

ABSTRACT

Over half the people currently living with HIV in South Africa are women. Since 2000, considerable progress has been made in expanding access to counselling and testing, prevention of mother-to-child transmission of HIV and antiretroviral therapy. However, HIV-infected women still face challenges and obstacles in accessing comprehensive services for sexual health, prevention of sexually transmitted infections, family planning and contraception, pregnancy, delivery, infant feeding, psycho-social support, counselling and treatment.

Provision of comprehensive and holistic care to HIV-infected women requires promotion of optimal therapeutic care and well-being through strengthening sexual and reproductive health services. It also entails enhancing integration of HIV and reproductive health services and providing guidelines for implementation. Other pertinent considerations include improving antenatal, obstetric and postnatal care; strengthening linkages with community based support structures and supporting HIV-positive women in their reproductive choices. It also entails building capacity of health providers in non-judgemental sexual and reproductive health service delivery; expanding access to provider-initiated counselling and testing; empowering women through increasing male involvement in sexual and reproductive health as well as through improvement of the socio-economic environment.

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INTRODUCTION

Globally, higher rates of HIV infection occur amongst women due to socio-economic, cultural and physiological reasons, with young women facing the highest risk of infection.¹ At the end of 2005, there were about 5.54 million people living with HIV in South Africa (SA), 3 100 000 (56%) were women aged 15 years and older. Young women aged between 25 and 29 are worst affected, with almost 39.5% of women in this age group living with HIV. HIV prevalence among young women (<24 years) has remained constant over the past three years, possibly indicating that the HIV epidemic among young people is stabilising.^{2,3}

The national Department of Health (DoH) has responded to the HIV epidemic by prioritising rapid implementation of its Comprehensive Care, Management and Treatment (CCMT) plan for HIV and AIDS and undertaking to strengthen programmes for women and maternal health as part of its strategic plan for 2006-2009.⁴ However, SA has a historical legacy of division of services. Stand-alone reproductive health, family planning and HIV services were initiated at different times and largely continue to operate as vertical programmes. Provision of health care to HIV-infected women is primarily through two sub-programmes: Maternal, Child and Women's Health & Nutrition and HIV and AIDS, STIs and TB. Although the CCMT includes integration of prevention of mother-to-child transmission of HIV (PMTCT) and antiretroviral (ARV) services, further integration of these and other Sexual Reproductive Health (SRH) services is essential to enhance comprehensive and holistic service delivery.

SEXUAL ACTIVITY

Few studies worldwide have examined the sexuality of HIV-positive women and the correlation between HIV symptoms, HIV illness stage, quality of life, meaning of illness, frequency of sexual intercourse and sexual function. Factors commonly reported to have a negative impact on sexuality, sexual confidence and desire for sex in HIV-infected women include fear of disclosure, fear of transmission in discordant relationships, condom use, cervical dysplasia and drug side effects e.g. lipodystrophy.^{5,6}

Little information is available on sexual activity amongst South African HIV-positive women. However one small study of 21 sero-positive heterosexual women, 14% of whom were African, identified the following issues: reduced libido, fears about transmitting HIV, avoiding relationships and dislike of condoms.⁵

A survey of sexual functioning and activity among HIV-positive women in all phases of HIV illness (asymptomatic, symptomatic, and HIV-related illnesses) in the USA, however, found that although most women (90%) remained sexually active after testing HIV-positive, few used safe sex practices, with more than one-third (37%) engaging in regular unprotected sexual activity. Although 51% reported consistent condom use, 25.4 % reported never using condoms. Few women reported that HIV itself caused a decrease in sexual functioning. Reasons for abstinence included: no current partner (31%), no interest in sex (27%), 'because of HIV' (19%), physical HIV symptoms (6%), and 'disinterested partner' (4%). After testing HIV-positive; over half the women reported that the quality of their sexual activity had either stayed the same (31%) or improved (21%); only 11% reported that their sex life became significantly worse. Sexual functioning did not change as a function of HIV illness stage.⁷

The existing South African health programmes do not address the sexual health needs of HIV-infected women despite widespread global recognition of its importance to women's well-being. Also there is minimal coverage of this subject in undergraduate health provider curricula. In several studies conducted in the country, HIV-infected women report limited receptiveness of health providers to discussing sexuality and childbearing issues.^{8,9} This attitude causes many HIV-infected women to avoid discussing sexual activity with their health care providers for fear of reprisals as a result of engaging in sub-optimal safe sex practices.

FERTILITY CHOICES

Ethics and human rights accord HIV-infected women the same reproductive rights as uninfected women (Box 1) i.e. the right to decide freely on all aspects of sexuality and reproduction, including the number and spacing of their children as well as the means to implement their reproductive decisions, since



with proper management and access to antiretroviral therapy (ART), the risk of mother-to-child transmission (MTCT) of HIV may be considerably reduced. However, the sexual and reproductive rights of HIV-positive women are often violated in health care settings⁹ and currently there is no policy, nor are there guidelines for the provision of fertility options and services for HIV-positive women in SA.

Box 1:
Reproductive Health Rights of HIV-Infected Women

HIV-positive women have the right to:

- ✦ Decide whether and when to conceive without being judged;
- ✦ Decide on the number and spacing of children;
- ✦ TOP or sterilisation on demand, without the consent of another person;
- ✦ Education on reproductive health options (labour, delivery, breastfeeding and PMTCT);
- ✦ Access to quality antenatal care (with or without being accompanied by a partner);
- ✦ Equal access to reproductive health care, regardless of social, economic or political status;
- ✦ Family planning information and decision making over the type and use of contraception;
- ✦ Access to disease preventative methods of contraception;
- ✦ Safe delivery, how and where they want;
- ✦ Assisted conception or artificial insemination;
- ✦ Accurate information about infant feeding options to allow informed decision making;
- ✦ Feed the baby the way they want to; and
- ✦ PMTCT and ART services.

Adapted from the ICW 'Young Women's Dialogue', Durban, 2004.⁹

HIV-positive women face a range of dilemmas, discrimination and barriers in upholding their reproductive rights to pregnancy and motherhood. As the following quotes illustrate, decisions around child bearing are influenced by a number of parameters including: the woman's desire, family and cultural pressure to have children, and advice and / or directives from health care workers not to have children. Having children generally raises the social status of women,

whereas women who do not have children may be stigmatised.

"If the in-laws paid lobola, then they decide how many children, because they brought you to sustain the clan. Even if you have many children you should continue falling pregnant until you have a boy. If you don't have children you are less of a woman. You lose everything even your inheritance. I have five children and am expected to have another because I do not have a son."

"My husband paid lobola and he must have a child."

Source: ICW Voices and Choices Workshop, Zimbabwe 2002.

The rights of South African HIV-positive women are often compromised by judgemental attitudes and an environment that stigmatises their reproductive choices as the following quotes illustrate:

"I had to put up with the judgemental attitude of the health care staff, including their disbelief that a woman with HIV would get pregnant."

"The nurses advised me not to have any children again. I gave birth two years later but my husband became ill and died of HIV/AIDS in the same year. The nurses shouted at me why I did not listen to their advice. I had her because I wanted a child in my life [...] the child is healthy and I don't think she is infected."

Source: Personal testimonies, HIV-positive women, South Africa

Advances in ART for PMTCT and increased access to ART and the resulting improvements in health have given many South African HIV-infected women a renewed optimism about their future and increased confidence about having children. They may reconsider their reproductive options; some decide to have children, and others resume sexual activity while wanting to avoid pregnancy. A number of programmes in sub-Saharan Africa have observed increases in unexpected (and often unwanted) pregnancies in women on ART.^{10,11}

Current studies indicate that HIV adversely affects ability to become pregnant. HIV-positive women who want to have children may attempt to become pregnant by having unprotected sex at the time of ovulation, which carries risks of infection or re-infection.¹² In developed countries, this may be prevented by using artificial

reproduction techniques such as 'sperm washing' self-insemination kits at home or insemination at a clinic using sperm from partners or donors (known or sperm banks).¹³ Often HIV infected women face challenges in getting partners to participate in these processes and negotiating for sperm, especially at sperm banks, may be prejudiced by the disclosure of their HIV status.¹⁴

CONTRACEPTION OPTIONS

Preventing unintended pregnancies amongst HIV infected women is said to be the most effective way of reducing perinatal HIV transmission.¹⁵ Contraception programmes were found to prevent 28.6% more HIV-positive births than the use of nevirapine for PMTCT at a similar level of expense in a hypothetical sub-Saharan African population.¹⁶

However, South African HIV infected women are reported to encounter numerous obstacles in preventing unwanted pregnancies, including a lack of information about the most appropriate contraceptive methods.^{8,17} Access to contraceptive methods for HIV-positive women in the postnatal period is still limited and promotion of condom use for pregnant women is not usually a part of antenatal care (ANC), although recommended by World Health Organization (WHO) in settings where HIV prevalence is high and a significant proportion of women become infected during pregnancy.¹⁸ It may also be difficult for pregnant women to justify use of condoms to their partners.

With increasing access to ART, demand for contraception among HIV-infected women is expected to increase. Hence, there is a need to update South African policies to align with the latest evidence-based contraceptive guidelines for HIV-positive women e.g. WHO 2004 Medical Eligibility Criteria for Contraceptive Use in HIV-infected women (Table 1)¹⁷ and to introduce new strategies for PMTCT of HIV in those wanting to get pregnant.

The WHO criteria¹⁹ advocate the unrestricted use of male and female condoms in HIV-infected clients, including those on ARV therapy, because condoms are the only available method that can prevent HIV and STI transmission and superinfection.^a The South African government includes male and female condoms in their

commodities purchasing plans, and ensures effective logistics management. In 2004/5 over 300 million male condoms were available free of charge at clinics and other public venues. Female condoms are available free of charge at designated clinics and for sale in some pharmacies. Plans are in place to expand availability of both male and female condoms in 2008/9.⁴

Hormonal contraception is freely available in SA public sector facilities with use of injectables being most widespread.²⁰ Based on available research, the WHO statement of 11 October 2005²¹ advises that women with HIV-infection and HIV-related illnesses can generally use hormonal contraception (oral and injectable) without any restrictions as they offer excellent pregnancy protection. Since current evidence is not sufficient to conclude otherwise, the WHO 2004 Medical Eligibility Criteria suggest that oral contraceptives (OCs) can generally be used by women on ART. There are however, theoretical concerns about potential interactions between enzyme inducing drugs (e.g. rifampicin, an anti-TB drug, some classes of ARVs [NNRTI and PIs] and hormonal contraceptives) that may increase or decrease the bioavailability of these drugs and alter their effectiveness. Theoretically, lower concentrations could reduce the effectiveness of hormonal contraceptives (and increase risk of pregnancy), while higher concentrations could increase hormone-related side effects.

The WHO Medical Eligibility Criteria on contraception for women who are breastfeeding should also be consulted and taken into account when counselling pregnant HIV-positive women, and women in the postpartum period, about contraceptive options. For instance, Combined Oral Contraceptives (COCs) are not recommended for women (regardless of HIV status) less than six weeks postpartum as there is some theoretical concern that the neonate may be at risk due to exposure to steroid hormones during this period. Also COCs diminish the quantity of breast milk. Progestogen-only hormonal contraceptives should only be recommended less than six weeks postpartum if other more appropriate methods are not available or not acceptable. However, progestogen-only contraceptives can be used from six weeks postpartum in breastfeeding women. The Intra Uterine Device (IUD) is generally

a Transmission of a different HIV strain to an HIV infected person.



recommended for women with HIV who are clinically well on ART.¹⁹

Male and female sterilisation are effective permanent methods of contraception and are suitable for HIV-infected women not planning to have children. Consistent condom use must be promoted in conjunction with sterilisation. Although available at selected health facilities in SA, increased awareness of services and more widespread availability of this service is required. Other barriers to access sterilisation services include lack of counselling by health providers on sterilisation and its benefits. Several reports exist of clients being denied access to information on sterilisation services, and of undue coercion to undergo sterilisation.⁹

“We should decide to keep baby or to terminate. But they do not tell you if you keep it – they don’t give you the option. They sterilise you. You feel obliged to take the option they offer you or you feel you can’t take the immediate service you need.”

“I went to clinic for counselling and abortion. They said why don’t you sterilise because you will have an HIV-positive child and because of your condition. They said it is no use having another child. Your health will deteriorate. I didn’t get sterilised. I always wish I can have a baby, a daughter – I have three boys.”

“I went to the hospital to be sterilised. They wanted the husband’s consent, but he wouldn’t as he did not have a boy child.”

Source: ICW members, South Africa.

TABLE 1:

Summary of Contraception Options for HIV-infected Women *

	Combined Oral Contraceptive Pills (COC)	Progestogen-Only Pill (POP)	Injectables (DMPA, Net-En)	Copper IUD
HIV-infected Women	No risk, can use without restrictions	No risk, can use without restrictions	No risk, can use without restrictions	Generally can use, but follow-up by provider may be appropriate in some cases
Women with AIDS	No risk, can use without restrictions	No risk, can use without restrictions	No risk, can use without restrictions	Generally can start or continue using IUD, if on ART and clinically well**
Women on Antiretroviral Therapy (ART)	Generally can use method, but follow-up by provider may be appropriate in some cases	Generally can use method, but follow-up by provider may be appropriate in some cases	Generally can use, but follow-up by provider may be appropriate in some cases	Generally can use if clinically well on ART
HIV-positive women on Rifampicin Treatment (anti-TB)	Should not use (not usually recommended)	Should not use	Generally can use, but follow-up by provider may be appropriate in some cases	No drug interaction Above guidelines apply

Source: Adapted from WHO, 2004 Medical Eligibility Criteria for Contraception.¹⁹

* Excluding lactating women or those who intend breastfeeding

** If not clinically well on ART, not recommended to start using Cu IUD unless other more appropriate methods are not available or not acceptable. However, can continue to use Cu IUD if not on ART.

EMERGENCY CONTRACEPTION

Emergency contraception (EC) provides protection against pregnancy but not against HIV or STI infection. It is the only contraceptive method available for use post-coitally. It is recommended as a back-up method for condom alone users in cases of inconsistent or incorrect use, burst or slipped condoms or inability to negotiate condom use. It is also an important contraceptive option for women who have unprotected sexual intercourse, but do not want to conceive, including women who have been raped. EC use is indicated in HIV-infected women, including those on ART.²²

EC is available free of charge at all South African public sector facilities. EC is also available over the counter in private sector pharmacies under the supervision of pharmacists. An EC Hotline service providing advice about EC and where to access it, is available in the Western Cape and KZN provinces.

Although EC uptake is low in South Africa,^{23,24} research findings suggest that if women have knowledge of EC, where to access it, and how soon to take it, they would use it.²³

TERMINATION OF PREGNANCY

SA is one of the few African countries which provide termination of pregnancy (TOP) on request. The Choice on Termination of Pregnancy (CTOP) Act (as amended) gives women the right to have safe and legal terminations and provides the service free of charge at state facilities.²⁵

Termination can only occur with informed consent and HIV-infected women cannot be forced to undergo TOP. Although South African women of any age can consent to TOP, the law requires health personnel to advise persons less than 18 years to consult with parents or family members before undergoing the procedure. However, this advice is not mandatory and parental consent is not essential. Although more than a quarter of South African women are reported to have accessed TOP since its introduction;²⁶ girls under 18 years constituted only 11% of those using the service in South Africa in 2004 and are reported to face prejudice from parents, nurses and doctors.²¹

The number of South African public health facilities that provided TOP services during 2004/5 increased by 10% compared to 2003/4; however, only 55% of



facilities authorised to provide TOP were doing so.²⁷ Despite lack of access to information and inadequate provision of TOP services, demand in SA continues to outstrip supply, despite high levels of contraceptive awareness and usage. There are still considerable gaps in awareness and standardising services across the country, particularly in rural areas. Most women do not know that TOP is available and legal and those who present at hospitals often find the process inefficient. Furthermore, women with HIV experience discrimination from health workers when seeking TOP-related care. In one South African study, TOP was found to be an ethical and moral challenge for health care workers and only 32% provided counselling on TOP as an option for the prevention of an unwanted pregnancy.⁸

In Gauteng, TOP outside designated services has continued partly because many women see self-medication as a primary health-seeking strategy when faced with unwanted pregnancy, but also because of lack of awareness of services and fear of ill treatment from health providers.²⁸

Although there has been a decline in TOP-related complications since legalisation, thousands of South African women die each year due to unsafe procedures performed by unskilled providers and the resulting complications. This problem may be even bigger in HIV-positive women. In 2002-2004 there were 274 maternal deaths due to pregnancy-related sepsis (8.1% of all maternal deaths) and 114 as a result of septic abortion reported.²⁹

South Africa's TOP Act stipulates that the service must be made available upon request to women during the first 12 weeks of pregnancy (first trimester). TOP during the second trimester is considered if a medical practitioner is of the opinion that the pregnancy would pose a risk to the woman's physical, mental or social well-being, or is a result of rape or incest.²⁵ Many women who try to access TOP are reported to be unnecessarily delayed because of long waiting lists and miss the second trimester which makes TOP unsafe.¹⁷ Further, women who undergo HIV testing at antenatal services are usually at about 14 weeks gestation, which would require a late termination involving labour.²⁶

HIV-positive women seeking TOP in SA have reported being sterilised without their permission.¹⁴ Sterilisation

should not be offered immediately after termination and should only be considered after adjustment to the trauma of a termination and / or HIV status if recently discovered. The provision of contraception and family planning services and referral for psycho-social support as part of post-TOP care is strongly recommended in SA.

PREGNANCY

HIV prevalence among pregnant women in SA has increased from 1.7% in 1991 to 30.2% in 2005.³⁰ Early and routine identification of HIV-infected pregnant women facilitates access to ART, contributes to postponement of orphanhood for children and results in decreased HIV transmission to children. Although counselling and voluntary HIV testing for pregnant women was introduced in SA in 2002, uptake is limited and the majority of women attending antenatal care do not know their HIV status. If HIV diagnosis occurs during pregnancy, women need sufficient time, accurate information and support to be able to explore all options before decision making.

There is no evidence that pregnancy accelerates the course of HIV-related diseases in asymptomatic women in developing countries and pregnant women were not found to be any more or less likely to develop HIV-related illnesses than other HIV-positive women. Several Western studies have found the prevalence of birth defects in infants with in utero exposure to HIV to be similar to those of the general population.³⁰

Recent South African research has, however, shown that HIV-positive women are more likely to experience adverse pregnancy outcomes, complications and mortality than HIV-negative women. HIV-positive pregnant women were more likely to develop anaemia, pregnancy-induced hypertension, have lower maternal weight, double the risk of developing urinary tract infection, a five-fold increase in the rate of syphilis, a higher rate of abnormal vaginal discharge, slightly earlier delivery and a 5% chance of in utero growth retardation of the baby.³¹ Further, HIV in pregnancy has been associated with increased severity of complications, TB, malaria, miscarriages and stillbirths.^{31,32} During pregnancy and lactation women are at increased risk of malnutrition.³³

South African guidelines on maternal nutrition in the context of HIV were completed and distributed in 2004/5. The national DoH has made it mandatory for all HIV-positive pregnant women to be screened for TB.³⁴

National statistics demonstrate a steady increase in HIV-related maternal deaths from 14.5% in 1998 to 20.1% in 2002-2004. In the 46.3% of maternal deaths where HIV status was known in 2002-4, 36% were HIV-positive and HIV-related illnesses were the most common cause of non-pregnancy related death, comprising 20.1% of all deaths. This figure could be higher considering the high number of HIV-related causes of death in women of unknown HIV status.²⁶ The high rate of HIV-related maternal morbidity and mortality in South Africa has been attributed to the absence of practical guidelines for midwives' antenatal assessment and management of HIV-positive pregnant women.³⁰ Guidelines that address specialised obstetric care for pregnant HIV-positive women and extended postnatal care are available³⁵ but not widely implemented.

The standard treatment for HIV-positive pregnant women in developed countries is triple antiretroviral therapy (HAART) throughout the pregnancy, delivery by caesarean section and formula feeding, which may reduce the risk of transmission to <2%. (Table 2). Standard ART should not be deferred in pregnant HIV-infected women as the only clear evidence of adverse effects of ART in pregnancy is a possible increased risk of premature delivery. Adverse effects of ART may, however, compound those of pregnancy – some ARVs can cause anaemia or insulin resistance, which tend to worsen in pregnancy. Ideally, triple therapy should commence from at least 34 weeks gestation to allow for at least 6 weeks of viral suppression. Women on ART should not stop treatment either before or on discovering that they are pregnant as this may carry a risk of viral rebound and also increase the risk of vertical transmission. Access to ART for pregnant women in SA and developing countries still reaches fewer than 10% of people who need it. This may partly be due to the fact that although public sector health care provides HIV-infected women with antenatal care, obstetric care and family planning services; these are often located at primary health care facilities and separately from HIV

services which are largely only available at hospitals and a few Community Health Centres (CHCs).^{33,36}

The drug Efavirenz (EFV) is associated with teratogenicity and is contra-indicated for women trying to conceive or who are already pregnant, especially in the first trimester. Women who conceive whilst taking EFV should be counselled about its potential effects on the unborn child and the options for changing therapy. Pregnant women should not use both ddI and d4T due to high rates of lactic acidosis; and those with CD4 >250 should not commence NVP use. Also, although 95% adherence rates are necessary for optimal ART, adherence rates between 34-80% have been reported in pregnant HIV-infected South African women.³⁷

DELIVERY

The standard method for delivery in HIV-positive pregnant women in developed countries is through Caesarean section (C/S). Obstetric interventions recommended in SA include caesarean delivery (available at hospitals); (though HIV is not an indication for an elective C/S especially in the backdrop of other life-threatening pregnancy complications that are not always HIV-related) and vaginal birth with avoidance of invasive tests, and birth canal cleansing.^{35,38}

Elective C/S births have been shown to reduce the risk of MTCT prior to the widespread availability of ART and have also been shown to reduce MTCT risk in resource constrained settings. They are, however, costly and have an increased risk of post-operative complications, morbidity and mortality. Complications such as postnatal infections are five to seven times more likely to occur after C/S with labour or membrane rupture compared to vaginal delivery. Although C/S complications appear to be the same in women with and without HIV infection, routine elective C/S is not recommended. C/S may be considered in cases where prolonged labour is likely and where obstetric complications may result in an increased risk of MTCT.³⁷

Most districts in South Africa reported high rates of C/S in 2004 with the highest rate being in KwaZulu-Natal at 21.0 per 100 deliveries.³⁹ The high HIV prevalence in the province may have an influence on this and it is anticipated that the availability of ART in



South African public sector services will ultimately lead to a decrease in the use of C/S for MTCT prevention.

TABLE 2:
Factors influencing perinatal transmission of HIV

Factor	Perinatal Transmission Rate (%)
No intervention	15-30
Vaginal Delivery	10.5
C/Section	1.8
Single dose NVP	12
Zidovudine (AZT) during pregnancy	<8
AZT + NVP during pregnancy	2
HAART+VL<1 000c/ml	1

Source: Modified from DoH 2001;³⁵ Oyango-Okeyo 2006;³⁷ Waugh 2003.⁵⁷

For vaginal deliveries, use of episiotomy, vacuum extraction or forceps may potentially increase risk of MTCT by increasing exposure to maternal blood and / or genital secretions through trauma to maternal or neonatal tissue. These techniques should be used judiciously together with interventions to shorten duration of labour to decrease likelihood of MTCT.³⁵

Routine Artificial Rupture of Membranes (AROM) in pregnant women with HIV for longer than 4 hours prior to delivery is associated with increased MTCT and should be avoided unless there are specific obstetric indications. Alternative methods of augmenting labour should be considered (e.g. oxytocin).³⁷

ACCESS TO PMTCT

SA implemented its PMTCT programme in 2002 and now has the largest PMTCT programme in the world with services available at 2 525 sites countrywide (more than 60% of all public sector health facilities offered PMTCT services during 2004-5).²⁷ Although PMTCT is widely accessible and free of charge at public sector facilities, transmission rates between mother and child remain unacceptably high. The PMTCT programme has been shown to be failing in parts of KwaZulu-Natal.⁴⁰ An MTCT rate of 20.8% (95% CI 18.2-23.6%) at six weeks has been recorded recently;

the expected rate is about 12%. The main reasons for this appear to be pervasive stigma and discrimination and the inability of current health services to ensure uptake of prescribed medications (NVP). In 2006 it is estimated that only 14.6% of pregnant women received prophylaxis to reduce MTCT.^{2,27} Many pregnant women do not take up voluntary counselling and testing (VCT). PMTCT data from the 53 health districts in SA for 2004 indicated that a relatively low proportion of mothers actually got tested for HIV, resulting in many deliveries in women of unknown HIV serostatus and missed opportunities to prevent MTCT.³⁹

The South African PMTCT programme offers testing and counselling services, single dose nevirapine (sdNVP) to mother and baby and free formula milk (Pelargon®) for six months. In some areas the programme is hampered by a lack of district management, shortages of lay counsellors and stock-outs of formula milk supplies.

Plans to integrate PMTCT with ART include assessing nutritional status of HIV-positive pregnant women (and supplementing accordingly), CD4 testing and referral for ART if CD4 count <200. If CD4>200, women continue with sdNVP as per the current PMTCT protocol. Bactrim prophylaxis is indicated for women waiting to commence ART. The referral of pregnant women with low CD4 counts to ARV initiation sites is still problematic and results in 'loss' of women most at risk of vertical transmission.

Although sdNVP to HIV-infected mothers during labour and to infants soon after birth is an effective method of reducing the rate of HIV transmission to infants to about 12%; studies in SA and Uganda found that 20 to 40% of HIV-positive women developed resistance to NVP after single dose monotherapy for PMTCT.⁴¹

Prior exposure to sdNVP does not necessarily compromise subsequent responses to NVP-containing ART, particularly if enough time passes between that exposure and the need for ART.

Women exposed to sdNVP who commence on Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTI) containing ART regimens within several months of delivery are less likely to achieve virologic suppression than unexposed women. Detection of NNRTI-

resistance mutations decreases over time suggesting that women who have longer to wait before initiating ART might have better responses to treatment.⁴² Studies in African women with prior single dose Nevirapine (sdNVP) exposure had lower viral loads compared to unexposed controls at week 24.^{42,43} Based on these findings, revised WHO guidelines on PMTCT⁴⁴ now recommend dual therapy ([azidothymidine] AZT and NVP) which could reduce HIV transmission to as little as two per cent and results in lower rates of Nevirapine (NVP) resistance in both mothers and infants. This has been adopted by the PMTCT programme in Zambia. In South Africa this is only being implemented in the Western Cape and should be considered as national policy. Nevertheless, NVP-containing regimens are still a good first-line option for ART for many sdNVP exposed women in resource-limited countries and use of NVP in repeat pregnancies could remain an effective option.⁴⁵

Ideally, South African women in immediate need of ART should be identified early in pregnancy and should either be enrolled directly into ART programmes, or be offered a short-course AZT/3TC post-delivery to prevent the development of resistance to NVP.⁴² At this stage, referral of pregnant women with low CD4 counts (those most at risk of vertical transmission) to ARV services is still problematic.

Although there is clear evidence that women benefit from ART, the increased risk of serious side effects to some ARV drugs in women highlights the importance of careful monitoring. Women are reported to be more likely to develop NVP-associated rash than men. Moreover, women who have >250 CD4 cells at the commencement of NVP use are at considerably increased risk of liver toxicity than men.⁴⁶ The SRH needs of women need to be considered when prescribing ART regimens, including those to women planning pregnancy. Women on ART may require additional counselling and support on sexuality and pregnancy prevention and childbearing. Further research in women is required on differences in dosage and reactions to ARVs, the effective delivery of ART for women, the effect of hormone level changes, the effects of pregnancy, and levels and implication of ARVs in breast milk and on ART in relation to fertility.

INFANT FEEDING OPTIONS

There is evidence to suggest that exclusive feeding, either breast, or with milk alternatives is most effective in preventing mother-to-child transmission of HIV (PMTCT). Several African studies⁴⁷⁻⁴⁹ have showed that exclusive breastfeeding resulted in a lower HIV transmission rate. HIV-positive mothers who breast-feed should do so exclusively. The better the adherence to exclusive breastfeeding, the lower the risk of MTCT of HIV or infant death. Findings by Iliff et al.⁴⁸ showed that early exclusive breastfeeding not only reduces the risk of postnatal HIV transmission, but also increases HIV-free survival. The study also showed that exposure to education and counselling was associated with increased adherence to exclusive breastfeeding, which was in turn associated with reduced postnatal HIV transmission.

HIV-positive mothers whose babies are HIV-negative after 6 months of exclusive breastfeeding should consider early cessation if safe alternatives (e.g. formula made with clean water) are accessible and mothers have adequate social support to implement these alternatives. The cost of alternative sources of milk puts this choice out of the reach of many women.

South Africa's Infant Feeding policy for HIV infected women⁵⁰ subscribes to the recommendations and guidelines of WHO/UNICEF/UNAIDS. The key elements of this policy relevant for re-examination of priorities include: provision of free formula milk, use of Pelargon® as the only formula milk, and supply of formula milk for six months (although this varies between provinces from 6 months to 12 months). The authors' contention is that this policy is inappropriate in a country where the overwhelming majority of women who utilise public health services are poor, often unable to exercise their own rights, and are conditioned by centuries-old culture and traditions. The 'Good Start' study contributes objective data which support the above criticism.⁵¹ For more details on infant feeding in HIV-positive women, refer to the chapter on HIV and Infant Feeding in this Review.



COPING WITH HIV AND MOTHERHOOD

HIV infected mothers are faced with coping both with the physical demands of their illness and child care and with the emotional burden of decision making about disclosure of HIV status, custody, fertility options, use of health care services, and use of ART. This may be compounded by additional problems, such as death or illness of a spouse, worries about a child's future, about their own death, about establishing and maintaining the mother-child relationship and grieving the death of HIV-positive children. Motherhood may be characterised by feelings of guilt, especially if a child is infected. There is also the burden that children (if uninfected) are likely to be orphaned before adulthood. As well as worrying about the rearing of young children, HIV-positive mothers may also worry about their older children becoming infected. When illness prevents them from physically mothering, they may practice 'virtual motherhood', which recasts their role as that of overseeing children and finding ways of remaining in their children's minds and hearts. Many women develop strategies to ensure this. Some create 'memory books or boxes' comprising family stories and family photos to give children a lasting idea of their parents and pride in their personal history.⁵² In some countries mothers receive training on making wills to ensure that their property gets passed to their children upon their deaths and is not taken by relatives or other community members.

Motherhood also provides HIV-infected women with positive aspects: social support, self esteem, and a reason to live and fight HIV infection. HIV-infected women report having to work hard to prove they are good mothers because of the stigma of HIV. An analysis of 56 United States (US) studies of mothers with HIV found that they sought to protect their children from HIV infection and HIV-related stigma.⁵³

To increase HIV client access to support services, the national DoH plans to link at least two organisations to each ARV accredited service point by 2007.⁴

DISCLOSING INFORMATION ABOUT HIV TO CHILDREN

South African studies show that disclosure to children is a complex process of negotiation and manipulation.⁵⁴ However, there is little local research to provide a broader understanding of emotional and physical benefits of disclosure for both parents and children. Several studies have highlighted the complexity of HIV disclosure and the process of negotiation that women undergo.^{54,55} Although significant research and policy concerns are directed to paediatric ART and HIV care, there is evidence to suggest that South African parents and caregivers still grapple with the issue of disclosing HIV status to children.

The new Children's Act states that a child can only be tested for HIV if the test is in the best interests of the child and the necessary consent has been given. Children over and under the age of 12 years, depending on their maturity, can request their own HIV tests. Parents or guardians of children only have the right to disclose the child's HIV test results if the child is under-12 years and not sufficiently mature enough to understand the consequences of such disclosure.

Research in developed countries indicates that disclosing HIV status to children and maintaining open communication about the disease results in better parent-child and family-health-facility relationships, less parental anxiety, and, in children, better psychosocial adjustment and coping, fewer behavioural problems, increased adherence to medication, and better preparation for safe sexual practices.⁵³

Parents are reported to generally partially disclose information about HIV without naming it and to delay full disclosure. The most frequently given reason for delay in talking to their child about HIV was fear that the child may accidentally reveal their diagnosis, thereby simultaneously revealing maternal HIV status and exposing the family to potential stigmatisation, discrimination and prejudice.⁵⁷

Disclosure to children is probably one of the most difficult tasks faced by HIV-infected women and requires considerable courage, preparation and time. Women throughout the world are faced with the complexity of HIV disclosure to their children, (either born infected

or uninfected), because the disease is life-threatening and highly stigmatised.^{58,59} Factors commonly reported to influence decisions around disclosure include: age and HIV status of the child, maternal health status, ethnic / racial and socioeconomic position, maternal temporal orientation, and mothers' relationships with health care providers.

Common negative factors related to disclosure to children include fear of the emotional burden, fear that the child will experience rejection, changes in children's behaviour, as well as uncertainty as to when, how and what to say to children.^{54,55} Other considerations include: protecting the child from the fear of death, worry about the ability of the child to be discreet and fear of public disclosure of the family condition,⁵³ children's reactions and (potential) questions about survival and disease transmission and impact of disclosure on the health of the child. Adults (caregivers and health care providers) tend to disregard or ignore children's capacity to understand. They fear that children may be sad, rebellious, angry or depressed after disclosure. For these reasons, mothers may delay disclosing HIV status to children and some may decide never to disclose.

Parents have varying opinions regarding whether to disclose HIV status to children, and the appropriate age at which to disclose. This will depend on the child's level of understanding). Although optimal age for disclosure to children is debatable, experts suggest that information given to children in response to questions about clinic visits and medications etc. and should be appropriate to the age and emotional development of the child. In one study children, who had been disclosed to had a mean age of 10.5 years.⁵⁹ HIV-infected mothers in Siphumelele, South Africa agreed that 10 years of age was about the right time to speak to children about terminal illness or death, however only one of the sixteen children of these eight mothers had been told of their mother's HIV status.⁶⁰ It is important to tailor discussions to the child's cognitive level and to personal and individual issues.

The recent South African Department of Health Guidelines on the Management of HIV-infected Children (2005) discuss reasons for disclosure of HIV status to children and make recommendations on how this should be done.⁶¹ The guidelines are based on the

UN Convention on the Rights of Children, which state that children have the right to participate in decision making about their own health care.

Before disclosure, consideration should also be given to the type of support the child will need, and whether it would be helpful to have someone with them in whose presence they feel at ease to express their needs and ask questions. This could be family members, children of other HIV-positive parents or close family friends. Some HIV-positive women have found that getting someone trusted e.g. a counsellor to talk to the child first to be very supportive, both for themselves and for the child. It is important that everyone involved is consistent in what they say.

Studies of rural, peri-urban and urban HIV-infected households in South Africa found that disclosing HIV status was of concern to parents; that patterns of disclosure differed across geographical settings; and that HIV challenged existing cultural practices of communication between children and adults in these African communities, especially concerning death.^{62,63} Social workers who participated in the study revealed that, as a normative belief and practice, death was not typically spoken about, either in relation to HIV, or in general and this impacted on parental ability to disclose their potentially life-threatening illness to their children.

ACCESS TO COUNSELLING

HIV testing and counselling services are widely available at South African public health facilities; more than 80% offered voluntary HIV counselling and testing (VCT) during 2004-5. However, the proportion of targeted people accessing VCT (23%) remains sub-optimal²⁷ and efforts to increase use of testing services must be made as VCT provides an entry point to care, treatment with antiretrovirals and support. Benefits for HIV-positive women, includes facilitation of informed decision making regarding sexual activity, fertility, contraception, CTOP, methods of infant feeding, and the opportunity of seeking early access to care. In South Africa, antenatal services provide pregnant women with access to VCT and referral for ART. Entry points for non-pregnant women and girls to VCT and treatment need to be more readily accessible.



SA uses the 'opt in' option i.e. HIV testing is not done unless the woman is counselled and requests testing thereafter. This is patient-centred and involves assessing, counselling, testing and supporting the patient. Alternative approaches to increase uptake of HIV testing services and care and support include 'Routine Counselling and Testing', (RCT) whereby HIV counselling and testing is routinely offered to all patients within the health care setting, irrespective of presenting illness. RCT is a provider-centred approach that includes voluntary, specific and informed consent and appears to be widely supported in Botswana.⁶⁴

In Zambia, guidelines stipulate routine HIV testing for all pregnant women; unless the women explicitly asks not to be tested i.e. the so-called 'opt out' option.⁶⁵ However, this option can result in females being tested without informed consent and could drive some women away from care.

CONCLUSIONS

South Africa has made significant progress in rapidly expanding access to PMTCT, VCT and ART, and has produced policies and guidelines supportive of high quality treatment and care for HIV-infected women; however, there are challenges and gaps in translating these policies into action. For the majority of South African HIV-infected women, despite having good access to therapeutic services, decision making around pregnancy and childbirth is characterised by a number of negative factors including obstacles to pregnancy prevention. These include a lack of information on contraception, interactions between ART, contraceptives and drugs for treatment of opportunistic infections; inability to use condoms and contraception consistently, lack of knowledge about their HIV status when they become pregnant; and lack of knowledge about fertility options and inadequate access to prevention of unwanted pregnancies.

The integration of HIV care with SRH (including family planning and STI services), and the availability of social support must be improved. Integration of services would increase opportunities for screening and prevention, reduce duplication of services, provide continuity of care, and make maximum use of finite resources.

RECOMMENDATIONS

Support for HIV-positive women who choose to have children should include:

- ◆ Information about the impact of HIV on the course and outcome of pregnancy and the impact of pregnancy on HIV disease progression.
- ◆ Addressing infertility in HIV-infected women by increasing awareness of and access to assisted reproduction techniques and possibilities of fostering and adopting.
- ◆ Developing linkages between health facilities and community based support groups and systems.
- ◆ Appropriate therapeutic care to optimise viral load and immune status prior to conceiving in order to minimise risk of MTCT.
- ◆ Counselling on the risk of pregnancy to mother and child and on PMTCT early in the course of HIV care, and prior to conception.
- ◆ Improved counselling on feeding options during PMTCT and revised selection criteria for counsellors.
- ◆ Expanding access to services for emergency obstetric care and enhanced postnatal care, especially in rural areas.
- ◆ Further research on effects of ART on hormonal contraception, breastfeeding, fertility, and sexual activity.
- ◆ Strengthening support for disclosure of HIV to children.
- ◆ Counselling for HIV-infected mothers on planning future care of children which should include information about social service organisations and supportive networks, and coordination of appropriate re-referrals.
- ◆ Referral of pregnant women with low CD4 counts (those most at risk of vertical transmission) to ARV services is still problematic and strengthening of this referral system is required.

Developing evidence-based policies and guidelines with involvement of HIV-positive women in policy making and programme implementation:

- ◆ Guidelines for midwives' antenatal assessment and management of HIV-positive pregnant women.
- ◆ Policy framework and guidelines for the provision of fertility options and contraceptive services for HIV-positive women.
- ◆ HIV-positive women also require counselling on a diverse range of SRH issues including contraception, fertility options, preventing HIV transmission and safe sexual behaviour. Given the large patient volumes at South African health facilities and the human resource constraints, an integrated HIV counselling and testing service delivery model could increase HIV testing of pregnant women and other high risk groups.

Expanding access to HIV counselling and testing so that HIV-positive women can access treatment early in disease progression:

- ◆ Minimising missed opportunities for HIV testing by ensuring provider-initiated HIV testing, as opposed to VCT and by expanding access to counselling and testing to women at STI and TB services, postnatal care, abortion-related care, emergency contraception and rape crisis services.

Integration of Reproductive Health and HIV services:

- ◆ Restructure vertical programming for sexual health care, reproductive health care and STI/HIV prevention and treatment by: integrating some services, adding and strengthening others, expanding outreach to new population groups and creating efficient referral links e.g. between antenatal and ARV services.

It is recommended that postnatal care guidelines for HIV-infected South African women emphasise evaluation of presence of infection, counselling on contraceptive options and infant feeding options.

Preventing Unwanted Pregnancies:

- ◆ Strategies to expand EC awareness are needed, as is provision of HIV counselling and testing to women accessing EC.
- ◆ Further research is required on the possible effects of hormonal contraception on infectivity of HIV-positive women and potential relationships between hormonal contraception and HIV-related illnesses progression.
- ◆ Clinical judgement and access to ongoing medical services must be provided for ongoing use of the IUD in patients with HIV-related diseases who are not on ART or not clinically well.
- ◆ HIV-positive women who decide to undergo TOP require extensive support and counselling. Decision making around TOP should consider factors such as the woman's views on termination and her religious beliefs.
- ◆ Strategy to increase awareness and availability of TOP services, EC and female condoms especially in rural areas should be developed.
- ◆ Provision of family planning and contraception services as part of HIV services, and post-TOP care.
- ◆ Addressing gender inequality by counselling on negotiating condom use and by implementing strategies to increase male involvement in SRH issues, including couple counselling.
- ◆ Promotion and provision of condoms during pregnancy and family planning / dual protection counselling in postnatal care.
- ◆ Counselling about appropriate contraceptives for HIV-positive women.
- ◆ Counselling for women diagnosed with HIV during pregnancy to facilitate the ability to make informed choices about opportunities to terminate pregnancy safely if desired, and future fertility.



Building capacity and skills of health care workers:

- ◆ Supportive services that promote non-judgemental open discussions of the sexual and reproductive rights of HIV-positive women are urgently needed in South Africa. To facilitate this, training in sexual health and counselling for doctors and nurses is required.
- ◆ Values clarification training including gender issues and reproductive health rights is required to facilitate non-judgemental support, information and services.
- ◆ Training on contraceptive options for women living with HIV.

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