV; increasing women's social and economic power and independence; interactive, creative HIV education which teaches 'living positively with HIV' for the community as a whole, avoids 'AIDS kills' as a central theme and enables men and women to see that challenging current sex role divisions is in their interest; and good services (including peer support) after diagnosis, including medical, social and psychological support as well as material resources essential for 'positive living'. HIV education and counsellor training should be culturally appropriate and gender-specific and include interventions for dealing with denial and avoidance. The development of such interventions should be supported by policy development and research.

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