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Living with HIV: Challenges in Reproductive Health Care in South Africa

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Abstract

Women in Africa are facing discrimination and challenges in relation to HIV/AIDS, particularly regarding their sexual and reproductive health care. This includes a lack of information regarding HIV and pregnancy, difficulties with contraceptive use, negative attitudes towards childbearing, and problems in accessing safe legal abortions. This paper addresses these issues in South Africa, based on an interview study with eight key informants and a literature review. The South African experience should inform policy-making and programmes in relation to HIV and reproductive health care in other African countries. (*Afr J Reprod Health* 2004; 8 [1]:92-98)

Key Words: *HIV, reproductive health, rights, pregnancy, abortion*

Résumé

Vivre avec le VIH: défis dans les soins de la santé de reproduction en Afrique du Sud. Les

femmes africaines font face à la discrimination et aux défis par rapport au VIH/SIDA, surtout quand il s'agit des services de la santé sexuelle et de reproduction. Ajouté à ceci est le manque de renseignement concernant le VIH et la grossesse, les difficultés liées à l'emploi des contraceptifs, les attitudes négatives envers la maternité et les problèmes d'accès aux avortements légaux et sans danger. Cet article étudie ces problèmes en Afrique du Sud en se fondant sur une étude effectuée à travers des intérieurs, à l'aide des huit principaux interviews et une analyse de la littérature. L'expérience sud-africaine devrait servir d'exemple pour la formulation des politiques et des programmes par rapport au VIH et les services de santé de reproduction dans d'autres pays africains. (*Rev Afr Santé Reprod* 2004; 8[1]:92-98)

Introduction

More than 15 years into the AIDS pandemic, people living with HIV/AIDS still face stigma and discrimination in societies around the world. This is expressed in many ways, ranging from being blamed for "bringing AIDS into the family", avoidance by family and friends, dismissal from jobs, abandonment by spouses, to outright violence. Some HIV positive people have even been killed. For example, Gugu Dlamini, a woman in South Africa, was murdered in December 1998, reportedly because she was open about her HIV status.¹

Women may also face more subtle discrimination and challenges in relation to HIV/AIDS, particularly regarding sexual and reproductive health care. Information regarding HIV and pregnancy may be lacking or difficult to access. HIV positive women may receive little information on contraceptive options or find it difficult to use contraceptive methods of their choice. If they choose to become pregnant, they may face highly negative attitudes and discrimination in their communities, as well as the health care sector. Women who wish to terminate unwanted pregnancies may find it difficult to obtain safe and legal abortion.

Methodology

An interview study and review of literature were carried out to address these issues in South Africa. The literature review focused on HIV, pregnancy and abortion, focusing on publications produced mostly between 1998 and December 2003. A search was done using the Medline, Popline, Sociofile, Psychinfo and Cinahl databases. Abstracts from the XIII and XIV International Conferences on AIDS, as well as research reports available on the internet and newspaper articles were used as information sources.

Interview Study

The interviews took place as part of a larger exploratory enquiry in 2002 on HIV, pregnancy and abortion with representatives of organisations working on HIV/AIDS and/or reproductive health in five countries (the other countries were Australia, India, Kenya and Thailand).² The study coordinator suggested a number of organisations to be approached based on their years of experience in HIV/AIDS and reproductive health care. The interviewer, a woman living with HIV who had previously been engaged in research and advocacy, also suggested some agencies that had knowledge and experience in HIV and pregnancy. The interviewer reviewed

the interview guide before use. All the respondents gave informed consent to participate in the enquiry having been guaranteed anonymity.

Eight key respondents from Braamfontein, Germiston, Johannesburg and Pretoria participated. Seven of them were female and one was male. All of them were involved in HIV/AIDS-related activities — persons working for organisations of people living with HIV/AIDS, staff of NGOs and a representative of the Department of Health.

The Context for Reproductive Decision-Making

Testing at South African public antenatal clinics in 2002 showed HIV infection ranging from 12.4% in Western Cape Province to 36.5% in Kwa-Zulu Natal, giving a national mean prevalence of 26.5% among women. HIV prevalence among pregnant women younger than 20 years decreased by 25% between 1998 (21%) and 2001 (15.4%). In 2002, the prevalence rate in this age group was 14.8%. Prevalence levels remained high among older pregnant women, with rates of 29.1% among women aged 20-24 years, 34.5% among those aged 25-29 years, and 29.5% among those aged 30-34 years. The Department of Health estimated that 91,271 babies had been infected with HIV through mother-to-child transmission in 2002.³⁻⁴

There are regulations and laws to protect women's reproductive choice in South Africa. A limited number of pregnant women have participated in programmes to prevent mother-to-child transmission (PMTCT) with antiretroviral therapy (ART) at 18 research sites throughout the country.⁵ The South African government resisted implementing PMTCT programmes nationwide until recently. In 2003, government threatened to withdraw registration of nevirapine (used in preference to zidovudine because it only requires one dose for the mother during labour and one dose for the baby postpartum) for PMTCT because of doubts about its safety.⁶ In August 2003, the government ordered the Department of Health to develop a nationwide plan for the provision of ART to people living with HIV/AIDS by 2008.⁷

Each year, 4.2 million unsafe abortions take place in Africa.⁸ In their 1998 guidelines on HIV/AIDS and human rights, UNAIDS and the Office of the United Nations High Commissioner for Human Rights stated:

*Laws should also be enacted to ensure women's reproductive and sexual rights, including the right of independent access to reproductive and STD health information and services and means of contraception, including safe and legal abortion and the freedom to choose among these, the right to determine number and spacing of children, the right to demand safer sex practices and the right to legal protection from sexual violence, outside and inside marriage, including legal provisions for marital rape...*⁹

South Africa has one of the highest rates of rape in the world, with the Law Commission estimating 1.6 million occurrences annually.¹⁰ South African research has estimated that those raped by an HIV positive perpetrator have a 30-40% chance of contracting HIV.¹¹ To address this problem, rape survivors have been able to receive ART to prevent HIV infection since April

2002.¹² However, the government has proposed to discontinue this measure and the provision of emergency contraception in an amendment to the Sexual Offences Bill in August 2003.¹⁰ Abortion is legally permitted upon a woman's request during the first 12 weeks of pregnancy. It is also allowed from the 13th-20th week of gestation if a medical practitioner decides, after consulting the woman, that the pregnancy resulted from rape or incest, would pose a risk to her physical or mental health, would carry a substantial risk of fetal abnormality, or if it would significantly affect the woman's social or economic circumstances.¹³

HIV and Pregnancy: Lack of Information

The AIDS Law Project at the University of Witwatersrand drafted a recommended code of practice concerning HIV and pregnancy in 1997, which emphasised women's right to continue or terminate a pregnancy regardless of their HIV status. Their hope was that the code would both influence policy and practice and contribute to a better understanding amongst women of choices they may make, and rights they may use in the public and private health sector. Accordingly, a key component of the code was to ensure that women have information which allows them to make informed decisions about reproduction.¹⁴ It is unclear whether and by whom this code of practice was adopted.

The Treatment Action Campaign to make ART available for PMTCT programmes received much publicity throughout South Africa. However, three of the eight key respondents in the 2002 interview study on HIV, pregnancy and abortion stated that too little information on HIV and pregnancy is available to the general public. A particular problem mentioned was a lack of information in local languages and for low literate women.²

Contraceptive Use and Unwanted Pregnancies

Dual protection - use of condoms together with another contraceptive method - is often recommended to achieve effective prevention of both HIV/STI infection and pregnancy. However, considerable numbers of people use only one contraceptive method. While perfect condom use results in a 3% pregnancy rate during a 12-month period, the rate for typical use (not used correctly or for every act of sexual intercourse) ranges from 10-14%.¹⁵

A survey in 1998-1999 at 12 public health facilities in four regions of South Africa found that 51% of the 554 respondents had used condoms in their most recent sexual encounter, while 34% used a different contraceptive. Only 16% had used a condom together with another contraceptive method. Qualitative data showed that men and women agreed that they felt less comfortable using condoms as a contraceptive than as a method for HIV/STI prevention. Dual method use tended to occur when a man's goal of protecting himself against STIs (through condom use) coincided with a woman's desire to prevent pregnancy.¹⁶ Research in 2000 using 146 simulated client visits to 31 public sector family planning facilities in two provinces found that barrier methods were offered to only 39% of clients, while 12% of clients were told about dual protection. Only 12% of the clients received counselling on HIV/STIs.¹⁷ A third study in 2002-2003 found that nurses at family planning facilities in KwaZulu Natal encouraged about

70% of their clients to use condoms to prevent HIV infection and pregnancy. However, in discussing contraceptive methods in general, the focus was on method effectiveness and instructions for use with little information being given on contra-indications, disadvantages, side effects and issues relating to HIV.¹⁸

Some efforts are being made to increase access to female condoms, which can give women somewhat greater control over protection against HIV/STIs and pregnancy. The Expanding Dual Protection Strategies Project reported that by the end of 2001, 114 sites provided female condoms throughout the country. The sites included primary health services, hospitals, services for sex workers, truck stops, workplaces, NGOs, HIV/AIDS support centres and youth centres; 80 trainers and 296 service providers had been trained.¹⁹ The South African government announced that one million female condoms were distributed through 200 sites in 2002 (compared to 220 million male condoms) and that 135,000 were sold at pharmacies at a subsidised price.²⁰

Nevertheless, many women, both HIV negative and HIV positive, lack decision-making power in their sexual relationships regarding whether and when to have sex, to use contraception, and to have children. This is due to gender inequities and fears of stigma and discrimination, which is particularly true of young women, who are at high risk of both HIV infection and rape.²¹ In 2002, 52,550 cases of rape and attempted rape were officially reported, 41% involving minors younger than 18 years.²² As at 2000, 22% of about 500 rape survivors treated at the Albertina Sisulu Rape Crisis Centre were HIV positive when they were assaulted.²³

It is reasonable to assume that at least some unwanted pregnancies are occurring among HIV positive women due to condom failure, lack of contraceptive use and unprotected sexual assault. At least some unwanted pregnancies can be prevented if a woman has access to emergency contraception (EC). However, a study in 1999-2000 indicated that availability is limited.²⁴ Researchers found that EC at public health facilities was usually only available during working hours on week days. While 54% of 197 providers had provided EC in the three months prior to their interview, only 23% of 1068 interviewed clients had heard of EC and 65% had had a pregnancy when they were not ready for it. Counselling on long-term contraceptive methods was given during 66.7% of simulated client visits carried out for the study, but, overall, little counselling was given regarding HIV/STI risks after unprotected intercourse.

As ART becomes more widely available, there is also need to pay attention to the interactions between hormonal contraceptives and antiretroviral drugs, such as altered concentrations of antiretrovirals or reduced contraceptive effectiveness.²⁵ This points to a need to ensure that HIV positive women receive targeted information and education on their contraceptive options, including emergency contraception. Nevertheless, workshops held in 11 municipal areas with key stakeholders, as part of a 2002 study on governmental and civil society responses to the HIV/AIDS epidemic, failed to mention activities to improve family planning services for people living with HIV.²⁶

HIV, Pregnancy and Stigma

Six of eight key respondents in the interview study indicated that community members and health care workers generally have negative attitudes towards HIV positive women who become pregnant.² Two of them commented that many people assume that women living with HIV are not, or should not be, sexually active. They also feel that becoming pregnant is irresponsible of women living with HIV due to the risk of having an infected child and leaving behind orphans. One representative from an organisation of people living with HIV/AIDS said a staff member resigned her appointment because she was harassed and the organisation where she worked was attacked when her pregnancy became known to the public. Another person commented that her organisation received many phone calls and letters from members of the public saying that HIV positive women should be sterilised.

Some health care professionals have shared such negative attitudes concerning the right of HIV positive women to bear children. For example, in October 1998, the *South African Medical Journal* published a letter from a staff member of a hospital in Western Cape that recommended making ART available to women only if they were sterilised.²⁷ Seven key respondents in the interview study felt that health care providers' attitudes regarding HIV and pregnancy had not changed or were only slightly influenced towards approving of pregnancy in HIV positive women since the introduction of ART for PMTCT.

HIV, Unwanted Pregnancy and Abortion

As noted earlier, HIV positive women may have unwanted pregnancies because of non-use of contraceptives, contraceptive failure, or unprotected sexual assault. Some women only find out that they are HIV positive when they undergo antenatal testing and may decide to terminate the pregnancy thereafter.

However, like other women, HIV positive women may have difficulties in accessing safe legal abortions. A review study carried out in 2002 at the Medical Research Council of South Africa found that women still lack access to abortion for a variety of reasons. Such reasons include ignorance of the law permitting abortion, acts of violence against clinics and physicians providing terminations and inequitable distribution of medical personnel between urban and rural areas. Other reasons include a failure to train health care providers to perform abortions, demands for abortions that exceed the availability of services, and hostile attitudes of health professionals who cite moral reasons for opposing abortion.²⁸ An analysis of HIV/AIDS services in KwaZulu Natal reported that in-service training of health care providers has neglected the issue of abortion; termination of pregnancy was mainly available at hospitals and not at community health centres or clinics, and only 4% of facilities had information materials on abortion available for clients. Only 18% of 228 staff at the 98 health facilities surveyed had provided counselling on abortion in the past three months and only 1% provided manual vacuum aspiration to clients.¹⁸

Some steps are being taken in South Africa to ensure that women living with HIV/AIDS do not have to carry unwanted pregnancies to term. The Treatment Action Campaign has produced an information leaflet on PMTCT that emphasises women's right to terminate pregnancies and to receive ART, formula milk and ongoing treatment and support when they decide to bear

children.²⁹ A guide on pregnancy and HIV by the Treatment Action Campaign and the AIDS Law Project stresses that health care providers have a duty to inform the public that every woman has the right to continue or end a pregnancy regardless of her HIV status.³⁰ A training manual for health care providers published by the Perinatal HIV Research Unit of the University of the Witwatersrand states that HIV-infected women should be given appropriate information to make informed decisions about continuation of their pregnancy and future fertility. It also states issues to be explored at subsequent post-test counselling sessions: termination of pregnancy where there is access to safe procedures.³¹

Enabling HIV Positive Women to Exercise Sexual and Reproductive Rights

All the eight key respondents in the interview study said political action is needed to protect the rights of women living with HIV/AIDS. They all believed that government and NGOs have not done enough to address the issue of unwanted pregnancy and HIV/AIDS.² The interviewer commented:

...everybody that I spoke to about this issue is keen to see the results of this study because we all realize that we have not done much and yet there is so much need to address these challenges facing women.

A 2003 literature review on gender-based violence and HIV/AIDS in South Africa states that the fact that more than 100,000 babies are born HIV-infected every year, and that there is a high incidence of new HIV infections in young women, necessitates accessible, safe and friendly termination of pregnancy services.²¹

South Africa's Treatment Action Campaign has been criticised for not focusing more on women's sexual and reproductive rights.³² Many challenges remain for HIV positive women in South Africa regarding reproductive health care. However, action is being taken to improve their situation. Intensive lobbying by NGOs, researchers and members of the health care sector has led to the adoption of laws, regulations and policies to protect women against HIV infection through rape, provision of ART through PMTCT programmes to reduce perinatal transmission of HIV, and informing women of their right to a legal abortion when they face an unwanted pregnancy.

Conclusion

The situation for women in other African countries regarding HIV and reproductive health is similar to that of South African women. Their ability to control reproductive decision-making is often limited while access to PMTCT programmes is only available to small numbers of women. Widespread domestic and sexual violence contributes to women's vulnerability to HIV infection,³³⁻³⁵ and unwanted pregnancies due to sexual assault continue to occur among both HIV positive and HIV negative women. This situation recently led the African Union to adopt a supplemental protocol to the African Charter on Human and People's Rights in which governments pledged to take measures to authorise abortion in cases of rape, incest and where

continued pregnancy poses a danger to a woman's mental or physical health or life or that of the fetus.³⁶⁻³⁷ This step should be followed by further action to enable all women - both HIV positive and HIV negative - to exercise their sexual and reproductive rights, including the right to have children and to prevent or end a pregnancy if that is their choice. In this regard, South Africa's experience can inform policy-making and programmes elsewhere on the continent.

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