Asserting rights: HIV-positive mothers accessing primary healthcare in Tshwane Metro

by

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Abstract

HIV/AIDS has sown devastation in post-apartheid South Africa. Women are particularly vulnerable to HIV-infection and the effects of HIV/AIDS as a result of disadvantaged social and economic positions. Women's positions have been structured by South Africa's colonial and apartheid past that excluded black South Africans from citizenship. The Constitution and Bill of Rights that followed the democratic transition in the 1990s, was a first step towards addressing the legacy of the past. In spite of gains in the Bill of Rights, women in post-apartheid South Africa still battle to realise their rights fully. This dissertation argues that a feminist conceptualisation of citizenship helps us understand why many South African women do not yet enjoy full citizenship. It explores the experiences of HIV-positive women who have accessed primary healthcare, and in particular, the prevention of mother-to-child transmission (PMTCT) programme. HIV-positive mothers struggle to realise their right to health in a post-apartheid context of neo-liberalism and gender inequality. Within the healthcare system they faced reproductive rights abuses which undermine their right to dignity and full citizenship.

Key terms: HIV/AIDS, women, gender, feminism, citizenship, human rights, reproductive rights, socio-economic rights, rights, healthcare, maternal-and-child health, prevention-of-mother to-child transmission (PMTCT)

Opsomming

MIV/VIGS saai verwoesting in post-apartheid Suid-Afrika. As gevolg van minderbevoorregte sosiale en ekonomiese posisies is vroue veral kwesbaar vir MIV-infeksie en vir die gevolge van MIV/VIGS. Vroue se posisies is gestruktureer deur Suid-Afrika se koloniale en apartheidsverlede wat swart Suid-Afrikaners uit burgerskap uitgesluit het. Tydens die demokratiese oorgang in die 1990s was die Grondwet en Handves van Menseregte 'n eerste stap om die verlede aan te spreek. Ten spyte van vordering in die Handves van Menseregte worstel vroue in post-apartheid Suid-Afrika steeds om hulle regte ten volle te realiseer. Hierdie verhandeling redeneer dat 'n feministiese konseptualisering van burgerskap ons help om te verstaan waarom baie Suid-Afrikaanse vroue steeds nie volle burgerskap geniet nie. Dit ondersoek die ervaringe van MIV-positiewe vroue wat primêre gesondheidsorg fasiliteite besoek het, en spesifiek deelgeneem het aan die voorkoming van moeder-na-kind oordrag programme. In 'n post-apartheid konteks van neo-liberalisme en gender ongelykheid het MIV-positiewe moeders gesukkel om hulle reg tot gesondheid te realiseer. Binne die gesondheidsisteem was hulle gekonfronteer met reproduktiewe regte oortredings wat hulle reg tot waardigheid en volle burgerskap ondermyn het.

Sleutelterme: MIV/VIGS, vroue, gender, feminisme, burgerskap, menseregte, reproduktiewe regte, sosio-ekonomiese regte, regte, gesondheidsorg, moeder-en-kind gesondheid, voorkoming-van-moeder-na-kind-oordrag

Statement by candidate

I declare that the dissertation, which I hereby submit for the degree at the University of Pretoria, is my own work and has not previously been submitted by me for a degree at another university. Where secondary material is used, this has been carefully acknowledged and referenced in accordance with university requirements. I am aware of University policy and implications regarding plagiarism.

SIGNATURE: DATE:

List of selected acronyms

ANC	African National Congress
AZAPO	Azanian People's Organisation
AZT	Azido-Thymidine
ART	Antiretroviral therapy
CGE	Commission for Gender Equality
CD4	Cluster of Differentiation 4
CSG	Child Support Grant
CODESA	Convention for a Democratic South Africa
CTMM	City of Tshwane Metropolitan Municipality
DALY	Disability Adjusted Life Year
DP	Democratic Party
FTC	Emtracitabine
HAART	Higly Active Antiretroviral Therapy
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
MDG	Millenium Development Goal
MRC	Medical Research Council
MTCT	Mother-to-child transmission
NDoH	National Department of Health
PAC	Pan African Congress
PCR	Polymerase Chain Reaction
PHC	Primary Healthcare Clinics

PMTCT	Prevention of Mother-to-Child Transmission
StatsSA	Statistics South Africa
STI	Sexually Transmitted Infections
TAC	Treatment Action Campaign
TB	Tuberculosis
TDF	Tenovir
WHO	World Health Organisation
WNC	Women’s National Coalition

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Chapter 1: "The greatest transmitter of HIV/AIDS": gender, race and class in South Africa

The world-wide Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) pandemic continues to sow devastation in sub-Saharan Africa, the region most heavily affected by the disease. In 2008, sub-Saharan Africa accounted for 67 percent of HIV infections worldwide and 72 percent of AIDS-related deaths. The disease is mainly a heterosexual epidemic and in particular affects a young, economically active population with devastating effects for households, communities and broader societies (Barnett & Whiteside, 2006; UNAIDS, 2009).

It is estimated that in 2009, 5.6 million South Africans were infected with the disease – the largest number of infected people of any country in the world. HIV/AIDS accounts for 31 percent of the total disability-adjusted life years (DALY) in South Africa and it is a major cause of death for mothers and children younger than five years (Barnett & Whiteside, 2006; Chopra et al., 2009; Coovadia, et al., 2009; Hogan et al., 2010; UNAIDS, 2010).

The South African government's early management of the disease has been severely criticized. They have been blamed for missing vital opportunities during the early stages of the disease - at the time of political transition - that could have changed the course of the epidemic. There has been some optimism following the change in political leadership in 2009. South Africa now boasts the largest antiretroviral therapy (ART) roll-out programme in the world and there seems to be progress, albeit slow, with certain aspects of the epidemic (Karim & Baxter, 2010).

Women, as a category, bear the brunt of the disease in numerous ways. Firstly, they are anatomically and physiologically more susceptible to contracting HIV through heterosexual contact. Women of childbearing age are particularly at risk and it is estimated that women in the age group 15 to 24 years are up to 2.5 times more likely to be infected than their male counterparts. Women are further affected by the possibility of transmitting the HI-virus to their children. In the absence of any intervention, between 15 percent and 30 percent of infants born to

HIV-positive women will be infected with HIV, either before birth in the uterus, during delivery or through breastfeeding (Barnett & Whiteside, 2006; Moodley, 2004).

Women's vulnerability to infection is however not only a result of a greater anatomical and physiological susceptibility, but also a disadvantaged social, legal and economic position that most women in sub-Saharan Africa still occupy. Absolute poverty is still the main determinant of health status and exposure to HIV/AIDS for a quarter of the world's population – with women representing 70 percent of the world's poor. There is no simple correlation between income and health in producing health inequalities. It rather has to do with a complex interaction of different social dimensions. With regards to HIV infection, the intersection and interplay of economic and gender inequality is seen as central to the spread of the epidemic. Empirical findings have demonstrated how "economic factors such as poverty, financial dependence and job security" often result in women being unable to negotiate safe sex and condom use (Booth, 2004; Gilbert &Walker, 2002; Shefer, 2009).

Gender-based violence (including rape) remains a major factor in women being unable to insist on condom use. Although rape occurs in all age groups, younger women, aged between 16 and 25 years, tend to be victims of rape (StatsSA, 2000). According to the *Victims of crime survey*, it was estimated that 55 000 South African women were rape victims in 1997. This translates into 134 women per 100 000 being raped in 1997. These crimes are also more likely to be perpetrated by men known to the rape victim. Studies have concluded that violence and controlling behavior in a heterosexual relationship increases the risk of HIV infection for women (Dunkle et al. in Titus & Moodley, 2009).

Traditional gender roles and unequal gender relations which undermine women's ability to practice safe sex and negotiate condom use are also associated with factors such as socialised sexual practices, where men are expected to be the initiators and leaders in a sexual relationship and women are expected to be passive and submissive. Also, studies on condom use have highlighted how men's needs and sexuality take priority over women's when it comes to decisions regarding condom use. Women have reported the fear of losing their partners, being anxious about men not enjoying sex with a condom, as well as being afraid that insisting on condom use will be interpreted as a lack of trust. Women are therefore often not in a position to demand safe sex (Shefer, 1999). This stands, however, in conflict with the expectation that they should take the responsibility for safe sex. According to the National Gender Opinion Survey (CGE, 2005:28) conducted in South Africa most participants (58.55 percent; n=844) agreed with the statement that "Since women are the ones who become pregnant, they should take more care in using protection than men".

The promiscuity of male partners puts women at risk of being infected with HIV. Colvin (2000 in Barnett & Whiteside, 2006) estimated that 60 – 80 percent of HIV-positive women have had only one sexual partner. Apart from not being able to negotiate safe sex (related to factors discussed above), many women could not prevent their male partners from having additional sexual partners (Booth, 2004).

In many societies women in long-term heterosexual relationships, in particular those who are married, face what Preston-Whyte (1999) calls 'the fertility conundrum'. This has to do with the cultural expectations in many societies that women should be fertile and that it should be achieved speedily. Fertility is connected to women's social position and ensuring care in old age. Even if a woman might want to use a condom to protect herself from HIV or defer pregnancy, this might be outweighed by the expectations and pressures within society to have children. In parts of South Africa it is said that 'Children are what we give iLobolo (bride wealth) for' (Preston-Whyte, 1999:143; cf. Barnett & Whiteside, 2006:23). Caldwell and Caldwell (cited in Barnett & Whiteside, 2006:23-24) highlight this emphasis in African society on ancestry and descent. Barnett & Whiteside (2006:23-24) conclude: "lineage time and safe sex do not hold the same power, they cannot be equated – the former must win".

Women are more vulnerable to be infected with HIV, but they are also disproportionately affected by the disease. This vulnerability is the consequence of a society's social and economic institutions that "makes it more or less likely that excess morbidity or mortality associated with disease will have negative impacts" (Barnett & Whiteside, 2006:178). Women in sub-Saharan

Africa are still constructed as the main care-givers, which places the burden of not only caring for infants and children, but also for the sick and dying on them. Hassim (2005) reports that in 2002 68 percent of caregivers in South African households affected by HIV/AIDS were female. Of these women 7 percent were younger than 18 years and 23 percent were older than 60. Morbidity and mortality rates as a result of HIV/AIDS are higher for women than for men – women are therefore more likely to become ill or die as a result of HIV infection (Gilbert & Walker, 2002).

Gender, together with the categories of race and class, remains “the greatest transmitter of HIV/AIDS” (Gilbert & Walker, 2002:1094). Paul Farmer’s concept of structural violence is useful when trying understanding why this is the case. Structural violence looks at how a person’s risk for diseases and other suffering is structured by historical processes such as political and economic forces. To explain women’s vulnerability to HIV/AIDS infection and its effects, individual biography must be embedded “in the larger matrix of culture, history, and political economy” (Farmer, 2005:41).

Many of the historical roots of the determinants of health in South Africa can be traced back to the country’s colonial and apartheid past. This includes the racial discrimination of more than 300 years where groups in South Africa were politically excluded and economically marginalised. Since the arrival of white settlers in the 17th century, the black population in South Africa was systematically dispossessed of land and rights. South Africa’s history was also shaped by the discovery of gold and diamonds at the end of the 19th century. This led to mining becoming the cornerstone of the economy, with the development of other industries such as manufacturing intrically linked to it (Coovadia et al., 2009; Terreblanche, 2002; Walker et al., 2004).

The Apartheid past has had particular negative consequences for Black African women, contributing to their vulnerable position in terms of health outcomes. Limited employment opportunities in the formal homelands together with a demand for cheap labour at mines fostered the development of the migrant labour system. As families weren’t allowed to join men who went to the city to work, it left women in precarious financial positions as wages were not always sent back regularly. Work on the mines also fostered aggressive masculinities. As urbanisation increased during the 1930s and 1940s, women started moving to the cities in search of means to support themselves and their families. Opportunities for black women in the formal economy remained limited and women were increasingly under pressure to enter into transactional relationships with men as a means of supporting themselves (Walker et al., 2004).

Black women had limited access to education. In 1995, 23 percent of black South African women older than 25 had had no formal education (compared to 16 percent of black men). A 1995 household survey found that 31 percent of black women identified pregnancy as the reason for not studying as far as they would have liked to. It interrupted their schooling. This is an indication of the limited healthcare, providing access to reproductive health services, available to black women. The stark difference in maternal and infant mortality rates for black and white women at the time attests to the differential access. For black women the maternal mortality rate in 1993 was ten times higher than that for white women (Chopra et al., 2009; Gilbert & Walker, 2002).

These historical inequalities systematically and over time structured women's risk of HIV-infection and other disease. It follows that if women's position, which put them at risk, is to be addressed the structural inequalities of the past need to be addressed. This was acknowledged during the negotiations for a democratic South Africa in the 1990s, with the women's movement playing a significant role in highlighting this reality. Following the transition in 1994 a new Constitution and Bill of Rights were the first steps in addressing the injustices of the past. The South African Constitution (1996) has been hailed as the most progressive constitution in the world, protecting the basic rights and freedoms of all its citizens. It is one of the few constitutions worldwide which extensively enshrines second-generation socio-economic rights such as food, water, housing, healthcare and education and social security (Dinokeng, 2008).

The African National Congress (ANC) government since 1994 set addressing existing inequalities as one of its priorities. As a result national state pension system and disability grants were unified. New grants such as the child support grant were introduced and the age of beneficiaries were gradually increased to include more children. According to Coovadia et al. (2009), social spending during the 1990s was limited and mostly directed at social grants. This meant that spending on especially health and education were severely constrained. In many regards inequality increased, as measured by the Gini coefficient, which rose from 0.56 in 1995 to 0.73 in 2005. It was 0.63 in 2009 (Gouws, 2005a; World Bank, 2012).

Realising the right to healthcare is crucial for women. Access to healthcare is an important right. It helps ensure women have a safe pregnancy and childbirth. The maternal mortality rate and infant mortality rate are used as indicators of access to and quality of healthcare services in a country, since most maternal and infant deaths are preventable. The extent to which women are able to access good quality healthcare structures their risk for HIV-infection.

In the context of HIV/AIDS access to healthcare is even more important. At clinics and hospitals women access information and technologies to practice safe sex, which can protect them against infection and re-infection with HIV/AIDS and other sexually transmitted infections (STI's). Since the advent of ART, access to healthcare has become a matter of life and death. Prior to ART, the wealthy had access to better nutrition and palliative care, but since ART became available, those with financial resources have been able to "literally buy extra days of life" (Barnett & Whiteside, 2006: 178). Access to ART means that women, who are still constructed as the carers of society, are in many cases able to stay healthy and raise their children to adulthood. For pregnant women, ART is an important measure in reducing the possibility of transmitting HIV to infants. If a child is infected with HIV, access to healthcare is crucial to manage the illness and keep it healthy.

The degree to which the South African government is successful in guaranteeing the right to healthcare and enabling citizens to exercise these rights is an indication of the progress South Africa has made in addressing the legacy of the past. It maps the extent to which citizens enjoy full citizenship and the progress in achieving justice and equality. This indicates the degree to which Apartheid and its structures have been dismantled.

This dissertation investigates the obstacles that HIV-positive women experience in realising their right to health and healthcare. A feminist conceptualization of citizenship is an appropriate theoretical framework within which to interpret these women's experiences. A citizenship perspective situates healthcare within a particular relationship, the relationship between the state and its citizens. It focuses on factors such as the social determinants of health, but also emphasises the role and responsibility of the nation-state in determining these social conditions that impact on the health of its citizens. Within this relationship with the state, the lives of citizens are profoundly shaped through economic and social policies which organise and direct their lives and access to resources. The concept citizenship, as well as its usefulness in a South African context, is discussed in Chapter 2.

The current South African health context has not only been shaped by a particular colonial and apartheid history, but by a post-apartheid political context as well. In Chapter 3 the post-apartheid healthcare context of South Africa is discussed. It focuses on the influence of HIV/AIDS and attempts to address the epidemic. The prevention of mother-to-child transmission (PMTCT) programme, which formed the backdrop for researching issues of women, health and citizenship in this study is described.

In Chapter 4 methodological choices, the course of the research and ethical considerations are discussed. In a post colonial and post-apartheid context the category 'women' cannot be considered a single or unified category, but intersects with other categories to determine women's experiences. These complexities require reflection on the role of the researcher when conducting research from a feminist perspective.

In spite of the government's attempts to address the social and economic situation of women, to increase their access to healthcare and to put health policies in place that are in line with World Health Organisation (WHO) recommendations, women are still struggling to access good quality healthcare and make informed decisions about their health and the health of their children. Chapter 5 describes the experiences of the HIV-positive women that access public healthcare. It highlights both the difficulties which they experience in realising their right to healthcare and ways in which they exercise their agency.

HIV-positive women have particular needs and interests as citizens. Chapter 6 considers their experiences and highlights the extent to which they have been included as citizens as well as ways in which they are still excluded.

In conclusion, recommendations are made on how the exclusion of HIV-positive women may be addressed.

This dissertation is an attempt to contribute to feminist research in South Africa by not only making visible women's experiences, but in doing so, also considering how social change may be brought about.

Chapter 2: Women and citizenship

Full citizenship is required to access the rights and privileges within a nation. Having access to health care therefore relies on the type of citizenship enjoyed by a nation. This chapter discusses the concept of citizenship.

2.1 Defining citizenship

Transition in Central and Eastern Europe with the collapse of the Soviet Union at the end of the Cold war, and transition in South Africa as well, placed questions of democracy and citizenship on the agenda, world-wide. Locally the democratic transition invigorated debates on citizenship which drew, amongst others, on new feminist critiques and theorising of citizenship. Providing a detailed exposition of citizenship however is not an easy task. Defining citizenship remains a crucial task. Mouffe (1992:25) argues "the way we define citizenship is intimately linked to the kind of society and political community we want". The nature of citizenship is further contested, as complex political, moral and ethical issues emerge when dealing with the individual and her/his relationship to the state and to society. The exposition below is based on the account of Lister (1997) who provides a feminist perspective of citizenship.

Lister (1997) contends that citizenship is rooted in two major political traditions. At the heart of mainstream debates about citizenship is the nature of rights and obligations and the balance between the two. Most theorists agree that rights and responsibilities are important. They differ on what the nature and balance of the relationship between rights and responsibilities should be, as well as on whose interests (and thus power relations) are reflected in the particular views on citizenship.

A rights-based approach is linked to the liberal political tradition which has its roots in the seventeenth century (era of enlightenment). In this approach an individual is acknowledged as sovereign. A limited state guarantees the freedom and formal equality of individuals through civil and political rights. Most modern rights approaches utilise Marshall's well-known description of the three components of citizenship namely civil, political and social rights. Marshall (in Lister, 1997:13) defines civil rights as those rights "necessary for individual freedom – liberty of the person, freedom of speech, thought and faith, the right to own property and to conclude valid contracts, and the rights to justice". Political rights refer to the right to participate in the exercise of political power. Social rights encompass a whole range of rights:

> from the right to a modicum of economic welfare and security to the right to share to the full in the social heritage and to live the life of a civilized being according to the standards prevailing in the society (Lister, 1997:13).

One of the key debates in the twentieth century has been whether the state should also guarantee social rights to its citizens. The importance of social rights in a feminist conceptualisation of citizenship will be discussed later.

Another approach to citizenship focuses on responsibilities as the essence of citizenship. It is linked to the ancient civic republican tradition of classical Greece. Citizens have the duty to participate politically, which expresses their "full potential as a political being" (Lister, 1997:13). The civic republican tradition places great emphasis on the public good. In many ways this tradition has given way to the liberal tradition (Mouffe, 1992).

A modern conceptualisation of liberal and civic republican approaches to citizenship is provided by Oldfield (1990 in Lister, 1997) who articulates the differences between the two approaches as citizenship as a status vs. citizenship as a practice. Citizenship as status prioritises the rights of the individual whilst citizenship as practice focuses on responsibilities and the interests of wider society.

2.2 The emergence of feminism

Feminism has been one of the key social movements during the past century. It has impacted on social and political institutions, bringing about important gains for women. One reason for the continued strength and sustainability of feminism is the dialectical critique and exchange the movement embraces. Self-critique is crucial for a politics of transformation and it is embedded in feminism. The emergence of poststructuralist, post-colonial, black and third world feminist approaches has strengthened and reinvigorated feminism. The feminist movement remains intimately connected to issues of citizenship (hooks, 2000; Scholz, 2010).

The chronological waves model tracks feminist activity historically charting the vicissitudes of the movement. It identifies three waves. The first wave is associated with struggles to obtain the franchise, a basic right of citizenship. This wave emerged in the 17th century and ended (or "paused") in the early 20th century when most women in the West were granted the right to vote. In some countries women remain excluded from this right (Scholz, 2010).

The second wave emerged between 1948 and 1960, reaching its peak between 1960 and the early 1990's. Feminist activity during this period highlighted other sources and manifestations of women's oppression besides formal legal rights. How women's bodies were being dominated, abused and stereotyped was considered, popularising the slogan 'the personal is political'. Women lobbied around issues such as domestic violence, rape and reproductive rights. They succeeded in getting states to accept responsibility for these issues – issues previously seen as private. During the second wave the movement sought a common sisterhood to be a force in bringing about change (Scholz, 2010).

As time went by the notion of a common sisterhood became criticised, as women did not all share the same experience. Race and class shaped women's position in society as well. Consequentially the current emerging third wave acknowledges diversity, "not only in identity but in subjectivity and thought itself" (Scholz, 2010:7). It also analyses thought and language as sites of oppression and employs various techniques, such as deconstruction, to challenge such forms of oppression. The third wave presents the political project of the women's movement with new challenges. For years feminists fought to justify a uniquely feminist standpoint. But if, as postmodernists demonstrate, there is no single feminist standpoint, no one's interests reflect the diversity across history, nationality and cultures. This raises the question whether 'women' as a category remains useful, politically. Feminists have to address these concerns (hooks, 2000; Scholz, 2010).

2.3 Women and citizenship in South Africa

Within the context of South African politics, women have engaged questions of citizenship. Since the early 1900s women participated in diverse organisations such as the Women's Enfranchisement Association of the Union (WEAU) and the African National Congress Women's League (ANCWL). The WEAU had primarily white working class women as members and the ANCWL black South African women. Whereas the WEAU focussed on obtaining the franchise, the ANCWL in addition protested against unjust pass laws and the issue of Bantu Education. However diverse, and at the time not necessarily framed in a feminist discourse, the political activity of both these organisations included feminist concerns such as motherhood (ANCWL, 2010; Walker, 1995).

Many women were politically active in the anti-apartheid struggle prior to the democratic transition within the country. Gender concerns were mostly subservient to nationalist goals. At the Nairobi Women's Conference in 1985 Frene Ginwala contended that to talk about gender inequalities "would be suicide" (Seidman, 1999:287). Within the anti-apartheid movement prior to the 1990's black women were primarily seen as mothers and wives. This domestic vision was undermined by feminist intellectuals within the anti-apartheid movement, who increasingly highlighted how black women and men were differentially affected by apartheid. They argued that if these differing needs were not explicitly addressed during the transition, the new political institutions would perpetuate gender inequality (Seidman, 1993 & 1999; Hassim 1991).

During the transition "women activists played a surprisingly important role in the negotiations, in the elections, and in designing the new state" (Seidman, 1999:288). The negotiation and transition to a racially inclusive nation, therefore, provided the opportunity for an explicit feminist movement and agenda to emerge in the context of extending the most basic human rights, such as universal franchise. The development of separate women's forums further facilitated the emergence of a gendered democratic vision. The forums aimed to increase participation of women at the grassroots level of the anti-apartheid movement. Activists argued women would speak more freely at meetings attended only by women and that it also allowed the participation by those whose husbands might otherwise had objected to their wives' political involvement. This grassroots mobilisation of women resulted in an "explicit gendered collective identity", according to Seidman (1999:292). It encouraged women to consider those inequalities which resulted from gender discrimination.

These processes led to challenging and reformulating the democratic vision of the anti-apartheid movement. Non-sexism was increasingly included in ANC slogans and discussed within ANC meetings as a result. There was some resistance within the ANC to this gender agenda. This necessitated feminist activists in some instances to publicly challenge recalcitrant male activists. Gender equality was however strongly supported by Nelson Mandela and other leaders at the ANC headquarters. By late 1992 it was official ANC policy that women must be included on all central committees. There was also increasing support for gender concerns within other liberation movements and political parties such as the Africanist Pan African Congress (PAC), Azanian People's Organisation (AZAPO) and the Democratic Party (DP). Women activists became increasingly visible during the national negotiations and this led to the agreement in 1991 that a Gender Advisory Board would be formed. Although this Board was to consider the impact of the negotiated agreements on gender, it was not present at the negotiations. In March 1993 ANC women activists, feeling the Board to be inadequate, stormed the negotiating chambers and insisted on being "given places at the [negotiating] table" (Seidman, 1999:292-294). Seidman (1999:294) comments on this "little publicized event":

> Amazingly, all 26 parties participating in the negotiation process accepted a gender quota – a decision that reflected the extent to which women on all sides had already raised issues of gendered representation in the construction of democracy. Fifty percent of each two-person team had to be female; thus, half of the negotiators who finally accepted a provisional constitution and set the elections in motion were women – a composition that had real implication for the kinds of institutions created under the new constitution.

The momentum the South African women's movement gained and the role they played during the construction of a new state in the 1990s was significant. Ten out of the 228 participants at the first Convention for a Democratic South Africa (CODESA) during December 1991 were female[1]. During the final negotiation for the provisional constitutions women had gained 55 percent representation. Seidman (1999) provides a thorough account of how feminist activists developed a collective definition of interests during the transition.

Despite apparent loyalties to their separate parties, women negotiators did form a women's caucus that managed to achieve some success. These successes included insisting on gender equality being respected above customary law; the creation of a body to ensure women's participation during the elections; and an advisory committee to consider the gender implications of new policies. However, their most important achievement was the introduction of gender issues into national debates. The importance that gender concerns had gained was apparent during the first democratic election campaign in 1994. During this campaign most of the political parties were at least paying lip service to gender equality (Seidman, 1999).

All these processes took place within the context of feminist ideas gaining a new visibility globally during the 1980s. These new ideas are associated with what became known as the third wave of feminism. As discussed, feminist ideas during this time increasingly acknowledged differences amongst women and included black, post-colonial and post-structuralist critiques. South Africans who spent time in North America and Europe as either exiles or students had been introduced to new feminist concepts and theories. The international feminist movement was able to support a South African gender agenda. Foreign donor agencies that supported the anti-apartheid movement had bought into the importance of gender equity within the democratization process and used their influence to promote such an agenda. This global context partly explains why "South African women activists [were] so willing to raise gender issues during the transition, and why male negotiators [were] apparently willing to listen" (Seidman, 1999:295).

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[1] Delegates from across the political spectrum attended the government-sponsered Codesa (Suzman, 2003).

The way in which feminists attempted to identify and articulate women's interests during the transition took the form of the development of a Women's Charter. This charter was to serve as a sort of gendered bill of rights. This process followed the ANC Women's League's launch of the Women's National Coalition (WNC) in 1991 which included women's organisations across the political spectrum. The development of the Women's Charter involved an 18-month campaign by the WNC. During this time 203 focus groups with 1 620 members were conducted as well as 2 973 individual questionnaires completed in addition to general discussions amongst members of the coalition (Seidman, 1999).

The Women's Charter gave voice to specific interests of women underlining how these interests differed from those of men. The charter reflects the demands of a broad range of South African women for equality at work and at home. It emphasises women's inclusion in policy-making and other public structures, as well as the need for improved access to formal employment and benefits such as healthcare, welfare and pension. The Charter also calls the state to provide protection and intervene where sexual harassment and violence occurs. Most importantly the right of women to control their bodies is emphasised (WNC, 1994; Seidman, 1999).

Feminists realised the inclusion of the charter in the new constitution would not automatically lead to the transformation of women's lives. The focus of feminist activity during the transition was on the creation of gender-sensitive institutions in the new democracy. South African feminists sought to ensure this objective by seeing to it that there were structures in place that would promote the gender implications of policies. In addition they lobbied for women to be in decision-making roles where policies would be formulated. There were calls for organising a mass-based women's movement (Seidman, 1999).

The extension of citizenship to all South Africans in 1994 was an important milestone. However, the limits of framing citizenship in a liberal rights discourse from a gender perspective are that it frequently ignores many of the obstacles which exclude women from exercising their citizenship fully. Equality in citizenship cannot be achieved without rights being guaranteed institutionally. Such guarantees open up "space for women's agency" (Gouws, 2005a:xiii). At the time of the transition, women activists recognised the potential that the transition offered to construct a gendered citizenship and the importance of seizing this opportunity. Activists realised that simply having women's interests included in the Constitution would not necessarily guarantee women's citizenship (Gouws, 2005a).

The reality in post-apartheid South Africa is that the concerns, rights and interests articulated in the Women's Charter remain an unrealised ideal for many South African women. This is of course no different to other post-independent states and many advanced democracies where *de jure* equality for women has not yet been translated into *de facto* equality. What makes South Africa different is that activists recognised and seized the opportunity which the transition presented to structure the relationship between the state and women differently to those of other countries. They managed to incorporate the interests of women into the Constitution, as well as see the formation of structures such as the Commission for Gender Equality (CGE). However, in the years following the transition there has been disillusionment with the state structures that were supposed to promote women's interests. Structures such as the CGE have been shrouded in a cloud of accusations of corruption and mismanagement. Scholars have also argued that the reliance on state structures have resulted in the demobilisation of the women's movement (Gouws, 2005a & b; Masondo, 2010; McEwan, 2000; Meerkotter, 2005).

The challenge for the feminist movement in South Africa remains how to effectively translate *de jure* rights for women into *de facto* rights. In trying to understand why it is so difficult to translate formal equality into substantive equality, it is necessary at this point to interrogate and re-evaluate the conceptual tool of citizenship itself. Its usefulness (or not) for future feminist analysis and activity will also be considered.

2.4 Developing a theoretical framework of gendered citizenship

Feminists have recently started to theorise citizenship. They argue that citizenship, which is often spoken of in universalist terms, is in fact a deeply gendered concept. The gendered nature of citizenship is evident in women's continued second class status despite claims that equality and justice have been achieved. As discussed in the introductory chapter, women continue to occupy a disadvantaged social, legal and economic position in societies such as South Africa. In general, women are more likely to be poor, more likely to depend on informal work, earn on average less than men and are more likely to be victims of domestic violence and more vulnerable to the HIV/AIDS epidemic (Gouws, 2005a; McEwan, 2000; Pateman, 1988).

2.4.1 Public-private debate at the epistemological level

A major contribution of feminists has been to show how both the liberal and civic republican conceptions of citizenship which appears to be gender-neutral, in fact, privilege men. For example, in South Africa laws such as the law of coverture was only abolished for white women in 1984 by the Matrimonial Property Act. This meant that unless an antenuptial contract was signed stating that a couple would be married outside of community of property, a husband held full marital power and “had the sole and unfettered power to administer their joint estate” (Suzman, 2003:257). A woman married in community of property had therefore almost no contractual capacity and less authority than an unmarried daughter over the age of twenty-one. Such an example demonstrates how citizenship has been gendered. The gendered nature of citizenship should be interrogated at an epistemological level. According to Lister (1997) many theorists have failed to grasp how deeply gendered the concept of citizenship is. She cites Benhabib (1992):

> The weave of the epistemological cloak, which has both hidden the man lurking behind the gender-neutral citizen and rendered invisible woman’s absence, is so tight that it is difficult to disentangle the separate threads out of which it is fabricated.

In probing citizenship epistemologically feminist theorists focus their analysis on the public-private dichotomy on which Western notions of citizenship are founded, which in turn constructs notions of the public and private. The public sphere comprises of the official economy regulated by the state, which also includes the provision of welfare services where principles of justice rule and all citizens (in theory) are treated equally. The private sphere is the world of the family. Here citizens have greater leeway to act according to their own ideas and morals. Traditionally the private sphere is seen as not the concern of political theorists and activists or state intervention (Lister, 1997; McEwan, 2000; Pateman, 1988; Voet, 1998 in McEwan, 2000).

Feminist theorists have highlighted that these spheres are "saturated" with gendered assumptions. The public-private dichotomy carries associations of gender. On one side of the dichotomy is the public sphere where citizenship is exercised. It is associated with an abstract, disembodied individual who is rational, impartial, independent and champions freedom. On the other side of the dichotomy is the private sphere that is associated with a particular, embodied non-citizen, who is emotional, partial, dependent and concerned with the domestic realm. The private sphere contains all the aspects considered incompatible with the public exercise of citizenship. Through essentialist notions of men and women's characteristics and abilities (which dominated the modern era), men have been associated with the public realm. And women have been relegated to the private sphere and are so deemed "antithetical to citizenship" (Lister, 1997:69). This relegation of women to the private sphere happens at both the level of discourse and as a result of women's physical exile to the private sphere. It is to this that the second wave of feminism speaks (Lister, 1997).

Feminist critiques have challenged the binary thinking of the public-private dichotomy and its associated dichotomies in a number of ways. Apart from exposing how the construction of a private sphere and the female association with it has been a barrier to women's citizenship, feminists have also shown how in reality there is no clear line between the two spheres. In certain countries women are participating in increasing numbers in the public sphere (although with difficulty as they still carry the primary responsibilities for care and domestic work). Furthermore there is not only direct state regulation of the family, but also indirect state regulation of the intimate sphere; regulation that might not be apparent at first. However, unlike females, males move easily between the two spheres. Despite this complexity, the public sphere continues to be constructed as operating independently from the private sphere (Lister, 1997; Pateman, 1988).

As highlighted by Tronto (1993 in Lister, 1997:120), a public-private divide erects a 'moral boundary' between the public (or 'political') and the private (or family). This boundary has profound consequences for women as it treats whatever happens in the private sphere as irrelevant to citizenship. It then serves as a justification for not addressing issues of oppression or injustice within the family. It also does not acknowledge the contribution made by domestic and caring work in enabling participation in the public realm of citizenship to the advantage of males. This ensuing collective advantage that males have over females forms part of what Connell (2010:142) has termed "the patriarchal dividend".

The public-private dichotomy is clearly a contested and changing construction. Most feminists call for a re-articulation rather than the dissolution of the public-private boundary. Lister (1997:22) asks: "Who has the power to decide where the line is to be drawn in any particular situation on any particular issue?" The feminist movement has had some important successes in challenging the public-private boundary with regard to issues such as domestic violence and marital rape (Lister, 1997).

2.4.2 Debating gendered citizenship

Following on from demonstrating how citizenship is a gendered concept, feminists debate whether citizenship *should* be gendered. This debate touches on dilemmas such as those articulated by Wollstonecraft over 100 years ago (Pateman, 1988). The dilemma entails demanding inclusion as 'gender-neutral' citizens, as articulated in particular by liberal feminists, whilst insisting on recognition as mothers and primary carers. Women therefore face a choice. They can conform to a male-defined model of citizenship and reject recognition of their difference to men, or be recognised as different to men and in doing so, risk essentialist notions of women. These essentialist notions also ignore the differences between women. To be included based on difference could also further lock women into the role of mothers and carers. These roles often serve as obstacles to women's full participation in the public sphere (Lister, 1997).

The question of whether citizenship should be gendered became further important in the context of poststructuralist, post-colonial and black women's critiques of the unitary category 'woman'. Poststructuralists such as Butler (1990) have made important contributions to the disruption of not only gender, but also sex categories and have shown how all of these categories are constructed. The implication of Butler's (and other similar) work is that the politics of woman is based on an unstable construct. Therefore, constructing a politics based on the 'ontology of gender' is bound to fail as it fixes and limits the subjects that it was hoping to liberate (Aslop, et al., 2002).

Black feminists' critique of the feminist movement reveals how interests and concerns of Black women have been marginalised. These critiques are of particular significance in the South African context. Feminist activity during the democratic transition and drawing up of the Women's Charter succeeded in giving voice to the specific interests of women and showing how these interests were different to those of men. Through the process of drawing up the Charter the women's movement succeeded in creating the impression that there existed agreement amongst South African women with regard to democratic goals (Lister, 1997; Seidman, 1999). However, critics such as Linzi Manicom (2005:26-27) find this political presentation of a category 'woman' during the transition and "exemplified in the Women's Charter" to be "both politically provocative and analytically testing". Manicom astutely asks:

> How was it that an apparently coherent political identity of women could be so confidently and powerfully asserted, given the social and cultural diversity amongst South African women, the vast inequalities in livelihoods and social capital, the array of political-ideological positions and the violently-imposed, racialised fissures of apartheid? It was, after all, the colonialist and apartheid institution of a racially-exclusive national citizenship that specifically and rigidly reproduced the divisions between and amongst South African women, depriving the majority of that fundamental tenet of modern liberal citizenship, the vote.

Manicom (2005) further highlights how, as a result of the prominence of 'race' and class in narratives on South Africa's history, many feminist accounts ironically ignore or de-emphasise the categories of race and class. Accounts such as those of Amina Mama (1992 in Lister, 1997:175) about the nature of the relationship of Black women in Britain with the welfare state are also relevant to the South African context. It demonstrates that states are not only patriarchal but often racialised and can treat marginalised groups in a punitive and coercive way through various “ideological mechanisms and administrative practices” (Mama, 1992 in Lister, 1997:175). The significance of such accounts that show how different groups of women stand in different relationships to the state is that policies will not necessarily represent the interests of all women. This relates not only to race, but also class, disability, age, sexuality and other categories of discrimination. The danger of insisting on a unitary category of woman is that the female citizen who is constructed will continue acting as an exclusionary tool for the citizenship of many women; in the same way in which feminists critiqued the traditional construct of an abstract, disembodied citizen (Lister, 1997).

2.4.3 Lister’s theoretical framework for gendered citizenship

These critiques beg the question whether the concept of citizenship can sufficiently be re-worked to be a useful conceptual tool for understanding the context in which women find themselves? Can such a concept be re-worked to be fully inclusive and serve as political instrument to further interests of women? If such a standpoint is inherently unstable as the poststructuralists contend, it follows that there is no universal feminist standpoint. Many feminists have grappled with these new dilemmas in feminist theory in the context of third wave feminism (see for example, Harding, 2004).

Lister (1997) provides a comprehensive feminist re-articulation of citizenship. She concludes that citizenship can be re-worked in a way that engages such differences between women whilst retaining the usefulness of the category ‘woman’ as a basis for mobilisation.

Lister argues that if citizenship is to be a useful tool for feminist analysis, it first of all needs to include a critical synthesis of the two traditions of citizenship. Citizenship must therefore be viewed as *both* a status and a practice. The relationship between status and practice must in addition be viewed as a dialectical relationship that continually redefines and transforms each other. The content of citizenship rights is therefore never static, but remains something to be struggled for. Therefore, starting with the two traditions of citizenship and running throughout her re-articulation Lister rejects binary thinking. This does however not mean that she outrightly rejects the different binaries in citizenship. Rather, where possible, she synthesises or re-articulates these binaries in order to make citizenship a useful tool for opening up possibilities to women. She emphasises that this is not simply window dressing in order to evade difficult theoretical dilemmas by sprinkling terms such as 'dialectical' "like so many conceptual croutons" (Elshtain, 1987:155 in Lister, 1997:198).

Lister (1997) suggests the two traditions need to be defined more broadly in order to be more inclusive of women. Social and reproductive rights need to be included in citizenship as rights to be guaranteed. With regard to participation, Lister argues that forms of informal politics in which women tend to participate in at community level should be included. Inclusiveness means that citizenship needs to be conceptualised as internationalist and multi-layered. This is important in the context of an increasing number of migrants in many countries. Migrant women are particularly vulnerable and citizenship can act as a harsh tool of exclusion from rights and participation for these women. A notion such as 'global citizenship', which Lister suggests, also brings to the fore the responsibilities of governments and richer nations to "translate human rights into effective citizenship rights" for all (Lister, 1997:196).

In dealing with the dilemma of whether women should aspire to a gender-neutral conception of citizenship or whether they should rather insist on being included on the basis of their difference, Lister suggests the notion of a 'differentiated universalism'. A differentiated universalism acknowledges the way in which women occupy a different structural position vis-à-vis men. Women therefore have different interests than men and are differently affected by social, economic and political policies. A differentiated universalism however also acknowledges the differences *between* women, as not to construct new ways of excluding some women from citizenship. The idea of a uniform citizen in the traditional universalist sense either conceals the interests of men or a particular group of women such as white middle-class, heterosexual women. She, however, retains the ideal of an inclusive citizenship, based on "a universalism that stands in creative tension to diversity and difference and that challenges the divisions and exclusionary inequalities which can stem from diversity" (Lister, 1997:66).

The differentialist universalism proposed by Lister (1997) adheres to a strategic essentialist stance proposed by Spivak (1990). Such a view recognises the constructed nature of the category 'woman' and the fixing of this within patriarchy, but is also aware of the pitfalls of deconstruction and how it could undermine women's claim to citizenship. Admitting that there is no unitary category 'woman' does not mean that the category cannot be useful in a political sense. The recognition of differences between women therefore does not nullify the project of promoting a gendered citizenship (Lister, 1997).

If citizenship is to no longer act as tool of exclusion the public-private dichotomy and its associated binaries also need to be reworked. This is an important project and has been a key element in feminist critiques of citizenship. Reworking of this binary involves three things. First, the gendered values that are associated with the two spheres need to be deconstructed. This would mean that the distinction between the public and private remains, but that the gendered meanings associated with the two spheres are done away with. The private should therefore no longer be associated with female attributes and the public sphere with male attributes only. Second, such a re-articulation involves acknowledging the many and different ways in which the public and the private influence and are connected to each other. It therefore means the rejection of the strict boundary drawn between the two spheres. It therefore, for example, acknowledges how women's contribution in the private sphere has enabled men to participate in the public sphere. Third, the fluid and changing boundaries between the two spheres need to be recognised. A reformulation of the public-private highlights how men and women relate differently to the two spheres as well as to the differences within each of these categories and how through these different relationships men as citizens are advantaged (Lister, 1997).

Lister's theoretical reworking of citizenship is useful as an analytical tool in a contemporary feminist context for a number of reasons. She continually disrupts and deconstructs the different binaries associated with citizenship emphasising the importance of gendered power relations.

Highlighting gendered power relations is of paramount importance in a feminist agenda. The appreciation of differences between women, including different ways in which women may be excluded from citizenship is continually emphasised as well. In this regard her articulation is appropriate to a postmodern, third wave context as categories are broken open to acknowledge 'otherness'. Her open-ended conceptualisation allows continual revision of the definition of citizenship as standpoints of different women are continually added. Emphasising agency and process are central to such a notion of citizenship (Lister, 1997).

Lister (1997) provides a conceptual reworking of citizenship for a feminist analysis that can be used to investigate and understand issues of healthcare in South Africa. The responsibility of the state towards citizens is a highly contested area, also in the field of healthcare. Healthcare is central to women's interests and their ability to live lives as full and equal citizens.

2.5 Social and reproductive rights and citizenship

From a feminist conceptualisation of citizenship two sets of rights gain new importance. The first set is reproductive rights, which include the right to reproductive self-determination but also access to family planning and reproductive healthcare. The second set of rights is social rights such as access to healthcare, education and welfare. Both sets of rights are important because women's unequal position in society stems from their relationship to the private sphere, as well as their exclusion from the public sphere. Civil and political rights might open up some possibilities for women's agency, but do not address many of the inequalities women face as a result of their positioning in the private and the public spheres (Gouws, 2005; Rahman, 2001).

There is an increasing acknowledgement that reproductive rights and social rights are often closely connected in women's lives. Part of a woman's reproductive rights is her right to reproductive healthcare, which may also be included in the socio-economic right to healthcare. But importantly, the two sets of rights are also closely connected in that women's lack of power over their bodies and their sexuality are exacerbated by their social and economic inequality. As has been discussed in the introductory chapter, this is of particular relevance in the context of the HIV epidemic (Albertyn & Meer, 2008).

Whether the state should guarantee social rights (and not only political and civil rights) to its citizens has been one of the key citizenship debates of the twentieth century. This debate became prominent in the post-war era, but has continued to be important in the light of neo-liberal policies that favour a market-driven approach to social and economic policies. Activists-scholars have lobbied for the rights concept to be extended to include social rights. These scholars argue that social rights do not stand independently from civil and political rights. In fact, they argue that when social and economic rights are absent political rights are rendered meaningless. Therefore, to have the right to vote does not protect poor citizens from dying untimely deaths from often treatable causes (Farmer, 2005; Lister, 1997).

David Held (1995) echoes this perspective, arguing that different clusters of rights are key to guaranteeing the principle of autonomy and to ensure equal political participation. Armatya Sen (1999) has also underlined the importance of healthcare, education and other social services. He argues that these social ‘opportunities’ are a ‘freedom’ that is closely interrelated with other ‘freedoms’ such as political freedom and civil rights. According to Sen (1999), the development of a country is determined by all these interconnected freedoms, and not only by the growth of the GDP.

Already 50 years ago the importance of social rights has been acknowledged in several UN declarations and covenants, including the 1966 UN International Covenant on Economic, Social and Cultural Rights. These covenants acknowledge that civil and political rights need to be backed up by social rights. These types of covenants and international treaties could however be seen as ‘manifesto rights’, which is seen as something to aspire to, rather than enforceable rights which is the responsibility of a specific party. Part of what makes South Africa’s new 1996 Constitution to be hailed as one of the most progressive in the world is the extensive recognition of human rights to be guaranteed, including social and economic rights. The South African government is therefore obliged to take responsibility for realising these human rights (as set out in UN declarations and covenants) (Lister, 1997).

2.5.1 Health as a citizenship right

During the 1990's the debate on social rights gained new momentum. Jonathan Mann, the founder of World Health Organisation's (WHO) Global Program on AIDS, working in the area of public health, argued persuasively that health as a social right is inextricably linked to human rights (defined as political and civil rights). Considering health and its relation to human rights, he argued health impacts on human rights, human rights abuses impacts on health and that health and human rights are "consonant paths to human well-being" (London, 2004:2). Mann (1995) made the case that "the promotion and protection of the rights of people is indistinguishable from and inextricably related to the ability to protect their health". What followed was the call for policies to reflect such a view. Mann and others' argument therefore supports a feminist conceptualisation of citizenship that emphasises the guaranteeing and realising of social rights (London, 2004:2; Mann, et al., 1999).

Health is an important human right to be guaranteed to all human beings. Women have particular needs and interests relating to healthcare. Women become pregnant and subsequently need antenatal and postnatal care. This is tied up with their reproductive rights, which include accessing information and services related to family planning and termination of pregnancy. It is therefore crucial for women to be included in citizenship as embodied citizens. In addition to pregnancy and reproductive health being central to women's health concerns, women remain constructed as the main carers of the young, the sick and the dying. The burden of accessing good healthcare for children and others in their care therefore mostly rests on their shoulders. These are all practical ways in which the public/private dichotomy plays itself out and how it affects women's lives differently to those of men. A feminist re-articulation forces us to investigate men's role in caring and also to highlight ways in which women's relationship to the private sphere (as carers) influence their relationship with the public sphere. In this case access to healthcare, pushes the public/private boundary focusing on women's reproductive rights and health services supporting these rights (Gouws, 2005a; Lister, 1997).

As discussed in the introductory chapter, women are at particular risk for contracting HIV which has to do with a mix of anatomical and physiological factors as well as complex gender dynamics. The approach suggested by Jonathan Mann, discussed above, emerged in the 1990's in the context of a growing HIV/AIDS pandemic. The violation of human rights such as not offering an HIV test or information on safe sex to every pregnant woman may have devastating health effects. Also, being HIV-infected may result in human rights abuses such as discrimination in the workplace and community. Health and human rights are also inextricably linked in the case of HIV. Research, for example has shown that the inability of women to negotiate safe sex due to patriarchal relations makes them vulnerable to infection (Mann et al., 1999).

In the context of HIV, the right to healthcare becomes imperative for survival in many cases, in particular receiving ART. Such treatments affect women's lives, significantly reducing the risk of HIV transmission from mother to child during pregnancy and labour. Using a feminist conceptualisation of citizenship, with a multilayered and trans-national view of global citizens is important here. The essence of such a view is a notion of rights and responsibilities that transcends the nation-state. This links to international human rights agreements and makes citizenship a more inclusive concept. Such a view helps to bring into focus struggles with international pharmaceutical companies in providing affordable drugs to citizens. It also highlights the responsibility of wealthier nations to assist poorer nations in enabling them to offer ART and other healthcare interventions to its citizens. Or in other words, enabling poorer nations to translate human rights into effective citizenship rights (Lister, 1997).

2.6 Conclusion

In South Africa, adopting a trans-national citizenship perspective is important because between three and six million immigrants live in the country's borders. Migrant women are often financially dependent on migrant men, leaving them vulnerable to exploitation. With no recourse to formal citizenship rights, migrant women often are some of the most marginalised and excluded people in a country (IOM, 2010).

A feminist conceptualisation of citizenship facilitates understanding other challenges HIV-infected women face, apart from accessing ART. An HIV-positive diagnosis often means that women have to deal with their bodies and their sexual lives in a new way. Going through pregnancy also subjects HIV-infected women to new medical interventions and experiences. It can change motherhood and practices such as infant feeding associated with it. Infected women face new stereotypes ascribed to them and to their bodies – such as being regarded as ‘irresponsible’, ‘loose’ or ‘bad mothers’. HIV-infection is therefore a further category of discrimination that women can experience. Lister’s (1997) concept of a differentiated universalism is useful in this regard. It acknowledges that HIV-infected women might be subject to particular rights violations. They may have particular needs and interests and are therefore in need to be protected as a category (Sontag, 1990).

Pregnancy, motherhood and HIV significantly influence women’s experiences of the social world and shape the particular needs that they have. Hence, it is not surprising that reproductive rights and healthcare is articulated as part of women’s interests in at least five of the articles in the South African Women’s Charter (WNC, 1994). Nevertheless, despite a constitutional commitment to reproductive rights, health and healthcare for women, the health outcomes of women and young children in South Africa are deteriorating at an alarming rate. South Africa is one of a few countries where the millennium development goal of reducing maternal mortality rates by half, by 2015, seems out of reach (UNDP, 2010).

In the next chapter the reasons for the poor health outcomes of women and young children are investigated. This includes outlining the restructuring of the South African health service post-1994, the impact of HIV/AIDS and interventions to improve maternal and child healthcare.

Chapter 3: Women and healthcare in the South African context

A feminist conceptualization of citizenship highlights the importance of social and reproductive rights if women are to enjoy full citizenship. These rights are shaped by and exercised within a specific political, social and economic context.

3.1 Health and healthcare in post-apartheid South Africa

During the political transition South African women articulated access to good quality healthcare as central to their interests and concerns in the Women's Charter. Consequentially, the Constitution of South Africa guaranteed healthcare as a citizenship right in Section 27 of Chapter 2 (The Bill of Rights), binding the government to take reasonable steps "within its available resources" to provide healthcare to its citizens (RSA, 1996).

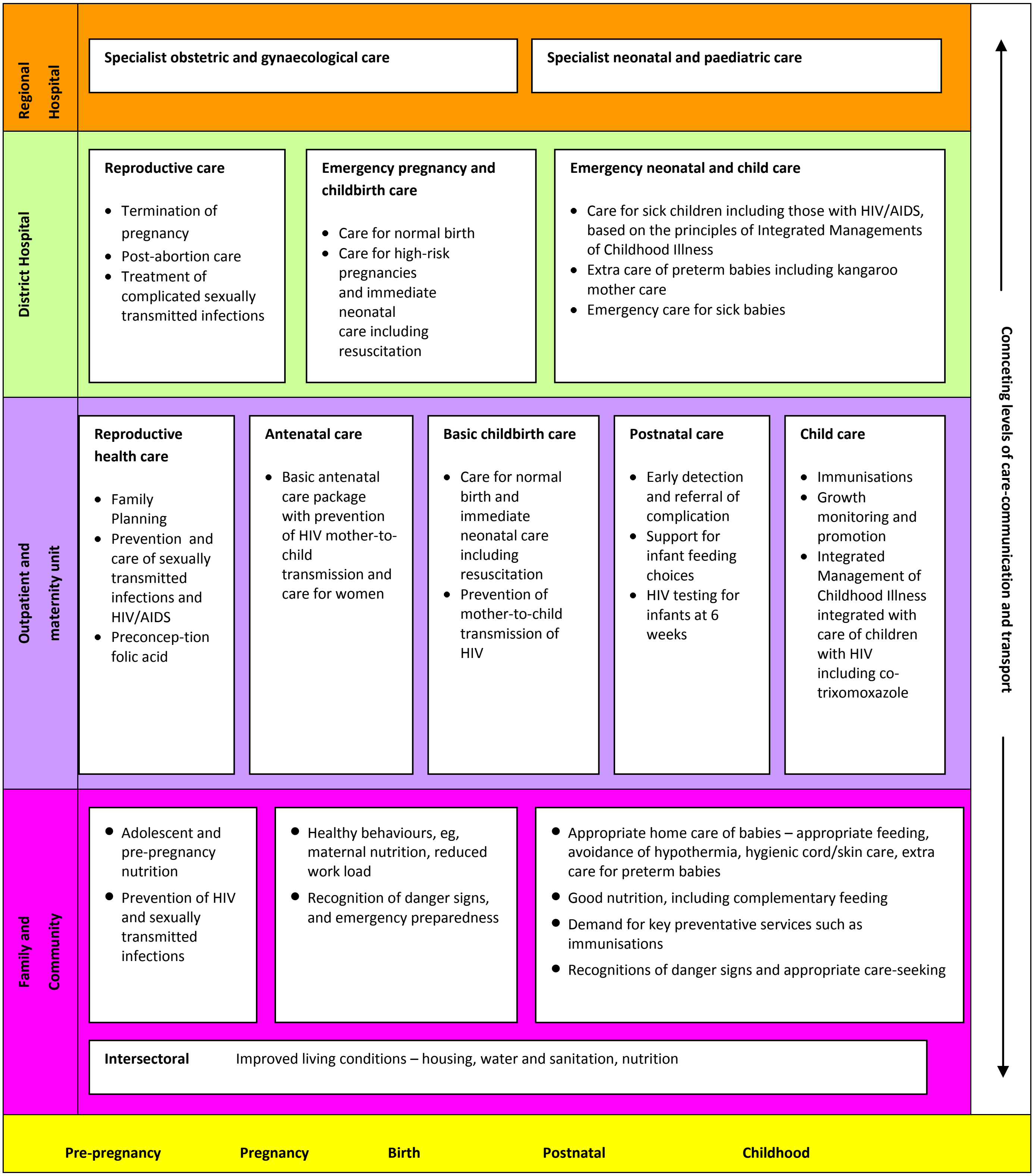
The health system the newly elected government inherited was racially fragmented, consisting of 14 separate departments of health. Funding was primarily directed towards urban tertiary hospital care. Although overall expenditure on health at the time of the transition was high, compared globally, it masked the fact that 60 percent of health expenditure was directed to 23 percent of the population. This inequality had particularly harsh consequences for black women and their children and was reflected in health outcomes at the time. In 1993 the maternal mortality ratio for black women at 130 per 100 000 live births, were ten times higher than that of white women at 13 per 100 000 live births. London (2004) argues that healthcare in South Africa during apartheid reflected a violation of human rights. Apartheid laws restricted most black South Africans' 'citizenship' to impoverished homelands where nutrition was inadequate and illnesses such as tuberculosis were widespread. Inadequate or absent healthcare services, impacting on health, further exacerbated the violation of the dignity of black South Africans (Chopra, et al., 2009; Dinokeng, 2008; Schneider, et al., 2007). In reaction to these abuses, healthcare activists joined with other activists in the anti-apartheid movement, illustrating how health and human rights "are consonant paths to well-being" (London, 2004:2).

In order to correct inequalities in the health system and ensure adequate healthcare to the population a number of initiatives were launched. The focus shifted from tertiary healthcare towards primary healthcare. The urban bias was addressed by improving health services in poorer, rural areas. In a commitment to improving maternal and child health, more than 1300 new primary healthcare clinics were built and user fees for pregnant women and children dropped.

Progressive legislation such as the Choice on Termination of Pregnancy Act (Act No. 92 of 1996) further supported the improvement of maternal health. The implementation of this legislation had an immediate impact on reducing the maternal mortality rate that resulted from unsafe abortions (Jewkes et al., 2002). Progress in healthcare was further boosted by improving infrastructure in impoverished communities and subsequently by increasing spending on social grants (Chopra, 2009; Heunis, 2004 in Von Holdt & Murphy, 2007). By 2008, child support, foster care and care dependency grants reached 84 percent of the families they were intended for and “are some of the most successful examples of cash transfer systems globally with demonstrated positive impact on the health of children and young women” (Chopra, 2009:835).

Four levels of care were identified in the restructuring of the South African health system: family and community services; primary health care (PHC) clinics; district hospitals; and regional and tertiary hospitals. A higher level of healthcare offers more intensive and specialist care than the level below it. The healthcare services offered to women and children according to the different levels of healthcare are illustrated in Figure 1 (see next page).

Community healthcare services focus on health promotion and care-seeking behaviour. This entry level of healthcare is not yet adequately funded and has not fully realised its potential (Chopra, 2009).



Regional Hospital

Specialist obstetric and gynaecological care

Specialist neonatal and paediatric care

District Hospital

Reproductive care

- Termination of pregnancy
- Post-abortion care
- Treatment of complicated sexually transmitted infections

Emergency pregnancy and childbirth care

- Care for normal birth
- Care for high-risk pregnancies and immediate neonatal care including resuscitation

Emergency neonatal and child care

- Care for sick children including those with HIV/AIDS, based on the principles of Integrated Managements of Childhood Illness
- Extra care of preterm babies including kangaroo mother care
- Emergency care for sick babies

Outpatient and maternity unit

Reproductive health care

- Family Planning
- Prevention and care of sexually transmitted infections and HIV/AIDS
- Preconcep-tion folic acid

Antenatal care

- Basic antenatal care package with prevention of HIV mother-to-child transmission and care for women

Basic childbirth care

- Care for normal birth and immediate neonatal care including resuscitation
- Prevention of mother-to-child transmission of HIV

Postnatal care

- Early detection and referral of complication
- Support for infant feeding choices
- HIV testing for infants at 6 weeks

Child care

- Immunisations
- Growth monitoring and promotion
- Integrated Management of Childhood Illness integrated with care of children with HIV including co-trixomoxazole

Family and Community

- Adolescent and pre-pregnancy nutrition
- Prevention of HIV and sexually transmitted infections

- Healthy behaviours, eg, maternal nutrition, reduced work load
- Recognition of danger signs, and emergency preparedness

- Appropriate home care of babies – appropriate feeding, avoidance of hypothermia, hygienic cord/skin care, extra care for preterm babies
- Good nutrition, including complementary feeding
- Demand for key preventative services such as immunisations
- Recognitions of danger signs and appropriate care-seeking

Intersectoral Improved living conditions – housing, water and sanitation, nutrition

Conceting levels of care-communication and transport

Pre-pregnancy **Pregnancy** **Birth** **Postnatal** **Childhood**

Figure 1: Integrated health-care packages for maternal, neonatal, and child health according to level of the health system in South Africa (Chopra et al., 2009:837)

At the primary healthcare level clinics are staffed by nurses. They provide reproductive health services (such as contraception and family planning counselling), antenatal care (including HIV testing and PMTCT interventions), partial postnatal care and basic child health services. The accessibility of new clinics has contributed to an increase in clinic visits from 67 million in 1998/99 to 102 million in 2007. It is estimated that 94 percent of pregnant women make at least one antenatal visit to the clinic and that 83 percent of children under one year are immunised (Chopra, 2009; Dinokeng, 2008).

The district level of healthcare provides in-patient care for women and children as well as caesarean sections. These services are provided at district hospitals staffed by generalist doctors.
The fourth level of healthcare includes regional and tertiary hospitals. Here women have access to specialists such as gynaecologists, obstetricians and paediatricians. Accessing these different levels of care functions on the basis of a referral system. In principle a person makes at least a first visit to the PHC clinic and would then be referred to the next level of care if necessary.

These services (or “packages” as they are often termed in public health literature), referred to in Figure 1, are evidence-based and follow World Health Organisation (WHO) recommendations. Healthcare statistics reflect high rates of use of these services available to women and their children (Chopra et al., 2009; Von Holdt & Murphy, 2007).

Paradoxically, in spite of these positive indications regarding access, health outcomes for women in South Africa are worsening. According to the South African Health Review (SAHR) (2010:3) South Africa is “definitely not on track to achieve Millenium Development Goal (MDG) 5”. MDG 5 has as its target the reduction of the maternal mortality ratio by 75 percent in 2015 from levels in 1990. Data suggests that the maternal mortality rate in South Africa has doubled since 1990. An estimated 2500 mothers die annually. Trends in other health outcomes for young children are bleak as well: in 2010 it was estimated that 24 per 1000 babies were stillborn, infant mortality was at 31 deaths per 1000 live births and a further 52 600 children died before they were five years of age. Rates of malnutrition are high for both mothers and children (Blaauw &

Kekana, 2010; Chopra, 2009; Cousens et al., 2011; Pattinson, 2011; RSA & UNDP, 2010; UNAIDS, 2010).

3.2 The impact of the HIV/AIDS pandemic

HIV/AIDS remains the major cause of poor maternal and child health outcomes in South Africa. Non-pregnancy-related infections (which mainly include HIV/AIDS) accounted for 43.7 percent of maternal deaths in the years 2005 to 2007. In South Africa the maternal mortality rate for HIV-negative women is 34 per 100 000 live births. This is in accordance with other middle-income countries like Thailand, Brazil and Argentinia. The maternal mortality rate for HIV-infected women is almost ten times the rate for HIV-negative women (Chopra, 2009; Blaauw & Kekana, 2010).

From the above data it is clear that both the prevention and management of HIV-infected women and children is a top priority in maternal and child health care. The health system offers both generic services and maternity-specific services in the management of HIV. The generic services include HIV and tuberculosis (TB) prevention, diagnosis and treatment. The maternity-specific services include HIV and TB screening in pregnancy, PMTCT and ART for pregnant women (Blaauw & Kekana, 2010).

Despite it being of crucial importance to effectively address the HIV/AIDS epidemic in reducing maternal and infant mortality, the management of the epidemic has had a chequered history in South Africa. The denialism of the Mbeki government was much criticised and resulted in the delaying of the roll-out of programmes as well as conveying mixed messages from politicians with regard to the origin and treatment of HIV. Following new political leaders and new ministers of health in 2008 and 2009, as well as the involvement and mobilisation of civil society, there have been recent improvements and successes. As of 2010 these successes include the largest ART roll-out programme in the world. However, as the maternal and infant mortality rates indicate, much still needs to be done to curb the HIV/AIDS epidemic (NDoH, 2010).

Access to good quality healthcare, medicine and health education is vital in preventing and managing HIV. However, if HIV is to be effectively addressed, interventions will also have to address social factors which detract from women's ability to exercise their right to health, healthcare and bodily integrity, as has been discussed in the previous chapters.

3.3 Prevention of mother-to-child transmission

The PMTCT programme is one of the services in the public health system that is offered to pregnant women. It has been said that this programme "exemplif[ies] the challenges for improving maternal, neonatal, and child health services" (Chopra et al., 2009:842). This has to do with the complex mixture of political, economic, cultural and other factors as discussed above, which have a direct impact on the effectiveness of the program. These challenges are evident in the fact that, until recently, South Africa was the country with the highest mother-to-child transmission rate in the world (UNAIDS, 2008).

Without any intervention, the risk of vertical transmission is about 30 percent. In spite of vertical transmission being almost completely preventable, 40 000 babies will be infected in South Africa in 2011. In making sense of this high rate, one has to look at the history of the programme, as well as the challenges of this programme. Mother to child transmission (MTCT) is considered eradicated in most high-income countries. With a few simple interventions this risk can be reduced significantly to a rate of fewer than 5 percent (Peltzer et al., 2011; UNAIDS, 2011; www.avert.org, WHO, 2012).

3.3.1 Historical context of PMTCT in South Africa

Until the mid-90's there was little known about mother-to-child transmission and no interventions were available in reducing the risk of transmission. The first significant breakthrough came in 1994 when clinical trials indicated that the use of the anti-retroviral drug Azido-Thymidine (AZT) reduced the chances of vertical transmission by two-thirds (Heywood, 2003). Subsequent trials in countries such as Thailand and countries in Africa supported the promising results of the earlier trials. The problem with AZT was that it cost an average of US $1000 per pregnancy and was considered too expensive for widespread use in developing countries (Berger, 2001).

It was considered a huge breakthrough when the results of a clinical trial done in Uganda in 1999 (known as the HIVNET 012 trial) revealed that use of the antiretroviral drug Nevirapine showed similar promise. With all eyes on South Africa, the results of this trial were presented at the XIIIth International AIDS conference held in Durban in 2000. In comparison to AZT, Nevirapine was cheap and easy to administer, a dose, at the time, costing only R30 per mother, as opposed to R400 for AZT. Mothers would take one dose a day from 28 weeks of pregnancy up to labour, while AZT had a more complex regime. Nevirapine therefore provided the best available option to prevent perinatal transmission of HIV in a developing country at the time (news24, 2007; Heywood, 2003; Peterson, 2006).

Following the results of these trials the South African government initiated a PMTCT programme in 2001 at 18 pilot sites in the country. The pilot PMTCT programme included the availability of Nevirapine to HIV-positive pregnant women. A reasonable expectation was therefore created that the government would eventually extend the PMTCT programme to all women in South Africa. However, despite numerous protests and requests by AIDS role-players such as the Treatment Action Campaign (TAC), a civil society organisation, treatment was not extended beyond the pilot sites. This eventually led to the TAC and other role-players taking the South African government to court over the issue of providing antiretroviral treatment to pregnant HIV-positive mothers in order to prevent vertical transmission. The TAC claimed that the South African government had breached the constitution by not taking reasonable measures to provide ART to HIV-positive pregnant women and therefore violated their constitutional right of access to healthcare (Budlender, 2001; Heywood, 2003). It has been argued that, through what has become one of the most well-known constitutional court cases to date, civil society not only held the state accountable, but it enabled citizens to “substantiate their lives as social and political beings” (Vandormael, 2007).

The Constitutional Court case situated PMTCT within a human rights discourse. This is important because, despite a human rights discourse in post-apartheid South Africa, the issue of healthcare has increasingly been framed as an issue of service delivery and away from being a human rights issue. Framing healthcare as a service-delivery issue might be more convenient to a government that, given the historical context, would prefer to avoid accusations of human rights abuses. The court case squarely put the issue of healthcare back within a human rights discourse. However, Albertyn and Meer (2008) argue that even within this human rights discourse women's rights were marginalized. They remind us that "rights are neither inherently progressive nor positively gendered" (Albertyn & Meer, 2008:30). It underscores the importance of a feminist conceptualization of citizenship and being vigilant in promoting women's rights and interests (London, 2004:12).

In 2001, in what has been framed as a victory for civil society, the High Court ruled that Nevirapine should be made available nationally to all pregnant women. The court further instructed the government to set up a national PMTCT programme. Despite the ruling and a time limit set by the court, the government continued to act reluctantly. This resulted in more protests and civil disobedience campaigns, including a march to parliament of 10 000 people in 2003. The government finally announced on 8 August 2003 that a national antiretroviral plan would be developed within a month. A national PMTCT programme was implemented soon after (Peterson, 2006).

Meerkotter (2005:169) contends that:

> The mother-to-child HIV transmission case succeeded […] because the demand already had wide support from communities and was propagated by communities themselves who experienced the need for this health service and saw the effect of its absence. The participation of people living with HIV/AIDS, especially women, in this campaign to assert their rights, notwithstanding the many obstacles to participation as 'active citizens', is very instructive.

Much has been written on this case, which, as Meerkotter (2005) indicates, provides important insights into citizenship in South Africa. The case study illustrates the importance of viewing citizenship as both rights and a practice with a dialectical relationship between the two. Here citizens mobilized to see substance given to a right as guaranteed in the constitution.

3.3.2 The South African PMTCT protocol

The PMTCT protocol has seen a few versions since its first adoption and implementation in 2003. As new research on both the social and medical aspects of the prevention and treatment of HIV/AIDS became available, the protocol changed and was adapted to a South African context. The most recent protocol was approved in 2010. The major adjustment in the 2010 protocol was the inclusion of AZT from 14 weeks (in addition to Nevirapine) (prophylaxis is thus started earlier) or lifelong Highly Active Antiretroviral Therapy (HAART) for pregnant women with a CD4 count less than 350 cells/mm^3. The protocol also includes infant Nevirapine prophylaxis for either six weeks or for the duration of the breastfeeding period. In response to programmes such as PMTCT being treated as vertical ‘silos’ in the health system and thus detached from other maternal and child health services, the guidelines “promote the integration of PMTCT services into routine maternal, newborn, and child health services” (MRC, 2011; NDoH, 2010).

A recent national survey conducted by the MRC between June and December 2010 on the effectiveness of the South African PMTCT programme shows some signs of progress. This survey with a sample size of 9915 infants (aged 4-8 weeks), attending public health facilities, showed a national HIV MTCT rate of 3.5 percent. Researchers feel that it is possible for MTCT to be effectively eradicated by 2015. There is still however variability in the provision of this service between provinces and different health facilities (MRC, 2011).

The PMTCT programme currently includes provider initiated HIV counselling and testing during antenatal care, CD4 cell count and clinical staging, counselling on safe infant feeding practices, dual-therapy ART prophylaxis or if appropriate, lifelong HAART for mothers, ART prophylaxis for infants, free formula milk for mothers who opt not to breastfeed for a period of 6 months, and infant HIV testing at 6 weeks. This protocol points to what can be called different “milestones” in the “journey” of the HIV-mother through the health system, where she requires information and support in order to make certain complex and critical decisions. Although psychosocial support is also included in the PMTCT protocol, women are often left with little or no support, especially as disclosure rates remain low, in making these decisions. Some of the decisions mothers are faced with when accessing PMTCT are illustrated in Figure 2 (Bergh, 2007; Doherty, 2006; NDoH & SANAC, 2010).

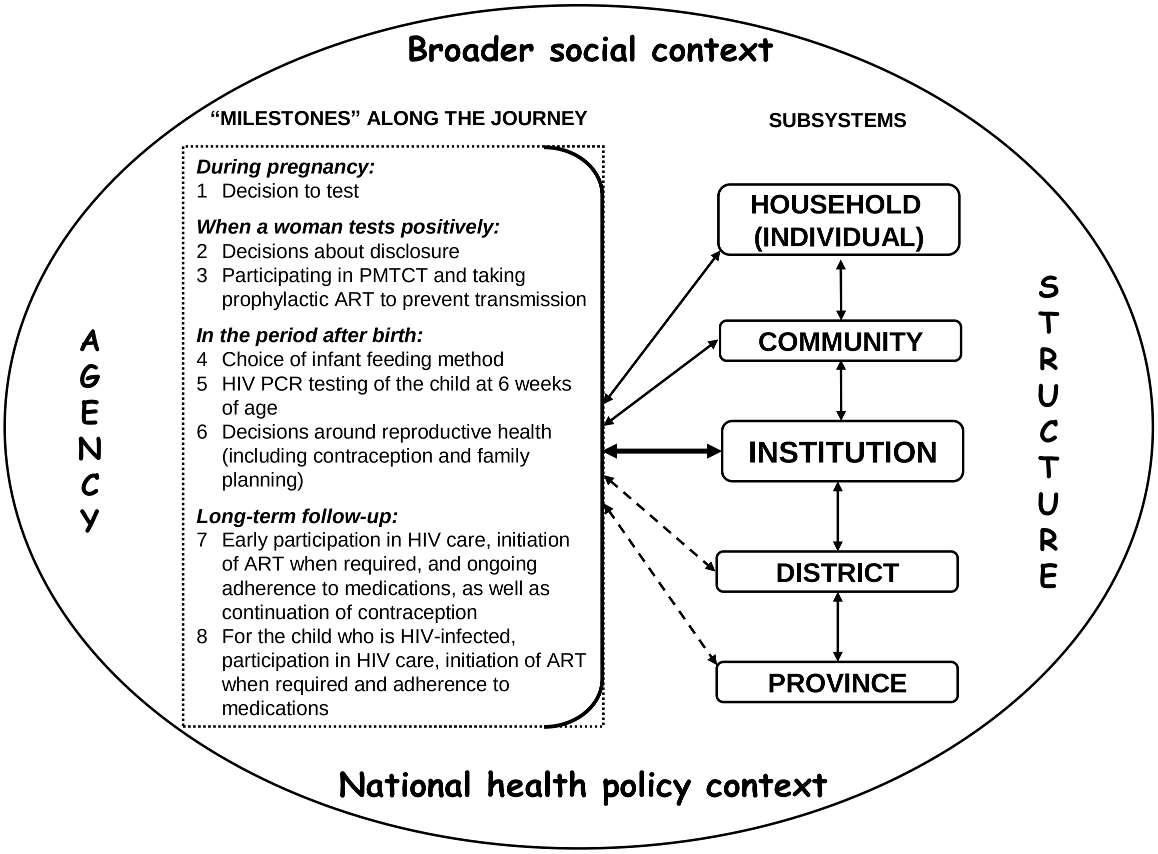


Figure 2: Decisions women face when accessing PMTCT services

The health journey of a pregnant woman is ideally conceptualised as follows: early in pregnancy she would visit the clinic for a first antenatal check-up. Here, she would be offered provider-initiated testing and counselling. If she tests positive she has to decide whether she is going to disclose her status and to whom – to her partner, family or friends or all of them. A CD4 count will be done on the same day. She would come back to the clinic usually within four to five days for feedback on the results of tests. If her CD4 count is below 350 cells/mm³ (or WHO stage 3 or

4), she will be referred to a secondary or tertiary hospital to be put on HAART. If her CD4 count is above 350 cells/mm³ (or WHO stage 1 or 2), she will receive AZT from 14 weeks of gestation and Nevirapine during labour and delivery, as well as a single dose of Tenovir (TDF) and Emtracitabine (FTC) after delivery. A CD4 count should be repeated every six months. The infant would receive Nevirapine drops for six weeks following birth. The mother will receive counselling on safe infant feeding practices which includes explaining the benefits and risks of both breastfeeding and formula feeding (NDoH & SANAC, 2010).

At this stage it is important to discuss some of the debates and developments that emerged with regard to the PMTCT protocol since its implementation in South Africa in 2003. This frames this research, providing the context for when interviews were conducted for this study and where it fits into the PMTCT context.

3.3.2.1 Counselling and testing

When the first protocol was introduced in 2003 it included voluntary counselling and testing (VCT). The VCT approach functioned on the basis of patients requesting to be counselled and tested for HIV. The voluntary nature of counselling and testing was hotly debated amongst clinicians, scholars and activists. Some argued that counselling and testing should not be voluntary, but should be part of routine testing during antenatal care, together with other tests such as rhesus testing. This is because HIV testing during antenatal visits is considered to be the entry-point for many HIV-positive women into a system of care and therefore a crucial service to be extended to more women (Rennie & Behets, 2006; Schuklenk and Kleinschmidt, 2007).

Researchers such as Schuklenk and Kleinschmidt (2007) argued that if there were a 25 percent increase in the number of pregnant women tested for HIV in South Africa, then between 11 000 and 15 000 infants could potentially be protected against the virus every year. These researchers, along with others called for an opt-out policy (rather than voluntary counselling and testing), which means that HIV tests should be part of the routine antenatal check-up, unless a woman specifically refuses to do the test (cf. Beresford, 2007).

What is at issue in the debate is the balancing of human rights with public health concerns. On the one hand the right of an individual to choose whether to have an HIV-test done should be protected. On the other hand, treatment can only be provided to HIV-positive individuals if their status is known. In an attempt to balance these two sides, the PMTCT protocol was adjusted in 2008 to include provider-initiated counselling and testing. An HIV test should now be routinely offered to every pregnant woman visiting a clinic but she still has the right to refuse the test. In 2008, 78 percent of pregnant women had had an HIV test done during pregnancy. This increased to 95 percent of women in 2009 (UNICEF, 2010).

3.3.2.2 Infant feeding

Possibly the most debated and controversial aspect of the PMTCT protocol is that of infant-feeding choices for HIV-positive women. This is also evident in the significant portion of available PMTCT literature dedicated to this issue. Infant feeding is an issue because of the risk of HIV transmission through breast milk. In the absence of any intervention (e.g. the use of ART), the chances of HIV transmission through breast milk is approximately 15 percent (UNICEF, 2011).

To exclude any chance of transmission through breast milk, many healthcare professionals initially recommended the avoidance of any breastfeeding. In the earlier protocols women were offered the choice of exclusive breastfeeding with abrupt weaning at 4-6 months or exclusive formula feeding with free replacement feeding provided until six months. Until recently the default discourse at many healthcare institutions was the recommendation of replacement feeding to all HIV-positive mothers. The use of replacement feeding in low-income settings is however problematic. This has to do with ensuring that all conditions as set out in the WHO guidelines for replacement feeding are met. It is argued that very few mothers in South Africa and other developing countries meet the requirements of replacement feeding being “acceptable, feasible, affordable, sustainable and safe” (AFASS) (WHO, 2010). Women and other carers experience difficulties ranging from the sterilisation of bottles, not having the financial resources to pay for replacement feeding (when not provided free after 6 months), as well as having to deal with contradicting community norms and values (Coovadia et al., 2007a). It appears as if in many cases health workers take a decision on infant feeding on a woman's behalf and that women's health and the health of their children have been compromised by the infant-feeding controversy, as it seems that "few [women] are receiving full information to help them reach an informed decision" (Seidel, 2004:168). This is evidence of how, despite having a right formally acknowledged, women in developing countries are often excluded from accessing good healthcare as a result of their social conditions.

Not meeting the requirements of safe replacement feeding results in replacement feeding being unsafe and unsustainable. Studies showed that the risk of replacement feeding in many settings was higher than the risk of HIV-transmission from breast milk. Coovadia et al. (2007a) found that infant mortality rates in low-income settings during the first three months of life is roughly doubled when infants receive replacement feeding (mortality=15 percent) compared to infants receiving exclusive breastfeeding (mortality rate=6 percent).

What further complicates infant feeding in the context of HIV, is that "neither exclusive breastfeeding nor exclusive non-breastfeeding are the cultural norms in most African settings and that mixed breastfeeding is the predominant method of infant feeding" (Doherty et al., 2006:91). Mixed feeding however puts infants at a higher risk for contracting HIV, due to damage to the infant gut with this mode of feeding (Coovadia et al., 2007a).

Because of all these difficulties, infant feeding practices in the context of HIV has been described by some as nothing short of a mess (Cilliers et al., 2009; Coovadia et al., 2007b). This has been partly addressed by the revised protocol in 2010. In this protocol women with a CD4 count below 350 cells/mm^3 are referred for HAART. As there is a link between a women's viral load and the transmission of HIV through breast milk, and with HAART reducing a women's viral load, HIV positive women can now "for the first time safely breastfeed their children" (NDoH, 2010:1).

Acknowledging how breastfeeding practices has been undermined by the supply of free replacement feeding to HIV mothers, the Minister of Health, Dr. Aaron Motsoaledi has recently signed the Tshwane Declaration of Support for Breastfeeding in South Africa. In addition to supporting exclusive breastfeeding amongst all HIV-positive mothers (since HAART is now provided to all breastfeeding mothers, as well as Nevirapine to breastfeeding infants), it declares that "formula feeds will no longer be provided at public health facilities". Ensuring that ART is initiated from 14 weeks has also been included in the government's negotiated service delivery agreement (NSDA, 2010-2014), of which the Minister is a signatory.

3.3.2.3 Antiretroviral therapy (ART)

Including more women in access to HAART by increasing the inclusion criteria from a CD4 count of below 200 cells/mm³ (2008 protocol) to a CD4 count of below 350 cells/mm³ has been widely welcomed by activists groups and others alike. This greatly reduces not only the chances of transmission through breast milk, but also transmission in the womb or during the labour process. It is also hoped that it will decrease the mortality rate amongst women in the postnatal period. Another major adjustment in the 2010 protocol was the inclusion of AZT from 14 weeks of gestation instead of 28 weeks (2008 protocol), which is then taken together with Nevirapine during labor. Infants also receive Nevirapine prophylaxis for the duration that they are breastfed, or if not breastfed, for the first six weeks (Hogan et al., 2010; NDoH, 2010).

Improving access to these antiretroviral therapies was not an easy process. Apart from taking the government to court in 2001 to gain access to Nevirapine, activists have since lobbied around a number of issues relating to ART. Giving women with a CD4 count less than 350 cells/mm³ access to HAART was also already recommended by the WHO in 2008, but not implemented by the government until 2010.

3.4 Conclusion

The context within which HIV-positive women make decisions about their health is directly influenced by the different health policies adopted and implemented. Political positions and decisions influence these policies and ultimately the choices and citizenship available to women.

The next chapter discusses the methodological choices made in this study, as well as the context within which interviews were conducted with HIV-positive mothers.

Chapter 4: Methodology

Feminist methods draw on existing concepts and tools to do research, but do so critically (Ramazanoglu & Holland, 2002). This chapter discusses the critical engagement of feminists with research methods, as well as the considerations and choices that were made in this study.

4.1 Exploring the experiences of women accessing PMTCT

Feminist researchers seek to understand why women still do not enjoy full equality, even in countries such as South Africa, which has a 'progressive' Constitution. This study focuses on women's right to health and healthcare, an important social right in effacing the second class status of female citizens. More specifically, one programmatic initiative, the prevention of mother-to-child transmission (PMTCT) programme which aims to give women access to HIV care and prevention interventions is considered. Access to interventions such as PMTCT is crucial in the healthcare of vulnerable women (Goldblatt & Mclean, 2011; Gouws, 2005).

Studying an initiative such as PMTCT provides the opportunity to learn about the access and quality of healthcare in the lives of vulnerable women. Health is a human right inextricably linked to other human rights. The degree to which social and reproductive rights of vulnerable women are realised, provides an indication of how well South Africa is faring in improving the status of women and erasing the legacy of apartheid (Gouws, 2005a & b; Meerkotter, 2005).

In spite of the fact that many health issues are framed in a human rights framework, especially in the context of HIV, there is a paucity of literature on the views and experiences of health users. Health users, in this case women, are the people who have the most to gain or lose from programmes and policies aimed at them. Literature on PMTCT typically focuses on the medical aspects and service delivery of the programme. Some literature refers to the behaviour or voices of women, usually in a limited way. This research aims to put the experiences and concerns of HIV-positive mothers at the centre of an effort to improve their and their children's well-being. The study poses a (research) question on why, in spite of formal policy guidelines and implementation of PMTCT, South African women still struggle to realise this right. The research aims are to explore:

- The perceptions and thus the broader experiences of HIV-positive mothers with regard to the many difficulties they face in making health related decisions.
- The ways in which HIV-positive mothers exercise their agency.

The methods which were considered the most appropriate to realise the research aims and answer the broader research question are discussed next.

4.2 Methodological choices

A feminist conceptualisation of citizenship provides a theoretical framework to research this question and explain why *de jure* rights of women have not translated into *de facto* rights. Such a framework emphasises women’s position in the private sphere, the importance of social rights and the redefinition of political participation to include the often informal participation of women in politics.

The redefinition of citizenship is a first step toward developing a feminist standpoint on citizenship. Experiences of women are more important than those of government authorities and experts. Women’s experiences present a truer reflection of reality. A feminist standpoint exposes the link between the production of knowledge and practices of power by juxtaposing the viewpoints of the marginalised and those in power (Harding, 2004; Stanley & Wise, 1993).

As feminist theories and a feminist conceptualization of citizenship underpin my reasoning about the rights of women, in particular with regard to accessing healthcare, it stands to reason that I will make use of a feminist methodology to conduct my research. Feminist researchers question whether any methodology ignoring the importance of gender can accurately reflect the social realities of women (Letherby, 2004a & b).

Although positivistically orientated quantitative researchers have been "particularly guilty" in either excluding women or distorting their experiences, the consensus seems to be that the debate is really about the way in which the research is conducted, whether qualitative or quantitative (Letherby, 2004a:177). Quantitative methods are in some instances less intrusive than qualitative methods and qualitative methods can be patronizing and exploitative. What makes research feminist is not a particular method, but rather the way in which it is conducted, for instance, acknowledging the power relations within the research provides an important step in determining the lived experiences of women (Landman, 2006; Jayaratne and Stewart, 1991 in Letherby, 2004a; Oakley, 2004).

DeVault (1996) argues that a feminist methodology is distinct in three ways. First, it is committed to "excavation and inclusion" – it aims to make known and include the positions and perspectives of all women. Second, it seeks to do no harm. This is because, in the past, researchers have often exploited women and scientific knowledge has served to sustain the oppression of women. Third, a feminist methodology wants to produce research that will lead to social change and benefit women.

For the purpose of this study I chose qualitative methods of enquiry as the most appropriate to answer the research question and develop a feminist standpoint. A standpoint is concerned with how marginalised people experience and understand their social realities. It views marginalised people as agents ascribing meaning to their situated contexts. It also considers the knowledges of oppressed people as a political resource for change. To explore this self-reflexivity of participants in my study, qualitative methods were considered to be the most appropriate (Harding, 2004; Morse & Richards, 2002).

Qualitative methods have traditionally been favoured by feminist researchers to determine women's experiences. It provides the opportunity for collaboration between the researcher and the participant and "a strategy for documenting women's own account of their lives" (Oakley, 1981:48). Qualitative research additionally contributes another dimension to research in public health, which has tended to rely on qualitative research (Oakley, 1998).

4.3 The value of qualitative research in the public health context

In public health quantitative research provides the bigger picture in order to assess and intervene in health matters towards the broader public good. Knowing mortality rates, staff vacancies, staff numbers, incidence and prevalence of HIV and TB rates, etc. enables the public health system to channel funds, implement policy, prioritise interventions and launch health education campaigns. It also gives the government an indication of how they are faring in providing healthcare to its citizens (Bowling, 2002).

A quantitative paradigm has limits. The ‘view from below’ is often lost. This may result in the design and implementation of health interventions without the consultation of those whom these interventions affect most – the health users. The contribution of a qualitative approach in public health research, which many researchers in the social sciences use to get the ‘view from below’, is important. It demonstrates how health interventions may be misguided and ineffective. Qualitative research contributes to a better understanding of how people understand and make sense of their health, sickness and illness and their health seeking behaviour. Together with an appropriate conceptual framework, it potentially highlights how these health policies, interventions and campaigns can reproduce capitalist, patriarchal and racist social relations (Sarantakos, 2005; Silverman, 2003).

4.4 Research design

In this section the design of the study with regards to site selection, participants and data gathering methods, as were considered appropriate for a qualitative research paradigm, are discussed.

4.4.1 The sites

Four primary healthcare clinics were identified in the City of Tshwane Metropolitan Municipality (CTMM) to conduct qualitative research into PMTCT. There were a number of reasons for focusing on women's access to healthcare in Tshwane. First, working as a research assistant for the MRC Unit collaborating with the department of health in Tshwane meant easier access to research sites. Second, at the time there was interest in the field of maternal and child health in determining why the PTMCT programme produced such poor outcomes despite good roll-out in Tshwane and a policy in line with WHO recommendations. This linked up with a broader question of why, despite a constitutional commitment, women still struggled to realise this right. Third, the CTMM encompasses Pretoria, the administrative capital of South Africa. It is located in Gauteng, the economic powerhouse of South Africa. Furthermore, it differs from the adjacent two metropolitan municipalities in the province in that its area of jurisdiction includes a sizable rural area as well. Fourth, it accommodates a sizable migrant population – the most marginalised category with regards to citizenship rights. Fifth, it was a convenient site for field research, working and living in CTMM at the time of the study (CTMM, 2006).

Due to apartheid policies of the past, the city's urban pattern was shaped in a particular way. As with several other cities in South Africa, it is in effect a divided city with a formal, well developed core and a low-income, poorly developed periphery which is dependent on the core. This urban pattern was further influenced by market forces and topography particular to the CTMM. An east-west alignment of ridges, limited North/South accessibility. Besides having a strong central core, these natural topographical constraints led to the establishment of secondary nodes. The municipality has attempted to "rectify the distorted urban form" and better integrate the peripheral areas (CTMM, 2006:16).

Clinics were purposively selected to reflect the settlement diversity of the city. It was important to select clinics accessed by vulnerable women which had adequate counselling available, taken the sensitive nature of the topic. To this end I approached the director of mother-and-child services of primary healthcare clinics in the CTMM at the time. He oversaw the PMTCT programme and training of health workers, also with regard to counselling, in this field. The director was instrumental in identifying suitable clinics. He referred me to four different clinics under the jurisdiction of the CTMM, which he considered meeting the necessary selection criteria.

The four different clinics were each in a different sub-district of CTMM. The first clinic, Clinic A, is in a ‘township’ to the east of the Pretoria core. Residents of this township supply both formal and informal labour to residents and businesses located in the east of Pretoria. The city has continually expanded eastwards and constantly sees new developments. This ‘township’ settlement has grown considerably as workers seek to be closer to their places of employment.

Clinic B is in a recently established settlement in the southwest quadrant of the CTMM. The main areas of employment for these residents is south of the city, the inner city area and Centurion.

Clinic C is situated in the inner city precinct. The inner city supplies more than half of the CTMM’s employment opportunities. It furthermore provides retail and entertainment to the northern and western areas of the city. This area houses many residents, including immigrants. In spite of expansion of and decentralisation in the city, the inner city remains important (CTMM, 2006).

Clinic D is to the north of the Pretoria core. The north is an important point of entry into the CTMM and the Gauteng province for many people and accounts for the rapid population growth in the area. The north has the largest population and most informal settlements are concentrated in this area. Although this clinic is in a middle-class neighbourhood, it attracts and serves the population of the adjacent poorer settlements (CTMM, 2008; Huchzermeyer et al., 2004).

4.4.2 The participants

In planning this study, it was decided that 24 participants would be selected from the four clinics – six participants per clinic. The participants had to be women who were HIV-infected and had participated in a PMTCT programme in the public health system. Their babies and infants preferably had to be at least six weeks old. This age (of the infant) was chosen as women routinely visit the clinic for follow-up examinations, immunisations and HIV-testing of infants at six weeks. When the infant is six weeks the major milestones of the PMTCT programme should have been reached.

As I was doing research at the clinics, participants would be asked to volunteer for the study with the help of clinic managers or nurses. This was because the health workers had knowledge of the HIV-status and participation of the health users in clinic programmes. Health workers could therefore identify potential participants who met the selection criteria for this study. Health users could also protect disclosure of their HIV-status by declining participation (as some did) to the health worker.

4.4.3 Data collection

Semi-structured qualitative interviews were chosen as methodological tool. Interviews offer the opportunity to explore participants' experiences and perceptions as both the interviewer and the participant may ask questions. This gives the interviewer the opportunity to repeat or rephrase questions or responses to ensure that they are understood. Interviews were also chosen because it was likely that participants who had only a basic education would not feel comfortable with other methods of data collection such as filling out questionnaires. Individual interviews compared to focus groups discussions furthermore protected participants' privacy and enabled maintaining confidentiality. In this regard, they were conducted in a private room where participants would be able to speak freely without fear of other health users or health workers overhearing. Emphasising the confidentiality of the interviews was important.

Semi-structured interviews were selected because it offered some structure to the interview process and helped the researcher to maintain focus during the interview, while allowing enough space to explore statements in depth and in this way gain a richer understanding of answers offered. To this end, an interview schedule was drawn up (see Appendix 1). The schedule contained ice-breaking and demographic questions. These questions intended to help participants feel at ease and build rapport. This was followed by core questions containing items related to the 'milestones', maternal and paediatric factors, HIV in general, issues around health and the provision of health care and other services. Questions more or less followed the steps of the PMTCT protocol and explored issues and experiences of women as it related to PMTCT. Other items included in the interview schedule were identified from the literature as being important (David & Sutton, 2004).

Since it was anticipated that participants in the study would speak African languages the help of an interpreter was secured. This was important to explore the subjective experiences and feelings of health users and ensure that participants, as far as possible, felt comfortable when expressing themselves. It was important that women had the opportunity to express themselves in their mother tongue if they preferred to do so.

In her classic essay about interviewing women, Anne Oakley (1981) argues that the qualitative interview can be sexist. She recalls how conventional textbooks providing guidelines on the interview ill-equipped her for challenges she faced during her research. While textbooks admonished researchers “that the interviewing situation is a one-way process in which the interviewer elicits and receives, but does not give information”, Oakley (1981:30) had a different experience. During the interviews she encountered women asking questions to her as the researcher – both personal questions and questions wanting more information. Far from being detached from the process (as conventional textbooks advised), she became friends with her participants and years later, still had contact with them. Oakley (1981) suggests that a feminist methodology is not wary of personal involvement or reciprocity in the qualitative interview process. She reminds us that research is always a social process where meanings are constructed by both participants and researcher.

4.5 The course of fieldwork

The director of maternal and child health at the Tshwane Department of Health emailed the contact details of the clinic managers at the four different clinics to me. I was granted permission to contact the managers of the clinics identified as the final research sites. The purpose of the research was explained via email and telephonic contact to the clinic managers. These managers either referred me to the sister in charge of PMTCT at the clinic, or indicated which days at the clinic would be suitable for the research to be conducted. Although clinics in Tshwane aimed to offer all available services each day of the week (the so-called 'supermarket' approach), some of the clinics seemed to be visited by particular groups (e.g. pregnant mothers) on particular days and I was advised by the different clinics to visit on particular days.

On arrival at the clinics we reported to the clinic manager. The clinic managers either introduced us to the nurse in charge of PMTCT, who showed us which room we could use to conduct interviews and who helped us to invite suitable candidates to participate in the research.

Twenty semi-structured interviews with HIV-positive mothers were conducted in the period May 2008 to November 2008 at the four different clinics. Interviews took between 20 and 90 minutes. We conducted no more than three interviews on a day as the interviews were not only time-consuming, but also emotionally draining. At clinic B only five interviews were conducted, as only two participants were willing to be interviewed the second and third time that we visited the clinic. One plausible reason for this was that these visits did not coincide with a designated clinic day for women-and-infants and that the clinic was reluctant to admit that they still had designated clinic days. This was also the case at Clinic C – two women were interviewed the first and second time we visited it. On the third visit, only one woman agreed to participate. An additional factor was a cold front that hit Tshwane at the time and probably discouraged women from attending the clinic with infants on that day.

Two interviews were conducted with HIV-positive mothers and their male partners, who had accompanied them to the clinic. Although not planned, it was decided that their insights might provide an additional dimension to the study. In spite of feminist research often being thought of as research by women, for women and about women, it is increasingly acknowledged that understanding men and masculinities are important if gender relations are to be changed. Not all masculinities are oppressive and it is important to investigate and understand ways in which men are supportive of women.

I also had a short informal conversation with a grandmother who came to the clinic to collect formula for her grandchild, on behalf of her daughter. She was introduced to me by the clinic manager, who thought that the experience of the grandmother might also prove valuable. As the grandmother was not aware that her daughter was HIV-positive (according to the clinic manager), I could only informally ask the woman about her daughter's health and the health and care of the infant. This case illustrated how the burden of care also falls on older women and how the stigma of HIV/AIDS complicates this care.

Following each interview, the interview schedule was revised to include, rephrase or exclude certain questions where this was deemed necessary. For example, some participants appeared nervous when I explained the purpose of my research. I realised that the women were eager to participate and tell their story, but felt anxious because they were unsure about what to tell me. I then made sure that I reiterated that I will ask specific questions to which they may (or may not) respond. Many women seemed to relax after this.

Prompts and probes were used to elicit additional information about core issues (e.g. 'Tell me more about…'), as well as to clarify questions and to ascertain the meaning of certain responses (e.g. 'Do you mean..?'). I noticed that participants only gave short answers to more general open questions such as 'What are the difficulties that HIV-positive women experience?' versus questions about their own experiences where they could elaborate. Very few of the women understood the question asked towards the end of the interview 'Looking back, is there anything you would have done differently in this PMTCT process?' I asked this question in the first few interviews, but excluded it from the later interviews as many of the participants did not seem to understand the various versions of this question I tried out. This probably had to do with the phrasing of the question and language barriers between the researcher and participants (David & Sutton, 2004).

The interviews were conducted in English. The assistant was extremely helpful as women were able to answer questions in their mother tongue, which was then translated immediately by the assistant. The language barrier was nevertheless a factor, which I discuss later in the chapter under 4.11.

The interviews were audio-recorded with participants consent. I made field notes following each interview and each clinic visit. Reflective discussions were also held with the assistant after each clinic visit. The content of these discussions were either recorded in writing and/or in audio.

4.6 Operationalising the research design

During the time of the study I worked as a research assistant for the MRC Unit for Maternal and Infant Health care Strategies. The Unit is based at the University of Pretoria and its mission is to find practical solutions to the health problems of women and infants in South Africa. The Unit works closely with both the provincial Department of Health and the CTMM Department of Health. This study formed part of a bigger study investigating PMTCT. My relationship to the MRC was invaluable in gaining access to clinics.

The MRC Unit made the services of a colleague available to act as a translator, if needed, during the interviews. She was fluent in most of the local African languages spoken in Tshwane. Although most interviews were conducted in English, the women occasionally struggled to express themselves in English. They were then able to tell their story or elaborate on an answer in their mother tongue, with immediate translation by my colleague. Her help and assistance proved to be valuable far beyond acting as a translator. As a retired nurse, she was well acquainted with the clinic settings and even knew some of the staff at the clinics. She helped to explain the purpose of our visit to the clinic, as well as what we required (such as a private room to conduct interviews in) while we were there. As all the women attended the clinic with their infants, she assisted in keeping infants occupied, feeding them or calming them while I conducted the interview. At the closing of interviews she was able to provide support and information to women in her capacity as a nurse, often advising them on what to ask the nurse at the clinic during their next consultation.

As Oakley (1981) had also experienced in her research on motherhood, the women did ask questions back. The assistant was both comfortable and experienced in discerning which questions should be referred to a nurse at the clinic and which questions we could give information on. During one interview, the baby was very upset and she took the baby out of the consultation room so that we could conduct the interview. She determined that the baby was very hungry and that’s why he was so upset. On questioning, the mother told us that she was advised to feed the baby only three times a day – “breakfast, lunch, supper” [Palesa]. The assistant’s help corrected the misconception of the mother, addressed underfeeding and enabled an interview to be conducted.

4.7 Data management

The interviews were all transcribed verbatim with the help of research assistants. Transcribers were briefed with regards to the confidentiality of the content of the interviews. They were also required to use a password on audio recordings and transcripts to protect the confidentiality of the interviews. On receiving the transcriptions back, each transcription was checked and compared to the audio recording by myself.

4.8 Data analysis

Identifying themes from the data is an iterative process. The transcriptions were used to do an initial analysis. Broad themes were identified across all the interviews. I also listened to all the audio-recordings of the interviews again, making notes during and following each interview and highlighting quotes that illustrated certain themes. I made use of a spreadsheet to organise all of the data according to the interview schedule, which made it easier to see all the responses of particular questions and themes organised together.

When writing up the findings I selected examples across all interviews. I used direct quotes extensively throughout my findings as it gives participants a voice (Creswell, 2007; Denzin & Lincoln, 2000).

The themes that were introduced during the interviews centred on decisions that the participants had to make with regard to their health and the health of their children. This included questions on the different ‘milestones’ of the PMTCT such as testing, disclosure, use of ART, etc. Themes identified in the literature were also introduced during the interviews. These themes dealt with partners, families and communities

The emerging themes of the study have to do with the difficulties that women encountered in exercising their right to healthcare and ways in which they negotiate these difficulties. These themes link to the citizenship of vulnerable women in post-apartheid South Africa and the degree to which their citizenship have been realised.

4.9 Politics and ethics of this study

When researching the lives of vulnerable women, it is crucial to consider the ethical implications of the study to avoid any harm. It is also important to reflect on the politics of the study, as I, a white, middle-class woman, am representing the lives of vulnerable women.

4.9.1 Formal ethical requirements

I obtained formal ethical clearance for my study from the following authorities:

- UP Faculty of Health Sciences Research Ethics Committee (Appendix 2)
- UP Faculty of Humanities Research Proposal and Ethics Committee[2] (Appendix 3)

A legal opinion was obtained with regard to consent from minors, should any of the mothers approached to participate be one.

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[2] When a study involves the participation of healthcare users, it has to be submitted for Ethical Clearance at the UP Faculty of Health Sciences Research Ethics Committee as well as the Faculty Ethics Committee in which the dissertation is submitted for degree purposes.

The nurses responsible to approach possible participants were briefed with regards to the voluntary nature of participation and the importance of confidentiality. It was explained that women should not be pressured to participate in the study and that they should be reassured that their confidentiality will be protected. This was reconfirmed with participants when introduced.

Written or verbal consent was obtained prior to each interview (see Appendix 4). The participant information leaflet and informed consent was explained to each person in their chosen language. A copy of the information leaflet and informed consent was offered to each participant. The importance of confidentiality was emphasised to reassure participants that their identities would not be revealed at any stage and that nothing of what they shared would be disclosed to health workers.

A condition set by the Research Proposal and Ethics Committee of the Faculty of Humanities was that adequate counselling should be available at clinics where interviews are conducted due to the sensitive nature of the research. HIV-positive women might require support and counselling following the interview. Previous research in South Africa had shown that inexperienced nurses and those with negative attitudes towards health users often did not treat women with the necessary sensitivity. To address these concerns and the principle of doing no harm, I asked the director of mother-and-child services in Tshwane that care be taken to select clinics where trained staff would be available to handle any further counselling required. The director’s responsibilities included the training of health workers in counselling and he was therefore qualified to select suitable clinics. He was asked to liaise with clinic managers to ensure that experienced nurses and counsellors would be involved in the referral process.

At the end of each interview I gave each participant R50 to contribute towards their travel expenses and in acknowledgement of their time used and their willingness to participate in the interview. Giving participants money when they participate in interviews is a controversial issue. The R50 was not mentioned during recruitment of the participants. Learning of the women’s financial difficulties in most of the interviews, I felt this gesture was appropriate.

4.9.2 Politics and ethics from a feminist perspective

This research aimed to advance the interests of women and is framed in a feminist paradigm. In this project I set out to give voice to the women who participated in my study, to contribute to the improvement of efforts which support women in exercising their right to health. In the context of third wave feminism reflection on the research process is required. Trying to speak on behalf of the subaltern is problematic. One needs to reflect on who may speak on behalf of the subaltern, 'the rules of engagement' and the politics of representation (Alcoff, 1991).

The speaker first of all needs to recognise her/his position with regard to the people she/he is trying to give voice to. Riessman (in Devault, 1996) argues that 'gender is not enough' to establish rapport between the researcher and participants. As a white, middle-class, childless woman, my experiences were far removed from the poor, black, mothers whom I interviewed. Not only were my experiences in many ways different to those of the women whom I am representing in this research, but I speak from a privileged position. Conducting the interviews in a consultation room in a clinic, immediately led many of the participants to assume that I was a doctor and I was so addressed by some of the participants. I did emphasise that I was not a doctor or nurse and that it was important to me that they felt comfortable to "speak freely". My research assistant helped to bridge the language gap, but as she was a retired nurse, there was also an age and class gap between her and most of the participants although, they could possibly have related to her as a 'grandmother'.

The ethics committee's concern about the availability of good counselling turned out to be valid and I am thankful that I was forced to think through possible consequences of the interviewing process. This was especially true for one of the interviews. The woman broke down in tears early in the interview when she started talking about her positive HIV-status. She was so upset that I decided to discontinue the interview. My assistant and I allowed her some time to cry. We took time to debrief during which the participant disclosed that was terrified that her cousin who is a nurse at the clinic would learn of her HIV status. This woman had not disclosed her status to anyone and was living alone with her infant. Following the debriefing session we called the clinic manager into the room and explained the situation to her. The clinic manager reassured the participant of confidentiality and that she will personally keep the participant's clinic file in her office so that the patient's cousin would not learn of her status. The manager also undertook to provide follow-up counselling to this woman.

Many of the women were upset during the interviews which were to be expected in the light of the issues we discussed. The participants were selective in disclosing their HIV-status to family members and the community and often did not have opportunity to discuss their feelings freely. The interviews were structured so that the women had the liberty to elaborate and talk about the issues which they preferred. Although the issues dealt with were upsetting to the women, having a no-rush environment to talk through some of their concerns, fears and to raise questions were therapeutic as well. Some participants, such as Elizabeth, expressed their appreciation by thanking us for listening. Even if women had encountered sympathetic health care workers during previous visits, there is seldom time during a consultation to debrief them (Oakley, 1981).

This research process irrevocably changed me as a researcher. As a white, middle-class woman I was confronted with my privilege. This was nowhere more stark than during an incident which happened at the time of the interviews. A friend was visiting Tshwane with her infant. One evening her baby became ill and was vomiting. She phoned me in a panic and asked me to take her to the hospital as she was without transport. I took her to a private hospital where a doctor (who was paid by her private medical insurance) immediately attended to the infant and reassured my friend. The stark contrast of how much easier it is to access health care when one has the resources to afford private medical care and have social networks with resources (such as cars), compared to being dependent on public transport and public healthcare (with little financial resources), upset and unsettled me.

4.10 Limitations

Every study has limitations. The qualitative research design places particular constraints on the study. During the course of interviews, language barriers proved to be a further constraint.

4.10.1 Language barriers

As English was not a first language of either the assistant or I, it influenced the way in which questions were phrased. Although many participants spoke English well, answering in a second or third language could have affected how they understood questions and potentially constrained the answers they provided. It influenced the way in which questions and answers given were understood by both participants and researcher. The following example illustrates some of these language difficulties. Because of my initial poor phrasing of a question, the participant interpreted the question as whether she had thought about the future of her children, whereas I had intended to ask whether she had thought about having more children in future. Realising this misunderstanding, I rephrased the question subsequently.

> Carolé: Have you thought about future children yet?
>
> Anna: Sometimes, I want, now they are getting money for grants and then I'm going to [get] them their [bank] cards for the school, I'm going to put money there for that, when they are growing up, to go to the school. To get a better life.
>
> Carolé: And do you think you will have more babies?
>
> Anna: No, I don't want any baby again.

4.10.2 Follow-up interviews

Listening to the audio-recordings and reflecting on the research process, follow-up interviews with the participants would have strengthened the study. It was difficult, if not impossible, to establish a close relationship during the course of one interview. If I had conducted follow-up interviews I would have been able to ask further questions after reflecting on the first interviews. Establishing a stronger relationship with the participants would have helped to break down the power relations between me as a white middle-class woman and the participants who were mostly poor, Black African women. However, follow-up interviews would have been difficult taking into account the scope and duration of my study. As my fieldwork was conducted at four different clinics, follow-up interviews would have considerably complicated the logistics of my study. Due to financial and other constraints women would not always have been able to travel to the clinic on certain days, even if I were able to make appointments for further interviews. The clinics were very helpful and patient with my visits there, but additional interviews might have inconvenienced the flow of work too much. Visiting women at their homes would be more intrusive than interviewing them in a private room at the clinic. It would also require more time and financial resources.

4.10.3 Sampling size and bias

Qualitative studies usually include fewer participants as methods such as in-depth interviews are time consuming. Qualitative research therefore tends to be small-scale studies. This is also a small-scale study and the findings cannot be generalised to a broader population.

My study focuses on the needs of vulnerable women and how it may be addressed. Vulnerable and marginalised women are not only found in rural areas, but also in urban and peri-urban areas. I selected clinics that are visited by the marginalised and vulnerable. I am, however, aware that in South Africa there are women who do not have easy access to healthcare or who cannot access the available care. These women are some of the most vulnerable in our society. Identifying the most vulnerable women is a difficult task as they are seldom organised. As I was conducting interviews at clinics, and vulnerable women often have little access to healthcare, I am aware that the experiences of these women are not represented in this study (UN Report, 2004).

4.11 Further dissemination of my knowledge production

This study formed part of a bigger PMTCT study conducted by the MRC unit. This connection to the MRC provided opportunities both for the dissemination of the findings of this study, as well as for learning to work as a social scientist within a broader team of scientists.

I presented some of the findings at a conference held by the Centre for the Study of AIDS at the University of Pretoria campus, as part of the agreement of funding which I received from them. I also presented the findings of the study at the Priorities in Perinatal Care Conference 2009 held in the Drakensberg as a poster presentation. It was encouraging that nurses and midwives in particular took interest in my study. The findings were also included in an article by the MRC on PMTCT (Pattinson et al., 2008).

A 'book of questions' was developed in conjunction with Anne-Marie Bergh. Bergh & Cilliers (2009) can be used by clinics and other health facilities as a tool to help clinicians and managers think through some of the service-delivery challenges women face who participates in the PMTCT programme. It also includes questions on the particulars of the protocol. It is designed to prompt health workers to think about the issues, without being prescriptive, and to help each facility come up with ways to improve their service to and assistance of women, which are appropriate to their specific context.

Working as a research assistant at the MRC Unit provided me the unique opportunity of witnessing how research in the broader public health context is used to inform practice and policy. It was edifying to see the practical outcome of research such as one instance where I attended a regional district health meeting (with representatives from provincial, district and other stakeholders) where, after some discussion, the protocol for the use of ART was amended for that district.

Working as a social scientist in the public health context nevertheless had its challenges. Having been trained in the area of gender studies rooted in a more critical tradition, I found it difficult to encourage such an orientation in a context where findings focus on practical solutions in public health in a task-orientated way.

4.12 Conclusion

The following chapter discusses the experiences of the women I interviewed at primary healthcare clinics in Tshwane Metro.

Chapter 5: At the clinic: women accessing PMTCT in Tshwane Metro

Making decisions about one's health and the health of others is influenced by a myriad of factors. The choices available are determined to a large extent by the political, economic and social context within which an individual finds herself. Within these contexts women maneuver and strategise to protect their health and the health of others.

5.1 Introduction

Since this study was conducted in primary healthcare clinics (PHC), all women interviewed had asserted their right to access reproductive and other healthcare services. They had attended antenatal care at a primary healthcare clinic and had participated in the PMTCT programme. These women continued to assert this right by accessing the primary healthcare clinic for postnatal and other health services.

The themes discussed in this chapter relate to the milestones of the programme and difficulties which affected women's ability to assert their rights. In sections 5.2 to 5.10 some of the difficulties women experienced with regard to the various milestones in their PMTCT journey are highlighted. These difficulties excluded women to a greater or lesser extent from critically needed support and information. Support and information are important because it empowers women to make informed decisions about their health and those they care for. At each step of the PMTCT programme (see figure 1 in Chapter 2) women had to make important decisions (e.g. whether to use prophylactic ART during pregnancy).

In addition, ways in which women contended with these difficulties are considered. They struggled in various ways to realise their right to health and healthcare. These women had to contend with socio-economic difficulties, language and literacy barriers and a whole range of health system factors in an attempt to exercise their right to health. Claiming and exercising rights do not take place in a vacuum but are mediated through different sets of social relationships. These relationships include those with health workers, with male partners, immediate and extended family and also their community. The relationships either serve to empower or detract from their ability to turn *de jure* rights into *de facto* rights.

Interviews were conducted between May and November 2008. The PMTCT protocol implemented in 2003 was adjusted in February 2008 just prior to the interviews being conducted. The most significant change in this protocol was the inclusion of provider-initiated counselling and testing and the inclusion of dual-therapy prophylaxis (AZT from 28 weeks of gestation and Nevirapine during labour). This revised protocol was implemented at the time that I conducted my interviews and findings of the study should be read against this background. Since then a revised PMTCT protocol was implemented in April of 2010. This protocol relaxed the inclusion criteria of HIV positive women qualifying for HAART. AZT is provided from 14 weeks of gestation. The first national PMTCT survey conducted after the implementation of the 2010 protocol demonstrates early indications of success as measured by the reduction in the number of infants being infected with HIV (MRC, 2011).

Although the protocol was adjusted in 2010 and there seems to be progress in reducing the number of infants infected, the findings of this study are still important for understanding healthcare provision for women in 2012. This is because the women I interviewed had all participated in a PMTCT programme and all of those whose infants had been tested for HIV, had tested negative. This group of women would therefore be considered ‘success stories’ within the public health paradigm. Does this then imply full citizenship for them?

Women participating in this study were aged between 18 and 40 years. The majority had an educational level of Grade 10 or higher. Most had more than one child. All had electricity in their houses and access to running water, either in the house, in the yard or close to the house. More than half were currently unemployed and most were the primary caregiver of the children. Some of their biographical information is recorded in Table 1 (see Appendix 5).

5.2 Deciding to test for HIV

All of the participants in the study were tested for HIV during their last pregnancy. Over half of the women (12/22) were tested for HIV for the first time during their most recent pregnancy even though for two-thirds (15/22) this was not a first pregnancy. HIV-testing remains a critical entry point for many women and children into the healthcare system. Without knowing her HIV-status a woman is unable to access healthcare services such as ART and the PMTCT programmes. It is emphasised in the HIV-literature that these services help a woman look after her own health. Being healthy is one of the most important factors for delivering an HIV negative infant (Chigwedere et al., 2008). Having access to appropriate healthcare and staying healthy also enables a woman to participate longer in the workforce. As women are still considered the main carers in South African society, being healthy enables a woman to take care of herself and her family. This includes accessing appropriate healthcare for her children (which might include ART). In principle, knowing her status also provides an HIV-positive woman the opportunity to plan future pregnancies safely with the help of health care professionals (Doherty et al., 2005).

When questioned on their reasons for deciding to test the majority of participants explicitly stated their desire to protect their children. Diane's response: "Because I wanted to protect my baby", was typical. Lesego said:

> I was thinking about it and I was, it was not easy to go for a testing, I was thinking about it. And then when I was pregnant [] I decided to go…so that I can keep my baby safe.

The message that steps can be taken to protect their unborn baby from HIV-transmission seems to be the one powerful message that motivated mothers to know their HIV-status. It was also one of the messages they remembered from counselling prior to or after testing, or in some cases from advertisements, as the quote by Anna illustrates:

> No, it is my decision because I see when they advertise...when you are pregnant you must test so that you can save the child. I just test.

The participants quoted above emphasised their agency in the decision to go for a test. They contend that they were aware of and were contemplating HIV-testing prior to going to the clinic. This agency could be a product of internalising public discourses on 'responsible' motherhood. With the exception of one woman, all the participants had received counselling prior to their HIV-test. Whether they had received counselling from a nurse or from a lay counsellor depended on which clinic they had visited. Participants framed the PMTCT intervention in a discourse of 'good' mothering, emphasising the responsibility of a mother to protect her children. In this discourse, women who do not test or, who did test but "failed" to keep their children uninfected, are branded as 'bad mothers'. Such a discourse places the responsibility of preventing vertical transmission solely on the woman while ignoring the responsibility of partners, communities and governments.

Three participants suspected that their partners were being unfaithful and this suspicion prompted them to test for HIV. Immaculate, relates her reason for deciding to go for a test:

> Immaculate: Cause I was not trusting my boyfriend, that's why I decided.
>
> Carolé: […] The sisters offered you the test?
>
> Immaculate: Ja, but it was my decision. Before they say, I wanted to do it.

One woman tested after being kidnapped and raped by a gang of unknown men. Four women tested as a result of other health concerns such as having flu, feeling sick or living with a TB sufferer. The majority's testing was linked to their pregnancy.

5.3 Dealing with a positive diagnosis

For the women in my study testing positive was often unexpected and a traumatic experience. Although it gave them access to biomedical treatment, it increased their anxiety as well. A key concern, on hearing the result, was potential rejection by partners and families.

Many participants struggled to come to terms with a positive diagnosis. Talking about testing and an HIV-positive diagnosis turned out to be one of the most sensitive questions asked during the interview as several participants cried when discussing this theme. Quite a few mentioned their initial shock and disbelief at a positive diagnosis. Cece said: “I feel sad” and started crying. Immaculate mentioned, “I was shocked, I did not know what to do. There was nothing I can do. I have to accept it”. Memory said that she initially felt “dizzy” after receiving the news, but that later she cried.

Participants were at different stages of the mourning process. Palesa related how she had planned to terminate the pregnancy right up until she gave birth, but never did. Although she attended antenatal care she told herself that she was going to abort the pregnancy – “I thought this was my secret abortion. I thought I’m going to do it, I’m not going to tell anyone”. She explained her behaviour as being in denial over her positive HIV status. Lerato was told that the positive diagnosis had to be confirmed and said that she would only accept the results if the second test confirmed this. At the time of the interview the second test still had to be done. She was still hopeful that the second result would be negative.

While discussing issues of testing one young woman, Keneilwe, was so upset that the interview had to be discontinued. She was living alone (with her baby) with little emotional support, and had not disclosed her status to anyone except the nurse at the clinic. She was still very upset as she did not have a history of many sexual partners and had not suspected that she could be infected. She was afraid that her cousin, who was a nurse at the clinic, would learn of her HIV status and this was a reason why she had not disclosed her status. She attended a clinic in a community where stigma was reportedly high.

After learning of their positive HIV-diagnosis, the women worried about transmitting the virus to their children. The research assistant translated the comments of Helen:

> Ja, when she tested when she was pregnant, she was anxious because this was an unexpected pregnancy. So she was worried about the baby, to see what was going to happen to the baby now.

Since the advent of ART, receiving a positive HIV-diagnosis on the same day that you confirm your pregnancy is not receiving ‘a life and a death sentence at the same time’ (Long, 2009). Whilst early public health campaigns focused on HIV/AIDS as a ‘killing virus’, more recent public health campaigns attempt to frame HIV/AIDS as a chronic condition. The participants in my study reported that health workers emphasised the message that if HIV was managed well they could expect to live a long life. The women were nevertheless worried about dying and how it would affect the future of their children:

> Ja, it was stressing, because you think about, what if like I die maybe before, after six months, or after my baby was born, after six months, after my baby is six months, then you ask yourself little questions like that. How is she going to grow up? How are they going to look after her? Are they going to give her the love the way I did? [Mpho]

They were confronted with a range of emotions and thoughts after learning that they were HIV-infected. A positive HIV-diagnosis often resulted in feelings of betrayal by partners, or if women disclosed, partners feeling betrayed. Sarah experienced tension in her relationship with her partner, according to the research assistant’s translation:

> She was not worried when she phoned him because she was surprised. She just took the phone and phoned him. But after delivery when they were talking about this issue the partner wanted to know how can he be negative and she's positive? How can it happen? And then she asked at the clinic and they told her a person can be positive for about seven years without any signs or symptoms and, maybe [she had become HIV positive] before she met this partner.

Trying to deal with all these emotions following a positive diagnosis made it very difficult for women to make important decisions. There were a whole range of complex decisions that women had to make ranging from disclosing their HIV status to accessing ART and feeding their infant.

Most of the participants had received post-test counselling from either a nurse or a lay counsellor. Their experiences of post-test counselling however varied. For some the counselling provided crucial emotional support in dealing with a positive diagnosis. For others, post-test counselling entailed only a brief session where they were given the results and some information.

Some of the participants were still coming to terms with a positive HIV-diagnosis. They made sense of and accepted the diagnosis in various ways. Patience explained the importance of acceptance: “you must welcome distance in your heart”. By expressing herself in this way, it became apparent that Patience meant that this ‘foreign’ threat had to be accepted and lived with. More than one participant mentioned adopting a “positive attitude”. Dee took solace in accepting HIV-infection as God’s will:

> I was shocked. I cried. But I didn't deny it, I just accepted it. Ja. Why me. Why me. But I think, the one thing is, God don't give you a way that He know you can't handle. [] God knows what is happening. He wrote the diary, it means I was the one He chose to have this disease. Why others, they get cancer.

Note, in equating HIV to cancer, a terminal disease with the possibility of managing the cancer, Dee confirms the notion of HIV as a manageable condition. Learning to live with HIV included having to learn about the disease and its management. Knowing about CD4 counts (when to have them done and what the count means), ART (when will one be eligible, when to take it during labour, possible side-effects, importance of adherence) and how to feed the infant was a way for participants to empower themselves. This was easier for participants who had a sense of their right to information and were not afraid to ask questions and confront rude health workers. It also helped if participants’ had a good relationship with a health worker (and in some cases the same class position) and if they were literate and articulate.

When it came to gender relations, women struggled to empower themselves. Very few women said that they could insist on consistent condom use by their partners. They adopted strategies such as avoiding sex and in some cases using the female condom. The main strategy for dealing with stigma was careful consideration of whom to disclose to. Disclosure is an important milestone following an HIV-test.

5.4 CD4 count and taking ART

Following an HIV test, a CD4 cell count and clinical staging should immediately be done so that an appropriate course of treatment can be decided on. At the time of interviewing the PMTCT protocol made provision for either dual-therapy ART prophylaxis during pregnancy or HAART therapy when a woman's CD4 count is below 250 cells/mm³ (Tshwane Department of Health took an early decision to provide HAART to women with a CD4 of below 350 cells/mm³). Dual-therapy included taking AZT from 28 weeks of gestation and Nevirapine during labour. If a woman qualified for HAART she would immediately be referred to a higher level hospital for treatment. Pregnant women were fast-tracked in the ART-programmes so that they could receive treatment as soon as possible.

Most women in the study had a CD4 count done. Generally they knew the exact number of both their first and their most recent CD4 count. Eight participants were not aware that a CD4 count should be repeated regularly every six months. They primarily attended two of the clinics. This may be an indication of the different types of information available at different clinics. Four had not had a CD4 count done at all or were not aware of it being done. This may also indicate differences in agency – some women take more initiative to know the details of tests and treatment than other women who depend on healthworkers to lead and remind them of necessary tests.

The inclusion of dual-therapy, which includes not only Nevirapine during labour, but also AZT from 28 weeks, was implemented in February 2008, just prior to the start of my study. As this new regime was in the early stages of being rolled out I expected to see varied experiences amongst participants. Eighteen had received Nevirapine during labour and six had additionally received AZT treatment. The AZT regime was varied, as some of the participants had taken it from 28 weeks, while others had taken it later in pregnancy. One participant took AZT only during the last week. Two of the women had heard about it from sources outside of the clinic and took the initiative to enquire about AZT from the sisters. This is how Mpho explained her experience four months after the revised protocol had been implemented:

> The one thing that I didn't understand is this, they told me a lot about Nevirapine when I'm in labour pains, I should take that Nevirapine. They didn't tell me about this four months, and this last four weeks, pills that I should take, that's why I didn't know about it, I heard from the [private] doctor and by then it was also, I was supposed to buy it cash by then and I didn't have that money, that kind of money. And even my auntie [who is a nurse] told me about it. Then I came to the clinic, then that's when they told me that 'we are very sorry', because I couldn't start the programme on time. We received the pills, I don't know, somewhere around June.

Mpho's experience illustrates how an approved policy can take considerable time to be implemented. In this case this includes training of healthcare workers and clinics procuring ART. Even if women have a right formally guaranteed, practical implementation can delay and limit possibilities available to them – and thus their ability to assert rights. Four participants were receiving HAART. The others felt that "the time will come" [Palesa] when they would be referred for ART and that this was related to their CD4 count. Most of these women relied on healthcare workers to refer them for ART when necessary. Some took more initiative in enquiring about treatment such as Mpho and Judith.

What complicated matters for women who were receiving HAART were that they could not access this at the clinic, but had to go to an ART-clinic at a higher level hospital. This fragmented their healthcare experience as they had to attend the clinic for antenatal and postnatal care, but also attend the ART clinic at the hospital for regular check-ups. It was costly in terms of time and money.

5.5 Dealing with birth and motherhood

The ages of the infants of the women in my study ranged between two weeks and two years. Most of the infants were under the age of three months. Adding to the pressures that women faced was the care that a small infant demanded. When questioned on the difficulties that HIV-infected mothers experience Prim answered, "No, because sometimes when I'm still busy with the baby, the other baby, he wants to play. So ja, it is a little bit difficult, I'll get used to it". Mandisa, emphasising the sacrifices that are made with motherhood, said: "Sjoe, for me as a mother. Waking up during the night, taking the baby, crying a lot sometimes…I don't have time for me…I'm having time for the baby now".

Participants drew on support from family members, especially female members such as aunts, mother and grandmothers to help with care of the infant. Such domestic arrangements and family support is considered in section 5.11.2. Being responsible for the care of the infant made it difficult for women to seek and find employment. This exacerbated their dependency on male partners. See section 5.11.1.2.

In addition to dealing with the care of a newborn many of the women were required to visit the clinic regularly for follow-ups, immunisations, tests and to collect formula milk. This became more demanding when women had to travel to different facilities for different services such as having an appointment for a PCR test (the HIV test for the baby at six weeks) at one facility and collecting the formula at another facility.

5.6 Feeding the infant

Infant feeding has had a contentious history within the context of HIV and PMTCT. The World Health Organisation (WHO) initially recommended the avoidance of all breastfeeding where it was possible to give the infant safe replacement feeding[3] (WHO, 2003). This emphasis on avoiding breastfeeding resulted in the recommendation of replacement feeding for HIV-exposed infants. For a long time, also during the study, the default discourse in the context of HIV was replacement feeding. It was therefore no surprise that 20 of the 22 women in the study were giving replacement feeding to their infants.

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[3] Replacement feeding: feeding infants who are receiving no breast milk with a diet that provides the nutrients infants need until the age at which they can be fully fed on family foods. During the first six months of life, replacement feeding should be with a suitable breast-milk substitute. After six months the suitable breast-milk substitute should be complemented with other foods (WHO, 2003:vi)

The reason why most of the women chose replacement feeding was because they wanted to avoid any chance of transmitting the virus to their children. This was a powerful message. When the emphasis on replacement feeding is not balanced with its risks it can have negative consequences. The so-called AFASS (affordable, feasible, available, sustainable, safe) criteria should apply in decisions on infant feeding.

Making an infant feeding choice is a complex process. A woman is supposed to receive counselling on the different advantages and risks of both exclusive breastfeeding and exclusive formula feeding and the dangers of mixed feeding. Avoiding breastfeeding will ensure that the infant will not be exposed to infected breast milk. Formula feeding, however, poses other dangers such as a significantly higher chance of suffering from diarrhoea and respiratory infections, which could be fatal. A mother needs to take into consideration her socio-economic circumstances, family and community stigma and practicalities of each method when making her decision. Women are often expected to make these complex decisions immediately after learning their positive HIV-status (Coovadia et al., 2007; Doherty et al., 2006).

As part of the PMTCT protocol women received six months free formula milk at clinics, after which they were required to buy their own supply. In 2008, when the field research was conducted, the price of a 400g tin of Nestlé Nan Pelargon was around R35.99. For a baby younger than six months, a 400g tin only lasts two or three days. This amounts to approximately R400 per month for the formula only. An infant aged between six and twelve months requires about two 400g tins of formula per week, which amounts to R300 a month. Buying bottles and sterilizing products are additional expenses. Depending on the clinic, women were required to travel at least once a month, often bi-monthly to fetch formula at the clinic. This often required using public transport, which was another cost. Women who accessed the child support in 2008 received R210 per month per child (under the age of 14) (Delany et al., 2008). This grant was not enough to cover the cost of feeding the child if the clinic could not provide the formula milk.

Clinics did run out of supply. At one of the clinics we attended, a notice was put up that stated that HIV-positive women should be aware that they are responsible to buy their own formula when the clinic runs out of supply.

All the participants, with the exception of three, were aware that they had to buy the formula after six months. When asked how they would pay for the formula participants were planning to use the child support grant (CSG), get financial support from the child's father or from family members such as mothers, aunties, brothers. Some were worried. Anna commented: "Yes, they explained to me [that I had to buy it after six months]. Sometimes I worry but sometimes I say I will buy it".

Dineo was not aware that she could get the formula for free from the clinic for the first six months. She was buying the formula. The day of the interview was her first postnatal visit to the clinic, but she had attended two postnatal check-ups at the hospital where she had delivered. This hospital strongly supported breastfeeding by HIV-infected mothers. The message that free formula milk is available was probably not emphasised.

Whether the family was questioning why the child was given replacement feeding depended on whether the participants had disclosed their status. Most of the participants had disclosed to some family members and said that the family did not have a problem with replacement feeding. Mandisa felt that her family was supportive but that the community continually asked questions about the bottle feeding:

> Now I've got this problem, each and every one ask me why are you bottle feeding the baby? Why can't you breastfeed the baby, you know such persons. You don't know how to answer them. And then you feel bad if someone ask you about that.

Only Patience mentioned how she had to handle questions from family who did not know about her and her husband's HIV-status:

> Ja, they asked, 'Why do you only give the baby the bottle? I say, I'm scared…, because of the first baby was breastfeeding [and he died]. So I don't know, maybe I'm sick. So, I

> don't want again. They say 'Okay, it's fine, it's all right'. Because, [in] 2005, 2006 … I was sick too much.

Two of the participants were breastfeeding. Both women attended the same clinic and both had delivered their infants at a hospital known to promote breastfeeding amongst HIV-positive mothers. Other participants who were attending this clinic and had delivered at the same hospital had also been advised that they could safely breastfeed their infants. This was the same hospital attended by Dineo, who wasn't aware that she qualified for free formula milk. Helen, who was formula feeding, also attended the same clinic and hospital and said that she had received "different messages" [translated] at the different facilities about breastfeeding and replacement feeding.

One participant, Diane, had not received any counselling on infant feeding. She said that she had made her decision to formula feed without receiving any counselling.

Infants should be exclusively breastfed or exclusively receive replacement feeding until six months of age. This means that they should not receive anything (including water, medicinal drops, porridge) in addition to milk. I did not question all the participants on whether they were giving anything additional to the replacement feeding or breastmilk. Those whom I did question mostly said that they are aware that the child should not be fed anything in addition to the milk. Some mothers reported that they occasionally give the child water, gripe water or medicinal drops. Exclusive feeding is not the norm in South Africa and whether the women practiced exclusive feeding was not explored.

5.7 The PCR test

There were no known HIV-positive infants amongst children of participants of this study. Since the implementation of the PCR test infants can be tested for HIV-infection as early as six weeks old. A follow-up test is done at 18 months. Testing the child for HIV-infection was anxiety-provoking for women who interpreted the outcome as a reflection on their mothering. The research assistant reported Helen felt anxious as her child was going to be tested on the day of the interview. A negative HIV-test implied that a woman had succeeded in protecting her child from HIV and was a ‘good’ and ‘responsible’ mother.

Ten of the infants had had a PCR test done, of whom seven were negative. The other three were awaiting their results. Five of the children were still under six weeks old and too young to be tested. Of the mothers of these five infants who were too young to be tested, three were unaware that the children should be tested at six weeks.

Four of the infants were due to be tested on the day of the interview. The remaining three infants should have had a test done, but had not according to their mothers: one infant was six weeks old, another two months old and the third one already 18 months. These women reported that they were not aware that a test should have been done at six weeks. Confusion about when the infant should be tested was not specific to any one clinic, but found across clinics.

5.8 Reproductive issues

Making decisions around reproductive health is an important milestone in the PMTCT programme. For HIV-infected women access to reproductive technologies offer protection against STI’s and re-infection with HIV. It also helps to women prevent unwanted pregnancies and if they plan to fall pregnant in the future, reproductive counselling should offer advice on the safest way to do this. A woman’s relationship with her male partner is an important determinant to whether contraceptive and safe sex methods are accepted. This relationship is affected by the discovery of HIV-infection.

5.8.1 Women’s subjectivities

An HIV-positive diagnosis changes a woman’s sense of herself as a family member, mother and partner. Some of the women said that they avoided all romantic relationships. The following in-depth description illustrates how Memory battled with her identity as mother and the reaction of her partner following a positive diagnosis. She adds that others had similar experiences:

> Yes, there are serious problems. First thing, the father of your baby is going to run away, it's a serious one that hits you every day. But I am lucky, now he is back, supporting the baby, because he just goes straight to the court…Yes. He is paying maintenance and he is apologising everyday now. And even him now is saying that ‘Now I want to see the baby’. It's like that now, now [he] knows the responsibility now, really. And there are others [other HIV-infected women], because the days at [the clinic in] the queues that we talk, the other one just told me straight, ‘By the time I was pregnant then I told him I was HIV positive, that guy just vanished like that, I never saw him’. Yes. And she never saw him, the baby it is almost one year, never saw the father, it's another thing, it's another thing. Because we don't know maybe this person [is the one] who infected you, maybe it's you who infected him, but now he is already gone. And the other thing, not to have a stable family, a family that can understand your situation is another thing that really hurts. And you are dealing with this thing alone, every day. It's not nice. It's really another story, and even if there is another guy, maybe he can come to you saying, 'I want to marry you'. You can't say, ‘Okay fine’. Even if you can see that 'Ja, I do have the feelings to go there', but you know that there is a thing that blocks you...And you can't tell everybody that you are HIV positive every time – [when] somebody is coming to you and saying something [romantic]. And you do feel that thing, you do. Even you, you want to be married, you're a woman. And you're having a child, that child, can [he] get the warm family and those [are the] things that [we] are thinking: ‘What if I can die, what is going to happen to my child?’ It's very difficult [Memory].

Memory talks about battling feelings of fear and guilt. There is fear of a partner leaving one when he finds out about a positive HIV-diagnosis and guilt of who infected whom. There is also fear of rejection by one’s family and having to deal “with this thing alone”. As an HIV-infected mother one feels guilty about the child and worries whether she/he will be taken care of in future. It is also clear how a positive HIV-diagnosis complicates romantic relationships. Women are reluctant to disclose their status to “everybody” and fear rejection by potential partners.

5.8.2 Contraception

Eight women were using an injectable contraception (either Nur-Isterate or Depo-Provera) or used it prior to the pregnancy. Alice said that she had used an injectable contraception, but because she had gained a lot of weight when using this method, she had stopped using it three months prior to the interview. She and her partner were now just using condoms. Only Cece had used oral contraceptives prior to her pregnancy. Nurses were encouraging the use of injectable contraception even if women experienced side effects with the use of a specific contraceptive.

Lerato, 39 years old with four children, and Judith, 40 years old and two children, were sterilised following their pregnancy. Both women said that this was their choice. Lerato felt that "four was fine" and Judith said that she requested the sterilisation. Ayanda, 23-years old with three children, was advised by a nurse to go for sterilisation, who offered to "book her for January". She said that she was "still thinking about it" and was going to discuss the option with her partner. In Ayanda's case she did not request the sterilisation, but was advised to do it by the nurse.

Anna, a 28-year old with two children had asked for a sterilisation because she did not want any more children, but the doctor refused, answering that a sterilisation was not permitted when a woman was younger than 35. She was struggling to deal with the unfaithfulness of her partner and the stress of not being able to break off the relationship. As a foreigner she was not able to access a child support grant (CSG) and was dependent on her partner for financial support. She was also avoiding sex with her partner at the time of the interview. Since many of the women had recently given birth they were in the customary period of abstinence and had not yet made a decision about contraception and safe sex practices.

5.8.3 Condom use

A majority of the women, fifteen in total, were keen on the use of condoms during sexual intercourse. Some raised difficulties in this regard. According to Mandisa her boyfriend "is complaining" about having to use condoms. Elizabeth and her husband only use condoms occasionally as her husband "is not comfortable with condoms". Dineo was not sure whether her boyfriend would agree to condom use. As many of the women were at the time of the interview abstaining from sex, as per custom following a pregnancy, many said that they were planning to use condoms in future, but whether their intention eventually would translate into practice is uncertain. Only six women reported that they and their partner had used condoms during sexual intercourse. Three of them used condoms occasionally. Helen said that she “never misses”. She had not disclosed her HIV-status to her partner and was careful to practice safe sex.

Anna and Prim – both attending the same clinic, were aware of the female condom as an alternative and preferred its usage, regarding it as safer, and enabling women to take control over this delicate matter. Anna justified her use of the female condom in the following way:

> Carolé: Okay, and male condom or female condom?
>
> Anna: Female condom.
>
> Carolé: Do you [prefer] that one?
>
> Anna: Yes.
>
> Carolé: Is there a reason for it?
>
> Anna: You see, that man that male condom, sometimes it is not safe.
>
> Carolé: Ja, why is it not safe? Just?
>
> Anna: Because [only] sometimes…[the men] come with it… I want to use that one, I have it on myself. I am deciding to use that.

The use of a female condom remains something that has to be negotiated with a male partner, which can be especially difficult in the context of an abusive relationship. However, the female condom potentially does give women greater control over this matter and can be a strategy that receives greater attention.

Prim’s reason for trusting the female condom had to do with the durability of the female condom. She described the female condom as “better” than the male condom as the male condoms fail: “sometimes they just blast [burst]”.

Both women who preferred using the female condom attended the same clinic. This could also indicate the importance of educating health workers about female condoms and promoting it as a strategy to reduce infection amongst them.

5.8.4 Reproductive intentions

Although almost all participants had knowledge of and had received at least some counselling on contraception and safe sex, the one theme that was glaringly neglected was their reproductive intentions. When probed about the family planning counselling that they had received, the interviewees mostly mentioned having been advised to use “the injection” as birth control method, offered sterilisation, and being counselled on the importance of double protection (condoms and another form of contraception). When asked whether the nurses had talked about the planning of future pregnancies, participants agreed that this was not the case: "No, they don't talk about it" [Patience] and "She didn't tell me anything" [Cece].

Participants had various responses to the question of whether they would like to have more children. Some women were firm in their answer that they did not want more children – like Ayanda, who was 23 and wanted to have a sterilisation. Others, such as Mpho, said that their male partner had other children so “I don’t think he’ll need another one”. She also mentioned that the cost of living is too high to have more children.

Some, like Memory, articulated their desire to have more children, but this was often accompanied by ambivalent feelings such as: “I do like to have more children, but if I'm still HIV positive there is no way”. She articulated her reason for this as being concerned about transmitting the virus to her child and she/he being stigmatised by the community:

> Ja, it is serious decision, because your are not going to think for yourself only now, there is another person that you have to think of. And you have to make actually every sacrifice to make sure that person is negative. Because if you leave her like that, you don't do the test, then you find out later that you've already delivered the baby that you are HIV-positive, you didn't do the test, that child even if he is coughing like that, the kids are going to say, 'Oh it is started', AIDS have been started. And you are going to have that worry every day and you can be sick early, stress. I can't advise somebody to have a child while they know they are HIV positive, not wise at all.

The possibility of transmitting the virus was again linked to a discourse of ‘good and responsible’ motherhood. Such a discourse pressured HIV-infected women not to have children.

Women felt embarrassed and guilty for wanting more children and also anxious about these children's future. These ambivalent feelings also had to do with the negative responses of health workers towards HIV-positive mothers as the case of the following participant illustrates:

> Carolé: Would you like to have more babies?
>
> Mandisa: [sighs]
>
> Carolé: Would you like to have more babies?
>
> Mandisa: I would love to have another baby.
>
> Carolé: You have a beautiful son.
>
> Mandisa: Another one - so I don't think I will do that because at the hospital they told us you must not come back here being pregnant again when you know that you are HIV positive. They are sick and tired of treating HIV people, their babies also.

Immaculate had decided not to have any more children after testing positive and that she "wants to close permanently" [translated by research assistant]. She then started to cry. Three participants had considered terminating the pregnancy after testing positive (see 5.3).

Instructions like the one above received by Mandisa, has been substantiated by others. Alice also indicated that she was told that "it's risky to fall pregnant when you are HIV-positive - maybe your baby can [be] disabled." Such instructions are intrusive and the response to Mandisa, that healthcare workers are "sick and tired of treating HIV people" attacks their right to dignity and care.

When it came to having more children, the reproductive needs of the HIV-positive women in this study was often violated, but more commonly, just ignored. Only a few participants had encountered sympathetic health professionals who had counselled them on safe practices on falling pregnant as an HIV-positive individual. Elizabeth, who had been raped, "was scared that maybe I will never have children". She was referred for counselling at a private therapist by her employer and subsequently received good information on planning pregnancies. Mandisa also later encountered an empathic doctor who “was so kind and explained everything to me if I want to have another baby.”

5.9 The healthcare setting

The healthcare setting, usually a clinic or hospital, is a public space where women access healthcare. In public healthcare this is one of the ‘actual spaces’ where citizens and the state meet. The way in which it is organised has a profound influence on women’s ability to exercise their rights – either promoting a supportive and informative environment or perpetuating discrimination and reproducing inequalities (Gillespie, 2002; McEwan, 2005a & b).

5.9.1 Lay-out of the clinic and practices

A healthcare setting often perpetuates stigma. At least one clinic in this study had a separate section for PMTCT. The community was very aware that going to that section meant that the woman was HIV-positive. Participants generally avoided clinics where they felt that the confidentiality of their status was not protected.

Mandisa:	I think here why they don't, because the treatment, maybe for HIV, they can give us treatment here, because at the nearest clinic that you are going, each and every one is talking about you. If they see you go there, meet someone said I saw ## at the clinic and then at that clinic, I don't know how to explain it, they write something like CV[4] or what, you know that if, CV falling under TB, HIV. Something like that. If you get there at the clinic you want to get the help, you go to CV, each and every one is looking at you said 'Oh, that one, she is HIV positive'.
Carolé:	So they must help the people [] to protect the confidentiality of their status.
Mandisa:	Yes. That's why I didn't want to go to that clinic. I came here.

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[4] Mandisa was referring to a CD4 count. A CD4 count will be taken after a person has tested HIV-positive (and then every six months). A CD4 count test or result is an indication to others that the person is HIV-infected.

Mandisa does not go to the clinic closest to her house anymore, but attends a clinic in a neighboring area. This clinic is reachable only by taxi or other means of transport.

Other clinic practices compromised women's right to privacy and confidentiality of an HIV-status as well. These include designated clinic days for services (e.g. PMTCT). Posters on walls in front of 'certain' consultation rooms containing information about formula or other HIV-services also compromised confidentiality.

5.9.2 Complexities of a tiered system

At the end of each interview, I, together with the participant, drew her 'health journey' to determine which and how many health facilities she had visited. The participants were referred to higher level health facilities when they were considered to have a high risk pregnancy (e.g. had a history of miscarriage, were over 35, or had high blood pressure), when they had a CD4 count under a certain threshold (and were referred for ART) or if they went into labour prematurely. In these cases women were often sent to different health institutions for follow-up examinations and tests. In many cases the tests could have been done at the clinic. During the week of the interview Judith had three different health appointments. One was for immunization of the infant at the clinic, another for the PCR testing of the infant at the hospital and a third appointment to have her CD4 count taken at the clinic, on a different day. All three appointments could have been made on one day at the clinic. The PCR appointment might have to do with health professionals at the higher level facility being careful that referrals back to the clinic do not fall through the cracks and that they preferred women to travel back to the hospital for follow-up. Although the hospitals were diligent in ensuring that tests were done, the additional health visits required time and added financial strain on participants since they were usually further from the participants' homes than to the local clinic.

5.9.3 Staff capacity

When asked what they would change at the clinic, six participants mentioned that the capacity of the clinic was too small. This resulted in nurses being "always rushed" [Immaculate] and in queues being “too long” [Sarah]. A rushed consultation has negative consequences in terms of the time that women have and the liberty they feel to ask questions.

5.10 Other barriers

5.10.1 Literacy of healthcare users

Participants were keen to access information. Many mentioned listening to programmes on HIV over the radio or on television. The one participant with a tertiary qualification, who was computer literate, accessed information through magazines, HIV courses and the internet.

Poor literacy resulted in an inability to read appointments on antenatal and other cards. Lerato wrote her name slowly and with difficulty on the consent form. She checked and re-checked whether she had written her name correctly. She said that she had not had her infant tested for HIV at six weeks. She however produced an appointment card on which a date was scheduled for this testing. She had not attended the appointment as nobody had explained the written information on the card to her. Poor literacy also excluded women from any written information, including posters in the clinic, leaflets or other sources such as the internet and books.

5.10.2 Language barriers

Women, who were not fluent in English or the local languages spoken at the clinic, struggled to formulate questions and understand answers. Immigrant women in particular were at a disadvantage struggling as they could not communicate with black nurses in a local language. Ayanda who could not read the date on her appointment card was advised to ask the nurse regarding her AZT treatment, which she reported to have discontinued following the birth. She responded that she has previously consulted a white nurse at the clinic and she was reluctant to ask the nurse questions, as she sometimes has difficulty to translate her questions into English or understand the answer given.

The research assistant facilitated the interview with Ayanda by carefully and patiently explaining questions asked.

5.11 Social relationships

Understanding the nature of the different sets of relationships within which women assert their rights are important. Relationships can serve to empower or disempower, support or discriminate as women make decisions or take action.

5.11.1 Male partners

One of the most important findings of HIV/AIDS studies in the 1990s was the realisation of the profound influence that gender relations have on the epidemic (UNAIDS, 2012). The nature of gender relations directly influences a woman's ability to negotiate safe sex, even if she does have the knowledge to protect herself. Understanding femininities, masculinities and the dynamics between these remain important to address HIV/AIDS more effectively.

5.11.1.1 Disclosure to male partners

As has been discussed, the women battled to deal with their positive HIV-diagnosis. For the majority of participants their first HIV-test was part of routine investigations during an antenatal visit. This partly explains the initial shock and disbelief as many of the woman had very little time to prepare themselves for the result and did not expect a positive diagnosis. Of the 22 women that I interviewed 13 said that they had disclosed their HIV-status to their partners. Of the 13 who had disclosed to their partners, eight women said that their partners accepted their diagnosis and a few mentioned that their partners were supportive. Five of the 13 participants who had disclosed recalled that their partner either reacted negatively or that after initial arguments over who infected whom the issue was ignored. Memory related how her partner "reacted very very badly" and accused her of "coming with that thing". Mpho argued that it was more difficult for men to accept a positive diagnosis and that women were more resilient. Whilst she was still alive her mother's cousin, who was HIV-infected, had already passed away:

> He didn't take it very well; he died, because he is a man. I don't think he take it like us. We women like [when] we get stressed, you end up like accepting everything, and men is

> not, even like, from my point of view, it’s not easy for them to accept.

Male partners did not feature in some women’s narratives. In one of the interviews, whether the woman had disclosed to her partner was unclear. When asked whom she had disclosed to, her partner was not mentioned. Her narrative centred on her family and the community. This may indicate that men played a lesser role in some women’s lives.

Of the 15 women who disclosed to their partners, less than half of their partners had tested for HIV. Since 2004 ART has been available to all men and women attending public healthcare with a CD4 count below a set threshold of cells/mm³ (Johnson, 2009). According to the knowledge of participants in this study, men did not make use of the available care.

One of the two male partners interviewed had not been tested for HIV. This was in spite of his supportive role and involvement in his partner’s pregnancy and subsequently with child care. He explained:

> Kathlego: Uh, I know that like as long as I live, as long as I didn't get tested, it means I am HIV. So I didn't get tested. Even now I didn't get tested. But we did arrange, we have come together [to the clinic] and so on. To check again. But since [the nurses] told me HIV doesn't mean I'm going to die, it's like I must just take it as a new life for me.
>
> Carolé: Okay, so you haven't been tested?
>
> Kathlego: …[Yes].
>
> Carolé: Okay, and how do you feel about it now, do you think you will be tested or?
> Kathlego: Ja.
>
> Carolé: You think you will be tested.
>
> Kathlego: Because at the time we said that we will come together. That's when she came, and we said no let's wait …[till the baby is born] and then we will come.
>
> Carolé: Then you'll come together and you'll be tested?
>
> Kathlego: I'll come end of this week or next week.

All the women in the study had a HIV-test included as part of routine antenatal care. They were encouraged to test so that their children could be protected and did not have the choice of waiting to do the test till they felt ready. In contrast the male interviewed, who had attended the clinic several times with his partner, had greater leeway in choice when to go for a test. He could deal with her positive diagnosis, talk to healthcare providers, and decide when he was ready to go. He could postpone the test for as long as he wanted without potentially putting his child at harm.

Other participants mentioned that their male partners said that it was not necessary to test as a positive diagnosis of the female partner meant a positive diagnosis for the male:

> Like me I think he didn't want to believe it because [he] just said 'How?', then ignored me. Then I told him, said, ‘You have to come as well’. [He] said, 'No, if you are, that means I am as well, there is no way that can change’. Then they gave me something to give to him [a note to come to the clinic]. And [he] told me, 'No, I would not go in there, ‘cause if you are, it means we are' [Palesa].

> Then he told me if you are positive it means we are positive. There is no need for him to go check. Then I was like, left it. To me he was changed, you know, not the way I used to know him. Then I thought, you know what, I see that now like I’m a burden to you, like, you didn’t do the things he was used to do with me, seeing me, all those things. He was changed. The distance. I told him, ‘you know what, I can notice the difference and the change so please just, if you want to go, go (inaudible) it’s not like now I’m positive now you have to feel like ‘ooh, here she comes’ <tone of disgust>, cause I could feel it and see it…I told him, you know what, if you are to go, just release yourself…[Palesa]

Five women explicitly stated that they had not disclosed to their partners. Fear was a main reason for not disclosing – “I am afraid” [Helen, translated by research assistant]. Two of the participants explicitly stated that they were afraid that their partners would leave them if they found out that they were HIV-positive. Immaculate, 21 years old, was an immigrant from Lesotho. She lived with her family, but no one in the household worked. As she was not a South African citizen she was unable to access a child support grant. She was therefore dependent on her boyfriend for financial support. She started crying as she explained that: “Ja, I think he will left (sic) me with the baby and then I don't know what can I do with the baby".

Ayanda "refused" to give the results to her partner after he had asked for it [translated by research assistant]. She wanted both of them to go to the clinic and be tested together. For this woman it was an issue that the partner had not married her and she mentioned this fact more than once in the interview: "It's a boyfriend, because he doesn't marry me". She explained that she had not disclosed to her partner because "if she shows [him] the result and this man has not married her, it is going to be problematic". Even though it is unconstitutional to not disclose a positive HIV-status to a partner, this woman protected herself and her children from rejection and loss of financial support by not disclosing. She was unemployed and although she received child support grants and occasional support from her sisters in Johannesburg, she was also financially dependent on her partner.

Many of the women participated in the custom of avoiding sexual relations for a period of time from pregnancy until the child was a certain age:

> Carolé: Okay. And have you thought about condoms at all or?
>
> Immaculate: What about condoms?
>
> Carolé: Using condoms maybe with your boyfriend.
>
> Immaculate: [sighs] From now...I will be alone [abstain, will not have sex]. Yes.
>
> Carolé: Have you been together with your boyfriend after you tested positive?
>
> Immaculate: No.

Although this is a well-known custom in South Africa, I got the sense that some of the women used this as a way of dealing with the diagnosis and buying some time before making a decision about the relationship, disclosure and sexual practices. It could be a way of not breaking off the relationship, but still receiving financial support without having to put themselves at risk of re-infection. Immaculate, from Lesotho, who did not disclose to her partner in fear of losing financial support and whose baby was already four months said that she will be "alone", meaning that she will not have sex again.

5.11.1.2 Cohabitation and financial support

Less than half the women (8) lived with their partners. One left her partner when the relationship became abusive. Another had moved to her parents but planned to move back to her partner when the infant was a few months old.

The partners of six women did not live in the same area as them. Most were working migrants. The contribution of migration to weakening of marital relationships and encouraging multiple sexual partners amongst men and women, and so fuelling the HIV-pandemic has been well documented (Brummer, 2002; Walker et al., 2004).

Eight women had some sort of employment to which they had returned or would return after maternity leave. Many of the women who were unemployed had some temporary work prior to this or a previous pregnancy. Most of the unemployed women were in a relationship with an employed male. Only Alice mentioned that her partner had not worked since 2005, but "was looking for work".

After women fell pregnant and were responsible for the care of young children, it was difficult for them to return to employment. Five also had children of their siblings in the household. Sometimes the siblings also lived in the household, but in some cases the siblings had passed away or were in the participants care for other reasons. Their caring responsibilities made it difficult for some of the women to look for work. This was particularly a concern for single women. Judith who had left an abusive relationship and was living in a shelter explained her situation:

> Judith: When I moved into the shelter I started teaching again, although I hadn't taught for quite some months. The principal called me and said, 'Are you ready to teach?' I said, 'Yes', so I taught for one month. Unfortunately by the following month, the baby was born, so I had to stop.
>
> Carolé: Are you still teaching now?
>
> Judith: No, I am not, because the baby is too small. And...I thought, I weighed my options and I couldn't go, because for one, I'm not financially stable to put the

> baby maybe in a crèche. At the same time I thought she's rather too small. I want to take care of her maybe for four months and start looking around.

As Judith was an immigrant from Kenya, she did not have the support of a partner or an extended kinship network to rely on. Although she did mention the support of friends and still being in contact with an ex- sister-in-law, her caring responsibilities made it difficult for her to go out and work. She was worried about her financial situation, but could not afford to pay for childcare so that she could find work. Judith was well qualified and had work opportunities, but could not pursue these. As an immigrant woman she could not access the child support grant to help support her and her two daughters. Judith survived on the little savings that she had and assistance from the shelter. Because of her care responsibilities (in the private realm), she was unable to work (in the public realm).

5.11.1.3 Gender violence

The women were not specifically asked about abuse from their male partners, but general questions about their partners as well as their partner's reaction to disclosure. Violence was mentioned in only two interviews, in the context of their HIV status and relationships. Judith's partner became abusive when she was pregnant and with the help of friends she left the abusive relationship. She was staying in a shelter until her infant was old enough to allow her to return to work and support them.

Elizabeth, in contrast, had not experienced intimate partner violence, but was kidnapped whilst travelling home from work and was raped by a gang of men:

> Yes, I was raped...I was in a taxi, I was working [for a major clothing chain], so I was in a taxi, there is this 7 o' clock shift, so I had to take a taxi home. So we were kidnapped in the taxi. We were four ladies and two guys. We were kidnapped on gunpoint and all that. So this guy was like they were going to sell us or something, because they were selling people or something. Then we were raped and with God's mercy they let us go.

After their ordeal at an unknown location they were released. She suspected the kidnapping might have been related to sex trafficking.

Physical violence by men is still a reality in the lives of many South African women and puts women at direct risk of HIV-infection and re-infection. Apart from the risk of HIV-infection, women are also damaged psychologically and often socially (WHO, 2004). Sexual violence is often underreported as women feel ashamed and unwilling to talk about it (WHO, 2002). The Medical Research Council (MRC) has estimated that one in four South African women experience physical violence at some point in their lives (MRC, 2009). In this study only two women had mentioned experiences of gender violence, but there might have been more women who had such experiences but were reluctant to talk about it.

5.11.1.4 Male partners' involvement

Two women attending the clinic were accompanied by their male partners. This provided an opportunity for interviewing them. These male partners were supportive and involved in the care of their female partner and infant.

Thabo was very eager to learn anything he might from us. He asked questions on sterilisation of bottles, inquired about support groups and held the baby for most of the interview on his lap. Kathlego had taken paternity leave at work to attend the clinic appointment with his wife. His wife lightheartedly told us that if she had allowed him, he would have attended all the clinic visits with her. He took a keen interest in the well-being of his wife and baby. However, in spite of knowing his wife's HIV-status, he had not tested for HIV.

Like their female partners, the men needed support and information to empower them to make informed decisions and act as active citizens, asserting their constitutionally guaranteed right healthcare services. Thabo illustrates the importance of support and information in making decisions about one's health:

> In my life I am so disappointed because I am HIV positive, but I take this [easy] because I am getting a good service in this clinic, and my wife is supporting me, that's why. So that's why.

Involving men in the PMTCT programme has been identified as a strategy to improve the commitment to the protocol. It can also encourage preventative behaviours such as condom use to reduce both men and women's exposure (Peltzer et al., 2011).

5.11.2 Family relations/ Kinship networks

Kinship networks provide a support structure for the poor and marginalised (Francis, 2006). It is therefore important to maintain these relationships. Disclosure of an HIV-positive status impacts these relationships and potentially could lead to further marginalisation and "social death" (Robins, 2006:312).

In the health system HIV-positive "patients" are pressured to disclose to a family or community member, especially if they are taking ART. Many ART clinics use the buddy system – where access to ART is contingent on patients having a 'buddy' who attends visits with them and who could collect the medication in the case of the patient being unable or too sick.

Participants desired to tell their family, but feared their reactions. Memory commented:

> My family is not [a] good [influence]…I can be applying for a serious mess in my life…They don't have that support, they don't understand, if I can tell them.

The anxiety of disappointing family is illustrated in Palesa's response on how her HIV-status would have affected her deceased mother:

> [The nurse] said 'Ja, it's still positive; it is there, you have to live with it and accept. I said, ooh, then my mother, ooh, eish. No, like, my mother when she passed away she said, 'Palesa, you know you're my last born, I love you, take care of yourself'. And where she is, ooh, she is turning in her grave.

Participants were selective in terms of whom they disclosed their HIV status to and whom not. Controlling disclosure was a major strategy for avoiding stigma. Eight had disclosed to their partners and to at least one family member. Seven had disclosed to their partner, but not to any of their family. Four had disclosed to family, but not to their partner. Two had not disclosed to anyone. Cece had disclosed to her family, but she did not mention whether she had disclosed to her partner.

Some of the participants expressed the desire to disclose to their family, but feared their reactions. They were thinking of how to best “prepare” the family and ways of doing it “softly” [Palesa]. Palesa kept emphasising both her longing and fear to disclose to her family:

> …If you are like free, you've got somebody to talk it is not much difficult [dealing with HIV]. But like me, [I], can't tell them this and this and this…But if you've got supportive family that you can tell 'I'm positive', I think it is much better. But if you're like me, if I talk I have to limit my words. But sometimes I forget…I tell them at the clinic they say this and this. Then they want to know, 'why did they say that?'. With this thing, it is eating me. I know if I tell my uncles they will go like 'oh', they will tell everybody 'she's positive', even those ones I don't want to know.

Reactions of family members following disclosure ranged from shock, sadness and worry, to acceptance and support – “She was so sad” [Cece]. Of the participants who said that they had disclosed to family members, only one, Anna, reported outright rejection by family. She was still very upset when relating how she was “fired” from her uncle’s home where she had been living with her uncle after her parents had died. Anna worked at the same place as her uncle’s wife who told other staff members of her HIV-status:

> No my, you see, my father’s brother, I was staying with them first here at Mamelodi. So her wife is useless because I work with her at the work, so I told her, I take her like my mother, so she told [participant starts crying]...I was living with them. They told people at the work.

Family support was however key in helping women deal with a positive diagnosis:

> Ja, actually for the first month it was a shock for them, actually they said two weeks it was a shock for them, but they tried by all means to keep the baby negative. Whatever they did, like they went outside and ask for the advice ‘if the positive pregnant lady, what must we do, what must she eat and the treatment’ and stuff like that [Mpho].

Family support was also very important in helping women survive financially. Almost all the participants mentioned a mother, a sister, an older brother, a nephew or an aunt who were working and helped them financially. Nine of the women lived with family members. Brothers and sisters often lived together.

Family also helped the mothers take care of the infant. This was especially the case if the woman had to or wanted to work. Fifteen participants had more than one child. Of the 15, five had an older child/children living with their mothers. The grandmothers sometimes lived far away, such as in the Eastern Cape or Zimbabwe, but some also lived close enough so that children could visit over weekends. The older children of one participant were living with her uncle and his family in the Free State after her house had been burned down. She planned to be re-united with her children at the end of that year.

Nine women lived in female headed households, which they were either heading themselves or where their mother or grandmother was the head. As discussed in 5.11.1.2, several of the women also were also living with siblings or took care of the children of siblings. These kinship networks were an important source of financial and social support. Only one woman was living by herself with the infant. This was the mother who was so upset we had to discontinue the interview.

Two of the participants were living in a shelter for a few months. One had an aunt whom she would go and live with after three months in the shelter. The other participant was from Kenya and had support from her ex-sister-in-law and some friends in Tshwane. It was not clear where she would move to with her daughters when she planned to leave the shelter. The participants who were immigrants had less family around to help financially and to help with the care of the baby and had to rely on other support.

I questioned some of the participants on whether they were aware of any family members that were also HIV-infected. Ten of the participants had knowledge of at least one family member who were HIV-positive or who had passed away from HIV-infection. This increases the burden of care on families, which are often the responsibility of women.

5.11.3 The community

Stigma of being HIV-positive in the community forced most mothers to disclose their positive diagnosis to only close family, often only one or two people. This left many women with very little or no support.

The fact that women were not disclosing their status to other members of the community resulted in them being excluded from support at this level (cf. Doherty, 2006). Most of the women expressed the need for a support group, but voiced concerns that this would mean having to disclose their HIV status. Women thus desired the potential support from community members which may follow disclosure, but feared the increased vulnerability disclosure requires. Few women had knowledge of available support groups in their community, as the following excerpts illustrate:

> I have friends but I did not tell them. The reason is that they are going to gossip…Yes. And I will end up feeling as if I'm not supposed to live [Lesego].

> Ja, our community does stigmatise people a lot. A lot. There is still that discrimination, when you are HIV positive, it feels like you are not a human enough. Ja, there is still a high rate of stigmatisation, even in our families. Ja, there are still those people who still chase their children away after they find that they are HIV positive. There are still those families that husbands and wives separate and all that [Elizabeth].

> The difficulties is when they are in the communities. There are many different stories they heard. Sometimes you end up feeling, eish, it is better when you are HIV positive, it is better to die…because of the stories [Lesego].

Stigmatisation remains a central part of women's experiences of HIV. The possibility of rejection prevented women from disclosing their infected statuses. These findings support other studies in South Africa on HIV and AIDS-related stigma (cf. Simbayi et al., 2007; Campbell et al., 2005; Skinner & Mfecane, 2004; Gilbert & Walker, 2010).

5.11.4 Healthcare providers

The relationship between health care providers and health care users is one of the most important relationships when it comes to women being able to make informed decisions and assert their right to health and healthcare. Having a good relationship with health care workers also helps a woman adhere to treatment regimes such as ART and to health decisions such as an infant feeding choice (Ciechanowski et al., 2001; Roberts, 2002).

With the biomedical model still dominant in South Africa, relationships with health workers are usually structured as power relationships with the health worker occupying the role of the "all-knowing" nurse or doctor and the health user expected to accept the doctor or nurse's 'prescription' and not ask questions. In isiZulu, the only verb to describe interaction with a health worker is translated as "to tell" (Doherty, 2006:93). In the context of a poor, vulnerable community health workers occupy a privileged class position. This reinforces paternalistic relationships.

One of the selection criteria for clinics in which to conduct interviews was the availability of good counselling. The reason for this was an ethical concern. This ensured that further counselling was available in case a particular woman was in need of it since only one session was held with each one. The requirement that adequate counselling services must be available at clinics very likely resulted in selecting clinics which had staff that were more compassionate and trained in dealing with HIV-infected women. As would be expected, several participants were satisfied with the emotional support which they received from the health care workers.

Nevertheless, quite a few women also reported not always being treated with respect and compassion. Helen [translated by the research assistant] explained how she had a negative experience with nurses:

> No, she says…it depends on the person. Sometimes you want to ask a question and the way the person looks like, you don't ask. Like when she first brought the baby. When she first came with the baby after been discharged at Kalafong they were just shoving her around. They didn't treat her well.

These negative reports often related, not to the clinic where the interview was conducted, but to other healthcare institutions that the woman had visited. These institutions included other clinics, often in the woman’s community, but which she avoided as a result of bad experiences and the attitudes of nurses. Women also reported negative experiences at hospitals to which they had been referred for treatment. Since the interview was conducted at the particular clinic, women potentially may have been less likely to criticise it.

Coming to terms with a positive diagnosis, as well as decision-making, is a process. Some of the women did not feel at liberty to ask nurses questions. Patience, for instance, did not want to ask nurses about having more children. Others felt that the nurses could not answer their questions. Judith had asked nurses about the exact time during labour that she is supposed to take the Nevirapine, but they could not give her an answer. Many of the women had questions on issues relating to HIV and also general questions on motherhood when asked whether there were some things that they would like more information on. Cece complained that nurses did not give her enough information and that she wanted “to know more”.

Several of the women had strong opinions about their relationships with nurses and other healthcare providers. Two women described their relationship with a particular nurse in family terms, indicating that they experienced the relationship as one of closeness and trust:

Memory: I'm having a mother here. [laughs]

Carolé: You have a mother here?

Memory: Ja. The one that I get from that day. Yes, it's a nice nurse...Very nice, very nice. And even my friends are, no I don't trust them. Because if I'm having problems I'm going to my mother here [at the clinic]. I speak to my sister.

Prim: No, no, into a room. Privacy. Just me and the sister.

Carolé: Privacy. And you felt you trusted the sister?

Prim: I do. Because I just wanted to see the [particular] sister today. I did ask 'Where is the sister?'[laughs].

Carolé: Okay, and you see her every time you come?

Prim:	Every time I come.
Carolé:	Because she knows you. [Mother nods] And can you speak?
Prim:	Ja, I speak and [she] ask 'What is wrong? Are you fine?' ‘No, everything is fine at home.’ I tell her everything. Also my fiancé [talks to her]. Sometimes he does come and talk to the sister....Because I have a sister who is my friend.

At one site several of the participants mentioned the name of a particular nurse whom they found very helpful and understanding. This is an indication of the significant influence one compassionate individual can have on women’s lives.

Support from nurses also seemed to be key in helping mothers deal with an HIV-positive diagnosis. Dee said of the nurses: “Then I came here for [Annette[5]], the white lady. She was so supportive, she didn't criticise, she was there for me. Then this [Sarrafina[6]], even feels like she knows me”. A key message that seems to have been communicated effectively during counselling and that was mentioned by several participants was that an HIV-positive diagnosis “is not a death sentence” [Lesego].

> I was worried, but me I said I'm going to die early, but they said I must come back and then they talked to me again. Ja, to talk with me and tell that there are other people live with HIV 20 years and that I must be strong [Lesego].

Palesa, who was convinced that she was going to terminate the pregnancy and admitted to being in denial over a positive diagnosis right until the birth, experienced additional trauma when her house in the Free State burned down by accident. Following this she travelled to Pretoria to be close to her aunt (the female head of the family) and delivered the baby a few days later. She reported to being so traumatised in the hospital that she was unable to answer any questions. A sympathetic and persistent nurse contacted her aunt and ended up arranging a prolonged hospital stay for her so that she could see the social worker who was away for the long weekend. The social worker organised a place in a shelter for her and her baby to stay for three months. As

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[5] Pseudonym

[6] Pseudonym

Palesa’s case illustrates, the role of social workers are also important in helping women to deal with social problems such as poverty, housing and abuse.

Not all participants experienced their relationship with health workers (especially nurses) as positive:

> It is the openness, I'll be like, they must be more open, like, cause they're not the same. This week you find [] this one she's cutting you're head off [Palesa].

Many participants mentioned of the nurses that “others are friendly but others are not” [Immaculate]. Ayanda said (as translated by the research assistant):

> When she first started here, she was hurt, because there was a sister here, sister [ ], who didn't talk to her nicely. That sister told her, after testing positive, this sister said 'why do you come here, why don't you go to Shoshanguwe. Because you are running away from Shoshanguwe because you are positive.

Another participant related with resentment how she was scolded at the hospital for falling pregnant when she knew that she was HIV-positive:

> Mandisa: At the clinic yes, they give me just [pre-counselling]. At the gynaecologist section they don't give me the counselling. They just tell you you are positive and then that's it. Don't do this, don't do that.
>
> Carolé: Okay, so at the hospital they give you the results?
>
> Mandisa: Yes.
>
> Carolé: And did they give you counselling at the hospital? [shakes head] No? When they gave you the results?
>
> Mandisa: No, they said “You were already know that you are positive. Then you go back and get pregnant, but you know that you are positive?

This same participant however told how she later encountered a sympathetic doctor at the clinic who explained to her that it was her right to have children. The doctor further gave her family planning counselling and explained the importance of having a CD4 count done prior to falling pregnant to decrease chances of vertical transmission.

5.11.5 A socially supportive environment

Apart from drawing support from family, health workers and occasionally partners, participants relied on other forms of support for survival and for dealing with an HIV-positive status and the demands of motherhood.

5.11.5.1 Other mothers who are HIV-positive

Participants received support from other women who were HIV-infected and supported others as well. Although stigma was attached to clinics where separate consultation rooms were reserved for HIV-infected women, these settings allowed women to talk to each other about their HIV-status:

> Like today I was talking with those ladies in there. One of them is having a big problem. I told them, 'No, don't be worried, everything is going to be fine'...As I told, we were talking us ladies in there, nê, so one of the ladies, his guy, he just told his guy that he is HIV positive and the guy just told her, 'No, it is over between me and you'. So, it is difficult. Uh, and they also have babies, two babies. It is too much...All I can say is you must ask more. Because some of them they do have problems at home. They don't want to talk about them, they just keep quiet [Prim].

Anna said:

> The only one [giving me support], there is another, my friend who was coming here last. She just told me that she is positive, we just talking and sharing. But today I didn't found her. I don't know where she is. Because we go with the 1:30 bus [Anna].

As women were often reluctant to disclose their status to family members, support from other relationships, like other women in a similar situation as they were, was very important. Having a friend who was also HIV-positive gave women the opportunity to share their fears and challenges with someone who faced many of the same emotions.

5.11.5.2 Support groups

My interview schedule initially did not include questions about support groups. During one of the interviews, the male partner of a participant enquired about support groups from us. Following this request I realised that some of the participants might have a need for a support group. I included this as a question in the subsequent interviews. Almost all the women indicated that they would like to join a support group. Some had concerns about support groups at the clinic or in the community and said they would prefer a support group in another area. A few of the participants were already participating in support groups. Some support groups were specifically for HIV-positive people. This is what one participant said about her experience in one of these groups:

> Carolé: You said you attended a support group in Bloemfontein?
>
> Palesa: Ja, the lady that started counselling me, she.
>
> Carolé: Was that at the clinic?
>
> Palesa: Ja, she told me that at the hall they normally does and at the library. Because she ask me do I think I can tell, I told her in my family, eish. She said it is free. If you talk about it you can live with it but if you don't talk about it you will get thinner and you'll think that is the HIV, because you.
>
> Carolé: worry.
>
> Palesa: Hmm. I thought oh, those I don't know, maybe it will be much easier. And I was like, I could ask questions you know, and after the session we would exercise and play and make fun. I feel like, ooh, I am with people who are like me and I would not worry too much. And I forget that it is something that would kill me.
>
> Carolé: So it helped you?
>
> Palesa: A lot and there are some things I didn't know but then I knew [after attending the group], like okay [now I understand this issue].
>
> Carolé: Okay, so they gave you good information because you asked questions.
>
> Palesa: Ja, like I was drinking before and then they told me and then I stop. I thought, oh, it don't do me any good.

Judith was living in a shelter was attending a general support group. Although issues of HIV were not specifically discussed, she found this group very useful and experienced it as a place of belonging. As this was one of the immigrant women, she had little family support in South Africa. She said:

> Judith: I joined a support group, but not because of my status. But these girls who came to the shelter and they had some pamphlets. I just took the pamphlet, so I go, oh, support group. I thought I could enquire about a support group, particularly for this, but afterwards I did not feel inclined to join any support group. So this time when I was reading the pamphlet I felt I just needed to belong somewhere, not necessarily for HIV or anything. So I have a support group. We meet on Thursdays, we talk about issues, from HIV to family to anything, you know.
>
> Carolé: Okay, that's wonderful. Is it with the church or with the?
>
> Judith: It's a clinic.
>
> Carolé: And you feel that that's been positive for you?
>
> Judith: It is very positive for me. I don't like missing any session. Although they don't even know that I am HIV positive. And we don't particularly talk about that.
>
> Carolé: Okay. So all sorts of issues?
>
> Judith: All sorts of issues.
>
> Carolé: Okay, oh, that's wonderful.
>
> Judith: Ja, it makes me feel nice.

Elizabeth works as a voluntary administrative clerk at an HIV and AIDS facility in a local community. At work she has access to support groups:

> Carolé: Okay, uh, have you ever felt any need for a support group or do you feel you get enough support?
>
> Elizabeth: I do attend support groups at work. At work we have support groups on Tuesdays and Thursdays. On Tuesdays we have open support groups and on Thursdays we have closed support groups. So I do attend both of them.
>
> Carolé: Okay. And do you find that a good experience?

Elizabeth:	It is, it is helping me as much as it is helping other people that we join together, yes.
Carolé:	So do you help to facilitate the support groups?
Elizabeth:	I do.
Carolé:	And you also share out of your life?
Elizabeth:	I do, yes.

Participants who had the opportunity to attend support groups experienced the groups as helpful. It provided access to information and support to deal with HIV and other life events. Emotional support is important, especially in the context of HIV, where women are often afraid of sharing their experiences and get rejected when they open up.

5.11.5.3 Child support grants

Most of the women were unemployed and the primary caregivers of their children. As member of poor communities, access to welfare is important. As all, except two, of the women were giving their infants replacement feeding, they had to buy bottles, sterilising equipment, and formula milk (from six months). If women became sick, they were unable to work or look for work.

Five of the participants received a government child support grant (CSG). I did not specifically probe the reasons for why other women were not accessing this form of support, although some of the women indicated that they were planning to get it later and immigrants did not qualify.

The youngest of the participants was still attending school when she fell pregnant the previous year with her firstborn child. She was planning to return to school the following year. This girl was supported financially by her older brother. She did not receive a CSG for her infant and simply gave the reason as “I didn’t register” [Dineo]. This case does therefore not support the common assumption that many teenage girls fall pregnant in order to receive a CSG. Research on this has not found any correlation between teenagers having children and receiving a CSG (Makiwane, & Udjo, 2006). Dineo was 18 at the time of the interview and falls into the age group (18-42) where women are more than twice at risk for contracting HIV than males (Moodley, 2004). She said that she does not know her boyfriend's age. It might have been that she did not feel comfortable to disclose his age. Young women who have older partners are also at higher risk for contracting HIV (Pettitfor et al., 2005).

The three participants who were of a foreign nationality had no recourse to public funds of this sort. This seriously limited the choices that they had. In Immaculate's case, which I discussed in 5.10.1.1, she was very upset about her partner's unfaithfulness, but felt that she could not break off the relationship as this would end his financial support. Being excluded from the child support grant left her dependent on a male partner.

5.11.5.4 Shelters

Two of the women were living in shelters at the time of the interview. The support of the shelter enabled Judith from Kenya to leave an abusive relationship. The support of the shelter was even more important as she could not access state funds as she was a foreigner. Judith had been living in the shelter for approximately seven months. The shelter had connected her to a support group which provided the opportunity to talk about emotional issues – "from HIV to family to anything". Judith tried not to miss any of the sessions as she experienced them as positive and helpful.

The shelter also assisted Palesa and her infant after her house had burned down. A nurse referred her to a social worker who, after consultation with her and her aunt, organised that she stays at the shelter for the first few months after the infant was born.

At this shelter women received a room for themselves and their children. There are communal kitchen and bathroom facilities. Both women spoke very highly of the shelter and the support that they received there.

5.12 Conclusion

Participants in this study often shared similar difficulties when it came to accessing healthcare. Faced with numerous constraints they, however, employed different strategies to cope and protect their interests and those of their children. Some took more initiative than others when it came to their health and this shows differences in agency. In the next chapter the implications of these women’s experiences for citizenship is considered.

Chapter 6: Marginalised citizens in post-apartheid South Africa

When considering the rights of citizens in any country, an understanding of both formal and substantive equality is necessary. Substantive equality takes into account power structures (such as gender) within social institutions within which rights are exercised.

6.1 Introduction

The transition in South Africa in the 1990s, saw the creation of new gender sensitive democratic structures. The new constitution and Bill of rights fundamentally changed the nature of citizenship available to South Africans. A majority of South Africans voted for the first time in 1994.

The Constitution not only guarantees civil and political rights (so called first generation human rights), it confers social and economic rights (second generation human rights) such as rights to housing, water and healthcare on its citizens as well. Women's reproductive rights are protected in the equality clause (Chapter 2, Section 9), which prohibits discrimination on the grounds of pregnancy. The clause on the freedom and security of the person (Chapter 2, Section 12) gives women the right to control their bodies and reproduction. These different sets of rights are important in addressing the unequal social and economic position that women still occupy (Lister, 1997).

These changes open up and offer new opportunities for women to exercise their agency. Women have seized the opportunities that citizenship in post-apartheid South Africa offers. Their access to education, housing, grants and services such as clean water has improved. Since the implementation of the Termination of Pregnancy Act (1996), which allows for safe termination of pregnancy, maternal mortality rates due to unsafe abortions have decreased. In general, more women in South Africa have access to healthcare services that save their lives and the lives of their children (Benson et al., 2011; Gouws, 2005a & b; RSA, 2012).

In spite of the improvements mentioned above, many South African women have not seen the guarantees of the Constitution materialize in their everyday life. The broad indicators of access provide a generalised picture of progress by the state in guaranteeing political, social and economic rights of its citizens. However this can gloss over the difficulties that men and women experience in realising their citizenship rights. These indicators tell us little of the quality of the services that people receive with regard to education, healthcare, housing and water for instance. It can also veil human rights violations that people experience. The different experiences of men and women and differences between women can also conveniently be masked by broad indicators.

This study explored the experiences of women who are HIV-infected mothers and who had accessed health care at primary healthcare clinics in order to take care of their own health and the health of their children. Participants had accessed the PMTCT programme – the public health programme implemented by the state to address the health needs of HIV-positive pregnant women and to prevent transmission of HIV through pregnancy and birth. The women in this study may be considered “success stories” of the PMTCT programme as those who had already tested their children, received a negative result.

In this chapter I connect the experiences of the women in my study to a feminist conceptualization of citizenship. I discuss the implications of these women’s experiences for citizenship. In doing so, I hope to contribute to a feminist understanding of citizenship in South Africa.

6.2 Towards differentiated universalism – HIV-positive mothers

Sweetman et al. (2011:350) remind us that “while the idea of citizenship today is based on the idea of universality, what it means and how it is experienced is not”. Conceptualising citizenship as differentiated universalism, as suggested by Lister (1997), requires us to consider universalism in creative tension with difference, acknowledging how women occupy a different structural position to men, but also to recognise the differences between women.

As a category, the participants in this study had in common being HIV-infected mothers of infants. Learning about a positive HIV-status was a traumatic experience. Such a status changed the way women viewed themselves and influenced their relationships with partners, families, communities and health workers. An HIV-positive status changed the needs, the meaning and the experience of health and healthcare for women.

Participants were selective in disclosing their HIV-status and feared the reactions of those who learned that they are infected. This influenced women's ability to access healthcare and to make health-related decisions. Visiting the clinic often meant having to queue in the 'HIV' or 'mothers-with 'HIV' section for antenatal or postnatal care or having to formula feed their infant in public. It compromised women's right to confidentiality of their HIV-status.

An HIV-positive status brings with it new health needs. Access to ART, technologies for safe sex and counselling for dealing with a positive status are important needs that HIV-positive women have. A balanced and nutritious diet becomes more important for maintaining health and when taking medication. Because there is still so many stigmas related to an HIV-infected status, women have to be assured that knowledge of their status will be kept confidential.

For most participants their HIV-positive status was confirmed on the same day as their pregnancy. As has extensively been argued in the literature, it is important to consider motherhood with respect to citizenship. Women become pregnant and are at risk of dying in childbirth. An embodied citizenship acknowledges sex differences. However, there are different (and contested) ways in which to consider motherhood (and non-motherhood), as women are differ and have divergent needs and interests (Suárez, 2010).

Studies suggest that motherhood foregrounds the child's needs and that mothers are expected to disregard their own subjectivities. For HIV-positive mothers, the notion of damage – the possibility that the child will be infected is added, contributing to the burden they shoulder and this colours the notions of what a 'good mother' is. The well-being of the child is paramount to that of the mother. This is evident in scientific discourse, like the name preventing-mother-to-child-transmission indicates. In explaining why they tested most participants framed their reason as wanting to protect the child. This suggests that they have bought into the discourse. It was also the message participants 'heard' from health workers: They must test, and if positive, they must start PMTCT, in order to save the baby. In the national PMTCT protocol (2010), women are regularly referred to as mothers. This defines them in relation to their children and implies the forepresence of the child (Long, 2009).

For the women in this study the ideals of motherhood changed following a positive HIV test. This was evident in such things as participants framing their reasons for testing in a discourse of 'good' motherhood. They related how health workers emphasised that women must test in order to protect the baby. Health workers also emphasised that HIV-positive women should not get pregnant again. A Foucaldian view of power explains how discourses such as that of 'good' motherhood serve to exert control over women. Power is not just coercion or repression by a dominant group of another group, but power is also, as in this case, productive. This means that by adopting discourses such as 'good motherhood', people are actively participating in shaping and reinforcing patterns of oppression. Women seemingly 'voluntarily' go to test, in order to be 'good mothers', but by framing the reason for testing in an ideology of 'good motherhood', they are in fact participating in their own oppression. Many of the women also heeded the message that if they are HIV-infected, they should not get pregnant again. The notion of 'good motherhood' implies that they should not put their children at risk and therefore denies them freedom of choice for having more children. Through internalising these discourses their damaged bodies are policed and controlled (Foucault, 1979).

The women in this study were the primary caretakers of their infants. This placed an additional financial and psychological burden on them. Apart from the two participants who were interviewed with their male partners (both partners were supportive), none seemed to have help from male partners with child-care – reconfirming the patriarchal context of everyday relations. Male partners primarily supported the upbringing of their children financially. The women in this study, like the majority of women in South Africa, still carry the greatest burden of care.

Recent television commercials in 2011 by the Department of Health on PMTCT attempt to emphasise the responsibilities of families and communities to prevent mother-to-child transmission. It is encouraging that the emphasis is not solely on individual responsibility of women. However, the emphasis is still on the child's needs and not the needs of women.

When considering HIV-positive motherhood with respect to citizenship, a dilemma emerges. If women are included as gender neutral citizens (therefore not differentiated from men and not differentiated as HIV-positive), their specific needs may not get recognised. These needs include access to public health care in order to go safely through pregnancy, access ART, information and support. They also require financial support. However, if women are included in this way (as HIV-positive women, thus based on gender difference), they may be further burdened with responsibility (e.g. keeping the child HIV-free) and care-giving tasks. This could contribute to their oppression by making it more difficult for women to participate in the public realm.

6.3 Social and economic freedom

Eighteen years after Apartheid South Africa is still battling to overcome poverty and economic inequality. President Jacob Zuma admitted in his 2012 State of the Nation speech that "the triple challenge of unemployment, poverty and inequality persists, despite the progress made". He conceded that South Africans who suffer the most from these challenges are "Africans, women and the youth" (State of the Nation, 2012). Feeling the pressure from civil society, political organizations and ordinary South Africans to address these problems more effectively, he and his cabinet "has resolved to do more". The solution, as set out in the New Growth Path, is to grow the economy and create jobs, especially in infrastructure development, tourism, agriculture, mining, manufacturing and the green industries (State of the Nation, 2012).

The New Growth Path has been criticized as being gender blind. It makes no reference to women's situation in the economy and there is no indication of whether women have benefited from initiatives such as the Job Fund or have easier access to loans. In response to President Zuma's State of the Nation address, the Commission for Gender Equality (2012) has asked:

"where are women in the new jobs referred to in the President's address?" Government still fails to take gender into account when conceptualising and designing policies (CGE, 2012).

Participants who had work, were mostly participating in informal, part-time or non-permanent economic activities. This excluded participants from resources such as paid maternity leave, family responsibility leave and pension funds, which formal employment often provides access to. Formal employment can also offer access to other resources, such as is the case of Elizabeth who was kidnapped and raped (and subsequently contracted HIV). She was working for a major clothing chain at the time of the incident. Following the traumatic experience the company organised and paid for counselling sessions, which she repeatedly mentioned had helped her deal with a positive diagnosis and also provided her with good information and counselling about family planning when one is HIV-infected:

> Carolé: Sjoe, that's very traumatic.
>
> Elizabeth: Ja. But I went for counselling and I still do.
>
> Carolé: Where do you go for the counselling? Private counselling or somewhere [else]?
>
> Elizabeth: No, [the company I work for] organised a counselling for me, so I go to…Rosebank.
>
> Carolé: ...And has that helped you with everything?
>
> Elizabeth: It did, it did a lot, it did a lot. Because it helped me to understand and to deal with my situation.

Black African women are economically one of the most vulnerable categories in South Africa. In the context of HIV their situation is worsened. They carry the major care burden for the young and the sick, which limits their opportunity to participate in paid work. There needs to be explicit policies addressing the economic situation of women.

The majority of participants in this study were unemployed. Because women were still carrying the major burden of child care, participating in formal employment was more difficult than it was for their male partners. Participants desired to work but even if women could put measures in place (such as a nanny or grandmother) to help with child-care, opportunities for employment were limited. Many of the participants were dependent on male partners for financial support. The official unemployment rate in South Africa remains high at 23.9 percent as calculated in the 4th quarter of 2011. Taking into account an extended definition of unemployment, approximately 4.1 million workers are unemployed, another 2.8 million are long-term unemployed and an additional 2.2 million are discouraged (have lost hope of finding employment) (National Treasury, 2011). According to StatsSA (2011b) 28.8 percent of women of working age are unemployed, compared to 23.3 percent of men (according to the official definition of unemployment). As HIV-positive, participants had additional financial burdens: transport money to visit the clinic or hospital regularly, buying supplements and nutritious food for themselves and their children and formula milk, bottles and other equipment (if they were bottle feeding their child), which were all necessary to maintain their health and the health of their children.

In such a context, access to the child support grant becomes important. In 2012, according to the annual Budget Review, state spending on social grants will increase from R105 billion in 2012/13 to R122 billion in 2014/15. It is estimated that at the end of 2011, 15.3 million people were eligible for social grants, compared to 2.5 million in 1998.

Since 2004, the state has increased spending on welfare pensions. However, at the time of the interviews, only five participants were accessing child support grants. Some were planning to access it at a later stage. Participants who were immigrants, could not access any of the grants as they did not have permanent residency.

6.4 Immigrant women

South Africa has seen an influx of immigrants into the country since 1994. It is estimated that in 2009, there were between three and six million immigrants (both documented and undocumented) living inside the country’s borders (SAPS, 2011).

Within the context of globalization, it is important that concepts of citizenship include transnational citizenship, which is based more on “universal notions of personhood” (Bloch, 2010: 234). Such conceptualizations link citizenship to international human rights. Within a feminist conceptualization of citizenship this inclusion is important as migrant women are a particularly vulnerable category. Immigrants are a vulnerable category because human rights are closely linked to citizenship rights. Bloch (2010) argues that human rights and citizenship is linked because they are both committed to political, civil and social rights. But, it is citizenship that allows people to practice their rights. Immigrants, especially undocumented immigrants, often do not have “the right to rights” (Bloch, 2010:233).

Migration legislation is “founded on notions of exclusion and control and is based on the assumption that people wish to abuse the system and come to South Africa to take and not provide anything” (Crush, 1999 in Neocosmos, 2008:589). He has argued that a public discourse of fear and xenophobia has been fuelled by government and the media. In line with this, officials from the Department of Home Affairs and police officers have great power over vulnerable people (Bloch, 2010; Neocosmos, 2008).

In 2008, South Africa saw a number of xenophobic attacks on people from Nigeria, Pakistan, Malawi, Somalia and Zimbabwe. This led to 62 deaths and up to 200 000 displaced persons. Popular opinion was that this was a result of conflict between South Africans and immigrants over access to employment and other resources (Neocosmos, 2008).

Under South Africa’s constitution, everyone who is physically in the country is entitled to free healthcare. However, evidence by rights groups suggest that immigrants are regularly denied access to clinics and hospitals. Immigrants also fear deportation and harassment if they seek medical care (Mail & Guardian, 2009). The immigrant women in this study had limited citizenship rights and could not access the child support grant (CSG). Only permanent residents may access child support grants and immigrants with visas, asylum seekers, undocumented foreigners and refugees are denied access (Blacksash, 2012). This made immigrant women economically dependent on others. As women have to build new social networks when they arrive in South Africa, the support that they can draw on is often limited. This makes it difficult for women to leave abusive relationships – as is evident from Immaculate's experience, who wanted to leave the relationship with her boyfriend, but could not, as she was economically dependent on him. As mothers of young infants, women had difficulty returning to employment, even if they were documented. This was because they had less social support to draw on when it came to child care. Judith, who was from Kenya, managed to leave an abusive relationship and was supported by a shelter. She felt, however, that she could not return to employment until her infant was at least a few months old, as she did not have immediate family support or a trusted person who could help her with child care.

6.5 Time to politicise the reproductive rights of HIV-infected women

The PMTCT protocol provides for a woman's right to have access to good quality health care for herself and her infant. This includes having access to pharmaceutical interventions which could reduce the mother's chances of transmission to her children, but it also recognises the need for adequate information through proper counselling in order to make informed choices concerning her own and her children's health. What is not so clear from the protocol is how HIV positive women's reproductive needs should be attended to in the health system.

The issue of HIV positive men and women deciding to have additional children remains contentious as this decision carries several risks. These include the risk of perinatal transmission of HIV and the risk of sexual transmission and re-infection of a partner when having unprotected sex. Policies until the 1990's had therefore discouraged HIV positive people from having more children (Thornton, Romanelli, & Collins, 2004 in Cooper et al., 2007).

Recent evidence seems to suggest that ART, together with other new technologies and procedures have influenced more favourable attitudes towards HIV positive individuals in developed countries who are keen to have more children. Recommendations in developed countries with regard to childbearing seems to have shifted to a "more nuanced, flexible approach" (Barreiro, Duerr, Beckerman, & soriano 2006; Semprini & Fiore, 2004 in Cooper et al., 2007). These recommendations have also been informed by international conferences in the 1990's, such as the United Nations (UN) Fourth World Conference on Women in Beijing in 1995 and the UN International Conference on Population and Development in Cairo in 1994, which recast reproductive health issues in a rights paradigm (Cooper et al., 2007).

The little research that has been done in South Africa on this topic seems to suggest that the national PMTCT programme and access to ART have had same effect on some individuals and communities - with attitudes being more favourable towards childbearing. A study conducted by Cooper et al. (2007) explored the reproductive intentions of HIV-positive individuals in South Africa. They found that men and women continued to have "strong desires to experience parenthood" and that for women motherhood remained key to their identity (Cooper et al. 2007). Nyanzi (2006:610) reminds us of the importance given to childbearing in our society and that "proven fertility…are powerful symbols of continuity and cohesion". A study by Feldman and Maposhere (2003) found that especially younger HIV positive women without children, desired to become pregnant, many times in spite of previous miscarriage or stillbirths.

A close reading of the PMTCT protocol (2010) reveals that the reproductive needs and rights of HIV-positive women are not addressed. In the introduction to the protocol, it is mentioned that different services should operate in an integrated manner, but the protocol provides no details on how this integration (e.g. between reproductive health services and PMTCT) can or should be achieved. The protocol (2010:15) states that "all pregnant women are HIV-positive should be counselled on safer sex, family planning, postnatal contraception and partner testing". It also states (NDoH, 2010a) that post-test counselling sessions should include information on: "HIV transmission risks; safe sex and the availability and use of condoms; contraception and future fertility". Nowhere in the protocol is there any mention of the specific reproductive needs and possible rights abuses of HIV-positive women. To mention that family planning should be included in counselling sessions could be interpreted by health workers as counselling women not to have children.

The lack of specific policies protecting the reproductive rights and addressing the reproductive needs of HIV-positive women was clear from my interviews. Several participants felt that the expectation of health workers is that HIV-infected women should not have children – that it is the "responsible" thing to do. If health workers discussed issues of contraception, it was mostly done within the context of protection against infection and re-infection of HIV. Participants had little recourse to family planning counselling where safe ways to plan and space pregnancies were discussed.

There is an urgent need for explicit policies that protect the reproductive rights and choices of HIV-infected women. Health care workers need to be trained in how to sensitively deal with the reproductive rights and needs of HIV-infected women. The focus of counselling should not only be on the biomedical aspects of reproduction (the so-called mechanics), as often happens, but also on the psychosocial aspects of sex and sexuality. Sexuality is a much broader issue to be dealt with and includes issues of masculinity, femininity, relationships and negotiation. Women have also different needs that changes across their life cycle and these differing needs should be catered for (Delvaux & Nöstlinger, 2007; Harries et al., 2007).

Women also need better access to contraception and reproductive health services. Gray et al. (2006) argue that choice is the primary factor in achieving safer sex practices. Choice is also important in the context of HIV-infection as ART could potentially interact with hormonal contraceptives. HIV-infection and ART can also influence a pregnancy. Participants in this study had little choice when it came to reproductive technologies. They also had little knowledge of contraception and family planning beyond the "dual-protection" mantra of protection against HIV-infection (Delvaux & Nöstlinger, 2007; Harries et al., 2007).

The findings of this study confirms that reproductive health needs to be better integrated into HIV prevention and care as has been suggested by Harries et al. (2007).

6.5.1 The Female Condom

Few women in this study reported consistent condom use during sexual intercourse. This was regardless of whether they had disclosed their HIV-status to their partners and in spite of knowing the importance of barrier methods in safe sex, even if one is HIV-positive.

When it comes to the prevention of HIV infection and re-infection, “male condoms are considered the gold standard” (Coggins et al., 2000 in Alexander et al., 2011:2). The difficulty comes when men or women are unwilling to use them. Some women in this study said that male partners either complained about having to use male condoms or they were unsure whether they would use it.

The female condom came to my attention when two participants said that they were using or were planning to use the female condom as a method of practicing safe sex. Both women attended the same clinic and both felt that the female condom was superior to the male condom. One of the women felt that she had more control when using the female condom.

The female condom was invented in 1984 by Lasse Hessels. To date it is the only method that can be controlled by women that has shown to be effective in protecting against HIV/AIDS, other sexually transmitted infections (STI’s) and pregnancy. Despite great hopes for methods such as microbicides that can be used by women to reduce the risk of HIV transmission, microbicide trials have shown poor results. Condoms is still the “single most efficient technology” available to reduce the risk of HIV transmission and STI’s during sex (Peters et al., 2010:119). But 25 years after its invention, the female condom still only makes up 0.28 percent of all condoms manufactured and is generally inaccessible to women.

Since its invention, three types of female condoms have been approved by the FDA. FC1 is made of polyurethane and FC2 of synthetic latex. Both are exclusively manufactured by The Female Health Company and are distributed by UNFPA and other public donors. FC2 is a newer version and received FDA approval in 2009. Because FC2 is made of synthetic latex, it can be manufactured more cheaply and it also does not make noise – a side-effect of FC1. The female condom can also be less restrictive for males and provide more pleasure for both male and female partners. Studies have shown good acceptability by users, but despite evidence to the contrary, a myth persists that women do not like and accept the female condom (Peters et al., 2010).

Peters et al. (2010) convincingly argue that access to female condoms is limited, not as a result of low acceptability amongst users, but as a result of low acceptability at international policy level. They question the current wide promotion and funding of male circumcision practices, where the advantages as far as women are concerned is far less known than that provided by the female condom for them. There are dedicated staff at UNAIDS and WHO to work on male circumcision but no corresponding unit for initiative to reduce risks for women by promoting the female condom. This might indicate how sexism is institutionalised in organisations like UNAIDS or WHO as well as how the welfare of men is prioritised over that of women.

A general objection to the female condom is that it is much more expensive than the male condom. Studies have however shown that distribution of the female condom can be cost-effective. The manufacturing cost can be lowered if the female condom is distributed in larger quantities and the infections that will be prevented will save the government ART and other healthcare costs (Dowdy et al., 2006:2097).

In South Africa the media has perpetuated the myth of the unacceptability of the female condom (Peters et al, 2010). Healthcare providers have been a barrier as well. If a healthcare worker does not personally have a favourable attitude towards the female condom, it is unlikely that she/he would promote it to health users.

6.6 Towards active citizenship

Stigma associated with HIV-infection is still a major reason why people do not seek care and do not disclose a positive HIV-status to family and other community members. Organisations such as the TAC have worked hard in breaking down stigma by encouraging their members to be open about their HIV-status. Part of the TAC's success has to do with providing information and support to their members, often becoming their "family" (Robins, 2004:662). Not just a watchdog of the state, as is a popular view of civil society, the TAC has provided citizens with opportunities to participate politically and become active citizens (Vandormael, 2007).

Within a feminist conceptualisation of citizenship, participation is defined more broadly so as to include the more informal networks of which women form part. A broader definition of participation not only includes involvement in more formal organisations such as the TAC, but could potentially also include participation in groups such as support groups.

A few participants had attended support groups and had said that the groups had helped them deal with many of the challenges they faced as HIV-positive people. The rest of the participants were all questioned on whether they would participate in a support group and all of them said that they would be interested. By bringing together HIV-positive women and mothers, informal support groups hold the potential of this category of women identifying their needs and organising around their interests as a group. Such a group could voice their needs to clinic and hospital management and so highlight any rights violations or unmet needs. Within the context of HIV/AIDS this holds potential for new forms of health citizenship in post-apartheid South Africa where women might seize initiative and draw on collective support (cf. Robins, 2004 & 2006).

6.7 Conclusion

Women in post-apartheid South Africa are still excluded as citizens in spite of formal recognitions of rights. HIV-positive women are particularly vulnerable to the effects of discrimination within social and public institutions.

Chapter 7: Conclusion

The MDGs was adopted in 2000 by all United Nations member states as a commitment to operationalise the Millenium Declaration that states that "every individual has the right to dignity, freedom, equality, a basic standard of living that includes freedom from hunger and violence, and encourages tolerance and solidarity". The target date for reaching the eight MDGs is 2015.

According to all indicators South Africa is not on track to meet the Millenium Development Goals (MDGs) relating to women's and children's health (R.S.A., 2010). As is apparent from the experiences of the women in this study, exercising of health rights in South Africa is complicated by a post-apartheid context of HIV/AIDS, neo-liberalism, poverty, unequal gender relations and entrenched power relations within public institutions such as the healthcare system.

The women in this study all exercised their right to access healthcare services for themselves and their children. All of the infants who had been tested for HIV at the time of the interview had tested negative. This is in line with indications that the rates of vertical transmission of HIV in South Africa are dropping for the first time since the start of the epidemic. HIV prevalence for women in 2011 was estimated to be at 19.4 percent (RSA, 2012; StatsSA, 2011c).

In spite of the apparent progress made in reducing the rates of mother-to-child-transmission (MTCT), one should be cautious to focus on a 'quick fix' (Richard et al., 2011:42-55). Addressing the health needs of a nation is a complex issue as people have different health needs across their lifetime, which has to be met throughout their lives. Berer (2011:7) argues that the "reductive simplification" of issues relating to the MDGs has led to diminishing the initial aims of the MDGs, which was reducing poverty and its impacts, including poor health. These are complex issues.

In this study I have investigated the experiences of HIV-positive women as they access health care and make health and health-related decisions. As a sex, women are the ones who become pregnant, give birth and carry the main burden of care of the young. As a gender, they have less power to negotiate sexual acts as well controlling their reproduction. Empowering women to have control over their reproduction remains an issue that insufficient attention is given to and this needs to be repoliticised.

In spite of a human rights discourse in post-apartheid South Africa, women's rights are still marginalised. This is evident from several aspects of the PMTCT programme. First, as the name indicates, the focus of the programme is on keeping the child HIV free. Although this is naturally important, such a focus neglects the needs of women. To address this, two terms have been suggested as alternatives in the literature: 'vertical transmission' and 'parent-to-child transmission' (Mushariwa, 2011). The first term, 'vertical transmission' shifts the focus from the 'responsibility' of the mother (and father) on keeping the child HIV-free. It describes one form of transmission, without implying that the responsibility lies solely with the mother to prevent the transmission of the virus. The second term, 'parent-to-child transmission' also acknowledges that HIV transmission is not solely a matter of transmission from the woman to the child, but it implies that the woman who is pregnant had sex with a man who is likely to also be HIV-infected - both have a responsibility to keep the child HIV free. Adoption of this change in medical and public discourse removes the blame attributed to women in this regard. It has been suggested that, together with such a change, men should be encouraged to attend at least one antenatal visit with women. Involving men in antenatal and other healthcare is important as it enables healthcare workers to reach heterosexual HIV-positive men, within public healthcare, who have been less inclined to seek medical care (Mushariwa, 2011; Segurado & Paiva, 2007). Often healthcare initiatives and reproductive health programmes primarily target women. Giving both men and women information and support when it comes to decisions about their health, reproduction and the health of their children is important. By treating them with respect and allowing them to be full citizens and have recognising their independence when making decisions grants them dignity. Dignity is an important element of substantive equality and citizenship (Fredman, 2011). Involving men in antenatal and postnatal care of the infant could encourage men to be more involved with child care. Evidence in this study suggests that there are men who are willing to be involved with the care of the child. This trend should be encouraged.

The NDoH has acknowledged that PMTCT should be a service integrated with other parent-and child health services. In addition to this, it is also important that the PMTCT service should be viewed with a lifecourse perspective on health. With regard to women, this means that the health needs of women should be addressed throughout their lives – including, but not only, when they are HIV-infected or pregnant. Such a perspective would focus on women's sexual health throughout their lives: when they become sexually active, when they consider having children (or not having children) when they reach menopause, etc. A lifecourse perspective also acknowledges that women have other health needs in addition to their sexual health and that these should be adequately addressed.

If women are to have full citizenship in South Africa, the institutions within which rights is exercised need to be transformed. This includes gender relations within the private sphere, power relations within healthcare settings. Unequal gender relations still put women at risk for HIV-infection and the effects of HIV/AIDS. In the healthsystem, healthcare workers need to be trained and kept accountable to protect and realize the rights of HIV-positive women.

Indications are that rates for vertical transmission of HIV are dropping since the implementation of the 2010 PMTCT protocol, but the rights of women are still violated in many ways. If the rights of HIV-positive women in South Africa are to be fully realized, their needs will have to be addressed and their rights protected. These women deserve to be treated with dignity and their decisions, including those relating to reproductive health choices, should be respected in the spirit of the South African Constitution.

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Appendix 1

SEMI-STRUCTURED INTERVIEW SCHEDULE FOR HEALTH CARE USERS (HIV-INFECTED MOTHERS)[7]

Introduction:

- Thank participant(s) for willingness to be involved
- Introduce information leaflet and informed consent
- Explain process of interviewing
- Conclude formalities and technicalities

Introductory questions:

Tell me/us a bit about yourself
Probes:
Mother: First child? Age? With whom does she live? Schooling?

The questions below are in the format for mothers (2nd person).

The main things we would like to hear from you is what difficulties have you experienced and ways in which you have tried to overcome these problems since you came to the clinic for your first antenatal visit. We will start right at the beginning and talk about your pregnancy, the birth and what happened up to now. Is that okay for you?

	Probes
During pregnancy:	
1 Decision to test	Tested in pregnancy? Why tested? When decided to test? How was the counselling done before she was tested? What did they say to her (in pre-test counselling)? What did they say when they gave the results? How was it when she got the results? What was she worried about? Where did she get help after diagnosis?
When a woman tests positively:	

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[7] The original was printed on a university letterhead

	Probes
2 Decisions about disclosure	Did she disclose? How long after testing? To whom? If not, why not? Was there support from staff? From family or friends? How about later?
3 Participating in PMTCT and taking prophylactic ART to prevent transmission	What kinds of tests were done and when? What did people tell her? Were there things she wanted to know that wasn't told to her?
In the period after birth:	
4 Choice of infant feeding method	What did she decide to feed her baby? How did she make decision? How counselled? What did people tell her (e.g. counsellor, nurse, relatives if disclosed)?
5 HIV PCR testing of the child at 6 weeks of age	Was it done? If not, was she told? Did she get an appointment or not? This is point to probe on fragmentation and what kind of clinics and places woman had to visit when and what for.
6 Decisions around reproductive health (including contraception and family planning)	Is she on family planning? If yes, how did she decide? If, no, probe gently for reasons? What counselling did she get from health workers?
Long-term follow-up:	
7 Early participation in HIV care, initiation of ART when required, and ongoing adherence to medications, as well as continuation of contraception	Has she had a CD4 count done? Is she on ARVs? If yes, since when? How is she monitored / treated by the system? If not, what kind of information was she given?
8 For the child who is HIV-infected, participation in HIV care, initiation of ART when required and adherence to	• How was HIV diagnosed? Has a CD4 count been done? Is child on ARVs? If yes, since when and how is s/he monitored / treated by the system? If not, what kind of information

	Probes
medications	was she given about when to bring the child? Probe for further understanding of process and requirements and adherence issues. • How is the baby? Was it difficult when it was found that the baby is HIV positive? What does caring for the baby involve? • If not in the management plan of the system, what keeps her from going for treatment?

Ask questions on the following issues where necessary:

- Reasons why mothers do not come for follow-up in general – perceptions of health care provision.
- Community memory in terms of use of health care services (e.g. preference to go elsewhere)
- Community involvement in the care for HIV positive people in general – check on implications specifically for mothers and children
- What do mothers perceive the main difficulties to be that they experience in making healthcare decisions for herself and her infant?
- Probe ways in which mothers attempt to contend these problems.

We have mentioned to you that the aim of doing the interview is to find out what difficulties mothers experience to make decisions about health care.

- *If you had a say in making changes to the clinic or hospital, what would you do differently?*
- *What are the things on which you would like more information?*
- *How would you like to be treated differently by health workers? By family? By the community?*

Probes: reasons for doing things differently – barriers and enablers

Ending questions:

1 *We have been talking about the health system and decisions you had to make for yourself and your child.*

What would you say are the most important things that we have just discussed?

Summarise / paraphrase important points mentioned by participant(s) – also probe about things you picked up in the course of the interview that participant(s) does not put forward at this stage.

Have we missed anything?

2 *How did you experience this interview?*
Any suggestions to improve on the procedure as a whole in future interviews?

3 Where feasible, check out participant's willingness to be contacted again in future, either for further discussion or to read through bits of a report, to see if his/her/their views are reported accurately or for giving comments on materials that will be developed.

Thank participant for her participation.

Appendix 2

Appendix 3

Appendix 4

INFORMATION LEAFLET FOR HEALTH CARE USERS (MOTHERS)[8]

TITLE OF STUDY

Asserting rights: experiences of HIV-positive mothers accessing primary health in Tshwane Metro.

INTRODUCTION

We invite you to participate in a study on the difficulties mothers experience in making healthcare decisions for themselves and their babies and ways in which they try to overcome these problems. This information leaflet will help you to decide if you want to participate. Before you agree to take part you should fully understand what is involved. If you have any questions that this leaflet does not fully explain, please do not hesitate to ask the interviewer.

AIM OF THE STUDY

When a woman has a baby she has many choices and decisions to make. She gets education and counselling from various people and these messages are sometimes confusing. She might also face some difficulties in her personal life and all these things can contribute to making it difficult for her to make decisions about her own health and the health of her baby. But women also many times have ways in which they try to overcome these problems. The aim of this study is to find out:

- What are the experiences of HIV-positive mothers with regard to the many difficulties they face in making health related decisions.
- To establish the ways in which HIV-positive mothers attempt to overcome these problems.

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[8] The original was printed on a university letterhead

PARTICIPANTS IN THE STUDY

The participants in this study are mothers who come to the clinic for the follow-up and immunisation of their babies at 6 weeks.

PROCESS

We will ask you a number of questions about your personal situation, your pregnancy, the feeding of your baby, contraception and your plans after discharge. You may experience some of the questions as personal and sensitive, especially those about voluntary testing and counseling (VCT).

The interviewers will be Ms Carolé Cilliers.

DURATION OF AN INTERVIEW

An interview usually lasts between 45 minutes and 1 hour.

ETHICAL APPROVAL

This study has received written approval from the Research Ethics Committee of the Faculty of Health Sciences at the University of Pretoria (protocol number: S……./2007). A copy of the approval letter is available if you wish to have one. The study complies with the ethical norms of bodies that protect the interest of research participants like you, for example the Medical Research Council and the Health Professions Council of South Africa.

WHAT ARE YOUR RIGHTS AS A PARTICIPANT IN THIS INTERVIEW?

Your participation in this study is entirely voluntary. You can refuse to participate or stop at any time during the interview without giving any reason. Your withdrawal will not affect you or your or your baby’s treatment in any way. Your honest and open response to questions will help us to gather trustworthy information. However, if you feel uncomfortable with any of the questions we ask, you don’t need to answer and don’t need to give a reason.

RISKS

Although there are no known risks to participating in this interview, some of the questions may cause discomfort. The interview will also take some of your time.

BENEFITS

There will be no direct benefit for you in talking to us. The results of our study will help us to provide better services to our clients in future.

CONFIDENTIALITY

All information that you give will be kept strictly confidential. Once we have analysed the information no one will be able to identify you or your baby. Research reports and scientific journals will not include any information that may identify you, your baby or your clinic or hospital.

CONTACT PERSON

The contact person for the study is the project leader, Dr Anne-Marie Bergh. If you have any questions about the study please contact her at 083 438 5902. Alternatively you may contact Professor Bob Pattinson at (012) 373-0825.

INFORMED CONSENT

I hereby confirm that the interviewer has told me about the nature, conduct, risks and benefits of the study on the difficulties mothers experience in making healthcare decisions for themselves and their babies and ways in which they try to overcome these problems (protocol number: S……/2007). I have also received, read and understood the above written information (Information Leaflet and Informed Consent) regarding the study. I am aware that the results of the study, including personal details regarding the interview will be anonymously processed into research reports. I am participating willingly. I have had time to ask questions and have no objection to participate in the interview. I understand that, should I wish to stop the interview, my treatment and that of my baby will not be affected.

I have received a signed copy of this document.

Participant's name ……..
(Please print)

Participant's signature .... Date......................................

Investigator's name ....………………………………………………..
(Please print)

Investigator's signature .... Date......................................

Witness's name ...……...
(Please print)

Witness's signature .... Date.....................................

VERBAL INFORMED CONSENT

I, the undersigned interviewer, ..., have read and have fully explained the participant information leaflet, which explains the nature, purpose, conduct, risks and benefits of the study on the follow-up of women and babies in the first 6 weeks after birth (protocol number: S……/2007), to the participant named ...., whom I have asked to participate in the study.

The participant indicates that she understands that the results of the study, including personal details regarding the interview will be anonymously processed into a research report. The participant indicates that she has had time to ask questions and has no objection to participate in the interview. She understands that should she wish to stop the interview her treatment and that of her baby will not be affected.

Participant's Name ....……...
(Please print)

Person seeking consent ....……...
(Please print)

Signature ....……... Date.................................

Witness's Name ....……..

(Please print)

Signature ....……… Date.................................

Appendix 5

Table 1: Biographical information of participants

Name	**Age**	**Highest Educational level**	**Language**	**Nr of children**	**Age of infant (wks)[9]**	**Employment**
1. Prim	25	Grade 11	Sesotho	2	1	Worked until baby was born. Did promotion work at a supermarket six days a week. Not planning to return to this employment.
2. Patience Thabo	24 29	Grade 12 Grade 11	SiSwati SiSwati	1	3	Patience is unemployed, but wants to work. Thabo works as a waiter. He would like more permanent work.
3. Anna	28	Grade 12	Setswana	2	4	Works as a waitress at a garden centre and coffee shop six days a week.
4. Diane	22	Grade 11	IsiZulu	1	18	Used to be a till packer at a supermarket. She stopped working there eight months prior to interview, because she was sick and had to be transferred to the hospital. Hasn't gone back. She wants to work again, but her employment was terminated. Says she might look for other work later.
5. Lesego	29	Grade 10	IsiNdebele	2	6	Not working. Did domestic work for two months previous year. Did not give a reason for not continuing.
6. Cece	26	Grade 12	IsiZulu	2	2	Works at a supermarket seven days a week. Works as a general assistant at the juice bar.
7.Sarah	33	Not answered	Portuguese	3	29	Unemployed.
8. Palesa	29	Grade 9	Sesotho	3	1	Unemployed. "Cause I don't know, right know I'm still confused, with many things in my life. I would really appreciate if I can find a job, I must still look for one, but if one comes then I think I can rethink my life. But now I'm stuck somewhere.

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[9] Rounded to the nearest week

9. Judith	40	Diploma	Swahili	2	3	Worked as a teacher prior to birth of the baby. She has a legal secretary diploma. Wants to wait till the baby is at least four months old before she starts with another job.
10. Memory	27	Diploma	IsiXhosa	1	33	Works for an insurance company. Has a diploma in business management. Previously had a temporary job, but when she returns she will be permanently employed.
11. Alice	28	Not answered.	Setswana	3	4	Unemployed. Worked at a clothing chain for a few months in 2006.
12. Lerato	39	No formal schooling.	Sepedi	4	3	Works as a domestic worker two days a week.
13.Keneilwe	30	Not answered.	IsiXhosa	2	1	Works in a food factory. Currently on maternity leave.
14. Elizabeth	27	Grade 12	Sesotho	2	2	Works as an admin clerk volunteer at an HIV and AIDS facility. Receives a government stipend for volunteer work.
15. Mpho	28	Not answered.	Setswana	1	2	Works as a receptionist.
16. Dee and Kathlego	28 33	Diploma Grade 12	Tsonga Sepedi	2 3	2	Couple works in retail. She has a diploma in Information Technology (IT). He has a permanent job, she has a temporary position, working 3 days a week.
17. Immaculate	21	Grade 5	Sesotho	1	4	Unemployed.
18.Mandisa	35	Grade 12.	Setswana	1	4	Unemployed. Previously did temporary jobs. Last time she worked was 2 years ago. Has completed a home based care nursing course. Mentions at end of interview that she is worried about the many health visits, especially if she works again. Mother can maybe help out when she works.
19. Dineo	18	Grade 9	IsiZulu	1	2	Was in school when she fell pregnant - grade 10. Planning to return to school following year.

20. Cindy	22	Grade 10	IsiZulu	2	2	Unemployed.
21.Helen	30	Grade 7	IsiXhosa	2	3	Unemployed
22. Ayanda	23	Grade 10	Setswana	3	2	Unemployed. Previously worked at a hairsalon in Centurion when she was pregnant with 2nd child. Stopped working when he was born.