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Antenatal HIV Screening and Treatment in South Africa: Social Norms and Policy Options

Memoona Hasnain

ABSTRACT

South Africa has one of the highest prevalence of HIV and AIDS in the world, with mother-to-child transmission being an important route for spread of the infection. For years, AIDS scientists and activists locally and internationally have been working desperately for the people of South Africa to have access to treatment for HIV and AIDS. Policymakers in South Africa have consistently maintained that HIV infection is not responsible for AIDS, thus creating the biggest obstacle to implementation of appropriate prevention and therapeutic programmes, including antiretroviral therapy for HIV positive persons. Only recently, people within the government and ruling party, defying previous policy, have agreed that antiretroviral drugs should be given to pregnant women with HIV. The social fabric of South African society is markedly different from that of Western countries. In this paper, the author analyses the likely implications of antenatal testing and treatment of pregnant women in South Africa, in light of the socio-economic and cultural status of women in that society. (*Afr J Reprod Health* 2004; 8[2]: 77–85)

RÉSUMÉ

Dépistage et traitement prénatals du VIH en Afrique du Sud: normes sociales et options des politiques. L'Afrique du Sud a une des plus hautes prévalences du VIH et SIDA du monde, dont la transmission de la mère à l'enfant est une voie importante pour la propagation de l'infection. Depuis des années, les scientifiques et des activistes du SIDA sur le plan local et international, travaillent désespérément pour que les gens d'Afrique du Sud aient un accès au traitement pour le VIH et le SIDA. Les décideurs en Afrique du Sud ont systématiquement insisté sur le fait que l'infection du VIH n'est pas responsable du SIDA, créant ainsi le plus grand obstacle à la réalisation de la prévention appropriée et des programmes thérapeutiques, y compris la thérapie antirétrovirale pour les personnes séropositives. Très récemment, les fonctionnaires et les membres du parti politique au pouvoir, au mépris de l'ancienne politique, ont accepté que les médicaments antirétroviraux soient donnés aux femmes enceintes séropositives. Le tissu social de la société sud africaine est remarquablement différent de celui des pays occidentaux. Dans cet article, l'auteur fait une analyse des implications probables du dépistage et traitement prénatals des femmes enceintes en Afrique du Sud, à la lumière de la situation socio-économique et culturelle des femmes dans cette société-là. (*Rev Afr Santé Reprod* 2004; 8[2]: 77–85)

KEY WORDS: *HIV screening, South Africa, pregnant women*

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Introduction

The World Health Organization (WHO) estimates that, worldwide, approximately 40 million people are living with HIV/AIDS; 22 million men, women and children have died and 14,000 new infections are contracted every day. Around the world, in the year 2003, the AIDS epidemic claimed an estimated three million lives, and almost five million people acquired HIV, 700,000 of which are children.¹ The global disparities in the incidence, prevalence and treatment access to HIV/AIDS certainly lend credence to the phrase “there are always two sides to a coin.” On the one hand, therapies exist today to substantially improve the quality of life of those living with HIV and AIDS in countries that can afford them. In Western countries, especially the United States of America, concerted action by multiple stakeholders supported by political will has shown results in curbing the epidemic. There are prevention strategies that work, and large sums of private and public sector monies as well as mutually rewarding private and public partnerships are being devoted to HIV/AIDS research. Most importantly, antiretroviral drugs with proven efficacy to prevent the transmission of HIV from mothers to their infants are available to a majority of those in need. The successful implementation of antiretroviral therapy for HIV positive pregnant women and their infants has led to dramatic reductions in pediatric AIDS in the United States and Europe.²⁻⁴

The other (bleaker) side is quite pessimistic. In the developing world, which bears the burden of more than 95% of the world's HIV infection, the HIV/AIDS pandemic continues to rage on and there is little hope for those afflicted. The AIDS epidemic in Africa bears little resemblance to that in developed countries like the USA. In Africa, AIDS is not merely a medical problem; it is inherently linked to and fed by the existing socio-economic conditions, particularly for women. This is unlike the scenario in developed countries where AIDS is limited to specific high-

risk groups, and brought under control through intensive education, vigorous political action and, most importantly, expensive drug therapy. In Africa, risk groups cannot be defined; everyone is at risk. Through vertical transmission from mother to infant, either before or during childbirth or via breastfeeding, even newborns become infected.

South Africa has one of the highest HIV infection rates in the world, even though the epidemic developed there later than in other hard-hit countries in sub-Saharan Africa. With a population of 43.6 million, South Africa has an adult literacy rate of 82% and urbanisation rate of 49%. In the past decade and a half, the number of people affected by HIV/AIDS has risen significantly. From 1985 to 2000, mortality rates rose 3.5 times among 25–29-year-old women and two times among 30–39-year-old men.⁵ According to UNAIDS estimates, more than six million South Africans (approximately one in seven) are currently infected with HIV. The impact on the health sector is considerable. The percentage of hospital beds occupied due to AIDS ranges from 26% to 70% for adults and from 26% to 30% for children. Due to premature mortality, HIV/AIDS accounts for 38% of total years of life lost, which is proportionately higher for females (47%) than for males (33%). The impact of HIV/AIDS is expected to more than double the burden of premature mortality by 2010.⁶

Despite these alarming statistics, the people of South Africa have not had access to antiretroviral (ARV) therapy for a very long time. For years, AIDS scientists and activists locally and internationally have been working for the people of South Africa to have access to treatment for HIV and AIDS. Policymakers in South Africa had consistently maintained that HIV infection is not responsible for AIDS, thus creating the biggest obstacle to implementation of appropriate prevention and therapeutic programmes, including antiretroviral (ARV) therapy for HIV-positive persons.

Similar to the hurdles to HIV prevention and therapy efforts for the general population, for a long time, the prevention message was not widely applied to pregnant women in the country. Mother-to-child transmission (MTCT) of HIV infection is an increasingly important route of disease transmission in South Africa. The seroprevalence of HIV in pregnant women increased from 0.7% in 1990 to 26.5% in 2002, reaching 36.5% in KwaZulu Natal.⁷⁻⁹ Thus, prevention efforts need a focus upon promoting HIV counselling and testing and offering therapy for HIV-positive pregnant women and their infants. For the past two years, people within the government and ruling party, in a reversal of previous policy, have agreed that antiretroviral drugs should be given to pregnant women with HIV. The purpose of this paper is to analyse the likely implications of instituting antenatal HIV screening, including treatment and substitute feeding of newborn babies of HIV positive women, in light of the socio-economic and cultural status of women in the South African society.

Socio-Economic and Cultural Status of Women in South African Society

Every human being has the right to live in an environment with minimum health risks and have access to health services that can prevent or alleviate their suffering, treat disease and promote good health. In South Africa, however, a majority of the female population is deprived of these basic human rights. Women's gender and the socio-economic and cultural context in which they live define their roles, as well as the amount of power they have in the society. There is an imbalance in power between women and men that is apparent in heterosexual relations as well as in the economic and social spheres of life, with men having greater power than women. Women are economically vulnerable because they do not have the same opportunities for education, training or employment as men do. Social inequalities in income and employment have been shown to be

predictors of HIV infection. Economic difficulty is associated with greater exposure to risky sexual experiences and sexually transmitted diseases, reduced access to preventive and therapeutic health information, and delayed or absent diagnosis and treatment.¹⁰

Poverty or abandonment, or both, is forcing many women in South Africa to sell sex in return for food for their families. In addition, domestic violence is a reality in the lives of many women.¹¹ A resulting sense of fatalism often reduces women's motivation to take care of their sexual health.¹² Lack of respect for female sexual rights, poor facilities for the affordable treatment of sexually transmitted diseases and many other factors are contributing to the increasing incidence of HIV and AIDS in women of childbearing age, which has a direct effect on their unborn children.^{10,13} To make matters worse, for a very long time, the South African government was not willing to provide antenatal HIV screening to pregnant women and antiretroviral drugs for those who might test positive.^{14,15}

Antenatal HIV Screening and Treatment: Issues and Implications

Globally, treatment modalities for HIV are rapidly changing as the result of scientific research. In 1994, research evidence showed the efficacy of zidovudine (AZT) in reducing mother-to-child transmission of HIV when infected women received oral zidovudine during pregnancy, intravenous zidovudine during labour, and neonates received oral zidovudine for six weeks. Subsequently, elective cesarean section has also been shown to reduce the risk of mother-to-child transmission of HIV. These preventive strategies, resulting in dramatic declines in pediatric HIV and AIDS in the USA and Europe,^{2,4} are costly options, and thus are not yet realistic solutions for resource-poor countries like South Africa.

Mother-to-child transmission of HIV occurs primarily during labour and delivery and after delivery through breastfeeding.¹⁶⁻¹⁸ As an

alternative to AZT therapy, it has been found that short course ARV regimens during the last four weeks of pregnancy reduce MTCT rates by almost half when women refrain from breastfeeding their newborns.^{19,20} Short course ARV regimes have many advantages for resource-poor countries in terms of feasibility, adherence and cost. For women who are diagnosed close to labour, a single dose of nevirapine, a non-nucleotide reverse transcriptase inhibitor when administered to the HIV-infected woman at the onset of labour and to her child within 72 hours of birth have been found to markedly reduce the rate of HIV transmission in newborns.^{21,22} Nevirapine therapy is not without potential disadvantages; some recent evidence suggests that administering nevirapine treatment in infancy may result in the development of resistance and greater vulnerability to infection following HIV exposure in later life. Despite these potential adverse effects, currently the benefits of nevirapine therapy for HIV-positive pregnant women outweigh the risks. In many instances, for women in developing countries, who first come to an antenatal clinic in late pregnancy or in early labour, single dose nevirapine therapy remains the only option. Presently the World Health Organization endorses this method as routine procedure for preventing mother-to-child transmission in HIV high prevalence developing countries.

Despite the evidence of ARV therapy being effective in preventing MTCT, until recent years the South African government remained opposed to its use. The reasons cited for this opposition included the toxicity of the drugs and questions about their safe administration. After much urging by independent groups like the Treatment Action Campaign (TAC), the government reluctantly agreed to institute a pilot programme in 11 sites across the country. The pilot programme was poorly conceived and implemented; all the sites were urban-based and not enough to meet the needs of tens of thousand of babies born every

year. The location of the sites resulted in unavailability of treatment for women in rural areas and litigation by TAC on grounds of violation of constitutional rights of patients. A first judgment in 2001 ordered the government to provide ARV therapy where medically needed and was followed by an appeal from the government. The appeal was turned down, and in July 2002 a constitutional court judgment ordered the courts to make nevirapine universally available to pregnant women infected with HIV. This was followed in October 2002 by a cabinet statement supporting wider access to antiretroviral therapy and the establishment of the MTCT programme.

For any prevention effort directed at pregnant women, it is also important to address HIV prevention needs in the general population. It is certainly encouraging to see that despite the controversy in the debate on the provision of antiretroviral rollout, South Africa's public HIV/AIDS treatment programme is taking a step forward. In August 2003, the South African cabinet finally approved the provision of ARV therapy for HIV-positive people through the public health system and instructed the health ministry to act "with urgency". A government special task team report stated that universal provision of antiretrovirals would see approximately 1.2 million South Africans on treatment by 2008, and was likely to save the lives of more than 1.7 million people between 2003 and 2010. The plan envisaged that within a year, there would be at least one service point in every health district across the country and, within five years, one service point in every local municipality. In April 2004, Gauteng Province's health department announced the beginning of the rollout of antiretroviral drugs as patients in five hospitals in Gauteng began receiving free antiretrovirals. The indication for ARV treatment is based on clinical assessment and CD4 cell count. The criteria for ARV initiation in adults and adolescents, including pregnant women, are $CD4 \leq 200$ cells/mm³ and symptomatic, irre-

spective of stage; or (1) WHO stage IV AIDS defining illness, irrespective of CD4 count, and (2) patient prepared and ready to take ARV treatment and adhere to therapy. The government representative reported that the province hopes to treat about 100 new cases a week, expanding to 10,000 people within a year.

The MTCT prevention programme recommends using the same eligibility criteria for pregnant women to start ARV therapy as other adults; with the default first line regimen including nevirapine as the NNRTI (non-nucleotide reverse transcriptase inhibitor) agent rather than efavirenz to avoid efavirenz's potential of causing fetal abnormalities. According to the recommended policy, all pregnant women with a CD4 count < 200 cells/mm³ should be started on ARV after the first trimester. Those with CD4 counts between 200 and 350 cells/mm³ should be considered for initiation of ARV therapy after the first trimester, with therapy to be continued for life. Women who are diagnosed with HIV infection before pregnancy and become pregnant while on ARV should continue therapy without interruption, including during the first trimester. For pregnant women who test positive to HIV during labour, single dose nevirapine is recommended.

With the change in government's stance and the resulting change in health care scenario with regard to HIV screening and treatment being made available to pregnant women, there are certainly opportunities to be availed. However, when embarking on a widespread HIV screening programme for pregnant women, there are a number of issues to be kept in mind. Asking pregnant women to determine their HIV status exposes them to stigma and discrimination at a time when they are most vulnerable and require the most protection. It is a cruel reality in South Africa that individuals whose positive HIV status is exposed are often ostracised, marginalised, abandoned and at times even killed.²³ The main reason for this is that in the African culture, HIV/

AIDS is considered to be a sign of witchcraft and a bad omen, a myth propagated in part by the traditional healers since they fail to treat these cases.²⁴

The existing imbalance in power between men and women has serious implications for women's ability to protect themselves from infection, to feel safe in determining their HIV status, to seek support and care when infected, and to make choices for their own welfare independent of others. Each of these factors has implications for the success of a vertical HIV transmission prevention programme. To be successful, providers and counsellors must, at a minimum, be aware of these realities. Political and economic concerns, historically powerful patterns of gender discrimination and neglect of women's sexuality, combined with cost and infrastructure, constitute the main obstacles to the development and implementation of interventions to prevent and treat perinatal HIV transmission.^{25,26}

Breastfeeding poses another problem for pregnant women who test positive for HIV. Research evidence shows that breastfeeding can transmit HIV from mother to infant,^{27,28} with the risk of infection highest in the early months of breastfeeding. Thus, HIV positive mothers are faced with the issue of finding an alternate method to feed their babies. As part of counselling in the MTCT programme in South Africa, HIV positive women are given all the information about the risks breastfeeding may pose for transmitting the infection to their newborns. However, in the end they are still faced with making the final choice. This is often a difficult decision, depending on their social circumstances; breastfeeding, like motherhood, is a strong social norm and expectation for women in South Africa as in many developing countries.¹³ Asking HIV positive women to stop breastfeeding their babies is an issue fraught with many side effects. If preventing the child from acquiring HIV infection were the sole consideration, all infected mothers would be ad-

vised to use formula feeding. This recommendation, usually given to HIV-infected mothers in the developed countries, has to be weighed with caution when given to mothers in poor countries who cannot afford formula milk. Thus, current South African policy also includes exclusive breastfeeding as an option for women who do not wish to formula-feed. For those women who choose to formula-feed their babies, they are asked to come for monthly check-ups and are provided formula for up to six months.

Large multinational corporations promoting formula as the best option for feeding babies exploit these women by providing free samples, just enough for the women's milk to dry up. Even when formula milk is available, the issue is further complicated by the fact that women may not have necessary sanitation to mix formula without exposing infants to diarrhoea and other pathogens. Hence, promoting infant formula feeding to prevent HIV without considering the related issues might increase infant morbidity, malnutrition and mortality.²⁹

Cost-effectiveness studies of perinatal transmission of HIV in developed countries have shown that testing and treatment of positive cases is cost-effective under all assumptions when compared to no testing and treatment.³⁰⁻³² In South Africa, antiretrovirals have been shown to be cost-effective for vertical transmission prevention across a wide range of settings with or without formula feeding interventions.³³ However, the results cannot be generalised to the whole country as the appropriateness of formula feeding is highly cost-effective only in settings with reasonable levels of child survival and dangerous where infant mortality is high or the protective effect of breastfeeding substantial.³³

Future Directions

Keeping in mind the stark differences in culture and society between developed countries and South Africa, effective implementation of an antenatal HIV prevention programme requires

much more than an efficient clinic-based intervention. It requires a broader community-based effort that acknowledges and addresses women's needs and concerns, the needs and concerns of their male partners, and the perspectives of the communities in which they live. Despite all the social and cultural barriers, the encouraging fact is that in countries in which antiretrovirals are already being offered to pregnant women, many women are stepping out to be tested and treated in order to protect their unborn children.³⁴

For a long-term solution, the foremost need is to strengthen women's socio-economic status. Investing in women by providing them with education, training and skills, technologies and services that are women-friendly, employment, and social support would increase the likelihood of healthy and productive women as well as healthy and productive children, families and communities. Most of the women who are forced into unwanted sex and consequently into the plague of AIDS could possibly be protected by simply having some financial independence. HIV/AIDS prevention will be successful only when the changing needs of women as well as men are recognised and responded to by local, national and international policymakers.³⁵⁻³⁹

For instituting a policy to advocate formula milk for babies of women who test positive for HIV, we must also find a way to help mothers overcome the cultural barriers and expectations that lay a great stress upon the role of breastfeeding in motherhood. This cannot be achieved by working with mothers alone. Older women and the men in their communities would have to be involved as well in order to find ways to help families and communities understand, accept and support an infected mother's decision for substitute feeding. Additionally, for those women who choose to formula-feed, adequate provision of formula milk as well as education about hygienic preparation needs to be provided.

Traditional healers play a critical role in South African culture. They survived even strict colonial legislation forbidding their practice. Numerous studies document traditional healers' enthusiasm for collaborating with biomedical health providers and show that their activities are sustainable as they generate their own income.⁴⁰⁻⁴² For any HIV prevention programme to succeed, collaboration with traditional healers is a key element.⁴³

Third world health systems usually imitate western models, which often do not meet the needs of the people, thus creating more problems. Hence, these models need to be modified to be effective when applied in developing countries. There is no doubt about the lack of resources in South Africa. However, the scientific knowledge for combating perinatally acquired AIDS in resource poor countries is available.^{18,44} Thus, for South Africa, in spite of being a low-income country, it should be possible to establish sustainable community-based antenatal health care programmes integrated within the primary health care system to provide the essential facilities for testing and treatment of HIV for pregnant women. It is critical, though, that any efforts directed at preventing mother-to-child transmission of HIV must take into account the social determinants of HIV.^{45,46}

In South Africa, unprotected sex, multiple sexual partners, migration, and low status of women have contributed to the spread of the HIV/AIDS epidemic. The drugs that can combat this deadly disease will not be available until global pharmaceutical companies find ways to provide them inexpensively.⁴⁷ Implementation of a successful MTCT HIV prevention programme nationwide requires appropriate delivery of counselling, testing and treatment services, improvement in health infrastructure, training of health care workers, education and involvement of communities, and the mobilisation of diverse stakeholders. Additional challenges include the constant change in policies and practices relating to drug availability. The latest example is the fact

that the use of nevirapine to prevent mother-to-child transmission of HIV in South Africa has come under threat after reports of irregularities during trials of the drug in Uganda. The antiretroviral drug could be de-registered by the country's regulatory body, the Medicines Control Council, after procedural flaws in the Ugandan trial led to its manufacturer, Boehringer-Ingelheim, withdrawing an application to have it approved in the United States.

Thus, with the myriad variables affecting the availability of drug therapy, the appropriate path to follow is to ensure that ARV therapy is only one of many prevention options available to women who seek to protect their unborn children from infection.⁴⁸ The most significant option must continue to be primary prevention because the best way to ensure that an infant is not infected is to protect the mother herself. Aside from cost-effectiveness, issues to consider in the introduction of antenatal HIV screening, antiretroviral therapy and substitute feeding interventions into the South African health care system include affordability, availability of human resources and infrastructure, equity and acceptability.³³

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