HIV / AIDS SUPPORT GROUPS IN BOTHA-BOTHE, LESOTHO: NAVIGATING DISCOURSES OF PREVENTION AND CARE

By

MANQOSA KHANG

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Declaration

Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in the Graduate Programme in the School of Education, University of KwaZulu-Natal, Pietermaritzburg, South Africa.

I, **MANQOSA KHANG**, declare that

The research reported in this thesis, except where otherwise indicated, is my original research. This thesis has not been submitted for any degree or examination at any other university.

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Student Name	**Name of Supervisor**
Manqosa Khang	Professor Julia Preece
Signature	**Signature**

Dedication

This thesis is dedicated to my late sisters (Felleng Lepheana – Mamosebatho Kholoanyane and Khubelu Lepheana – Masehlotsoana Ntsala) [may their souls rest in peace] who brought to my attention that even if I was not a medical doctor as they wished I would be (because the two were nurses), they still wished I could study to the point of being awarded a PhD. During school break, these two would ask if I was losing interest and no longer wanted to further my studies. According to them, I was not supposed to have a school break. They expected me to read non-stop to prove to them that I was going to make it.

I think that was why when I was doing my degree, Nqosa (as a toddler) complained to Masehlotsoana that I was never home. I am not sure of the response he was given so he accepted my being away. But I learned when his younger brother Tsiu made the same complaint too that Nqosa told him I was doing a PhD. It was this chain of responses which gave me energy to pursue my studies to this level. Bo abuti, Mummy has finally reached the destination you set for her with your grannies during your toddler age when I know you did not even understand what a PhD was. I am sorry that your beloved grannies are no longer with us to celebrate their wish.

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To the three support groups which allowed me the opportunity to collect data from them: Mothers- in-law, Fathers-to-Fathers and Mixed support groups. This is the point at which I dedicate my time to give each one of you a high five as a token of appreciation for making my PhD a success because if you did not allow me to observe your monthly learning proceedings, this thesis would never have been at this stage today.

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List of acronyms

ABC: Abstain, Be faithful and Condomise

AIDS: Acquired Immune Deficiency Virus

ANC: Antenatal Care

ART: Antiretroviral Therapy

ARVs: Antiretroviral Drugs

AU: African Union

CBDA: Community Based Distributing Agent

CITC: Client Initiated HIV Testing and Counselling

CCC: Correct and Consistent Condom use

CoP: Communities of Practice

DHMT: District Health Management Team

EMTCT: Elimination of mother-to-child HIV transmission

FAQs: Frequently Asked Questions

GBV: Gender-Based Violence

HF: Health Facility

HIVST: HIV Self-Testing

HIVOFT: HIV Oral Fluid Test

HIV: Human Immunodeficiency Virus

HCW: Health Care Worker

HTC: HIV Testing and Counseling

HTS: HIV Testing Services

IPC: Interpersonal communication

KYS: Know Your Status

M&E: Monitoring and Evaluation

MCSP: Multiple and Concurrent Sexual Partners

MoHCC: Ministry of Health and Child Care

MOT: Modes of Transmission

NAC: National AIDS Commission

PEP: Post Exposure Prophylaxis

PITC: Provider Initiated Testing and Counselling

PMTCT: Prevention of Mother-to-Child Transmission of HIV

PrEP: Pre-Exposure Prophylaxis

PSI: Population Services International

SADC: Southern African Development Community

SAEs: Social Adverse Events

SAFAIDS: Southern Africa AIDS Dissemination

STI: Sexually Transmitted Infection

TB: Tuberculosis

UNAIDS: Joint United Nations Programme on HIV/AIDS

UNICEF: United Nations Children's Fund

VMMC: Voluntary Medical Male Circumcision

WHO: World Health Organization

WV: World Vision

Abstract

This study explores how HIV and AIDS support groups in Botha- Bothe, Lesotho negotiated their understanding of discourses about HIV, its prevention and care. Data for this study was collected over a period of six months from three support groups at their monthly meetings in the Botha-Bothe Government Hospital in Lesotho. The purpose was to explore how Basotho made meaning from the information, education and communication they received from their health care workers (counsellors, nurses and pharmacists), the other support group members and from their social networks. The research was framed within the interpretive paradigm and used an explorative, multiple case study approach, through observation of the three support groups and their interactions.

Data was collected through non-participant observation of the monthly meetings and digital recording of the participants' discussions to ensure the support group members felt free to speak their minds during their learning and sharing process without interference from the researcher. Data was analysed using a descriptive, discourse analysis approach. Discourse analysis explored the nature of the participants' interactions and the language they used to help them understand and interpret the medical discourses surrounding the prevention, care and treatment of HIV and AIDS. The data was then interpreted through the theoretical lenses of Communities of Practice, Social Capital and Transformative Learning.

The findings highlighted that the support group meetings demonstrated strong elements of social capital in terms of mutual trust, reciprocity and different networks which could be categorised as bonding (close ties), bridging (using people known or connected to their communities) and linking (drawing on expertise from officials and external sources such as non-governmental organisations). The learning which took place relied heavily on sharing, seeking out information and bringing that information back to the support group meetings. Finally, the learning process was through dialogue and use of culturally relevant metaphors. This learning often followed the ten different phases of transformative learning as outlined by Jack Mezirow. Nevertheless, it was evident that not all participants reached the same stage of transformative learning and resultant behavioural change towards the prevention and care of HIV transmission. This means that

ongoing dialogue is essential, but it must be done through culturally sensitive language and opportunities to interact and share experiences with others over extended periods of time.

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Chapter One: Background Information

Part One

1.1. Introduction

This chapter is divided in to two parts. Part one provides an overview of the problem statement and motivation for the study. Part Two provides the context for the study. The introduction of three different categories of support groups in Botha–Bothe for people who are infected and affected by HIV and AIDS is a country-wide innovation. It followed the example of a country-wide Mothers to Mothers (M2M) initiative by the Elizabeth Glaser Paediatric AIDS Foundation (EGPAF). The M2M initiative aimed to reduce new infections among children born from HIV positive mothers by encouraging other mothers to learn from and support each other. However, the local health clinic in Botha–Bothe decided to form similar support groups for males (infected and affected) and for elderly women, usually the in-laws of infected child-bearing mothers. These support groups followed similar shared learning strategies which will be outlined later in the chapter. At the time of the start of this study this innovation had been operating for three years without any substantive evaluation of its impact on behavioural or attitudinal changes. However anecdotal evidence from M2M and the Ministry of Health suggested that the M2M group was having some impact on reducing new infections (Help Lesotho, 2016). There was also anecdotal evidence that the other support groups were contributing to increased adherence to treatment and easy disclosure of HIV positive status, amongst other benefits. Moreover, other districts were expressing interest in replicating these additional innovations (for example Mafeteng, Leribe and Mohale's Hoek (Help Lesotho, 2016). But the ways in which the support groups were achieving these outcomes had not been assessed, particularly the ways in which participants negotiated the contradictions between myths, cultural beliefs and medical messages over time. It was important, therefore, before any roll-out programme was promoted, to have a better understanding of how these groups were operating, how individuals within the groups negotiated the different discourses associated with HIV and AIDS, its prevention and care, and how they developed new meaning over time as a result of different inputs and information seeking activities. Since the literature uses the terms HIV/AIDS and HIV and AIDS interchangeably this thesis also use these terms interchangeably.

This study therefore aimed to analyse the patterns of interaction and meaning making within the different support groups, using communities of practice, social capital and transformative learning theories. The analytical lens also applied a discourse analysis approach because it focused on language and behavior by the participants. Research questions were as follows.

1. How do the support groups function as a community of practice?
2. How do the support groups make meaning out of the different discourses associated with HIV and AIDS, its prevention and care – for example:
    a. Medical messages?
    b. Cultural value systems?
    c. Myths and community beliefs?
3. How does their meaning-making impact on new learning?

1.2 Problem statement

Prior to the start date of this study in 2012, the Lesotho Demographic and Health Survey (LDHS)(GOL, 2009) indicated that, annually, there were 18 000 new HIV infections in the country. This incidence rate is too high particularly in a small country like Lesotho with a small overall population of less than 2 million people (ibid). Research has shown that support groups of HIV infected and affected people can help curb the situation through the sharing of information education and communication (Mosuoe, 2016). However, there is limited evidence about how support groups, particularly in Lesotho, negotiate the contradictions and challenges of medical instructions in relation to local myths, beliefs, and societal expectations.

It has been shown that context is an important influence on how HIV prevention messages are received and employed (Mosuoe, 2016). But in Lesotho very little in-depth research has been undertaken to examine the extent to which Basotho negotiate the different discourses associated with HIV and AIDS, its prevention and care.

1.3 Motivation for the study

There is always a rationale for every researcher to undergo such a tireless task. As an HIV/AIDS counsellor, I was interested in the efforts the three support groups were demonstrating in gathering information which could help them understand their chronic situation better. My main problem was: What do we know about how these support groups develop new understandings in a way that will help to curb the disease and help people in their community manage the disease? The topic of this thesis was influenced by my previous line of employment. I worked for the Ministry of Health and Social Welfare (MOHSW) as a Senior Counsellor. This office was mandated with the task of ensuring that every Mosotho knows his/her HIV status by the year 2020. Therefore, my office had to make sure that all HIV Testing and Counselling (HTC) activities taking place in the district were performing in line with national policies and guidelines. As a major player in the fight to prevent the spread of HIV and AIDS, I was therefore well positioned and highly motivated to explore in more depth how HIV infected and affected support groups develop new understandings of HIV prevention messages as well as how they negotiate the contradictions in the myths, beliefs, traditions and medical messages about HIV new infections and the reduction of HIV-related opportunistic infections.

1.4 Purpose of the study

The purpose of this study was to investigate how HIV infected and affected support groups contribute to the meaning-making of HIV prevention strategies and how the support group participants make meaning, and reconcile the contradictions and challenges of medical instructions, local beliefs, and societal expectations with their individual sense of self.

Part Two

1.5 Contextual overveiw

This section introduces global and African facts and figures for HIV and AIDS. It then introduces Lesotho, the country, and the historical context of HIV and AIDS in Lesotho - that is when the disease first became recognised by health authorities, and the measures that have been taken at different phases, including national guidelines, policies and implementations. The chapter then details the different information education and communication (IEC) strategies that have taken place up to the present day, the rationale for introducing them, any documented

lessons learned and reasons for changes in strategies at each point in time. This is followed by an explanation of the current prevalence rate and current literature on HIV and AIDS generally in Lesotho and specifically in Botha-Bothe, which is the location of the study. Basotho culture will be explained in terms of tradition as expressed through proverbs and behaviours in relation to gender relations, values and beliefs, but also drawing on relevant literature.

1.6 Global HIV prevalence

The recent state of HIV/AIDs prevalence, taken from UNAIDS publications from 2016 and 2017, is as follows:

> The world has committed to ending the AIDS epidemic by 2030. How to reach this bold target within the Sustainable Development Goals is the central question facing the United Nations General Assembly High-Level Meeting on Ending AIDS, to be held from 8 to 10 June 2016. The extraordinary accomplishments of the last 15 years have inspired global confidence that this target can be achieved. UNAIDS recommends a Fast-Track approach: substantially increasing and front-loading investment over the next five years to accelerate scale up and establish the momentum required to overcome within 15 years one of the greatest public health challenges in this generation. (UNAIDS, 2016, p. 1)

UNAIDS (2017) provides overall figures concerning the pandemic, cited in its text as follows:

> 19.5 million people were accessing antiretroviral therapy in 2016. 36.7 million [30.8 million–42.9 million] people globally were living with HIV in 2016. 1.8 million [1.6 million–2.1 million] people became newly infected with HIV in 2016. 1 million [830 000–1.2 million] people died from AIDS-related illnesses in 2016. 76.1 million [65.2 million–88.0 million] people have become infected with HIV since the start of the epidemic. 35.0 million [28.9 million–41.5 million] people have died from AIDS-related illnesses since the start of the epidemic. In 2016, there were 36.7 million [30.8 million–42.9 million] people living with HIV. (UNAIDS,, 2017, p. 1)

HIV/AIDS has emerged as a significant health and development crisis since the 1980s. The disease is widespread, as the global facts sheet above indicates, although it is particularly prevalent in Africa. In summary, HIV spreads like a wild fire. This condition forces those governments whose countries have a high prevalence rate to address the pandemic as a priority and allocate funds to fight the pandemic (GOL 2006).

1.7 Regional HIV Information

Although there is evidence of a global lessening of the upward trend of infections, and an increased number of people with access to anti-retroviral therapy (ART), Africa more than other regions has been badly hit by the HIV and AIDS pandemic. For instance, Ghana suffered severely in the early stages of the pandemic (UNAIDS 2014) and there are indications that Eastern and Southern Africa account for more than 43% of new infections, even though between 2010 and 2016, the number of AIDS-related deaths in the region fell by 42% (UNAIDS, 2014). Africa therefore remains at the centre of the pandemic. In 2006 the African Union (AU) agreed to implement the Maputo Plan of Action, calling for countries to strengthen their commitment to achieving universal access to sexual and reproductive health services, including family planning and to recognise the importance of these services to HIV prevention efforts. In 2010, the Southern African Development Community (SADC) recognised that strengthening linkages between sexual and reproductive health rights and HIV and AIDS was key in achieving its target of a 50% reduction in new HIV infections by 2015.

The Lesotho 2016 Review (Help Lesotho, 2016) indicates that the African Region has held several review meetings to check on the progress of the disease and it indicated there had been a recent decline in infections due to intensive administration of anti-retroviral therapy (ART) in the region which includes community initiation of ART to improve availability and access.

1.8 Lesotho the country

According to the Lesotho 2016 Review (Help Lesotho, 2016), Moshoeshoe became chief of Basotho in 1820. Due to brutal attacks by his neighbours, he had to appeal to the British for help and Lesotho became a British protectorate known as Basutoland and its present-day boundaries were established then. The Lesotho Review indicates that Lesotho is a land-locked state in Southern Africa, surrounded by South Africa.

Lesotho is a small mountainous country with a total area of only 30 355 square kilometres. It gained its independence on the 4th October 1966 and has been a sovereign kingdom with a parliamentary democracy since then. The country has ten districts. Five in the lowlands, (Maseru, Mafeteng, Mohale's Hoek, Berea, Leribe); three in the highlands (Mokhotlong, Thaba

– Tseka and Qacha's Nek); and two in the foothills (Botha–Bothe and Quthing). The Transformation Resource Centre (TRC) (2011) indicates that each district offers health services through hospitals, of which there are eighteen (18) in the whole country, with 156 Health Centres which run under the supervision of the Lesotho Government and the Christian Health Association of Lesotho (CHAL). According to the Lesotho Bureau of Statistics (2015), the country's total population stands at 1 944 748 and it is growing at an annual average rate of 0.17%. The map below provides an outline of the Lesotho HIV landscape with prevalence per district.

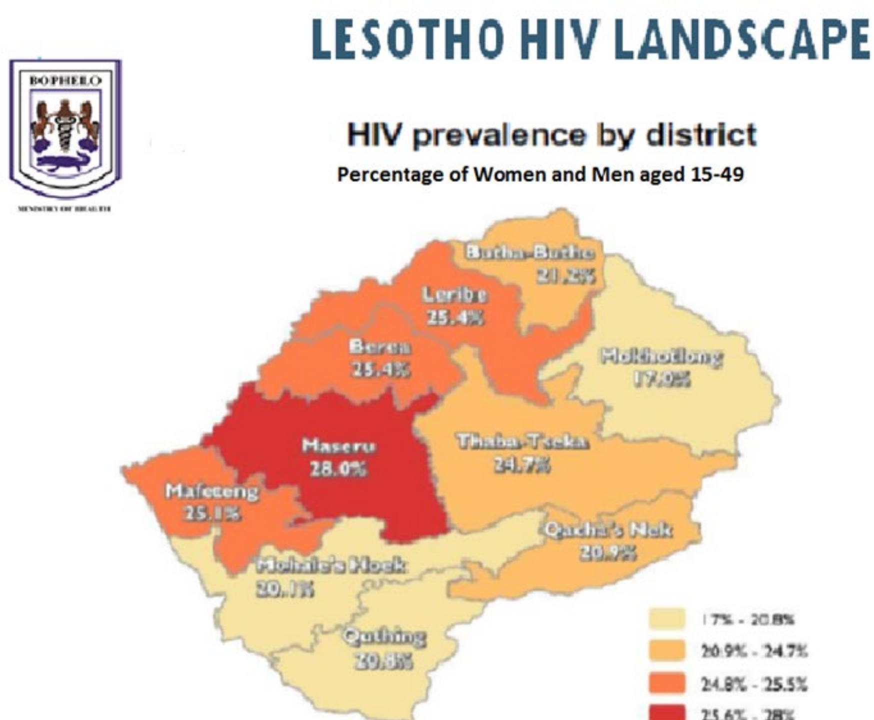

Figure 1: HIV prevalence by district. (Source: UNAIDS, 2018)

1.9 Lesotho HIV and AIDS facts and figures

According to UNAIDS (2018), Lesotho has the second highest HIV prevalence rate in the whole world. Stigmatising beliefs are a major barrier to the effective use of HIV related services including testing, counselling and the use of ART. It is hypothesised that these issues are culturally related (GOL, 2010).

This study therefore undertook an in-depth exploration of cultural attitudes and beliefs towards HIV and AIDS to see whether there is an association between the fear of discrimination and the responsiveness to HIV prevention strategies. The findings are crucial for designing prevention strategies that can make a difference in fighting the HIV epidemic.

1.10 The growth of HIV in Lesotho: background information

According to Kimaryo, Okpaku and Githuku-Shongwe (2004) the first AIDS case was reported in Lesotho in 1986. This case was found in Mokhotlong district. The Transformation Resource Centre (TRC, 2011) indicates that the doctors struggled to care for the expatriate patient who was also a doctor (male) but who showed no signs of getting better regardless of the tireless efforts undertaken to save his life. However, his referral to the Queen Elizabeth II hospital in Maseru forced a team of doctors to collaborate and conduct several tests to diagnose the patient's illness. During an informal conversation with Dr. Mosotho (personal communication 24th March 2012), he highlighted that, while they were still struggling to help the patient, another doctor suggested that an HIV test should be included. He recalled the shock they experienced when the results were HIV positive in August 1986 after the patient had been hospitalised in February the same year.

According to Sechaba Consultancy (SC, 2000), after this incident was announced, the country struggled to ensure that all health services were HIV competent. Kimaryo et al. (2004, p.3) explain that HIV and "AIDS competence means a society whose citizens are knowledgeable about what HIV is, what AIDS is, how one contracts the disease, what one should do to avoid getting it", and other related basic information concerning the virus. Sechaba Consultancy (2000) further indicates that technical support was given by the World Health Organization (WHO) which constructed information and education material that spread awareness across the country at large.

According to the Lesotho Review (Help Lesotho, 2016), HIV in Lesotho had spread rapidly since 1993. The Government of Lesotho (GOL, 2008) indicates that risky sexual behaviour is one of the largest obstacles facing the management of the HIV infection rate in the country.

Groups most at risk of being infected include former miners, migrant laborers, factory workers, the unemployed, female sex workers and young people, especially teenage girls.

The Government of Lesotho's report on behavior change in Lesotho (GOL, 2008) indicates public reaction to the pandemic was very slow due to lack of understanding and most importantly because the public associated HIV with expatriates, so to Basotho this virus was just a myth, hence their interpretation for AIDS was the American Idea for Destroying Sex. However, the Ministry of Health and Social Welfare (MOHSW) made efforts to provide information to all leaders, including chiefs, traditional healers, spiritual leaders and everyone who was considered to be a stake holder in relation to health information dissemination. The Lesotho Prime Minister appealed to Basotho culture by referring to the proverb *lehlanya le a bokaneloa*. This means that a mentally challenged but hostile person needs a lot of people to calm him/her down since they can bring in many ideas on how he/ she can be controlled not to harm other people. In the Lesotho context he meant that everyone must play their part and act in the capacity of the offices they hold, to curb the spread of the disease. In spite of these early interventions, adult prevalence of HIV rose steadily and in 2017 was standing at 23.2% (UNAIDS, 2018). Lesotho remains the 2nd most affected country in the world behind Botswana. The UNAIDS country factsheet for Lesotho (2018) reports that the highest prevalence rate is among the ages 30 to 39 at 40%.

1.10.1 Prevention interventions to 2018

The first policy framework was developed in 1995 by the National AIDS Prevention and Control Programme within the Ministry of Health. The framework emphasized the mainstreaming of HIV and advocated the implementation of Know Your Status (KYS) campaign. This was followed by the first National Strategic Plan of 2000/01 – 2003-04 introducing the KYS initiative and many more HIV prevention interventions in Lesotho. This involved the multisectoral approach that included the establishment of care and support groups of people living with HIV and AIDS and other community home based care support strategies. In 2006, the king declared HIV a national disaster resulting in the revised 2006 policy.

The revised Lesotho National Policy Strategic Plan HIV and AIDS 2006–2011 (GOL, 2006) was geared towards achieving the 2015 targets for the Millennium Development Goals as well as the objectives of its Vision 2020 (GOL, 2006a). Amongst these targets and objectives were targets for new clinical services and increased enrollment of people into HIV treatment as well as ensuring implementation of various HIV prevention strategies facilitated by WHO and UNAIDS. The Lesotho situation within the African continent is particularly severe, considering its geographical location (surrounded by South Africa which also has a high prevalence rate), own population size of less than 2 million and impoverished development status (UNAIDS, 2016). The following is a summary of the key strategies undertaken as documented by Kimaryo et al. in 2004 (Kimaryo et al., 2004) which are still used to date.

Know Your Status (KYS) – This was a Lesotho blanket coverage campaign which intensified testing services throughout the country. Testing services were offered in churches, schools, and tertiary institutions, where clients were eligible to consent for their own testing.

Abstinence, Be faithful to one sexual partner who knows their HIV status, Correct and consistent condom use, Delay sexual debut, Early detection and treatment of STIs (ABCDE) – This intervention became popular when Lesotho first began to intensify educational material with the hope of creating awareness that HIV existed and was continually infecting Basotho's own sexual partners because most Basotho believed HIV was a foreign disease and therefore could not infect them.

Door to Door (D2D) – HIV testing services were taken to the community by all levels in the health structure starting from the community structures namely Village Health Workers, the professional counsellors under the District Health Management Team (DHMT) and other NGOs such as New Start and Elisabeth Glaiser Paediatric AIDS Foundation (EGPAF), University Research, CHAI and SOLIDARMED which was a Swiss funded organisation. This intervention became famous due to its intense spread and because it attracted huge funding for its implementation.

Post Exposure Prophylaxis (PEP) – This intervention was established to assist people who had been at risk of acquiring HIV infection. They were categorised by (i) individuals who were accidentally pricked by a used object, (ii) persons who were raped, and (iii) those whose condom broke during sexual intercourse. For one to access PEP, the procedure required that the one who had been at risk to undergo an HIV test. If the result was negative, one was to be given ARVs temporarily for 28 days but if one was diagnosed HIV infected during the test for PEP eligibility, then one was to be fully initiated on ARVs.

Prevention of Mother to Child Transmission of HIV (PMTCT) – This intervention was intended to be implemented with the child-bearing age group which was expected to attend maternal health services to access education on exclusive breastfeeding and exclusive formula feeding, as well as the use of mother baby pack which was given to all expectant mothers but had different contents inside the pack depending on the recipient's status. For instance, in the HIV positive mother's pack, the contents included ARVs while in the HIV negative pack, contents included supplementary pills such as ferrous and folic acid.

Provider Initiated Testing and Counselling (PITC) – This was where health service providers were expected to diagnose the patient based on the illnesses that presented themselves. If the illness was suspected to be an opportunistic infection, then a patient had to be tested for HIV.

Client Initiated Testing and Counselling (CITC) – This was a voluntary test where a client was to be educated on the importance of knowing one's status on time, then expected to go for HIV testing voluntarily. If the client did not feel like testing, such individual would not be forced.

Pre-Exposure Prophylaxis (PrEP) – This intervention was introduced alongside the test and treat programme. Its main focus is on discordant couples where the HIV negative partner is initiated with ARVs to use as preventive medication in case of direct exposure such as unprotected sex to protect them from acquiring HIV. PrEP can also be used by sex workers because there are times when their prices differ depending on whether the customer used protection or not. Therefore, in cases when condom use is conditional, PrEP can be used.

Since 2015 three new strategies have been introduced as follows.

Voluntary Medical Male Circumcision (VMMC) – This intervention focused on males from infancy to the age of 65yrs to reduce HIV infection by 60% in all circumcised males. However, the intervention encouraged males to use dual protection where condoms are still needed to complement the remaining 40% protection gap (jhpiego n.d.).

Test and Treat (T&T) – This was implemented in Lesotho on the 1st June 2016 (Pedaids, 2016). This initiative was put in place for practice by all health related organisations to intensify initiation of HIV infected clients within three days of knowing their HIV status. Every infected individual is given two weeks treatment to take immediately after testing, regardless of the place where the client got tested because ARVs are dispensed at both health centres and at community level. This intervention advocates for a 90 90 90 strategy. This means the Ministry of Health indicates that by the year 2020, 90% (first 90) of the population must have been tested for HIV, 90% (second 90) of HIV infected individuals must be put on ARVs, while 90% (last 90) of people tested and initiated must be viral suppressed. Therefore, every individual on ARVs is advised to test their viral load after every six months. The benefits of test and treat to a country which is identified as the second most infected by HIV in the world are countless because evidence has shown that the earlier one begins to take treatment the better, since ARVs suppress the virus and in the process the immune system gets a chance to recover. The preventive interventions are presented in a circular manner because all are still operational depending on interest of the HIV service provider.

HIV Self-Test (HIVST) - This strategy was launched by the Ministry of Health in December 2017 (Lesotho Times, 2017). HIVST is intended to be used as a screening tool for clients who feel they need more privacy and to do the test alone in their comfort zone. The test is self-explanatory and self-instructional to allow one to use it alone. HIVST is intended to arouse interest for one to confirm HIV results so as to be able to take action about one's status should the need arise. Self-test kits are distributed to people who may show an interest in testing but do not have time to wait in a long queue outside the mobile tent or at a New Start site. Such

individuals are given the kit to use while relaxed at their own setting. This kit can be given to an HIV infected client who has a sexual partner with unknown HIV status to take home and request the partner to use.

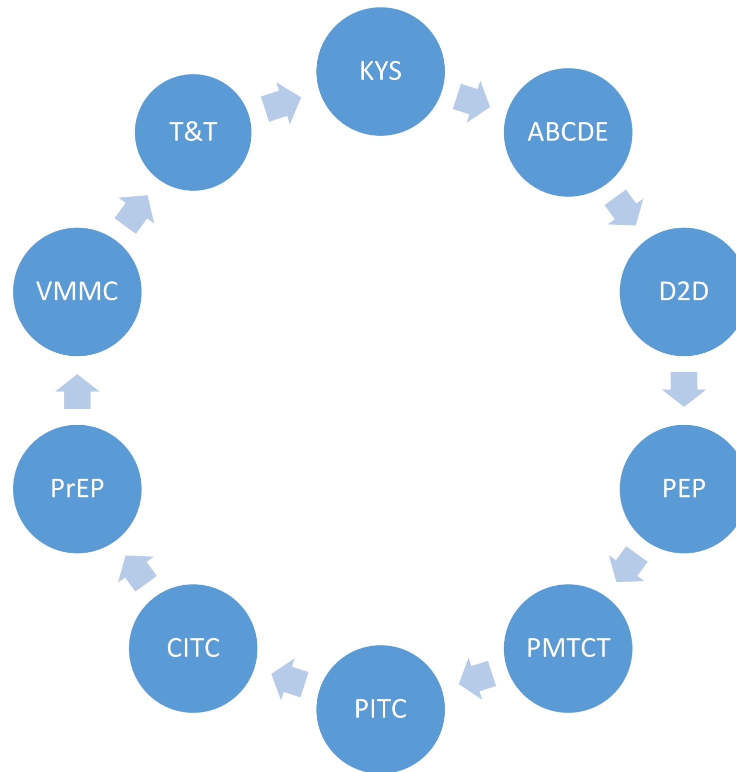

Figure 2: Chart showing the different Lesotho prevention interventions since 2004 to date

1.11 Policy strategies for Lesotho

In 2001 the Lesotho AIDS Programme Coordinating Authority (LAPCA) was established within the office of the Prime Minister to coordinate and oversee national efforts to address the HIV epidemic. National AIDS strategic plans have been developed since then, focusing on multi-sectoral collaboration in HIV prevention and control. The National AIDS Commission (NAC) was established in 2004 to supersede LAPCA and to coordinate implementation of the National HIV and AIDS Strategic Plan. A director for HIV and AIDS was appointed to provide technical advice and to advance the health sector's response to the epidemic (Kimaryo et al., 2004).

Lesotho is among the countries which signed up to the eight Millennium Development Goals which were ratified in 2000 by all member states to the United Nations. The aim of goal number

6 was to combat HIV and AIDS, malaria and other diseases, with a target to halt and begin to reverse the spread of HIV and AIDS by 2015. In order to achieve this goal, in 2003, Lesotho designed its national policy and guidelines which serve as a guide to all parties that have a role in combating HIV and AIDS in this country. Lesotho has also signed up to the Sustainable Development Goals (SDGs) (GOL, 2015). In order to achieve this new goal, Lesotho signed its national policy and guidelines in 2015 to serve as a guide to all parties that have a role in combating HIV and AIDS in the country (GOL, 2015). The policy included the forming of support groups as an affordable means to facilitate health-related education among Basotho.

The policy includes a number of prevention strategies. The HIV Testing and Counselling (HTC) strategy (GOL, 2010) indicates that counselling for prevention is the core business in HTC. Once a person has determined his/her HIV status, whether positive or negative, it is important that they either prevent transmission of HIV to other people or avoid contracting HIV themselves. Usually the most unpopular prevention method is the use of condoms because there are many socio-cultural obstacles to their use. Nevertheless, this strategy was accelerated by the Know Your Status campaign (KYS) which took place in Lesotho between 2005 and 2007.

This intensity of this campaign helped to reach even the most forgotten villages and HIV and AIDS messages spread throughout the country. Diagnostic Testing (DT) – now called Provider Initiated Testing and Counselling (PITC) – was introduced in 2008 by UNAIDS as a result of perceptions that the health sectors miss the most appropriate clients in hospital premises who may have already been hospitalised due to related opportunistic infections from the HI virus. Therefore, it is now mandatory for health professionals to encourage patients presenting with minor and major illnesses to get tested, for both outpatient and admitted patients. As a further impetus for opening as many HIV testing centres as possible to reach all Basotho, the disclosure strategy was introduced by WHO in 2005 (WHO, 2005) as a result of its success in Uganda. The strategy empowered health professionals with skills to encourage all individuals who have tested for HIV to disclose their negative or positive HIV status to their relatives with the intention of increasing social support and reducing stigma and discrimination among the population.

The Consistent and Correct Condom use (CCC), strategy was introduced in Lesotho by UNAIDS in the same year. UNAIDS (2009) indicated that the condom had previously been introduced in Lesotho as one of the most trustworthy contraceptives. But this meant that most Basotho only interpreted the condom as a contraceptive method and nothing more. Using a condom consistently was a burden to sexual partners. Furthermore, the myths surrounding condom use among the Basotho also increased reluctance to try them (GOL, 2008). An example of a few myths on condom use are: (1) A condom is used by promiscuous couples only; (2) Condoms are small in size and cannot fit Basotho males; (3) Condoms have an oil like substance on them (lubricant), which contains HIV to infect Basotho purposely; (4) A condom is used with sex workers only; (5) Condom have worms intended to reduce males' libidinal desire; (6) Women using condoms fail to give their sexual partners pleasure; and (7) Women using condoms for a long time give birth to blind children (MOHSW, 2007).

As a result of the escalating prevalence of HIV in spite of the above measures, further interventions were introduced. This included the Behaviour Change Communication (BCC) strategy (GOL, 2008). The Lesotho Review (Help Lesotho, 2016) points out that the national BCC strategy is one of several HIV and AIDS prevention strategies. This strategy has been developed to empower communities and individuals of all ages to change their behaviours for better health. It is aimed at promoting sustainable positive healthy behaviour through people's own efforts. Behaviour change and avoidance of risky sexual behaviours remain key in combating HIV and AIDS. This strategy takes a multi-sectoral approach to reducing the sexual transmission of HIV through the promotion of responsible practices. Sechaba Consultancy (2000) indicates that the BCC strategy focused on the gender equality issues, stigma, high risk behaviour such as multiple partners, and higher use of prevention services.

Mother to child transmission is a leading cause of HIV infection in infants and young children. According to the GOL (2010), treatment sites for Prevention of Mother To Child Transmission (PMTCT) of HIV programmes have steadily increased. The strategy is expected to help achieve the slogan which says 'strive for an HIV free generation.' This would also hope to be achieved through the use of a new and improved Mother Baby Pack (MBP) which was launched in January 2011. In this Management of Sexually Transmitted Infections (MSTI) strategy, all

patients presenting with Sexually Transmitted Infections (STIs) are treated and given a treatment package for one sexual partner. The sick person is then asked to bring the sexual partner for check-ups so that a thorough follow up is done on both of them (GOL, 2010), including Post Exposure Prophylaxis (PEP). The national HIV and AIDS policy (GOL, 2006) is of the view that HIV transmission can be reduced, if there is suspicion of possible contact with HIV infected materials, by administration of PEP drugs within two hours. If this is not possible it should be administered within 72 hours. In spite of these strategies, the Ministry of Health (GOL, 2016) indicates that prevalence rates have barely declined. In 2016 People Living with HIV totaled 290 000. Although there seems to be a downward trend of infections among teenagers there is an increase in prevalence of between 34% and 40% among ages 30 to 40 (GOL, 2016). Since the statistics indicate that strategies are having a limited effect it is important to look at why this is the case. One possible reason may be related to cultural beliefs and attitudes which are creating a disjuncture in acceptance of the prevention strategies.

These concerns have been supported by other research. For instance Murphy (2003) indicates that Sierra Leone also experiences high challenges regarding myths around HIV. Such myths include traditional beliefs and attitudes towards women and condoms. There have been increasing concerns that culturally sensitive prevention and education methods must be adopted to encourage adoption, ownership and sustainability of HIV prevention and treatment (Price, 2009).

1.12 Culture and HIV / AIDS education

There is evidence that culture impacts on the way people respond to health services and treatments in Lesotho (Monyake, 2010; Mahloane-Tau, 2016; Mosuoe, 2016). Ntseane and Preece (2005) support this concern in relation to cultural discourses of sexuality in the Botswana context, where it was revealed that sexual practices amongst different ethnic groups are gender-laden, and embedded within particular contexts which are reinforced through the language of taboos and proverbs. There were high levels of mistrust amongst the different ethnic groups about the information being provided about HIV and AIDS, particularly in relation to its lack of synergy with cultural values and beliefs. The HIV/AIDS education messages have generally been derived from the West. Kemboi, Onkware and Ntabo (2011) suggest that the supposed

superiority of western culture is the basis on which it has been extended beyond the centre to the periphery, namely through western science and education. However, the western educational model which is deemed useful and selected for practice has to be deconstructed and translated to suit context specific cultural categories and practices. In Lesotho's case it is suggested that this process of deconstruction needs to be used so that Basotho can translate western messages into Basotho's own cultural categories in order to make the IEC materials meaningful and context specific.

This notion is supported by Price (2009) who has encouraged the cultural adaptation of proven interventions so that they could be used in the African region. Price recognised the need for countries to develop interventions which would be culturally relevant but which also followed tried and tested methods from other countries. However, Price emphasises that health messages, which are language and culture specific to harmonise with a specific country, must not devalue and compromise content.

Wilce (2011) explored issues of myths and witchcraft associated with AIDS patients in Zimbabwe. When myths are seen as the primary cause of HIV and AIDS then medical efforts to treat the disease are deligitimised. In other words, as Basotho have been saying anecdotally, if there is an evil force behind the disease, then neither prevention nor a cure will help. This agent will find another way to harm them!

Petzer, Oladimeji, and Morakinyo (2001) argue, in relation to Nigeria, that people often claim that malicious agents have contaminated the condom lubricant with HIV, thus preventing people from using condoms because they feel that it actually exposes the user to a direct risk. Such evidence in Nigeria supports the widely held view that such concerns need to be considered when designing culturally appropriate HIV interventions and educational campaigns. Culturally sensitive campaigns would increase receptivity to information about preventing HIV-infection.

Tavrow, Muthengi-Karei, Obbuyi and Omollo (2012) indicate that Kenya, too, holds myths and misconceptions about condom use. The contaminated condom narrative is usually embedded in statements that condoms promote promiscuity and therefore AIDS. The belief that condoms are

contaminated with HIV symbolises the perceived danger of using a condom. Something with the condom is dangerous, this may be HIV itself, or HIV may just be a metaphorical expression for something else regarded as dangerous, such as promiscuity which is viewed as risky. Such sexual behaviour leads to a high risk for acquiring HIV.

One way in which to address cultural issues is to introduce support groups that facilitate the opportunities to address the contradictions. One of the first support groups that was introduced in Lesotho was the Mothers to Mothers group sponsored by the Elizabeth Glaser Paediatric Foundation. In Lesotho, Mothers to Mothers (M2M) operates in every hospital and clinic that offers PMTCT of HIV services in Maseru and three other districts (Botha-Bothe, Leribe and Berea). M2M offers monthly couple support and encourages the use of PMTCT services in order for children to be HIV negative regardless of their parents' HIV status.

1.13 Botha-Bothe context

Botha–Bothe is a small town in the north of Lesotho. It has an estimated population of 109 907 which is 5.8% of the total population, as identified by the Lesotho Demographic and Health Survey (LHDS) (GOL, 2009). HIV prevalence in Botha-Bothe is lower than elsewhere in the country at 16% (Help Lesotho, 2016). This district started HIV care and support in May 2006 and offers chronic care to 12 897 clients district wide of which 10 773 are taking Antiretroviral Treatment (ART) while the remaining 2 124 are on pre-ART care and both groups attend monthly check-ups. The fact that support groups were introduced in the Botha-Bothe district may be a significant factor in the relatively low prevalence rates.

1.13.1 The response in Botha-Bothe – establishment of support groups

In order to encourage people in this district to join the learning support groups, health workers had to be persistent. The HIV and AIDS situation in the district was reaching alarming rates. More and more people were presenting in health centres with HIV-related ailments. Health centres including the hospitals were admitting more and more patients. Patients who were treated seemed not to be adhering to treatment requirements. The health centres were experiencing re-infection and co-infection cases among HIV patients and to some extent, patients presenting with opportunistic infections such as tuberculosis and sexually transmitted infections. Additionally,

there were cases of infants born with HIV and AIDS, despite the PMTCT Programme which was already in place. With the influx of HIV patients presenting with these ailments, the health centres were no longer able to cope with the work load. In this regard and to try to mitigate this, the Botha-Bothe Hospital of the Ministry of Health, working with its partners such as Elizabeth Glaser Paediatric AIDS Foundation (EGPAF) initiated the establishment of Support Groups for HIV infected and affected individuals in 2009. According to the Ministry of Health and Social welfare (GOL, 2009), the objectives of these groups were to scale up HIV and AIDS prevention care and treatment messages among and across the groups and create a platform for the groups to share and learn from each other's experiences. Another objective was to create a more coordinated organisation which would enable interaction as well as ease of follow-up by health professionals. Therefore, the support groups were initially formed by a few members who felt the need for learning about the dynamism of HIV because they believed the slogan: 'know your enemy's strengths and weaknesses to be able to defeat it'. The response began very slowly with people determined to learn about and understand HIV and AIDS to be able to manage and support each other. The groups initially started with a few people joining and the number increasing gradually until joining in was stopped in order to maintain a manageable group size.

The structure of the groups

The groups have been structured into three categories: support groups for people living openly with HIV and AIDS; support groups for mothers-in-law; and support groups for men.

a) Support groups for people living openly with HIV and AIDS: This is a 'mixed group' of males and females who are already taking Anti Retro-Viral treatment (ART) on a monthly basis. Some of the group members are not yet receiving treatment but are just on HIV care because of their CD4 count that is above the threshold of 350. The group that is on ART meets on a monthly basis when they come to the ART centre for their medical follow-ups (check-ups). On their meeting date, the support group arrives very early in the morning to submit their health booklet which has ART file numbers at the reception. Then they meet in the ART lecture room for two hours. In these meetings, members discuss topics of their interest which were given to other members on a previous visit to research. After this discussion, one member of staff presents on the topic chosen by the members and given to him/her on their previous meeting. Before the end of the meeting,

support groups allocate topics for discussion on the next monthly meeting to the staff and other support group members. After the meeting, members of the support group go to the waiting room to join the rest of the people who have come for their monthly refills and queue up for routine triage. This includes: TB screening, taking and recording their monthly weight, drawing blood for various medical reasons, meeting the counsellor for psychosocial support, adherence preparation and adherence monitoring, consulting the nurse or the doctor when necessary and getting medication at the ART clinic pharmacy. The other sub-group of HIV positive members who are not yet initiated in ART do attend the monthly meetings of the group but undertake health check-ups on a six month's basis for CD4 count and other medical examinations.

b) Support group of mothers-in-law known by the group itself as 'Mothers to Mothers' (M2M): This support group is formed for elderly women who are considered to be the in-laws of the HIV positive mothers at child bearing age and attend Ante-Natal Care. Mothers-in-law meet every month on a scheduled date in the hospital premises at the Mothers to Mothers offices' waiting area. The purpose for this support group is to empower each member of the group with information relating to PMTCT of HIV. These elderly women learn about the prevention measures which a family can agree on to help the HIV positive expectant mother not to infect both the unborn baby and the infants.

   Topics of concern in this support group include: HIV mode of transmission, prevention strategies for all age groups in the family, discordant couples, the importance of three DNA/PCR lab tests for a child, exclusive breastfeeding, formula feeding, food preparation and hygiene, importance of condom use and the support expected from them by their daughters-in-law. One becomes a member of this group until the grandchild is six months old.

c) The last group is called 'Fathers to Fathers', which was initiated by concerned males who thought that men were not doing enough in the prevention of HIV. This support group intended to increase male involvement in health issues by equipping males with health information and training them to become the male focal persons in their different

villages. These males meet quarterly and get trained on different health issues by qualified health personnel. The topics include: HIV transmission and prevention, correct and consistent condom (CCC) use, discordant couples, how to access post exposure prophylaxis (PEP), the importance of male circumcision, and family support in the Christian and cultural context. Most topics are suggested by the support group while sometimes their questions form topics for the next meeting.

A support group as a concept is used in this context in a broad sense to mean a group of people who come together to talk about a challenge, an experience and/or role that they have in common without being judged, blamed, stigmatised or isolated (Namwamba-Ntombela, 2010).

Support groups have been supported by a number of writers because they are a source of emotional support, especially for people who are HIV positive. Mosuoe (2016), Atanga, Atashili, Nde and Akenji (2015) outline that the benefits of joining support groups need to be individually felt. Atanga et al. further indicate that such benefits must include good adherence to antiretroviral therapy and improved individual physical and psychological health among people living with HIV and AIDS. Support groups are also useful for family, friends and community members of people living with HIV and AIDS.

This study focuses on the learning processes that have been involved in creating such benefits.

1.14 Significance of the study

The study will be of great significance to the Ministry of Health (MOH) mainly the STI, HIV and AIDS directorate (disease control) which is mandated to ensure the reduction of new HIV infections and also to the Health Education department of the same ministry since it is entrusted to impart skills and knowledge concerning all health-related issues. The findings will inform them of the contribution made by HIV infected and affected support groups in the meaning-making of prevention strategies. This study could therefore help the government of Lesotho to formulate policies which could strengthen the support groups' efforts in negotiating the contradictions in the myths, beliefs and traditions in relation to medical messages on HIV prevention messages.

1.15 Scope of the study

This study covers Botha–Bothe district. The respondents were drawn from three different support groups in Botha-Bothe Government Hospital (PLWA, affected individuals, Mothers to Mothers' facilitators, nurses and counsellors).

1.16 Organisation of the study

Chapter One has provided the introduction and background information regarding the HIV / AIDS problem globally, in Africa and in Lesotho. The response then focuses on the challenges in Africa and cultural perceptions about the disease in African contexts including contradictions between myth and reality, medical versus social interpretations of the disease and its management. This is followed by an outline of the Lesotho response, the strategies put in place, educational messages and the history of the support groups in the Botha–Bothe government hospitals. It also introduces the purpose of the study and research questions.

Chapter Two discusses the literature review regarding support groups, where the authors did their studies (Western or African countries), and what methods or theories they used. It addresses the following issues: a) the infected and affected people, how they cope with challenges relating to HIV and AIDS stigma, discrimination, opportunistic infections and disease progression; b) the individual sense of self as an HIV infected person; c) the misconceptions around treatment and challenges which the support groups encounter; d) the local and social beliefs on HIV prevention, transmission, and disease progression as experienced by the infected and some by the affected; e) the societal explanations of the disease; and f) the collective meanings given to explain the experiences (side effects).

Chapter Three discusses the theoretical framework of Transformative Learning, Social Capital and Communities of Practice and the role of Discourse Analysis. This provides the basis for analysing the findings and discussing how people in the support groups negotiate the contradictions in the myths, beliefs, traditions and medical messages about HIV, its prevention and care.

Chapter Four covers methodology, research paradigm, design, population, sample, instruments, and data collection. It also describes the researcher's experience of data collection and analysis.

Chapter Five focuses on research question one which asks how the groups operated as a community of practice.

Chapter Six (Fathers-to-Fathers) focuses on research question two in relation to how the group makes meaning out of medical discourses. Chapter Six reveals how cultural value systems and gender issues could assist or hinder PMTCT interventions.

Chapter Seven (Mothers-in-law) also responds to research question two in relation to the cultural value systems and gender issues prevailing in Lesotho.

Chapter Eight (Mixed Support Group) addresses research question two in relation to myths and community beliefs, such as those promoted by the youth. This chapter, along with Chapters Four, Five and Six additionally respond to research question three in terms of how their meaning making impacts on new learning.

Chapter Nine (conclusion chapter) summarises and reflects on the whole study. It reflects on the methodology used for this study and discusses the lessons learned.

Chapter Two: Literature review

2.1 Introduction

Literature on support groups in Lesotho is very limited. Therefore, this study draws on literature mostly from across Africa and the rest of the world. The literature review looks at how other people have explored issues of support groups, it examines the epidemiological reason for infection and also the nature and range of prevention strategies that have been in existence, with particular reference to any educational rationale behind those support groups and the way they negotiate the contradictions, myths, beliefs and medical messages about HIV, its prevention and care.

The structure of this chapter includes discussions around support groups, what other authors have written on support groups, where the authors did their studies (Western or African countries), and what methods or theories they used. It addresses the following issues: a) The infected and affected people, how they cope with challenges relating to HIV and AIDS stigma, discrimination, opportunistic infections and disease progression; b) The individual sense of self as an HIV infected person; c) The misconceptions around treatment and challenges which the support groups encounter; d) The local and social beliefs on HIV prevention, transmission, and disease progression as experienced by the infected and some by the affected; e) The societal explanations of the disease and f) The collective meanings given to explain the experiences such as side effects.

2.2 Support groups

There are various studies around the world addressing the issue of how different support groups (infected and affected) respond to HIV education in different perspectives. For instance, there are studies in America amongst African-American men that explore personal beliefs and attitudes towards AIDS (Aguilar, 2014). While Aguilar discusses gender power relations affecting African-American women in sexual relations, other studies explore the impact of HIV prevention interventions on women in Latin America (for example Kalbfleisch & Cody, 2012), the influence of religion on attitudes to HIV testing in Kenya (Kemboi Onkware & Ntabo, 2011), as well as family influences on HIV infected individuals in South Africa (Kim & Motsei, 2002). Efforts have also been made to assess peer education strategies in HIV prevention (Monyake, 2010).

None of these studies, however, looked into how the support groups learned and shared their understanding of the medical discourses with significant others.

Mosuoe (2016) and Gonzalez (2013) among others, have shared similar perspectives regarding the role of support groups and this will be discussed in more detail.

Gonzalez (2013) indicates that by support groups, one refers to supportive functions performed for the individual by significant groups of others such as family members, friends and co-workers to demonstrate their love and caring, sympathy and understanding of the challenge their loved one encounters. Spirig (1998) specifies that support groups, within the health care perspective, focus on the provision of emotional support, and informational assistance from members who possess experiential knowledge. 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 Vyankandondera, Mitchell, Asiimwe-Kateera, Boer et al., 2013). Mosuoe (2016) adds that another support group role is to assist its members to return to health, work and normalcy. This is witnessed in a case where the better mental and physical health of members, enables them to function effectively, with an 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. Mosuoe further indicates that from the responses collected in her study, it becomes apparent that support groups create a conducive environment for their members to learn, interact, share and belong. Mosuoe’s (2016) study was of women in the Lesotho context and it is likely that the women’s support group discussed in her study influenced the establishment of the Botha-Bothe support groups.

According to Namwamba-Ntombela (2010) support groups help members cope with the emotions and challenges they experience when knowing they are infected. This was evidenced by Mosuoe (2016) in her analysis of how members of the Phelisanang Bophelong joined a support group after their HIV positive diagnosis and experiences of suicidal thoughts (such as a drowning at Katse Dam). Such thoughts subsided after meeting other infected people openly living with HIV. In a group, they learned that they are not alone in that situation therefore they

make choices and decisions that will improve the quality of their life and prolong it. They acquire better skills from each other to deal with opportunistic infections. The National Association of Social Workers (NASW, 2011) emphasises that support groups should work together with community members and other assisting professionals aiming to promote support groups' efforts to learn new ways of coping with HIV and work towards broader social changes in attitudes towards HIV. Support groups increase the potential for effective capacity building, communication and advocacy as indicated by Hodgson, Nakiyemba, Seeley et al. (2012). Although support groups are encouraged to be innovative and creative, they need to recognise that relationships are paramount (Namwamba-Ntombela, 2010). Kothari et al. (2015) state that it is essential for support groups to be broad-spectrum in nature to allow the discussion of numerous topics which can benefit and add value to the wider community and to avoid the establishment of micro-groups which may start to address topics considered to be out of their learning range.

Atanga, Atashili, Nde and Akenji (2015) indicate that support groups consequently widen the scope of, and access to, information that their networks can learn from. Atanga et al. (2015) and Hodgson, Nakiyemba, Seeley et al. (2012) share the same view that countries which experienced a 'red flag' (danger zone) due to the HIV pandemic, experienced relief from the intensive implementation of support groups. Such groups enabled a wide coverage on promoting HIV prevention and encouraged open discussion on people living with HIV (PLWH). Gonzalez (2013) further argues that group sessions can lessen the burden of the impact of stress. Support group members can however become over-protective of their members by focusing too much on ensuring all is well for the affected members. Atanga et al. (2015) further indicate that for stressed individuals, it is possible that perceived support can worsen the illness if membership has not been professionally classified and group members carefully selected. Individuals with higher depressive symptoms are advised to avoid forming support groups. For instance, if the support group is likely to increase depressive symptoms this can lead to poor adherence or prolonged use of depressants. Another support group role is to assist its members to return to health, work and normalcy. In spite of these cautionary observations, Hodgson et al. (2012) indicate that researchers have demonstrated a growing interest in how support groups help manage health and illnesses.

Several studies have revealed various reasons why people need and form support groups. Spirig (1998) and Walstrom et al. (2013) for instance suggest that viable support groups can enhance individual well-being because people share their experiences and feelings and help each other to work out strategies for managing their situations.

Mosuoe (2016) also maintains that support groups help each other, including when knowing that their siblings are infected and trying to help them during their suffering caused by the AIDS stage. Carnaham (2012) noted that support groups also help as social networks. This is where members develop empathy for one another. Support groups operate in different ways. Mowat (2007) mentions that membership in some support groups is formally controlled, with admission requirements. This is the case with the Botha-Bothe Mothers-in-Law support group which requires one to have an HIV infected childbearing daughter-in-law in order to join in. Other groups, according to Mowat (2007) are open and allow anyone to attend an advertised meeting, for example, or to participate in an online forum. In Botha-Bothe's case one can cite the Mixed support group (Thusanang Bakuli) and Fathers to Fathers support groups as open groups because their membership is only controlled by the size of the room which they use for regular meetings.

Some formal support groups are entirely online. Mo and Coulson (2010) indicate that the practice of support groups meeting online is increasing. Individuals living in 'self-imposed exile' can benefit from this mode as struggling for face-to-face contact can be costly. Although online support groups seem to be popular in the USA, individuals still need to meet their counterparts on a face-to-face basis for comparison reasons in cases where ART has enforced long-term side effects (Mo & Coulson, 2010). There is a growing critique of online programmes observed from the Western population. Reeves (2001) criticises online support groups by indicating that they do not meet intended purposes because sensitive issues are discussed offline and deny other potential listeners a chance to benefit from the solutions to the issue. The argument is that such private conversations, if they were openly discussed could benefit other members and even non-members. It could therefore be argued that online support groups are a waste of resources due to the manner in which they operate and handle crucial but personal issues.

Brindley, Blaschke and Walti (2009) emphasise that an online support group is just a one piece of the complex puzzle needed when facilitating a more effective HIV and AIDS response. Hodgson et al. (2012) condemn and label online support groups as a 'failing focus'. They indicate that in online support groups, members do not value closeness, oneness or joint local home-based care clubs where members portray great dedication to assist one another by offering unpaid nursing and welfare assistance, which easily happens in face to face support groups. Hodgson et al. further comment that support groups need to meet for empathy, care and consolation sessions after ill-treatment by other societal members. Most authors have the same understanding that support groups need to be established for motivational and health promotion purposes. This is why Hodgson et al. (2012), and Reeves (2001) for instance, negatively comment about online support groups and disapprove of efforts made in such groups. The efforts are labelled as a failing focus and a waste of resources. On-line contact was not a feature of the Botha-Bothe Hospital support groups due to a scarcity of technological devices and technical know-how. This study therefore focuses on three face to face support groups because these forms of support group are deemed more suitable to the Lesotho context.

Namwamba-Ntombela (2010) argues that support groups cannot replace the practical medical or counselling needs of individuals living with HIV. Support group capabilities have to be publicised prior to members joining to reduce expectations and allow informed decision making.

It has been recognised that different social groups require targeted interventions (UNAIDS, 2016a). Support groups, however, are often established for short-term, research purposes without taking into account the long-term expectations of each member about the support. Consequently, UNAIDS (2016a) discourages funding for support groups which have less than three year's survival history. As early as 1998 UNAIDS indicated that funding for newly formed support groups can create jealousy and conflict among groups which hold a long survival history. According to UNAIDS (1998) funding must be accessible to support groups which are clearly able to indicate their sustainability plan after the end of the donor funding period. According to Dr. Gupta (Personal Communication (PC) 2013), the support groups in the Botha-Bothe hospital premises are expected to run for a minimum of five years. After five years the groups are expected to continue independently in the community with minimal follow-up from the hospital.

However, during the beginning of the fourth year, new support groups are formed with the same purpose and criteria. New groups then run parallel to the already existing ones and meet at different times on a monthly basis so they equally utilise limited resources such as housing and health experts (guiding staff- counsellors, nurses, pharmacists and laboratory technicians).

It is important to note that all the above authors have the same view that joining support groups makes people realise they are not alone in their situation. This means the focus of establishing support groups is aimed at creating a platform for the ventilation of individual concerns and opportunity to learn how they can be overcome.

Literature on support groups intending to meet for informational support is minimal, regardless of its usefulness. Goldsmith and Domann-Scholz (2013) point out that informational support has proven to be more appropriate if given to members prior to their consultative meetings with the nurse or a doctor as this type of support can reduce waiting periods for patients being consulted by the doctor because questions and worries get addressed through the informational support system. This point illustrates the importance of establishing support groups such as those in Botha-Bothe. These three support groups are distinctive because they focus on acquainting themselves with medical discourses that are frequently used during their treatment sessions.

Some authors do question the formation of support groups for learning purposes. For instance, Modo, Modo and Enang (2011) suggest that such programmes (support groups) targeted at commercial sex workers, for instance, to promote consistent condom use are more effective through the use of mass media (radio) and entertainment (music and drama). They argue that such initiatives have had a significant impact on overall HIV prevalence in the country without necessarily establishing support groups for them. Therefore, Modo et al. (2012) and Motley et al. (2017) criticise the formation of support groups and conclude that they limit their lessons to only the small group who have enrolled for support. This form of education erodes funds and scarce qualified human resources are confined to assisting only those specific people who join support groups. They also argue that it would be more beneficial to encourage the experts to work with journalists so that they can broadcast crucial health information to all listeners around the globe.

It can be argued, however, that if support groups can be used to inform the wider community about what they have learned in the group, then this latter concern can be addressed.

The issue of culture, particularly in a country like Lesotho, is paramount in this respect and there is a need to provide learning opportunities that take culture and traditional attitudes into account in order to influence behavioural and attitudinal change. Hence this study seeks to find out: 1. How support groups in Botha-Bothe function as a community of practice and what new meaning do the support group members develop over time (for example as a result of the educational input, discussions and independent information seeking exercises that are generated in the support groups); and 2. What impact these new meanings have on how they respond to the epidemic in terms of HIV management, behavioural change and social relations.

Some authors have the feeling that the significance of culture in providing information to support groups is not visible. A case in point is cited by Price (2009) who says culturally adapted and audio-technologically HIV awareness raising programmes tailored towards the needs of support groups in rural communities are needed. Price (2009) encourages the establishment of programmes that emphasise the use of culturally adapted and technologically assisted educational interventions that are widely accessed in order to make them cost effective. Thus, HIV prevention is both affected by, and reinforces, culture. Modo et al. (2011) point out that with support group educational efforts, the main task has to be on recommending actions for change in a culturally sensitive manner.

Walstrom et al. (2013) elucidate that in countries where support group programmes have not been implemented, studies have shown there is an interest from various groups to initiate such intervention. In the few towns where support groups began, members highlight their success in understanding and supporting each other's situation better.

It is worth noting that most support groups, in western or African countries, have focused on what other people outside the support group structure did or failed to do for them as individuals living with HIV. A common point of concern in support group discussions focuses on reports of how the members were treated previously by their relatives and community at large. A lot of

their precious time is spent on sharing how they overcome the challenges of ill-treatment posed by people closer to them. This behaviour indicates that support groups are a key resource for attention and sympathy. It can be argued, however, that HIV infected individuals need a changed focus whereby their support groups focus on delivering survivor messages that go beyond enabling people to lament their condition and experiences.

The continual improvement of lives of infected individuals inclined the work of Tsarenko and Polonsky (2011) to indicate the positive changes in knowledge and attitudes brought about by sustainable youth support groups. These addressed sensitive health issues such as sexual and reproductive health, including condom use for those who no longer abstain from sexual activities. Tsarenko and Polonsky indicated that the power and energy for youth to sustain their obligations through the support groups emanated from the effect of sharing these various obligations. The effect of openly sharing their sexuality and sexual status binds all members to abide by their obligations.

A growing body of literature from developing countries, as revealed by UNAIDS (2016a), indicates that youth support groups have influenced positive changes in knowledge and attitudes in youth sexual and reproductive health. The ARK Evaluation Programme (2002) for instance, found that youth support groups had increased knowledge about safe sex practices, access to and use of services through the utilisation of adolescent health corners. UNICEF (2014) reported that through such support groups, positive attitudes towards community leadership increased, with delayed initiation of sex, increased abstinence and better family communication. As a result of youth support groups the input, education and communication content improved across six participating areas (California, Texas, Geneva, Ohio, Toronto and Turkey the ARK programme gained popularity and funds increased for the initiation of similar youth support groups the programme became a strong intervention strategy which created a remarkable reduction of new HIV infections (Ark, 2002).

The Government of Lesotho (GOL, 2010) indicated the need for Botha-Bothe to begin educational support groups for HIV infected persons as an initiative to maintain or reduce the 16% HIV prevalence in the district. It will be seen that the Botha-Bothe support groups have

taken a different approach to that described in the literature. The three Botha-Bothe support groups worked hard to understand medical discourses that were regularly used during their health education and counselling session on monthly check-ups. This does not mean that the members ignored what each other went through during early stages of HIV diagnoses. But, they decided to learn and be resourceful support groups for their friends, neighbours and community, even including a desire to compensate for scarce literature in their vicinity. They decided to become conversant with general health issues and HIV specifically, regardless of their past experiences of psychological and emotional ill-treatment.

2.2.1 Benefits of support groups

Mosuoe (2016) and Harrison (2014) argue that women's support groups are of great benefit to the group members and those outside the groups. The groups create the right platform for women's empowerment to disclose their HIV status to their children, partners and in-laws without fear of rejection or divorce. This is because they have had guaranteed support from the group members who assist members to disclose their status for the benefit of good adherence to treatment and health management. The willingness of members to support each other emotionally in their studies ensured that every member was able to pick up the pieces and cope with the current life and behaviour changing chronic illness.

Walstrom et al (2013) cited a participant's statement on an electronic bulletin board about a group he had belonged to:

> I could share with these people my deepest secrets and still be loved. I would give up an arm or leg to have a new support group. I have tried to start one but it never panned out ... When I first became sick it was the group that gave me the strength to keep going. In the group we talked about life and we also got a guest to come in and teach us nutrition, legal aspects, alternative medicine and many other programs ... It saved my life so I know how important it can be for others. (Walstrom et al., 2013, p. 1509)

The above expression is an indication of trust and hope for real support which this member had already predicted she would get from support group members because they share the same sentiments. Atanga, Atashili, Nde and Akenji (2015) argue that membership in an HIV support

group needs to ensure that every member maintains the group's secrecy and oath of confidentiality as a means to allow members freedom to share deep feelings and express their own emotions to people who understand the situation well. Atanga et al. (2015) emphasise that the benefits of support groups for people living with HIV have long resulted in exceptional adherence to antiretroviral therapy in part at least due to the opportunity to empower members with relevant education about the disease. This has been particularly important for women.

2.2.2 Women and support groups

Most literature with regards to women and support groups has focused on African American women. Aguilar (2014) reported findings on how African American women (AAW) students were unable to negotiate safe sex and child spacing. Aguilar (2014) emphasises the role played by support groups in building assertiveness skills for African American women. However, Aguilar (2014) also indicates that the acquisition of these skills was not easy for AAW because they were expected to maintain their submissiveness and ignorance of HIV and AIDS. Therefore, such topics had to be concealed under more acceptable programme labels such as Income Generating Activities (IGAs) which were openly provided across their countries through support group meetings. Aguilar (2014) also points out that AAW joined support groups as a result of referral from social workers as an intervention strategy when the women reported their family challenges on related topics.

Mosuoe (2016) indicates that *Phelisanang Bophelong* (PB) in Lesotho was initiated to create the platform for women to cope with their newly diagnosed HIV positive status and to learn from other members' experiences to prove they were not alone and that other infected individuals did cope and lead positive healthy lives. Mosuoe (2016) and Aguilar (2014) share the same view that acquisition of life skills such as coping with an HIV status had never been easy due to women's low sexual assertiveness and men's perception of considering women as submissive and ignorant towards reproductive health.

This study intends to provide an opportunity to examine whether any support group members amongst the three groups covered in the study addressed similar challenges in terms of submissiveness. Davies and McCartney (2003) for instance, point out that knowledge among

women in most African cultures had to be limited to the kitchen and raising children. African men are believed to be the custodians of African culture; they regard women as inferior and believe that women should obey men and their decisions. Davies and McCartney (2003) state that men prefer to be consulted for both minor and major decision making to prove recognition of their status as heads of families. However Davies and McCartney argue that men did not consult women in any of the decisions made in various aspects of life even sometimes including deciding the number of children a woman should bear. A woman usually does not even know the wealth of her own family unless she is the only one left without a male figure in the family.

Such issues are also supported by McCartney (2013). Aguilar (2014) and Davies and McCartney (2003) expressed their concern about females' culture of silence which increases their risks for HIV infection. Aguilar (2014) therefore encourages the formation of women's support groups. Their argument is that it is important to provide females with enough information to create awareness on how to avoid HIV transmission. They argue that support groups are a substantial resource for people living with HIV and AIDS to access information and education relating to their lifetime condition, and support groups can offer free therapeutic sessions for each other.

The outcomes of research on the role and effect of support groups differ depending on how data for a particular study was collected. Some qualitative methods such as interviews, observation and focus group discussion bring the researcher and the respondent closer because these methods build a rapport to enhance respondents' openness (Blaikie, 2010).

However, a questionnaire and online interviews can yield useful results without necessarily knowing the respondents. Therefore, one has to check how data was collected from the previous studies before making judgements about their usefulness in helping to understand how support groups function because data collection methods can influence the credibility of results and therefore influence recommendations made about the results. The following section discusses these issues in more detail.

2.2.3 Data collection methods and theories in support group studies

Methods of collecting data from the western support groups can be more technical than those used in Africa and more specifically in Lesotho. For instance, collecting data through teleconferencing whereby support group members shared their experiences on how they coped with being HIV infected after diagnosis is cited as a good example by Furlong (2006). However, the barriers to using technology was a demotivating factor and a major consequence for poor participation. Another example is that of 'being there for them' whereby support group', members offer each other support through the online mode. Furlong also collected data on-line from various support groups in western countries. In some incidences, the researcher would pay for an on-line slot to ask the support group members questions and receive responses. In another incident the researcher held a satellite session for a certain support group and expected members' responses to be written on the website (Furlong, 2006). Therefore, online, satellite, teleconferencing and phone-in programmes indicate the use of advanced technological devices to collect data. All African studies cited in this thesis collected data through the use of totally different modes. Questionnaires with structured interviews conducted on face to face mode were employed, in some instances complimented with focus group discussions. Mosuoe's (2016) study in Lesotho, for instance, used questionnaires, interviews (one-on-one and group interview) and focus group discussions. This signifies the importance of conducting this current study because it uses the observation method which has not been used in researching support groups in the previous studies.

There are two theories that have been used to interpret the context of support groups intending to familiarise themselves with medical discourses and meaning making in a comprehensive manner that allows the group to share their knowledge with friends and neighbours. The first is Transformative Learning (Mezirow, 2000). The emancipatory learning theory of Freire (1972) has also been used in the analysis of other support groups. These two theories are grounded in a belief that education should be for the conscientisation and freedom of the oppressed and the voiceless to be empowered. Mezirow's transformative learning theory was employed by Namwamba-–Ntombela (2010) blended with Freire's emancipatory theory. Namwamba-Ntombela (2010) used transformative learning theory, emancipatory theory and socialisation theory as a means of analysing how support groups learn to change their behaviour and attitudes

towards HIV prevention, in her study of South Africa's 'Spring of Hope support group (SOH). SOH support group core activities included educating members at different levels and in different contexts, awareness raising campaigns, encouraging community openness about HIV status to attract support from fellow members, skills development, clinics and hospital support and conducting HIV and AIDS workshops. Their purpose for meeting was to learn from each other in a similar fashion to the way that the Lesotho support groups were established. The transformative learning theory is also employed in this thesis. However, the theories of communities of practice and social capital were also used as an innovatory combination of theories and these are discussed in Chapter Three.

One other crucial aspect picked from the literature review on support groups is their places of origin (where studies were conducted). Most studies are executed in western countries, with data collected from western support groups as outlined earlier in this section. However, A key recent study in Lesotho by Mosuoe (2016) focused on one women's support group formed by people living with HIV. Her study focused on how the women picked up the pieces of facing reality and re-integrating into their community. This study focuses on support groups formed for three different purposes of which the most significant one is that of supporting HIV infected daughters-in-law and with a commitment to learn about HIV, its prevention and care. Nevertheless, there are issues relating to the experiences of becoming HIV positive that can be drawn from Mosuoe's study to inform this research into how people who are infected and affected learn to cope and manage in their families and communities.

This remaining literature review therefore is arranged under the following key themes: the infected, the affected, individual sense of self, the challenges of being infected, adherence, confidentiality, side effects, disclosure, and challenges of negotiating discourses about HIV its prevention and care.

2.3 The infected

To infect is described by Ministry of Health and Social Welfare (MOHSW, 2007) as to contaminate with something, for instance a pathogenic or micro-organism or to affect a wound with disease producing germs. In this case the concept refers to human beings being infected

with HIV as an incurable virus. According to MOHSW (2007) people who are infected by HIV share common issues that are both physical and psychological. Some of these issues can lead to physical problems that sometimes are experienced for a lifetime. WHO (2003) argues the following points which are summarized here:

•It is important to recognise that persons infected with HIV can occasionally experience sore throat or oral thrush and have difficulties in eating which may cause malnutrition and loss of weight.

•Despite regular management infected people receive from their Health Centres, they experience frequent ill-health due to declining CD4 cell count caused by various biological processes.

•They begin to miss their routine activities such as work and household chores.

In the context of HIV, infected people seem to go through a trend of similar emotions. Hodge (2010) for instance, confirms that these include depression, anger, insomnia, poor concentration, anxiety about the future, isolation and discrimination.

Poverty is also a common effect of HIV since in most cases the infected person may have eroded all the finances and sometimes other household properties were sold or exchanged for favours that benefited the infected person. In Lesotho, household furniture items as well as land can be exchanged or sold to pay for transport for the infected to travel to the health centres. Sometimes these items or property are sold to cover funeral expenses. Kimaryo et al. (2004) in the context of Lesotho therefore attribute the lack of care for an infected person's health on the lack of income to pay for health services. Animals reared by the infected person are taken away by relatives for care when adults get attacked by AIDS and sometimes die. Children in such families would be left with nothing due to dishonesty from relatives and they struggle to look after each other. Such outcomes are also supported by Kalichman, Eaton and Cherry (2010) who argue that support groups are an important resource in such cases.

Among the authors sharing 'the invisible' burden HIV infected people have, Maile (2011) argues that people who are infected by HIV have lots of challenges and fears. However, caregivers have ways to help them deal with these problems. Usually the infected people themselves need each

other's opinions on how to deal with such experiences, and this becomes the right time for them to form support groups. Alongside the challenges infected people encounter on a short- or long-term basis, neighbours and friends also get affected directly or indirectly by watching their loved ones suffer and deteriorating to death irrespective of whether they have disclosed their status or not.

2.4 The affected

'Affect' as a concept means 'make a difference to', and usually refers to emotions or symptoms (Oxford English Dictionary n.d., webpage). WHO (2003) applies similar interpretations for the word affect. These interpretations focus on negative connotations such as to be harmed, but affected can also mean a) being impressed, b) being moved and / or c) touched.

People with HIV and AIDS in resource-constrained countries are likely to die earlier and suffer additional problems such as poverty, or infect other family members (ANECCA, 2004).

Jackson (2002) argues that affected people are those that are left with the pain and trauma of knowing that your loved one is infected and sometimes encountering the loss of a friend or family due to some kind of illness. MOHSW (2007) shows that people affected by HIV and AIDS may also experience socioeconomic challenges such as homelessness which is common for children who are affected by HIV and AIDS and have lost their parents. Coates, Richter and Caceres (2008) indicate that people affected by their loved one's chronic illness need to learn about such illness to ease the offering of care and support without fear.

Although many studies have revealed concerns on the infected and affected individuals, my study also considers how the individual sense of self both benefits others and benefits from others in support groups.

2.5 Individual sense of self

Definition of the word 'self' is somewhat problematic. Winnicott (1960) sees self to be the cognitive and affective representation of one's identity or the subject of experience and emotional development. Kohut (2012) argues that the notion of the self can be difficult to grasp

because it depends on experience and location. Kohut further says the current view of the self in psychology positions the self as playing an integral part in human motivation.

Most illnesses have challenges; the biggest challenge with HIV infected people arises from the fact that it is acquired through intimate contact. This leaves most infected people with a list of unanswered questions and mixed feelings about the self, beginning with guilt, blame and fear of the unknown (Kimaryo et al., 2004).

2.6 Challenges of being infected

Harrison (2014) argues that infected individuals in most African countries delay internalising their HIV positive status or taking action to properly care for themselves,which leads to delays to employ coping strategies and learning about their disease. Instead, infected individuals spend a lot of time holding on to the perceptions that HIV and AIDS occur as the result of either sorcery or a conspiracy. These perspectives have some obvious implications for raising awareness about HIV and AIDS and its treatment. But for people who are infected these non-medical beliefs divert attention from realising how the disease is transmitted.

In many countries, developed and developing, the challenges in relation to HIV infection still persist and need closer attention to how one reacts to the virus in order to curb the spread of the disease. They include having to interpret and comprehend one's HIV positive results, accepting living with the virus, stigma and discrimination, attempting to be productive often among young, active, child-bearing age groups who occupy industries or family businesses. The burden of coping with various emotions can start with anger and trauma and reach the stage where productive resources get diverted for access to medical needs (such as agricultural work being neglected) and with devastating effects on children (WHO, 2003). Therefore, WHO urges researchers to explore the functioning of support groups in relation to each of the challenges with a view to encouraging support groups to employ innovative solutions which can protect lives and enable strategies for treating millions of people in future.

One big challenge for individuals infected by a complicated virus such as HIV is that they have to learn to understand their illness and strive for better self-management to prolong life. The

challenges of being infected are very hard for African women who still observe the importance of patriarchal lineage. This issue delays acceptance and practices of prevention strategies by women because they need to seek permission from males for services they need as women. Buckley (2013) argues that, culturally, men enjoy occupying the high-ranking position of the family which had to be occupied by their sons during temporary or permanent absence of the father. Buckley points out that the male cultural practice signifies the protection of patriarchal lineage. The Government of Lesotho (GOL) (2016) indicates that it is appropriate for a small nation like Basotho to compromise their culture to protect life such as adhering to the PMTCT programme. This programme demands several behaviour changes which at some point involves compromising culture to save life.

Hodge and Nadir (2008) postulate that most African cultures believe that women are the cause of HIV and AIDS and that men can only be infected by women. Davies and McCartney (2003) indicates that women are not free to speak of their HIV positive status to their partners for fear of violence, divorce and blame imposed by other family members who do not even know their own HIV status and therefore keep their distance from necessary information about the disease. There is a significant association between the challenges of being infected and adherence, hence this study also looks at other factors contributing to re-infection and mother to child transmission of HIV, adherence being one of them. Harrison, Colvin, Kuo, Swartz et al. (2015) elucidate that women have long been stigmatised for many reasons which are mostly beyond their control, such as staying unmarried without a choice, or being labelled barren without checking the male partner's fertility, and a sustained high HIV incidence in young women in Southern Africa.

Daniels and Sabin (2002) see adherence as yet another challenge due to limited medical resources and requires counselling. Counselling concerns itself with helping clients accept themselves in order to focus on the positive elements of their being, in order to cope with and stick to the demands of their new lives.

The task of ensuring sustainability in taking medication is somewhat challenging. However, GOL (2008) argues that treatment success is highly dependent on the patient's ability to adhere to their medication schedule. Adherence is viewed by GOL (2008) as a journey which starts with

behaviour change communication strategies and proceeds to exploring ambivalences about condom use and practicing condom negotiations. He indicates that the two practices need to be considered as core skills required for remarkable adherence progress.

It is significant that the Botha-Bothe support groups in this study decided to discuss adherence at every clinical visit. According to these support groups (personal communication with health care worker 23rd November 2013), barriers to adherence can include lack of access to refills, insufficient food and water with which to take the medications, inability to get to the clinic for scheduled appointments because of bad weather conditions (river floods and sometimes heavy snow falls), problems with transportation and lack of a personal support system.

According to Namwamba-Ntombela (2010) one way the support group can help members maintain good adherence to their medication, is by giving each other tips on how to effectively and consistently take medication. There are a number of tips given. Some of them include a) brushing one's teeth every morning and using this activity as a cue to take the morning dose of medication, b) using radios – linking a particular radio programme as a reminder to take medication, or c) developing pill count calendars for themselves which indicates when a pill is taken.

Masentlhe, Jacques and Mmatli (2013), however, argue that for some patients the task of taking medication every day for the rest of their lives without missing a dose is still daunting. Masentlhe et al. therefore discourage patients' adherence to self-assessment without monthly supervision because patients mask poor or non-adherence practice when they experience treatment fatigue or manifest as poor negotiators who may not have disclosed even to very close relatives. This means they usually do not get a chance to take their medications secretly and miss some doses due to fear of being seen. Maile (2011) indicates that good adherence improves health, and as a result, self-esteem increases and coping mechanisms are enhanced. This suggests there is a need for interventions geared towards members' involvement in sharing experiences throughout the support group sessions. The Department of Health states that acceleration in adjusting to treatment also depends on confidentiality between doctor and patient and between

patients. However, it will be seen that in relation to HIV treatments confidentiality becomes problematic.

2.7 Issues of confidentiality

WHO (2005) stipulates that confidentiality should be kept between patient and physician starting from counselling and testing for HIV. An exception is made when there is a need for shared confidentiality between the patient, counsellor and other health professionals and sometimes involving both partners in order to enforce thorough patient management.

The improvements in coping with treatment and treatment fatigue rely on confidentiality because adapting to the use of life time treatment might take a longer period for some, hence the need to take time before disclosing to avoid personal regrets. WHO (2005) argues that it is essential for patients and health practitioners to observe confidentiality. Health practitioners must consider patient retention in health services. However, confidentiality in medical discourses is not considered essential to Basotho. Disclosing someone's status is just a normal conversation even if one is HIV infected (Monyake, 2010).

Moreover, although both HIV support groups and the health professionals may in practice, for day to day activities, take confidentiality seriously, the side effects are often too obvious so that even if individuals are silent, their bodies reveal what is not spoken. Therefore, it is worth noting what other authors say about side effects.

2.8 Side effects

Labhardt et al. (2014) point out that most medicines can cause side effects but failure to adhere to drugs can cause drug resistance. Labhardt et al. (2014) indicate that side effects as a medical discourse may sound simple and straight forward but in reality, the term has several categories which are deemed complex for the support groups to comprehend without the assistance of experts in the medical field. Therefore, learning about side effects from each other's experience on such a complex discourse may create more confusion and needs the presence of an expert to unpack and simplify the term to accommodate the learners' level of understanding.

Mosuoe (2016) argues that some side effects add to the stigma attached to HIV (since the side effects are very visible). Physical changes on the body such as lipoatrophy can be socially disturbing and attract peoples' attention. For instance, herpes zoster on the face is very visible and can lower one's self-esteem and self-confidence. Hence the need for each client to be equipped with coping strategies and learn about the infection. GOL (2006) indicates that some side effects of treatment of diseases are difficult to avoid, such as the experience of losing hair, vomiting and diarrhoea when undergoing chemotherapy treatment for cancer. GOL therefore encourages detailed on-going education for people faced with such experiences. GOL believes that the fear of side effects surpasses the fear of the illness itself. GOL therefore argues that there is a strong need for information education and communication because once a person is sufficiently educated, anxiety lowers to zero as most anxiety is caused by fear of the unknown.

Namwamba-Ntombela (2010) confirms that support groups, in turn, build each member's confidence regardless of the physical changes one encounters. Increased confidence can motivate individuals to disclose. Infected individuals can therefore gain support through disclosure. Hence the need to review what other authors say on disclosure.

2.9 The challenge of disclosure

According to WHO (2004) disclosure is a situation where information about one's HIV status is shared with one or more people (spouse, children, parents, friends, caregiver, employer etc). This entails making decisions about whom, how, and when to tell. Disclosure is an act or process of revealing or uncovering what has previously been confidential. Harrison, Colvin, Kuo, Swartz and Lurie (2015) stipulate that disclosure is a crucial element of adherence to any treatment. Therefore it has to be carefully done strictly observing the personality of the individual disclosing. Harrison et al. (2015) emphasise that disclosure for any illness has to be done as one of the coping strategies employed not only in support groups but also in a hospice, where elderly people are kept each with their own traumatic chronic illness and therefore disclosure acts as a coping mechanism requiring a lot of appropriate care. Tompkins (2007) indicates that adherence to ART in Kenya, Uganda and Zambia had been high because it was implemented alongside forced disclosure to the next of kin.

WHO (2004) points out that many HIV infected people who have lost hope for survival live longer when they have disclosed their HIV positive status. Disclosure motivates people to adhere and improve their independency towards self-management and self-care. It increases the sources of support for a client. Namwamba-Ntombela (2010) comments that higher levels of disclosure in the population are important from an individual point of view as disclosure has positive implications for prevention, testing and treatment. Namwamba-Ntombela indicates that lack of disclosure is a major barrier to adherence of antiretroviral therapy and therefore support groups are entrusted to empower members to unleash their bravery and disclose for improved adherence over time. GOL (2008) emphasises that disclosure serves as a silent plea for family and friends support and involvement in risk reduction programmes and encouragement for positive living. GOL (2008) emphasises that disclosing is a necessary process that will help save favourable relationships and instill behaviour change strategies.

Coates, Richter and Caceres (2008) indicate that support group meetings allow discussion on impact mitigating programmes and home-based care. These include rehabilitative programmes, strategies to reduce HIV transmission, preparing members for individual decision–making and great dedication in providing unpaid nursing and welfare assistance to its members. Coates et al. (2008) further indicate that rehabilitation programmes target individuals who had disclosed to Village Health Workers or support group members entrusted to observe confidentiality. Mosuoe (2016) indicates that the significance of disclosure is seen where improved adherence to ART depends on the sexual partner testing for HIV because one had disclosed his or her HIV status. Therefore, Mosuoe sees disclosure as a motivating factor for family and friends to take up an HIV test without fear of being discriminated against.

Namwamba-Ntombela (2010) argues that fear of disclosure results in some individuals being reluctant to join support groups due to fear of the consequences of their disclosure. In many cases individuals fear people finding out about their status even though they are potentially important avenues of support (such as family, friends and the community). Therefore, it is obvious, according to Namwamba-Ntombela, that reasons contributing to delay of disclosure must be recognised and it takes time to convince an individual that there will be no far-reaching detrimental effects. The overall impact of encouraging disclosure as an intervention strategy

would seem to be relatively long term, but ultimately beneficial. Mosuoe (2016) sees the benefits of disclosure as: a) Enabling a client to begin dealing with transmission reduction and obtaining support; b) Access to care, support and treatment; c) Ability of the client to protect his /her partner; and d) Avoidance of rumours and suspicion. It may be necessary to help the client to take time to make a decision.

Coates et al. (2008) encourage support groups to share skills and techniques relating to disclosure because disclosure is what most clients want to do if they are given skills and techniques. Such techniques include being assisted to choose which people to disclose to, and helping them practice what they will say in supportive rehearsal situations. Clients need to think about the response and plan the answers. It is wise for a client to choose a suitable place for disclosure and be reminded to speak calmly and clearly but at the same time be prepared for a shock or hostile reaction. Support groups need to allay clients' fears by role playing disclosure in a group setting to allow for more comments and assistance. The Centre for Disease Control and Prevention (CDC, 2018) advocates for the need to consider barriers to disclosure and discusses the following: fear of stigma; discrimination and rejection from people being disclosed to; fear of possible conflicts; ignorance about HIV infection and disclosure; fear of shame and public opinion; fear of blame and the possible breakdown of relationships. CDC emphasises that non-disclosure is ultimately more harmful than disclosure: 'non-disclosure has shown ruthless consequences to families and the entire communities' (CDC, 2018, p. 41). These consequences range from lack of support, risk taking behaviour, re-infection, defaulting treatment and missing appointments, and lack of care to suspicion from friends and families.

Mosuoe (2016), Coates (2008) and CDC (2018) all share the same opinion that disclosure bears positive results on the patient's health because it paves the way for appropriate support from close friends and relatives. Lack of disclosure allows room for suspicious members of the community to gossip instead of being supportive. Disclosure is a medical discourse which the three support group members in this study wanted to gain a better insight into through group discussions. This study sought to find if these authors' opinions were also the case in Lesotho. In other words, if disclosure is timely, do patients gain positive relationships from people they have disclosed to?

2.10 Building safe relationships

Schlechty (1994) indicates that warm relationships can increase learning and engagement. Support groups maximise members' participation and create an acceptable platform for members to share reproductive health information and HIV related issues, thus building safe relationships. In particular, they are a space to discuss bereavement issues (Namwamba-Ntombela, 2010). John (2016) sees relationship in the form of intimacy between two or more people which embraces warmth and trust which enhances openness to share without fear of being judged. John indicates that family relationships are building blocks for good family and community health because they allow for open links to be established between the home and communities as domains of the support group member. Therefore, it can be argued that support groups can help to build maintain warm relationships and assist members with problems experienced in families and communities. Mosuoe (2016) specifies that support groups for PLHIV should only contain PLHIV. However, in terms of relationship building it can be argued that there are many ways that people who are HIV negative can support PLHIV. For example, in the Botha-Bothe hospital guide for support groups (GOL, 2009a), it is argued that individual community members who are HIV negative may serve as 'treatment buddies' for PLHIV who belong to support groups.

Bad relationships of friends and family members result in unwanted hatred and tensions. Labhardt et al. (2014) highlight that frequent defaulting (lack of adherence or bad adherence practices) results in treatment failure due to drug resistance (when a person encounters opportunistic infections and increased viral load yet one is on ARVs). This calls for assessment for second line eligibility. This second line is said to be complex (taken four times a day and some of these medications need to be kept at certain temperature levels in a refrigerator). It is therefore not surprising that the government initiated the establishment of support groups. There is nevertheless a real danger of medical discourses not being understood due to competing myths, local and social beliefs in communities, as the next section shows.

2.11 The myths, and local and social beliefs on HIV

Every society encounters challenges by myths and social beliefs which sometimes hinder developmental activities. According to Modo et al. (2011), a myth is a traditional tale with

secondary or partial reference to something of collective importance. Myths usually originate in oral culturesand they are passed down by word of mouth. Since they are traditional, myths are created by a collective cultural process and not by one author. Myth may refer, however, to religious concepts or practices like rituals or natural events like the seasonal floods, or to psychological archetypes.

Atanga, Atshili, Akenji and Nde (2015) indicate that each chronic illness is to be assumed a health hazard where relevant health education must be considered, prepared and disseminated as the best prevention and self-management strategy. Davies and McCartney (2003) indicate that the significance of education is to get rid of lies, myths and exaggerations that pertain to an illness. Atanga et al. (2015) and Balogun et al. (2016) hold the same view that human beings normally project their inactiveness and misunderstanding about new concepts through use of metaphors and myths which usually lead their community through a complex route to understand what real prevention is about. This behaviour allows infections such as HIV to spread. Subbiah et al. (2010) indicate that through dialogue it is possible to unpack myths, expose their dangers and pave the way for alternative understandings. Modo et al. (2011) indicate, for instance, that body cleaning after sex had been commonly practiced by Americans to protect themselves from STIs and HIV. This practice was done with the intention to reduce the spread of infections. This indicates that the Americans were mythically preventing STIs by the practice of such a strategy.

In communications, myths and misconceptions have a greater chance to distort information and portray a totally different connotation to what was intended by sender and the receiver. Wilce (2011) argues that, knowing the myths prepares the ground for clarifications about HIV. Clearly, ordinary people, even people who have had the privilege of education, are struggling to come to terms with what HIV and AIDS means for them. GOL (2008) indicates that communities, by contrast, especially those that have been subjected to social discrimination, need to be educationally advantaged especially on HIV and AIDS education to avoid the spread of the pandemic. However, such communities have been relying on myths and misconception and ignoring the reality of the spread of HIV and AIDS. For instance, one general myth is that HIV is only for the gay community and promiscuously behaving individuals (GOL, 2008). People infected with HIV were considered to be promiscuous and rightfully receiving God's punishment

through the illnesses (opportunistic infections). The issue has led to considerable distraction and distrust of information pertaining to HIV and AIDS (GOL, 2006). Other literature indicates that myths are normally believed and used by groups who are short of factual knowledge and therefore vulnerable to acquiring infections. In the process they miss prevention strategies. Harrison et al. (2015) and Pitikoe (2016) share this view in relation to herd boys who are culturally trusted to look after animals in remote pasture land. The owners of flocks of animals have a tendency to locate such individuals in areas that are less developed and where it is difficult for the herders to improve their livelihoods. Such areas deprive herd boys of the necessary information about HIV and they subsequently rely on impractical information from peers. Saller (2009) indicates that common myths that are usually trusted by naïve individuals include the body cleaning practice as prevention for STIs and HIV after sex.

Harrison et al. (2015) and Pitikoe (2016) point out that herd boys believe and practice myths that expose them to HIV infection because herd boys are a population difficult to access through education and HIV information. Pitikoe (2016) indicates that males usually opt for being herd boys due to high poverty rates resulting from low educational level. As herd boys reside in areas trusted to provide suitable sustenance for theirlivestock, they become proud to be herders in areas difficult for a man to survive because their duration in such areas is not less than six months. This is considered to be long enough to turn weak boys into tough men yet they become prone to HIV infection due to their ignorance.

According to Modo et al. (2010), in Lesotho, the local belief was that HIV was for foreigners. They were thought to be the only ones who could infect other people with HIV. For instance, people who knew their HIV status and became open about it, were thought to have had extramarital affairs with the foreigners, mostly African foreigners (*Makoerekoere*), while Basotho men and women, were thought to be free from HIV infection and could not infect each other. Every other person thought of HIV as a monster which could attack a certain group of people but not ones self. An infected person would be labelled to have undergone an illegal abortion, while a man must have had sex with a lady who had chosen to have an abortion and therefore is now receiving a punishment from God for killing the child. Moreover, HIV is seen to be a disease for people who never cleansed after an abortion was performed or after the death of

a legal or illegal sexual partner (Modo et al. 2010). In the early 1990s, people who were very sick due to AIDS-related illnesses were thought to have been bewitched by their jealous relatives, neighbours and friends for their outstanding successes. Most young people, especially at the child-bearing age, believed that ARVs destroy reproductive health and reduce libidinal desire. Health care workers had to convince patients through the support groups that ARVs performed the opposite, for instance they improve adult fertility, increase libidinal desire and improve their psychological fitness and coping mechanism (Mosuoe 2016). The challenges of negotiating discourses about HIV, its prevention and care have been a great speculation for health service providers (Maile, 2011).

2.12 The challenges of negotiating discourses about HIV, its prevention and care

According to Saller (2009) believing in myths is a general challenge for African countries because most prevention strategies in African countries have failed due to strong beliefs and practices that rely on myths and misconceptions. Myths surrounding the mode of HIV transmission hinders the dissemination of correct preventive measures. John (2006) and Kemboi et al. (2011) indicate that in prevention strategies where cultural beliefs and norms have not been taken into account, prevalence rates of HIV and AIDS continue to rise. This points to the importance of seeing educator development and practices as socially situated and context bound. This encourages one to look into the challenges of negotiating discourses about HIV and its prevention and care.

As earlier indicated, most African countries consider HIV to be connected to myths. Prevention interventions were delayed because, in most African countries, AIDS had different connotations from its real meaning. Wilce (2011) argues that understanding the myths is critical for making decisions about HIV prevention education. Clearly, ordinary people even people who have had the privilege of education are struggling to come to terms with what HIV and AIDS means for them. However, such communities have been relying on myths and misconceptions and ignoring the reality of the spread of HIV and AIDS (Saller, 2009). The challenges of negotiating medical, cultural, and other discourses can become the responsibility of support groups.

2.13 Concluding chapter summary

This chapter has reviewed relevant literature in relation to support groups, benefits, data collection methods in support group studies, challenges of being HIV infected, myths and local and social beliefs on HIV, and the challenges of negotiating discourses about HIV its prevention and care.

Attention was paid to the purposes for various support groups to form and learn, and how members network within and outside their boundaries to enhance their learning. The chapter has also underlined the fact that literature on support groups in Lesotho is limited and therefore relies heavily on Mosuoe (2016) for local comparison. The wider literature on support groups, however, has indicated that they are increasingly being seen as a valuable resource for those affected by the disease. The literature suggests they can be an important resource for collective learning and sharing of experiences to facilitate a better understanding of living with HIV.

The chapter looked at methods used for collecting data from the groups indicated above. Methods of collecting data from the western support groups can be more technical than those used in Africa and more specifically in Lesotho. For instance, collecting data through teleconferencing whereby support group members shared their experiences on how they coped with being HIV infected after diagnosis is a good example (Furlong, 2006). The chapter revealed issues surrounding the infected, affected, individual sense of self, challenges of being infected, confidentiality, side effects, disclosure and relationships as articulated by different authors. This review has also identified the importance for all health professionals to be aware of the social and psychological impact of the disease so that they are able to provide appropriate help to clients. This literature highlighted the significance of treatment adherence and disclosure in order to avoid re-infection and as a means to strengthen prevention of mother to child transmission of HIV.

Myths in this literature are seen to originate in mostly oral cultures. Since they are traditional, myths are created by a collective cultural process and not by one author. My interest was to understand if the cultural value system, the myths and community beliefs can contribute in the

spread of the disease in Lesotho. Since it is important to analyse the study through a relevant theoretical framework the next chapter discusses the three theories used for this purpose.

Chapter Three: Theoretical Underpinnings

3.1 Introduction

The previous chapter focused on literature that has covered issues and other studies on the role of support groups for people affected and infected by HIV/AIDS. It highlighted a number of theories which help to explain how the health care workers and the support groups discuss and clarify the misconceptions caused by the myths, local and social beliefs, and medical messages about HIV, its prevention and care. They also help to explain the ways in which people learn about the disease, transform and adjust to the new expectations.

The theories identified for this study are communities of practice, social capital and transformative learning. In addition, the nature of discourse became relevant as a means of explaining people's use of language to help them understand the different kinds of discourses that pertain to HIV, its prevention and care. The analytical lens therefore also applied a discourse analysis approach because it focused on language and behavior by the participants. Discourse analysis was used for all research questions as a basic approach. Research question 1 focused primarily on communities of practice. Research question 2 focused on social capital, communities of practice and transformative learning. Research question 3 focused on transformative learning.

This chapter will now discuss these theories. The discussions around these theories show the linkages between transformative learning at an individual level and learning as part of the community of practice which is the thrust of the study. Communities of practice are discussed first, followed by social capital which relates to aspects of the communities of practice theory.

The transformative learning theory focuses on the concept of meaning making as a feature of transformative learning which took place during the communities of practice exchanges.

3.2 Communities of practice

Etienne Wenger is the initiator and first presenter of this theory. Through his communities of practice (CoP) theory, Wenger (1998) provides an explanation that individuals belong to a number of communities where they spend most of their time - at work, at school, at home, in

their hobbies. (For example, there are some people who perform a certain activity for a long period until they become associated with some activities so much that, when we see them, we begin to realise that they form a community). Wenger emphasised that communities of practice are described as the basic building blocks of a social learning system*,* as they are the 'social containers of the competences that make up such a system' (Wenger, 2000, p. 229). The competence of CoP is often an aggregate of three elements. First Wenger argued that members are bound together by their collectively developed understanding of what their particular community is about and, by joining as a group, they hold each other accountable to this understanding. Second, members build their community by interacting with each other over issues of mutual concern. Third, communities of practice share a repertoire of communal resources such as language, sensibilities, tools, stories and styles. Therefore, to be competent in CoP means that individuals understand why they are together and feel able to contribute to the shared purpose of their group. The major essence of CoP is to interact with the members of a particular community and be trusted as a partner in these interactions. Wenger-Trayner and Wenger-Trayner (2015) elaborate to define CoP as a learning partnership among people who find it useful to learn from and with each other about a particular concern (for instance, health issues in this thesis); they use each other's experience of practice as a learning resource. They join forces in making sense of and addressing challenges they face individually or collectively. This study will reveal whether the support groups also met for the same purpose as Wenger et al. (2015) describe. Wenger (2006) claims that engagement in social practice is the fundamental process by which we learn and so become who we are.

Membership of communities of practice can include core members and also people on the periphery. People often start on the periphery (as apprentices) and ultimately become part of the core. This migration to the core is known as process of legitimate peripheral participation, whereby new participants can be seen as apprentices until they fully understand the workings of that particular learning community. These notions of CoP can be seen in community settings where the practice is enacted. Wenger (2006) further explains that, if social change and sustainability are ultimate goals for communities of practice, we need mechanisms which explore how participation, knowledge, identity and power are enacted in community settings. Therefore, CoP may be one step towards creating engaged and inclusive communities. Wenger's (2006)

argument can be applied to this study to find out what new meaning the support groups develop over time as communities of practice and in relation to their social capital networks (for example as a result of external educational input, group discussions and independent information seeking exercises).

Wenger McDermot and Snyder (2002) explain that CoPs embrace three crucial concepts to consider in the use of social learning systems as distinct modes of belonging through which individuals participate. These concepts are known as engagement, imagination and alignment. These concepts are explained as follows.

3.2.1 Engagement

This refers to members' participation in doing things together, talking and helping a colleague with a problem or contributing meaningfully to the agenda of the meeting. The manner in which people engage with each other and the world, profoundly shapes their experiences of who they are. As a result of this engagement, human beings should be able to set achievable goals which improve their imagination of how to succeed in life.

3.2.2 Imagination

This refers to ways in which members explore possibilities for growth and development. The act of imagination requires construction of images that make sense to all members. Imagination acts as a motivation to reach the end product and pursue one's goals regardless of the challenges. For instance, a member in a support group may reveal his imagination at the planning stage when he foresees the group being successful commercial farmers and employing jobless neighbours. In this case, motivation is needed to keep participants aligned because less motivated individuals can derail easily from their goals.

3.2.3 Alignment

This process of being in a CoP means making sure that local activities are sufficiently aligned with other processes so that they can be effective beyond the CoP members' own engagement. The concept of alignment refers to a mutual process of coordinating perspectives, interpretations and actions so the participants collectively realise higher goals.

3.2.4 Networks

CoPs also contain different elements (Wenger-Trayner et al., 2015). These elements can be identified as different network connections – social networks, specific networks, community and learning communities, which all contribute to the building of new identities and levels of confidence. They are discussed here briefly.

3.2.4.1 Social networks

Social networks are sets of connections among people. They use their connection and relationships as a resource in order to quickly solve problems, share knowledge and make future connections. Yousefi-Nooraie et al. (2012), Boh (2014) and Kothari et al. (2015) have all shown that the use of external social networks for information seeking purposes in CoPs is a beneficial strategy for individuals as they move from a stage of confusion to a stage where one is competent and able to use jargon easily as a result of collaborative efforts to collect information from organisations and individuals.

3.2.4.2 Specific networks

Specific networks refer to relationships, personal interaction and connections among participants who have personal reasons to connect. They facilitate information flow, make helpful linkages, and contribute to joint problem solving and knowledge creation. The value of specific networks as learning resources depends on an individual's judgement to act as a responsible communication point and evaluate the relevance of the network's potential information flows for the CoP. Communities of practice are mostly self-sufficient, but they can benefit from some resources, such as outside experts (counsellors, nurses and pharmacists) meeting facilities, and communications technology. It will be seen that the concept of social capital is particularly relevant to Wenger's notion of networks.

3.2.4.3 Community

Community can refer to the development of a shared identity around a topic or set of challenges (Battacharyya 2004). It represents collective intentions which focus on a domain of knowledge in order to sustain learning about it. Through personal and community networks, multiple networks are connected and confidence is built through learning (Wenger, 1998).

A learning community is a community which has created a social space in which participants can work together to further their learning partnership related to their common purpose. This partnership can be formal or informal and its intention can be explicit or tacit. The key characteristic is the shared practice of both individual and collective learning. Over time, the shared experience of learning together also becomes its own resource among the participants because they have built up a shared repertoire of cases, techniques, roles, stories, concepts, and perspectives. The challenge of community is that it requires sustained identification and engagement. Preece (2014) argues that learning as a group helps to simplify complex issues and enables sharing of resources such as expertise. Therefore, she sees the importance of Wengers' (2006) CoP through utilisation of the collective responsibility for their learning. The three support groups in this study were analysed for the extent to which they negotiated and renegotiated their reason to learn together, helped each other, followed up on ideas, developed shared resources, and sustained a social space for learning. It is important therefore to explore how Wenger defines the process of learning through networks and the impact that has on confidence and identity.

3.2.4.4 Learning and networks

The connections in a network can function as learning ties providing access to information flows and exchanges (Wenger, 1998). The learning value of a network derives from access to a rich web of information sources offering multiple perspectives and dialogues, responses to queries and help from others because of personal connections. Contacts made through networking enable people to gain access to relevant learning resources. Bates (2014) argues that the significance of acquired learning should be seen through knowledge management where acquired learning is shared to widen the scope at which learners benefit. Trahar (2006) cautions, however, that learning outcomes are never universal between individuals even if exposed to the same stimuli, due to the uniqueness of each learner. Personal connections and networking are nevertheless resources to enhance each learner's understanding. Dugan (2012) also confirms that access to learning resources acquired as foreign materials are likely to need assessment and domestication to ensure familiarisation of discourses and to ease acceptance by the local community of

learners. This process results in confidence for individuals who are engaged in the learning process.

Confidence in relation to learning

Broekmann and Scott (1999) explain that confidence in relation to learning is the knowledge or belief that one can learn to do whatever is expected of one. This linking of confidence to being a learner concurs with the aim of this study. Lave and Wenger (2002) highlight the significant role of confidence in the learning environment as it enables the learner to seek clarifications and to share accumulated knowledge, hence the power of networking for learning and identity purposes. Murphy (2003) argues that confidence is usually gained through the teach-back strategy where information intended to be shared gets repeated over and over amongst the participants until each has understood the information.

Identity development

Gee (2000) suggests that identity development includes new ways of being 'identified' by others. Identity is crucial in learning groups for many reasons. First, our identities evolve through our enhanced competence and experiences so that we develop new ways of knowing. Identities enable us to associate with others and build trust with those who matter to us. Identities are not necessarily strong or healthy. A strong identity requires that people can establish deep connections with others by sharing histories and experiences, which can result in reciprocity and trust. The work of identity building is an evolving process which re-shapes who we are and how we learn.

Communities of practice are group/s of people who share a similar or common problem, who engage in a process of collective learning in a shared domain of human endeavour. Communities of practice theory is linked with social capital theory because both theories are concerned with how individuals and societies who share similar or common characteristics or attributes get involved in the learning activity systems occurring in their surroundings. They provide a means of understanding how networks and relationships help to introduce new knowledge and skills that address their problem, resulting in changes of perceptions and behaviour which can be identified as transformative learning. Therefore, transformative learning theory, social capital

theory and communities of practice theory can be used together as an analytical lens to explore how support groups show their capability in exploring and responding to certain information, education and communication strategies in relation to the contradictions they encounter in their families, communities and from the support group members themselves.

3.3 Social capital

According to Bourdieu (1985), widely accredited as having originated the theory, social capital is understood as the social norms of behavior in a society or group that bind them together and the networks of social connections that enable people to act collectively and enjoy the benefits of each other's association. It is regarded as one of many capitals, the others being financial (economic) and cultural (which means people have internalised social behaviours through birth and socialisation that enable them to interact with more elite members of society). Two people have developed the term since then (although many others have also discussed the concept). The first is Coleman. Coleman (2000) defined social capital in terms of relationships that build a sense of reciprocity and trust. The second is Putnam. Putnam (2000) focused on the role of networks that result from social relationships of trust and distinguished between different layers of networking which he named bonding, bridging and linking social capital. Gauntlett (2011) defines social capital in terms of the number and variety of the benefits to be gained by the group because each member of the group brings with them access to different resources. The combined ownership of these different resources by a network of people could have either come together officially or casually.

Social capital therefore is concerned with relationships that are formed through societal interactions built around trust and mutuality. The concept has been used in a variety of contexts, for instance by farmers who mutually exchange their production and marketing experiences. In this case the more there are of group members the merrier they can function because techniques are gathered from members themselves and family and friends in a social setting (World Bank, 2001; McIntyre, 2012; Thomas, 2002; Ferlander, 2007). Some studies, for instance Pitikoe (2016), argue that social capital has long been practised by Basotho in performing specific activities such as farming, herding and raising both a girl and a boy child in the community. Pitikoe believed that such activities (farming, herding and raising children) relied heavily on

trust. She talks about the role of social capital as a social glue, binding societies together due to commitment and trust for each other. On herding activities, Pitikoe found out that herd boys practiced social capital as a reciprocal relationship because they would share their learning when they alternated days to attend school. While Boy A had gone for classes, Boy B would be herding flocks for both of them and vice versa. According to Pitikoe this activity relied on trust and reciprocity among the boys to achieve their common purpose (learning) regardless of their responsibilities towards flocks of sheep or cattle. Pitikoe (2016) supports earlier research such as by Portes (1998) and Ferlander, (2007) because all authors conclude that non-financial resources can compensate for lack of other forms of capital in sustaining livelihoods and lifestyles.

Thakaso (2017), in a study of youth attitudes to citizenship in Lesotho, also argues that social capital is used as a resource among young people who build networks through trust, reciprocity and sharing among group members. Thakaso provides an example of a youth choir where the youth rely on sharing new and old songs and human qualities that the choir needs to possess in order to work together. Woolcock (2001) and Putnam (2000) both refer to the three concepts of bonding, bridging and linking social capital.

3.3.1 Bonding social capital

Bonding social capital reflects the strong interpersonal relationships and sense of community that people value in close knit relationships. Bonding refers to deep inward-looking relationships characteristic of primary social groups such as families, which reinforce alliances among similar types of people. Woolcock (2001) argues that bonding social capital denotes ties between people in similar situations, such as immediate family, close friends and neighbours. Portes (1998, 2001) and Putnam (2000) similarly indicate that bonding social capital is made up of the strong ties between people who share similar demographic or social characteristics such as friends, close family members, neighbours and work colleagues. The relationships a person has with friends and family, usually reflect the strongest form of social capital. Therefore, family relations are significant in this aspect. Although Putnam (2000) acknowledges that criminal gangs can also create bonding social capital through close networks, he also refers to social groups such as choirs and bowling clubs. These more formalised societies can also have a role in creating bridging social capital.

3.3.2 Bridging social capital

Bridging refers to the next layer of social networks that can occur between socially heterogeneous groups. Woolcock (2001) argues that bridging social capital encompasses less distinct ties between people and these can be termed as loose friendships or collegial relationships within the work situation. Such bridging social capital links can enhance bonding networks by providing additional resources to a situation. This is where the building of norms and trust is needed between networks to enhance mutual participation and mutual benefit in completing a task. This study therefore explores the extent to which support group members identified outside contacts in a way that widened and strengthened opportunities for information access. Putnam (2000) argued that joining an organisation cuts in half an individual's chance of dying within the next year due to information and health tips accessed from new organisational networks. This study explored how support group members made bridging links from their groups and involved their outside networks in information provision. Linking social capital is an extension of bridging social capital.

3.3.3 Linking social capital

Linking social capital as discussed by Putnam (2000) reflects the relationship between an individual, groups and the outside world such as government officials, influential bodies in the community or other elected leaders. Linking social capital might become crystallised when the support group members utilise their relationships with government and non-governmental ministries for information access and clarity of topics of their interest. The support groups' relations with institutions and other levels of power, could therefore provide a base for identification of diverse information resources.

Putman (2000) emphasises the value of social capital networks and norms for mutual or collective benefits. Others including Coleman, emphasise the benefits occurring to individuals. This theory is used to analy5e the findings because it is deemed relevant to this study.

3.3.4 Relevance of social capital to the study

Negotiating discourses about HIV, its prevention and care by itself calls for a more unified approach – by communities learning and sharing experiences together. The support groups

discussing and sharing their views on issues of their concern were mechanisms to release them from the daunting challenges brought by HIV and AIDS to their lives. It will be seen in later chapters that meaning making would not have been easy for the three support groups in this study had it not been for the consultations made with their respective networks. The outcomes of these consultations were brought along to the support group as a resource for further learning. Social capital is therefore relevant to the study in that it provided concepts that could identify the different kinds of networking that may contribute as resources of information and knowledge for learning.

Bonding social capital tends to be a close-knit kind of relationship, and is likely to occur in small communities. Bonding social capital can be identified as learning that promotes stability rather than change (as it occurs between and amongst the support groups). Bridging and linking social capital can be associated with finding new information outside of the small group (seeking clarity of some issues from other members of the community, their relatives and friends and bringing back their responses to the support groups as bridging social capital and seeking information from professionals or wider networks as linking social capital). Social capital theory has proven to be versatile in its functions and has been applied in many settings – for example educational, economic and sociological (McClenagham, 2000), in relation to reducing corruption in societies); health (Seid, 2016 in relation to social groups supporting each other in avoiding risky health behaviours); and political (Putnam, 2000 in relation to forming strong democracies). Baron, Field and Schuller (2000) also refer to these three forms of social capital in terms of their usefulness for lifelong learning.

3.3.5 Critiques of social capital theory

A number of scholars have raised concerns about the lack of a precise definition of social capital. Portes (1998, p. 2), for example, noted that the term has become so widely used, including in mainstream media, that 'the point is approaching at which social capital comes to be applied to so many events and in so many different contexts as to lose any distinct meaning.' Robison, Schmid and Siles (2010) reviewed various definitions of social capital and concluded that many did not satisfy the formal requirement of a definition. They argue that many proposed definitions of social capital fail to satisfy the requirements of capital. They propose that social capital be

defined as 'sympathy'. The object of another's sympathy has social capital since in times of need, friends, relatives and the significant others tend to offer sympathy as priority. Those who have sympathy for others are considered to provide social capital. Nevertheless, the concept of social capital as reflecting networks of resources and relationships of reciprocity and trust, was deemed relevant for elaborating on the ways in which the support groups operated as a community of practice.

The support groups in this study were analysed in relation to the extent to which they underwent transformative learning.

3.4 Transformative learning theory

Transformative learning theory is the theory emanating from Mezirow which he developed in the 1970s but which he has refined over time (1990; 1996; 2000; 2009). Mezirow defines transformative learning as the condition of being human by understanding the meaning of our experiences. He highlighted that individuals develop autonomous thinking where one makes his or her own interpretations rather than acting on the purposes, beliefs, judgements and feelings of others. Mezirow indicates that, throughout their life time, people make meaning out of their experiences by using new experiences to build on and make sense out of old experiences. Cranton (2006) supports Mezirow's argument that transformative thinking results in change in life attitudes or behaviour. Mezirow (2000) emphasises that, when learning, people build a way of seeing the world, a way of interpreting what happens to them influenced by values, beliefs, and assumptions that determine their behaviour. Much of people's belief systems are uncritically absorbed from family, community and culture. Mezirow argues that people do not normally stop to question everything that happens to them or everything they see and hear.

Transformative learning is a process therefore, that evolves internally and is different from other forms of learning that require memorisation of facts or practical application of new skills. It requires adjustment of old frames of reference or meaning perspectives so that new insights and understanding develop as a result of refining or re-assessing old ways of thinking. Mezirow (2000) discusses ten phases of thought processes that lead to transformative learning. These ten phases guide the analysis on how each support group learned throughout their observed

meetings. My interest was to analyse whether members were able to make meaning out of the different discourses associated with HIV and AIDS, its prevention and care. The use of transformative learning theory was a tool to assess whether Basotho learned and followed the same pattern as Mezirow's identified ten phases. The theory provided a lens though which to analyse how meaning making impacted on new learning which people came across in their support group meetings. The ten phases are briefly summarised here, as cited by Taylor (n.d.):

1. A disorienting dilemma
2. Self-examination with feelings of guilt or shame
3. A critical assessment of assumptions
4. Recognition that one's discontent and process of transformation are shared and that others have negotiated a similar change
5. Exploration of options for new roles, relationships and actions
6. Planning a course of action
7. Acquisition of knowledge and skills for implementing one's plans
8. Provisionally trying out new roles
9. Building of competence and self-confidence in new roles and relationships
10. A reintegration into one's life on the basis of conditions dictated by one's new perspective (Taylor, n.d., p.8).

It is interesting to note that six of the ten phases have to do with individual preparation for learning. Therefore, these phases can be compared with the experiences of the three support groups in Botha-Bothe Government Hospital (BBGH) to assess whether they went through the same steps while learning and whether their learning as Basotho did or did not follow Mezirow's ten steps sequentially. It is important to recognise that Mezirow's transformation theory forms a framework for how adults interpret their life experiences, and how they make meaning in life. In fact, he defines learning as a meaning making activity: 'Learning is understood as the process of using a prior interpretation to understand a new or revised interpretation of the meaning of one's experience in order to guide future action' (Mezirow, 1996, p.162). In relation to adult learning, this point is supported by Gee and Hayes (2011) who emphasises that adults learn best if their learning moves from the known to unknown, from simple to complex.

Mezirow's theory is highly relevant for this study since it can help to show how support group members may negotiate and act on their own purposes, values, feeling and new meaning making rather than those they have uncritically assimilated from others in the past. This theory is

associated with key concepts such as meaning making, self-directedness, assertiveness, self-confidence, self-esteem and habits of minds. Reviewing these key features that are used to characterise transformative learning creates a basis for one to understand the role of experiences in learning and how each concept contributes to transformative learning. Meaning making results in learning and must crystalise in individuals involved in learning.

3.4.1 Critiques of transformative learning theory

Not all authors have accepted Mezirow's work uncritically. For instance, Cranton (2006), Taylor and Cranton (2013) and Ntseane (2011) reflect on learning modes and cultural issues of omission in Mezirow's thinking.

Cranton (2006) suggests that the process as described by Mezirow is too prescriptive and does not take account of different learning contexts. Ntseane (2011) argues, from an African perspective, that the process does not recognise the role of culture and its influence on how people learn. In other words, she suggests that Mezirow focuses too much on the individual's learning journey through critical reflection without taking enough cognisance of the influence of collective dialogue on meaning making.

This observation is relevant to the study since the myths and medical challenges that the support groups encounter had been highlighted in the literature as being culturally misinterpreted, resulting in the need for health care providers to provide information education and communication which can help the support group members to transform and prepare for their new, revised perspective. However, it is also wise to look into the meaning making process in order to fully understand how and what can best assist the support groups not just to learn but also to understand what is needed of them to have new perceptions about living with HIV/ AIDS.

John (2016), for instance, indicates that there is a collective perspective which is not well reflected in Mezirow's more individualistic depiction of transformative learning. John (2016) argues that young adults in his study, in a context of harsh circumstances and difficult early lives, came to a place of emotional healing and wholeness through listening collectively to each other's stories. They all showed evidence of what Mezirow called perspective transformation, but

through a collective process of discovery. When perspectives are transformed in a collective space, emancipatory learning takes place, allowing for personal transformation to occur.

John (2016, p. 283) while engaging the critique of transformative learning theory in his study, indicates that:

> Some of the studies reviewed signaled the need for considerations of the role of intense emotions and prior stressful life events, of readiness factors for change, of non-rational ways of knowing such as intuition, empathy and spirituality, and of the centrality of positive relationships in transformative learning.

It will be seen in this study that the sharing of emotions is an important collective learning process. There are many Sesotho proverbs which emphasise the role of the collective in contributing to emotional healing and learning. For instance *"Harele bakana likelello letsona lingata hare hloloe"* roughly translated means "if we think together with many heads we cannot be defeated".

3.4.2 Learning through collective interaction

John (2016) and Gonzalez (2013) therefore maintain that discussion needs supportive functioning to enhance performance by all. According to John and Gonzalez supportive functioning maximises participation. Both authors articulate various methods that can be used as supportive functioning. They argue that learning through collective interaction is easier for some individuals because they can explore ideas through pictures or imagery which can be discussed as a shared activity. This study sought to examine whether a similar collective process of meaning making would take place in the support groups.

In addition to the above considerations there are some key concepts associated with transformative learning which would benefit from a more elaborate explanation.

3.4.3 Meaning making

This concept refers to making a sense of an experience, making an interpretation and subsequent application of new understanding. Interpretation is used to guide decision making or action, and consequently meaning making becomes learning (Cranton, 2006). Understanding meaning

making has been a problematic issue for many decades. Kitchenham (2008) argues that making meaning is a collective process of internalising arts, activities, ideas, phrases and then interpreting them to reach a common comprehension and form a collective context. Gauntlett (2011) however, understands meaning making as related to perception and cognition in which even visual perceptions are formed according to the significance for the individual that contributes to the social meaning of creativity.

Bates (2014) believes that meaning making is the process of understanding and valuing one's own life regardless of past painful experiences and the social history of learning. My study sought to find if this also applies to these three support groups. Schuller (2001) indicates that individuals can collectively negotiate meaning making based on their experiences and connections on the basis that meaning making results from the accumulation of relevant data and information within a context which helps to establish a sense of 'knowing' or adds to a body of knowledge and positively impacts on lifelong learning. For the purposes of this study, meaning making in the support group context can be understood to be a collective process of internalizing ideas, perceptions, and activities interpreted to reach a common comprehension based on a collective experience. This means that an idea can only make sense to a certain group of people if their perception is common due to their common experience on such an idea and therefore they can collectively come to comprehend that experience and make sense of it. However, it is worth recognising that not all people in that collective context may reach the same level of understanding, bearing in mind the uniqueness of individuals. Bates (2014) indicates that the uniqueness of an individual is not only observed through the historical learning processes, but also the illness experiences, needs to be looked at in three ways – through social, cultural and medical lenses. Through these different lenses it can be seen how an illness becomes complex to understand, and preventive strategies difficult to implement which can result in delays in use of treatment as prevention and cure.

Kitchenham (2008) also indicates that meaning making is a collective action, for instance through the ability to think, communicate and work together. Meaning making in this respect is thought to have evolved to be an inherently collaborative effort and a social process. This

process enables the human mind to construct meaning which is socially acceptable across generations.

However, merely ‘knowing’ (for example in relation to medical treatment discourses) is not the same as ‘understanding’. Meaning making is highly crucial in this study as it can help the researcher find out how and what the support groups learn from each other in terms of understanding rather than simply knowing.

3.4.4 Self-directedness

The use of this concept in transformative learning is usually associated with adult education due to the perception that the learner is expected to set their own educational goals and means to acquire knowledge. Johnston (2013) sees the concept as bearing the same connotation as autonomously building new frame of reference in learning. This means that learning is pursued intentionally but also independently with little guidance from the expert. Transformative learning in this aspect includes a similar process whereby an individual can voluntarily take steps to develop a critical questioning of beliefs, assumptions and perspectives that allows them to transform their understanding. Merriam (2008) argues that self–directedness is inseparable from transformative learning in the sense that when one has undertaken a process of critical reflection, as suggested by Johnston (2013), one’s cognitive analysis skills are broadened and a certain level of transformation occurs as a result.

3.4.5 Self–concept

This is defined by Merriam (2008) as a process of self-construction where an individual goes through self-knowledge to effect change in life. The process comprises critical self-awareness to realise one’s potential strengths to draw from, and the potential weaknesses to improve on, to enable meaningful participation in life. Developing one’s self-concept allows for critical introspection that permits new meaning making which leads to transformative learning.

3.4.6 Self-confidence

According to Mezirow (1997) and Ntseane (2011), self-confidence surfaces in individuals who have acquired some knowledge and are able to move on after a disorienting dilemma. Self-

confidence crystallises when individuals make efforts to explore options for new roles, relationships and actions.

3.4.7 Habits of mind

This concept refers to individuals' perceptions of certain issues, influenced by previous background, experiences, culture and personality (Mezirow, 2000). Habits of mind are said to cripple one's thinking capability to allow new perspectives. For instance, growing up in a small rural village where everyone was trusted and known to each other may have influenced one not to trust strangers. Therefore, individuals need to identify and work on their habits of mind to accommodate transformative learning.

Although transformative learning theory is a useful tool to explore how the support group members, both individually and collectively, arrived at new meaning perspectives, the process of acquiring information in the support groups was often through networks and interactions with people outside their support groups such as friends and neighbours. Their networking with close relationships outside the community contributed to how they developed new meaning perspectives.

However, since the support groups in this study were struggling with a variety of discourses, for instance, medical, cultural and other myths, it was appropriate to take a discourse analysis approach to exploring the data. This process is briefly described here.

3.5 Discourse analysis

The definition of discourse is somewhat problematic. However, a number of writers refer specifically to discourse as a social practice. Gee (1989; 1990; 2000; 2005) Gee and Hayes (2011), Wetherell (1998) Wetherell, Taylor and Yates (2001) and Foucault (1977; 1982; 1988) all talk about discourse in terms of use of language and behaviours that can reflect certain genres, cultures or professions. Gee (1990, p. 142) refers to discourse as 'a sort of "identity kit"' which comes complete with the appropriate costume and instructions on how to act, talk, and often write, so as to take on a particular social role that others will recognize. Gee (1990, p. 143) further explains discourse as 'a socially accepted association among ways of using language, of

thinking, feeling, believing, valuing, and of acting that can be used to identify oneself as a member of a socially meaningful group or social network', or to signal that one is playing a socially meaningful 'role'. Another way to look at discourses, as argued by Wetherell et al. (2001), is that they are always ways of displaying (through words, actions, values and beliefs) membership in a particular social group or social network (people who associate with each other around a common set of interests, goals and activities). Fairclough (2003) also argues that discourse is language and behaviour representing attitudes, beliefs and assumptions that are crystalised in rationales that people use for justifying their point of view, behaviour and attitudes. There are medical discourses, gender-based discourses, political discourses, economically based discourses and culturally embedded discourses (as manifested in proverbs).

Rule and John (2011) indicate that by discourse they mean a particular use of language which serves particular purposes and interests. Gee (2005) argues that human beings use language to signal what sort of relationship we have, want to have or are trying to have with the listener(s), the reader(s) or other people, groups, or institutions with whom we are communicating. That is to say, language is mostly used to build relationships but can also be a source of tension:

> The various discourses which constitute each of us as persons (or subjects) are changing and often are not fully consistent with each other. There is often conflict and tension between the values, beliefs, attitudes, interactional styles, uses of language and ways of being in the world which two or more discourses represent (Gee, 1990, p. 7).

Wetherell et al. (2001) further indicate that discourses shape the way people view the world and are therefore not just a mere reflection of an already ordered reality. They further suggest that a discourse would include specialist language, concepts, conventions and authoritative texts. The discourse of medicine for instance would use specialist language and concepts associated with anatomy, disease, medication and particular conventions for applying these in practice. However, some authors do not see discourse as languages. For instance, Gee (1990, p. 7) argues that a 'discourse is not a language or a text but a historically, socially and institutionally specific structure of statements, terms, categories and beliefs'. Mahloane-Tau (2016) indicates that because discourses are socially constructed, there are strong chances of HIV discourses

misleading mostly youth and this in turn carries a high chance of fueling the transmission of HIV.

In summary it can be said that discourses are words that indicate a certain meaning understood by a particular group of people having the same orientation, values and beliefs that influence their thinking and actions. Such words can portray meanings understood by that particular group.

This study is premised on the assumption that support groups exhibit strong features of collective participation and learning. It is also assumed that the three support groups established in the hospital setting to discuss health related issues have a common understanding of some words and use them to suit their interests and expectation. Their monthly meetings and discussions result in particular conventions and uses of special languages and concepts to suit their practices. This study focused on HIV and AIDS support groups in Botha-Bothe, Lesotho. It explored how the groups negotiated the contradictions, myths, beliefs and medical messages (as different forms of discourse) about HIV and its care. The primary research focus therefore was to unpack what discourses were used and how the members interfaced with each other using these discourses – and how the discourses informed each other so the participants were able to make new meaning out of their HIV situation.

The works of Wenger (2006), Putnam (2000) and Mezirow (2000) have been useful in providing a collective theoretical framework to analyse how the support groups learned as a collective. Discourse analysis was the tool to explore their social practices in using language, particularly the vocabulary that they selected to communicate amongst themselves. However, most studies reviewed in this chapter are taken from western contexts. In view of the cultural context of this study it is important to take cognisance of writers who emphasise the influence of African perspectives on some of these theories. In this respect, of particular interest is the notion of the collective and how this influences learning.

3.6 African perspective as a consideration in relation to the above theories

In the African context, community-building activities and inter-dependence are regarded as more valuable for learning purposes than autonomous learning. This African communal approach to

learning is an important source of meaning making which has the potential to enable a multidirectional borrowing and lending of knowledge across and within nations (Ntseane, 2011). Ntseane (2012) indicates that efforts need to be made for individuals to understand the relationship between medical discourses and culture because in African contexts, a patient begins to seek help from traditional healers who talk and connect with ancestors for directions on how a patient can be helped. Ntseane (2012) argues that at times cultural efforts fail to save individuals from the slavery of illnesses because the patient has wronged the ancestors who are said to be so angry that a patient is denied cure. This study explored whether the support group members included reference to ancestors when discussing medical issues or whether they had acquired an understanding of medical models of care for the purpose of HIV/AIDS prevention and care.

Matsela (1990) indicates that Africans have always lived in a collective manner. Collectively they rejoice with a family that has a new born, they would collectively fetch water from the well and bring mealie-meal. Some would bring fire wood and wash all the dirty linen for that family. They would collectively plant their fields, weed, and harvest them in groups of youths and women, while other activities such as building a hut for the newly wed, *leqatha*, hunting or planting would collectively be done by males only. This suggests that the idea of support groups as a learning collective, sits easily within a culture that expects to do things communally.

As a Mosotho girl, I, as the researcher, became involved in several communal activities done by my age mates before marriage. These activities bear teaching and learning purposes. Girls would collectively weed neighbours' fields for cash to buy Christmas necessities for themselves and their families. While weeding, elderly girls teach younger ones and practice songs for *Lesokoana* (an activity played by girls and young women to pray for the rain in times of drought). Girls would sometimes collectively fetch water from a spring and wood for the family where a pig was to be slaughtered so they are given pig intestines. During this process, older girls teach younger ones how to clean pig intestines before cooking and how best they can maintain good hygiene to reduce infections. Boys would collectively herd flock of animals and be rewarded with milk. Herding flocks of animals meant spending the whole day in the wilderness without lunch boxes. This is where elderly boys teach the young ones how birds can be trapped and made into a good

braai. They would be taught hunting and types of wild plants to be eaten (like wild carrots and berries).

As a newly married Mosotho woman, one was oriented by a group of young women during weekend songs and games called *pitiki* to respect the husband and the in-laws. All these experiences connected me with the multiple relations and connections that define my reality along similar lines to the experiences outlined by Ntseane (2012).

According to Chilisa (2011), the key African learning values, such as 'communal/collective/participatory' and 'interconnectedness/independence' for social change and empowerment, are unique ways in which African philosophies and theoretical perspectives inform ways of seeing, knowing and reconstructing reality. This is what is encapusulated in the Southern African concepts of *botho* and *Ubuntu* (collective humanism of human beings). In Botswana *botho* involves sharing, compassion, respect, commitment and sensitivity to the needs of others, patience and kindness (Chilisa, 2011). This concept of *botho* in Botswana bears the same connotation as in Lesotho. This study sought to investigate whether such concepts were evident in practice among these three support groups in Botha-Bothe hospital.

3.7 Chapter summary

This chapter has discussed the theories that support the study. The key theories here are the transformative learning theory (Mezirow, 2000) and communities of practice theory (Wenger, 2000). This is supported by social capital theory (Bourdieu, 1985; Putnam, 2000; Coleman, 2000). The discussions around these theories have shown the linkages between transformative learning at an individual level and learning as part of the community, which is the thrust of the study.

The review of literature on the African perspective relating to the study was influenced by the research interest to understand the support groups in an African context. Most of the literature on African perspectives reveals that communality-building activities and inter-dependence are more valuable for learning purposes than autonomous learning. This African communal approach to learning is an important source of meaning making which has the potential to enable a

multidirectional borrowing and lending of knowledge across nations and within nations (Ntseane, 2012). Hence, this study sought to investigate whether this is the practice within these three support groups in Botha-Bothe hospital. The next chapter (Chapter Four) will elaborate on methods used for data collection in the three support groups under study.

Chapter Four: Methodology

4.1 Introduction

The previous chapters laid a foundation for this chapter by closely reviewing the literature around the globe, regionally and locally on support groups, how they learn and offer support to each member in times of hardships such as when diagnosed to live with a chronic illness. This chapter provides information about the research methodology and, as the researcher, my own data gathering experiences from three HIV and AIDS support groups in Botha-Bothe, Lesotho. The first part of this chapter looks at the research design in terms of the research paradigm and different approaches used in this study, data collection methods, sampling and data analysis. In the second part my position as a researcher and the ethical considerations are included. The aim of the study was to explore how support groups in Botha-Bothe negotiate discourses about HIV, its prevention and care. The purpose was to explore how Basotho make meaning from the information, education and communication they receive from their health care workers (counsellors, nurses and pharmacists), from the other support group members and from their social networks. As the researcher I spent some time in the field attending the support group meetings in order to collect and subsequently analyse the patterns of interaction and meaning making within the different support groups, drawing on the communities of practice, social capital and transformative learning theories.

It was necessary that a design be selected that would enable the research questions to be answered properly. The overall research question was: How do people in the support groups negotiate the different discourses associated with HIV and AIDS, its prevention and care –for example: medical messages, cultural value systems, myths and community beliefs?

The sub questions were:

1. How do the support groups function as a community of practice?
2. How do the support groups make meaning out of the different discourses associated with HIV and AIDS, its prevention and care?
3. How does their meaning making impact on new learning?

4.2. Research paradigm

According to Terre Blanche, Kelly and Durrheim (1999) the word ‘paradigm’ is of Greek origin and refers to a certain pattern of ideas, values and assumptions which the study follows and which a researcher can use in defining the nature of the study based on those three dimensions. Chilisa and Preece (2005, p. 21) understand the word paradigm to inform the researcher's understanding about the ‘conceptual framework or theoretical framework’ that guides the choice of the research problem to explore, the formulation of the research objectives and the ‘research design, instruments for collecting data, data analysis and reporting of the research findings’. Bassey (1999, p. 42) explains a paradigm as ‘a network of coherent ideas about the world and of the functions of researchers which, adhered to by a group of researchers, conditions the patterns of their thinking and reinforces their research actions’. Bassey (1999) further indicates that a paradigm operates like a lens that poses a clear picture of how the world should be interpreted and helps a person to position him or herself in such a world, to be able to understand it and create further knowledge out of the picture created.

Babbie (2004) describes a paradigm as a model or frame of reference. There are various paradigms that guide the research. These are usually, as discussed by Guba and Lincoln (2005), identified as: positivist, post-positivist, interpretive and critical. Terre Blanche Kelly and Durrheim (1999) conclude that the paradigm reflects its three major components, namely, ontology, epistemology and axiology. Ontology refers to the researcher’s sense of self, while epistemology focuses on what counts as knowledge according to the researcher, and axiology refers to the values attributed to the researcher’s world. The epistemological focus in this study was on the efforts made by support groups to learn and share at their monthly meetings their understandings of medical discourses on HIV prevention and care. The interpretive paradigm supports a subjectivist ontological standpoint that asserts that what can be seen as real, depends on the society concerned. Therefore, as the researcher, my ontological position in this study was to adopt the interpretive paradigm so that I could focus on understanding the expressed concerns, realities and meaning making of the research participants.

4.2.1. Rationale for interpretive paradigm

Bassey (1999) maintains that the purpose of research, according to the interpretive paradigm, is to contribute to the knowledge base about the world by gaining an understanding of the shared meanings that people attribute to their particular contexts. Investigating how HIV and AIDS support groups negotiate discourses about HIV, its prevention and care lends itself to the interpretive paradigm. My desire to use this paradigm was mainly influenced by Terre Blanche, Kelly and Durrheim (1999), and Terre Blanche and Painter (2006, p. 7) who explain that with interpretive paradigms, the researcher 'believes that the reality to be studied consists of people's subjective experiences of the external world'. So, the researcher has to understand a phenomenon from different perspectives. Therefore, this study selected the lens of interpretivism to be used as key to guide the researcher's methodological approach. Ponterotto (2005, p. 128) cites Schwandt where he asserts that 'interpretivism maintains that reality is formulated in the individual's mind depending on what one wants to believe not what other people believe in'. This paradigm supports the belief that knowledge is subjective because it is socially constructed and mind dependent. It was therefore believed to be the most appropriate paradigm for this study. 'Interpretive paradigm therefore aims to explain the subjective reasons and meanings that lie behind social action' (Terre Blanche, Durrheim & Painter, 2006, p. 7). Interpretive paradigms, however have their critiques.

4.2.2. Critiques of interpretive paradigm

Some scholars have critiqued this paradigm due to its nature of focusing on qualitative approaches to collecting and analysing data. They claim that it lacks a scientific rigour and therefore lacks consistency. Secondly these scholars indicate that it portrays an inability to come to terms with the one common understanding of how knowledge is constructed (Demetrion, 2005). Nevertheless, in this study, the interpretative paradigm was found to be appropriate for me to use due to its ability to show how the three support groups in the study developed their own understanding about HIV prevention and care. Having briefly defined what a research paradigm is and the rationale for using an interpretive paradigm in this study, it is appropriate to describe the research design.

4.3. Research design

Research design can be understood as a technical document developed to guide a research project. It encompasses all the structural aspects of a study. It explicitly indicates the types of respondents who will take part in the study to allay fears about biased responses emanating from uneven representation. This is where the study indicates areas that need to be compared and why. It addresses how to implement the strategy, the bridge between research questions and the execution or implementation of research (Terre Blanche, Kelly & Durrheim, 1999; Gravetter & Forzano, 2009; Blaikie, 2010). This study used a case study design due to its nature of intensive investigation of the support groups.

4.4 Case study

This section highlights the definition of a case study, types of case study, and some of the scholars' perceptions about case study application or practice as a case methodology. Many scholars have different opinions when it comes to case studies. Some define it as an in-depth exploration of particular individuals that are expected to reveal experiences and knowledge in context with the topic under study (Lindegger, 2006). Rule and John (2011) indicate that case study is defined in multiple ways by different authors (such as Bogdan & Biklen, 1992; Bassey, 1999; Creswell, 2002; as cited in Rule and John, 2011). Rule and John (2011) summarise the definition of a case study as an intensive inquiry of a certain aspect of social interest with the purpose of creating evidence-based knowledge.

Case study is explained by Babbie (2004) as a thorough inquiry of a social challenge, for instance to determine how the challenge impedes development or affects human beings, by selecting a group that can be trusted to reveal results that can be representative of the larger group. The researcher identifies the single instances of some social phenomenon, such as a village, a family, a juvenile gang or a community. Various types of case studies are outlined by different scholars.

4.4.1 Types of case studies

Rule and John (2011), together with many other scholars, highlight the use of several types of case studies, but the most prominent and commonly used are exploratory, explanatory, descriptive, intrinsic, instrumental and collective. Yin (2003) sees a case study taking many

approaches but identifies the main approaches to be exploratory and descriptive. Stake (1995) affirms that a case study can be explained in several ways of which the most outstanding are: intrinsic, instrumental and collective case studies. The main types of case studies are discussed below for justification of the type chosen for use in this study.

An explanatory case study seeks to answer questions that sought to explain the phenomenon with the intention to simplify and explain complex issues. It explains the occurrences in a clearer manner for the user to understand the real context in which the incident happened. An exploratory case study focuses on understanding relatively under-researched phenomena (Yin, 2003). The instrumental type is used when a researcher aims to access and utilise a certain solution for a specific condition. This type of case study is highly specific and must come up with solutions specific for the challenge upfront. Stake (as cited in Baxter and Jack, 2008) indicates that the collective case study (as the name implies) is used to identify a group of case studies that are similar in nature and description to more than one case study (or for one to gather knowledge on more than one occurrence, for instance a population or general condition) (Yin, 2003).

Rule and John (2011) argue that a case study is used to address the research questions in a study in a way that puts together in-depth, but orderly arranged, information relevant to one unit of analysis. In this study, my single bounded unit of analysis was the support group. However, the collective case study approach involved three support groups. In this particular study, the cases were the three support groups formed of the mothers-in-law, the mixed support group and the fathers-to-fathers support group.

The type of case study most appropriate for the research

In this research the researcher opted for an exploratory case study approach but used a collective case study design. Punch and Oancea (2014), and Rule and John (2011) argue that a multiple or collective case study approach makes it easier for the researcher to compare the results across the cases. This increases one’s competence in the compilation of results, analysis and making conclusions.

My study is exploratory because investigations were conducted into relatively unknown areas of research. Therefore, one had to explore in order to discover what happens in this particular study in the Botha-Bothe district of Lesotho because there had not been a study of a similar nature. Although it is primarily exploratory research, it has an observable feature of descriptive elements in that it provides an in-depth description of the case, and explanatory elements since it allows the use of theories such as communities of practice theory, social capital theory and transformative learning theory to make sense of data.

Koshy (2005) argues that case studies are an ideal way of disseminating information related to the topic under study because they can present precise information for the readers' consumption especially readers seeking for outcomes of the research project. Therefore, the findings will be disseminated back to the support groups through meetings with the three support groups, hospital authorities, youth group leaders and people interested in knowing what the support groups in hospital were doing.

4.4.2 Limitations of the case study

Many authors have discussed the limitations of case study. The most prominent ones include Pillay and Harvey (2006) and Yin (2003) who both indicate that the key limitation, among many, is the quality and rigour of case study, especially if the researcher is not fully conversant with the methodology. The generalisation of case study findings, especially from single cases, may not be possible in many incidences. The other limitation is its possible bias due to over exposure of the researcher to human subjects during data collection. Therefore, these limitations may lead to problems with the validity of information. Since I used multiple case studies and multiple visits which were recorded digitally, it was hoped that the limitations of bias would be minimised and the benefits of having rich descriptive data would overcome concerns with rigour. Although I was a non-participant observer, it must be assumed that I was not totally exempt from influencing the dynamics of the meetings. Nevertheless, it will be seen that my presence did not hinder the participants' willingness to speak openly at all times.

The most appropriate research approach for the interpretive paradigm is a qualitative one, which is outlined below.

4.5. Research approach

Many scholars in favour of the interpretive paradigm argue that the qualitative approach is more suitable for collecting verbal data. Neuman (2000) argues that a qualitative approach involves probing human experiences in a certain manner in order to obtain a clearer understanding of issues pertaining to the real context. This study focuses on the verbal articulations of support group experiences. This implies that the manner in which the support groups share their views and the different emotional views portrayed during experience sharing and learning were critical for the findings because they signified the seriousness and particular characteristic of how the issues were discussed. The manner in which the issue got communicated, for instance, 'specific communicative intentions', had to be highlighted to identify the 'linguistic context' which the support groups used (Terre Blanche, Kelly & Durrheim, 1999, p. 274).

A qualitative approach is expressive, therefore detailed responses collected from conversations of the respondents had to be collected in a manner that enabled every word to be useful data. Therefore, it is of great importance to use reliable tools (for example voice recorders) to collect data because it is mandatory for the researcher not to miss any information from respondents. Punch and Oancea (2014) advise researchers to take their time to select the most appropriate method to collect data intended for a quality descriptive data. For instance, it is essential to be conversant about transcribing and translating in order not to miss the context in which data was given and its implications. The researcher has to be observant, and not to miss respondent actions, or non-verbal behaviour. Qualitative research is holistic in nature therefore it has to be conducted in the field to capture incidences as they occur in real life settings.

Chilisa and Preece (2005) indicate that a qualitative study is legitimate, credible or valid when it presents such accurate descriptions that people who share those experiences would be able to recognise, associate with, claim or own the descriptions. Gephart (2004) further states that qualitative research focuses on examining experience and the construction of its social meaning. This focus and the narrative nature of qualitative research, as stated in Neuman (2000), Trahar (2006), and Gephart (2004) helped me to determine and interpret the discourses the support groups learned and shared with other community members. Therefore, my data is presented as

qualitative data, as descriptive, analytical, narrative research. The methodology needs to justify how long quotes have been used to build a picture of the environment and atmosphere of the support groups and as a way of illustrating how the laypeople's discourses (thoughts and behaviours) would meticulously 'pick through' the different layers of meaning making in order to make sense of, but also apply, the messages behind the medical discourses in ways that would not undermine culture or destabilise fragile gender relations.

4.5.1 Rationale for the use of qualitative approach

The reason why a qualitative approach was picked for use in this study was because the qualitative approach values respondents' experiences and encourages data collection techniques such as observation, voice recording and some short note taking – all of which were used in this study to elicit responses from the people. According to Terre Blanche, Kelly and Durrheim (1999), Simons, (2009) and Rule and John (2011), qualitative research focuses on how people feel, think and act. The next part looks at data collection methods and processes, data generation and analysing and reporting.

4.6. Methods

Simons (2009) argues that collecting case study data entails employing several methods which include: interviews, documentation, archival records, direct observation, and non-participant observation, transect walk, questionnaires, focus group discussions and physical artefacts. The method which was deemed appropriate for this study was an observation technique. Initially the intention was to interview some individuals for further clarification of points raised in a meeting. However, the meetings produced such rich data that it was deemed unnecessary to follow up with interviews. Observation was therefore chosen as the only method. Simons indicates that the researcher in an observation method remains a silent body whose stand remains that of an inquisitive spectator who needs to record every incident. The observer uses the eyes to notice even the non-verbal cues which could help inform the study. A brief description of this method is provided below. This method was also appropriate to be employed in the six consecutive months to ensure data would be sufficient and convincing.

4.6.1 Observation

The method used to collect data for this study was through observations (appendix 1) which I did of three support groups during their monthly meetings over a period of six months per support group. Each observation lasted approximately two hours. Stewart, Brown, Donner, McWhinney, Oates, & Jordan (2000) describe observation as a strategy to collect data from the real setting using reliable techniques to collect verbal incidences for future use. Observation refers to noting or recording a fact or occurrence in order to compile the proceedings for future use of information. This case study used a voice recorder that collected conversations at every learning and sharing meeting over a period of six months. Simons (2009) argues that in cases where the researcher is a participant observer, the likelihood is that the researcher's presence might influence the conversations to suit the researcher's demands. Therefore, the decision was to collect data through the use of the non-participant observer method because it gave the support groups a chance to speak their minds during learning and sharing processes without the influence of the researcher because the researcher's interaction with the respondents is minimal. The non-participant observer method does not allow any platform for formal interactions with the participants during the process. The non-participant observer method gave the researcher ample time to observe the proceedings and notice different emotions and attitudes portrayed during the meetings. This method allowed the researcher to gain insight into what the support groups wanted to achieve during their learning and sharing method. Moreover, to help minimise the participants' consciousness of the observer, several meetings were observed over a six-month period so that participants became accustomed to the researcher as a silent observer. However, because the support groups were communicating in Sesotho as their mother tongue, the researcher had to listen to the recording and compare with her notes taken during the proceedings. She had to transcribe the group interactions word by word which, for the study purposes, required translating in order to produce tangible data which could be discussed with her supervisor.

4.7 The population

According to Terre Blanche, Durrheim and Painter (2006, p. 133) population is the main focus of a study, which in most cases is larger than its sample. They state that, 'theoretically speaking, the population encompasses all the elements that make up our unit of analysis'. Terre Blanche et al.

(2006) argue that the population for data collection has to be carefully identified to maintain the significance of the study and avoid violation of the researcher's interest. The phenomenon identified for this study was all HIV infected and affected individuals in Botha-Bothe. There are various reasons that can prevent the researcher from reaching out to the whole population of the study. Amongst the reasons are time to attend to the entire population, costs that one could incur and the accessibility of the large population. Simons (2009) stipulates that this smaller group or subset is the sample and it is therefore advisable to use a smaller group representative of the whole population. The population from which my data emanated was the infected and affected people who attend HIV monthly services, either directly because they live with the virus, or affected because they accompany close relatives to access services in this particular hospital. In this case the sample for this study had to form a good representation for the entire population.

4.7.1 The sampling process

According to Walliman (2015), sample refers to the manner in which a small portion of the entire population is used as a representative of its larger group. The sample has to have exactly the same characteristics as its larger population to allow responses to have the same value and same context even though responses are sourced from the smaller representation. Babbie (2004) sees sampling as the action of giving the researcher a manageable number as representation of a bigger group but relying on the responses of the smaller and manageable group to provide precise responses one expects from the bigger group. The smaller group provides information that could be obtained from the larger group. As a result, the significance of the smaller group is the same as the significance of the larger group (Mason as cited in Silverman, 2004). Blaikie (2010), Babbie (2004) and Silverman (2004) argue that the selection criteria of the representative population must not be biased against nor be in favour of the researcher because the intention is to obtain information from the generalised population of the study.

Silverman (2004) argues that generalisation in qualitative research can be addressed in part through sampling. Generalisation is concerned with the representatives of the research sample and also the degree to which one can then make inferences to other contexts or populations. Baxter and Jack (2008) share the point that in quantitative research designs, generalisability is achieved through statistical sampling procedures because data is quantified to indicate its

implications and direct the researcher to the meaningful action to be taken in response to the implication. In qualitative research, participants are not selected randomly and the size of the sample is usually quite small to allow the researcher to work on the manageable data responses. It is befitting at this juncture to indicate that purposive sampling was used in this study. Silverman (2004) designates that purposive sampling as the name implies (from purpose) is based on the need of the researcher to decide on the respondents that reflect the researcher's interest or those identified by the researcher to have the knowledge and responses that would help answer the research questions.

The researcher is at liberty to classify the type of respondents that can best fit the criteria. Simons (2009) highlights that purposive sampling is used in order to access knowledgeable people; that is those who have in-depth knowledge about particular issues. The power of purposive sampling emanates from the perfect selection of respondents to the study based on knowledge of the matter understudied. For instance: seeking responses on the impact of studying PhD in cohorts can best be responded to by learners who have been in a PhD cohort. This implies that the responses gathered from a population that best experienced the cohort method can best suit the needs of the researcher (Patton, 1990). The selection should take account of cost effectiveness, ease of access and manageable procedural demands which are the pre-requisites for selecting a good sample for a project (Neuman, 2000). As the researcher in this study I had to consider the financial constraints under which the study was conducted because I had no permanent job to finance myself. The support groups were therefore purposively chosen and therefore became representative samples of all HIV/AIDS infected and affected people in Botha-Bothe. But the case study design meant that they also constituted the whole population of each of the support groups (subject to attendance at any particular meeting) since I observed the support group meetings in their entirety.

The total population for my study was people who are infected and affected by HIV/AIDS. The sampled population was the members of three support groups.

Each support group consisted of between 12 and 27 people who attended one or more of the groups' meetings during the period of observation. In addition, guest speakers such as youth

leaders, nurses or other medical staff who attended the meetings also became part of the observed sample.

Each support group members' composition increased as time went on because members encouraged less reliable members to attend because they realised the impact that was made by shared and collective learning to the support groups and to the community.

Table 1 below indicates the attendance of people observed at the beginning (February), in the middle (May) and during the last meeting (August) per support group as an example of attendance rates. It also indicates visitors as subject specialists per meeting. The table shows that the total observed number of participants in the research across all three support groups could range from 43 to 66 per month.

Table 1: Indicators of attendance rates across the support groups

Dates	**Support Group**	**Topic Discussed**	**Attendance**
08 / 02 / 2013	Fathers-to=Fathers (F2F)	New committee elected, confirm the use of voice recorder in next meeting.	12 Males 1 Nurse 1 Counsellor
07 / 05 / 2013	F 2 F	Defaulting and treatment failure	16 Males 1 Nurse 1 Counsellor
16 / 08 / 2013	F 2 F	Preparing for a trip to Mafeteng	17 Males 1 Nurse 1 Administrator to assist with logistics.
08 / 02 / 2013	Mothers-In-Law	Post mortem of previous meeting	13 Females 1 Nurse 1 Counsellor
07 / 05 / 2013	Mothers-in-Law	Nutrition and HIV	14 Females 1 Nurse 1 Nutritionist 1 Counsellor
16 / 08 / 2013	Mothers-in-Law	MCSP reduction	15 Females 1 Nurse 1 Counsellor
13 / 03 / 2013	Mixed Support Group (Thusanang Bakuli)	Basic HIV and AIDS, Transmission, rules and regulations disclosure	18 Females 1 Nurse 1 Counsellor

08 / 05 / 2013	Mixed Support Group	MCSP Reduction and sexual partner infection	24 Females 1 Nurse 1 Counsellor
28 / 05 / 2013	Mixed Support Group	Cleanliness and living exemplary life	27 Females 1 Nurse 1 Counsellor

4.8 Translation

Koshy (2005) sees translation as the rendering of something into another language or into one's own from another language. Translation is rather a challenging process because it requires a skilled person in both languages (original and translated one) to minimise mistakes and avoid compromising the data. For this study, assistance was initially recruited for the translation but (as Koshy indicated) the task of translation needs to be done skillfully. Two people who had been recruited to assist in translation failed to do so accurately. For this reason, I decided to do my own translations which were verified by other Basotho doctoral students to ensure accuracy of translated information because they better understood what was academically required.

4.8.1 Transcribing

Koshy (2005) argues that transcribing is the change or conversion to another form, appearance and transformation or just a swift translation of thoughts into action. All of the audio-recorded information had to be transcribed to be turned into useable data. However, the translation and transcription in this study were done simultaneously since the researcher is fluent in both languages (Sesotho and English).

4.9 Data analysis

According to Yin (2003), this stage requires the researcher's time and energy in order to keep focused on data analysis because it involves the narratives which are expected to be precise to reflect the true picture of what really happened. Discourse analysis explored the nature of the participants' interactions and the language they used to help them understand and interpret the medical discourses surrounding the prevention, care and treatment of HIV and AIDS. The data was then interpreted through the theoretical lenses of Communities of Practice, Social Capital and Transformative Learning. In relation to these lenses there are four key areas of concern. These are discourse, narrative, descriptive and thematic analysis. Each of these areas of concern is discussed below:

4.9.1 Discourse

Discourse is defined by Fairclough (2005) as language based on meaning making. As mentioned in Chapter Three, Fairclough (2005) views discourse as language and associated behaviour patterns that connect social processes and assists human beings in relation to meaning making. This indicates that understanding types of language is crucial in the interpretation of narrated stories and in helping the listener form vivid pictures during the description of incidences. Fairclough further indicates that discourse is also a means of creating a conducive basis for interaction and for those interacting to mutually conceptualise beliefs, values and desires. This indicates the significance of face-to-face conversations which the researcher observed during data collection. The researcher was able to hear about medical discourses which bothered support group members. Through the lens of discourse analyses the researcher was able to see members' worried faces change when they had been unable to make meaning and conceptualise such complicated medical discourses. At this juncture the researcher was able to identify the impact of language on discussions such as this. Language influenced different moods, based on the narrated stories and the capabilities of the narrator to describe incidences and occasions in a manner that made sense to other support group members. While describing situations they once encountered, support group members used metaphors and proverbs to help frame clear pictures and enhance understanding of their fellow listeners. Discourse analysis seemed to be of great significance in this study because it showed how the support groups used their own language and frames of reference to unpack some words like're-infection' and 'adherence' as medical discourses. They needed to understand such words because health service providers referred to these medical discourses repeatedly. Support groups made sure that each medical discourse was understood because they wanted to adhere to their antiretrivirals (ARVs) to suppress viral load and because the meaning making that was drawn from discussing these medical discourses would enhance prevention, care and management.

4.9.2 Narrative research analysis

The data was presented in narrative form since this was the best way of portraying the atmosphere of the meetings and of the discourses (language and behaviours) used by all participants. Narrative research analysis, according to Trahar (2006), refers to the

methodological use of story and usually is concerned with storytelling from individuals with the purpose of persuading listeners to understand their context often with a view to motivating listeners to change. Narrative research analysis is concerned with interpreting general memories which are narrated as previously encountered experiences. Narratives are classified as personal stories based on a thorough personal knowledge of the subject of interest. Narrative research analysis relies on interpretations of histories and personal perceptions of the past shared across the individuals. This on its own allows the listener to conceptualise the context which the narrator refers to.

Narrative research aims at exposing individual experiences but also with a view to making meaning out of the narrative. Individual cultural backgrounds play a major role in the meaning making. Some cultures rely heavily on narratives to impart cultural values and societal expectations. This is supported by Trahar (2006) who refers to communities that preserve their histories, practices and developments through stories which are narrated through friendship networks and intergenerational interactions. Such stories are often used to express their deeply felt joy or pain.

In this study it will be shown that members in the three support groups narrated their stories with the intention of influencing change among the listening members. The stories were internalised and narrated with a view to creating awareness among members to appreciate life and learn from each other's experiences that HIV/AIDS is a manageable condition. This study therefore observes the significance of narrative research analysis because the support groups were telling their lived experiences to instill change in attitudes and behaviour among members who thought living with HIV was an end to their lives. In most cases, support group members narrated their critical histories and appreciated their learning networks because they believed that most ideas on how to manage HIV/AIDS emanated from such stories. However, the narratives which occurred in the three support groups depended on particular forms of language (in terms of vocabulary and metaphors for example) used by the story tellers. The language used was intended to encourage the listeners to paint images in their mind regarding the topic or concept under discussion. In order to fully capture the essence of this process, descriptive analysis in this study is a central feature of discourse analysis of the narratives.

4.9.3 Descriptive analysis

Descriptive analysis is undertaken so that the reader can understand the imaginary pictures that the participants presented in order to understand the scenario being depicted. Descriptive analysis allows the researcher to give the richness, depth and breadth of the phenomenon through verbatim use of language that was used by the participants to influence each other and motivate them to understand medical concepts, or to arouse curiosity as well as to instill fear in the individual to stop habitual risky behaviour. For instance, in this study context, one woman from the mothers-in-law support group described how stubborn her son was towards engaging in protected sex and that she was reluctant to talk to him. She instead intended to invite one man from the fathers-to-fathers support group to assist. Everyone in the mothers--law support group who listened to this description became curious to know the age of her son, and the number of children he had already lost due to HIV infection because he would not use a condom and claimed that only his wife was infected yet he did not know his own HIV status.

Silverman (2004) indicates that descriptive analysis draws on stories that are shared in many ways and which have different functions in different cultures and communities. Silverman further indicates that researchers employing descriptive analysis may be led to reflect on their own learning and educational identities. This type of analysis was made famous through programmes which were intended to represent the stories of minorities who were seen as different or those whose voices might otherwise go unheard or unnoticed. It is the researcher's contention that the stories of these support groups, whose disease has marginalised them in many ways, should be heard and noticed.

Narrative, descriptive and discourse analyses are significant for this study because the research questions were answered in a narrative form and language use was an important aspect of the findings. Therefore, discourse analysis played a major role in interpreting how the narrated stories became useful to each support group member, influencing them to change their behaviours especially those behaviours that put others at risk of being infected by HIV. An example is that of the youth who rely on disinfectants such as Dettol which they think can be used for bathing after practicing unprotected sex to prevent HIV transmission. As this was

narrated and described, group participants could understand that youth practicing this behaviour were at risk of being infected. This led to support groups organising a youth rally to address the myths that put youth at risk of being HIV infected.

4.9.4 Thematic analysis

Thematic analysis was organised in phases after the translation and transcribing of data. The elaboration and interpretation of data was done through the thematic grouping of similar information because I, as the researcher, wanted explanations to reflect the true sense of the stories narrated in support groups without losing any meaningful data. This study therefore thematically organised and analysed information from the learning and sharing proceedings which were held to keep support group members abreast with ongoing HIV information. In order to find themes that best reflected participants' stories, inductive analysis had to be employed through reading and re-reading data to extract significant themes. Silverman (2004) indicates that written data has to be kept for reading and internalising in order to formulate themes from such material. This information from narratives bears the same value and weight as data collected from an interview or questionnaire. Finally, deductive analysis had to be employed to compare the findings and initial themes with the theories of communities of practice, social capital and transformative learning.

The following table summarises the themes and sub themes that emerged from the data in relation to theoretical concepts and also key topics that were discussed in the groups.

Table 2: Indications of emerging thematic analysis and sub themes.

Themes	Sub themes
Communities of practice	- a) Collective decision making - b) Hunters seeking information
	- d) Collective learning - e) Sharing and Learning
	- f) Using external networks for information
	- g) Sense of belonging - h) Identity building
	- i) crossing multiple boundaries
	- j) Developing over time as communities of practice

Social capital networks	- a) portraying a bonding feature
	- b) portraying a bridging feature
	- c) portraying a linking feature
	- d) overlaps
	- e) networking
	- f) interactions
Educational input	- Behavioural change and social relations
Discussions and independent information seeking exercises	- a) Hunting for information
	- b) New meanings
	- c) Gender issues
	- d) Men as heads of families
Myths and community beliefs discussed	-
Transformative learning: New meaning making	- Prevention
Impact on new learning	- Condom use
Resistance	- Behaviour change

4.10 Ethics

Weiner (2015) states that it is important to bear in mind that when the research is conducted on human beings, it must be done in a way that shows respect to all. Respect can be shown by letting people know the researcher's intentions of the research because normally a study is done to address societal challenges. Respect towards humans to a large extent depends on the researcher's commitment to avoid treating human beings like objects and the researcher needs to ensure that the results obtained from the study benefit society. This is where the largest area of ethical concern lies in research. WHO (2006) emphasises the importance of observing the aspect of respect and working together as health professionals within and across countries whenever a social problem calls for investigation in the form of research. Therefore, researchers need to bear in mind that research participants are human beings who have rights that need to be observed. Rule and John (2011) argue that a study bears quality results only if the relationship between the researcher and respondents, or research participants, reflects professionalism of high quality. In this respect, research participants need to feel comfortable and not intimidated in order to ensure useful findings.

My role as researcher in this process was particularly important. I had previously been employed as a senior district counsellor and placed in the Botha-Bothe hospital premises to provide

preventive education to the vulnerable groups such as the youth who are said to be exposed to HIV because they are highly likely to take risks with sexual encounters. I would then provide education to these groups, building on what they already know about topics such as HIV, sexually transmitted infections and TB. I was also mandated to form HIV learning groups where the groups were expected to sit together and discuss topics of their choice relating to HIV prevention, transmission and treatment. Therefore, I would be guiding monthly lessons in each of the mentioned groups. This means there was a significant interaction between myself prior to my research role and the various support groups formed in the hospital premises. All the support group meetings were guided to enhance quality education provision even though the groups played a major role in their own learning because their learning was participatory and every member of the group was expected to take part. In view of my existing interaction and involvement in such groups, I therefore felt well placed to conduct the study. Although it might be argued that I would potentially be biased in my analysis of data or that my dual role might compromise the willingness of participants to speak freely, it will be shown later that the contrary was the case and that my familiarity with the participants on such a sensitive topic proved beneficial.

In my research role I had to contact the head of health services in the district to seek for permission to observe the three support group meetings in order to observe hospital protocol to ensure ethical considerations would not be compromised. This included being invited to district health heads of departments to explain verbally that I was a scholar intending to pursue my PhD at the University of KwaZulu-Natal. I explained my study required me to play the role of the observer in the three support groups' monthly meetings for six consecutive months. These heads of department granted permission and were grateful to receive information and the request for consent. However, a letter was also written seeking for permission (appendix 3), so it could be filed for future reference.

The letter was written because it was the university prerequisite and because it was a demand for the hospital documentation. I, as researcher, also informed the panel of heads of departments that I had already contacted Health Headquarters to seek permission and for assessment of sensitivity of my topic. The health district head explained on the researcher's behalf to the panel that,

according to his judgment, the topic did not indicate that it would impinge on sensitive issues nor harm the participants, therefore he urged heads of departments to grant permission to continue with data collection. A human resource officer was delegated to formalise the request by physically escorting the researcher to the doctor heading the Anti-Retroviral Treatment (ART) Centre to inform him of the request and tell him that the hospital heads of departments had granted permission to commence the study. The head of the ART Centre also needed a letter from the district heads of departments. The letter was written and submitted with signatures from all members of district heads of departments (appendix 3). The doctor responsible for the ART Centre introduced me as the researcher to the senior nurse at ART who in turn introduced me to the support groups to formalise the request and to instill a sense of importance of the study to the support group. This doctor repeatedly said to the nurse:

> Make the support groups understand that Mrs Khang holds a different portfolio this time. She undergoes the study this hospital should have done a long time ago. Let her collect data without any frustrations. I trust she will not violate patients' rights because she is well aware of the ethics.

Then he turned to me, the researcher, and said:

> Let me know if there are any challenges you encounter during this process because I desperately want this study to be a success. I want to offer you all the support you need for the benefit of this study especially because you have done the topic I have long been procrastinating to do.

As the researcher, I had to approach each support group about my request to attend their monthly meetings with a voice recorder to capture the meeting proceedings. This is because several scholars have indicated that an ethically sound approach by the researcher enhances the quality of research and contributes to its validity. Chilisa and Preece (2005) argue that the research participants should be provided with information about the study, its purpose, how it will be carried out and its duration, risks and benefits to participants. The research participants should be made aware that participation is voluntary and that they can withdraw from the study before its completion if they so wish. This universal ethical code has, however, been violated across time, space and culture. In most cases it is the marginalised and powerless whose consent the researchers ignore. In respect to what Chilisa and Preece deemed significant, I wrote letters to

address each support group and requested permission to collect data during their normal monthly meetings (appendix 2). The response was verbal but I recorded their response and accepted it as a formal agreement based on Walliman's (2015) explanation that obtaining the respondents' consent to take part in research depends on their willingness to participate in it.

The researcher has to provide detailed information to the respondents to allow a fair assessment by the respondent that leads to giving informed consent because the nature and context of the research must be understood prior to mutual agreement. Some key factors to consider, according to Walliman (2015), are: clarity, so that the content of the research has to be clearly understood; and brevity and frankness so that the researcher is expected to be open enough to indicate areas in the research where the respondent has to remain calm, brave and collected due to the sensitivity of the issue to be discussed. Clarity, brevity and frankness are key attributes needed in information sharing to allow full participation. Such verbal explanations allow the research participants to understand their rights. This is why such an explanation is recommended to be in written form. Time may be needed for the participant to consider the implications of taking part, and perhaps also for consulting others. When dealing with organisations, written consent is always required.

Therefore, in my case, as the researcher, obtaining the informed consent of the research participants was mandatory and had to involve informing the support groups from whom data was to be collected prior to resuming my observations. I had to clearly explain the purpose of my observations during their meeting procedures and that the observation would do no harm to anyone and the recorded sessions were for future use when transcribing and translation begins so their information would be treated as real without additions or subtractions. Therefore, I had to follow this procedure to ensure that I had not violated the participants' rights or taken advantage of their vulnerability, also to ensure one was loyal to the support groups. As the researcher I had to remind each support group that I was attending the meeting as a researcher and not as a counsellor who could respond to points raised during the proceedings. I was initially worried that the member's reaction towards me would change because I was not attending their meetings to provide my usual guidance. But to my surprise all members in the three support groups felt free to participate and shared their different experiences such as on gender inequality and men as

heads of families without fear. I also had to remind them that they had the right to stop me if they no longer felt comfortable with my recordings because it had to be done for the six consecutive months. I decided to repeat the ethical implications of my study before each session commenced to ensure the support groups were still comfortable about my presence as an observer and the use of a voice recorder at every session.

As the researcher, I had to make sure that all was explicit enough for the support groups to understand and deal with the information presented. To ensure clarity, I had to ask support group members to indicate points at which they would request clarifications and allow members to digest my information without my presence for about five minutes. This is because I knew Basotho were likely to be silent in my presence, but members could feel free to discuss my request during my five minutes absence. However, it was interesting to see that what Weiner (2015), and Rule and John (2011) considered as ethically sound and showing respect for the respondents, was not the case with Basotho. For instance, members in different support groups asked for photos to be taken alongside the audio recordings to indicate who was talking because members believed there was nothing to hide since those that were infected lived openly with the virus. Similarly, those that joined because they were supporting their infected daughters-in-law also did not understand, even after several attempts to explain, why photos would not be taken during the sessions. Members kept on asking me as the the researcher to seek permission from the university to take their pictures as evidence that they were healthy and talking from the bottom of their hearts. It was quite difficult for some members of the support groups to understand that I had to keep the promise of confidentiality and anonymity because it was not guaranteed that all members would feel the same. As an experienced counsellor, I was also aware that what makes the first person feel good might not make the second person feel the same.

This was the reason I could not generalise one person's request to imply that all members were comfortable to have photos taken. Significantly, Rule and John (2011) indicate that taking a picture of a group has to be agreed by each member to allow for differences prevailing in each individual. Anonymity, confidentiality and respect for the translated word in this research situation were maintained to the maximum level. Nevertheless, it was always interesting to

observe the support group members running to the meeting room during the data collection period because they wanted to be on time.

However, there has never been a road without twists and turns. For instance the mothers-in-law support groups they missed their scheduled monthly meeting because they had visitors to attend to. On the day of their next meeting, I also had to attend supervision sessions at Pietermaritzburg and therefore had to ask the mothers-in-law to re-schedule another day. Then their transport costs and lunch had to be reimbursed because they had travelled long distances to and from the hospital premises for this special meeting. Support group members had also extended the long hours of their stay in the hospital due to sessions which were recorded for data collection. I made it a norm to always thank the groups for allowing me the chance to collect data through observation and digital recording. I guaranteed to them that the recordings would only be used for academic purposes and never be used for anything else. My professional role (because they already knew me) and multiple visits made to the support groups helped them get used to my presence and to some extent carried the potential to positively influence people who were being observed to feel less worried about my presence.

I believe it was my profession too that made the support groups trust I would keep their proceedings confidential. Many scholars (for example Rule & John 2011) argue that keeping confidentiality includes ensuring the safe storage of such data. Therefore, a computer password had to be created to ensure that the data was kept and stored safely to prevent unwanted access.

4.10.1 Non-maleficence

Hammersley (1990) argues that the principle of non-maleficence in research is the process whereby the researcher scrutinises the researcher-participant's relations, the research tools used for data collection and questions that will be used to seek responses. The aim is to avoid causing any harm to the participants Therefore non-maleficence is of great significance to any study particularly during data collection process. This is why there is always a need for approval from an authorized body. For example, no study can be conducted in Lesotho on health-related issues unless the researcher is granted consent by an authorized body after checking its potential maleficence to the participants. Therefore, social challenges such as TB and HIV which are said

to be contagious, risky and fatal cannot be researched unless such authorisation has been contained. Hammersley (1990) emphasises that the more sensitive and health threatening a topic seems, the more it requires other parties entrusted to protect human rights issues to consider whether the topic is not just a taboo for the participants but also demonstrates no likelihood of harm or hurt to the participant respondent's emotional well-being. Hammersley encourages arranging for a professional to be available during the sessions so that, in the event that the respondents or research participants feel emotionally disturbed, the professional such as the counsellor or psychologist can attend to their emotional needs. This study observed the aspect of non-maleficence at all costs which mainly includes adhering to the ethics and ethical considerations as recommended by many scholars. A counsellor was made available in case any participants felt damaged by conversations that were covered during the data collection sessions.

4.10.2 Autonomy and respect for the dignity of persons

Every human being has the right to be treated in a way that does not indicate traces of belittling or lowering of human dignity. Dignity is explained by Rule and John (2011) to be an essential ingredient that improves self-esteem and self-confidence. Therefore, it is mandatory that researchers observe human dignity when encouraging active participation from research participants. Rule and John emphasise that research has to be conducted according to acceptable standards of practice and without fraud, deception or dishonesty. According to Punch and Oancea (2014), the principle of autonomy and respect are key in the research process. It is essential to ensure that participation is voluntary, and it must be based on providing informed consent. 'Informed consent' means the researcher must provide participants with the topic of the research, the rationale behind the topic, the expected procedures to be followed, the possible risks which the participants might encounter during the proceedings and the possible benefits the participants might access as a result of the study, so the participants can decide whether to participate or not. Punch emphasises that ensuring the research process is confidential is another way of ensuring respect for participants. This process was ensured as outlined above. Furthermore, to ensure anonymity, all participants were given pseudonyms as shown in table three.

Table 3: Anonymous naming of support group research participants.

The support group participants are referred to anonymously as follows:

Fathers-to-Fathers Chapter 6	Sticks, Lucky, Rocky, Zabie, Soony, Nicky, Nkaoza, TeeBee, Lepzer, Zille, Docky, Madala (Elderly-man) and Zaga. All names are used as is in the study because even participants themselves never referred to each other as 'Ntate' in their group. Every member was called by his name without any salutation.
Mothers-in-law Chapter 7	Mrs Brown, Blue, Grey, Black, Snow, Red Rose, Apple, Peach, Plum, Nuts, Lady Bird. Each name was given the 'Mrs' title because group participants always used a salutation 'mme' before each member's name was called.
Mixed Support Group Chapter 8	Participants are distinguished as male or female as follows: Mr Timber, Mrs Coal, Mr Chain, Mrs Forty, Mrs Boxer, Mr Range, Mrs Fats, Mr Wool & Mohair, Mrs Initiator (Pula-Maliboho), Ngaka-ea-Sehlopha (male)

4.10.3 Beneficence

Johansson (2003) argues that the research has to ensure that the benefits of the research for the participants are maximised. It will be seen that the benefits could emerge during data collection times since some of the discussions involved deep thinking leading to behaviour change, while other discussions became an eye opener and provided for specific ways of understanding human behaviour. Moreover, the participants have to enjoy the benefits of their involvement in a research project, from this juncture till the end when data is analysed and presented. They are entitled to know the results and the recommendations emanating from the study. The support groups were promised that on the completion of this study an arrangement would be made with the hospital management to grant permission to gather all support groups for feedback access and share the outcomes of this study. However, there were still some limitations encountered in this study which contributed to the delay in undertaking data collection.

4.10.4 Trustworthiness

In qualitative research, the purpose of trustworthiness is to ensure that the findings of the study are "worth paying attention to" (Lincoln & Guba, 1985:290). Lincoln and Guba posit that trustworthiness in qualitative research means that attention was paid to four aspects, namely: credibility, transferability, dependability, and confirmability**.** Credibility refers to whether the data is believable; transferability relates to whether the findings can be applied elsewhere;

dependability refers to the appropriateness of data collection methods. Confirmability measures how closely the findings reflected the data collected. During the data collection process, I obtained consent from the participants to audiotape the interviews. I also asked their permission to take notes during the process. This ensured dependability and confirmability of the findings. In addition, I spent a considerable amount of time in the field during the data collection process to ensure credibility. The three support groups enabled comparison of the data collected as a way of addressing the transferability of the findings.

4.11 Limitations to the study

Conducting a study on HIV related issues has always been a challenge because stigma and discrimination surface in different forms. In Lesotho there is still a lot of stigma and discrimination associated with the disease to the point that members of these support groups meet in a vacant hospital building where no one would think that people seen in that area were dealing with anything relating to HIV. These groups were initially accommodated at the ART centre but new members who later joined the support groups were not comfortable about the choice of space, hence the move. The second limitation was the delay in accessing authorisation from the heads of departments for Botha-Bothe hospital to conduct the study and collect data from the support groups because they were busy implementing another project which took their focus and compromised frequencies for their normal meetings. It had been a great limitation for this study to have to request the National Health Ethics Committee (NHEC) for permission to conduct this study because the committee had to assess if the topic would not cause any harm to the respondents nor compromise their rights. This committee took its time to give permission and therefore contributed to the delay to start data collection. Absence of other support groups of this nature in Lesotho (to the best of my knowledge) became one of the limitations to access local literature to refer to for local information and local context.

4.12 Reflecting on methodology: my experiences as a researcher

During my tenure of office in the Botha-Bothe district, the three support groups had a strong relationship with myself and relied on my office for guidance on the steps to be followed in case of invitations for external resources and other health-related information sharing. Being alone in the office of the senior counsellor in the district sometimes posed challenges because there were

times when I had to miss my own training schedules where I had to be capacitated with more skills to facilitate their meetings because the support groups were considered to be 'my baby'. In many incidences I would postpone their meeting dates when I had to be away for some other office responsibilities. This meant I had to request for their transport reimbursement in cases when members had to come to the hospital premises twice a month (for a meeting and for their medical refill). However, I enjoyed working with these support groups so much that I decided to volunteer in the office for a year after my contract expired. I did this due to the strong ties I had with all members. My relationship with these support groups made it possible for my study to employ the observation method without any reluctance because I was strongly convinced that all members were not going to feel intimidated by my presence in their monthly meetings even though I was initially worried that they would not feel comfortable when I used a voice recorder during their meetings. However, my fears were allayed when they all consented to it.

During my first encounter with the support groups, I was reluctant to use my voice recorder to collect data because I thought due to the low level of education of the members, my explanations about the use of a voice recorder in consecutive meetings might not have reached the members' level of understanding. I had expected rejection of the use of the gadget. Instead of rejection members wanted to have photos taken of them because they said their voice contributions alone were not enough, they wanted to be seen by the world as they claimed to have lived with HIV for a long time and wanted publicity. However, I explained this amount of exposure was against the ethics of my study.

Reflecting on methodology, the support groups expressed their appreciation for the observation method of collecting data. They personally indicated that many studies collected data from them using self-administered questionnaires, which they felt exploited them as feedback from such methods was minimal. In addition, they indicated that they preferred a more direct interaction with the researcher. They therefore welcomed this methodology since their information was taken during the session which required the researcher to be part of the learning groups. They individually indicated that observation did not make them feel uneasy about the presence of the researcher. The observation method that I used in this study made me realise that my work as senior counsellor in the Botha–Bothe district where this study was conducted, had created a

useful platform to observe the support groups during their learning process. It was by virtue of this position that I hold that the support group members trusted me and discussed even sensitive topics without hesitation or worrying about my presence during observation. During my term in the office of the senior counsellor, I was mandated to train the support groups on confidentiality, the relationship between ethics and human rights and for them to understand the importance of keeping shared personal information within the groups and that every member had the right to sue the other when confidentiality was broken. The content obtained from such initial trainings played a major role in enhancing trust among the support group members. The length of time I had already worked with the support groups before conducting this study had enabled me to build enough rapport with the groups so that confidential information in my presence was not an issue for them.

4.13 Chapter summary

This chapter has discussed the general research proceedings which entailed outlining the design and methodology. The study utilised the interpretivist paradigm which explicitly recognised that there are multiple truths and interpretations and this paradigm would allow for interpretation of the participants' multiple realities. This chapter indicates that to avail quality descriptive data from the three support groups the researcher had to employ a qualitative approach to collect and analyse data. The chapter further identified the 'case' or unit of analysis within this study, which had been shown to be the three support groups under study. Sources of data, methods engaged in collection of data and how data was analysed, were highlighted in this chapter. Ethical considerations observed in this chapter were underlined together with the step by step procedure followed to access permission to collect data without the suspicion that research participants' rights might be violated. This included meeting the government authorities and requesting their authorisation as a pre-requisite to enhance ethical considerations. Finally, the limitations to the study were discussed to highlight the short falls encountered during data collection process. The next chapter (Five) deals with analysis of the findings focusing in particular on research question one.

Chapter Five: The Support Groups in Action: functioning as communities of practice

5.1 Introduction

The three theories, communities of practice, social capital and transformative learning, guided my analysis of how the support groups operate and learn. This chapter starts with a discussion of how the mixed support group (*Thusanang bakuli*), fathers-to-fathers and mothers-in-law (*Bo-matsale*) support groups operated as communities of practice during their learning and sharing monthly sessions. This chapter illustrates how the support groups reflect the dynamics of communities of practice theory as outlined by Wenger (2006) and its relationship to social capital. Subsequent chapters explore the contribution of social capital theory and transformative learning to analysing how the participants negotiated their understanding of the various discourses that impact on HIV/AIDS information and behaviour.

5.2 The support groups in learning

Learning, according to Mezirow (2000), occurs when an individual encounters an alternative perspective and prior habits of mind are called into question. This means an individual is only able to question his or her belief when exposed to new information. In order for new information to make sense and learning to occur, there has to be some analysis of the new information. Rather than focusing on myth and misconception about HIV and AIDS, the support groups were seeking facts and truth. They were interested in distinguishing between discourses that aim to provide medical information and those discourses that commonly circulate within communities which may or may not be true. Morojele (2013, p. 5) shares the same view and argues that discourses can be described as the 'historically constituted repertoires, systems of social relationships, belief or "knowledges", which we normally take for granted as if they were fact'. Although medical discourses are 'fact' to the medical fraternity, they often compete with more culturally embedded 'fact' in Basotho communities.

The communities of practice theory was used as an initial framework to analyse how the three support groups established in Botha-Bothe hospital worked together to disentangle different discourses in order to achieve their intended learning goals. Wenger-Trayner and Wenger-Trayner (2015) summarise communities of practice as 'a group of people who share a concern or

a passion for something they do, and learn how to do it better as they interact regularly' (Wenger-Trayner et al., 2015, webpage). Wenger outlined various elements and characteristics which delineate how communities of practice operate. For instance, he describes communities of practice as the basic building blocks of a learning system because the community participants are the 'holders' of the competences that make up such a system (Wenger, 2006). In this study, members were bound together by their collective need to acquire knowledge and understanding relating to HIV infection which they needed to deal with directly and indirectly on a daily basis. Therefore, members gathered knowledge through mutual engagement with experts in different fields. Members interacted with one another and professionals to share knowledge and enhance mutuality through those interactions. Communities of practice commonly produce a shared repertoire of communal resources including language, routines, sensibilities, stories, styles and many other things. This means that being in such a community can produce a collective set of meanings only understood by the group through relationships and personal interactions as well as connections among participants. Members in communities of practice use each other's experience of practice as a learning resource. Through these shared repertoires of communal resources learning becomes effective. As a result, members gain competence to share their information with a wider community. They consequently identify themselves as confident individuals to be consulted by others who encounter challenges that are related to their field of competence. The challenges they meet as individuals and as a group are the key elements for their existence. In other words, they 'have become a shared repertoire for their practice'.

These processes were evident in the support groups that were observed in this study. The support groups learned together, using their experiences to clarify complex issues. As a result, they formulated common meanings as a group. Through their learning efforts, members gained a common identity.

Some of these aspects will be further illustrated in Chapters Five, Six and Seven but this chapter concentrates on how the support groups functioned as a community of practice and how their networks of friends, relatives, neighbours, and other organisations were identified as a resource for learning. The support groups created a comfortable learning space. In the process they benefited from and developed networks amongst themselves and other support groups as well as

amongst connections from inside and outside the district. This space created opportunities for many of the support group members to work through challenging issues (such as the concept of re-infection and multiple and concurrent partners) and, through their monthly discussions, they were able to make sense out of these HIV related concepts. When they felt comfortable with their new understandings, they often identified opportunities where they could act as teachers to other members of their wider communities. Mosuoe (2016) posits that her studied support group of Phelisanang Bophelong members collectively learned to accept their HIV status, learned to deal with various emotional abuse from close relatives (husbands/wives, mothers-in-law etc.), fought stigma and turned negative criticism into an opportunity. They realised that the community might call them names irrespective of the knowledge, experiences and the potential accumulated by members in assisting the community to prevent the spread of HIV.

5.3 Support groups functioning as a community of practice

I observed the three support groups in six consecutive meetings which started in March 2013 and ended in August 2013. This chapter illustrates how these meetings functioned. It highlights the elements of those meetings which reflected communities of practice according to Wenger's definition. These include: a) Collective decision making; b) Hunting as a term used to gather information from individuals and organisations; c) Learning networks: internal and external; d) Information seeking; e) Taking collective responsibility; f) Integrating / engaging new members (group forming); g) Sense of belonging; h) Identity building; and i) Crossing boundaries.

5.3.1 Collective decision making about topics of interest

Topics to be discussed in the next meeting were brainstormed at the end of the previous meeting so that members could identify action to take and explore who would be needed in terms of outside support for clarification. During discussion, members were expected to take part in the conversations by asking questions and making some additions, to demonstrate their understanding on a topic. All topics were selected primarily with the intention of learning and with the hope that the topic would influence members to change their perceptions, behaviour and attitudes on HIV and AIDS and other health related topics. The collective nature of the learning network and its activities and relationships enhanced the individual growth of each participant through a process of becoming members of a collective identity. Therefore, all members were

expected to benefit from it. Members valued and practiced collective decision making about the topic of interest.

For example, Mr Range in a mixed support group had realised the power of performing tasks as a group. He reminded the group to observe the power of networking and importance of collective action.

> Mr Range: Unlike the other two support groups, ours has greater advantages over information acquisition because we are a mixed group of males and females. This gives us greater opportunities to easily network with the outside world. By this I mean information can always be accessible to us if all members are devoted. Every one of us has to take action to ensure our learning becomes a success. Testing for HIV and disclosing one's HIV status can be a simple task if it is not an autonomous responsibility but treated as a collective action.

They recognised that the practice encouraged active participation by all. Members had to take part in several ways, including hunting and reporting back to the group, others discussed and related the topic discussed to the HIV experiences each member had in their life. The experiences were shared for collective learning to enhance informed collective decision making. Figure 3 below indicates with arrows the frequency of exchanges each person made during collective learning and sharing.

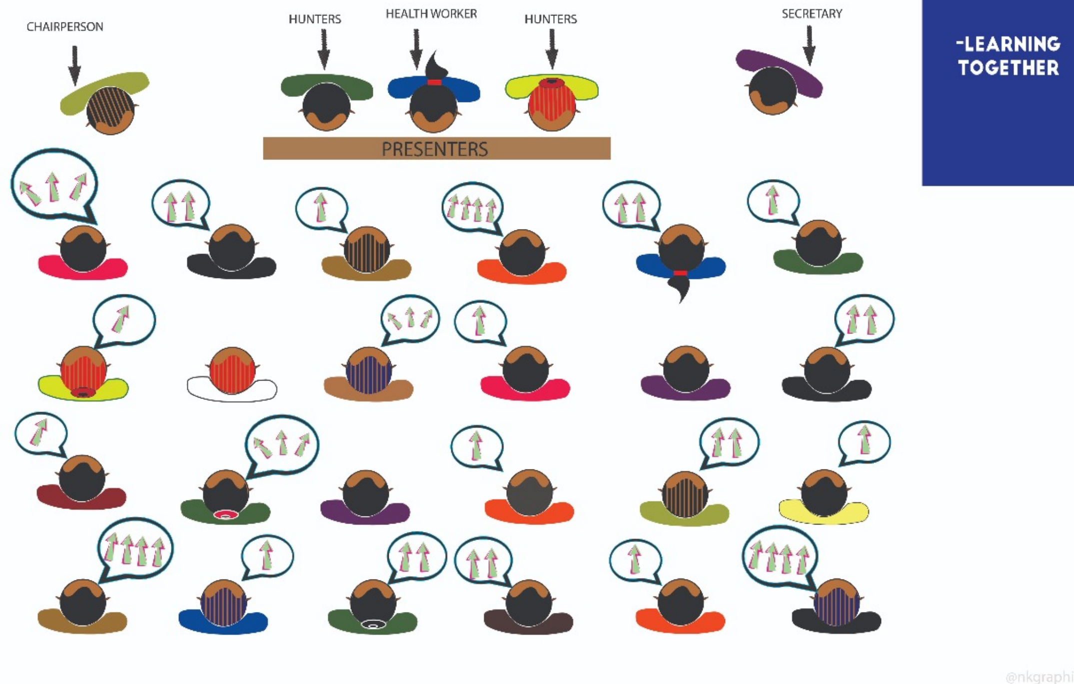

Figure 3: Example of exchanges in community of practice at Botha-Bothe hospital

The arrows indicate the number of interventions per participant. These interventions were in response to each other but were managed by the chairperson.

Sometimes when a topic was of interest, the group would be excited and noisy since everyone would want to be given a chance to voice his/her opinions. This was the time one could notice the occurrence of some side meetings amongst the members regardless of the rules and regulations of running the groups and the training they received regarding their behaviour in meetings (for example, talking without raising a hand, laughing, giggling, and holding side meetings).

Table 4 provides a sample of dates and topics per support group.

Table 4: Sample of topics and meetings per support group

Name of support group	Dates of visit	Topic of interest discussed
Mothers-in-law Discussed in Chapter Six	08 / 03 / 2013 16 / 08 / 2013	-PMTCT & men as heads of families -Multiple and Concurrent Sexual Partner (MCSP) reduction.
Fathers-to-fathers Discussed in Chapter Seven	04 / 05 / 2013 18 / 07 / 2013	-Defaulting and treatment failure -MCSP reduction
Mixed support group (Thusanang Bakuli) Discussed in Chapter Eight	08 / 05 / 2013 03 / 07 / 2013	-MCSP reduction -Treatment failure and myth

Topic selections determined the number of people needed to seek information and places where information could be accessed. It was a must that each person, designated as a 'hunter' should seek information from a place or person as agreed by the support group.

5.3.2 Hunters seeking information

Deciding what to talk about in a meeting became a joint venture for each group. Members in each group would brainstorm topics of their interest which could be discussed during the next meeting. Topics that were agreed upon would determine who was invited as a subject matter specialist to assist each support group with professional explanations to reinforce their learning. They allocated each other tasks to search for information relating to the topic to be discussed in future. Members who were given tasks to search for information on a certain topic were called 'hunters' (*Litsomi*).

This is because they did hunting in the true sense of the word; it is just that they hunted for information and education not for prey. It also indicates that each group could discuss intensively and formulate collective understandings and new meanings about issues. This is where members in each group showed their commitment and their interest in the support group in general and in the learning specifically because sometimes they did not wait for a nomination but volunteered themselves to search for information for the group. They all considered their hunting task to be a 'duty' to collect and disseminate information to the group in the presence of the invited health specialist for that session who would then be asked to confirm or correct what they had collected.

Through this process of information seeking and sharing, new members would gain an identity alongside more established members of the group. Ultimately, they too became experts by copying how activities were done in their respective groups. They would also volunteer to become 'hunters'. For example, the chairlady in the mixed support group said:

> Chairlady: We have reached a point where a topic for next meeting needs hunters. I can see four hands which I know are volunteers for hunting. I am suggesting that we sing while waiting for volunteers to meet right now and divide areas to hunt on to avoid hunting one aspect or duplication.

Hunters would then become part of the trusted members and the group relied on their information hunting skill. Once they became core members of the group they in turn were able to help other new members gain self-confidence and increase participation (as a social practice) in the community of practice. This hunting process facilitated their collective learning process where all members benefited.

5.3.3 Collective learning

Wenger (2000) indicates that communities of practice historically existed because cultural and tribal practices had to be communally learned to reflect oneness. Wenger sees communities of practice from an organisational point of view to be used, for example, by a group of nurses in a ward working out how best to assist a patient or by engineers interested in car parts design. This indicates that communities of practice are versatile in nature because they can operate in a formal, non-formal or informal setting for the purpose of collective learning.

In an African context, collective learning is a strong resource because it reflects the African tendency towards communal growth and advancement rather than individualism (Maskell, 2000). An example from the fathers-to-fathers support group from a man named Madala (also known as Elderly-man) illustrates this. Elderly-man wanted to share his skill with other members to confront their boredom challenges which he suspected was pushing some of the support group members into engaging in unnecessary activities that risk catching infections. He was willing to network with other handicrafts producers, so the group had a wider choice on what to do.

> Elderly-man: Therefore, I suggest that we all get engaged in other activities that can fully engage us from morning to evening. I am suggesting that we go and think of income generating activities so we go for those [only] and occupy our minds on useful activities when we have not come to these meetings nor hold educative sessions like I mentioned earlier. You know I am making small silos for a living and selling to individuals who buy them for decoration purposes. I am willing to share that skill to gentlemen with good will to learn and keep ourselves busy so we [can go to] sleep tired and avoid catching many human infections. We need to agree on the number of silos to make in a month so we work hard to reach the target and create a stable market. Saga has a skill in making Basotho hats. We won the first prize in the tourism competition. Maybe next time we can come up with several other suggestions on activities that can generate our income. It can be easy for most of you to choose the one that suits your interest.

The aspect of collective learning for Basotho is strong. It is embedded in cultural practices and place names such as the notion of *Thakaneng* (place selected for youth gatherings to learn culture) and *Khotla* (a place where males gather for problem solving and learning law and order.) This communal learning atmosphere was an important learning resource because in this collective learning space it became very apparent that medical discourses alone could not be the only source of information about HIV. The medical discourses needed to be understood from within the Basotho cultural context. One example can be seen from a comment from one of the women in the mixed support group (Mrs Forty) when she revealed how she had not understood the value of avoiding breast milk when one is HIV infected:

> Mrs Forty: Today I learned that it takes some time for most people to disclose their HIV infection. That was why my relative could not tell us immediately what disease she had. I am saying this because I was the first person she disclosed to when she was ready. The second thing I learned today is that, before I got tested for HIV, I used to be very annoyed by the ladies who would not give their new born babies breast milk. … I have changed all I believed in back then. It is unfortunate that I have become knowledgeable late in my days when I have said and done things that embarrass me and I do not want to recall them.

The groups demonstrated that there were several discourses that competed with each other around HIV, for instance: adherence, reinfection, Multiple and Concurrent Sexual Partner (MCSP) reduction and many more which will be explored in detail in Chapters Six, Seven and Eight. It was imperative that a forum such as community of practice could enable those discourses to be discussed and integrated with the medical messages and discourses. This, it is argued in this study, has been the strength of these support groups and the way they have

operated as communities of practice. Collective learning practice led members automatically to share and learn for all members to benefit from the collected information.

5.3.4 Sharing and learning

Sharing and learning is a crucial aspect of community of practice theory in that shared learning and interest of its members are what keeps the group together. The group exists because participation has value for its members and gives identity to all members. A community of practice's life cycle takes a while to come into being and may live long after a project is completed or an official team has dispersed (Wenger, 1998). The group members in this study had accumulated their knowledge in this way through monthly discussions over the past three years, although observations for this study only took place over a period of six months.

The following extract from the mothers-in-law meeting, held on 08/03/2013 where fourteen (14) members discussed Prevention of Mother to Child Transmission (PMCT) of HIV and the role of men as heads of families, illustrated how sharing as a means of learning was an integral part of their learning process and identity building.

> Chairlady: Who can be willing to share her stories? You know very well that your stories have made us who we are because they have been our books since this ‘school’ (support group) does not have books for us to read but we see ourselves being cleverer (sic) and wiser every day.

They were giving and receiving vital information and social support through their participation. At the same time, they were developing confidence to act as advocates of their knowledge to other community members. This is where communities of practice system is regarded as a dynamic system where discussions could take many directions but remain focused on the shared topic of interest (Nielsen, 2010).

The activities of the communities of practice became an integral focal point for framing their conversations and for analysing their external engagements from within the collective membership. The three support groups intensified their search for information and perfected their hunting skill through visiting other organisations in order to access information. The use of

external networks to gather resourceful information for other members became habitual and beneficial for the groups.

5.3.5 Using external networks for information

These three support groups ran their meetings like formal learning sessions where the chairperson for the day facilitated member's participation to share what they had collected. Members asked for information from their families, their neighbours and relatives, they made use of external networks where private organisations and various government ministries were visited for information seeking purposes. They had strong links with organisations such as World Vision, Red Cross and Lesotho Planned Parenthood Association (LPPA). These organisations effectively acted as social capital networks. Families, friends and neighbours could be described as bridging social capital. The wider organisations performed the function of linking social capital (Woolcock, 2001).

For instance, Mrs Blue from the mothers-in-law group was a short woman labelling herself pony (referring to the shape of pony horses). She was very vocal and expressed her concerns as follows:

> Mrs Blue: There is need to pay a three day visit to Lesotho Planned Parenthood Association (LPPA) to learn whether education given to young women who had gone to access Family Planning in that organization can be of benefit to mothers-in-law.

She was certain that health issues are dynamic and believed there was a lot of information given to young women which could be of benefit to them as mothers-in-law to share amongst the support group and with their daughters-in-law.

> Mrs Blue: ...Learning from LPPA will help us know what to teach them when they get back to us at MCH, not so? We might as well ask for a slot to give education on topics we feel are a must for young women to learn about. I hope I had not been distracting by making this suggestion when we are already waiting to meet visitors. Chairperson, please make sure I attend LPPA sessions with someone next week. Remember the nurse in-charge of LPPA is interested to see us being educated. Every time she visits the hospital and finds us seated for these meetings, she usually comes and motivates us.

This use of external networks was also reflected as part of Wenger's notion of engagement as a form of belonging – as will be explained below.

Over time the three support groups became more assertive and confident about performing their tasks. This was the time when group forming became crystallised and membership remained constant and more people were eager to join and learn from various sources of knowledge as the existing members did. Therefore, group forming became exceptionally important.

5.3.6 Group forming

There was a process of group forming as identified by Wenger, McDermott and Snyder (2002). The first time new members took part, they had automatically seated themselves on one side (near the wall and seated in a row so they could all see, none of them at the centre or anywhere else in the room) as if mixing with others was wrong. This was observed during March and April 2013 meetings. Sitting on their own side indicated that they felt they were outsiders (on the peripheral side of the room). It symbolised the notion of legitimate peripheral participation (LPP). They had not identified their relationships with the rest of the group members yet. According to Wenger (1998) these members cannot learn much at this stage as they are trying to figure out how the support group is run, how others get a chance to participate, how much experience they have, what is it that they know which can be shared with the rest of the group, and whether what they know can be valuable to other group members. Therefore, new-comers were allowed access to such a community of practice but they spent some time at the periphery of the practice and only gradually moved to the centre of the practice to become full participants.

At each meeting members agreed on goals and formulated strategies for tackling their identified task for the following meeting. This was observed as a common practice in all of the three support groups. During the subsequent meetings, newcomers copied how the meeting was run and began to mix with other members, until they could also participate and saw their opinions and ideas being considered and their points raised being approved. After some time, these new members no longer sat in a row on one side of the room, they began to sit in a scattered form across the room and were actively participating like everyone else (they became active members

of the group). They had built a sense of belonging to the groups and could be given roles of being on 'high table' as chairpersons or secretaries.

Woolcock and Narayan (2000) emphasise three concepts for individual and community development: common knowledge, collective recognition and identity. This emphasis crystallises communities of practice in action for the support groups.

The involvement of new members impacts on the giving out of information to the community and taking topics which need to be researched. It was for this reason that new members would be inducted into the rules of the support group each year. During the first meetings of the observation period (in March 2013), all support groups went through the same procedure. First, they introduced themselves to each other; their introduction had to include each member's expectations and what prompted them to join the support group. Then they read old and amended rules and regulations to the rest of the members for familiarisation. An example follows from the transcribed observation and recording of the mixed support group:

> Chairperson: As you can see, we have eight (8) new members, they should be given the rules and regulations so they feel at home and are able to participate. Please continue reading them aloud (pointing to the lady sitting next to me).

Secretary for the day began reading the rules and regulations but asked for attention from old and new members as this activity becomes a yearly refresher education for old members of the support group.

> Secretary: May I have your attention ladies and gentlemen, thank you chairperson for the opportunity you are giving to me now. I am beginning to read you the rules and regulations which we are abiding by as a support group which we are hoping will keep this support group vibrant and growing. (She took a few steps from where she was seated to the front of the room and wiped her smiling face with her left hand while she was talking. She looked happy and felt very proud to be given the task of reading the rules and regulations).

My observation was that these rules and regulations were formulated during the January and February meetings in all the groups. The other ten months of the year were allocated to learning

only. If any member identified a point to be added in the rules and regulations, they just noted points in their individual note book and used them as amendments to the rules and regulations the next year at the same time (January and February). They had realised the importance of orientating new members and that new members normally feel as though they do not fit in anywhere and might initially feel unimportant to anyone.

The introduction was read from the book by the secretary:

> These rules and regulations were formulated by the members of the support group during their sitting as a group in four consecutive meetings. Every member of the group contributed with very good suggestions which were seconded by other members before each rule and regulation could be considered as final. This is to say they were not imposed on us by any authority anyhow. We are always very happy to abide by them because we made them ourselves.

The secretary then read out the rules and concluded:

> Thank you, chairperson, for allowing me chance to remind all of us of our rules and regulations and I would also like to thank every one of you for being so attentive, my fellow group members. (She went back to her seat with a song, most of them seemed to know it and sang with her until the chairperson for the day raised a hand and all kept quiet).

From my observations of each group, all the rules and regulations were the same, except in the fathers-to-fathers where there was an additional rule of no smoking. Orientation for new members through reflection on rules and regulations emphasised to members the values of the groups and prompted a sense of belonging for all. This enhanced all members' commitment to active participation in various activities assigned to the group from time to time.

5.3.7 Sense of belonging

Sense of belonging is defined as the experience of personal involvement in a system or environment so that persons feel they are an integral part of that system or environment (Cherkowski, Walker & Kutsyuruba, 2015). Usually this sense is built after several incidences of members' compliance to perform duties indicating their full involvement, ethical decision making and participation. Sharing responsibilities is a crucial aspect to enhance participation and

boost a sense of belonging in the support groups. One way to do this is for information gathered from friends and families to be shared among the members of the group, which reinforces their learning. These interactions enabled the groups to commit themselves to each other and strengthen their sense of belonging to each other. This was very evident during the discussions on topics like multiple and concurrent sexual partners' reduction where all members took part and the duration of the meeting was extended because members felt they needed to execute all points and allow all members to contribute.

Lambert, Stillman, Hicks, Kamble, Baumeister and Fincham (2013) argue that individuals feel a sense of belonging when they can appreciate the depth of their social relationship and connectedness to others. Bonding with other people can enhance happiness and contribute to a meaningful life.

In the support groups information gathered from friends and families was shared among the members of the group, which reinforced their learning. A sense of belonging therefore influenced identity building for these members.

Different Modes of Belonging

Wenger (1998) discussed three modes of belonging in communities of practice which evolve sequentially as follows: a) engagement b) imagination and c) alignment. Wenger says in a normal situation, members first need to be engaged to prove their membership, then imagination comes as a result of the manner in which one got engaged and can imagine one's level of involvement in certain activities. This in turn enables one to align and gain strength to work harder for the benefit of the group. In the communities of practice as operated by these three support groups, the three modes of belonging reinforced their self-directed learning process which was embraced with increasing competence and confidence. For example, one could see an element of competence in running a meeting as a chairperson or taking minutes for the day and people showed confidence in sharing how they operated. By the end of the observation period (six months), all these groups demonstrated the existence of three modes of belonging to their different support groups as outlined by Wenger (1998).

As the first mode of belonging, engagement became crystalised when the support group members were engaging with other members and the rest of the community. This was where all the three support group members were participative and doing activities intended to provide the groups with knowledge to enhance their learning sessions. An example of this relationship that crystalises member's engagement is seen when Rocky, a male in his late forties in fathers-to-fathers support group, encouraged members to continue requesting information from organisations relating to their topic. Therefore, he tried to direct the support group to meet government ministries which might contribute to the support group's learning process. In this way members used their connections and relations as a resource in order to solve their problems quickly, share knowledge and make connections with organisations, all of which indicates a community of practice in action. Rocky emphasised the importance of indicating to new organisations that the group had a good reputation and recognisable relations with other ministries who had previously offered help and he encouraged members to approach new ministries who might be able to open further avenues of communication.

> Rocky: World Vision is supporting most of our efforts which are beyond our financial scope because we tackle our problems as a group and they have seen that we never disappoint them. So let us try Ministry of Trade and Development to assist us because our challenge this time is to ensure that our businesses are sustainable. Our letter must indicate all these other organisations which we have good relations with so that they too may not hesitate in helping us through this challenge.

The way in which members engaged with each other while helping a colleague with a problem and their relations with the organisations which gave them some explanations had reached a point of mutual trust. Making connections became an integral part for all the support groups to access information from knowledgeable individuals, groups and ministries. This attitude, too, is aligned with Wenger (2000) who emphasises that engagement is an integral part of communities of practice. Shared activities and problem-solving are core features of such engagement.

The second mode of belonging in communities of practice discussed by Wenger (2000) is imagination. This aspect can also be aligned with identity building (discussed below). It can be illustrated here in the way that these three support groups considered themselves to have gained enough knowledge that allowed them to call themselves 'male nurses' in their different

communities and be consulted on health issues. They saw themselves using their accumulated knowledge to rescue other community members who may be at risk of getting infection. They imagined a changed identity due to the projects they intended to begin and engender hope for success.

For instance, Lucky from fathers-to-fathers support group imagined how the group was helping others in his community through his identity as a 'male nurse'.

> Lucky: Again, they tend to forget that we did not vote to be HIV infected and may be one day they too will be infected, who knows? By then we will be 'male nurses', like my friend used to say, and treating them with the knowledge we are gathering in this SG. Maybe they are lucky because we hold some public gatherings and give them preventive education to delay their infection, otherwise they could have been infected a long time ago as I know some of them are very careless when it comes to sexual activities.

Imagination went further than identity building. Mr Timber, in a mixed support group, imagined an improved standard of living of the group emanating from the financial contributions made by members to establish a vegetable project. This was seen as a viable income generating activity which could assist the support group to grow and change their lives. He motivated members to establish this vegetable project by constructing a positive imagination of members gaining a good reputation in their area, and who might change neighbours' perceptions because their hard-work would be addressing unemployment challenges for their community. Mr Timber's vision was to see members working hard for the success of their project. His deepest aspirations were to see members creating employment for the group and their respective neighbours. Giving this big picture might be enough to motivate the support group members to act.

> Mr Timber: When I look at this project, it can take us far, we can change our name automatically from a bunch of HIV infected people to commercial farmers who might soon create jobs and employ even our biggest enemies who are sitting in house shadows and watching our steps (where we are going).

According to Wenger (2000) this imagined role is not just a fantasy but rather indicates reality because these groups had demonstrated that they had gathered the necessary knowledge to respond to community needs and demands relating to HIV and AIDS as well as other health issues. Such initiatives to work together and pass on their knowledge and skills were evident

across all three support groups. For instance, Zille, Elderly-man and Mrs Peach, clearly specified their interest in how the groups could enjoy the shared benefits of learning together, and sustain their networks which resulted in collective benefits. When members had constructed a new image for the group in the community, they easily aligned and deeply engaged in their different activities.

The third mode of belonging for Wenger is alignment. The support groups were making sure that their interests were sufficiently aligned with other health processes so that these other health issues could be sufficiently addressed during different health activities and effectively handled even if they were beyond the health provider remit. Therefore, members aligned with other health related matters such as growing vegetables that could be sold. In this aspect, members emphasised the use of fresh vegetables as opposed to preserved ones to maintain good health. These ideas in turn could promote their vegetable market idea.

For instance, mixed support group announced its intention to produce vegetables on a bigger scale to become commercial farmers. They brainstormed the market opportunities together to ensure they did not keep their produce for a long time. They planned their market strategies together in this business and foresaw it thriving. Wenger (2000) indicates the importance of trust in communities of practice relationships, not just personally, but also in their ability to contribute to the enterprise of the community so that members feel comfortable addressing real problems together and speaking truthfully. This aspect is illustrated by Zille who was certain that their enterprise could prosper through outreach activities. Zille was a business minded male in his early forties.

> Zille: Let us take our vegetable produce to the outreaches because many people who gather at the health outreach can buy them. We are the ones mobilising for these outreaches, so we can even sensitise the community during mobilisation that they should not forget the importance of good nutrition as vegetables are a good source of preventive nutrients.

Elderly-man (Madala) as his name implied, looked older than the rest of the group members. Elderly-man suggested the need to market their various skills to prepare for a future when their term as hospital support groups had expired. He quoted the success of a ‘joint myth campaign’

which they held through the financial support of Ministry of Sports Youth and Culture earlier in 2013. Therefore, he was certain that his suggestion could benefit both the group and the community. Elderly-man reflects Wenger's notion of 'alignment'. He saw that their local products could effectively benefit the external population, thus going beyond the group's own engagement. He foresaw the possibilities that through more determination the group could align the three support groups' practices with the demands of their community.

> Elderly-man: We need to be pro-active, plan for future to avoid boredom. We can utilise our multi-skills to establish a consulting firm of experts. We have knowledge as a big resource that no one has in our respective villages. We need to register with an umbrella body of people living with HIV so that we can be authorised to hold workshops for special groups I usually talk about. I have already researched that churches have included HIV education in their calendar, let us take the opportunity to collect as little as M100 from each church when we give HIV education. Then other activities will come up as we proceed.

5.3.8 Identity building

In this study, building identity was a group's effort prompted by members being aware of their level of understanding and capabilities to impart knowledge to the rest of the community. During the process of my observation period it became apparent that the eight new members no longer felt isolated, but they were proudly styling themselves with new collective identities such as 'educated village nurses' through having acquired health enhancing knowledge. (Meeting of the 03/ 07/ 2013 by the mixed support group discussing treatment failure and myths.)

Lucky from fathers-to-fathers support group, for instance, was confident in identifying the group as educated teachers because he felt they had undergone a specific training which equipped them with skills and techniques to share with their learners. This man was confidently talking about their collective identity as teachers and educated village nurses.

> Lucky: So this can only be achieved if we allow ourselves to learn so we become not just [ordinary school] teachers, but 'educated teachers'. You have already seen that our community members have been relying on us when they need health related information. To them it does not matter where they meet you but they throw in questions expecting one to give a convincing response. We have been considered as 'educated village nurses' since a long time ago. Let us work for our titles and prove them right.

Some group members had accumulated their knowledge in this way through monthly discussions over the past three years, although observations for this study only took place over a period of six months. As they became involved as equal members of the support group, they learned to reflect on their experiences, synthesise different kinds of information, effectively evaluate situations and make difficult decisions. Such decisions included disclosing their HIV positive status and reducing multiple and concurrent sexual partners for good, as a sign that their participation in the support group had made a great impact on their lives and had changed their behaviour. One man summarised the way in which the fathers-to-fathers support group operated to some visitors and newcomers:

> Sticks: Maybe we can even show them that there are a lot of people who want to establish their own new support groups because they could see that our support group has made a great impact on our lives and that we have changed a lot since we have been meeting and learning together, which is easier because none of us considers himself number one while others are 'number last'. Do you know why I like the way we are learning? It is because we are not writing tests since people like me left school because we were failing and hate tests. Look at us, even without writing tests we are male nurses and can cure a lot of them by only giving them knowledge.

Fathers-to-fathers identified themselves as male nurses due to knowledge gained through sharing experiences and learning together. Mothers-in-law (*Bo-Matsale*) also identified themselves as not just women but knowledgeable women who need to multiply in numbers. While in the mixed support group (*Thusanang Bakuli*) they identified themselves as a group of experts who know HIV from their own personal experiences and from the clinical point of view.

> Mrs Boxer: The idea of putting us together to discuss HIV related issues was intended to make us understand our condition better so we adhere to treatment. But we have exceeded this intention because we are now educated referral points for our friends, neighbours, relatives and the community at large because they realise that we are not just women supporting daughters-in-law, but we are far more knowledgeable. … look at us, HIV education is in our blood.

These practices reflect Wenger, McDermot and Snyder's (2002) notion of communities of practice where they emphasise the power of imagination as a mode of belonging that allows the community to see itself in new reflective ways due to its new competences that inspire

participation. Wenger et al. describe this learning as expanding one's horizons so that one is able to access expertise from wider social structures in more efficient ways. For instance, the support groups constructed their image in the context of a bigger picture where they saw their new knowledge helping them fit into a wider resource network of experts.

The mothers--n law members identified themselves as 'books' with the understanding that one gains knowledge, information and education from a book that is similar to their manner of learning through sharing their experiences. The one narrating his or her story becomes a book to be read by other support group members. In the mothers-in-law support group, the chairperson laid the ground for the members to share with each other. When these members compared their understanding and acquaintance of medical discourses to being human books that can be read and from which information can be sourced, they illustrated an increased self-confidence and new sense of identity. This was what the chairperson had to say:

> …Let me give a chance to the ladies who said they are our books to be read by sharing the stories of their experiences related to the Mother Baby Pack [MBP].

Mrs Peach, a woman in the support group responded:

> Mrs Peach: I just want to allay your fears about contents in the Mother Baby Pack. It has proven to have all contents a mother and the baby needs pre- and post-natal. If you could remember, there was a time health workers were told to provide inclusive services. 'Treat an expectant mother like you will never meet her again, in case she is not able to return for follow up services, then it becomes less of our worries'. Nowadays support groups are educated and are included in the health structure because there is a lot they can offer to the public educationally.

The support group now had such a reservoir of specialist knowledge about HIV. The chairperson compared the support group with an institution of higher learning, labelling it 'university' due to the efforts they were making in acquiring information for the group and ensuring that other people benefited from it.

> Chairperson: Do not learn to forget these things ladies because if you want to think deeply you can realise that we have opened a university here in the hospital premises. Is it not so ladies? It is so. (All were shouting and clapped hands.)

Wenger's (1998) theory reflects what this support group member was saying in relation to how learning impacts on an individual's sense of self.

The different communities of practice had 'become associated with finding, sharing, transferring, and archiving knowledge, as well as making explicit 'expertise', or 'tacit knowledge' (Wenger 1998, p. 1). The support groups created a comfortable learning space. In the process they benefited from and developed networks amongst themselves and other support groups as well as amongst connections from inside and outside the district. As a result, they crossed multiple boundaries.

5.3.9 Crossing multiple boundaries

Crossing multiple boundaries according to Wenger (2000) involves effecting actions through inviting participation of different levels of connections. Crossing boundaries entails the use of connections, negotiations, coordination and transparency for positive end results. The chairperson in the fathers-to-fathers support group was aware that members had gained knowledge which he urged them not to forget so they could share it with those who did not get the same chance to learn as they had. While comparing the support groups with a university, the chairperson saw the breadth and scope of the group's identity expanding; they had already crossed multiple boundaries. He foresaw multi-membership directly or indirectly participating as a result of new possibilities to learn. This was where members felt confident to share knowledge with their different social groups such as funeral schemes (regarding condom use), initiation schools (in relation to all health issues), and *pitiki* (women's competition) activities (PMTCT and MBP) to impart learning.

Support group members expanded their learning programme by jointly taking new initiatives of educating other members of society. Crossing multiple boundaries needs strong ties and networks by the members. For instance, Nkaoza in the fathers-to-fathers support group intended to share his message and skills about consistent and correct condom use with a burial group. The burial group is not even concerned with health issues. Nkaoza's decision was based on his desire

to share his knowledge with the group that would benefit from his intervention because he had previously identified the need raised from this support group.

> Nkaoza: Can I be allowed to take these [instructional] steps with me next time and use them with a group of my burial society? Because previously we had a discussion on condom use and they said it tears off easily even if it is put correctly. But now I have learned that the little nipple on top of the condom is necessary to prevent it from breaking, so it has to be left hanging like a real nipple.

In addition, they considered running a myth campaign for youths as a means to create awareness of the damage that myths can do to spread HIV infection, and as a means to promote HIV prevention methods. The campaign illustrated efforts to cross multiple boundaries by shifting their focus from educating adults in a confined hospital space to holding a youth campaign. The chairperson for fathers--o fathers support group wanted to invite officials from the Ministry of Sports and Recreation responsible for youth activities, the District Administrator, District Councils, District Health Manager, Public Health Nurses and World Vision. The intention of the three support groups was to bring all the youth together (literate and illiterate) for educative sessions on myths and facts about HIV prevention. Their intention to address a larger audience meant involving relevant officials for moral support and guidance.

> Chairperson: We have invited your offices [to a youth officer invited to the SG meeting] because we intend to hold a big campaign to address all sectors of youth under the two principal chiefs in Botha-Bothe. We thought of outsourcing guidance from you so we do everything right. The youth encounter the same challenges imposed by their age. These three support groups are concerned about our youth and intend to protect our future leaders from HIV. Therefore, we thought a health campaign can be a cheaper means to address them in great numbers.

A member of the fathers-to-fathers support group also suggested that members pay a visit to the traditional initiation school owners (*Bo-Ramephato*) and hold an educative meeting with them that would propose the introduction of HIV education in the initiation school. This would take place while initiates were still in the Lesotho mountains where initiation schools take place. The aim of the speaker was to provide orientation on how HIV prevention can be enforced and the role that initiates can play when they come out of such a school. These plans indicate there was a determination to cross multiple boundaries through the use of local structures and authorities

such as initiation schools who may not be conversant about the prevention of HIV infection. Rocky (in the fathers-to-fathers support group) highlighted that most members in the support group had attended initiation school during their youth. He considered that as an advantage for them to share their knowledge with the initiates. He was aware that if their behaviour was left unattended to, HIV would spread like a wild fire, therefore something must be done to save new initiates. This was where the element of crossing cultural boundaries could be seen among the support groups.

> Rocky: you have heard that I am concerned about our initiation schools. We usually praise ourselves to be educated when it comes to health related issues. We need to demonstrate our education by imparting it to people who need it most. My plea right now is for us to propose a meeting with initiation school owners (*Bo-Ramephato*) to allow us time in their schools to educate their boys so they graduate with all sorts of information. I want to use my position in the initiation schools committee to take your request to the authorities to allow us time before initiation school term ends.

These support groups also aimed to cross geographic boundaries, for instance, visiting the nearby district (Leribe) to ensure establishment of new support groups, and gender boundaries, where they insisted on the inclusion of their alcoholic husbands, and social boundaries to share their experiences with a larger community through requesting slots in public gatherings. For example, the mothers-in-law support group recommended 'hunting' alcoholics who never bothered about health issues. The concern was that populations usually found in bars never attend any educational forums. The members were aware of their relationships with such populations. They quoted the common saying that if Mahomed would not go to the mountain then with God's power the mountain has to move to him. Mothers-in-law were concerned that if they did not cross the boundaries and merely stayed confined in monthly support group meetings, the significance of their formation would not be known. Therefore, they were determined to make a positive impact by contacting neglected social groups. Mrs Blue pointed out that alcoholics are their sons, fathers to innocent children, husbands to their daughters and added that women too are alcoholics and need help before it is too late. She was worried that delaying to offer information delayed their behaviour change; as a result, more damage would occur. Mrs Blue expressed her concerns as follows.

> Mrs Blue: I have previously asked if we are not running late to address the alcoholics. I have already proposed if fathers-to-fathers can join us to attempt the task. We need not forget the importance of relations we have with the alcoholics in the community. They form the best part of the population which, if neglected, could raise HIV infection rate higher than it is now. They need to change their sexual practices and maybe we could be lucky and rescue a lot of them even from alcohol. They need to be reminded of their responsibilities in their respective families which alcohol does not allow them to exercise.

The chairperson in the mothers-in-law support group was aware of the determination her members had towards the task of sharing and learning health information. She was aware that the group was indomitable in crossing the boundaries to disseminate their familiar and newly acquired medical discourses. This was expressed in her concerns that members should spread the word in relation to everything that they were taught.

The three support groups met individually to discuss strategies to ensure the success of their task to cross their district boundaries by taking the initiative to assist other districts such as Leribe and Mafeteng to establish their own support groups which could operate in a similar manner. They prepared different speakers during their invitations to these districts so they could demonstrate that every member had a voice and all had acquired the same knowledge.

In spite of their increased self-awareness most members felt the need for involving outsiders as knowledge experts to contribute to what they were learning. They wanted to do their own hunting first so that they could demonstrate their own learning, partly to impress their visitors with how they were seeking out knowledge but also to show how everyone was a participating learner.

Wenger emphasises that the act of being a community of practice deepens the mutual commitment of members when they take responsibility for a learning agenda which pushes their learning practices further. Activities towards this goal include exploring new knowledge. It was at this stage when the newly acquired knowledge and skills for implementing a new course of action became realised. This was confirmed by what the chairperson in the mixed support group said.

> Chairperson: … Ladies and gentlemen, we have a new task to perform in this community which is to impart knowledge. Our level of understanding can be reflected by sharing what we have with people who do not have access to information. Joining the support group gave us new roles to act like *basuoe* (teachers) which we already perform in our families and different neighbourhoods. I just wanted to emphasise to all of us that we need to commit ourselves and extend the roles to the community at large. … when do we join *Pela-tsoeu* villagers to perform this task?

Brookfield (2000), Kegan (2000) and Guba and Lincoln (2005) describe the process of planning a course of action as acquiring technical and practical knowledge that allows members to share and interpret their experiences and construct new understandings. Their emphasis is on individuals being able to produce technically useful knowledge. These authors recognise knowledge as a key source of competitive advantage in the world. In the case of HIV infection, having knowledge about HIV and its prevention represents having a competitive advantage in the African context. Systematically addressing the kind of dynamic 'knowing' that makes a difference in practice requires the participation of people who are fully engaged in the process of creating, refining, communicating, and using knowledge.

The process of hunting and networking in communities of practice literature has strong connections to the relationship building process that is identified in social capital literature. The next section therefore expands on how the support groups utilised and expanded their social capital through their engagement as communities of practice.

5.4 Social capital

The way in which members networked reflects the concept of social capital as outlined by Woolcock and Narayan (2000) who discuss how bridging and linking with external networks enhances collective participation. Bonding capital is associated with close knit ties and is contrasted with bridging capital, which enables the individual to access resources outside of his/her homogeneous group (McClenaghan, 2000).

The social capital literature highlights the importance of bonding, bridging and linking social capital in providing opportunities to gain access to sources of knowledge, skills and ideas. However, the capacity and confidence to develop and nurture this form of social capital is largely learnt through having access to, and being embedded in these social relations in the first place.

This broad concept of social capital embraces values such as solidarity, communality and compassion, dignity, and respect as ingredients for harmonious group working. Social capital relationships comprise bonding, trust, and norms of behaviour within a social setting and this culminates in reciprocal relationships which is a give and take relationship. In the support group context, members gave out information to their families, neighbours and friends and sometimes they went back to them to seek clarifications to be taken back to their members for educational purposes. In this way they collectively learned and identified themselves as knowledgeable groups. These support groups had adopted norms and networks that enabled them to act collectively and enjoy benefits of networking, bonding, bridging and linking ties which contributed positively to their learning.

5.4.1 Support groups portraying bonding features

Bonding refers to deep inward-looking relationships characteristic of primary social groups such as families, which reinforce alliances among similar types of people (Bochenek, 1999; Tsarenko & Polonsky, 2011). In this study, there are indications that all members in the three support groups relied on close ties. For instance, family members and close relatives had access to information and education from the groups. This is witnessed by the statement from one of the mixed support group members as cited below:

> Mrs Coal: We have been given information on HIV and AIDS. The group does not expect us to keep this information but rather share it with family, and friends. My personal advice for you is to build warm relations starting from our respective families where we are able to openly discuss our challenges including seeking all sorts of help from people whom we believe support us, then we can expand our relations to a wider community and seek help without fear of being discriminated against.

Bonding social capital alone, however, is insufficient for the purpose of educating a nation about the risks and challenges of HIV/AIDS. There was evidence that the support groups as communities of practice also created opportunities to develop bridging forms of social capital. When members had drained their bonding social ties, they felt the need to consult other sources for information seeking and began to explore wider contacts.

5.4.2 Support groups portraying bridging features

Bridging social capital is made up of the ties which exist between more distant acquaintances from other circles, groups or social classes, for instance loose friendships and workmates (Woolcock, 2001). This is a relevant concept for support group members who are connected to wider community members. Bridging in this Lesotho context brought support group members in touch with a wide range of resources as well as giving them the ability to leverage these resources to become informal teachers. Bridging social capital, in other words, was important for members to reach beyond their immediate community to participate in the wider community of professional educators. Mrs Forty for example, from the mixed support group, planned to go further than what the group initially thought of doing. Mrs Forty used her ideas to bridge the group across health education to agricultural connections. Following the suggestion from one of the other members to develop income from agricultural produce, Mrs Forty identified another department that could assist the group with trade and marketing. Her suggestion effectively moved the group from an inward-looking group of victims to an outward-looking group of survivors who can contribute to society. Below is Mrs Forty's statement:

> Mrs Forty: we could help each other with the capital and sell fruit and vegetables at a market place, share business ideas and contribute. We also have a resourceful department of trade and marketing. They can offer free training on how best we could meet our market demand. We need to divert from being offered sympathy and turn to offer it to those who may need it. We need to show people that we are no longer patients. We also need to invite our neighbours who are active in food production to join us. These will prevent the community from vandalising our produce. Bringing more people into the project will also reduce stigmatisation and labelling. Remember, we were once taught to avoid stigmatising ourselves.

There were other examples of how group members drew on their bridging social capital networks to enable them to take an active role in society through a joint process of education about HIV, become self-sufficient themselves and also contribute to community needs. Tee-Bee from the fathers-to-fathers support group was determined to have a potato production business. He invited his members to make business connections so they had a collective production and market supply. His invitation also included a notion of a bridging social capital since he intended to use the relations with his son-in-law who produced vegetables elsewhere. He also included reference to his white friend across the border. Tee-Bee's response is cited below:

> Tee-Bee: Those of you members who will be growing potatoes, I am certain about market access. I have a son-in-law who produces all sorts of vegetables except potatoes; he supplies a big reliant market in town. He is the one who encouraged me to produce potatoes on a large scale to supply his market. This is why I propose to you that we need to work together and secure that market throughout the year. I can even make sure we access hybrid potato seeds from my white friend's farm across the Caledoon border so we get the right seeds.

While bridging networks in these support groups often use relatives to connect with people who can extend their access to new resources, linking networks, by contrast, are better for linkage to external assets and for information diffusion.

5.4.3 Support groups portraying linking features

Linking is an extension of bridging networks. Such networks can lead to contacts with professionals such as the medical profession, people who are brought in to widen the network of resources for the support groups. Linking social capital reaches out to people in dissimilar situations, such as those who are entirely outside of the community, thus enabling members to leverage a far wider range of resources. In this case, further analysis indicates that members in the support groups were members of a diverse range of groups such as church groups, initiation schools, entertainment groups such as *pitiki*, burial societies, parliamentarians and their sports tournaments as well as vegetable production schemes. They demonstrated further linking ties by inviting contributions from other departments such as World Vision, Labour Department, Local Government, Ministry of Agriculture and Food Security and Ministry of Youth, Sports and Recreation.

These relations meant that they had connections with a wide spectrum of people making it easier for them to access various resources from their extended relationships. Linking ties were crystalised when the support groups were invited to establish similar groups in other districts such as Leribe and Mafeteng. For instance, fathers-to-fathers held a meeting with the Mafeteng district males. The chairperson in this support group was determined to see their visit becoming a success. He focused on preparations for a shared agenda to allow sharing of ideas and resources.

> Chairperson Soony: I am intending to ask the group that we prepare a joint agenda in order to be focused on what to share with Mafeteng males. A joint agenda will be shared amongst three people who will be presenting to break monotony and justify that we always work as a team. This will also be a strategy to arouse interest in our audience and proof that every member of the group is an expert. Remaining members in the trip should be given a chance to respond to questions arising. Ministry of Health gave us a chance to share how and what we learn as the pioneers of these kinds of support groups. I believe mastering the task will open broader avenues for us.

Linking ties were also evident when the mothers-in-law support group intended to visit World Vision to inquire about the financial resources which were previously given to children as transport to the ART Centre to access their medication.

> Mrs Blue: World Vision (WV) has been a strong shoulder for the support group by funding bus trips for HIV infected children to collect their medication (ARVs) from the hospital. Orphans and vulnerable children who need food and shelter are liaised with World Food Program (WFP) to assess the condition of the children prior to food packages' distribution. There is also UNICEF that supports with school fees and school uniform, while WV extended its focus by building Orphans and Vulnerable Children's homes and provides life skill training for all people linked to the organisation.

Woolcock (2001) and Ahern and Hendryx (2003) highlight that social capital networks provide a base for identifying additional resources that could be used to address weaknesses in a particular group and the nature of external resources may complement the group's existing resources. The idea of support groups deciding to learn together and share health related challenges seemed to be the core business amongst all the groups. Members felt that being in support groups reinforced close interaction amongst members and expanded their access to information. The notion of collective learning was visible and reinforced by strong bonding, bridging and linking social capital.

The diagram below illustrates how social capital concepts manifested amongst the support groups. It indicates the networks of internal and external resources where bonding, bridging and linking elements of the theory were crystallised.

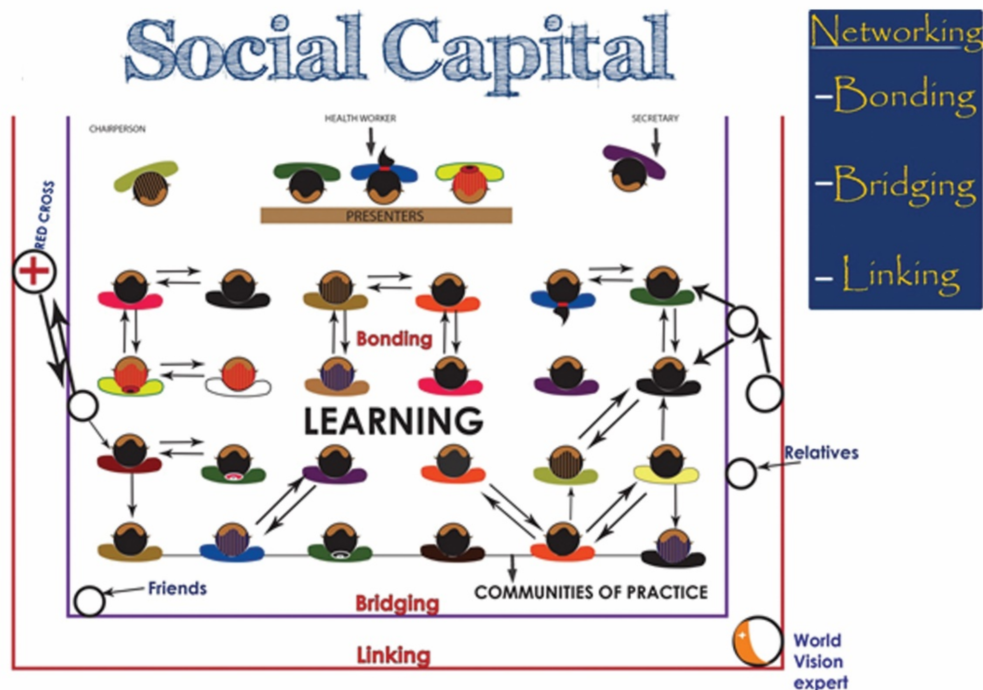

Figure 4: Social capital in action

5.5 Comparison of concepts between the two theories

There are a number of overlaps between communities of practice and social capital theories. Both theories refer to similar concepts as follows: networking, interaction, sharing and learning, people acting collectively, collective identities, participatory approach, strengthening of internal and external relationships. While the emphasis of communities of practice is on learning, the emphasis in the literature on social capital is the building of social cohesion and resilience. In the context of HIV/AIDs needs and the support groups, however, these two emphases complement each other because people affected and infected by HIV/AIDS need to both educate others and build their own resilience against the disease and community stigmatisation. The following section summarises how these overlapping concepts can be understood in relation to this study.

5.5.1 Networking for information acquisition

The term refers to a set of connections among people. In the context of my study, all support groups rely on their networks for information acquisition. They realised the importance of accessing information from their friends, neighbours and relatives every time when need arose. They admitted that joining their various support groups was not because they knew more but because they needed to learn more. In social capital theory, networking occurs in three levels (bonding, bridging and linking ties,) The three groups showed evidence that they were able to develop and capitalise on these different network levels to facilitate coordination and cooperation of members and information exchange with the outside world.

A learning and sharing platform was sometimes given to the organisations outside the health sector such as Lesotho Planned Parenthood Association, World Vision, Red Cross and Blue Cross. In the six months of my observation, they had two groups of visitors who came to see how their support group operated. One group was from Partners in Health (PIH) because they were intending to introduce such groups in the rural clinics where PIH operates. The other group was a delegation from the Ministry of Health who had come to see the groups' progress and who gave them learning materials (adherence flip chart, male circumcision flip chart and many brochures on health related topics). The Ministry also provided flip charts and stands and a blackberry cell phone which would be given airtime monthly to help them organise their meetings effectively and be able to liaise with other resourceful organisations where they would want to get the services from.

5.5.2 Interaction as a learning tool

The aspect of interaction appeared to be crucial as a learning tool and a means of building resilience. The significance of interaction becomes central when members identify individuals and organisations that can provide needed learning materials. An interaction facilitates participation of the three support groups; it enhances members' involvement and opens learning opportunities. Both networking and interactions made it easier for the group to create connections and engage into learning. For instance, this was what Zille in the fathers-to-fathers group said:

> I would like us to make our visitors aware that learning in this form does not change an individual overnight. Hence the need for interactions with various people who can support, motivate and assist us on several issues. They need to know that we are in the third year since the formation of the support groups in this hospital. Therefore, in short they need to have patience and strong interactions with people who understand the importance of learning in groups. Had it not been for individuals and group interactions outside this support group, some of us would have not gained knowledge we have now.

Through interactions these groups participated in broader learning systems in which their knowledge was distributed diversely to their families, their community members as well as in other districts such as Mafeteng and Mohales' Hoek. Other formal and informal societies visited them to learn how they conducted themselves in a meeting.

Interaction also improved members' confidence and expanded their horizons so they developed new ideas for resilience and self-sufficiency such as producing vegetables for marketing.

5.5.3 Sharing and learning

In the context of this study, sharing and learning entails using connections and relationships as a resource in order for support group members to solve their problems. Knowledge, skill and experiences were shared for learning purposes by these three support groups to anchor the learning process. This process of sharing and learning is a feature of communities or practice (Wenger, 1998). It is also regarded in the literature on social capital and lifelong learning (Field, 2002) as a process that contributes to building social capital. Moreover, this learning through a sharing process reflects the African communitarian commitment to the collective (Ntseane, 2011). Through these practices, members feel that their experiences are of value to others in the group, and they are therefore motivated to share more frequently.

5.5.4 People acting collectively

Communities of practice and social capital elements of cooperation and collective action are evident in this study when members shared roles in searching for their learning materials and discussed the benefits of their lessons together. This collective activity bound members in the three groups to develop a shared understanding of their learned material. Acting collectively therefore enhanced mutuality as all members in the three groups were able to trust each other to

bring needed information that would enlighten all members. Acting collectively enabled a rich fabric of connectivity among people.

5.5.5 Networks of relationships

Each individual amongst the support groups had their own network of relationships from whom they would gain information in order to benefit the whole group. These relationships enabled members to infiltrate the community without the need to set an appointment. Support group members relied on relationships to access information. Therefore, relationships of mutual acquaintances and recognition were crucial for all members.

Figure 5 illustrates the summary of overlaps in communities of practice and social capital theories.

Figure 5: Shared concepts between the two theories

5.6 Chapter summary

This chapter explored how the support groups operated as communities of practice and how social capital both contributed to, and developed, as a result of their communities of practice activities.

The three groups had planned and created an innovative way of learning. Members decided for themselves what they wanted to learn about during their next meeting. They would also decide on subject matter specialists who could visit them during their discussion to expand on their selected topic so they could build a common understanding. However, they also took the initiative to do their own research on the topic and allocated each other tasks to research on and report back during the next meeting. This was where the name 'hunters' emanated from, since members who were given tasks were called the 'hunters'. These members seemed to be therefore learning as a group. They shared their experiences of life to assist each other in solving a challenge.

Communities of practice and social capital theories emphasise the significance of relationships and networking as the means to access information (hunting), and sharing experiences to enhance the information hunted and to reinforce understanding amongst the group members. The group members practised what they had learned, for example the practice of exclusive breastfeeding new-borns for the consecutive six months which saved more children from HIV infection. The groups began to gain respect from families, neighbours and friends for managing HIV and ensuring zero new infections in children born from HIV infected parents. This was enough for the groups to gain fame and new identities as 'village nurses' and 'teachers'. The communities began to consult them whenever health related challenges were encountered. These factors also reflect an African perspective as outlined by Undie and Benaya (2006) which values the concept of the collective as a learning resource.

In communities of practice theory (Wenger, 2000), identity building is a crucial element of the process and outcome of learning together. In the process of finding their own identity, members created bridges across communities because in developing their own identity, they saw themselves as 'hunters' (information seekers), 'books' (sources of information) and 'nurses' (people who could provide care and support). A strong collective identity developed, involving deep connections with others through shared histories and experiences, reciprocity affection and mutual commitment.

This study has shown the balance between internal and external networks where bonding, bridging and linking forms of social capital were clearly shown. In this study, different ministries and private organisations significantly assisted the support groups with needed information, guidance and education. This access motivated these groups to develop educationally.

The following chapters explore in more detail how each support group in turn addressed a topic of interest as a result of their communities of practice approach. These chapters identify how the different discourses were negotiated and how many of the learners went through transformative learning processes. The chapters also highlight where such learning did not necessarily take place.

Chapter Six: Fathers-to-fathers Support Group Meeting on Re-infection and Condom Use

6.1 Introduction

This chapter answers research question 2: how do the support groups make meaning out of the different discourses associated with HIV, its prevention and care? It specifically addresses question 2a which looks at the relationship between medical discourses and layperson's discourses. It illustrates how this support group navigated the medical discourses in relation to re-infection and condom use, during the time of data collection. It shows how the men were developing in confidence as a community of practice, but also highlights how participants were not all at the same level of understanding, which impacted on their transformative learning process and willingness to adopt the new medical discourses. The findings therefore also answer research question 3 – how does meaning making impact on their new learning?

The support group had been meeting monthly since 2011 with the purpose of learning and sharing information relating to HIV and many other health related issues. These monthly meetings gave the group enough time to address unclear issues and ensure that every member gained new knowledge to share with friends, neighbours and the community at large. The group's monthly meeting discussion was usually specific and directed towards the day's agreed topic. However, each topic would be discussed at length to ensure members' satisfaction and their understanding of different medical discourses such as re-infection and condom use.

Although there was an overall progression in terms of attitude towards HIV issues, the members generally discussed and dealt with one topic per meeting. Members were always determined to discuss each topic until they believed that everyone had reached a common understanding and acceptance of a goal for moving forward. If the goal was behaviour change, the group would ensure that most members were willing to change and make a plan of action for developing their lives. During the data collection period of 2013 the following topics, as outlined in the following table, were covered. The number of attendees per meeting is given to illustrate members' increasing interest and eagerness to learn regardless of the recording procedure taking place in each meeting.

Table 5 – Topics discussed by fathers-to-fathers group

Dates	Number of Attendees	Topics Discussed
08/02/2013	12	Election of new committee and confirmation of the use of voice recorder in the next meetings
08/03/2013	15	Re–infection and condom use
04/04/2013	17	Discrimination
07/05/2013	16	Defaulting and treatment failure
20/06/2013	17	Male Circumcision
18/07/2013	15	Multiple and Concurrent sexual Partner (MCSP) Reduction
16/08/2013	17	Preparing for a trip to Mafeteng District. Water Based Lubricants

For the purposes of this chapter the focus is on the meeting that discussed re-infection and condom use since it provides a good example of how medical discourses interfaced with a layperson's interpretations and meaning making.

6.2 Re-infection as a medical term

Re-infection is a medical term which needs to be understood from cultural and layperson's perspectives. According to Bernard (2010, webpage), ''re infection refers to an HIV positive person acquiring a second strain of virus from someone else with HIV''. The first part of the meeting endeavoured to address the meaning of this process. It will be seen that several layers of understanding emerged among the members before a final definition was crystalised. This meeting endeavoured to enable that learning process and enhance meaning making.

All monthly meetings started with a prayer. This one included a plea for spiritual guidance from God for the health professionals regarding the topic in question. Members believed they needed extra energy and guidance from God to 'soften' their brains so the new information on re-infection and condom use would become easier for them to understand. They believed in the role of spiritual power to carry every member through difficult times such as this one where they were faced with the struggle to simplify complex health issues in a way that would meet their

level of understanding. It is an important aspect of the support group's collective appreciation of spirituality as a support mechanism that was reinforced by the meetings but also became a uniting force between meetings. For instance, the prayer ritual at the start of each meeting was a feature of their bonding social capital relationship. This feature of spirituality as a contribution to learning is rarely mentioned in western literature but is referred to by Ntseane (2006), for instance, in relation to transformative learning and African perspectives. Basotho, like many Christians and Africans, believe in the presence of the supreme power for intervention and guidance when they need to perform beyond their ability. Therefore, this group invited God's presence in their meeting with the same hope.

> Chairperson: We pray for our health professionals and those we have invited to come today and share their knowledge Lord, that their mouths be filled with good information to educate us and show us the good way to follow in order to remain positive in life regardless of our HIV status, Lord. We have prayed and called for your love to be with us all, in Jesus Christ our saviour, Amen. (All said Amen and pulled their chairs again to sit down).

The chairperson reminded members of the previously agreed topic for the day (re-infection) and encouraged hunters to be ready to share their 'prey' (findings) across the room for all members to learn from. All members knew that some men had been appointed as hunters to seek out information from relatives, friends and neighbours to bring back their findings to the group, thus reflecting the self-directed learning dimension of a community of practice which made good use of social capital networks. Preece (2014) reflects on a similar process of self- directed learning in a very different context of university doctoral students. Preece further indicates that learning in a cohort system relied on collaborative and self-directed learners for the cohort arrangement to yield positive results. It was evident in the support group that similar learning strategies were being employed.

> Chairperson: Three men took assignments to go and ask what re-infection means, how it occurs. (One of the men raised his hand to show he wanted to speak and was given a chance to report back).

Sticks was a short young man in his mid-thirties. He had a deep voice and great sense of humour. Members laughed every time he spoke. He indicated that he had used his bridging social capital

networks of lay people, starting with relatives and friends and even proceeding to a neighbouring village, to seek his desired information: ‘I asked two friends living in a village across from mine about re infection’, Sticks said:

> Sticks: If you have TB and use medication, then you get another disease, let’s say HIV, you are being re-infected because TB is an infection and HIV also an infection, so you have two infections together that is why it is called re-infection.

This interpretation missed the point of the above stated medical version of re-infection. Sticks said that two or more different diseases attacking one person at the same time was re-infection. This was an indication that Sticks collected information beyond his level of understanding. However, his interpretation provided evidence of how the community discourse differed from the medical discourse. Re-infection in his layperson’s term seemed to focus on the notion of ‘re’ meaning ‘two’ so that re-infection was interpreted as two infections.

From my observation, the explanations of re-infection seemed to be overwhelming to these support group members. Gupta et al. (2018) argue that people with limited health literacy often lack knowledge or have misinformation about the body as well as the nature and causes of disease. Such individuals usually remain naïve and misinterpret health terms. Labhardt et al. (2014) also indicate that in many other countries, health knowledge deficit has a negative impact on behaviour and results in the misinterpretation of crucial terms. Labhardt et al. therefore advocate community learning support for individuals intending to understand the relationship between medical terms and their lifestyle. In this exchange, Sticks was looking down and playing with his bracelet while talking until another member asked him to face the audience (‘*taba li mahlong*’). Perhaps that was also an indication that Sticks was uncomfortable with a medical discourse which cannot be explained or translated easily as a cultural or behavioural issue.

This medical concept was elaborated further by the second hunter. Lucky was a man in his late forties. He usually volunteered to take on hunting tasks as he believed that his neighbours were always interested and helpful in ensuring that he did his assignments as accurately as possible. His neighbours proved to be a rich resource for the group’s community of practice and they also acted as source of social capital. Both Woolcock (2001) and Cuddapah (2011) argue that suitable

learning can be accessed formally and or informally from individuals that surround the learner (neighbours, family and friends). In this case, however, it would be seen that the complexity of the term could not be fully answered through such bonding or bridging social capital resources alone.

> Lucky: Re-infection is, if you are infected with TB and you take treatment to get better and finish your six months of treatment, but after some time that TB comes back again, you become sick and get more medication of TB which also has pills and injection and you can then be treated for more than 6 months. This is because you were re-infected with TB and had a much stronger TB; that is why you are no longer taking pills only but also taking an injection too to fight that re-infection. Re-infection is having the same type of disease twice, yet one had already treated that type of disease when it attacked for the first time.

This interpretation of the medical discourse for the term re-infection used the example of TB, thus showing it did not necessarily always relate to HIV. It also indicated the complexity of the term for lay people because they were supposed to be searching for HIV related re-infection. However, the third hunter, Rocky also joined in. He was a man in his mid-forties, He usually took his hunting assignment beyond the minimum requirements. He never researched from one person alone but would go to different places for information seeking. He believed that a hunter had to fully understand the information that was collected before taking it to the groups. This time, he indicated that re-infection could also mean transferring the same infection to different people, for instance infecting a spouse and a concubine. He was confident that his explanation was right and simple to understand.

> Rocky: I don't recall this person's wording, but he said re-infection occurs when one person, who has a certain disease, for instance, who has STIs infects more than one person, going to several people and infecting them can be some kind of re-infection, that person infects and re-infects and re-infects and so on and so forth.

Even the notion of re-infection had different meanings for individuals within this group, because, as a medical term it was effectively a theoretical concept. That is, the word had its own medical meaning. The meaning this hunter gave to the word was on the basis of his daily understanding of the notion of repetition. It appeared therefore that the lay concept of the word was interpreted either as an activity that repeats itself, as a repeated action on one person, or across several

people. This created confusion in the group. The explanations produced strong reactions from other group members. There was a roar of response from the men who were listening. They seemed to be roaring because they did not believe it. This was also indicated from the continued conversation below.

> Chairperson: Let us keep quiet gentlemen and let these men finish what we have asked them to find out for our benefit. If you feel what he reports is out of line, just keep quiet and wait for your turn. (Looking at the second reporter), are you through my man with your report?

Actually, the chairperson had already realised that Rocky was not yet finished with his explanation. Rocky was hoping that the last portion of his hunted information might be impressive to the members. He believed that varied opinions from people from whom he hunted information gave him an array of information from which he could choose suitable answers for the group. This practice made him the usual hunter (researcher) because he normally contributed even if he was not appointed a hunter. Bates (2014a) indicates that usually socially strong groups need to recognise and accept the uniqueness of their individual members, to realise their different levels of commitment to improve working relations. Bates gave an example that levels of passion in human beings differ. Members need to encourage each other to strive for best performance regarding attainment of their intended group goal. For instance, in this group it was evident that Rocky was allowed to reveal a higher level of passion in hunting tasks than others in the support group.

> Rocky: Let me finish off with this small clarification so that my peers *(banna bana ba heso)* cannot roar like I am lying. (He continued): This individual will first be infected with itchiness, others with very strong discharge *(Seso se Setona)* (literal translation is a male discharge which has been persistent even when treated with home prepared medication). Another infection will be a very offensive smell, later on he will be infected by the person who has some wounds around the genital area and definitely (*kea o hlapanyetsa* – I swear) our person will have the same wounds at the same area and you should know that when he has some wounds he is approaching death *(o fothola kepa* - dies) (he frowned and sat down).

This time, Rocky focused on the symptoms rather than the process of infection through interaction which once more took the audience away from understanding how re-infection

occurs. Rather the emphasis was put on what the infection itself may look like. It seemed he painted such a threatening picture in order to emphasise his points to the support group members. But it also stimulated the group discussion so that several members contributed their own meaning making. The lay definitions of this term prompted several people to respond. Members could sense that each definition that had been collected from hunting was not right. Each of the hunters wanted to share what he had collected with the aim of giving the best information. But the confusion in explanations illustrated that some medical discourses needed to be explained by professionals. Zabie was a tall and slender man in his late thirties. He usually blamed the infection for exposing him to poverty because it drained all his funds before he realised he was HIV infected.

> Zabie: I was murmuring because what this gentleman was told about STIs was not true. But I would rather say, he forgot what was said, like he said, he forgot the words of the person who explained to him. What happened was that, this gentleman had infection, (pointing to a man near him) and that other person also had infection of some other kind, then the first and the second person infect the third, that third person will be infected and re-infected with two diseases. [The presence of] STIs did not mean that it was the STI which was from Mr. X who had STIs initially; there was no way doctors could see that this STI was from Mr. X.

There was a sense that this person was trying to shift the focus of 're-infection' away from its connection with multiple partners because that was an activity that he, as a man, was unwilling to acknowledge in terms of its contribution to re-infections. Instead he argued that it was simply an infection of two separate diseases. Weiner (2015) indicates that a large number of males are unwilling to stop infidelity and cheating. Their behaviour is a set-back to re-infection concerns that usually centre on betrayal and multiple partners. Weiner argues that such behaviour is a threat in the millennial era where TB, STIs and HIV impact negatively on families and marriages. This attitude seemed to be reinforced by another member. Soony was a man in his mid-thirties. He supported Zabie's opinion and the two were not willing to change their behaviour towards the practice of multiple partners, instead they found means to avoid how re-infection takes place. Their explanation avoided being specific on the negative impact caused by the practice of multiple partners. Soony endeavoured to distinguish between the different explanations, by diverting the group focus on re-infection of HIV to STIs so the concept would carry less weight:

> Soony: Thank you, Mr. Chairperson, the first hand said exactly what I wanted to say, I wanted to ask the reporter whether he has ever had STIs, then how can one identify that three people who are infected and have seen the doctor were infected by one person? There is no way how that can be identified, therefore, with your permission Mr. Chairperson can we throw away this second report and pretend we did not hear it because it is misleading. Thank you!

He sat down and there was clapping from other members. That suggested there was a persistent denial among some of the members of the reality implications behind the medical discourse of re-infection. The suggestion that one can be infected through multiple contacts challenges their own lifestyles of multiple partners, so there was a sense that they chose to side-line the idea that one person can infect multiple partners.

The different explanations of the one term re-infection therefore suggested that lay interpretations of medical discourses needed constantly re-visiting because the lay interpretation was understood in relation to people's existing meaning perspectives so one would only get a selective understanding. Murphy (2003) and Monyake (2010) argue that subsequently a lay person's interpretation of health beliefs (for instance: it is a woman's problem if the family does not have a child) remain embodied in their minds until education regarding such issues is internalised. Therefore, through discussion and further exploration the men would slowly come to terms with the medical version of the terminology. This meeting illustrated how the members were constantly trying to negotiate an understanding of medical concepts in a way that would enable them to internalise their understanding within their own meaning perspectives.

At that point the chairperson intervened and summarised the confusion as a way of introducing the health professional, a female nurse:

> Chairperson: Ok! Ok! Guys it is true that re-infection seems to be a difficult topic for us to tackle alone. I am of the view that even the first reporter was not right in all the information he got from two people he asked.

The medical professional was invited to contribute to the understandings expressed in the group. Since she had heard the men's own understandings, she was able to build on what they knew and

thus provided a clearer explanation. The support group members had demonstrated their devotion to learning and their persistence in trying to simplify complex issues like, for instance, re-infection. They had heard of that medical discourse in health education sessions even before they tested for HIV. The chairperson also illustrated the effectiveness of this community of practice approach by acknowledging the nurse as a form of linking social capital, but only after allowing the members to conduct their own research and discuss their findings. He continued:

> Chairperson: However, because we have two topics to discuss let us not waste our time and take too long even when the topic is difficult for us to give out what we know, let us give the nurse a chance to explain what is meant by re-infection so that we all learn from her. Nurse, we wanted to try re-infection on our own before you could help us through but it seems like re-infection is not child's play, it might take us too long before we get it right. Therefore, I am giving you a chance to talk, we need to admit when we have failed to do our job, or when the task was very difficult for us to handle,… Quiet please! ... Nurse the platform is yours.

The nurse's approach also acknowledged the men's individual efforts. It was significant that she had obtained a degree in adult education and thus appeared to utilise adult education principles by starting where people are. Pitikoe (2016) and Mosuoe (2016) for instance indicate the significance of starting from known learning concepts and proceeding to more complex and unknown issues relating to the same concepts. The nurse took care to encourage their learning strategies, ensured she did not belittle their efforts, and also appealed to their masculinity, thus paving the way for a more receptive appreciation of her own messages, as well as encouraging further efforts to learn independently. Mezirow (2009) argues that a learning process begins with a meaning scheme, which is the collection of concept, belief, judgement and feelings that shape a particular interpretation by linking known concepts to new learning. Mezirow (2009) believes that new learning begins with connections of simpler terms to complex ones. Therefore, it is argued that new learning practices generally need to be connected with older information already familiar to the learner to make learning easier.

> Nurse (female): Thank you Mr. Chairperson, I want to thank every one of you gathered here for the sake of learning together. What you do is a great job. I have always wanted to congratulate you for the wise thinking of accessing free education in relation to health issues because you all know how expensive education is these days and I wish none of you is taking these efforts for granted. Education is a treasure that even the most

intelligent thief cannot take away from the person who has it. I like it because most of you have families to lead. These families should not only depend on you for security at night because you are a male and have huge muscles. The family must also depend on you for education too. When the head of the family has education the whole family becomes educated and also the community because he will assist the neighbours and relatives with that education he has. Let me go back to the point of explaining what re-infection is, but before I continue, please give a big hand to all gentlemen who have shared what they found from friends and neighbours about re-infection.

After due group appreciation, the nurse continued:

> Nurse: Thank you guys. Re-infection is very simple, it has to do with getting an infection, passing it to someone else but at the same time getting that same disease again from the other person. We talk of re-infection, when the person who has a disease or infection gets that same infection again from the other person.

The nurse brought the dialogue back to HIV specifically, to ensure the group understood the consequences for HIV re-infection. The nurse's definition differed from those of the hunters who gave reports. All the hunters' definitions were not convincing because the first hunter associated re-infection with TB while the second hunter associated re infection with two different illnesses infecting one person. Their responses indicated that hunting efforts were made but hunters brought responses that were not totally accurate. However, the similarity in the three definitions was that the two hunters and the nurse focused on diseases and a person being infected while already ill. It is important to note that the nurse spoke in metaphors to emphasize her points and in order to reflect the Sesotho language and culture of talking through metaphors. Bernard (2010) indicates that an illness that bears a foreign name is usually interpreted through the use of metaphors as an education strategy for familiarisation purposes. Bernard further emphasises the significance of using metaphors to interpret an illness for adoption of strategies required to prevent its occurrence. The nurse used metaphors to attract members' attention and to ensure simplicity.

> Nurse: Let me give you a straight example where re-infection is mostly used, in HIV infected people if one person is HIV infected, and this person for example will have HIV which has a head and horns like that of a cow in his body. This person then purposely or not purposely indulges in unprotected sex with another sexual partner who has HIV too. Then he finds out that the second sexual partner has HIV which has wings like a bird. Then, the first person whom we know was HIV infected with HIV that has a head and

> horns, is found to also have another type of HIV which has wings, then we are saying, our first person is re-infected. It is called re-infection because it is one infection on top of the other infection in the same blood and body. Remember guys that every time one indulges in unprotected sexual intercourse with an HIV infected person one gets infected again and again.

The nurse provided animal imagery that was intended to relate to the men's understandings but then she also reiterated in plain language what re-infection means. So she used the medical discourse in a culturally acceptable way in order to try and reinforce the medical message. Bernard (2010) indicates that unless an illness is looked at in three ways: through social, cultural and medical lenses, the illness becomes too complex to understand. Bernard's argument supports the way the nurse attempted to accommodate these three factors to explain infection in a culturally acceptable way. The Ministry of Health and Social Welfare (MOHSW, 2007) also argues that, ensuring understanding of a foreign concept can best be done through the use of metaphors as a means to enable the mind to shift from simpler and familiar concepts and develop a new but correlating vocabulary. Maybe the nurse drew on animal metaphors because these support group members had named themselves hunters. She moved into technical language slowly so the audience would have a better chance of following her explanation:

> Nurse: That is why even the number of HIV in his body would increase even if one was taking ARVs. It is sad because every time one practices unsafe sex, with an infected person, their HIV exchanges with even the HIV infected one who was using medication (ART) and will go and infect that other person. You cannot believe that a person who was infected by the one on ARVs gets HIV ARVs in them. This means that if this second person who was infected by the one on ARVs chooses to take those ARVs which the person who infected him/her was using, the medication will not work. One will have to be given ARVs which are different from the ones used by his/her sexual partner. That was why sometimes you will find that because nurses, counsellors and pharmacists will not be aware that the individual was re-infected with HIV (in spite of using ARVs) they will only realise when ARVs are not functioning and CD4 goes lower regardless of the use of ARVs. Then after several tests, this individual will be told that his body was resistant to treatment and then other types or regimen of ARVs will be tried till the right type (regimen) was found which can work and CD4 increases while viral load decreases. I hope you all still understand and I hope you are clear about what re-infection is.

The members were nodding and with clear facial expressions. Their positive response could be because the nurse started from a popular position of animal imagery, moving from there to the unknown vocabulary and therefore the complex issues became simple. The nurse once again

referred to the layperson's own dialogue and put it into context to allow the mind to shift from known to unknown:

> Nurse: The small clarification which we were given by the second speaker, explains STI steps as the infection progresses if the individual is not consulting a doctor when he first feels the itchiness, then the same STI will create an offensive smell and progresses to wounds if not attended to. However, I am grateful that you all attempted to hunt on this difficult topic. I hope at this juncture you can ask me questions that will assist you in gaining more understanding of this topic. I will therefore have to wait for questions which might seek clarity so that you are never given the wrong information relating to re-infection.

She sat down, opening the floor to a discussion that continued to encourage engagement of support group members with the medical discourse. The chairperson invited further commentary but since there was silence he took the opportunity to reflect on the medical version of 're-infection' by once more paraphrasing into layperson's language but with an emphasis on the consequences of unprotected sex. Yousefi-Nooraie et al. (2012), Boh (2014) and Kothari et al. (2015) have all shown that the use of external networks for information seeking purposes in communities of practice is a beneficial strategy for individuals as they move from a stage of confusion to a stage where one is able to use medical jargon easily as a result of collaborative efforts to collect information from organisations and individuals. Yousefi-Nooraie et al. (2012), Boh (2014) and Kothari et al. (2015) further indicate that communities of practice can be a resource that ministries, private and public sectors can contribute to with information regarding health services provision and informed decision making. Mosuoe (2016) indicates that through on-going conversations such as the ones indicated above, community members would make sense of their experiences and manage their knowledge by sharing their concerns, validating their practices with each other, and developing new care strategies. With time, the accumulation of experiences would increase not only the group's explicit knowledge (written documents, standardised care plans), but also their tacit knowledge or practical know-how that emerges through reflective practice and the collection and sharing of story narratives among professionals. Mosuoe's study indicated the importance of networking, learning and sharing and suggested that not only lay persons rely on this process. Professionals too rely on communities of practice strategies for patient mortality reduction. The nurse's interaction with the chairperson

was a case in point. The chairperson paraphrased to ensure the group understood the information from the nurse.

> Chairperson: This means that HIV from a sexual partner will not know that there was already HIV in the body of the other sexual partner and it enters every time one has unprotected sexual intercourse. That was why you said viral load was when the number of HIVs in the blood increases?

Again, the nurse replied very sensitively, never telling people they were wrong, but building on what they already knew and once more elaborated on the medical discourse. The nurse's sensitive attitude towards the group motivated active participation by all. Members knew that their responses would be taken into consideration without prejudice. Mosuoe (2016) and Thakaso (2017) maintain that discussion needs supportive functioning to enhance performance by all. According to Mosuoe and Thakaso supportive functioning maximises participation. Both authors articulate various methods that can be used as supportive functioning. For instance, provision of emotional appraisal is highlighted as the most effective strategy where participants are praised for their efforts without being ostracised or chastised for giving an incorrect response. However, both authors specify the significance of informational assistance from specialists to correct wrong information sensibly, as the nurse's own responses illustrated:

> Nurse: Yes you are right Mr. Chairperson but the number of HIVs in the blood, increases in two ways: the first means is through entering the body and blood every time one has unprotected sex or oral intercourse, the second means is that HIV on its own enters in the blood as a solid but can make many other HIVs when it has been in the blood for some time.

Once more the nurse elaborated by using the medical discourse. But also once more she reverted to culturally known images to illustrate the medical message. She knew that Basotho men take care of their animals and field crops hence examples were made with relevant imagery. Pitikoe's study (2016) supports the nurses' idea of framing examples around pictures or imagery of what the support group knows best as a strategy for the group to understand better.

> Nurse: I used to give an example of a pea or bean sown in soil, that after some time in the soil it prepares to make many other peas or beans then it will break to show maturity so it can grow some roots and that it is ready to bear other beans/peas; that is when one gets to

> realise that there are some beans/peas in the soil during germination and that is when we can get more peas/beans.

After reverting to culturally known images to illustrate the medical message the nurse kept track of what she wanted to convey to them. She then made the connection between the agricultural images and the medical discourse, using the concept of germinating peas as a metaphor for the HIV virus, thus reinforcing the connection between social, cultural and medical imagery:

> Nurse: The same happens to HIV when it enters the body; after some time it makes sure it can make many other HIVs in your body, so it will behave like a germinating bean or pea by breaking; and the parts which are separated become able to break after some time and make other HIVs. This process continues until the body is heavily loaded with the virus. Hope you now reach a deeper understanding? Thank you very much.

All seemed happy. Some were nodding while others were clapping hands. Fairclough (2000) comments that discourse is a process of meaning making. Discourse is embedded in social context and time. The challenge for the nurse was to bridge that gap of cultural context and medical knowhow so that new meaning making could take place. The nurse was trying to break down the power relations between the dominant, socially constructed powerful discourse of medicine and the socially constructed cultural discourse of the layperson.

6.3 Perfecting condom use skill

The topic then shifted to condom use as an important strategy for avoiding infection as well as re-infection. Before inviting the nurse to contribute, the members were invited to have their say. The chairperson introduced the topic with the nurse's pre-prepared list of steps on condom use provided in the form of paper strips which needed to be put in order as a group activity. The second activity was to attempt to use the condom on a rubber penis model as a practice for correct use. The members were divided into two groups to complete the correct condom use activity and the nurse was invited to inspect their progress. The activity itself once more followed adult learning principles, this time in terms of adult learners' preference for practical application of learning. Thakaso (2017) specifies that adult learning encompasses motivational activities. Mahloane-Tau (2016) points out that for adults to learn best, the adoption of respectful attitudes to learners alone is not in itself enough motivation because adults are motivated to learn if their learning content embraces rapid applicability. In other words, adults learn best when

convinced of the need for knowing the information (Lawson & Flocke, 2009). Meaningful learning can be intrinsically motivating because adults enter into the learning process with a goal of immediate application in mind and generally take a leadership role in their learning. The nurse realised the need for allowing the members to perfect their skill on condom use because she was aware of their need for immediate application to reinforce their intrinsic motivation. After completing the exercise, the nurse encouraged them further:

> Nurse: You guys are intelligent; you have made it So! So! So! well. All the steps are correct; there is a group which missed just one step but I think I could also do as they had done because these steps could come first or last, it doesn't matter. This is why I am saying all groups are correct. I think that you have learned a lot because the steps are done practically by yourselves with the help of others while placing one step after the other. Do you think there is still anything you want to learn in the Consistent and Correct Condom use (CCC)?

The replies from the group indicated that the men both understood the exercise and were willing to pass on the information to others:

> Zabie: We think we can wear a condom right and can teach other people to wear it because we have done it practically. This time we will beat HIV and beat re-infection.

As mentioned in Chapter Four, one member even volunteered to use the materials to teach another group in his community thus extending his learning from his immediate community of practice to his wider social capital networks. Laxton and Applebee (2010) indicate that learners build relationships that enable them to learn from each other. In the process, learners try out new ideas to build their competences regarding their topic of interest. Coates, Richter and Caceres (2008) argue that real learning results in permanent behaviour change, a factor which Nkaoza portrayed in his response. Nkaoza, for instance, as shown earlier, proposed that they could share their newly acquired knowledge with external bodies, and instill their refined understanding in others.

This aspect is supported in the literature by Bates (2014) who argues that the significance of acquired learning should be seen through knowledge management where acquired learning is shared to widen the scope of learners who benefit. The support group's behaviour also signified

an element of identity building within the community of practice. Laxton and Applebee (2010) indicate that enhanced information acquisition results in changed identity because information sharing creates a new sense of competence. In this instance the fathers-to-fathers group even gave themselves new identity labels by identifying themselves as 'male nurses' with new knowledge and understanding. The label reinforced their confidence and sense of who they were, reflecting symbolically the new knowledge that they felt able to impart through the notion of being qualified to wear a 'white coat' regarding this matter. Nkaoza would thus use his wider social capital networks, not only as a resource for helping him bring community understandings into the support group, but also as an outlet for introducing new medical knowledge back into the community – which in turn would be shared with others.

> Nkaoza: Please Madam Nurse I want to borrow these things for my burial society. If I can be lent these toys (penis model) and those steps, I swear that all of the members will respect me and all of you for knowing such good things. Most of them do not know much about condom use. I have been a member in that society for several years now and I know their views about a condom all are left behind with prevention education, mostly condom use, so I volunteer to close that gap. I will be putting on a white coat that day and demonstrate like a big doctor could do.

In this meeting, the nurse continued to play a strong linking social capital role, full of encouragement. Woolcook (2001) and Ahern and Hendryx (2003) confirm that linking ties in social capital connect the inner members with their outside world through extended relationships that ease access to various resources through mutual trust in providers. The group's relations with a wide spectrum of people made it easier to access various resources from their extended contacts.

As a reinforcing encouragement to the men the nurse indicated that, through their ambitious behaviour and intended prevention strategies, it would be possible for the group to combat HIV infection. It was evident, therefore that the nurse drew once more from her adult education experiences that if the group was motivated and their efforts acknowledged, their performance would improve and they would be inclined to attempt a better understanding of complex HIV issues.

> Nurse: HIV needs people who are as ambitious as yourself, you always amaze me by the way you tackle your issues and participate in your meetings … This gentleman (referring to the man who asked for the models to take them along so he could demonstrate condom use to his burial society members) has made me see him on the day when he has all these models to demonstrate to his other group members, his imagination of that day when he becomes a doctor in his burial society is a clear vision to all of us. I cannot turn a blind eye to the efforts you make to ensure that other groups which you already belong to in the community access what you know by sharing with them all that is done in this group.

Learning and meaning making about the different medical discourses was not, however, universal as can be seen from the following section. The process of meaning making was highly dependent on collective discussion.

6.3.1 Female condom use and transformative learning

Resistance to female condoms

There were examples where group members identified resistance or differential stages of understanding over the same topic. This next section provides an example of resistant learning around the topic of female condom use and also how the subsequent dialogue impacted on new meaning making. Members discriminated against the female condom due to its structure. They complained about its size that it looked too big. Most members said it was embarrassing to wear it in the presence of a sexual partner because it requires positions that are too explicit. Other members swear not to wear a female condom because it has to be supported with hands during penetration to avoid entering by its side. The feeling revealed here was that the female condom was not user friendly hence some members resisted its use. This is what Zille said:

> Zille: A female condom is shameful, I personally hate it, I never found a soft spot for its use, therefore, I am the last person to advocate for its use. But I am okay with male condoms anyway.

The following discussion on the use of female condoms indicated that new learning and understanding within the group had continued in different ways, suggesting that even if one was resistant during discussion, new attitudes could materialise over time. Zille was aware that a friend of his (Dockie) in the support group had already taken a bunch of female condoms with him. He knew the friend previously had negative attitudes towards the use of female condoms. Zille was also aware that his friend now had positive attitudes towards them and used them.

> Zille: Good members, you should be aware that simple but persistent health education changes attitudes. My friend Dockie understands all preventive measures and has adopted female condoms use so much that he always makes sure he has them with him. Right now he can show you a bunch already in his pocket.

Dockie took out female condoms from his pocket; he put them on the table for everyone to see. His smile indicated that he felt he had made a good decision. He then said:

> Dockie: I had this bundle of female condoms because I am using them in my family. You know very well that my first wife died in 2007 and it was only last year (2012) when I decided to marry another wife to help me raise my kids. You once said, 'in HIV if one does not use ears to listen one will feel the pain on the skin *(Haosa utloe ka litsebe, otla utloa ka letlalo)'*. You taught me a good lesson. I once accompanied my wife for Ante-Natal Care at Mother and Child Health where I got brief education on the advantages of using a female condom. I used to hate them, but that lesson went straight to this small head. All examples from your life experiences also helped me change. I never thought I would use a condom no matter whether it was a male or a female condom. But my coming here to this support group has made me a changed person.

At this juncture, one saw an evidence of the value of the support group – as a collective, as a resource for sharing and a resource for learning through dialogue. Malpas and Lavoie (2016) highlight the benefits which the support groups gain through working together. The benefits signified positive collective impact achieved through networking and resource sharing which led to positive social change. Therefore, medical discourses could be re-stated and made more intelligible through local cultural language or images. Price (2009) indicates that efforts need to be made for individuals to understand the relationship between medical discourses and culture. Labhardt et al. (2014), in the context of medical criticism and cultural health, argue that at times cultural efforts fail to save individuals from the slavery of illnesses, hence there is a need to emphasise the significance of seeking medical opinions when such times emerge. Dockie continued to show his appreciation to the group for being patient with him during the time when he had not understood the importance of using condoms. He acknowledged the value of their persistence in talking to him until he changed his attitudes.

> Dockie: My attitudes have changed because I use to tell myself that Ministry of Health have introduced all these interventions to make us run to the hospital like babies. But

> now I know it is to save people like myself who have already lost a wife and a kid due to my resistance to change. Most of the support group members like myself; used to claim to be a die-hard until now. Now I do not want to burn or get hurt again for losing people I love – and just look at me carrying a bunch of condoms home. I am now used to them and like them. To me it is good because I used to hate wearing a condom but with this one I do not feel that barrier which I had because it is worn by her and I never feel that distraction at all. So during sex, mine is just to work like a strong saw in the hands of a knowledgeable tree cutter. That is why I have already taken this many from the dispenser.

He sat down and they laughed, he did not mind them but busily started to collect his female condoms from the table where he had displayed them while talking and started to put them back into his pocket. By using the medical discourse of consistent female condom use, but re-wording it for his layman's language he introduced new knowledge. Sowa (2015) argues that the use of medical discourse has been complex through-out the years. Re-wording it for layman's language may result into a slight deviation from the original meaning. Therefore, proper networks and sources need to be used for appropriate re-wording that sustains the actual meaning. Nevertheless, Sowa (2015) argues that rewording complex discourses for laymen's understanding had been a brilliant strategy that shapes understanding. Such examples as those portrayed in the above examples show the powerful role that culture and language play in adult learning. Dockie's speech was evidence of transformed learning and acquisition of a new meaning perspective. Nabb and Tann (2009) confirm that the process of transformed learning and acquisition of a new meaning perspective requires an individual to purposively question their own assumptions, beliefs, feelings and perspectives to allow for educational maturity because personally explored options for new roles, relationships, and planning a course of new actions play a pivotal role in learning. In the support group context, the collective nature of the community of practice also played a pivotal role in facilitating that process of new meaning making.

The nurse realised those improved attitudes and behaviour from the die-hard members of the support group. She felt compelled to congratulate the change of behaviour that she had observed. She knew that if members received motivation for minor positive changes, the good behaviour would be repeated. Harrison et al. (2015) show in their study on managing unwanted behaviour, that good behaviour (minor or major) is likely to be repeated if it receives positive reinforcement.

Harrison et al. further indicate that a positive approach to promotion of good behaviour benefits all. The assumption for this group indicated that members would attempt to adapt and change in several other activities.

> Nurse: Thank you Dockie for sharing how it feels to use female condoms. Dockie is a good example that education can influence change of attitudes from negative to positive. Is there anybody else to share?

'Yes!' That was from Zaga seated next to me. The chairperson realised that Zaga was eager to share his views about condom use and gave him the platform.

> Chairperson: Zaga I have observed your hand and your eagerness to share with the respective support group how you previously felt about condoms. Please continue.

Zaga was a hefty man in his early forties. He was usually very silent in the support group but always eager to go for hunting and said he enjoyed hunting tasks because it gave him exposure to how people inside and outside the group felt in relation to different health topics. Zaga stated that he had previously hated condoms and was totally against women using them, because he associated them with medical supplies given to women and children who attended monthly health services. Therefore, he previously thought encouraging condom use was belittling for him:

> Zaga: I would first like to apologise to members of the support group who used to show me the benefits of using condoms. I know that I was rude when encouraged to use condoms because I never liked them and thought that being encouraged in the correct and consistence condom use was indirectly belittling me. Dockie, you have gained by your persistence in encouraging me to try condoms. These days I am confidently giving my testimony and swear by my living God that I will use male and female condoms forever. I am asking if the same support group can be formed for HIV negative individuals so that they change their negative attitudes towards condom use before any damage occurs.

In a study by Preece and Ntseane (2004), Batswana men illustrated similar feelings about condom use and it was argued that their reluctance contributed to a delay in HIV protection, thus encouraging the spread of HIV. Mazama (2008) indicates that referring to the male as 'head of family' was a valued slogan in most African countries which implied the family brain of a man could decide whether or not to use a condom with the spouse or a concubine. Mazama further

states that the phrase was commonly used in African communities in order to demonstrate the value of responsibilities and obligations that males had in families. As a result of this understanding Fletcher (2007) indicates that African women negotiating safe sex is considered a big turn off for males, in that such women are thought to be too westernised in attempting to direct males on what to do and what not to.

The nurse in that support group was highly appreciative. She encouraged participation by always motivating members for their good participation. The Nurse congratulated Dockie for being patient with Zaga until he recognised him for adopting condom use practices.

> Nurse: Thank you Zaga for sharing your previous experience of female condoms. I am grateful that Dockie has done that wonderful job to educate you and encouraged you to take them for trial again. I bet you will love them like he does and next time you will share a different story. Is there anyone else to share or can I proceed?

It was evident that the sharing and dialogue amongst the group members had the effect of influencing the thinking of others in the group. Bates (2014a) indicates that working together to acquire knowledge, information and education, impacts positively on learners and leaves them empowered and confident in their own field too. In Bate's study collaborative learners understood that knowledge was co-created and all members of the support group took part.

The nurse still felt the need to give words of encouragement to the group. After each revelation by group members she always gave a positive reinforcement to them for doing well in encouraging their support group members even outside their scheduled monthly meetings. She acknowledged the importance of their informal meetings as friends and neighbors. There was a silence, so she continued.

> Nurse: I want to start by convincing you that really the female condom has improved and no longer has the distractions it had before. Nowadays it can be worn just when the couple gets into bed due to its user friendliness. Lesotho has improved condom distribution, so it is even available in all health providing institutions. I want to encourage all of you to take even just two to go and try them. Like I said, you will all like them. Next time when you discuss this topic I want to be there to hear how it went. Give yourself a big hand for discussing condom use because if we can work hard on it, we will have reduced the spread of HIV since this is the core of prevention intervention.

That piece of the medical discourse she repeated several times in that support group. She consistently made the link between condom use and reduction of HIV and that almost became a ‘strap-line’ so that a message that became associated with condoms then turned into a ‘common-sense’ discourse about condoms. Fairclough (2005) argues that discourse includes language and behaviour representing attitudes, beliefs and assumptions that crystalise into rationales that people use for justifying their point of view, behaviour and attitudes. There are medical discourses, gender based discourses, political discourses, economically based discourses and culturally embedded discourses (as manifested in proverbs etc.). Fairclough argues that social change comes about through a discursive process that links personal needs and social practices to accommodate social expectations. On this aspect, the support group realised that for members to practice condom use as a foreign idea, it had to be linked with the reduction of HIV because the members had deceased friends and family members due to HIV and they realised the need to take action. When the new, legitimised common sense is adopted its existence can be sustained, such as the discourse about condom use to reduce HIV infection. The practice in Lesotho to advocate for, network about and legitimise condom use has become a new social practice, articulated as a discourse for HIV prevention.

> Nurse: Therefore, we will be proud to be part of people who reduce occurrences of new HIV infections in the country.

Fairclough (2005) further talks about re-contextualising a practice. By this he means that it is possible to position new or different discourses to enable meaning making. Similarly, Laclau and Mouffe (2001) indicate that through networking, a foreign discursive substance or object can become part of new, legitimized ‘common sense’.

6.4 Meaning making was not universal

As has been stated earlier, however, not all discourses were culturally acceptable to everyone. Transformative learning is not guaranteed through the community of practice dialogues. A new gender specific but culturally embedded discourse then emerged in that meeting. That was that women were still blamed for the disease (even though they had caught it from men, for example: from those who worked at the Highlands Water Project – a large dam construction that recruited

workers from far and wide). That was an illogical discourse in medical terms, but it served to deflect the blame for infections from men in similar fashion to that outlined by Preece and Ntseane (2004) in their Botswana study.

In this support group it was reinforced by one elderly man, derived from his personal experience with his wife. The man (Zille) stood up to share his views about condom use. He rationalised all meaning making in a way that reinforced his own gender position. He was hurt that his wife once separated from him and went away with a male foreigner who worked in the Lesotho Highlands Water Project and came back home empty handed but sick. He suggested that condoms would be good if worn by women only because he blamed women for promiscuous behaviour. Zille continued to say women needed to wear a female condom as a punishment while men could be enjoying themselves. Zille was certain that if it was not due to women's behaviour, HIV would not have spread the way it has. Zille also generalised his attack on women as carriers of the virus by associating the disease with women testing frequently as if they were seeking to obtain the virus like a pregnancy. He said women were curious to know if they were infected because they do not take necessary preventive measures, instead they would prefer to test every time they had been at risk of being infected.

Butterfield (2013), referring to African contexts, argues that both males and females are responsible for preventing the infection from spreading. Butterfield argues that blaming females for spreading infections, including HIV, does not only have a negative connotation but remains unfounded. The blame process is an indication of how males undermine the power of a female's decision to leave dysfunctional marriages to begin her life elsewhere. Sometimes culture obliges the same female to remain in polygamous marriages because she does not bear children. Konate (2007) indicates that African women do not have a voice, especially in HIV/AIDs matters; their critical thinking ability is likely to be ignored in families and in communities. That means that it is difficult for women to share any knowledge they acquire with their male counterparts. Zille reflected these traditional cultural attitudes towards women. He continued:

> Zille: I want to tell you that yes I will try to use this female condom, but deep down in my heart, I have a feeling that if I still had a wife, she would be the one who wears her condom every day I want sex because these women were the ones who brought this

> disease (HIV) into our families by running around (being in love) with men at the Highlands Water Project road contractors and leaving their husbands as if we were the horse's bone marrow, (*joalo ka mmoko oa pere* the literal translation means: as if we were useless trash). Like mine who got married to one of them for six years living in a foreign country, not being ashamed of leaving me with four kids, and came back home when she was useless and died after two months of her return. I think that foreigner had drained all the good juice she had and infected her. When she was useless he gave her bus fare to come back home without even a blanket. For those of you who still have wives, teach them to wear female condoms every day during sex as a punishment while you will be moving up and down enjoying sex and working like a saw in the hands of a tree cutter as it was said previously. But also make sure that they do not bring you HIV. This was because those women keep – on - testing (said in a slow motion) every year and stop only if they are told that yeah! (also said in a slow motion) now we have found what you have been looking for all these years; 'di-de' is there (meaning, that thing is there - HIV). So be careful with these women and make sure they do not take your lives as that will be killing these support groups too.

Zille sat down but looked very sad. There was abnormal silence and the nurse put her right hand on his shoulder. She looked sad but worried too. I thought she would try to emphasise the benefits of frequent testing to Zille, or to convince him otherwise about his gender biased assumptions, but she decided to remind the chairperson that their time for that particular meeting had elapsed. Although the nurse was under time constraint, the nurse could have informed the support group that HIV prevention was binding to both males and females. Instead the nurse seemed to avoid the final confusing views imposed by Zille onto other members.

> Nurse: When I look at your time, we are supposed to have been through fifteen minutes ago, (looking at the chairperson) I thought I was almost through so that I can go back and draw blood for the last group of patients waiting for me in phlebotomy room, also to be on time with blood samples before the laboratory closes. However, the speech we have just listened to needs us to respond to it. Does it have to be today or can we call it a day for now and I can come for your next meeting to respond?

Once more the nurse was extremely sensitive to the mood of the group and very tactfully tried to draw the session to a close without denying the man his sadness or confusion. The chairperson had no means to convince the nurse to stay longer to address concerns laid by Zille before she left. Zille's speech was a good example that behaviour change was not an easy task for everyone. Essen and Ostlund (2011) designate that new learning in adults occurs at different levels so that some absorb new information quickly and improve on it to suit their needs while others may take

ages to understand what is required of them. Schmidt and Frohling (2000) and Schuller (2001) share the same view that progression in new learning among adults tends to emerge in different ways. They categorised learners according to the ways in which this new learning manifests itself. These categories of learners can be identified as innovative individuals who can suggest more relevant and applicable topics to be discussed, the fast learners and the slow learners. In adult education terms, Zille could be classified as part of the slow learning group due to his slower level of acceptance towards changes. In terms of the transformative learning goals of the support group as a community of practice, it was evident that some members would take longer to understand the complexity of HIV and AIDS and not everyone would reach the same level of meaning making at the same time. However, members continued to share their views on condom use. Their experiences were intended to influence Zille in adopting correct and consistence condom use. Therefore, the chairperson was willing to continue with the topic in the absence of the nurse who was in a hurry to provide services to other clients. The chairperson continued trying to convince his fellow members to use condoms. The chairperson agreed that the nurse may leave the group while the group wrap up the topic with the hope of contributing some further meaning making for Zille. However, she stayed for a while to respond to the ongoing discussion.

It was evident that, in spite of all these positive learning experiences and interactions, even within this socially cohesive and long-standing community of practice not all men were at the same stage of meaning making or willingness to change their habitual practices. It may be significant that one particular man, Lepzer, was one of the younger members who perhaps was more sensitive to peer pressure to conform to traditional masculine behaviour. It demonstrated the complexity of introducing medical discourses which do not necessarily interface with culture.

> Lepzer: I have kept quiet for too long because I have been thinking about myself as an individual, I find the decision of using a condom at every sexual encounter being too harsh for some of us and am wondering whether I can truly say I can start from my age to practice CCC and continue till I die. If I understood you well, you meant that with every sexual encounter one has to be protected till one goes back to the cold soil (dies). I want to tell you that I am still very young, younger than all my fellow members in here, do you expect me to swear to start wearing a condom every time I indulge in sex and say I will be consistent till I become a grandfather? *Bo-ntate* (guys) I am a full member of this

support group but there are other things like this one which I think I do not agree with and will not comply.

Srikrishman, Venkatesh, Solomon, Kosalaraman and Mayer (2008), in a study where medical discourse interfaced with culture, indicate that domestication of medical discourses has never been an easy task, hence the need to consider culture and identify crossing points in order to address the complexity of the issue. According to Wasko and Farai (2005), in relation to enforcing cultural belief systems a member like Lepzer would rather position himself as an 'impartial observer' who feels detached because the concept at hand is against his belief systems (he believed he was too young to comply regarding correct and consistence condom use). His self-position and identity are further explained by Johnston (2013) who states that individuals take time to build new frames of reference in such communities of practice. For Lepzer his personal self-awareness had not changed even though he joined the support group with the belief that he met the criteria for joining. Over time his frame of reference towards condom use had not yet changed because his original belief system dominated the way he made meaning out of the discussion. Lepzer spoke politely but positioned himself outside the medical discourse. His identity as a young male meant he could not accept the medical message for what it was. Lepzer seem to be at phase three and four of transformative learning which indicates that a member conducts a critical assessment of internalized assumptions but whereby the individual recognizes discontent rather than transformation (Mezirow, 2000). In terms of the formative stages of being within a community of practice, Lepzer had reached the information seeking stage for him to understand that without protection HIV infects young people in the same way it does older people. However, Lepzer openly excluded himself from the full transformational learning culture of the wider group. Instead he positioned himself as a representative of his peers so that his comments indicated that a new discourse or language of persuasion would be needed for that age group. Lepzer was assertive enough to confront the group and stated that he would not opt for lifetime condom use as a prevention strategy. He used his age as an excuse for not complying with preventive measures.

Harrison (2014) in a study conducted on community HIV adherence, confirms that medical demands and instructions often pose a great fear of compliance in patients, therefore individuals often search for reasons to justify their non-compliance attitudes. For instance, common excuses

were age (being too young to comply with a lifetime treatment) and issues to do with multitasking (being too busy to remember and comply).

> Lepzer: I am hoping that you understand my situation well, I do not mean to be rude or be uncontrollable in this group, but I know that even our friends in the community are going to reject this idea so much that if we do not tighten up our shoe laces, (meaning we must be well prepared to deliver a convincing speech) more especially by being ready for more people who may not understand it like myself and we might be too embarrassed and lose focus if we are not expecting it.

This perspective is supported by Taylor (2009) and Cranton (2006) who emphasise through their articulation of the transformative learning theory that the process of perspective transformation has three dimensions: psychological, convictional and behavioural. One saw Lepzer going through psychological changes in understanding of the self, requiring revision of his belief system and changes in lifestyle, but at this stage he was not ready to enact new attitudes or behaviour.

The nurse's response was to retain his interest. Once more she acknowledged his position and did not tell him he was wrong even though she knew his decision not to use a condom every time ran huge risks health wise. She knew it was better to recognise where he was coming from in the hope that eventually he would come to realise its importance.

> Nurse: I am happy we have people like you Lepzer (calling him by name) who can clearly let us know where he stands. Every one of you is unique from the other in here. That is why we want to believe that it is due to that uniqueness that you end up having a different perception from the rest of us in here. At least you have the knowledge to share with others and when time comes for you to find the importance of using a condom every time you indulge in sex, you will already have the skill and just do the right thing. It helps the group in order to work harder; to give you the consequences of not using a condom until you understand and become less resistant to the practice. I want to tell you that as health professionals, we become very happy when we see young men of your age joining Support Groups of this nature.

She introduced a compromise discourse (his entitlement to his uniqueness and willingness to share) that left open the space for continued dialogue. The nurse also allowed the group to realise that making good health decisions was a benefit to an individual, a community and a nation at

large. The nurse emphasised the importance of committing oneself to a healthy life as a strategy to achieve their main goal: zero new infections.

> To us it says at least they will be knowledgeable on time while they can still be in a strong position to assist the ministry to reduce the spread of HIV or even get to zero new infections like your slogan sometimes says.

The nurse recognised that learning outcomes were not universal. The group collective allowed space for discussion but it also allowed space for different points of view. Schuller (2001) confirms that learning outcomes are never universal between individuals even if exposed to the same stimuli due to the uniqueness of each learner. The above authors both conclude that learners may be exposed to the same content at the same space and time, but their comprehension level will differ. This is the point that the nurse also acknowledged.

> Nurse: So you should know that saying your views and giving us your stand on this issue does not make us upset by you as people are very different from each other, so the level of understanding and the decisions we take after every lesson will never be the same, like I have already indicated to you guys.

This was a true reflection that even the level of adoption to new practices differs due to the fact that individuals are different and unique from each other. This was proven by other members who seemed to resist the use of condoms regardless of various views shared on the use of male and female condoms as a preventive method. The meeting began to draw to a close.

> Chairperson: We are almost done madam nurse you can go and help our brothers and sisters who are still waiting for your services too. You have given us a handful (the right information); it is up to us to go and practice because we are always being told that we are the valuable assets in this district since other districts learn from us and we need to make sure we maintain that trust from the Health authorities. As you can see with the education we got today starting with re-infection, guys, we are nurses too. Let us give ourselves a big hand. Remember some of us were being laughed at in our community when we came to the hospital every month for this education, who could have given it to us if we were not so wise like the nurse said.

This speech illustrates the communities of practice process where sharing and learning through the use of external networking had enabled collective actions that resulted in identity building,

new meaning making, collective actions and collective decision making. It also revealed the level of confidence members had acquired through a learning space which was based on trust and reciprocity. Cherkowski et al. (2015) articulate how a sense of belonging results from the experience of personal involvement in a learning environment. Kop and Hill (2008) argue that the sharing and learning, in communities of practice, are usually exhibited as collaborative learning. Kop and Hill (2008) emphasise that, in a learning environment, where members rely on external networking and member's experiences, learners enjoy the benefits of expanding their understanding that stretches beyond the facilitator's scope and schedule. Kop and Hill (2008) and Cherkowski et al. (2015) conducted their research studies on support groups that are actively participating online in western countries. But their analysis reflects the same results as this support group in Lesotho where participants were actively participating in face-to-face mode.

At this stage of the meeting, the chairperson realised that members had exhausted the points and therefore a closing prayer was required as a norm: 'Anyway, let us pray and let the nurse go while we brainstorm the next topic and find new 'hunters.' They sang a hymn and prayed and the nurse said goodbye in a loud tone. I concluded that her pitch of voice was a sigh of relief, then she went out. Topics for the next discussion were brainstormed and hunters were given tasks for the next meeting, then it adjourned.

The nurse effectively had to adapt to their way of learning rather than the other way around. In other words, she did not follow the normal pattern of doctor-patient relationship – it was organised as a shared meaning making relationship through conversation and interaction. But at the end of the day, her discourse had 'authority to know' over and above the discourses of the SG members – hence their interest in being labelled doctors and nurses as people who now also had authority to know in their communities.

6.5 Chapter summary

This support group meeting demonstrates that one medical word requires in-depth discussion and dialogue in a manner that interfaces with culture and cultural language in order to make meaning that can be well understood. It takes time to get information across and ensure comprehensive understanding of all the different issues related to HIV infection. The support groups therefore

serve as educational tools for learning and transformative learning in a way that cannot be provided through other forms of education (such as media).

The role of the nurse was a critical factor in this meeting. The role that she played and the manner in which she worked with the group reflected her own training as an adult educator. She encouraged active participation from all members by congratulating them for active participation and making them feel the need to share more with the entire group.

The nurse motivated the group at every step of their way even when their explanations or efforts were obviously wrong. However, the nurse would correct members' information without being harsh or making them feel small. This seemed to be a working tactic to encourage active participation even during difficult discussions. The nurse motivated the group to keep on trying by acknowledging every effort that the members brought from their hunting task to the meeting house. None of the members seemed to be embarrassed about bringing wrong answers to the group because the nurse was supportive and encouraging. However, the nurse made the group realise that other medical discourses which the group was eager to learn about are complicated and need professional assistance for the group to understand. One realises the nurse used several culturally relevant examples like for instance, animals and crops as strategies to win their concentration and interest in the topic. However, there was evidence of individual attitudes crystallising even while discussing simple topics such as the proper use of condoms. For example, during discussion of this discourse, one member exhibited reluctance to understand the importance of condom use but rather opted to distort the message and blame women for exhibiting careless and promiscuous behaviour which would bring HIV into their families and infect their 'innocent' husbands. This illustrated how gender discrimination prevails on this aspect, and the member merely encouraged others to consider introducing condom use as a 'punishment' for females. Chapter Seven discusses Mothers in law support group in relation to cultural attitudes towards PMTCT and gender relations.

Chapter Seven: Mothers in law – PMTCT and Men as Heads of Families

7.1 Introduction

This chapter, like Chapters Six and Eight answers research questions 2 and 3, which seek to understand how the support groups make meaning out of the different discourses associated with HIV, its prevention and care and to explain how meaning making leads to new learning. These chapters draw substantially on Mezirow's transformative learning theory to explore how, and the extent to which, the group members make meaning and transform their thinking, as a result of the support group discussions. This chapter addresses question 2b which explores Basotho cultural value systems, especially in relation to gender issues in the mothers-in-law support group. The chapter reveals some of the challenges of meaning making between the medical discourses and those of laypeople – particularly in relation to culture and gender power relations. However, the final part of the chapter reveals a substantial shift in meaning making as the women begin to seek new solutions to their gender and cultural challenges.

Sen (2000) argues that gender relations in African contexts have always emphasised that males hold an elevated position in the family and community. As an example of how this power relation is embedded in society, Sen refers to the manner of celebrating the birth of a baby boy in most African families which is deemed special and celebrated as such. Kimaryo et al. (2004) point out that the Basotho society is still very patriarchal, with the man deemed as the head of the family and the sole decision maker, based on the customary and common laws enshrined in the constitution. This situation would influence the discussions that the mothers-in-law support group had in exploring strategies to improve male support for matters relating to childbirth and HIV care.

This support group was formed of women who had daughters-in-law at child bearing age who had tested HIV positive. These mothers-in-law were expected to offer a great support to their sons, infected daughters-in-law and grand-children who were suspected to be exposed to infection. They decided to form a support group in order to ensure that they were equipped with information regarding what was really expected from them. They wanted to be fully supportive to these new families by obtaining up to date information and education that could help them do things appropriately to ensure that the new born children were HIV negative. This group meets

monthly with the purpose of learning and sharing information relating to HIV and many other health related issues. In this support group, members' attendance increased, instead of declining in spite of the interference of my monthly observation visits. However, they behaved in a slightly less disciplined way than the other two support groups in terms of following meeting protocols, so they often spoke before being given permission. They also had a tendency to digress from the topic. The schedule of topics discussed is presented in Table 6 below.

Table 6: Topics discussed by mothers-in-law group

Date	**Attendance**	**Topic Discussed**
08/02/2013	13	Post mortem of the previous activity and arranging for the next one (**not recorded**)
08/03/2013	14	PMTCT and Men as Heads of Families.
04/04/2013	15	Mother Baby Pack (MBP)
07/05/2013	15	Nutrition
20/06/2013	15	Male Circumcision
18/07/2013	15	PEPFAR Visitors
16/08/2013	15	MCSP Reduction

This chapter focuses on the discussions of the second meeting concerning the Prevention of Mother To Child Transmission (PMTCT) programme and the attitudes of men as heads of families towards the programme. It follows the order of the meeting itself with reflections and analysis as the narrative unfolds. The group decided to explore collectively how males can be convinced to support PMTCT requirements because the members were aware that without the males' support, the programme would be a failure. This is because, culturally, males were initiators and decision makers on matters concerning their children and wives. The group began the meeting with a prayer as usual, but this time the group prayed specifically for the orphans whose parents had died due to HIV infection. The emphasis was on requesting that God help the group achieve its main goal, which was to ensure that no other child lost a parent due to HIV and no child gets infected with HIV. They asked for guidance from God to give the group tactics to

persuade Basotho males to take part in the programme because the programme needed the males' approval and involvement as the ideology of the programme challenges some of their cultural beliefs. They also prayed for wisdom, integrity and energy to plan and implement their plans. Finally, they prayed for Basotho males to change their attitudes towards health issues and comply with the existing child survival programmes. The chairperson and secretary worked hand in hand to ensure the meeting was viable and that members adhered to the agenda.

> Chairperson (Mrs Brown): Ladies let us continue, today, we shall be discussing topics which we previously agreed upon: can you remind us secretary and remind us names of people who were given assignments to research on those topics (hunters).

The secretary reminded the group that PMTCT was a new initiative which none of them had tried. They were only sensitised about the programme in their previous meeting and worried about its publicity. However, they were determined to learn about it. Members were concerned about how men would react to the topic. Without wasting much time, the chairperson allowed the secretary to remind the house what the agenda for the day was. Then they agreed to hand over the session to the health professional allocated at Maternal and Child Health (MCH) who had come to guide the support group on this new initiative so they could all learn. This means that the group was willing to introduce change among their male community. However, they were all aware that they would need some sort of external reinforcement to appeal to males in health related issues.

> The secretary (Mrs Red Rose): (She read the agenda then said) this time we did not have hunters because we agreed that we need nurses only to clarify for us as we suspected that the concepts were new to everyone and we might get only myths from the community which might not be useful for anyone. We concluded that it might be difficult to identify the myth if one does not know the truth. Therefore, the topic was agreed to be handled by a health professional like other new interventions. Finally, we had agreed that each member should think about the tactics to use in order for us to bring more males into health programmes because we had agreed that if we are not closely knit with them, we may not succeed with our slogan 'zero new infections' mostly in our children.

7.2 Building the ladder rung by rung

Mrs Brown (the chairperson) a single woman in her mid-forties, expressed her gratitude to the rest of the members for accessing first-hand information which would contribute to the survival of their grandchildren. She urged members to be attentive and bear in mind that the Ministry of

Health had shown devotion and creativity in implementing new programmes. Mrs Brown congratulated members for punctuality so that none of them would miss information. However, she ended her speech by indicating that her main worry was how males might get involved in the programme because they act as if they own Basotho culture and males were over-protective of it. Therefore males might not like any recommendations that were introduced by females which compromised cultural beliefs and behaviours.

> Mrs Grey: There is a saying that if one is not informed, one becomes reluctant to say yes or no to whatever myth that she comes across. One becomes '*monna tonki*' like donkey man story and cannot make up her own mind or her own decision because one is never sure of the right or wrong. However, I suggest that we begin today's programme on time since our educators are here, as you know they are always on time. Time keeping is one of the silent strengths that our educators are giving to us because they are never late for our meetings. So we also need to copy that punctuality aspect. Let's go on with PMTCT right now to save our day. Lastly ladies I cannot hide my worry about the kind of males we have. They act as if culture is their baby, they are very over-protective of it, yet females too honour culture. It is just that as females we become flexible to let go some of our values to earn good health.

Letuka, Matashane and Morolong (1997) confirm these concerns in their studies where they indicated that African men believed they were the custodians of African culture and regarded women as inferior and believed that women should obey men and their decisions. Letuka et al. (1997) argue that men preferred to be consulted for minor and major decisions in order to reinforce recognition of their status as heads of families. However, Letuka et al. (1997) point out that men did not involve women's contribution in any of the decisions made in various aspects of life that sometimes included deciding the number of children a woman should bear without the concerned woman's involvement. In the face of such cultural traditions this support group was taking the initiative to be sufficiently informed so they would be in a better position to argue their case in their families.

The chairperson reminded the group of the significance of sharing experiences relating to the topic.

Schlechty (1994) indicates that maximum participation in a learning environment is important to maximise absorption of information. Schlechty points out that adult learners need diverse

learning strategies to increase their engagement with the content. The chairperson agreed with the nurse that the new programme (MBP which was intended to strengthen PMTCT) would be more effective if they were all abreast with the current programme: Prevention of Mother To Child Transmission of HIV (PMTCT) and Mother Baby Pack (MBP). She emphasised its importance for them to learn the information and what tactics had been working for them to incorporate males in PMTCT and MBP so the nurse would add to what they had previously achieved as a result of being involved in the previous programmes.

> Chairperson (Mrs Brown): Our topic is on PMTCT and MBP. We are starting with the importance of PMTCT as it was agreed previously when we were inviting the nurse. We are all aware that our schedule is tight because we need to share PMTCT information and find out whether the specialist will identify the gaps from our conversation and our reports. We might not take too long because these two topics are similar and fall under one umbrella. However, I am aware that during our previous meeting, the nurse already laid the ground for us to continue. Maybe it is also important to report to her that unlike all other topics for which we used to have hunters, with these two topics we have agreed that we call the professional to help us – unless there is one of us who has experiences which we can learn from. Who can be willing to share her stories? You know very well that your stories have made us who we are because they have been our books since this 'school' (support group) does not have books for us to read but we see ourselves being clever and wiser every day. Madam Nurse, you can continue to assist us with what you have prepared for the group.

Mrs Black, a widowed woman in her early forties, responded to the chairperson's request of sharing their experiences for the rest of the group members to learn from them. She blamed herself for not sharing prevention messages, as a result her son never got tested and Mrs Black suspected he was the one who infected his wife during pregnancy and the new-born child also got infected because the mother thought she was HIV negative from the two results she got during pregnancy. Mrs Black responded to Mrs Brown's worry about culture by telling the group that as females, they had a mandate to bear children and save lives; if culture had to be compromised in the process so be it.

> Mrs Black: My experience has been one of its kind. My daughter in law was HIV negative for the first two phases when she got tested. It was during her first three months of pregnancy and when she was thirty-six weeks pregnant. I suspect she was not using protection because we found out when she had taken a baby for the six week check-up that she was infected. I also suspect that she mix fed her baby because she said she

> introduced the baby to bottle feeding. That was where the child too got infected because the child's first and second DNA test came out HIV positive. I was really hurt and abandoned them (daughter–in-law, my son and the child) for three months. Being the only male in my house, it was not easy to confront him [my son] with health issues as you all know Basotho males feel insulted if encouraged to attend health services, especially HIV testing. I was also reluctant to emphasise the significance of exclusive bottle feeding when the mother could not produce enough milk for the baby because my son would accuse me of weaning the child early so the mother could have love affairs. I was hurt and blamed my son for infecting two people (his wife and the child). However, I learned later that I too was to blame because I never warned them from the first time I learned about PMTCT. I kept the information to myself for fear of compromising culture. Thank you for being attentive fellow members.

Buckley (2013) argues that in these situations a woman is made to feel like an outsider in her own family. Culturally, men enjoy occupying the high-ranking position of the family, a position which had to be occupied by the sons during temporary or permanent absence of the father. Buckley points out that the male cultural practice signifies the protection of patriarchal lineage.

The nurse did not wait for the chairperson to invite her to comment, she seemed to be touched by Mrs Black's story. However, she started her address with a positive note. The nurse wanted the support group to realise the significance of their meetings and encouraged them to document their lessons for the future generation. This was an indication that the nurse appreciated the good work and a huge contribution these members were making for Basotho education. To the issue of compromising culture and confronting males about new health practices, which directs parents (mostly women) to bypass cultural practices, the nurse explained the importance of following the policy and the guidelines in situations such as this.

> Nurse: I am very grateful to be called to your meeting because I have learned that your meetings are beneficial and I hope that you could be documenting what you are doing as I could see that these meetings will one day be educative to your children and many other generations to come when you are no longer alive. On the issue of compromising cultural practices, I want to make the group aware that you are protected by the National PMTCT Policy and the National PMTCT Guideline which acts like a law that protects everyone who compromises culture to protect life.

The nurse's observations are supported by Jackson (2002) who indicates that many times, health innovations emanating from scientific research, get executed under strong observation of policy

but the guidelines cause tensions between cultural dimensions and policy. Jackson further suggests that foreign motives for putting pressure on locals to attach laws to policy often results in imposing the implementation of foreign ideas without the consent of locals. Hussain (2011), too, argues that the pressure enforced on service implementers to bridge the gap between domestic and international practices through the use of policy and strict laws or guidelines usually causes conflict between programme implementers and clients. Hussain further indicates that normally the conflict is due to the slow pace of accepting change at the grassroots, regardless of its significance to the community. In this respect, the nurse was faced with the same dilemma: that the PMTCT programme ignored the fact that the programme compromised community cultural values. While programme innovators feel protected by the guidelines, they take little cognisance of the need to engage with cultural differences.

The government of Lesotho (GOL) (2006) indicates that it is acceptable for a small nation like Basotho to compromise their culture to protect life. GOL further indicates that the significant role of the process of formulating national guidelines and policy was to invite the community leaders in their different cadres, to encourage them to acknowledge the need for compromising culture to save life. In this aspect, community leaders play a mentoring role in their communities because people look up to them. Their involvement in policy and guidelines formulation reduces tensions between policy and culture. The nurse continued.

> Nurse: I hope you all understand what these abbreviations mean in Sesotho. MBP in full is (she held up a paper already written 'Mother Baby Pack' and explained it briefly in Sesotho, *(ke mekotlana kapa mabokose a tsetseng lipilisi tsa mme le ngoana ho sa tsotellehe boemo ba bona ba* HIV). It is a bag or box holding pills for mother and the baby regardless of their HIV status. It is just a component of Prevention of Mother to Child Transmission intervention. (Then she explained PMTCT in Sesotho.) You have all heard that PMTCT is an umbrella initiative under which we get MBP and many other programmes that could assist in the reduction of new infections mostly in our new generations. Lesotho has piloted MBP and shown it to be working very well. Many African countries have come to copy our successes and challenges so they could go to their respective countries to start. Therefore, PMTCT and MBP are inseparable. Previously you invited me to explain exclusive breast feeding, the strategy that ensures the safety of new born from infection, mostly babies, from HIV infected mothers. I am trying to say we can prevent HIV from being transmitted to a child by employing several strategies like exclusive breast feeding and exclusive infant formula feeding and never give our children breast milk if we have started giving other fluids such as *nepe* (a type of

> porridge) which I know is a custom for many people in Botha-Bothe. They start their first food taste with *nepe* before they could taste their parent's breast milk. (Looking around) do you understand what PMTCT is?

It has already been indicated that this group usually was less inclined to follow the meeting protocols that were exhibited by the fathers-to-fathers support group. Lady Bird (as she was nicknamed) a married woman of her late thirties, was less inclined to follow the meeting protocols that were exhibited by the fathers to fathers support group. She just shouted to the nurse and asked if she could touch MBP to see the contents in each box. Lady Bird then showed her concern that she was doubtful about the strengths of pills. Her concern was that if the pills were powerful, children would still be given *nepe* to avoid deformed babies (the myth was that this was what happened if the baby was not given this type of porridge).

> Lady Bird: I just needed to see the MBP contents even though it might be difficult for me to pronounce all these pills one finds in each pack. At least I am in a position to know which pack holds medication for HIV positive mother and which one holds the ones for HIV negative individual. On the issue of convincing males to deny newborns this special porridge (*nepe*) I still believe there is a need for this to be announced in a wider manner over different media before we explain to our close family members. Most programmes are publicised by the government to a wider community before we could be bound to sell that initiative.

While Lady Bird was talking, the nurse and most members were nodding to indicate their support for what Lady Bird was saying. This interjection was an indication of how important it was for community members to have a tangible understanding of medical discourses especially when the information seemed foreign or complex. It was evident that verbal or written communication alone was not enough. It must also be accompanied by visual and practical interaction with the artefacts involved to enhance learning. This practice was confirmed by Kitchenham (2008) who states that adult learners must have a practical element for knowledge reinforcement.

However, the nurse had not yet finished her lesson. She mentioned the importance of the 'accompaniment' model which was a component in the programme that would assist in involving males and reduce their anxiety over PMTCT programme.

> Nurse: PMTCT encourages males to accompany their wives to the clinic. This intervention was intended to involve males in health services so that males would get professional reassurance that would maintain their manhood. Maybe it is also worth mentioning that those males who take the responsibility and bring their children to MCH for health services will be served before anybody else. Ladies, advise your daughters-in-law to adhere to the feeding option she has chosen because it is so expensive and hurting to raise an HIV infected child. It is true they could grow up like a normal child, but they erode the finances in their families while trying to help them cope with opportunistic infections and preventing minor and major illnesses. With PMTCT intervention, every expectant mother gets tested for HIV as a routine test like they do with other blood tests and urine tests to find out other illnesses they have which could be infectious to the unborn baby. An example here could be that of another type of STI which can be dangerous to the unborn baby. When an expectant mother is found to be HIV negative, we try to find out how many months the pregnancy is, so her duration could determine the frequencies she could test before giving birth. If she is found to be HIV infected, then she is given ARVs which she has to take in order to protect the unborn baby as those ARVs will reduce the viral load and thereby reduce chances of infecting that expected child. However, we are just waiting for the new ARVs guidelines to be printed and arrive at our facility which have revised the advice on taking ARVs during pregnancy depending on CD4 cell count. With the new guidelines, if the expectant mother is found to be HIV infected, we are not going to mind the CD4 cell count any more. The expectant mother will be initiated on ARVs and will not stop them after delivery like it happens now when we mind her CD4 cell count. This means that the woman will be served at Mother and Child Health (MCH) corner, until her child is two years old. Then she will be given a transfer to be given her monthly services at Paballong ART centre for further management and monthly check-ups. However, I want to accept the fact that being resistant to change is normal according to researchers. Therefore, it is already expected that both males and females might delay to internalise this wonderful programme and adapt when their children are already HIV infected. I would at this juncture like to put a big full stop on PMTCT but wait for some questions or comments that could help clarify more.

These comments show that the programme itself was endeavouring to recognise the challenge of male cultural attitudes by seeking ways to engage men in the programme as a strategy for ensuring the programme's success. The Chairperson (Mrs Brown) wanted the group to participate fully on the chosen topics because they were all aware that PMTCT and MBP needed males to change their behaviour and females needed to make decisions for their children based on the parent's HIV status. Females needed male's approval for minor and major decisions they had to make yet males were not informed on health related issues because they did not attend health lessons as they thought they were childish and feminine. Berman and Bourne (2015) and Couto et al. (2010) share the same view that males find health services untrustworthy and childish due to

the phrase 'be a man' which is normally used to mock males seeking to be relieved from suffering. The phrase customarily translates as 'don't complain because you are a man'. Therefore, being sick, regardless of frequency and severity of a man's suffering was being childish. Couto et al. further indicate that in most cultures, health services are mythically feminine, childish and occupy a lower status. The comments in this support group showed that males needed to keep their high status, therefore females in this particular group had to put their heads together in order to compile facts that would convince males to actively participate in PMTCT prior to introducing the programmes in their different families.

> Chairperson: Actually, we had intended to tackle the importance of PMTCT and MBP together with men as heads of families because they are inseparable. I am happy that the nurse has allayed member's fears and given advice about the cultural implications of the programme. To my knowledge, good members, it is not every family that practices the use of *nepe* porridge to the new-born. … Do you have questions, ladies, before our nurse leaves us?

Mrs Blue, a woman in her late forties, was a woman separated for more than ten years. Her husband stayed in the same village as hers but was taking care of another family. Although the Nurse had already indicated that she was through, Mrs Blue had a concern which needed to be clarified. She needed to know what happened to the expectant woman who declined all the services. Mrs Blue suggested that the accompaniment model should also target expectant mothers.

> Mrs Blue: Madam Nurse, I am wondering if these expectant mothers are expected to agree or refuse to be tested even those that are HIV positive, are they being asked if they can take ARVs or not? I want to believe that if they are denied a chance to consent to such services, it appears as if the programme punishes them for being pregnant. Are those who refused to comply with the programme demands not being denied services as well? We were previously taught that every individual has to give consent for such services except for rape suspects who are mandatorily being given such services (HTC). On the issue of bringing males on board for approval of compromising cultural practices as a means to enhance zero new infections mostly to children, my suggestion would be to promote the accompaniment model, which targets expectant mothers and their lovers to visit the clinic at least twice before a child is born, this practice can work best. This practice can enable people to familiarise themselves with health practices that can save children's lives while at the same time help them understand the significance of such programmes.

The nurse incorporated Mrs Blue's concerns on PMTCT and MBP in the next part of her talk and tried to allay her fears. The nurse was certain that if the support group followed the procedures, they might achieve their goals to promote the programme. Preece (2014) argues that the purpose or attraction of a community of practice is that it is a means of encouraging participants to 'take collective responsibility' for their learning as the learning outcomes should be greater than the sum of their parts. It was the expectation, therefore, that the group would move forward collectively, even if at different speed levels, from confusion to better understanding. The nurse outlined the procedure for testing and accompaniment as follows:

> Nurse: Ladies I have already indicated that HIV test is done like other routine tests which are performed with blood and urine for a pregnant lady to assist the unborn child not to be infected with her mother's illnesses during pregnancy. They are being informed of all the tests which will be performed. None of them is forced if there can be anyone who can reject the services. Instead of forcing them to accept the services, we give them to an expert patient /counsellor working at MCH so that she encourages her and gives the importance of the program to herself as the mother and to the unborn child. Also the consequences of not taking the full services are also discussed so that if the lady ends up not abiding, she will at least be informed. Thank you for that wonderful question lady, none of those expectant ladies is coerced to begin those services. This is why the programme requires them to be accompanied by their husbands during their first visits so that they could both be tested for HIV together to reduce stigmatisation and discrimination. After the first visit we expect them to come with you mothers-in-law so that you help them in their feeding options and other major decisions which they need to take because we believe that mothers-in-law are the ones enforcing customs and values of the family regardless of how dangerous they could be to the new-born child. The intention of inviting you to come with them for support is mainly because they normally do not have a say in your family and you keep on reminding them that they have to adopt and adapt to your family expectations. Is it not so mothers-in-law? (They all broke into a huge laughter instead of answering her question. The nurse sat down but also smiling. There was no other hand raised in request to talk although in this support group, they raise a hand and talk before being given permission to do so. This is why sometimes two would speak at the same time). Mrs Blue, no expectant woman can be denied any services because the Ministry of Health still believes that they may one day comply even though some comply with the second born child when the first born is already HIV infected.

This chapter signifies the role of mothers-in-law for enforcing customs and values. The medical discourse was once more endeavouring to work with the culture in its efforts to promote effective health behaviour. Buckley (2013) emphasises that it takes a strong group with close ties and clear goals to enforce a certain community to influence customs and values because actually

the importance of culture is in the owner's mind. Therefore, Buckley argues that unless a bit of pressure is pushed for the community to realise the importance of compromising some bits of cultural practice, medical discourses such as PMTCT cannot be of benefit to Basotho as a whole. Buckley (2013) outlines that in a normal communal setting, males play a significant role which mostly relates to enforcing law and order for peace and stability, while females, especially mothers-in-law, are entrusted to enforce customs and values. So, the aim of the meeting was to enable medical discourses to blend well with culture to promote effective health behaviour. Therefore, it was of great significance that each family member should be convinced about the importance of their participation in plans to improve health.

After a long session given by the nurse, the chairperson was willing to wrap-up and adjourn the meeting because she believed that members understood the core content. However, the chairperson realised that strategies on how to talk to males had not been exhausted. Therefore, she reminded the group that their main concern was to exchange ideas on strategies of how to talk to males with the hope of familiarising males with regards to health services especially child survival programmes. The chairperson wanted the support group to discuss this gender related issue to its conclusion because she said they had a commitment to be the ambassadors for the Ministry of Health, therefore they needed to work hard to ensure the success of health programmes. The chairperson realised the importance of motivating members and referred to their learning as 'a university' in the hospital premises.

> Chairperson: In the absence of questions, I want to thank you very much nurse for visiting and feeding us with PMTCT information today. We need to value this programme without undermining it as if it has happened as a foreign intrusion. Our knowledge in this aspect will tie the group together strongly enough to persuade the community to value PMTCT too. We believe every one of us is going to give advice accordingly based on the information you have given. You are granted the permission to ask us when you find an infected child at MCH because you have taught us the main preventive strategy. As our counsellor said one time, PMTCT is an umbrella strategy which all other strategies are striving to achieve. (Pointing at those sitting direct to her across the room.) Do not learn to forget these things ladies because if you want to think deeply, you can realise that we have opened a university here in the hospital premises. This was a good quality university lecture. Is it not so ladies? It is so (all were shouting and clapped hands. She raised both hands up to call back their attention, then they kept quiet). Therefore, we are releasing you (to the nurse) while we have taken enough information from your mouth and will chew on it because as you can see, we are aged

> except for only two members. So, the information you have given to us is a good provision for every member to take home this month. Thank you.

The Nurse felt gratified and encouraged by the chairperson's words. She was worried that she might have given a lot of information all at once. Therefore, she promised to be available for them during their next meeting so that she could attend to their concerns if they had some. When the nurse encouraged the support group members to think she had given a university lecture, the statement had two connotations. First it gave authenticity and authority to the nurse's talk, allowing the members to feel they were absorbing authoritative knowledge which is associated with university knowledge. It also served to recognise that the women had had to concentrate at a high level and needed time to internalise the new vocabulary and content because the learning was complex and detailed. These meant if the group did not understand her well, meaning making or contextualising the content was a challenge.

The nurse also made a comment about the strategies on how to talk to males. She made the group aware that although they had proven to be hard workers and changed many aspects in relation to HIV prevention, Basotho males may still resist changing. Their efforts might be considered or rejected by males for fear of being dethroned. Understanding the women's perspective and current situation was a boost for every female to work harder in the fight against HIV. This indicated her understanding that new meaning making would impact positively on how the women responded to the epidemic in terms of HIV management, behavioural change and social relations.

> Nurse: With this note Mrs Chairperson, can you please allow me to leave you so I could attend to some other activities at MCH? Please share the strategies of how to talk to males. The programme is faced with a lot of gender issues which would need your efforts to work on. Also be aware that you might need to gather all sorts of strategies, but males may reject all the efforts due to fear that you want to be in their powerful seats. Males usually resist change due to fear that females are power hungry and intend to rule. I will be around during your sitting for next month because the office of the matron has allocated me to be with you for quite some time. (The nurse stood up and waved a good bye and left the room.)

A similar issue is raised by Dugan (2012) that, often, men's fears emanate from knowing how it feels to be overpowered. Fear of change stops people from taking action. Dugan further indicates

that males’ social orientation instills superiority of males over females, therefore female’s efforts on development contribute to instilling fear in males and adds to the complexity towards relationships between males and females. John (2016) indicates that life experiences, and complex gender relations impact on the levels of fear, trauma and oppression generally experienced by women. John further points out that the experiences of most women of trauma and fear in life reflect how society structures and shapes such individuals.

Ntseane (2012) indicates that the African value system and learning features a sense of responsibility where most African males focus on one side of responsibility which includes deciding the number of children to make and deciding whether a boy child must be culturally initiated or not and many other decisions. They ignore the health side (allowing a wife to attend maternal health services, vaccinate the child, practice child feeding options etc.) because health services have been a female’s domain. Mrs Blue continued to be worried about the nurse’s response on how they would explain to males, who are believed to protect cultural values in their families, on the value of exclusive breast feeding, without babies being given *nepe.* She also queried how PMTCT and MBP can be explained without the support of written Sesotho material since Sesotho is the home language. Mrs Blue suggested that in the absence of Sesotho written material, the Ministry of Health needed to hold intensive male awareness campaigns which she believed would reduce male resistance to the programme. She also raised several issues in relation to the supply of condoms:

> Mrs Blue: Is there a special reason for this mother baby pack to have male condoms only yet those packs are given to ladies? I was thinking the condoms included in there are female ones but they are all male condoms. Maybe I could suggest that MBP include both male and female condoms. Providing both condom types will improve accessibility and availability to the public. Let alone knowledge to use them, very few people are able to use female condoms. Lastly I do not feel content with the nurse’s response on how PMTCT and MBP can be introduced to Basotho males, mostly the components which go against our culture such as ignoring the importance of *nepe* to a new-born child and focusing on exclusive breast feeding. If we are only told about the policy and guidelines which are written in a foreign language (English), we still need to have convincing facts to share with males to avoid conflict of culture and this wonderful preventive intervention.

That was an important opinion because it raised a number of discursive challenges in relation to the medical model of introducing the programme vis-a-vis the reality of Basotho culture and the applicability of the programme in communities. Mrs Blue's concerns highlighted that the process of meaning making was complex and required attention to several issues. For instance: that of the practical application of condoms, the cultural contradictions regarding feeding practices and the linguistic insensitivity of a medical message which failed to use the local language to communicate with local people. Similar concerns were raised by Preece and Ntseane (2004) regarding medical interventions that neither take account of local language nor culture. Therefore, ignoring language and culture adds to the complexity on such intervention and delays adoption and behaviour change.

The chairperson realised the need to release the nurse. Therefore, she allowed the nurse to go and, reluctantly, continued to chair the meeting since the members wanted to continue discussing their concerns about possible strategies that could be used to persuade males to accept the eradication of those cultural values that contributed to the spread of HIV infection to new-born babies. Discussing these strategies prolonged the session beyond its normal timespan. At this point, only layperson discourses were available to make meaning out of the nurse's information. Every member felt obliged to contribute, all discussions were now without the assistance of professional help. Maybe the nurse left the group with the hope that discussing cultural values which hindered males to support prevention programmes that could benefit their children might not impose any challenges. The other reason could be that the nurse did not feel she had any more to offer in relation to the cultural and gender issues. Nevertheless, the following conversations reveal that women were faced with many gender and cultural contradictions in relation to the medical advice that they had received.

Mrs Navy, a married woman in her early fifties, felt compelled to share her experiences about Mother Baby Pack (MBP). She shared how she had tried in the past to manipulate gender and cultural contradictions to ensure the new born was not infected. She advised her group mates to follow exactly what the programme required.

> Mrs Navy: I second the idea that the meeting could be adjourned before we are angry about time. We always claim to be professionals when we have done things right. Even on the issue of time, I think we need to act like professionals. I know we have the weakness of being carried away by the topic when we discuss an interesting one. But I also want to volunteer myself to tell you the story I experienced in my family about the MBP and how I was struggling to ensure my grandchild was safe since the father (my son) did not want his wife to use MBP contents because he believed MBP was my idea and did not want to give in. My son thought agreeing to MBP would make him *(selehe)* obedient if it was my idea because he considers himself head of the family.

Mrs Powder, a widow in her mid-fifties offered a more positive view about Mother Baby Pack, unlike the rest of the support group members who were totally new to the programme. Mrs Powder had been supporting her HIV positive daughter-in-law while her son did not like any contraception including condoms. He threatened not to provide financial support to the family if his wife were to test for HIV. His masculine attitudes, mind-sets, and ways of looking at life's challenges were totally negative if ideas originated from a female. Nirola et al. (2011) confirm that patriarchal societies commonly put males in the driver's seat to make decisions for any activity and do not compromise the patriarchal practice in any case.

> Mrs Powder: Unlike the rest of you my fellow support group members, I had to assist my daughter-in-law to hide her MBP when she gets home from her monthly check–up and when she wants to go for a check-up when her husband is around. This is because she is HIV positive while her husband, (my son) does not know his HIV status as we speak. He has warned his wife during my presence that if she could turn out to be HIV infected she should pack her bags and go straight to her maiden home because their marriage would be over, yet he does not want to know his own HIV status. (She frowned and loosened her jersey buttons as if she felt hot.) You all know that I am a widow, I am also depending on the money this stubborn ugly boy, who looks and acts like his father, brings home. I suspect that my daughter-in-law got infected by this same boy (her son) because he became ill for a long time without disclosing what the problem was. At the same time, he throws condoms into the toilet when I am trying to intervene and encourage them to use condoms. This girl (my daughter-in-law) is informed but cannot negotiate safer sex at all. That is why I felt compelled to support her to take ARVs in order to protect the child from being HIV infected. My fear is that, this couple will have the third child because they are not practicing safer sex and my son seems to hate condoms. There was a time he left us with only M100 when he was going back to the mines because I had encouraged his wife to use female condoms. His children were left without even Vaseline. … Like I have already indicated, I am being very tactful towards him because he wants to live like a wild cat in my family.

All the women showed evidence of what Mezirow (2000) calls a disorienting dilemma which was challenging existing mind sets. John (2016) confirms that young adults still faced many of the harsh realities caused by HIV infection, the same realities pushed people like Mrs Powder into a tight corner to the point that she agreed to join the support group with the hope she would gain ideas on how to soften the heart of her son. Mosuoe (2016) indicates that infected women of Phelisanang Bophelong (PB) had to deal with the burden of being infected with HIV alone, coping with side effects which sometimes were too obvious, stigma and discrimination, without their sexual partner's or spouse's support. Mosuoe further indicates that women participants in PB went through tough times and labelling from their own spouses who had not even tested to know their own HIV status. Male spouses for PB members acted as if they were immune from HIV because the pressure and burden of living with HIV was too heavy on each of the members. Mrs Powder continued, explaining her strategies for addressing her family concerns:

> Mrs Powder: He is young but told himself he will not take any advice from any women including myself (his mother). He takes advantage of the fact that he is the only male in my house and that he is providing for all of us financially, since we depend on him to provide everything. This is why I have asked Mr Zaga in the fathers-to-fathers support group to target him and help me talk to him about everything pertaining to health every time he is home, so that Mr Zaga may soften his heart as they are both from initiation school, he may be in a better position to win him over. I know that the issue of initiation school will make my son trust him since I have realised that it connects both of them in many incidences … One day I will find his wife employment so that she has her own money and freedom like women of her age. I have already talked to the nuns at St Paul to spare her some space to do even the jobs like that of the household (domestic work) so that this lady can be awayfor a while and maybe even use contraceptives without his knowledge, you cannot believe how silly and arrogant that boy is towards me and his wife. When we talk about child spacing and contraceptives, he would comment that his wife wants to bully him.

Mrs Powder's concern signifies several discursive challenges in relation to cultural orientations on the female status being considered as low or non-existent in the family as opposed to the male status that ignores the female figure in the house. Mrs Powder's concerns highlight the need to identify and work on males' habits of mind to nurture new perspectives that will result in transformative learning. However, the process is a complex issue that requires attention to several matters where cultural contradictions in regard to the male's involvement in health practices

pervade for fear of female dominance which results in males continuing to resist both medical interventions and discourses that imply the need for cultural change.

Everyone seemed to be touched by Mrs Powder's story. The group realised the challenges female headed families encounter. They were hurt by the behaviour that young man portrayed in his family, especially when it put his family at risk of being HIV infected. This story revealed that gender power relations were entrenched at all levels of the family and even when women attempted to address such power relations they must do so 'via the back door'. Mosuoe (2016) argues that HIV infected females of Phelisanang Bophelong survived only because they supported each other during the dark days of their illnesses when they had lost hope and were faced with death. Otherwise members would not have survived gender power relations which prevailed in their own families.

It was also interesting to note, however, that Mrs Powder took the opportunity to exploit the bridging social capital potential of connecting with the other support groups as a resource to facilitate communication with men. In this case Mrs Powder wanted to involve a man from the fathers-to-fathers support group to relay the required health messages. She also endeavoured to find ways to make her daughter financially independent. This was a sign of a new sense of agency that might not have emerged without the HIV crisis. Mosuoe (2016) also points out the power of agency that women develop as a result of their circumstances. Members in the PB might have struggled due to HIV infection but finally all members strengthened and picked up their pieces and developed strong coping mechansisms. But importantly, the only way Mrs Powder's daughter-in-law could adhere to the medical discourses of care was to do so secretively. The medical language of HIV prevention therefore had to be navigated through different layers of local discourses and behaviours. Hodgson et al. (2012) confirm that HIV infected individuals survive longer if granted various sources of support. In this case Mrs Powder was the support for her HIV infected daughter. The opportunity to access positive forms of support reduces stress levels and addresses both emotional and financial needs. According to Hodgson et al. (2012) support groups are especially important to persons who are HIV positive. So many emotions confront people after they have been diagnosed to live with HIV. As they face changing social and financial situations, they can become frightened, bewildered, and worried.

From Mrs Powder's story, it seemed that the husband would not support the idea of her wife taking lifetime medication (ARV) for any reason even if this male was fully oriented regarding the issues. Carnahan (2012) argues that support groups are especially needed where individuals are denied such support in their closer relations. Groups enable caregivers to discuss concerns with others, sharing the same experiences and emotions and to work out complex feelings of worthlessness, frustration, or alienation. Medical expectations alone had not made room for individuals to cope when they were denied other forms of support due to cultural practices exercised by males as heads of families. Such cultural practices often mean that males resist change even if the practice costs a life.

Mrs Lemon was a separated woman in her mid-fifties. She shared her concerns about how Mrs Powder's daughter in law tried to take her pills in the presence of her husband.

> Mrs Lemon: Fellow members, I want us to stay attentive to these stories. None of us can deny the fact that we have all been victims of men as heads of families. Stories like that of Mrs Powder hit the scars we already suppress for the benefit of keeping peace in our families. I would like each member to realise the significance of the topic so we all stay attentive. It seems like your son Mrs Powder is not only stubborn, but he resists changing his behaviour and attitudes towards prevention. This makes me worried about the contents of Mother Baby Pack, how did your daughter-in-law use her medication when her husband (your son) was home?

Mrs Powder revealed how she became a treatment supporter for her daughter-in-law:

> Mrs Powder: I know the pills she was using because I use to come with her every time she comes for a refill. So when her husband was home during pill time, I always try to assist her so that she could take them on time and adhere, I normally take them and will put them in her pocket while her husband is looking in a different direction *(ke mofa ka style)*, then she will hide and try to take them before her time elapses. Sometimes when her husband was home I always sent her to bring my blood pressure medications from the other house *(ka Heising)*. Then she will get a chance to take hers.

Actually, Mrs Powder was the one who kept the pills at all times. She felt responsible for her daughter-in-law's adherence. She used a range of surreptitious strategies to ensure her daughter-in-law's adherence even during her husband's presence. Mrs Powder revealed how gender power

relations are navigated through a range of manipulative behaviours that effectively become a feminine discourse for HIV adherence. Mosuoe (2016) cited Kimaryo et al. (2004) as they highlighted that one of the underlying structural contexts of HIV and AIDS are power relations that exacerbate the spread of HIV and AIDS:

> 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).

That cultural discourse was one that the nurse as a medical practitioner had not taken part in. The question that was raised, therefore, was whether the medical discourse was aware of these required strategies or whether the women's discussion of these strategies and tactics (since they were discussed after the nurse departed) simply remains separated from the medical model of care. According to Davies and McCartney (2003) and Modo, Modo and Enang (2011), support groups are effective because members receive first-hand advice and share such manipulative behaviour to employ for HIV adherence approaches that they learn from peers who are coping with very similar circumstances. This means that the guidance is not theoretical, but practical, personal, relevant and involving.

The discussion continued. It revealed time and again the challenges of gender power relations and the need to find ways to involve men so that they become part of decisions about healthy lifestyles in order to avoid the impasse between medical needs and family resistances.

> Chairlady: The second person was Mrs Grey, can you share what you have madam?

Mrs Grey earlier on had shared her concern about the negative attitudes Basotho males have towards health issues. Her main worry was whether the current health programmes realise that even though women are expected to implement all sorts of programmes, males have to bless or discourage such implementations because in Lesotho, a woman needs a final blessing from a male figure in the family to perform some of the family responsibilities. She indicated therefore that implementing an HIV health programme cannot exclude the involvement of Basotho males. Mrs Grey then shared her personal experiences about exclusive breast feeding. She considered

the support group to be a safe and non-judgemental atmosphere where she narrated her sad stories on how lack of knowledge contributed to infecting her own child.

> Mrs Grey: My fellow members, I want to narrate a brief story about my experiences relating to the topic of the day (in terms of men as heads of families). I have four children of which two are dead. When I was breastfeeding this last one, my daughter-in-law was also breastfeeding her first born. I opted for exclusive breastfeeding. Because I knew I could not afford to buy milk formula for exclusive bottle feeding. I also knew that the father to the child would not want to listen to why I was not breastfeeding. The group which I attended, Ante-Natal Clinic (ANC), was of younger age compared to myself. They started a revolving fund whereby they bought each other milk formula each time we came for a check-up. I was not part of the revolving fund because I never trusted my financial resources to last me. But I liked the idea and took it to my community for people who can afford to start their own fund. Therefore, my daughter-in-law opted to not breast feed and fed her child milk formula because she could afford to. Every time she had to go away, she left me with her baby. This is how mine got infected because I would give my child a feeding bottle of this other child for a while, and later on breastfed mine. I never understood the seriousness of exclusive breastfeeding, therefore I was mix-feeding mine and the child got infected in the process. I regret what I did. I was informed by one member of the new family who would have attended Mother and Child Health (MCH) services. They also concluded that if a young woman may not be breastfeeding for one reason or the other, the boyfriend had to know and be consulted before such a decision was made (mostly because the intention was for the couple to raise a sustainable family). They agreed that it should not be up to the female youth to decide whether to breast feed or not because the two were expected to start a family together and begin to make joint decisions.

UNAIDS (1998) argues that support groups are not just about money issues; they are about sharing both wonderful and challenging moments. Such groups give each other emotional support to cope and create a space where an individual freely discusses the illness in a safe, non-judgmental atmosphere. This process, as discussed in Chapter Five, reflects the purpose and outcomes of learning as a community of practice because members openly learn as a group and gain mutual benefits from their learning and sharing in meetings. Maskell (2000) indicates that participating in these ‘communities of practice’ is essential to an individual’s learning. Maskell further specifies that in groups where communities of practice become central, lack of knowledge turns out to be an integral reason for joining, sharing and learning in groups. Modo et al. (2001) also confirm the emotional support value of support groups where people are able to share similar experiences.

This discussion also suggested that members had reached phase eight of the transformative learning process, when learning for transformation went through a stage of acquiring knowledge and skills for implementing a new course of action (Mezirow 2000). The mothers-in-law recognised the importance of the female youth compelling their boyfriends to attend health services as a means of orientating them to family involvement issues. This group had previously discussed the importance of targeting youth to attend MCH and ANC services.

Addressing the youth

Mrs Snow took up the task of being a hunter for the functional youth corners. These are small rooms in hospitals labelled youth corners where youth can seek health advice.

> Mrs Snow: I want to remind you that previously I took the task to go and hunt for the places where our young daughters-in-law get health services from in the Botha-Bothe district and nearby districts such as Leribe. For those who were not here, we discovered that most of these young daughters-in-law were reluctant to attend Ante-Natal Care (ANC) and Mother and Child Health (MCH) sessions because they were afraid of facing older women like Mrs Grey who have come for the same services. We have realised that for those who are HIV infected, they cannot refill their medication freely since they are in the same room as the elderly ones. They would rather take a nurse for a private conversation to avoid suspicion from those that are attending. Therefore, we thought it was wise for us to find out whether health services have catered for such age groups or not. That was because one of our fellow members told us that in a referral hospital Maseru there are such corners where all young mothers below the age of 25 are being attended to. In short, I found out that Botha-Bothe has an adolescent health corner for both pregnant and non-pregnant youth while Leribe has a corner which only provides services for pregnant youth while the non-pregnant have no such corner. They are expected to mix with their elderly mothers to access other health services.

They agreed that the youth corner should be functional if it provides all health services including free access to ART, prevention commodities such as males and female condoms, and including all sorts of contraceptives. The Support Group then seemed to move into Mezirow's new phase (the final, tenth phase) where members re integrate into society with the new perspective (Mezirow as cited and expounded by Merriam 2008). The support group used their prior interpretation to understand a new or revised interpretation of the meaning of their experience in order to guide future actions. New epistemic habits of mind were developing because members were applying their new knowledge not only to understand PMTCT but also to find ways of

practising its requirements within their cultural constraints, to ensure their grandchildren were born HIV negative regardless of their parents' HIV status. Their interaction enabled the group to commit themselves to each other and strengthen a sense of belonging amongst themselves. That sense of belonging is an important feature of Maslow's (1968) hierarchy of needs as a pre-requisite for conducive learning.

It was also evident in the ensuing discussion that generational discourses needed to be considered in order to address medical needs and concerns.

Mrs Five, a very tall, married woman in her late thirties, insisted that some members should take up a hunting task to search for youth welfare corners. She argued that females are exposed to early pregnancy challenges in any case irrespective of whether their boyfriends take responsibility for any of the dangerous stages a female goes through. She said it was the duty of mothers-in-law to search for functional youth health corners before they mobilise young males to accompany their pregnant girlfriends to access health services. Her reasoning was preceded by the fact that females are not allowed their own decisions without their male partners' blessing (Ntseane 2011). She intended to assist the youth to start taking joint decision making responsibilities at an early stage of their life. She was certain that females are always hurt by the fact that as females, they were not made sufficiently aware of the consequences of being married whereby males are automatically expected to be heads of families. They simply got married with the hope that they were going to share ideas and implement them together with their partners and make joint decisions. She made a point that all of them (as women) had never been given a chance to participate in family issues. Males would rather gather at the kraal with their boys to discuss family concerns and come to women with their ready-made concrete decisions. Mrs Five was blaming older generations for failing to warn the youth that Basotho families reinforce gender inequality because it was perceived normal for males not to involve their female counterparts in either minor or major family decisions.

One suggestion was that the Lesotho Planned Parenthood Association (LPPA) might be invited to be involved. The support group's intention had been to visit such institutions to make the youth aware of the significance of orientating both males and females to allow each other to

practise and appreciate decision-making as a shared practice between couples. Such arguments would fit well with traditional African value systems which believe that knowledge is communal because social change depends on collective responsibility (Ntseane, 2011). Nevertheless, intergenerational differences needed to be respected. The efforts of segregating young clients from the old so the young could articulate their concerns in a less threatening environment has long been practiced by Basotho through the use of small learning institutions called Thakaneng. These small learning institutions were deemed helpful in providing information on youth and adult education in the country (Setoi, 2012). Mrs Red Rose, a single woman in her early fifties, contributed to the discussion by referring to a previous hunting activity. She said:

> Mrs Red Rose: On the task I had gone to hunt, I went to LPPA but they said they do not have a youth corner except for the fact that school children are served on Fridays only and adults are not allowed for services on Fridays except those who come with proper emergencies. The matron in this hospital said they are intending to resume the youth corner that will not only concentrate on pregnant young ladies but also breastfeeding mothers of the same age. I hope that lessons at the corner could emphasise partnership, factors leading to sustainable happy and happy families. I trust the Ministry of Health can formulate a gender awareness programme with the hope of eradicating gender insensitivity. There should also be a policy that forces males to attend health services. All decisions made at the kraal area where women and girls are not allowed to go, should be non–existent in such families. I am sorry for narrating such a long story and taking too much of your time.

Mrs Red Rose demonstrated that gender inequality in health related issues had been an ongoing issue of concern in their group. She suggested that cultural values, contribute highly to gender inequality. This was the second time that the topic was brought forth for discussion because the group wanted to tackle the topic from all angles. These women were concerned about cultural value systems which encourage gender inequality. Their main concern was the efforts mothers-in-law could put in place to ensure good health for all. Members complained that most efforts do not succeed due to male resistance to change. The mothers-in-law had a general feeling that it was high time males had to change. The group had realised that adhering to those cultural values which no longer add value to human survival needed to be reversed – a key stage in perspective transformation, but one which still had to confront the reality of culture.

7.3 A change of mood and new sense of assertiveness

Mrs Red Rose's plan was to visit law and policy makers such as the District Administrator (DA) because she wanted him to support the idea that all men whose wives are pregnant must visit the health centre at least twice before their baby is born. This is a distinctive step that suggests a new kind of empowerment and sense of agency in the group, very different from their earlier complaints and sense of helplessness. Taking the initiative to visit the DA's office denotes a sense of assertiveness that contrasted with their own image of being helpless in the face of male dominance. Taylor (2009) argues that dominant societal values need to be identified and reconstructed if they are to enhance human development. Life affirming values that are largely perceived intolerable to contemplate or impossible to attain by the majority can at some point be recreated to suit the needs of a population.

The group encountered challenges as individuals and as a group. These challenges entailed sharing resources, strategies or experiences for addressing these challenges. In other words, this support group become a shared repertoire for practices that worked well in their lives. Learning together in their support groups and using their experiences to clarify complex issues, assisted them to formulate common meanings as a group. In this case it included understanding the need for males to attend health services to support their wives and children. Consulting with the DA for assistance indicated that the group was in the fourth and fifth phase of transformative learning (Mezirow, 2000) because they related their discontent to the similar experiences of others, recognising that the problem is shared. As a result, they explored options for new ways of acting as suggested by Mrs Red Rose.

> Mrs Red Rose: Gender inequality in health related issues seems to be our main problem. Our laws and culture favour males and describe them as heads of families, even those [men] that are mentally retarded. Men own properties, animals, lands and us as their mothers and wives. That is why in most cases males do as they wish without consulting anybody except for their male counterparts if they are present in families. I want us to visit the District Administrator (DA) to see if we can challenge the law. The nurse has already informed us that we are always backed up by the policy and guidelines. Therefore, my suggestion is to request the DA through the use of district councils to announce that no man should resist health measures intended to protect children.

The Chairperson smiled at Mrs Red Rose's suggestion. She passed a brief remark intended to motivate the group for the hard work and for good intentions that the group had. The group seemed to be ambitious. The Chairperson further indicated that ambition is an inner drive that boosts the group's energy to achieve many efforts including this one*: 'Ke hlokometse hore kaofela rena le mochofane o lekaneng hore reka etsa tse kholo ho kenyeletsa le tsona tsena.'* (literally translated as I have realised that we have enough energy – motivation to perform huge things which include learning as a means to address our challenges). The chairperson reflected Maslow's (1968) view that an individual needs an inner drive as energiser to pursue and achieve most intended plans. The inner drive was a motivating force for the women to work harder to attain their goals. The collective nature of the learning network and its activities and relationships enhanced the individual growth of each participant through a process of becoming members of a collective identity. Therefore, all members were expected to benefit from it.

Mrs Blue also seconded Mrs Red Rose. She suggested that she was looking forward to visiting Leribe as a neighbouring district so that they could influence the newly informed mothers-in-law in Leribe to make a louder noise to encourage males to attend health services in order to be informed before they make huge decisions concerning their children's lives The women were arriving at what Mezirow (2000) in his transformative learning theory suggests as gradually reaching the stage where meaning schemes are revised through critical reflection. Mrs Blue suggested that they needed to book a slot at the HIV and AIDS commemoration event like they once did in a previous year.

> Mrs Blue: I just want to second the chairlady and Mrs Red Rose for encouraging us to take actions on Leribe group. They already had a bit of information about how our support group operates in order to learn. They learned about us and got interested in 2011. Therefore, we need to address high ranked people and government officials at a national celebration on HIV and AIDS day commemoration in Leribe. We managed to attract support groups to use our learning style in order to be able to support each other as individuals, and to support their daughters-in-law without any element of discrimination. Above all, our speech managed to attract funding from the American Embassy as they saw that we are trying our level best to be informed so we could inform the rest of our families. With this note I think we need to increase our efforts to make sure that Leribe has a group of mothers-in-law to follow in our footsteps. Our concern on the cultural values that consider males as heads of families, even when they do not bother about the survival of their own children, has to be challenged.

A new sense of voice was coming out in this stage of the meeting as the support group indicated their intention to widen their support to the neighbouring district. Hodgson et al. (2012) suggest that viable support groups are perceived as a multifaceted resource in which individual well-being is enhanced through such mutual and supportive exchanges. Mosuoe (2016) highlights that coping in support groups includes how people help others manage their information; deal with their emotions; or appraise potentially threatening situations. Wenger (2000) refers to groups who have gathered for collective learning purposes as crossing multiple boundaries in communities of practice. The members expanded their learning programme by jointly taking new initiatives of educating other members of society. Crossing these multiple boundaries entails using strong ties and networks by the members. The support group therefore also illustrated their use of linking social capital, as they planned to reach out to people in similar situations, but who are entirely outside of their own community. They planned to reach out as far as Leribe district, thus enabling members to leverage a far wider range of resources than were available in their immediate community.

This support group indicated they had moved through from phase six, building competence in new roles, to the tenth phase of transformative learning as tabulated by Mezirow (2000). Now the support group realised they could use their competences to equip a new group encountering similar challenges to theirs. The phases they appeared to have moved through seemed to reflect Mezirow's identified phases: phase six - building competence and self – confidence in new roles; phase seven - planning a course of action; phase eight - acquiring the knowledge and skills for implementing a new course of action; phase nine - trying out new roles and assessing them; and finally with the ultimate target of phase ten - reintegration into society with the new perspective.

The challenge of male dominance, however, was a sensitive one, which needed retrospection and caution. The chairperson, throughout these interventions from the members, persistently encouraged the group to feel empowered. She indicated a lot of incidences where they had managed to achieve change in attitudes or behaviour. The chairperson suggested, however, that the topic on cultural values, where males have complete autonomy, had to be discussed with fathers-to-fathers before they could attempt to influence higher government officials.

> Chairperson: Ladies, I have a feeling that we may have good intentions, but it may sound too sensitive to male authorities whom we are intending to address. To test if that may be the case, I am suggesting that we share our views with the fathers-to-fathers support group. Their responses as males will give us a direction to know if the topic is too sensitive to publicise or not. We need to avoid being shunned by the community because we still have a long way to go. The Ministry of Health is banking on us for most programmes which are concerned about child survival. Discussing cultural values with the intention of persuading males to change their behaviour and encouraging them to be more supportive and caring to their children's health services, needs to be handled with care. I need to remind you once again that Basotho males have had power since they were born. They were oriented to practise their ruling powers in their families. Therefore, change of behaviour might be a challenge to them.

These exchanges between the women indicated that they were thinking critically and purposefully. At the same time, they maintained their new sense of authority to know those aspects of culture which should be challenged, in spite of their low status as decision makers. Even though they understood the challenges, they did not give up. The AIDS epidemic and its seriousness was their lever to act for change (Mosuoe, 2016).

The discussion returned to the theme of addressing youth. Mrs Apple, a married woman in her mid-thirties recalled that youth related events became a success when they had invited the Ministry of Sports, Youth and Recreation. She asked the support group to allow her to visit the department to find out the youth meeting schedules. She realised that most mistakes took place because males were oriented as heads of families and treated their wives like children. As heads of families, they are never taught the importance of giving each member of the family support, including over the issue of unborn children. Males view health issues as childish and as a female concern (Ntseane, 2011).

> Mrs Apple: We need to employ other strategies which worked well for us. There was a time when we needed to educate youth on the hazards caused by myths in the youth's life. The Ministry of Youth, Sports and Recreation played a major role in assisting us to organise the youth from all spheres of life. We learned from this ministry that all the youth are vulnerable because they lack experiences to refer to. Therefore, we were advised that educating all the youth regardless of their social status was a great investment. I would encourage you guys to follow that strategy again. I believe that by educating both male and female youth, the problem of lack of support of their wives and their children would come to an end. If we keep on inviting them to health activities,

> they will get used to health programmes and find it easy to participate in health programmes when the need arises.

As a further consideration Mrs Peach, a married woman in her early forties, suggested that they also invited the pastor who specialised in marriage counselling from her church. Mrs Peach indicated that the pastor usually addressed congregations of the youth on different topics including life skills. She was persistent on this issue because she believed that the youth from her church behaved in a unique manner and were more responsible if compared to other youth especially when faced with challenges such as pregnancy and other life threats which could lead to school drop-out. Some members were nodding while Mrs Peach shared her views with the group. All these discussions demonstrated that these women were moving into a new stage of taking charge of their situation and being willing to take action for change. This was all without any professional involvement. They were finding solutions to their own problems through dialogue and reflection, all important illustrations of the transformative learning process. Chilisa (2011) and Ntseane (2012) indicate that the key African learning values, such as "communal/collective/participatory" and "interconnectedness/independence" (Ntseane, 2012, p. 275) for social change and empowerment, are unique contributions to the way in which traditional African societies think, know and construct reality. This discussion evolved through the notion of being a collective activity and illustrated Ntseane's reflection of how transformative learning theory needs to take account of culture. The learning was a collective process and people were bouncing ideas off each other.

7.4 Cutting the web of gender power relations

As if sensing the mood of the group, the chairperson shifted the theme, this time to a discussion of gender power relations and women's assertiveness.

> Chairperson: I am trying to peruse my previous notes to check what the lady from Gender talked about one day. I find it in the 2012 November notes that she once visited us and talked about sexual assertiveness, she wanted us to practice a 'no' response to whatever sexual related activity we are not comfortable with doing. She encouraged us to practice the skill and said the skill must begin with us.

Mrs Plum, a single woman in her late forties, responded to the chairperson's comments and took the support group back to the lessons they had learned from a gender official who once trained

them on assertiveness. The support group was taught by gender officers to demonstrate exceptional behaviour in their community because they were now equipped with understanding the importance of being assertive in order to live longer. Mrs Plum requested every support group member to take the initiative to share assertiveness skills with young couples to change their cultural perceptions.

> Mrs Plum: The lady from gender gave an example of living in a leaking mud house because everybody has this kind of house in your community and feels comfortable [in it] yet one has the ability to build a cement and brick house. She explained that our cement and bricks are skills, mostly sexual assertiveness, and sexual communication which we need to practice in our families so we can share the skills with our daughters-in-law. I believe this is the right time that each member of the support group commit herself to share the skill because we were told those skills are essential weapons in fighting HIV infection and reaching our goal (zero new infections).

John (2006) indicates that in prevention strategies where cultural beliefs and norms have not been taken into account, prevalence rates of HIV/AIDS continue to rise. Patzer (2007) and Saller (2009) have argued that safer sexual behaviour is problematic because of the power dynamics which means that, often, men alone control the use of condoms in a relationship. In the light of these alarming contexts, the need for assertive behaviour that protects lives becomes very evident.

Lesotho's gender officials therefore reflected Di Clemente and Wingood's (2013) position that HIV prevention programmes must promote assertiveness skills among women for self–protection. Di Clemente and Wingood believe that prevention against any disease has to begin by differentiating myths from facts regarding cultural matters which can spread the disease because usually individuals conform to cultural directives.

The women took up the discussion and in the process revealed the complexity of using a simple notion of assertiveness within the context of the Basotho culture. Mrs Nuts is a married woman in her mid-fifties. Mrs Nuts reminded the group that Basotho males were oriented to have power over their wives and children. She indicated that they needed to be persistent because they had realised how stubborn their husbands had been.

> Mrs Nuts: We were taught to communicate for a reason. We were told that couple communication has to include initiating wanted sex and refusing unwanted sex. Mothers-in-law, can any one of you be honest with the group and tell us if it has been easy for her to practice all? I am asking this question because I tried several times and my sexual partner tells me I have no word when it comes to bed activities. He tells me I must dance to his tune because he is the one who proposed love to me. One day he told me maybe during resurrection (when the dead arise from death), when all miracles happen, then I will be a man and will do as I wish in bed. Therefore, he cannot even use protection. I am telling you all this and request your experience in this because I wonder if our daughters-in-law will be able to convince their husbands to comply with all these lessons we are trying to recall from that gender facilitator.

Gregg (2012) highlights that well planted seeds are difficult to uproot as is the case with well-practiced and repeated behaviour. Therefore, Gregg confirms the need for one to gather strength and tactics to uproot gender power relations.

The chairperson reminded the women that they needed to brainstorm as many tactics as possible as a means of cutting the web of gender power relations because letting the bad practices portrayed by men towards their partners continue, was like taming a wild old lion with the hope of changing its desire for human flesh. She prompted the group to be aware that pledging for zero new infections was never a joke. Therefore, she urged every member to participate so they all get equipped with the necessary assertiveness skills.

> Chairperson: Mrs Nuts posed a question which I think will assist us to seek help in this topic. (men as heads of families) responding to her question might give us broader picture of what to expect from Basotho males. It will also give us enough tactics to give to our daughters-in-law when they confront their husbands on prevention. We have pledged zero new infection; that was a huge step for us. Therefore, fighting a wild and dangerous animal called HIV needs us to be well equipped to defeat the enemy. We have all witnessed the damage this monster did to our lives.

Once more the local discourse draws on symbolic images to reinforce a theoretical or abstract concept. Gregg (2012) supports the idea that abstract information has to be introduced from a familiar angle to ease understanding and responsiveness from the psychological point of view. Gregg believes that the mind connects best if new information is linked to the old to avoid psychological confusion. The women approached the problem from several angles. In each case they would provide examples of personal stories to illustrate their argument. The personal stories

would resonate with other members and served to create a collective identity – a core feature of communities of practice (Wenger 1998). Mrs Red Rose took the group back to her suggestion about consulting the DA to advise on the possibilities of challenging the law that positions males as overseeing females yet males take little or no responsibility for their children's health. She supported her request with a story on how her family lost two grandchildren. She highlighted the efforts she made before her daughter-in-law got infected.

> Mrs Red Rose: Earlier on I proposed that we meet the District Administrator for advice if we are determined to challenge the law. That was because my family lost two grand-children due to HIV infection. Everybody in the family had known that my son was HIV infected. We tried to give him a lecture when he got married. We educated our daughter-in-law immediately when she joined us. We were disappointed when their first born died; we tried our level best to make the couple understand factors that could contribute to their child's death. But the second one died because my own son undermined my advice and told his wife he was the head of the family and could do as he wished to his wife. My colleagues, we really need to do something. This third child survived because we separated from this stubborn boy labelling himself head of family, yet I am still alive.

Such bold choices were often hard won, however, and some of the women had physical as well as emotional scars to show for it.

7.5 Gender power relations and violence

The group now focused on male power and the violence that erupts as a consequence of males not appreciating their female partners' efforts towards raising their children alone as females. Mrs Snow shared her experiences with the support group. She pointed at the scar on the forehead above the eyelashes and said that males always feel very superior to every creature God has made on earth. Mrs Snow urged the support group to develop a hard core towards male power relations which manifests under violence. She proposed that the scars some of them have due to violence must be the last.

> Mrs Snow: I begin by showing you my scar so you could understand that *re lokela ho tiisa maqhoele a lieta re tlame litjale hantle* (literally meaning we need to tighten our shoe laces and shawls around our waist) because we are inviting a fight when discussing how males as heads of families can take the title together with responsibility. The scar on my forehead was caused by a plate full of food which my partner threw and which hit me because his meal did not have meat as he expected. I had given the last piece of meat to the child not him and he got angry with me, threw the plate, spilled the food. Hetold me I

gave the child that piece of meat because I had forgotten he was the head of the family, not vice versa.

She openly indicated that most of the support group members have life time observable scars. She indicated her determination to put to an end to this through education of both females and males. She told the group that her worries increased when she realised that children rely on female parents for various basic needs because males have lost sight of their parental responsibilities.

The group revealed their experiences of ill treatment which men employed to demonstrate their power. In the process, female partners were left with scars and sad memories which they revealed to the group to enforce understanding that males abuse their status of being heads in families. Letuka, Matashane and Morolong (1997) highlight that African males misdirect their powers as husbands and as brothers and focus on hurting the feelings of their female counterparts by failing to extend a helping hand; rather they would extend a harmful hand to people who love, trust and expect protection from them.

Carnaham (2012) confirms that amongst other reasons support groups are important for, relating personal experiences, listening to and accepting others' experiences, providing sympathetic understanding and establishing social networks. This is where members develop empathy for one another. A support group may also work to inform the public or engage in advocacy on matters relating to their field of concern (males as heads of families). This group believed that through education, their daughters-in-law would develop a hard core of resilience to cope with male violence because males may not change overnight. Through these practices, members felt that their experiences were of value to others in the group, and they were therefore motivated to share.

The mothers-in-law recognised from Mrs Snow's story that they too had been exposed to domestic violence by males who use force to instil in females the message that they are heads of families. All the members shared their stories of ill-treatment by males in their families, they perceived males' ignorance towards health related issues as part of the ill-treatment. Mrs Apple also shared her family experiences that indicated that in Lesotho, men's dominance will not

adequately be addressed because it is regarded as normal (Morojele, 2010). It is obvious that most Basotho males understand their positions as heads of families and demand to be regarded as such, but ignore the responsibilities attached to their status. Mrs Apple was worried that Basotho women have been victims for a long time. She said it was reason enough to give them strength to fight and avoid letting their daughters-in-law be victims. Mrs Apple's views signified the concerns of the elderly members of the support group who believed that bringing their bad previous experiences of ill-treatment to light was a good strategy to end similar bad practices in future because discussing how they felt and how they survived as women during such attacks might be a lesson for the future generations.

> Mrs Apple: I want to begin by thanking Mrs Snow for giving us the story which reminds me that my firstborn son once encountered a genital problem as a child of about seven years. He was supposed to be operated on while his father was at the mines. His father denied me the chance to give consent for his operation and wanted doctors to wait for him when he had come on leave because he claimed to be head of the family and said children were his not mine. However, the doctors signed consent on his behalf because the operation had to proceed immediately. My partner was pleased that the consent got signed by doctors not me.

Kalbfleisch and Cody (2010) argue that gender power relations cause great damage to the individual with less power (mostly females and children). Kalbfleisch et al. (2010) further contend that gender power relations are a generational curse which calls for involvement and active participation of various stake holders to collaborate on the practical solutions. Kalbfleisch and Cody (2010) highlight that gender power relations pre-dispose women to HIV infection through sexual violence. Gender relations result in a biased view of gender which in most cases involves a lack of communication in human relationships that results in compromised relations where those holding power dominate the powerless in decision making. In the process the powerless get hurt emotionally and physically.

Mrs Snow and Mrs Apple's views portrayed the face of worried members who did not hesitate to expose their dirty linen (bad personal experiences) to other members of the support group with the hope of learning from and rescuing other community members from similar power relations - which depicted a trend of violence in most families. This element of trust between the members indicates communities of practice as a strong bonding form of social capital because, through

their relationships, members take collective responsibility to develop their core goals (Wenger et al., 2002), to facilitate behaviour change in their communities; and to influence males to take their responsibilities as heads of families more positively. There were many similar stories from the women. Mrs Peach, for instance, informed the group that she had nine children because her partner did not allow her to use contraceptives. Mrs Peach emphasised that daughters-in-law must be empowered to make their own decisions because they are informed, unlike their mothers-in-law who could not question their husbands; decisions because they were not informed. Mrs Ladybird made the support group aware that sharing how their partners treated them does not only indicate how males behave in families but also became a therapeutic act for the group. Mrs Apple in her turn blamed the government for implementing programmes which challenge men's power without involving them at the initial stage where men could accept or reject such programmes before its implementation stage.

These women seemed to be open to each other. They each had a sad story that indicated their fear of males as heads of families. All of them recalled hurtful events where males did not allow female contributions to save lives. Instead they lost the lives of their own children and those of their grand-children because they could not share health education with their male spouses. The stories revealed several offences which could have taken the perpetrators to jail due to child abuse, early child marriage, forced marriage, violation of child rights for education and the right for parental protection (UNICEF, 2014). But in the Lesotho context, such acts were often accepted as normal. The stories also confirmed WHO and Uganda Ministry of Health's (2005) assertion that women living with HIV were more likely to have experienced violence and women who experienced violence were more likely to have HIV infection. In spite of the perceived normality of their experiences the telling of them increased the women's awareness that normality did not necessarily mean acceptability. Mrs Grey, for instance, highlighted how she had initially not understood or supported the idea of being assertive because it would challenge normal family relations. However, by the end of the discussion, she admitted that it influenced her to understand the need for change and practice sexual assertiveness as a preventive strategy.

> Mrs Grey: I am pleased to know that most of my group members had not considered the assertive aspect in sex related issues negatively like I did. In our female initiation school, we were taught that males have the right over their own body and their wife's bodies,

> also that sex has to be in their control. So what those females were talking about was a total opposite. It took me a while even to discuss assertiveness with other mothers-in-law because I thought the new practice was too modernised. Remember it has been male's decision on the occurrences of sexual encounter and whether or not to use a condom in each incident. We are intending to reduce the spread of HIV infection in Lesotho by striving for zero new infections. This is why I wanted to converse and change my attitudes towards this matter, so I can be helpful in the PMTCT programme like other members of the support group.

Mrs Grey's story signified the existence of transformed behaviour, through a process of transformational learning as a result of collective dialogue (Ntseane, 2011). Acting collectively emanated from the sharing of cultural practices to reflect collective learning. This aspect bound members in the support group to develop understanding of their learned material together.

The Chairperson summarised her support for so many sad stories.

> Chairperson: I hope we have all learned from these personal and general stories that it may not be very easy to convince males otherwise when it comes to health related issues. Our sons have seen and heard their fathers doing all sorts of bad things to females because they were demonstrating the power males had in families as heads. It is our sons' turn to do the same. It is unfortunate that we all live in the HIV and AIDS era. Most of what our sons have learned from their fathers may be poisonous and kill their families.

She cautioned the group, therefore to think carefully about strategies for change.

7.6 Reshaping the rock

Finally, the meeting came to a point where they had to balance the reality of their circumstances with planned strategies for change. The chairperson pointed out that for males to identify themselves as heads of families was not a new subject because it began before they were born. The chairperson therefore warned the women that their intention to create awareness among males of their responsibilities in respect of their status was not a minor issue to be resolved overnight. The chairperson was aware that discussing health issues with males might be impossible. Therefore, she invited the group to begin with smaller forums before addressing bigger groups because the women needed to gather enough patience and information to build their confidence.

> Chairperson: I hope we all understand that it was culture which gave males authority over females' a long way back. It might be difficult for us to win the fight. My fear in this regard is the platform to which we invite males. The health platform bears a sensitive connotation which males avoid because they view health related topics as complex. I want us to discuss health issues in smaller manageable forums before we address bigger groups to gain the insight of the activity. We also need to invite the Gender Officer from the outset to allow them enough time to correct our information before going to a wider community.

The chairperson insisted on the need to educate males to understand their importance in families and in communities. She advised members to gather enough patience when dealing with males because most males may feel threatened if females seem to complain about their position as heads of families. Steinberg (2012) indicates that the problem arises when women question males' decisions as it sounds like questioning their competences. This behaviour manifests in organisations and in social relations where families tear apart due to misunderstanding resulting from power relations. Steinberg further suggests that males feel more comfortable to live with submissive females than assertive ones because males psychologically lack reasoning power and enjoy giving directives and orders. Therefore, males feel intimidated by a female with strong reasoning power. Steinberg encourages females to gather enough patience while trying to convince males on the significance of compromising and adopting a power sharing behaviour. This advice was also articulated by the chairperson.

> Chairperson: My fellow colleagues, we need to gather enough patience even before attempting to convince males to adopt shared power relations where decisions made accommodate female views.

Mrs Plum responded with her suggestion to join youth meetings to create awareness among male youth of the significance of consulting their female partners before decisions were made and re-align their orientation that only males can make final decisions without consulting the female partner. Mrs Plum indicated that orienting young males before marrying and starting families could benefit the whole Basotho society and turn Basotho males into appreciable individuals to live with. It was essential that young males were made aware of the negative consequences of their behaviour in families. Mrs Plum believed in the Sesotho proverb*: thupa e otlolloa esale metsi,* literally meaning a stick easily gets bent and straightened while fresh from the tree, but not if it is dry.

The group agreed to Mrs Plum's suggestion. Mrs Plum believed that the group had a bigger role to play to educate youth on the consequences of bad gender relations before youth begin their families. However, Mrs Plum revealed it was of great importance for the mothers--n law support group to exist because the group was entrusted to provide information and education on various topics of the groups' interest. She indicated the significance of learning and sharing topics which the group deemed to be important in the fight against HIV. The mothers-in-laws' role in the fight against HIV led to the group members' realisation that the practice of males as heads of families impacts negatively in various ways so that many members had got infected with HIV because their experiences had shown that violence and male dominance contributed to the spread of HIV, not only to the group members but also to most Africans (Ntseane 2006).

7.7 Chapter summary

In conclusion, this chapter focused on how medical education from a health professional was delivered to the support group. The group was capacitated with knowledge and skills on techniques to lead longer healthy lives. But in order to do this, they had to translate the medical, factual information and advice into strategies that would accommodate gender and cultural differences. However, they also, in the process, moved one step further and began to re-envision their own roles and their own values regarding gender power relations. One could see the women themselves trying to be proactive in making themselves, as mothers-in-law, aware that even though culture had made them believe males are heads of families and can therefore make family decisions without consulting their wives, there was a lot they could do as women to minimise the spread of HIV infection if they were given a chance. Therefore, the mothers-in-law decided to create small steps for change. They had realised that their efforts to instill education into their sons and husbands could be extended to reach other people who may resist PMTCT and Mother Baby Pack as a prevention intervention. Norms and practices that contributed to the persistent spread of HIV may be complex, but the women identified they have a role to play in convincing males to re-think their attitudes and behaviours. The cultural beliefs and practices impact negatively on women and increase the spread of HIV and AIDS in communities, like Lesotho. WHO (2005) indicates that gender based violence is a significant driver of HIV infection among women in Lesotho. This is due to the fact that violence against women is often both a cause and a

consequence of HIV. The mothers-in-law reflected back on an earlier Gender Officer's visit which tried to introduce practices that would help support group members to avoid or modify their behaviour in order to minimise the spread of HIV and AIDS infection. This chapter highlighted several incidences and transformative learning stages, in relation to how members analysed males as heads of families, coming to an enhanced understanding of how cultural beliefs and influences of initiation schools affected different lives in an unacceptable manner.

As a result of the transformative learning process this support group came up with many suggestions and ideas for addressing the youth in order to avoid a repeat of the experiences they had suffered as women. The group worked hard to find strategies to approach their husbands and their sons to convince them about the significance of adopting and adapting to new experiences that will ensure the survival of their children. The efforts already taken by the mothers-in-law in the fight against HIV were considered to be valid and practical. However, Basotho as a nation are steeped in myths, misconceptions and cultural concerns related to HIV. The following chapter discusses how the mixed support group addressed these challenges.

Chapter Eight: Mixed support group – Thusanang Bakuli

8.1 Introduction

This chapter shows how the mixed support group addressed myths and cultural concerns and how these discussions interfaced with medical discourses about HIV prevention and care. The findings analysed in this chapter emanate from the meetings observed and voice-recorded during the Thusanang Bakuli's six consecutive meetings which operated from March 2013 to August 2013. This group comprised 11 males and 16 females who visit Paballong ART centre monthly to collect their ARV supplies. The medical supplies are collected after every twenty-eight (28) days as per the requirement of the ART pharmaceutical supply department and the Lesotho ART national guidelines. These members arrived at the ART clinic before seven o'clock in the morning so that their meeting could run from seven thirty until eight thirty (7:30am – 8:30am).

The meetings were held on the following dates in the six months of their observed occurrences.

Table 7: Topics discussed by Thusanang Bakuli Mixed support group

DATE	ATTENDANCE	Topic discussed and related thematic focus
13/03/2013	18	Basic HIV and AIDS transmission. Rules and Regulations –disclosure discovery and denial.
10/04/2013	19	Importance of testing for HIV on time and Disclosure
08/05/2013	24	Reduction of multiple and concurrent sexual partner (MCSP) infections.
06/06/2013	27	Treatment failure and food production
03/07/2013	27	Treatment failure and Myths
31/07/2013	27	Burning Issues – Debriefing session
28/08/2013	27	Cleanliness and living an exemplary life.

This group, like the other groups, functioned as a mediator to disentangle the discourses behind the myths and culture in relation to HIV, its prevention and care. This chapter shows how the medical discourses were discussed and understood in context and in relation to the metaphors and existing understandings of community members. There were many examples of these myths

and different discourses across the different topics but there was one meeting where the focus of the meeting itself addressed the link between treatment failure and myth. Since this particular meeting illustrates a number of levels of learning, the discussions from the 3rd July meeting provide the main content for this chapter. The particular meeting in question had decided to focus on some of the disorientating dilemmas that confront young adults and which often put them in tension with their elders in relation to HIV prevention strategies. To this end, the support group had invited a youth leader as the special guest, to attend the meeting. A nurse was also present because the support group believed that health professionals were necessary to correct misleading information that may have been accessed from the hunting process. Therefore, the presence of the nurse as an expert in health issues enhanced the quality of shared health information. Table 8 summarises the most common myths in this respect.

Table 8: **Some of the myths and cultural discourses that surround different medical messages**.

Cultural Discourses	**Medical Discourses**	**Myths**
Nepe (wheat porridge given to new-born regardless of mothers' HIV status.)	Disclosure Transmission Confidentiality	Men cannot postpone their sexual feelings like women. Males are like a pumpkin plant while females are like cabbage. Frequent visits to a hospital obviously exposes one's HIV status.
Labelling. Only females can change their behaviour while males cannot. Males are heads of families and eligible to decide alone without female's opinion.	Discrimination Prevention Shared Decision Making CD4 Cell Count	HIV infected persons cannot prepare food. Bathing with Dettol or Savlon after unprotected sex reduces the risk. Females can say no to sex but they mean yes. Why not the same with condom use? Traditional medications are strong enough to kill HIV and boost CD4 counts.
A small penis equals boring men. Males are meant to support ladies financially.	Sexually transmitted infections	Men need different women all the time for sexual gratification
Lack of sexual	Behaviour change	Males can't hold their sexual

techniques. Males cannot control sexual feelings like females.	Correct and consistent condom use.	desires.
Males have to be strong and keep everything to themselves even illnesses.	Re infection Opportunistic infections (OIs) Promoting disclosure Side effects	ARVs make people smell badly Using herbs improves potency. Every HIV infected person has to be thin. ARVs from other countries make patients slim.
Stress is normal to every adult.	Stress and Self - management	Working hard causes stress.
Men like clean women.	Hygiene Infection control	Poverty and stress make people forget to bath.

The chairperson made an inclusive welcome address to the visitor (the youth leader) and highlighted the purpose for the support group to meet on a monthly basis and learn together. The chairperson went on to explain that there was a need to learn the vocabulary associated with HIV and AIDS because terms associated with HIV are constantly being renewed as doctors learn about new complications and issues during treatment of patients, including complications which even doctors themselves learn about as they treat patients. He indicated that the group's urge to hold monthly learning sessions was propelled by this dynamism of HIV. The chairperson clarified that as HIV infected people, they feel obliged to learn about their life time infection, so they take good care of themselves and their loved ones. His explanation indicated that HIV seemed to be spreading rapidly because there were myths and misconceptions which prevailed in Sesotho culture and which needed to be discussed by the group with the intention of raising awareness among the youth about the negative impact caused by using such myths in the spread of HIV.

8.2 Taking decisive action

Due to the group's great concern about the myths and cultural concerns which are believed to delay preventive messages, they decided to act without hesitation. They decided to embark on the myth commonly used by adults through the proverb *monna ke mokopu o oa nama, mosali ke cabbage o oa ipopa,* literally translated as a man is like a pumpkin plant which spreads the leaves as it grows. It can even spread to the neighbouring yards. However, a woman has to be like a cabbage plant which grows upright only and would never spread. This myth and metaphor

implied that men were the only ones entitled and expected to have extramarital love affairs while women should not do it at all. This myth was even publicised by Basotho musicians (a song title in Sesotho – *Monna ke hlooho lerato le basali ketsa hae – Mosali ithlomphe o tsebe ho fuoa lerato* - literal translation – man is head therefore love and women are his – woman have self–respect so you will be given love). The myth also reinforces the cultural assumptions that a female has to maintain good cultural values, morals and behaviour that include valuing and keeping her virginity until she gets married. Yet the same values and behaviours cannot be expected from a male of the same age (Modo et al., 2011). The chairperson indicated that even though this myth was usually used to justify why it was right for an adult male to have extra marital affairs, it could be that youths too have additional myths which could put them at risk of being infected. The support group also believed that youth were prone to believe and act out some of the myths. This was why the group became interested in inviting the youth leader to discuss such myths in his presence and obtain clarification on what the youth appeared to believe, before the group ventured out to talk to the wider youth population.

> Chairperson: Thank you Mr Timber for that short prayer, today we have invited two visitors as specialists to discuss topics that are going to be conferred right now. Our name is *Thusanang Bakuli* (patients assist each other). We are males and females around the Botha-Bothe district who are living with HIV except for only two members who are HIV negative but happened to be our members because they had brought their patients in this hospital for ARVs collection when the group initially started this support group. We do not know much about our distractor of peace (HIV).

The chairperson kept on reminding the group that they had made a good decision to invite the youth leader as a specialist in youth activities to their meeting because as the group learned about the circulating myths and misconceptions regarding HIV and AIDS, the group could also begin to plan their strategies to discuss myths with youth in the community. Therefore, they wanted the youth specialist to give the support group some direction. As with the other support groups this group demonstrated their community of practice in action whereby the discussion of concepts (myths) was conducted with outsiders, for instance, the youth leader. The intention was to bring in and share knowledge from elsewhere to enhance the group's learning practice and participation (Wenger 2006).

Chairperson: We have invited you sir because we want to visit the youth and discuss myths that are circulating in the country because we as a group feel that such myths have contributed to the wild spread of HIV in Lesotho. We became worried when we realised that adults act on the famous myth saying*: monna ke mokopu ooa nama ha mosali ele cabbage a ipopa.* We have agreed that it is our responsibility to discuss such myths with Botha-Bothe youth as they are the group in the community which gets misled easily. Being a leader in the youth's offices, we thought you may know that group better than us since you can mix with them easily and we know that there are a lot of topics which they feel free to discuss with you. When you are in this SG you become one of us, therefore this support group is happy that you have accepted our invitation and have arrived on time. We welcome you, so feel free (to participate).

The chairperson continued to explain that they have realised that most people default on treatment due to lack of knowledge and inability to differentiate myths from reality with the result that they do not only default but also become re-infected. The group believed that the session was a learning process to the rest of the members as usual.

Chairperson**:** Ladies and gentlemen, I want to remind you that our main topic is treatment failure. Previously we discussed treatment failure and food production as we thought most of our people taking ARVs complain that they usually miss their medications when they do not have food for the day. While we were discussing that, we realised that the other major obstacle which influences infected persons to fail their life time treatment is the myths circulating around our people. By discussing such myths, we are ruling out obstacles hindering our people to adhere and are therefore also reducing chances of re-infection. Since we are learning, we have concluded that we can play our role of learning and reinforce what we have learned by taking our knowledge to other people because we believe we will end up being informed more than they are. We have agreed that in the winter months we allow only two hunters to go and search for information we need so that we can save our reporting time.

After this brief introduction, members shared public opinions about HIV and some of the myths which were believed to contribute largely to the spread of HIV. The hunters had deliberately collected information on the myths that were familiar and commonly used by youth as their target group for the coming campaign. As with the other support groups the practice crystalises the behaviour of communities of practice because members bring in and share knowledge from elsewhere (Wenger, 2006). The first hunter spoke:

Mrs Coal: First of all, I met two male youths walking from school. I asked them whether they can distinguish a myth from reality regarding HIV related issues. The one who

> responded first said there is no myth concerning HIV. All he has heard about HIV is true. Then I asked him to tell me how an individual who does not have HIV can get it. The boy said: Basotho are lazy to bath after sex. If they were taking a good bath, they would not be infected, maybe it is because they enjoy sex with their MCSP and do it while they have gone to perform other roles like gathering fire wood or weeding in the fields. So you can see they cannot get water for bathing. As if I did not hear him well, I asked if he means it is true that taking a bath after having unprotected sex is a safer and easier method of preventing HIV transmission, then they laughed. The other one looked at me in the eyes to show he knows what he is saying and said yes it is true because even those who bath do not use Dettol or Savlon to bath as those two kill all the bacteria and harmful germs in the body. Otherwise one cannot get infected if those two detergents can be used. I said to them HIV cannot be killed by the use of soap or any other disinfectant because they clean outside the body. The blood will be infected so there is no way one can wash his or her blood with anything. These two gentlemen laughed at me and wanted to go away as if they were saying I am wasting their time because I am talking nonsense. They told me their livestock are going astray so they have to go and the one who responded first ran away. I made arrangements with the second one and invited them to our meeting at Likileng Public Gathering Ground so we could discuss more of these myths which can put them in danger if left unattended to and practiced. (Looking at her neighbour), make sure when you talk about the youth you include herd boys because they are the ones I was talking to. (She sat down.)

The speaker (Mrs Coal) was referring to herd boys who spend most of their time in the mountains and away from the media (Pitikoe, 2016). This narration indicates that youth prefer to believe the myth about cleaning their bodies as a means of HIV prevention, rather than believing the medical fact that infection takes place in the body fluids (blood and semen). Saller (2009) indicates that body cleaning in prevention for STIs and HIV after sex had been commonly practiced by Americans in fear of STIs and HIV. This practice was done with the intention to reduce the spread of infections. Saller further indicates that the practice was not scientifically proven and was not evidence based. This indicates that the Americans were mythically preventing STIs by the practice of such a strategy. Since the speaker was referring to herd boys who spend most of their time in the mountains and away from the media, this indicated the seriousness and relevance of paying attention to how myths can distort the medical information that is available. Pitikoe (2016) confirms that it is a generally known problem in Lesotho that herd-boys lack information due to their area of employment where they spend only winter seasons at home but during summer, autumn and spring they reside at the cattle post. This narration also indicates that prevention interventions have not spread as expected because herd boys seem to be uninformed. It also indicates that since herd boys are a minority group which is

illiterate in most cases, they may not have been well included in the formulation of information education communication materials. Bruns, Rakotomala and Mingat (2003) and Pitikoe (2016) confirm that herd boys are culturally trusted to look after animals in areas with the potential for animal pastures and their owners of flocks of animals have a tendency to locate such individuals in areas less developed where it is difficult for herders to improve their livelihoods. Pitikoe (2016) indicates that males usually become herd boys due to high poverty rates which are a cause of low educational levels.

It was argued in the group that relying on myths contributed largely to the persistent spread of HIV regardless of the efforts put in place. The use of myths cuts across the ages (elders and youths) because in Chapter Seven we observed the support group of mothers-in-law trying to find strategies to employ in order to reduce MCSPs but that group also identified several myths used in their community. For instance, as stated previously, males were said to be pumpkins and had to spread like one, while women were expected to behave like a cabbage plant and grow upright. The discussion continued.

> Chairperson: It has come to my attention that myths are used as the only information available by the illiterates. This happens because illiterates also would not go around telling everyone they do not know. Rather they speak about what comes to their minds as the only information they have.

The meeting was participative and involving from the outset. Members wanted to report back and share their views on what the community thought of the myths discussed. Their interaction enabled the group to commit themselves to each other and strengthen a sense of belonging amongst the support group members. While the support group was taking decisive action, they began to realise that every road has its curves and steep hills to cross over in order to reach the destination. They discussed the accessibility of reaching the herding community.

> Mr Chains: I am wondering Mrs Coal whether you made sure you know where we could find those herd boys to invite them to attend our campaign. I am afraid that they might already be infected because their myth is one of its kind and that shows they are totally lost or totally uninformed. If you know the owner of the animals they were herding, please direct me after this meeting so I could assist them to get permission from the owner of animals to attend the anti-myth campaign.

The discussion revealed the range of strategies that would be required to reach their target audience.

8.3 Slowly climbing up the steep hill

A gradual incline seems to slowly rise up. This group was faced with the challenge of convincing their own community about the importance of dissecting cultural beliefs and practices emanating from myths and misconceptions which had the potential to expose the community to risky behaviours. They revealed this was a challenging task similar to climbing up a steep hill. According to Kemboi et al. (2011) most prevention strategies in African countries have failed due to strong beliefs and practices that rely on myths and misconceptions. Myths surrounding the mode of HIV transmission hinders the dissemination of correct preventive measures. Kemboi et al. confirm Mrs Chain's concern that if such myths prevail amongst the youth, especially herd boys who struggle to access information, then most of them might already be HIV infected since myths have proven to be more widely spread than factual information. Davies and McCartney (2003) and Morojele (2013) refer to the power of gender and culture in the use of myths and misconceptions. Davies and McCartney (2003) blame the practice of myths that promote male promiscuity because it impacts negatively on the women already experiencing subordination to men which could directly be linked to the increased number of infected women, children and youths. The authors share the same sentiment that HIV would not have been widely spread had it not been due to culture, gender power relations and myths. This support group seemed, nevertheless, to be determined to gain knowledge and appropriate information regarding tactics to reduce myths amongst the community.

> Mrs Coal: I asked the man whom I met after those boys had gone because they were running when they left me, so I had to ask someone else who they are and how I could find them because I thought of this activity since you had already indicated that we need to collect the youth, so I wanted to be able to find them when the need arises. Allay your fears, we will be able to find them. I went to the extent of finding their owners' (employers) phone numbers so we will use them to invite the boys.

The myth under discussion indicates the seriousness of the impact caused by not knowing that one plays with fire (trying dangerous practices without realising their danger). This discussion

indicates that the youth in the communities nearby might already be infected taking in to consideration the fact that the youth always become eager to try new practices (Saller, 2009). However, Mrs Coal and others showed a strong commitment to ensuring that the boys in question were given the opportunity to learn the real medical facts about HIV infection. That was an indication that the support group itself motivated the participants to pass on their knowledge to the wider community. Once more they demonstrated that in order to reach people it was necessary to draw on a wide range of resources as a medium for communicating the HIV and AIDS messages. Though it has to be a culturally sensitive medium.

However, Mrs Forty made the groups aware that herd boys amongst all the youth, need to receive appropriate information. Harrison (2014) confirms that HIV education needs to focus on the most vulnerable groups because they are the ones most likely to lack access to information and education hence the more they are at risk of being infected with a variety of illnesses. The meeting continued with a new speaker.

> Mrs Forty: Mr Chains had already taken a slice of cake from what I wanted to talk about. I was also worried about how we can access herd boys. I raised my hand because I wanted to ask if it is easier for school youth and herd boys youth to learn together as I want to suggest that we can change the clientele and focus on herd boys only. From what we are told, these boys will buy Dettol and bath after continuing with unprotected sex. My worry is this kind of myth. I know myths are highly misleading hence why we have agreed to discuss them with the respective clientele in order to rescue lives. (She sat down.)

There were also indications that this group did not just absorb information. They critically analysed the implications of the known myths in order to consider reasons for treatment failure, which was an on-going concern for HIV and AIDS. Labhardt et al. (2014) indicate that taking time to discuss health related terms also designates willingness to get rid of illiteracy in health related issues and to enrich knowledge for all members engaged in the learning process. Labhardt et al. (2014) indicate that the health knowledge deficit has a negative impact on behaviour and results in misinterpretation of crucial terms. They therefore encourage community learning groups to work together to understand how to interpret medical terms in a way that gives meaning to lay people. This was also observed in the fathers-to-fathers support group discussion about re-infection and condom use (Chapter Six). Therefore, these support groups

seemed to share the same sentiment of striving for a general understanding of their own illnesses. Ngaka ea sehlopha, a man in his mid-forties, raised the following question:

> Ngaka ea sehlopha: Thank you chairperson, I thought you had forgotten that I had raised a hand a long time ago. I wanted to ask the whole group not only the hunter who came up with this information. What do you think about the myth from those herd boys? Do you think there is a link with treatment failure? Remember we came up with the idea of talking to the youth because we were discussing treatment failure, so how do you analyse this myth in relation to our concerns? (He smiled and murmured something to people closer to him. Four hands were raised to respond to his question: it was three ladies and one gentleman.)

> Chairperson: Let us give chance to ladies first to answer you my man, (one of the three ladies was already standing and she continued).

This question was answered by a knowledgeable member of the group, Mrs Boxer. She highlighted the possibilities of new HIV infections and re-infection to people who may be relying on the Dettol myth. Mrs Boxer, a woman in her early forties, also linked the discussion of misunderstanding cleanliness as a resource against infection of bodily fluids to the issue of practicing unprotected sex:

> Mrs Boxer: I am happy you are asking these questions while we are still here as a group. Remember we have agreed to discuss the myths before meeting our youth since we thought it will help us gain more knowledge on how the youth think about HIV and because we thought that most of the youth are taking part in assisting their relatives to take medication but sometimes they get discouraged by the myths circulating around our communities. Coming back to your question, Big Doctor of the group, I hope you all still remember that one of the causes of treatment failure is unprotected sex. Therefore, if people just indulge in unprotected sex hoping to bath with Dettol to reduce the spread of HIV, that practice can be highly dangerous because even people who are already taking ARVs will not practice safer sex if they think Dettol can reduce their chances of being re-.infected and then their treatment will not function. I see this myth impacting negatively on all community members. (Looking around with a huge smile and preparing to sit down.) I hope I have answered you well, Big Doctor.

Mrs Boxer connected the danger of unprotected sex with the myth very well and foresaw the negative impact of the myth to the community at large. Mrs Boxer revealed that the whole group had become very competent in discussing the nuances of HIV communication issues. They now saw the limitations of the official publicity which circulated among the youth and the aged who

remained unexposed to comprehensible information about health issues. The support group realised the benefits of the efforts that they had put into learning because they increased the amount of accessible and knowledgeable human resources among the community members. This would ease the means to spread HIV education where it was badly needed.

It was evident that a full discussion was required in relation to each myth. For instance, the myth about Dettol continued to be discussed from a range of angles. Different opinions emerged about how to address the youth regarding myths. Mrs Boxer held the same views as Mr Tree in Chapter Five who believed that myths must have significantly hindered appropriate treatment and prevention strategies because myths in relation to HIV had been circulating since the arrival of the infection in Lesotho. Some members felt that they should focus on particularly damaging myths during the youth campaign because time might not allow them to address every single myth that was raised in this meeting.

The members' shared participation and discussion had improved their understanding and resulted in increased self-confidence about their ability to inform others. Woolcock (2001) for instance indicates that members in communities of practice normally outsource each member's experiences of practice to be used as learning resources. This type of learning gives rich information to the learners because members in support groups consult relatives, neighbours, friends and family to ensure that information is shared. As a result of this participatory learning, members had gained competence and self-confidence about how to share information with the wider community. In order to ensure they fully comprehended all the implications of myths, each individual explored the problem in their own way and introduced new implications for not addressing the myth. Bates (2014a) indicates that usually learning groups needs to recognise and accept the uniqueness of individual members (like Mr Tree and Mrs Boxer), to realise different levels of devotion to harmonise learning and working relations. Bates gave an example: that levels of passion in human beings differ. Members need to encourage each other to strive for best performance regarding attainment of their intended goal. The discussion continued:

> Chairperson: Thank you Mrs Boxer, your point is really valid and motivates the group to really take action and save lives which were not yet infected. Mr Respect-men, I observed your hand and think it is your turn to share what you had in mind.

Mr Respect-men**,** a man in his late forties, looked worried and talked with his hand on his chin. To reinforce his points, he drew on a number of metaphors which served to emphasise the seriousness of their challenge. In this case he likened their efforts to a spoon trying to stop a flowing river and the need to 'create a smell' as an indication of how they needed to impact on the community. Metaphors were a common strategy among the support groups to help people understand both medical terms and also the seriousness of their topic. Kulick (1997) emphasizes the significance of using metaphors to interpret an illness for adoption of strategies required to prevent its occurrences. Mahloane–Tau (2016) confirms that in other African languages, metaphors are strong and interesting communication strategies that attract the listener's attention.

> Mr Respect-men: To continue responding I want to give the Big Doctor of the group an example, supposing those two young herd boys had girlfriends, do you realise that they would just indulge in unprotected sex without condoms because they would be thinking of Dettol as their solution in the reduction of HIV? Imagine where the herd boys get Dettol from, they will not even have this to hand every time, so there are times when they will not even be washing with Dettol because they do not have it. Even if it was the truth that Dettol could help, besides the herd boys who have come up with this myth, how many of us can afford Dettol in here? I know that none of us can. It seems we have not yet done much in the four years of the formation of our support groups. We are just taking a spoon and using it to stop a flowing river. If we can work harder than this, I think we can make an impact on our society. We need to make sure that we create a smell that the whole of the district will be able to sniff and spread our smell to other districts. We can see that we still have a lot to do out there. We have committed ourselves to come and learn with the purpose of educating others, if our children still think of Dettol to reduce the spread of HIV, this means we still have a long way to go.

Weiner (2015) indicates that a large number of males are unwilling to reject myths that are used for HIIV prevention even though they are ineffective. Holding onto misleading myths increases the vulnerability of more people being infected. The reflections made above indicate a number of consequences and implications that would arise from this one myth. The group highlighted the issue of costs which would deter the herd boys from even using their mythical solution to HIV prevention. The members also highlighted that the herd boys were particularly vulnerable to myths in view of their exclusion from other sources of information. The concerns raised here showed the implication of following a myth that was likely to prevent people from taking safe sex measures. But the reflection also showed that discussion of the myth itself had motivated

members to think harder about the role they must play in their communities to curb the spread of HIV.

> Chairperson: Thank you very much Mr Respect-men, your points have been very powerful in this aspect. I do not think you were discouraging us instead you were shaking a bit of commitment out of each member. We are at the point where we can give the second hunter chance to report. It is your turn, Mr Range.

This group was amazed to learn about another myth which also incorporated costs which the group believed herd boys could ill afford. This time the myth was that sleeping tablets could prevent HIV. Mr Range, a man in his fifties, wanted the group to work out what means of HIV prevention education provision might be acceptable and convincing to the youth.

> Mr Range: Thank you very much Mrs Chairperson, I met three girls and a boy walking together and asked them what can be done in order for one not to be infected with HIV. While we were at the end of the conversation, one girl said when one has had unprotected sexual activities, they should take sleeping tablets to make the virus tired and sleep while the exposed person is also sleeping. Their belief is that when one takes the sleeping tablet, HIV will sleep and stop, neither moving, eat nor replicate and therefore die before it infects the exposed person. I even asked them whether they just thought about it or they have heard it from someone. Then I learned that it was a circulating myth because they know that even anti-allergy tablets can perform the role of the sleeping tablets. While asking them how they access sleeping tablets or antihistamines, they told me that aged people have them as they use them more often therefore it is just a matter of communicating to their aged mates to access them. They also know that antihistamines tablets can be accessed from a pharmacy without a prescription.

These additional stories showed that practices of denial about the medical facts about HIV were very prevalent among the youth. The role of the support group and its community of practice in this instance was to enable such understanding about these malpractices amongst youth to circulate more widely. But the community of practice in this instance revealed an additional, emotional component of learning. By telling these stories in a group, the group as a whole were motivated to take responsibility for re-educating their wider community.

Previous chapters have already indicated that the different explanations of medical terms needed constantly re-visiting because the lay interpretation was understood in relation to people's existing meaning perspectives so one would only get a selective understanding without deeper

discussion and exploration. Murphy (2003) and Balogun-Mwangi et al. (2016) argue that lay persons' interpretation of health beliefs, (for instance: it is a woman's problem if the family does not have a child) remain embodied in their minds until education regarding such issues is internalised.

Mosuoe (2016) indicates that through on-going conversations, community members make sense of their experiences and manage their knowledge by sharing their concerns, validating their practices with each other, and developing new care strategies. This is where myths are shared and practiced. With time, the accumulation of experiences would increase not only the group's explicit knowledge on myths and the impact caused by them in the community, but also their tacit knowledge or practical know-how that emerges through reflective practice and the collection and sharing of story narratives among professionals.

8.4 Taking positive action

Wenger (2000) emphasises that the act of being in a community of practice can deepen the mutual commitment of members when they take responsibility for a learning agenda which pushes their learning practices further. This support group realised that imparting knowledge to the herd boys on the dangers that myths could expose them to HIV was a strong preventive measure in order for the herd boys to survive. Mr Range showed that similar myths had indeed impacted on the support group members when they were younger, once more highlighting that there is a wide gap between the practice and education of medical knowledge and the reality of everyday lives in cultural contexts. Mr Range continued:

> Mr Range: This group also told me that there are those who believe that if a couple does not have a condom, and have not tested for HIV, they can continue to have sex if they have a Panado to put under the tongue when having sex until that Panado dissolves. Just imagine the mentality of these people? They would rather buy a Panado to put under the tongue instead of making sure they access free condoms to wear. This shows that many of us got infected due to wrong information which we have been holding onto. It is the same as the myth we used to practice when we were boys. When one of us had nose bleeding, he was told to close one eye and nose bleeding was expected to stop. Did any of you see nose bleeding stops because we were closing one eye? It has never stopped. This is the story I told them and also invited them to the campaign, where I told them that many of their age mates will be there and a lot of new games will be played and most of them will be educational games.

The chairperson was aware of the positive impact their meetings had for every member including health professionals who attend for different reasons. The same was hoped for the youth leader and that he had not only attended to give advice to this group. But members were certain that this leader would learn too.

> Chairperson: Thank you very much Mr Range, unlike all other meetings, this one is special because we are teaching a youth leader who is sitting amongst us to have some information or just an idea of what to take with him before meeting his group of youths. Therefore, I know we are all not worried about how long we take but want us to throw out as many myths as we can so we all have an idea of the myths which mislead our children. Therefore, our intention is to leave no stone unturned in order for the group to be resourceful. This support group offers free education to the community and visitors who had come for different purposes.

These invitations to the youth leader demonstrated the sense of responsibility the group felt towards their community and the lives of their future generations. The chairperson seemed to be aware that their group was capable of teaching other people new tricks to employ in relation to behaviour change. The group had acquired strength through capacity building which had empowered every attendee, including knowledgeable health professionals who attended such meetings, to offer corrected information.

There are many examples of how myths in different cultures have served to militate against responding to medical messages and scientific disease prevention. For instance, Johansson (2003) recorded how a native American community relied on use of raw shanva plant to smear on the genitals before and after sexual encounters to prevent sexually transmitted infections (STIs). The occurrence of STIs among this tribe was blamed on the quantity (too much or too little) used by the patient. The plant was also trusted to cure wounds. If the wound became septic during the use of shanva, then blame for infection would be placed on delaying the use of it (Johansson 2003). The wild spread of HIV among the native American community is attributed to this myth. Similarly, during the early 1990s African wild potato was mythically used by HIV positive Basotho to boost their CD4 cell count, cure the occurrences of opportunistic infections to the already infected person and to prevent infecting a sexual partner with STIs and HIV (Balogun et al., 2016). Balogun et al. state that the African wild potato was commercialised in

the South African streets by Zulu tribes to cure minor illnesses such as headache. Johansson (2003) and Balogun et al. (2016) blame the spread of HIV on the mythical and exaggerated use of these medicinal plants.

However, each generation has its own discursive practices and language. Fairclough (2005) argues that the power of spoken words even in the same language can build or destroy social structures. In other words, if generational or context specific words are used with the wrong audiences they have the potential to either fail to get their message across or even damage social relations between the communicating parties. Mr Wool and Mohair**,** a man in his late forties, made a different point from the rest of the group members who had raised their hands to share the myths they had learned about. He requested clarification relating to the language which the group should use to address the youth but then turned to a myth that was common among adults.

> Mr Wool and Mohair: I am directing my questions to the youth leader who is invited here amongst us today. I am asking about the kind of language used in the youth groups because we normally call spade a spade in our support groups. Therefore, we need to know if we are supposed to be language sensitive when we get to the youth. However, I talked to adults not youths and asked them if they know of any myth which they think could prohibit people from taking their medications well until those medications do not work properly in his/ her body. The responses I got are that, people sometimes do not adhere to their treatment because they say ARVs make one smell badly. I take this to be a myth because there was a time we were taught about the side effects of the ARVs. I was listening very well because I delayed starting ARVs as they were saying one loses his potency when he uses ARVs. My tape recorder (pointing at his head) did not get that type of side effect. I did not want to be one of the men who only swallow their saliva when they see a woman without practicing my manhood duties allocated to me by God which is to please women with my body. As you can see, people may stop collecting their ARVs because no one would like to smell badly due to ARVs when he was already HIV infected.

Mr Wool and Mohair revealed his side of a story which was a myth about ARVs nearly destroyed his life if it were not for the fact that he had already been informed about ARV's side effects prior to hearing about such a myth. He counted himself lucky to have been educated in time otherwise he would have been reluctant to be initiated on ARVs. This indicates the positive impact that properly informed education has on individuals and on group members.

Mr Wool and Mohair wanted information to be clarified in order to broaden his learning horizon and increase members' participation in the group. This attitude, too, is aligned with Wenger (2000) who emphasises that engagement becomes an integral part of communities of practice. Shared activities and problem-solving are core features of such engagement. Woolcock et al. (2000) indicate that the way in which members network, share activities and problem solve are core features of their engagement. Such networks yield positive implications for development and the sustainability of future generations. This is where the youth became significant beneficiaries in this meeting because once myths that fuel the spread of HIV have been identified and facts about HIV are shared among youths, educational growth for human well-being is possible.

> Chairperson: Thank you very much Mr Wool and Mohair, I am happy that you directly or indirectly shared your own myth which could still cause treatment failure if not discussed. I would then like to give the officer from the youth offices a chance to respond to Mr Wool and Mohair's question. Please continue, Sir.

It was evident that this form of collaborative learning was helpful to the support group. Trahar (2006) indicates that collaborative learning develops higher levels of thinking skills.

The youth officer realised the importance of this support group's learning methods. He appreciated the group's intentions of creating awareness among the youth of the dangers of myths in relation to HIV. He also thanked the group for thinking of educating the youth regarding HIV and AIDS myths, which his office had never thought about doing. Importantly, he also highlighted the role that culture and age-sensitive language play in communicating to different social groups.

> Youth Officer: Sir, I want to accept the fact that in your support group, there is that type of language used which suits adults when they are gathered together. When we are gathered with our youth, we normally call body parts using their slang because youth slang has a name for each body part. I know you may not be familiar with these slang words, therefore my advice is for you to aim at separating boys and girls when you are at the show grounds. This will enable your female members to attend to girls and males to attend to boys so that you are able to speak the language which your gender will be familiar with. It is by the end of the campaign that you can give them a chance to mix and share what they have discussed in different gender groups. They will facilitate it

> themselves as they are used to doing it. We are mostly happy about the topic you will be discussing with them because it is through circulation of the myths that the country has high unwanted and unplanned teenage pregnancy and school drop outs. Lastly, I thank the support groups for inviting me while you discuss youth related issues because this indicates the maturity of your support group to realise that we need to work hand in hand and back each other up in the upbringing of our children. I want to pass a vote of special thanks for including herd boys in the campaign as they tend to be a forgotten group of the youth, yet it is the one that needs most of our attention. I have heard that some of the herd boys are practicing gay activities, this is where a male has sex with another male. Many of them complain of STIs and were not using condoms because they were saying condoms have worms. My office will assist you with a mobilisation task to ensure that our youth attend this event in great numbers.

The myth that condoms contain worms was also highlighted in research conducted in Botswana by Preece and Ntseane (2004). This condom information was a further concern to the support group because it indicated non-utilisation of condoms by the youth because they did not know that a condom will not decay. It appears to have worms during exposure to excessive heat or sun light or any form of heat because it is a latex which only has water-based lubricant that cannot allow the formation of worms even under careless conditions. As a result of the group's feedback, members refined their own understanding of how to interact with youth discourses. This was an indication of continuous meaning making in transformative learning as indicated by Mosuoe (2016) where the group of women living with HIV in her study concluded that through their shared experiences it was easier for them to make meaning out of specific contexts.

This support group took it upon themselves to ensure that the youth learn the difference between myth, misconception and reality. Reaching this level of meaning making motivated the participants to work hard to assist the youth to reach the same level.

> Chairperson: Thank you very much Sir, our support group is very grateful that you have come. Sometimes we get to realise the importance of forming a support group when we realise that not only these members in front of you are benefitting from the gatherings of HIV infected people like us. At least other people benefit from our support groups. You have also become one of our hunters for bringing that myth of condoms not being used because they have worms. Let us give our new hunter a big clap then.

All these concerns were raised and discussed as a collective, leading to the common goal that the youth and especially herders are ill-informed about HIV prevention. The members had a fear that

they might have delayed assisting the youth and many might be infected due to the myth being wide-spread. As with the earlier myth discussion, however, it was necessary to allow a variety of people to speak and explore every angle before laying the concern or myth to rest. The participants agreed to let a variety of myths be tabled because they too were learning to understand why HIV spreads so much.

These lengthy discussions held at every meeting were intended to instil understanding regarding the meeting's selected topic among members, bearing in mind the different levels in individual's comprehension of the subject. The discussions would equip the support group with a variety of myths to address during their youth campaign. The debate exposed further myths that were now realised as having contributed to the spread of HIV. Although the myth that condoms have worms had been widely recognised as an inhibiting strategy to prevent the use of condoms as Preece and Ntseane (2004) highlighted in Botswana, it was also important to recognise other on-going myths which continued to challenge the acceptance of medical discourses. These included the comments that ARVs make one smell badly. Further concerns related to the fact that there was very little attention given to addressing homosexual practices which potentially may generate other infections, depending on how this form of sex is being practised. All these concerns were raised and discussed as a collective, leading to the common realisation that the youth and especially herders are ill-informed about HIV prevention. The various reports from different group members showed the value of focusing this meeting on this topic. It was evident that their strategy of employing 'hunters' to identify the myths in current circulation and possibly practiced by youth was preparing them well for understanding how to impart factual information that could challenge youth belief systems.

A new speaker became involved in the discussion and introduced a new myth issue. As the new myth was narrated, members took notes and looked at the narrator with eyes full of unspoken words but shocked. As parents, members began to be worried that their youth were naïve and might have been HIV infected a long time ago.

Mrs Initiator, in her late thirties, stood up without notifying the chairperson and boldly said:

> Mrs Initiator (Pula-Maliboho): Thank you very much for giving me chance to ask. I would like to know if the herd boys who were practicing male to male sex were found in Botha-Bothe because when we hear the rumors talking about that type of practice, it was as if it were boys in another country, not Lesotho and not in our district. So we realise how crucial the case may be if our own children are doing that kind of behaviour. My second question is whether there is a special condom for that kind of sex? I also want to share with you that I came late to the support group today because I went via a neighbour's house. While I was there, I learned that the gentleman is taking ARVs because I saw the bottles lying near his bed, his wife knows the husband's condition but does not say a word when her husband is continuously taking herbs together with ARVs because he says herbs improve his sexual energy. You all know that my neighbour is abusive and always violent. He takes those herbs continuously even after he was told to stop them as they prohibit functioning of ARVs. Is this issue of herbs and sexual desire another myth or not?

Mrs Initiator raised a new myth about mixing herbs with ARVs. But she also indicated some sense of denial when it came to sexual practices. She believed that males having sex with other males cannot be practiced in Lesotho by its own boys but must be practiced in other countries. Maile (2011) indicated that Lesotho delayed taking, action to prevent HIV because they projected this problem onto other nations and HIV was therefore considered a foreign problem which Basotho need not bother about. Mrs Initiator's view needed immediate attention and serious attention by the authorities to educate youth on prevention regardless of their sexual practices because they needed to be told that all sexual practices could expose one to HIV unless protection is consistent and correctly used. Davies and McCartney (2003) indicate that the significance of education is to get rid of lies, myths and exaggerations relating to illnesses. They advocate for a model of healthcare which combines medical, psychological and social issues with education and treatment to strengthen understanding for any individual at risk of acquiring chronic illnesses. The model is trusted to provide a holistic approach where the mind, body and social life is taken care of to save the life of the vulnerable individual.

The participating nurse now intervened. As was done for the other support groups, she allowed members to articulate their concerns and information in their own way before intervening. She realised the importance of such meetings and complimented the group on their commitment. The nurse indicated that health professionals also learn from community members in these fora. She also clarified that homosexual behaviour was either a matter of convenience for people deprived of female company or an innate sexual orientation.

> Nurse: First of all, I want to congratulate you for thinking of discussing this topic. I have also learned a lot from it, myths are usually very strong and circulate more rapidly than anything else. I want to agree with the person who says most people who are HIV positive got infected because they did not know the truth about HIV but they had all these other myths circulating in their heads and thought they were safe. Having gay sex for other people is a hobby or just a practice which most people indulged in because they were bored and took the nearby option. To other people it is in-born, they cannot run away from it as they were born with that desire. Finally, I want to congratulate you for unpacking all causes of treatment failure as it is the main worry for Ministry of Health. You have come up with a very good idea of talking about the myth as many people quit their medication due to false information which is exactly the myth you are discussing today in order to prepare for the campaign. Don't be surprised to find other new myths when you get on the ground during the campaign. I just want to tell you that the best way to beat our enemy for treatment failure will always be your thirst for the right information. With knowledge I do not have a doubt or fear because I know you have a lot [of knowledge]. You are far better than many of us as nurses because you research every day before you meet and make sure you share a lot of fresh and researched information. This makes you more knowledgeable than most of us in these hospital premises. (They couldn't wait for her to finish but clapped their hands and made ululations to show their appreciation of what they were told.) I was here in April when you were discussing importance of testing for HIV on time and disclosure. You cannot believe how impressed I have been since then. … because you were emphasising that information changes hence why you always find other people's views on a topic before you talk about it. All the health professionals who visit you usually leave this meeting with a bit of behaviour change for the better because the way you run your educational meetings is really very informative.

The chairperson then gave the youth officer a chance to report. The youth officer also expressed his appreciation. He told the group that they were skilled in convincing people to take action about their lives. He wanted to believe that the group would do the same to the youth they were preparing to meet soon. Kothari et al. (2015) in the study of health practices emphasised that the use of external networks for information seeking purposes in communities of practice is a beneficial strategy for individuals as they move from a stage of confusion to a stage where they are able to use medical jargon easily. In this aspect, the group was preparing to educate the youth to do away with confusing myths and build a new frame of reference which they could use to communicate meaningfully in their own communities. Johnston (2013) argues that individuals build a new frame of reference over time in communities of practice. The youth officer demonstrated that their discussions had already impacted on his own sense of responsibility towards HIV prevention.

> Youth Officer: I thought of also showing appreciation for the education you have given me today and want to tell you it is adding to the impression I had about you when I first met you at DA's offices when you had visited heads of departments who meet there every month. I also want to tell you that after that same meeting, I was able to fight my fear to know my status for the first time and if you can remember, you had gone there to mobilise heads of department to offer support to our employees to attend their scheduled check-ups without problems. Then you said to us, one day it will be those officers who are HIV infected and ashamed to attend monthly check-ups and you mentioned the fact that no human being is immune to HIV. You should know that you were able to influence the hard nut like myself to test and I got tested the same day for the first time. (The group clapped hands and ululated.) Therefore, I thank you very much indeed. That is all I wanted to say to show you the impact you leave in our lives. This is why I feel like inviting all sorts of youth to gather because I know you are going to change their lives. Thank you. (He sat down.)

Responses such as these reflect on-going transformative learning where information does not simply get received in the mind but impacts on an individual's readiness to transform and act accordingly (Mezirow, 2000). It was evident that most attendees moved at some point from the stage of a disorienting dilemma to the level where they appreciated and acted upon the new information. Mosuoe (2016) confirmed that for the infected and affected by HIV and AIDS support group members, there was often an impact regarding readiness to transform and act according to new information acquired. As the youth officer and the group explored options for new ways of acting, they were all illustrating the transformative learning process.

> Chairperson: I am happy that both of you professionals have common statements of encouragement though they are said in different wording. I think we are at the edge of the meeting. We have said all we needed to discuss, we have gained knowledge on the myths that contribute to treatment failure. Let us be alert and ready to facilitate the campaign for our youth on the myths that contribute to treatment failure. I think we have come to an end and thank you for being so participatory in this meeting. I hope we are all satisfied and can adjourn this meeting.

The chairperson's confidence that members had gained enough experience and knowledge on how to work on myths and misconception so much that members could address their intended audience, indicates that the support group went through many stages to learn and make meaning out of the content they had discussed as suggested in transformative learning literature.

8.5 Transformative learning and its evidence

Previous chapters have also revealed how participants experienced the different stages of Mezirow's transformative learning process as initially outlined in Chapter Three.

The last stage of this process - re-integrating into society with a new perspective - was where this particular group had reached (Mezirow as cited and expounded by Merriam, 2008), now that they intended to hold a campaign on the contribution of myths in the spread of HIV. Members acquired revised frames of reference as each member of the support group adjusted to their condition and developed. It is at this point that transformative learning is said to have occurred (Mezirow as cited in Ntseane, 2011).

This group illustrated their transformational journey and efforts they had made to shift from their first disorientation phase about the impact that myths impose on the youth in relation to the spread of HIV amongst the nation. However, the group did not only undergo a self-examination (phase two) about their challenge but also explored options for new ways of acting as a group in the fight against HIV (phase five). This group then undertook a new initiative to talk of a targeted youth awareness campaign focusing on myths commonly used by youth with a view to formulating educational messages. This support group, like the other groups, demonstrated increased competence and self-confidence in their new educational roles (phase six). They indicated that they had reached Mezirow's tenth phase of perspective transformation when they intended to re-integrate this new perspective into the discourses of their wider community. However, as has been stated in earlier chapters, not everyone reached the same level of transformative learning (Cox & John, 2016).

8.6 Non-transformative learning

Although the meeting about myths did not reveal a lack of transformative learning, an earlier discussion about multiple and concurrent sexual partners in this group had revealed a similar unwillingness to change behaviour that a man in the fathers-to-fathers group had displayed.

Mr Fats in his late forties argued that he was certain that he could not lie to the group about his behaviour change concerning MCSP because he was not yet ready for the change. Fats felt the

need to be loyal to his friendship in the community rather than changing his behaviour for his own good. He was worried about his status with his friends and the labels he might face without a concubine. To him, gaining respect and keeping his manhood in the community were all that mattered. Fats made his point clear during the discussion on MCSP reduction and strongly said:

> Mr Fats: You can all reduce and totally divorce your concubines except for myself. I want to keep mine because I have other male friends in the community beside this group. We share the concubines' stories every time we meet. What can I talk about during the days I spend with them in the village before coming here just for half a day that I spend with you if I no longer have concubines? Please do not count me in when you count those who reduce nor divorce their MCSP starting from today. (In Sesotho - *ke hlale nyatsi tsaka? 'lekhale'* - literal translation: 'divorcing my concubines? never').

This indicates that cultural practices are hard to disrupt when they are embedded in belief systems about personal identity. Mr Fats' concerns were much more focused on his life outside, when he was not at the support group. This man indicated that he had friends that he discussed his extra marital affairs with in the community. He made it clear to the support group that being able to cheat his wife, proved his manhood to his friends. Therefore, his multiple and concurrent sexual partners were his assets as it gave him a well-recognised status amongst his male friends. In his words he indicated that it was 'impossible for a car to take a journey without a spare wheel'.

8.7 Chapter summary

This chapter illustrated how myths and cultural discourses cannot be seen in isolation from medical discourses for Basotho. That is, community members need a learning space where they can explore and distinguish between myth and reality on their own terms. In other words, the findings indicate that medical discourses alone will not promote understanding or new thinking unless there is recognition of where the participants are coming from and what discourses are embedded in their thinking practices. From the beginning of the discussion, the support group took decisive action by trying to exhaust the myths that they suspected were circulating to delay preventive measures. This group identified myths as one of the factors which have influenced the rapid spread of HIV among the youth. During this process the support group members slowly walked up the steep hill of understanding with the intention to identify myths highly believed and practiced by the youth, particularly herd boys, and school drop-outs. The members hunted

the common myths used by the youth which were associated with spreading HIV. To accomplish their mission, they realised the need to hunt amongst the youth groups themselves, such as herd boys.

This chapter showed how the support group used strategies to intervene and better inform the youth. They did this with consideration of generational differences and with a view to obtaining as much information as they could in order to ensure that the way they imparted the message about HIV prevention would be acceptable to the target audiences. It was also evident that the learning process was multi-directional – the support group members learned from each other and the professionals such as the nurse and youth officer. But, equally, these professionals indicated that they were also learning from the on-going learning initiatives undertaken by the group themselves.

The discussion held by these members on hunted myths indicates that for medical information to have an effect in Basotho culture, all these different contexts need to be taken into account and the appropriate mechanisms to be used to pass on the medical education – it cannot just be done out of context. To run the myth campaign in an inclusive way, the group was faced with another steep hill (great challenges) which they slowly had to climb, that included finding the youth who were circulating threatening myths about HIV prevention. However, the support group was aware that learning has to take place through discussion in those different contexts. Therefore, members took it upon themselves to take action to make the myth campaign a success because this campaign was intended to be the learning platform for all youth categories.

At this juncture, Chapter Nine will provide a concluding summary of the key findings and provide recommendations for future research on support groups as a means of learning about HIV prevention and care.

Chapter Nine: Summary, findings, conclusions and recommendations

9.1 Introduction

This chapter provides a brief summary of the whole thesis. It offers a brief description of the Lesotho policy in relation to HIV and AIDS which has been elaborated in Chapter One. The chapter also takes the reader through the main issues discussed in the literature review, taking into consideration the theoretical framework that informed the study. This is followed by a summary of the methodology. The key findings in relation to the theoretical concepts are summarised followed by concluding reflections and recommendations.

9.2 Background information

HIV has been a serious concern in Lesotho since 1986 when the first HIV infected client was diagnosed. To respond to this threatening situation, Lesotho constructed an HIV policy to facilitate the reduction of HIV transmission among all populations especially among vulnerable groups (GOL, 2006). The policy included a number of prevention strategies. The HIV Testing and Counselling (HTC) strategy (GOL, 2009) indicates that counselling for prevention was the core business in HTC. Once a person has determined his/her HIV status, whether positive or negative, it is important that they either prevent transmission of HIV to other people or avoid contracting HIV themselves.

Many strategies - such as the Know Your Status campaign, Door to Door, Post Exposure Prophylaxis, Prevention of Mother To Child Transmission of HIV, Provider Initiated Testing and Counselling, Client Initiated Testing and Counselling, Pre-Exposure Prophylaxis, Voluntary Male Medical Circumcision, Test and Treat - were implemented to curb the problem but all were challenged by stigma and discrimination in Lesotho. Mosuoe (2016) in her study of the Phelisanang Bophelong support group confirms that stigma remains an overriding issue.

According to UNAIDS (2016; 2018), Lesotho has the second highest HIV prevalence rate in the whole world. The principal mode of transmission of HIV in Lesotho is through multiple and concurrent sexual partners (Centre for Disease Control and Prevention (CDC), 2016). The Ministry of Health introduced the concept of support groups as a means of enabling health practitioners to talk collectively to clients during monthly medical check-ups. It was also a

means of encouraging HIV infected and affected by HIV and AIDS people to learn collectively and support each other through the changes they encounter physically in their body and challenges that individuals encounter in their respective villages. This strategy was introduced and implemented in 2010 as an educational and preventive intervention to reduce the time usually spent by health professionals in answering individual client's questions during monthly check- ups. At the time of the study the support groups in Botha-Bothe had been operating for three years. As a district senior counsellor and implementer of these support groups I, as the researcher, wanted to explore how and to what extent the support groups were operating as educational and support structures. This study focused on analysing the patterns of interaction and meaning making within the different support groups, using communities of practice, social capital and transformative learning theories.

9.3 Literature in support of the study

Literature on support groups in Lesotho is very limited; therefore, this study draws literature mostly from across Africa and the rest of the world. There are various studies around the world addressing the issue of how different support groups (infected and affected) respond to HIV education in different perspectives. For instance, there are studies in America amongst African American men that explore personal beliefs (Saller, 2009) and attitudes towards AIDS. Aguilar (2014) discusses gender power relations affecting African American women in sexual relations. The literature review in this thesis addressed the following issues: a) The infected and affected people, how they cope with challenges relating to HIV and AIDS stigma, discrimination, opportunistic infections and disease progression; b) The individual sense of self as an HIV infected person; c) The misconceptions around treatment and challenges which the support groups encounter; d) The local and social beliefs on HIV prevention, transmission, and disease progression as experienced by the infected and some by the affected; e) The societal explanations of the disease; and f) The collective meanings given to explain the experiences such as side effects from the drugs. Mosuoe's study of a support group in Lesotho indicates that for an HIV infected person to live a longer healthy life, sources of support need to be identified. Mosuoe further argued that a delay in accessing support results in individuals delaying in accepting their HIV status and disclosure. A delay to disclose leads to the spread of HIV to other HIV infected individuals.

The literature review also identified that myths and social beliefs across societies can hinder developmental activities. According to Modo et al. (2010), a myth is a traditional tale with secondary or partial reference to something of collective importance. Myths originate in cultures without writing (called oral cultures) and they are passed down by word of mouth. Since they are traditional, myths are created by a collective cultural process and not by one author.

Three theories were used to help to explain how the health care workers and the support groups discuss and clarify the misconceptions caused by the myths, local and social beliefs, and medical messages about HIV, its prevention and care. They also helped to explain the ways in which people learned about the disease, transformed and adjusted to the new expectations. The theories which informed the study are communities of practice, social capital and transformative learning. Wenger-Trayner and Wenger-Trayner (2015, webpage) summarise communities of practice as 'a group of people who share a concern or a passion for something they do, and learn how to do it better as they interact regularly'. This means that being in such a community can produce a collective set of meanings only understood by the group through relationships and personal interactions as well as connections among participants. Members in communities of practice use each other's experience of practice as a learning resource. Since a core feature of communities of practice is to build trusting relationships within the group and also to seek to enhance the group's knowledge by networking with those outside the group, it was useful to explore the role of social capital as a learning resource which complemented the communities of practice literature. Social capital is explained by Putnam (2000) as an appropriate analytical framework for diagnosing the strength and weaknesses of the social networks present in a community. The way in which members networked also reflects the concept of social capital as outlined by Woolcock (2001) who discuss how bridging and linking with external networks enhances collective participation. Bonding capital is associated with social support and reciprocity, and is contrasted with bridging capital, which enables the individual to access resources outside of his/her homogeneous group. Linking social capital is an extension of such bridging resources and entails making connections with peripheral sources of expertise.

While communities of practice and social capital theories explain how the support groups directed themselves to learn, in order to find out the ways in which individuals and group members demonstrated new learning and understanding, Mezirow's (2000) transformative learning theory provided an additional analytical tool to explore this process. Transformative learning explains how people's meaning perspectives can become disorientated with new and challenging information. As a result, they can go through a number of reflective phases before they arrive at revised frames of reference. As a result of this new meaning making process, transformative learning is said to have occurred (Mezirow as cited in Ntseane, 2011).

A research design was selected in order to maximise the opportunity to understand this learning process.

9.4 Research design

The study adopted an interpretive paradigm through a case study approach to explore how three different support groups functioned as a community of practice and how they navigated their understanding of medical discourses. The data collection method which was deemed appropriate for this study was observation. I decided to choose observation because, as Simons (2009) indicates, the researcher in an observation method remains that of an inquisitive spectator who needs to record every incident. The observer uses the eyes to notice even the non-verbal cues which could help inform the study. Observation was undertaken over a six-month period of the three different support groups which met during their collective learning sessions held monthly at the Botha-Bothe government hospital premises. The sessions were recorded and the findings reported in narrative form in order to capture the atmosphere of the discussions and to help illustrate the learning strategies used amongst the participants. The method seemed to be appropriate to came up with the responses discussed below.

The research questions were:

1. How do the support groups function as a community of practice?
2. How do the support groups make meaning out of the different discourses associated with HIV and AIDS, its prevention and care – for example:

a. Medical messages?

b. Cultural value systems?

c. Myths and community beliefs?

3. How does their meaning making impact on new learning?

The findings are discussed in Chapters Five, Six, Seven and Eight. Chapter Five addressed the first research question in relation to all three support groups. Chapters Six, Seven and Eight took each support group in turn and analysed a specific theme that was discussed in that support group. Chapter six focused on medical messages, chapter 7 focused on cultural value systems. Chapter 8 explored myths and community beliefs.

9.5 Findings

9.5.1 How do the support groups function as a community of practice?

The communities of practice theory was used as an initial framework to analyse how the three support groups established in Botha-Bothe hospital worked together to achieve their intended learning goals. Wenger (2006) summarised communities of practice as groups of people who share a concern or a passion for something they do and learn how to do it better as they regularly meet.

The key features of communities of practice that were observed included: a) Collective decision making; b) Hunting as a term used to gather information from individuals and organisations; c) Learning networks: internal and external; d) Information seeking; e) Taking collective responsibility; f) Integrating / engaging new members (group forming); g) Development of a sense of belonging; h) Identity building; and i) Crossing boundaries. It was also evident that the use of social capital was a key feature of, in particular, information seeking and crossing boundaries.

My observations as researcher revealed that each of these support groups functioned as a learning group in the following ways. First, the groups managed their own learning at their own pace and their meetings were chaired and managed on a rotational basis by the members themselves. Second, members in each of the groups allocated themselves tasks to hunt from neighbours, friends and families seeking for clarifications of some complex medical terms. One of these terms was, for instance, ‘reinfection’ which became problematic for members’ level of

understanding. At every meeting the support group members discussed the hunted findings with each other, and discussed the challenging medical practices and terms together with an invited specialist to find a common understanding and prepare for potential behavioural change. Some of these medical practices were Prevention of Mother To Child Transmission (PMTCT) of HIV; Mother Baby Pack and complex practices like Exclusive Breast Feeding and Exclusive Formula Feeding. These medical practices seemed to interfere with cultural practices and expectations. However due to the collective learning style used by the support groups, members were able to identify, for instance, areas where PMTCT as a preventive intervention compromised societal norms and values and then members clearly planned the manner in which such a preventive intervention could be introduced to males as custodians of culture.

The study identified ways through which people addressed dominant constructions of HIV information, particularly relating to prevention of the spread of HIV amongst the Basotho nation. It identified examples where the support groups actively chose to engage with discourses that challenged their existing knowledge on HIV as support group members. They chose to impart their new understanding to the communities where they lived but also they chose to consult with those community members to gain clarity on what were the common understandings that might need to be addressed.

9.5.2 Other examples of the communities of practice elements

Collective decision making

The collective nature of the learning network and its activities and relationships enhanced the individual growth of each participant through a process of becoming members of a collective identity. Therefore, all members were expected to benefit from it. Members valued and practiced collective decision making about topics of interest. They recognised that the practice encouraged active participation by all. Members had to take part in several ways, including hunting and reporting back to the group, others discussed and related the topic discussed to HIV experiences each member had in life. The experiences were shared for collective learning to enhance informed collective decision making.

Collective decision making was observed as members would together agree on a topic to be discussed in the next meeting, decide on the specialists to be invited to address their challenges

and through the use of dialogue and culturally familiar metaphors come to a shared meaning making about the topic under discussion. On the issue of decision making, for example the mixed support group collectively decided to invite the fathers-to-fathers support group and mothers-in-law support groups to jointly address such myths in the form of a campaign. Of particular interest was the way the support groups used their own self-identified labels to explain their activities. Hunting, for instance, was a term used to gather information from individuals and organisations.

Collective learning

In an African context collective learning is a strong resource because it reflects the African tendency towards communal growth and advancement rather than individualism (Maskell, 2000). Wenger (2000) indicates that communities of practice historically existed because cultural and tribal practices had to be communally learned to reflect oneness. The aspect of collective learning for Basotho was strong. It is embedded in cultural practices and place names such as the notion of Thakaneng (place selected for youth gatherings to learn culture) and Khotla (a place where males gather for problem solving and learning law and order). This communal learning atmosphere was an important learning resource because in this collective learning space it became very apparent that medical discourses alone could not be the only source of information about HIV.

Sharing and learning is a crucial aspect of community of practice theory in that, the shared learning and interest of its members are what keeps it together. The group exists because participation has value to its members and gives identity to all members. A community of practice's life cycle takes a while to come into being and may live long after a project is completed or an official team has dispersed (Wenger, 1998).

A sense of belonging is defined as the experience of personal involvement in a system or environment so that persons feel they are an integral part of that system or environment (Cherkowski et al., 2015). Usually this sense is built after several incidences of members' compliance to perform duties indicating full involvement and participation. This is where one realised that these support groups functioned as a community of practice.

All support groups valued this collaborative manner of learning and collecting educative information which enabled them to move beyond their personal scope of knowledge and understanding. Members chosen as ‘hunters’ collected information for the groups from elsewhere and brought it back for knowledge sharing. This indicates that the support groups valued collaborative learning which strongly involved outsiders because information that was needed by the groups had to be collected from their friends, neighbours and relatives.

An illustration of their identity building could be seen in the way members described themselves as ‘male nurses’ (as in the fathers-to-fathers support group). Similarly, the groups saw themselves as becoming ‘books’ of knowledge and having attended a ‘university’ because of the level of knowledge they had gained about HIV and AIDS. An example of how they built a sense of belonging could be seen in the way they shared their personal experiences within the group. For example, the mothers-in-law‘s group shared their experiences of the abuse that some of them had encountered during childhood while some shared the abusive practices males imposed on them as a means of demonstrating the challenge of gender power relations.

The communities of practice theory showed strong overlaps with social capital since both theories emphasise the role of networking. The social capital theory made it possible to explore the different kinds of networks that operated at different times in the support group meetings. For instance, there are three commonly cited forms of social capital – bonding, bridging and linking (Woolcock, 2001).

Bonding social capital in this study indicated that support groups demonstrated a strong belief in accessing information that would be additional to their little knowledge on health related issues. As an initial strategy, the three support groups relied on close ties. For instance, family members and close relatives had access to information and education from the groups. Once a task to be hunted was tabled, members would volunteer to hunt, based on close relationships that each member had that would enable them to access information.

Bridging social capital in this study refers to broad, outward-looking relationships such as those found among colleagues or business connections that created diverse coalitions among different kinds of people. Bridging in the Lesotho context brought support group members in touch with the wide range of resources available in the teaching profession as well as giving them the ability to leverage these resources to secure employment as teachers (though not employed to do this teaching nor was it paid). The use of bridging social capital meant that members were able to suggest that non-support group members be invited to join their proposed activities – for example an agricultural project - with the aim that such an initiative would reduce stigma. These suggestions effectively moved the group from an inward looking group of victims to an outward looking group of survivors who contributed meaningfully to the society.

Linking social capital in the support groups was an extension of bridging networks. Linking social capital, means reaching out to people in dissimilar situations, such as those who are entirely outside of the community. This strategy enabled members to leverage a far wider range of resources than is available in the community. The support group was able to identify additional resources that could be used to address weaknesses of understanding in a particular group with the aim that external resources may complement the group's existing resources. Private organisations like for instance World Vision, Blue Cross and government organisations such as the Ministries of Gender and of Agriculture were invited to address support group challenges relating to organisational specialisation.

The next three chapters took one theme in turn from each of the support groups to answer research questions two and three.

9.5.3 Research question two

Chapters Six, Seven and Eight addressed research question two: **How do the support groups make meaning out of the different discourses associated with HIV and AIDS, its prevention and care?**

Chapter Six focused on re-infection and condom use as discussed by the fathers-to-fathers group. The topic PMTCT and men as heads of families, as discussed by the mothers in law group, was

the focus of Chapter Seven. Chapter Eight focused on cultural myths as discussed at one meeting by the mixed support group.

The community of practice style of collective learning provided the framework for enabling this to happen but the meaning making process took place through constantly exploring the same issue from different angles until the members understood the meaning of the medical terms and implications for not adhering to medical advice. They also made meaning by exploring ways in which they could navigate power relations to circumvent opposing viewpoints.

The use of metaphors, exploring the same point from several angles, allowing each person to tell their story which revealed the consequences of not understanding the significance of the medical discourses provided the learning process which enabled the participants to slowly come to a collective understanding of the medical terms and discourses for HIV prevention and care. Each member would refine their own understanding as a result of group feedback. At times, a member illustrated their own understanding as a result of group feedback while, in several encounters, members used their own experiences to inform or critique other's inputs.

Meaning making crystallised when members in the three support groups agreed to try out new ideas with others in the group. One example of this process came from the fathers to fathers support group in Chapter Seven in which males debated on condom use during sex. Some were doubtful about the practice because condoms were perceived as a foreign object which distracted the pleasure gained from sex. However, during the prolonged discussion on condom use, members began to understand the significance of condom use and some members eventually changed their perceptions about the importance of condom use as a preventive measure.

The second prominent incident where these members clearly indicated the effectiveness of their strategies for meaning making was during a discussion on Multiple and Concurrent sexual Partner (MCSP) reduction. Initially members at group level discussed, through metaphors, how it was impossible for a car to take a journey without a spare wheel. This argument referred to a sexually active individual being unable to live without a concubine. Eventually members understood the importance of reducing sexual partners because they began to realise that

possibilities of being infected were high if one engages in unprotected sex with several sexual partners.

However, it was also evident that not all participants would come to a shared understanding of issues. At an individual level, for instance one younger male member openly resisted the idea of MCSP reduction. He indicated the fear of being rejected by friends and being mocked as having 'lost his manhood' if he did not have his 'spare wheel' (extra marital sexual partner). It is evident, therefore, that the process of meaning making takes time and requires ongoing dialogue and discussion.

9.5.4 Research question three

Research question three, **how does meaning making impact on new learning**? was discussed in relation to Mezirow's transformative learning theory and was also addressed in Chapters Six, Seven, and Eight.

Learning, according to Mezirow (2000), occurs when an individual encounters an alternative perspective and prior habits of mind are called into question. This means an individual is only able to question one's belief when exposed to new information. In order for new information to make sense and learning to occur, there has to be some analysis of the new information. Rather than focusing on myth and misconception about HIV and AIDS, the support groups were seeking facts and truth. The support groups portrayed their transformational journey and efforts the group had made to shift from their first disorientation phase, through a number of different phases as tabulated by Mezirow (2000). The members themselves became educators and demonstrated increased competence and self-confidence in their new educational roles. All the support groups appeared to go through Mezirow's (2000) 10-step process for transformative learning. Many indicated that they had reached Mezirow's tenth phase of perspective transformation whereby they intended to re-integrate their new perspective on HIV and AIDs into the discourses of their wider community. For instance, they gained a deeper understanding about the impact that myths impose on youth in relation to the spread of HIV throughout the nation. However, the sequence was not always the same and the participants did not necessarily go through each phase in turn.

Nevertheless, there was evidence of each phase in the meetings, either from individuals or from collective responses as follows.

i) The first phase of experiencing a disorientating dilemma became visible when the support groups were confronted with medical words like re-infection. For the participants the term was new and difficult to understand even after the word was 'hunted' from different angles. Explanations brought to the group indicated that even hunters did not understand what re-infection meant in this context. This was seen when all three hunters brought three different explanations and it required the nurse's careful input using appropriate metaphors and examples to enhance clarity.

ii) Mezirow's second phase where the learner experiences a process of undergoing self-examination of their own meaning schemes, was evident among members in all three groups (mothers-in-law, fathers--o fathers and mixed support groups). For example, the process of collecting different interpretations of the word re-infection, and discovering there was no consensus of understanding, prompted the participants to seek additional help from the nurse.

iii) There was also evidence that individuals made a critical assessment of their internalised role assumptions (phase three) even feeling a sense of alienation from traditional social expectations. For example, the mothers-in-law re-assessed their experiences of gender power relations, and individuals in the fathers-to-fathers group began to realise the health dangers of practising multiple and concurrent partnerships.

iv) Mezirow's fourth phase, relating discontents to the similar experiences of others, included recognising that one's problem is shared and not exclusively a private matter. This was seen when a mother-in-law decided to ask one man in the fathers-to-fathers support group to talk to the bossy son who refused to let his wife practice exclusive breast feeding until the first-born child was infected. This mother-in-law sought an intervention from fathers to fathers to ensure that the second born would not be infected too. The mother-in-law freely narrated her experiences to the support group because all members shared similar experiences. Then she proceeded to suggest an intervention from another member in the fathers-to-fathers support

group because she trusted that his son would listen better to another man especially because both men attended initiation school together.

v) Mezirow's fifth stage was exploring options for new ways of acting. The participants explored options for new ways of acting when they went 'hunting' to collect information needed in their respective groups for knowledge enhancement and to identify knowledge gaps in the community which they hoped to fill. For instance: at the meeting held in July 2013 by the mixed support group, members decided to hunt for myths that fuel the spread of HIV among the youth before the youth could be gathered together to be educated on facts about HIV transmission.

vi) Building competencies and self-confidence in new roles was Mezirow's sixth phase in the learning process. This was strongly practised by the three support groups in that they allowed various external specialists into their meetings to strengthen their understanding and build their capacity for knowledge dissemination. Support group members worked hard to collect information that would increase their level of education. All groups explored new ways of acting and realised the need to acquire more education in different health aspects before action was taken. Therefore, various subject specialists were invited to capacitate support group members and build their competence before members went back to their communities.

vii) The seventh phase, planning a course of action, was evident in the different strategies the members, individually and collectively, decided to take action on. For instance, all groups made decisions to visit other societies in their community to raise awareness of HIV/AIDS prevention and care issues. A fathers-to-fathers individual member wanted to encourage and demonstrate correct and consistent use of condoms at his local burial society. The mixed support group collectively agreed to organise a campaign to talk about myths that can fuel the spread of HIV among the youth.

viii**)** The eighth phase, acquiring the knowledge and skills for implementing a new course of action, could be seen in different ways. The new skill of managing meetings, when all support groups were trained in how to conduct a meeting by the Department of Cooperatives, was obtained initially. In order to ensure all members could have access to and practice this skill,

members decided to rotate official group positions such as chairperson, secretary and welfare officer. During the discussions themselves the members arrived at a more enhanced understanding of HIV related issues and medical discourses. This new knowledge, acquired through a combination of metaphors, clarifications and dialogue in lay persons' language, meant that members felt they were educated enough to take new courses of action and share their knowledge with the rest of the community.

ix) In terms of trying out their new roles and assessing the impact of these new roles (phase nine), it could be seen that the members were initiating the establishment of Mafeteng and Mohales Hoek support groups which were similar to the existing Botha-Bothe hospital groups. They also identified themselves as 'nurses' and 'university books' with the intention that these roles could be used to extend vital information to the wider community. The extent to which these new roles were assessed could not be analysed from these meetings, but it was evident that such initiatives were a result of the discussions and information seeking practices which the members had undertaken.

x) Finally, Mezirow's last phase of re-integrating into society (as cited and expounded by Merriam 2008) with the new perspective on HIV/AIDS was evident, not only through the above phases but also in subsequent actions and decisions that emerged at the end of each meeting. For instance, the mothers-in-law support group proposed that men as heads of families should be more active with regard to health related issues so men would understand that their decision making role as fathers and brothers extended to sharing with the female community a care role for people living with HIV. The three groups therefore re-integrated their new perspectives on HIV into the community including taking responsibility for orientating the community on various HIV preventive measures.

Not all members reached the same phase of new meaning making. This was evident where cultural discourses and belief systems are strong. In the mixed support group, when members pledged to make a new beginning and to divorce the habit of multiple and concurrent sexual partners, one physically strong member swore not to divorce his concubines and said it would be cowardly of him if he admitted to the support group's plan. This man made an excuse that he

would not fit in with his circle of his friends if he did not have extra marital affairs. This indicates that cultural discourses and belief systems remain strong in any society especially when faced with peer pressure to conform to the established norm.

9.6 Concluding personal reflections

There are a lot of surprises that the study unveiled. Some of them are the manner in which the support group members conducted their learning sessions. From my observation, I had never seen this practised anywhere in Lesotho. I assumed that to hold learning sessions in the form of a meeting needed skillful people to conduct such meetings. I was surprised to see members doing well in their rotation of the official desk where one had to volunteer to sit at a chairperson's desk and the other member at a secretary's desk without much guidance or complaint. It was a surprise to see each member holding an official desk (chairperson or secretary) performing the task like a professional. That was an indication that the support groups had received intensive training in running such offices. It was also an indication that each member in the support groups was willing to practice and perfect the skill. Realising that each member from the three support groups was determined to acquire knowledge through fully contributing towards accessing and hunting from anybody who seemed to be their potential health expert, was surprising to me. There were times when members had to travel in search of the information needed by the respective group. Each member felt a need to incur their own transport costs in pursuit of the information needed without expectation for any form of transport reimbursement. It also surprised me to learn that all the support group members were not empty vessels into which new knowledge could simply be poured. Everyone had something to share as past experience and they used their previously accumulated experiences to understand the current information. This included their personal experiences when they learned that their daughters-in-law and other siblings were HIV infected. These experiences included personal and confidential stories shared about the ill treatment they encountered from their male parents when they were teenagers. These types of ill treatment led to forced marriages that the members entered into. The ill treatment extended even to their own children whose husbands displayed gender power relations over them thus making marital life unbearable to them.

Another surprise emerged when I learnt that not all the members made positive meaning out of the content delivered. This was indicated by one male in the mixed support group who clearly indicated to other members that he would never intentionally reduce or divorce his multiple and concurrent sexual partners because that would mean a compromise to his manhood among his male friends. He indicated that he would not comply with the support group recommendations while he still associated with his male peers. This male indicated to the group that there was a lot he learned from the group members which he intended to put in to practice except for the issue of MCSP reduction. This indicated that not every member of the support group made meaning out of the content immediately but rather demonstrated that there continued to be resistance to change among individuals irrespective of the information obtained. Also, one female in the mothers-in-law support group clearly spelled out that, notwithstanding the information from the learning sessions, she was not in a good position to confront her own son to offer support to his HIV infected wife nor to encourage the son to test because she was culturally expected to remain a child in her own house due to prevailing gender inequalities. She opted instead to involve a male stranger from the fathers-to-fathers support group to intervene by talking to her son because she was of the opinion that her son would give that male stranger a listening ear as they shared the same cultural values from the initiation school.

All sorts of personal experiences were shared without fear that other members may disclose it in forums outside the support groups because members believed that they were protected by the rules and regulations the groups had agreed to observe and abide by. The members practised the same method of learning throughout the observation period – a process which made the method famous to other support groups in the neighboring districts (Leribe and Mafeteng). It was amazing how the three support groups' knowledge on HIV and AIDS improved from the level where members were experiencing a disorienting dilemma (first phase) to the phase where they were in a position to shed light on their respective communities. This was an indication that they now had acquired a different perspective towards information that they had previously been negative about. I realised that members were willing to go into society with their new perspective (the tenth phase as articulated by Mezirow, 2000). It was astonishing to witness all the groups going through Mezirow's ten phases of learning through the discussions each month. But the groups did not shy away from engaging with official information sources. Different government

officials were invited to such meetings to assist the groups with their expertise in cases where the group discussed a topic in line with the official's specialisation area. This was done to allow room for corrections and additions on various topics which the members debated. It was during these undertakings that it was evident that not only the members learned from this method, but the subject matter specialists also learned from the members depending on the topic under discussion. It was evident that these participants were taking a great undertaking to empower their own communities with knowledge that could be explained within their own cultural contexts.

9.6.1 What I learned from conducting this study

I learned that my several visits to the support groups as a researcher were not disruptive as I had initially feared but rather were a motivation for members to attend: participation was constantly increasing throughout the meetings (six months). The rationale for the constant participation and motivation emanated from the fact that I was the first researcher to interact with the support groups since their establishment in 2010. Therefore, members were excited to realise that their long overdue efforts of learning and sharing what they have learned were finally going to be published and practiced beyond their boundaries.

I learned that support groups of this calibre need to be established country-wide due to their significance in HIV preventive education provision. I also learned that this method of learning is highly effective for the attainment of the Lesotho government strategy to achieve 90/90/90/ by 2020. (where 90 % of the adults know their HIV status by 2020, those who tested positive at least 90 % are put on treatment and that of those who are on treatment, at least 90% are adhering to treatment and their viral loads suppressed).

9.7 Concluding summary of the findings

The findings demonstrated that a community of practice approach to understanding the medical discourses that are deemed essential in the prevention and treatment of HIV and AIDS has to be organised in a culturally sensitive way. The use of metaphors and opportunities to interpret medical terms through culturally normative language is an essential tool to enable those affected and infected by HIV and AIDS to find coping strategies and make new meaning out of their

situation. The support groups, however, were more than a learning resource, they enabled the participants to develop new identities, find new voices and take new initiatives to challenge misconceptions and disempowering cultural behaviours. The collective nature of their learning was a primary resource in assisting individuals to come to a deeper understanding of the disease and how to address it. It was evident, however, that such learning and support relies on ongoing dialogue and constant interaction with the medical profession because individuals, even within a collective, do not learn or come to conclusions at a homogeneous pace. Support groups, therefore need to be sustained over a long period of time.

9.8 Recommendations

My overall recommendation therefore is that the Botha-Bothe support group members should be formally invited to explain how they have learned and developed to the Ministry of Health and that the support group members should be invited to accompany further support group training initiatives across the country to demonstrate what can be achieved. It is important also to highlight that such learning needs to be ongoing because not all individuals learn at the same pace and some require further discussions before they can overcome cultural resistances to change.

9.8.1 Recommendations for further research areas

More information could be gained from in-depth interviews with individual support group members about how they felt they learned to negotiate the different discourses.

A useful further study would be to obtain more information from males in support groups regarding the extent to which they were able to influence other males in their communities regarding behaviour change and HIV prevention and care.

A further study could investigate the contribution made by support groups to learning among adolescents and youths in different categories (herd boys, school dropouts) in the fight against HIV.

9.9 Chapter summary

This final chapter has summarised the thesis and its findings. This chapter has reflected on the research questions. There is reflection on what new meanings the support groups developed over time as communities of practice and in relation to social capital networks, what impact these new meanings had on how they have responded to the epidemic in terms of HIV management and behaviour change and also in terms of social relations the groups had. The study answered my most dominant question: how the support groups make meaning out of the different discourses associated with HIV and AIDS, its prevention and care.

This chapter has covered discussions on my relations with the support groups which might have contributed to smooth data collection. The methodology of observation was chosen because of its appropriateness in capturing both the atmosphere and discussions in relation to the medical information that needed to be understood by lay people. I reflected on my experiences while conducting this research and the narratives provided by members of the support groups. I also summarised what I learned from conducting this study as well as recommendations for further research areas.

My final statement about this thesis is as follows. I have observed the three support groups working to build their own strong knowledge base around HIV and AIDS. This was where they employed their hunting skills to gather information which helped them to identify one another as 'university teachers'. There were times when I realised that members tried to work as a collective in order to adapt and adjust to challenging cultural conditions. All members in the three support groups worked as communities of practice, using each other's experiences as learning resources. There were times when they had to slowly climb up the steep hill because 'hunting' for health information has never been easy for any group due to the sensitivity of HIV related information and due to the complexity and dynamism of the hunted information. Therefore, they had to take courage most of the time to advocate for HIV prevention, attending those already infected and encouraging them to begin treatment early before they lost their remaining strength.

After time, members identified themselves as confident individuals to be consulted during encounters with challenges related to their field of competence. The challenges they met as

individuals and as a group strengthened their existence. That entailed sharing resources, strategies or experiences for addressing common challenges. I have realised that these support groups succeeded in achieving their main objective for learning together because they relied on the utilisation of external networks where they collected information (hunting). Therefore, external relations were of great significance in this process. This study enabled me to profile the existence of these particular support groups in Lesotho, but even more to reveal their resourcefulness and strength of character which they displayed in the six months of our interaction. I conclude that the support groups were justified to identify themselves as doctors and nurses due to their tireless efforts of instilling information about HIV preventive measures into families and their respective communities.

9.10 Post script

Subsequent to my data collection period, the support groups continued to function in the hospital until 2016. They were given an extra year because some of the members had died and were replaced with new comers. So it was decided that the group should remain under the auspices of the hospital for the benefit of the new members. The three groups have since 2016 continued to meet in their communities. Since the members came from separate villages, the groups rotate their meeting places around their respective villages. They now play an educational role to the wider community in very much the same fashion as they had planned to do during my observations. That is, they collectively share their expertise supporting each other across the villages through scheduled talks to community organizations as well as more spontaneous requests for assistance from individual community members.

In recognition of their effectiveness, the Ministry of Health (formerly MOHSW) has now formally designated them as Community Adherence Groups (CAGs) supported by a government stipend. The group members are expected to provide ongoing counsellng and support to newly diagnosed HIV infected people. The stipend is used to facilitate individual expenses connected to diagnosis and treatment of community members. This is an indication of the success of the support group programme which continues to grow with the establishment of new support groups in the hospital.

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Appendices

APPENDIX ONE: Observation schedule – for support groups

Three support groups: six observations per support group over a period of 6 months.

All dialogue exchanges to be recorded digitally. Other personal notes include the following:

What information the support group members bring in and where they identify their source of information and how it is shared (eg reflecting bonding or bridging social capital; communities of practice)

How discussed – emotions around the different discourses (any evidence of the phases of transformative learning)

Which discourses are used and by whom – e.g. medical; myths; cultural; gender biased etc [mapping of who speaks in the groups]

Content topic and focus of medical inputs; group member inputs – what questions are asked, what comments are made

How individuals behave when medical practitioner presents – reactions to medical clarifications

How individuals behave when group members present – reactions to layperson clarifications

In what manner do members talk to each other (e.g. positive, negative, metaphors, vocabulary, representations of the world, rationalisations, ideologies)- drawing on discourse analysis themes

APPENDIX TWO– Consent form

RESEARCH PROJECT INFORMATION LETTER/CONSENT FORM

1. Study title and Researcher Details

Department: Adult Education

Project title: HIV / AIDS Support Groups in Botha – Bothe Lesotho: Negotiating Discourses about HIV Prevention and Care

Principal investigator: Manqosa Khang

Supervisor: Professor Julia Preece

Ethical approval number HSS/0078/013D

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 conducted with the purpose of documenting HIV and AIDS support group members views while discussing about HIV its Prevention and Care. The study will also help to identify how and when support group members learn to cope with HIV, its prevention and care. The findings will help to inform other hospitals how best to set up similar support groups.

4. Why have I been chosen?

You have been chosen because your support groups are unique in Lesotho and that I believe your support group is appropriate for explaining how people learn about HIV its Prevention and Care – I am proposing to hold three or more sessions with the support group members a) to observe your discussions during your meetings in order to get the gist of your discussion so as to pick up what is being discussed during your conversations. b) the final phase will be to hold interviews with some of the participants for further clarification.

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 not 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 so.

6. What will happen to me if I take part?

The study will take place between January 2013 and December 2015. I will record the discussions with your permission. I will also jot down some notes as you talk to help me note points that need clarification later.

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 recognize you from the information that you 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

Thank you

Manqosa Khang (date)

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).**

IWe 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

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APPENDIX 3: Permission request to hospital manager in charge of support groups

RESEARCH PROJECT INFORMATION LETTER/CONSENT FORM

1. Study title and Researcher Details

Department: Adult Education

Project title: HIV / AIDS Support Groups in Botha – Bothe Lesotho: Negotiating Discourses about HIV Prevention and Care

Principal investigator: Manqosa Khang

Supervisor: Professor Julia Preece

Ethical approval number **HSS/0078/013D.**

2. Invitation paragraph

I am requesting permission to undertake this study with the three support groups in Both-Bothe hospital. 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. Thank you for reading this.

3. What is the purpose of the study?

This study is conducted with the purpose of documenting HIV and AIDS support group members views while discussing about HIV its Prevention and Care. The study will also help to identify how and when support group members learn to cope with HIV, its prevention and care. The findings will help to inform other hospitals how best to set up similar support groups.

4. Why has this hospital been chosen?

Your hospital has been chosen because your support groups are unique in Lesotho and a deeper understanding of how they operate will help to explain how people learn about HIV, its Prevention and Care – I am proposing to hold three or more sessions with the support group members a) to observe their discussions during their meetings in order to get the gist of their discussions so as to pick up what is being discussed during the conversations. b) the final phase will be to hold interviews with some of the participants for further clarification.

6. What will happen I give permission for the hospital to take part?

The study will take place between January 2013 and December 2015. I will observe the support groups with your – and their permission. I will also jot down some notes as people talk to help me note points that need clarification later.

7. **Will my taking part in this study be kept confidential?**

I will not include any recognizable details about the hospital in this study, unless you specifically request it. I will do this so that nobody can recognize the participants from the information that they give.

8. What will happen to the results of the 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 anyone's name or address in any presentation, report or book.

9. Who is organizing 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

Manqosa Khang (date)

N.B. Please sign the attached slip if you consent to being interviewed.

I /We... consent to the study being undertaken with the support groups at Botha-Bothe hospital in relation to research project (**HSS/0078/013D).**

Date …………………………..

Thank you

14 February 2013

Mrs Manqosa Mapotlako Ellen Khang 212558053
School of Education
Pietermaritzburg Campus

Protocol reference number: HSS/0078/013D
Project title: HIV/AIDS support groups in Botha - Bothe, Lesotho: Negotiating Discourses about HIV, its Prevention and Care.

Dear Mrs Khang

Expedited Approval

I wish to inform you that your application has been granted Full Approval through an expedited review process.

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 and Methods must be reviewed and approved through the 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.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

....

Professor Steven Collings (Chair)
/px

cc Supervisor Professor Julia Preece
cc Dr Marintjie van der Merwe
cc Academic leader Dr MN Davids and Dr R Mudaly
cc School Administrator Ms Bongekile Bhengu

Professor S Collings (Chair)
Humanities & Social Sc Research Ethics Committee
Westville Campus, Govan Mbeki Building
Postal Address: Private Bag X54001, Durban, 4000, South Africa
Telephone: +27 (0)31 260 3587/8350 **Facsimile:** +27 (0)31 260 4609 **Email:** ximbap@ukzn.ac.za / snymanm@ukzn.ac.za

Founding Campuses: Edgewood Howard College Medical School Pietermaritzburg Westville

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