

CHAPTER 2:THE CASE OF PMTCT IN SOUTH AFRICA—

A LITERATURE REVIEW

As briefly stated in the Introduction, the prevention of mother-to-child transmission of HIV (PMTCT) is a social issue that involves a complex array of gender, sex and power relationships in society. This chapter will discuss the controversy surrounding PMTCT in South Africa, and its significance for women's health. The literature that will be discussed includes:

- What is PMTCT, how is it a development concern for South Africa, and what are the interventions that presently exist in South Africa;
- The politics of PMTCT in South Africa: the landmark court case in 2002;
- The current debates around the use of Nevirapine for PMTCT in South Africa;
and
- Issues of women's health in the terrain of PMTCT and HIV/AIDS in South Africa.

2.1 PMTCT in South Africa – A women's health concern

After unprotected heterosexual sex (which accounts for 90% of HIV infections), mother to child transmission of HIV is responsible for the highest HIV incidence in sub-Saharan

Africa each year (UNAIDS, 2004). Approximately 90% of HIV infections in children are a result of vertical transmission from mother to her infant (Newman, 2004). While there are international targets for PMTCT, such as reducing the proportion of infants infected with HIV by 20% by 2005, and by 50% by 2010 (WHO, 2004; UNICEF, 2002); it is estimated that current PMTCT programmes have only been able to reach 5% of all HIV-infected women (McIntyre, 2005). Thus, a cornerstone of any effective prevention intervention on the continent is a good PMTCT programme. The WHO (2005) recommends a “comprehensive strategic approach” for public health which includes:

- (1) Primary prevention of HIV infection;
- (2) Prevention of unintended pregnancies among HIV-infected women;
- (3) Prevention of HIV transmission from HIV-infected mother to their infants;
(PMTCT) and
- (4) Care treatment and support of HIV-infected mothers and their children.

While all four components are vital for a holistic approach to HIV prevention and treatment, this research is focusing primarily on components 3 and 4: PMTCT and further long term care and treatment for both mother and baby.

In 2003 HIV prevalence among pregnant women in South Africa was 27.9%, which was slightly higher than previous years in 2002 and 2001. An overwhelming majority of the 1.9 million children (younger than 15 years) living with HIV at the end of 2004 in Sub-Saharan Africa were due to MTCT during pregnancy, delivery, or through breastfeeding

(UNAIDS, 2004). With an intervention, which includes administering anti-retrovirals (ARVs) to mothers 'in utero' (during pregnancy), or during delivery, or 'postpartum' (after birth) to the infants (it does not help giving mother's ARVs post-partum to reduce transmission during birth, although it may reduce transmission through breastmilk), some studies and clinical trials show that the rate of infection can be reduced by 50% in developing countries (Barnett & Whiteside, 2002; WHO, 2004). In the absence of intervention, 15% to 45% of children born to HIV-positive mothers will also become infected. Transmission occurring during pregnancy accounts for about 15-20% of infections, 50% during labour or delivery, and 33% during breastfeeding (UNICEF, 2002).

Presently in South Africa there is a basket of interventions for PMTCT which include:

- Voluntary counselling and testing (VCT) for HIV for pregnant women: In South Africa, pregnant women are given the option to know their status through VCT services, where the woman is offered the option of an HIV test and must give informed consent for the test to be done. This is referred to as an 'opt in' system;
- Single-dose Nevirapine is given to mothers during labour and Nevirapine syrup to the babies up to 72 hours after birth;
- Mothers are then counselled on infant feeding options and given free formula for six months if needed. The WHO (2005) recommends that breastfeeding be avoided when infant formula is available, affordable and sustainable because

of the possible transmission of the virus through breast milk. However, in resource limited situations, infant feeding is often not sustainable because there are concerns of water supply and sanitation which can result in diarrhoea and other complications for the baby. In these situations, mothers may be inclined to ‘mix feed’, which involves partly breastfeeding and partly bottle-feeding. However the WHO states that mix feeding should be avoided at all costs and in where there are limited resources, exclusive breastfeeding is recommended for the first months of life (WHO, 2005);

- Access to support groups where disclosure, practising safe sex, and family planning are discussed; and
- Infant follow-up testing: Babies are tested at 14 weeks with an expensive but definitive PCR (polymerase chain reaction) test to reveal babies HIV status (Abdullah, 2004, p. 249). Fareed Abdullah, head of the AIDS programme in the Western Cape Province of South Africa, states that this PCR test results in “early referral for long-term treatment for any infant testing positive and a better all-round knowledge of the health status of the mother and infant pair” (ibid).

The questions around treatment for PMTCT, particularly the use of Nevirapine, have stirred continued political controversy in South Africa surrounding HIV/AIDS. In the following section the political history of HIV/AIDS and notably PMTCT in South Africa will be discussed.

2.2 PMTCT Debates- The political history of HIV/AIDS in South Africa

Many HIV/AIDS researchers in South Africa have pointed to the dominance of politics surrounding HIV/AIDS policy for treatment and prevention (Connelly & MacLeod, 2003; Schneider, 2002; Mbali, 2004; Heywood, 2003). Since the *National AIDS Plan for South Africa* was introduced in 1994 (Ngwenya & van Rensburg, 2002), AIDS policy in the post-apartheid context has continued to be full of contestation, if not a well publicised power struggle between the state and civil society. Helen Schneider states (2002, p.153):

In the context of an emerging post-apartheid state, [HIV/AIDS] represents a battle between certain state and non-state actors to define who has the right to speak about AIDS, to determine the response to AIDS, and even to define the problem itself

The debates between state and civil society are represented by two major players: the National Department of Health (most notably the Minister of Health, Manto Tshabalala-Msimang), and the Treatment Action Campaign (TAC).

This politicisation reached a climax in July 2002 when the Constitutional Court ruled in favour of the TAC and found the policy of limiting the provision of Nevirapine for PMTCT to a small number of 'pilot sites' to be unconstitutional (Heywood, 2003). In *Minister of Health and others v Treatment Action Campaign*, the government was ordered to provide antiretroviral drug Nevirapine for the treatment of PMTCT, wherever there was capacity in public health facilities. The TAC argued that the government's reluctance to rollout ARVs, or limit it to a few 'pilot sites,' was a violation of the right to life and the right to have access to health care services; infringing on the human and

socio-economic rights, constitutionally protected rights, of HIV-positive mothers and generally HIV-positive citizens of South Africa (Ngwena & van Rensburg, 2002; Heywood, 2003). The basic arguments of the Minister were that universal access to the drug was unaffordable and the risks of toxicity and resistance posed major threats for the future of infected mothers.

‘Resistance’ implies that because of Nevirapine’s potency, a single dose during labour may cause a mother to develop a viral resistance to this particular ARV and consequently other ARVs in its class (Non-Nuclease Reverse Transcriptase Inhibitors [NNRTIs]). Considering that the first line regimen for women of child-bearing age in the public health sector is Stavudine (D4T), Lamivudine (3TC) and Nevirapine, the implications of viral resistance is that successful antiretroviral therapy at a later date may be compromised. These concerns about single dose Nevirapine have led to a continued controversy surrounding PMTCT and Nevirapine in particular.

Since the ruling, there have been provisions to rollout Nevirapine in public facilities to infected mothers as well as the announcement in November 2003 by government to provide treatment for all people living with HIV and AIDS (Heywood, 2004). Still, there are major obstacles that have hindered this process of rolling out ARVs, and in particular single-dose Nevirapine for mothers and babies. These challenges include poor infrastructure at public facilities, lack of human resources (nurses, doctors, counsellors), transportation to clinics from rural areas, low levels of ‘treatment literacy’ about

Nevirapine and ARVs, inconsistency in care because of poor record keeping (lack of computerization), and a general overstretched public health sector (Abdullah, 2004).

For some, the major impediment to a comprehensive treatment and care programme for those living with HIV is the lack of political will by the government of South Africa, particular the Minister of Health. This lack of political commitment is linked to the President and Minister of Health's denialism³ about the impact of HIV/AIDS in South Africa (Heywood, 2004). President Thabo Mbeki and Health Minister Manto Tshabalala-Msimang have been known to engage AIDS dissidents publicly, by questioning the causal relationship between HIV and AIDS, questioning the AIDS mortality rates, and whether or not ARVs are safe and efficient (Mbali, 2004; Schneider, 2002; Heywood, 2003).

President Mbeki and the Minister of Health's 'flirtation' with denialism and AIDS dissidents has influenced the delays in the policy process to roll-out antiretroviral therapy as well as fuelling public questions about the lack of political will in fighting the pandemic. It follows that if one does not believe that HIV causes AIDS then one would also believe that ARVs are unnecessary. In fact, a common argument amongst dissidents in South Africa is that ARVs like AZT are "poisonous", "toxic" and will lead to death (see www.tig.org.za, for instance). In this kind of context the roll out of ARVs, including Nevirapine, becomes a highly complex and deeply politicised domain.

³ Mandisa Mbali suggests that, "this denialism was driven by Mbeki's belief that AIDS was a post-colonial, racist conspiracy to discredit African sexuality" (2004, p.27). Although this is a strong statement its claims are on the whole accurate: in an attempt to find other ways to explain the high prevalence rates in Southern Africa outside of the racist paradigm (based on well-worn stereotypes) that black Africans are hypersexual, Mbeki found credence with a dissident 'band' of scientists who refute that AIDS is caused by a sexually transmitted virological phenomenon, HIV. Thus, instead of refuting the 'hypersexual' myth Mbeki has inadvertently caused widespread societal confusion about the virus (ibid).

The debates around the use of Nevirapine have contributed to the highly politicized issues surrounding PMTCT in South Africa; and these controversies have been dominant in AIDS coverage in the news media (Finlay, 2004). This research highlights media coverage of these issues and discusses the implications this may have on women's health.

2.3 Current Debates of 'resistance' to Nevirapine

For this research, the news media analysed includes newspaper articles between July, 2004 and July 2005: this section discusses the significance of this period. In July, 2004, Minister Tshabalala-Msimang raised questions about the toxicity of and resistance to Nevirapine at the 15th International AIDS Conference in Bangkok, Thailand, stating that this regimen had been "forced" on government by civil society, the TAC in particular, through the Constitutional Court Case (Valentine, 16 June 2004).

In the December 17-23, 2004 issue of *ANC Today* article entitled, "Nevirapine, drugs and African guinea pigs" it was stated that the Medicines Control Council (MCC) of South Africa was correct in its suggestion that single-dose Nevirapine for PMTCT should not be used. The article also stated that while government was pressurised to roll-out Nevirapine, the MCC was fully justified in its cautions on Nevirapine based on the reports from the Associated Press in early December that the HIVNET 012 Nevirapine trial in Uganda in 2002 (which was a key study to determine the efficacy and safety of single dose Nevirapine for PMTCT) "was scientifically faulty and could not be used to

authorise the use of nevirapine for MTCT.” In addition the article alleged that the HIVNET 012 study did not disclose information about the adverse affects and deaths due to Nevirapine (ibid). The article went on to say that the US National Institute of Health (NIH) conspired with pharmaceutical companies to “tell lies to promote the sales of nevirapine in Africa, with absolutely no consideration of the health impact of those lies on the lives of millions of Africans” (ibid).

Interestingly, at the same conference where the Minister of Health was expressing doubt over Nevirapine, Sue Valentine reports that South African scientists found that six months after the mother has taken the single-dose of Nevirapine, resistance dramatically decreases. According to this report (16 July 2004):

South African virologist Dr Lynn Morris showed that although there was high resistance to nevirapine six weeks after a woman had taken a single dose, this dropped to 14 percent after six months.

Although this is one of the few studies which have indicated that a single-dose of Nevirapine can result in viral resistance, there is no conclusive evidence to indicate its extent and seriousness.

Recently in Johannesburg, Prof James McIntyre of the Perinatal HIV Research Unit (PHRU) at Chris Hani Baragwanath Hospital presented a study, based on a trial with 61 mothers, found that if Combivir (AZT and 3TC combined into one drug), was added to a single dose of Nevirapine, the resistance of Nevirapine was considerably reduced

(Valentine, 16 July 2004). The toxicity and possible resistance to antiretroviral therapy is not a new debate, and more studies need to be carried out in order to determine the potential resistance build-up or toxicity for the future of infected mothers. Nevertheless, in June 2005 the WHO reaffirmed its view that concerns over drug resistance should not delay the extensive use of Nevirapine for PMTCT while also recommending that “programmes consider introducing more complex ARV regimens where possible” (WHO, 2005).

There are safer, albeit slightly more expensive, interventions, for example dual therapy (AZT and Nevirapine) from 36 weeks which are better for the mother’s long-term health. The Western Cape, in South Africa, is the only province to have adopted this regimen in its PMTCT programme up to date, and has reduced the transmission rate to below 5.5 percent (Abdullah, 2004, p.249). Since the success of dual therapy in the Western Cape, considerably reducing transmission rates, there has been recent discussion to extend this programme throughout South Africa.

The above discussion points to some of the background of PMTCT in South Africa and the various complexities that need to be considered when addressing the issue. Nevirapine is central to any discussion of PMTCT in South Africa, because of the political controversy, and this has been demonstrated in the news media (Finlay, 2004; Stein, 2002). However, this report discusses other various and important parameters included in the context of PMTCT and HIV/AIDS in South Africa, particularly the human development of women. Essentially, one of the key aims of this research is to

investigate to what extent these integral issues are adequately covered in the selected print media.

2.4 Issues of women's health and human development in the realm of PMTCT in South Africa

While PMTCT remains high on the list for development trajectories, the health of women and particularly young women seem to be neglected. There has been a feminisation of the disease in view of the fact that the face of the pandemic has become an impoverished young woman (Msimang, 2003). In South Africa, out of the approximate 5.3 million people living with HIV/AIDS in 2003, approximately 2.9 million are women and girls, ages 15-49⁴; 77% of young (aged 15-29) South Africans living with HIV are female.

The Reproductive Health Research Unit (RHRU) and Medical Research Council conducted a survey on sexual behaviour among young South Africans found in the age group 20-24, one out of four women surveyed were HIV-positive (24.5%), whilst one-in-thirteen men (7.6%) were HIV-positive (in UNAIDS, 2004, p. 24). These statistics indicate that young women are disproportionately at risk of HIV infection. These survey results reveal social problems of sexual violence (10% saying they were forced to have sex) and gender inequalities that shape the sexual behaviour and choices of young women. Fassin and Schneider (2003, p. 496) discuss cases of "survival sex," whereby young women in townships use their bodies as an economic resource to feed their

⁴ All statistics are approximations.

families and themselves once they migrate from rural areas. This prostitution, in addition to the epidemic of sexual violence contributes to the rapid spread of HIV among young women in South Africa (Msimang, 2003, p. 111)⁵.

While cases of survival sex and lack of bargaining power for safe sex are integral concerns for addressing high statistics of young women infected with HIV, it is important to note that these women are also of child-bearing age. The issues of childbirth are important to women worldwide, and in African societies, for both men and women, fertility is seen as central to continuing one's lineage as well as an investment in the future of one's community (Barnett and Whiteside, 2002, p. 21).

For women, in particular, it is a role that confirms her social and cultural identity. Carovano comments on the societal pressure on women to have children in this way: "motherhood legitimizes a woman's sexuality—and often her life" (in Welch-Cline & McKenzie, 1996, p.132). For women, negotiating safe sex through use of condoms is seen as a threat to her ability to bear a child which would endanger her lineage and jeopardize her identity as a woman (Barnett and Whiteside, 2002, p.21):

Lineage, time and safe sex do not hold the same power, they cannot be equated—the former must win. People may want to avoid HIV infection; they may want to defer marriage or childbearing; but the pressures of lineage, family, gender roles and short life expectancy may often be for sex now (preferably reproductive, fertile sex) rather than for deferred sex and the use of a condom

⁵ Nevertheless, these are social issues that require more in-depth analysis and discussion than I can give in this report.

The seemingly conflicting issues around child-bearing and HIV/AIDS are multifaceted. The role of the woman in PMTCT is intriguing as the burden of choosing to continue her lineage, over her individual life, rests within her womb⁶.

Many times, pregnant women are the first to know about their sero-positive status of HIV through ante-natal screening or when a baby becomes sick (Msimang, 2003, p. 112). While it gives women the opportunity to start treatment, going home to tell her family and community that she is positive results in the stigma of her being identified as bringing the infection into that community (ibid). Thus women are often perceived to be the “vectors of transmission to their children and male sexual partners” (Welch-Cline & McKenzie, 1996, p. 388): infecting their male counterparts and new born babies. However, it is noted throughout literature that women run a higher risk of being infected (ibid) because of their lack of decision-making power to engage in protected intercourse, as well as exposure to widespread sexual violence.

If women are generally perceived as being the ‘vectors’ of transmission of HIV/AIDS, a normative argument could be made that women are also the primary route to solving the social challenge of HIV/AIDS. This is illustrated in the case of PMCT, where the onus is on HIV-positive pregnant women to prevent infection to their babies; hence the term *mother- to-child transmission* (MTCT). Anecdotal evidence suggests that women are locked into a dilemma of “save my baby” or “save myself”; her rights to healthcare as an

⁶ It is just as critical to understand the importance of child birth for men in these societies for a holistic view of issues concerning lineage and family structure; however, for this research, I am particularly looking at the presence of child-bearing on women’s development in South Africa.

individual and the ‘responsibilities’ to protect her vulnerable baby as implicitly debated as mutually exclusive.

The case of PMTCT demonstrates complex and interdependent developmental concerns that involve the issues of gender, political agendas, macroeconomics of HIV/AIDS policy and the role of the state and civil society. As stated in the Introduction, a woman’s health and development is irrefutably connected to her social and economic power and her ability to access information (World Bank, 2002; UNAIDS, 2004). I suggest in this research that a media for development considers this accessibility of marginalised communities and contributes to development by stimulating pertinent dialogue about issues that affect such communities. The next chapter will frame this discussion within relevant media theories.