

**EXPLORING HIV RELATED STIGMA EXPERIENCED BY WOMEN ENROLLED IN
THE PREVENTION OF MOTHER TO CHILD TRANSMISSION (PMTCT)
PROGRAMME IN ETHEKWINI, KWAZULU NATAL
A DESCRIPTIVE PHENOMENOLOGICAL STUDY**

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**In Partial Fulfillment of the Requirements for the
COURSE WORK MASTERS DEGREE IN NURSING
(COMMUNITY HEALTH NURSING)**

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Date: March 2011**

Declaration

I Zamasomi PB Luvuno, declare that this dissertation entitled “Exploring HIV related stigma experienced by women enrolled in the Prevention of Mother to Child (PMTCT) programme in the EThekweni District, Kwazulu Natal” is my original work. It has not been submitted for any other degree or academic qualification as a thesis or any other University. I also declare that resources and information utilized in this work have been acknowledged in the reference list.

Mrs. Zamasomi P.B. Luvuno

Date

Mrs. J Naidoo

Date

Dedication

My Husband Sbusiso for his support and undying love.

My Sons, Minenhle, Buhle and Ndabuko, for never complaining and understanding and allowing me time to pursue my studies.

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Abstract

The purpose of this Qualitative study was to explore HIV related stigma experienced by women enrolled in the Prevention of Mother to Child (PMTCT) programme in the EThekweni District, Kwazulu Natal. Descriptive phenomenology informed the study design, data collection and analysis.

Despite increasing access to Prevention of Mother to Child Transmission initiatives, including anti-retroviral drugs, the Stigma of being HIV positive, particularly for women, largely outweighs the potential gains from available treatments. HIV/AIDS related stigma drives the epidemic underground and is one of the main reasons that people do not wish to know their HIV status

Purposeful sampling was used to select seven women attending PMTCT programme in the EThekweni District. These women were selected in four clinics in the District.

Data was collected through in-depth interviews lasting about 45 minutes to an hour. These interviews were tape recorded and later transcribed to aid analysis. The Colaizzi method of data analysis was utilized.

Four themes emerge from the data, each with three to eight subthemes confirming the experiences and presence of stigma during programme participation. All participants reported incidence of being stigmatized, particularly in the Health care setting. They took great strides to keep their HIV status confidential to a point of going against programme directives to ensure secrecy of their status thus avoid HIV related stigma.

Number of recommendations were made in relation to the PMTCT programme and if accepted will assist in mitigating stigma in HIV related stigma in the PMTCT programme and thus reduce vertical transmission.

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ABBREVIATIONS AND ACRONYMS

3TC	Lamivudine
ANC	Antenatal Care
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
ART	Antiretroviral Therapy
AZT	Zidovudine
d4T	Stavudine
DT	Dual therapy
DOH	Department of Health
EFV	Efavirenz
EPI	Expanded Programme on Immunisation
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency virus
LPV/r	Lopinovir/ritonavir
MTCT	Mother-to-Child Transmission of HIV
NDOH	National Department of Health
NHC	National Health Council
NSP	Strategic Plan

NVP	Nevirapine
PCR	Polymerase Chain Reaction
PMTCT	Prevention of Mother-to-Child Transmission of HIV
RTHC	Road to Health Chart
sdNVP	Single-Dose Nevirapine
SADOH	South African Department of Health
TDF	Tenofovir
UNAIDS	United Nations Program on HIV/AIDS
UNICEF	United Nations Children's Fund
UNMDG	United Nations Millennium Development Goals
VCT	Voluntary Counselling and Testing
WHO	World Health Organisation

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CHAPTER ONE

1. INTRODUCTION TO THE STUDY

The transition to motherhood and expecting a child is a big event in a woman's life that calls for adjustment and preparation for the new life. For some women, this is complicated by being diagnosed with HIV/AIDS during pregnancy. HIV/AIDS is a disease that not only affects the physical and psychological wellbeing of people living with it, but also their ability to interact socially with others because of the stigma associated with the disease. This study aims to elicit the experiences of stigma in HIV positive pregnant women enrolled in the Prevention of Mother to Child Transmission of HIV/AIDS programme.

1.2. Background to the study

HIV/AIDS is an emotionally charged issue that is frequently associated with fear, stigma and prejudice. Myths, misunderstanding, and mistreatment of HIV infected people can result from the sense of panic that surrounds HIV/AIDS (Engenderhealth, 2004). AIDS-related stigma manifests as anger and negative feelings towards HIV positive individuals, the belief that they deserve their illness, avoidance of people with HIV/AIDS, and support for public policies that restrict the human rights of those with HIV/AIDS (Herek, Capitanio, & Widaman, 2002).

1.2.1 Stigma Defined

More than four decades ago, Goffman (1963, p 3) defined stigma as "an attribute that is deeply discrediting", and proposed that the stigmatised person is reduced "from a whole and usual person to a tainted, discounted one". Erving Goffman conceptualised a stigma framework and described it as an attribute that was deeply discrediting within a particular social interaction. His theory is grounded in the concept of social identity that is based on establishing those who are

“normal” as separate from those who are different or “deviant,” the stigmatised. Goffman also described the relationship between stigmatising attitudes and acts of discrimination, with the former often resulting in the latter. In the current literature, acts of discrimination are often referred to as “enacted stigma,” while stigmatising attitudes are often referred to as “expressed stigma”. According to Herek et al., (1988) AIDS shares many characteristics with other diseases that are highly stigmatised, such as its perception to be unalterable, degenerative, and fatal; its contagiousness and transmissibility; and the repellent, ugly, and upsetting appearance of the afflicted in the advanced stages of the disease. They go on to state that this reaction is amplified by a tendency among a significant portion of the public to blame people living with HIV/AIDS (PLWHA) for their illness, since the acquisition is perceived to be as the result of immoral and voluntary actions, for example, participating in homosexual and promiscuous sex and the sharing of infected needles among injection drug users (Andrien and Chien, 2008).

Sabatier (1988) predicted discrimination at individual, community and national levels, which would have major implications for the epidemic. It was suggested that divides would be created between those who are vulnerable to infection and those who are more distant, and that the HIV epidemic has followed in many respects the trajectory of those who are most victimised by discrimination anyway has heightened that divide (Crewe, 1992).

1.2.2 Outcome of Stigma

The potential impact of stigma and discrimination has been of ongoing concern to those involved in addressing the HIV/AIDS epidemic. Jonathan Mann spoke of a third epidemic of discrimination that would follow the HIV and AIDS epidemic. He asserted that this third phase would be as central to the global AIDS challenge as the disease itself (Mann, 1987, cited in Parker, Aggleton, Attawell, Pulerwits and Brown, 2001). The first phase is the initial epidemic of HIV infection (i.e. the disease entering the community silently and unnoticed). The second phase is the

epidemic of AIDS, which appears when HIV triggers life-threatening infections. Thirdly, the phase of the epidemic of stigma, discrimination, blame and collective denial follows, which makes it difficult to tackle the first two effectively (UNAIDS, 2000). Stigma is an important factor in the type and magnitude of societal reactions to the HIV/AIDS epidemic (Malcolm et al., 1998). Stigma and discrimination relating to HIV/AIDS undermine public health efforts to combat the epidemic (Cameron, 1993; Goldin, 1994; Malcolm et al., 1998). Therefore, it is important to identify the correct and effective interventions for reduction of HIV/AIDS stigma, and to translate such evidence into practice to combat the HIV/AIDS epidemic. The discrimination and stigma are as deleterious as the disease itself (Mann, as cited in Parker & Aggleton, 2003).

Stigma is common when societies face problems that seem inexplicable or outside of their control, such as the HIV epidemic (Panos Institute, 1990). It is well documented that people living with HIV and AIDS experience stigma and discrimination on an ongoing basis. This impact goes beyond individuals infected with HIV to reach broadly into society.

Epidemiologists initially linked AIDS to already marginalised groups, identifying AIDS as an illness of the four H's: homosexuals; heroin addicts; Haitians; and haemophiliacs (Oppenheimer, 1988). When women were finally recognised as people with AIDS, they were perceived as vectors of the disease for their partners or their children (Trieckler, 1999). As Farmer noted, "the majority of women with AIDS had been robbed of their voices long before HIV appeared to further complicate their lives" (1999, p.62).

In other words, AIDS-related stigma reproduces and worsens existing inequalities. For example, women often experience the stigma of AIDS multiplied by the stigma that results from gender, sexuality, and racial/ethnic minority status (Parker & Aggleton, 2003; Sandelowski, Lame, & Barroso, 2004). Sandelowski et al. (2004) conducted a qualitative metasynthesis that integrated the findings of

93 studies exploring HIV positive women's experiences of HIV/AIDS related stigma. They concluded that perceived and actual stigma was pervasive in the women's lives. HIV positive women lived in fear of social rejection, violence, and discrimination from their relationships with their children, partners, relatives, friends, and health care providers. Women described female-specific stigma including the stigma associated with the assumptions that they infected their children, or had been infected via prostitution, promiscuity, and drug use. HIV/AIDS researchers have conceptualised the notion that stigma can influence women's sexual risk behaviour through its impact on HIV status disclosure to sexual partners (Gielen, O'Campo, Faden, & Eke, 1997; Gielen et al., 2000) and psychological distress (Clark, Linder, Armistead, Goffman, 1963).

Stigma and discrimination have a shameful history internationally. The first cases of HIV positive individuals diagnosed happened to be gay men in America. They were labelled as promiscuous, and as such, deserved the diagnosis because of their "unnatural" life style (Shilts, 1988). Furthermore, the first women to be diagnosed with HIV/AIDS were prostitutes and drug users, which helped to fuel the stigma associated with the diagnosis (Burkett, 1995; Shilts, 1988). HIV/AIDS is highly stigmatised in many countries, and people with HIV may experience social rejection and discrimination (Karim et. al., 1995).

In South Africa, it took a particularly horrendous form in the apartheid system. A major role that stigma plays in society is to create 'difference' and social hierarchy, and then, in turn, it legitimises and perpetuates this social inequality (Parker, Aggleton, Attawell et al., 2001). Discrimination arises out of any point of difference that can be consistently labelled; for example, physical deformity or disfigurement, racial differences, or any other factors that set up the person as different to the perceived norm. In this case the norm is generally defined in terms of who is powerful in the community (Goffman, 1963). Major focuses for discrimination have been on race, gender, sexual orientation, handicap, religion and age, amongst others. The attachment of discrimination to illness has a long

history with it impacting on people with mental illness and physical disorders such as cancer, TB, STDs and leprosy (Sontag, 1988). The nature of stigma and discrimination is complex, varying across time, person and context (Skinner and Mfecane, 2004).

1.2.3 Consequences of Stigma

This is mainly connected with sexual stigma. Stigma associated with HIV/AIDS is among the greatest barriers (Vidanapathirana et al., 2009) to preventing further infections, providing adequate care, support, treatment and alleviating the impact of the disease. There is evidence that HIV-related stigma makes it difficult for people to take actions to reduce their risks. For example, stigma can negatively affect people's abilities to access HIV education (India, 2002); exchange needles (Ford et al., 2004) and negotiate condom use (Roth, 2001). Stigma may even lead women who know they are HIV positive to breast-feed their infants, rather than to arouse suspicion of their sero-status through formula feeding (Doherty, 2006). It also can obstruct an array of HIV prevention interventions including HIV testing, harm reduction, treatment adherence support and prevention of mother to child transmission (Chesney & Smith, 1999). Evidence indicates that knowledge of one's HIV sero-positivity can lead to earlier treatment and improved outcomes, (Herek, 1990) and voluntary counselling and testing can lead to the practice of safe sexual behaviours (Flaskerud, 1997; Coates, 2000).

Even though HIV was first discovered in 1981 more than two decades ago, this disease continues to kill people like no other epidemic has done before. Internationally, studies and statistics indicate that HIV and AIDS is becoming a major health crisis, as the prevalence of HIV remains high. Globally, about 33.4M people were living with HIV by the end of 2008, (WHO/UNAIDS, 2009) with 70% of the HIV/AIDS burden in sub-Saharan Africa (SSA). South Africa has been identified as the epicentre of the HIV epidemic with an estimated 7.6 million people in this country living with HIV and AIDS (Development Bank of South Africa, 2007).

HIV/AIDS remains a major cause of infant and maternal morbidity and mortality in resource limited settings (McIntyre, 2005a, 2005b; Newell et al., 2004). In Uganda, by the end of 2007, about 1M people were living with HIV. Women are infected more than men across the age spectrum from birth to ages between 45 and 49 years (60% for women versus 40% for men) and this poses a high risk of mother-to-child transmission of HIV (MTCT). The annual incidence reached 132,500 new cases in 2005, including 25,000 mother-to-child transmissions which account for 95% of paediatric HIV disease (UAC, 2008). The risk of MTCT HIV ranges from 25 to 48% in populations that practice prolonged breastfeeding (De Cock et al., 2000; Austin, 2003; Katz & Nevid, 2005). In addition, AIDS-related stigma hinders the success of HIV prevention and care programmes by preventing women living with HIV from accessing the needed health and social services, disclosing their status to their partners, and talking openly about their sexual risk practices (Valdiserri, 2002).

It has emerged widely in literature that one of the reasons for the failure of HIV prevention strategies is that people do not disclose their HIV status early enough in order to receive the necessary support (Kebaabetswe, 2007). Fear of being identified as someone infected with HIV increases the likelihood that people will avoid testing for HIV, disclosing their HIV status to health care providers and family members, or seeking treatment and care, thus compromising their health and wellbeing (Nyblade et al., 2009). Berger et al. (2001) mention disclosure concerns relating to controlling information, keeping one's HIV status secret, or worrying that others who know the respondent's HIV status will reveal their stigma status. The fear of stigma was so overwhelming that, on diagnosis, the women were not concerned with the possible physiologic changes or death, but rather the psychosocial ramifications that accompany this disease. This fear became a barrier to women achieving the goals necessary for them to maintain and enhance their health. Women who have tested and disclosed their status have related a number of negative responses to their disclosure. Physical abuse related to HIV is a reality throughout the world. HIV-positive women in India have

endured rape and forced prostitution from their partners. Medley et al. (2009) summarised 17 studies from peer-reviewed journal articles on barriers to the disclosure of HIV status among women in developing countries. This review builds a strong case for the impact of perceived stigma on fear of disclosure of HIV status as these articles suggested that between 3.5% and 14.6 percent of women reported experiencing a violent reaction from a partner after HIV disclosure. Barriers to disclosure included fear of accusations of infidelity, abandonment, discrimination, and violence. Varga et al. (2006) reported on HIV disclosure among 31 women from Johannesburg, South Africa. Their study further proved that while many women disclosed their status to secure adequate infant care, disclosure often resulted in rejection, stigmatisation, and the withholding of financial support (Daftary et al., as cited by Dlamini et al., 2009). Some of the barriers to disclosure include the fear of discrimination; the anticipated disruption of relationships; concern about insurance benefits and employment; a desire to protect oneself and others emotionally, and in some instances, the possibility of verbal and physical abuse.

Furthermore, relevant studies done in Africa indicate that stigma is one of the causes of poor programme uptake in the area of HIV and AIDS (Peltzer, 2007). The literature reviewed has identified three main challenges which contribute to this poor PMTCT programme uptake, namely, 1) culture and gender related issues 2) stigma towards HIV positive individuals emanating from different levels within society and 3) poor resource utilisation (Thorsen et al., 2008).

HIV and AIDS is the one disease that knows no age, gender, social class or any other form of discrimination (Pretorius et al., 2005). However, women and children tend to be more affected by the disease than men (Thorsen et al., 2008). Relevant studies have shown that women account for 55% of the people living with HIV, with women in the age group of 25 to 29 years of age mostly affected, with a prevalence of up to 40% (Health Systems Trust, 2004). The literature has shown that the highest incidence of HIV infections has been found in the age

group 15 to 49 years, peaking in women in the age group of 20 to 30 years (Health Systems Trust, 2004). The women in the 25 to 29 years age group have prevalence 5.6 times higher than that of males (UNAIDS, 2008). Worldwide, 200 million women become pregnant annually, of which 2.5 million are HIV positive (UNAIDS, 2002).

1.2.4 Societal Influence of HIV related Stigma

Mann described male domination as a threat to the public health and the success of HIV prevention efforts (Mann, 1995). Sexism and gender inequity influence women's sexual risk practices in complex ways. Firstly, patriarchy and sexism compromise women's opportunities for economic and educational advancement. Poverty, racism, and sexism intersect to intensify women's challenges. Therefore, women are at higher risk for participating in sexual risk behaviours because of the disadvantages and dependencies associated with poverty and racism as already described.

In South Africa, stigma is of significant concern with this country's history of racism and other stigmatising beliefs (Skinner & Mfecane, 2004). These include the murder of Gugu Dlamini in December 1998 for openly stating that she was HIV positive (Baleta, 1999; Kortjaas & Msomo, 1998; Nicodemus, 1999; Rusnak, 1998); the murder of Mpho Mtloung and her mother by her husband, who then also committed suicide (TAC, 2000); not allowing HIV-positive children into schools (Sapa, 2002; Streak, 2001a); exclusions or attempted exclusions from the workplace (Ngqalaza, 2000a; Viol, 2000). Some authors in their study findings have argued that HIV and AIDS in the South African context is associated with black and poor women (Lercler-Madlala, 1997; Skinner and Mfecane, 2004). This form of prejudice results in pregnant black women being largely stigmatised at different levels of society (Lercler-Madlala, 2002). Other literature has shown that there is also an attachment of gender issues to the diseases, leading to women being blamed for spreading the disease. It has also been widely reported that in South Africa and other African countries, men blame

women for infecting them and spreading the virus (Lecler-Madlala, 1997; 2002). Reports of stigma are pervasive, extending even to the health professions. The AIDS Law Project reported that the Health Professions Council of SA did not act against 28 doctors who breached patient confidentiality. The patients were mostly domestic workers whose employers had been told of their diagnosis, many of whom were subsequently dismissed (Altenroxel, 2001).

African countries are viewed as patriarchal, whereby women have very little autonomy over their lives, they become preoccupied with concealing their status and anxious about involuntary disclosure, and do not tell anyone that they are HIV infected (Shisana and Davids, 2004). Studies from Tanzania and Kenya have shown that women who share HIV test results with their partners may experience a range of reactions from support and understanding to denial, accusations, discrimination, physical violence and abandonment (Maman et al., 2001; 2002; Temmerman et al., 1995). The findings of two studies conducted in Tanzania revealed that only 17% and 40% of the women, respectively, had disclosed their HIV status to their partners, even after a considerable follow-up period (Antelman et al., 2001; Kilewo et al., 2001). The main reasons cited for not disclosing their HIV status were fear of stigma and divorce (Antelman et al., 2001; Kilewo et al., 2001); fear of losing confidentiality (Antelman et al., 2001); women's low decision-making power, communication patterns between partners, and male partners' attitudes to VCT (Maman et al., 2001).

1.2.5 HIV/AIDS in Children

In 2009 it was estimated that there were 2.5 million children living with HIV worldwide (UNAIDS, 2009). Furthermore, it has been argued in various literature that over 95% of HIV infections in children below the age of 15 years are due to vertical transmission or mother-to-child transmission (MTCT) (Peltezer et al.,

2005; UNAIDS, 2006). According to the literature reviewed, the vast majority, about 90% of these HIV-infected children are in sub-Saharan Africa (UNAIDS, 2004). Half a million children have already died from HIV and AIDS, and this is undermining child survival gains made in earlier years through child survival programmes (UNICEF, 2003, p.8). In the absence of effective intervention, the risk of mother-to-child transmission of HIV is predicted to be around 15-30% without breastfeeding, and can go up to 30-45% with prolonged breast-feeding (UNAIDS, 2005).

1.2.6 The PMTCT Programme

At the end of year 2000, a decision was made by the South African National Department of Health (NDoH) to implement a pilot programme for the prevention of mother-to-child HIV transmission (PMTCT) (NDoH, 2000). A total of 18 pilot sites, 2 in each of the 9 provinces, have been purposively selected to include an equal representation of urban and rural sites, as well as a mix of primary and secondary level facilities (NDoH, 2008). The aim of the PMTCT programme as explained by the NDoH (2000) was to offer voluntary counselling and testing, and to issue single dose Nevirapine to all women attending Ante Natal Care (ANC) clinics if identified as HIV infected, together with their infants (NDoH, 2004).

HIV positive pregnant women who are not eligible for lifelong ART are given a PMTCT regimen for prophylaxis to reduce mother-to-child transmission. The regimen includes antenatal, intrapartum, and postnatal components. The maternal PMTCT regimen is: **Antenatal** Zidovudine (AZT) from 14 weeks; **Intrapartum** single-dose Nevirapine (sdNVP), 3 hourly AZT, and a **postpartum** single dose of Tenofovir (TDF) + Emtracitabine (FTC) Antenatal AZT which is initiated from 14 weeks gestation or as soon as possible thereafter. AZT is contra-indicated if laboratory findings indicate that the mother is severely anaemic (i.e. Hb<8g/dl) or if the woman is clinically pale. Iron and foliate supplementation are provided to all antenatal women routinely. Women return monthly for AZT (PMTCT Guidelines, 2010).

Initiation of ART is recommended for all HIV positive pregnant women with a CD4 cell count of 350 or less, irrespective of WHO clinical staging, and for all HIV-positive pregnant women in WHO clinical stage 3 or 4, regardless of CD4 cell count, and women co-infected with TB/HIV. Pregnant women initiated on lifelong ART are seen two weeks after ART initiation, and then monthly. Monitoring for treatment failure and toxicity follows the recommendations in the adult ART guidelines. The HIV-exposed infants are initiated on NVP prophylaxis immediately after birth. Infants born to HIV-positive women should receive daily nevirapine for six weeks, with dosing determined by the weight of the infant. (NDoH, PMTCT Guidelines, 2010)

The women are counselled on infant feeding. To choose between exclusive breast-feeding on demand, or exclusive formula feeding. All women, whether on ART or not and their infants should receive follow-up consults at the health facility within the first three days postpartum, and should be seen again at the health facility prior to six weeks postpartum. Thereafter, follow-ups should occur at the well-infant clinics, as per the IMCI guidelines. HIV exposed infants then undergo a PCR test at six weeks. (NDoH, 2010)

According to the South African NDoH, (2007) during the 2005/06 financial year, 70% of the ANC attendees were counselled and tested, of whom 26% tested HIV positive, and 60% of those who tested positive received Nevirapine (NVP) (NDoH, 2007). These results show that even with PMTCT being universally accessible, not all women receive the full package of the prescribed PMTCT programme.

Although the South African Government has put some strategies in place to ensure that ARVs are accessible to HIV positive women, there seem to be other stumbling blocks to the full utilisation of these services. The literature has

identified various reasons for women not to enroll or adhere to the PMTCT programme guidelines, and one of these reasons has been HIV related stigma (Pelzer et al., 2007). Studies done elsewhere on HIV and AIDS indicate that HIV related stigma is one of the barriers which insidiously undermines the PMTCT programme (Kebatswe, 2007). This HIV related stigma has been demonstrated by poor adherence to treatment guidelines because of fear of revelation of being HIV positive (Thorsen et al., 2008; Kebaatswe, 2007) The findings of a study conducted in Malawi which aimed to identify potential stigma initiators in the PMTCT programme showed that, because of HIV related stigma, some pregnant women prefer not to test, as they fear that their husbands would accuse them of having been unfaithful, hence the need to test for HIV (Thorsen, Sundby and Martison, 2008). Women who do test positive and disclose their status face dramatic negative results on their own and with their children (Viva et al., 2008). Fear of being identified as someone infected with HIV increases the likelihood that people will avoid testing for HIV, thereby disclosing their HIV status to health care providers and family members, or seeking treatment and care, thus compromising their health and wellbeing (Nyblade et al., 2009).

This argument is further supported by the findings of a study conducted in the Eastern Cape province of South Africa at 20 antenatal clinics (ANCs) whereby ANC records reviewed showed that 76% of ANC attendees received HIV counseling during their clinic visits, but only 67% end up undergoing HIV testing, (Peltzer et al., 2007) meaning that 33% of the women who attend the ANC clinic never undergo testing (Peltzer, 2007). These findings may be an indication that a number of HIV positive pregnant women miss the opportunity to benefit from the PMTCT programme for fear of being stigmatised because of their HIV status.

1.2.7 Stigma in the Health Sector

The literature has also indicated that the health sector is sometimes another setting, other than the community where HIV-positive individuals and those

perceived to be infected experience stigma and discrimination (Andrewin & Chien, 2007). Stigma and discrimination by health workers compromises their provision of quality care, which is critical for helping patients adhere to medications, and to maintain their overall health and wellbeing. Stigma also acts as a barrier to accessing health services for both the general population, as well as the health providers themselves if they contract the virus (Nyblade et al., 2009).

The renowned HIV physician and medical anthropologist Paul Farmer (2005) has referred to the harm inflicted upon individuals by systems of oppression and inequality collectively as “structural violence”, and has insisted that mitigating HIV risk depends primarily on the freedom of disenfranchised women to make decisions, rather than their knowledge or skill levels (Farmer, 1999). This is seen as one of the reasons women don’t access health care. As a result of their culture and the place of women in the community, they feel they need permission to make decisions. In addition, HIV/AIDS researchers and clinicians conceptualise poverty as a root cause of HIV among women (Farmer, 1992, 1999, 2005; Parker, Easton, & Klein, 2000; Poundstone, Strathdee, & Celentano, 2004). Unequal access to education, employment and economic resources diminish women’s control over their lives and their negotiating power in relationships. Poverty also restricts women’s sexual networks, and increases their likelihood of unsafe injection drug practices and exchange or survival sex (Kalichman, 2000). Women’s lack of basic needs may prevent them from prioritising safe sex, forcing them into unhealthy and risky sexual situations, or preventing them from accessing prevention interventions and risking reduction messages.

A study conducted in Botswana which aimed at identifying factors that hindered women from participating in PMTCT programmes, showed that the negative attitudes of health workers were some of the barriers to patient participation in PMTCT programme uptake (Kebaabetwe, 2007). A similar study conducted in

Belize, (Latin America) showed that pregnant women were more likely to participate in the PMTCT programme if the health providers had positive attitudes towards the HIV infected pregnant women (Andewin et al., 2007). Furthermore, it has been found that a lack of support from the male partners was cited as part of the reason for not wanting to participate in the PMTCT programme (Kebaabetswe, 2007).

HIV-related stigmatisation is both a social phenomenon and a process that results in a powerful and discrediting social label (Link and Phelan, 2008). Stigmatising individuals due to their HIV status has been found to radically and negatively change the way these individuals are viewed and treated by others (enacted/attributed stigma), and how they view themselves (self/personal stigma) (Chiu et al., 2008). For pregnant women who consider disclosing their HIV status, the thought of being stigmatised by their community and significant others often elicits fears of abandonment, ostracism, domestic violence, or being blamed (felt stigma) (Viva, Thorsen et al., 2008). Studies have shown that such women tend to opt out of being tested (if tested, they rarely disclose), or do not complete their scheduled visits, or do not abruptly cease breastfeeding as recommended by the programme (Makin et al., 2007).

Until recently, studies conducted on HIV related stigma have focused on the HIV programmes' utilisation. No study has been conducted to determine how these women experience the stigma directed at them. In South Africa, there has been no study conducted to explore the how HIV positive pregnant women are experiencing HIV related stigma.

1.3 Problem Statement

Since their recognition in 1981, HIV and AIDS have evoked very strong emotional responses. Stigma often heightens existing prejudice and inequalities for people who are already socially marginalised and closely associated such as women, sex workers, men having sex with men, and drug users (Weiss and Ramakrshna, 2001). People who are, or are presumed to be HIV positive have

been subject to a variety of negative reactions, including physical and verbal abuse.

In South Africa, the political response to the HIV and AIDS epidemic has resulted in further exposing those affected to stereotyping, prejudices and political injustice (Grundling, 2001, p.8). People living with HIV and Aids (PLWHA) in this country still have difficulties with stigma and discrimination, and this area of the disease is largely ignored. As with most other countries worldwide, South Africa has reported a large number of incidents linked to HIV related stigma, including the murder of the HIV infected and affected individuals. (Baleta, 1999; Kortjaas & Msomo, 1998; Nicodemus, 1999; Rusnak, 1998) and some suicides (TAC, 2000). Studies conducted on HIV related stigma in South Africa have explored stigma in HIV infected people and adherence to treatment, but not specifically directed at pregnant women who are on a PMTCT programme (Mokoae et al., 2007; Naidoo et al., 2007). It is therefore important to explore the stigma as experienced by the women enrolled in the programme, as this may give insight as to how these women experience this stigma, and how it affects their participation and adherence to the PMTCT programme guidelines. Little attention has been paid to this issue, particularly in low-resource countries grappling with the rapidly increasing HIV epidemic.

1.4 Purpose of the Study

The purpose of this study is to explore the HIV positive pregnant women's lived experiences on HIV related stigma with the focus on those who are participants in the PMTCT programme.

1.5 Objectives of the study

1. To explore the HIV positive pregnant women's lived experiences of HIV related stigma.

1.6 Research Question

1. What are the HIV positive pregnant women's lived experiences of HIV related stigma?

1.7 Operational definition of terms

Experience:

General Definition:

As a noun this refers to knowledge and familiarity (Collins, Thesaurus A-Z, 2004, p 253).

Operational Meaning:

It is the perception of the women in relation to their feelings during the PMTCT programme.

Pregnant woman:

General Definition:

The period from conception to birth. After the egg is fertilized by a sperm and then implanted in the lining of the uterus, it develops into the placenta and embryo, and later into a fetus. Pregnancy usually lasts 40 weeks, beginning from the first day of the woman's last menstrual period, and is divided into three trimesters, each lasting three months. (Rao, 2010)

Operational Meaning:

Women who have had their pregnancy confirmed by a health worker.

HIV Exposed Babies:

General Definition:

Infant born to an HIV-positive woman (PMTCT guidelines, 2010).

Operational Meaning:

Babies born to HIV positive mothers, following enrolment in the PMTCT programme.

PLWHA:*General Definition:*

People living with HIV-Aids (UNAIDS Terminology, 2008).

Operational Meaning:

People who have been tested and have been found to be HIV positive or to have full-blown Aids.

HIV positive woman:*General Definition:*

Refers to women who have taken an HIV test which showed a positive result and who know their result. (PMTCT Guidelines, 2010).

Operational Meaning:

This refers to pregnant women who have contracted HIV, who test positive for antibodies to HIV.

PMTCT Repeat cases*General Definition:*

Prevention of mother-to-child transmission in HIV cases enrolled more than once on the programme.

Operational Meaning:

Women who have been through the PMTCT programme with a previous pregnancy.

PMTCT:*General Definition:*

Transmission of HIV from an HIV-positive woman to her child during pregnancy, delivery, or through breastfeeding. The term is used because the immediate source of the infection is the mother, and does not imply that any blame is attributed to the mother (PMTCT Guidelines 2010)

Operational Meaning:

This means methods used to prevent the transmission of HIV from mothers to their babies during pregnancy, intra-partum and post-delivery including modified delivery methods and feeding practices.

Rural Clinic:

General Definition:

Pertaining to less populated non-urban areas (en.wiktionary.org/wiki/rural).

Operational Meaning:

Clinics serving the informal settlements and/or areas under Kings and Indunas.

HIV related Stigma:

General Definition:

According to Collins Thesaurus (2001, p.694) stigma can also be called disgrace or dishonour.

Operational Meaning:

For the purpose of this research stigma will be viewed as any action inflicted on HIV positive pregnant women to embarrass or belittle them because of their HIV status.

Urban Clinic:

General Definition:

Relating to, or concerned with a city or densely populated area; "urban sociology"; "urban development"(wiktionary.org, 2010).

Operational Meaning:

Based within the CBD or within a 20 km radius of the city of Durban.

Mother to Child Transmission:

General Definition:

Vertical transmission, also known as **mother-to-child transmission**, is the transmission of an infection or other disease from mother to child immediately before and after birth during the perinatal period. (Answers .com, 2010).

Operational Meaning:

Transmission of HIV from an HIV positive woman during pregnancy, delivery or breast feeding to her child. In this study this term will be used interchangeably with vertical transmission.

1.8 Significance of the Study

Paediatric HIV remains an important public health problem in HIV high-burden countries, with more than 90% of new HIV infections in children occurring through mother-to-child transmission (MTCT).

In South Africa in 2006, an estimated 38 000 children acquired HIV infection around the time of their birth, and an additional 26 000 children were infected through breastfeeding (Risspel et al., 2009). This is in spite of the availability of preventive services such as the PMTCT programme. Studies have shown that such women tend to opt out of being tested (if tested, they rarely disclose), opt out of PMTCT programmes, do not complete the scheduled visits, or do not abruptly cease breastfeeding as recommended by the programme (Rispel et al., 2009; Delva et al., 2006; Spensley et al., 2009). The 2002 evaluation of South Africa's PMTCT of HIV at 18 sites reported that 56% of antenatal attendees were tested (Thorsen et al., 2008). Studies indicate that women identify programme characteristics and activities that might inadvertently disclose their HIV+ status potentially initiating the stigmatisation process. They would rather not test so as to avoid testing positive.

Effective implementation of the PMTCT programme has the potential to allow South Africa to fulfil the Millennium Development goals (MGD) 4, 5 and 6 (PMTCT Guidelines, 2010). The direct experience of stigma is terrible when you consider how it impacts on those who feel the discrimination. Stigma impacts beyond the individual infected with HIV, to affect all those associated with the disease. It can also impact on society more generally, by extending the epidemic, and undermining whatever behaviour and treatment interventions are already in

place. Thus interventions need to be introduced to reduce stigma and encourage acceptance (Skinner and Mfecane, 2004).

The health care setting has been identified as one of the major settings in which stigmatisation urgently need to be addressed. While many of the studies conducted thus far were conducted among health care workers (HCWs) in Africa (Nyblade et al., 2009; Nassali et al., 2009), fewer studies have investigated the phenomena among HCWs in Latin America and the Caribbean. A study conducted among sports coaches in Barbados emphasised the need for understanding the experience and expression of AIDS stigma among those delivering HIV/AIDS services (such as health care providers) in diverse cultures, as a first step towards the development and cross-cultural validation of tools for assessing stigma, and subsequently, for the design of targeted interventions. As a corollary, little is known or documented about the attitudes and practices of HCWs in Belize regarding the treatment of HIV/AIDS patients. (Chien and Andrewin, 2006).

The attachment of gender discrimination to HIV stigma has led to women being blamed for spreading the epidemic. Thus women are contradictorily expected to provide sexual services to men generally, to be chaste and pure, and to take on the responsibility of preventing pregnancy and disease (Crewe, 1992; Leclerc-Madlala, 2002). There are many examples at a national level of discrimination introduced by socially conservative governments, including policies of restriction of admissions, deportation of foreigners and mandatory testing. A prime impact of discrimination is that it pushes the epidemic underground, forcing people who have contracted HIV, and anything else associated with the disease, into hiding. An acknowledgement of HIV becomes difficult, if not impossible. Likewise, any association with the disease or people with HIV can be a basis for that person being excluded from their community, so it is denied. The disease itself then remains hidden, so its perceived threat is reduced. It also makes the disease someone else's problem. The stigmatising beliefs then facilitate the use by individuals and communities of denial and distancing as defensive processes

against the epidemic, again reducing the need to adapt (Skinner, 2001). Distancing or creating barriers between those infected and the rest of the population consumes considerable energy that could be more profitably used, and robs the intervention of some of the best advocates for behaviour change, namely those who are directly affected. Thus the epidemic disappears, or at least has few public faces, leaving the space open for the scape-goating of any person or group associated with the disease. These scape-goating processes can be dangerous, as they pin the blame on a small section of the population, leaving the rest with the mistaken belief that they are safe (Douglas, 1995; van der Vliet, 1996). A greater problem arises when those with the power to construct interventions use discrimination as a basis for not implementing such programmes. For communities as a whole, or for those responsible for structuring interventions, blaming infected people can be a substitute for tackling the problem itself. So even when interventions are developed on this basis, they are constructed in such a way as to discriminate against those in affected groups, and to reinforce a false sense of safety in the majority of the population.

Discrimination has significant impacts on diagnosis and treatment. For the individual, it can delay diagnosis, and can therefore also delay entry into treatment and adoption of a healthy lifestyle. There is no motivation to be tested, as the person sees no benefit, when the diagnosis of HIV is seen as equivalent to death, and they are likely to experience discrimination (Abdool Karim, Tarantola, Sy & Moodie, 1992). In certain contexts, research respondents have been shown to be more fearful of the stigma than of the disease itself, so even with treatment, stigma may be a block to access (Lie & Biswalo, 1994). This has already been shown to be a problem in the case of PMTCT, where HIV-positive women fed into their sense of self, causing them to feel compromised and to blame for their situation. Similar results were found with a sample of HIV positive women (Strebel, 1993). When this stigma is internalised it might influence the ways affected individuals look at themselves and how they interact with others,

including health care providers (Lee, Kochman & Sikkema, 2002). This again impacts on a person with AIDS coming to terms with his/her illness.

The results of the study will be shared with programme managers to help review programme processes that may be stigmatising women in the PMTCT programme unduly, causing them to drop out of the programme.

As programme participants, HIV positive women were given a voice to share their experiences. Such experiences are used to empower other women who find themselves pregnant and HIV positive, and who need to be part of the PMTCT programme. The findings and recommendations will be forwarded to PMTCT programme managers to allow the HCW to hear the voice of the patients.

1.9 Conclusion

This chapter discusses the background of the study, the purpose of the study, research objectives and the significance of the study for HIV positive women enrolled in the PMTCT programme in the eThekweni District. The outcomes of this study are hopefully going to give insight to the Health Care workers who work with the HIV positive women on a daily basis on how to mitigate the stigma that may be felt by the women in the PMTCT programme. The aim is to increase programme adherence and improve PMTCT outcomes.

CHAPTER 2

2. LITERATURE REVIEW

2.1 INTRODUCTION

This chapter reviews the empirical evidence on HIV and AIDS related stigma, with a special emphasis on pregnant women. The following search databases were utilised for the literature review, Medline-Ebscohost, Pubmed, CINAHL, Science Direct, Cochrane Library, LWW Journals full text and Biomed Central. The following search terms were entered on the data bases: “PMTCT and stigma”, “HIV and AIDS related stigma”, “Stigma in the health care setting”, “Barriers to PMTCT”, HIV and AIDS disclosure” and “gender issues in HIV and AIDS”. Approximately 165 articles were retrieved, and 118 were found to be relevant to the study.

2.2 Introduction to the Phenomenon of HIV related stigma

Although the study is phenomenological in approach, literature review was done to provide context of the phenomenon of stigma in relation to HIV/AIDS and in particular to PMTCT.

Most of the research on HIV/AIDS stigma has been conducted in the US, a country with large research resources, an early epidemic, and pronounced stigmatisation of gay men, and African-Americans and Haitian immigrants as carriers of HIV/AIDS (HSRC, 2005). Considerable research attention is now being focused on HIV/AIDS research in general in Africa, because of the severity of the African epidemic, the politicization of the HIV/AIDS issue, and the fact that HIV/AIDS seems to be highly stigmatised in the region. However, the relative lack of scientific research on the manifestations of HIV/AIDS-related stigma in sub-Saharan Africa still presents a serious challenge to the understanding, alleviation and prevention of HIV/AIDS-related stigma (Lorentz & Morris, 2003). The problem of HIV/AIDS stigma in Africa has been raised in related research on

barriers to VCT, treatment, care and adherence (Uys, 2003; Weiser, Wolfe, Bangsberg, Thior, Gilbert, Makhema, Kebaabetswe, Dickenson, Mompati, Essex & Marlink, 2003); on quality of life (Kigozi, Wabwire-Mangen, Black, Sewankambo, Serwadda, Gray, Wawer & Wu, 2004); and on social responses to HIV/AIDS and gender related stigma (Leclerc-Madlala, 2002).

2.3 Stigma defined

In regard to racism, the tendency to define a concept so that it includes an ever-widening range of phenomena has been dubbed 'conceptual inflation' (Miles, 1989). Like racism, stigma has suffered from conceptual inflation because much of the research on stigma defines it as something that results in discrimination (Link & Phelan, 2001), or does not clearly separate the two concepts. Conflating stigma and discrimination is not often perceived as a problem, because the major concern about stigma is that it can cause unfair discrimination.

'Stigma' is a Greek term denoting a mark that, in ancient times, was burned or cut into the flesh of an unsavory character, a traitor, criminal, or slave (Harvey, 2001). Goffman (1963, p.3) defined it as "an attribute that is deeply discrediting within a particular social interaction", as a "spoiled social identity" and "a deviation from the attributes considered normal and acceptable by society" Following this interpretation, Herek (2002) defines HIV/AIDS stigma as an enduring attribute of an individual infected with HIV who is negatively valued by society, which thus disadvantages and discriminates against people perceived as having HIV/AIDS, and is directed at individuals, groups, and communities which are seen, or assumed to be associated with HIV positive individuals. Alonzo and Reynolds, (1995) for example, provide a more complex reading of Goffman, suggesting that stigma is not merely an attribute, but represents a language of relationships, as labelling one person as deviant reaffirms the normalcy of the person doing the labelling (Goffman, 1963 , as cited in Alonzo & Reynolds, 1995). UNAIDS defines HIV-related stigma and discrimination as: "... a 'process of devaluation' of people either living with or associated with HIV and

AIDS ... Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status."

People allocate more blame to those who contract stigmatised diseases that are perceived as controllable and stable, than to those who have supposedly less controllable and less stable stigmatised diseases (Weiner, Perry & Magnusson, 1998). Attributing stigmatized medical conditions such as obesity or HIV/AIDS to a lack of personal responsibility, (such as over-eating) or to the perceived negative characteristics or behavior of a specific group (such as promiscuity among gay men) helps to distance the 'moral majority' from risk (Munyinda et al., 1997). Risks perceived to be the most serious and the most easily controllable are those which help people to legitimise moral principles (Joffe ,1999). STIs form a potent moral vehicle, since both disease and sexuality have long been associated with the 'other' (Crawford, 1994). People with HIV/AIDS may not have any visible signs of the disease, yet they are more likely to be stigmatised because others may view them "as contributors to their own problems and unworthy of the care directed to more legitimate victims of illness" (Jillings & Alexis, 1991:62). Alonzo and Reynolds (1995:304) defined stigma as "a powerful and discrediting social label that radically changes the way individuals view themselves and are viewed as persons". Insideout Research (2003) describes a large collaborative study on stigma in South Africa, and reports that stigma "can be felt (internal stigma), perceived or emic. Felt stigma is seen as a complex process that involves internalising and devaluation from people around the PLWHA (Nyblade, 2003). This type of stigma includes the thoughts and behaviors of the person's own negative perception based on his or her own knowledge of his/her HIV positive status (Geef et al., 2008). Emic refers to the felt part of the stigma leading to unwillingness to seek help and access resources. Perceived stigma refers to an individual's perception of social attitudes towards the PLWHA, and his or her personal knowledge of being infected (Berger et al., 2001; Sandelowski et al., 1995). The indicators for internal stigma are self-exclusion and social withdrawal (Siyamukela, 2003). On the other hand, enacted stigma refers external stigma, and etic, leading to

discrimination on the basis of HIV status, or association with someone who is living with HIV/AIDS. External stigma refers to all types of stigma directed at PLWHA as experienced and described by them. This refers to the enacted type of stigma leading to discrimination on the basis of HIV status (Siyamukela, 2003). Studies indicate that people often act in ways to reduce opportunities for enacted stigma as a form of self-protection. External stigma is demonstrated and indicated by avoidance, moral judgment and rejection. The third type of stigma is associated stigma; this is another form of external stigma. Associated stigma is stigma that is directed at people who work or associate with PLWHA.(Siyamukela,2003)

Nyblade (2003) reported on the results of 700 interviews with community members, persons living with HIV/AIDS, youths, caregivers, religious leaders, NGOs, and employers in Ethiopia, Tanzania and Zambia. The objective was to disentangle stigma, and thus provide a four-part framework based upon the content analysis of their interviews. The study suggested that stigma could best be understood from the perspective of (i) causes of stigma; (ii) context of stigma; (iii) experiences of stigma; and (iv) effect of stigma on programmatic efforts.

2.4 Stages of Stigma

Biology is a vital factor in understanding variations in the strength and content of stigma within a disease. Stigma is not static, Stigmatisation changes as the disease itself progresses through various biological stages. These changes can affect how stigma is experienced by PLWHA. Alonzo and Reynolds (1995,310) suggest that in different phases of HIV/AIDS, PLWHA experience stigma differently. They describe this changing experience of stigmatisation as a 'stigma trajectory' with four phases: "(1) at risk: pre-stigma and the worried well; (2) diagnosis: confronting an altered identity; (3) latent: living between illness and health; and (4) manifest: passage to social and physical death". They argue that we need to "conceptualize how individuals with HIV/AIDS experience stigma and to demonstrate how these experiences are affected by changes in the

biophysical dimensions of HIV/AIDS". Link and Phelan (2001) articulate three mechanisms of stigma. One is direct discrimination on a person-to person level, where activities devalue, reject, exclude or blame the other person. The second is structural discrimination, in which social contexts, such as a sign identifying an HIV/AIDS clinic enforce stigma without person-to-person actions. The third mechanism is self-stigmatization, a socio-psychological process that operates through the stigmatized person. Stigmatised persons apply labels to themselves, believe in these labels, and live accordingly. (Link & Phelani,2001)

In the case of care-givers stigmatising the patients, evidence of stigma appears in three forms in nursing and patient care, according to Jillings and Alexis (1991, 305): "(1) the labels and stereotypes attached by society to particular illnesses; (2) the patient's behaviors toward others as a result of feeling stigmatised; and (3) the values and assumptions of nurses themselves in relation to selected illnesses". Nurses and other health workers who care for persons living with HIV/AIDS have their own emic view of stigma that may lead them to promulgate prejudice and discrimination toward their patients (Jillings and Alexis, 1991,304).

2.5 Stigma, discrimination and power

The blaming model of stigma as described in the HSRC (2005) documents explains the politics of stigma without resorting to a functionalist definition of stigma. The process of stigmatisation helps to create a sense of control and immunity from danger, at an individual and a group level, as it distances people emotionally from risk (HSRC, 2005). The choice of who is identified as the outgroup depends on personal identities and historical power relations, and is thus highly variable. For example, Joffe's work has shown that some black South Africans blame Western scientists for HIV/AIDS, while some white heterosexual British men blame black Africans for it (Joffe, 1999). These socially constructed representations are all functional to the individual in distancing him or her from risk and thus reducing anxiety, but they only result in discrimination, and the reproduction of structural inequalities when other enabling circumstances such

as the power and opportunity to discriminate, come into play. The status loss ascribed to the stigmatised by the stigmatiser may lead to discrimination against stigmatised people, depending on the existence of power differentials and an enabling context. It may also result in an internalization of stigma. When a particular group of stigmatising ideas is validated by a powerful person or group, (in the media, in communities and so on) and deployed as part of broader power struggles, it becomes pervasive, entrenched and very difficult to shift. The powerful nature of dominant group 'othering' in a society can override other representations, and can even cause widespread self-stigmatisation (HSRC, 2005). A major role that stigma plays is that it separates people, creating a feeling of superiority for those who are not affected by the stigmatising trait, and establishing a feeling of shame in or towards the group which is stigmatised (Skinner & Mfcecane, 2004). To stigmatise, the stigmatiser, the person who inflicts stigma is in a position of power, and this also allows the stigma to take effect. This means that those in positions of power like health workers, who hold power, are effectively able to stigmatise PLWHA.

2.6 Mechanism of Stigma and adherence

For those people who have access to ARV medications, adherence is essential. In contrast to other chronic illnesses, HIV requires very high medication adherence rates in order to decrease the viral load, and to increase CD4 counts. Strict adherence is also required in order to avoid the development of medication resistance which would render the drugs ineffective at preventing viral replication. Researchers have investigated stigma as one of a number of factors related to varying ARV medication adherence. (Dlamini et al, 2009) There have been several studies on ARV medication adherence in Southern Africa that have demonstrated the challenge of maintaining high medication adherence, as well as pinpointing stigma as one of the significant barriers to medication adherence. Nachega et al. (2001) documented a strong relationship between the failure to refill ARV medication prescriptions and survival in a large sample of patients in South Africa. This further supports the need for maximum adherence to HAART.

It is possible that refilling a prescription is a trigger that results in increased stigma. Wolfe et al. (2003) interviewed 112 patients in Botswana and explored the relationship between HIV stigma and adherence to ARV medications. Ninety-four percent of the patients reported keeping their HIV status secret from their community and 69% from family members. Forty percent reported that they had delayed getting tested for HIV. Much of the failure to disclose was described as being related to perceived HIV-related stigma. Nachegea et al. (2001) examined adherence in a sample of 66 patients with HIV in Soweto, South Africa. They reported that adherence decreased considerably, in relation to the fear of being stigmatised by a sexual partner (Nyblade et al., 2009).

Stigma and discrimination have been identified internationally as the main barriers to HIV control and prevention in every country and region of the world, posing challenges to preventing further infections, alleviating the impact, and providing adequate care, support, and treatment. In health care settings, HIV-related stigma discourages people living with HIV and AIDS (PLWHA) from seeking care if they have previously experienced unwelcoming treatment, or if their confidentiality has not been respected. Previous studies have documented service providers' discriminatory attitudes and behaviours toward PLWHA, and the direct negative consequences of this on the quality of life for PLWHA. Factors contributing to these stigmatising and discriminatory responses include lack of knowledge, such as basic knowledge of HIV/ AIDS and universal precautions, provider attitudes, and perceptions that caring for PLWHA is pointless because HIV and AIDS is incurable (Sheng wu et al., 2008). There have been several studies on ARV medication adherence in Southern Africa which have demonstrated the challenge of maintaining high medication adherence as well as indicating stigma as one of the significant barriers to medication adherence. Weiser et al. (2005) examined barriers to medication adherence in a sample of 109 patients, using both qualitative and quantitative research methods. The principal barriers to medication adherence were financial constraints (44%), stigma (15%), travel/migration (10%), and side-effects (Dlamini, et al., 2009).

Experienced and perceived stigma and discrimination are associated with a reduced utilisation of prevention services, including programmes to prevent mother-to-child transmission (Zukoski and Thornburg, 2009).

Studies in Senegal and Indonesia documented that men who have sex with men, and injecting drug users, respectively, often avoid or delay accessing HIV-related services, including treatment for other sexually transmitted diseases. Likewise, researchers in Botswana and Jamaica found that stigma leads many people to seek testing and treatment services late in the progression of their disease, often beyond the stage of optimal drug intervention (Bond et al., 2002). (Nyblade, Stangl et al., 2009). Researchers have investigated stigma as one of a number of factors related to varying ARV medication adherence. Using a three-item assessment to quantify stigma, Rintamaki et al. (2008) found that people in the United States with high HIV stigma concerns were 3.3 times more likely not to adhere to their medication regimen than those with low concerns.

There is extensive literature available on the medical management of HIV/AIDS, which often leads to the assumption that people living with HIV infection want to be tested and, if found to be positive, want to engage with care. In the United States (USA) however, it is estimated that as many as one-third of the HIV-positive population do not know their HIV status (Kaiser Family Foundation, 2004). Even in countries where studies have documented high rates of HIV infection, many individuals are reluctant to get tested, and are often slow to access care (Newman, Grusky, Roberts & Rivkin, 2002). The stigma of HIV/AIDS is one factor affecting people's decisions to get HIV tested and seek care. AIDS stigma and discrimination have a considerable influence on people living with and affected by HIV, as well as on their health care providers, particularly in southern Africa, where the burden of AIDS is so significant (African Development Forum, 2000). Stigma has emerged as a major limiting factor in primary and secondary HIV/AIDS prevention and care (Weiss & Ramakrishna, 2001). It

interferes with voluntary testing and counseling, and access to care and treatment, increasing suffering and shortening life (Newman et al., 2002).

Many health care workers in southern Africa have come to the conclusion that, unless stigma is conquered, the illness will not be defeated (Uys, 2000). In a study of women who refused to be tested for HIV at Ethiopian antenatal clinics, Kumbi, Bedri, Abashawl, Isehak, Coberly and Ruff (2002) concluded that fear of, and the stigma associated with HIV was significantly related to the women's decision. Munhenga, Chiwara, Jena et al. (2002) reported similar results regarding antenatal clinics in Zimbabwe. In preparing patients for lifelong HIV care, stigma should form part of the discussion, as it would appear that it plays a major role in adherence to recommendations.

2.7 Disclosure

When the HIV-infected individuals first learn their status, they experience an internal struggle about whether or not to disclose their HIV-seropositive status (Marks et al., 1992). The decision to disclose is selective, and consists of several steps including adjusting to the diagnosis, assessing one's disclosure skills, deciding whom to tell, evaluating the recipient's circumstances, anticipating the recipient's reaction and having a motivation to disclose (Kimberly et al., 1995). The decision to tell one's family members is reported to be especially difficult (Kimberly et al., 1995; Serovich et al., 1998). A certain level of disclosure is necessary to access AIDS-related health care resources. HIV-infected individuals who disclose their seropositive status have been found to make fewer physicians' visits and have better immune functioning (Pennebaker et al., 1990). Choosing to disclose may result in less social isolation, and facilitate accessing social support, health. Disclosure of one's HIV status to sexual partners is essential in stopping the spread of HIV infection (Kalichman and Nachimson, 1999). Over 20 states have enacted laws, making it a criminal offence for an HIV-infected individual to fail to reveal to a sex partner that he or she is HIV-infected (Lisko, 1998). Yet many HIV-infected individuals do not disclose to all sex partners.

Kalichman and Nachimson concluded that HIV-seropositive women have greater difficulty disclosing their HIV status to sexual partners than do men (Kalichman and Nachimson, 1999).

Unfortunately, disclosure doesn't always have the desired outcomes, as indicated in the study by Medley (2004). He summarised 17 studies from peer-reviewed journal articles on barriers to the disclosure of HIV status among women in developing countries. These articles suggested that between 3.5% and 14.6% of women reported experiencing a violent reaction from a partner after HIV disclosure. Disclosure of HIV infection by women may present unique risks. A woman's disclosure of her own HIV status may lead to stigmatisation and discrimination of her children (Moneyham et al., 1996). Simoni et al. (1995) found that one in five women who disclosed her HIV status to her partner was abandoned. A woman's disclosure of her HIV infection to sexual partners may trigger violent episodes (Rothenberg and Paskey, 1995; Zierler, 1997; Zierler et al., 2000). Gielen et al. (1997) found that one-fourth of the women in their study had experienced negative consequences of disclosure that included rejection, abandonment, and verbal and physical abuse.

Barriers to disclosure included fear of accusations of infidelity, abandonment, discrimination, and violence. This review builds a strong case for the impact of perceived stigma on the fear of disclosure of HIV status. In turn, no disclosure makes it difficult to access HIV care.

2.8 Stigma and Community

The communities view HIV/AIDS with fear and awe. It is something they talk about in lowered voices and in veiled words. The general view is that people with this illness have no hope. Nyblade et al.'s (2003) study in three African countries points out that much of the stigma is being caused by a lack of in-depth knowledge, the fear of casual transmission, and the fear of death. The songs quoted by Lwanda (2003) show the same trend, although one of the songs

indicates an understanding that only a concerted community-level response will be effective in stemming the tide. In the song, "*Kunja Kuno Kwaopsya*," the epidemic is equated to a war, with the virus as the weapon and the condom as the shield (Lwanda, 2003). It might be that the community uses indirect and metaphorical descriptions to cope with the serious threat that HIV/AIDS poses for families and communities. For instance, in Malawi, the population is encouraged to be open about the illness, but they still use words to lighten and soften references to the illness. People in African societies often create their own language to talk about private or sensitive issues (Uys et al., 2005). Sex and sexual behavior is a very private topic in most of the communities studied, and it should therefore not be surprising that oblique terminology is developed to talk about it. It is also true that even some of the PLWHA used such terms to talk about their status in a veiled way, for example, "I am nice, are you too?" However, most of the descriptions apportion blame, are negative, and hurtful. Nyblade et al. (2003) also list some of these descriptions, and point out that they highlight deviant behavior, are euphemisms for death, and blame people for their infection and for being a burden on those around them. In the Tswana community of South Africa where research was done, there is an idiom, *leso legolo ke ditshego*, which means that when the situation is bad, we make a joke. Many of the descriptions reported in this study are sharp and witty and may reflect this kind of community coping. (Nyblade et al.2003)

Muyinda et al (1997) described two processes by which societies make the unfamiliar familiar. The first is anchoring, which refers to naming the unfamiliar in terms that compare it with what is known. In this study, terms such as *the clothes hanger* and *lightning* are examples of anchoring. The second process is objectification, which refers to names that make abstract notions concrete. The terms *drum* and *ladybird* are examples of this (Uys et al, 2005). Parker and Aggelton (2003) suggest the need for community-level mobilisation, with the goal of unleashing the power of resistance on the part of PLWHA, in tandem with intervention at the structural level to respond to stigma effectively. Important structural targets include religious leaders, the judiciary and the legislative arenas

(Parker et al., 2003; Ehiri et al., 2003). Parker et al. (2003) suggest that in certain settings, specific manifestations of stigma are indeed more psychologically damaging than others. Psychological distress was most strongly predicted by three specific manifestations of stigma occurring in family settings – avoidance, exaggerated kindness and being told to conceal one's HIV status. Stigmatisation by family may be particularly detrimental, as families are not chosen, and are often considered an important source of unconditional love and support. Stigmatisation by family may thus threaten a fundamental human need, namely the need to belong (Lekas et al., 2006).

In South Africa, a large number of incidents of stigma have been reported. These include the murder of Guru Lamina in December 1998 for openly stating that she was HIV positive (Balata, 1999; Kortjaas & Msomo 1998; Nicodemus 1999; Rusnak 1998); the murder of Mpho Mtloung together with her mother by her husband, who then also committed suicide. The connection of stigma around HIV to historical racism and gender has developed a particular form of discrimination. Blame is often assigned to black people or to women. Men blame women for infecting them and spreading the virus (Leclerc-Madlala, 1997, 2002; Shefer, 1999). In couples, this can lead to violence against the woman, or her exclusion from the household (Strebel, 1993). Many research studies have found a significant number of respondents who want people living with HIV (PLWH) to be clearly identifiable, to be separated from the rest of the population, or excluded from contact in schools, the workplace and the general community (Skinner and Mfecane, 2004).

A judgmental discourse has distinguished sharply between those 'innocents' who contract HIV via organ or blood transfusions, the children of women with HIV, and women whose partners are unfaithful; and those who are considered guilty and almost 'deserve it' (Schellenberg, Keil & Bem, 1995). Religious groups may intentionally or inadvertently contribute to discrimination by making explicit or implicit judgments against those who are infected with HIV (Paterson, 1996). Attempts to label the epidemic as God's punishment for sinners, especially gays,

prostitutes and drug users, have often been documented (Crawrod, Allison, Robinson, Hughes & Samaryk, 1992; Johnson, 1995).

Communities are where most of the stigma plays out. The Health care workers also form part of the community, and as such, their stigmatising behavior can be read as signs and symptoms of the community at large. Sadly, even the religious fraternity, where people would normally hope for comfort and protection, are shown to be just as judgmental.

2.9 HIV/AIDS in Southern African.

The global epidemic appears to have stabilized in most regions. The UNAIDS 2009 Report states that of 22.4 million HIV positive individuals worldwide, sub-Saharan Africa remains the most heavily affected region, accounting for 67 per cent of all HIV infections worldwide, 68% of new infections among adults and 91% of new HIV infections among children . The sub-Saharan region also bore the brunt of the world's AIDS-related deaths, at 72% of AIDS' deaths worldwide (National Antenatal Sentinel HIV & Syphilis Prevalence Survey, 2009).

South Africa has the highest number of people infected globally, estimated at around 5.3 million, including 220 000 children under the age of 15 years, in 2008 (UNAIDS 2009).

South Africa ranks in the top five highest HIV prevalence countries in the world, with 17.5% of the population estimated to be infected. The UNAIDS 2009 Global Report Epidemic Update estimated that in 2008, 310 000 people died from AIDS in South Africa. South Africa is regarded as having the most severe HIV epidemic in the world.

In South Africa, the National Antenatal Sentinel HIV & Syphilis Prevalence Survey, 2008 reveals that the estimated national HIV prevalence amongst women has remained stable over the past three years at around 29%. This

concur with the projections by UNAIDS that the HIV epidemic curve is reaching a plateau. However, the UNAIDS Global Report on HIV, 2008 suggests that this plateau does not appear to be indicative of major behavior changes, but rather the natural progress of a long wave epidemic.(UNAIDS,2008)

The burden is not felt evenly across the country. The results show that the highest HIV prevalence are recorded on the north-eastern side of the country, and the lowest prevalences in the western regions of South Africa. While the national average of HIV-positive women attending antenatal clinics in 2008 was 29.3%, the province of KwaZulu-Natal continues to have the highest prevalence at 38.7%, followed by Mpumalanga at 35.5%. The lowest recorded prevalence of women attending antenatal clinics is in the Western Cape, at 16.1% (National Antenatal Sentinel HIV & Syphilis Prevalence Survey, 2008).

2.10 HIV/AIDS in women.

From June 2008 to March 2009, South Africa conducted the third in a series of national population-based surveys to assess HIV prevalence, incidence and HIV-related knowledge and behaviour. A comparison of data from this survey with the data from the two previous surveys conducted in 2005 and 2002 shows a very sizeable increase in the proportion of respondents reporting access to HIV testing services in all provinces. Only 20% of respondents aged 15 years and older had ever done an HIV test in 2002, increasing to about 50% in testing uptake was reported by respondents in the recent survey in 2008. Progress is evident among both sexes, although it is more marked among women. In 2002, an equal proportion of female and male respondents (21%) reported ever having received an HIV test. In 2005, 33% of the women and 28% of the men had never had an HIV test, with the figures increasing further to 57% and 43%, respectively, by 2008. Between 2005 and 2008, the percentage of women and men who reported having received an HIV test and the test results in the 12 months preceding the survey increased nearly two-fold, from 13% to 29% among women, and from 10% to 20% among men (UNAIDS, 2007).The effects of the AIDS epidemic is reflected in the dramatic change in South Africa's mortality

rates. The overall number of annual deaths increased sharply from 1997, when 316,559 people died, to 2006 when 607,184 people died. This rise is not necessarily due solely to HIV and AIDS, but it is young adults, the age group most affected by AIDS, who are particularly shouldering the burden of the increasing mortality rate. In 2006, 41 percent of deaths were attributed to 25 to 49 year olds, which had increased from 29 percent in 1997. This is a strong indicator that AIDS is a major, if not the principal factor in the overall rising number of deaths. (Shisana et al,2009)

The South African Government launched a major HIV counselling and testing campaign (HCT) in 2010, by raising awareness of HIV Prevention of mother-to-child transmission. The national transmission rate of HIV from mother-to-child is approximately 11%, because the virus is transmitted from the child's mother in cases of mother-to-child transmission; the HIV-infected child is born into a family where the virus may have already had a severe impact on health, income, productivity and the ability to care for each other (Chiu et al., 2008).

An unacceptably high number of babies, around 70,000, are born with HIV every year, reflecting poor PMTCT uptake. HIV and AIDS is one of the main contributors to South Africa's infant mortality rate which increased significantly between 1990 (44 deaths per 1000 infants) and 2008 (48 per 1000), when all other regions of the world saw decreases. The campaign aims to reduce the HIV incidence rate by 50 percent by June 2011 (NDoH, 2010).

HIV prevalence among pregnant women in SA has increased from 1.7% in 1991 to 30.2% in 2005. Early and routine identification of HIV-infected pregnant women facilitates access to ART, contributes to the postponement of orphanhood for children and results in decreased HIV transmission to children. Although counseling and voluntary HIV testing for pregnant women was introduced in SA in 2002, uptake is limited, and the majority of women attending antenatal care do not know their HIV status. If HIV diagnosis occurs during pregnancy, women need sufficient time, accurate information and support to enable them to explore

all options before making decisions. South African research has, however, shown that HIV positive women are more likely to experience adverse pregnancy outcomes, complications and mortality than HIV-negative women (Garenne et al., 2001).

HIV positive pregnant women were more likely to develop anaemia, pregnancy-induced hypertension, have lowered maternal weight, double the risk of developing urinary tract infection, a five-fold increase in the rate of syphilis, a higher rate of abnormal vaginal discharge, slightly earlier delivery, and a 5% chance of *in-utero* growth retardation of the baby.(PMTCT Guidelines,2010)

South Africa's HIV prevalence is one of the highest in the world. Annual sentinel site HIV prevalence studies in antenatal clients have been ongoing since 1990, and reveal the explosive growth of the HIV epidemic from a prevalence of less than 1% among pregnant women in 1990, to 29% in 2004. In the country's 9 provinces at least 25% of pregnant women are now HIV positive, the highest number being in the KZN province. In 2005, the HIV prevalence in KZN among antenatal clinic attendees was estimated to be at 39.1 %. (NSP, 2007-2011), making KZN the province with the highest HIV prevalence amongst pregnant women.

A high number of babies born to HIV positive women are likely to be infected (Muko et al., 2004). Every day, an estimated 1 800 children under 15 years of age become infected, and 1 400 children die from the disease, with the majority of these in sub-Saharan Africa. HIV infection in children is preventable. In Europe and the United States, MTCT rates have been reduced to fewer than 2%, and few HIV-infected babies are born in these countries (HST, 2006).

UNICEF in its 'Unite for Children, Unite against AIDS' campaign of 2005 estimated that 42% of deaths in children under 15 in 2004 were due to HIV. Pregnant women have a higher risk of acquiring HIV than non-pregnant women,

and the risk of transmission is increased in women with high viral loads, found primarily in patients with acute primary HIV infection (HST, 2006).

The primary aim of the PMTCT programme is to decrease the number of HIV infected babies born to HIV positive mothers. Primary prevention remains paramount in women of childbearing age. Optimal prevention of MTCT of HIV requires identification of the mother's HIV status during pregnancy. Universal HIV testing of pregnant women is standard care in developed countries like the United States of America (Link and Phelan, 2000). Identification of HIV infection early in pregnancy allows the greatest ability to treat the pregnant woman for her HIV infection for her own health, and to prevent MTCT of HIV. Rapid HIV antibody testing allows for timely identification of HIV infection in women even late in pregnancy, during labour, or in the immediate postpartum period, as well as HIV exposure in their newborn infants. The results can be available quickly enough to implement successful ARV interventions that can reduce MTCT of HIV when administered to the mother during pregnancy, in labour, or to the infant when administered within the first few hours of life (Link and Phelan, 2000).

In recent years, lack of identification of maternal HIV-infection status has been the primary reason for new infant HIV infections; effective interventions cannot be implemented unless maternal HIV status is known. Rapid HIV antibody testing methods now allow identification of HIV-infected women or HIV-exposed infants in 20 to 60 minutes (Piot, 2004).

According to the 2005-2007 saving mothers report AIDS was the most common non obstetric cause of maternal deaths in. The increasing availability of antiretroviral therapy makes maternal deaths due to AIDS avoidable and it is not surprising there has been an increase of clearly avoidable deaths from 9.1% of the non-pregnancy related infections and 4.5% of the AIDS deaths in 2002-2004 to 23.4% of non-pregnancy related infections and 17.6% of AIDS deaths... (Saving Mothers report, 2005-2007)

HIV testing during pregnancy allows identification of HIV infection in women who might not know they are infected. This is important for the health of the woman, because knowledge of her HIV-infection status will allow appropriate evaluation, including CD4⁺ T-lymphocyte count and HIV viral load quantification, initiation of comprehensive care, and appropriate ARV treatment. HIV antibody testing early in pregnancy has the added benefit of allowing the most effective interventions to prevent MTCT of HIV being initiated, including ARV prophylaxis, planning an appropriate mode of delivery (elective caesarean delivery or vaginal delivery, depending on maternal viral load near delivery), and avoidance of breastfeeding. HIV antibody testing later in pregnancy, or even after delivery of the newborn infant, still allows initiation of effective ARV interventions that can reduce the risk of MTCT of HIV (Garenne et al., 2001).

The Saving Children 2004 report which reviews the causes of and factors related to infant and under-5 child deaths in several sites across South Africa. One of the most striking findings of this report is that over 50% of all deaths are associated with HIV-related disease or AIDS. It can be assumed that almost all of these deaths resulted from mother-to-child transmission of HIV.

Africa is a patriarchal country, with many rules and practices favoring men. Women don't have a voice, and, as such, they bear the brunt of stigma. In most cases, they are seen as the people who bring HIV to the family by virtue of testing first, and thus are blamed for infecting their unborn children (Perez et al., 2004). In testing, part of the support should be helping and supporting the women through the journey and facing the community, rather than once-off post-test counseling. Traditional attitudes towards women in South Africa help fuel the stigma and stereotypes in which women are seen as subordinate to men, socially, psychologically and economically. This shapes the way in which the HIV positive women are seen by society (Bennette, 1990). In African societies, men's needs are seen as paramount. This makes it difficult for women to negotiate fidelity and safe sex, and this further fuels women's vulnerability to HIV/AIDS (Paterson, 1996).

2.11 Stigma and access to treatment

Discrimination has a significant impact on diagnosis and treatment. For the individual, it can delay diagnosis and therefore also delay entry into treatment and adoption of a healthy lifestyle. There is no motivation to be tested, as the person sees no benefit when the diagnosis of HIV is seen as equivalent to death and they are likely to experience discrimination (Abdool Karim, Tarantola, Sy & Moodie, 1992).

In certain contexts, research respondents have been shown to be more fearful of the stigma than of the disease itself, so even with treatment, stigma may be a block to access (Lie & Basal, 1994). This has already been shown to be a problem in the case of PMTCT, where women have expressed fear of being tested (Grange, Story & Zumla, 2001). In the same way, the use of formula feeding rather than breastfeeding can become a problem. Many women feel restricted from being able to breastfeed for fear of family observation and questions. Stigma and discrimination by health workers compromises their provision of quality care, which is critical for helping patients adhere to medication, and to maintain their overall health and wellbeing. Stigma also acts as a barrier to accessing services, both for the general population, and the health providers themselves. This can have serious implications for health workers and health facilities when HIV-infected health workers delay or avoid care and become seriously ill or die, causing further strain on an overburdened health care system. Secondly, there is insufficient capacity among health care managers regarding how to effectively address stigma and discrimination through programmes and policies (Uys et al., 2009).

Even for those who are aware of their status, discrimination can limit access to care and treatment (Grange, Story & Zumla, 2001; Rehm & Franck, 2000). Many are not able to acknowledge, even to their families, that they are infected, and so are denied that level of care.

2.12 Coping with HIV Stigma

Stigma impacts on the PLWH themselves, as it is internalised into their self-perception and sense of identity, impacting on their perceptions and how they interact in the world. Research has found that people with HIV feel isolated, guilty, dirty and full of shame which is then often incorporated into their identity (Kalichman, 2004).

Stigma often heightens existing prejudices and inequalities. HIV-related stigma tends to be most debilitating for people who are already socially marginalised, and who are closely associated with HIV and AIDS, such as sex workers, men who have sex with men, injecting drug users, and prisoners (Nyblade et al., 2009). Conversely, other studies have shown that women are particularly vulnerable to stigma, including violence, one of the harshest and most damaging forms of stigma.

A major concern in relation to a stigmatised disease is that the social marks of inferiority or blemish may lead patients and their caretakers to conceal their disease. This has serious consequences for both the health of the individual and the containment of infectious diseases for the population. It was mentioned earlier that bearers of stigmatised diseases are seen as a great danger to the community, because of the assumptions that they have somehow violated the moral taboos, especially those on sexuality. This leads to feelings of guilt and shame. Obviously then, diseases that directly relate to sexually taboo behaviour bring questions of guilt and shame much closer to the surface (Veena, 2008). However, it is not only individuals who are targeted as the bearers of stigma and blame in the case of sexually transmitted diseases, there is also a political geography of blame that comes to arrange the world in terms of “guilt” and “innocence”. The case of sexually transmitted diseases such as syphilis and AIDS provides telling examples of the way in which stigma of various kinds

comes to be configured together in informing the public discourse on stigmatised diseases, (Veena, 2008) and behavior that symbolically marks the bearer as “culturally unacceptable” or inferior, with the consequent feelings of shame, guilt and disgrace.

It has been said that the decision to carry out an alternative feeding method could not be taken by the women alone. The involvement and support of the husbands was regarded as essential for women who chose to carry out an alternative feeding strategy, and the reactions of the local community were perceived to be a substantial obstacle. Neighbours and close relatives will start questioning why you are not breastfeeding your child. You will lose your hope and become very skinny because of lack of support and worry about your child (De Paoli, Manongi and Klepp, 2004). In Tanzania, the medical recommendations for the prevention of mother-to-child transmission (PMTCT) of HIV made by the PMTCT programmes are often difficult for women to implement because of community norms, values and beliefs. For example, taking medication during pregnancy, and using a breast milk substitute or exclusively breastfeeding and then weaning early are not normative practices for women. Many women are uncertain of the effect of these recommendations on their pregnancy and infant. Moreover, women may face stigma and other social costs if they follow providers’ PMTCT recommendations (Baeketal, 2007). Increased rates of disclosure may, in turn, facilitate other positive behaviours around HIV and AIDS such as adherence to ARV prophylaxis and treatment, and an exclusive method of infant feeding.

2.13 Mechanism to Reduce HIV/AIDS in South Africa

According to statistics obtained from the Ministry of Health’s statement, and the HST report, more than 90% of government clinics (3382 out of 3663) are currently providing PMTCT services. Of the approximately 800,000 public sector births in South Africa in 2006, about 580,880 pregnant women were offered PMTCT services. From the antenatal survey, we can estimate that about 168,000

(i.e. 29%) were HIV-positive in 2006. Yet only 74,052 women received nevirapine prophylaxis i.e. less than half the eligible women. Of this amount, the sub-set of babies who were tested for HIV was just 19,758. About 18% tested positive.

This means that, of the approximately 800,000 public sector births, we know the HIV status of less than 3% of the infants. And of these, the results are poor – far above the 5% transmission rate target (NDoH, 2007).

The 19th National Antenatal Women HIV and Syphilis Sero-prevalence Survey has provided further evidence that the national HIV prevalence in South Africa is stabilising at around 29% since 2006.

This is a trend observed in many countries with generalised epidemics. The results of this survey show that the HIV prevalence among women in the age group 15 to 19 years has increased from 13.1% in 2007, to 14.0% in 2008 (Table 3). The HIV prevalence estimate in the 20 to 24 year age group, the target age group for the MDG 6, stands at 28.0% in 2006 and 2007 compared to 26.9% in 2008. The HIV prevalence in the older age groups (30 to 34, 35 to 39; and above 40 years) remains high (above 30%) with a slight decrease from 20.6% in 2007, to 17.6 % in 2008 for the 45 to 49 year olds.

At the end of 2000, a decision was made by the National Department of Health of South Africa to implement a pilot programme for the prevention of mother-to-child HIV transmission (PMTCT). A total of 18 pilot sites, 2 in each of the 9 provinces, were purposively selected to include an equal representation of urban and rural sites, as well as a mix of primary and secondary level facilities. These were to serve as research and learning sites to assess the feasibility of, and requirements for implementing PMTCT services more widely. The package of care for the pilot programme included offering all antenatal clients voluntary counselling and testing (VCT) and a dose of Nevirapine to those women identified as HIV infected, and their infants. The efficacy of single-dose Nevirapine in PMTCT of HIV in the HIVNET012 trial was 11.9 %. This means that

a vertical transmission rate of 12% was expected with the single dose Nevirapine. As part of the programme, free formula milk was provided for a period of 6 months for women choosing not to breastfeed. The programme also stipulated that all infants should be followed-up and tested for HIV with a rapid antibody test at 12 months. There has been progress in increasing the uptake of Mother-to-Child Transmission Prevention (MTCTP) services, and in providing dual ARV therapy to infants, which is more effective than the single dose Nevirapine at first grudgingly provided by the government. There is also recognition of the need to focus on saving mothers' lives and parents' lives, not just babies' lives. The need for HIV to be integrated into health services, and for TB and HIV to be addressed in tandem has also been acknowledged.

The South African PMTCT programme offers testing and counseling services, single dose nevirapine (sdNVP) to mother and baby, and free formula milk (Pelargon®) for six months.

The plan was to pilot the programme to explore the side-effects as well as the operational requirements. A total of 18 pilot facilities were selected to serve as research and learning sites to assess the feasibility of, and requirements for implementing the PMTCT services more widely (NDoH, 2008).

In 2008, the PMTCT guidelines were updated to add Zidovudine (AZT) prescribed from 28 weeks pregnancy, and during labour 300mg 3 hourly. In addition, the Infant was also to be given AZT syrup for seven days of 28 days depending on the mothers' duration on AZT (NDoH, 2008). Furthermore, infants were to undergo a PCR test at six weeks.

More recently, the SA government's response to the HIV and AIDS epidemic made a commitment to an ambitious, but achievable National Strategic (NSP).

The NSP identifies four priority areas: (Two of the areas related to the PMTCT are mentioned below)

Priority Area 1: Primary Prevention

Target: reduce the national HIV incidence rate by 50% by 2011.

Priority Area 2: Treatment Care & Support

Target: provide an appropriate package of treatment, care and support services to 80% of the people living with HIV and their families by 2011 (NSP, 2007).

Several studies conducted in sub-Saharan Africa have shown that despite the availability of the PMTCT, vertical transmission remains high (NSP, 2007-2011). An evaluation of the PMTC programme conducted in 18 sites in the year 2002 in South Africa indicated that 18% of the infants born to HIV positive mothers tested positive. This is further confirmed by NSP (2007-2011). In 2006, an estimated 38 000 children acquired HIV infection around the time of birth, and an additional 26 000 children were infected through breastfeeding. The results of another study done in Kwazulu-Natal whereby dry blood spot testing was used at immunisation clinics to test the prevalence of HIV, revealed that, despite the availability of the PMTCT programme, the transmission rate was estimated at 20.8 % (Rollins et al., 2006).

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

A couple of studies have been done to identify factors that prevent PLWHA from participating in the HIV and AIDS programmes, and in particular, pregnant women from partaking in the PMTCT programme. Many countries reported low

uptake of HIV testing. The most important barrier to using the services was found to be the fear of stigma and discrimination among HIV positive pregnant women (Nguyen et al., 2008).

HIV infected mothers are faced with coping, both with the physical demands of their illness and child care, and with the emotional burden of decision-making about the disclosure of their HIV status, custody, fertility options, the use of health care services, and the use of ART. This may be compounded by additional problems, such as the death or illness of a spouse, worries about a child's future, about their own death, about establishing and maintaining the mother-child relationship and grieving over the death of HIV-positive children. Motherhood may be characterised by feelings of guilt, especially if a child is infected. There is also the burden that children (if uninfected) are likely to be orphaned before adulthood. NDoH, 2008).

2.14 Stigma and PMTCT Programme

The PMTCT is part of the preventive measures available to HIV positive women to reduce vertical infection, stigma and to prevent mother-to-child transmission. Pregnant women may avoid participating in PMTCT programmes because of the fear of stigma, discrimination and violence, particularly from partners when disclosing their HIV status (Eide et al., 2008; Vagra et al., 2006). Numerous studies have demonstrated that going against community norms of feeding leads to questions about mothers' HIV status, unwanted disclosure, and the fear of stigma from partner, family and the community (Thairu et al., 2005). Interventions aimed at engaging male partners in PMTCT services, such as sending an invitation home with the partner with a direct request that the man attend the clinic with his partner to receive HIV testing or couples counseling, have been tried with varying success . Community-level education about specific PMTCT services, targeting pregnant women, community leaders and people of childbearing age is critical to improving the acceptability of services and diminishing the effects of stigma (Sripipata et al., 2007; Perez et al., 2004)

2.14.1. Disclosure through PMTCT Guidelines

Programme guidelines disclose the HIV status of women, e.g. infant formula distribution at clinics was identified as a barrier to the PMTCT programme. Rejecters mentioned that they were discouraged by bad remarks about formula feeding which they heard from other women. These remarks occurred when a mother, who was seen going into the nurses' room empty-handed, returned with many cans of formula and people concluded that she was HIV-positive. This finding is consistent with other studies which show that where breast-feeding is universally accepted and stigma is high, formula distribution and feeding may be perceived as a way of revealing one's HIV status to family (Nyblade et al., 2009).

The most commonly recommended infant feeding options for HIV-positive women in South Africa (SA) are replacement feeding with commercial infant formula provided free through public health services. Approaches to reducing or preventing the risk of postnatal transmission through breastfeeding include the avoidance of all breastfeeding through the use of exclusive replacement feeds, or exclusive breastfeeding for a limited duration with early and rapid cessation of breastfeeding around 4-6 months of age, or exclusive breastfeeding with early cessation (SAHR, 2006). A study in SA found that infants who received both breast milk and other feeds were significantly more likely to be infected by 15 months of age, (36%). Twenty women, (80%) who had chosen exclusive breastfeeding had introduced other liquids within the first month because of pressures placed on them by family. The experiences of individual mothers were echoed by the community health workers who confirmed the authority that family members have over infant feeding practices. The influence of family members may be related to the extremely vulnerable situation of these women. Thirty, (75%) of them lived with their mothers, mothers-in-law or grandmothers. These participants were financially dependent on family members since partners or fathers of their children were largely absent (Doherty et al., 2006).

Early identification of HIV-infected children is vital for a child's entry into comprehensive care and to monitor the efficacy of the PMTCT programme. HIV Deoxyribonucleic acid (DNA) PCR testing was introduced in 2004 for early diagnosis of infants from 6 weeks of age. In January 2006, approximately 5 500 PCR tests were performed nationally, equating to 22% of the total capacity required. Cotrimoxazole (CTZ) prophylaxis for the prevention of pneumocystis jirovecii pneumonia (PCP) and other commonly acquired infections reduces mortality in HIV-infected children by as much as 43%. PCP has a peak incidence in children between 3 and 6 months of age, carrying a very high mortality. SA follows WHO guidelines in advising CTZ prophylaxis from 4-6 weeks of age for all HIV-exposed infants, continuing with those with a definitive diagnosis of HIV until such time as a demonstrated CD4 response has occurred on ART (NDoH, 2008).

Disclosure to children is probably one of the most difficult tasks faced by HIV-infected women and requires considerable courage, preparation and time. Women throughout the world are faced with the complexity of HIV disclosure to their children. (Greenberg, 1999).

According to Greenberg, (1999) common negative factors related to disclosure to children include the fear of the emotional burden; the fear that the child will experience rejection, changes in children's behavior, as well as uncertainty as to when, how and what to say to children. Other considerations include: protecting the child from the fear of death, worrying about the ability of the child to be discreet, and the fear of public disclosure of the family condition, children's reactions and (potential) questions about survival and disease transmission, and the impact of disclosure on the health of the child. Adults (caregivers and health care providers) tend to disregard or ignore children's capacity to understand. They fear that children may be sad, rebellious, angry or depressed after disclosure. For these reasons, mothers may delay disclosing their HIV status to their children, and some may decide never to disclose (Makhokha, 2000).

Muyinda et al. (1997) noted that, for communities as a whole, or for those responsible for structuring interventions, blaming infected people can be a substitute for tackling the problem itself. So, even when interventions are developed from this basis, they are constructed in such a way as to discriminate against those in affected groups, and to reinforce a false sense of safety in the majority of the population.

Discrimination has significant impacts on diagnosis and treatment. For the individual it can delay diagnosis, and can therefore also delay entry into treatment and the adoption of a healthy lifestyle. In certain contexts, research respondents have been shown to be more fearful of the stigma than of the disease itself, so even with treatment, stigma may be a block to access.(Kebaatswe,2007)

Other researchers have also reported low levels of disclosure in mothers diagnosed with HIV during antenatal care. This lack of disclosure makes adherence to drug regimens or infant-feeding guidelines difficult. For example, even in a well-resourced setting such as Botswana, only 40% of HIV-positive women who started a short course of Zidovudine completed their treatment. In Zambia, more than a quarter of women (26%) were not adherent to the even simpler single-dose nevirapine regimen (Doherty et al., 2006). The phrase 'prevention of mother-to-child transmission' is most commonly used to refer to programmes whose goal is to prevent HIV infection among unborn children and newborns (and children under two who may be breastfed) during pregnancy, childbirth or breastfeeding. This terminology can imply that pregnant women, or new mothers living with HIV are solely responsible for the transmission to their newborn infants (Thorsen, Sundby and Martinson, 2008). Alternative phrases that the PMTCT program could consider using as references are: prevention of 'parent-to-child transmission' or 'perinatal transmission', as considered by UNAIDSs. As the HIV and AIDS pandemic continues to evolve, much has been documented of the social, as well as the bio-medical impact that it has on

individuals, their families and their communities. HIV and AIDS-related stigma, and its associated discrimination, is known to negatively affect all aspects of HIV prevention, diagnosis, treatment and care (Bond et al., 2002). HIV related stigma has been problematic for people living with HIV since the beginning of the epidemic, and has been associated with several health outcomes including HIV testing and health care seeking behaviours, psychosocial functioning, and sexual risk behaviours. Studies have documented that the stigma and the shame associated with HIV represents a significant barrier to screening for the disease (Dowshen, 2008). Reports of stigma are pervasive, extending even to the health professions.

It is evident that disclosure is still very difficult for most PLWHA, because of the fear of being stigmatised (UNAIDS, 2002). Despite efforts to provide greater access to HIV specific services, a number of issues continue to adversely affect those infected with HIV. This is common, even in communities with specialised services. People decide not to access social and medical care as this will reveal their HIV status and, in this way, they will expose themselves to being stigmatised (Kegeles et al., 1989). There is a high degree of denial and secrecy around HIV/AIDS. People try to search for any possible cause to explain the high morbidity and mortality, looking for supernatural causes. Stigmatisation results in silence, secrecy and denial. This has serious implications for the prevention of HIV with such a long subclinical phase causing people not to want to be tested and this leads to personal denial. (Duffy, 2001).

2.16 Stigma in the health care setting

At least 70% of the caseload in the public health system is taken up by HIV and AIDS cases, many relating to increasingly drug-resistant TB. (Skinner and Mfecane, 2004).

Health care workers have been overwhelmed by the impact of the epidemic on the public health service, with the majority of resources in many facilities going to treat people presenting with opportunistic infections or dying from AIDS-

related illnesses (Blackstock, 2005). This has resulted in overcrowding of under-resourced hospitals, meaning that patients cannot receive adequate care, and health professionals are working under very difficult conditions. Many health workers are living with untreated HIV and AIDS and bear the brunt of complaints about the health system. The working conditions are made worse by the lack of specialised training and staff shortages. In KZN, the worst affected province, 37% of the health posts in the province were vacant in early 2005 – and some hospitals did not have pharmacists (NDoH, 2006).

One research study (Centre for International Health, CIC, 2005) found the attrition rate among nurses in the public sector to be more than 9% in 2004. In that study, the burden of work, excessive patient loads, poor working conditions and stress/depression from dealing with increased HIV-related morbidity and mortality were among the reasons that nurses gave for resigning.

In their research into the prevalence of HIV infection among health care workers at two Johannesburg hospitals in 2005, the Centre for International Health (CIC) found that 11.5% of hospital employees were HIV-positive. Of these, at least 19% should have been on ART already, since they had a CD4 count of less than 200 (CIC, 2005).

While many health workers have responded to the crisis by leaving the country to work in better-resourced clinics and hospitals overseas, many others have joined the lobby for access to treatment as part of a wider campaign to build the public health service (Dlamini et al., 2009).

There are many ways in which HIV-related stigma manifests in health care settings. A study in Tanzania documented a wide range of discriminatory and stigmatizing practices, and categorized them broadly into neglect, differential treatment, denial of care, testing, and disclosing of HIV status without consent, and verbal abuse/gossip (Reynaut, 2003). Similarly, a study in Ethiopia found that common forms of stigma in health facilities took the form of designating

patients as HIV positive on charts or in wards, gossiping about patients' status, verbally harassing patients, avoiding and isolating HIV-positive patients, and referring patients for HIV testing without counseling.

Health workers also stigmatise their peers. In Zambia, health workers report knowing peers who are hiding their own HIV status, are afraid to talk about their situation to others, and are suffering in silence. One indication of health workers' fears around HIV testing is their interest in self-testing. A national study of health providers in Kenya found that nearly three-quarters of them would be interested in testing themselves for HIV if such an option existed. Interest was greatest among those who had never tested, among medical doctors, and among health providers from the province with the highest prevalence of HIV in the country. The main reasons given for their interest are that self-testing eliminates a potential breach in confidentiality, and pre-empts stigma and suspicion from colleagues, since they would not know that someone had tested for HIV (Makin et al., 2007).

While health workers living with HIV may face the same kinds of stigma as their patients because of perceived improper or immoral behaviours, their self-blame and shame may be compounded by their relatively higher social and educational status in the community. As noted by one hospital manager in a Zambian study, "In the end it was us that were stigmatising ourselves. I feel people that are more educated, like nurses, find it most difficult to discuss and disclose their status (Perez et al., 2004).

Health providers interviewed in another study in Zambia reported that medical personnel who become infected with HIV are commonly seen as failures in the community. Nurses in Thailand expressed concern that their professional status would not give them the benefit of the doubt from their colleagues regarding whether they acquired their infection occupationally, or through sex or drugs. For them, women with HIV violate gender norms and thus are guilty of being promiscuous. This suggests that health providers fear a loss of status and moral integrity if their peers find out they are HIV positive.

With regard to moral judgements, studies have demonstrated that the assumption that people with HIV have conducted themselves in some improper or immoral way contributes to health workers' negative attitudes toward HIV-positive people, and permeates client-provider interactions. Researchers in Botswana and Jamaica found that stigma leads many people to seek testing and treatment services late in the progression of their disease, often beyond the stage of optimal drug intervention (Kebaabetswe, 2007).

Although stigma is a pervasive and daunting problem in the health care setting, much can be done to address its causes and consequences. A key lesson that has emerged from recent research and field experiences is that to combat stigma in the health care setting, interventions must focus on the individual, environmental and policy levels, raising awareness about stigma, and allowing for critical reflection on the negative consequences of stigma for patients, such as reduced quality of care and patients' unwillingness to disclose their HIV status and to adhere to treatment regimens, can be considered important first steps in any stigma-reduction programme (Vidanapathirana, 2009).

A better understanding of what stigma is, how it manifests, and what the negative consequences are can help reduce stigma and discrimination and improve patient-provider interactions. In the physical environment, programmes need to ensure that health workers have the information, supplies and equipment necessary to practice universal precautions and prevent occupational transmission of HIV. This includes the use of gloves for invasive procedures, sharps containers, adequate water and soap or disinfectant for hand washing, and post-exposure prophylaxis in case of work-related, potential exposure to HIV. Posting relevant policies, hand washing procedures or other critical information in key areas in the health care setting enables health workers to maintain a better quality of patient care (Vidanapathirana, 2009).

The lack of specific policies or clear guidance related to the care of patients with HIV reinforces discriminatory behaviour among health workers. Health facilities need to enact policies that protect the safety and health of patients, as well as health workers to prevent discrimination against people living with HIV. Such policies are most successful when developed in a participatory manner, clearly communicated to staff, and routinely monitored (Nyblade et al., 2009).

Three types of stigma were identified from the data: received, internal and associated. The stigma process can be triggered or activated by a variety of factors, such as an HIV diagnosis or disclosure of HIV status. A trigger is any action that allows people to label themselves or others as HIV-positive. In the view of many authors, the trigger includes an element of “a marker of difference” (Royal Tropical Institute, 2004). Received stigma can be triggered by, for example, disclosure. Continued association with a person(s) who is either suspected of being HIV-positive or having AIDS, or is definitely infected can trigger associated stigma. Internal stigma can be triggered by the suspicion of being infected, or the confirmation of an HIV-positive diagnosis. This duality (fact or suspicion) also activates received and associated stigma. Many persons living with and affected by HIV and AIDS indicate that the suspicion of being HIV-positive is enough to trigger stigma towards a person living with HIV and AIDS, as experienced or described by themselves or others (Weiss et al., 1992). Sub-categories of received stigma include neglecting, fearing contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping. Internal stigma comprises thoughts and behaviours stemming from the person’s own negative perceptions about themselves based on their HIV status (Stein, 2003).

Sub-categories of internal stigma include perception of self, social withdrawal, self-exclusion and fear of disclosure. Associated stigma involves examples of stigma that result from a person’s association with someone living with, working with, or otherwise associated with people living with HIV and AIDS. This can include, for example, having a family member who is HIV-positive, or working with people who are HIV-positive (Holzemer et al., 2006).

However, the current national guidelines clearly reflect a western country's context. Paradoxically, local cultural dynamics have major implications for the initiation of risk behaviours, such as drug use and sexual activities, leading to HIV transmission. Cultural factors also closely interlink with the process of the stigmatisation of people living with HIV and those practicing risk behaviours. Almost all HIV and AIDS-related interventions in Nepal are funded by donor countries, bilateral agencies and the United Nations (Chandra and Madison, 2009).

To be able to enroll in the programme, pregnant women have to submit to Voluntary Testing and Counseling (VCT). Skinner and Mfecane (2004) suggest that stigma introduces a desire not to know one's HIV status, thus delaying the testing and accessing of care. This can be quite dangerous in the case of the PMTCT as it may result in vertical transmission.

Nurses have been cited as also perpetuating the HIV and AIDS stigma. This may be due to their fear for personal safety, as with exposure to HIV positive patients they may fear infection. Personal prejudices may play a role as well as a lack of knowledge (France, 2001, as cited by Poku et al., 2005). The nurses and other health workers dealing with HIV positive people are also targets of stigma. There is some literature available which can be used for the health workers to mitigate stigma and to deal with their own prejudice. Abdool (2004) indicated that it is important to study the role of the health workers in HIV stigma, as they may be the people who are likely to help combat stigma. In addition, some of the recommendations of the PMTCT may inadvertently disclose the women's status; many people know that breast feeding is not recommended in HIV positive women, so failure to breastfeed in to the community may mean that the women are HIV positive (Muko, Tchangwe et al., 2004).

Stigma is common in HIV and AIDS, and this calls for the health workers to combat this stigma, as the confidentiality surrounding the disease may simply be informing the communities that HIV is something to be feared and hidden (Boyer

et al., 1997). In the case of the PMTCT, perhaps some of these recommendations to help the mothers could be reviewed, so that the mothers are not so easily exposed to stigma. Stigma and discrimination by health workers compromises their provision of quality care which is critical in helping patients adhere to medication and maintain their overall health and wellbeing. Stigma also acts as a barrier to accessing services, both for the general population, as well as the health providers themselves (Andrewen and Chien, 2007).

There are many ways in which HIV-related stigma manifests in health care settings. In Indian hospitals, stigma and discrimination manifested itself in the form of health workers informing family members of a patient's HIV status without his or her consent, and doing the following only with HIV-positive patients: burning their bedding upon discharge, charging them for the cost of infection control supplies, and using gloves during all interactions, regardless of whether physical contact occurred (Behet et al., 2006).

Wright (2000) advocates that stigma and discrimination in the health care setting and elsewhere contributes to keeping people, including health providers from adopting HIV preventive behaviours and accessing needed care and treatment. Fear of being identified as someone infected with HIV increases the likelihood that people will avoid testing for HIV, and will avoid disclosing their HIV status to health care providers and family members. Both experienced and perceived stigma and discrimination are associated with reduced utilisation of prevention services, including programmes to prevent mother-to-child transmission or seeking treatment and care, thus compromising the health and wellbeing of those infected (Andrewen and Chien, 2008).

2.17 Strategies to prevent stigma

Stigma penetrates deeply, impacting on multiple aspects of the lives of people living with HIV/AIDS, and more broadly on members of society, creating disruptions in social functioning, and increasing people's vulnerability to infection

and reducing the overall caring capacity of communities. Stigma has had particular implications for South Africa (SA) given our history of racism and other stigmatising beliefs (Skinner and Mfecane, 2005). Goffman (1963) defined stigma as a deeply discrediting attribute that reduces a person to someone who is in some way tainted and can therefore be denigrated.

Some strategies have been introduced in South Africa with the aim of dealing with HIV and AIDS stigma, such as living positively, which aims to challenge the expectation that HIV necessarily leads to rapid death, an assumption which contributes to fear and stigmatisation. Stigma reduction is also a first step in creating services to address the needs of HIV-positive health workers. The availability of tested stigma-reduction tools and approaches has moved the field forward. What is needed is the political will and resources to support and up-scale stigma reduction activities throughout health care settings globally. Given the detrimental effect of stigma on both individual health and wellbeing and public health outcomes, it is clear that health care managers cannot afford inaction any longer (Nyblade et al., 2009).

With its potentially devastating consequences on care-seeking behaviour, stigma represents a major "cost" for both individuals and public health. Both experienced and perceived stigma and discrimination are associated with reduced utilisation of prevention services, including programmes to prevent mother-to-child transmission, HIV testing and counselling, and accessing care and treatment. In addition, research has demonstrated that the experience or fear of stigma often results in postponing or rejecting care, seeking care far from home to protect confidentiality, and non-adherence to medication. It is important to include stigma prevention education as part of clinical training on HIV/AIDS, as fear of stigma may hinder the preventive and management effort of the disease. This means the HCW should be competent in the management of the clinical side of HIV/AIDS and the stigma attached.

2.18 Coping with Stigma

Siegel (1998) described strategies of coping with stigma among gay/bisexual men. They described a variety of strategies that could be arranged in a continuum from reactive to proactive, based on the extent to which the person implicitly accepted or challenged the social norms underlying the stigmatization of HIV. Reactive strategies were used by respondents to avoid being discredited through hiding their HIV status and controlling information about HIV within their close social networks. Proactive strategies were used to construct and promote alternative views of HIV that undermined societal stigma. The most proactive responses addressed the meanings, values, beliefs, practices, and power imbalances behind the stigma, rather than situations in which stigma might be experienced. Moneyham et al. (1998) noted that avoidance was used as a coping strategy in the early stages of the disease when symptoms were fewer, while the onset of disease-related symptoms evoked the use of active coping strategies.

Rationalization is one of the emotional coping strategies used by PLWHA. This was identified by Mokoae et al. (2008) in a study done in five African countries. This refers to utilizing the cognitive processes to make the stigma less painful. This is done by focusing on positive thinking, and having alternative explanations for the illness (Mokoae et al., 2008). In some cases, problem-based coping methods are employed, such as joining a support group. This benefits the PLWA by giving them the opportunity to learn from others and keeping them busy.

2.19 Conclusion

HIV/AIDS related stigma is the greatest obstacle to action against the epidemic for individuals and communities including religious leaders and government (UNAIDS, 2002). HIV stigma is a mental and social reaction related to many factors including culture and personal and social fears, denial and misconception

and myths about the epidemic. Ultimately, the women bear the brunt of HIV stigma, especially at a community level.

Strategies such as education and legislation to combat stigma are vital, but these need to be accompanied by community mobilization (Duffy, 2005). HCW can play a vital role in linking communities and legislators to enhance understanding of the contextual issues in people's lives in relation to HIV/AIDS stigma, and thus to mobilize dialogue between the stakeholders.

Chapter 3

3. RESEARCH METHODOLOGY

3.1 Study approach and design

The study utilized a qualitative approach. Qualitative approach enabled the researcher to study the phenomenon under study in depth and detail, producing a wealth of information about a much smaller number of people (Patton, 1990). To be able to extract the richness of the human experiences of this group, the study utilized Heidegger's phenomenological research approach.

The primary aim of the study is to explore the lived experiences by women enrolled in the PMTCT programme in the eThekweni PHC facilities in the eThekweni District KZN, South Africa. This was done by describing how individuals make sense and give meaning to the stigma experiences due to their HIV diagnosis. The Heidegger phenomenological approach was chosen to guide the study, as this approach emphasizes the lived experiences as a source of knowledge and also because this methodology allows for analysis and for presentation of these experiences in a systematic and rigorous manner. Phenomenology emphasizes the world as lived by a person and not world and reality being separate from a person. (Van Manen, 1990) Phenomenology is an essential study with a purpose to understand the phenomenon from the participant's point of view. Phenomenology is the study of experience or consciousness. Phenomenology has been described by psychologists as subjective point of view or as the world seen in the eyes of that individual's perspective. (Churchill, 2002)

3.3 Study approach

Phenomenology is concerned with studying the lived experiences and description of phenomenon presented into the conscious mind. Even though Edmund Husserl (1859-1938) is regarded as the founder of phenomenology, there are two schools of phenomenology, as described in Polit and Beck (2008: 228). These are descriptive (Husserl, 1962) and interpretive (Heidegger, 1962) phenomenology. Both Husserl and Heidegger argue that phenomenology is an approach to exploring and understanding people's everyday life experiences (Polit & Beck, 2008: 227). By phenomenology Husserl (1913, 1962) meant the study of how people describe things and experience them through their senses (Patton, 1990: 69) Husserl rejects the notion that perception is a result of stimuli imposed from outside. The idea of phenomenology is that individual's reality is as the individual sees it. Husserl developed this phenomenon of the response to the dominant positivism scientific approach dominant at the time. He argued that scientific investigations failed to include lived experiences in subjective form and resulted in one sided forms of understanding (Held, 2003) As a result Husserl designed a prepositionless science based on the conviction that if we refrained from accepting preconceived ideas and existing theories, we could attend to and describe phenomenon as they present to awareness (Giorgi and Giorgi, 2003) Heidegger, a former assistant to Husserl disagreed with the notion that phenomenology is a preposition less science. He believed that social, personal and personal experiences form part of humans report and understand the world. He felt that the presuppositions need to be incorporated rather than set aside. (Polkinghorne, 1983) Heidegger's hermeneutic approach opened other ways of conceptualizing and extending and describing lived experiences. In the recent years Spielberg (1982) describes phenomenology as a movement rather than a discreet period time. This means that the view of is not static but ever evolving (Lavery, 2003). This witnessed by the fact that ideas vary between philosophers and within philosophers.

Even though at a glance the approaches may look different each a based on the premise that the starting point of investigating a phenomenon should be everyday lived experiences. (Patton, 2002) Phenomenology approach explores lived experiences by describing the meant features of an object, the qualities of an act as well as the correlation between them. (Steinbock, 2001) Hesserl's approach confirms that phenomenology is descriptive and not explanatory (Welton, 2003) One of the implications of phenomenological studies is that it focuses on what the people experience and how they interpret the world, in which case one can use interviews without actually experiencing the phenomenon oneself (Patton, 1990: 69) Phenomenology makes a number of assumptions including the meaning making experience in lived experiences is an individual one and the individuals are reliable witnesses of their subjective experiences.(Ashworth,2006).The primary task of phenomenology is to describe everyday experiences as they are told by the participants.

Descriptive phenomenology was used utilized in this study since the researcher aims to only describe and not to interpret the phenomenon under study. The study aims to describe the experiences of stigma in patients enrolled in the PMTCT programme. The goal was to describe the lived experiences and to determine how the stigma manifests. Experience is a product of intrinsic relationship between the individual and the world (Polkinghorne, 1989) as people continually interact with the world, they form and create experiences. Phenomenological study tries to understand these experiences from the perspective of the individual. Experience is the reality that occurs as people become aware and open to the world, cannot be reduced to either mental or physical sphere (Kruger, 1997) Husserl introduced the term "lived-world or "lived experiences" This is the world as lived by humans and not as seen by the positivists as independent from humans (Valle, et al., 1989)

One of the strategies of Phenomenological research is Bracketing. This was utilized by the researcher to ensure that pre conceived ideas don't cloud the data results from the study to ensure that data is approached in its pure form (Polit

and Hungler 1995). The participants were viewed as experts of their experiences, as such this required continuous bracketing of theoretical and personal presupposition about the experience at hand. (Giorgio, 2006) Ahern's method was utilized; a reflective journal was utilized to help with bracketing. In addition none directive interviewing technique was used to, this allowed each participant to describe their experience as openly as possible rather than following a preset method by the researcher (Ashwoth, 1996)

Intuiting was done by the researcher to ensure that she remains open to the meanings attached to the topic as described by the subjects who have experienced the phenomenon.

3.3. Research paradigm

The study adopted a naturalistic paradigm. Qualitative are naturalistic in that the researcher does not attempt to manipulate the research setting (Patton, 1990: 39). Qualitative research is a method of inquiry aims to gather an in depth understanding of human behavior and the reasons that govern such behavior. The qualitative method investigates the why and the how of the decision making, not just what, where, when. In this way smaller samples are utilized, the belief is that reality is not a fixed entity but rather a construction of the individuals participating in the research and those realities exist within a context (Polit & Beck, 2008). Furthermore, the naturalistic paradigm assumes that knowledge is maximized when the distance between the inquirer and the participants in the study is minimized. Hence, interviews were conducted with the participants.

3.4 Study setting

The study was conducted in selected Primary Health Care clinics in the in the eThekweni District. This is a city within the province of Kwazulu Natal.(Please see appendix 6 for the map of the district) The district has 113 primary health care clinics, 60% of the clinics belong to the Provincial government and the rest are

run by the Local Authority Government. All these clinics offer Primary Health Care services including maternal and child health services such as; PMTC, Post natal care, including immunization services for babies.

3.5 Sampling Strategy of the Primary Health Care facilities.

The EThekwini district is divided into three sub districts, South, West and the North sub districts. Permission was sort from the Municipal head of health to conduct the study. (Please see letter granting permission in appendix 5). This was followed by request of permission from the respective area managers and the facility operational managers. Two high volume PMTCT clinics were purposively sampled per sub district ,this made it six PHC facilities. This allowed for equal representation of the three sub districts. In Ethekwini District. The participants who met the inclusion criteria were selected from these facilities. .

3.5.1 Sampled Participants:

Participants were selected from PHC Facilities that gave permission for the study. Because of the sensitivity of the subject, the clients were not approached directly, but rather through the Professional Nurses running the PMTCT clinic. The Professional Nurses then referred those women who agreed to be interviewed. Purposive theoretical sampling was utilized to obtain a sample of seven participants. This involves selection of sample as the study progresses. In addition participants were selected using the criteria advocated by Polkinghorne (1989), which states that the participants need to have experienced the phenomenon under the study and willing to talk about it.

This type of sampling is suitable for this type of study as the aim was to interview women who have been through the PMTCT program, to Explore HIV related stigma experienced by women enrolled in the PMTCT in Ethekwini. In the end seven participants were interviewed. The researcher stopped interviewing the

participants were the point of saturation was reached in terms of information from the interviews.

The intention of using this type of sampling was for the researcher to be able to purposefully select the suitable participants (Polit & Hungler 2005: 297).

The subjects were both pregnant women attending PMTCT clinic and those who have already delivered their babies and therefore have been through the programme process partially. These women were identified while bringing their children for Polymerase Chain Reaction for HIV testing and/or immunization.

3.5.2. Inclusion Criteria

Subjects were selected according to the following criteria:

- ❖ They were all able to communicate in IsiZulu.
- ❖ They were all HIV positive
- ❖ They have been through the PMTCT programmed at least once in the past six months.
- ❖ They were 21 years or older.
- ❖ Delivered a live baby or in the second or third trimester of their pregnancy.
- ❖ Willing to be interviewed and tape recorded.

3.7. Data Collection process and instrument

Data collection was done through individual in depth interviews. The interviews were conducted within the PHC facilities using private consulting rooms provided by the staff at the facility. Interviews allowed participants to give a rich and detailed account of their experiences. In depth individual interviews were conducted, the researcher used probes to encourage discussion and allowed participants enough time to discuss the phenomenon. The interviews were conducted in IsiZulu and tape recorded following permission from the participants

to do so. The phenomenological interview principles require interpersonal engagement within a relationship of safety and trust; this calls for rapport between the researcher and the participant. Because of the nature of the subject, some participants became emotional, the researcher as a trained nurse offered debriefing at the end of all the interviews. In a case one participant, formal counseling was suggested.

Techniques such as probing, paraphrasing questioning and summarizing to were used to obtain more information from the participants. The questioning included questions about HIV testing, disclosure, adherence to the programme and stigma in the context of PMTCT programme. (Refer to tool in appendix 4)

The Primary Health clinics were used be used as the interview venue but a private space was requested for use during interviews. Participants who agreed to participate in the study were taken into a private room in the clinic, where further information regarding the study was being given. Once the consent had been signed, the researcher using a self-developed interview guide conducted individual interviews. All interviews were recorded on a tape recorder and notes were taken for non-verbal cues, with the permission of the participants.

The role of the researcher during the interviews was that of facilitator. In addition, the role of the researcher was clearly explained to the participants, as participants perception of the researcher could have implications on how they respond to the questions and how they inter act with the researcher, as the role of the researcher may be a foreign concept to the participants and this may have implications how they respond to the questions. Further more the researcher did not discuss own knowledge of stigma in the PMTCT programme context. It was also kept in mind that some differences such age, social class may have influenced how much the participants share with the researcher as well as the view that the researcher may part of the HCW may have influenced the responses, although not explicitly stated during the interview. (Ashwin, 1996) The participants were assured of confidentiality and anonymity throughout the

process. Keeping in mind also is that many respondents were reporting retrospectively on incidents that happened a couple of months ago. As such their reliability is only as good as respondents' memory, which is likely to retain selectively the less pleasant experiences.

3.8 Data analysis

Data analysis represents a critical stage of phenomenological research study; it is intended to extract from collected data a description of critical and essential features of an experience. (Valle et al. 1989) Data analysis started simultaneously with data collection.

To analyze the data Colaizzi's method (1978) was utilized to guide the analysis, using the seven stage phases as described by Colaizzi.

To begin a phenomenological analysis the concept of epoche need to be applied. Epoche is a Greek word that means refrain from judgment and stay away from everyday way of perceiving things (Patton, 2002).

With this in mind, the researcher read the narratives by participants in order to a feeling of their ideas to understand them.

Colaizzi. Seven-step analysis is as follows:

- The first step in analysis depth with extracting words, phrases and sentences relating to the stigma. This was done with the aid of the NVIVO 08 programme. These were called free nodes.
- At this point an attempt was made to formulate meanings for each significant statement.
- Once these means were formulated, and they were grouped into clusters, making clusters of themes or tree nodes according to NVIVO 08 programme.

- The next step involved integrating the resultant clusters into exhaustive descriptions of stigma. At this point an excel table was designed to further make data more manageable and form structure.
- This was then reduced to an essential structure. This was then written out as will be seen in chapter four and giving meaning to the statements.
- The last phase is to return to the participants, to further interview to validate the researcher's description to see if the full meaning has been carpeted. This was telephonically done with two of the participants because of the nature of the topic, and to further maintain confidentiality.

These steps flowed and were fluid and required a lot of flexibility.

Literature review of qualitative studies discussing HIV and AIDS stigma, PMTCT were identified. These were read in conjunction with the South African PMTCT Policy and guidelines.

In finding out experiences the researcher explored how clients experienced the HIV positive status as some were finding out for the first time during pregnancy. Explore the role of Health workers in stigmatizing the clients. In addition discover self-imposed stigma by the clients.

3.9 Data management

The researcher herself did data collection, by doing in-depth interviews. This was done to ensure that confidentiality is maintained as much as possible. A computer with a special log in code known to the researcher only was used. The interview data was locked in a locker accessible to the researcher only during the research period. Data will then be kept for a period of five years in a secure location with arrangement by the supervisor at school. After five years data will be disposed of by incineration.

The interviews were conducted in IsiZulu and recorded in IsiZulu. The voice recordings were then transcribed in IsiZulu and then translated to English verbatim. After the formal interview, the tape recorder was turned off and a more informal discussion took place, which served as a form of debriefing and generally showed the researchers interest on participants as individuals rather than just research subjects.

The formal interviews took about 30 minutes to an hour. These transcripts were then transferred to NVIVO 08 programme for the purpose of analysis.

3.9.1 Data Quality

A well designed study should convince the researcher and the readers that it is credible by maintaining certain standards. (Rubin and Rubin, 1995). Quantitative researchers use credibility and validity to refer to these standards. In the case of qualitative research these concepts are known as trustworthiness, credibility and transferability. According to Polkinghorne (1989) suggest that data should be grounded on evidence and remove the following out:

- ❖ That researcher did not influence the participant's interview responses?
- ❖ The transcriptions are true reflection of the participant's utterances.
- ❖ The data analyses of statements are accurate and no other conclusion could be drawn from them, either than the one done by the researcher.

3.9.1.1. Transferability

This refers to the extent to which the research findings can be applied to other contexts. When the study is read by the researcher of any reader, the themes and labels, should be clear how they study apply to other contexts. (Burns and Grove, 2006)

3.9.1.2 Confirmability.

Conformability of data will be ensured through having two independent researchers who will assess data for relevance and meaning.

3.9.1.3 Credibility and confirmability

Credibility focuses on how interpretations are grounded on data and whether they are formulated in ways consistent with the available data. (Graneheim and Kudman, 2004)

Credibility of data was ensured by collecting Data or conducting interviews from multiple sites and three different sub districts of EThekweni. Additionally, two participants were called to confirm the themes extracted from the transcripts. (Sandelowski, 1993)

Additional Colaizzi's method of data management and representation is another effort by the researcher to maintain rigor of the study.

3.9.1.4 Dependability

All the participants were interviewed using and probes were used to encourage discussion.. This was to ensure that all the participants respond to the same questions. Additionally all the interviews were done were tape recorded. (Polit and Hungler 1999, pg 717)

3.9.1.5 Time Triangulation

This was done by collecting data from those who have delivered and from pregnant women still taking part in the PMTCT programme. Data was also collected in six different facilities at different times.

3.10 Ethical Considerations

Permission to undertake research was sort with the UKZN ethics committee (Please see appendix 5). Permission was also sort with eThekweni health District and PHC supervisors in charge of the clinics. All communication to the participants will include the researcher's name and contact details contact details. (Please see appendix 3)

3.10.1 Confidentiality

The participating clinic names will not be divulged rather the clinics will be called clinic A, B and so on.

Real Participants' names will not be used in any part of the study, rather pseudonyms chosen. The master copy with the codes will be kept under lock and key. This will be communicated to the participants. They will also be informed that when the data is published their names will not be mentioned.

3.10.2 Informed Consent

Informed consent was drawn (Please see appendix 2). The risks and benefits were explained. Permission to record the participants will form part of the informed consent; they were informed of their right to refuse. Additional permission was sort from the participants to record the interviews. It was explained that this will ensure that all the discussion are captured accurately. All the participants gave permission for recording the interviews.

3.10.1 Voluntary Participation

The clients will be made aware that participation is voluntary and declining to take part will not disadvantage them as participants in the PMTCT programmed in any way. Participants were informed of their right not to participate.

The study was explained in full to the participants and their right to withdraw at any point of the study.

3.10.2 Respect for dignity

This principle includes the right to self-determination and the right to full disclosure. **Self Determination:** this means that the participants have the right to decide voluntarily whether to participate in the in a study without the risk of incurring any penalties. This includes freedom from coercion. **Full disclosure:** The researcher described the study fully; explained potential risks and benefits of the study and the patients' rights to refuse participation. (Polit and Hungler 2004:136) The researcher ensured adherence to these principles.

3.10.3 Privacy

All participants have a right to privacy. The researcher ensured that the questions were not more intrusive into people's personal lives than necessary and privacy was maintained at all times. At no point will the names of participants any identifying information of the individuals be used. Research report was done using aggregate information.

3.10.4 Beneficence

This principle of not doing any harm to the participants. This principle contains multiple dimensions namely: **Freedom from Harm**, because this is a Qualitative study about experiences, care was taken to not to cause psychological harm. The Questions were phrased carefully to ensure minimal psychological harm. Another one is **Freedom from exploitation:** The participants were assured that the information they shared with the researcher would not be used to disadvantage them or expose them in any way.

3.10.5 Potential benefits

There will be no direct personal benefit for the participants nor monetary benefits for taking part in the interview.

3.11 Limitations of the Study

3.11.1 Limitation

This is a qualitative study and data analysis was done while collecting the data. According to (Burns & Grove, 2005, pp 569) some researchers are concerned about the fact that results from the qualitative studies can not be replicated. To solve this problem the qualitative researcher forms a trail of information of how data was collected and analyzed by the original researcher to obtain the same results. This is called *audit ability*.

Another issue phenomenological research is that the researcher may have preconceived ideas about the subject and research topic because of prior knowledge; this may have had an effect on how she collects and interpret data. The process of bracketing, setting aside previous beliefs and knowledge, enabled the researcher to remain neutral.

The other limitation is that the results cannot be generalisable, as the purposive sample will be utilized as the aim of the study is to gain in depth insight of the women's experiences of stigma while enrolled in the PMTCT programme.

Chapter 4

4. Introduction

This chapter discusses and presents the findings of the study. The presentation of the results will be according to the aim of the study, namely, exploring HIV related stigma experienced by women enrolled in the Prevention of Mother-to-Child Transmission (PMTCT) Programme in Ethekewini, KwaZulu-Natal, using phenomenological analysis. Interviews were the main data collection tool. All the participants were asked the same questions, with the difference being in the sequence of questions, depending on how each individual responded to the questions. The answers were recorded verbatim.

To start off with, a brief description of the study setting and a concise description of the participants' profiles will be presented.

4.1 Data Collection Setting

The data was collected in the Primary Health Care Clinics (PHC). The interviews were often conducted in the consulting rooms allocated to the researcher by the clinic staff. The PHC clinics, in general, are like a market, a hive of activity with large numbers of clients who are there for various services.

There are usually large numbers of people moving up and down the passages to various rooms, and just as many people seated in long lines, all awaiting their turn to be seen by the Health Care Workers (HCW). The place is often noisy and chaotic, what with the voices of people chatting and the voices of crying babies. It is in the midst of all this that the researcher tried to find a quiet place conducive to interviewing the participants.

4.2. Participants description:

Below is a table summarising participant's information. A thick description of the participants follows below.

Table 4.1 Participants description

Participant code	Pseudonym	Age	No Of Kids	Marital STATUS	Programme Enrolment	Employment
1	Nikiwe	28	1	Single	1	Yes
2	Thandiwe	31	3	Co-habiting	1	No
3	Fikile	28	3	Single	1	No
4	Mancane	21	1	Single	1	No
5	Phambili	28	1	Single	1	No
6	Nokukhanya	34	2	Single	1	Yes
7	Thabile	31	3	Single	1	Yes

4.3 Thick Description of the participants

All the participants were asked to choose a pseudonym which could be used when referring to them as part of the analysis of the research. This would contribute to preserving confidentiality, and offer some form of respect and recognition of self-worth.

4.3. 1. Participant 1

She will be known as **Nikiwe**.

Nikiwe is a 28 year old women, she came across as a self-confident, eloquent woman. She is the only pregnant participant. The only time this polished well-groomed exterior fell apart is when she was talking about her partner and the father of the child she is carrying.

Nikiwe became quite agitated and emotional. Strangely, she kept on going back to discuss him, and how, after she had disclosed her status, he abandoned her. Nikiwe said she had come to terms with this fact, but her body language told another story, and indicated her desire to have him support her. It may be that this was the first time she had had a chance to share these intimate feelings with anyone, and that she saw the interview as an outlet for her feelings, hence she kept on discussing her partner, although it was clear that this caused her a great deal of distress. She was most disturbed because she felt he had brought the disease to her, and that the least he could do was to care for her and support her emotionally.

Although Nikiwe does receive support from her sisters and employer, she still needs care from her partner, of the kind that only a partner can provide. She even revealed that he had stopped being intimate with her, since she made him aware of her status. Nikiwe knew this exactly, as she has been keeping a diary of these events!

Nikiwe is also the only participant who went for an HIV test before she was aware that she was pregnant. The motivation for her testing was to ensure that she was able to care for herself, and to ensure that no one discerned her status because of becoming ill. She is afraid of becoming dependant on others. Nikiwe decided

to take the test so that she could take the necessary action before becoming sick and burdening others with her care.

Nikiwe has one child, an eight-year-old son whom she is very keen to protect and to ensure that he does not discover her HIV status.

She disclosed her status to her two sisters, her employer, as well as her partner, the father of the child. She seems to have a plan in place to ensure she follows the PMTCT guidelines well, and ensures the safety of her unborn child.

4.3.2. Participant 2

Her chosen name is ***Thandiwe***.

Thandiwe is 31 years of age. This is her first time on the programme as she tested negative with her first two children.

Thandiwe appears to be a demure, soft-spoken lady. She is smart and carries a well-dressed baby. Thandiwe appears generally to be a very clean-looking, healthy, happy person. She is the only woman out of all the participants who had her partner with her at the clinic. Her partner was present, carrying her bags, and generally caring for her and the baby. Initially, she asked her partner to remain outside while we talked. Thandiwe later asked if he could be allowed in so that we could talk about his testing and generally discuss discordant couples.

Thandiwe was at the clinic for her six-week post-delivery check-up and to have PCR done for her baby. She has two older children. The two younger ones are by the current partner, and they have been together for nine years. She decided to disclose her HIV status only to her partner. Thandiwe lives with her mother on a part-time basis, and spends the rest of the time with her partner. She has not said anything to her mother. She found it very hard to keep her status secret from her mother. Thandiwe describes her mother as someone who wants to know

everything and who is very nosy. She has made a point of ensuring that her mother has never seen her taking her medication, to the extent of hiding in the bathroom to take her medication. She has also had to empty the baby's medication into a Gripe water container to hide the fact that she is on the PMTCT programme.

When she disclosed her status to her partner, he also decided to go and test for HIV. He tested negative twice. Thandiwe is most amazed about the fact that he has still stayed with her. She kept on saying how grateful she was, and that her partner has done everything possible to support her, even moving out of his parent's home to rent a room so that they can have privacy when she visits him, as in that way it is easier to follow the PMTCT guidelines without the prying eyes of family members.

Thandiwe is keen to find out as much information as possible to protect her HIV negative partner.

4.3.3. Participant 3

Her name is *Fikile*.

Fikile looks very tired, unhealthy and unkempt, and the baby looks just as bad. She has a sad, distant look about her. Fikile makes poor eye contact, is jumpy and generally looks uncomfortable.

Fikile is 28 years old and has three children. This is the first time she has enrolled in the PMTCT programme. Fikile has been through a great deal of trauma and emotional grief.

Fikile shared with the researcher that she lost both her parents while she was still very young, and, as a result she was brought up by her uncle. She is currently

residing in his home together with her male cousins. Fikile did indicate that she misses having a woman in the house to assist her with childcare.

Fikile lost a child of eleven months, quite recently. The current child is her fourth child. She is not sure what was wrong with her baby. He died in his sleep, and she is not sure of the cause of death. She was visibly traumatised by this experience, having woken up to find that her child next to her was dead.

On being diagnosed as HIV positive, she disclosed her status to her partner and a female friend. It was actually the friend who told her to disclose her status to her partner. No family member is aware of her HIV status. She feels that because there are only men in the house, they do not know why she is taking tablets and giving the baby syrups. Fikile thinks they assume that this is what all pregnant women do and what small babies need. Fikile is thus able to keep her HIV status private. She did feel a bit of pressure from well-meaning neighbours to breastfeed. Fikile told them she is not able to do so because of health reasons.

Fikile is worried about how she is going to feed her baby. She decided on artificial feeds as she was not aware that there is a way to breastfeed while one is HIV positive. Had she known about this, she would have decided to breastfeed.

The HCW have told her that the formula milk will no longer be supplied by the state. She is not sure how she is going to feed her child should that happen, as both she and her partner are unemployed.

While she is talking, her eyes are on the floor, fixed on one spot throughout the interview.

4.3.4. Participant 4

She will be known as *Mancane*.

Mancane looks very young and could pass for a 15-year-old child, although she says she is 21. Even her manner when she speaks is very child-like. While talking, she kept giggling, as a typical teenager would, for no apparent reason.

Mancane has already delivered, she was at the clinic for postnatal care. This is her first child. Mancane is from an urban area, with easy access to the health care facility. She enjoys good support in terms of baby care as her Mom and Granny are helping her. She has not told either of them about her status. Mancane decided only to disclose her status to her partner who did not seem to take this seriously. He refused to take the HIV test.

It turned out that her CD4 is low, and she is eligible for HAART and was referred to an ARV site to be initiated on HAART. She decided not to go. Mancane feels she is not ready, and that she needs to get used to her new HIV status, so much so that, at this point, she says she even forgets that she is HIV positive. Mancane admitted to having a problem even adhering to the Dual therapy, taking the AZT only when she remembers, and found the general PMTCT guidelines hard to follow. She explains amid fits of giggling. This provides all the more indication that she needs support from people who reside with her in the house, like her Mom and Granny.

Mancane had a Caesarean section, and she found this very traumatic as she was alone.

Mancane opted to bottle-feed, but will not collect from the public facilities as a way to conceal her status, as if she is seen with Pelagon, people will suspect she is positive. She plans to buy from the shops, but not the brands offered by the public sector.

Mancane said that she found that the nurses adopted a parenting role with her, scolding her because of her age. She had a few questions about contraception and thought the nurses had injected her with contraception post-delivery without her knowledge.

4.3.5. Participant 5

She will be called ***Phambili***.

Phambili is very outspoken, and speaks with exaggerated hand gestures almost standing up from the chair, although she has a baby in her arms. She is very descriptive and elaborate in the way she recounts her story. You could see she cherished the chance to tell her story.

Phambili has two children including the one she has just delivered. This is her first time on the PMTCT programme. She only started the ANC at 34 weeks as she was not aware she was pregnant because she had been menstruating throughout her pregnancy. It turned out that she also had a low CD4 count, and was asked to return for HAART initiation soon after delivery.

Phambili only started to take AZT at 34 weeks as opposed to 14 weeks as indicated by the PMTCT Dual guidelines. In addition to this, her waters broke while she was still at home. She feels all this is the cause of her baby being sick post-delivery.

A couple of days post-delivery, her baby was diagnosed with Meningitis. Phambili had to go back to the hospital and be a lodger mother for a couple of weeks. This means that she was not able to return for HAART as instructed. She was not able to return for HAART after delivery as her baby became sick and she stayed in the hospital as a lodger mother.

She is very vocal and passionate about having to make her partner support her emotionally. She makes him accompany her to the classes and has made him her treatment supporter. She plans to make him support her psychologically, even though the love relationship may be gone. He is the only person who knows her status, and as such, is obligated, according to her, to stand by her so that she can do the same for him.

Phambili says she wants to ensure that they both stay alive and bring up the child. She is very spirited and is motivated to live a full life despite her HIV positive status.

4.3.6 Participant 6

She will be known as ***Nokukhanya***.

It is her first time on the programme. Nokukhanya has an eight-year-old child. She is very shy and down-to-earth. She speaks softly.

Nokukhanya started the PMTCT programme as normal, but, because of being in the rural area, she was unable to reach the health facility in time for delivery, so she had a home delivery.

A problem with the MTCT is that the highest risk of infection is during confinement, yet she delivered at home, presumably with the assistance of family members who obviously would not have Personal Protective Clothing, like gloves and goggles etc. They were possibly not even aware of the risk they were taking helping her deliver. Nokukhanya also missed out on taking the prescribed ARVs that are taken before and during labour and delivery.

This caused a great deal of grief and guilt for her, and the nurses also berated her when she finally made it to the hospital post-delivery. This means that she

did not take the single dose NVP, and the three-hourly AZT during labour. She is very worried about the health of her baby.

Nokukhanya decided on exclusive breastfeeding. She feels she will enjoy this, as she did not breastfeed her first child and Breast feeding is seen by Nokukhanya another way to ensure that no one will suspect that she is HIV positive.

Nokukhanya has not disclosed her status to her partner, only her mother knows. She wants to gain strength first, and get used to her own HIV positive status before disclosing this to her partner. She is scared of being abandoned by him and stigmatised by the community.

4.3.7. Participant 7

Her pseudonym is ***Thabile***.

Thabile is a 31-year-old mother of three. She looks very smart and sophisticated. She tries to preserve her smart facade. It was only when we started discussing her status that she began to fall apart, especially when talking about her partner. Then she became visibly distressed.

Thabile started the PMTCT programme via the private sector. She attends the Public Sector PHC for vaccinations. She feels very unhappy with the PMTCT program in the private sector. According to her there is a lack of information and inadequate preparation for both PMTCT and HAART initiation.

Thabile feels as if they just pounced on her and tested her. There was no formal request for her consent, nor was she offered counselling before and after testing.

A doctor told her she was positive, and she was given a script to start HAART. Thabile received no literacy classes, nor any form of information about taking ARVs. The whole approach and care she received left her feeling exposed and

not properly cared for. Thabile had so many questions about the programme and her expectations.

Thabile has three children from one partner. She is so devastated about her HIV status and is very angry with her partner. She feels betrayed and sickened by the fact that he infected her, following numerous warnings that she gave him that this would happen. What gets to her is that, in addition to her own infection, she must now help him deal with his own HIV status when she feels he is the cause of her infection. She will do anything to hide her HIV status. Her ARV tablets have been emptied into a multivitamin container, but she still wants to adhere to the guidelines. Thabile is very hungry for information about HIV and AIDS.

Before leaving the room, she asks me to hold the baby while she puts herself together again, taking out a mirror and wiping away her tears, and sorting out her make-up before facing the world as a presentable, classy woman.

4.4 Extracting Significant Statements

The researcher used NVIVO 08 for data analysis. The researcher started by reading and re-reading each transcript which expressed the participant's experiences of the phenomenon.

The statements were grouped into nodes using the programme. The statements were labelled on NVIVO and grouped under nodes. The nodes were further grouped into significant themes. This was done using an Excel spreadsheet set out into columns, and grouping themes into significant meanings. Fourteen significant statements and phases relating to participants' experiences of stigma, particularity in the health care system, were identified.

4.4.1. List of Themes

The below is a summary of all the themes that emerged from the data.

Table 4.2

Themes		Sub-themes
Antecedents of Stigma		Disclosure Denial Secrecy Protection of others Blame
Experience of Stigma	Internal	Fear and anxiety Suicide Blame Guilt
	External Stigma	Loss of support Loss of control Physical exclusion Denial of care Verbal abuse Exclusion, Isolation Neglect Lack of empathy
Consequences of Stigma		Feeding practices Initiation/Adherence to HAART Defaulting programme
Coping With Stigma of HIV and AIDS		Resigned Motivation to live for children Positive living Support group Plans for the future

4.5. Antecedents and experience of Stigma

These are important background themes identified from the data, they relate to how stigma is experienced by the sampled participants in the PMTCT programme. Although not an aspect of stigma these, were found to be actions and omissions caused by the fear of what could occur due to the assumption that they would be stigmatised if discovered to be HIV positive.

All Participants in the study felt the need to disclose their status to someone, the people chosen to disclose to, were trusted would not share the information with anyone.

The participants also exhibited denial of their status through their actions in order to protect their loved ones, especially children from associated stigma. The participants reported a couple of actions taken to ensure that they were not seen to be HIV positive, or to be associated with HIV and Aids, some of these actions included, hiding when taking medication, buying baby formula (against collecting from the clinic) and decanting ARVs into other containers. A strong feeling of being scared and secretive of their status to protect themselves from received stigma was also a common category that emerged within this theme.

4.5.1. Disclosure

This refers to Participants sharing their status with their significant others. In this study most Participants disclosed their status to their partners and close family, mainly for emotional and financial support. Disclosure of HIV status is done carefully. Only the trusted close people were informed of HIV status, this was often received with mixed reaction, Family members were by and large very supportive, while the partners in most cases, had negative response.

As evident in the selected extracts below, it was apparent that there was a great deal of fear and worry experienced by the participants before disclosing their

status. The fear of being judged and received in a different manner was one of the primary reasons why many participants chose to hide their status.

Yes, I did, [disclose my status] [pause] but I was scared. I told him. We talked. We decided that he must also go and test the next day. I accompanied him to the clinic; he discovered he was HIV negative. I thought he was going to leave me. He is negative and I'm positive. He did not. We are still together and okay. We have been together for nine years. (Thandiwe)

I have not told anyone in the area. I see how they treat people they suspect to be positive. So I will hide my status. For that reason, I have only told my mother. (Nokukhanya)

It also appeared as outlined in the selected extracts below, that disclosure particularly to partner's was also motivated by the need to solicit their partners and motivate them to seek care and also get tested for HIV. The participants viewed this as being important so as to foster adherence between both partners in terms of treatment and care plans for the management of HIV/Aids, despite their partner's lack of willingness to be tested.

I did not tell anyone except my boyfriend. He did not seem to be shocked [when I told him]; it was like he was expecting it, or he knew. I asked him to go and get tested. He refused. (Mancane)

Yes I did [disclose HIV status]. He did not seem to take me seriously; he did not even acknowledge what I told him with an answer. He just kept quiet. I then asked him to also go and test and he refused. [Sigh]. I then left it at that. (Fikile)

Disclosure resulted in various reactions and responses .In some instances, the partners of the participants did not treat the HIV status with the seriousness one would expect as noted by the participants. Many participants noted that in many instances, their partners either ignored the news or reacted with a general indifference and even anger. In some cases as was evident in the case of Nikiwe, their disclosure resulted in distancing and withdrawal from their partners.

I told him [partner] I'm HIV positive. No, [intimacy] ever since I told him I'm HIV positive. When I told him about the pregnancy he accepted it and seemed pleased. He even said he wanted a boy. It was only when I told him of my status that things changed. (Nikiwe)

The other end of the spectrum though is shock and disbelief on learning the status as in the case of Phambile below.

Yes, he is the only one I told [of my positive HIV results]. He was so shocked. He did not want to believe it. I asked him to also go and take the test. He refused. I said, "If you test it will help because we can be together in this" [putting arms together for emphasis], "I can also help you". (Phambili)

He knows, I told him [of my HIV status]. I think I know when it happened [got infected]. We had an incident, a burst condom and he tried to hide it. I asked him but he said there was no problem. I think he must have suspected that he was HIV positive. After the incident of the burst condom we decided not to use condoms any more. I felt, what is the use, if I'm pregnant, it has already happened, why bother with a condom. I think that is when I fell pregnant and got infected. (Thabile)

4.5.2. Secrecy

This dimension is about the participants keeping their status private and only informing or disclosing their status to specific people who they trust to keep their status secret.

Although all participants disclosed their status to significant others, they still wanted to keep their status private and they yearned confidentiality. The participants tried to minimize stigma by closely controlling who knows about their HIV status as stated by Nikiwe.

They don't know because I'm still well. I have also not made them aware, only my sisters and my close friend [know my status] and all have kept it quiet. That is why I tested early, so that no one will ever find out, as sometimes people discover your status when you become ill, and it is like an advert for everyone that you are POSITIVE. So no one knows. (Nikiwe)

The secrecy stems from the fear of how the community will treat them and their families, upon knowing their HIV status. The participants voiced fear of being excluded and shunned from the main stream community if their diagnosis was known. This was evidenced by the excerpts from Thandiwe and Nokukhanya. The fear of the reaction and the resultant outcome of stigma namely the abuse or exclusion from social activities was a major trigger that fuelled and was an enabler of secrecy that was expressed by the participants.

I'm just scared people will treat me differently. They will be too scared to touch me and will even make me use separate plates and spoons. I don't want that [pause]. This will also affect my kids, no! [rising voice for emphasis] I will not disclose my status I would rather die! People may say they will accept you no matter what while you are still talking, [that is] before they know your status, but I know people, once they know, they change. (Thandiwe)

I have not told anyone in the area, I see how they treat people they suspect to be positive. So I will hide my status. I have only told my mother for that reason. (Nokukhanya)

Furthermore, secrecy was also used as a mechanisms to sustain and save relationships that offered them financial (in the form of security and shelter) or emotional support (of being single and dealing with a new child) to deal with their lives. This illustrated in the following extract.

I know how my mother is, it would be a big problem. She will disown me. I also have this very rude brother. If he were to find out, I would never have a place again at home [if HIV status were known]. I can just imagine the fights that would break out. (Thandiwe)

In some cases the secrecy is temporal allowing the participants to get used to her HIV status before disclosing to others. This allows them to develop coping mechanism, so that they can deal better with the outcomes of disclosure. This is seen in the case of Nokukhanya.

I decided not to tell him, [partner] until I also get used to the situation. I'm scared of how he is going to respond. I hear the way he talks about HIV even when we are just talking. (Nokukhanya)

Drastic measure are taken in some cases to hide the HIV status as in the case of Thandiwe, they decide to even move of out of their regular residence to be away from prying eyes as indicated by Thandiwe.

We decided to move out and rent a room so that we can be free. Otherwise, no one knows, so we wanted to keep it that way. (Thandiwe)

4.5.3 Protection of significant others

Keeping their HIV positive status secret from their significant others is a way of protecting them from the emotional pain of knowing that they are HIV positive. They are mainly concerned about their kids, discovering that the participants are HIV positive. The significant others who are deemed to be fragile and cannot deal with the news adequately are not informed of the HIV status., they are especially concerned about children as Illustrated by Thandiwe and Nikiwe..

No, never! I don't want them [the older kids] to know. It will cause them unnecessary stress. (Thandiwe)

No I'm scared. I think he [her ten-year-old son] is very sensitive. I have asked him if he knows about HIV. I realised that he is not ready. So I have not told him. Maybe I will tell him when he is 15 years old. He has seen me taking the ARV for PMTCT, although he does not know why. He often helps me by bringing the medication to me and giving me water, but he does not know why I take these tablets. (Nikiwe)

The family in some cases is not informed to protect them as there is a fear of how it will affects them. This is a way of protecting the family learning of potentially distressing news, as seen in the case of Nikiwe and Mancane below.

Yes, I told my two older sisters. My mother is alive, but she is not at home, she is away training to be a 'Sangoma', so she stays where she is training. I'm particularly scared to tell her as I feel she will experience a great deal of stress, so I have not told her. (Nikiwe)

I just did not want to worry them [Granny and Aunt]. My granny is old and does not pay much attention. My mom's sister has not noticed either. (Mancane)

4.5.3. Denial

This theme is about trying to block the HIV positive status from the mind by pretending it is not there, so the woman can forget she is HIV positive. It appears denial is used as a coping mechanism, to allow the participants piece of mind and not having to deal with HIV.

You know the problem; [pause] is that I also forget sometimes that I'm HIV positive. That is why I also sometimes forget to take my medication. (Mancane)

4.6 Experience of Stigma

4.6.1. Internal Stigma

This refers to self-stigmatisation. It incorporates thoughts and behaviours from the person's own negative perceptions about herself, based on her own HIV positive status. This is the stigma that one brings to oneself.

This happens even before the participants are exposed to stigmatising behaviour. It occurs just from the knowledge that HIV positive people are prone to being stigmatised.

4.6.1.1. Fear and Anxiety

This refers to the internal fear and anxiety of being stigmatised by others once they have been discovered to be HIV positive.

There internal dialog of the PLWHA of fears that are felt by the participants. This is often based on assumed and anticipated reception they are going to get from the significant others, as stated by Thandiwe and fears that even the HCW will not give them proper care thus endanger their lives.

HA! I cried the whole day when I got home. It got better when I told my sister, as before that, I could not talk to anyone. She calmed me down and also advised

me to tell my partner. I was very scared to tell him [partner], I thought he would leave me. (Thandiwe)

The other thing that scared me was the delivery. I have often heard how people die in childbirth because of the nurses' negligence and because they know your condition so they do not care. Luckily, things went well when I had my baby. (Thandiwe)

The fear of being exposed as HIV positive compelled testing in the case of Nikiwe. This is done in attempt to manage the HIV so that they never have to fall sick as this will bring out suspicion of being HIV positive. Managing the disease will allow Nikiwe in this case to pass as HIV negative.

I came to the clinic and I was not aware that I was pregnant at the time. I felt the need to know my status with all the drive on the TV and radios about knowing your status. I was healthy, and not feeling sick at all, I just decided to come to the clinic for the test.

I wanted to be sure that I'm able to take care of myself, and be able to share with my family, so that, even if I'm positive, I'm still able to do things for myself. I have seen people who find out when they are too ill and need help, even to take medicine. That is when problems start and people have something to gossip about, and treat you badly; everybody ends up knowing you are HIV positive. (Nikiwe)

4.6.1.2 Blame

This is about the blame of infection, by participants trying to figure out who infected them. The other component of blame, is fear of being seen as the one causing the infection of others, and ultimately being blamed for their deaths.

Testing HIV positive brings about question of the origin of infection. The PLWH try and look for the source of infection and who to blame. In the case of Nokukhanya, she is certain of the source of infection and there is some resentment and anger towards the boyfriend. Despite that she is planning to stay

in the relationship as her boyfriend is the only source of income for herself and the child.

[Laughs shyly] He does not think he will ever have HIV. When we talk, he says he will never be HIV+. I know he infected me. I'm sure he infected me! [pause and stare at the researcher] I think he will blame me and leave me. I cannot care for the child on my own. I don't work. (Nokukhanya)

The Participants have tested and confirmed their HIV positive status. In the eyes, of the community, they will be seen as the people who brought the HIV into the relationship, as against the untested unknown partner. Thandiwe indicated this phenomenon.

More often, the people who have had a relationship with you, like ex-boyfriends and their current girlfriends will say you infected them. You will be a laughing stock and get blamed for all the deaths that occur to those people. There is no way I will tell people I'm positive. (Thandiwe)

4.6.1.3. Suicide

This refers to thoughts about harming oneself rather than being exposed as HIV positive and thus being stigmatised for being HIV positive. These thoughts of harming themselves arise due to the fear of stigma and being stigmatised.

This indicates the degree of fear of being *HIV positive*. and the reactions of others *towards once* know to be HIV positive. This is equivalent to end life as they knew it, so the *participants feel* it is best to die rather than face the inevitable. This is as evidenced by the statements by both Phambili and Thabile.

You know that day, [pause] I felt like killing myself, thinking there is no hope for me, when the nurses shouted! (Phambili)

I always thought I would hang myself if ever found myself to be HIV positive! (Thabile)

4.7. External Stigma experience

This refers to all types of external stigma as experienced and described by participants in this study. This was reported by all the participants. The reports were mainly in the Health Care context. Seven sub-themes were identified:

4.7.1. Loss of Support and/or relationship

This sub-theme relates to the experiences of the participants concerning the loss of emotional and financial support because the participants have disclosed their HIV status. The emotional support refers to simple things like phone calls, enquiring about health, and general empathy from a partner. The emotional loss reported in some cases involved partners moving to other relationships, and also generally neglecting the participants.

There is evidence that disclosure of HIV status is seen as the reason partners lose interest and no longer want to be associated with the participants. In the case of Nikiwe, the pregnancy was welcomed by the partner with enthusiasm, only when she disclosed her HIV status she noticed change. She mourns the loss of intimacy and there is a sense of betrayal with the partner moving on with his life, starting new relationships when she so desperately needs his emotional support, to deal with being pregnant and HIV positive.

No, ever since I told him I'm HIV positive. When I told him about the pregnancy he accepted it and seemed pleased. He even said he wanted a boy [change in facial expression and the voice is lowered, tone of sadness]. It was only when I told him of my status that things changed. I asked him to also go and check [his HIV status], I even offered to accompany him to the clinic, but he kept avoiding the issue and said he would go on his own. He did not go. Not only that, he has started to behave differently towards me. I think he has started relationships with other women. I'm pregnant and HIV positive! I need love. He is not showing me the love and support that I expect from him! (Nikiwe)

The intimacy is seen as an indicator of existence of a love relationship, once this stops, the participants see it as the end of the relationship and an indication that the partner must be with other women, as stated by Phambili and Nikiwe.

The fact that the Participants don't work and those who work are unskilled, so the end of a relationship also translates to the end of financial support by the partners.

I also then told him, "I'm like this now [HIV+], and we must use condoms". He did not like that. I will be honest with you, Sisi; we have not had sex since that day! [raising voice] Fortunately we do not live together. Hayi-ke, I'm sure he is involved with other women now. I told him I would not sacrifice my blood for love. [Using hand for emphasis] I want to live and look after my kids. I tried to convince him by telling him that since I will be on treatment, it is dangerous for him to have sex with me without a condom. (Phambili)

I'm pregnant, he must still call me, and come and visit me, and he should do this, just as he did before I told him my status. He does not even care how things are going with my pregnancy, or even if I'm well or sick. [Close to tears]. I'm HIV positive! If a person does not call you the whole day, just to ask how you are [pause, while looking at researcher] - he used to do all these things before my disclosure that I'm HIV positive. (Nikiwe)

I can see that he is no longer interested in being intimate with me. Ever since I told him, we have not been together in that way. I can see he has lost interest. I think it made it worse that I told him I would only have sex with him if he uses a condom. I won't lie; I think he no longer wants me. I suspect he is involved with another person. (Phambili)

4.7.2. Loss of Control

It is not possible to conceal the HIV status from the HCW, as they need the information in order to offer care. Unfortunately the HCW sometimes disclose the HIV status of their patients without their permission through their actions. Thus failing to respect the right to privacy and confidentiality.

The information is shared verbally or on medical records.

This results in loss of self determination and respect of personal space the minute the PLWHA enter the Health care system.

The gesture of creating protective physical barrier, drawing of curtains, before sharing information are desired action and shows respect for participants and are seen as preserving confidentiality.

Eish, I was exposed to two hospitals. I started at hospital X; they screen [curtain around the bed] you before giving you your medication, so no one knows what is happening. I was moved to hospital Y. There, [pause] they don't care... They talk aloud, saying, "You have to take this tablet" and calling out its name for everyone to hear and see. They come in and ask for your CD4 loudly, so all can hear. (Thandiwe)

Even after delivery when we were moved to the ward, they [HCW] could do better. The beds are so close together, yet they do not even try to close the curtain. They just give instructions in front of everyone. (Thandiwe)

Recording on the medical notes is seen as another form of disclosure of status by HCW without the permission of the participants and this brings about resentment as in the case of Thandiwe.

They write on the card that the baby was given Nevirapine. This means I cannot ask anyone else to take my child to the clinic, as I will have to give him or her the card, and then they will then see what is written on the card. I also worry that when the child goes to school the teachers will see this. They [HCW] must come up with something private, which only the nurses will know and write on the card, so that the other people will not know. Even my clinic card also says that I am positive. I have to hide all my cards now! They must let us decide when we want our status to be known and not publicise it on the cards. (Thandiwe)

4.7.3. Verbal abuse

These are verbal utterance directed at the participants with the intention of harming them. This was reported by all the Participants, as shouting and taunting with the aim of degrading and embarrassing them.

The Participants are blamed for being HIV positive and thus the cause of infecting their children. This is evident in statements by Nokhanya and Fikile.

They were made by the HCW to feel that, they caused their own illness and now they were at fault for the causing harm to their children.

They scolded me so much, saying my child will contact the virus because of me. Why I did not come to the hospital on time? I was hurt, as I did not do it deliberately. I went to the hospital and they kept me there for one night and gave the child medication. I hope my child will be safe, even if I did not take the tablets before and during labour. (Nokukhanya)

The shouting, making us feel bad because we were making our children sick, when I know it is not my fault? What could I have done differently, nothing? You just ignore them and pray that you are discharged quickly with your baby. (Nokukhanya)

All this broke my heart. I was not able to respond and she was saying all this in the labour ward full of other women. I started crying, but she did not seem to care. I could still hear her talking, but was not sure what she was saying, as she was moving away from me, yet I could see she was still talking about me. I thought I'm here because I need help, she starts judging me and generally taking my misfortune and using it against me. (Fikile)

There was a sense that the participants were made to feel like irresponsible individuals who deserve to be HIV positive, this as stated by Mancane and Phambili. The HCW also showed instances of denying care to the individuals as stated by Phambili, refusing to give tablets as were seen as having caused their own illness.

When I went to the Sister for palpation, she scolded me so much because of my age, and the fact that I was pregnant and HIV +. She kept on asking why I had not used condoms. Have I never heard of condoms? I tried to ignore her, but she just carried on about how irresponsible I was and so forth. She does not even know me. (Mancane)

I had mine [AZT] in my bag; I then told the Sister and asked her to help me get it from my bag. She became very angry and started shouting at me saying, "You sleep around collecting diseases and you come here to worry us about tablets. You carry on having children with no fathers and you become our problem". (Fikile)

There is evidence that the participants are treated with distaste and don't get much help in making informed choices in self care as in case of Phambili. Women are also blamed for making incorrect decisions e.g. Feeding choices as in the case of Fikile.

When I went to collect the CD4, there were [nurses] Sisters there. First I saw their eyes; they seemed to be talking with their eyes. I got such a fright; I thought my CD4 count must be so bad. They then started shouting asking why I had taken so long to return for the results and so forth. I had no chance to respond, in addition, I was so scared, thinking this meant that I was dying. At the time I thought I must just stop coming to the hospital as I was going to die anyway. The way the nurses were shouting, you would have thought I had killed someone. (Phambili)

The other problem started with the feeding choice. I choose to bottle-feed. In the ward after delivery, the nurses shouted asking how I could bottle-feed when I was unemployed. How would I afford to buy the milk? I did get five tins of milk with lots of shouting accompanying those tins. The nurse said we will soon see what will happen, this milk supply will stop soon. (Fikile)

4.7.4. Physical Isolation

This refers to placing the women in a separate area because they are HIV positive, so that they are separated from other people. This was experienced in the Health Care setting.

There participants felt as sense of exclusion from the general population in the hospital. This they felt was exposing them as being different because of their HIV status and felt isolated and exposed to other women in the labour ward, as people to be avoided, as indicated by Thandiwe and Fikile.

Even after delivery, they make us sit in another area of the room, so everybody can see we are different. You find that there are two or three of you, you hear them talking to the other people next to you, asking questions out loud and you can see , all those who are positive are made to sit here. That makes it obvious to all the other women that there is something wrong with us. That causes even the other women to discriminate against us. (Thandiwe)

You are separated and put aside [those who are HIV positive]. It is as if they want people to see that you are different. (Fikile)

4.7.5 Denial of Care/Treatment

Denial of care or treatment refers to avoiding offering the normal care, or giving sub-optimal care to persons known to be HIV positive. Different things happen to different Participants; in some cases, it is refusing to offer water, failing to help during labour and including failure to offer counselling.

Testing positive for HIV is a traumatic life changing event, but the participants felt it was not treated as such by the HCW. There is feeling that the necessary care is not afforded to them to help them deal with this traumatic event. As stated by Thandiwe and Thabile. Both expressed a lack of adequate counselling to prepare them for the test as well as the possible outcomes of the test.

When I was with the counsellor, I was very scared and concerned about my test. I was tested, and I tested positive and started crying. The counsellor just did not seem to care. She just carried on talking as if nothing had happened. She just ignored me. To this day, I have no idea what she was saying or doing. In my mind, her role as a counsellor is to help me deal with the situation I found myself in, and to assist me to learn to cope. She just did not seem to care. She just carried on doing whatever she was doing. She even got me to leave the room while I was still crying! She had no words of sympathy or general counselling to HELP me cope with the new diagnosis. Seeing that this was new to me, is this not her job? (Thandiwe)

I tested in [names a private hospital], I was admitted to a hospital because I had just miscarried at three months. I also had a belt [shingles]. While there, my doctor requested that I have bloods taken, including HIV bloods. A Sister from a private lab came to take my blood. She just came and took my blood. She did not say a word about the bloods she was taking. I also thought she would give me some counselling. (Thabile)

Simple request for care is denied, as the participants felt the HCW saw them as the cause of their illness and thus did not deserve care. This is stated by Phambili below.

When I got there I asked for water to take my tablet. Wow, was I in trouble? They said I had delayed coming to the hospital and taking the tablet. Why did I come to this hospital instead of hospital X as I live there? (Phambili)

After this scolding they just left me there on the chair for what seemed like hours. I was in pain with labour pains and I was wet. I remember thinking I was supposed to get those tablets (AZT) every three hours, but no one was paying attention. By chance a nurse from another unit came in and saw me and said, "This person is going to deliver on the chair, her water has broken". They were really trying to chase me away. It was only then that they started paying attention and I had my baby soon after that. I did not get those tablets they told me about in the clinic. Maybe that is why my child is sick, I wouldn't know. (Phambili)

4. 7.6. Lack of empathy

This refers to the lack of sympathy and feelings for the HIV positive. This is again seen mainly in the Health Care context. This can take the form of just ignoring the women or failing to be sensitive about their HIV diagnosis.

The participants have a sense of being seen and treated as objects by the HCW, they are more interested in getting their job finished and no concern of the participants, and assisting them to deal with their diagnosis. This was stated by both Thandiwe and Fikile.

Yes, the counsellor must give you a chance to deal with the situation and help you calm down, not just carry on, showing that she is in a hurry. She should have given me time to think and compose myself, seeing that I was also pregnant at the time. I think it could have been dangerous for the baby for me to be so stressed. She just did not comfort me. She made me feel like I was wasting her time and that as this was my fault, I must deal with it. (Thandiwe)

The counsellor was not that kind; she just matter-of-factly showed me my results, as if to say, whatever! They are more concerned with pushing the line along than caring about the patients. (Fikile)

4.8. Consequence of Stigma

This dimension refers to the actions taken by the Participants in response to the internal or external stigma. These actions are taken in an attempt to conceal their HIV status. These reactions may have a detrimental effect on the health outcomes of the participants, as well as their babies.

4.8.1. Feeding Practices

This refers to the feeding choices women make in relation to PMTCT guidelines. The women end up making feeding choices guided by the fear of stigma, and trying to ensure that they are not identified as being HIV positive.

Some participants chose breast feeding as this will conceal the fact that they are HIV positive and will pass as negative.

I chose to breastfeed, that way no one would suspect my status. I will not have to collect milk tins at the clinic, as this is one of the things that show that you are positive. People will ask you why you are not breastfeeding and they will see you bringing the tins with you and they will know. (Nikiwe)

I'm breastfeeding. I would not want to collect tins. People talk when you collect tins. So I breast feed. I did not get a chance to breastfeed my first one, so this is a good chance for me. (Nokukhanya)

The participants tell of pressure at home from relatives to breast feed, this causes a great deal of distress and in some cases the participants even consider deregistering from the programme. This is likely to lead to poor adherence to medication and general programme advice. This is stated by Thandiwe.

Hey, you have no idea! My mother, in particular, was not happy. She insisted that I breastfeed even if only for a short time. She asked me why I was depriving the child of breast milk. How could X [mentions name of partner] allow me to use tinned food instead of breast milk? I was under so much pressure with my family that I almost left the programme. It started with me having to take AZT while I was still pregnant. I had to hide the pills and also hide while I was actually taking the pills. You know how these tablets are taken at specific times. I had to hide from my mother, sometimes even hiding in the toilet to be able to take my medication. I found that I experienced the same difficulties with giving my child

NVP. My mother is the type of person who needs to know everything! I have somehow managed to conceal the medication. I pretend I'm giving my child gripe-water. (Thandiwe)

Those who opt to formula feed would rather buy milk from the shop, despite being unemployed rather than be seen with milk from the clinic. This signifies the lengths people are willing to go to pass as being HIV negative rather than face being stigmatised. This is clear in Mancane's statement.

I chose the tins. I will not collect them from the hospital. I will also not buy the ones like Nan and Pelagon [those given by the public sector facilities] as people will see that I'm HIV+. I will buy Infacare from the shop. (Mancane)

The participants are also confused by what they are supposed to do, to ensure that they protect their children and also conceal their status. They need information to make informed decisions. This is stated by both Fikile and Thabile.

Yes I do, but they have told us here at the clinic that they will not be giving us milk. Not sure what I will do after the hospital milk is finished. You know I could maybe have breastfed if they had taken the time to explain to me nicely what the options are and how they worked. (Fikile)

I must say that I'm still really confused by the whole medication for the baby and for me. I wish I had received those classes that they give in the public sector [more questions about baby medication]. It is still not clear to me why the baby takes medication. I have received no explanation at all about what is going on. (Thabile)

4.8.2. Not starting HAART

This refers to the instances where women have decided not to take up treatment as recommended to make sure that they are not identified as being HIV positive, due to the fear of stigma.

Treatment is deferred, the participants are scared to start treatment as this will expose their HIV status, thus expose them to being stigmatised. They are more

concern about avoiding stigma then consequences of AIDS. This is indicated by Thandiwe's statements.

I know, [I need to start treatment] I'm just not ready to start treatment, as I'm scared it may be revealed that I'm HIV positive. I'm particularly worried about my family finding out. I have told my sister and nobody else at home. I trust my younger sister; I know she will never tell anyone at home. I just don't want my mother and brothers to find out. (Thandiwe)

The staff must make sure that they do not expose us as being HIV positive, because they make it hard for us to come to them for help. You feel like stopping the programme. (Thandiwe)

Submitting for treatment means they will have to increase the number of people who know their HIV status, another group of HCW and according to Thandiwe they are cannot be trusted to keep the status confidential.

I even thought, maybe I should not have tested for HIV, at least I would not be exposed to so many people because of the nurses who fail to protect my status. I think they do it deliberately. We trust them with our information and secrets and they expose us. (Thandiwe)

4. 8.3. Moving Facilities

Participants in some cases have moved facilities to escape being stigmatised; to seek services elsewhere so as to avoid being stigmatised.

I never went there again. I started coming to this clinic. You are in trouble and you get scolded. (Mancane)

4.9. Coping with HIV and related Stigma

This refers to how the Participants respond and cope with being HIV positive and deal with the stigma associated with it.

4.9.1. Acceptance/Resigned to status

This refers to how Participants accept and resign themselves to the situation of being HIV positive and take it as it is.

The participants see HIV positive status a part of their new reality and part of their new life. Some participant's have accepted and are incorporating strategies to cope and moving on with life This is stated by T habile, Nikiwe and Phambili.

I have made my peace with this situation. I have decided to also ignore him [partner], as this will cause me to be sick with other illnesses like high blood pressure. Maybe he is helping me not to be sick, as he may be, if we carry on being intimate while he is busy with his other friends. He is going to bring disease to my unborn baby and to me. I want this child to be healthy. (Nikiwe)

I just told myself that this thing is all around. I may be looking after myself, but I don't know how my boyfriend is behaving. So I just told myself I will accept whatever the result is, and try to learn to live with it. What else can I do? (Phambili)

I just need to accept that I'm now HIV positive and learn to live again. I need to try and take it as it is. I have told myself that it means it was meant to be that I became HIV positive. (Thabile)

Despite the stated need to want to move on, there is still that part that wants to be loved and be in a relationship as seen in Nikiwe's case. She has to deal with rejection by the father of her child.

My employer seems to understand [participant's attitude changes again, look of sadness]. You see, the only person who seems to have a problem is the father of my child. Maybe it helps that he longer cares, and is not sleeping with me... It keeps my child and me safe from disease. I also told him that if we are ever intimate again he must use a condom, so I think this is another reason he may have lost interest in me, I don't know.....

I think I'm all right, I am getting used to the situation. (Nikiwe)

4.9.2. Support Group

This refers to Participants who have tried to identify other women in similar situations so that they can deal with the situation together.

Support from other HIV positive is invaluable, as they share the same problem, Even the external stigma does not feel that bad as indicated in the statement by Nokukhanya.

I did sometimes feel that we were not treated the same as the other people who are negative. I found that identifying other women who are also HIV positive helped. We get to support one another. That way, whatever is done by the hospital staff does not feel that bad. Knowing that you are not alone helps. (Nokukhanya)

4.9.3. Positive Living

This refers to the efforts made by the Participants to stay healthy and prolong their lives in any way possible. In some cases, this involves helping the partners to stay healthy as well. It is like taking back control of their lives.

The participants want to be healthy and additional they feel the need to help their partners to benefit from their positive efforts by getting them to also start caring for themselves. This is stated by both Phambili and Thabile.

You know what I will do, I will make sure I get him to the clinic. I have decided to care for myself to look after my baby. I'm glad I have my own place to live. He also lives on his own and I don't have to see what he is doing. My life has been so hectic with my baby being sick, my HIV status, and now the added burden of having to coax my boyfriend to look after himself. I have to help him too, so that we can look after our child. I don't like it, but I have to. I have no choice. (Phambili)

Right now, I'm also not really used to the idea of being HIV positive and being on ARV and on top of this I was pregnant, now I have a baby. I still need to get used to my new life, before I start to deal with him. I need to take care of myself. (Thabile)

There is a drive and eagerness to follow clinic directives to keep healthy, attending classes and taking medication as directed by the HCW. This is clear with Nikiwe and Phambili.

I'm not fussy about what I get, as long as the child is healthy. This child in particular must be healthy because of my HIV status. I'm very careful about ensuring that I do everything they tell me to do here at the clinic. I want to make sure that my child is healthy. (Nikiwe)

Sis I still want to live for my children. I have attended the classes and next week I'm starting the treatment. I'm relieved. (Phambili)

There is a desire for a normal life and existence despite the HIV positive diagnosis. HIV is equated with other chronic disease that people suffer from but still lead a normal life. That is the aim for Nikiwe.

They were shocked and cried a lot, but said they still love me and will still treat me the same way as before. They will try and help me. I'm glad I'm employed. Even though my job does not pay that much, I can take care of myself. This is what motivated me to test to be able to take care of myself, so that I don't end up being bed-ridden and needing help even to swallow those ARV tablets, if it gets to that stage. I have seen people who die because they cannot eat, and as a result they cannot take the tablets and need other people to help them. I just want to be able to be like those people with high blood-pressure (Hypertension) and sugar (Diabetes). They go to work and take their tablets and no one worries them or asks questions about their illness. (Nikiwe)

4. 9.4. Plans for the future

This dimension refers to the strategies which the women put together with a view to securing a future for themselves and their families. The plans involve personal care and childcare and hopes for the future.

Concrete plan have been put in place, there is desire to carry on leading a normal life despite the HIV positive status. This is with the support of families and in some cases the employer. This is stated by both Phambili and Nikiwe.

I'm using the bottle. I decided to bottle-feed as I need to go back to work soon. I will take my child back to Lusikisiki to be cared for by my family back home. I will buy the milk and I hope the father of my child will also help me, which is why we must stay healthy to work for our child. I just hope my baby is free from HIV. I did the test today (PCR), I hope it turns out negative. (Phambili)

I have made arrangements with my employer to live with my child in her house till the baby is six months old. I will then give the child to my sister to care for after that. Fortunately, there is enough space in the house; [house of the employer] there are three bedrooms and it is just my employer, her husband, their ten-year-old child and the grandchild I look after.

I thought I would have to stop working. They asked me to carry on as I care well for the child and I know the status. They don't want another person who will then know about the child and the family's HIV status. I will stop in August just before I deliver. My sister will work in my place for a couple of weeks. I will then take over when I feel I'm ready to return to work. I'm happy with the arrangement. This will also protect my status. I just hope my baby will be healthy. (Nikiwe)

Chapter 5

A discussion of the major findings, recommendations, limitations and the conclusion will be presented in this chapter.

5.1. Introduction

This chapter presents the summarised themes of the phenomenon of stigma which emerged from the analysis of the experiences of selected women participating in the PMTCT programme at selected PHC clinics in the eThekweni region. The findings will also be explored in terms of empirical evidence that has been documented by various researchers regarding HIV related stigma. The chapter will also conclude with recommendations that can be used by the respective health policy managers, clinic nurse managers, nurse practitioners and nurse educators. The limitations that have been experienced by the researcher in terms of data collection and design will also be discussed in this chapter followed by a final conclusion of the research study.

The experiences of stigma will be presented in line with the identified themes as presented in Chapter 4 (pg 80-114)

5.1 Antecedents of stigma

HIV is an especially stigmatised illness because of the strong blame and dread attached to it, as it is connected to stigmatised groups and sexuality. HIV/AIDS is incurable and contagious. Diagnosis not only brings fear of death and devastation by the disease, but it also brings social issues of self-blame and dread in the self and in others (UNAIDS, 2002). It is against this backdrop that the participants of the current study do their HIV tests and are diagnosed as being HIV positive.

Six of the seven sampled participants tested for the first time during their antenatal care (ANC) visit. It was established that they tested because the HCW offered the HIV test as part of the battery of tests done for pregnant women attending the ANC clinic. In the Kwazulu-Natal province, HIV testing during the first Antenatal visit is mandatory. Even though most of the women were reluctant to test, they agreed to test because they were concerned about the health of their unborn children. Most of the women indicated that the counselling offered before and after testing their HIV status was not adequate to prepare them for their positive HIV results. As such these women were not adequately prepared emotionally to adjust to life with their newfound HIV status.

In sub-Saharan Africa, there is a drive to expand the Prevention of Mother-to-Child HIV Transmission (PMTCT) programme. This means that a large proportion of women will be tested upon entry into ANC. Consequently, this phenomenon will become an increasingly common experience for pregnant women, i.e. adjustment to an HIV-positive test result superimposed upon the cares and concerns of motherhood (Klitzman & Bayer, 2003). The same phenomenon was also uncovered in the current study, with most participants being diagnosed for the first time during their routine Antenatal care visit.

In the current study, when the participants received a positive HIV result, the initial reaction for most women was shock, denial, sadness, hurt and confusion. These reactions, according to Tilley (1990) are normal expected psychological responses. The women sampled in this study were shocked by the positive result however, over time, they gradually accepted their results. This is supported by a study done by Mukhoka (2000) who researched and analysed the psychological reactions to HIV positive results.

Following HIV positive diagnosis, the participants in the current study, had a desire to disclose their HIV status to their significant others. The women wanted a few carefully chosen people to know their status hence they disclosed their status discreetly. They disclosed their status to people they trusted and were

confident would keep the news secret. Family members, usually female (which included mothers and sisters) and spouses or partners formed the main group to whom the participants disclosed their status. According to some reports, partners are the most likely disclosure target (Antelman et al., Kilewo et al., 2001; Matthews et al., 1999). The same is true in this study, with most of the women choosing to disclose to their partners.

Disclosure, which was a major catalyst of stigma, was experienced and reported by all the study participants. Holzmer et al. (2006) in their study indicate that the stigma process can be triggered or activated by a variety of factors, such as an HIV diagnosis or disclosure of HIV status. A trigger is any action that allows people to label themselves or others as HIV-positive, in the view of many authors; the trigger includes an element of “a marker of difference” (Derlerga et al., 2002).

The phenomenon of disclosure was reported by a study conducted by Varga and his colleagues (2005) who discovered that disclosure of HIV-positive status is an important part of coping with the disease. In addition, a study by Greeff et al. (2007) identified disclosure as a major stressor, and found that women especially, feared to disclose because they experienced negative social effects, including rejection, discrimination, and violence. It has been suggested that, compared to their non-pregnant counterparts, pregnant women may be at increased risk for negative outcomes of HIV-disclosure (Maman et al., 2003). The outcomes of disclosure in the current study were indeed negative, especially with partners. Family members were, by and large, supportive. The negative responses were mainly received from the partners. On disclosing their HIV status to their partners, the women in the current study were rejected and neglected, and in most cases it spelled an end to their relationship.

It is possible that the partners rejected the women as they did not want to be associated with HIV positive individuals. This may have been in an effort to avoid associated stigma and indirect disclosure. Holzemer et al. (2006) stated that

associated stigma involves examples of stigma that result from a person's association with someone living with, working with or otherwise associated with people living with HIV/AIDS. This can include, for example, having a family member who is HIV-positive, (partner) or working with people who are HIV-positive. Further studies indicate that many persons living with and affected by HIV/AIDS indicate that the suspicion of being HIV-positive is enough to trigger stigma. That is why they try and maintain their status as secretly as possible, and avoid being associated with HIV. In this case, having an HIV positive girlfriend implies that you are also HIV positive. Part of the reason the women disclose to their partners is financial support, as most of the participants reported a lack of employment. Rejection by their partners also meant a loss of financial support. Although no mothers reported partner violence as a result of disclosure, they did state that their spouses/partners had deserted them, or cut off their financial support. Mboi (1996) states that in many instances, African customary law entrenches women's economic insecurity. Society's dependence on women and girls as care-givers within the household makes it impossible, or very difficult for females to enter the public sphere and realm of political decision-making. According to Mboi, (1996) these traditional concepts of mothering mean that the 'private' is not allowed to become 'public', and the result is that women remain impotent, suppressed, and thus societally and economically insecure. Most of the women in the current study are unemployed; those who are employed are employed as unskilled labour and depend on their partners for financial support for themselves and the babies they are carrying. This means that, in disclosing their status, they not only lose a relationship, but also their livelihood. In the studies by Cusick & Rhodes (1999) and Green & Sobo (2008), research indicated that mothers harboured fears of the consequences of disclosure, including physical violence, rejection, blame and abandonment.

The fear of disclosure can reduce access to care, support, and treatment both for HIV-infected persons and for those who care for them (Holzemer & Uys, 2004; Hong et al., 2004; Link & Phelan, 2006). This can have a profound impact on the spread of the epidemic. Health professionals should therefore assist PLWA and

not recommend disclosure without first exploring the possible consequences and different alternatives carefully with PLWA.

5.2. Experiences of Stigma

In this study, participants reported the experience of stigma even before being stigmatised by others. This was coded as experiences of internal stigma. These are the thoughts and feelings of the person diagnosed as HIV positive. This is demonstrated and by the participants' declarations of fear and anxiety they experience at the thought of being known to be HIV positive and the fear of stigma they assume will be leveled against them once they are known to be HIV positive. They fear that the blame will be attached to them for infecting and killing other people, as they will be seen as the people spreading HIV to the community. This brings about thoughts of suicide and the desire to harm themselves rather than face the stigma associated with being HIV positive. Varga et al. (2005) describes self-stigmatisation as a socio-psychological process that operates through the stigmatised person. Stigmatised persons apply labels to themselves, believe in these labels, and live accordingly. This is a concept similar to the emic view of stigma, or the person's perceived or self-interpreted view of stigma (Weiss et al., 1992). Themes related to internal or felt stigma include, self-exclusion from services and opportunities, poor perception of self, social withdrawal, overcompensation, and fear (Holzemer & Uys, 2004).

The internal stigma is closely linked to external stigmas, which are external stigmatising behaviours inflicted on the participants as experienced by them. This theme had eight sub-categories as described by the participants. This was reported by all of the women in this study. This type of stigma was reported in multiple settings, in the personal relationships, community, and health care.

Received stigma refers to all types of stigmatising behaviour towards a person living with HIV/AIDS, as experienced or described by themselves or others. It is similar to the concept of the etic view of the world, where others direct stigma-related remarks or actions at the person living with HIV/AIDS (Weiss et al.,

1992). Sub-categories of received stigma include neglecting, fearing contagion, avoiding, rejecting, labelling, pestering, negating, abusing and gossiping.

All of the participants in this study reported stigma experienced in the Health Care setting. It is not possible, nor is it wise to conceal the HIV status within the health setting. Once the women entered the Health Care setting, they experienced a loss of control and a loss of self-determination. The women took great care to ensure that they kept their HIV status confidential, but once in the Health Care setting this was lost. They found that they were physically isolated by being kept separate from other women; they felt this exposed them as being different. Additionally, their medication and the tests done for them were called out publicly for all within earshot to hear and so to conclude that they were HIV positive. The participants further gave reports of suboptimal care received from the health workers because of their HIV status. This was seen as avoidance and a failure to offer basic care. In the cases where they were attended to by HCW, they reported a lack of empathy. Most importantly, all the participants reported verbal abuse from the health care workers. This was directed at the participants, disguised as health education. They were blamed for being HIV positive and a burden to the health care system. Additionally, these women were held responsible by the HCW for deliberately infecting their children. The abuse came in the form of scolding, shouting, gossiping and mockery. To further compound this, this was done in front of other patients, thus exposing their HIV status to the general community.

Aggleton (2000) suggests that while nurses and other health workers who care for persons living with HIV/AIDS have their own emic view of stigma that may lead them to promulgate prejudice and discrimination toward their patients, the impact of this type of stigma on patients is unclear. A study of stigma against persons with HIV/AIDS in Uganda demonstrated a strong gender bias (women were more stigmatised than men), rejection by their families, increased suspicion and gossip, and isolation from communities (Aggleton, 2000; Monico, Tanga & Nuwagaba, 2001). Dlamini et al. (2007) reported that in their study they found

that there was also the notion among health care workers that PLWA would die anyway, hence treating them meant that the resources in the hospital were being wasted. In the current study, participants were refused care and were treated with no respect or regard for their human rights. Similar findings were reported by Hong et al. (2004) in Thailand, where doctors stated that they did not discriminate against the PLWA, but insisted on not giving injections to PLWA because they feared this would lead to infection.

It is clear that the issue of the right to treatment should be addressed clearly and directly by health service authorities in each nation in order to ensure compliance with legal requirements for equal access to care for PLWA. In this regard, a human rights approach to the continuing education of health professionals should be considered. It is a frightening phenomenon that people facing serious illness and even death are neglected by their families, their communities, and even their health care providers. Although it seems that much of this neglect is based on fear of contagion and limited resources, it may also be based on judgmental views, if the utterances by the HCW are to be taken into account in this study.

The National AIDS Research (date) which conducted a study on the high prevalence rate of HIV related stigma in health settings. This study by Mawar & Salovey (2006) showed that (i) a wide range of feelings was exhibited by clinicians about HIV positives who often made moral and non-clinical attributions about individuals' past "misbehaviour," and "misconduct"; (ii) few providers reported fear of touching HIV/AIDS patients, while others considered it a special duty. Initial testing and disclosure often occur without the patient's knowledge, consent, or counselling; (iii) hospital practices, such as a separate AIDS ward, HIV diagnoses on open charts, and the conspicuous use of biohazard labels serve to discriminate against HIV/AIDS patients; and (iv) hospital policy is often unclear to clinicians, and the hospital practices often have discriminatory consequences.

Individuals with HIV and AIDS are stigmatised because their illness is associated with behaviours that are not acceptable socially, both as a product and producer of such behaviour.

Sutterheim et al. (2009) indicate that individuals with HIV and AIDS are stigmatised because their illness is associated with behaviours that are not acceptable socially, both as a product and producer of such actions. It is viewed as the responsibility of the individual (Taylor, 2001), tainted by a religious belief as to its immorality and/or thought to be contracted via a morally sanctionable conduct, not well understood by the general community, and viewed negatively by health care providers. All these factors influence the appropriate health care that an HIV infected individual is otherwise entitled to as a right (Mawar et al., 2005).

HIV programme implementation and targets can be hindered by stigma. Much effort is needed to ensure that the stigma is also included in planning, if the HIV programmes are to be successful.

5.3 Consequences of Stigma

Being stigmatised brought about feelings of despair and loss of control, with some participants even contemplating suicide. Stigma and discrimination have been identified internationally as main barriers to HIV control and prevention in every country and region of the world, posing challenges to preventing further infections, alleviating the impact, and providing adequate care, support, and treatment (Sheng et al., 2008). The HCW in some cases disclosed the status of the PLWHA to other patients and the general public. The other form of abuse manifested by some health workers was in the form of refusing treatment of PLWA or at least limiting their access to certain treatments.

While such an association has yet to be scientifically substantiated, several studies have revealed anecdotal evidence suggesting that participation in PMTCT initiatives places women at risk for involuntary disclosure through

engagement in socially stigmatised practices such as breastfeeding, avoidance or use of a particular infant formula brand (Bond et al., 2000, 2002; Brookes et al., 2004; Nyblade & Field, 2002; Varga, 2002, 2003a). Similar results were noted in the current study. Women decided on feeding choices based on what method they thought would bring less attention and questions from relatives and the community. In some cases, the women even when using artificial feeds would rather buy from shops, to avoid being seen with a specific brand of baby formula milk that is known to be supplied as part of the PMTCT programme. In some instances, the participants go against the guidelines just to protect the secret of their HIV status. This may be one of the reasons for programme failure, as 30 % (Coovadia, 2009) of vertical transmission occurs in the postpartum period.

The social consequences of both felt and enacted stigma are experienced by the individuals in terms of their rights, freedom, self-identity and social interactions that often influence the decisions to seek HIV testing and to access prevention services. Link and Phelan (2001) proposed that stigma contains five elements. Firstly, differences are identified and labelled. Secondly, differences (labels) are linked to undesirable attributes. Thirdly, a separation of 'them' and 'us' occurs. In the fourth instance, the resulting discrimination and loss of status leads to devaluation, rejection, exclusion, and blame, which Fife and Wright (2000) described as social rejection, financial insecurity, internalised shame, and social isolation. Finally, this process can take place only if a group is able to enforce the stigma.

Environmental factors include the cultural, economic, political, legal and policy environment (Castro & Farmer, 2005). Politics, in the sense of power relationships, may play a role in the approach taken towards people living with HIV/AIDS in the cultural, economic, and legal and policy environments. There may be secondary gain for those involved in stigmatising people living with HIV/AIDS, and this might lead to them using their power to stigmatise (Bird et al.,

2004). In the case of the current study, HCW are in a position of power and are able to use this power to stigmatise the PLWHA who need their care.

The other theme that emerged from the study is that the stigma had consequences for the women stigmatised. In response to the stigma women took certain actions to respond to the feeling of being stigmatised and to find ways to minimise the stigma. Three sub-themes emerged from the analysis, i.e. change in feeding practises, initiation and adherence to HAART and defaulting on the PMTCT treatment guidelines.

It appears that stigma impairs the PLWHAs' ability for self-care, to access care or to participate in HIV preventive programmes. This means some people prefer not to know their HIV status, for fear of loss of confidentiality and the associated risk of stigma, loss of jobs, break-up of relationships, social ostracism or even violence. It also means people may not take preventive measures to protect themselves and their partners from HIV infection. A study conducted in Botswana to indentify the barriers to the PMTCT programme uptake pinpointed one of the barriers as fear of exposure of being HIV positive through the PMTCT process, which would result in being stigmatised (Kebaabetswe, 2007). In the current study, choices are guided by the attempt by the women to ensure that they are not identified as being HIV positive and thus stigmatised.

In the case of feeding options, the women seemed to choose methods according to their circumstances that would not raise questions about their status. Some women decided on exclusive breastfeeding to avoid the pressure and questions anticipated if they decide to bottle-feed. The reason given was that if they were seen collecting tins, this would be a form of behavioural disclosure; this would expose them to the community as being HIV positive. Those who decided to use artificial feeds did so with a plan to buy the tins from the shop, rather than risk being seen bringing home the government supplied milk formula and thus being seen to be HIV positive.

More detrimentally, women who were informed that they are eligible for HAART opted not to start the treatment as they feared this would be a form of disclosure to their families. There is also a fear that the HCW don't treat their status as private, and talk about them, exposing the women's HIV positive status to others.

Some participants reported moving facilities, in order to move away from Health Care facilities where they are known, and the community using that Health Care facility will know them.

5.5 Coping with Stigma

Kylma et al. (2000) described hope as an essential resource in life which can be viewed as a baseline of life. Feelings of hope emerged from the data of their study which examined hopelessness and hope in HIV/AIDS, indicating that hope is “believing life to be worth living at the present and in the future”. Similar themes also emerged from the current study, with the participants choosing to live, and not only that, but making plans for the future. The motivation comprised the need to live long enough to see their children grow up. In the same study by Kylma et al. (2000), optimism emerged as an attribute of a person who experiences hope. The meaning attached to this was that a positive attitude was adopted, and in some cases those studied referred to a denial of reality.

Coping by seeing oneself as okay, is a strategy that reflects a strong will to survive in the face of illness. This was manifested through being socially active, and participating in community and social gatherings. Talking to others builds social networks through formal or informal networks, and these networks provide platforms where all can tell their stories, share their pain, chat, and develop friendships. Nyblade et al. (2003) reported on a woman who said that when she met with and saw each one of the support group members, she knew that they shared the same problem. They talked about their illnesses and began to visit each other. (Makoae et al.,2008). Another method of coping is by letting the situation be, or avoiding confrontation. This is a passive way of protecting oneself. Some researchers, Horizons Programme (2002) believe that being proactive in disclosure may expose the stigmatised person to more stigma and discrimination, including violence, and they support a coping strategy of being more passive. Others argue that avoidance behaviour can lead to activities or mental states such as social withdrawal, increased alcohol consumption, or risk-

taking behaviours, which keep HIV positive people from directly addressing the stressful event. In the current study, some of the participants used the same passive coping mechanism, coded as acceptance and resignation to being HIV positive. These participants decided not to respond in any way to their HIV status, but just to accept it as their new reality.

5.6 Conclusion

The study successfully met its aim, notably to explore experiences of stigma in HIV positive pregnant women enrolled in the Prevention of Mother to Child Transmission programme. The phenomenological approach allowed for the exploration of stigma experienced by women in the PMTCT programme without imposing a framework on the study regarding what might be found out about the phenomenon. Phenomenological analysis confirmed the complexity of the concept of stigma as well its impact on care.

In the study, women's experiences of stigma emerged in various forms and different settings. Most worrying, is the stigma experienced by the participants in the Health Care setting. This has a detrimental effect, as the women reported the tendency to avoid Health Care facilities, and this is closely linked to poor adherence to programme recommendations.

Stigma and discrimination fuel the HIV/AIDS epidemic by creating a culture of secrecy, silence, ignorance, blame, shame and victimisation. This causes increased pain and suffering and devastating social and economic consequences for the people living with HIV/AIDS (PLHA), their families and communities. The stigma and discrimination felt by individuals are major barriers to utilising health services for prevention, diagnosis and treatment. The shame associated with "felt stigma" discourages individuals from seeking voluntary counselling, testing and treatment.

Discrimination against people living with HIV/AIDS is a violation of their human rights. A framework based on human rights provides a means of monitoring and

enforcing their rights, as well as addressing discriminatory practices. Similarly the UN Commission on Human Rights' (2006) resolutions have confirmed, that, "discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards".

5.7 Recommendations

5.7.1 Community Action

HIV/AIDS-related stigma and discrimination is a challenge for everyone which includes the communities, health care workers and civil society, as these are the areas where stigma is played out. Success in the fight against HIV/AIDS can only be achieved if PLWHA are treated with dignity and compassion. Interventions to address stigma are necessary. To be effective, interventions must involve all the stakeholders, through partnerships between governments, health care professionals and civil society.

Hopefully, this strategy will increase communities' knowledge and positive attitudes towards those infected with HIV/AIDS, and contribute to a willingness to treat them with dignity.

Spirituality is one of the coping strategies used by the PLWHA, manifested through prayer, meditation and hope in God. Religion as a self-care strategy for HIV has also been reported as a strategy to relieve HIV-related symptoms, and as a form of emotional support (Cichocki, 2010). Religious organisations and their leaders are seen as part of the community, and are trusted to shape behaviour and morals. Religious leaders should thus participate in providing spiritual and emotional support, and incorporate ways to reduce stigma in the community, through their religious services.

5.7.2 Practice

Counselling can decrease stigmatising behaviour. It is for this reason that mental health should form part of the Antenatal care team's regimen would allow the

women to access continuous support through the journey of the PMTCT programme.

The disclosure of results to significant others is important. Health Care workers need to assist patients to disclose their status and should offer continuous support (Chou, Holzemer, Portillo, & Slaughter, 2004).

5.7.3 Research

It is important that a further study be carried out on these women a few years from now, to see if the stigma subsides as they learn to survive with HIV/AIDS. A more longitudinal study would be desirable, as well as a follow-up on the post-natal stage.

Additionally, it could be of value to conduct a study to explore the feelings of Health Care workers on caring for PLWHA, stigma inflicted on them and how it affects the type of care they render to the PLWHA.

5.7.4 Limitations of the study

The study was performed with a homogenous race group. This means the study results cannot be generalised to all race groups of South African society.

All of the women interviewed had known their HIV positive status for less than a year. There was no way of telling how they would progress with their dealings with stigma or even their own viewpoints as time passed. Furthermore, all but one woman underwent testing because they were told to go for testing by the clinic staff as part of their routine ANC. This may indicate they were not yet ready to know their HIV status, and were thus more likely to be sensitive to stigma, and more likely to experience internal stigma as they had not had time to think about and deal with the consequences of a positive HIV result, compared to people who volunteer for an HIV test.

Interviews were done at the clinic which may have inhibited the women from expressing their experiences about the HCWs freely, for fear of being reported and also in the fear that they might be discriminated against as a result of their participation, in terms of the care they received.

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Interview 1

Date: 23 June 2010-06-28

Time Started: 10h15

Time finished: 10h55

Venue: Operations Managers' office

Age: 28 years

First time on PMTCT.

Gestational age: + 24 weeks

So this is your first child?

No my second one, but I was negative with the first one. **How old is the child?**

He is 10 years old; he will be turning 11 on the 21st of August. He is in Grade 6, he started school early.

Wow, he must be clever. So you now hope for a girl?

Yes, he has never failed. Other kids his age are in grade 4 and 5.

I'm not fussy about what I get, as long as the child is healthy. This child in particular must healthy because of my HIV status. I'm very particular to make sure that I do everything they tell me to do here at the clinic. I want to make sure that my child is healthy.

Is this your first time on the PMTCT programme?

Yes it is.

How did you find out that you are HIV positive?

I came to the clinic and I was not aware that I was pregnant at the time. I felt the need to know my status with all the drive on the TV and radios about knowing your status. I was healthy not feeling sick at all, I just decided to come to the clinic to test.

I wanted to be able to make sure I'm able to take care of myself and be able to share with my family, so that even if I'm positive I'm still able to do things for myself.

I have seen people who find out when they are too ill and need help even to take medicine. That is when problems start and people have something to gossip about and treat you badly, everybody ends up knowing you are HIV positive.

I see....

(A staff member walks into the office to collect some supplies; the client keeps quiet till the staff member leaves the room)

I came here (clinic) on the 18th of March this year for my test. They tested me and found that I'm HIV positive. On the same day they took blood and said it is check my CD 4 count. I was told to come back after two weeks for my CD 4 results.

When I returned for my results, they told me my CD4 is 695. They asked me to attend literacy classes and said I must check my CD4 again after three months.

I then went home, a couple of weeks later I realized that I was pregnant. I then came back to join the clinic for pregnant women. That made things easy for me, as I did not need to be retested and they already knew all my results. The Nurses also said that I did well by testing myself, now things are quick and easy no delays. I came with all my papers, I was just showing them.

They said they will redo my CD4 in October after I deliver. My baby is coming in September. They said it (CD4 count) may drop they just want to make sure that I'm okay.

After testing positive did you share this information with any one?

Yes, I told my two older Sisters. My mother is alive but she is not at home she is away for training to be a 'Sangoma' so she stays where she is training. I'm particularly scared to tell her as I feel she will experience a great deal of stress, so I have not told her.

I called my three sisters who are older than me. So I can get their support. I also told my one friend that I really trust.

How did your Sisters take this?

They were shocked and cried a lot, but said they still love me and will still treat me the same way as before. They will try and help me. I'm glad I'm employed, although my job does not pay that much I can take care of myself. This is what motivated me to test to be able to take care of myself, so that I don't end up being bed ridden and need help even to swallow those ARV if it gets to that stage. I have seen people who die as they cannot eat and as a result they cannot take the tablets and need other people to help them.

I just want to be able to be like those people with High, high and sugar. They go to work and take their tablets and no one worries them or asks questions about their illness.

You have the right attitude

My sisters love me. They said I'm going to be fine. I don't stay at home, I live where I work. I look after a retarded child. The child attends school during the day. I go home three days or so a month where I'm off.

How is the rest of the community treating you?

They don't know because I'm still well, I have not also made them aware only my sisters and my close friend and all have kept it quiet. That is why I tested early, so that no one will ever find out, as sometimes people discover your status when

you become ill and it is like an advert for every one that you are POSITIVE. So no one knows.

Have you told the father of your child about your status?

(Total change in the stance, look of sadness. No longer maintaining eye contact, close to tears) yes I have told him, he did not take it well. Ever since I told him things have not gone well.

Do you mean ever since you fell pregnant?

No ever since I told him I'm HIV positive. When I told him about the pregnancy he accepted it and seemed pleased. He even said he wants a boy. It is only when I told him of my status that things changed.

I asked him to also go and check, I even offered to accompany him to the clinic, and he kept avoiding the issue and said he will go on his own. He did not go.

Not only had that he started to behave differently towards me. I think he started relationships with other women.

I'm pregnant and HIV positive, I need love. He is not showing me the love and support that I expect from him!

What do you mean?

Like as I'm pregnant, he must call me, come and visit me as before I told him my status. He does not even care how things are going with my pregnancy or even if I'm well or sick. I'm HIV positive. If a person does not call you the whole day, to just say how are you? He used to do all these things before my disclosure that I'm HIV Positive.

Other people care for me, when I'm pregnant with his child! I don't want to say he infected me, but are we not suppose to be in this together?

Look, I'm sure it is because of my HIV status that he no longer wants to be associated with me. When I told him I was pregnant he was fine, but since I told

him of my status he is neglecting me. The last time we were together, I mean intimately was the 21 of May. I have a habit of noting everything down, so I know the date for sure. I also know when I told him I'm positive. So it a couple of weeks after disclosure, he is no longer interested in me?

I tried to keep the relationship going, by calling him to tell him, things that are happening in my life, my clinic visits etc. He never seems to care. He no longer bothers to even come and visit me at work as he used to. Maybe he now finds me irritating (uyangaliswa), he no longer has desire to be with me.

I have made my peace with this situation. I have decided to also ignore him as this will cause me to be sick with other illnesses like high blood. Maybe he is helping me not to be sick as may be if we carry on being intimate while he is busy with his other friends he is going to bring disease to me and my unborn baby. I want this child to healthy.

So how did you find the staff at the clinic when you first came for testing?

I was really scared, the counselor helped to try and relax. She did the test and told me it was positive and counseled me.

In general health workers have not been bad to me. The Sisters ask me a lot of questions about my health. They say I must be open tell if anything is painful or any worries about my health. You know even if they were not that kind to me, I would not have cared, I just want my baby to be free of HIV!

You are now past 14 weeks, have you started on the ARVs? How is that going with the people who live with you, are you able to take the tablets without fear? Will you be able to follow all the other things you need to do with the PMTCT programme?

You know the child that I care for is also HIV positive besides being retarded. So when I discovered my status I told the women I work for. She is a nurse, she works at (Names the clinic); she also told me she is HIV positive. The child I look after is her grandchild, so I had no idea that she is also positive. So I was very

lucky to be employed there. She also told me she has started ARVs. She said you are better off because you have not started taking ARVs. She has started taking ARVs.

My employer seems to understand. *(Participants' attitude changes again)* You see the only person who seems to have a problem is the father of my child. Maybe it helps that he longer cares, and not sleeping with me..... It keeps me and my child safe from disease. I also told him if we are ever intimate again he must use a condom, so I think this is another reason he may have lost interest in me, I don't know.....

I think I'm alright, I getting used to the situation.

Do you feel that if you had not told your boy friend about your HIV status, things would have been different; you would still be together like before?

I think so, but as I said maybe he is helping me to stay healthy.

Have you told your 10 year old child about your status?

No I'm scared. I think he is very sensitive. I have asked him if he knows about HIV, I realized that he is not ready. So I have not told him. I will tell him maybe when he is 15 years. He has seen me taking the ARV for PMTCT, although he does not know why, he often helps me to with bringing them to me and giving me water, but does not know why I take these tablets.

Did you experience any ill effects when you started to take the tables?

Not really. Once I started to have an itch in my privates and a bad smelling discharge and I told the Sister and she gave me some tablets to take. That has since resolved.

Have you been given the tablet you take before labour?

Oh yes the Nevarapine? I always carry it with me, so there will be no problem when labour starts.

What was your feeding choice?

I chose to breast feed, that way no one will suspect my status. I will not have to collect the milk tins at the clinic as this is one of the things that show you are positive. People will ask you why you are not breast feeding and they will see you bring the tins with you and they will know.

How are you going to manage exclusive breast feeding because you are employed?

I have made arrangements with my employer to live with my child in her house till the baby is six months old; I will then give the child to my sister to care for that after. Fortunately there is enough space in the house; there are three bed rooms and it just my employer, her husband, their ten year old child and the grandchild I look after.

I thought I would have to stop working, they asked me to carry on as I care well for the child and I know the status they don't want another person who will then know about the child and the families HIV status. I will stop August just before I deliver; my Sister will work in my place for a couple of weeks, she will then fetch when I feel I'm ready to return to work. I'm happy with the arrangement; this will also protect my status. I just hope my baby will be healthy.

It looks like you have a plan worked out.

Yes.

Do you have any questions for me?

No

Thanks for your time.

Interview 2

Date: 09/07/2010

Time started: 09h45

Finished: 10h30

Venue: Consulting room in the Clinic

The Participant is bringing her baby for 6 weeks vaccination and PCR test. Her partner is with her to give support.

Age: 31

Interview:

Is this your first baby?

No, it is my 3rd one. The old one is 11 and followed by a 6 year old then this one. One girl and 2 boys. The first one does not belong to my current partner.

How old is the baby?

He is six weeks old. We are here for PCR testing, I'm so worried. I hope my child tests negative.

Let's hope for the best.

***(Explained the purpose of the study.)*What do you understand by stigma or discrimination?**

"Ukubandlulula" Treating you differently in a bad way.

What made you to test .When did you first discover that you were HIV positive?

I first tested when I fell pregnant with my current child. The clinic offers the test with all other pregnancy bloods.

How was that experience of testing?

HA! I cried the whole day when I got home. It got better when I told my sister. As I could not talk to anyone. She calmed me down and also advised me to tell my partner. I was much scarred to tell him, I thought he will leave me.

Did you tell him?

Yes, I did but I was scared. I told him. We talked. We decided that he must also go and test the next day. I accompanied him to the clinic; he discovered he was HIV negative. I thought he is going to leave me. He being negative and I'm positive. He did not. We are still together and okay. We have been together for 9 years.

He went again to test now in June and he is still negative. I also got my CD4 test at the time and the results came back and they told me it is 345.

So you are eligible to start treatment?

I know, I'm just not ready to start treatment as I'm scared I may be exposed that I'm HIV positive. I'm particularly worried about my family finding out. I have told my sister and nobody else at home. I trust my younger sister; I know she will never tell anyone at home. I just don't want my mother and brothers to find out.

WHY?

I know how my mother is; it would be a big problem. She will disown me. That is where I feel I will be stigmatised, by my own family. I also have this very rude brother, if he were to find out, I will never have a place again at home. I can just imagine the fights that will break out.

I see, so you feel you will definitely be dishonoured at home if they ever found out.

Oh yes. I will do anything to make sure they never find out.

What about in the health facilities, how did you find you were treated? Let's start with when you first tested?

I will say good and bad.

Tell me more.

When I was with the counselor, I was much scared and concerned about my test. I was tested and I tested positive and started crying. The counsellor just did not seem to care. She just carried on talking as if nothing has happened. She just ignored me. Up till now I have no idea what she was saying or doing.

In my mind her role as a counselor is to help me deal with the situation I found myself in and assist me to learn to cope. She was just did not seem to care, just carried on doing whatever. She even got me to leave the room while I was still

crying, no words of sympathy or general counseling to HELP me cope with the new diagnosis.

Seeing that this was new to me and is this not her job? It is like I caused my own illness.

I only got sympathy with the young man responsible for taking bloods. When I walked into his room I was still crying. He at least stopped and spoke to me and tried to help me see that I will still live and see my baby grow up, it up to me to take care of myself. He said this is not a death sentence it is just a disease like any other. He said people live long and other people die of car accidents. That is when I started to feel a bit relieved.

So you feel counselling is vital?

Yes, the counselor must give you a chance to deal with the situation and help you calm down, not just carry on, showing they are in a hurry. She should have given me time to think and compose myself, seeing also that I was pregnant at the time. This I think it could be dangerous to the baby to be so stressed. She just did not comfort me. She made me feel like I was wasting her time and this is my fault, I must deal with it.

I only felt better after the encounter with the guy who takes bloods. The other thing that scarred me was delivery. I have often heard how people die in child birth because of the nurses' negligence and because they know your condition so, they do not care. Luckily things went well when I had my baby.

Did you get any information from the counselor, like feeding choices and why specific choices?

I think she did ask me, it is just that I was too upset. I was only able to make that decision with subsequent visits.

We decided with my partner that I will bottle feed as he will be able to buy the milk, as he is employed.

Have you experienced any pressure from family and friends to breast feed?

Hey, you have no idea. My mother in particular was not happy. She was insisting that I breast feed even if it is for a short time. She was asking why I'm depriving the child breast milk. How can X (mentions name of partner) allow me to use tinned food instead of breast milk.

I was under so much pressure with my family. I almost fell off the programme. I started with me having to take AZT while I was still pregnant. I had to hide the pills and also hide when taking the pills. You know how these tablets are taken at specific times. I had to hide from my mother, sometimes had to hide in the toilet to be able to take my medication.

I found I have the same problem with giving my child NVP, my mother is the type of person who needs to know everything! I managed somehow to conceal the medication. I pretend I'm giving my child gripe water.

On your partners side does anyone knows?

We decided to move out and rent a room, so that we can be free, otherwise no one knows, so we wanted to keep it that way.

How did you find the hospital experience?

Eish, I was exposed to two hospitals. I started at hospital X; they screen you before giving your medication, so no one knows what is happening. I was moved to hospital Y. There, they don't care. That is where I really felt discriminated. You are separated and put aside (those who are HIV positive). It is as if they want people to see that you are different. They also talk aloud, you have to take this tablet, calling it out by name for everyone to hear and see. They come in and ask your CD4 count out loud for all to hear.

Even after delivery they make us sit in another area of the room, so everybody can see we are different. You find there are two or three of you, you hear them talking to the other people next to you asking questions out loud and you can see them, all those who are positive are made to sit here. That makes it obvious to all the other women that there is something wrong with us. That causes even the other women to discriminate us.

Even after delivery when we moved to the ward, they can do better .The beds are so close together, they do not even try to close the curtain. They just give instructions in front every one.

How do you feel we can improve this?

The nurses must call you aside and explain things in private. That way no one will know. Often as I'm worried people can hear my story, I don't even consecrate well to what is being said to me.

I even though, maybe I should not have tested for HIV at least I will not be exposed to so many people because of the nurses who fail to protect my status. I think they do it deliberately. We trust them with our information and secret and they expose us.

Another issue is, why write on the baby's card my status?

What do you mean?

They write on the card that the baby was given Nevaripine. This means I cannot ask anyone to take my child to the clinic, as I will have to give them the card, they will then see what is written on the card. I also worry when the child goes to school the teachers will also see this. They (Nurses) must come up with something private, only the nurses will know and write that on the card so that the other people will not know. Even my clinic card is also written positive. I have to hide all my cards now! They must let us decide when we want to be knowing our status, not publicise it on the cards.

The staff must make sure they do not expose us as being HIV positive, because they make it hard for us to come to them for help, you feel like stopping the programme.

May I find out what is your greatest fear if people were to find out your status?

I'm just scared people will treat me differently. They will even be too scared to touch me and even make me use separate plates and spoons. I don't want that. This will also affect my kids, no, I will not disclose, rather die!

People may say they will accept you no matter what while you still talking, before they know your status, but I know people, once they know they change.

More so if the people who have had a relationship with you like ex boyfriends and their current girlfriends will say you infected them. You will be laughing stock and get blamed for all the deaths that occur to those people. There is no way I will tell people I'm positive.

Do you think you will tell your older kids at some point?

No never, I don't want them to know. It will cause them unnecessary stress.

Interview 4

Date : 14/07/2010

Start: 09h00

End: 09h48

Age: 28 years

Residence: Urban

First time on programme

How many kids do you have?

Four, but one died last year while he was 11 months old.

How did the baby die?

He died in his sleep.

So sorry to hear that. How old are the other kids.

11 years 6 and current baby who is 10 days old.

What do you understand by the word Stigma or discrimination?

It when people talk about you and treat you bad, because of something they know about you.

When did you first test for HIV?

The tested when I was pregnant with the current child.

How was that experience of testing?

Very traumatic, I cried a great deal. I did not expect to be HIV positive. I was really devastated, not able to accept my status. I was not adequately prepared.

That day, I felt the clinic as soon as I heard my status; I did not do most of the clinic things that day. I did not even see the Sr.

Why did you leave?

I was not ready to face the clinic people and the general public. Since I was so shocked, I felt so sensitive. I just if someone were to say one thing that did not I agree with me, it would have been a big problem. You know how sometimes they clinic people talk to you anyhow. I would have caused a scene. So I thought I better leave. More so once they know your status. I felt like not returning to the clinic ever, but I thought of my unborn baby.

The counselor was not that kind, she just matter of factly showed me my results. Like whatever. They are more concerned with pushing the line than caring about the patients. I did return a week later when I felt better.

Did you share this with any one when you got home?

Initially I was not sure who to tell. You see I stay with male in the house. My uncles and cousins. My parents have died. I eventually decide to tell my friend.

Did you tell your partner?

Yes I did. He did not seem to take me seriously; he did not even acknowledge what I told him even with an answer. He just kept quite. I then asked him to also go and test and he refused.

I then left it at that.

I see. Please tell me what discrimination if any have you felt towards you, from health workers since you became positive?

The clinic people were not so bad. I did not see any change in treatment or being targeted. It is only when I went to hospital X that I can say I felt the discrimination?

Why? What happened?

You know one of the things they told us that when we start labour pains we take the Neviripne and then we will be given tablets every three hours in the labour ward. We were told we can use the same AZT that we were taking at home to tell the nurses if we still have some left over.

I had mine in my bag; I then told the Sr and asked her to help me get it from my bag. She became very angry and started shouting at me saying: "You sleep around, collecting diseases and you come here to worry us about tablets. You carry on having children with no fathers and you become our problem"

All this broke my heart. I was not able to respond and all this she is saying in the labour ward full of other women. I started crying, she did not seem to care. I could still hear her talking, but just was not sure what she was saying as she was moving away from me, but I could still see she is still talking about me. I thought I'm here because I need help, she starts judging me and generally taking my misfortune and using it against me.

The other problem started with the feeding choice. I choose to bottle feed. When in the ward after delivery the nurses shouted there, asking how I can bottle feed when I'm UN employed. Will I afford to buy the milk? I did get five tins of milk with lots of shouting accompanying those tins. She said we will what will happen; this milk is going to stop soon.

I was glad to leave the hospital.

SO sorry to hear that. Do you still have the milk?

Yes I do, but they have told us here at the clinic that they will not be giving us milk. Not sure what I will do after the hospital milk gets finished. You know I could have maybe breast feed if they had taken time to explain to me nicely what the options are and how it works.

You did not get much pressure at home to breast feed?

Some relatives and neighbours did ask me, I just said, I'm not able to feed, I have no milk in my breast.

How did you manage at home to take tablets and follow the other advice from the clinic?

At home I was fine. Because I leave with men, they do not know much about the things that I done when pregnant. So I took my tablets in front of them and they never knew any better.

I tried to involve my boyfriend on what was happening, with the aim of encouraging him to test as well. He just does not show nay interest. I even offered to accompany him. That is that.

I'm just interested to make sure that my child is healthy. *(Child starts to cry)*

Thanks for your time

Interview 4**Date: 15 /07/2010****Start: 10h00****End: 10h30****Tell me about the time you came for a test?**

I tested at the hospital. They said I have to test because I'm pregnant so that we can protect the baby I went in to test.

Were you not scarred?

I was a bit, but it helps that they talk to us in a group and then again alone before they prick your finger one person talk to you and then you go to another room to prick the finger and then they tell you.

How did you feel with positive result?

I was shocked, I cried a bit. The testing person tried to help me. When I went to the Sr for palpation, she scolded me so much because of my age, being pregnant and HIV +. She kept on asking why I did not use the condoms. Have I ever heard of condoms? I tried to ignore her; she just carried on about how irresponsible I was and so forth. She does not even know me. I never went there again. I started coming to this clinic. You are in trouble and you get scolded.

After the HIV test did you share the outcome of your HIV test with any one?

I did not tell anyone but my boyfriend.

How did he take it?

He did not seem to be shocked; it was like he was expecting it or he knew. I asked him to go and test. He refused.

Who leaves with you at home?

I lived with my granny while pregnant and I never told her anything. After I delivered my (Mamncane) My Moms sister said I must come and live with her so she can look after me and help me with the baby. I did not tell her either.

Why not? Did you not have a problem with taking your AZT and giving NVP in front of them?

I just did not want to worry them. My granny is old and does not pay much attention. My Mom's sister has not noticed either. You know the problem is that I also forget sometimes that I'm HIV positive. That is why I also forgot my medication sometimes.

Is that not why you need someone to remind you? Did you check Your CD4?

Yes, they said it is 394. They said as soon as I deliver I will be started on ARVs. They said they do not want to confuse me as I started the clinic late.

Where did you deliver your baby?

I went to the local hospital; I was then transferred to hospital X. There I was done an operation because they said the baby was big.

How did that go?

I don't remember much from that experience, lots of pain then I was told I needed to be operated. I was just scared and alone. I was made to sign some papers and I was not even sure what I was signing. No explanation.

Which feeding method did you choose, breast or bottle?

I choose the tins. I will not collect them from the hospital. I will also not buy the ones like Nan and Pelagon (those given by public sector facilities) as people will see that I'm HIV+. I will buy Infacare from the shop.

How are you going to pay for the milk?

My Boyfriend , he does work, he will buy the milk.

Is there anything you would like to ask me?

No.

Thanks for your time

Interview 5**Date: 13 July 2010****Start: 08h30****End: 09h18****How many kids do you have?**

Two, this is my second one. The oldest is 8 years.
I'm from the Easter Cape; I'm here with my boyfriend.

When did you first test?

When I was seven months pregnant. It was the first time. I was not aware that I was pregnant I was menstruating the whole time, that is why I started the clinic so late.

How did you cope?

I just told myself that, this thing is all around. I may be looking after myself, but I don't know how my boyfriend is behaving. So I just told myself I will accept whatever the result and try and learn to live with it. What can I do?

I have been through a lot. Just after I delivered my baby he became ill. They told me he has got meningitis's I had to stay longer at the hospital. I was not able to do anything about my status. We were also referred to another hospital to test my baby to see if he can hear and many other tests.

After I was discharged, I went back to the hospital that had first tested my CD4. You know that I started the clinic late so I was too advanced to be started on ARV and they told me return as soon as I deliver. I was not able to do that as my child was sick. I only went back two months later.

When I went to collect the CD4, there were Srs there. First I saw their eyes, like talking with their eyes. I got such a fright; I thought my CD4 count must be so bad. They then started shouting saying why I took so long to return for the results and so forth. I had no chance to respond, in addition I was so scared, thinking

this means I'm dying. At the time I thought I must just stop coming to the hospital as I'm going to die anyway, the way the nurses were shouting, you would have thought I killed someone.

I was only relieved when I decided to attend classes anyway as I was thinking about my kids, I went to the classes for treatment; they told me my CD4 is 180 or something like that. I also heard other person talking saying their CD4 is much lower than mine. I remember one in particular who said their CD4 is 3.

You know that day I felt like killing myself thinking there is no hope for me, when the nurses shouted! Sis I still want to live for my children.

I have done the classes and next week, I'm starting the treatment. I'm relieved.

How did you find other people who helped you?

Shame they treated me well.

Did you tell your Partner about your HIV results?

Yes, he is the only I told. He was so shocked. He did not want to believe it. I asked him to also go and test. He refused. I said; if you test it will help because we can be together in this. I can also help you.

He still refused?

You know the other thing they ask you to do there is to bring a partner to the social workers before you start medication.

I said to him you are the only person I have told, you will be coming with me to support me as I will do the same for you. There is no turning back. This is it. That seemed to win him over, he came with me. I told him his turn will come and I will be there for him.

I also then told him, 'I'm like this now (HIV+), and we must use Condoms'. He did not like that. I will be honest with you, Sisi we have not had sex since that day! Fortunately we do not live together. Hayi-ke, I'm sure he is having other women

now. I told him; I will not sacrifice my blood for love. I want to live and look after my kids. I tried to convince him by telling him that since I will be on treatment it is dangers for him to have sex with me without a condom.

I try and talk to him when I see him and tell him this is our life now this HIV.

When you went to deliver, how did it go?

You know the Srs get angry.

What do you mean? Tell me more?

When I had my first child I was young and had my family around and elders who have had kids. They were able to tell me; yes you are in labour and so forth. This time, I was saw waters running out of me. I told the neighbor who said I'm in labour. I had this tablet, I was supposed to take. I took it with me in my bag. I boarded a taxi and went to the hospital of my choice. When I got there I asked for water to take my tablet. Wow was I in trouble! They said I delayed coming to the hospital and taking the tablet. Why did I come to this hospital instead of hospital X as I live here?

After this scolding they just left me there on the chair for what seemed like hours. I was in pain with Labour pains and I was wet. I remember thinking I was supposed to get those tablets (AZT) every three hours no one was paying attention. By chance a nurse from another unit came in and saw me and said, this person is going to deliver on the chair, her water has broken. They were really trying to chase me away. It is only then they started paying attention and I had my baby soon after that. I did not get those tablets they told me about in the clinic. Maybe that is why my child is sick, I'd not know.

After that things were not so bad. I delivered, I went home and we can back again when my baby became ill. The care was okay in the hospital with my baby. You know, I'd not want to blame all the nurses, people are not the same. Some of the nurses took good care of us; it is not all of them.

My challenge is to get my boyfriend to test and we together live and look after our child.

I can see he is no longer interested in being intimate with me. Ever since I told him, we have not been together that way. I can see he lost interest. I think it made it worse that I told him I will only have sex with him if he uses a condom. I won't lie; I think he no longer wants me. I suspect he is having another person.

You know what I will do; I will make sure I get him to the clinic. I have decided to care for myself to look after my baby. I'm glad I have my own place to live, he also lives on his own, and I don't have to see what he is doing.

My life has been so hectic with my baby being sick, my HIV status and now an added burden of having to coax my boyfriend to look after himself. I have to help him also, so that we can look after our child, I don't like it but I have to. I have no choice.

How are you feeding your baby?

I'm using the bottle. I decided to bottle feed as I need to go back to work soon, I will take my child back to Lusikisiki to be cared for by my family back home. I will buy the milk and I hope the father of my child will also help me, which is why we must stay healthy to work for our child.

I just hope my baby is free from HIV, I did the test today (PCR), I hope it turns out negative.

Is there anything you would like to ask me?

No, Sisi.

Thanks for your time.

Interview 6

Date: 14 July 2010

Start: 09h00

End: 09h32

Age: 34 years

Attending well baby clinic.

Is this your first baby?

No, I have an 8 year old child.

Wow you look so young?

Yes I had my child early. She is in school now in grade 2.

Is this your first time on the PMTCT programme?

Yes.

When did you first test for HIV?

I tested with my first pregnancy.

What was the result?

I was negative.

I tested again with this pregnancy when I was three months pregnant.

Mhh, which is 12 weeks....., so when you tested where you did test?

I tested at a hospital.

What made you test this time?

The Sr motivated me to test; she said I can protect the baby if I'm positive.

So you accepted the test, and it came out positive, how did you feel?

I felt bad, but the talk before testing helped.

After testing positive, when you got home, did you share this information with any one?

I told my Mother. She stays in Eastern Cape, which is my home.

Do you only live with your mother?

Yes, my father stays here in Durban where he works.

Did you tell the father of the child?

No, I have not told him.

I decided not to tell him, until I also get used to the situation. I'm scared of how he is going to respond. I hear the way he talks about HIV even when we are just talking.

Tell me a bit more how you found care in the hospital and clinic?

I did sometimes feel that we were not treated the same as other people who are negative. I found that identifying other women who are also HIV positive helped.

We get to support one another. That way whatever is done by the hospital staff does not feel that bad. Knowing that you are not alone helps.

How do you mean you were not treated the same?

The shouting, making us feel bad as were making our children sick, when I know it is not my fault? What could I have done differently, nothing? You just ignore them and pray you are discharged soon with your baby.

I see, how did you manage with the tablets (AZT) that you took while pregnant since your boyfriend does not know your status?

He does not know much pregnancy and medication needs to be taken. I took them in front of him and he did not know what I was taking.

At home in the area?

I have not told anyone in the area, I see how they treat people they suspect to be positive. So I will hide my status. I have only told my mother for that reason.

Were you able to take (NVP) that tablet that you take when you start having contractions?

No, I did not. I delivered at home. I went to the hospital with the baby.

What did they say at the hospital?

That is where I really felt mistreated, what .did you call it, the stigma. They scolded me so much, saying my child will contact the virus because of me. Why I did not come to the hospital on time. I was hurt as I did not do it deliberately.

I went to the hospital and they kept me for one night and gave the child medication. I hope my child will be safe, even if I did not take the tablets before and during labour.

Let's hope so. How are you feeding your baby?

I'm breast feeding. I'd not want to collect tins. People talk when you collect tins. So I breast feed. I did not get a chance to breast feed my first one so this is good chance for me.

How are managing exclusive Breast feeding?

I'm at home the whole time, so it not too bad. My mother is also at home she helps me.

Did you say you are still together with the father of your child?

Yes we are together. I'm using condoms now.

How did you introduce the condoms?

I told him after I had the baby that I'm not able to use the contraceptives, they make me sick. So he agreed.

Will you at some point share your status with him?

Yes when I get used to the idea of being HIV positive I will tell him.

May I please find out why you are reluctant to tell him?

(Laugh shyly)He does not think he will ever have HIV, when we talk, he say he will never be HIV+.I know he infected me, I'm sure he infected me. I think he will blame me and leave me. I cannot care for the child on my own, I don't work.

Is there anything you would like to ask me?

No

Thanks for your time.

Interview 7**Date:** 12 July 2010**Start:** 08H45

End: 09h32

Is this your first baby?

No, my third child.

How is the baby?

Alright, just weighed her, she is gaining weight

Hmm, nice.

Please share with me your experience of your first test?

I tested with my second baby and it was negative. So I was fine.

This one I tested in (Names a private hospital).I admitted to a hospital because I had just miscarried at three months. I also had a belt (Shingles) .While there my Dr I requested that I have bloods taken, including HIV bloods. Not even telling me! The next thing I see a Sr from a private lab coming to take my blood. She just came and took my blood. Not a word about the bloods she was taking! I also thought she will give me some counseling. Is because of the disease I'm having?

How did you feel?

I always feel like there is a gap. How can you just do an HIV test without counseling?

You know I remember with my second child, I came to a public clinic. I got counseling before testing, at the time I was HIV negative, still they counseled me. I can say I know how it should be done. The Sr just came in the ward and said, did I get counselling I said, no. She then just taking bloods and said I get my results from my Dr. I was expecting some form of counseling before the bloods were taken. Nothing!

So how did you get your results?

My next appointment with my Dr, he told me I was HIV positive. I must say I had even forgotten about the bloods. I also did not fear that I may be HIV positive. I did not change anything from the time I tested the last time. I was shocked. The Dr did try to talk to me but, it did not help much, I was in too much shock and lack of counseling before testing made it worse. Maybe I could have been more prepared it was counseled before testing.

So you feel there is a gap?

Yes, the Sr said, just take all the bloods once off, it is the same, I was just confused so I agreed to having HIV bloods without any counseling.

By the way how many kids did you say you have?

This is my third one. All girls. They all have the same Father. So I know he infected me. I discovered that he has another child with another woman. My kids are 8, 6 and then this one. This child by the other women is younger than my older kids.

Oh...

I think whenever I'm pregnant my partner always gets himself another sexual partner. He believes he must have someone on the side each time I fall

pregnant. That way his sex life stay on track as he believes that, he must not have sex with a pregnant women. To keep himself sexually active, when I'm pregnant he gets himself a new sexual partner. I think that is how he contracted HIV, probably during my second pregnancy and I tested negative at the beginning of the pregnancy.

Mh..

In addition following my positive test I was done a CD4 count and they found it to be 210. The Dr said my CD4 is too low. He then gave me a script to go and collected ARV from the chemist. He said I can start taking the tablets any day. He said I must choose the time. I chose 8. Is that fair? Is that part of the stigma for the people who are HIV positive? No information!

Today I did not take the tablets as I did not eat. Now I'm not sure what to do then I missed a dose. I never even had any one tell me how to take these tablets. I'm just in the dark. (She shows me her tablets; she has decanted the tablets to a multivitamin bottle)

I'm just trying to be compliant, but not sure how to be good as didn't have information. No one ever told me anything. (Short discussion on mode of action of ARV drugs). I must be doing something right as the Dr said my CD4 has increased to 400. I need I think I need more information on these tablets.

I just need to accept this, that I'm now HIV positive and learn to live again, try and take it as it is. I have told myself that it means it was, meant to that I become HIV positive.

Have you shared your status with your partner?

He knows I told him. I think I know when it happened. We had an incidence a burst condom's he tried to hide it. I asked him he said there is no problem. I think he must have suspected that he is HIV positive. After the incidence of the burst condom we decided not to use condoms any more. I felt, what is the use, if I'm

pregnant it has already happened, why bother with a condom. I think that is when I fell pregnant and got infected.

Do you think he got tested?

No, he must just suspect. To make matters worse he drinks a lot. He is probably making himself even worse by drinking. If my CD4 was so low, his must be just as low.

Right now, I'm also not really used to the idea of being HIV positive and being on ARV and on top of this I was pregnant now I have a baby. I still need to get used to my new life, before I start to deal with him. I need to take care of myself.

I tried to ask him to come with me to my private Dr, to get him to test. Hayi, he refused. As I said I need to care for me.

That is nice.

Initially when I told him I was positive he did not believe me. He said I looked so calm he thought I will throw a tantrum. I thought, how will being angry help me? He only believed me when after delivery, my baby was not well. He had weak lungs and I was not discharged. The Dr wrote a script for him to collect ARVs for the baby. It is only then that he started to be believed and it started to sink in for him.

I started to notice that he lost weight because I think he was stressed. To make matters worse, he does not have a family. Now I have to look after him as well, when it is his fault we have this HIV.

He also started to have these verbal outbursts! I feel this is so unfair, he infected me now it my problem and is verbally abusive.

Hmm..

You what hurts me is that I kept on telling him that we may end up being HIV positive if he carries on with these other women. One time asked him to break up

till he sorts himself out, he refused. Look what has happened now. Immediately after I talk to him, it seems like he stops his affairs, but only to go back to his old ways.

Hmm..

He now feels I should be angrier, so I think that is why he doing this for me to say something to make me angry, so that I also burst so that it can easy his guilt so that he can say I said this and that.

How did you find the care in the hospital?

Hayi Sisi It was quite good. My Dr also took good care of me. It just that I had a belt (Shingles) while I was pregnant. I started immediately after imitating treatment. Dr said it is part of recovery. My immune system is waking up, I will be fine.

I'm just praying for my God to keep me safe and to live long so I can care for my kids. I will try and visit my Dr, the hospital and the clinic to try and keep myself healthy.

Hmm..

We have not been intimate with my boyfriend ever since my pregnancy. Not sure why, maybe it is because I told him I'm positive or it is that I said, if we ever resume sexual activity, I will make sure I protect myself. That is why I told him my status

Which feeding option did you choose?

I'm bottle feeding. You imagine the questions, but I tell the people that I work, I cannot breast feed.

I believe I will be fine. I always thought I would hang myself if ever found myself to be HIV positive. So scared of how people will treat me if they ever found out, I coped. What made me decide to live is my parents died, I look after my siblings. The only relative is my Mom's sister. She can't live with us for a couple of months. She looks after me and the baby. She reminds me to give the baby medication; she cooks for us and generally is a shoulder to cry on. She is the only family member who knows my status. I want to keep that way.

I think support is important if you are HIV positive. There is no way I could have coped with the baby and being HIV positive at the same time.

I must say I'm still really confused by the whole medication for the baby and for me. I wish I had those classes they give in the public sector. (More question about baby medication) It is still not clear to me why the baby takes medication. No explanation at all about what is going on.

I must say I have not had any side effects? The only thing was the belt. I must say I would love to know more about my illness. I will give myself time to find out once I get used to being HIV positive and my baby is a bit bigger.

I have no parents and now I end up with this problem. If anything happens to me what will happen to my younger siblings and my kids. I need to stay healthy; too many people depend on me.

Is there anything you would like to ask me?

No, not at the moment.

Thanks for your time

Appendix 2

Consent For

Ethics approval number: HSS/0051/10M

Name of Investigator: Zamasomi Luvuno

Title:

Exploring HIV related stigma experienced by women enrolled in the Prevention of Mother to child Transmission (PMTCT) Programme in EThekweni, KwaZulu Natal.

Purpose:

You are invited to participate in a study find out about your experiences of discrimination if any, that you may have felt while you were a part of the programme that aims to prevent your unborn baby from getting infected with HIV and AIDS while you were pregnant. This discussion will take about 45 minutes to an hour.

I will talk to about ten women from different clinics.

Procedure:

We will find a quite spot within the clinic to sit and talk. This conversation will take about 30 minutes to an hour. I will be recording the conversation, so that I can make sure that I can capture our discussion accurately will then type this out word for word in IsiZulu and later translate it into English.

Benefit and Risk:

You will benefit by learning a bit more about prevention of HIV and AIDS in pregnant women as you can ask me questions as we talk if you need information. This information may help you as you take care of yourself and your baby.

There is no risk to your life, maybe minimal psychological discomfort. The major inconvenience is the time it will take for our discussion.

Cost:

There is no cost to participate in the study and no money will be paid to the participants.

Confidentiality:

Your name will not appear on any of my research material .I will use only use code number, I will assign this numbered and it will be known only to me. The purpose is to file accurately and you will not identify. The information will be confidential.

The decision whether to participate or not will not prejudice you, you can withdraw any time without penalty.

Please feel free to ask any questions you may have about the study and your rights as a participant in a research study.

I can give you a copy of this form to keep. Your signature show that you are willing to take part, and you may withdraw from the study at any point.

Signature of Participant _____ Date _____

Signature of Investigator _____ Date _____

Appendix 3

Information Sheet

Name of Investigator: Zamasomi Luvuno

Student Number: 208528960

Contact details:

Cell: 0832646394

Email Address: luvuno@ukzn.ac.za

Name of Institution: University of KwaZulu Natal School of Nursing

Name of Supervisor: Mrs Joanne Naidoo

Contact Details of Supervisor

Email Address: kisternjr@ukzn.ac.za

Telephone Number: (031) 260 2213

Appendix 4

Interview probes

How old are you?

Where do you live?

Who stays with you in the house?

How many children do you have?

How old are they?

Tell me, why did you do an HIV test?

Tell me about the time you first did an HIV test.

Tell me about the time you found out you were HIV positive?

Did you tell anyone about your HIV status?

What was the reaction from the people when you shared this information with them?

Probing: How did they treat you after they found out about your HIV status?

How have you experienced your relationship with health workers who cared for you during the PMTCT programme?

Tell me about the time you were attending the PMTCT clinic

How did you experience the PMTCT guidelines such as: VCT, CD4 count, Treatment, feeding choices, labour ward experience?

How did you manage to stay within the programme?

In general how have you experienced being an HIV positive woman who is in the PMTCT programme?

What have been your experiences because of your HIV status?

Probing

Would you say you have experienced stigma because of your HIV status

(Researcher to explain this in simple terms if the participant does not understand stigma)

Probe further

Thank you for your participation!



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02 February 2010

Mrs. D P B Luvuyo
Faculty of Health Sciences
School of Nursing
Mkandaweni Campus

Dear Mrs. Luvuyo:

PROJECT: "Exploring HIV related stigma experiences by women enrolled in the Prevention of Mother to Child Transmission (PMTCT) Programs in Winkhulu, KwaZulu-Natal"
ETHICAL APPROVAL NUMBER: HSS/0072/1006

In response to your application dated 27 January 2010, student number: 40090760 for Humanities & Social Sciences ethics approval, our considered the above mentioned application and the proposed methodology is **ETHICALLY APPROVED**.

Research Data: Research data should be securely stored in the school department for a period of 5 years.

I take the responsibility of writing you everything of the best with your study.

Yours faithfully

PROFESSOR STEVE MKHIZE (Chair)
HUMANITIES & SOCIAL SCIENCES ETHICS COMMITTEE

cc: Department (Ethics Approval)
cc: Mrs. P. Luvuyo

Responsible Officer: Mr. Mkhize Mr. Mkhize Mr. Mkhize Mr. Mkhize Mr. Mkhize Mr. Mkhize

Appendix 6

P.O. BOX 671
Kloof
3610
15 March 2010

The Manager
9 Old Fort Place
Durban
4000

Dear Sir/Madam

**REQUEST FOR A PERMISSION TO CONDUCT A STUDY IN ETHEKWINI
MUNICIPALITY PRIMARY HEALTH CARE CLINICS**

My name is Zamasomi Luvuno. I am student currently studying with the University of KwaZulu Natal, Howard College.

I'm doing course work masters in Community Health Nursing. As one of the requirements for my masters' course work I have to conduct a mini dissertation as part of my studies.

The purpose of the letter is to request a permission to conduct a study in the PHC Clinis. The title of the study is: ***EXPLORING HIV RELATED STIGMA EXPERIENCED BY WOMEN ENROLLED IN THE PREVENTION OF MOTHER-TO-CHILD TRANSMISSION (PMTCT) PROGRAMME IN ETHEKWINI, KWAZULU NATAL.***

Attached are the research proposal and the letter of approval from the University of KwaZulu Natal's ethical committee.

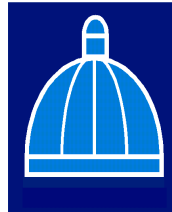
Kind Regards

Zamasomi P.B. Luvuno

Student Number:208528960

Appendix 7

ETHEKWINI MUNICIPALITY
Health, Safety and Social Services
Health Unit



9 Old Fort Place
Durban 4001
P O Box 2443
Durban 4000
Tel: (031) 3113679
Fax: (031) 3113710

Website: <http://www.durban.org.za>

Enquiries: Dr Cheryl WEAICH
0313113500

14 April 2010

MASTERS COMMUNITY NURSING UKZN
Zamasoni Luvuno
Cell 0832646394

PROTOCOL TITLE: PMTCT Related Stigma

Approval is granted for research to be conducted at Ethekwini Local Clinics:

We wish you all the best in your research. Please provide us with a report on completion of your study..

Please contact Dr. Cheryl WEAICH on 031 – 311 3500 for any queries

Yours faithfully

Dr Ayo Olowolagba
CLINICAL SUPPORT

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HEAD: HEALTH

APPENDIX 8

Free Nodes

Name	Sources	References	Created On
Disclosure	4	6	2010/07/23 10:31 PM
Partner Disclosure	4	5	2010/07/23 10:33 PM
Abandonment	4	8	2010/07/23 10:35 PM
Fear of testing HIV Positive	1	2	2010/07/23 10:38 PM
Concern for Safety of the unborn child	5	11	2010/07/23 10:42 PM
Protection of older children	4	6	2010/07/23 10:44 PM
Concealing HIV Positive Status	4	15	2010/07/23 10:47 PM
Discordant Couple	1	1	2010/07/23 11:27 PM
Uncaring attitude of health workers	4	7	2010/07/23 11:35 PM
Involuntary Disclosure	4	9	2010/07/23 11:40 PM
Isolation	1	4	2010/07/23 11:44 PM
Stigma and default from programme	2	4	2010/07/23 11:49 PM
Judgement and Blame	6	15	2010/07/23 11:52 PM
Programme default	4	7	2010/07/24 10:16 PM
Domestic Violence	2	2	2010/07/24 10:17 PM
Pressure to breast feed	3	3	2010/07/24 10:18 PM
Community action	3	4	2010/07/24 10:23 PM
Discosure outside family and Partner	2	3	2010/07/24 10:28 PM
Support	6	10	2010/07/24 10:30 PM
Fear of AIDS stage	2	3	2010/07/24 10:31 PM
Partner testing	3	3	2010/07/24 10:34 PM
Desire for partner support	2	3	2010/07/24 10:37 PM
Source of Infection	4	4	2010/07/24 10:42 PM
Coping mechanism	5	9	2010/07/24 10:43 PM
Positive experience at health facility	5	5	2010/07/24 10:45 PM
Adherence to Programme recommendations	6	14	2010/07/24 10:51 PM
Health worker indifference	2	4	2010/07/25 09:37 PM
Self Stigmatisation	4	9	2010/07/25 09:41 PM
Fear of Poor care due to HIV status	1	1	2010/07/25 09:45 PM
Betrayal by Health workers	2	4	2010/07/25 09:57 PM
Suggestion to Improve programme	2	4	2010/07/25 10:00 PM
Death of a child	2	3	2010/07/25 10:06 PM
Neglect	2	3	2010/08/15 08:28 PM
Reason For testing	7	9	2010/08/15 08:35 PM
Poor outcome for mother and child	1	1	2010/08/15 10:07 PM
Overwhelmed	6	12	2010/08/15 10:13 PM
Hope for the future	3	4	2010/08/15 10:16 PM
Support Group	2	2	2010/08/15 10:27 PM
Desire to help the partner	1	1	2010/08/15 10:42 PM
Outcome and or response to disclosure	4	5	2010/08/16 10:52 PM
Confidentiality	1	1	2010/08/16 10:58 PM
Planned delay in disclosure	1	1	2010/08/16 11:20 PM
Unintentional disclosure due to following PMTCT	2	2	2010/08/16 11:23 PM
Fear of partner abandonment	2	3	2010/08/16 11:35 PM

Appendix 9		
Cluster meaning	Significant Statement	Code
Judgment and Blame(By health care workers)	I then told the Sister and asked her to help me get AZT tablets from my bag. She became very angry and started shouting at me saying: "You sleep around, collecting diseases and you come here to worry us about tablets. You carry on having children with no fathers and you become our problem" 5	External stigma
	When in the ward after delivery the nurses shouted at me, asking how I can bottle feed when I'm un-employed. How will I afford to buy the milk? I did get five tins of milk (from hospital) with lots of shouting accompanying those tins. The nurse said, "we will see what will happen; this milk is going to stop soon". 3	External stigma
	They scolded me so much, saying my child will contract the virus because of me. Why I did not come to the hospital on time. I was hurt as I did not deliver at home deliberately. I went to the hospital and they kept me for one night and gave the child medication. I hope my child will be safe, even if I did not take the tablets before and during labour. 6	External stigma
	When I went to the Sisters room for palpation, she scolded me so much because of my age, being pregnant and HIV +. She kept on asking why I did not use the condoms. Have I ever heard of condoms? I tried to ignore her; she just carried on about how irresponsible I was and	External stigma

	<p>so forth. She does not even know me. She calls me irresponsible!</p> <p>4</p>	
	<p>When the one Nurse pulled out my results, she showed them to the other Sisters. First I saw their eyes, like talking with their eyes. I got such a fright. They then spoke amongst them self, I could not hear them, but I could see they were talking about me or my results. I thought my CD4 count must be very bad. They then started shouting saying why I took so long to return for the results. Saying I have delayed initiation of ARV, that is how we die because we are careless, that is how we get infected and who will care for my child and so forth. I had no chance to respond, in addition I was so scared, thinking this means I'm dying</p> <p>5</p>	External stigma
	<p>When I got to the hospital, I told the Nurses about my HIV status and the tablets I had to take (3 HOURLY AZT) I then asked for a glass water to take my tablets. Wow was I in trouble! They (Nurses) said I delayed coming to the hospital and taking the tablet. Why did I come to THIS hospital instead of hospital X, as I live in another area? I though they do not want to care for me because of my HIV status, maybe they are scarred I will infect them. They were thinking of all sorts of excuses not to give me care. The hospital I went to seemed more convenient for me and easy to get to since I was in labour. If I had tried to go hospital X, I would have taken so long as I needed to board two taxis.</p> <p>5</p>	External stigma

<p>Judgment and Blame (By partner, family and community)</p>	<p>I decided not to tell him (My partner), until I also get used to the situation. I'm scared of how he is going to respond. I hear the way he</p> <p>Always talks about HIV even when we are just talking. I fear he will blame me for the infection and leave me.</p> <p>6</p>	<p>Internal stigma</p>
	<p>More so if the people who have had a relationship with you like ex - boyfriends and their current girlfriends will say you infected them. You will be a laughing stock and get blamed for all the deaths that occur to those people. There is no way I will tell people I'm positive.</p> <p>2</p>	<p>Internal stigma</p>
	<p>(Laugh shyly)He does not think he will ever have HIV, when we talk, he says he will never be HIV+.I know he infected me, I'm sure he infected me. I think he will blame me and leave me. I cannot care for the child on my own, I don't work.</p> <p>6</p>	<p>Internal stigma</p>
	<p>This is my third one. All girls. They</p>	<p>Internal stigma</p>

	<p>all have the same Father. So I know he infected me. I discovered that he has another child with another woman. My kids are 8, 6 and then this one. This child by the other women is younger than my kids.</p> <p>6</p>	
	<p>You know what hurts me, is that I kept on telling him that we may end up being HIV positive if he carries on with these other women. One time asked him to break up with me, till he sorts him out, he refused. Look what has happened now. Immediately after I talk to him, it seems like he stops his affairs, but only to go back to his old ways.</p> <p>7</p>	Internal stigma
	<p>Before testing, I just told myself that I may test HIV positive, because this thing (HIV) is all around. I may be looking after myself, but I don't know how my boyfriend is behaving. So I just told myself I will accept whatever the result and try and learn to live with it. What can I do?</p> <p>5</p>	Internal stigma
	<p>I did not want to blame him, but I know he infected me. He did not like that. I will be honest with you, Sisi; we have not had sex since that day (Day of disclosure of HIV status)! Fortunately we do not live together. Hayi-ke, I'm sure he is having other women now. I told him, I will not sacrifice my blood for love. I want to live and look after my kids. I tried to convince him by telling him that since I will be on treatment it is dangers for him to</p>	Internal stigma

	<p>have sex with me without a condom.</p> <p>5</p>	
Concealing Status	<p>I wanted to be able to make sure I'm able to take care of myself and be able to share with my family, so that even if I'm positive I'm still able to do things for myself.</p> <p>I have seen people who find out when they are too ill and need help even to take medicine. That is when problems start and people have something to gossip about and treat you badly, everybody ends up knowing you are HIV positive.</p> <p>1</p>	External stigma
	<p>My mother is alive but she is not at home she is away for training to be a 'Sangoma' so she stays where she is training. I'm particularly scared to tell her of my HIV status as I feel she will experience a great deal of stress, so I have not told her.</p> <p>1</p>	Antecedents of stigma
	<p>That is why I tested early, so that no one will ever find out, as sometimes people discover your status when you become ill and it is like an advert for every one that you are POSITIVE. So no one knows.</p> <p>1</p>	Antecedents of stigma
	<p>I chose to breast feed, that way no one will suspect my status. I will not have to collect the milk tins at the clinic as this is one of the things that show you are positive. People will ask you why you are not breast feeding and they will see you bring the tins with you and they will know</p>	External stigma

	6	
	Oh yes. I will do anything to make sure they never find out. 4	External stigma
	4	Antecedents of stigma
	We decided to move out and rent a room, so that we can be free, otherwise no one knows, so we wanted to keep it that way. 2	External stigma
		External stigma
		Antecedents of stigma
	I choose the tins. I will not collect them from the hospital. I will also not buy the ones like Nan and	External stigma

	<p>Pelagon (those given by public sector facilities) as people will see that I'm HIV+. I will buy Infacare</p> <p>from the shop. That way no one will know or suspect my status.</p> <p>4</p>	
	<p>He does not know much pregnancy and medication needs to be taken. I took them in front of him and he did not know what I was taking.</p> <p>6</p>	Antecedents of stigma
	<p>I told him after I had the baby that I'm not able to use the contraceptives, they make me sick. So he agreed to use condoms.</p> <p>6</p>	Coping with Stigma
Adherence to Programme guidelines	<p>I'm not fussy about what I get, as long as the child is healthy. This child in particular must healthy because of my HIV status. I'm very particular to make sure that I do everything they tell me to do here at the clinic. I want to make sure that my child is healthy.</p> <p>1</p>	Coping with Stigma
	<p>Oh yes the Nevarapine? I always carry it with me, so there will be no problem when labour starts.</p> <p>1</p>	Coping with Stigma
	<p>I almost fell off the programme. I t started with me having to take AZT while I was still pregnant. I had to hide the pills and also hide when taking the pills. You know how these tablets are taken at specific times. I had to hide from my mother, sometimes had to hide in the toilet to be able to take my</p>	Coping with Stigma

	<p>medication. 2</p>	
	<p>found I have the same problem with giving my child NVP, my mother is the type of person who needs to know everything! I managed somehow to conceal the medication. I pretend I'm giving my child gripe water. 2</p>	<p>Antecedants of Stigma</p>
	<p>When in the ward after delivery the nurses shouted there, asking how I can bottle feed when I'm unemployed. Will I afford to buy the milk? I did get five tins of milk with lots of shouting accompanying those tins. She said we will what will happen; this milk is going to stop soon. 3</p>	<p>External stigma</p>



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To whom it may concern

**EDITING OF RESEARCH DISSERTATION OF ZAMASOMI LUVUNO BY
CATHERINE EBERLE**

I hereby confirm that I was employed to edit the above document. I have an MA (Eng) from University of Natal, and am frequently employed by students to provide this function.

I have edited her text and initiated changes with regard to spelling, punctuation, language, grammar and syntax. I have not edited content as I am not a subject expert. I have provided an Error Report which makes suggestions for changes, remedies for layout issues, clarification, etc. and provides examples of errors which I cannot rectify, but which need to be addressed prior to the document being deemed correct.

The student has indicated that she will make the necessary corrections and adjustments as deemed appropriate.

I trust that her document will then prove acceptable in terms of language and presentation.

Yours sincerely

CATHERINE P. EBERLE (MA)