

Title

**Coping strategies and learning of Basotho women living with HIV and AIDS:
A case study of a group of women belonging to Phelisanang Bophelong
Association in the Leribe District.**

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Abstract

This study in the field of Adult Education explores the coping strategies and learning of Basotho women living with human immunodeficiency virus (HIV) and the acquired immune deficiency syndrome (AIDS). It investigates the mechanisms these women employ to cope with these life threatening ailments and the effect of life-long treatment on their day-to-day encounters with their families and the rest of society. The group of women selected for this study are from the Phelisanang Bophelong Support Group (PBSG). This support group for people living with HIV and AIDS is located in Lesotho, about 100kms north of the capital Maseru, in the Leribe district.

The case study methodology, located within the paradigm of interpretivism, sets out to critically document the journey that the women took, exploring deeply their emotions and feelings within the compass of the life threatening disease from which they suffer. It narrates their lived experiences in the context of their relationships with their environment (partners, children, in-laws, friends and society), and analyses and theorises the practises and various learning encounters of these women. Data were collected from the thirteen women through questionnaires, one-on-one interviews, a focus group discussion and a joint telephone interview with three programme management team members of the PBSG.

This case study was grounded in theories of African feminism, transformative learning and communities of practise.

Key findings include the existence of a patriarchal system which promotes male hegemony and female subjugation in some instances, but at the same time the study noted the gradual challenging of the status quo by the women, through claiming their rightful position in the fight against HIV and AIDS. The notion of equal partnership between the sexes within families

began to emerge. Reproductive health issues which were once a male territory, now became a shared area among some partners. Health information that was shared by parents with their children and the subsequent support and resilience demonstrated by these children in relation to their HIV positive mothers, are other findings that the study revealed.

Consequently, the reduction of the once rife social stigma and discrimination about an HIV and AIDS positive person subsided, and it was found that instead the disease was now viewed by those suffering from it or otherwise effected by it, as a manageable health condition rather than a deadly one. These developments are partly attributed to the HIV and AIDS support group discussions and capacity building efforts that these women were exposed to.

The thesis has as its conclusion a proposal for a more robust family health education system regarding the HIV and AIDS epidemic for Lesotho. The institutionalisation and strengthening of the support groups based on the PBSG model proved critical to the success of this, as was the issue of greater male communication and involvement in HIV and AIDS responses.

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My colleagues at work, many thanks for the support and kindness you showed. I know that my frequent absence from work caused many disruptions to the normal week to week work schedules, but you accommodated me in many material ways, to that I say thank you for your understanding.

Declaration

I, Malithapelo Mapaseka Mosuoe, declare that:

The research presented in this thesis is my original work. Where there are contributions of other scholars, I have indicated this clearly with references to the literature.

This thesis has not been submitted for any degree or examination to any other University

Signed:

Malithapelo Mapaseka Mosuoe

March 2017

As the candidate's Supervisor, I agree to the submission of this thesis.

Signed:



Dr Peter Rule

March 2017

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Abbreviations

ABC	Abstain, Be faithful and Condomise
ANC	Antenatal Care
AZT	Zidovudine
AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
COP	Communities of Practice
D4T	Stavudine
DHMT	District Health Management Team
EFV	Evafirenz
GDP	Gross Domestic Product
HDI	Human Development Index
HIV	Human Immunodeficiency Virus
IDU	Injecting Drug User
KYS	Know Your Status
3TC	Lamuvudine
LACs	Local Adherence Coordinators
LAPCA	Lesotho AIDS Programme Coordinating Authority
LENEPWHA	Lesotho Network of People Living with HIV and AIDS
LLP	Legitimate Peripheral Participation
MOT	Modes of Transmission
NAC	National AIDS Commission
NVP	Nevirapine
PB	Phelisanang Bophelong
PBA	Phelisanang Bophelong Association
PBSG	Phelisanang Bophelong Support Group
PMTCT	Prevention of Mother-to-Child Transmission of HIV and AIDS
PEP	Post Exposure Prophylaxis
PrEP	Pre-Exposure Prophylaxis
SADC	Southern African Development Community
SAFAIDS	Southern Africa AIDS Dissemination
TB	Tuberculosis
TDF	Tenofovir

UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNICEF	United Nations Children's Fund
USD	United States Dollars
WHO	World Health Organization

CHAPTER ONE: Scene Setting

1.1 Introduction

This chapter looks into how women who live with HIV and AIDS are coping with their HIV and AIDS positive status. A case study methodology of a group of women belonging to the Phelisanang Bophelong Association in the Leribe District is used to investigate this. The purpose of this study is to explore the coping strategies of HIV and AIDS seropositive women of child bearing age.

The chapter is divided into two parts.

Part one gives a general background on HIV and AIDS at a global level, then within the African states and more specifically within sub-Saharan Africa, with a particular focus on Lesotho, the study country

There are discussions that highlight:

- statistical information about HIV and AIDS;
- information about HIV and AIDS regarding women, with special emphasis on African women but particularly women in Southern Africa;
- the status of women within the HIV and AIDS era and the factors that fuel or render them vulnerable to HIV and AIDS;
- child-bearing within the African context and the challenges of women on antiretroviral therapy;
- in conclusion the chapter looks at the interventions in place to curb the spread of the epidemic among women.

Part two focuses on the methodological layout of the study;

- the objectives of the study,
- the research questions,
- significance of the study as well as the scope, and
- finally, at the end of these two parts a concluding paragraph is provided which sums up the contents of the chapter and maps a way forward for the next chapter.

Part One

1.2 The Global Context

The latest statistics of the global HIV and AIDS epidemic as published by the Joint United Nations Programme on HIV/AIDS (UNAIDS), the World Health Organization (WHO), and the United Nations Children's Fund (UNICEF), (2015) indicate that as of 2015, 36.7 million people were living with HIV. Of this number, 2.1 million people were newly infected with HIV. The number of people who were put on antiretroviral therapy (ART) by June 2015 was 17 million. AIDS-related deaths registered 1.1 million. Since the start of the HIV and AIDS epidemic the number of people infected totals 78 million, and the number of people who have since died of the disease is 35 million.

Access to antiretroviral therapy: As of December 2015, there were 17 million people who were accessing HIV treatment, which is an increase from 15.8 million in June 2015 and 7.5 million in 2010. Forty-six percent of adults and 49 percent of children living with HIV were accessing treatment- an increase from 23 percent and 21 percent respectively, in 2010. Among pregnant women who were attending ante natal care (ANC) the figures reflected a 77 percent increase in access to ART in 2015.

New HIV infections: Globally there were 2.1 million recorded cases of people (adults) who were infected with the virus in 2015. This figure shows a decrease from the 2.2 million of related cases in 2010. There were a 150 000 recorded cases of children who were newly infected with the virus in 2015 which indicates an almost 50 percent reduction from the 2010 figures of 290,000 child cases.

AIDS related deaths: The figures have fallen by 45 percent since its peak in 2005. In 2015, 1.1 million people died from AIDS related illnesses compared to the two million in 2005.

Regarding investments made to fight the epidemic, the UNAIDS report highlights progress that the world is making in meeting the target expressed within the Political Declaration on HIV and AIDS in which the global community committed to mobilizing up to United States Dollars (USD) 24 billion for the AIDS response by 2015. By 2014 a total of USD 20.2 billion was invested with 57 percent made up from the domestic resources of both low and middle income countries. UNAIDS estimated that a total of USD 31.1 billion will be required for the AIDS response by 2020, with USD 29.3 billion required by 2030, if the world is to attain the 90/90/90 global target of ending AIDS (UNAIDS, 2015, p.1).

The 90/90/90 strategy commits countries to ensuring that 90 percent of HIV positive people should know their status by 2020; 90 percent of these should be receiving ART; and 90 percent of these should have fully suppressed their viral loads, if the world aims to achieve an HIV and AIDS free society by 2030 (Williams, Gows, Somse, et al., 2015, p. 196).

The global 10-year HIV trends as extracted from the 2015 fact sheet by UNAIDS are provided in the table below:

Table 1. 1 Global HIV Trends 2005 - 2014

	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
People living with HIV	32.0M	32.4M	32.9M	33.3M	33.8M	34.4M	34.9M	35.6M	36.2M	36.9M
New HIV infections (total)	2.7M	2.6M	2.5M	2.4M	2.4M	2.3M	2.3M	2.2M	2.1M	2.0M
New HIV infections (adults)	2.2M	2.1M	2.1M	2.0M	2.0M	2.0M	1.9M	1.9M	1.8M	1.8M
New HIV infections (children)	500 000	490 000	470 000	400 000	400 000	360 000	330 000	280 000	250 000	220 000
AIDS related deaths	2.0M	2.0M	1.9M	1.7M	1.7M	1.6M	1.5M	1.4M	1.3M	1.2M
People accessing treatment	--	-	-	-	6.1M	7.5M	9.4M	11.4M	13.0M	14.9M
Resources (in billion USD)	9.4	10.3	12.1	15.7	15.6	15.9	18.2	19.6	20.4	20.2

Source: UNAIDS fact sheet 2016, Global Statistics 2015, 2030 Ending the AIDS epidemic.

The overall global trends that are reflected in the table, indicate an increase in the number of people living with HIV, a decline in new infections, an increase in those receiving ARV treatment and a decline in the mortality rate due to HIV and AIDS interventions. Since more people are receiving treatment, fewer people are dying from the disease. The increase in people taking treatment is also reflected in increasing allocation of resources to counter the pandemic.

1.3 HIV and AIDS in southern Africa

Southern Africa is home to approximately 20 percent of global HIV infections and still continues to experience high rates of new HIV infection, despite the efforts made to halt the spread of the infection such as the scale-up of treatment and prevention interventions (Delva & Karim, 2014,

p.99). This situation poses serious challenges to the global commitment of attaining an HIV-free society by 2030.

The first ten countries in the world's ranking of HIV prevalence among the 15 – 49 year age group, were reserved for southern African countries. These are (by order of percentage of population infected) Swaziland, Lesotho, Botswana, South Africa, Zimbabwe, Namibia, Zambia, Mozambique, Angola and Malawi. While some of the southern African countries may seem to have stabilized their national HIV prevalence rates, we should not interpret this as representing the status quo. On the contrary, the region seems to be the place hard-hit by HIV- related burden of disease over recent years (Delva & Karim, 2014, p. 99).

Unlike the other regions of the southern Africa's HIV and AIDS trend is characterized by heterosexual transmission which is the dominant mode. The epidemics are described as mature, generalized and hyper-endemic, resulting in an unprecedentedly high HIV prevalence, continuing high rates of new HIV infections and a large number of patients living with AIDS (Delva & Karim, 2014).

Key factors that fuel the epidemic

Heterosexual population: The epidemic particularly affects people who have multiple sex partners and those people's regular partners who may not have other sex partners. The incidence of infection seems common in stable mutually faithful but discordant relationships whereby one partner is HIV positive and the other HIV negative. There are some variations however, in the proportion of new infections among key populations such as sex workers and their clients, men who have sex with men (MSM) and injecting drug users (IDU). MSM and their female partners contribute to one percent of infections in Zambia, but 10 percent in South Africa. Sex workers and their clients as well as regular partners of clients contribute two percent of new infections in Lesotho and 20 percent in Mozambique (Delva & Karim, 2014, p. 102). **Intergenerational sex:** This is another factor that fuels the epidemic. The HIV prevalence and high incidence rates in

young women are driven by age disparity and transactional sexual relationships between highly susceptible young women and older men with a high cumulative risk of HIV infection. This then explains higher HIV incidence and prevalence in young women in the 15 – 24 year age group, as compared to their male counterparts. The age disparity and transactional sexual relationships are typically facilitated by unstable family and home environments, coupled with age and gender-inequality in material wealth and social status. Some young women may favour relationships with older men in an attempt to avoid any physical and emotional abuse they may be experienced with younger men or in the home. These views are expressed by Delva and Karim (2014, p. 103) as well as in Harrison, Colvin, Kuo, et al., (2015, p. 207).

Alcohol Consumption: Identifying alcohol as one of the key factors that fuel southern Africa's HIV epidemic, Kalichman, Simbayi, Kaufman, et al., (2007) categorise it as the most commonly used psychoactive substance that impacts negatively on decision making and whose consumption is proven as a most prevalent factor associated with risky sexual behavior and the concomitant increased rate of sexually transmitted infections (STIs). They further claim that it elevates sexual risks through multiple channels, especially for those individuals with a personality type that enjoys risk-taking (Kalichman et al., 2007, p. 141)

Unequal power relations: Unequal power relations are high in southern Africa. These manifest in gender-based violence where young women often become victims of domestic abuse and sexual assault. Women under the age of 18 years are mostly at risk of gender based violence. In their study of social, behavioural and structural factors that promote HIV infection among young women, Harrison et al., (2015) identified a strong association between the experience of violence within intimate partner relationships, sexual abuse, trauma, abuse, and other forms of sexual violence as risk factors leading to greater HIV infection rates (Harrison et al., 2015, p. 207).

Below is the map of Southern Africa

Figure 1.1 Map of Southern Africa



1.4 Women as caught up in the middle of the epidemic

The HIV and AIDS pattern within southern Africa regrettably places women at the very centre of this epidemic in a number of ways.

Firstly, the age disparity between partners in marriage has problems associated with it. The average range between a husband and a wife is approximately 3 – 5 years, with men typically being the older partner. This practice is common and mostly celebrated in Africa. It however renders women more vulnerable to negotiate for safer sex and often leads to violence from their husbands if they insist on condom use (Harrison et al., 2015, p. 208).

In the second instance, is how the males' greater economic power translates into relationships. Women's economic vulnerability is reflected in their limited access to employment or family resources. Women characteristically succumb to risky sexual demands from men in the hope that they will receive some small gifts and this often indicates long-term dependence on transactional sex for survival. This practice may often provide a means of paying for school or associated costs such as books, uniform or transportation. This gender inequality is associated with women's greater risk of acquiring the HIV infection as a result of their not being in a position, to negotiate safer sexual practices. The inequality is pervasive in social, economic and political spheres where women are minimally represented and cannot therefore, bring about changes in the way certain things are handled. An example in this regard relates to practices of widow inheritance, widow cleansing¹ and in some aspects, the notion of women's place as being on the periphery (Uwah & Wright, 2011; and Harrison, 2014).

In the third instance, the biological make-up of a woman puts them in a position of being susceptible to HIV infection due to cervical ectopy (a condition in which cells that normally line around the opening of the cervix get eroded, thus causing vaginal discharge). This is particularly pronounced in younger women and is exacerbated by the presence of co-factors such as sexually transmitted diseases and the greater ease of transmission from men to women. For young women in southern Africa, the risk for HIV infection is particularly high in the later years of adolescence, between the ages of 18 and 25 during the transition into adulthood. Across the region, 35 – 40 percent of women have their first child by the age of 19. "...this signifies increased HIV risk though high levels of unprotected sex" (Harrison, 2014, p. 208).

¹Widow cleansing – a practice whereby a woman is compelled to sleep with a stranger with a belief that she removes bad omen following her husband death – the challenge with this practice is that the stranger with whom the woman sleep, might be HIV infected and in turn infects the widow who in turn passes it on to the inheritor Uwah and Wright (2011, pp. 18-19)

In the fourth instance, the reproductive needs of child-bearing is another factor that exposes women to great risks of HIV infection. Most of the ways in which the virus affects women is during pregnancy, childbearing or breastfeeding. HIV infection and pregnancy are inseparably linked and younger women face a particularly high risk through unintended pregnancy which happens commonly as a result of unprotected sex. Pregnant women experience higher rates of HIV infection in comparison to their non-pregnant counterparts.

In South Africa, for instance, the 15 – 24 year age group of non-pregnant women account for HIV prevalence of 20 percent whereas their pregnant counterparts' prevalence is 39 percent. Generally pregnant women experience higher rates of HIV infection.

In the fifth instance, labour migration, as part of marriage and family dynamics, creates a situation where partners are separated from each other. Men mostly move from one place to the other, with frequent periods of absence from their homes. This movement or migration negatively impacts on family cohesion, household dynamics and well-being by creating high levels of marital and family instability and increasing the on-going epidemic of sexually transmitted infections (Harrison et al., 2015, p. 210).

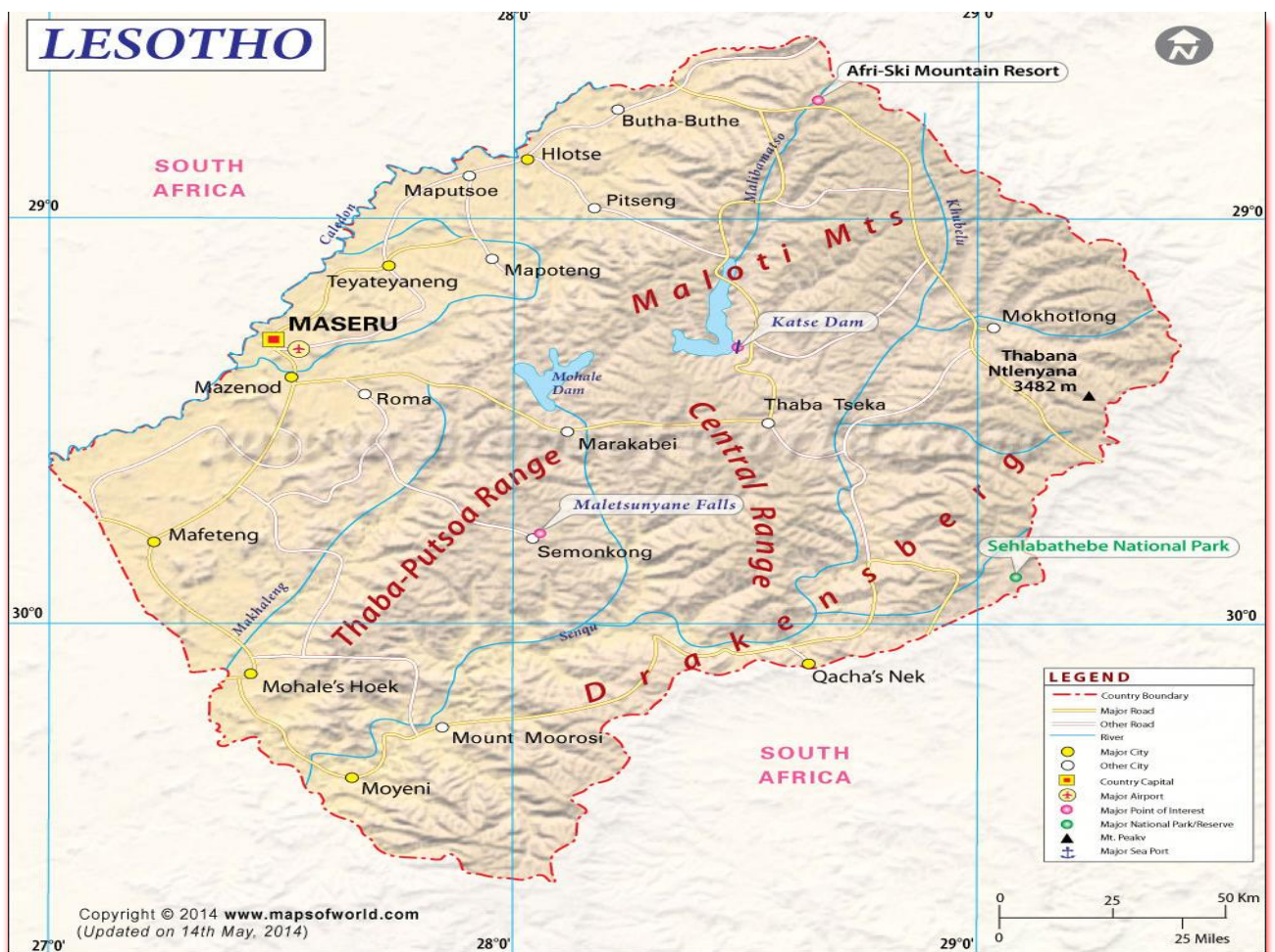
Lastly, certain socio-cultural practices put women at risk of contracting HIV and AIDS. An example is the traditional practices of female genital mutilation, early and compulsory marriage of girls and sexual abuse of women and girls, cosmetic tattooing and administration of charms, widow inheritance and widow cleansing, as well as the perception among African communities that sexual activity is related to social status and for the benefit and exclusive pleasure of males. This view of sex has a double standard in that if a man sleeps around, the community celebrates it and regards that man as popular; the same cannot be said for women who sleep around. Unfortunately women bear the plight of that practice because of their vulnerability to negotiate safer sex even if they suspect their partners to be sleeping around.

The next section deals with a review of the HIV and AIDS epidemic in Lesotho, and its impact on women and the interventions that are put in place to curb the spread of the epidemic.

1.5 Lesotho Country Profile

Lesotho is a small land-locked mountainous country in southern Africa, entirely surrounded by the Republic of South Africa. The country has a total area of 30 355 square kilometers with a population of 1 880 661 consisting of approximately 964 379 females and 916 282 males (Bureau of Statistics, 2006).

Figure 1.2 Map of Lesotho



Notes: The Leribe district, where this study was conducted, has its administrative headquarters at **Hlotse** (100km north of Maseru district, as reflected in the above map)

The HIV prevalence stands at 23 percent (2009 Demographic Health Survey), placing it as the second most infected country in the global ranking after Swaziland. HIV has become the single most demanding challenge to the development of the country.

In terms of its ranking in the Human Development Index (HDI) of 2014, the country stands at 161 out of 188 countries with an HDI value of 0.497, putting the country in the low human development category. Average life expectancy at birth for adults stands at 49.8 years of age. In terms of expected years of schooling and mean years of schooling, the country stands at 11 and 5.9 years respectively. Its per capita gross national income (GNI) is United States Dollar (USD) 3 306 United Nations Development Programme (UNDP, 2015).

The statistics show that Lesotho remains disadvantaged in a number of ways. The combination of its size vis-à-vis its population, its low economic indicators and its geographical position, predisposes the country's labour force to migrate to its neighbouring state, South Africa, for livelihood purposes.

1.6 HIV and AIDS country situation – The national response to the epidemic

The first HIV and AIDS case in Lesotho was reported in 1986. Since then, the government made efforts to scale up the fight against the epidemic. Firstly, the government established an AIDS programme within the Ministry of Health and Social Welfare in 1987, with a mandate to create public awareness about the pandemic and to sensitize the public, using all forms of media, about HIV, as to what it was: how it was transmitted and what the public needed to do to avoid being infected. The key message then was “use a condom” for those that were already sexually active, and “abstain”, a message directed at the youth (UNAIDS, 2014). The “ABC” strategy as it was popularly known stands for:

- Abstinence (not engaging in sex, or delaying first sex);

- **Being safer, by being faithful to one's partner or reducing the number of sexual partners; and**
- **Correct and consistent use of condoms.**

However, by 2000, the epidemic was taking a high toll on the people. There were many people infected and the death toll was on the rise. The country's leadership, embodied by His Majesty King Letsie III, declared HIV and AIDS a national disaster and called upon all levels of leadership (community, electoral division, churches, district and national levels) within the country to heed to his call to help manage the pandemic. At the time of this announcement, the country's prevalence was estimated at 30 percent, which translated into 350 000 people then living with HIV, with about 70 people dying each day of AIDS-related illnesses (Kimaryo et al., 2004).

The first National AIDS Strategic Plan with a multi-sectoral response was then developed.

In 2003, Lesotho AIDS Programme Coordinating Authority (LAPCA) was set up to oversee implementation of the national strategic plan. To facilitate implementation, the Government set aside a two percent budgetary allocation from every Ministerial department in order to address the pressing HIV and AIDS priorities in their respective sectors.

While these efforts were put in place, there was another threat which seemed to reverse the gains that would otherwise be made by the Government. This was the famine which struck the Southern African Development Community (SADC) region. In Lesotho, in 2003, there were over 700 000 people needing food assistance as a result of the structural food insecurity. At that stage a new dimension of the epidemic began to surface, and the burden of orphans began to emerge.

It was estimated that over 70 000 children between 0 –14 years old had lost one or both parents due to HIV and AIDS, which number was still expected to rise given the high death rate witnessed among the workforce – farmers, engineers, teachers, nurses, public servants etc (Kimaryo et al., 2004, p. 20).

It is worth noting that, according to UNAIDS figures for 1999, Lesotho had 240 000 adults living with HIV and AIDS, out of which women constituted 130 000; infected children aged between 0–14 years totaled 8200, and there was a total recorded deaths from AIDS related illnesses of approximately 16 000 people (Jackson, 2012).

In 2004, the country's first Demographic and Health Survey (DHS) was conducted, which assessed progress made in creating awareness around prevention of HIV and thereby providing an estimated adult prevalence rate. The results revealed that prevalence had decreased marginally to 23.2 percent from the estimated 30 percent and that knowledge around HIV had slightly improved although the issue of safe sex practices remained at lower levels, with an increase in multiple and concurrent sexual partnerships (Ministry of Health, 2004) .

In 2004, the Government piloted the provision of antiretroviral treatment at the Senkatana Centre of Excellence which was a designated learning centre for Lesotho's National ART programme. The initial intake was not more than 30 patients per day for quality assurance purposes.

In 2005, ART was finally rolled out country-wide. Despite this there were still challenges both at an institutional level and at the consumer level. There were few health centres which had the capacity to manage the drugs; there were backlogs of patients (at most 30 patients a day were given service), patients waited long periods to be treated, there were debates over the threshold for initiation of treatment - whether to initiate at a CD4 cell count (a laboratory test that measures the number of T lymphocytes in a blood sample) of 250 and below, or a CD4 cell count of 350 and below). At the consumer level, there were anxieties and resistances at the thought of enrolling for a life time treatment plan that comes with stringent measures attached.

By 2005, the World Health Organization (WHO) developed a strategy for ensuring the countries' compliance to treatment which meant treating an estimated 3 million people by 2005. This was popularly known as the 3x5 approach, which set a global target of putting a minimum of 3 million people on antiretroviral treatments by the year 2005 (WHO, 2003). Each country was given its target. In compliance with this strategy, Lesotho was given a target of 28 000 people to be treated with ARVs, representing 50 percent of its total infected adult population, in order to support its treatment availability acceleration. Implementation of this urgent intervention however, encountered some challenges which ranged from provision of the ARVs to HIV-infected pregnant women for prevention of mother-to-child transmission (PMTCT) as well as to HIV-infected children. These challenges were evident by the end of 2006 when only 32 percent of patients who were in need of treatment had been enrolled. Children accounted for only eight percent of patients. Similarly only 15.6 percent of HIV pregnant women received ARVs for PMTCT by the end of 2006 (Ministry of Health, 2010).

In 2005, four major interventions were put in place to mitigate the HIV epidemic. The first was the establishment of a semi-autonomous body mandated with the coordination of the national response known as the National AIDS Commission (NAC). The second was an umbrella body for people living with HIV and AIDS known as the Lesotho Network of People Living with HIV and AIDS (LENEPWHA), whose mandate was to promote and advocate for human rights of people living with the virus as well as to encourage disclosure of HIV positive status, as a way of minimizing stigma and discrimination which were very rife then. The third was the launch of the Know Your Status (KYS) Campaign implementation plan which was an aggressive plan aimed at conducting a door-to-door country-wide campaign around HIV testing. By this time, more and more people came into the open and declared their HIV status, and more and more community-based HIV interventions such as home-based care groups mainly women

volunteered to care for the other community members, and organizations of people living with HIV and AIDS were formed and supported by organizations such as UNAIDS, Southern Africa AIDS Dissemination Service (SAFAIDS), and the Global Fund etc.

The fourth intervention was the decentralized approach which saw the first local government election in which women were given a 30 percent representation in the democratization process at the local level. The local structures were mandated by the gateway approach, to coordinate at the local level, all HIV and AIDS related interventions including to ensure that the KYS campaign was being conducted at the community levels. The presence of more women in local government was therefore expected to assist in encouraging women to come forward for testing.

The second multi-sectoral HIV and AIDS Strategic Plan 2006 – 2011, was developed, charting the way forward for all stakeholders to implement programmes and projects. Alongside the plan, was the HIV and AIDS policy which provided a framework for each role player in the guidelines for implementation of HIV and AIDS interventions (NAC, 2006).

The result of these major structural interventions alluded to above, was that a large number of Basotho flocked into the testing centres to know their HIV status. The Government expanded testing services to the communities by providing HIV and AIDS trainings to community members on testing and counseling. A new category of personnel was established (Lay Counselors) which served as a community-based wing of the Ministry of Health to expand community-based HIV testing.

At the inception of the initiative, only four ART centres were established, but by the end of 2009, there were 107 operational ART centres country-wide. Since more and more people were beginning to require treatment, treatment was rolled out nation-wide with upgrading of health centres as well as accreditation of such centres to provide antiretroviral treatment. By the end of 2010, there were 80 695 people enrolled for ART (representing only 36 percent of the total ART

needs). The country had thus enrolled approximately 36 percent of people who were in need of ARVs by 2010 (NAC, 2011, p. 40).

In 2009, the Lesotho Government conducted a comparative study to assess the HIV situation in the country. The study looked at the knowledge, attitudes and practices of civilians towards HIV. Additionally statistics were compiled and findings revealed that HIV prevalence rate had decreased to 23 percent, representing a reduction of 0.2 percent from the 2004 prevalence. This was due in part to the HIV and AIDS knowledge, attitude and behaviours that were beginning to play a role (as referred to in the study mentioned above). Other findings included the following:

- The annual incidence rate fell to 2.1 (annual infection rate).
- The annual new infections totaled 18,000.
- The number of people on Antiretroviral treatment was 97 000.
- The AIDS-related deaths constituted 60 people per day.
- The AIDS –related orphans amounted to 127 000.

Source: Ministry of Health, 2009

In 2016 the Government adopted the “test and treat” approach, which was aimed at accelerating efforts to halt and reverse the HIV epidemic, by providing HIV treatment to every person living with HIV and AIDS, as soon as they knew their status, irrespective of their CD4 cell count (Lesotho Government 2016). The objective of the 5th edition guidelines for HIV and AIDS care and treatment, was to provide the best care possible in order to reduce the morbidity and mortality burden that is caused by HIV and to halt further transmission of HIV.

At the time of development of these guidelines, the HIV statistics for Lesotho stood as follows:

Table 1.2 HIV and AIDS Statistics for Lesotho in 2014

Indicator	2014
HIV prevalence	23 percent
New HIV infections	52 per day
Number of people living with HIV	319 000
Of which are children	19 000
AIDS related deaths	26 people per day
HIV positive pregnant women	25.9 percent

Source: (Lesotho Government 2016)

Comparing these 2014 statistics with those of 2009, the study notes that ART country-wide roll-out improved the lives of the people. The daily number of AIDS-related deaths decreased from 60 to 26 and the HIV prevalence seemed to have slightly reduced by 0.2 percentage points from the 2004 statistics.

1.7 Positioning Lesotho women within the epidemic

Women in Lesotho are no exception to the general HIV statistics within sub-Saharan Africa (as I have outlined in the previous sections). They constitute 55 percent of the national HIV prevalence rate. The high rates of infection among women are attributed to factors already discussed (social, legal, biological and economic conditions). These conditions take on a character shaped by the Lesotho context, as I explain below.

Social issues: The Basotho community has deep-rooted cultural traditions especially when it pertains to marriage. In the Sesotho culture, a woman gets married to her husband's family to "serve and uphold" the values of the entire household and its extended family. Unlike in western culture, where a wife is married to her "husband," the Sesotho culture absorbs her into the extended family mainstay. It would be expected that she would transform in terms of identity,

hence she is given new marital names and is expected to identify with those names. Matobo and Makoae, (2001, pp. 133- 159) confirm this statement by explaining the cultural practices as far as management of family resources are handled. They posit that the wife manages domestic intra-familial activities, while the husband manages the inter-household activities since he is the household head. Likewise, decision making and implementation are determined by the nature of the activity. Furthermore, they state that gender relations are viewed as being more important than educational relations. They put it thus:

...the level of education of the wife at intra household level tends not to be a major determining factor of how decisions would be implemented. The level of education of the husband shapes the level at which decisions would be implemented (Matobo & Makoae, 2001, p. 133).

This statement indicates that the decision-making function within a household is bestowed upon the husband, or simply put: what the husband says, goes. With regard to the issue of multiple and concurrent sexual partners, the Modes of Transmission (MOT) study conducted in 2009 revealed that in Lesotho on average, a man had more than seven sexual partners within a period of 12 months, while a woman had only two to three sexual partners in a 12 month period. The resulting sexual web of relationships puts women at most risk of HIV infection (World Bank, 2009).

The legal status of women in Lesotho

Prior to enactment of Married Persons Capacity Bill in 2007, women in Lesotho were regarded as perpetual minors with no rights in their own lives. It is improper for a woman to deny her husband sex even if she suspects that the husband may not be faithful. Society shuns a wife who denies the husband sex or even proposes condom use, and she may even have reason to fear for her own life. While there are legal instruments available such as the Sexual Offences Act of 2003 (Government of Lesotho, 2003), the reporting of sexual offences by women was very minimal or almost non-existent. Since the wife was controlled wholly by her husband's household, reporting of coerced sexual activity would be simply reflected as ill-mannered behaviour on the

part of the wife. Thus, despite some changes in legislation, women still remain culturally subservient in the context of marriage.

Economic participation: Because of a women's legal status being akin to that of a minor, women were not legally allowed to make decisions pertaining to themselves and their households. They were not allowed to enter into any contract. They could not be an executor for a deceased estate, even if it were their own husband's. They could not be engaged in highly paid employment such as being a director of a company, or to act as a trustee of an estate (Nedbank Lesotho 2007). In terms of taking part in economic productivity, such as taking care of livestock and ensuring food security in the absence of her spouse, who in most cases would be working in the South African mines away from the homestead, a woman was given some powers to manage a household economy at that level but this was limited to food production and did not stretch to being able to decide on the sale or otherwise of livestock and or grain from the harvest, without approval from the husband.

1.8 The current situation

In 2007, the Government enacted a bill which gave women decision making powers which are almost on par with their husbands. This was the Legal Capacity of Married Persons Act no. 9 of 2006, which paved the way to empowering women to undertake meaningful participation in economic, social and legal matters. The act repealed all laws that were otherwise prohibiting women from enjoying equal benefits with their male counterparts. It effectively abolished the minority status of married women. This meant that women are now legally entitled to own land in their own names, to be sued and to sue, and to register immovable property in their own names (Government of Lesotho Gazette, 2006).

In order to protect women, the Government enacted the Sexual Offences Act of 2003, which gives women authority and control over their sexual lives (Government of Lesotho Gazette

2003). This came about as a result of evident incidences of rape in the household wherein a husband would coerce his wife into sleeping with him whenever and in whichever way the husband wanted. In most cases, this meant demanding unprotected sex despite knowledge that he may be HIV infected and or was suspected to have or was even being treated for sexually transmitted infections. The act has created opportunities for the reporting of rape cases to legal authorities where the victim could either sue the perpetrator or request for post exposure prophylaxis (PEP) to be administered in case of HIV infections. In spite of this, very few women come forth to report incidences of sexual assault by their spouses (Government 2003).

1.9 Child bearing as a societal expectation

It is not only an African society's expectation for women to bear children, but rather a global expectation for a married woman or any women of a child bearing age, to have children – married or unmarried, but the practice seems however more prevalent in Africa (Marcellin, Boyer, Protopopescu, Dia & Ongolo-Zogo, 2011). Even in the era of HIV and AIDS, that expectation still holds. Every married couple not only develops a desire to have children, but often find themselves pressurized by circumstances and societal expectations to have children. In Lesotho for instance, payment of dowry signals the expectation for child-bearing in the husband's family. This is verbally communicated by the groom's family even during the wedding reception. In addition, some clans or cultures delay naming the newly-wed women.. This woman will only acquire her new name after she has given birth. The act of naming a newly-wed woman signifies a welcome and a complete socialization into her new home. In the event where child bearing is not possible or somewhat delayed, a lot of pressure is put on the couple and the man may be shunned by others for being impotent, likewise the woman may be looked at as a disgrace to the family. In a study conducted in South Africa relating to the desire to have a child among infected women on ART, Cooper, Haris, Myer, et al., (2007, pp 274-283) confirm this growing desire for women to have a child. There is a social context which considers motherhood as a

cornerstone of a woman's identity. It is not surprising therefore to notice growing numbers of pregnant women who enroll in Prevention of Mother-to-Child Transmission of HIV (PMTCT).

1.10 Women on Antiretroviral Treatment

This section now looks at women who are already taking HIV treatment and are at child bearing age. It discusses the biomedical and social challenges that they face. Lesotho rolled out HIV treatment in 2004 and earlier treatment for PMTCT in 2002. Prior to treatment enrolment, as has been explained in the previous sections, HIV was associated with stigma and discrimination. Due to these factors most people hid their HIV positive status and continued with their reproductive health as if everything were normal, but later on, when the illness took its toll on them, they died leaving behind orphaned children.

Life-long treatment seemed a mammoth undertaking for patients who were to be enrolled. The fact that the identified threshold for treatment was a CD4 cell count of 250/mml and below, meant that people were enrolled at very late stages in the infection and often times lost their lives. This created fear among patients because they then believed that even with treatment, people still died. The 2008 revised ART guidelines (WHO, 2008) increased the threshold to 350/mml which then enabled patients to be put on treatment while they were still not too sickly, which enabled them to respond more positively to treatment. The primary requirement was that they adhered to the ARV treatment regimen.

Adherence to ARVs: Issues of adherence meant that women experienced challenges such as travelling long distances to the drug collection centres (with only 107 country-wide); most consumers are poor people who may not be able to afford the transport costs. Part of the known reason for non- adherence therefore, was found to be lack of funds to pay for transportation to the health centres on the scheduled dates. Other reasons included the fact that people sometimes have to move around the country as a result of work-related migration requirements and the

complexities around treatment intake such as the acute side effects of the treatment that demotivate the patient from continuing treatment. Other problems concern the packaging and storage of some drugs, and difficulties of adherence to the prescription requirements, such as avoidance of certain foods while taking a particular drug. Genberg, Lee, Rogers and Wilson in their study on four types of barriers to adherence to ART, classify them under “problems with schedule and routine” (PSR) (Genberg et al., 2015 and Field, 2015). There are also myths and misconceptions around treatment such as the assumption that certain herbs that are purported to “boost” the immune system, could be taken instead of the prescribed medication.

...because many patients turn to so-called complementary or alternative therapies, it is important for health care providers to complete medication history, including over-the-counter drugs and nutritional supplements.... (Pham & Barditch-Crovo, 2000, p. 396).

It is against this background, that the study seeks a deeper understanding of how women living with HIV who already take ART are coping in the midst of all these challenges. A major aspect of this coping process, is the learning changes that take place amongst the women as they acquire new understandings and strategies.

1.11 The Problem Statement

Women in African countries, including Lesotho, suffer gender discrimination and unequal power relations, particularly in relation to HIV and AIDS-related issues. Evidence from outside of Lesotho suggests that women have adopted coping strategies in response to their HIV status and circumstances. However, no study has ever been conducted in Lesotho to find out the nature of those coping strategies and the associated forms and processes of learning. There is thus a lacuna in the scholarship regarding the kind of learning processes that women who are on ART at child-bearing age go through, to enable them to cope. But looking at the complexities of a life-long treatment of this nature, which undoubtedly disrupts the day-to-day activities of these young

women, whom society still expects to lead normal child bearing functions, it can be assumed that women's survival in these challenging conditions may involve transformative learning.

1.12 Research questions

To get to the core of the study, I developed these research questions which I used throughout the data collection and chapters on analysis, to explore the coping strategies that the women adopt in relation to their HIV and AIDS condition. These four questions have been enveloped in one overarching question which formed the gist of this study. The key question therefore was:

1. What coping mechanisms do Basotho women living with HIV and AIDS devise to address social, medical and cultural perceptions and pressures related to HIV infection?
 - a) What learning experiences do women of child bearing age go through regarding antiretroviral therapy and societal pressures in relation to child bearing?
 - b) How does that learning manifest itself at different stages of the coping process?
 - c) To what extent do they experience transformative learning? What are the coping mechanisms that women adopt as a result of any transformative learning?
 - d) What can we learn from these learning experiences that can assist us in educating or supporting other women embarking on ART?

The next part looks at how the study has been structured.

1.13 Theoretical frames

The most appropriate theories that inform this study are the feminist approaches, the transformative learning and communities of practice; all of which are dealt with in-depth in Chapter Three (Theoretical Framework).

The next section provides a synopsis of the theories to enable the reader to appreciate the relevance of them with regard to the study in general, and to this chapter in particular.

Feminist approaches as developed and modified by many scholars, denote a conception of relations between men and women in a society; with an approach aimed at establishing equal rights between men and women, an ideology about resistance to the invisibility and silencing that leads to the oppression of women (Meena, 1992; Zalewski, 2000; Tuyizera, 2007; and Tallis, 2012). This family of approaches is particularly relevant to this study because of the focus on women and HIV and AIDS in the context of gender oppression.

Transformative learning theory originates from Paulo Freire's articulation of the theory of adult learning, whereby he saw learning as a phenomenon that brings about social change. Building on this notion, Jack Mezirow, the chief architect of the transformative learning theory, developed this theory in 1978, with a primary focus on the critical dimensions of learning in adulthood, that enable adults to recognize, reassess and modify their structure of assumptions and expectations (Mezirow, 1978, 1991, and 1997). The theory has further been developed and refined by many scholars such as Cranton, (2006); Taylor, (2009); and Ntseane, (2011).

Communities of practice theory focuses on how people learn through their regular interaction in informal settings, in their quest to refine their practice. Developed by its chief architect Etienne Wenger, the theory's key tenet is engagement in social practice which is seen as the fundamental process by which people learn, and so, become who they are (Wenger & Lave, 1991 and Wenger, 1998).

Part Two - The Methodological Structure of the Study

1.14 Methodology

This study uses a single case study methodology within an interpretivist paradigm. The study sets out to critically narrate, analyse and theorise the learning, identity development and meaning making of Basotho women of child bearing age who are living with HIV as they interact,

participate and acquire new identities, as well as to make meaning of their HIV and AIDS condition. As I indicated at the beginning of the chapter, the purpose of this study is to explore the coping strategies of Basotho women of child bearing age who are living with HIV and already taking antiretroviral treatment.

The unit of analysis for this case study is a group of women of child bearing age who are members of the Phelisanang Bophelong Association (PBA) in the Leribe district. Data collection included self-administered questionnaire answered by 12 of the participants, 13 in-depth one-on one interviews, and focus group discussions with eight of the participants and three of the programme management staff of the (PBA). A detailed description of the entire design and methodology forms the gist of the discussions in Chapter Three.

1.15 Motivation for this study

This case study is important as it documents the stories of Basotho women who are living with HIV and AIDS, their life experiences with HIV and AIDS – how it impacted on their lives and relations with their families and the communities. The study aims to add value to the wealth of knowledge that exists on women with HIV and AIDS. Most research on ART has tended to focus on the biomedical aspects but very little is known about how the recipients of these drugs cope as social beings in their own environments.

It is worth mentioning that a study of this nature has not been conducted in Lesotho, as far as I have ascertained. Since this will therefore be the first case study of its kind conducted in the country, it will be a reference point in the future for those working with women going through a similar situation with their HIV positive diagnosis and for further studies on the topic.

Another motivation for the study stems from my previous job as an HIV and AIDS District Coordinator from 2007 to 2011 in Leribe. My extensive encounter with the PBA which, apart

from being in a series of HIV and AIDS technical meetings with them, I was also providing strategic direction on the management of HIV and AIDS programmes to the PBA. This experience illuminated my interest in further investigating the coping strategies and forms and processes of learning of these women, for my doctoral studies.

1.16 Scope of the study

This study is located within the adult education field. It is informed by many disciplines such as psychology, sociology and history. It explores how adults (women) learn to cope with situations that require drastic changes in their lives. This study focuses on women living with HIV and AIDS who are of child bearing age in the Leribe district who are members of the PBA – a non-governmental organization of men and women who are openly living with HIV and AIDS. There is an association of this population in the Leribe district. The association is funded through a United States Government (USG) HIV and AIDS funding window (compact) referred to as PACT that has the aim of building the capacity of its members to be HIV and AIDS competent. The study explores how much learning has taken place and whether this could be regarded as learning for change.

1.17 Outline of the chapters of this thesis

This thesis has been organized into eight chapters. Beginning with this chapter, which provides a background or framework upon which all the chapters evolve. While almost every chapter is backed with literature on most issues being discussed, the second chapter in particular, draws purely on relevant literature for the case study of Basotho women of child bearing age who are living with HIV and AIDS age and how they cope with this life threatening pandemic. The third chapter, discusses the theoretical framework that grounds the study. Chapter Four focuses on the design and methodology of the study. Chapters Five and Six present an analysis of the

narratives from the study participants. Chapter Seven looks at the findings in relation to the grounding theories of the study and the last chapter (Chapter Eight) wraps up all the narratives, and provides the researcher's reflections and conclusions.

Chapter Two: Literature Review

This chapter brings in scholarly views about a number of areas including HIV and AIDS and women; gender power relations, patriarchal system and how it impacts on the effective utilisation and accessibility of HIV and AIDS services. The other areas focused on are women's disclosure of their HIV positive status and the various reactions from their partners, children, in-laws, friends and communities to that disclosure. Scholarly reflections detailing the stigma and discrimination as distinct barriers to the effective utilization of HIV and AIDS services among women, and the reproductive needs of women as well as the societal expectation of young women, within the marital circles. The issues concerning processes of learning form part of the literature that this chapter reviews, in order to explore various forms of learning that the women go through.

Chapter Three: Theoretical framework

The study is grounded in three bodies of theory: feminist approaches; transformative learning; and communities of practice. Each of the three theories is discussed broadly in their individual sections. The first section looks at the four waves or approaches to feminism: how they evolved and the key tenets of each wave. It identifies which approach the study adopts and examines the women's ability to challenge the status quo of breaking the silence around HIV and AIDS. Part two examines the theory of transformative learning as proposed by Jack Mezirow in his 10-phase learning process and the reviews of his theory by other scholars such as Cranton, Taylor and Ntseane. Part three discusses communities of practice theory as developed and refined by Lave and Wenger.

Chapter Four: Research design and methodology

This chapter locates the study within a case study methodology that uses an interpretivist paradigm with the unit of analysis being a group of Basotho women belonging to PBA who are living with HIV and AIDS, and already taking HIV treatment. The data was collected through questionnaires, individual interviews and group discussions. The data was then analysed, using coding and thematic content analysis. Throughout the data collection process, ethical considerations were maintained.

Chapter Five: Taking a bold step

This chapter presents the first phase of analysis and theorization of the narratives. The discussion centres around the metaphor of ‘taking a bold step’ on HIV testing, HIV disclosure and reaction by partners, children, in-laws, friends and society. These two key processes within HIV and AIDS continuum are considered bold steps that the women took. Each step has been unpacked to reflect the bold step process.

Chapter Six: Picking up the pieces and moving on

This chapter is the second phase within the taking a bold step continuum. It looks at the women when they make informed choices of regaining and reclaiming their health; when they ‘pick up the pieces’ of their lives, after the life shattering news that they have been infected with HIV, by accessing treatment as well as joining the HIV and AIDS support groups to learn within the groups and thus transforming the communities’ perceptions about HIV infection.

Chapter Seven: Findings in relation to the theories

The chapter critically looks at the findings in chapters five and six and relates them to the study’s three theories of feminism, transformative learning and communities of practice.

Feminism: Key discussions centre around patriarchy, oppression, solidarity decision-making and partnership.

Transformative learning theory: Building on the 10-phase learning continuum as developed by Mezirow, the findings centre on identification of a disorienting dilemma, reflection and perspective transformation.

Communities of Practice Theory: Using the communities of practice lens, key findings are discussed along identity, participation, from periphery to centre, moving from novice to expert, meaning-making, and networking.

Chapter Eight: Conclusion and Next steps

This chapter provides various reflections within the case study, the research questions, reflections on the narratives and it ends with my reflections about the methodology-and what learning emerges from conducting this case study. It includes the various lessons that have been learnt, recommendations for the future on this topic and new areas discovered that require further research and finally the concluding comments about this particular case study.

Conclusion

The chapter sets the scene or a foundation for other chapters to follow. It looked at the general global HIV and AIDS situation first, narrowed matters down to Africa and in Southern Africa in particular with a focus on women. The HIV and AIDS situation in Lesotho, the study country, was explored and explained where Lesotho is, in terms of the HIV situation and the efforts made thus far to halt the spread of the epidemic. This chapter provided an overview of the case study design and methodology. The structure of the thesis and chapter summaries were also provided. The next chapter looks at what other scholars have written about women of child bearing age who are living with HIV and AIDS, their experiences, feelings and emotions in dealing with HIV and AIDS and their relations with their partners, family and society as a whole.

CHAPTER TWO: Literature Review

2.1 Introduction

A research project does not exist in isolation, but draws on the previous works that have been developed relating to similar topics (Kaniki, 2006, p. 19).

A literature review is a selection and critical review of documents that contain information, evidence or ideas written in relation to the nature of the topic being studied. It involves identification and analysis of information. Other scholars' views of related topics are pertinent in the presentation and analysis of the narratives. Therefore this chapter is crucial as it helps to uncover the essential parts of research bearing on the problem (Kaniki, 2006; Krathwohl, 2009; and Punch 2009).

Its purposes

Literature review as identified by Punch, (2009) serves a number of purposes. a) It describes current knowledge by bringing together and summarising the empirical evidence about the research questions - what Punch terms "research literature"; b) It assesses the overall state of knowledge on the topic and the state of research, the thinking and theorizing on the topic (theoretical literature); and, c) It locates a study in relation to literature. Krathwohl, (2009) describes the literature review as providing an overview of the area of the study as well as serving to find the important sources of information that support the study. Kaniki, (2006) too brings other perspectives which build up to the purposes of the literature review. These are to:

a) identify knowledge gaps and develop [the] research problem; b) identify a theoretical framework; c) identify issues and variables related to the research topic, d) identify conceptual and operational definitions as well as e) identify methodologies (Kaniki, 2006, p. 22).

The literature review therefore serves as a signpost that directs the research study.

This chapter looks into other scholars' perspectives in relation to the topic of women who are living with HIV and AIDS and how they cope with their HIV positive condition. The literature review covers the following areas: a) gender relations and how they impact on women's decision-making powers on issues of sexuality; b) HIV prevention; c) HIV testing; d) HIV disclosure and

the subsequent reaction/s from partners, children, in-laws and friends; e) treatment enrolment; and f) adult learning both as individuals and in groups. The chapter concludes by summing up each of the perspectives in relation to the study.

2.2 Gender relations

Defining gender as a social relational phenomenon, Scott in Tuyizera, (2007), perceives it as “differences between the sexes and as a primary way of signifying relationships of power” (Tuyizera, 2007, p.130). The experiences of womanhood and manhood are inseparable from relations of power and domination. Pearson, Whitehead, and Young as cited by Tuyizera, (2007), refer to gender relations in terms of the general character of male-female relations within the household, in particular, those of male dominance and female subordination. In patriarchal society two main structural processes disempower women. These are:

assertions of male superiority based on their physical and intellectual ability, and the control exercised by men over the prime factors of production and economic factors (Tuyizera, 2007, p. 129).

This section adopts the two definitions of gender relations and presents scholarly perspectives of how gender relations ultimately render women vulnerable to adverse decision-making within the homestead.

In the traditional African context, the male figure is the one that dictates almost every activity that needs to happen within the homestead. He decides which house to build; when a wife must come home; what she should wear; who she talks to and what they talk about; how many children they should have; how children have to be spaced with respect to age gaps between children. He also chooses partners for their daughters and sons. The women’s role is to feed the family by growing crops, and to ensure that there is sufficient food for the family for the whole year. Sexuality is perceived as a site for women’s subordination. Through marriage, a woman’s

sexuality is placed under her husband's control for his pleasure and for patrilineal procreation (Lewis, 2008).

How male domination positions women at a disadvantage

In their document or framework for guiding the Lesotho Government on how best to respond to the escalating rates of HIV and AIDS, Kimaryo, Okpaku, Githuku-Shongwe, Feeney, (2004) highlighted that one of the underlying structural contexts of HIV and AIDS are power relations that exacerbate the spread of HIV and AIDS. They asserted that:

....even when they have the necessary information and knowledge, women often lack the power to determine when and with whom to have sex, let alone to insist that their sexual partner uses a condom (Kimaryo et al., 2004, p.51).

This assertion is supported by scholarly views which touch on the not so useful knowledge around HIV and AIDS that women may possess, which in material terms does not translate into any behavioural change within the homestead. This is evident in studies by Raffaelli and Suarez-Al-Adam, (1984); Ximena, Clara, Maziel and Caceres, (2009); and Tallis, (2012).

Looking at this power imbalance within the home setting, Apusigah, (2008) draws on its negative consequences for women, especially in home-based couple testing, in discordant couples, where the HIV-negative partner is usually the woman. In that setting and given the power imbalance that is skewed against the woman, she gets caught up between maintaining both her HIV negative status and saving her marriage. Due to fear of infection, women refuse to engage in unprotected sexual activities. This refusal often leads to intimate partner violence or to the man moving out of the home to look for other sexual partners to satisfy his desire, which further increases the woman's vulnerability.

The other contributing factor that Langen,(2005); and Tallis, (2012) draw attention to, is the age gap in marriages in the African setting, whereby a male partner is usually relatively older than

his female counterpart, thus further unbalancing the power relationship. This is particularly so within a patriarchal society where age and seniority are considered important in social life (Langen, 2005, p. 188). Muller, (2005) provides insights into early socialization of girls by their mothers, aunts and grandmothers whereby women are taught to be subordinate and to respect men's wishes. She therefore blames these practices and argues that they contribute towards making women subservient to men. These inequalities she posits, make it difficult for women to discuss and successfully negotiate safer sexual practices with their partners.

In addition, culture plays a role in shaping the passive behavior of women and girls during sexual encounters which mostly place between young women and older men (Muller, 2005, p.32). Some communities, Langen, (2005) opines, share the idea that at some level it is culturally acceptable for a husband to beat a wife or hit her when he is angry. If a man makes a woman angry, she must just apologise and has to respect the man. Building on this notion, Griffiths, (1997) highlights that in marriage relationships, men and women find themselves differentially situated regarding the kinds of claims they can make on one another as spouses. It is culturally acceptable for a man to directly address his wife's infidelity in the public sphere, but society considers a similar claim coming from a wife as inappropriate conduct. Views expressed from Mozambique on gender and sexuality opine that if there is that behaviour coming from the man, the wise thing for a woman to do will be to wait until the bedroom privacy, and to settle the matter through seduction, not confrontation. Arnfred puts it thus:

...if your husband does something you do not like, then make love to him, prepare him a nice meal. The next day he will say you are "his mother" which means he will pay you respect, and follow your lead (Arnfred, 2011, p. 139).

In the case where the husband neglects to provide for his family, Arnfred, (2011) proposes that this issue be raised in an indirect manner. A woman therefore is not culturally allowed to question or request compensation or material support from her partner (contrary to her

husband). The marriage attributes certain characteristics as forming or making a good wife.

These include:

...she who always attends to her man regardless of when he came/returned home or where he has been; she who always prepares food for him; washes his clothes and works hard to develop their household. The only time she is allowed to lodge a complaint about his sexual affairs with other women is when the husband neglects her or their children. On the contrary, societal perceptions of a good husband is: he who may have sexual affairs outside of his home, as long as he does not ill-treat, neglect or fail to support his family; he who does not leave his wife or live apart from her without cause; and he who does not use her household property to support another woman (Arnfred, 2011, p. 140).

These factors that support male infidelity outside the home have a negative impact on the economic and social conditions of women as well as their ability to make informed decisions about their lives as well as their health. The section below looks at the literature on HIV prevention as an entry point towards an effective fight against HIV and AIDS.

2.3 HIV Prevention

As my study is situated within the coping strategies for women living with HIV and AIDS, HIV prevention is the critical step towards ensuring better health and easy access to health services by people. As I indicated in Chapter One, the global HIV and AIDS prevalence in general, but in southern Africa in particular, shows that women are the section of the population that are hit very hard by HIV transmission, given their position of gender-vulnerability (as explained in the previous section). It is imperative for these countries that are greatly affected by the pandemic to develop programmes and policies that place emphasis on the prevention of HIV and the spread of AIDS, in order to sustain the lives of the people.

The HIV prevention efforts that the country adopted since 2000 include the ABC strategy, the KYS approach and now the newly launched HIV prevention approach that the

Government of Lesotho has adopted called “the test and treat” approach. This treatment as a prevention initiative or approach is believed to be an effective tool that has a 93 percent reduction of HIV transmission among sero discordant couples when the HIV positive partner was on antiretroviral treatment (Lesotho Government Report, 2016). Preventing new HIV infections is critical to controlling the HIV epidemic. Providing HIV testing services in health facilities and communities is essential for identifying people who are HIV negative and providing them with the appropriate education, counselling and prevention strategies to help them stay negative. Treating people living with HIV with life-long ART to prevent new HIV infections, has emerged as a powerful additional prevention tool benefiting people of all ages. Through this treatment-as-prevention approach, it is believed that a 100 percent prevention of new HIV infections is possible when the viral load of the HIV positive partner is fully suppressed by ART. This was explained as follows:

...this intervention is effective regardless of the route of HIV exposure (vaginal, rectal, or percutaneous) and patient group (heterosexual men and women, homosexual men and women, transgender persons, commercial sex workers and people who inject drugs)... (Lesotho Government Report 2016, p. 3).

The approach carries similar prevention components to what Harrison, (2014) terms “state of the art” approach to HIV prevention which touches on a broad spectrum of social, behavioural and bi-medical matters.

In the social context, Harrison suggests male involvement in HIV and AIDS prevention interventions. She argues that males constitute the “forgotten fifty percent” of the population (Harrison, 2014, p.19) and are often neglected in discussion of gender and sexual and reproductive health. She stresses the importance of these areas as she sees them as not only improving men’s individual health, but also as bettering health outcomes for women. She terms this a gender-transformative approach. Her view is supported by Gqola, (2008) who argues that the reduction of gender-based violence should form part of HIV prevention

programmes. Gender-based violence is directly relevant to the HIV risk of young women who often experience trauma of forced sex of any kind – rape, dry sex or lack of readiness – with an infected partner. The fear and power differentials associated with gender-based violence, increase gender inequalities and are important causes of the inability of those affected by gender-based violence to make and implement prevention decisions.

Uganda on the one hand uses creative art as an HIV prevention strategy. As a social practice in the African context, creative art has a transformative potential because of its ability to enable marginalised people to express their opinion and thus generate their capacities for their concerns to be heard and addressed. Eze, (2008) does allude to the fact that in the majority of cases HIV and AIDS affects people who are hardest to reach, therefore she advises on the use of print, broadcast medium channels, music, drama, horns, village criers and story tellers as effective channels for disseminating messages in rural societies, where the communication by the population tends to be predominantly oral.

Malawi on the other hand, uses grandmothers (Agogos) as a strategy for HIV prevention among adolescent girls, who they prepare for motherhood. The Agogos are being capacitated by the health professionals and serve as additional health education agents to communicate HIV prevention messages to the adolescent girls to prevent unintended pregnancies (Osha, 2008).

Within the behavioural context, the interventions include use of family planning by women living with HIV and AIDS as it prevents transmission of HIV to the unborn babies and at the same time being used as a protection among uninfected women to prevent both HIV and pregnancy. Harrison, (2014) also highlights the importance of adolescent HIV prevention and sexuality education at both schools and non-school settings.

The biomedical HIV prevention includes interventions such as treatment-as-prevention e.g. pre-exposure prophylaxis² (PrEP), post-exposure prophylaxis (PEP) and microbicides. As alluded to above, PrEP provides maximum benefits at both individual and population levels. For these benefits to be realised PrEP needs to be combined with other effective prevention interventions. Chin-Chi and Benaya, (2008) and Harrison, (2014) assert that effectiveness of this intervention needs to incorporate the women's daily lives which may include a desire for pregnancy or, even a desire to prevent pregnancy. This tallies with what the Government of Lesotho proposes for PrEP effectiveness, where the focus is on preventing HIV infection in women, preventing unintended pregnancies among women with HIV, preventing vertical transmission of HIV from mothers to their infants during pregnancy, delivery and breastfeeding, and providing care, treatment, and support for mothers with HIV and their children (Lesotho Government Report, 2016). Harrison, (2014) suggests multi-purpose prevention technologies (MPT) which includes vaginal gels with HIV prevention and contraceptive properties, as well as the need to situate women's HIV prevention in a broader reproductive health context.

General HIV prevention methods include knowing one's HIV status, condom and lubricant education and provision, risk reduction counselling and diagnosis and treatment of sexually transmitted infections. Risk reduction messages need to focus on encouraging abstinence, avoiding having multiple concurrent sexual partners for individuals who are sexually active, as well as correct and regular use of condoms for sexual intercourse whether vaginal, anal and oral (Lesotho Government Report, 2016).

²Antiretroviral medication in which HIV uninfected persons with on-going HIV risk use to reduce their risk of acquiring HIV infection

The next section now looks at what scholars say about HIV testing.

2.4 HIV Testing

HIV testing is an important entry level requirement to help assist with HIV transmission prevention and treatment efforts by the infected. It is a dynamic process which consists of inter-related elements. These are a) making a decision to be tested, b) accessing testing services, c) testing and d) waiting for the results. Key considerations within the testing continuum includes HIV pre-test and post-test counselling processes which are integral components of most national HIV and AIDS prevention strategies in Southern Africa (Badejo, 1998). In a study conducted with clients who were returning for counselling after HIV testing, Kalabamu, (2006) discovered that pre-test and post-test counselling have become standard components of HIV antibody testing and, when effectively conducted, they enhance uptake of HIV services such as enrolment into HIV care and treatment in the case of HIV positive condition. While HIV testing is voluntary, there are a number of factors that prompt individuals to take an HIV test. These are pre-exposure due to occupational reasons, provider-initiated (usually recommended by doctors/medical personnel for further inquiries into a patient's ailment) and through prevention of mother-to-child transmission programmes (PMTCT) for pregnant mothers, and for sexually assaulted people (Lesotho Government Report, 2014).

2.5 Equity in testing

Equity in testing entails “people at higher risk of HIV infection such as women who do not use condoms regularly, or those with multiple partners, or those who suffered gender based violence as well as those who are unable to implement prevention choices” (Mitchell, Cockcraft, Lamothe et al, 2010, p. 1). A study conducted in Southern African countries by Badejo, (1998), which

assessed whether there was a desire to undertake an HIV test among the group that has been categorised above, revealed that none of the associated groups ever wanted to test for HIV. Relating testing to gender, Badejo, (1998) pointed to the fact that in the six out of ten countries studied, women seemed the majority of people who sought testing for HIV. Some of the explanations given for women's testing include their enrolment into antenatal care and PMTCT programmes. They noted, however, that even when antenatal HIV testing is done under a routine opt-out system, not all women get tested and not all return for their test result. These findings are echoed by Dirkx, (2012) in their study of men's involvement in HIV testing, treatment and care in sub-Saharan Africa where they noted that men were significantly underrepresented in HIV and AIDS testing and treatment services. The men's increased perceptions of masculinity explained as male gender norms associated with toughness and control, and sexual power as a way of asserting manhood, could act as barriers for men preventing them seeking HIV care and support even in times of vulnerability and ill health (Reardon & Govender, Bila & Ergot as cited by Dirkx, 2012).

Factors that prompt people to get tested

People who perceive themselves to be at risk of HIV and who have knowledge about available HIV treatment options are more likely to intend to be tested. Badejo, (1998) also discovered that in the ten studied Southern African countries (Botswana, Lesotho, Malawi, Mozambique, Namibia, South Africa, Swaziland, Tanzania, Zambia and Zimbabwe), people who had talked to others about HIV or received information from clinics or health centres, were more likely to have been tested. Mitchell, Finkelhor, Jones and Wolak, (2012) also indicate that the ability to talk about and discuss HIV and AIDS is associated with HIV testing. These assertions are made based on the examples of Uganda and South Africa where conversations about HIV were reported.

Barriers to HIV testing

Based on a study conducted in Europe, Bandura, (1997) identified the following barriers to HIV testing: a) low risk perception in which participants in the study held the feeling that black Africans were the ones who were at risk of infection and not them; b) fear of dying; c) worries about confidentiality; and d) concerns about entitlement to medical care. Comparing these barriers to the African settings, the key barriers in the African context are the issues of stigma and discrimination that are associated with testing, along with the inherent fear of a positive result (Strauss, Rhodes, & George, 2015). The next critical step after HIV testing, is the disclosure of the HIV status whether it be a negative or a positive result. The next section looks at disclosure and the reactions to an HIV positive test result. I have located this case study within the patriarchal system. It is befitting therefore to look at what the literatures says about disclosure to partners and the reactions by partners, children, in-laws, friends and the community, to the outcome of the results.

2.6 HIV and AIDS Disclosure

The disclosure of HIV positive status is important for coping with the disease and understanding the circumstances surrounding it. It is equally critical both in preventing HIV and mitigating its impact (Varga, Sherman & Jones, 2006). These scholars identify four forms of disclosure. These are voluntary, involuntary, direct and proxy disclosure. Each of the forms are described thus:

...voluntary disclosure denotes divulging one's HIV status through a decision made without coercion whereby an individual is in control of when, how and to whom disclosure takes place. Involuntary disclosure is a situation where HIV status is revealed without the individual's consent. Direct disclosure refers to a situation where an individual does a straightforward divulging of their HIV status. Proxy disclosure is when an action or association directly suggests one's HIV status without it being openly articulated (Varga et al., 2006, p.952).

The following sub-sections will look at scholarly views of disclosure as they relate to the partner, children, in-laws and friends, as it is believed they form an important part of the socially close-knit African setting.

Disclosure to partner

Disclosure is considered critical for carrying out fertility intentions and preventing HIV transmission, as well as reducing risk behaviours, and increasing adherence to medication. In addition, disclosure serves as motivating a partner to go for voluntary counselling and testing. These views are expressed by Zamudio-Haas et al., (2012) as well as Houwer, Barnes-Holmes, and Moors (2013). At the same time, the disclosure of HIV positive test results to one's sexual partner, however, may pose a challenge, particularly if the anticipated reaction of the recipient is negative. Furthering this view Monsin, (2012), Tallis, (2012) and Zamudio-Haas, Mudekunye-Mahaka, Lambdin, et al., (2012) mention the factors that can exacerbate this challenge. These factors range from the fear of being rejected and/or being accused of bringing the virus into the home; stigma, unstable relationships, verbal abuse and harassment. Other scholars add the element of fear of becoming divorced or separated (Baumgartner, 2003; Maman, Mbwambo, Hogan, et al., 2003; Ostrom, Serovich, Lim & Mason, 2006; and Obiri-Yeboah, Amoaka-Sakyi, Baidoo, et al., 2015).

Deribe, (2008), notwithstanding, stresses the importance of disclosing one's HIV positive status, highlighting its benefits such as that:

- a) it allows the partner to engage in preventive behaviours; b) it enables access of necessary support for coping with a seropositive status or illness; and c) it motivates partners to seek testing or to change sexual behaviour, in a way that ultimately decreases the transmission of HIV (Deribe, 2008, p.1).

Building on the views as expressed by Deribe, (2008), Obiri-Yeboah, et al., (2015) brings in the element of ensuring adherence of clinical care and ARV therapy by the infected partner. In addition, Elope, Westfal, Mugavero, Zinski, et al., (2016), in their study to establish the level of adherence to ART at a clinical level for disclosed and non-disclosed patients, identified benefits of disclosure as facilitating a patient's ability to deal with the initial confusion and despair and also to prepare for emotional and practical support received from the family, when one discloses one's HIV positive status to them.

In trying to ameliorate this fear that exists about partner disclosure especially in the case of women, Obiri-Yeboah et al., (2015) identify strategies and procedures for disclosing, suggesting the use of health facilities as settings and peer counsellors as semi-professional structures that assist with the disclosure process.

In spite of the fears that have been mentioned above, the research supports the notion of disclosure of one's HIV positive status to one's partners for gaining the aforementioned identified benefits. There is another level of disclosure that is key within familial relationships. That is when making disclosures to children. The section below reviews scholarship on disclosure to children.

Disclosure to children

Disclosure of HIV positive status to children has attracted debates around two key issues. The first issue is concerned with the appropriate age of the child when disclosure needs to take place, and the second issue is whether or not disclosure should even be done by the parent to their children. I have divided this section into these two issues and have identified research that looks at each of the views.

Debates about appropriate age for disclosure to children: The following scholars, Pope and May, (1995); Lachman, (1997); Marshal, (2005); Kennedy, Cowgill, Bogart et al., (2010); and Houwer, Barnes-Holmes and Moors, (2013), provide options for mothers to decide when; and at what age and how they will disclose their illness to their children. They do acknowledge however the complexities and challenges of disclosure to children. In addition they acknowledge that the parents' fear that comes with disclosure (the psychological burden of shock and stigma) may make it difficult for children to bear but do stress the need for parents to disclose their HIV status to their children, in spite of this.

In terms of age, the child's level of understanding and maturity level were found to be key considerations. In a study conducted by Gachanja, Burkholder and Ferraro, (2014) about the age for disclosure, parents expressed that children developed and matured differently, thus the decision to fully disclose, needs to be assessed on an individual basis. In terms of age, parents suggested a minimum of five years of age and above, as the appropriate age at which disclosure can begin to happen. The reasons the parents give for this range from the realisation that while disclosure to a child was important, it should be done in stages to enable children to absorb the news, with less negative impact, and in that way they will not forget what they have been told.

Another key debate in this section is whether children need to be informed of their parents' HIV positive status. Several scholars emphasise the need for parents to disclose their HIV positive status to their children. For instance Murphy, Roberts and Hoffman, (2003); Tompkins, (2007); Kennedy et al. (2010); and Gachanja et al., (2014) are in agreement that children need to be informed about their mothers HIV positive condition. They provide various reasons for disclosure. Some of the many pathways through which a child can learn that his/her parent is HIV positive are from a member of the family or a non-family social network or through observing behaviours and symptoms that indicate a serious health problem with the parent. If a child knows his/her parent's HIV status, in that way, there are high possibilities of mistrust between a mother/parent and a child. Murphy et al. (2003) put emphasis on the need for parents to disclose their HIV positive status. Talking about the possible dangers of delayed or lack of disclosure, they opine that, while it may stay as a secret, it will be for a limited duration as:

...children may guess the secret or it might be revealed by someone else or might reveal it in a moment of stress, which would deprive mothers the opportunity to plan their disclosure to make its delivery as supportive as possible (Murphy et al., 2003, p.308).

Tompkins, (2007) in stressing on the importance of disclosure to children, indicates that it not only decreases parental distress associated with keeping a secret and hiding health seeking behaviour; it also decreases distress in children, related to living with an unnamed illness, and it also improves communication. He, however, cautions about factors such as the age of a child; the child-parent relationship and the general cultural influences such as how the child relates to other family members – how informed the child is about HIV and AIDS lest he/she reacts in a negative manner towards the infected mother. These factors, Tompkins, (2007) highlights as key prior to HIV disclosure.

Tompkins, (2007) presented his views about parental disclosure to children and he identified the close connection between the disclosure and social class structures. The lower the social class of the mother, the more likely Tompkins, (2007) claims, that the mother will disclose their HIV positive status. He established this linkage himself basing it on the practical limitations of the lower social classes, such as the lack of privacy and inadequate child care; arguing therefore, that parents may feel more obliged to share their HIV positive status with their children. Tompkins indicated that women seem to be more comfortable disclosing the status to their daughters, than to their sons, and he attributes this preference to the fact that there are higher chances of reaping more benefits. One of those benefits is that daughters might take on an increased responsibility for attending to household chores when their mothers are ill.

Tompkins' assumption of disclosure is based on the notion that mothers may not be so concerned per se, about whether or not their HIV positive condition will remain a secret, all the mothers are concerned about is the provision of both the emotional as well as the instrumental support, so that they do not feel alienated by their HIV diagnosis.

Hayes, (2000) study about women's disclosure to their children revealed that women who disclosed did so for a number of reasons. Key among them were: a) wanting to be the ones sharing that information; b) the child's right to know; c) not wanting to keep it a secret; d) child maturity; e) as a way of demonstrating or soliciting emotional support; and f) to respond to some of the child's daily inquisitiveness about the mother's sickness.

Kennedy et al., (2010) further advised that as where disclosure seems a difficult process, parents need to find an appropriate person or professional who should make the disclosure on their behalf, as may be needed.

There is however a different view that has been expressed by Ostrom et al., (2006) in the study they conducted there where parents that felt that disclosure to the children was not appropriate. This was in keeping with the notion of as "carefree a childhood as possible, that is, not wanting the child to worry about the mother and not wanting the child to be hurt by the reactions of others" (Ostrom et al., 2006, p.62).

These views were expressed by mothers who experienced HIV-related stigma and who did not want their children to go through similar ordeals. For those who reported not having disclosed their seropositive status, the reasons advanced were that: a) mothers did not want to scare their children; b) they wanted their children to live a carefree life; c) the age of the child was a barrier; d) there was fear of the child becoming angry with the mother; e) fear of losing the respect of the child; f) fear of the child owning the diagnosis as their own and g) fear of the child not keeping it a secret.

This literature is relevant to my study, as most of the Women living with HIV and AIDS in this study have had children and have faced the question of "if, when and how" to disclose

their status to their children. Within the familial ambit, are the in-laws of the women whose views are pertinent in this case study. The literature about disclosure to them is relevant. The section below presents the scholarly views about the in-laws.

Disclosure to in-laws

Disclosure, as viewed by Zamudio-Haas et al., (2012) especially if negative reactions from the male marital partners are encountered, often includes the issue of disclosing the female marital partner's HIV status, to his family members. In their study conducted in Zimbabwe about the reactions of in-laws to an HIV positive daughter-in-law, some of the statements that the in-laws make to their sons were:

...how can you stay with a snake in your house? Leave her at the roundabout close to the taxi rank, she will figure out where to go... Zamudio-Haas et al., (2012, p.21).

UNAIDS collection of essays and reflections of women living and affected by HIV under the heading, "When health care becomes an act of violence", claims that women in Southern Africa (Namibia) reported incidences of trauma, physical abuse, stigmatisation and discrimination suffered at the hands of their in-laws, especially the mother in law (UNAIDS, 2014). The women reported that they were being accused by their mothers-in-law as 'witches', they are being shouted at and even being accused of bewitching their sons. WHO (2004, p. 19) however does make assertions on the importance of disclosure to the mother-in-law which they say is associated with increased social support, while a disclosure to father-in-law is more rare and generally occurs with disease progression. The issue of father-in-law becoming angry or withdrawing after disclosure is also mentioned as occurring. Having viewed scholarly views about disclosure and the reactions of the in-laws, this study now looks at disclosure and the reaction of friends.

Disclosure to friends

Disclosure to a friend is particularly influenced by the strength of social networks and the level of the relationship, at the time of disclosure. This view is expressed by Hult, Wrubel,

Branstrom, Acree and Maskowitz, (2011). Friends' support upon disclosure is witnessed by Lee, Harris, Harper and Ellen, (2015) in their study about HIV positive youth disclosure to their friends. The responses from the study pointed to the fact that friends and family members continue to socialise with HIV infected youth after disclosure. That level of acceptance of their status gave them a higher level of perceived social support.

The literature about disclosure to friends is relevant in this study as the women interacted with a number of people during their HIV positive journey of coping with their condition. Having reviewed scholars' perspectives about HIV positive status disclosure to various groups, the next section looks at what scholarship says about HIV treatment enrolment.

2.7 HIV Treatment Enrolment

Antiretroviral therapy (ART) is an intervention that is aimed at promoting quality of life as well as to prolong the lives of people living with HIV and AIDS. The HIV infection in resource-limited countries such as those of sub-Saharan Africa, has been identified as an international health care priority. The aim of antiretroviral treatment is to restore lost immune responses thus decreasing the risk of morbidity and mortality. The public health approach to scaling up ART is through the use of standardised and simplified treatment regimens which are consistent with international standards and appropriate to local settings. The use of antiretrovirals (ARVs) is also to prevent mother-to-child transmission of HIV (Mosha, Ledwaba, Ndugulile et al., 2014).

HIV treatment encompasses conducting of further laboratory tests to have a better understanding of how the HIV is affecting the immune system. There are two key mandatory tests to be taken prior to ART programme enrolment – the CD4 count and the viral load.

There could also be the need to do some drug resistance test to determine the best medication options for each person. The result of all of these tests will provide a baseline measurement for future tests (Meintjes, Black, Conradie, Fox et al., 2014). In their guidelines for adult initiation with regard to ARV therapy, Meintjes et al., (2014) provide holistic principles on ART initiation. Key among them are: a) the standard of care which emphasises the strict adherence to medication for maximum suppression of HIV, b) the available regimen in southern Africa, c) the indication for initiation on ART including the CD4 threshold, d) all investigations prior to starting ART, e) ART failure and f) indications for changing or switching to other regimens.

While the literature does not dwell extensively on the medical aspect of HIV treatment enrolment per se, it is worth noting all the available treatment regimens for southern African countries. These are the first regimen also known as the first line; the second line regimen or second line drugs are those given to patients when failure of first line regimen is noticed and the final level or the third line, which are drugs dispensed when the two other types fail to suppress the viral load as expressed by Woldemedhin and Wabe, (2012); Van Zyl, Liu, Claassen, Engelbrecht et al., (2013); Koigi, Ngayo, Khamadi, Ngugi et al., (2014); Meintjes et al., (2014); and Mosha et al., (2014). Depending on the outcome of the tests and general clinical appearance of an individual, the health care professionals may conduct some other tests such as complete blood count; the blood chemistry which will include liver and kidney function tests; tests for sexually transmitted infections; tests for hepatitis B, tuberculosis or toxoplasmosis; urinalysis for proteinuria and serum creatinine and calculation of creatinine clearance. These tests are done in order to assess the type of treatment regime suitable for a particular person.

Starting on HIV treatment

Meintjes et al., (2014) put emphasis on individual readiness as key towards effective uptake of HIV treatment. In their guidelines, considerations are given to health provider-client education about the benefits of ART; the importance of good adherence to AR; lists of all the possible side effects, including what to do and who to contact, if serious side effects occur; development of a personal treatment plan; issues of disclosure to partners and/or family members; encouraging patients/clients to join support groups or identification of treatment buddy, as well as provision of on-going counselling for the patients and his/her family members, and on-going education on reproductive health.

While these drugs are available for free in most countries (including the study country), there are still some costs that are associated with getting them. These costs include transport for regular visits to the hospitals or clinics. These visits range from at least once in three months, with laboratory monitoring every six months to once a year (Rosen & Fox, 2011; and Lesotho Government Report, 2016). While initially the CD4 cell count was a threshold for initiation to ART, there are recent developments within the HIV and AIDS treatment regime, whereby all persons who are tested and found HIV positive are immediately put on treatment. This initiative or approach is termed “test and treat” and was launched in Lesotho in June 2016 (Lesotho Government Report, 2016). This approach works hand in hand with other approaches such as the KYS, and various condom promotion campaigns. The test and treat approach, however, is believed to be an accelerated approach towards stabilisation and reduction of annual HIV new infections, which has since placed Lesotho at the second highest position within global HIV and AIDS prevalence rates (as mentioned in Chapter One). This ambitious approach is expected to contribute to the global commitment of attaining an AIDS free society by 2030 (UNAIDS, 2015).

Factors that undermine adherence to ART

In the event of a low income status, patients who are supposed to visit the clinics may end up not being regular visitors. Given that Lesotho is a poor country, this is especially pertinent to my study. Ngarina, Popenoe, Kilewo et al., (2013) noted the following barriers: a) decreased motivation especially if a woman is diagnosed during pregnancy, b) a feeling of hopelessness, c) overwhelming demands of everyday life such as having to carry treatment around every time one has to travel, d) having to set aside other activities whenever it is time to take medication, e) poverty and f) lack of empowerment. Another area identified by De Mossa et al., (2013) that negates adherence to treatment, is the element of not fully understanding the initial ARV education session. This deficit in understanding, they note, is very crucial for patients to overcome as it may promote adherence or create non-adherence to medication. As a result emphasis is placed on the issue of disclosure to family members, in order to get treatment support, as outlined by Meintjes, (2014) above.

Having reviewed scholarly writings about treatment enrolment, the next section looks at the research focusing on adult learning, as this forms part of the knowledge acquisition when it comes to HIV and AIDS.

2.8 Learning

This section looks holistically at learning. It views different forms of learning and looks at adult learning in general, with particular focus on how women learn, as a particular domain for this study. It further looks at how learning happens in relation to HIV and AIDS.

Learning is defined as a process of knowledge creation. It is a change in behaviour that occurs as a result of experience. Learning is seen as a function that maps experience onto behaviour; a process of using prior interpretation to construe a newer revised interpretation

of meaning of one's experience as a guide to future learning (Mezirow, 2000; and Houwer, Barnes-Holmes & Moors, 2013). Lachman's contribution regarding learning is that of viewing it as a constant modification of a stimulus-response relations within an individual. He sees learning as "as a consequence of functional environmental interaction via the senses" (Lachman, 1997, p. 479).

Colardyn and Bjornavold, (2004) maintain that the scope of knowledge and skills that individuals hold constitute learning, irrespective of the context within which that learning took place. In this regard they suggest categories of learning: formal, non- formal and informal and argue that they constitute what they term "lifelong learning" which requires that all learning outcomes from different settings and context be linked together (Colardyn & Bjornavold, 2004, p. 69).

In this paragraph, I briefly discuss each domain, but my key focus is on informal learning, which becomes part of the knowledge building within the communities in which adults are found, and is most pertinent to my study on the learning behaviours of women living with HIV and AIDS who are already on antiretroviral treatment.

Learning Domains

Formal learning is defined as learning that occurs in a classroom setting with a specific curriculum and learning outcomes, and is teacher or instructor facilitated. **Non-formal learning** denotes any remedial learning that is provided to learners and is mainly facilitated at work environments through workshops, seminars etc. The last learning domain is **informal learning** and it is about all the learning that takes place outside the curricula, or within the parameters of both formal, and non-formal education. It is pertinent also to note that while it may not happen within the confines of the curricula, informal learning can take place inside formal and non-formal educational institutions, although such acquisition of

knowledge is independent in nature and often times, not subscribing to the goals of the curriculum (Schugurensky, 2000).

Informal learning

This type of learning is perceived by different scholars as a process of giving meaning to, or seeking to understand life experiences. It is the process of transforming experiences into knowledge, skills, attitudes values and beliefs. It is about the continuing process of making sense of everyday experience. Marsick, Volpe and Watkins, (1999); Schugurensky, (2000; 2006; 2008); Marsick and Walkins, (2001); and Colardyn and Bjornavold, (2004) provide reference for these views. Most of the significant learning that individuals acquire throughout life, is part of this informal sub-system of acquiring knowledge. Dewey, Inderman, and Coady, the gurus and pioneers of adult education, as cited by Schugurensky, (2000), claim that informal learning facilitates community engagement and helps to generate intelligence to better understand and transform reality. Informal learning, however significant, is invisible and results in tacit knowledge acquisition which Polanyi describes as “knowing more than we can tell” (Schuguresky, 2006, p.167).

Embedded in the concept of informal learning, are self- directed learning, incidental learning and socialisation (Schuguresky, 2006). The discussion of these forms of learning will lead us to the identification of informal learning characteristics, which will in turn lead us to identifying how adults learn.

Self- directed learning takes place when individuals are alone or when they are part of a group, without the assistance of a teacher, instructor or facilitator. Self-directed learners may, however, draw upon a resource person, who may not regard him/herself, as an educator (Knowles, as cited in Taylor & Cranton, 2013). Self-directed learning is seen both as intentional and conscious. Intentional because it is purpose-driven, and conscious in that the

individuals are aware that they have learned something. Schugurensky, (2000) provides a myriad of examples about this type of learning, ranging from a group of high school students learning about political economy to a group of neighbours who want to embark on developmental activities to improve their neighbourhood.

Incidental learning is driven by experience. Initially the learner had no intention of learning something, but out of the experience he/she becomes aware that learning has actually happened. This type of informal learning is described by the common saying that ‘experience is the best teacher’. Schuguresky, (2000) cites an example of a toddler who touches a hot iron and gets hurt and then immediately learns about the dangers of getting burnt. Again he provides a scenario of a teacher who is exposed to a different environment and this experience challenges his or her initial assumptions about teaching

Socialisation is internalisation of values, attitudes, behaviours, skills that occur during everyday life. The learning process happens with no intention of acquiring skills and learners may not even be aware that they learned something. Learning through socialisation is usually an unconscious process (at its initial phase) but with time, it manifests within the process of retrospective recognition which Schugurensky, (2000) says ‘could be internal and/or external’ (Schuguresnksy 2000, p.5).

Characteristics of informal learning

Features of informal learning as identified by Marsick and Volpe in Marsick and Watkins, (2001), include the following:

...a) that it is integrated with work and daily routines, b) that it is triggered by an internal or external jolt, c) that it is not highly conscious, d) that it is often times haphazard and is influenced by chance, e) that it involves an inductive process of reflection and action and f) that it is linked to the learning of others (Marsick & Watkins, 2001, p.28).

Adult Learning

Adult learning depends on many internal and external conditions; it is not only viewed as a cognitive function. Key to adult learning are motivating factors (both intrinsic and extrinsic) that prompt learning to happen. Adults may be motivated when they perceive that the learning will bring satisfaction to one or some of their intrinsic basic needs (security, acceptance, respect, power, achievement, self-esteem). Other people become motivated by extrinsic factors such as monetary rewards, providing benefits, titles and recognition (Marsick & Watkins, 2001).

Central to these features, is the notion of the process of reflection, which is a key tenet of transformative learning and adult-based learning as developed by its chief theorist Mezirow (1990; 1997 and 2009) and further refined by other scholars such as Cranton, (2006); and Taylor, (2009). Transformative learning theory is dealt with in-depth in Chapter Three as part of the theoretical framework of the study. It is based on the premise that how we perceive the environment, is the product of our knowledge, culture, language and our human nature. The linchpin to transformation lies in critical reflection. Individuals who critically reflect and understand their experiences especially those that are brought about by what Mezirow terms a “disorienting dilemma” as articulated in his ten-phase transformative learning process (Mezirow, 2000, p.22) are learning by transformation. It is through critical reflection that adults engage in transformation through examining assumptions about the production of both technical and practical knowledge. This leads to the discussion of how adults learn.

How adults learn

This section has drawn heavily on Merriam’s theory of adult learning. The rationale for reliance on this theory is its comprehensiveness in addressing the multi-dimensional learning domains, as I have already described them. I have also supported this theory with other research on adult learning. Merriam, (2008), acknowledges that from the 20th century adult learning was

understood from the cognitive process; only where the mind took in facts and information to convert to knowledge. Lately as the scholarship around adult learning widens, learning has begun to gain recognition as a broader activity involving the body, emotions, spirit as well as the mind. Within this multi-dimensional nature of learning, Merriam provides an example of Taylor's writing on transformative learning, in which he acknowledges the critical role the mind plays in processing information. He said:

...for the brain to make meaningful connections, learning needs to be tied to physical, embodied experience...without such physical responses, there is no basis for constructing meaning. (Merriam, 2008, p. 95).

The body is another dimension that is seen as responding to learning. Merriam uses the example of miners and athletes who are acutely conscious of embodied space. The body, she asserts is more visible as a source of knowledge and as a site for learning.

Spirituality also emerges as another dimension that has a relationship with learning. The individual's spirituality focuses on the creation of an ultimate meaningful relationship with a higher sense of self, or God, or a Divine spirit to which individuals connect to and perceive themselves to be as whole. Regarding experience with the sacred, Tisdell, (2008) notes the significance of images, symbols, metaphors, music or kinetics sensory experiences that are often beyond the rational. These things are central to the meaning making that often people connect to the spiritual. In their study conducted about cultural aspects in Botswana and how they shape the learning process, Merriam and Ntseane, (2008) acknowledge spirituality's significant role in promoting learning. They note inter-connectedness between individual, community, nature and ancestral spirits as fostering learning.

These scholarly perspectives are particularly relevant to my study, as they look at coping and learning in the context of individual, familial relations and community levels.

Adult learning uses narrative learning as a way to theorise learning. Clark and Rossiter as cited by Merriam, (2008) observe that individuals narrate their lives to give meaning to their experiences. This, Merriam refers to as “meaning making” – therefore narratives are forms of learning:

...learning through stories of others helps to establish the logic and to figure out how it is related to what we already know (Merriam, 2008, p. 96).

How adult learning is promoted

Merriam, (2008) reminds us of the importance of adult learning through contexts of mind, body emotions, relations and cautions that several structures need to be promoted or encouraged. Key among these structures are reflection and dialogue, either with the self, another person or with a group in a critical manner. The central structure here relates to engagement and involvement with other people as a learning platform. This view is further developed by Merriam and Ntseane, (2008) where they view learning from a belongingness, connectedness, participation and centredness contexts whereby human existence is viewed in relation to existence of others (Merriam & Ntseane, 2008, p. 186). Critical reflection is also seen as essential for engaging in new social movements and for developing brain capacity and confronting or assessing self-power as well as connecting new learners with their previous experiences. The promotion and/or inclusion of creative and artistic modes of inquiry such as non-western and indigenous knowledge systems of viewing elders as key sources of knowledge, which Merriam and Ntseane, (2008) posit, exert powerful influence on the “who, what and when” of learning.

Within the African context, the work cited above indicates that key considerations in adult learning include: the collective nature of learning; cultural aspects, including spirituality; the centrality of emotions as expounded by Ntseane, (2011) in her findings from the role that spirituality plays in transformative learning, giving the example of Botswana where meaning perspectives are shaped by culture and language. Its people, Batswana, pay a lot of respect for

human life, mutual help, generosity, respect for older people and harmony and preservation of the sacred (Merriam & Ntseane, 2008; and Ntseane, 2011).

Women and learning

Another important aspect within the learning spheres, is the way in which women – the focus of this study – learn. This section touches on some of these learning sites. They refer to the formal educational settings; the workplace, home and family; religious associations; leisure activities and in community groups and the community. These are collectively termed “social contexts for women learning” (Hayes, 2000, p.23). Hayes uses a feminist lens to discuss these social contexts within which women learn. Within formal institutions, she asserts that the development of a curricula and texts, promote stereotypical roles and images of women and men. She gives an example of leadership roles being portrayed by males and domestic roles by women.

Within the workplace, women’s on-the job training may be challenging in occupations that are dominated by men. Behaviours that help men to become successful may not work for women, given their femininity. For instance a woman manager may be viewed as “overly aggressive” if she adopts similar direct methods of confrontation as a male manager might (Hayes, 2000).

Learning in the home and family: Women acquire different roles and relationships within family and home. These lead to different learning experiences such as learning to be self-reliant, establishing a stronger network of friends who can be used as sources of information and learning. In addition, women’s dissatisfaction with existing family structures and roles and a desire for change, can be a motivating factor for learning. Care giving is a skill learned by women, within the home and the family. The family and home can serve as important sites for learning and questioning gender roles and relationships. The patriarchal structure of society is

replicated in many families and it is within this structure, that women have learned to sacrifice their own interest in favour of their families' interests (Hayes, 2000).

Looking at how women learn in the community, Hayes, (2000) brings in the element of community groups who are dominated mostly by women. It is in these groupings that women's learning occurs through a wider range of experiences. These experiences are obtained from church groups, clubs, political groups, organizations or agencies that serve particular groups of women, such as single mothers, small business owners. These community groups promote emancipatory learning among women. Examples of emancipatory learning include self-help groups that are focal in the movement for creation and sharing of new health-related knowledge among women (Hayes, 2000).

The research that focuses on women and learning, now leads on to the central issue of this study, which is to view learning, in relation to the HIV and AIDS pandemic.

Adult learning in relation to HIV & AIDS

Learning is a life-long endeavour for individuals. Likewise, learning to live with HIV and AIDS is a life-time commitment that individuals engage in, which commitment requires 'meaning-making' of the disease, both in terms of the medication that is used to extend life, as well as with social interaction. It therefore requires a transformational learning process Courtenay, Merriam and Reeves, (1998); Merriam, Courtenay and Baumgartner, (2000); and Baumgartner, (2000), in a study conducted about meaning-making of HIV/AIDS positive men and women, noted the phases that adults go through in relation to their HIV and AIDS condition. These are the initial feeling of fear, anger, guilt or shame. In time, adults practiced critical reflection and re-evaluated their assumptions about the world and in the process, they realised they were not alone, and that there were others out there, who were going through a similar ordeal. They began to accept their HIV status and participated in what Mezirow, (1991) terms "reflective discourse" by talking to

others about their HIV condition. This is the stage or process that Tsarenko and Polonsky, (2011) refer to as taking full ownership of the disease. Through this process, adults gain knowledge and skills for implementing their plans to live with their HIV condition in as healthy a way, as is possible (Baumgartner, 2002).

Social interactions seemed a prominent factor within the transformational learning process. This is supported by scholarship on the role of HIV and AIDS support networks noted by Rule and John, (2008); Walstrom et al., (2013); and Atanga et al. (2015) when they outline the critical role that support networks play towards enhancing transformational learning among HIV/AIDS infected individuals who often feel more comfortable disclosing their illness to the support groups, than to their own family members, and furthermore these individuals come to view a support group as a “family” in which they have been accepted and affirmed (Rule & John, 2008, p. 90).

2.9 Conclusion

This chapter presents different layers of the context of scholarship within which this study is located. The key issues identified from the scholarly writings that are relevant to this study are: a) gender relations, b) HIV prevention, HIV testing and disclosure to various sectors, c) HIV treatment; and d) adult learning dimensions including women in learning. Each of these identified issues, form part of the perspectives of the study participants, which are then dealt with in-depth, in Chapters Five and Six.

The study now discusses its grounding theories of feminism, transformative learning and communities of practice in the next chapter. This is the theoretical framework for the study.

CHAPTER THREE: Theoretical Framework

3.1 Introduction

This chapter begins with a description of theoretical framework as articulated by Grant and Azadeh, (2014). The theoretical framework serves as a blue print for the study. It is the foundation from which all knowledge is constructed. It acts as a support for all research elements such as the rationale for the study; its purpose; the literature review; the design and the analysis of the findings.

The theoretical framework that grounds this study are feminism, transformative learning and communities of practice. This chapter discusses these theories in three parts. The first part discusses feminism as examined by a number of scholars such as Meena, (1992); Dube, (1997); Zalewski, (2000); Tuyizere, (2007); Gruss, (2009); Ntseane, (2011); Arnfred, (2011); Tallis, (2012); and Eze (2014).

The second part discusses the transformative learning theory as developed and revised by its chief theorist Jack Mezirow in his various writings (Mezirow, 1990; 1991; 1997; 2000; 2009). This was reviewed and further developed by Cranton, (2006); Taylor, (2007; 2008; 2009) and critiqued by Merriam and Ntseane, (2008) and Newman, (2012; 2014).

The third part discusses communities of practice theory (COP) as initially conceptualised by Lave and Wenger, (1991) and further developed by Wenger, (1998); and Wenger, McDermott, and Snyder, (2002). The discussion of the theory also looks into several critiques of communities of practice as advanced by Roberts, (2006a; 2006b); Fox, (2000); and Probst and Borzillo; (2008). Each of the three theories discussed in this chapter begin with the basis for the inclusion of the theory in this study. This is followed by a discussion of the theory itself, critically looking

at the theory's origins and its contextual roots as well as other scholars who have made some contributions on it. In addition, these theories have been contextualised to the African setting and the study foci.

3.2 Part One: Feminism

I give a brief general definition of feminism; types or approaches of feminism and when and how they evolved; then I narrow it down to African feminism with special focus on gender and sexuality within the African context. Feminism, as I have already indicated, is concerned with women within their political, economic, cultural and legal protection, contexts and their health relationships, with their partners and the African kinship system, in general.

Feminism defined

Viewed by a number of scholars, feminism denotes an umbrella of related theories which have certain things in common, such as focus on women and their oppression, and a commitment to their liberation (Meena, 1992; Tallis, 2012; and Zalewski, 2000). Feminism is an approach that aims to end women's discrimination because of their sex. It holds a belief that women have specific needs which remain negated and unsatisfied and whose satisfaction requires a radical change in the social economic and political order. A critical underpinning of all feminisms is that the personal is political (Tallis, 2012).

How feminism evolved

Feminism emerged around the 18th century in England as a social movement aimed at achieving equality between men and women or rather the two sexes males and females (Tuyizere, 2007) . It made a lot of strides to widen the horizon of women in the field of voting, education, politics, public life and the profession. This movement worked to challenge the oppression of women wherever they may be. Feminism as a social movement was pioneered by middle class white

women, from western Europe and north America. It started around 1846 and moved in waves (1846 – 1899; 1900 – 1920; 1921 –1970 and 1980 – present). Maggie Humm and Rebecca Walker in their history of feminism, outlined the three approaches within which feminism manifested. The first approach was in the nineteenth century; the second from 1960 to 1970 and the third approach from 1990 to what they referred to the present. However, other scholars such as Diamond, (2009) identify the fourth approach which emerged from around 2009 to the present. These approaches have been termed liberal, radical, Marxist and post-structuralist, with the fourth approach encompassing the narratives expressed in the other three approaches. The focus has been to look at feminism as a holistic gender issue that aims for social change – from eradication of poverty to creating a sustainable development. In each of the approaches feminism advocated for the liberation of women with regard to various aspects, ranging from the economic to the reproductive and the social.

Liberal feminists

The key concern within this approach centred on the promotion of equal opportunities, equal rights, equal participation in political organizations (Tuyizere, 2007; and Meena, 1992). The focus was on challenging women’s invisibility and marginalisation of their experiences and arguing for the equal rights of men and women to jobs, choices and decision making through democratic processes. The key debate within this approach is that equality should be accorded to the two sexes as men and women have the capacity to express their views. The liberal feminists maintain that it is possible for change to happen, without altering the structure of society. Changes that the liberal feminist advocate for are reproductive and abortion rights, protection against sexual harassment, rights to vote, women’s full participation in education, equal pay for equal work, affordable childcare, affordable health care, and information dissemination and awareness creation around acts of sexual and domestic violence against women.

Second approach (Radical Feminism)

As the first approach unfolded, the feminists realized that political and economic powers were not sufficient factors within their quest for equality but rather it required an inclusion of cultural rights. There emerged another approach –radical feminism, which was prominent from 1960 to 1980. This approach aggressively demanded transformation of the oppressive gender relations. It puts sexuality and reproduction and patriarchy at the centre of the political arena and seeks to change women’s political consciousness. Their slogan is the personal is political, which sees women’s cultural and political inequalities as inextricably linked and encourages women, to understand aspects of their personal lives as deeply politicized and as reflecting a sexist power structure. This approach, according to Zalewski, (2000), is aimed at empowering women to analyse their lives as part and parcel of common experiences within a patriarchal society.

Radical feminists are unpopularly known as “man haters” as their approach seems to alienate men. They see men as a problem in that they are always at the centre of things, controlling women, occupying top jobs, having more wealth, property and the most of the privileges. The key debate within radical feminism is that while political and legal equality are important, they are not the means to an end in terms of ending women’s oppression. There are still additional aspects to be considered in the form of various other kinds of sexist oppression. The radical approach holds that sexist oppression is not simply rooted in legal and political arrangements. Radical feminists maintain that feminism must demand full economic equality for women rather than simple economic survival as thought of by the first approach. Radical feminists claim that the division of labour based on biological sex, marks out the women as the other, while men are accorded high status. They therefore advocate for a gender-based division of labour; the valuing of women’s domestic work and equal pay for both genders. In addition they advocate against sexual abuse and harassment, all exploitative pornographic literature, art and movies, as well as prostitution and the trafficking of women. The other area that it focuses on is relational issues in

human social life such as marriage, motherhood, heterosexual relationships and woman's sexuality. The debate is that these are areas that play a pivotal role in human relations and therefore require not only reform, but a radical transformation of almost every aspect of personal and political life. Hence there is a struggle against the idea that motherhood is a natural need among women and that heterosexuality is the natural order (Tuyizere , 2007, p. 103) .

Third approach (Marxist feminism)

This approach emerged from 1990 to 2009. The key debate within this approach is that capitalism and class societies contribute to gender inequality. The Marxists see the family as a unit linked to the labour market by the husbands and their relationship to production. Women produce the labour force biologically by child bearing and socially, by child rearing, over and above caring for men. The Marxist approach argues that education seems to reinforce the division of labour in the economy and the family. Certain courses of study are offered on the assumption that the different sexes have different needs and interests, thus technical schools seem to be male territory as opposed to female territory. Their other tenet rests with the argument that women's subordination in class relations leads to a sexual division of labour, thus locating women in the domestic sphere and not in the labour force (Tuyizere, 2007).

Marxism remains a part of the political debates about structures and processes of all kinds of oppression as well as division in the social world, and the activities needed to change the order of things. In the same way Marxism has become a major debate in terms of the oppression of women and the strategies that need to be put into place to counteract oppression (McLaughlin, 2003). The approach challenges the attempt to isolate gender from social class. The approach advocates for liberation of women from oppressive social class and pushes for the recognition of women's participation in public spheres (Meena, 1992).

Fourth approach

The fourth approach began in 2009 up until the present. This approach puts gender as the centre of narratives for social change. According to Pythia Peay one of the pioneers of this approach, it integrates the unfinished issues and contradictions of the last three waves in an overarching vision that combines spiritual practice with political action and economic power and the insights derived from psychoanalytic theory and practice. The approach puts a lot of emphasis on women being bold and decisive, citing the narratives of Bolgar where she draws crucial distinction between equal rights and an internalized sense of gender equality. Looking at the three other approaches, Hedda identifies some flaws, which among them are, the over-reliance of the approaches on the idea that inequalities could be redressed primarily in a socio-political manner, through affording inadequate attention to women's internal conflicts and conflicting desires. The tasks of mothering and caretaking provide alternative experience to success or productivity, in a male-dominated professional world and for the foundation for styles of action and imaginative visions, including spiritual ones that might bring women into conflicts both internally and externally, with that world. Bolgar, (2009) recognizes the strength of women and alleges that when women are given career opportunities and encouragement, social changes are possible.

The approach that this study adopts is the fourth wave feminism which puts emphasis on social action and spiritual practice as conceived by Jane Fonda in Diamond, (2009) where she documents women's narratives as they struggled to integrate meaningful work with motherhood, creating relationships that would integrate autonomy, mutuality and commitment with sexual passions. The social action and spiritual practices form what I discuss below as the foundations and principles of African feminism.

African perspectives of feminism

The African feminist scholarship is rooted in the colonial era, which saw feminism as anti-colonial and anti-father stance. The development of African feminism therefore took a different

angle or view from that of the west. It became propelled towards being anti-western feminism. It sought female agency and autonomy while still maintaining an all-gender inclusiveness (Lewis, 2008).

Many African scholars have made contributions to their conception of African feminism – some blaming patriarchy as a power-base for male domination. Some of these scholars are Tuyizere, (2007); Chi-Chi and Benaya, (2008); Osha, (2008); and Eze, (2014). In her contribution to African feminist theory, Tuyizere, (2007) draws on the African women's recognition of their unequal power position and relations with their male partners. She talks about poverty, colonialism, post-colonialism, culture, race, war and under-development which she claims “negatively affected women more than their male partners” (Tuyizere, 2007, p. 98). Issues of gender such as culture (dowry, female genital mutilation), heterosexuality (polygamy) and marginalization by socio-cultural, economic and power structures are some of the oppressive practices these authors highlighted.

Other scholars embrace the African practices of positioning women as custodians of culture claiming that a lot of powers, are culturally placed on women. In this section I am drawing on the scholarship from Dube, (1997) who equates African feminism with a hen that searches for a lost needle with its feet. The metaphor that she uses depicts the complexities, dangers and possibilities of defining feminisms in the context of post-colonial Africa. She argues that during the post-colonial era, both men and women were facing a higher enemy – that is, the former colonisers who were now wearing the gowns of neo-colonialism and globalization. While the African men and women scratched and searched side by side for survival, it is the man who looks up and does the talking, while the woman focuses on looking down, searching hard for the lost needle.

...the woman fights for the basic survival needs such as food and shelter to keep life of her family going (Dube, 1997, p. 214).

The needle in Dube's context symbolizes the borrowing of western cultural and economic systems which came with colonization. The latter, according to her, now manifest into movements such as neo colonialism and globalization, all of which expose women as to be double-oppressed. This means they are colonized by imperial and patriarchal forces. During colonization and post-colonial eras, African women of various backgrounds have been left with no time to speak for themselves. Their focus during these times was nationalism which was an essential identity that depended on suppressing racial, ethnic, age and class differences within African countries during the years of the struggle for independence. Women joined hands with their men to fight colonization (during the process, the fight for gender-empowerment was suspended as they were urged to shelve their concerns and join the men in the fight for their conquered land). Ever since that period, Africans adopted the essentialist philosophy – a product of certain shared experiences, determined by geography, time, community, cultural institutions, individuals, race, gender, sexuality and class. These shared qualities are a strategic means of survival and cooperation.

The African feminist approach is founded upon the principles of traditional African values that see gender roles as complementary, parallel, asymmetrical and autonomously linked in the continuity of human life. African feminism emphasises female autonomy and co-operation and sisterhood among women which is then carried across to the extended family. It questions features of traditional African cultures, without denigrating them. The involvement of men is key within African feminist principles. Mekgwe, (2008) puts it thus:

it is not antagonistic to men but challenges them to be aware of some aspects of women's suppression which differ from the generalized oppression of all African people (Mekgwe, 2008, p. 17).

Some African feminist scholars such as Emecheta, (1997; 1994), Leslie, (1994); Aidoo, (1996); and Oyewumi, cited in (Mekgwe, 2008), strongly uphold the principle of heritage within the African feminism. They maintain that the African woman needs to be conscious not only of the fact that she is a woman, but that she is both an African and a third world person; therefore in her identification of the flaws of her culture, the African woman needs to be careful not to reflect that at the expense of her own African customs. They hold a belief that, while African women may have been subjected to some forms of equality with men, in as far as power is concerned, the notion of feminism is not alien to the African context (Mekgwe, 2008). African feminism focuses on culture, the centrality of children, multiple mothering and kinship. It recognises the inherent, multiple roles of women and men in reproduction and production and the distribution of wealth and responsibility for the sustainment of human life.

This perspective is underscored by traditional mythical beliefs and religious practices found in African traditions and festivals that place women at the centre of the social order as custodians of the earth, fire and water and uphold men as the guardian of women's custodial rights (Badejo, 1998, p. 94). Women of Mozambique for example were used as the custodians of cultural female initiation – a primary system used to socialise young girls to prepare them for motherhood (Arnfred, 2011).

Ntseane and Mikelle (1995) likewise see African feminism as a discourse that recognizes men as partners in the initiative to end gender oppression, as opposed to the radical feminism that sees men as oppressors. Within the African perspective, feminism they posit, is more of a complementary than a conflicting relation of the two genders. Ntseane (2011) further presents the example of the cultural practice of Botswana that admits the importance of partnership with men in ending the oppression of women. She uses Dube's (1999) metaphor about a 'hen that scratches the ground for a lost needle' which denotes that for an African woman, the struggle for

gender equality is complex and thus requires a negotiation between males and females. Unlike with the western perspectives that I have outlined earlier, African feminism looks more into communal and collective responsibilities. Mikell (1997) calls it a “group oriented initiative”.

This approach seems unique, in that it has promoted women’s organizations around economic empowerment, informal education and training, as well as political representation. Both Mikell and Ntseane refer to this approach as “bread, butter, cultural and power issue” (Ntseane 2011, p. 315 and Mikell, 1997, p. 5).

Critique of the feminist theories

Many critiques of feminism emanate from the Western practices, which are viewed as not favouring men. The African feminism established its roots within the primacy of the anti-colonial struggle. The application of feminist theories to the writings of the African women bear the authority of the West and therefore perpetuate the self/other divide whereby discourses of the developing nations are considered politically immature (Mekgwe, 2008). Feminism has always been critiqued for raising the issue of women’s lack of power and criticizing men’s dominance in public life, the economy, politics and society. Feminism is purely seen as predominantly a white westernised experience that too often sidelines issues of racial differences, hence the need for African scholarship to develop black feminist perspectives that would more accurately reflect the realities and culture of black women.

Relevance of the African feminism to the study

Given these criticisms, feminism bears relevance to this study for a number of reasons.

In the first instance it creates awareness of joint collaboration in the development of lives and co-existence within families and communities. Feminism creates an opportunity or window for women to express their views both within families and in public spheres.

In the second instance, African feminism, whose primacy is on collaboration with men, promotes healthy relations, knowledge sharing, mutual understanding and partnership within families and among communities.

In the third instance it draws heavily on culture, extended family and collective power. It creates an opportunity for women to challenge any practices that perpetuate dominance against women and creates awareness of the way women are socialized, thus advocating for a conducive environment for women to take part in activities aiming at improving the lives of the individuals within the communities.

In the fourth instance is the notion that a woman's identity is not static. This is a powerful notion that empowers women. The conception of feminism to be that of recognising women as participating fully in socio-cultural issues, of challenging the status quo, of seeing women's existence not at the periphery but rather at the mainstream of health, culture and development, is the power-base which this study is exploring.

The fifth instance is the element of kinship, sisterhood, motherhood and the extended family, all of which are embedded within the African feminism, and are key factors towards the promotion of relations both in the families and the communities within which this study is focusing.

3.3 Part Two: Transformative Learning Theory

This section discusses transformative learning theory as another relevant theory that grounds the study. Transformative learning, according to Mezirow, is the process by which adults learn to reason and make value-based judgement about their lives. This is in contrast with the actions that are based on assimilated beliefs, values, feelings and the judgement of others. Mezirow

identifies elements such as power and influence, ideology, race, class as contributing towards promotion of transformative learning. Mezirow's conception of learning is that of:

assisting in making meaning and sense of our experiences (Mezirow, 1997, p. 5).

He posits that learning can result in change in one of our beliefs or attitudes, or it can be a change in our entire perspective. Perspective transformation as stated by Cranton, Mezirow and Taylor is key to transformational learning. Their elaboration of transformative learning encompass a learning process by which previously uncritically assimilated frames of reference (assumptions, expectations and habits of mind) are questioned and revised, so that they may generate beliefs and opinions that will prove to be true and are then justified, to guide action for the transformative learning process (Cranton, 1994; 2006) and (Mezirow & Taylor, 2009).

Transformative learning has two possible forms. One of which Mezirow suggests as gradually taking place over a period of time, during which a person's meaning schemes are revised through critical reflection. Another form involves a swifter and more dramatic transformation of the person's worldview. Transformative learning therefore involves participation in constructive discourses to use experiences of others, to assess reasons for justifying these assumptions and making an action decision, based on the resulting insight.

Development of the theory

Transformative learning theory was developed by Jack Mezirow in 1978. His conceptions of transformative learning emerged from a comprehensive study of consciousness raising to explain the unprecedented expansion in the number of women returning to higher education in the United States. This study was conducted in twelve diverse community college programmes, and comprehensive analytical descriptions of an additional twenty four programmes, and the subsequent responses by another 314 programmes was looked at. Mezirow's study revealed a

10-step process in which transformative learning process happens. These are:

- i) experiencing a disorientating dilemma;
- ii) undergoing self-examination;
- iii) conducting critical assessment of internalized role assumptions and feeling a sense of alienation from traditional social expectations;
- iv) relating discontents to the similar experiences of others – recognising that one’s problem is shared and not exclusively a private matter;
- v) exploring options for new ways of acting;
- vi) building competencies and self confidence in new roles;
- vii) planning a course of action;
- viii) acquiring the knowledge and skills for implementing a new course of action;
- ix) trying out new roles and assessing them; and
- x) re-integrating into society with the new perspective (Mezirow as cited and expounded by Merriam, 2004, pp. 61-63).

This theory is about how we make meaning of our experiences through the frames of reference that we develop as we become adults. The moment we experience or encounter something that does not fit into these frames of reference, this triggers processes of critical reflection on previous assumptions, in an attempt to make sense of it. When critical reflection causes an adjustment or changes to our frames of reference, transformative learning is said to have happened (Mezirow as cited in Ntseane, 2011, p. 308).

Transformative learning is concerned with how individuals may be empowered to learn to free themselves from unexamined ways of thinking which impede effective judgement and action (Mezirow, 1978). Learning is also making sense of our experiences. It can result in change in one of our beliefs or attitudes, or it can be a change in our entire perspective.

Building on this definition, Cranton and Taylor (2013) view transformative learning as learning created by the experience of what happened in one's past, which then becomes the primary medium of transformation. The revision of the meaning experience then becomes the essence of learning (Taylor & Cranton 2013, p. 35). Briefly put, transformative learning theory emphasises meaning, using meaning structures to filter and provide the context of experiences (Mezirow as cited by Ntseane, 2011). The meaning structures act as culturally defined frames of reference that are inclusive of meaning schemes and meaning perspectives.

Meaning Schemes: These are smaller components that are made up of specific attitudes, knowledge, beliefs, value judgements and feelings involved in making an interpretation. They are the tangible signs of our habits and expectations that influence and shape a particular behavior or view. An example would be how we may act when we are confronted with a certain situation.

Meaning perspectives: These are broader perspectives or world views, or personal paradigms involving collection of meaning schemes. Mezirow puts it thus:

...they provide us with the criteria for judging or evaluating right and wrong, bad and good, beautiful and ugly, true and false appropriate and inappropriate (Mezirow, 1991, pp 34 -35).

Since its development, transformative learning has become a pivot of discussion in adult education and has inspired a broad range of scholars and adult educators. Mezirow (1991) maintains a view that transformative learning is dependent on adult life experiences and a more mature level of cognitive functioning, than what is found in childhood. Its essence is that through sudden or dramatic experience, people are changed in way that they recognize themselves and others.

The theory stands on solid ground in terms of articulation of adult learning, whereby it views learning as the process of using prior interpretation to construe a new or revised interpretation of the meaning of one's experience, in order to guide future action (Mezirow, 2009). Taylor (2007) sees it as a theory that is partly developmental but even more so, it denotes where learning is understood to be a process of using prior interpretation, to construe a new or revised interpretation, of the meaning of one's experience.

Critique of the Transformative Learning Theory

Transformative learning theory has drawn considerable critiques from wide range of scholarship. For instance, Taylor, (2007) in his review noted that the theory lacks attention to context and culture, and it over-emphasises cognitive process, rather than focusing on a more holistic conception of learning. Taylor further proposes transformative learning to be explored in-depth, to provide a greater understanding of the varying nature of the catalyst process of learning. He puts emphasis on the disorienting dilemma, the significant influence of context and the minimization of the role of critical reflection, while also increasing the role of other ways of knowing (Taylor as cited in Dirkx 1998).

Newman, (1994) claims that the theory is based on the prioritization of individual transformation over social change. Mezirow's response to this critique, however, touches on that fact that dichotomizing the individual and society seems to be counter-productive in trying to understand the learning process. His argument is that

...while learning is a social phenomenon, it takes place in the individual (Mezirow, 1997, p. 62).

The theory's development and employment within the western context with a largely middle-class sample, raises another critique among scholars such as Taylor, (1997); and Ntseane, (2011; 2012). They claim that there has emerged a body of studies in other contexts e.g. the African

context that acknowledges the role of culture in shaping meaning-making in the transformative learning of individuals. The element of interdependence (the key principle) within African philosophy seems to be ignored in the theory; instead emphasis is placed on autonomy and independence (Merriam & Ntseane, 2008). Ntseane, (2011) further argues that Mezirow's version of transformative learning could be useful if applied in a way that is culturally sensitive.

Its common rhetoric that implies a necessity of extraordinary events or "aha" moments are what prompts authors such as Dirkx to bring forth their critique, claiming that those moments are not necessary; instead transformative learning can be the product of ordinary and everyday experience (Dirkx, 1998). Supported in this view are claims from other scholars that learning is an inherently emotional and imaginative process grounded on the premise and assumptions of Jungian psychoanalytical framework of individuation³. They claim that transformative learning should be based on a dialogue between the conscious and the unconscious, among the anima-animus, shadow, and archetypes, using images and symbols (Cranton and Roy cited in Kaccikaydin and Cranton, 2012).

Michael Newman critiques this theory by indicating that its applicability in the every-day life may not be feasible as it places a lot of emphasis on theoretical issues. Strengthening his case Newman argues that there is not exceptional feature of the theory:

...all acts of learning share basic characteristics and that what many scholars are calling transformative learning, should in essence be called "good learning" (Newman, 2012, p. 66).

Newman's critique has received a counter critique from Dirkx, (2012) who argues that Newman's analysis is based on a sociological understanding of self-formation which minimizes

³An ongoing life-long process in which adults differentiate their sense of self from the collective of humanity and simultaneously integrate their sense of self with the collective, in such a way that their position in the collective is more consciously articulated

psychological dynamics associated with conscious developments. He actually supports this statement by making emphasis on the direct linkages between a conscious relationship with one's unconscious, which he says:

...represent a central hallmark of a critical theory of self and of transformative learning (Dirkx, 2012, p. 399).

The impact of relationships is another missing element when it comes to transformative learning theory. Baumgartner's contribution to the theory noted that learning through relationships and the importance of such factors as support and friendship in the transformational learning process, have not been directly addressed by the theory (Baumgartner, 2002, p.57).

Relevance of the theory to the study

This theory attracted a lot of scholarship within the formal, non-formal and informal contexts. Applied within this study context, transformative learning is being used within the informal setting to examine the learning that takes place as a result of women who have been diagnosed with HIV and AIDS and how the learning they are undergoing helps to transform their habits of mind. The written material on this topic draws on views expressed by Baumgartner, (2000; 2002); Taylor, (2009); and Nohl, (2015) when they assert that adults develop, during the course of their lives, their sense of seeing and being in the world, over time.

Transformative learning helps adults to develop deeper understandings of the ways they think about themselves and the world. The theory is more emancipatory as it helps adults to analyse, pose questions and take action on the social, political, cultural and economic contexts that shape their lives. This will be explored in more detail in the next chapters, in the context of women who are diagnosed with HIV and AIDS, and how their coping strategies.\

3.4 Part three: Communities of Practice Theory

The communities of practice approach was developed by Lave and Wenger, (1991) as a social theory of learning with a focus on how people learn through their everyday informal interaction with their environments in the course of their shared practices. In this section, I define communities of practice, its development, its key principles and critiques, as well as how it is relevant to this study.

Communities of practice theory defined

Communities of practice denotes a group of people who share a similar or common problem, who engage in a process of collective learning in a shared domain of human endeavor. McDermott, Wenger and Synder provide parameters within which communities of practice exist.

They explain its range from:

....a tribe learning how to survive, to a band of artists seeking new forms of expression, or a clique of pupils defining their identity in the school, or a network of surgeons exploring new techniques, or a gathering of first time managers helping each other cope. It is therefore a group of people who share a concern, or a set of problems, or a passion about a topic, and who deepen their knowledge and expertise in this area by interacting on an on-going basis (McDermott, Wenger & Synder, 2002, p. 4).

The origins of the communities of practice

The theory was developed by Etienne Wenger and Jean Lave around 1991 following the publication of a book, *Situated Learning: Legitimate Peripheral Participation*. The book also launched the concept of communities of practice as the environment of important learning, a term which Wenger cemented in 1998 and elaborated further in his book, *Communities of practice: learning, meaning, and identity*. He defined communities of practice as a set of relations among persons, activity and world over time and in relation with other tangential and overlapping communities of practice. While the use of the term has become quite widespread, the term actually stems from theories based on the idea of learning as social participation (Wenger, 1998).

To better understand the concept of communities of practice, it is befitting to have a solid understanding of social learning theory. Social learning theory emerged as a contribution to the work of Bandura in the late 70s. Bandura, (1977) emphasized the importance of observing, behaviours, attitudes and emotional reactions of others. He believed that most human behavior is learned through observing while others are doing. As people observe, they in turn acquire information which helps them change their behaviours and at later stages, this information serves as a guide for action. He acknowledged the important role that social interaction plays in the development of cognition (Bandura, 1977).

Key concepts in communities of practice theory

In bringing forward the ideas of social learning theory, Wenger begins with the four main premises. These are:

1. that we are all social beings – a central aspect of learning;
2. that knowledge is a matter of competence with respect to valued enterprises;
3. that knowing is a matter of participating in the pursuit of such enterprises, that it, active engagement; and
4. that meaning – our ability to experience the world and our engagement with it as meaningful – is ultimately what learning is to produce (Wenger, 1998, p. 4).

Wenger brings forward that learning is part of a more encompassing process which positions individuals as active participants in the practices of social communities. In addition Wenger presents components of social participations which characterize learning. These are:

Meaning: a way of talking about our changing ability – individually and collectively.

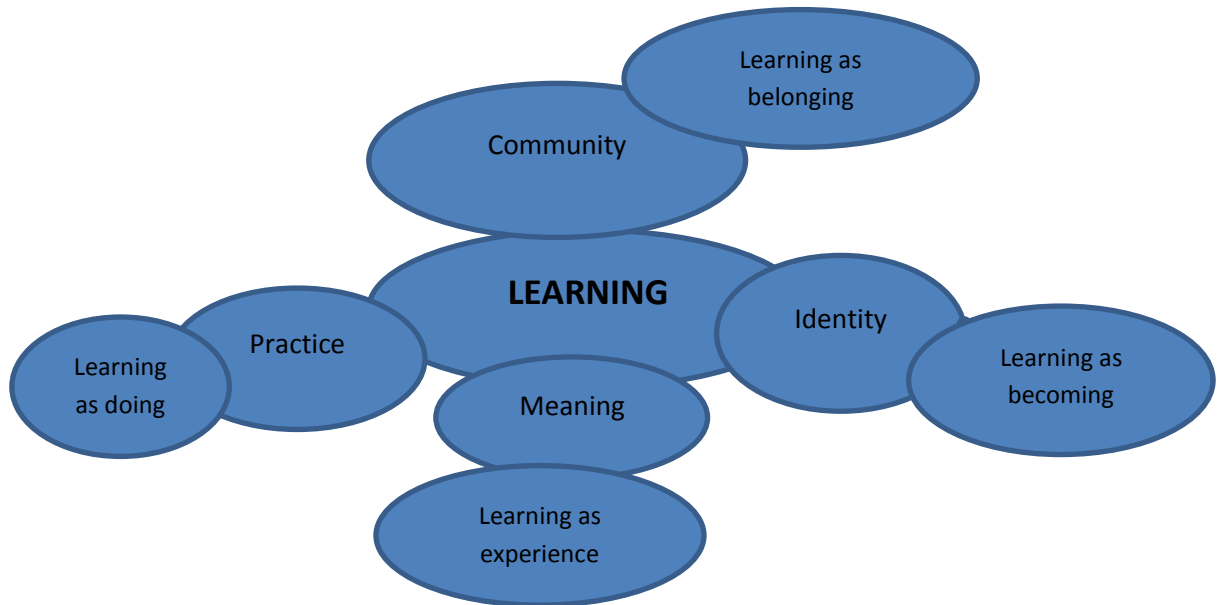
Practice: a way of talking about the shared historical and social resources, frameworks and perspectives that can sustain mutual engagement in action.

Community: a way of talking about the social configurations in which our enterprises are identified as worth pursuing and our participation is recognizable as competence.

Identity: a way of talking about how learning changes who we are and creates person's histories of becoming in the context of communities (Wenger, 1998, p. 5).

All the four elements mentioned above are interchangeable with their relationship to learning, as depicted in the diagram below:

Figure 3.1 Components of social theory of learning



Source: Wenger, (1998, p. 5).

According to Wenger, (1998, pp. 73-85), communities of practice theory delineates itself along the three dimensions that are related to the practice. These are mutual engagement, joint enterprise and shared repertoire.

Mutual engagement entails interaction with each other, establishing norms and relationships.

Joint enterprise refers to the situation where members are bound together by an understanding of a sense of practice and **shared repertoire** relates to a situation where members produce overtime, sharing of resources such as common language, routine artifacts or stories.

Below are some common features of a community of practice:

- Sustained mutual relationships – harmonious and conflictive
- Shared ways of engaging in doing together
- Rapid flow of information and propagation of innovation

- Absence of introductory preambles, as if conversation and interactions were merely the continuation of an on-going process
- Very quick set up of a problem to be discussed
- Substantial overlap in participants descriptions of who belongs
- Knowing what others know, what they can do and how they can contribute to an enterprise
- Mutually defining identities
- The ability to assess the appropriateness of actions and products
- Specific tools, representations and other artifacts
- Local lore, shared stories, inside jokes, knowing laughter
- Jargon and shortcuts to communication as well as the case of producing new ones.
- Certain styles recognized as displaying membership
- A shared discourse reflecting a certain perspective.

Adapted from Wenger as cited in Roberts, (2006)

Communities of practice bear some characteristics which vary from practice to practice. There are those that have names, some are formal, others are fluid and informal but in all of these characteristics what stays common, is the fact that members are brought together by joining in common activities and by what they have learned through their mutual engagement (Lave & Wenger, 1991; and Wenger, 1998).

Alongside this theory, is another important idea, which relates to the notion of communities of practice and social learning theory. This is what Lave and Wenger, (1991) refer to as “legitimate peripheral participation” which denotes

...a particular mode of engagement where a learner participates in the actual practice of an expert, but to a limited degree (Lave & Wenger, 1991, p 14).

This is a type of situated learning and a process that reiterates the focus that learning is fundamentally social rather than psychological. This assumption is substantiated by Lave and

Wenger's observation of different apprenticeships (midwives, tailors, naval quartermasters, meat cutters and non-drinking alcoholics) as they moved from the periphery towards the centre of the practice, as they became more competent.

Nature of participation in communities of practice

Wenger, McDermott and Snyder (2002) provides a comprehensive description of different levels of participation within the communities of practice. They identified three levels of participation – the first one as a small **core** group of people who actively participate in discussions, debates, and public community forums. This group often takes on community projects, identify topics for the community to address, and as the community matures, this core group takes a leadership role within the community. The second level is the **active** group. Members at this level attend meetings regularly, and participate occasionally in forums. This group too, is usually small in number. The last level or portion of community members are the **peripheral** group. This group rarely participates. Instead they keep to the sidelines, watching the interaction of the core and active members. Their justification for peripheral participation includes the fact that members may feel that their observations are not appropriate for the whole group or that their contributions do not carry any authority. Members at this level may also lack time to contribute more actively.

Critique of the Communities of Practice Theory

Communities of practice theory has received a number of critiques from some scholars. The critiques that I intend to focus on relate to power relations, trust, predispositions, size and spatial reach, and fast versus slow communities downside, as put forward by Fox, (2000); Chua, (2002); and Roberts, (2006). In addition to these scholars I have viewed the writings by Probst and Borzillo, (2008, p. 343) about the main reasons for failure of communities of practice as an addition to the limitations of the theory. These are a) lack of core group, b) low level of one-to-one interaction between members, c) rigidity of competencies d) lack of identification with the

community of practice, as well as e) practice intangibility as some of the factors that negate effective operationalization of the theory. I deal with these factors broadly in the sections below.

Power relations

Fox, (2000) posits that while communities of practice theory does place emphasis on a group of people all involved in a shared practice, there is an element of power conflict that the theory has not addressed. He gives the example of masters (old timers), young masters and apprentices (new comers) and he links that with the practice of quartermasters within the US Navy (Fox, 2000, pp. 853-855).

Trust

Roberts, (2006) sees trust as a major contributor in making communities of practice work in any organization. The presence of a relationship of trust between individuals indicates an ability to share a high degree of mutual understanding which in turn contributes to successful transfer of tacit knowledge. The theory seemingly overlooks the element of trust, given its pivotal role in maintaining healthy relationships, within organizations.

Size and spatial reach

Fox, (2000) sees these as inhibiting factors in the effectiveness of learning within organizations. Communities of practice as presented by Wenger et al., (2002) are considered for large multi-national organizations with large memberships. At the same time, there are those with small groups of people working in close proximity. Roberts, (2006) view of the size of the practice is that it may not always be possible to apply similar principles to the two different communities, which will have different sizes and spatial reaches.

Fast versus slow communities

Fox (2000) talks about the vast changing business environment that carries the characteristic of complexity and intensification of competition. He also talks of a growing demand for continuous improvement of business performance. These factors, he stresses, demand that businesses need

to transform their competitive landscape. He then suggests that communities within business organizations will face difficulties forming, when the pace of change is accelerating. He sees this factor as a great inhibitor towards making the communities of practice effective and cautions that in the era of fast capitalism there is every likelihood that groups emerge and dissolve rapidly.

Narrating on why communities of practice may fail, Probst and Borzillo, (2008) identified in their study of 57 companies who used the practice, the following factors, which I have used as part of the critique of communities of practice. These are:

- a) **Lack of core group:** This is actively engaged in activities such as regular meetings, the inflow of fresh ideas and the support that is provided to other members for problem solving.
- b) **Low level of one-to-one interaction between members:** Members often run into the habit of not conducting one-on-one facial, telephone or email, discussions regarding practices that they use in their respective units.
- c) **Rigidity of competence:** Members develop over time trust of their competence to the total exclusion of views of others, thus demonstrating less willingness to integrate practices originating from other practice members.
- d) **Lack of identity with community of practice:** Another challenge with communities of practice, is that members do not view their participation in their practice as meaningful for their daily work, thus they do not perceive other members as peers who can assist them with useful knowledge and practices
- e) **Practice intangibility:** This applies to a situation where members fail to engage with one another in a way that allows them to illustrate the practice to make it concrete enough for other members to understand and visualize its functions (Probst & Borzillo, 2008, p 343).

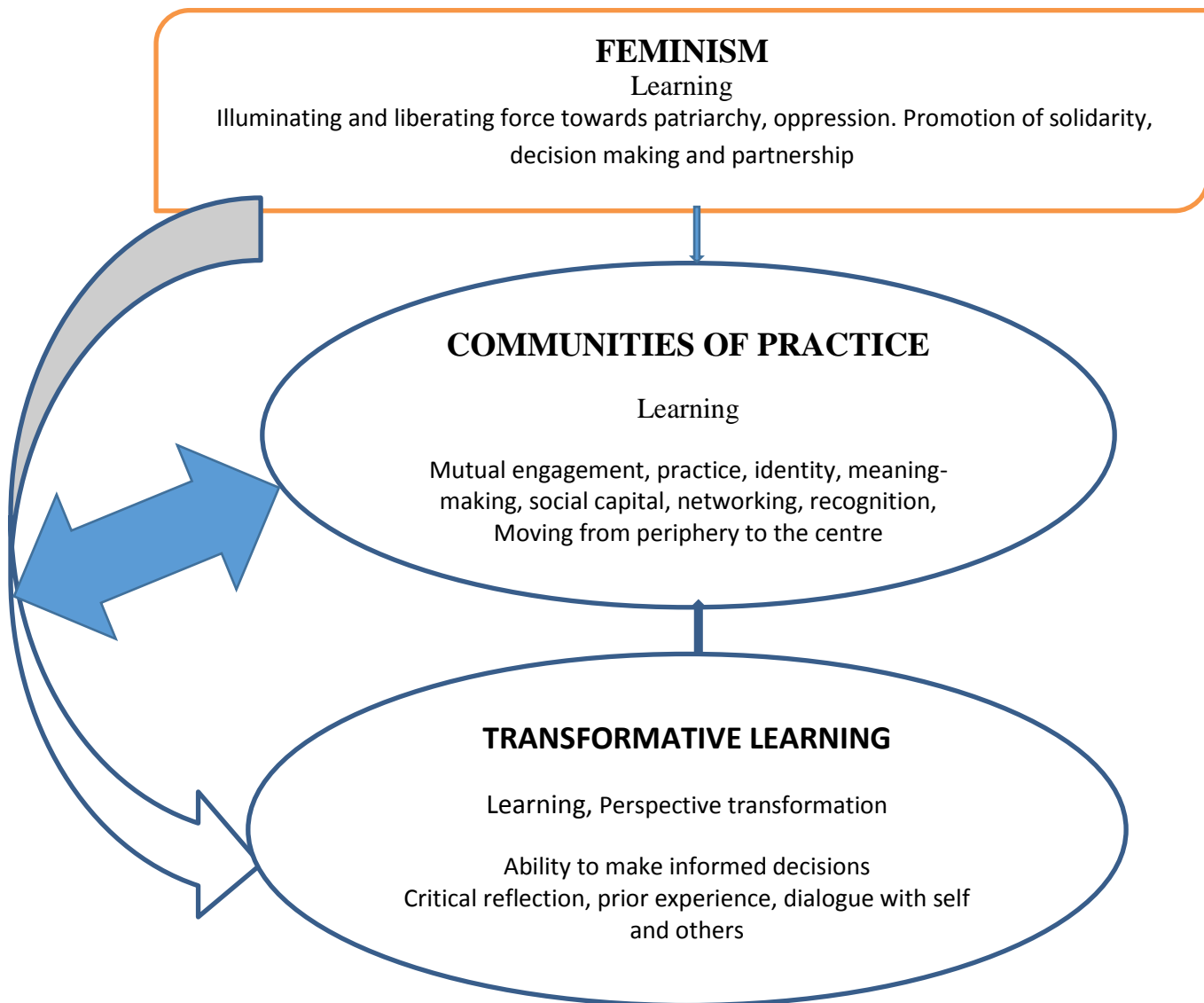
Using Communities of Practice as a lens for this study

Communities of practice is the linchpin for this study. The element of learning from each other, the level of participation of the participants from being at the periphery to becoming full members of the practice, as well as mutual engagement is what bears reference to what the study seeks to explore regarding coping strategies for dealing with an HIV positive condition.

Linkages between the three theories

Feminism is about liberating the oppressed women, creating a conducive environment for women to show case their potential within the political, economic and social spheres. Transformative learning is about learning for change, transforming the taken-for-granted habits of mind and engaging into critical reflection – to question the integrity of deeply held assumptions and beliefs based on prior experience. It facilitates dialogue with oneself and other people in seeking to provide the most accurate and complete information, ensuring freedom from coercion and distorting self-deception; encouraging an openness to alternative points of view, developing an ability to weigh evidence and assess arguments objectively. Similarly communities of practice, is about learning, participating, engagement, identity and meaning-making in discourse analysis and knowledge sharing and becoming an expert within a particular knowledge network, thus moving from being a novice to becoming an expert. The apex of the linkage is learning and becoming a new person as a result of being exposed to knowledge. These linkages are illustrated in the diagram below:

Figure 3.2 Linkages between feminism, transformative learning and communities of practice.



3.5 Conclusion

The chapter identified three key theories that grounded the study. These are feminism, transformative learning theory and communities of practice theory. The chapter provided a discussion of each of the theories; their relevance to the study as well as the critique of the theories. In terms of the linkages between the theories, the chapter identified inter-connectedness of the theories with learning as their intersection; learning for emancipation and liberation from oppressive forces; learning for self-awareness and decision making and learning for participation and meaning making – moving from being a novice to expert.

The next chapter presents the research design and methodology for this case study.

CHAPTER FOUR: Research Design and Methodology

4.1 Introduction

The previous chapter laid a foundation of the theories upon which to ground this study. The methodological explorations of this chapter serve as a preparatory stage for obtaining information from the field relating to this case study. This chapter outlines the methodological approach, steps and processes that this study employed in order to obtain data from the field. It introduces the relevance of this chapter for this study. The chapter is divided into four parts. The first part looks at the methodology – research design and different research paradigms, and in particular the interpretivist paradigm selected for this study. The second part looks at the participants, sampling process and case study methodology with a discussion on the “case” for this particular case study. The third part examines the sources of data; data collection methods and processes and data generating, analyzing and reporting. The final part identifies the researcher positioning in the whole study – the ethical considerations, limitations of the study and conclusion.

I begin this chapter by recapping the purpose of this study. This study explores the coping strategies of Basotho women of child bearing age who are living with HIV and AIDS and are already on antiretroviral treatment; how they cope and thus learn to survive with their HIV and AIDS condition.

The Relevance of this chapter for this study

Methodology outlines a step by step process of investigating a research study. It provides a sense of vision, what it is that the researcher wants to investigate with the research. Its purpose is for a researcher to get out in the field to discover what is really going on; to examine the relevance of the theory/theories with the grounded data (Strauss and Corbin, 1990). This chapter is relevant to this case study, in that it provides a framework that helps to elicit the responses from the Basotho women of child bearing age, who are living with HIV and AIDS and are taking lifetime HIV treatment. It does so in order that their lived experiences with HIV treatment are known. Kaniki, (1999) advises that the more a method has been tested for use in studying a specific problem, the more reliable it will be.

Part One

4.2 Methodology

Methodology is defined by a number of scholars to mean the study of procedures used in research to create new knowledge. It spells out the nature of the scientific method adopted and its implication for conducting social research (Blanche & Durrheim, 1999; Babbie, 2010; Blaikie, 2010; and Hammersley 2011).

Research design

Research design as is viewed by a number of scholars, denotes a technical document that is developed to guide a research project. It is an integrated statement of and justification for, the technical decisions involved in planning the research. It encompasses all the structural aspects of a study. It specifies whether the study will involve groups or individual participants; whether it will make comparison within a group, or between groups and how many variables will be included in the study. It addresses how to implement the strategy bridge between research questions and the execution or implementation of research (Durrheim, 1999; Gary, 2009; Gravetter & Forzano, 2009; and Blaikie, 2010).

Having briefly defined what a research design encompasses, it is befitting to describe a research paradigm which is a linchpin, for all the processes that I discussed later in the chapter.

Research paradigm

The notion of a research paradigm stems from earlier scholars such as Guba and Lincoln (1994), and has since been adopted and used by other scholars such as Johnson, (2004), Krauss (2005), Ponterotto, (2005) and Weinstein and Foard (2006). In their definition of a research paradigm, Guba and Lincoln, (1994) see is as:

...a basic belief system or world view that guides the investigator not only in the choice of method but ontologically-theory of the essence of things, their true nature; and epistemologically - theory of the grounds of knowledge, i.e. how things can be known (Guba and Lincoln 1994, p. 107).

A paradigm represents a world view that defines for its holder, the nature of the world, the individual's place in it and the range of possible relationships, to that world and its parts, in the same way that cosmologies and theologies do. Guba and Lincoln, (1994) and Ponterotto, (2005) add other dimensions to paradigms. These are the axiological (the study of the nature, types and criteria of values and of value judgement, especially in ethics) and methodological lenses to a study enquiry. As the discussion of the different paradigms unfolds, I must state that the section has drawn heavily on Ponterotto's review of paradigms. A paradigm sets the context for the study. There are numerous paradigms that guide the research but key among them are those that are found to be the most concise and manageable. These are the ones commonly discussed by Guba and Lincoln, (1994): positivism, post-positivism, interpretivism and critical ideology. I focus on interpretivism, explaining its underlying philosophical assumptions and why it is an appropriate location for this study.

Interpretivism: This is regarded as alternative to the positivist orientation. Positivism holds an objective view of reality and a realist epistemology. It is based on the belief that social and natural science should incorporate the same hypothetical deductive method and should have the same goals. Interpretivism, in contrast, adheres to a relativist position that assumes multiple, apprehendable and valid realities. Ponterotto, (2005, p.128) cites Schwandt where he asserts that interpretivism maintains that reality is constructed in the minds of the individual rather than being an externally singular entity. Schwandt further points out that meaning is hidden and must be brought to the surface through reflection. This reflection can be stimulated by the interactive researcher-participant dialogue.

The key element that distinguishes this orientation from the rest, is its outstanding belief in centrality of the interaction between the researcher and the object of investigation. It maintains that it is by interaction that a deeper meaning can be uncovered.

Assumptions of this paradigm: This research philosophy holds a view that understanding of lived experiences from the point of view of those who live it day to day, is key. And that lived experiences occur within a historical social realities. They may be outside the immediate awareness of the individual but could be brought to consciousness. This orientation is often the primary foundation for a qualitative design (Krauss, 2005; and Ponterotto, 2005).

The study's positionality within the paradigmatic continuum and the rationale for its choice

I now position and justify this case study of a group of women living with HIV and AIDS, who are on HIV treatment, within the paradigm of interpretivism. The rationale for this approach lies in the very features or assumptions of the paradigm that holds a belief in a researcher-participant interaction as a way of exploring lived experiences by participants in order to uncover rich in-depth data from a phenomenon. This study therefore looked at perceptions and feelings of a group of women of child-bearing age who are living with HIV and AIDS and are on ARVs treatment. These women belong to (PBA). It examined the learning that took place, as the women went through their HIV and AIDS positive journey. It documented this journey, exploring deeply their emotions and feelings within the compass of this life threatening disease. It documented their "lived experiences" in the context of their relationships with their environment (society, partners, children, in-laws and friends). It explored the meaning-making that their newly acquired identity and status generated among them and the perceptions of the community about their HIV positive status. These meanings were explored and brought to the surface using reflection (a key tenet in Mezirow's ten-phase transformative learning). Krauss, (2005) citing scholars such as Frankl, Dewey, Lofland and Lofland and Chen, expounds on meaning and meaning-making and alludes to the fact that an individual draws meanings from or gives meaning to events and experiences. Meanings provides explanation and guidance for the experiences.

It is individual's subjectivity or phenomenological world, that forms the very core for meaning originating and evolvement...meaning is the underlying motivation behind thought, actions and even the interpretation and application of knowledge (Krauss 2005, p. 763).

Krauss further posits that the construction of meaning is the task of qualitative research.

How the study fits within the interpretivist paradigm using the philosophical lenses of ontology, epistemology, axiology, rhetorical structure, and methodology (Ponterotto, 2005, p. 132)

Ontological review: This paradigm holds a belief that there exists multiple constructed realities rather than a single true reality. Reality, according to this approach is subjective and influenced by the context of the situation (a position known as the relativist position).

Conducting research within an interpretivist model: In order to elicit reality with the available data, this model interviews only a handful of clients for a longer period of time.

Using epistemological lens: The interpretivist model advocates a transactional and subjectivist stance that maintains that reality is socially constructed and therefore the dynamic interaction between researcher and participant, is key to capturing and describing the "lived experiences" of the participants.

Applying the axiological review of the interpretivist paradigm: Axiology is concerned with the values in the research process. The values and lived experiences cannot be divorced from the process hence the researcher should acknowledge, describe and bracket his/her values but NOT eliminate them. They refer to this process as an inter-dependent researcher-participant interaction.

Rhetorical review of the paradigm: More attention is paid to subjectivity. An interactive researcher role prevails when presenting the report. The orientation uses first person and the report is often personalized. The researcher's own experience, expectations, biases and values are detailed comprehensively. Furthermore the impact of the research process on the emotional and intellectual life of the researcher, is reflected upon and discussed openly (Ponterotto, 2000, p.132).

Methodological review of the paradigm: The interpretivist paradigm's stance rests on the centrality of intense researcher-participant interaction and on the need to be absorbed over longer periods of time in the participants. It embraces naturalistic designs whereby the researcher is entrenched in the community participating in day-to-day life with his/her research participants. Methods such as in-depth face to face interviews and participant observation are key within this paradigm (Ponterotto, 2005, p. 132).

Having provided the paradigmatic position of the study, I now move on to discussing the participants, sampling process and the case study methodology with a particular discussion on the "case for this case study.

Part Two

4.3 Participants and Sampling

Participants:

Participants were women of child bearing age living with HIV and AIDS, who are members of the PBA in the Leribe district in 2013. PBA is an HIV support group of men and women who are openly living with HIV and AIDS. Below is the table that lists the participants using pseudonyms to protect their identities. The criteria and rationale for sampling are provided in Section 4.4 below.

Table 4.1 Participants' information

Participant	Age	Occupation	No of children	Ages	Year of HIV positive diagnosis
Thato	30	HIV lay counsellor	2	11,8	2008
Thabitha	25	HIV lay counsellor	2	7, 2	2010
Palesa	35	HIV lay counsellor	2	8 , 2	2007
Maliketso	34	HIV lay counsellor	3	13, 10, 7	2006
Joyce	22	HIV lay counsellor	None	n/a	2010
Puleng	26	Programme Officer	2	8, 11months	2004
Thandiwe	20	HIV lay counsellor	1	4	2011
Tukane	28	HIV lay counsellor	1	7	2006
Queen	31	HIV lay counsellor	3	13,11,8	2004
Libuseng 1	33	HIV lay counsellor	2	14,12	2006
Libuseng 2	23	HIV lay counsellor	1	11months	2013
Papali	32	HIV lay counsellor	2	5, 11months	2013
Portia	23	HIV lay counsellor	1	6	2010

4.4 Sampling

This is the selection of participants from the entire population which the study focusses on. It involves decisions in terms of which people, settings, events, behaviours and processes to observe.

The unit of analysis or the case, influences what will be sampled (Kaniki, 1999). There are different types of sampling techniques, which are random, snowball, purposive and stratified sampling. This study used purposive sampling.

Purposive sampling: Due to the nature of the inquiry, the study purposively selected 13 women of child bearing age; the youngest was 20 years old and the oldest was 35 years old at the time of the study. The participants were selected from PB when they came for their monthly meeting. It would be befitting to highlight briefly the educational background of the participants. While their occupation is that of HIV lay counsellors, suffice to say that this is the occupation they acquired as a result of training and capacity building efforts that they have been exposed to by the PBA, to assist them to cope with the HIV infection. They were not awarded as a result of

educational exposure per se. These were women who had completed primary education. There was one exception though – that of participant no.6 (Puleng) who went as far as tertiary education and was employed by the PB as the programme logistics officer. Details of selection/recruitment is provided in the next section under data collection process.

Sampling for self-administered questionnaires on the women

A total of 12 women participated in filling out the questionnaire. This was administered in June 2013. The questionnaire elicited basic information (age and experience with HIV and AIDS) in order to prepare for stratification for the next level of data collection.

4.5 Case Study Methodology

Exploring different perspectives about the case study methodology

I begin this section by providing a bird's eye view of some of the authors' perspectives about the current application or practice of case study methodology, the features of the case study, the definition of a case study, types of the case study, strengths and limitations of the case study, the case in the case study and I end by positioning this study within its appropriate context.

Case study approach seems to be one of the principal means by which inquiry within the social sciences is conducted. Despite the popularity of this design, it has been argued by most scholars that there is little agreement in the way the structure is organized. Research practitioners continue to apply/use this design but fail to clearly articulate what is it that they are doing. These views are expressed by among others Verschuren, (2003); Yin, (2009); Rule and John, (2011; 2015) and Thomas, (2011). These scholars point to the many flaws which render this methodology inappropriately employed. These flaws range from the very definition of case study, to the application of the methodology itself. Verschuren, (2003) identifies ambiguities with this design. Key among them is the perception that most people see it broadly as any type of research, or case study as a type of research as being clear, or the object to be studied and

how it is looked at as well as the results obtained, are not clear. His other argument is that the scholars' perception of a case study is confined to one single case only, instead of being looked at, as a way of doing research at a broader level. The definition of the case study, too, he claims, seems too hazy – it is given little specificity by some scholars while others advocate for its use in any context, as long as it contributes to the knowledge of the case to be studied. Verschuren further points to the results of the inquiry using this methodology and questions the researcher's independence due to his/her interactive role with participants as opposed to researching 'from a distance', which then makes the results of the inquiry questionable. Yin, (2009) confirms the argument by pointing out that some researchers see it as the exploratory stage of some other type of research method, thus submerging it or under-representing it, in such studies. He, however acknowledges some of the prejudices against case studies, and he provides a number of variations within case studies, as a research methods. These flaws are elaborated in Yin, (2009, pp 19–20).

Key features of a case study

In trying to close the misconception gap within the case study methodology, VanWynsberghe, (2007); and Yin, (2009) provide the following key features of a case study. A case study calls for an intensive and in-depth focus on the specific unit of analysis. It requires a small sample size than would be in a survey. It should give a reader a sense of "being there" by providing a highly detailed contextualised analysis of an instance in action and in addition, it employs multiple data sources.

With these arguments and features of the case study methodology in the next section, I provide a definition of a case study; how I identify a case within a case study and; the strengths and limitations of a case study.

Defining a case study

There are a lot of scholars who contributed to the definition of a case study, for example Tellis, (1997); Harling, (2002); Johansson, (2003); Simons, (2009); and Rule and John, (2011). They

point to the features such as the empirical nature of case study, its focus on a contemporary phenomenon, its depth and attention to context, and its spatial and temporal boundedness.

Yin, (2009) looks at case study holistically and gives it two lenses. The first lens looks at a case study as scope-based and his second lens, sees case study within its technical context. Referring to a scope-based lens, Yin talks about “real-life context” and in its technical contexts. He includes data collection and analysis strategies such as its reliability regarding multiplicity of data sources and data needing to converge in a triangulation fashion, and how it benefits from development of theoretical propositions to guide data collection and analysis. Written as a complete and perhaps more encompassing case study it denotes:

...an empirical inquiry that investigates *a contemporary* phenomenon in-depth and within its *real-life* context, especially when the *boundaries* between phenomenon and context are not clearly evident. The case study inquiry copes with the technically distinctive situation in which there will be many more variables of interest than data points, and as one result. It relies on *multiple sources of evidence* with data needing to converge in a triangulation fashion, and as another result. It benefits from the prior development of theoretical propositions to guide data collection and analysis (Yin, 2009, p.18).

Types of case studies

There are several types of case studies, but the most prominent and commonly used ones are exploratory, explanatory, descriptive, intrinsic, instrumental and collective. Yin, (2003) identified the first three types: exploratory, explanatory and descriptive; while Stake, (1995) added three more, which are: intrinsic, instrumental and collective case studies. Each type of case study, is briefly explained below:

Explanatory: Seeks to answer questions that sought to explain the presumed causal links in real life interventions that are too complex for the survey. The **exploratory type** explores situations in which the intervention has no clear, single set of outcomes. The **descriptive** type is used to describe an intervention or phenomenon in its real life context.

The **intrinsic** type is driven by the particular interests of the researcher, due to an interest in learning about a particular case because of its unique features. The **Instrumental** type is used when a researcher aims to accomplish something other than understanding of a particular situation. This type provides insight into an issue or helps to refine a theory (Stake, as cited in Baxter and Jack, 2008).

The **collective** case study (as the name implies) is used when collective case studies are similar in nature and description to multiple case studies (where a particular case is extended to cover several cases, to learn more about the phenomenon, population or general condition (Yin, 2003).

Identifying the case in the case study

A case in a case study is determined by the boundaries of the case. It is the unit of analysis. It is the “what” of the study. It ranges from a person, a class, a practice, an institution, a programme, event, policy or a relationship. Issues for consideration when constructing a case are: a) the decision on what will constitute a case; b) the delimitation of the time frame (whether spatial – settings where this case will be investigated); temporal (setting out chronological boundaries e.g. whether it is contemporary or historical) and thematic (identifying issues to be investigated with the case) and c) consideration on what will be investigated with the case (Rule & John, 2011).

Strengths of a case study

This approach is used for a number of purposes as it bears particular strengths. Key among them, are that it can generate an understanding of insights into a particular phenomenon by providing its comprehensive description and illuminating its relations to the broader context. It can be used to explore a general problem or issue within a limited or focused setting. It can also be used to generate theoretical insights, either in the form of grounded theory that arises from the case study itself in developing and testing theory with reference to the case (Rule & John, 2015). It is flexible in terms of what it studies. It can employ a wide variety of methods (in data collection

as well as in data analysis) depending on what is appropriate to the case (triangulation i.e. process of using multiple sources and methods to support propositions of findings).

With the elaboration of the strengths of the case study methodology, in the next section I use scholarly writings to identify possible weaknesses or limitations that the methodology has.

Limitations of the case study methodology

Some authors (Pillay, 2006; and Yin, 2009), have identified some limitations on the use of case study methodology. Key among them are its quality and rigor, especially if the researcher is not fully conversant with the methodology. There may be problems with the validity of information. Case study's generalization of finding especially from single cases may not be possible. The other limitation is its possible bias due to over exposure of the researcher to human subjects.

Having briefly discussed the case study methodology in general, the study now takes its positionality about the type of case study that it used, as well as the rationale for its application.

The type and case for this case study

In this particular study, the case is a group of Basotho women belonging to the PBA. This case study uses both the exploratory and instrumental type (as described by Yen and Stake in the previous section). It is exploratory because investigations were conducted into relatively unknown areas of research. Within the study area, there has not been a study of a similar nature. Although it is primarily exploratory research, it also has descriptive elements in that it provides an in-depth description of the case, and explanatory elements since it uses theoretical lenses (feminism, transformative learning theory and communities of practice theory) to make sense of the data. The instrumental type was relevant for this case study in that it sought to understand more than what was obvious to the researcher; it provided insights into an issue and helped to refine a theory (Tellis, 1997, p.1).

The focus within this case, is on the learning experiences of the women as they went through various processes of coping and learning about their HIV positive condition, the ARV programme and the wider socio-cultural situation of the district and the country. The case study examines these women, from the period 2005 to 2012. This case study uses a qualitative style that I describe in the section below.

A qualitative style

A qualitative approach involves taking people's subjective experiences as the essence of what is real for the study. This style makes sense of people's experiences through interacting with them, listening carefully to what they say and to make use of data collection techniques such as interviews, questionnaires, group discussion etc, to elicit responses from the people. Situated within the paradigm of interpretivism, qualitative style relies on first-hand accounts, and it tries to describe what it sees in rich detail and it presents its findings, in engaging and sometimes evocative language. The style according to the following scholars (Blanch, Kelly, and Durrheim 1999; Simons, 2009; and Rule & John, 2011), focusses on how people feel, think and act.

The next part looks at data collection methods and processes, data generation and analyzing and reporting.

Part Three

4.6 Data collection methods

Data collection methods for case study research are many. Some of them are interviews, documentation, archival records, direct observation, and participant observation, transect walk, questionnaires, focus group discussions and physical artifacts. This case study used questionnaires, interviews (one-on-one and group interview) and focus group discussions. A detailed description of each of the applied methods is provided below. Suffice to mention that

for each method, the researcher used the vernacular to enable the participants to understand what is being asked.

Duration of the data collection process:

The questionnaires took a maximum of one hour to complete. The one-on-one interview ranged from a minimum of 45 minutes to a maximum of 1 hour for each participant. The focus group discussion, as I have already mentioned, dragged from the 20 minutes that was initially allocated to 1 hour. It is befitting to reiterate on the longevity of the focus group, that participants seemed to be willing to participate, given the nature of the study which they seemingly enjoyed.

Each of the methods are described below:

Questionnaires

Marshall, (2006) provides a holistic view of the questionnaire as a data collection instrument. In elaborating on its uses, he brings in the element of its ability to collect data from a large number of people simultaneously. It has a bi-purpose nature of using both open or close-ended questions or items that measures facts, attitudes or values. Close-ended questions compel a participant to respond only to the asked questions. The open-ended questions allow participants to provide a more complete or comprehensive response. While open-ended responses might seem difficult to analyse, Marshall, (2006) argues that open-ended responses provide specific and meaningful information.

Strength of this tool

Questionnaires can yield high quality usable data. The researcher is likely to achieve a good response rate with the use of questionnaires. Questionnaires provide anonymity, thus it encourages more honest and frank answers. They also reduce some element of bias. The majority of participants understand what is being asked of them, therefore there are high possibilities of getting relevant responses to the questions asked.

Limitations with the use of questionnaires

Questionnaires are unsuitable for illiterate people and the visually impaired, unless they are suitably modified. The questionnaire format has the potential of creating gaps in the completion of information because the researcher may not be able to monitor its completion. Confusions caused by the questionnaire cannot be easily clarified. Questionnaires may pose the challenge of unlimited presentation of information – does not have room to probe for additional information (Marshall, 2005).

Special considerations for using questionnaires

The response success rate with the use of questionnaires requires careful planning and design as well as an effective method of distribution. Marshall, (2005) identified some of the considerations that the researcher needs to be aware of when designing a questionnaire. These include the issue of wording. The questionnaire should use every day wording to enable participants to understand what is being asked. It should use simple and easy to use words that participants can easily relate to. Other elements to consider include minimum use of jargon as more jargon can end up distorting the meaning of what is being asked. The other issue relates to the sequencing of questions which Marshall cautions that it is better to begin with easy, non-threatening and less sensitive questions, then to gradually delve into more complex ones as the process continues.

Interviews

A number of scholars provided their contribution about the interview as a data collection instrument. Some of them are Simons, (2009); Yin, (2009); and Rule and John, (2011). They view interviews as the most common sources of case study information. Interviews are conducted at two levels; an in-depth interview – which asks about the facts of the matter, as well as opinions about events. The other level is the focused interview; in which a person is

interviewed for a short period of time – leaving the interview still open for an open ended session, as and when additional information becomes necessary.

Confirming the richness of data emanating from the in-depth interviews, the following is the purpose of in-depth interview: to document the interviewee's perspective on the topic; to promote active engagement and to offer flexibility to change direction to pursue emergent issues. It probes the topic thereby eliciting or deepening a response. This method has the potential to uncover and represent unobserved feeling and events that could otherwise not be observed.

Focus Group Discussion

The focus group discussion is a conversation or dialogue between groups of people who share similar types of experiences. It is useful for gaining a sense of the discussion in a group setting. The diversity of views, of how dialogue/conversation shifts, the understanding of members in a group, are what promote the discussion. Focus group discussions are used to generate information on collective views and opinions as well as meanings that participants make behind those views. They are also useful in generating rich understandings of participants' experiences and beliefs. A focus group discussion is useful when the researcher has a series of open-ended questions and wishes to encourage research participants to explore the issues of importance to them in their own vocabulary, generating their own questions and pursuing their own priorities (Kitzinger, 1995; Gill, Steward, Treasure & Chadwick, 2008; and Simon, 2009).

4.7 Data collection process for this case study

Due to the sensitivity of the topic, as it touches the human subjects, the researcher submitted an application for permission to conduct the study to the Ethics Committee of the Ministry of Health of the Kingdom of Lesotho, prior to conducting the study. The request was made in the form of a proposal detailing what methodology would be applied in the study. This was in line with

Simons, (2009); and Rule and John, (2011) articulations of research ethical procedures. When approval was received, I telephonically informed the management of PB that I intended to conduct a study within their organization. In the conversation, I mentioned the aims and objectives of the study and the value added of the study to the organization. At that level too, I received approval.

Process focus

The study included self-administered open ended-questionnaires, in-depth one-on-one interviews, group interview (with PBA management) and focus group discussions. While most of the responses were of a qualitative nature, there are some areas where data has been presented in table format. These particular areas pertain to the participants' bio-data and statistical information and the global, regional and national, HIV and AIDS situation.

The questionnaire administration process

To set up the questionnaire session, I contacted telephonically the PB management to allocate a suitable time and date for me to present on the study. The management arranged an appointment for me to meet with the participants. During their monthly meeting in June 2013, the programme management gave me a slot to present my mission. I introduced myself and the purpose of my visit as well as the benefits that the study would have to the organization. I then requested any women of the age cohorts mentioned in the sampling section above, to voluntarily participate in the study. I explained the format of the questionnaire- how it was going to be administered. I told them about the need to have their written consent before filling it out. Simons, (2009) stresses on the importance of seeking a written consent prior to engaging in a data collection method that it demonstrates an element of good ethical practice. I explained about the issue of confidentiality in that all information requested would remain with myself and the research team. Initially there were 23 women who volunteered to participate, but when I did the screening in terms of age,

eleven of the women did not qualify due to age. They were relatively older than the required age cohort. I was then left with only 12 women who I regard as participants in this study. Each participant filled out the consent form and later on, completed the questionnaire.

The questionnaires were distributed by myself and my Research Assistant. The questionnaires were written in the vernacular to enable the participants to fill them out with ease (a copy of which is attached and labelled Annex “6”). I read out each question with the participants and allowed them time to ask questions for clarity. I clarified the issue of anonymity explaining that the participants would remain anonymous throughout and even after the study has been completed. I emphasized their choice to participate or withdraw from the study anytime they wanted to. After the question time, the participants completed the questionnaire. The questionnaires were mostly open-ended, with a few sections on bio data that were close-ended type of questions. After completing the questionnaire, I told the participants that I would call them for another level of data collection whenever I felt that additional information was required. Each one of them gave me their contact details.

The Interview process

These were conducted in July 2013 with 13 women. Suffice to mention that during this second visit, an additional participant (Joyce) who was not present during the first visit, expressed her willingness to join the study. This made a total of 13 participants. The interviews took two days to complete. The duration for each interviewee ranged from 60 – 67 minutes. Since the participants had been aware that a second level of data collection might be needed, it became easier to invite them for the next level. I called the PBA Programme Management, to request them to inform the participants that the second level of data collection was being requested. As in the previous meeting, I took advantage of their monthly meeting in July, to do the one-on-one interview.

Before the interviews commenced, each participant was reminded about their option to withdraw from the study anytime they felt like it and were assured of their confidentiality and anonymity, throughout the study period. One element that was included in the meeting was that a voice recorder was going to be used. Their consent for their voices to be recorded was given. To ensure anonymity, I asked each one of them to choose their pseudonyms which the study was going to use throughout the interview. The additional participant (Joyce) too fill in the consent form. For the rest of the participants, the consent forms that they had filled in before, were still relevant for the interview sessions.

The interviews were conducted in the vernacular, translating the English version into Sesotho, to allow participants to respond with ease. In the first part of the interview, the participants were asked if there was anything they wanted to tell which was otherwise not covered in the questionnaire. Most of them noted that the issue of how they felt when they discovered they were living with HIV and AIDS, was not asked and that became the starting point for the story telling which they did in a self- directed and open-ended fashion. At the end of the interview I reassured each participant that additional information would from time to time be requested as necessary. In addition, participants were informed that there would be another level of data collection in the form of focus group discussions on the topics that would be chosen. They all expressed their desire to join in the discussion. At the end of the interview I informed PBA of the next steps in the data collection process. They gave me permission to continue.

Focus Group Discussion

One focus group discussion was held with the participants in January 2014. A total of eight women participated in the discussion. The focus group discussion was conducted to explore more deeply some of the issues arising from the interviews and as a way of observing these women in

a discussion – how each one of them was participating on each discussion point. There were four topics that the women were deliberating on. The topics are listed below:

Topics

- **Family reaction towards a woman who live with HIV and AIDS**

Did you receive support when you told your husband you were living with HIV and AIDS?

What happened to your sexual relations?

How did you approach the issue of safer sexual practices? What did you say? What was his reaction?

If your partner hears that you are a member of the Association of people living with HIV and AIDS how does that make him feel, and what does his reaction towards you make you feel?

- **Child Bearing**

How did you deal with your spouse, in-laws and community who pressurize you into having a child? What did you tell them?

- **Treatment intake**

How do you feel about life-time treatment?

What do you do to ensure that you do not miss it?

Are you comfortable taking medication in the presence of other people- at work, at home, during gatherings (where there are many people)? If some people who do not know about your HIV status see you take medication and ask about it, do you tell them the truth about the drugs you are taking?

How has the exclusive 6 months breast feeding programme affected you – what are your experiences?

- **Your participation in a support group**

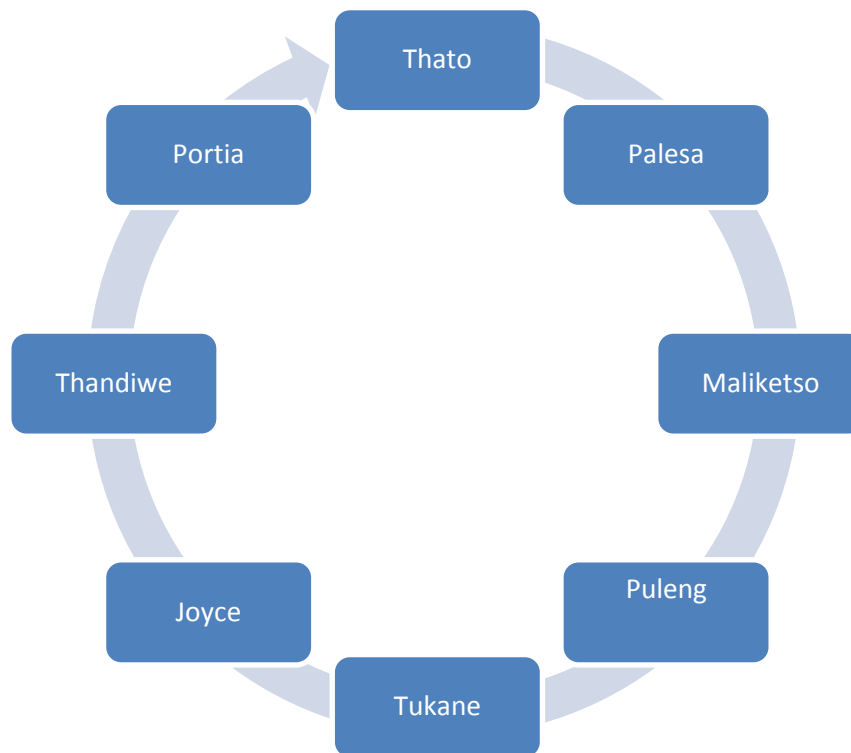
What have you learned from your membership in the PBA?

Apart from HIV and AIDS competency, are there other skills that you have developed as a result of your participation at PBA?

The maximum time allocated for the focus group discussion was 20 minutes but it dragged for close to 1 hour.

Below are participants at a focus group discussion:

Figure 4.1 Participants of the Focus Group Discussion



The focus group discussion process

I telephonically informed PB management about the third level of data collection process. They (PB) gave me the date when the participants would be available for their monthly visit. The exercise was conducted in January 2014 (almost six months since we last met). I introduced myself and highlighted the importance for participants to freely and voluntarily participate or opt out of the study. The eight women who participated all expressed their desire to participate in the discussion. Likewise their anonymity and confidentiality of the issues to be discussed was assured. I received permission to record the discussions using a voice recorder. I then explained how the focus group discussion would be conducted. Key issues clarified by the participants were the need to allow each participant to share their perspectives; to stay within the allocated time and to be mindful not to dominate the discussions. Surprisingly, they still recalled the

pseudonyms that they had given me during the interviews in July 2013. The discussions were at first slow but as the second topic was being discussed, more perspectives came through until the allocated time lapsed. Participants asked for more time in order to finish discussing all the four topics. At the end of the discussion I informed the PBA management about my intention to visit them, to verify some of the data reported by the participants, especially the data regarding knowledge acquired from their participation in the PB.

Telephone interviews with PBA programme management staff

Three programme management staff of the PB Association (The Programme Manager, Programme Officer and Monitoring and Evaluation Officer) were interviewed jointly. It was deemed important to interview the programme management staff in order to elicit their responses for the various coping processes that the women had reported to have happened. In addition, as a way of testing the communities of practice theory, the data were especially imperative in order to assess the level of participation of these women in the association and to allow for triangulation of data. In his discussion of data triangulation Yin, (2009) encourages researchers to collect information from multiple sources, corroborate it in order to minimize potential problems of construct validity, because multiple sources of evidence provide multiple measures of the same phenomenon. The telephone interviews were conducted in March of 2014. The interview took 22 minutes. The gist of the interview centered on some key tenets of the communities of practice theory (community, identity, meaning and practice).

The Group interview process

The PBA management was initially approached for an individual interview. Later on, I was informed that it would not be possible to have each staff member separately for an interview, given the work load. Instead a group interview would be the better option. I sent via email, a set of questions that was going to be asked. In the email I highlighted issues of anonymity and confidentiality as well as voluntary participation in the study. On the day of the interview, the

PB management arranged a telephone conference. Each of the programme staff members responded to almost all the questions. Whenever a question was asked, they took turns in responding. Where clarification was sought on certain issues – especially on meaning-making – every officer gave their understanding of meaning-making until the responses made sense to me (a summary of the PB responses are annexed to the study).

Transcription of the vernacular responses: All the responses that I received from the questionnaires, interviews and focus group discussions were transcribed by myself only, as a way of complying with the ethical considerations of protecting the participants' sensitive information from any possible identity.

4.8 Data analysis process

Yin, (2009) identifies five techniques to be used when analyzing case study research. These are pattern matching, explanation building, time-series analysis, logic-models and cross-case synthesis. In the five techniques, the appropriate technique that the study used, is explanation-building which according to Yin, occurs in narratives form:

...because narratives cannot be precise, the better case studies are the ones in which the explanations have reflected some theoretical significant propositions (Yin, 2009, p.141).

Similar to the explanation building technique is the thematic and content analysis – a systematic examination of text (field notes) by identification and grouping themes and coding, classifying and developing categories. Yin, (2009) posits that data undergoes five key steps, these are familiarisation, inducing of themes, coding, elaboration and interpretation and checking.

Expounding on thematic and content analysis, Rule and John, (2011) indicate that after coding of data, the researcher now identifies patterns such as similarities, differences and code absence from data. The codes are grouped into categories and are given a name.

...from the categorization and search for patterns of meaning now comes themes ...
(Rule & John, 2011, p. 78).

This case study collected data from three sources, as discussed in the data collection process section), from the data, similar meanings/connotations were grouped together to generate a sub-theme, out of which a large collection of similar data was later on grouped together to generate a theme, then the theme became the content for analysis.

The themes and sub-themes that this case study generated, appear in the table below:

Table 4.2: Generation of themes and sub-themes for this case study

Themes	Sub-Themes
HIV testing	Factors that prompted an HIV test HIV positive results Initial disclosure
Male domination	Out right support Delayed support Lack of support
HIV disclosure	Reaction by: spouse, children, in-laws, friends and community
Stigma and discrimination	As demonstrated by: spouse in-laws community
Child bearing	Development around HIV positive mothers and child bearing Not being afraid to bear children per se but challenge with financial stability
Picking up pieces in the family	Mending relations with spouses Mending relations with children
Picking up pieces towards personal health	Accessing treatment Surviving with treatment Side effects Mitigating side effects
Joining support group	Motivation for joining support group Role of support groups Breaking the silence around HIV and AIDS Gaining more knowledge about HIV and AIDS Additional skills acquired Contributing and sharing the knowledge gained Recognition by the community

The last part now identifies the researcher's positioning in the study. It looks at the ethical considerations, limitation of the study and conclusion.

Part Four

4.9 Researcher's positioning, trustworthiness, ethical considerations and limitations

Researcher's positionality

The researcher's positionality in the study and ethical considerations are vital for ensuring trustworthiness and quality as well as rigor of this study. Therefore the last part of the chapter looks at who the researcher is, how is she related to the study as well as what measures were put in place to protect the study and its subjects.

In a case study research, it is important to make explicit the researcher's positionality. What role does he/she have in the study, whether he/she holds a position of influence which might have facilitated and or hampered the smooth implementation of the study? In addition does the researcher have any vested interest in the study?

Likewise, I outlined my position in this case study, the motivation behind the study and how my position of power may have influenced the outcome of this study. Rule and John, (2011) send out a word of caution for a researcher's position in the study, and how it can potentially influence the study's quality. They emphasise the researcher's sensitivity to issues of power and relationships which could compromise the quality of the study.

In this case, my position with the participants was that from 2007 to 2011, I had had a direct contact with management of the PBA as an HIV and AIDS district coordinator. Apart from being in series of HIV and AIDS technical meetings with this organization, I also provided strategic direction on the management of HIV and AIDS programmes. This previous position accorded me the opportunity to obtain data from the participants with ease. Suffice to say that I bore that in mind, and kept reminding and assuring the participants that the information that I was

requesting from them was purely for my academic advancement, it did not have any bearing on the work that I did with them or that I was doing in my current portfolio.

I continuously reminded the Association that they should look at me as an individual who had no authority over them anymore. My personal interest in the work of the Association within the district illuminated my interest to document that work in my doctoral studies. The existing relationship helped participants to be open. My previous position of authority could have created a situation whereby participants would have not fully expressed their emotional feelings, given my previous day-to-day professional encounter with them.

Trustworthiness: A case study research undergoes series of alternative measures in order to assess its quality and rigor. Trustworthiness therefore denotes rigour and professional ethics of the research. To ensure trustworthiness attention is given to the four key elements. These are the study’s transferability, credibility, dependability and confirmability (Guba as cited in Rule & John, 2011). Each of the elements as expounded by Shenton, (2004) are listed in the table below:

Table 4.3 –Elements of trustworthiness in Case Study Research

Quality criterion	Possible provision made by researcher
Credibility	<ul style="list-style-type: none"> • Adoption of appropriate, well recognised research methods • Early familiarity with culture of participating organizations • Triangulation • Tactics to help ensure honesty in informants • Interactive questioning in data collection dialogues • Negative case analysis • Debriefing sessions between researcher and superiors • Description of background, qualification and experience of the researcher • Member checks of data collected and interpretations/theories formed • Comprehensive description of phenomenon under scrutiny • Examination of previous research to frame findings

Transferability	<ul style="list-style-type: none"> • Provision of background data to establish context of study and detailed description of phenomenon in question to allow comparisons to be made
Dependability	<ul style="list-style-type: none"> • Employment of overlapping methods • In-depth methodological description to allow comparison to be made
Confirmability	<ul style="list-style-type: none"> • Triangulation to reduce effect of investigator bias • Admission of researcher's beliefs and assumptions • Recognition of study's methods and their potential effects • In-depth methodological description to allow integrity of research results to be scrutinized. • Use of diagrams to demonstrate "audit trail"

Source: (Shenton, 2004, p. 74)

The case study compliance to trustworthiness

Each of the four criterion quality measurements have been adhered to in this study.

Credibility: to ensure that the study meets the credibility criterion, I applied some of the steps. For instance, I adopted appropriate, well recognised research methods (as outlined earlier in this chapter). I conducted this study in Leribe with participants that I am familiar with (my positionality section bears reference). In terms of triangulation, the study used two sets of informants – the women living with HIV and AIDS and their programme management team. I did a debriefing session with both the participants and the programme management team at the end of each session and proposed possible dates when I would come for the next level of data collection.

Transferability: The study has been able to provide background data pertaining to the HIV and AIDS position at the global, regional and local contexts in chapter one.

Dependability: The study has the potential to be replicated under different circumstances due to its rich description of HIV and AIDS and women.

Confirmability: The study has been able to minimize bias through engagement of different data collection methods. The study used questionnaire, interviews and focus group discussions. My beliefs and assumptions about the methodology is documented in Chapter Eight.

4.10 Ethical considerations

A study cannot be a good study, unless proper ethical considerations have been maintained. Rule and John, (2011) opine that conducting research in an ethically sound manner enhances the quality of research and contributes to its trustworthiness.

A sensitive topic of HIV and AIDS is among those that require strict adherence to ethics. In fact researching any sensitive topic requires the researcher to constantly assure participants of safety and protection of their information. Sometimes it is important to preface sensitive questions; for example, it is best to forewarn the interviewee of the types of questions or information that is going to be requested from him/her.

Research ethics as observed by Hen, Weistein and Foard, (2006) are moral principles which they claim

...guide activity from inception to completion. They are factors which arise when we try to decide between one course of action and another, not in terms of expediency or efficiency, but by reference to standards of what is morally right or wrong (Henn et al., 2006, p.67).

Some of the ethical considerations or ethics that this case study observed, were in line with the ethics of qualitative social work research, as viewed by Peled and Leichtentritt, (2002) in which a researcher sought informed consent from the participants and demonstrated honesty (non-deception). Research participants each filled in a consent form in which they agreed to participate in the study. At each level of data collection, I kept reminding the participants that they were free to withdraw from the study whenever they felt like.

I ensured absence of psychological or physical harm. To this effect, I engaged a psychologist to take care of any unpleasant emotions and any harm that may have been experienced by the participants during the course of the study. I had the benefit of using one of my colleagues at school to stand in as a psychologist. She is a renowned HIV and AIDS counsellor, with a strong background on psychology and was working in the district in which the study was conducted. Every time I held interviews with the participants, she joined me, although located in a separate room from where the interviews were being conducted. I advised the participants about the availability of the psychologist and that they were free to meet with her, anytime they felt like it, during and after the interview.

In terms of privacy and confidentiality of the data, I kept all data for this case study at a place known to myself only. To protect participants' anonymity, the study used nicknames for all the participants and used pseudonyms in the presentation of the data. The interviews were conducted in an environmentally friendly atmosphere, participants were given refreshments before, during and after the interviews. Participants were reimbursed with respect to their transportation costs to and from the study area. My research assistant assisted with the transport and meals logistics during the interviews. This was done due to long distances some of the participants travelled, and the long hours they each waited to be interviewed, which extended beyond the normal lunch hours.

4.11 Limitations of the study

Due to sensitivity of the study – which directly touched on the feelings and emotions of the human subjects, delays in obtaining Ethics Committee approval from the Ministry of Health of the Government of Lesotho was encountered.

Participation criterion became a barrier to obtaining data from a diverse group as detailed in the sampling section. In addition it was not feasible to obtain data from all the three categories stratified sample groups. The 14 – 19 age category did not have any participants therefore the study has high possibilities of missing the perspectives of young teenage women living with HIV and AIDS, who would have been newcomers within the motherhood realm.

The data for the study relied on the availability of the participants who came for their monthly meetings at PB, otherwise participants were spread across the Leribe district, which made it difficult to contact them directly individually as and when I would have liked. The stratification of participants for the focus group discussion, was not possible given the small number of participants who were available for the group interview.

4.12 Conclusion

The chapter discussed the overall research design and methodology for this case study. The study has found its location within the interpretivist paradigm and alluded to the four philosophical lenses of epistemology, ontology, axiology and methodology. The case study employed a qualitative style. The chapter further identified the “case” or unit of analysis within this case study, with its justification for identifying this “case” within a case study methodology. Sources of data, methods employed in collection of data and how data were analysed, were discussed. At the end of the chapter, I identified and discussed the researcher’s positionality within this case study as well as the ethical considerations and the study’s limitations.

Having discussed the methodology, the next chapter looks at what the participants narratives under the metaphor of “taking the bold step”.

CHAPTER FIVE: Taking the Bold Step: Presentation, Findings and Analysis

5.1 Introduction

This is the first of the two chapters that present the findings and analysis of data acquired from the field. The objective of this chapter is to bring to the fore, some of the learning experiences that women living with HIV and AIDS go through regarding HIV testing and disclosure to their families and communities.

The core motif that the chapter adopts is the notion of “taking a bold step”. This motif emerged from a meta-analysis of the data and is used to organize and link the women’s experiences of HIV and the initiatives they took in response to these.

What I intend putting forward as my key argument for this chapter, is that it takes a bold step for a woman to go to the health centre to test for HIV. It further takes a brave face for a woman to disclose her HIV status to her partner (whom she never sought permission from prior to testing), to her children, in-laws, and to her friends.

The bold step denotes a journey that the women living with HIV and AIDS take towards learning and transformation. In this journey, as will be seen, there were often obstacles and resistance received from their families and community. These steps have had multiple effects across the women’s lives. The key actions I consider bold steps in their journey to learning and transformation are: i) HIV testing; ii) disclosure to different people (partner, children, friends, in-laws, parents and community) and subsequent different reactions; (iii) enrolment on HIV treatment; and (iv) joining the support network/group. Each of these steps has been illustrated by responses from the women and further supported by literature drawn mainly from the African perspective as well as insights from elsewhere.

It is worth noting the overlap between some bold steps with the findings of the next chapter on “picking up pieces and moving forward” but this chapter has been structured such that it discusses HIV testing and HIV disclosure, to partners, children, in-laws and friends only. The issues of treatment enrolment and joining the group or support networks are discussed in the subsequent chapter under the title “Picking up the Pieces” (Chapter Six). The chapter discusses some of the possible barriers for HIV testing and subsequent disclosure within the African context. These are related to gender relations as they impact on HIV and AIDS. The chapter concludes with a summary of the findings and discussions as well as identifying any new learning as a result of the responses made.

The study participants are thirteen women whose profiles are documented in the methodology chapter (Chapter Four).

As will be seen from the data presentation, most of these women have partners who work in the mines in the Republic of South Africa. The literature reveals that the tradition of Basotho men taking up work in the South African mines, is a critical explanation for the high level of HIV and AIDS in Lesotho.

...this is so because mine workers are typically housed in single-sex hostels, around which a vibrant sex industry established itself.....(Kimaryo, et al. 2004, p. 70).

This statement, however, does not in any manner suggest that the source of the specific participants’ infection is their partners who work in the South African mines per se, but rather positions some of the factors that form the pattern for the HIV infection for the country. Some of the responses as will be seen pointed to the fact that some women living with HIV and AIDS had HIV negative partners but later on became infected (Portia, Libuseng² and Palesa).

5.2. Gender Relations

I intend to situate this chapter within the framework of gender, noting that these are African women whose lives were shaped by the gender norms of their predominantly patriarchal society, even if at times they chose to resist these norms. It could be assumed that gender relations would negatively or otherwise impact on the women's ability to undertake the journey of knowing their HIV status. As has been documented in the literature review (see Chapter Two), unequal gender relations position women at a disadvantage compared with their male counterparts.

I provide here a bird's eye view of how gender relations impact on the general well-being of women, quoting some of the statements made by the study participants, as well as backing up the statements with reference to the relevant scholarship.

Unequal power relations as discussed in Chapter One, manifest in gender-based violence; levels of which are high in southern Africa. Young women are often victims of non-fatal violence such as domestic abuse and sexual assault. Harrison et al., (2015) identifies a strong association between experience of violence within intimate partnerships, sexual abuse and women who experience trauma, abuse, or other forms of sexual violence as being at increased risk of HIV infection. Women's lack of power (given their vulnerable position), too, prevents them from negotiating for safer sex. Male gender norms of engaging in risky sexual practices coupled with the societal expectation of male authority, are viewed by a number of scholars (Langen, 2005; Boer & Mashaba, 2007; and Dirkx, 2012), as limiting men's ability to show vulnerability.

This gender power imbalance was reported to be very strong in my study. From the one-on-one interviews with the women, it became clear that men were primarily the ones refusing or preventing their partners from getting tested. In some cases, the males apparently seemed to have known their own HIV status (they had tested elsewhere: most of them tested for HIV while they were in the mines in South Africa; others tested in the country during HIV testing campaigns -

but somehow they hid their HIV status from their partners). Maliketso, Thabitha, and Queen are some of the women who witnessed the effects of power imbalances with their partners who refused to test for HIV. She explained it in this way:

...he said, "Ummm when I was on my way home, I met people along the way. They tested me, they said I have that thing, but they were not telling the truth. I don't and I can never have that thing" (Maliketso explaining her husband's statement about testing).

Male dominance in the HIV and AIDS context unfortunately translates into breaking up of relations, not only between the couples but also among the in-laws. Once the males go to report their partners' HIV positive status to their parents, conflicts erupt in the entire home.

Male dominance has become an innate intergenerational practice among societies that now seemingly interferes with other safety nets that the society might opt for to sustain their lives. The classical example of this is the notion of women who opt to leave their marriage due to their partners' refusal to use a condom. Queen for instance has had to leave or end her marriage in order to manage her HIV treatment. In some instance, some women, in an attempt to keep peace, they often times, succumb to having unprotected sex. Thato has this to say regarding her partner's demands for unprotected sex:

...he said he does not like to use a condom, we continued with unprotected sex in the house, hoping that he will eventually change his mind. I also thought by so doing I will calm him down and then later on reintroduce condom use (Thato confessed, almost in tears).

Linking male dominance to a low economic status of women, it has been identified in Chapter Three (methodology chapter) that the study participants had a low educational level – only one participant had a university degree, while the rest of the team had gone as far as junior secondary education – the level at which it was difficult to be gainfully employed within both the private

and public spheres. The advantage that men had over their spouses, was that they were employed as labourers by the mines in the Republic of South Africa and thus were the bread winners. Women, for fear of being denied food and other household needs and materials that are provided for by their spouses, would not argue with them over safe sex. – In fact even culturally, a woman is supposed to be submissive and not question her spouse’s decisions. This is explained by some scholars thus:

...even if a woman knows or suspects that her partner engages in sexual activity outside the relationship, her subordinate status will likely leave her unable to insist on preventive measures (Marcella, Raffaelli & Soarez-Al-Adam, 1998, p.21).

Male dominance is attributed to culture as posited by Bassadien and Hochfield, (2005). They state that culture is an effective tool for affirming and maintaining male dominance across races and religion. In support of this assertion, the participants often repeated their partners’ responses as saying:

...because what is the point of having a wife if one cannot enjoy them? - having sex with a condom is like eating a sweet that is covered... (Palesa).

Similar responses came from Portia’s spouse who said:

When I use a condom with you, it is like I hate you, I enjoy it more without a condom (Portia).

After this discussion on gender relations and how they impact on the lives of women, I now discuss the various processes within the “bold-step continuum”. I argue that, despite the mostly sour relations some of them experienced, the women nevertheless took bold steps to improve their individual health. These bold steps included HIV testing, followed by disclosure and then by reaction from a number of people (partners, children, friends, in-laws and community). Each of these bold steps is outlined below:

5.3. The Bold step – Testing for HIV

Taking an HIV test marks an entry point to HIV prevention, treatment and care.

There are three motives that prompted the women to test for HIV. The first one was a response to their own deteriorating health (Maliketso, Tukane, Palesa, and Libuseng1), the second motive centred around pre-medical entry requirements for sexually assaulted and for pregnant mothers' enrolment into antenatal care (Queen, Papali, Puleng and Libuseng2), and the third one was a voluntary move resulting from learning about HIV through attending various workshops (Thato, Thabitha, Portia, Thandiwe and Libuseng1). I discuss each of these motives in turn.

Response to own ill health

While HIV is only detectable through the blood samples at a clinical level, there could be signs of its associated opportunistic infections such as frequent coughs (which could suggest pulmonary tuberculosis), wasting, fatigue, headaches, fever, enlarged lymph nodes, rash muscle aches and diarrhoea (Godin, Naccache & Pelletier, 2000). Upon detection of some or all of these signs, individuals are advised to visit the health centres to receive medical attention. Likewise some of the participants took a bold step upon suspecting some of these signs. The example of Maliketso regarding the first motive is given below:

I had frequent coughs, I was losing weight too, so I decided to go and test. I told my friend that I wanted to test. She asked me if I was not afraid to uncover the hidden (Maliketso).

Despite being ill advised against testing by her friend, Maliketso takes the bold step to investigate more about her health.

Testing as part of prevention of infection from mother to the unborn baby

As a policy requirement all women attending antenatal care (ANC) in the health centres need to undergo an HIV test in order to detect early, the presence of the virus and to prevent it from

infecting the unborn baby, as well as to improve the health of the pregnant mother. This programme, Lesotho Minimum PMTCT Package, provided pregnant mothers with minimum short-term HIV treatment for the duration of their pregnancy. It was introduced in Lesotho in 2007 (Mdougal, Moteete & Mohai, 2010). To comply with this requirement, some of the participants undertook the test. Queen had this to say:

.....when I first knew I was living with HIV and AIDS is when I was pregnant. I was very hurt, because at that time it was common to associate HIV with adultery and knowing that I never had any sexual relationship, also the fact that my partner was unfaithful; he would spend nights and nights away from home. I felt very hurt that I have been betrayed by my husband (Queen).

Testing as a voluntary move

HIV testing is a voluntary activity that individuals can decide to do. As I mentioned in Chapter One, a lot of campaigns were made in Lesotho, to create awareness among the people about the importance of getting tested to know their HIV status. Some of these participants took the leap to participate in the KYS campaign. The other bold step of testing as demonstrated by Thato reads thus:

I tested once at LPPA because I learned from an HIV session during a workshop for support groups that even though a person may look healthy, she can still have HIV. I then realized that I too was still healthy despite my occasional chest pains, I thought I needed to test, after all HIV can affect anyone (Thato).

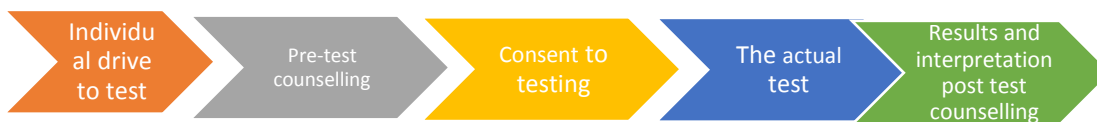
Thato's motivation for testing was intrinsic and two- fold. It could have been prompted by the knowledge she acquired from the workshop, or it could have been prompted by the "occasional" minor chest pains that she felt, which she then decided required further medical investigations.

In the three scenarios illustrated above, it is worth noting the bold nature of the steps that the women took. In the first example, Maliketso could still have opted for other investigations around her cough other than testing for HIV (as will be seen from the literature about women in other countries who resorted to traditional herbs). In the second case, Queen too could

have decided not to enroll in the Prevention of Mother-to-Child Transmission of HIV (PMTCT), and in the third case, Thato could still have attended a workshop, and done nothing about the knowledge that she acquired from it. In all these cases, I consider the steps that the women took, bold steps of acting on the information available and of making further inquiries about their health. This step required courage and initiative.

To bring things into perspective, let us briefly look at the HIV testing process as illustrated in Figure 5. 1 below:

Figure 5.1 Steps in HIV testing (voluntary testing)



Source: Ministry of Health HTC guidelines, 2010

In each of the steps in HIV testing, it should be noted the multiple bold steps that are involved. Taking a decision to step into the unknown, uncovering the stone when you do not know what is hidden underneath it metaphorically speaking, takes a lot of bravery and effort. In the earlier chapter (Chapter Three), I gave a profile of these women and noted that all of them only went as far as primary education with one exception, who also had tertiary education. The majority entered the testing process with only that basic education, and found themselves all of a sudden being overwhelmed with medical terms and processes such as “counselling” – a session that enquires about one’s sexual life – let alone talking about ones sex life being a taboo in the Sesotho culture. This notwithstanding, the women took a bold step of going ahead with it, divulging their sensitive personal information about their sexual practices, the number of partners they have had and whether or not their sexual encounters were protected and the possibilities of having

HIV as a result of unprotected sex etc. Over and above that, these women are faced with the daunting experience of watching the blood sample going through a testing process to determine whether or not HIV is there, while simultaneously being taught about what to expect; then the waiting period which can be fraught with anxiety followed by the arrival of the results, and one having to communicate the result to the counsellor in order to ensure that they understood the lesson she/he gave during the session. When asked what the result says, the woman then has to respond to the counsellor saying "it is positive", and this act can be seen as another bold step of coming to terms with this life time condition.

Maliketso said, "*I was happy about the HIV positive result*" - perhaps "relieved" would be a better word, as she was somewhat anticipating the diagnosis due to her frequent cough.

There is another step after the result – that is being spot-on in terms of further steps – making thorough investigations of the HIV strand through conducting a CD4 test to establish the body's immunity level. This is another bold step these women take when they, after testing HIV positive, still undergo the additional critical step of determining whether or not they needed to start on HIV treatment. The final step within the HIV testing phase is the issue of who they disclose to; how will they react and who will act as one's buddy for treatment support? The next section is where we find what the women have to say about disclosure and the various reactions from the different people (partners, friends, children and community) that they disclosed their condition to.

5.4 Initial Disclosure

Disclosing one's HIV positive status is a requirement for one to be able to identify a buddy who would support with treatment intake (especially for people who were already eligible for enrolment in treatment). These women likewise, had to do some disclosure to their preferred

people in this regard. Disclosure, apart from being a precondition for treatment, could be seen as levelling or un-levelling the playground and seeking support or even inviting rejection or name callings, as has been the case with some of these participants. Disclosure in this context seemed to have opened up a critical discussion about gender relations as I have talked about some of these relations under section 5.2 above. It is through disclosure that a lot of responses about partners' reactions began to surface.

Prior to discussing these reactions or concerns, it would perhaps be worth reflecting on the extent to which communities and/ or societies have developed fear around HIV. Very few people until recently, could ever stand up and disclose their HIV status – even though they are able to do that, it still costs them a lot of courage to expose themselves publicly. HIV and AIDS therefore still creates a lot of fear and suspicion within society. This fear takes many forms: fear of being associated with it, fear of disclosing it (even when it is inevitable), fear of lining up in the health centre queues even as one just goes for treatment for other ailments, fear of bearing children lest one gets tested as part of antenatal care services and found to have the virus, fear of violence, fear of upsetting the family members and fear of rejection (WHO, 2004). Although this fear has been somewhat ameliorated by the shift in the nature of the disease from a terminal to a chronic illness, the stigma surrounding it, is still strongly prevalent.

This section explores how some women have managed to overcome that fear and the consequences they faced as a result of taking the bold step of saying, “I am HIV positive.”

Disclosure and Reaction

The women seemed very uneasy about having sex without a condom, but unfortunately there seemed very little that they could do to stop this practice, given their voiceless position which circumscribes their livelihood options.

Despite the challenges they face, the women still took the bold step of disclosing their HIV positive status to the very partners who refused sex with a condom. This is considered a bold step by the participants –because it involved penetrating a male-dominated world to try to put things into perspective, thus challenging the status quo. The section below addresses whether or not the women actually made a breakthrough in their endeavor to change their sexual practices.

Disclosure to and reaction by partner

Disclosure and reaction by partner is classified under three main categories: a) those women who received immediate support upon initial disclosure; b) women whose partners only tolerated them (delayed acceptance); and c) others whose reactions suggested no support at all. The table below provides a description of behaviours demonstrated under each of these categories and classifies each participant according to the reaction received:

Table 5.1: Summary of reaction to an HIV positive partner

Immediate support		Tolerance		Castigation	
	Participants		Participants		Participants
Accepts partner's status	Portia	Continues to live with partner	Thato	Violence	Maliketso
Changes behaviour (uses condoms)	Libuseng 1	Does not change behaviour (no condoms)	Palesa	Blame	Queen
Goes for testing	Puleng	Initially denies status, but comes to accept it	Libuseng 2	Neglect and/or abandonment	Papali
Assists with medication etc.	Thandiwe				
	Joyce				
	Thabitha				

It must be noted that all the women indicated above, did a disclosure to their partners. The only woman who never disclosed her status to her partner is Tukane, perhaps because she was not married and could have feared to be rejected (her reactions to her HIV positive status is discussed in the coming section under “disclosure to parents)

In these three categories or levels of reaction, while one would anticipate some level of vulnerability on the part of the women, the notion of taking a bold step still surfaces strongly across all the levels.

Immediate support

Of the thirteen women who participated in the study, 12 of them seemed to have disclosed their HIV status to their sexual partners. Of those that disclosed, six of them received support. Those women were Portia, Libuseng1, Puleng, Thabitha, Thandiwe and Joyce. Immediate support is demonstrated with responses such as:

....my spouse knows about my HIV status. I married him when I already had HIV. It does not bother him. He did not believe me when I first told him but later he told me it was good that I told him because then he will be more careful. I know his status too, he does not have HIV. We can talk freely about HIV and AIDS. I regularly give him all the information regarding HIV and AIDS (Portia).

This support, as has been demonstrated could be attributed to the closeness of their relationship which created a platform for HIV education to happen. Klause and Geiselhart, (2008), in their study conducted in Botswana on changing inter-generational relationships and intra-family communication patterns, acknowledged the importance of getting families fully informed and educated about HIV and AIDS. They found it to reduce the severity of the impact of HIV and AIDS disclosure.

....My husband knows my HIV positive status. He was supportive from the day I told him. I was the one who did not accept my own status because I had tested positive and him negative (Libuseng1).

Perhaps it would be worth noting the reasons for their immediate support, in contrast to their colleagues who were confronted with resistance from their partners. It should be noted that there are many factors that need to be in place before disclosure can take place. Some of these factors are social support, self-efficacy and prior communication about HIV testing with the partner as articulated by many scholars (WHO, 2004; Gari, Habte et al., 2010; and Zamudio-Haas, Mudekanye-Mahaka et al., 2012). They argue that individuals with high social support tend to disclose their result more often, than those without such support. The assumption therefore is that disclosure and subsequent support received by these women was facilitated by such pre-existing social factors.

Puleng's interview confirms this notion. She received a supportive reaction from her partner. Her partner married her as already living with HIV and AIDS. Puleng contracted HIV through sexual assault during her teenage years. The boyfriend knew about the incident and continued supporting her from that stage until they decided to get married. If Puleng had not taken the bold step of disclosing her sexual assault to her boyfriend, perhaps this support and subsequent marriage could not have been realised.

Thandiwe has a partner who works in the mines in South Africa. Her partner's reaction demonstrated a supportive attitude. She has this to say:

I got his support. This is because he knows that before we met as boyfriend and girlfriend I was sexually assaulted, there could have been possibilities that I could have HIV (Thandiwe).

At the time of the study, Thandiwe was expecting a child, whom she confirmed was healthy and that they both followed a doctor's advice regarding the pregnancy.

Along similar lines, Joyce had this to share:

...he supported me and continues to support me through and through (Joyce).

Thabitha too had this to say, demonstrating the support she received from her partner:

...I received support from the spouse upon initial disclosure. I told him about my status before we got married, he accepted me... (Thabitha).

Partners who delayed support/were merely tolerating their partners

As alluded to earlier, HIV seropositive status disclosure creates shock among families. Not all the women who disclosed to their partners experienced a positive reception of their news. The examples of Thato, Palesa and Libuseng² demonstrate this kind of response. While these women's partners did not show acceptance straight away, neither did they display outright rejection because somewhere along the way, they seemed to show a little support and pity towards their HIV infected partners. Some of them reacted with naivety which could be interpreted as disbelief. Thato's partner displayed mixed sets of reactions (at one point rejecting her and other times showing remorse, but still not complying with sexual safety practices).

Rejection statements often included elements of threats to the marriage. Thato said:

I accepted my status, the only thing was my spouse who is very cruel. I had difficulty telling him because I did not know how he would take it..., he came in November. I told him I was HIV positive, he was very very angry, he threatened to leave me, to go to RSA, look for a place to stay, come back to take his children and leave me... (Thato).

This, notwithstanding, Thato eventually took the bold step of treading into a territory filled with uncertainties and animosities, not only by disclosing her status to her partner but also by confronting him about his threats. She recalled her response:

.....it is okay if you leave me but it is painful that you separate me from my children. I never thought you would leave me, and there is no where you vowed to leave me when I am in trouble or in need of your help, sadly you yourself do not know whether you have HIV or not (Thato).

Thato's brave step of confronting her partner about his decision to leave her, and her counter statement regarding his HIV status, could have been some of the factors that influenced him to reflect on his wife's HIV status and eventually change his mind. Some of the reported statements were as follows:

....after some time of unprotected sex, I told him that I had to be enrolled in ARVs. I explained to him that I was now going to use ARVS. My CD4 cells count was 259 when I first tested. I told him that according to my status, it is not safe to have unprotected sex as I will infect him. I spoke pretending he did not have HIV..... I collected female condoms and insisted that we use a condom. We would have sex with a condom, he didn't like condoms, and he did not seem to enjoy sex. I forced him to talk, when he is home, I would sit next to him, he would not talk to me, and even during sex he would not talk to me (Thato).

Despite the tension in their relationship, Thato still pursued open ways of communicating with her partner. She said:

.....we continued with unprotected sex hoping he would finally come to terms with my HIV positive status. Eventually he seemed to be calm, but talking about HIV and AIDS in the family would disturb the little peace we had. We don't talk about HIV in my house (Thato).

Thato's perseverance to get her partner's support proved fruitful when out of nowhere she experienced some level of tolerance. Thato ascribes this sudden change of attitude to her changed approach towards him, which involved speaking more softly to him, unlike in the past, when she was noisier.

....when he came home after a long time (from work), he was happy, I could not believe my eyes. He was the same husband I knew, a changed person, and that is how my family changed (Thato).

Palesa is another example of the women whose partner's support was uncertain. While the partner did not display outright support, there were often actions which demonstrated elements of disbelief, which resulted in no behaviour change.

She said:

He knows about my status. At first he thought I was joking because I talked about it in an informal/casual manner. Each time I asked him to test he never believed me. ...at times he would say that there is nothing like HIV, we like to bring in diseases from outsiders and own them (Palesa).

This initial support, therefore, as has been indicated earlier, could be interpreted as reflecting some level of naivety. This is demonstrated by Palesa's partner's reluctance to change his sexual practices.

He never agreed to using a condom, I told him I needed a safe sex, but he would say to me "Can you enjoy a candy that is covered, no! that is not candy." He would refuse a condom and we would have unprotected sex. When he tested, after three years of our relationship, he tested HIV positive (Palesa).

Libuseng 2 also received some level of tolerance from her fiancé. To support this Libuseng2 said:

... When I told him, he did not look surprised. The only thing he said was that I should not tell anyone, it should remain with the two of us only (Libuseng2).

At the time of the study, they were preparing to get married. They had an 11 month old son who was being taken care of entirely by Libuseng and her partner.

No support at all

The "no support at all" category, implies a situation whereby the spouse never wanted to be associated with a wife who is HIV positive, and who has rejected her, and who has labelled her negatively and who has then subsequently deserted the family.

The spouse's vehement rejection was demonstrated in the cases of Maliketso, Queen and Papali whose statements were:

I told him that I was going to test. Even when I came back, I told him the results that I was HIV positive. He said to me I was a loose woman, a loose woman, no wonder I have HIV (U le lekatsi) (insult). Afterwards he left me and never came back. I tried everything to bring him back but to no avail (Maliketso).

Queen too had this to say:

...my husband accused me of infecting him with HIV, he used to beat me; he accused me of being a loose woman and has been fooling around with men. ... knowing that I never had any relationship, also the fact that my partner was unfaithful he would spend nights and nights away from home, I felt very hurt that I have been betrayed by my husband. I ended

up leaving that marriage. The sad part was that I never had extra marital relations while we were still married (Queen).

Some of the responses that denoted lack of support came from Papali. She reported thus:

My partner has deserted me. Ever since the child was born he has not come to visit me. We used to have very good relations until I told him I had HIV. He no longer provides any financial support to me and the baby like he used to before I had HIV. In fact we are not married; he still has a wife and I think that he went back to his wife after I told him I had HIV (Papali).

These women were confronted with various levels of ordeal disclosing their HIV status to their partners. Nevertheless, these different kinds of reactions to their disclosure, did not prevent the women from seeking further assistance after HIV testing. They took the step of enrolling for HIV treatment, in order to improve their health (as discussed in the next chapter). This must be considered as a bold step in the midst of all the mixed feelings of pity, resistance and rejection from their partners.

There is another category of women who never disclosed their HIV seropositive status to their partners. Part of the reason for this, was that they were not married and perhaps thought they had no obligation to disclose. One example of non-disclosure was Tukane. She did, however, make a disclosure to her mother and to the community.

Summary of partners' reaction to seropositive status

Looking at these statements from the point of view of taking a bold step, it is worth commending on the one hand, the great strength of these women, who have survived the tortures, rejection, abandonment and name calling, from the closest person to them – their husbands.

On the other hand, it is worth commending on the diverse reactions of the males to their partners' seropositive status. It refutes in a way, the normal trend of males who fail to take positive action

to resolve family crises, especially when it affects their wives. In fact, one can see that taking the bold step of disclosure by women has helped in many of the cases to unleash the positive attitude of some men towards their spouses. This seemingly creates a culture of openness around health issues which should then subsequently work to dilute the notions of the superiority of men which still exists in many households.

With regard to non-disclosure, Tukane's example could be attributed to the fact that she was not married, hence feared disclosing to her sexual partners, perhaps for fear of abandonment as indicated in WHO, (2004). The only person she disclosed to, was her mother, who in turn gave her support.

The next section looks at how the children of these infected women reacted, when their mothers disclosed their HIV seropositive condition to them.

Disclosure to Children

The previous section discussed disclosure and the subsequent reactions by the spouse. This section now takes a look at how the children received the news of their mothers' HIV positive status. It should be noted that most of the children in this study come from the mothers who are aged up to 35 years. In the African context, it is common for women to have their first born child when aged between 12 – 15 years. A number of studies revealed that in southern Africa, most girls get married below the age of 18 (Sibanda, 2011; and Walker, 2012). In Lesotho in particular a campaign entitled “child marriage should end with us” was launched in 2016, in which the country's leadership was mobilizing support from the masses to help stop early child marriage (Lesotho Times newspaper clip dated 7 June 2016).

In this study, we are looking at children aged from 11 months to 14 years of age and mothers aged between 20 and 35 years of age as at 2013. (Refer to table in 5.1). I looked at how they reacted to their mothers' HIV positive condition; what thoughts and fears came into their little minds – as they grappled to understand the concept of HIV, let alone the fact that their own mother is an HIV sufferer.

At these young ages, one can assume that the level of understanding of complex issues such as HIV and AIDS, would still be relatively vague. This knowledge however, did not prevent some of these women from taking yet another bold step to disclose their HIV positive status to their children. Disclosure to this group could possibly result in two things: a) that the children would fear that their mother would soon die and leave them alone; and b) that the entire community could stigmatise and discriminate against their families. Despite all these possible negative consequences, the women wore a brave face and disclosed their health status to their children.

Below are some of the reported responses and reactions coming from children upon disclosure by their mothers:

My children (13, 11, 8) do understand about HIV. I am not staying with them, they live with their father. The eldest one always tells me that their father does not take medication regularly (Queen).

The eldest child's reaction indicates a clear understanding about HIV. Their concern over non-adherence to medication by their father demonstrates some level of knowledge about the effects of not being regular with treatment. This further marks that the level of emotional support that exists in children for the infected parents is high.

While to some children the disclosure came as a shock, they ultimately went on to demonstrate some degree of support for their mothers. Thato's response about this issue went as follows:

My children (11, 8) know about my HIV status but I hid it from them for a year. When I started taking ARVs I lied to them that I was taking medication for ulcer....one night they overheard our argument with their father over my HIV status. I had to tell them the truth that the reason why their dad and myself are fighting in the house was my HIV positive status and that I am already taking ARVs to control the virus (Thato).

While there seemed to have been support coming from children, the truth still remains that these children were not yet ready to accept or come to terms with the fact that HIV as a life threatening virus, let alone that it has infected their mother and also the notion of the virus subsequently becoming a killer as the disease progresses. The news of a positive status for HIV still appears to create a lot of fear and it still manages to generate a lot of secrecy around it. Thato said:

...they kept the secret about my status. They never told anybody and refused when I wanted to tell the community about my status (Thato).

The children's responses could be interpreted from the fear and confusion point of view. For children from five years of age and below, whose level of understanding is seemingly still vague, the thought of being told that their mother was living with HIV and AIDS, created a feeling or perception that anyone taking any kind of medication in the family, is HIV infected. This notion is confirmed by Klause et al.,(2008) when they emphasise the need for parents to educate their children about HIV and AIDS.

Palesa's children are aged eight and two years of age respectively. The eight year old boy has a fair understanding of HIV – what it is and how it could affect other people. He was reported by his mother thus:

Mum, please take your medication. You know if you don't take it you will die. Don't you know that HIV kills?...(Palesa).

He has accepted his mother's status and furthermore he keeps reminding his mother about taking the medication. While this could be an indicator of support for his mother, this action could also be seen as a sign of fear that his mother might die due to being HIV infected.

Maliketso's story introduces another dimension to disclosure to children and their reaction. She reported that her children aged 13, 10 and seven were "happy" when she came home from the clinic, and told them she tested HIV positive and they reacted by wanting to be tested too. In trying to explore the meaning of "happy", it could be assumed that these children may have been relieved now that their mother was finally properly diagnosed with her ailments (as discussed in the previous section). This could also suggest a readiness to support the mother and to acquire more responsibility as can be seen by the younger one, who at the age of seven even volunteered to support her mother with treatment adherence. The elder child on the contrary reacted negatively towards her mother's disclosure.

My first born (13) never talks about HIV, all he is interested in is his school work.... The one who sometimes talks is the second born, He would tell me that the teacher taught them about HIV (Maliketso).

This negative reaction by the elder child, could be interpreted as "fear and denial": fear of not wanting anything to do with HIV and not accepting that his mother has HIV and his focus on schoolwork, could be viewed as an escape from the reality of the HIV infection his mother suffers from or perhaps this is one of the ways he is trying to cope, with the notion that HIV is in their home and they have to live with the situation. Another way of looking at this reaction, could be that it is causing him such a deep level of psychological distress that he rather avoid the issue.

While the support by the second-born child (10 years) might reflect knowledge and understanding of HIV, there is still a lot of fear associated with his perceived fragility of her mother due to her HIV condition. Maliketso had this to say:

...they usually ask when they too will go and check for HIV. They usually ask to check for TB (tuberculosis). ...sometimes they would say, the way they cough they want to test for TB, ...They are open and calm. When I am not too well, the second born always says, "No! Do not bother my mum. Don't disturb her"...etcetera (Maliketso).

These kinds of statements by the children imply that they have developed fear of HIV and that there is a growing suspicion, about their own lack of good health.

Portia's six year old son does not know his mother's HIV status. Portia feels the son is still too young to understand.

Libuseng1's case indicated a lot of denial by her children to accept her HIV positive status (ages 14 years and 12 years). They may have been supporting her with treatment, setting up reminders on their phones, reminding her on medical check-up, but the fact that they wanted this information to stay confidential among themselves, was very crucial to them. This might suggest a great fear of stigma and discrimination both towards them, by their peers, as well as towards their mother by the community.

I told my children I was HIV positive. I did not want them to hear from anybody else. The eldest one did not want to know anything about it; he did not want me to disclose (Libuseng1).

Overall children's support of their HIV positive mothers was good, except in the cases of Maliketso and Libuseng1, who did not receive full support from one of their children. The disclosure to children is considered a bold step for these mothers since HIV infection often results in rejection and does not sit well in the minds of many people.

There were, however, some women who opted not to disclose their status to their children, for a number of reasons, as reflected in Table 5.2 below:

Table 5.2 Summary of Disclosure to Children

Participant	Ages of children	Disclosed to children		Reason for disclosure or non-disclosure
		Yes	No	
Queen	13,11,8	<input checked="" type="checkbox"/>		For support purposes
Thato	11,8	<input checked="" type="checkbox"/>		To correct the previous statement of saying she was taking 'ulcer' medication
Palesa	8,2	<input checked="" type="checkbox"/>		For support
Maliketso	13,10,7	<input checked="" type="checkbox"/>		To allay their fears of a sickly mother
Portia	6		<input checked="" type="checkbox"/>	She felt that her six year old child was too young to understand
Libuseng 1	14,12	<input checked="" type="checkbox"/>		For support, which she unfortunately did not receive
Libuseng 2	11mths		<input checked="" type="checkbox"/>	The child was still too young (11 months old). Also her fiancée advised that her HIV positive status should be kept secret.
Tukane	7		<input checked="" type="checkbox"/>	She was not yet married and feared that it might destroy her child's mind
Puleng	8, 11mths		<input checked="" type="checkbox"/>	She felt she was not ready to disclose to her children
Thabitha	7,2		<input checked="" type="checkbox"/>	She was not ready as yet to disclose
Thandiwe	4,		<input checked="" type="checkbox"/>	She felt she was not yet ready to disclose to her four year old son
Papali	11 months		<input checked="" type="checkbox"/>	Her child was still too young (11 months)

Their lack of disclosure is confirmed by the studies conducted in South Africa on disclosure by pregnant women in Tompkins, (2007); and Makin, (2008) in which they claim that the nature of the relationship with the children can become a barrier to disclosure. Emphasis here is put on communication which they claim is a challenge for most parents. They claim

that disclosure is an overwhelming experience and some parents would not know where to begin; some even stated that their children were too young to understand, therefore they would not be able to keep a secret. Others stated that they were worried that their children would undermine them, be disappointed in them, or disrespect them as a mother. This is confirmed by responses in this study from Tukane, Portia, Libuseng2, Pulie and Thandiwe.

Disclosure and Reaction –Relatives

Within the African family setting, there exists a close-knit family structure that comprises of a biological mother, father and siblings. For an African woman, the in-laws (mother in law, father-in law and brothers and sisters in law) are also part of this structure. Additionally there is another structure that is referred to as “extended family” or kinship - here the list further widens to include aunts, cousins, uncles, nephews, grandmothers and grandfathers. This section looks at each of the critical relationships within the family in relation to the women in this case study e.g. mother-in-law, own mother, and siblings. The study focuses on mothers-in laws’ reactions because of the major roles they play in socialising the young women into motherhood in this African context.

Mothers-in-Laws’ Reactions

For mothers-in-law, the data reveals that they seem to take sides with their sons and join hands in mocking the HIV infected spouse, without any attempt to even enquire about the son’s HIV status. Of the six women who described the reaction of their mothers in-laws upon disclosure (Maliketso, Thato, Thabitha, Portia, Queen and Puleng), only two of them (Portia and Puleng) received support. Among those who were rejected, Maliketso had this to say:

...when my husband married another wife, I went to my in-laws to report. I told them that my spouse had left home and married another woman. Instead of my father-in-law responding, my mother-in-law replied that it was not anything new for a man to marry again, all he needed to do was to build me a house so that each one of us should have their own home (Maliketso).

Thato's mother-in-law reacted thus:

...she insulted me saying that she hates girls who do not respect their elders. If I disrespect my husband, I should watch out – she is not the type of person I can disrespectI assume she (my mother-in-law) already knew about my HIV positive status because she used to tell some people that my husband and I are fighting, I brought AIDS in the family, I went to many places that is where I have gathered AIDS. So from her statements, I assume she knows about HIV and AIDS (Thato).

Similarly Thabitha reported negative reactions received from her in-laws:

My mother-in-law knows my status. I am the one who told her. I was with my husband when I told her. I told her in the presence of my sister-in-law, she did not take it easily (Thabitha).

Likewise Queen had this to say:

...My mother-in-law accused me of infecting her son.

In spite of this ill-treatment that is characterised by rejection, and ultimately even divorce to some of the participants, Thato, Thabitha, Queen and Maliketso stood up and disclosed their status to their in-laws which is a demonstration of a bold step.

Data revealed that HIV positive status is still a tremendous shock to parents. This fear could perhaps be associated with child bearing – that old notion of assuming that a woman who is living with HIV and AIDS may not bear children. The manner in which they handled the news about it, especially when it affected their daughters-in-law, was said to create hostility in the family.

Support Received from Mothers-in-Law

Mothers-in-law support upon disclosure of an HIV positive status has on the contrary been witnessed among some of the women: Puleng is an example. Outlining this support, Puleng (also a widow) says:

My in-laws are very supportive. They know about my status. They have accepted and do recognise me. During family gatherings I always get invited to talk about HIV and create awareness among my family members (Puleng).

Portia's in-laws too are very supportive of her, although she has not disclosed her status to them – They only know that she helps people living with HIV and AIDS. This statement could be interpreted as “being accommodating about HIV and AIDS issues” but it leaves room to wonder how the mother-in-law would react if she found out that Portia herself was infected with the HI virus. Apparently, at Portia's home there are a lot of HIV infected people – other daughters-in-law, the sisters and the other brothers, and her “perceived” support for HIV and AIDS people could be understood as the reason for her mother-in-law's support towards her. As I earlier indicated, it does not fully justify the support. Until the mother-in-law gets to know about Portia's status, it is not possible to actually gauge this support, hence this positive reaction could not be relied upon entirely.

Disclosure to own parents (Mother)

It is most common for a child, especially a girl child, to report something extra-ordinary to their mother or parent. Perhaps the socialisation of girls that puts strong emphasis on the domestic chores as belonging to the girls and their mothers, create and cement the bond between mothers and their daughters, thus creating an experience conducive to sharing. Some of these women, felt that they needed to share their HIV positive status with their parents. This could have been done as a way of soliciting new ways of coping with this daunting situation or to seek emotional support in the midst of rejection by the spouse (as we have already seen in the previous section). Others may have disclosed to the parents because they were the only existing structure to lean on. Some of these women were not married and therefore shared their distress and happiness with their parents, as their closest people.

While the women might have taken differing steps to disclose to their family members (with some starting with a friend, sister, spouse and mother or in-laws), disclosure to this group illustrated that initially there was a sense of self-pity among the women – the example of this can be seen with Libuseng1. When asked how she felt when she was told she had HIV, she said:

I have always asked myself why me? - at my age especially. What will my spouse, children and my mother say when I tell them about HIV positive result?

In terms of what was going on in her mind, Libuseng1 reported that she thought she was going to die.

Palesa had been thinking that HIV was the result of adulterous behaviour. When she discovered she was living with HIV and AIDS, the first thing that came into mind was her mother:

...what am I going to say? How will I explain “adultery” and where I got HIV from?
(Palesa).

When she finally took the bold step of disclosing to her mother, her mother encouraged her to join support groups to be able to acquire more information about HIV. Tukane also disclosed to her mother and received emotional support from her.

Having looked at disclosure and reaction from in-laws, and own mothers, the next section looks at how the friends and peers reacted to the news of the women’s seropositive status.

Disclosure to and reaction by friends

HIV disclosure, as stated earlier, is often stressful. However, disclosure has, in many instances, been associated with improved physical health and improved psychological well-

being. Disclosure to friends and/or disclosure in general is associated with less medication-hiding which in turn promotes treatment adherence, as the literature illustrated.

The women experienced varying reactions from their friends and peers. It should be re-emphasized from this initial stage that HIV has created shock among people. At a peer level it would almost be impossible to imagine one's peers infected with HIV; it is no wonder some of these women were firstly rejected by their peers and some of their friends upon discovery of their HIV status. Maliketso's friend almost discouraged her to test for HIV. If it had not been for her persistence, Maliketso's condition would not have been diagnosed and she may not have recovered.

Participants themselves at first had a sense of self-pity upon discovering they were HIV infected. This pity extended into their friendship web, so that they sometimes denied support from their very friends with whom they used to share almost everything.

Thato had this to say:

I was ashamed of myself. My friend and I used to eat from the same plate before, but this time I would dish out food. When I am about to dip my hand in the same dish as hers, I would pull it out thinking that my friend would not like to share food with me anymore (Thato).

After discussing that negative behaviour by Thato, her friend vowed to support her throughout. Other women, like Queen and Portia, narrated a different story:

Most of my friends know my status. In fact some of them are living with HIV, their approach to me is fine. Even those who do not have HIV still treat me fine (Queen).

Confirming this support Portia indicated that:

...my friend told me that many people I am related to had HIV. Some had passed on, others were still alive and are leading a healthy life, so I should accept it and move on (Portia).

Another indication of the bold step taken by these women surfaced within their friendship circle. It is remarkable how these women, who disclosed their status mostly in those times when HIV and AIDS seemed a “not-talked-about subject”, were able to disclose to their friends. From the data, it does seem like there were a few cases of HIV positive friends to whom disclosure was made. This act by women re-emphasises the notion of taking a bold step as a journey towards an attempt to heal and cope (as will be seen in Chapter Six).

Despite the positive reactions received from friends, there were still some cases when friends seem to have “unwelcomed” their peers’ HIV statuses. Palesa and Libuseng1 are the examples of this lack of support.

Palesa narrated as follows:

...when I am with my peers and they have an ill talk about people who are HIV infected, I get hurt and always tell them that it is not proper to treat people like that. HIV is a disease like any other and that HIV could be there with them just that they are not aware yet (Palesa).

Libuseng1 encountered statements such as:

...those that have AIDS should not be part of food preparation in the village (Libuseng1).

For most of the women who participated in the study, peer support was almost non-existent. Stigmatising statements, signs of rejection, name callings and discrimination were some of the things that were experienced throughout the early stages of these women’s HIV diagnoses.

I now take a look at how the community reacted to the women living with HIV and AIDS.

Disclosure and reaction by community

In this section, disclosure and reaction is discussed in line with the community's reaction to disclosure by these women. While none of them first disclosed their status to the community, it is worth discussing the community's reaction and whether the community could establish a base for the women's coping strategy in response to the array of factors that surrounded their HIV positive condition.

This section will just briefly provide the synopsis of the community's initial reaction upon hearing of the women's positive condition. Otherwise, the issues related to women themselves disclosing their HIV positive condition to the community will be dealt with in the next following chapter (Chapter Six). The rationale for treating the two scenarios separately is to demonstrate the community's perceptions towards HIV and AIDS from a hearsay point of view and to later demonstrate how personal public disclosure influences positive change of perceptions around a particular phenomenon (as will be seen in Chapter Six).

Community's perception towards people living with HIV and AIDS

As has been discussed in the previous sections, HIV disclosure was characterised by stigma and discrimination. The responses by the peers was no different from the community reactions. In the first instance, perhaps due to lack of knowledge, these women were isolated – they were called AIDS sufferers, “those that stepped on the “electrical cable” (meaning those who are approaching a death bed). Even for those who were not ready to disclose, the HIV signs were beginning to show, thus exposing them to stigmatisation.

Palesa had this to say:

...they uttered painful words, even at the streams when I go to draw water they used to say, “Oh! We are sick and tired of these heavily infested people, who are bringing this disease here. We cannot drink from the same stream as these people.” All these remarks kept tormenting me. I ended up confronting my peers to tell them that HIV is not transmitted through sharing of water, there are other ways in which HIV is transmitted (Palesa).

Only until Palesa was being stigmatized and tormented did she indirectly disclose her HIV positive status to the community. Note her statement “I ended up confronting.....” which denotes that her HIV positive signs were showing and communities were beginning to alienate her.

With other women, news was already spreading in the community that they were infected (refer to Maliketso and Thato’s stories when they went to report their HIV status at their matrimonial homes). Queen also suffered stigmatising and discriminating practices as follows:

....another issues is that of the community who were delegating us odd jobs such as making fire and drawing water from the stream, instead of cooking or peeling or even getting in contact with food saying that we would infect them (Queen).

The ill-treatment that the women suffered did not, however, stop them from participating in public or community gatherings and communal places. What is significant about their participation in these places was their ability to realise the community’s lack of knowledge about HIV and AIDS. They in turn took the opportunity of their interaction with the community to admit to their HIV positive condition and to educate them about HIV. This is a demonstration of a bold step, in the midst of rejection and stigma.

To improve their health conditions, these women apart from making a disclosure which served as an aid to emotional healing, there is also an issue of ensuring clinical improvement to their HIV condition in the form of treatment use. This will be discussed in the next chapter.

5.5 Discussion

I argue that it takes a bold step for a woman to know their HIV and AIDS status, to disclose her status to a partner and children and to finally enroll in treatment. It takes a bold step to understand and comprehend in the midst of fear and frustration, all the testing processes and medical terms and still participate in those processes. I further argue that it takes a bold step as a woman, to undergo these processes without the consent or approval of a partner. Throughout the study, none of the thirteen women ever sought permission from their partners to test. Even after disclosure and rejection, for those that received such responses, none of them ever sought clearance or permission from their partners to take their diagnosis for further enrolment into care.

The gist of the chapter is on the notion of “taking a bold step”. This bold step is contextualised around disclosure of an HIV seropositive status. The disclosure to different people (spouse/partner, children, in-laws, friends and community) helped open up a whole new ways of thinking about HIV and AIDS. The partner disclosure introduced a new perspective of how a partner can react to their HIV seropositive status. A lot of gender issues came to the fore. Male domination is one critical element that surfaced whereby spouses began to feel their status quo was being questioned. On the other hand, some spouses began to demonstrate the much needed support for their seropositive partner which, as most authors have indicated, was not strongly evident in other studies. Thus modifying some of the statements or claims made that males were the superior figures within the home stead. It must be mentioned that the majority of males (7 out of 12) were reportedly supportive in response to the disclosure of their spouses’ HIV positive status.

5.6 The new learning that the chapter brings home

In a recent study conducted in Eastern Uganda on women living with HIV and AIDS experiences and support needs, the women who received support reported that the support statements made by their husbands included commitments such as “we shall help each other” meaning that they have accepted that HIV is in the family and it is their collective responsibility to overcome the challenge (Rujumba, 2012).

As has been noted from the literature, male domination is reported as very rife. Of significance is the fact that some spouses/partners (six out of 12) supported their wives immediately upon disclosure of their HIV positive status. This is seen as a significant move by males that is commendable. It possibly suggests the beginning of a paradigm shift within families towards the gradual emergence of partnership within a patriarchal system.

This is breaking new ground; the notion that HIV and AIDS is bringing in more equality between husbands and wives within the African kinship. This creates a juxtaposition of partnership within patriarchy whereby during the HIV and AIDS era, power imbalances that were once reported to be rife, are beginning to gradually get subsumed in partnership as the husbands or partners become supportive of their spouses HIV positive condition. Issue of sexual and reproductive health, a once male-dominated territory, is now being dealt with by both partners on more equal terms.

This furthermore leads us to reflect critically on the bold step that the women took to break the ice in relation to HIV and AIDS which was once initially characterised by fear, condemnation and rejection, to creating the very real possibility of unleashing their full potential of making substantial meaning out of their “perceived” hopeless situation.

5.7 Conclusion

The chapter adopted the term ‘the bold step’ as the metaphor to present and analyse the findings of this study. The bold step was used in the context of HIV testing and HIV disclosure to various parties (spouses, children, in-laws, own mothers, friends and community) and the subsequent varying reactions received from them as well as the perseverance demonstrated by these women towards improving their health in the midst of stigma and discrimination.

The chapter further identified some level of acceptance among most men of their partners HIV seropositive status. This move indicates the emergence of some degree of ownership, partnership and joint responsibility within the households.

The findings indicate another element and that is of the children’s resilience with regard to disclosure and their capacity to maintain support of their HIV infected mothers – a demonstration of responsibility at a young age.

Having identified the steps and reactions of the women and the responses they received within their various environments, their counter action to those claims made, the continued bold steps they took towards wholeness, the next chapter (Chapter Six) looks at the women as they pick up their pieces and move on to rebuild, reshape and reclaim their self-worth.

CHAPTER SIX: Picking Up One's Pieces and Moving On

"We all at certain times in our lives find ourselves broken. True strength is found in picking up the pieces" (Jeromy Shingongo).

6.1 Introduction

This is the second chapter in the series of findings, analysis and theorisation of the responses for the study. "Picking up the pieces" is another metaphor that I adopt to explore the findings of this study. I have deliberately named the chapter as such because I have documented the journey taken by the 13 women who represent the participants in this study – how they walked through the painstaking process of taking several bold steps of undergoing testing and then disclosing their HIV positive status to various people and receiving, in return, varying responses – some supportive, others negative.

The "picking up pieces" notion needs to be understood in the context of a step-by-step journey from a starting point of being heartbroken to a state of wholeness. The motif behind this chapter is taken from the above mentioned quote by Jeromy Shingongo that reads "...true strength is found in picking up the pieces" (Shingongo, 2016 – unnumbered). This motif is discussed in-depth as the chapter unfolds. It is noteworthy that the chapter is a continuation of a bold step process taken by these women towards attainment of their normal health. Whereas "taking the bold steps" focuses more on the women's initial responses to HIV and AIDS in testing and disclosure, "picking up the pieces" focuses on how they regained their physical and psychological integrity (through treatment) and social efficacy (through mending family relations and involvement in support groups and the wider community).

The objective of this chapter is to identify the various processes undergone by the women and to explain how these processes manifest in transforming them and their environment.

Within these two broad themes that guide the chapter, emerge five sub- themes. Two are related to taking HIV treatment. They are a) picking up the pieces in the family – mending relations in order to ease treatment intake; and b) picking up the pieces towards personal health (adhering to treatment in spite of all the odds). The other three sub-themes are related to joining support groups. They are a) picking up the pieces through reintegration with the society (breaking the silence around HIV and AIDS and coming out in the open); b) picking up the pieces in livelihoods activities; as well as c) picking up the pieces by sharing the knowledge gained with the communities.

I maintain that the findings in this chapter support the notion of picking up the pieces towards wholeness. As I mentioned, the wholeness issue comes out clearly as the women boldly access HIV treatment, withstand treatment complexities, survive with HIV, regain their health, improve their livelihood status and subsequently become experts and resource persons in HIV and AIDS at the community level.

This chapter uses theoretical lenses of transformative learning and communities of practice to analyse the findings; however, in-depth discussions on the findings in relation to the theories are discussed in the next chapter (Chapter Seven).

6.2 Picking up pieces in the family

This stage becomes critical, especially in a case where there was some resistance to the women's seropositive status from a member or members of the family, whose resistance would perhaps

interfere with the overall treatment intake. Thato, Queen, Maliketso, and Portia are examples of the women who worked hard to mend the relationship with their partners and their children from the time they discovered they were HIV seropositive up until the time when they eventually joined the support group.

Queen had to make a choice between staying in a marriage where her health and life were threatened and quitting to be able to regain her normal health. Below is her assertion about her partner's reaction:

....we never discuss HIV issues in the house because our relations were not good....No! He never agreed to use a condom, he would come home drunk and would force me to sleep with him. This action hurt me a lot because what he was doing would cause a reinfection in me....I decided to leave the marriage because he used to assault me (Queen).

Prioritising health over marriage, is a bold step and an act of picking up the pieces towards wholeness. If it had not been for her decision to go to the extremes of quitting the marriage that exposed her to risky practices, Queen would not have gathered strength to deal with her HIV condition effectively, given that she discovered she was HIV positive when she was pregnant – a critical stage where she had to ensure her own and her unborn baby's survival through compliance with prevention of HIV from mother-to-child (PMTCT) requirements. She explained it in this way:

When I first knew I was HIV positive that is when I was pregnant. I was very hurt, because at that time it was common to associate HIV with adultery and knowing that I never had any extra-marital relationship, made me very angry (Queen).

Thato had a mean partner who did not entertain any discussion on HIV and AIDS at the house. He never liked to use a condom (Thato's statement in Chapter Five bears reference). Some of the utterances between Thato and her partner included:

...I told him that according to my status, it is not safe to have unprotected sex....tension erupted again in the house. He threatened to marry another wife. He started to have suspicious movements leaving the home early, coming back late at night. He did this for two weeks (Thato).

Apparently for Thato that did not mark the final step in her efforts to mend the relationship. Her partner still demonstrated a lot of dislike for her attendance of information or knowledge-seeking forums. This is what she further said:

...I remember there was recently an HIV event in the community, I participated. I was resource person to teach about PMTCT and HIV education. My husband commented on the event and said that all speakers were good except myself, that I was actually boring... I told him that I was not boring, it is just that what I was talking about you did not like, but please note that whether you do like to talk about HIV or not, you will have problems accessing treatment...(Thato).

Thato talks vehemently to her partner to make him understand the importance of knowing about HIV and AIDS. The result of this conversation, over time, brings about change in Thato's relations with her partner. She said the following on the matter:

...When he came home after a long time, he was happy. I could not believe my eyes, he was the same husband I knew, a changed person, and that is how my family relations changed. I think it is because since I was diagnosed with HIV, I was taught to control my temper, I started to practice it, I speak with him softly and [it is] less noisy in the house (Thato).

Thato might have ended the relationship given her husband's initial reaction, but her persistence and ability to change her own interactions with her husband and rebuild the relationship, show her commitment to "picking up the pieces" and saving the marriage...

Mending relations with children

The participants' relations with their children were also crucial in their attempts to pick up the pieces. On the issue of mending the relationship with her family, Thato intended to correct the lies that she had told her children about the medication she was continuously taking. She explained that:

When I started taking ARVs, I lied to them (children) that I was taking ulcer medication.I told them that the medication I am taking is for HIV. I reminded them of my continuous ill health. I then assured them that I was now going to live longer and healthier. I then told them that I do not have AIDS but HIV (Thato).

This explains perhaps why Thato, despite her one-year period of hiding her HIV status and treatment intake from her children, had to adopt ways of mending her family relationships in order to freely sustain her treatment in-take. This is another signal of strength that Thato demonstrated as a way of picking up her pieces and moving on with her lifetime of treatment for a life threatening condition.

Maliketso, Portia and Libuseng¹, too, experienced a lot of difficulty building their children's confidence and acceptance of their mothers' HIV condition. While each of the women fought their battles from different angles, all of them displayed a lot of strength to make things right with their children. For example, the fear and denial around HIV and AIDS that is demonstrated by Maliketso's children, clearly prompted her to regain strength to convince them that she would no longer become as sickly as she was prior to testing for HIV. The quest of the children to go to check about their health status, suggests their growing fear that they might have been infected too. She said that:

My children usually ask when they can go to check for HIV and to check for TB (Maliketso).

This statement posed a challenge to Maliketso. She had to work hard to convince her children that she was the one with HIV and not them.

Libuseng¹, too, has had to work hard to convince her children of the importance of public disclosure of her HIV positive status. Her children had, after a long time accepted her status but did not want her to disclose it publicly. The fact that Libuseng¹ eventually joined the support

group and openly declared her status indicate that it took a lot of strength to convince her children of the importance of public disclosure. She said that:

My children nowadays understand my status, they support me with medication. I am the one who told them, the elder one did not want to understand my situation, but the younger one was ever supportive. The elder one in fact did not want anything to do with my being HIV positive (Libuseng1).

This statement denotes that Libuseng1 had a tough time to make her children accept her HIV condition. The “nowadays” implies that in the past it was not an easy task breaking the HIV news to her children. However, she found strength in “picking up her pieces” by continuously talking about her HIV condition to her family until she finally won the battle.

Having heard insights regarding picking up the pieces from the family’s perspective, it now becomes necessary to look at this metaphor from a personal perspective- how the participants themselves reacted to a lifetime treatment – its intake, reaction/effects of treatment on each individual and how each one coped with the treatment.

6.3 Picking up the pieces towards personal health

Building on this metaphor, personal health relates to accessing HIV treatment. Tsarenko and Polonsky, (2011) contribution to this metaphor centres on the decision to either live or die. They see life-changing illness such as HIV as a condition that people often times accept to varying degrees. They regard acceptance as taking “ownership”. They refer to it as such, in view of the fact that it compels individuals to undergo a transformation process that begins with a deep feeling of detachment, later on this changes to acceptance of one’s life and subsequently to empowerment and a feeling of being in control of one’s HIV status and in control of one’s life. As a way of picking up one’s pieces, Tsarenko and Polonsky, (2011) suggest that it becomes an individual’s choice either to spend their lives dying or to spend their lives living. In this context,

living implies taking action to own the illness and to do something about it; that is, taking and adhering to ARV treatment. Now let us hear what the participants had to say about their lives with HIV treatment.

Surviving with HIV treatment: Criterion for initiation into HIV treatment

Initiation into antiretroviral therapy (ART) is a critical step within the HIV positive continuum. Its aim is to sustain the health of HIV positive patients. Enrolling in ART takes a lot of effort and commitment to embark on a lifelong treatment intake. I consider this as part of picking up the pieces of transforming the HIV infection from deadly to chronic and a demonstration of responsibility for one's health.

Initiation into ART was mostly prompted by a fall of the CD4 cell count to below 250 mm³ for these women (since most of them were initiated around 2004/2005). Twelve of them, with the exception of Portia, were on HIV treatment at the time of the study. They were all on first line regimen (which I describe below). At the time of the study Portia was in the process of ART initiation.

First line regime

The standard first line regimen for adults comprises Stavudine (d4T) Tenofovir, (TDF), Lamivudine (3TC), Nevirapine (NVP), Zidovudine (AZT) and Efavirenz (EFV). Stavudine was however, discontinued in many countries from 2009 due to its consistent toxicity levels. The participants have all remained on the first line regimen due to their consistency and adherence to the treatment requirements. The commitment and consistency that the participants show, reflect their eagerness to lead healthy lives- an indication of picking up the pieces of their lives and moving on.

Participants' initial reactions to treatment

Side effects of the treatment

Some of the side effects of treatment under this regimen include uneven body fat distribution (lipodystrophy), diarrhea, nausea, vomiting, anemia, rash, fatigue, peripheral neuropathy and metabolic disturbances. To mitigate some of the side effects, the most common drug, Stavudine – known for most of these side effects - was recommended to be phased out by the World Health Organization (Duber,Dansereau, Masters, et al., 2015).

It is worth noting that at the time of the participants' initiation into ART, the recommendation to phase out d4T had long been made but given the poor resource settings for Lesotho, health facilities were still giving the regimen to the patients. From its use, some participants (Thato and Tukane) experienced major side effects. Here is what they had to say:

I used to have a beautiful body, with curves, but ever since I took ARVs I began to notice changes in my body, with my feet and legs growing thinner, but my upper abdomen getting larger. In 2006 ARVs changed my looks. It was very painful seeing a good figured person changing into a huge big-tummied woman. I developed muscle wasting, I was wearing a towel and leggings inside to increase my hip line to hide my thinning out (Thato).

Tukane's story regarding treatment side effects went like this:

I had just commenced treatment. Members of Phelisanang Bophelong support group did not want to associate with me. They feared that I was going to take their boyfriends..... I also felt good about my beautiful body. Look at me now! The use of d4T has transformed my figure to this unbalanced fat deposit. Now I am no longer their threat, because all that beauty is gone (Tukane).

Thabitha reported that her treatment regimen has negative side effects at first. These effects that the medication presented were not regarding physical appearance as was the case with the rest of the participants. Hers were that she could not swallow them with ease, due to their size.

...but I kept going on. I now have healthy children (Thabitha).

Palesa developed ringworm, and people were beginning to notice abnormal skin lesions that were showing. The disfiguration of their bodies did not, however, stop them from continuing with their treatment regimen.

Mitigating the side effects of the treatment

In essence, the participants did nothing to mitigate the effects of treatment. It was only until recently, when the participants learned of the policy to change the drug (d4T), to another regimen that they wore brave faces and confronted health centres about their treatment.

Here is what Thato had to say about her treatment change:

...I then changed the regimen through “telling” the nurses to change the regimen. I actually told them the type of regimen that was suitable for me (Thato).

The concept of “telling” (*ka ba joetsa – in Sesotho*) which denotes: “take it or leave, it!”, “I demand that action should be taken to correct this”. These words come out strongly in Thato’s statement. This not only denotes some level of knowledge on the subject but also an instruction for concerned people to take action. Additionally, it demonstrates the confidence in using this knowledge to change one’s treatment situation. This is especially striking considering the typical nurse-patient relationship, with nurse as expert and agent, and patient as passive recipient. It further demonstrates the bold step of picking up the pieces of her life in an effort to stay in good health.

Queen, on the other hand, did not experience any side effects with the treatment but switched from d4T to another regimen given the global decision to switch patients from one particular drug to the other.

Comparing these reactions with what Musheke, Bond, and Merten, (2012) discovered, HIV infected people opt for herbal therapies instead of taking HIV treatment. These herbal therapies

are believed to treat opportunistic infections and are purported to promote or improve appetite levels. These therapies or herbs comprise garlic, ginger and aloe vera. Other options that HIV infected people resort to are faith healing therapies such as prayer, anointing water and anointing oil. All of these therapies they emphasise, “put HIV infected people at the risk of early AIDS-related deaths” (Musheke et al., 2012, p.12).

Linking this observation with what the data reveal, it is worth mentioning that none of the 12 participants put on treatment (with the exception of Portia), resorted to self-care practices. Perhaps it could be due in part to the fact that their low economic status would not allow them access to those therapies or that, given their lower educational level, such therapies never existed within their knowledge realm. It might also mean that they did not wish to disclose such practices (given my positionality in the study as outlined in the Methodology Chapter).

Their adherence to HIV treatment guidelines as prescribed by the medical practitioners reflects their level of commitment to regaining their health, thus picking up the pieces of their lives and from viewing their disfigured bodies negatively, to accepting this as their new normal.

Responding to a question on how free the participants were when taking their medication in public, the participants gave varying responses. Some participants (Tukane and Palesa) mentioned that they were initially reluctant to take their medication in the public eye but with time they opened up. Their responses were:

When I take my medication and someone asks me, I always tell them that I was once sick and later on I went to test, this is the medication that I take to mitigate my sickness (Tukane).

Palesa’s statement read as follows:

I used to have a challenge taking medication in public because there used to be a lot of people saying, “You will see those that swallow drugs, you will notice them (Palesa).

These statements suggest that these women were initially not comfortable taking their ART in public. While Tukane did acknowledge that she told people that she takes this medication following her test, she did not explicitly say which test she took. This could indicate that, while she might have already been aware that people were suspicious of her regular drugs intake, she seemed to be not ready to open up to them.

Thabitha and Palesa seemed to be worried or shy about what people would say if they publicly took their medication. They might have perceived stigma and discrimination as a threat given their reluctance to take their medication publicly at the initial stage.

Thabitha's side of the story went like this:

When I first started to use this treatment I was annoyed by the fact that I needed to bring a buddy to help me with treatment....I did not know who to bring because I do not have a mother. What I did was to keep asking the nurses why I could not be given treatment without a partner....It was around 2005. It was still a confidential issue. I was not ready to tell anyone (Thabitha).

Thabitha, with time, however, decided to gather strength to "pick up her pieces". She went to the person who encouraged her to test. Note her statement when she eventually gathered her strength to confront her treatment requirements. She said the following:

Hey you! This "thing" that you said I should test for, now requires me to bring a partner (Thabitha).

This statement denotes a gradual change of mind from being afraid to access treatment, to some level of readiness to regain her health back.

Likewise, Palesa's change of mind about treatment perception helped her to openly disclose that she was taking treatment – an indication of picking up her pieces and moving on. Palesa now

began to perceive her HIV positive condition through a different lens – she started to accept or own her condition. Now she says:

...but with time I developed a coping strategy – that of assuring myself that I would be a fool to let myself die when I could avoid it (Palesa).

Her change of mind-set enabled her to face the realities of living with HIV and taking lifetime treatment to mitigate the further spread of the infection in her body. This reaction blends well within the transformative learning theory in which HIV diagnosis is perceived as a disorienting dilemma, and disclosure as new meaning perspective (I demonstrate this relationship in-depth in Chapter Seven). This change denotes a step of truly “picking up one’s pieces” and moving on, thereby developing a sense of personal agency. Her statement of “...I would be a fool.” is analysed within the context of Palesa challenging that the stigma and discrimination she may endure would not be allowed to stand in the way of her regaining good health.

Other perspectives regarding HIV treatment in-take

Maliketso, Queen, Thato, Joyce, Thandiwe and Puleng all mentioned that they never had any challenges taking their HIV treatment.

Here are some of the statements they made regarding treatment:

When I was told that my CD4 cells count was very low and that I needed to go on treatment, I brought my neighbour who acted as my treatment buddy to attend with me treatment sessions. Then I took the medication and continued with it without any problems (Maliketso).

Queen actually enjoyed taking her ARVs openly in public places.

I always take my treatment everywhere I am, in public places, in taxis etcetera (Queen).

Perhaps Queen does this as another way of educating communities about HIV, in that taking lifetime treatment is possible, or it could be seen as a way of reinforcing the strict instructions that come with treatment.

Thandiwe, too, has no problem taking her medication openly. While most of the time she kept her medication at home, every time her treatment supporter reminded her to take it, she would comply. This indicates her openness with her treatment. In fact, Thandiwe confirms that even if she were to be asked by anybody if she took ARVs or not, she would boldly say “yes”.

Having discussed picking up the pieces of one’s life in relation to personal health, the next section discusses breaking the silence around HIV and AIDS and coming out into the open and reconnecting with the society, joining support groups and then moving forward from isolation and alienation, to belonging.

6.4 Picking up the pieces in social life

I now look at another aspect within the process of picking up the pieces. This is the aspect of reintegration; both amongst participants themselves and with the communities they live in. I look at this reintegration from the collective perspective of belonging to a support group of people living with HIV and AIDS where the participants are now members. I followed them from when they joined the group, and investigated what prompted them to join, the learning they acquired from the group and how they utilised that learning for their individual groups as well as shared it with the community. All of these perspectives are clustered under “picking up the pieces” in respect of the social life of these women.

As it will be recalled (throughout the previous chapter), data reveal that the participants were each dealing with their own HIV positive condition in isolation. Some grappled with treatment adherence and its side effects individually and in some instances, with the few people to whom they had disclosed (the closed circle). Now, as part of “picking up the pieces”, this section watches them as they decide to widen their circle to disclose to the broader community, thus

breaking the silence around HIV and AIDS and challenging the stigma and discrimination that seems still to be rife.

Libuseng2, Queen, Thato, Maliketso were among the first participants to break the silence around HIV. Libuseng2 said:

...my community knows about my HIV status. I disclosed my status. I have no problem interacting with my community. I think the fact that I openly disclosed, made it easier for me to be accepted. There are no signs of discrimination (Libuseng2).

In terms of the utterances that were coming out from the community about the people who were suspected to have the virus, Palesa was the one who was indirectly pin-pointed with utterances such as “*Ba Hometsoe*”(a belittling statement that means “those with ringworms, they are infected all over by the disease”).

Coming out in the open for the participants meant joining the support groups of people living with HIV and AIDS, within their areas and later on moving to the core group, which served as the umbrella organization of support groups with HIV and AIDS in the district. This is the Phelisanang Bophelong Support Group (PBSG) which is one of the foci of this study.

At this point, it is worth providing a brief description of the PBSG, its origins, pioneers and how it is structured, as well as its linkages with other HIV and AIDS organizations in the Leribe district. The information from this section is drawn from two main sources: The first one is my own experience working as the HIV and AIDS District Coordinator in the Leribe district, where I had regular interaction with the support group. The second source is the interview I had with the Programme Management Team of the PBSG. This will provide an organizational context for understanding the participants’ efforts at social reintegration.

Phelisanang Bophelong Support Group (PBSG)

PBSG is a support group of people living with HIV and AIDS. It is located in the Leribe district.

The support group was established in 2004. The purpose of this support group is to improve the quality of life of vulnerable groups, by ensuring access to HIV treatment, care and support services. The PBSG is an affiliate of the Lesotho Network of People Living with HIV and AIDS (LENEPWHA) – an umbrella organization of people living with HIV and AIDS, whose key mandate is to advocate for the rights of people living with HIV and AIDS.

Origins

The support group was established by individuals who tested HIV positive from the Motebang Clinic (the only health centre in the district that provided ARVs then) who wanted to support each other with issues of treatment adherence, mitigating stigma and discrimination. Participation in the support group is open to both men and women of all age groups. It is purely voluntary, but one of its conditions is public disclosure of one's HIV status.

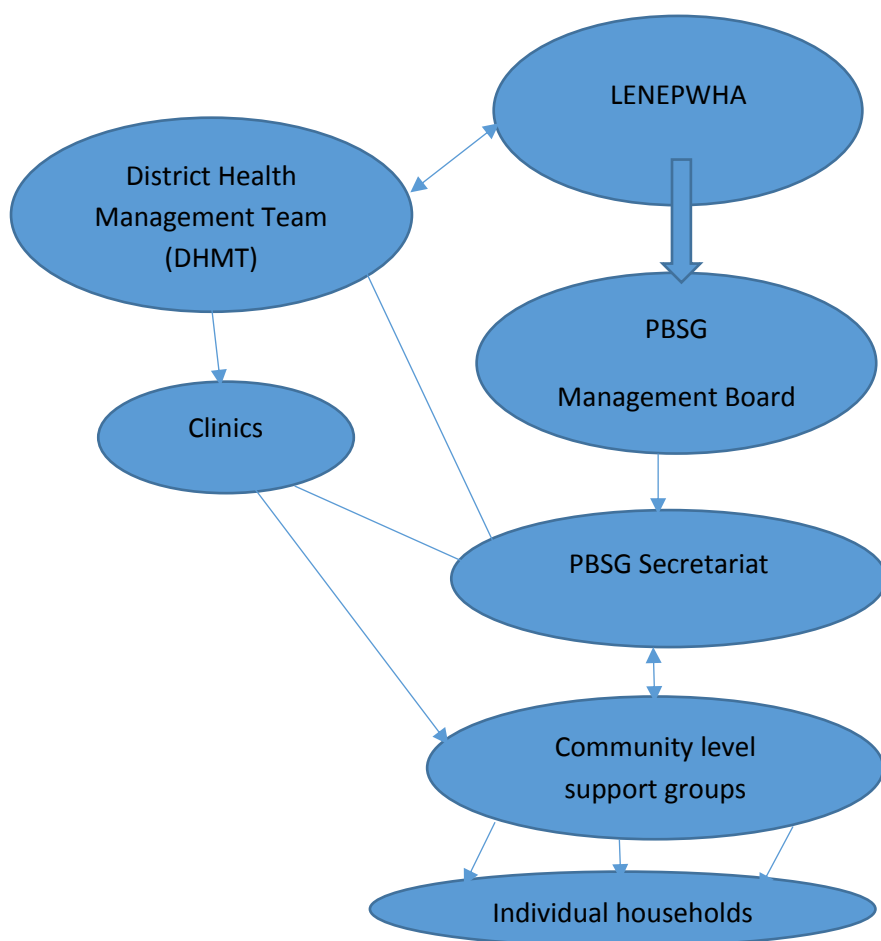
Structure

PBSG has a formal structure. It has a governing body (Board) whose key role is to provide strategic leadership in the management and coordination of PBSG activities. This includes the Secretariat – the implementation arm of the PBSG. It comprises technical staff who oversee the day-to-day functions of the organization. It is staffed by a Programme Manager, Programme Officer, a Monitoring and Evaluation Officer and an Office Administrator. Below the Secretariat, are the community-level support groups who educate communities about HIV and AIDS. Within this structure emerge the study participants who PBSG has attached to the health centres (clinics) to support issues of adherence. They are referred to as Local Adherence Coordinators (LACs) who work with the individual households either directly or through the health centres as the need arises.

PBSG Activities

PBSG’s mandate is to educate communities about HIV and AIDS, to promote HIV counselling and testing, to conduct treatment literacy to newly enrolled clients, to promote adherence to HIV treatment and positive living and to provide psycho-social support to individuals and families of HIV infected people. The support group harnesses most of the HIV technical knowledge from the district level health management team (DHMT). DHMT is a multi-sectoral team of health service providers of which PBSG is a member. Information that is discussed at DHMT level is filtered through the clinics and LACs for dissemination to the communities. The diagrammatic view of the PBSG structure is illustrated below:

Figure 6.1 Phelisanang Bophelong Support Group Structure



Source: Researcher

The PBSG meets on a monthly basis. A typical monthly meeting of the support group would involve presenting progress reports on different tasks assigned to each member, sharing skills and experiences regarding members' assignments at the clinics, discussing modalities of bettering their work and the group, as well as sharing any new knowledge/information regarding HIV and AIDS. It is at these forums that members usually suggest additional initiatives that would improve economic status. Some of these initiatives include savings clubs, stokvels, small livestock rearing, vegetable gardening and small business activities. These additional income generation activities, are not a core business of the PBSG per se, but rather come as a way in which members prefer to make a living at individual levels.

Having briefly discussed the PBSG, I now look at factors that prompted these participants to join the group.

Factors that motivated participants to join the group

There were different motivating factors for joining the support group among these participants. The motives range from escaping the feeling of loneliness, by running away from the stigmatising and discriminating environment, as Cassidy, (2010); Atanga, Atashili, Nde and Akenji, (2015) put it. Another motive is locating a new home with a new supportive family (especially for participants who never received support at their homes) and obtaining more knowledge, information and skills around HIV and AIDS in order to deal with it more effectively. The issue of a "new family in this context is supported by Rule and John, (2008), in their study of HIV and AIDS support groups, in which participants in the study alluded that a support group is a "family where they feel accepted and supported, thus giving them strength to live openly and positively in their communities" (Rule & John, 2008, p. 90). Joyce had this to say about a support group:

...when I was told I had HIV, I was scared. I did not want to share the news with anyone. I did not want my mother to know, but later on I decided to tell her I was HIV positive. She encouraged me to join support groups because I would learn a lot about dealing with my HIV positive condition. My mother was providing home-based care to the sick people in the village (Joyce).

Others joined the group unexpectedly and involuntarily, but were bound circumstantially to become part of the group. For instance Papali said:

I joined the Association (PB) in 2013, I am very new to the association. I was referred to it by a nurse at the Motebang clinic after being tested HIV positive during my antenatal care visit (Papali).

Puleng, joined the group based on the advice she was given as well as her desire to learn more.

This was what she has to say:

I joined PB in 2005. I was advised by the nurse at my clinic about the association of people living with HIV. I decided to join because I wanted to learn a lot about HIV (Puleng).

Each of the participants joined at different times and for different motives. The majority of them (Queen, Maliketso, Palesa, Puleng, Tukane and Libuseng¹) were actually among the pioneers of the support group as they joined somewhat earlier than the rest of the participants.

Thato is of the view that if she did not join the support group, her life would not have changed. Perhaps the change that she was looking for could have been the change that she witnessed from her spouse's ultimate acceptance of the HIV positive condition, or the change in terms of the knowledge and resilience that she developed over time. Of all the participants, Thato seems to be the only one who was change-driven to join the support group. Here is what she said:

I joined Phelisanang Bophelong (PB) support group during World AIDS Day commemoration at St. Denis Health centre. We had already established a support group at the community. We were seven in the group. I was nominated to attend a workshop on home-based care and was told that if I perform well I will then join PB and conduct community awareness trainings.... When I received nomination I was worried about my husband's reaction. I went to the priest and told him about my nomination, how I fear about my husband's reaction. He advised me to go and learn more about HIV, maybe what I will learn there will change my life (Thato).

As I explained in the previous section about the group's establishment, some members were recruited from their homes when the association was doing HIV awareness programmes in the communities (the case of Libuseng2).

There are those who joined the group from the already established mixed HIV status "informal" support groups in their communities (Thato, Thandiwe and Maliketso). I refer to them as informal because these were support groups where there was no formal structure such as entry requirement for joining. They were non-registered, with a lack of affiliation to an umbrella organization of people living with HIV and AIDS, etc.

Some of these members belonged to the already existing support groups duly established by the health centres, in order to support their treatment adherence initiatives. Below are some of the responses by these women:

I think it is because I joined a support group in my village then Phelisanang Bophelong went and established support groups of people living with HIV. That is why I got closer to them, attended their training workshops. I then became a full member (Maliketso).

It is worth mentioning that Maliketso, Puleng, Palesa, Libuseng2 and Papali were encouraged by the health centres where they were being treated, to join the PBSG. This action by the health centres could be seen as contributing towards reinforcing the concept of "picking up of the pieces" – which by itself denotes taking further steps, towards regaining self-worth and towards building one's identity, as well as discovering more knowledge about HIV treatment; the sharing of experiences and learning about what other women with similar experiences have been through.

In terms of those participants who may have joined in search of a new home with new members of the HIV positive family, Libuseng2 and Palesa are such examples. It will be recalled that the

stigma and discrimination that Palesa suffered both from her own community and the health centre nurse regarding her HIV positive status (community utterances such as “those that are heavily infested! We cannot drink from the same stream as them!” etc.) was more reason that she and Libuseng² decided to join a new family where the members speak the same HIV language. PBSG went to the health centres (clinics) to create awareness about their existence and to encourage HIV positive patients to join. It was where Libuseng² and Palesa’s quest for a new family was fulfilled.

6.5 Picking up the pieces with respect to livelihoods activities

While this was not the initial motive for joining the support group, the participants’ membership to the core group illuminated their zeal towards wholeness – wholeness in their health condition as well as wholeness in their economic well-being. In an effort to pick up the pieces of their lives, the participants began to see economic opportunities within their support group interactions. As I explained in Section 6.4 above, the activities of the support group included the establishment of income-generation activities such as small livestock rearing, savings clubs, stokvels and vegetable production (however informal and voluntary and outside the scope of the PBSG). The women developed these initiatives by themselves. Not all of them however, showed initiative and commitment, but for those that did, they were able to secure some income to support their families.

Palesa and Thato attribute their improved nutritional status as well as their household economic well-being, to the PBSG.

...I now have food at home – legumes, vegetables, cereals and broilers....I do not get hungry at all. The community looks up to me to produce food and vegetables because now they come to buy from me, I make money (Palesa).

Likewise, Thato narrated her story on how she moved from a ‘nobody’ to a greater person who can raise money for her family:

I was just an ordinary person. I went as far as standard 7 education. I never thought in life that I would do anything. What I learnt from PB is that one can do something that can empower one. I run a small catering business. It has now grown, I rent a house where I do my business. I have someone whom I have employed to manage the business. My business has improved, it has attracted many customers. I work from my business in the morning, then later in the day go and do the Phelisanang Bophelong activities (Thato).

Joining the support group for Thato was an eye opener. She was able to move from grappling with HIV and AIDS to becoming a small business holder, who feeds for her family, something she never “dreamt” about before in life. The activities which are otherwise not part of the core activities of PBSG came about as the group interacted and identified other ways of enhancing their livelihood statuses.

Maliketso too confessed that unlike in the past when she lived entirely on handouts from relatives, she now goes to the market to sell clothing and makes money.

The Phelisanang Bophelong⁶ Programme Management team confirmed the women’s sense of having something to contribute. Over and above the core activities of the organization, the members had acquired some skills from the support group which they would probably not otherwise have developed for example:

...they [the participants] have formed money saving/lending schemes. They buy presents for each other, and they arrange support visits at their implementation sites. They developed strategies of how they can best deal with problematic clients at the health centres where they are placed as well as how to reach their targets in cases where some are still much far behind. In addition, the members know how to tackle/solve family and personal problems (PB Management).

The responses pointed to the fact that members have themselves even gone beyond learning about HIV and AIDS, to developing livelihood strategies in the form of stokvels (fund raising initiatives).

The section below now looks at how participants within the support group engage and interact amongst themselves and with the communities they live with. It looks at how they pick up the pieces of their lives by contributing the knowledge they gained, to the communities and how the community in turn reacted or responded to the information given to them by the participants.

6.6 Picking up pieces by contributing the knowledge gained

The once rejected, stigmatised and discriminated participants are currently back in the community sharing knowledge and skills they have gained from their membership of the support group. Queen, Thato, Libuseng, Portia, Palesa, Puleng, Tukane asserted that they are who they have become, because of the PBSG. Their thorough knowledge about HIV and AIDS eased their state of health, and their literacy around treatment made them able to penetrate the health systems to forge better relationships with health professionals, thus sharing information and getting regular updates about HIV and AIDS.

How the participants picked up their pieces in relation to the community

It is noteworthy that the participants were placed in the local clinics as local adherence coordinators to support HIV treatment adherence, to encourage communities to test for HIV and to promote prevention of HIV transmission to the unborn children (as explained in earlier sections). In their effort to conduct that business, some of them encountered resistance from health professionals, perhaps due to their perceived low formal educational status or to resistance among medical personnel to the change that was introduced within the health system, whereby lay persons are attached to the health centres. Queen, for instance, had this to say in regard to Prevention of Mother-to-Child Transmission of HIV and AIDS (PMTCT):

...where I am placed, my relations with the nurses were initially not so good. I received negative responses whenever I went to inquire about forbidden drugs that were seemingly

given to HIV positive pregnant mothers.... However, with time that negativity stopped. Maybe they realised that I had knowledge of PMTCT issues. Our relations are now good (Queen).

The participants reported that they shared the knowledge they have on HIV and AIDS with the community. Queen went on to say:

...the community has a lot of trust in me. The clinic staff also has a very strong support for me. Even the health centres know that whenever there are HIV patients, it is my responsibility (Queen).

Thato, too, has become a community consultant on health issues. She explained that:

...whenever there is a sick person in the community, I am called upon to assist. The health centre invites me to educate communities about HIV and AIDS. I was the resource person during World AIDS Day at the health centre (Thato).

Maliketso became both a health reference point and a lay nutritionist. The community celebrated her presence among them. This is what she found:

One of my neighbours said to me, 'Ahh! We know you, every time you come to us you bring new things. Your cooking style, how you handle patients' – it is remarkable. I always encourage community members to test for HIV and to disclose their status. I tell them that HIV is manageable and give the example of myself that I even had TB (Maliketso).

Portia has acquired a new title in her community. She said:

They treat me as a leader in health care issues. They even refer to me as "nurse". I am called upon anytime of the day when there are health-related emergencies. People have a lot of trust in me (Portia).

Public speaking is another skill that the participants have developed, and through it, they have been able to impart the knowledge to their communities. Puleng, Tukane and Portia confirmed that they were shy and somewhat quiet in nature, but through their participation in the support group, they have lost those inhibitions.

Portia brings in another critical issue through her knowledge-sharing with the community. She said:

I am able to read their (community) facial expressions. While they may seem to be uttering statements that mock me about my HIV positive status, indeed I have noticed that there are those who do so as a cry for help (Portia).

The statement implies that not only is Portia knowledgeable about HIV and AIDS but is also fully aware of the community's hidden perceptions about HIV and AIDS.

Overall, the community reception of the knowledge that the participants brought to them, seemed overwhelming. The fact that they moved from just ordinary, isolated and mocked women to becoming health reference points, indicates a shift in the acceptance level of community's HIV and AIDS positive status. Statements such as "come and help this person he/she seems to have this sickness of yours" (as was said by a community leader to Maliketso) indicates some level of knowledge of HIV and AIDS by the community.

Tracing back stigmatising statements made to Palesa, Queen, Maliketso which ranged from forbidding them from drawing water from the same stream as the rest of the community, denying them cooking during community feasts and utterances such as "those that are hit by goods train", meaning those that are infected, all seem to have subsided and the community instead views the participants with a positive lens of "life savers" and leaders. Even when the community expresses negative sentiments towards the women, as with Portia above, they have the confidence and insight to hear the "cry" that lies beneath the insult.

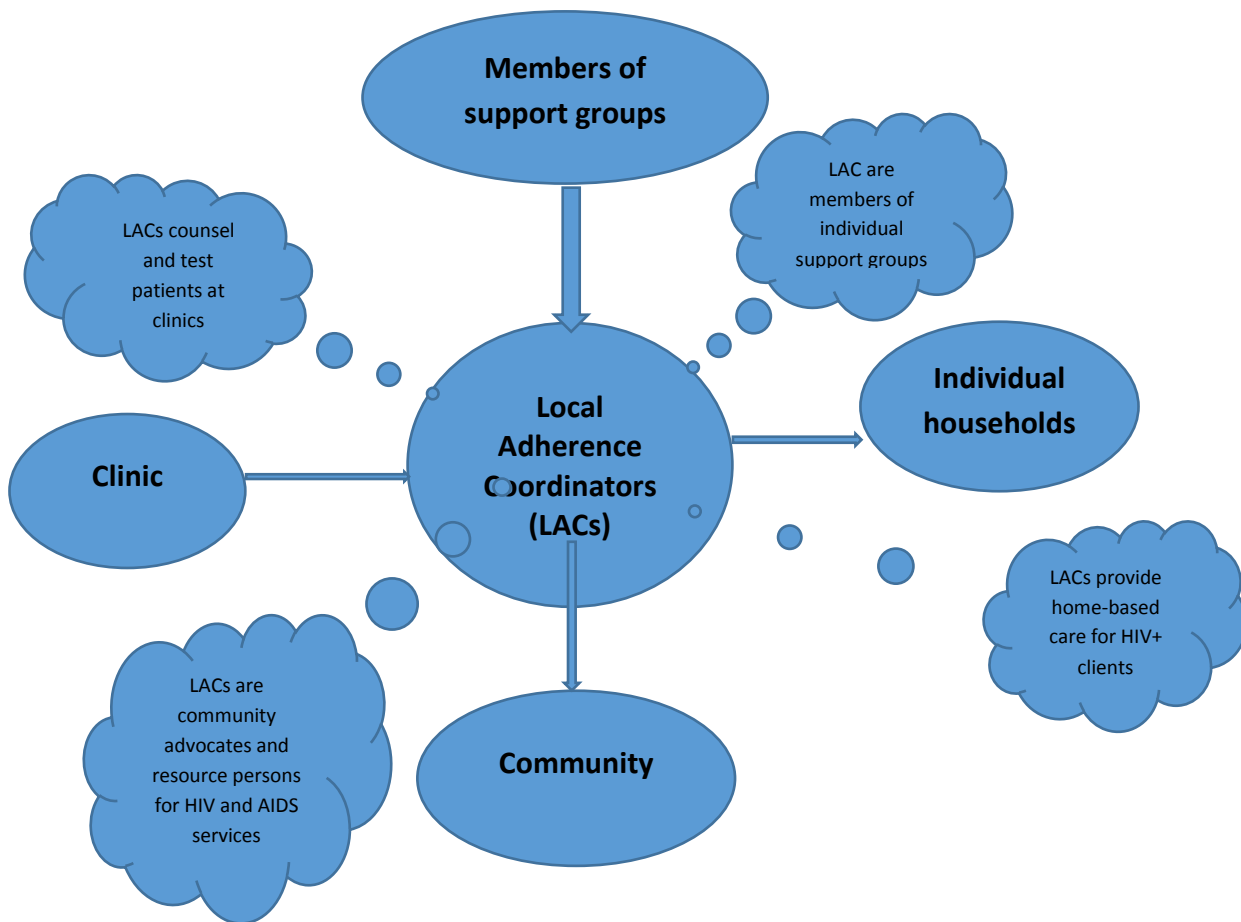
There are some additional skills that the participants acquired within the support group. These are: report writing skills, maintaining confidentiality and team work. While participants did not explicitly talk about them per se, their PBSG Management highlighted them in their joint interview with me: They said:

Most of our volunteers (participants) were never employed before being engaged as volunteers with PB. This has given them a wealth of working experience and they can now safely understand the world of work – taking instructions and reprimands positively; complying with reporting deadlines; meeting targets; confidentiality; taking responsibility even without being pushed or watched daily (Phelisanang Bophelong Management).

This statement from their Management I consider the apex of the picking up of pieces towards wholeness; in that participants acquired a lot more than what they joined the support group for. The self-directed approach demonstrated when doing their work, as well as their ability to acquire knowledge about HIV and AIDS while maintaining the patient's confidentiality – have demonstrated some degree of professionalism. The participant's ability to adjust to the world of work with minimal supervision justifies the element of wholeness. The low educational level of the participants (as talked about in Chapter Three) versus their pursuit to rise above HIV positive condition, all contribute to picking up of the pieces of a shattered life and moving on..

The roles and activities of the Local Adherence Coordinators are summarised in the diagram below:

Figure 6.2: Roles and activities of LACs



Source: Researcher

Now that I have discussed the various kinds of knowledge and the skills acquired through the participants' participation in the support group, I see it befitting to give a brief yet holistic view of the role of support groups as viewed by different scholars. I do this, in order to compare what the participants gained, in relation to support group practices as reported by other scholars.

The role of support groups

It would seem necessary to briefly look at the role of support groups – perhaps not to be viewed as just groupings of people with similar characteristics or motives, but rather to critically identify key activities that happen within these groupings, with a view to assessing any benefits that members are seen to gain from participation in them. In doing this, I will explore the relevance of my findings about PBSG, to the wider scholarship on HIV and AIDS support groups.

One of the key roles of support groups, is economic empowerment of its members. Walstrom, Operatio, Zlotnick, et al., (2013) emphasise the need for support groups to have viable funding to sustain programmes and projects for its members. I have already discussed how economic empowerment adds value to the well- being of its members (the example of Thato, Palesa and Maliketso above).

Another crucial role of support group is to facilitate the disclosure of HIV positive status to the other family members, especially children, as well as the community as a way of eliminating stigma. Walstrom et al. (2013) cite a study that they conducted in Rwanda, whereby disclosure to children was influenced through participation in a support group. The reaction confirms what Thato did to her children by initially lying to them and saying that she was taking ulcer medication, while in fact she was taking ART, but later on “picking up her pieces” to mend her relations with the family by telling them the truth (as discussed in section 6.2 above).

Promotion of a sense of belonging, is another role of a support group. Participation of members in support groups creates a feeling of rebirth and motivation to survive – this implies gaining true strength to continue with life to its fullest (Walstrom et al., 2013, p. 95). This is witnessed in the various testimonies by the participants, on the various skills acquired from their participation in the support group. The knowledge sharing and team work as demonstrated by them, are clear indications of their interaction level both amongst themselves and with the community.

The acquisition of new names such as “leaders” and “nurses” all bear reference to the critical role, they each played in the support groups. Failure to belong to a support group could lead to

unpleasant consequences, just as one participant (from the Walstrom study referred to above) confessed her wanting to kill herself upon discovering she was HIV infected.

This statement is similar to Palesa's feeling upon HIV positive diagnosis (as discussed in Chapter Five under HIV testing and disclosure). She wanted to commit suicide; to drown herself in the Katse Dam. Had it not been for her family's support and subsequent joining of the support group, the act of committing suicide could have perhaps happened.

Apart from being the support for home-based care facilities within the communities, support groups are social mechanisms that connect existing groups of people living with HIV together and they connect them with other systems, including health services (Walstrom et al., 2013). This view is witnessed by the PBSG which harnesses knowledge about HIV and AIDS from other district structures, such as the District Health Management Team (DHMT) and the clinics, as well as conducting district-wide mobilisation of support groups of people living with HIV and AIDS to connect them with PBSG.

Support groups increase the potential for effective capacity building, communication and advocacy as indicated by Hodgson, Nakiyemba, Seeley, et al., (2012). Support groups or networks are active in the promotion of income generation, music, drama and vocational skills development.

Through their participation in support groups, Thabitha, Palesa, Maliketso, and Libuseng1 have established small businesses which help them generate income for their families. They no longer depend on hand-outs.

In terms of drama, Thato has acquired communication skills which she uses to transmit HIV and AIDS messages to the community. During a district-level commemoration of AIDS day, Thato uses drama to convey the messages on the importance of prevention of Mother-to Child transmission of HIV.

Support groups were used in Uganda as a vehicle for HIV testing and counselling and uptake increased, there was greater access to HIV and general health services by following up on TB and HIV treatment and performing prevention of mother-to-Child Transmission of HIV (PMTCT) services (Hodgson, Nakiyemba, Seeley, et al., 2012, p.1369). Similar roles are seen played by PBSG where it has placed participants in health centres to promote HIV and AIDS services.

Support groups, in addition, are perceived as places of safety and validation – a safe space for sharing with and being heard by other HIV infected peers; a space where there is less loneliness and increased connection and unity with other group members. Examples drawn from Rwandan women read:

...you know when I came to the group we didn't use to talk about HIV, we didn't have friends. And here we met women who have the same problem, we talk, we discuss, we visit each other (Walstrom et al., 2013, p. 94).

In terms of improving adherence to HIV treatment, Atanga et al., 2015 mention that

support groups have the potential to modify factors that are associated with poor treatment adherence (Atanga, et al., 2015, pp. 1-2).

The example of this role is with the PBSG that has attached its members to the health centres to promote treatment adherence for HIV infected people. This structure is called Local Adherence Coordinators – 12 of the women, with the exception of Papali, are recruited and attached to the clinics for this exercise.

Another support group role is to assist its members to return to health, work and normalcy. This is witnessed in a case where better mental and physical health of members, enables them to function effectively, with improved sense of personal competence, self-esteem and independence.

In terms of maintaining or mending relations between partners, support groups seem to be playing that crucial part. Thato noticed a change in her once sour relations with her partner, which I have alluded to in the earlier section.

From the responses made as well as the literature listed, it becomes apparent that support groups create a conducive environment for their members to learn, interact, share and belong. The ultimate goal of participation in this forum is to gain more strength, change perceptions about life and improve relations both with the family and the environment the members are in, thus justifying the “picking up pieces” notion of moving from being a centre of mockery to one of wholeness. The statement made by Palesa below bears testimony to the critical role and identity transformation played by participants as members of support group. She said the following:

...my community now comes to me for advice and guidance. They come to say that I should advise them on what to do with HIV and AIDS.... The very people who were stigmatising me before now come to me and tell me about their health condition and used to ask me if I would encourage them to test. Those that were HIV positive are now taking medication. They are the very people who ask me to become their treatment supporter. I give my community all the information about HIV and AIDS (Palesa).

6.7. Discussion

I argue that true strength is found in the “picking up of pieces” and moving on. I further reiterate, that it takes a bold step to mend the fractured self, in the midst of a lack of education and a lack

of resources coupled with lack or little support from the family and community. In this section therefore I intend focusing on these women, as they conduct further investigations about their health and seek a new “home” of people who are undergoing similar experiences as themselves. The efforts that they made to ensure that they regain their health and dignity as human beings by accessing treatment, as well as claiming their self-worth through acquisitions of new roles, skills and knowledge by joining the support groups, are evidence of their desire to truly re-build themselves and their communities. This could turn the HIV and AIDS tide around so that communities are able to look at HIV seropositive status as an ailment that can be managed.

It is befitting to note the level of transformation that the women gained, from taking treatment through to joining the support group. An average woman, who went as far as primary school education, now becomes a health reference point in the community. A once novice, now an expert (at the community level) – educating communities about HIV. Development of competencies such as public speaking – breaking the silence around HIV and AIDS, reflects the knowledge that the women acquired as a result of their participation in HIV infected support group. Over and above these skills and competencies, the issue of being gainfully employed by the health centres, to promote treatment adherence, is another benefit that the women accrued following their participation in the support group.

6.8 New learning that the chapter brings forward

The data reveals that “picking up pieces” and moving on in the midst of an HIV and AIDS positive diagnosis seemed a tough journey for the women, given the fact that some of them were already showing signs of ill health prior to treatment. It seemed even tougher because at the time of their treatment enrolment there were not many treatment options available. The initiatives by

the women therefore show their determination throughout their journey. What this implies, is that it takes a lot of commitment and determination to reach a desired destination. Additionally, in terms of joining support groups, the group membership illustrated that the whole is greater than the sum of its parts.

The low level of their formal education, their cultural background (that of not been allowed to speak in public) would under normal settings, become barriers to their development as individuals, but their participation in the support groups of people living with HIV and AIDS has helped to unleash their hidden potential and to break the cultural barrier, that puts women on the periphery.

The stories that they told about their life prior to joining the group and the testimonies they gave when they are now within the PBSG do indicate a major shift in their perspectives about life. Thabitha, for instance, confirms that she gained a better understanding of issues than before she joined the support group. There are elements of resilience and assertiveness that have been acquired by the participants.

When these participants joined the support group, there was no mention about benefits other than training workshops for treatment adherence and HIV testing in the communities, but their regular participation qualifies them for more surprises, such as their ability to gain more competencies and to have a stipend to financially support their families.

Of interest is the team work and sense of belonging that each one of them developed – moving from loneliness to becoming part of the bigger team. They have shifted from being vulnerable and a focus for mockery within the community, to now being points of reference on health

matters in the communities. They have moved from being voiceless beings to becoming vocal health advocates and trusted partners to health professionals in the community.

6.9. Conclusion

The participants have acquired some degree of knowledge and competency around HIV treatment enrolment. Their zeal to foster HIV and AIDS acceptance among communities marks a positive step in HIV and AIDS testing, treatment uptake and subsequent joining of support groups by new members. The data indicates some change of perception in the family relations as a result of participating in the support groups, by the participants. The new identity and recognition given to the participants by the community are milestones towards the community's acceptance of HIV infected persons. There emerges another level of acceptance of support group members within the health professional cadre, that of treating the PBSG members as part of the technical support staff in enrolling patients into HIV treatment and HIV testing initiatives.

There is evidence of greater knowledge and skills gained by the participants. Some of this knowledge (while they themselves do not notice) has been highlighted by the Programme Management to which they belong. The knowledge of producing reports, programme monitoring as well as HIV and AIDS treatment competency, helped the participants to move from that of a novice to that of a community expert. The initial lone journey of HIV testing, disclosing HIV status to the family, accessing treatment, now yields positive outcomes for the participants as they regain their health and share experiences with their peers in the support group that they joined. In addition, the gains made from the support group participation have contributed to changing the livelihood status of both the participants and their families and communities as a whole.

Having discussed these findings, the next chapter now looks at how these findings link to the theories of feminism, transformative learning and communities of practice.

CHAPTER SEVEN: Linking Theories to the Findings

7.1 Introduction

This chapter concretises the theoretical framework chapter (Chapter Four) by directly linking each of the theories that ground the study, to the specific findings that have been articulated in Chapters Five and Six of this case study. As I indicated in Chapter Four, the study is grounded on the three theories, that of feminism, transformative learning and communities of practice. Chapter Four discussed these theories- each in isolation, but in this chapter, I intend to link each of the theories to the findings from Chapters Five and Six (Taking the Bold Step and Picking up Pieces and Moving on).

In summation, the findings from these chapters are based on key themes of a) testing for HIV; b) disclosure and reaction to an HIV positive status; c) accessing HIV treatment and d) joining support groups. The discussion of these findings uses a feminist lens to look at patriarchy, oppression, solidarity, decision-making and partnership. The transformative learning theory lens looks at the issues of the disorienting dilemma, reflection and perspective transformation. The communities of practice lens is used here to link the findings to the issues of identity, participation at periphery to centre and novice to expert basis, meaning-making, social capital and networking.

7.2 Feminist lens

Feminism, as defined in Chapter Four, denotes an umbrella of related theories which have certain things in common, such as focus on women and their oppression, and a commitment to their liberation. Meena, (1992); Tallis, (2012); and Zalewski, (2000) provided insights into this definition. They view it as an approach that aims to end women's discrimination because of their

sex. Feminism holds a belief that women have specific needs which remain negated and unsatisfied and whose satisfaction requires a radical change in the social economic and political order. This case study looks at African feminism and how women have made contributions to it. Key issues that I identified are patriarchal powers, verbal and sexual abuse, decision-making and solidarity.

Patriarchy: Patriarchy is a gendered power system that puts all power and control of political, social and economic relationship in the hands of males. Patriarchy defines women's status, privilege and rights in the society (Kalabamu, 2006). Subsumed within patriarchy is the phenomenon of oppression which I disaggregate into verbal and sexual abuse, decision-making, power and economic power. Each of the elements as identified in the data are elaborated below.

Verbal abuse: In the study, one way in which men exercise power over women, is through verbal abuse. This is witnessed in Maliketso's statement when she disclosed her HIV positive status to her husband. He referred to her as "letsekatsi" (a loose woman who sleeps around with other men) which is a direct insult. Thato too, suffered this abuse when she participated as a resource person at one ceremony in her community (commemoration of district-level World AIDS Day). Her partner did not acknowledge the important role that she played in the ceremony, but instead belittled her with the words such as:

...everyone else performed well in the drama, except yourself. You were boring! (Thato)

These examples illustrate patriarchal oppression in men's attempts to define women living with HIV and AIDS and to determine the value of their social contribution.

Sexual abuse was reported to be rife by participants such as Queen and Thato – despite their partners' knowledge that they were living with HIV and AIDS, they forced them to engage in unprotected sex. She said that:

...he would come home late at night drunk and force me to sleep with him (Queen).

Thato's partner profusely refused to use a condom and threatened to leave the marriage if she insisted on the condom use. She explained that:

...for the sake of peace I succumbed to unprotected sex (Thato).

Again this kind of sexual abuse is a direct form of patriarchal oppression which exploits women's vulnerability in the unequal domain of relationships. This refusal to use a condom imperils the health of both partners, who may be infected or re-infected by the virus.

Decision making is a task that is delegated to men as heads of households in a patriarchal society. The study noted that some partners refused to allow their wives to get tested for HIV. Thato, for instance, joined a support group at her village and provided support for sick people in her community. Her husband did not like her to offer that support. When she tested positive to HIV and she shared the news with him, he is reported as saying:

...your things that you like to attend to, are the ones that made you go for HIV testing I understood "my things" to mean support groups. He didn't like me attending support groups. ...yes, he did not want me to test, he accused me of testing for HIV (Thato).

Here the man seeks to control the women's health as well as her social engagements around HIV, which give her a measure of independence from his control. This blame shifting is confirmed by Battle et al., (2015) in a study conducted in Uganda about disclosure of HIV test results by pregnant women to their partners. They found that one of the factors that inhibit women from disclosing their HIV positive status, is the fear of being blamed for testing without her partner's consent.

Power: The matrimonial authority that is delegated to men, also extends to the extended family, the in-laws are viewed as custodians of culture and the legitimate authority for passing this on to

the younger generation. This linear position of power unfortunately favours men and does very little to protect women's status, within the matrimonial homestead. Maliketso's feeling of devastation about her partners marriage to another woman, did not receive any attention from her in-laws. The following was said on the matter.

When my husband married another wife I went to in-laws to report. I said, "My mum and dad, I am here to tell you that my spouse has left home and married another woman". Instead of my father in-law responding, my mother-in-law replied that it was not anything new for a man to marry again, all he needed to do was to build me a house so that each one of us should have their own home.

This statement by Maliketso's mother-law shows that men's misbehaviour, as perceived by the wife, is condoned by the in-laws: as long as men can provide for their wives, the number of partners he may have, is not an issue. This practice has negative effects and is a factor that fuels the spread of HIV and AIDS as has been confirmed by the Modes of Transmission study on multiple and concurrent sexual partners (World Bank, 2009).

Economic power is also a key dimension of patriarchal relations. Exercising patriarchal oppression through economic power harshly affects women living with HIV and AIDS because men are typically the breadwinners in a patriarchal society. As has been alluded to in Chapter One, partners of the participants were mostly employed in the mines in the Republic of South Africa, while their partners were housewives, taking care of the homestead. Their source of living was primarily their partners' income. Denial of economic support from the partner created difficulties of taking care of the children. Maliketso, Queen, and Papali are examples of the participants whose partners refused to provide for the family and eventually deserted them.

When I told him I tested HIV positive, he left me and never came back... He never came to see or supported his child (Papali).

Maliketso, too, was left on her own to care for her three children with the youngest child at one month and one week old. Her husband went and stayed with another woman and left them stranded. She has had to seek employment in the Republic of South Africa.

Likewise, Queen left the marriage after she suffered economic hardships at the hands of her partner who refused to support her and the children.

This oppression did not, however, prevent the women from displaying bold faces to access HIV services (from testing, accessing treatment through to joining support groups of people living with HIV and AIDS). Through this, they exercised their agency, thus challenging patriarchal assumptions and structures and demonstrating that male power and control, is not absolute. This resistance is seen in other parts of Africa (Kenya, Zambia, The Gambia and Upper Volta) among women who are engaged in agricultural production and who refused to share their production with their husbands, and then refused to render unremunerated labour in the agricultural production:

...each time agricultural schemes provided men with inputs and credit, the assumption was that men as heads of households would have access to their wives' unremunerated labour, but each time that was the case, problems would develop.... In bargaining with patriarchy, the insecurities of African polygyny for women are matched by areas of relative autonomy that they clearly strive to maximise. Men's responsibility for their wives' support in some instances is in actual fact low...women are primarily responsible for their own and their children's upkeep which include meeting the costs of their education....(Kandiyoti, 1988, p. 277).

The findings of my case study suggest some level of independent decision-making in some instances, even though there are areas where the women still succumbed to patriarchal powers, such as engagement in unprotected sex. Their justification, however, was that it was to maintain peace while they pursued other strategies to calm their partners (the example of Thato's perseverance in Chapter Five).

Solidarity denotes a thread that binds a group or society together. As Hooks, (1986) argues, solidarity strengthens resistance struggle and it creates hope to change and transform society as a whole. Solidarity is based on a united front. It implies bonding with one another, speaking with

one voice, advocating for change in the ways systems operate. In this study, we see a group of women who call themselves “a support group” beginning to emerge from their hidden corners into the open to talk about the then “feared” epidemic that no one ever wanted to be associated with. In this study, these women, each of who came from their respective families, join a support group of people who are going through a similar situation as themselves. In the support group they learn how to help each other with treatment adherence. For example, Thato suffered side effects with treatment, she developed lipodystrophy (deposits of fats on the upper abdomen) due to the treatment regimen she was put on. She said:

I attended a workshop on adherence, I got to learn more about ARVs – it was a week-long training. Facilitators had suffered side effects, they showed us how the ARVs transformed their bodies, and I was scared of the side effects and began to worry. Immediately I too experienced side effects. They transformed my figure, had fat deposit on my upper abdomen.....In 2010, I noticed the positive changes on one of our BP members who had similar side effects with, how she had improved. I then changed the regimen through telling the nurses to change the regimen, I actually told them the type of regimen. At first they didn't agree with me but I insisted on the change, now I have changed a lot, I am gaining back my normal figure (Thato).

As Thato was engaging with her other colleagues in the support group, as well as reflecting from the training she attended, she realised that she, too, could ask to change her regimen. It is interesting that solidarity plays out in women learning from each other. Thato gathers strength and vows to improve her condition just as others whose looks and figures were initially damaged by ARVs had gradually regained their good looks. She gathers the strength to tell the nurses to change the regimen. Solidarity here is linked to increasing confidence and assertiveness as expressed in statements such as “I insisted on the change of regimen”. The isolated women living with HIV and AIDS, whose bodies were subjected to men at home and to medical professionals at the clinic and hospital, through their solidarity begin to assert control over their bodies and reclaim them as “normal”.

This solidarity within the group helped the women to face the outside world and take initiatives to improve their lives. It extended to promoting the economic well-being of these women. Within

their group, creativity and enterprise emerged. They formed savings clubs, engaged in small businesses, conducted stokvels and raised money for their families.

Thabitha confirms the solidarity that exists within the support group. One of the things that she upholds from her group interactions is the emphasis made on HIV. She said:

Every time we were told that we were sick and we have to depend on handouts – through series of skill training, we realized that HIV was not sickness but a condition – so I stood up to make a living for my family. I engage in small business – selling fruits, sweets, I carry them everywhere I go. Initially I was worried that people would not buy from me, but now people come in large numbers to buy my goods. I now have business skills, I know how to run a business (Thabitha).

Thabitha talks in a collective form. She uses “we” when she relays the messages or skills that they have been given in their support group. The notion of being told that they should not perceive themselves as sick, is a powerful motivation that helps them to move out of a circle of dependency and into a circle of independence and interdependence.

The solidarity that was instilled among the women within the support group, manifested itself in multiple ways in the women’s engagement with their communities. Suddenly the once voiceless rural women are out in the public spaces “mobilizing” people to access HIV and AIDS testing and giving testimonies about themselves, that they are HIV positive. Suddenly in community meetings (which are always chaired by a male chief or his male representative), these women transformed conventional community gatherings into community education forums around HIV and AIDS. These views were expressed as follows:

I impart knowledge to the community. Just yesterday, one of the neighbours said to me, ...Ahhh we know you, every time you come to us you bring new things!” I always encourage community members to test for HIV and to disclose their HIV status. I always tell them that HIV is manageable, I always make the example of myself that I even had TB (Maliketso).

At first when the community knew about this disease they uttered painful words, even at the streams when I go to draw water they used to say, “Oh! We are sick and tired of these heavily infected people, who are bringing this disease here. We cannot drink from the same stream as these people... ..” I always encourage people to test, give them all the information about health related issues. Their reception now is good, because some of them now come to me for advice and guidance, to say that I should advise them on what to do with HIV and AIDS (Palesa).

Queen grabs every opportunity in a public space to talk about HIV and AIDS. When she and other members of Phelisanang Bophelong are using public transport, she introduces the HIV and AIDS topic and gives personal testimony about it. She said that:

...just a week ago, when we came back from our meeting, on our way home, in the taxi we discussed about people who hide their HIV status. We openly told the commuters that we were from the clinic to refill our HIV medication. The driver of that taxi and some commuters did not believe us... ..we showed them the medication (Queen).

It now appears that the once rejected women living with HIV and AIDS are gradually gaining recognition as a result of their bold actions of penetrating a male dominated territory of speaking in public. Solidarity is evident in the move of the women out of the isolating patriarchal structure of the family to a support group of women with similar experiences and challenges, and from there out into the community. From my experience, in the Sesotho culture, it is almost unheard of for a woman to be seen in the midst of a formal or organised male gathering; let alone to raise an opinion. These women have gathered strength and have been able to break or challenge the status quo in this community and have openly declared their HIV and AIDS status, setting the example for future generations. The diagram below depicts the various levels of transformation of women from the family, to the support group, to the community and back to the family.

At the initial level, the women are in isolation from each other, trying to come to terms with their new HIV positive condition, negotiating and lobbying support at the family level (with spouses, children, in-laws and friends), often times encountering rejection and blame shifting (as I

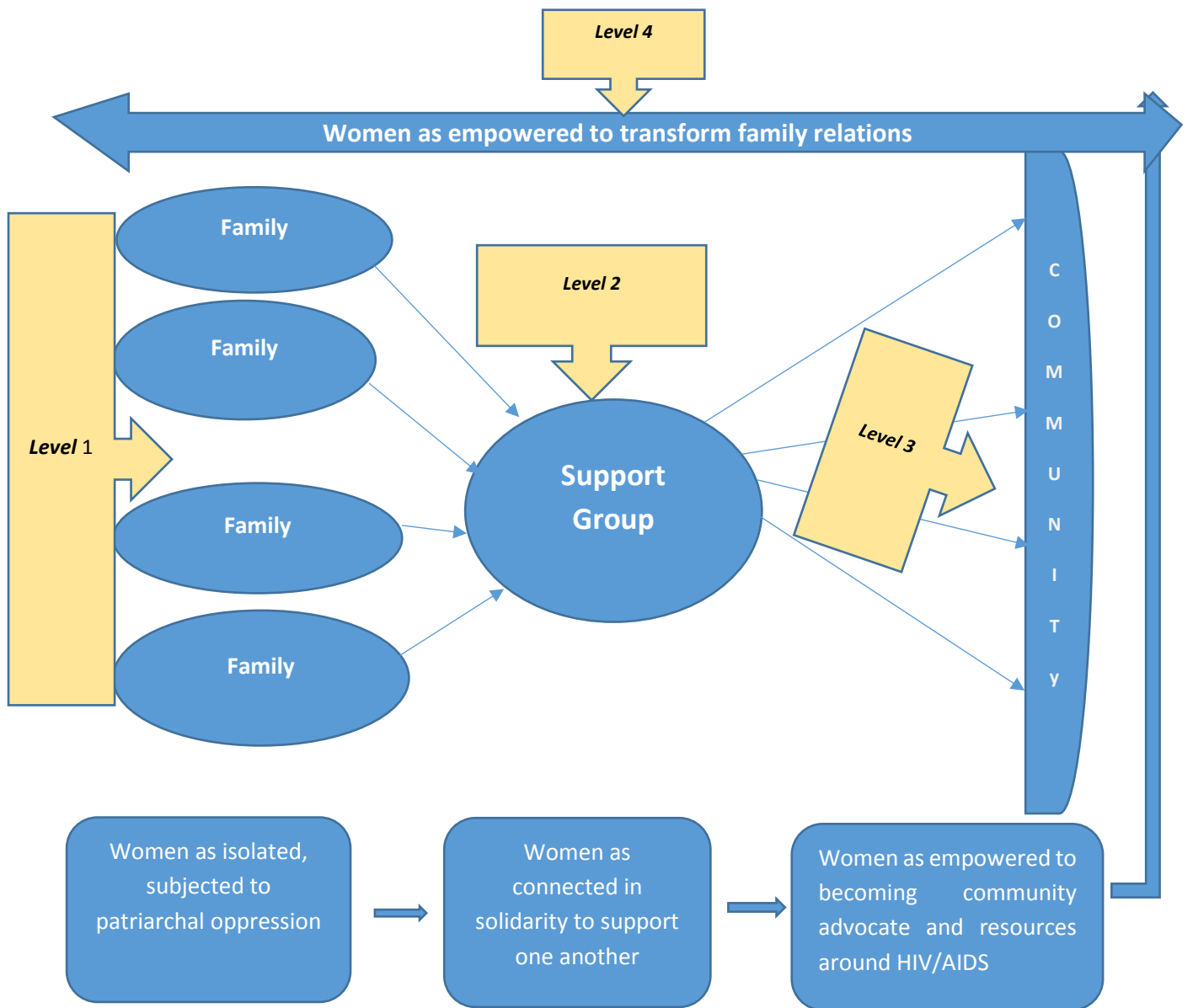
demonstrated with Thato, Maliketso, Queen, Papali). In between these negotiations for support, comes the treatment stage where the women grappled with treatment side effects alone.

At the second level, the women join the support group, where they learn more about HIV and AIDS, attend workshops, develop their public speaking skills, learn to interact with others, share their experiences with HIV medication and become not only HIV and AIDS competent, but also acquire livelihood improvement skills.

At the third level, this knowledge and skills they have acquired now flows into the community. The women come out into the open with no restriction, to give testimony about themselves – how they dealt with their HIV positive condition and to encourage the community to come out and test for HIV. The community as a result begins to recognize the skills that these women have acquired and they now look to the women for help with their health problems. They give them new titles such as “nurse”, “leader” and “nutritionist” which is in itself, a verification of their new found acceptance within the community.

By level four, these titles and the recognition they have received, spill across the community and back into their own families, where the women now demonstrate power and the ability to transform their own family relationships and their partners’ perceptions around HIV and AIDS. This becomes possible because the women have gained confidence through the recognition and affirmation they received within the support group and in their community work, and are thereby empowered to begin to re-form their domestic relationships. This process is not without conflict and setbacks, but is a clear trajectory towards female empowerment in the data. The four levels are illustrated in the diagram below:

Figure 7.1. From Isolation to Empowerment



The knowledge sharing that the women harnessed from the support group was therefore extended and spread across the communities and then back into the families where the women came from. The results of this community-wide education programme about HIV and AIDS is witnessed by the change in men’s perceptions about the partner’s HIV positive condition, which I will discuss below.

Partnership

The final theme that emerges in the findings using a feminist lens, is that of partnership. The gradual acceptance of their partners' HIV positive status by the husband, as discussed in Chapter Five (Table 5.1) indicates the beginnings of a shift in structure from patriarchy to partnership, within families – not in all, but certainly in some. One example is how Thabitha's partner supported his wife's disclosure which seems somewhat extra-ordinarily unique and something worth noting. This is what Thabitha said:

He accepted and did lunch to invite all my family so that I could disclose. During that organised lunch, as we were eating, I began "... I am sure you have been wondering why I was not breastfeeding the baby, I know some of you were angry with me when I refused when mummy wanted to wash my clothes, etc. I had a reason for all of that – it is because I live with HIV." They all looked each other with a surprised look. They asked me when I got it, and if I met their brother already infected. I told them, "Yes, I met your brother who didn't have HIV then, he has accepted me, and vowed to love me" (Thabitha).

I consider the manner in which this disclosure to the family was handled, as an act of partnership and ownership of the HIV and AIDS situation within the family. From my experience, it is uncommon for an African man to "prepare lunch" for family gatherings, even more so when news about such an ordeal was going to be announced. His physical presence during Thabitha's announcement of her HIV positive status to her in-laws, and the resultant reactions from his parents (surprised look), indicate the unwavering support he has for his partner, a sign of full ownership of this family. In our Sesotho culture, this act is associated with a mythical expression of someone who has been given some "muti" (traditional charms) in order to manipulate her/his right frame of mind (*o fuoe phehla*). This myth is associated mostly with women whose husbands love them exceedingly. In the Sesotho culture, there is nothing like "intimate love"; instead, a marriage is viewed as more of joining of a newly-wed, to the family of her husband. Love is symbolised or attached to economic support; that is why even in family disputes when a wife goes to report her husband's misbehaviour, the first question that the in-laws ask her will be, "Is he giving you money? Do you go hungry? Does he neglect the family?" If the answer to the

questions is “yes” to the giving of money and/or reflects positive support for the family, then there is no case against the husband. Given this cultural context, the attitude and actions of Thabitha’s husband show a remarkable shift from patriarchy towards partnership.

The partnership in marriages is again witnessed by Portia, Puleng, Libuseng¹, Joyce and Thandiwe whose partners showed them support when they disclosed their status. While their actions were not tangible per se, compared to Thabitha’s, their verbal expression is worth noting. Some of the reported statements were:

....He did not believe me when I first told him but later he told me it was good that I told him because then he will be more careful (Portia).

In terms of relating this support that Thabitha and the other women received, to what scholars say about African feminism, Ntseane and Mikell, (1995); and Badejo, (1998) would see this action as a discourse that recognises men as partners in the initiative to end oppression of women. African feminism is perceived in terms of complementarity rather than conflict between the two genders (Ntseane, 2011). Dube, (1991) uses the metaphor of a hen that scratches the ground for a lost needle which denotes that African feminism is a complex phenomenon that require the collective males and female’s effort to manifest. The indications of partnership in the data, although not the predominant trend, suggest some movement away from unquestioned patriarchal norms in relations between men and women, who are infected and/or affected by HIV and AIDS.

The next section looks at the findings in relation to transformative learning theory.

7.3 Transformative learning lens

Transformative learning theory is about how we make meaning of our experiences through the frames of reference that we develop as we become adults. The moment we experience or encounter something that does not fit into these frames of reference processes of critical reflection on previous assumptions is triggered, in an attempt to make sense of the experience. When critical reflection causes an adjustment or changes to our frames of reference, transformative learning is said to have happened (Mezirow, 1991). Transformative learning is concerned with how individuals may be empowered to learn to free themselves from unexamined ways of thinking, which have impeded the effective judgement and action of that individual (Mezirow,1978). Learning can also be described as making sense of our everyday life experiences. It can result in change in one of our beliefs or attitudes, or it can be a change in our entire perspective.

Building on this definition, Cranton and Taylor view transformative learning as learning from what happened in one's past, which becomes the primary medium of transformation, and that it is the revision of the meaning experience that becomes the essence of learning (Taylor & Cranton, 2013, p. 35). Mezirow, (1991) outlines two processes through which transformative learning happens. In the first instance, transformative learning occurs gradually over a period of time during which a person's meaning schemes are revised as a result of critical reflection. In the second instance, transformative learning involves a more dramatic change in the person's world view. Briefly put, transformative learning theory emphasises "meaning making" using meaning structures to filter and provide the context of experiences Mezirow as cited in Ntseane, (2011, p. 308). The meaning structures act as culturally defined frames of reference that are inclusive of meaning schemes and meaning perspectives.

Meaning Schemes: These are smaller components that are made up of specific attitudes, knowledge, beliefs, value judgement and feelings involved in making an interpretation. They are the tangible signs of our habits and expectations that influence and shape a particular behavior or view. An example is how we may act when we are confronted with a certain situation.

Meaning perspectives: These are the broader perspectives or a world view, or personal paradigm involving a collection of meaning schemes. They shape and delimit perceptions, cognition, feelings and disposition by predisposing our intentions, expectations and purpose. Meaning perspectives provide the context for making meaning within which we choose what and how a sensory experience is to be construed (Mezirow, 2000, p.16)

In this section, I look at three key elements that contribute to transformative learning in this study. They are disorienting dilemma, critical reflection and perspective transformation. The relationship between the three elements is illustrated in the diagram at the end of the section.

Disorienting dilemma: This is the first level of the ten-phase linear process of transformative learning that Mezirow articulated. Baumgartner, (2002) describes it as an event that causes people to question their beliefs and assumptions about the world. She cites the example of an HIV and AIDS diagnosis which she says brings fear, anger, guilt and shame to the individual (p.45). She sees it as a trigger towards transformative learning in that it compels people to practice critical reflection and then re-evaluate their assumptions about the world, while in the process realising that they are not alone and that others have or are engaged in a similar process.

Baumgartner (2002) focuses on HIV diagnosis as a disorienting dilemma and this provides a relevant example for this case study. These women were all of child bearing age. Child bearing gives a woman a social status and full acceptance as well as recognition within the motherhood

stage. It is a valued contribution that young women are expected to make. In the Sesotho culture, a newly wed is not given a matrimonial name until she gives birth. Upon giving birth she acquires a name which symbolizes some level of acceptance into her new family. Failure to bear children denies the woman full respect and acceptance in her homestead. These women, too, wanted to be fully recognized as mothers. The desire for children keeps appearing in their narratives. No wonder Queen decided to undertake a surgical operation to tie out her fallopian tubes to prevent another birth, as she realised that her life and her dreams were shutting down due to HIV positive diagnosis. In addition, all the women in the study seemed to be having normal healthy relationships with their partners (most of whom were working in the mines in South Africa) as well as their in-laws. Despite not having any symptoms, during pregnancy, some of them (Queen and Papali), discovered that they were HIV positive. Others had minor ailments such as coughs (Maliketso, Tukane and Thato) but upon taking further steps to inquire about their health, they discovered they had TB and HIV. Thato had tested negative after attending a workshop organised by her community, but five months later when she went to repeat the test, she tested HIV seropositive. Puleng was diagnosed HIV positive following her sexual abuse encounter. All these incidents came as a shock to the participants given, as I mentioned earlier, their age, their relationships with their partners, their in-laws, parents and friends. The disorienting dilemma of nearing their deathbed (as most of them were diagnosed when treatment was not available, or where available, came at a cost) shattered all their young motherhood dreams. The alarming rates of AIDS-related deaths that Lesotho was already experiencing, which was sixty deaths a day (Ministry of Health, 2009), made it evident to the participants that they too, were nearing the end of their lives. Reflecting upon their young children that they would soon leave behind, the much already talked about rejection, stigma and discrimination upon the infected people, and thoughts of being labelled promiscuous (as was commonly perceived), contributed to their disorienting dilemma.

Below is the table that shows some aspects of the disorienting dilemma experienced as a result of an HIV positive diagnosis from the participants.

Table 7.1 Disorienting Dilemma Experienced from an HIV Positive Diagnosis

Narratives	Disorienting dilemma	Associated emotions	Associated Relationships
<p><i>....the reason for that surgical operation was that I thought my life was shutting down. (Queen)</i></p> <p><i>...I was very hurt, because at that time it was common to associate HIV with adultery and knowing that I never had any relationship, also the fact that my partner was unfaithful he would spend nights and nights away from home, I felt very hurt that I have been betrayed by my husband. I thought it would be better if it was me who actually brought HIV at the house (Queen).</i></p>	<p>Life plans shattering; death nearing</p> <p>Being labeled as adulterous.</p>	<p>Panic</p> <p>Hurt</p> <p>Betrayal</p>	<p>Self (I – my life)</p> <p>spouse</p>
<p><i>I have always asked myself why me, at my age especially? What will my spouse, children, mother, boyfriends say when I tell them about HIV positive? These issues kept bothering me. This was in 2004.</i></p> <p><i>I thought I was going to die (Palesa).</i></p>	<p>Social misfit</p>	<p>Hopelessness, death, self-pity</p>	<p>Family</p>
<p><i>When I noticed I was HIV positive, and after what the counselor told me about living positively, I accepted my status. The only problem was my spouse who is very cruel/mean. I had difficulty telling him because I did not know how he would take it (Thato).</i></p>	<p>Losing the marriage</p>	<p>Uncertainty</p> <p>Fear of reaction</p>	<p>Spouse</p>
<p><i>I was ashamed of myself. My friend and I used to eat from the same plate before, but this time I would dish out food, when I am about to dip my hand in the same dish, I would pull it out thinking that my friend would not like to share food with me anymore (Thato).</i></p>	<p>Sharing and relationship with friends</p>	<p>Being a worthless thing, rejected by friends and family, nearing the death bed</p>	<p>Self (I – myself)</p> <p>Friend</p>
<p><i>...because I was one person who felt like committing suicide, especially thinking of my friends out there, even at home I did not think my mother would accept my HIV status so it</i></p>	<p>Facing reality of being HIV positive</p>	<p>Suicidal due to fear</p>	<p>Friends and family</p>

<i>was better that I drown myself in Katse dam....</i> (Palesa)			
<i>I told my friend that I wanted to test, but she discouraged me.... eventually I went to Motebang and tested. I felt OK and indeed was happy that I finally knew my status. The nurses wanted me to bring somebody to become my treatment buddy. I told them [the nurses] that I had fully accepted my status that I did not want to involve anyone about my health. I went home and disclosed to my children</i> (Maliketso).	Involving others in knowing her status	Confusion	Friend and children

A striking aspect of the disorienting dilemma is that it often creates a crisis in the woman's relationship with herself (e.g. "ashamed of myself", "feeling suicidal") which is also often reflected in a crisis of relationships with others (e.g. friend, spouse, family). These crises of relationship are associated with very powerful emotions (e.g. hurt, shame, betrayal, confusion). One key aspect to moving beyond this crisis, is critical reflection, to which I refer to below.

Critical reflection: This is the process of "critically assessing the content, process, or premise of our efforts to interpret and give meaning to an experience" (Mezirow, 1991, p.104). Through critical reflection, people explore options for new roles, relationships and actions. They make a plan and participate in what Mezirow as cited in Baumgartner, (2002) refers to as reflective discourse by talking to others about their new perspective. Through reflective discourse, people gain knowledge and skills for implementing their plan.

Relating this theoretical assumption to what transpired with the participants, the study noted several reactions made by the women upon an HIV diagnosis. While some decided to disclose to their partners, children and in-laws immediately, there were others who decided to delay disclosure. Palesa's reflections included:

What will I say to my mother? How will she react? If she asks me where did I get this, what will I tell her? Now that HIV is associated with promiscuity, who will I point at as having given me this? (Palesa)

Tukane debated on whether to disclose to her boyfriend and to her sister-in-law

How will I start to tell him [her boyfriend]? Is he going to believe me or still love me? About my Grandmother, how will she take it? At my age, what will I do? (Tukane)

Portia did not have a problem disclosing to her partner as she married him already having HIV.

The challenge was with her child-and how she would tell him the news.

Thato and Maliketso are among the women who engaged in critical reflection about how they would break the HIV positive news to their partners. Both of them waited for their partners to come home for a weekend from work in South Africa, in order to tell them.

I first disclosed to my sister, then waited for my husband to come home. My husband came home after a month of knowing my status, I knew my status in October, and he came in November (Thato).

Upon critically reflecting on her HIV diagnosis, Thato decided not to disclose to her children.

It was at the time that she was fighting with her husband, that she began to correct the lies that she had told her children about the “ulcer” medication that she was in fact taking ARVs following her HIV positive test result.

Maliketso first disclosed her status to her children. While she had decided that she would tell everyone she met of her diagnosis, when she left the counselling room, it seems she engaged in a critical reflection about who to tell first, perhaps in terms of who would support her. That could be why she decided to tell her children. As it will be recalled in Chapter Four, Maliketso did ask her friend to accompany her to the clinic to test (who refused and discouraged her), but when she received the test results, she decided to disclose to her children first. She informed her friend only at the stage where she had to bring her to the clinic to support her with treatment. She had this to say:

I told my children and said, "I went to the clinic, I tested positive." They said, "Oh! mum you are positive, then we all need to go and check".... My second born son volunteered to support me with treatment– he said, "Mummy I am the one who will help you with the reminders". He has been very supportive (Maliketso).

Due to the seemingly sour relations with her partner, Maliketso waited for the time when her partner came home in order to break the news. This is an indication of the lack of support which she already envisaged she would get from her husband.

Queen was with her partner when she tested. It perhaps left her with no room to reflect on whether or not to disclose to him. She, however, further disclosed to her children, perhaps upon discovering lack of support from her husband.

Critical reflection found expression in the participants asking themselves questions such as: Should I disclose my condition? Who should I disclose to? How do I decide who to disclose to first? What will the consequences be for me and my family? The decisions that emerged from the critical reflection created an opportunity for some of these participants to receive support. In fact the majority of the women, received support from the initial people they disclosed to.

The study also shows that critical reflection is not a purely cognitive process but is tied up with affective and social factors (as indicated in Table 7.2), for example the choice of who to disclose to first had a connection with the relationship level. Where the relations between partners had all along been good, the participants disclosed to them first, but where the relationship were somewhat uncertain, partners were secondary in the disclosure sequence. This is consistent with the literature on transformative learning that criticised Mezirow's neglect of emotions and relationships, as put forward by Taylor, (2000); and Ntseane, (2011) where friendship, support and trust are seen as vital to critical reflection and to a transformative learning process, as a whole.

Perspective transformation is a linchpin in transformative learning, as it represents both the accumulation of prior learning and the new learning. The worldview that adults bring to experiences in life are made up of meaning perspectives that adults acquire during life. They consist of specific knowledge, beliefs, value judgements or feelings involved in making an interpretation. Perspective transformation is concerned with the activities of perceiving, understanding and remembering, Mezirow as cited by Baumgartner, (2002).

Linking this theoretical assumption to the study, I identified the following key steps in the participant's HIV and AIDS journey:

1. **Personal commitment:** Considering their location (rural women) and their low education level, the women, made a commitment to reverse the disorienting dilemma experiences that I have outlined above, by using every opportunity to learn about HIV and to follow the advice of the nurses and the doctors. They familiarised themselves with their treatment in order to regain their health. In spite of the rejection and stigmatising statements from their different relations, the women took further steps towards the future. This indicates that perspective transformation involves an act of the will, along with that of cognitive change.
2. **From stigmatised outsider to community educator:** The women were brave to move beyond the notion of viewing an HIV as a deadly disease, but observed the lack of knowledge by the communities and took the opportunity of their mockery, to educate them about the importance of getting tested and accessing HIV treatment. Tukane, a single parent (unmarried), goes to her community council to ask the Chiefs and local Councilors (high ranking officials at the community level) to allow her a slot in their public meetings to educate her communities about HIV and AIDS. It is culturally

uncommon, let alone unbecoming of the woman (the unmarried one for that matter) to penetrate male dominated territory to talk about issues of sexuality in the midst of her elders. Tukane however wore a brave face to “rescue” the HIV and AIDS illiterate community.

3. **From ‘deathbed’ to public spheres:** The communities’ perception about HIV and AIDS gradually changed following a series of training programmes and the advice given by the participants to the communities. The communities began to view them as health professionals at the village level, instead of their initial perception of Women living with HIV and AIDS as “those that are nearing the death bed” (see Palesa and Queen’s narratives in Chapter Six).
4. **From passive recipient to patient expert:** The other area of perspective transformation, is the relationship that they developed with the health centres’ staff. The knowledge that they accumulated around HIV and AIDS, enabled them to demand change of treatment regimen in cases where there were very unpleasant side effects noticed, as well as to help other HIV positive clients who visited the health centres. Note, Thato’s statement when she confronted the nurses through “telling” them that the treatment regimen prescribed to her was not suitable (see section 6.3). In the Sesotho culture, it is uncommon to question the decision of a medical doctor or an authority who is perceived as a “knower”. These women are gradually challenging this notion and putting forth their knowledge about HIV.
5. **From isolation to solidarity:** While each of the women was dealing with HIV and AIDS on their own, at their respective various places, they decided to join support groups of people living with HIV and AIDS to learn more and to be among people, who share

similar experiences. This is a form of personal perspective transformation, moving from the common notion of being on familiar ground, to exploring other avenues of interacting with and networking with strangers. Hooks, (1986) supports the notion of solidarity as helping to transform society as a whole. While she uses it in the context of political movement, the same manner as John, (2015) did in his further writings on the HRDD project, solidarity within our African context denotes “humanism and Ubuntu” (Ntseane, 2011; and John, 2015). It implies collectivism. Hayes, (2000) echoes this, by reflecting on voice and power as elements of solidarity and how they help women to speak in a collective voice as “we” rather than “I”.

This section explored various ways in which the participants engaged in transformative learning which was triggered by their HIV and AIDS positive diagnosis. The change in their meaning schemes, meaning perspectives and critical reflection became the linchpin towards their transformation. Transformative learning in this section has been demonstrated in the following ways:

- a) the women’s ability to move out of their sickly condition, to seeking solutions at the health centres;
- b) their decision to move out of their stigmatizing environments to seek safer spaces, that is, joining support groups of people going through similar ordeals;
- c) the resilience they demonstrated when they were being stigmatized and rejected by their families and community and;
- d) their eventual move from the level of novices to local experts which came with new identities such as “nurses” are all processes of transformative learning.

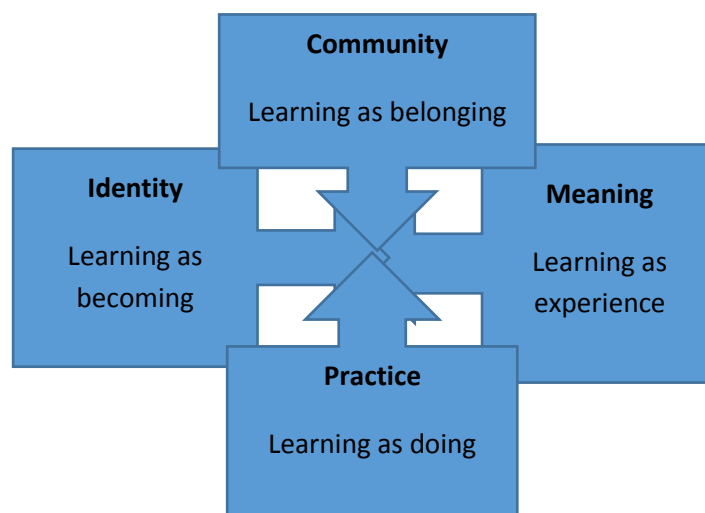
From this, we see the change in meaning perspective from passive illness (“I HIV positive as ill”) to active engagement (“I HIV positive as capable”). The change in perspective goes along with actions that reflect the new perspective.

The next section now looks at the findings in relation to the communities of practice.

7.4 Communities of practice lens

Communities of practice is a social theory of learning with a focus on how people learn through their everyday informal interaction with their environment (Wenger, 1998). Its core dimensions are meaning (through learning and experience); community (through mutual engagement, joint enterprise and shared repertoire); identity (through learning and use of shared resources); and practice (shared goals, learning as doing). These four inter-related dimensions are illustrated in the diagram below:

Figure 7.2 Core dimensions of Communities of Practice



Adapted from Wenger, (1998)

This section will draw upon elements of communities of practice theory, in particular identity, participation at periphery-centre, and meaning-making, and link them to the findings in this study.

Identity: This involves a process of understanding who we are and in which communities of practice we belong and are accepted (Handley, Sturdy, Finchman & Clark, 2006). Identity building is an integral part of social theory of learning. It consists of negotiating the meanings of experience of membership in social communities (Wenger 1998, p. 145). The findings pointed to the fact that each participant was a member of the PBSG. They joined at different times and for different motives. Some were motivated to join by the nurses in the clinics where they were accessing treatment. (Thato, Maliketso and Palesa); others used the support group as an escape from the feeling of loneliness, stigma and discrimination and used the support group as a new home for obtaining more knowledge information and skills around HIV and AIDS (Queen, Thandiwe, Tukane Libuseng¹, Thabitha, Joyce and Portia) which confirms Chiu, Hsu and Wang, (2006) views about the factors that make people join communities of practice. There are those members who joined unexpectedly and involuntarily, but were influenced by circumstances to become part of the group (Papali). This case relates to women who were diagnosed HIV positive during their antenatal care and were subsequently referred to the PBSG for counselling.

Within the group, the participants developed a number of skills such as supporting HIV and AIDS interventions at the community level (being called Local Adherence Coordinators) attached to all the clinics in the district of Leribe to create awareness about HIV testing, monthly report writing and conducting home-based care to people living with HIV and AIDS.

Participation from periphery to centre: is a notion used by Lave and Wenger, (1991) to discuss how novices develop their expertise in the community of practice. They view it as a

process that allows a novice to take part in the peripheral aspects of the practice and to be recognised as legitimately doing so, while gradually being inducted into more central, and often more complex aspects of the practice. Thus the novice practitioner gradually takes on more and more expert and important tasks, until eventually she becomes an old timer. Through their acknowledged legitimacy of their participation, novices learn to be full participants in the community of practice. Participation is viewed as central to situated learning, since it is through participation that identity and practice develop. Participation as suggested by Wenger cited in Handley et al., (2006), refers not just to local events of engagement in certain activities with certain people but to a more encompassing process, of being active participants in the practice.

Drawing on the concept of legitimate peripheral participation as developed by Lave and Wenger (1991), Paechter, (2003) contextualises it in the gender socialisation process whereby boys learn through apprenticeship by observation of the men they encounter. Likewise girls learn through apprenticeship to women; taking part with adult women in activities pertaining to womanhood in the community (helping with cooking, cleaning or child care).

...the perfection of the practice gradually qualifies each gender to become full members of the practice and thus creates a possibility of mutual recognition and the ability to negotiate meaning (Paechter, 2003, p. 542).

Linking this theoretical assumption with the findings from this study, it is worth indicating that participants were assigned to the local clinics to work as local adherence coordinators to support treatment adherence, to encourage communities to test and to scale up prevention of HIV from mother to the unborn child. They became part of the existing health personnel at the local level. Due to their perceived low educational level, often they encountered resistance from qualified or old-timer health professionals. Perhaps this resistance was attached to the fact that this was a fairly new structure within the health system to have lay persons attached to the clinics. They were often met with negative responses whenever they raised a concern about the drugs

dispensation that was given to HIV positive pregnant mothers (refer to Queen's narratives in Chapter Five). However, with their perseverance, that negativity subsided and they were absorbed and accepted as part of the knowledge base of the clinics. Linking this finding with the theoretical underpinning, Merriam, Courtenay and Baumgartner, (2003) and Handley et al., (2006) drawing from Wenger, (1998) regard this process as legitimate, peripheral participation by which newcomers become old-timers through a series or levels of participation in the practice. Legitimate peripheral participation (LPP), they claim, is a process of changing participation and changing identity (our identity is something we constantly renegotiate during the course of our lives (Wenger 1998, p. 153). Section 6.4 articulated the various levels of participation in the practice starting with the core group, the active group and the peripheral group.

The PB management confirmed this theory by noting as thus:

...from what we have seen, though new members are made to feel at home, old members seem to dominate in terms of ideas (PBSG management).

In enhancing participation in the practice, the PBSG management devised a strategy of group sharing of experiences where each member in a group is allocated time to share. In this way members were able to gradually move from the periphery to the centre of the practice.

The case study thus identified two communities of practice among the participants. The first practice is that of participants sharing a practice of being members of a support group belonging to PBSG. The second community of practice is that of participants becoming members of the health centres (clinics) staff where they shared information regarding administration of patients diagnosed with HIV. In the table below, I list the two communities of practice and their corresponding tasks.

Table 7.2 Participants' different participation in Communities of Practice

Community of practice	Support Group	Clinic
Purpose	To mobilise communities to access HIV and AIDS testing; to share information among members related to how work is done, conduct home-based care visits	To support HIV positive clients with treatment adherence, dispensing of ARVs, to track treatment defaulters back to the system
Focus of practice	Inward on relations among members	Outward on relations with community
Nature of membership	Voluntary: Women living with HIV and AIDS decide to join group	Skills-based. Members had to attend series of training workshops on HIV treatment in order to become skilled to effectively participate as Local Adherence Coordinators
Practice	Solidarity and support: HIV and AIDS knowledge sharing, home-based care provision formation of informal clubs (stokvels, income-generation clubs)	Service: Delivery of HIV and AIDS services (testing, treatment adherence education and medical dispensing, support structure to the clinic/hospital, medical follow-ups for defaulting patients). Advocacy
Member identity	Support group member, 'sister' PB member, friend, colleague, neighbor	Local adherence coordinator, community 'resource person', 'leader'; paramedical: 'nurse', 'nutritionist'.

The dual roles played by the participants – first as members of the support belonging to, PBSG and second as community health workers working in the clinics as Local Adherence Coordinators, strengthened their membership in the two communities of practice. On the one hand, the information and knowledge they acquired from PB, helped them to perfect their practice at the health centres. For example, in the case of the HIV treatment regimen, public speaking was core for smooth integration within the world of work. Treatment adherence education helped the health centre clients or patients to adhere to treatment and improve their

quality of lives. The public speaking skills that they possess, facilitated awareness campaigns around HIV testing by the communities. Note Queen's statement expressing her thorough knowledge of PMTCT issues, where she identified the wrong medication that was being dispensed to pregnant HIV mothers. The knowledge that she acquired from her participation in another practice, saved the patients from what could have been quite negative effects of the medication and their unborn babies. On the other hand, the professional world that they become exposed to from the health centres, shaped their ways of relating and perceiving themselves and the communities. Note Portia's acquired skills of being able to read the minds of the community that even as they were mocking her about her HIV positive condition, she interpreted this as more of a "a cry for help" because deep down the community was distressed about the pandemic (Chapter Six).

Meaning making: This is a learning activity within the communities of practice. It implies that people talk candidly, share their experiences and insights and find meaning together as individuals and in teams. This is expressed by Wenger, (1998) and Merriam et al., (2003). Meaning making is one of the four key principles of communities of practice. Linking this theoretical underpinning to this study, and as articulated in Section 6.4, the participants broadened their HIV positive condition disclosure to the wider community, thus breaking the silence around the epidemic. This they did when they joined the support groups. Within the support groups they were allocated time to share their experiences. In terms of how they construct meaning from experiences of others, PB management indicated:

....yes they do. They even contribute by giving examples drawn from their own unique working environment (PBSG Management).

The next sections sum up the issues discussed in this chapter.

7.5. Conclusion

The chapter drew upon content from the theoretical framework chapter, as the theories in relation to the findings as elaborated in Chapters Five and Six were discussed. I identified key findings in this study based on the themes a) testing for HIV; b) disclosure and reaction to an HIV positive status; c) accessing HIV treatment; and d) joining support groups. I discussed these broad themes using the three theoretical lenses that ground this study. First, I used feminism to look into issues around patriarchy, oppression, solidarity, decision-making and partnership. Secondly, I used transformative learning theory to look at the issue of the disorienting dilemma, reflection and perspective transformation. Communities of practice was the final theoretical lens that I used to link the findings around the core dimensions of communities of practices (identity, community, meaning and practice), participation at periphery-centre and meaning-making.

The next chapter concludes this thesis by synthesising all the findings in relation to my research questions; reflecting on what was learnt from the study and then mapping the way forward, for future research on related topics.

CHAPTER EIGHT: Conclusion, Lessons learnt and Way forward

8.1 Introduction

This is the final chapter that summarises, provides key highlights and concludes the main findings of the case study. It has five sections. In the first section, I begin with reflections on the research questions to assess the extent to which the narratives have responded to my quest for undertaking this case study. In the second section, I present my reflections on the methodology – what I have learnt from this study and how this case study has changed my whole understanding of the research endeavor. In the third section, I give my reflections on the narratives while the fourth section discusses the lessons learnt from this case study as well as the contribution that this case study is bringing to the body of knowledge that has as its focus all the issues related to the world-wide HIV and AIDS pandemic. The final section is the conclusion and my final statement about the study.

8.2 Reflections on the Research questions

As I have indicated in the beginning chapter, this case study is guided by the key research question that looks at how Basotho women who live with HIV and AIDS cope. This coping is assessed within the social, cultural and medical dimensions and perceptions of Basotho on issues of HIV and AIDS. From this broad question emerges four sub-questions which I find to be key in assessing the extent to which women who live with HIV and AIDS of child bearing ages are coping with their HIV condition within these elements.

I used my research questions as my headings to reflect on the learning and the coping strategies of these women. The questions are:

1. What coping mechanisms do Basotho women living with HIV and AIDS devise to address social, medical and cultural perceptions and pressures related to HIV infection?
 - a) What learning experiences do women of child bearing age go through regarding antiretroviral therapy and societal pressures in relation to child bearing?
 - b) How does that learning manifest itself at different stages of the coping process?

- c) To what extent do they experience transformative learning? What are the coping mechanisms that women adopt as a result of any transformative learning?
- d) What can we learn from these learning experiences that can assist us in educating or supporting other women embarking on ART?

Learning experiences that Women living with HIV and AIDS go through regarding ARVS and how they cope with ART

The learning experiences that I elucidated on, in this case study, relate to both the individual and the group commitment that surfaced throughout the study. Firstly, these women were alone at their homes, leading normal village lives. Some of them were not even aware of the HIV and AIDS epidemic (given their educational level, their rural background and the then limited information and knowledge about the epidemic). Secondly, as a societal norm and practice, these women, like all other women of their age groups within Lesotho society, expected to bear children. It was during their antenatal care that some of them discovered they were HIV positive.

While one would have become devastated and kept the HIV positive status to oneself, the women came out and disclosed their status to their partners, children and in-laws. The disclosure to the partner could be justified as a way of soliciting support and joint care for the unborn baby, but extending this to the in-laws could to some extent be inviting rejection and stigma- given the then limited interventions around prevention of infection from the mother to the unborn baby and the communities' perceptions around HIV and AIDS at the time. In spite of these, the women soldiered on and faced the challenges and its consequences.

At the individual level, they learned to cope with their HIV condition through adhering to treatment requirements. They learnt to trust their partners and children for support with the

treatment, or to change their domestic arrangements if their partners could not support them. Some of them learnt to share their HIV condition with their own parents and friends in order to cope.

At the group level, they learned to interact with each other and share their experiences regarding treatment side effects as well as the latest developments concerning treatment regimen. They gained knowledge about ways of improving their lives and health.

How does this learning manifest itself at different stages of the coping process?

This question is answered by the various learning processes within the women's journey with HIV and AIDS. Firstly, as I have alluded to above, their HIV positive condition created opportunity for communication about this new phenomenon with the clinic staff, in their families and also within their circle of friends. In each or all of these arenas, some women received support and encouragement. Secondly, the manifestation of this learning is witnessed by the strong support demonstrated by their children (at those tender ages) to set reminders for their mothers to take medication, by always being inquisitive about their own health and regularly asking their mothers when they too can go and check for HIV (refer to Maliketso's narratives about her children's support in Chapter Five) and by monitoring their parents adherence levels (refer to Queen's children who reported to Queen that their father is not being regular with medication). These acts demonstrate some degree of responsibility that HIV has brought to the families. In the third instance, some women received unwavering support from their partners which made it easier for them to cope with the epidemic (Thabitha's partner's unique support as indicated in Chapter Seven). Even for those who never received support from their partners, the safe environment created by their support group, was conducive to learning and coping.

To what extent do they experience transformative learning? What are the coping mechanisms that women adopt as a result of any transformative learning?

Transformative learning is especially evident in the women's responses to HIV diagnosis. This moment of crisis, creates a disorienting dilemma which forces them to reflect on their new situation and to decide upon new courses of action. Their responses, which reflect and instigate transformative learning, include disclosure to others, adoption of lifelong treatment regimens, joining the support group, and engaging with the wider community. What emerged from the study was that transformative learning was often a collective process that relationships were crucial to the process, and that emotional, spiritual and somatic aspects played an important role along with cognitive changes.

From this case study, I noticed the gradual improvement in family relations of the women. The once patriarchal system that had been characterized by abuse, social and economic oppression is being gradually diluted. Women are demanding change with regard to the risky sexual practices that their partners subject them to (Thato and Palesa). While some of them did mention that they complied to keep the little peace that was there, their justification was that it was just a temporary measure while they explored other avenues. Indeed, Thato eventually made a breakthrough in convincing her "mean" partner about the need to practice safer sex.

Transformative learning experienced by the women is seen in Queen who learnt that the longer she stayed in the marriage that was characterized by physical, sexual and verbal abuse, the more risks or dangers she would experience. She decided to quit the marriage, instead of re-infecting herself with HIV from an infected partner. Palesa transformed the community's mockery of her HIV infection and used the occasions of such statements, as a forum to educate the community about the importance of testing for HIV, and indeed later on, the very same people who once

mocked her, come and asked her to be their HIV treatment supporter. Likewise, Portia interpreted the community's mocking statements, as a "cry for help".

What can we learn from these learning experiences that can assist us in educating or supporting other women embarking on ART?

The lessons learnt from this case study are the importance of disclosure of an HIV positive condition to the family, as it helps directly with treatment adherence. In addition, from this study, I have identified the critical role of support groups towards facilitating the disclosure of a person's HIV status; the acquisition of knowledge about ARVs; the sharing of information pertaining to treatment in-take and collectively discussing the ways of decreasing any side effects about treatment.

From this case study, the learning that emerges is that of the development of resilience and self-confidence, in the midst of atrocities. By this I mean the rejection, stigma and discrimination that the women faced, coupled with adversities of the treatment in-take itself, did not deter them from seeking further medical assistance regarding their HIV positive condition. Their low educational levels and the cultural hegemony that shape the African woman in general, and the Mosotho woman in particular, could have become barriers to HIV and AIDS enrolment processes and treatment literacy (given the processes as well as medical jargon that comes with the HIV treatment), but the women wore brave faces to learn and to familiarise themselves with their treatment regimen, to improve their quality of life.

8.3. Reflections on methodology

In this study, I adopted the interpretivist paradigm due to its rich emphasis on interaction and meaning, and its relevance to the type of data I set myself for obtaining. Its emphasis on a researcher-participant interaction as a way of exploring lived experiences from participants, interviewing a handful of clients for longer periods of time in order to elicit reality, their

meaning-making through the available data, are what guided me. Below are some of my methodological thoughts about this study.

My relationship with the participants: The participants belong to an organization that I was working with from my past employment in the Leribe district. While I did not meet the participants during my tenure in Leribe, face to face, per se, I was informed from the monthly reports from their organization, about the work that they did. Their programme managers were the ones I interacted with. What I knew about them was that there was a group of local people who decided to form a support group of people living with HIV and AIDS and that they did not have any formal educational background per se.

My encounter with the participants: I encountered a lot of surprises, interacting with the participants. Firstly, I had a perception that due to their low level of education, I would encounter delays in data collection processes (discussing the questionnaires, interview guide and explaining the ethical considerations etc). I thought it would take this study days to explain the whole process and some lengthy period to collect the data too. With this in mind, on the first day, I brought two research assistants with me to help with explanation of the questionnaire. I was surprised by the level of understanding they possessed regarding the process. The research assistants' role was to distribute the questionnaire and to collect the completed questionnaires.

Secondly, from the onset I was received with welcoming statements which pointed to their eagerness to participate in the study and to have their views and perceptions captured regarding HIV treatment. Some of their statements were that “often times we are told by the clinics that studies are made about HIV and AIDS, about the various regimens, but none is ever made about us – the consumers of these drugs, we are happy that a study of this nature is being done on us.” In fact, many wanted to take part in it, but it was only when I explained the participation criterion (age limit) that I was left with only 13 women.

What learning I experienced from conducting this research: The interpretivist paradigm's model using the epistemological, ontological, axiological and rhetorical lenses as was explained in Chapter Four, when followed to the letter, generated rich descriptive data that enhanced the study. My numerous visits to the participants, and the longer the periods I spent with them, created trust for them to share with me their deep thoughts and feelings about their condition. The fact that it was their first time, that a study about them was conducted, was advantageous to me, because I received such overwhelming responses.

Reflections on the theories

The theories used for this case study were relevant to the findings. For instance, the feminist lens that I adopted, that aims to end women's discrimination because of their sex, has manifested in the case study. The women have strived to have a say in male dominant structures of their society and their home. The patriarchal system which translated into all forms of abuse, was noted in the case study. Nevertheless, the women diluted the notion of male hegemony and turned it into partnership. Transformative learning theory and its assumptions, surfaced throughout the case study. The disorienting dilemma which resulted from HIV diagnosis (at their tender ages) triggered action among the women. The critical reflection that they engaged in, surfaced in their narratives.

The communities of practice theory with its core dimensions of community, identity, meaning and practice, was displayed throughout the case study. The participants formed a community of people living with HIV and AIDS, who are engaged in a practice of HIV and AIDS sensitization and education among themselves, their families and the community.

8.5 Reflections on the narratives

Gender relations

Unequal power relations, as discussed in the first chapter, manifest in gender-based violence in intimate partnerships and sexual abuse. Women's lack of power, due to their vulnerability, serves to prevent them, from negotiating for safer sex. Likewise, men due to the gender norm of engaging in risky sexual practices, coupled with the societal expectation of male authority, limit them to openly display any vulnerability. In this case study, this male domination seemed rife. Some of the participants – Maliketso, Thato, Palesa and Queen – experienced a lot of resistance trying to convince their partners to test for HIV and to practice safer sex. Notwithstanding, the women challenged the status quo by openly disclosing their HIV positive condition to their partners, their children, their in-laws and to the broader society. Those that encountered some level of rejection at the initial disclosure (Thato, Palesa and Libuseng²) kept pursuing other avenues to win the support of their partners. The mechanisms or strategies employed included: a) succumbing to unprotected sex with the hope that their partners might change their minds (while at the same time still pursuing medical attention for the HIV positive condition;) and b) seeking advice elsewhere on how to mend family relations. (The example of Thato who reported that following the advice she was given, she began to speak to her partner in a soft manner, positive changes in their relationship began to occur. For participants who received an outright rejection (Maliketso, Queen and Papali), the broken relationships did not prevent them from seeking further medical attention about their HIV positive condition, that is by enrolling in treatment programmes and the subsequent joining of a support group.

The other category of the women who received immediate support from their partners (Portia, Libuseng¹, Puleng, Thandiwe, Joyce and Thabitha) expressed this in statements such as “we can talk freely about HIV and AIDS. I regularly give him all the information regarding HIV and

AIDS”. This statement denotes some level of intra-family communication patterns among partners – a relatively new phenomenon within the African family setting which I view as breaking the barriers imposed by patriarchy, in order to pave way for partnership within families.

8.6 Lessons learnt from this case study

Some of the lessons that this case study uncovered was that when faced with a devastating situation, women have the ability to by-pass the pre-determined gender norms of positioning women secondary to their male partners. While in almost all family commitments, especially on production and reproduction matters, men are the custodians of this territory, this case study has revealed that as far as health matters are concerned, women will take the step to investigate their own health conditions and strive, without the approval or authorization from their partners, to regain their full health through accessing health-related treatment and through engagement and interaction with other women going through a similar experience. The knowledge that these women acquired from the various forums was transferred to their families and to the communities. Although some initially kept the results about their health condition to themselves, they went on to share their results with their partners, in order for them (partners) to know their HIV seropositive status and to then take appropriate action.

HIV and AIDS, however devastating the illness may be, has created avenues for families to engage in communication of issues of common interest. This seems a new phenomenon, given the fact that in our Sesotho culture, men and women are delegated different tasks and roles, which create a divide between the two sexes. The issue of reproductive health rests solely with the man, while women are just recipients of the male decision-making. From this case study, emerges a different scenario however, where women have successfully penetrated the previously male dominated territory, to break the silence around HIV and AIDS and sexuality.

The case study has revealed another important element within the family relations – that of information sharing by women with their children. While it would be common to hide an HIV positive status or any sensitive and life threatening health condition from the children (as is the norm in the African practice to delineate certain information to parents only) the women broke that norm and extended this information to their children, perhaps as a way of soliciting their support and maintaining the mutual trust between them and their children, or as a way of educating them and preparing them for any eventuality about HIV and AIDS (given its level of sensitivity to the general community at the time). I consider this action a breakthrough in family relations.

This case study demonstrates another element and that is of the children's resilience when told of the diagnosis. The children supported their HIV infected mothers, despite the rejection some women suffered from their partners and other family members. The paradigm shift that HIV and AIDS brought to the children at those tender ages – of having to prioritise their mothers' health over their own interests, by setting reminders about taking medication etc., is an indication of a sense of responsibility, that these children have, and which has been shown to surface at a comparatively young age.

The other lesson that this case study brings to the fore, is that of males who seem to be gradually gravitating towards the centre of the fight against HIV and AIDS. The immediate support demonstrated by some males to their partners' disclosure is a vital move worth noting. The level of buffering that some men provided to their partners, against the demeaning statements that came from their in-laws (the case of Thabitha) clearly demonstrates the level of ownership and partnership that exists within families.

The turnaround from negative and discriminatory to positive and affirming behaviour demonstrated by the community members to the participants indicates the acceptance of HIV as

no longer a death sentence, but rather a chronic illness that can be mitigated through adherence to HIV treatment. This acceptance, it is noted, has been realised through active involvement of the participants by advocating for change in how communities perceived HIV and AIDS.

8.7 Way forward for policy, practice and research

I have categorized this sub-section into three parts. Firstly I look at the way forward at the policy, practice and research level.

At Policy level

The institutionalization of HIV and AIDS support groups, seems to be a grey area in Lesotho. Based on the activities, level of knowledge and acquisition of skills by members of the PBSG (as I have documented it) the study recommends the establishment of similar formal structures across the country in order to support HIV services uptake, at both the local clinics and in the communities. While I acknowledge an existing community-based structure that works with the clinics (the village health worker program), their level of exposure and skills does not equate to the caliber of the PBSG, therefore to maximize the attainment of the country's 90/90/90 strategy, (ensuring that 90 percent of the adult know their HIV status by 2020, ensuring that of the adults who tested positive at least 90 percent are put on treatment and that of those who are on treatment, at least 90 percent is adhering to treatment), the Government with the support of other health partners, needs to consider engaging the PBSG model, given its insightfulness.

The HIV and AIDS support group system that operates in the country comprises mixed member voluntary participation, which often times does not function optimally, given the dynamics around HIV and AIDS and issues of confidentiality. This case study's findings revealed the need to have a system that is led and managed by "concerned" groups in order that their agenda is realized.

The disclosure of HIV status to children facilitated care and support and strengthened and instilled resilience among children at their tender ages. To formalise this, I recommend the Family Health Division within the Ministry of Health to develop or revise (if any policy exists) a policy that would create an enabling environment for parents and children to communicate with their parents in matters concerning the disclosure of an HIV positive condition, in order to develop the mutual trust.

At the practice level

Male communication of and involvement in HIV and AIDS interventions, seems a critical point for effective HIV and AIDS responses. There is need to involve, engage and build the capacity of all community leadership (mostly male-led) to lead a country-wide campaign on regular communication between the families on behavioural changes, especially during this era of HIV infection. The effect of male hegemony and female subjugation is fueling the spread of the HIV epidemic, as this case study revealed.

Family health issues need to be a priority at the household level. The example set by some women in the case study; that of disclosing their HIV positive condition to their children, unleashed the caring potential that the children had with respect to their parents. Not only should this practice stay with the study participants, but it also needs to be emulated across all households and to be guided on a regular basis by professional psychologists, to ensure “no harm” to the children.

Area for further research: This study relied heavily on the verbal statements or stories from the participants, and fewer reactions from their programme management team. In this instance further research might be necessary to observe how these participants independently engage in both support groups and in the clinics.

Further investigations into the work of local adherence coordinators and its feasibility as a national model is needed.

Another area to be explored could be a wider study of HIV and AIDS support groups in Lesotho and their contributions regarding support, community outreach and advocacy.

In addition a wider study into the role of men as partners with women in HIV and AIDS initiatives is another area for further research.

8.8 Conclusion

The final chapter presented reflection on the overall discussions, methodology and narratives as well as recommendations about this case study. I presented my experience conducting this study – the surprises I encountered and the gaps I noted in the scholarship. I have also provided recommendations for further research. Key contributions that the study has made to scholarship, is the notion of the gradual dilution of patriarchy where males dominate and the promotion of partnership in families. The breaking of the wall of silence that concealed vital information from the children in regard to all the aspects of the diagnosis of HIV and AIDS in the mother. This is a unique area of study. The disclosure served to release the hidden potential of children so that they could provide care and support for their parents and it furthermore served to instill a sense of responsibility in these children, at their very young ages. The other unique contribution this study makes is the duality nature of participation of the participants in the communities of practice - first in their support group as home based care providers and information sharing group, and second as Local Adherence Coordinators, providing health services to the clinics' clients. In conclusion there is the calling for a more robust family health education system to be implemented in Lesotho to tackle the HIV and AIDS pandemic.

8.9 Final statement about the thesis as a whole

This thesis documents a long journey that the women took towards changing their own lives and the community's perceptions about HIV and AIDS. Significant things that came out of this journey include; taking the bold step of treading into formerly male-dominated territories by breaking the silence around the epidemic in the public sphere, and talking about the "feared" epidemic that has elements of sexuality (a taboo in our African context to discuss issues of sex in the open) without the permission of the head of the family; leaving the home to go to town to join a support group of people living with HIV and AIDS and coming back home with messages such as "I am HIV positive" in these times when HIV and AIDS still carries connotations of promiscuity. These are all bold steps that this case study uncovered. As if that was not enough, the participants emerge as leaders in the village. They are working in the clinics to provide care to the communities which once stigmatized them. The communities in turn, have begun to appreciate and value their support and have given them titles such as nurses and nutritionists. Indeed, these women show that, through taking their "bold steps" and "picking up the pieces" of their shattered lives, they have become richly resourceful persons in their own families and communities.

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Annexes

Annex 1: Consent Form



CONSENT FORM

RESEARCH PROJECT INFORMATION LETTER/CONSENT FORM

1. Study title and Researcher Details

Department: Adult Education

Project title: Coping Strategies for Women living with HIV and AIDS Aged between 14 and 35 years, Already on Antiretroviral Therapy (ART) – Transformative Learning Perspectives”

Principal investigators: ‘Malithapelo Mosuo

Supervisors: Dr Peter Rule and Professor Julia Preece

Ethical approval number: HSS/O079/013D

2. Invitation paragraph

You are being invited to take part in this educational study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with other members of the management team if you wish. Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

This study is intended to document HIV and AIDS positive women’s personal experiences regarding ARV treatment intake and their responses to societal pressures around child bearing. The study will also help to identify any transformative learning processes that are being used to cope with HIV and AIDS.

4. Why have I been chosen?

You have been chosen because your association is working primarily with people living with HIV and AIDS, who have extensive experiences around issues of anti-retroviral treatment. I believe your organization is appropriate for bringing out issues related to women of child bearing age living with HIV and AIDS – their experiences and how they have responded to the challenges encountered.

I am proposing to hold three or more sessions with your organization to a) distribute a questionnaire that seeks information of a profile setting nature, b) the next level will be to hold one-on-one interviews with some selected members, and c) the final phase will be to hold focus group discussion with the participants.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part, I will give you this information sheet to keep and I will ask you to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. Withdrawal from the study will not have any negative consequences for anyone choosing to do this.

6. What will happen to me if I take part?

The study will take place in Leribe within the Phelisanang Bophelong premises. I will mostly ask questions to individuals and groups. The meetings with your team members will last between one to two hours. I will tape record the interviews and discussions with your permission. I will also jot down some notes.

The study will take place between January 2013 to December 2015. The data collection exercise however is scheduled from May to December 2013.

7. Will my taking part in this study be kept confidential?

I will not include your name or your address in this study. I will do this so that nobody can recognise you from the information that you will give.

8. What will happen to the results of the research study?

The final research report will be made available at the University of KwaZulu-Natal

The results of this study may also be presented at a conference and published in a journal. I will not write your name or address in any report or book.

9. Who is organising and funding the research?

The University of KwaZulu-Natal.

10. Who has reviewed the study?

My supervisors at the University of KwaZulu-Natal

11. Contact(s) for Further Information

If you have any concerns regarding the conduct of this research project please contact:

Professor Julia Preece: Professor of Adult Education at the Centre for Adult Education, University of KwaZulu-Natal, Education Building, Pietermaritzburg, Email: preecej@ukzn.ac.za

Dr Peter Rule: Head of Department at the Centre for Adult Education, University of KwaZulu-Natal, Education Building, Pietermaritzburg, Email: rulep@ukzn.ac.za

Professor S Collings, Humanities & Social Sciences research Ethics Committee, Westville Campus, Govan Mbeki Building, Durban, Email: ximbap@ukzn.ac.za

Thank you!

Malithapelo Mosuo

2 October 2012.

N.B. Please sign the attached slip if you consent to being interviewed.

I /We..... consent to being interviewed in relation to research project (APPROVAL NUMBER).

I/We consent to my interview being tape recorded

I/We consent to taking part in a focus group discussion if requested

I/We consent to the focus group discussion being tape recorded

I/We consent to completing a questionnaire in relation to this study

I/We understand that my/our real name will not be used in any public report, unless authorized by our/myself and that I/we are free to withdraw from the study at any time, without any consequences for my/our status at the university or in the community.

.....
Signature

.....
date

PART 2: Knowledge about HIV and AIDS

- 14. When did you first hear about HIV/AIDS? (1 – 5) (6 – 10) (10+) years ago
- 15. How did you know about it? (Through a friend/ newspaper/ radio/ through public gathering)
- 16. What was your reaction after hearing about HIV and AIDS? Explain.
.....
.....
- 17. When did you 1st test for HIV? The past 1 –5 yrs ; 6 –10 yrs 10+ years
- 18. What prompted you to do a test? Explain
.....
:.....
.
- 19. What result did you get during your first test: Neg/Pos
- 20. In the negative result: Did you disclose the test result to your partner?
.....
- If yes what was his reaction, explain?
.....
- 21. When next did you go for another test?.....
- 22. Did you invite him to come go with you (yes/no) if yes, did he agree to go with you? Yes/no
- 23. In a positive status during the first test: How long did it take you to disclose? A week; a month; a year
- 24. Who did you first disclose information to?..... (spouse/parent/friend/church pastor/chief etc
- 25. What made you choose to disclose to him/her? explain
.....
- 26. What was her/his first reaction when you disclosed and advise he/she gave you?
.....
- 27. If you did not first disclose to your spouse, after how long did you tell him? (1 week;) (1 month), (1 year); (never)
- 28. Any reasons for telling him later or not telling him at all? Explain
.....
.....
- 29. Do you know your spouse’s HIV status? (Yes/no)
- 30. If yes, how did you know his status?
Explain.....

31. When did you start taking anti-retroviral treatment? (immediately upon diagnosis) (a few months later) (a year or so afterwards)

32. Do you have a thorough understanding of its usage, including any side effects, if any? (yes/no)

33. If yes, where did you obtain this knowledge? Explain
.....

34. Have you experienced any changes in your body as a result of taking ARVs? Yes/no

35. If yes, what were the changes? Explain
.....
..

36. How have you handled the treatment situation? Explain
.....
.....

PART 3: Relationship with Environment;

37. Are you an active member of a community? Yes/no

38. Do you attend community gatherings/ celebrations, and other rituals within your community? (Yes/no)

39. Do other members of your community know about your HIV positive status? (Yes/no/not sure)

40. If yes, did you openly disclose your status to them? (yes/no)

41. If yes, what made you disclose?
Explain:.....
.....

42. How does your community react to your HIV positive status?
.....

43. Does your family (in-laws) know of your HIV status? (Yes/no/not sure)

44. If yes, how did they know about it?
(self/others).....

45. If self disclosure, what has been their reaction in terms of
 - a) knowing you were HIV positive?
.....

b) hearing that you were openly disclosing your status?

.....

46. What kind of support (emotional, financial etc) are you receiving from your spouse? Explain

.....

47. When did you hear about Phelisanang Bophelong Association? 1; 5; 5+ years

48. How did you hear about it? Explain

.....

49. After being diagnosed HIV positive, how long did you take before joining the Association?

50. What motivated you to join?

.....

51. What are the new things that you learnt as a result of your participation in the Association?

Explain:.....

.....

Thank you for your participation

Annex 3: Sample vernacular questionnaire

Foromo ea Pokello ea Litaba

Sehloho sa Taba/Boithuto: Boits'ematleolo ba Basali ba Basotho ba Phelang le Ts'oaetso ea HIV le AIDS, ba lilemong tsa 14 ho isa ho 29, ba seng ba ntse ba enoa litlhare tse thethefatsang HIV maling (ARVS) – Re ithuta eng?

Selelekela: foromo ena e reretse ho bokella litaba ho basali ba lilemo tsa 14 ho isa ho 29, ba phelang le ts'oaetso ea HIV ba seng ba netse ba enoa litlhare. Sepheo ke ho fumana maikutlo a basali bana , liqholotso tseo ba thulaneng kapa ba thulaning le tsona le hore na ba li feta/fetile joang, ba ithutile eng ka boemo bona ba bona ba tsoaetso ea HIV. Re tlo utloa mekhoha eo ba e sebelisang ho itsematlala khahlanong le liqholotso tseo ekabang li teng, ekaba ke tse bakoang ke balekane ba bona, baamani le bona le sechaba ka kakaretso, tse ka tlišoang ke lebaka la boemo ba bona ba tsoaetso.

Rea u mema ke hona hore u kenye letsoho boithutong bona, ka ho tlatsa foromo ena. Re tiisa mona hore litaba tseo u tla fana ka tsona e tlabang lekunutu, me le keke la phatlalletsoa mang kapa mang. Moo ebang re hloka ho sebelisa tse ling tsa lipolelo tsa hau, tlalehong eo re tlo e bopa, Mabitsa a batho a keke a boleloa hohang. Tseba hape hore ho nka karolo boithutong bona, ke ka boithaopi, ha u ikutloa hore u lakatsa ho emisa ho nka karolo, o bolokolohing ba ho etsa joalo.

Haeba u lumela ho nka karolo, re kopa u tekene Foromo ea Tumello" ea ho nka karolo ena.

Foromo ena e bokellang litaba, e likaroloana li tharo (3). Karoloana ea pele e botsa litaba tsa hau tse amanang le lilemo, boemo ba thuto, boemo ba lenyalo joalo joalo; karoloana ea bobeli eona e batla ho tseba ka litsebo ka kakaretso ka litaba tsa HIV le AIDS, ha karoloana ea boraro, eleng ea ho qetela, eona. Ts'oea lebokosana kapa lesakana leo u lumellanang le lona.

KAROLO EA PELE

29. Lilemo tsa hau: 14 – 18 yrs
 19 -24 yrs.....
 25 – 29 yrs.....
30. Na u kene sekolo? (ee/chee)
31. Haeba karabo ke ee, u fihletse lengolo lefe? (Primary/high school/university level)
32. Na u nyetsoe? (ee/chee)
33. Haeba karabo ke ee, u na le lilemo tse kae lenyalong? (1 – 3); (3 – 4); (5+)
34. Na molekane oa hau oa sebetsa? (ee/chee)
35. Le na le bana ba bakae?
36. U qetsetse ho ba mokhachane neng?
37. Ngoana oa hau oa e monyenyanane o mo kae?
38. Na una le morero oa ho etsa ngoana e mong hape? (ee/chee)
39. U lula kapa u ahile kae? (teropong/ka thokoana ho teropo/metseng, mahaeng)

40. Na u lula le ba-bohali bah au (bo matsale le balamo joalo joalo)? (ee / chee)

41. Haeba karabo ke ee, ke nako e kae u lula le bona? (1-3); (3 -4); (5+)



KAROLO EA BOBELI: TSEBO KA HIV LE AIDS

42. U qalile ho tseba neng ka HIV/AIDS? Lilemo tse (1 – 5) (6– 10) (10+) tse fetileng

43. U ile oa tseba oang/kang? (motsoalle/ka pampiri ea litaba/sealemoea/ ka utloela ka eona pitsong)

44. Ha u qala ho utloa ka lefu lena la HIV le AIDS, u ile oa etsang eng? Hlalosa.

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45. U ile oa qala ho hlalobela kokoana hloko ea HIV neng? Lilemong tse 1 -5 yrs ; 6 -10 yrs 10+ tse fetileng

46. Se neng se u khanela ho ea hlaloba ke sefe? Hlalosa?

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.....
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47. U ile oa fumana sephetho sefe qalong? Neg/Pos

48. Haeba uile oa fumana hore ha u so be le ts’oatso, na u ile oa bolella molekane oa hau?

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Haeba u ile oa mo bolella, u ile a re eng ka boemo boo? Hlalosa?

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49. U ile oa boela hlalobong neng hape?

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50. Na uile oa mema molekane oa hau ho tsamaea le uena ho ea hlalobong? Ee/chee.
Haeba karabo ke ee, na u ile a amohela memo? Ee/chee

51. Haeba u ile oa fumana hore una le ts’oatso khetlong la pele feela ha u hlaloba, ho ile hoa u nka nako e kae ho phatlalatsa boemo bah au ho molekane oa hau? Beke/khoeli/selemo

52. Ha u lemosoa hore u na le ts’oatso, u ile oa bolella mang pele? (molekane, motsoali oaka/motsoalle/moruti/morena/ngoana oaka)

53. U ile oa khetha ho joetsa motho eo pele ho ba bang ka mabaka afe? Hlalosa.

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54. Ha u ne u mo tsebisa boemo ba hau ba tso'aetso, o ile a reng? O ile a u fa boelets'i bofe?

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55. Haeba ha u kaba oa joetsa molekane oa hau hang ha u lemoha hore u na le tsoaetso, u ile oa nka nako e kae pele u ka mo tsebisa?(beke) (khoeli), (selemo); (Ha ke ea mo joetsa)

56. O na le mabaka a ho se mo bolelle pele, kappa a ho se mo bolelle hohang boemo ba tso'aetso ea HIV le AIDs? Hlalosa

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29. Na u tseba boemo ba molekane oa hau ba ts'oaetso? Ee/chee

46. Haeba karabo ke ee, u tsebile boemo ba hae joang/ Halosa?

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47. U qalle ho sebelisa litlhare neng? (Hang ha ke qeta ho fumana hore tsoatso e teng) (Likhoelinyana ka mor'a moo) (Selemo le ho feta ka mor'a ho fumana ts'oaetso)

48. Na u tseba ts'ebeliso e ntle ea tsona, 'moho le litla morao tse ka bakoang ke tsebeliso ea tsona? (ee/chee)

49. Haeba karabo ke ee, u fumane tsebo eo kae? Hlalosa

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50. Na u kile oa bona phetoho e teng 'meleng oa hau, eo e kabang e tlišoa ka tsebeliso ea litlhare tsee? Ee/chee

51. Haeba ho joalo ke liphetoho life? Hlalosa

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52. U ile oa etsa maleba leba a fe ho hlola boemo boo? Hlalosa

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KAROLO EA BORARO: LIKAMANO TSA HAU LE BATHO BAO U PHELANG LE BONA MOTSENG, LAPENG, LELOKONG

53. Na u motho ea nkang karolo litabeng tsa sechaba motseng oo u phelang ho ona? Ee/chee

54. Na u tsamaea lipitso/mafua le mekete ea motse?

55. Na karolo ea sechaba sa heno e tseba ka boemo bah au ha HIV? Ee/chee/ha kena tsebo e hlakileng)

56. Haeba ba tseba, na ke uena ea phatlalaltseng boemo ba hae ho bona? (ee/chee)

57. Haeba ke euna, u ile oa susumeletsoa ho phatlalatsa keng? Hlalosa

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58. Sechaba sa heno se nkile taba ea ts'oaetso ea hau joang? O bona ba u atamela joang? Hlalosa.

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59. Na ba bohali ba hau ba tseba boemo ba hau ba ts'oaetso? (ee/chee/ha kena bonete)

60. Haeba ba bo tseba, ba bo tsebile joang? (ka 'na/ka batho ba bang)

b) Haeba ke uena ea ba boleletseng, u ile oa bona taba ee ba e amohela joang? Hlalosa.

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b)Ha ba utloa hore u bua ka boemo ba hau pepene ho sechaba, taba ee ba e nkile joang? Hlalosa:

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52. U fumana tsetso efe ho molekane oa hau (ea maikutlo/ ea lichelete). Hlalosa.?

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53. U ile oa utloela neng ka Mokhatlo oo oa Phelisanang Bophelong? Lilemong tse 1; 5; 5+ years

54. U ile oa tseba ka ona joang? Hlalosa.

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55. Ka mora hore u bolelloe hore u na le ts'oaetso, u ile oa nka nako e kae pele u kena mokhatlong oo?

56. U ile oa khothaletsa ke eng ho kena mokhatlong oo?

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57. Esale u kena mokhatlong ona, ke lintho life tseo u ithutileng tsona tse ka ntlafatsang boemo ba hau ba bophelo?

Hlalosa.....

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Ke ea leboha ka ho nka karolo ha hau.

Annex 4 : Interview Guide

Semi Structured Interview Guide

Title of the study “**Coping Strategies for Basotho women living with HIV and AIDS aged between 14 and 35 years , Already on Antiretroviral Therapy (ART) – Transformative Learning Perspectives**”

Introduction: This interview guide is intended to collect information from women between ages 14 and 35 years who are living with HIV and AIDS and are already taking anti-retroviral treatment. The study seeks to obtain views and feelings of women regarding their personal experiences with HIV and AIDS – how they are perceived by the communities in which they live as well as how they cope with any pressures exerted to them by their own environments (peers, spouses, parents, own children and the society as a whole)

The tool has a set of guiding questions, which will be followed by a lot of probing in order to obtain in-depth information about the issue being asked. We therefore urge you to freely participate in the study. It must be stressed that information that you will provide here will bear no identity of yourself, apart from the fact that all of this information shall be treated with strict confidentiality.

Questions	Responses
<p>Identity: Are you comfortable giving me any identity – nickname or a code (other than your name) that you and I will use during the interview?</p>	
<p>General Issues You participated during the questionnaire session. Are there any areas that you felt should have been discussed regarding your experiences with HIV and AIDS? Be specific. What makes you want to talk more about them? When we talk about them what memories do they bring? Explain</p>	
<p>Child bearing Number of children Their age/ages Age of the youngest child? Have you thought of having a child or another child? If yes, is there anything specific that makes you want to have a child? If no, what makes you feel you do not want to have a child? Tell me about your children’s understanding your HIV and AIDS situation, if they know and how they got to know? If they know, what specifically do they say when they talk about HIV and AIDS either learning it from school or from their peers? How do they handle a situation where any of their peers at school or in the community mocks them about your HIV positive status? How do they tell it to you? How do you always handle that situation?</p>	
<p>Relationship with Spouse: Tell me if your spouse knows about your HIV positive status? If he knows, what was his first reaction? How has he been reacting afterwards? Any major change from the initial reaction?</p>	

<p>If he ever behaves in a weird manner, how does that make you feel? Are you comfortable discussing his weird reactions towards your HIV condition?</p>	
<p>Has your spouse tested for HIV? If yes, is he comfortable disclosing his HIV status to you? Does he want to discuss about HIV and AIDS issues in general? If yes what issues in particular? If he tested positive, does he openly visit health centres for regular checkups? Tell me if you both can go to the health centre for your regular checkups Tell me if your in laws know about your HIV positive status? How did they know? Are you the one that told them or they got the information from elsewhere? If they got it elsewhere, how did they approach you? How informed do you think your in laws are about HIV and AIDS in general? Can you rely on them for psychosocial support?</p>	
<p>Relationship with the Community Are the people in your community aware of your HIV positive status? If yes, what has been their responses towards you? Are they comfortable interacting with you, accepting gifts, foodstuff, sharing sanitation facilities etc with you? Tell me about any specific roles or tasks that your community assigned you? When you raise a view point in any community gathering or discussion, how is your view taken? Is it considered? How does that make you feel? When you are in the midst of your age mates or colleagues at either work or at home, how do you always feel when they shun people living with HIV and AIDS? How can you help to dilute that perception?</p>	
<p>Biomedical Considerations How long have you been taking ARVs? In the period you have been using them, how have you experienced changes in your body in general? Have you ever, during the time of intake of ARVs experienced any side effects? If yes how have you dealt with them? How are your relations with health care professionals? When you raise your opinion about your treatment regimen, how much of it is being considered? During your last pregnancy,(if you were already on ARVs) how did you find compliance to a 6 months exclusive breastfeeding like? What did you do to convince in-laws and other relatives about compliance to Prevention of mother to child transmission of HIV (PMTCT) programme?</p>	

<p>How has compliance by your spouse regarding zero new HIV infection been? Does he support your treatment regimens?</p>	
<p>Transformative Learning Initiatives</p> <p>Your participation in the Association of People Living with HIV and AIDS I believe was prompted by something. Can you say what it is that made you want to join?</p> <p>Is there any value added joining the Association" if yes</p> <p>You must have learned new things in general, resulting from your participation in the Association. Tell me some of them.</p> <p>When you share this knowledge with the people around, what has been the reaction?</p> <p>Whatever knowledge you acquired, how are you using it?</p> <p>What is community's perception of the knowledge that you share with them?</p> <p>Since the time you discovered you were HIV positive, what has been your most painful and daunting life experiences?</p> <p>How have you dealt with the challenges?</p>	

Annex 5: Sample vernacular Interview Guide

TOKOMANE E TATAISANG LIPUISANO TSA MOTHO HO MOTHO

Sehloho sa Taba/Boithuto: Boits’ematleolo ba Basali ba Basotho ba Phelang le Ts’oatso ea HIV le AIDS, ba lilemong tsa 14 ho isa ho 35, ba seng ba ntse ba enoa litlhare tse thethefatsang HIV maling (ARVS) – Re ithuta eng?

Selelekela: foromo ena e reretse ho bokella litaba ho basali ba lilemo tsa 14 ho isa ho 29, ba phelang le ts’oatso ea HIV bas eng ba netse ba enoa litlhare. Sepheo ke ho fumana maikutlo a basali bana , lintho tseo ba thulaneng kapa ba thulanang le tsona le hore na ba li feta/fetile joang, ba ithutile eng ka boemo bona ba bona ba tsoatso ea HIV. Re tlo utloa mekhoha eo ba e sebelisang ho itsematlela khahlanong le liqholotso tseo ekabang li teng,ekabake tse bakoang ke balekane ba bona, baamani le bona le sechaba ka kakaretso, tse ka tlisoang ke lebaka la boemo ba bona ba tsoatso.

Rea u mema ke hona hore u kenye letsoho boithutong bona, ka ho tlatsa foromo ena. Re tiisa mona hore litaba tseo u tla fana ka tsona e tlabana lekunutu, me le keke la phatlalletsoa mang kapa mang. Moo ebang re hloka ho sebelisa tse ling tsa lipolelo tsa hau, tlalehong eo re tlo e bopa, Mabitso a batho a keke a boleloa hohang. Tseba hape hore ho nka karolo boithutong bona, ke ka boithaopi, ha u ikutloa hore u lakatsa ho emisa ho nka karolo, o bolokolohing ba ho etsa joalo.

Haeba u lumela ho nka karolo, re kopa u tekene Foromo ea Tumello” ea ho nka karolo ke ena.

Lipotso	Likarabo
BOITSEBISO: Na u ka lakatsa ho mpha lebitso la bosoaso leo u ka ratang hore re u bitse ka lona olemong oa puisano ee?	
Litaba tse arakaretsang U ile oa nka karolo ho tlatseng foromo e neng e bokella litaba (questionnaire), na ho na le litaba tseo u utloang eka re ka be re buile ka tsona moo tseo li neng li sa botsoa? Litaba haholo holo tse amanang le lintho tso u thulanang le tsona ka HIV le AIDS? Toba taba.
Ke eng e etsang hore u batle ho bua ka tsona?	
Ha re bua ka tsona, li tlisa eng mehopolong ea hau? Hlalosa	
Ho etsa bana	
Bana bahau ba ba kae ka palo? Banana/Bashanyana	
Ba lilemong tsa kae?	
Oa ho fela eena o mo kae?	
Na u kile oa nahana ho etsa ngoana e mong haufi tjee? Haeba	

karabo ke ee, na ho na le lebaka le ikhethang le etsang hore u battle ho etsa ngoana?	
Haeba karabo ke chee, ke lebaka lefe leo u sa lakatseng ho ba le ngoana e mong?	
A ku mpoelle ka mikhoa oo bana bah au ba utluisang boemo bah au ba tsoaetso ea HIV le AIDS.	
Na ba ea tseba hor u na le tsoaetso? Na ke uena ea ba boleletseng? Haeba chee, ba tsebile joang Haeba ba ea tseba, ba bua joang ka HIV le AIDS, ekaba ba u utluile sekolong kapa ho methaka ea bona?	
U ee u bone ba nka joang, boemo boo emong oa methaka ea bona sekolong kapa motseng a ba somang ka boemo bah au ba ts'oaetso?	
Ba u bolella taba ee joang?	
Uena ebe taba ee u e atamela joang?	
LIKAMANO LE MOLEKANE	
A ku mpoelle, na molekane oa hau u tseba boemo bah au ba ts'oaetso? Haeba oa tseba, u ile oa bona a nka taba ee joang ha u no u mo bolella? Ka mor'a moo u bona a e nkile joang? na ho na le phetoho e kholo ho eena ho tlosa ha u ne u mo tsebisa? Moo u boneng a etsa boits'oaro boo u sa bo tloaelang, seo se u ts'oara joang Na u ka phuthuloha ho qoqa ka boitsoaro boo ba hae le eena, u bo nyalanya le boemo ba hau ba tsoaetso?	
Na molekane oa hau o hlahlobetse HIV Haeba karabo ke ee, na o phuthuloha ho bolela boemo ba hae ba ts'oaesto ho uena? Na o rata ho bua ka litaba tsa HIV le AIDS kamehla? Haeba karabo ke ee, ke taba e feng haholo eo a ratang ho bua ka eona? Haeba u hlahlobile a fumana a ena le tsoaetso, na o etela litsi tsa bophelo a sa ts'abise? Na bobeli le etela litsing tsa bophelo 'moho? Na ba bohali bah au ba tseba boemo bah au ba tsoaetso?	

<p>Haeba ho joalo, ba tsebisitsoe ke mang? Na ke uena, kapa ba boeletsoe ke motho e mong feela? Haeba ba utluile ka motho e mong feela, u bona taba ee ea boemo bah au ba e nkile joang? Na u bona eka ba bohali bah au ba utluisisa litaba tsee tsa HIV le AIDS Na u ka ba ts'epela hore ba ka u fa tsehetso ea maikutlo?</p>	
<p>LIKAMANO TSA HAU LE SECHABA</p>	
<p>Na sechaba sa haeno motseng ba tseba ka boemo bah au ba ts'oaetso? Haeba ho joalo, u bona katamelo ea bona e le joang ho uena? Na ba thahasella ho bua le ho etsa lintho le uena; mohlala ha u ba fa limphonyana, lijo, ho arolela matloana le tse ling le uena? Aku mpoelle mosebetsi kapa boikarabello boo sechaba sa heno se u fileng bona? Ha u hlahisa maikutlo lipitsong kaa moo batho ba bokjaneng teng, na e nkeloa hlohong joalo ka ha u e hlahisa? Haeba ho joalo, see se u etsa hore u ikutloe joang? Hau ena le batho babang, methaka kapa metsoalle ea hau, u ee u ikutloe joang ha ba bua lipuo tse hobosang ka batho ba phelang le ts'oaetso? U ka thusa joang ho hlapolla menahano eo ea bona?</p>	
<p>Ts'ebeliso ea Litlhare U na le nako e kae u noa litlhare? U kile oa ba le qholotso life bophelong ba hau ka kakaretso? Na u kile oa ba le nako eo u neng u eba le litla-morao tse ts'ebeliso ea litlhare? Ha u ne u ena le boikutlo bo joalo, u ile oa etsa eng ho fumana thuso? Liknomo tsa hau le basebetsi ba tsa bophelo li joang? Ha u hlahisa maikutlo mabapi le litlhare tsa hau, ba arabela litaba tsee tsa hau joang? Nakong eo u neng u le mokhachane, haeba u no so ntse u ena le ts'oaetso, u ile oa fumana kanyeso ea lesea e ikhethang ea likhoeli tse tseletseng ele joang? U ile oa etsa eng ho kholisa ba bohali ba hau ka bohlokoa ba kanyeso e ikhethang ea lesea la hau?</p>	

<p>Taba ee u bona ba e nkile joang? U bone molekane oa hau a u thusa ha kae ho qoba ts'oaetso pheto ea HIV? U u ts'ehetsa ha kae mabapi le ts'ebeliso ea lithhare tsa hau?</p>	
<p>Liphetoho tse tlišoang ke boithuto Ho ba setho sa mokhatlo oa batho ba phelang le ts'oaetso ea HIV le ADS, ke lumela ho bakiloe ke ho hong. Na u ka bolela hore na ke eng e entseng hore u kene mokhatlong o joalo?</p> <p>Na ho na le molemo oo u kholang ka ho ba karolo ea Mokhatlo oo? Haeba karabo ke ee, ke lumela hore lintho li teng tse ncha tseo u ithutileng tsona. E kaba tse ling tsa tsona ke life.</p> <p>Ha u ena le batho ba bang bao e seng litho tsa mokhatlo, joale u leka ho arolelana le bona lintho tseo u ithutileng tsona, u ee u bona ba li amohela joang? Litsebo kapa malebela ao u a fumaneng mokhatlong, u a sebelisa joang sechabeng sa heno? Sechaba sona se amohela litsebo tsee tsa hau joang?</p> <p>Ho tloha nakong eo u neng u tsebisoa hore u phela le ts'oaetso ea HIV le AIDS, ke life lintho tse kileng tsa nyotobetsa maikutlo a hau? U ile oa li rarolla joang?</p>	

Annex 6: Focus Group Discussion Guide

(8 – 10 members per group)

Title of the study “**Coping Strategies for Basotho women living with HIV and AIDS Aged between 14 and 35 years, Already on Antiretroviral Therapy (ART) – Transformative Learning Perspectives**”

Introduction: This focus group discussion is intended to collect information by way of discussion around particular topics. The issues to be discussed will be about women aged between 14 – 35 years who are living with HIV and AIDS and are already taking anti-retroviral treatment. This is the gist of the study. In the discussion, participants are expected to deliberate on the topic, thrash it out and then move to the next topic. We have provided this type of data collection method to allow participants to get a chance of sharing their knowledge, views and thoughts in a group. We request that as we discuss, we do it in turn in order to give each other space to say something.

Each topic will be allocated 40 minutes. It is hoped that at the end of the time allocated, all the three topics will have been discussed at length.

We therefore urge you to freely participate in the study. It must be stressed that information that you will provide here will bear no identity of yourself, apart from the fact that all of this information shall be treated with strict confidentiality.

Group name:

Topics:

- **Family reaction towards an HIV positive woman**
Did you receive support when you told your husband you were HIV positive?
What happened to your sexual relations?
How did you approach the issue of safer sexual practices? What did you say? What was his reaction?
If your partner hears that you are a member of the Association of people living with HIV and AIDS how does that make him feel, and what does his reaction towards you make you feel?
- **Child Bearing:**
How did you deal with your spouse, in-laws and community who pressurize you into having a child? What did you tell them?
- **Treatment intake:**
How do you feel about life-time treatment?
What do you do to ensure that you do not miss it?
Are you comfortable taking medication in the presence of other people- at work, at home, during gatherings (where there are many people)? If some people who do not know about your HIV status see you take medication and ask about it, do you tell them the truth about the drugs you are taking?
How has the exclusive 6 months breast feeding programme affected you – what are your experiences?

Lipuisano tsa Sehlopha

(Bakeng sa litho tse ka bang 8 ho isa ho 10 sehlopheng ka seng)

Sehloho sa Taba/Boithuto: Boits'ematleolo ba Basali ba Basotho ba Phelang le Ts'oaetso ea HIV le AIDS, ba lilemong tsa 14 ho isa ho 35 ba ntseng ba ntse ba enoa litlhare tse thethefatsang HIV maling (ARVS) – Re ithuta eng?

Selelekela: foromo ena e reretse ho bokella litaba ho basali ba lilemo tsa 14 ho isa ho 35, ba phelang le ts'oaetso ea HIV ba seng ba ntse ba enoa litlhare. Sepheo ke ho fumana maikutlo a basali bana , liqholotso tseo ba thulaneng kapa ba thulanang le tsona le hore na ba li feta/fetile joang, ba ithutile eng ka boemo bona ba bona ba tsoaetso ea HIV. Re tlo utloa mekhoa eo ba e sebelisang ho itsematlela khahlanong le liqholotso tseo ekabang li teng, ekabake tse bakoang ke balekane ba bona, baamani le bona le sechaba ka kakaretso, tse ka tlišoang ke lebaka la boemo ba bona ba ts'oaetso.

Mokhoa oo lipuisano tsena li tlang ho ts'oaroa ka ona:

Bohle ba nkileng karolo ba lebeletsoe ho qoqa holima sehloho se tla behoa, ba se qhaqhohle ba qete, ban to fetela sehlohong se seng hape joalo joalo. Re entse tokiso ena ea hore sehlopha se qoqe ka taba, ele hore bohle ba nkileng karolo, ba tsebe ho eolelana litsebo tsa bona mabapi le sehloho kapa taba e behiloeng. Re kopa ke hona hore ha re ntse re ts'ohlka taba kapa sehloho se joalo, re fananeng sebaka emong le emong, ho hlahisa maikutlo a hae.

Nako ea lipuisano: Sehloho ka seng se tla fuoa metsotso e sa feteng mashome a mararo(30 minutes). Me ho tla ts'ohlola lihlooho tse ka bang tse 3 phuthehong ka ngoe. Tebello ke hore ka mora nako e behiloeng, sehlopha se tla be se ts'ohlile taba e joalo ka botebo.

Rea u mema ke hona hore u kenye letsoho boithutong bona, ka ho tlatsa foromo ena. Re tiisa mona hore litaba tseo u tla fana ka tsona e tlabala lekunutu, me le keke la phatlalletsoa mang kapa mang. Moo ebang re hloka ho sebelisa tse ling tsa lipolelo tsa hau, tlalehong eo re tlo e bopa, Mabitso a batho a keke a boleloa hohang. Tseba hape hore ho nka karolo boithutong bona, ke ka boithaopi, ha u iikutloa hore u lakatsa ho emisa ho nka karolo, o bolokolohing ba ho etsa joalo.

Haeba u lumela ho nka karolo, re kopa u tekene Foromo ea Tumello" ea ho nka karolo ke ena.

Lebitso la sehlopha (Lebitso leo sehlopha se tla lumellanang ka lona):

Lihloho tse ts'ohloang:

Katamelo ea lelapa ho mosali ea phelang le ts'oaetso ea HIV le AIDS

Na u fumane tse'ehetso ho molekane oa hau ha u ne u mo bolella hore u phela le ts'oaetso ea HIV le AIDS?

Na likamano tsa lona ka lapeng tsa thobalano li amehile ke boemo boo ba hau?

U bona a se a its'oara joang ha a u lebile?

Molekane oa hau ha a utloa hore u kene mokhatlo oa batho ba phelang le ts'oaetso ea HIV le AIDS o reng? U bona taba eo a e nkile joang? Maikutlo ao a hae, uena u bona a u ts'oara joang?

Litabeng tsa pelehi:

U ile oa sebetsana joang le kahlamelolo e tsoang ho molekane oa hae, bo-matsale 'moho le sechaba ka kakaretso ha ba ne ba ena le tebello ea hore u etse ngoana?

U ile oa ba hlalose tsa joang mabaka a neng a u sitisa ho etsa bana? Haeba u anyesa lesea likhoeli tse tseletseng u sa le tsoakele, u bone liqholotso tseo u kopaneng le tsona e bile life?

U ithutile eng liqholotsong tseo?

Tsebeliso ea lithare

U ka reng ka kalafo ee ea bophelo bohle ba hau?

U etsang hore u se ke ea lebala ho noa lithare?

Na u phuthuloha ho noa lithare boteng ba batho ba bang, ekaba metsoalle ea hau, lapeng, motseng, mosebetsing joalo joalo?

Haeba ho ena le batho ba s a tsebeng boemo bah au ba ts'oaetso ea HIV le AIDS, 'me batho ba joalo ba u bona u enoa lithare 'me ba botsa hore na ke lithare tsa eng, na u ba bolella 'nete mabapi le tsona?

Annex 8: Interview Guide for Phelisanang Bophelong Management

Title of the study “Coping Strategies for Basotho Women living with HIV and AIDS aged between 14 and 35 years - Transformative Learning Perspectives”

Introduction: This interview guide is intended to collect information from women between ages 14 and 35 years who are living with HIV and AIDS and are already taking anti-retroviral treatment. The study seeks to obtain views and feelings of women regarding their personal experiences with HIV and AIDS – how they are perceived by the communities in which they live as well as how they cope with any pressures exerted to them by their own environments (peers, spouses, parents, own children and the society as a whole)

The tool has a set of guiding questions, which will be followed by a lot of probing in order to obtain in-depth information about the issue being asked. We therefore urge you to freely participate in the study. It must be stressed that information that you will provide here will bear no identity of yourself, apart from the fact that all of this information shall be treated with strict confidentiality

LEARNING PRACTICES

Item	RESPONSES
Do members of PB discuss work with other members of the association during their meetings	
When you give individual feedback regarding their work, do they share the feedback with other members.	
Apart from their regular monthly meetings, do members hold meetings with other members of the association outside of the Association to discuss work and to learn what each one is doing?	
Do they reflect on and discuss issues/concepts with other members of the Association after the input sessions	
Do they interact with the members to share experiences? What specific experiences do they share?	
Whenever they acquire new knowledge be it from their personal contacts or sources, are they comfortable sharing it with the rest of the members of the Association? If yes, what has been the response from other members?	
From your observation, Do you feel that they form sub groups of the association to discuss their work	

LEGITIMATE PERIPHERAL PARTICIPATION

Item	
How are newcomers being treated in the Association? Are they learning from the established participant members?	
Do the newcomers bring in new ideas to the established group? If yes, what ideas are mostly brought in?	
Do members share knowledge acquired either from their families, community, peers or work situation with other members during their meetings?	
When they encounter challenges in their work, do they share such challenges with the rest of the members? What has been their response to each others' challenges?	

Whenever any member encounters challenges regarding their work, Do other members assist them? If yes, in what ways?	
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PROCESS OF BECOMING/IDENTITY

Item	
Do you think that they regard their experiences as being of value to others in the Association? How often do they share them ? How has the response of the entire group been?	
In your opinion, do you think they have moved at different times from feelings of confusion and anxiety to better understanding of what they are supposed to be doing in their work? Would you boldly attribute that change to them becoming a member of the association?	
Are they familiar with the Association's 'jargon' words? Are they comfortable using them in their conversation with other members?	

PLEASE ELABORATE ON THE FOLLOWING SENTENCES IF THEY APPLY TO YOU

Members have changed how they interpret their world or their work	
They have moved from feeling like an 'outsider' to feeling like an 'insider'	

MEANING MAKING

Item	
Do they contribute to group feedback when others do presentations?	
Do they refine their own understandings as a result of group input to their presentation?	
How do they apply their knowledge and experience during group meetings, especially when other members are presenting their work?	
In a group do they always try out new ideas? If yes, are they always welcome?	

COMMUNITY

Item	
When they first arrived in the Association, which members did they mostly mix with? The ones they were meeting for the first time <input type="checkbox"/> Members who have been with the association before them <input type="checkbox"/> Members whom they already knew before they joined the organization. <input type="checkbox"/>	
In the time that they have been with the association, who do they now mix with? Members they did not know at the beginning <input type="checkbox"/> Members that they meet for the first time <input type="checkbox"/> All members <input type="checkbox"/>	
Do you think they share their experiences with the rest of the members? What kind of responses do they always receive?	
Do they socialise with other members in the Association? How do they take it?	

Do they socialise with other community members? If yes, how do the community take it?	
OTHER COMMENTS – PLEASE ELABORATE – in relation to their participation within the Association	
What particular activities do they do in the association, that binds them as a group	
In terms of sharing knowledge and experiences, apart from HIV treatment, is there any area that they mostly share experiences on?	

Annex 9: Sample Responses Coding

Response Coding	Statements
Introduction	<p>Good morning and welcome to our meeting 'me. This is the second stage in the series of our conversation for this study. Like I indicated before, your name will not be revealed anywhere throughout the study. I am only going to request you to give me your nickname – which will be your identity for the purpose of this study. Will that be ok with you?</p> <p>Yes, My nickname is 'M'e Thato</p>
Recap	<p>From the questionnaire that you filled out previously, do you feel that there is something that we ought to have covered, but was omitted?</p> <p>Yes. There is. The form was not in-depth enough. I wanted information about what did one do when they discovered they were HIV positive? Who did I tell and what was the reaction? This is what I would want to share with you.</p> <p>OK that says there are things that you want to share with me?</p> <p>Yes.</p>
Personal commitment	<p>I tested once at LPPA because I learned from an HIV session during a workshop for support groups that even though a person may look healthy, she can still have HIV. I then realized that I too was still healthy despite my occasional chest pains, i thought I needed to test, after all HIV can affect any one.</p>
Participation in Community issues (PC)	<p>After the lessons, I tested and tested negative.</p> <p>How did you feel?</p> <p>When I tested negative I felt good (look of happiness) I continued taking care of the sick people in my community. In particular, I took care of my sick cousin. She eventually died.</p>
Change ©	<p>I tested again after 5 months, in fact I was told to come after 3 months, I did not come at that time instead I tested again after 5 months, I came out HIV positive. Acheeee! (Deep sigh)</p>
Acceptance of one's status (AS)	<p>When I noticed I was HIV positive, and after what the counselor told me about living positively, I accepted my status.</p>
Male dominance (MD)	<p>The only problem was my spouse who is very cruel/mean (silence) I had difficulty telling him because I did not know how he will take it.</p>
Initial Disclosure and reaction (IDR -F) – family members	<p>The counselor asked me who I will tell first, and I told her that I will tell almost everybody that I want to tell, I did not want to make it a secret (confused look). I first told my sister, who told me she too was living with HIV and that I will also manage the HIV. I didn't know that my sister had HIV. I later on went and told my neighbor who is also my friend that I tested HIV positive</p>
Self Pity (SP)	<p>I was ashamed of myself. My friend and I used to eat from the same plate before, but this time I would dish out food, when I am about to dip my hand in the same dish, I would pull it out thinking that my friend would not like to share food with me anymore.</p>

Support – Friend (SF)	She asked why I was doing it, I told her that now that I am HIV positive, perhaps I am not supposed to share food with her (long silence) – she told me that she was my friend whether I have HIV or not, that I should never display that negative behavior to her again .I laughed and told her that i thought she would not like to be my friend. My friend asked “why would I refuse to eat with you”? then I said to her “because now I am HIV positive” she told me she would never stop being my friend despite everything else.
Disclosure and Reaction – Spouse (DR -S)	My husband came home, after a month of knowing my status, I knew my status in October, he came in November. I told him I was HIV positive, he was very very angry, he threatened to leave me, to go to RSA, look for a place to stay, come back to take his children and leave me.(almost in tears, shaky voice) I said to him “ it is OK if you leave me but it is painful that you separate me with my children, I never thought you would leave me, there is no where you vowed to leave me when I am in trouble or in need of your help”, sadly you yourself do not know whether or not you have HIV or not..
Male dominance (MD)	Things got worse in the home. <i>What were his specific words/actions?</i> He used to say that “Your things that you like to attend to, are the ones that made you go for HIV testing”. <i>What did you understand “Your things” to mean?</i> I understood "my things" to mean support groups. He didn't like me attending support groups, <i>Meaning he did not want you to test?</i> Yes, he did not want me to test, he accused me of testing for HIV. <i>Meaning that he did not blame you for attending support group meetings per se, but did not like the idea that these things that you know, have made you to even go further to test for HIV?</i> Yes, I think that is what he was implying.
Knowledge versus Sacrifice (KS) Male Dominance (MD)	<i>What is his level of understanding about HIV?</i> His understanding of HIV is still not there, as we speak. But now he supports me, that was after a year. We had to use a condom, but he said he does not like to use a condom, we continued with unprotected sex in the house hoping that he will change his mind eventually. I also thought I will calm him down. <i>Did you agree to this?</i> Yes we agreed and continued with unprotected sex
Male Dominance (MD)	I knew the consequences of engaging in unprotected sex but for peace sake and seeing how angry he was, I had to succumb to it, besides we were not regular because he was not staying at home he came home after a long time.
Knowledge (K)	After some time I had to be enrolled in ARVs. I explained to him that I was now going to use ARVS. My CD4 cells count was 259 when I first tested. I told him that “according to my status, it is not safe to have unprotected sex as I will infect you when you have to start on treatment it will not help you” I spoke pretending he did not have HIV .

Male Dominance - Spouse Reaction MD – SR	Tension erupted again in the house, he threatened to marry another wife, he started having suspicious movements for 2 weeks, leaving home early, coming back late or not coming back home at all (low voice).
Personal Commitment (PC)	I did not care whether he came home or not, I developed the I don't care attitude, all I cared for was to take care of my life for my children's sake and did not care whether he marries another wife or not. When he was doing all these, did he have anything to say? When he is sometimes home, he will sit there quietly, uttering no word to me. He told me that whenever he leaves the housewife, he goes to search for a new wife.
Transformation/ Change of mindset (T)	I collected female condoms and insisted that we use a condom. We would have sex with a condom, he didn't like condoms, he did not seem to enjoy sex. I forced him to talk, when he is home, I would sit next to him, he would not talk to me, even during sex he would not talk to me.
SR -anger	Was he still proving for you? He would always be sitting home giving me an angry look. He was providing for the family ever since we got married though it was at a very small scale. He never used to give me money.
SR- Fear	Did he eventually know his status? He never knew his HIV status
Coping Mechanisms – Acceptance (CM –A)	In the midst of these problems, I became very angry, I developed a journal of all painful things that happened to me – since I got married, how I got infected with HIV, how he treated me, how I got HIV infected, every thing about me, I wrote it in the book, I had a 2 pager of all events that happened to me. Meaning you suspected he might have infected you? No I don't mean that, while it could have been a possibility, but I didn't want to let it sink in me.
Disclosure – Relatives Reaction (D- RR)	At some time I asked him to go to my inlaws (mother and father). There was a nurse that was working from the outreach centre. I asked the nurse to invite my mother too, to tell them to come to the nurse's office so I can break the news once to all of them. My husband refused to come with me, my in laws too refused to come to the meeting, only, my mother was there. Do you think your mother-in-law knew already? I think she did. the nurse broke the news to my mother.

<p>Disclosure – Inlaws reaction (D- IR)</p>	<p>I think my mother-in law already knew because she was already saying nasty things about me and my HIV status. I went to my inlaws personally to tell them, when I arrived there my elder sister went and asked my mother –in-law to hurry home I was there, when she appeared, she started insulting me that she hates girls who do not respect their elders, if I disrespect my husband I should watch out she is not the type of person who I can disrespect. She was very very angry. My father-In –law told her to stop insulting me and to come and listen to what I had to say.</p>
<p>Family support –(FS)</p> <p>Blame shifting</p>	<p>I just told them that “I am HIV positive” just as briefly. Initially I had planned to tell them and educate them about HIV, but noting the reception I received from them, I just bluntly told them about my HIV status. I then left them.</p> <p><i>Do you think she understood your message?</i></p> <p>She didn’t say anything. I don’t know whether she understood my message but I assume she already knew because she used to tell some people that my husband and I are fighting, I brought AIDS in the family, I went to many places that is where I have gathered AIDS. So from her statements, I assume she knows about HIV and AIDS.</p> <p>My father-in law was the one who showed a little bit of support . he said “my daughter go and make peace” then I left and there was still no peace at my house. There was still no peace at my house despite that.</p>
<p>Change of attitude – spouse (CA-S)</p>	<p>My husband was home the whole time on leave, he works in the industries in Pretoria. He left for work after some time.</p> <p>When he came home after a long time, he was happy, I could not believe my eyes, he was the same husband I knew, a changed person, and that is how my family changed.</p>
<p>Coping – Accepting (CA)</p>	<p>I am staying with the most cruel man. My life changed immediately after taking ARVs, a life I never knew before.</p> <p><i>What do you think brought the change in the house?</i></p> <p>I think it is because since I was diagnosed with HIV, I had to control my temper, perhaps that is why he changed too noting that I speak to him softly, and less noisy in the house.</p> <p>I noted that he was appreciative of me whenever I speak softly to him. Because I was taught to control my temper, I started to practice it.</p> <p><i>But do you talk about HIV</i></p> <p>We do not talk about HIV issues, I remember there was recently an HIV event in the community, I participated at the event, I was a resource person to teach about PMTCT and HIV education – he commended on the event and said that all speakers were good except myself – I was boring.</p> <p>That helped me to open up an HIV discussion. I told him that i was not boring, it is just that what i was talking about, you did not like but please note that whether you do not like to talk about HIV or not, you will have a problem accessing treatment. Our discussion</p>

	ended quickly because he did not want to talk about HIV. He hates talking about HIV.
Change of attitude - Treatment support (CA- TS)	He supports me with treatment, he always reminds me to take medication, every 7pm he would say "mama remember to take your medication", every morning when I go to work, he would remind me to take my medication with me. I have a small livelihood project (I serve tea to the motorists) every morning when I leave he reminds me to take medication.
Family influence vs Adjustment	Lets talk about this sudden change of support and care by your spouse. What do you think is the cause? My husband loves me very much. He gets easily influenced especially by his parents, that is why he keeps changing his mood. I think that is the reason why he sometimes treats me badly like this. I moved away from my inlaws – I think that is a reason for this change.
Disclosure – children reaction (D-CR)	Let us talk about your children. Do they know your status? My children know my status but I hid it from them for a year. When I started taking ARVs I lied to them that I was taking ulcer medication, so I said to them "don't let me forget my medication". They supported me. When we were quarreling with their father they would hear some of the statements leading to me taking medication.
Children reaction (CR)	I then called them told them that the reason for the fight is because I tested HIV positive. (pause, a sad face..) I told them that the medication I am taking is for HIV, I reminded them of my continuous ill health, I then assured them that I was going to live longer and healthier. I do not have AIDS, but HIV. When I told them they were surprised to learn of this new thing. How were they taking this? They were all surprised
Fear of HIV among children (F)	What happened afterwards? Afterwards, they have been supporting me, they were more supportive than their father. My younger daughter would say "mum if you die I will die with you and be buried in the same grave as yourself, the way dad ill treats us, I don't think I can survive your loss". I told them that i was going to live longer, that they will even marry and leave me still going strong.
Support by children (S)	Issues relating to HIV are taught or spoken even at schools. What was their reaction regarding HIV messages they got from peers and school? When my children hear about what students think of HIV, they asked me to visit schools to educate students about HIV. Meaning there was a possibility that they could have disclosed your HIV status? No, They kept the secret about my status, they never told anybody.
Spouse Reaction (SR)	Now that your spouse supports you, do you go to the clinics together?

	<p>When I go to the health centres, my husband never comes with me. It is because every time I talk about HIV, he gets angry so I never invite him for the sake of our peace.</p>
Coping ©	<p>What is his reaction about sexual practices now that you have resolved your differences? Regarding sex, it took us a long time to practice safe sex, but have been on it for a while longer. I was only surprised last December when he was not happy with the sex and said, he will not tolerate use of condom in his house to the wife whom he wedded; I told him that unfortunately that will not change until a cure for AIDS is found.</p> <p>How did his statement make you feel I was hurting because i never thought we would fight over this issue again. I told him that this issue brings back sad memories of when he was threatening to marry, how hurting that was to me, I asked him not to make me recall those sad moments because now I am living for my children only.</p> <p>Didn't you want to take advantage of your conversation to encourage him to test? No, I never thought about it. But I told him all I live for was to see my children through. As far as sex is concerned, I am not in it, therefore I cannot sacrifice my life for sex .I told him that all I wanted was for him to talk about was when he will test.</p>
Adjustment (A)	<p>He was angry after our conversation, but the next day he was happy and fine.</p> <p>Which means he does not want to talk about HIV One day he told me he tested while at the mines but he would not tell me – in fact he said he never do those things, my husband is a very rural and backward-minded man (laughing out loud).</p>
Support by community (S –C)	<p>What made you join Phelisanang Bophelong? I joined PB during the World Aids Day commemoration at St Denis Health Centre. We established a support group, we were 7 in a group from the group, I was nominated to attend a workshop on Home-based care and was told that if I perform well I will join PB and conduct community awareness trainings around HIV and AIDS. When I received nomination I was worried about my husband's reaction.</p> <p>I went to the priest and told him about my nomination, how I fear about my husband reaction. He advised me to go and learn more about HIV, maybe what i will learn there, will change my life. I then left for the workshop.</p>
Knowledge and Coping mechanism (K-CM)	<p>After the workshop, I was well armed with tools about HIV and I felt that nothing was going to come in my way of the knowledge I had about HIV.</p> <p>What do gain from being a member of phelisanang? I acquired counseling skills, self confidence, self acceptance, besides we have stipend that we earn on a monthly basis, that improved my household economic level.</p>
Transformation and community participation (TCP)	<p>What are things that you thought you would never have been exposed to had it not been for Phelisanang Bophelong?</p>

	<p>I was just an ordinary person, I went as far as standard 7 education, I never thought in life that I would do anything. What I learnt from PB was that one can do something that can empower her. I run a small catering business, it has now grown, I rent a house, I have someone whom I have employed to manage the business. My business has improved, initially I used paraffin stove to cook, but now I use gas to cook. It has attracted many customers. I work from my business in the morning, then later in the day go and do the Phelisanang Bophelong business.</p>
Treatment competency (TC)	<p>We are nearing the end of our interview. Now let us talk about your experiences with treatment?</p> <p>Treatment in take- I encountered problems – I never had any side effects except for mood swings, I was very smelly while I was on CTX , and that made me feel moody.</p> <p>When I started on ARVs this smell subsided. I attended a workshop on adherence, I got to learn more about ARVs – it was a week-long training facilitators had suffered side effects, they showed us how the ARVs transformed their bodies,- I was scared of the side effects and began to worry muck. Immediately I too experienced side effects – perhaps as a result of some myths I transformed my figure, had fat deposit on my upper abdomen.</p>
TC – Relations with Health professionals Treatment Knowledge	<p>What did you do to mitigate the side effects?</p> <p>In 2010, I noticed the positive changes on one of our BP members who had similar side effects with, how she had improved. I then changed the regimen through telling the nurses to change the regimen, I actually told them the type of regimen. At first they didn't agree with me but I insisted on the change, now i have changed a lot, i am gaining back my normal figure.</p>
Knowledge – Rights K-R	<p>What are the most painful moments you experienced in life as a result of your HIV positive status?</p> <p>The most daunting moments in my life was when my husband threatened to marry another woman. Because I already had self confidence, and self esteem I told him that even if he marries, that will not change the fact that I am his wife.</p> <p>You think that that your self esteem has helped you to be where you are now?</p> <p>Definitely</p>
Reaction - Community (R-C) (stigma, conflicts, disagreements, gossips, lack of knowledge)	<p>Thank you mme. Is there anything that we might perhaps have left out out, that you may want to talk about?</p> <p>Yes there is. It is actually my relationship with my community: I was not regular in my support group, I told the SG management that I was HIV positive, also that there have been conflicts in my house as a result of my HIV positive status. The support group management accepted my statement. I was welcomed back into the group.</p> <p>A conflict erupted within the SG because I was given some food parcels which were given only to HIV positive people. The members were angry with me, they started gossiping about me, they alienated me, stigmatized me etc.</p>

	<p>Because I was still looking healthy, they would quarrel among themselves over whether or not I was indeed HIV positive. When I arrived from the workshop, I disclosed my status among the SGs members. They were all very disappointed. Later on they came to accept me.</p>
Reaction – community(RC)	<p>I believe this acceptance of your status has been extended to the general public. Is that so?</p> <p>Yes. The community initially thought that I have been paid by the clinic to spread the lies about HIV. I always tell them that I too take medication, HIV is real. Now they have accepted me and know that I am HIV positive. Always tell them that those who know me from before, will bear witness that I was good and round bodied but ARVs have changed my outlook.</p>
Child bearing and Knowledge of PMTCT (CB – K PMTCT)	<p>Would you like to have another child?</p> <p>No. I have three children, I don't plan to have another one. It is not due to my HIV status per se, but due to economic situation. If I had some means I would have another child to prove to the world that an HIV positive woman can have a healthy baby.</p>
Closing	<p>Thank You 'M'e Thato for this interview. Let us end this conversation here, There is another final level where I will invite you again for the interview. As I indicated, your real name will not feature anywhere in the report, nobody including PB management will get to read or even know the contents of our meeting.</p> <p>Thank you for your time.</p> <p>Thank you 'm'e</p>

Response Coding	Statements
Introduction	<p>Good morning and welcome to our meeting 'me. This is the second stage in the series of our conversation for this study. Like I indicated before, your name will not be revealed anywhere throughout the study. I am only going to request you to give me your nickname – which will be your identity for the purpose of this study. Will that be ok with you?</p> <p>Yes, My nickname is 'M'e Thato</p>
Recap	<p>From the questionnaire that you filled out previously, do you feel that there is something that we ought to have covered, but was omitted?</p> <p>Yes. There is. The form was not in-depth enough. I wanted information about what did one do when they discovered they were HIV positive? Who did I tell and what was the reaction? This is what I would want to share with you.</p> <p>OK that says there are things that you want to share with me?</p> <p>Yes.</p>
Personal commitment	<p>I tested once at LPPA because I learned from an HIV session during a workshop for support groups that even though a person may look healthy, she can still have HIV. I then realized that I too was still healthy despite my occasional chest pains, i thought I needed to test, after all HIV can affect any one.</p>
Participation in Community issues (PC)	<p>After the lessons, I tested and tested negative.</p> <p>How did you feel?</p> <p>When I tested negative I felt good (look of happiness) I continued taking care of the sick people in my community. In particular, I took care of my sick cousin. She eventually died.</p>
Change ©	<p>I tested again after 5 months, in fact I was told to come after 3 months, I did not come at that time instead I tested again after 5 months, I came out HIV positive. Acheeee! (Deep sigh)</p>
Acceptance of one's status (AS)	<p>When I noticed I was HIV positive, and after what the counselor told me about living positively, I accepted my status.</p>
Male dominance (MD)	<p>The only problem was my spouse who is very cruel/mean (silence) I had difficulty telling him because I did not know how he will take it.</p>
Initial Disclosure and reaction (IDR -F) – family members	<p>The counselor asked me who I will tell first, and I told her that I will tell almost everybody that I want to tell, I did not want to make it a secret (confused look). I first told my sister, who told me she too was living with HIV and that I will also manage the HIV. I didn't know that my sister had HIV. I later on went and told my neighbor who is also my friend that I tested HIV positive</p>
Self Pity (SP)	<p>I was ashamed of myself. My friend and I used to eat from the same plate before, but this time I would dish out food, when I am about to dip my hand in the same dish, I would pull it out thinking that my friend would not like to share food with me anymore.</p>

Support – Friend (SF)	She asked why I was doing it, I told her that now that I am HIV positive, perhaps I am not supposed to share food with her (long silence) – she told me that she was my friend whether I have HIV or not, that I should never display that negative behavior to her again .I laughed and told her that i thought she would not like to be my friend. My friend asked “why would I refuse to eat with you”? then I said to her “because now I am HIV positive” she told me she would never stop being my friend despite everything else.
Disclosure and Reaction – Spouse (DR -S)	My husband came home, after a month of knowing my status, I knew my status in October, he came in November. I told him I was HIV positive, he was very very angry, he threatened to leave me, to go to RSA, look for a place to stay, come back to take his children and leave me.(almost in tears, shaky voice) I said to him “ it is OK if you leave me but it is painful that you separate me with my children, I never thought you would leave me, there is no where you vowed to leave me when I am in trouble or in need of your help”, sadly you yourself do not know whether or not you have HIV or not..
Male dominance (MD)	Things got worse in the home. What were his specific words/actions? He used to say that “Your things that you like to attend to, are the ones that made you go for HIV testing”. What did you understand “Your things” to mean? I understood "my things" to mean support groups. He didn't like me attending support groups, Meaning he did not want you to test? Yes, he did not want me to test, he accused me of testing for HIV. Meaning that he did not blame you for attending support group meetings per se, but did not like the idea that these things that you know, have made you to even go further to test for HIV? Yes, I think that is what he was implying.
Knowledge versus Sacrifice (KS) Male Dominance (MD)	What is his level of understanding about HIV? His understanding of HIV is still not there, as we speak. But now he supports me, that was after a year. We had to use a condom, but he said he does not like to use a condom, we continued with unprotected sex in the house hoping that he will change his mind eventually. I also thought I will calm him down. Did you agree to this? Yes we agreed and continued with unprotected sex
Male Dominance (MD)	I knew the consequences of engaging in unprotected sex but for peace sake and seeing how angry he was, I had to succumb to it, besides we were not regular because he was not staying at home he came home after a long time.
Knowledge (K)	After some time I had to be enrolled in ARVs. I explained to him that I was now going to use ARVS. My CD4 cells count was 259 when I first tested. I told him that “according to my status, it is not safe to have unprotected sex as I will infect you when you have to start on treatment it will not help you” I spoke pretending he did not have HIV .

Male Dominance - Spouse Reaction MD – SR	Tension erupted again in the house, he threatened to marry another wife, he started having suspicious movements for 2 weeks, leaving home early, coming back late or not coming back home at all (low voice).
Personal Commitment (PC)	I did not care whether he came home or not, I developed the I don't care attitude, all I cared for was to take care of my life for my children's sake and did not care whether he marries another wife or not. When he was doing all these, did he have anything to say? When he is sometimes home, he will sit there quietly, uttering no word to me. He told me that whenever he leaves the housewife, he goes to search for a new wife.
Transformation/ Change of mindset (T)	I collected female condoms and insisted that we use a condom. We would have sex with a condom, he didn't like condoms, he did not seem to enjoy sex. I forced him to talk, when he is home, I would sit next to him, he would not talk to me, even during sex he would not talk to me.
SR -anger	Was he still proving for you? He would always be sitting home giving me an angry look. He was providing for the family ever since we got married though it was at a very small scale. He never used to give me money.
SR- Fear	Did he eventually know his status? He never knew his HIV status
Coping Mechanisms – Acceptance (CM –A)	In the midst of these problems, I became very angry, I developed a journal of all painful things that happened to me – since I got married, how I got infected with HIV, how he treated me, how I got HIV infected, every thing about me, I wrote it in the book, I had a 2 pager of all events that happened to me. Meaning you suspected he might have infected you? No I don't mean that, while it could have been a possibility, but I didn't want to let it sink in me.
Disclosure – Relatives Reaction (D- RR)	At some time I asked him to go to my inlaws (mother and father). There was a nurse that was working from the outreach centre. I asked the nurse to invite my mother too, to tell them to come to the nurse's office so I can break the news once to all of them. My husband refused to come with me, my in laws too refused to come to the meeting, only, my mother was there. Do you think your mother-in-law knew already? I think she did. the nurse broke the news to my mother.

<p>Disclosure – Inlaws reaction (D- IR)</p>	<p>I think my mother-in law already knew because she was already saying nasty things about me and my HIV status. I went to my inlaws personally to tell them, when I arrived there my elder sister went and asked my mother –in-law to hurry home I was there, when she appeared, she started insulting me that she hates girls who do not respect their elders, if I disrespect my husband I should watch out she is not the type of person who I can disrespect. She was very very angry. My father-In –law told her to stop insulting me and to come and listen to what I had to say.</p>
<p>Family support –(FS)</p> <p>Blame shifting</p>	<p>I just told them that “I am HIV positive” just as briefly. Initially I had planned to tell them and educate them about HIV, but noting the reception I received from them, I just bluntly told them about my HIV status. I then left them.</p> <p>Do you think she understood your message?</p> <p>She didn’t say anything. I don’t know whether she understood my message but I assume she already knew because she used to tell some people that my husband and I are fighting, I brought AIDS in the family, I went to many places that is where I have gathered AIDS. So from her statements, I assume she knows about HIV and AIDS.</p> <p>My father-in law was the one who showed a little bit of support . he said “my daughter go and make peace” then I left and there was still no peace at my house. There was still no peace at my house despite that.</p>
<p>Change of attitude – spouse (CA-S)</p>	<p>My husband was home the whole time on leave, he works in the industries in Pretoria. He left for work after some time.</p> <p>When he came home after a long time, he was happy, I could not believe my eyes, he was the same husband I knew, a changed person, and that is how my family changed.</p>
<p>Coping – Accepting (CA)</p>	<p>I am staying with the most cruel man. My life changed immediately after taking ARVs, a life I never knew before.</p> <p>What do you think brought the change in the house?</p> <p>I think it is because since I was diagnosed with HIV, I had to control my temper, perhaps that is why he changed too noting that I speak to him softly, and less noisy in the house.</p> <p>I noted that he was appreciative of me whenever I speak softly to him. Because I was taught to control my temper, I started to practice it.</p> <p>But do you talk about HIV</p> <p>We do not talk about HIV issues, I remember there was recently an HIV event in the community, I participated at the event, I was a resource person to teach about PMTCT and HIV education – he commended on the event and said that all speakers were good except myself – I was boring.</p> <p>That helped me to open up an HIV discussion. I told him that i was not boring, it is just that what i was talking about, you did not like but please note that whether you do not like to talk about HIV or not, you will have a problem accessing treatment. Our discussion</p>

	ended quickly because he did not want to talk about HIV. He hates talking about HIV.
Change of attitude - Treatment support (CA- TS)	He supports me with treatment, he always reminds me to take medication, every 7pm he would say "mama remember to take your medication", every morning when I go to work, he would remind me to take my medication with me. I have a small livelihood project (I serve tea to the motorists) every morning when I leave he reminds me to take medication.
Family influence vs Adjustment	Lets talk about this sudden change of support and care by your spouse. What do you think is the cause? My husband loves me very much. He gets easily influenced especially by his parents, that is why he keeps changing his mood. I think that is the reason why he sometimes treats me badly like this. I moved away from my inlaws – I think that is a reason for this change.
Disclosure – children reaction (D-CR)	Let us talk about your children. Do they know your status? My children know my status but I hid it from them for a year. When I started taking ARVs I lied to them that I was taking ulcer medication, so I said to them "don't let me forget my medication". They supported me. When we were quarreling with their father they would hear some of the statements leading to me taking medication.
Children reaction (CR)	I then called them told them that the reason for the fight is because I tested HIV positive. (pause, a sad face..) I told them that the medication I am taking is for HIV, I reminded them of my continuous ill health, I then assured them that I was going to live longer and healthier. I do not have AIDS, but HIV. When I told them they were surprised to learn of this new thing. How were they taking this? They were all surprised
Fear of HIV among children (F)	What happened afterwards? Afterwards, they have been supporting me, they were more supportive than their father. My younger daughter would say "mum if you die I will die with you and be buried in the same grave as yourself, the way dad ill treats us, I don't think I can survive your loss". I told them that i was going to live longer, that they will even marry and leave me still going strong.
Support by children (S)	Issues relating to HIV are taught or spoken even at schools. What was their reaction regarding HIV messages they got from peers and school? When my children hear about what students think of HIV, they asked me to visit schools to educate students about HIV. Meaning there was a possibility that they could have disclosed your HIV status? No, They kept the secret about my status, they never told anybody.
Spouse Reaction (SR)	Now that your spouse supports you, do you go to the clinics together?

	<p>When I go to the health centres, my husband never comes with me. It is because every time I talk about HIV, he gets angry so I never invite him for the sake of our peace.</p>
Coping ©	<p>What is his reaction about sexual practices now that you have resolved your differences? Regarding sex, it took us a long time to practice safe sex, but have been on it for a while longer. I was only surprised last December when he was not happy with the sex and said, he will not tolerate use of condom in his house to the wife whom he wedded; I told him that unfortunately that will not change until a cure for AIDS is found.</p> <p>How did his statement make you feel I was hurting because i never thought we would fight over this issue again. I told him that this issue brings back sad memories of when he was threatening to marry, how hurting that was to me, I asked him not to make me recall those sad moments because now I am living for my children only.</p> <p>Didn't you want to take advantage of your conversation to encourage him to test? No, I never thought about it. But I told him all I live for was to see my children through. As far as sex is concerned, I am not in it, therefore I cannot sacrifice my life for sex .I told him that all I wanted was for him to talk about was when he will test.</p>
Adjustment (A)	<p>He was angry after our conversation, but the next day he was happy and fine.</p> <p>Which means he does not want to talk about HIV One day he told me he tested while at the mines but he would not tell me – in fact he said he never do those things, my husband is a very rural and backward-minded man (laughing out loud).</p>
Support by community (S –C)	<p>What made you join Phelisanang Bophelong? I joined PB during the World Aids Day commemoration at St Denis Health Centre. We established a support group, we were 7 in a group from the group, I was nominated to attend a workshop on Home-based care and was told that if I perform well I will join PB and conduct community awareness trainings around HIV and AIDS. When I received nomination I was worried about my husband's reaction.</p> <p>I went to the priest and told him about my nomination, how I fear about my husband reaction. He advised me to go and learn more about HIV, maybe what i will learn there, will change my life. I then left for the workshop.</p>
Knowledge and Coping mechanism (K-CM)	<p>After the workshop, I was well armed with tools about HIV and I felt that nothing was going to come in my way of the knowledge I had about HIV.</p> <p>What do gain from being a member of phelisanang? I acquired counseling skills, self confidence, self acceptance, besides we have stipend that we earn on a monthly basis, that improved my household economic level.</p>
Transformation and community participation (TCP)	<p>What are things that you thought you would never have been exposed to had it not been for Phelisanang Bophelong?</p>

	<p>I was just an ordinary person, I went as far as standard 7 education, I never thought in life that I would do anything. What I learnt from PB was that one can do something that can empower her. I run a small catering business, it has now grown, I rent a house, I have someone whom I have employed to manage the business. My business has improved, initially I used paraffin stove to cook, but now I use gas to cook. It has attracted many customers. I work from my business in the morning, then later in the day go and do the Phelisanang Bophelong business.</p>
Treatment competency (TC)	<p>We are nearing the end of our interview. Now let us talk about your experiences with treatment?</p> <p>Treatment in take- I encountered problems – I never had any side effects except for mood swings, I was very smelly while I was on CTX , and that made me feel moody.</p> <p>When I started on ARVs this smell subsided. I attended a workshop on adherence, I got to learn more about ARVs – it was a week-long training facilitators had suffered side effects, they showed us how the ARVs transformed their bodies,- I was scared of the side effects and began to worry muck. Immediately I too experienced side effects – perhaps as a result of some myths I transformed my figure, had fat deposit on my upper abdomen.</p>
TC – Relations with Health professionals Treatment Knowledge	<p>What did you do to mitigate the side effects?</p> <p>In 2010, I noticed the positive changes on one of our BP members who had similar side effects with, how she had improved. I then changed the regimen through telling the nurses to change the regimen, I actually told them the type of regimen. At first they didn't agree with me but I insisted on the change, now i have changed a lot, i am gaining back my normal figure.</p>
Knowledge – Rights K-R	<p>What are the most painful moments you experienced in life as a result of your HIV positive status?</p> <p>The most daunting moments in my life was when my husband threatened to marry another woman. Because I already had self confidence, and self esteem I told him that even if he marries, that will not change the fact that I am his wife.</p> <p>You think that that your self esteem has helped you to be where you are now?</p> <p>Definitely</p>
Reaction - Community (R-C) (stigma, conflicts, disagreements, gossips, lack of knowledge)	<p>Thank you mme. Is there anything that we might perhaps have left out out, that you may want to talk about?</p> <p>Yes there is. It is actually my relationship with my community: I was not regular in my support group, I told the SG management that I was HIV positive, also that there have been conflicts in my house as a result of my HIV positive status. The support group management accepted my statement. I was welcomed back into the group.</p> <p>A conflict erupted within the SG because I was given some food parcels which were given only to HIV positive people. The members were angry with me, they started gossiping about me, they alienated me, stigmatized me etc.</p>

	<p>Because I was still looking healthy, they would quarrel among themselves over whether or not I was indeed HIV positive. When I arrived from the workshop, I disclosed my status among the SGs members. They were all very disappointed. Later on they came to accept me.</p>
Reaction – community(RC)	<p>I believe this acceptance of your status has been extended to the general public. Is that so?</p> <p>Yes. The community initially thought that I have been paid by the clinic to spread the lies about HIV. I always tell them that I too take medication, HIV is real. Now they have accepted me and know that I am HIV positive. Always tell them that those who know me from before, will bear witness that I was good and round bodied but ARVs have changed my outlook.</p>
Child bearing and Knowledge of PMTCT (CB – K PMTCT)	<p>Would you like to have another child?</p> <p>No. I have three children, I don't plan to have another one. It is not due to my HIV status per se, but due to economic situation. If I had some means I would have another child to prove to the world that an HIV positive woman can have a healthy baby.</p>
Closing	<p>Thank You 'M'e Thato for this interview. Let us end this conversation here, there is another final level where I will invite you again for the interview. As I indicated, your real name will not feature anywhere in the report, nobody including PB management will get to read or even know the contents of our meeting.</p> <p>Thank you for your time.</p> <p>Thank you 'm'e</p>

Annex 10: Ethical Clearance Certificate from the Lesotho Government



Ministry of Health
P.O. Box 514
Maseru 100

May 23, 2013

Malithapelo Mapaseka Mosuo
Student No.212557757
PhD Candidate
University of Kwazulu Natal

Dear M.M. Mosuo

Re: Coping Strategies for HIV Positive Women of Child-Bearing Age 14-29 years, Already on ART: Transformative Learning Perspectives (ID 60-2013)

Thank you for resubmitting the above mentioned proposal. The Ministry of Health Research and Ethics Committee having reviewed your protocol hereby authorizes you to conduct this study among the specified population. The study is authorized with the understanding that the protocol will be followed as stated. Departure from the stipulated protocol will constitute a breach of the permission.

We are looking forward to have a progress report and final report at the end of your study.

Sincerely,

A handwritten signature in black ink, appearing to read 'Jill Sanders'.

Dr. Jill Sanders
Co-Chairperson of the Research Ethics Committee

Received 11/06/2013
Malithapelo Mosuo.



08 April 2013

Ms MM Mosuoce 212557757
School of Education
Pietermaritzburg Campus

Protocol reference number: HSS/0079/013D
Project Title: Coping strategies for HIV positive Basotho Women of Child-bearing Age already on Anti-Retroviral Treatment (ART): Transformative learning perspectives.

Ms Mosuoce

Full approval notification – Committee reviewed protocol

This letter serves to notify you that your response in connection with the above study has now been granted full approval.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years.

Best wishes for the successful completion of your research protocol

Yours faithfully

Professor Steven Collings (Chair)

/pk

cc Supervisor Dr P Rule
cc co supervisor Professor J Preece
cc Academic leader Dr MN Davids
cc School administrator Ms B Bhengu

**Humanities & Social Sc Research Ethics Committee
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