

# Sacrificing the woman

*By prioritising the health of the baby in mother to child transmission prevention programmes, women are treated as dangerous carriers of disease and not as people with a right to information and choices says Marion Stevens.*

One of the striking features of the HIV epidemic in sub-Saharan Africa is that it disproportionately affects women. But the debate about HIV treatment in South Africa largely neglects the issue of women's sexual and reproductive health.

This is clear from the language used in the field of Prevention of Mother to Child Transmission (PMTCT): HIV-positive women are likened to an instrument or body for potentially passing on the virus to a child. Examples of this include health workers who refer to HIV-positive pregnant women as "suicide bombers", and proposals in the area of PMTCT entitled "Saving unborn babies".

The emphasis in PMTCT is on the unborn infant, not the HIV-positive woman (Eyakuze *et al* 2008). Many HIV-positive women, after dealing with the initial diagnosis and treatment, express a desire to have a child. For these women, there is a clear absence of guidelines for treatment, which could include Highly Active Anti-Retroviral Treatment (HAART).

There is a need to move from an HIV/AIDS maternal health paradigm to one that embraces women's sexual and reproductive health and rights.

And the media should present the bigger picture by including a focus on women's health.

## Contradictions

Efforts to address the HIV/AIDS epidemic are informed by various different kinds of prevention paradigms. Most prevention activities focus on limiting sexual activity; for example, the ABC (abstain, be faithful, use condoms) strategy. The prevention paradigm is a negative one. It is about denying and limiting sexual activity.

The language that informs prevention has also not managed to circumvent the negative reality of preventing: it is about "stopping, avoiding, standing in the way".

It is also closely related to the language of contraception and family planning. Women are instructed to engage in prevention activities, but do not have much power to do so in their relationships with men. They learn that life-prolonging HAART treatment is contra-indicated in pregnancy – though treatment can stop transmission to the unborn child.

These contradictions do not affirm women in the choices that they make, or allow them to control their fertility.

This is in contrast to the discussions at the International Conference on Population and Development which turned around the population control agenda. Women, empowered

by information and supported by development (housing, water and education), can make informed, life-affirming choices to determine their futures (United Nations, 1994).

## Stigmatised choices

A key gap is the area of sexual, fertility and reproductive intentions. HIV-positive women who would like to have a baby are not generally viewed as part of the continuum of care (De Bruyn 2004; De Bruyn 2006). Attitudes are often judgemental.

A study reviewing reproductive intentions noted that most respondents had not discussed their desire to have children due to anticipated negative reactions. Those who had, found the counselling environment unsupportive (Cooper 2007).

It's also notable that those who want to get pregnant wanted to ensure that they themselves would also have access to treatment, and not just have treatment to protect their unborn baby. It is, however, important to note that 50% of pregnancies are unplanned (WHO 2006; Gipson 2008) and that many women are not able to negotiate safer sex.

## Ignoring the central issue

Given an international epidemic that primarily affects women, pregnancy is clearly a central issue. Yet the Department of Health and Human Services' 127-page "Guidelines for the use of anti-retroviral agents in HIV-1-infected adults and adolescents", published in January 2008, devotes two paragraphs to this issue (DHHS 2008), suggesting merely that "... in women of reproductive age, antiretroviral regimen selection should take account for the possibility of planned or unplanned pregnancy... sexual activity, reproductive plans, and use of effective contraception should be discussed with the patient".

The WHO guidelines on "Sexual and reproductive health of women living with HIV/AIDS" begin to address these issues conceptually and suggest possible treatment options, yet the guidelines are tentative and exploratory (WHO 2006).

Currently the first-line regimen for women contains Efavirenz, which is contra-indicated in pregnancy. It is viewed as teratogenic, and there is positive evidence of human fetal risk. Tenofovir, which may become a first-line drug replacing D4T, has not been adequately tested for use by pregnant women. It is also currently not registered for use in children, suggesting that this is not a good choice for a woman of reproductive age.

In protests by treatment advocates in South Africa leading to the registration of Tenofovir,

women activists commented that they were keen to replace D4T with Tenofovir as they were "losing their figures" as a result of lipodystrophy, a side-effect of D4T which causes "tummy tyre" and thin arms and legs. The fact that they were aware of this side effect, but not of the potential consequences of Tenofovir for pregnant women, is significant.

## Contraceptives

At a meeting of the International Community of Women Living with HIV/AIDS in December 2007, it became evident that some women in South Africa and other Southern African countries were receiving injectable contraceptives as part of their HAART regimen to ensure that they would not become pregnant. Women were counselled to not become pregnant and had varying understandings of the side effects of the treatment. Some reported that it was only later on that they realised that they were receiving an injectable contraceptive and that



# for the child

this was not their informed choice.

This kind of treatment is like the era of population control, where women were not provided with information regarding treatment in a paternalistic fashion.

## Invisible guidelines

In most of the literature on and guidelines for treatment, the clear priority is to reduce transmission from the mother to unborn infant. "The intersection between HIV and pregnancy," says Eyakuze (2008), "exposes the ethical and legal inequalities inherent in a societal structure that places more value on a women's reproductive capacity than her own individual well being."

It is a missed opportunity to help women who choose to get pregnant while HIV-positive, and who find out they are pregnant and choose to have an early abortion (De Bruyn 2004). One can choose to be pregnant and then negotiate the treatment

options to avoid transmission, but the journey and processes guiding women along this path are invisible to them.

Women of reproductive age bear the brunt of the epidemic. For prevention to work, we need to be affirming women and providing them with better choices. There is a need to move away from a maternal paradigm that conceptualises treatment

for women only as mothers.

With the highest rate of infection, women of reproductive age need a continuum of care that takes into account their sexual, reproductive and fertility intentions. Most crucially, they need appropriate and well articulated information and support. And in this the media can play a constructive role.

## References

- Eyakuze, C, Jones, D, Starrs, A and Sorkin, N. 2008. "From PMTCT to a more comprehensive AIDS response for women: a much-needed shift." *Developing World Bioethics* 8(1): 33-42.
- Cooper, D., Harries, J., Meyer, L., Orner, P. and Bracken, H. 2007. "Life is still going on: Reproductive intentions among HIV-positive women and men in South Africa." *Social Science and Medicine* 65: 274-283.
- De Bruyn, M. 2006. "Women, Reproductive Rights, and HIV/AIDS: Issue on which research and interventions are still needed." *J Health Popul Nutr* 24(4): 413-425.
- De Bruyn, M. 2004. "Living with HIV: Challenges in Reproductive Health Care in South Africa." *African Journal of Reproductive Health* 8(1): 92-98.
- DHHS. 2008. *Guidelines for the Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents*. (OARAC): 1-128.
- Gipson, JK, M and Hindon, M. 2008. "The Effects of Unintended Pregnancy on Infant, Child and Parental Health: a Review of the Literature." *Studies in Family Planning* 39: 18-38.

