Perceived barriers to participation in HIV Support Groups among People Living with HIV and AIDS at Katlehong Township - South Africa.

By
Kekana Mamma Olga

National School of Public Health
University of Limpopo- Medunsa Campus

Submitted to University of Limpopo
Faculty of Health Sciences, Medunsa campus
School of Public Health

In partial fulfilment of the requirements for the degree of Master of Public Health

Supervisor: Dr. Sphiwe Madiba

2011
Declaration

I Mamma Olga Kekana hereby declare that this research on “Perceived barriers to participation in HIV Support Groups among People Living with HIV and AIDS at Katlehong Township - South Africa” is my own independent work and that, to the best of my knowledge and belief, no portion of the work referred to in the dissertation has been submitted in support of an application for another degree or qualification to this or any other university or other institution of learning

Mamma Olga Kekana

Signature ____________________________ Date _____________________
Acknowledgement

I will like to thank Ramokonopi Health Care Centre managers for granting a permission to conduct the study and participants who gave us consents to do the study with them.

Special thanks Samukelisiwe and Vhali for assisting in collecting the data.

To my supervisor, Sphiwe Madiba who assisted me throughout the process of my research protocol. I appreciate your support and dedication.
Abstract

Background
Support groups are an informal resource that attempts to provide healing components to a variety of problems and challenges. An informal support outside of family, friends, or professionals often provides greater understanding, more similarity (from individuals experiencing similar life events), an opportunity for empathy and altruism, and a sense of identity for participants. Learning new ways to handle challenges, cope with changes, and maintain new behaviors are all important aspects of the support group experience.

Purpose
The aim of the study was to determine what HIV positive people perceive as barriers to participate in HIV support groups.

Methods
This was a quantitative study design using structured questionnaires on 248 participants who gave written consents to participate in the study.

Results
Majority were female 63% participants, single (52.63%), unemployed (60%), between ages 31-40 and 52.02% attained secondary education. Participants who were currently on HIV treatment (prophylaxis and ARV) has attended HIV support groups before while participants who were not on any treatment have never attended HIV support groups. Participants who never attended HIV support group also never attended other support groups. The main reasons that participants gave for not attending in HIV support groups was that they are concerned about their privacy and HIV status being known by others. Barriers preventing attendance of HIV support group were support groups are hard to find, work schedules and lack of transport money.
Conclusion

It is important that the support groups be designed to meet the needs of PLWHA. Participants in this setting preferred a small size gender mixed support group, composing of similar age group and be conducted by professional person. This will increase a greater involvement of PLWHA in the development of support groups. It is recommended that support groups should be designed in a way that they allow PLWHA to exit when they have been empowered to manage their HIV diagnosis.

Keywords: HIV support groups; people living with HIV and AIDS; perceived barriers; participation, non participation; attendance.
**List of Abbreviations**

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immune Deficiency Syndrome</td>
</tr>
<tr>
<td>ART</td>
<td>Antiretroviral Treatment</td>
</tr>
<tr>
<td>ARV</td>
<td>Anti-Retro Viral</td>
</tr>
<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
</tr>
<tr>
<td>NGO</td>
<td>Non Governmental Organization</td>
</tr>
<tr>
<td>PLWHA</td>
<td>People living with HIV and AIDS</td>
</tr>
<tr>
<td>VCT</td>
<td>Voluntary Counselling and Testing</td>
</tr>
<tr>
<td>WHO</td>
<td>World Health Organization</td>
</tr>
</tbody>
</table>
# Table of contents

| Declaration                                      | ii |
| Acknowledgement                                 | iii |
| Abstract                                        | iv |
| List of abbreviations                           | v |
| List of figures                                 | ix |
| List of tables                                  | viii |

## Chapter One: Background and Introduction

1.1. Background on HIV support groups.........................1
1.2. The importance of support groups.........................1
1.3. The benefits and effectiveness of HIV support groups........2
1.4. Barriers preventing participation in HIV support groups........2
1.5. Problem statement........................................3
1.6. Aim of the study..........................................4
1.7. Research objectives........................................4
1.8. Research questions........................................4
1.9. Study significance........................................4

## Chapter two: Literature review

2.1 Introduction..................................................5
2.2. Overview of HIV support groups............................5
2.3. Purpose of HIV/AIDS support groups........................5
2.4. Benefits of support groups..................................6
2.5. Reasons for participating in support groups................7
2.6. Characteristics and experiences of HIV support groups........8
2.7. Barriers affecting participation in support groups...........9
2.8. Gender aspect of HIV support groups.......................10
2.9. Disclosure of HIV status ......................................................... 11
2.10. Management of HIV stigma .................................................. 13

Chapter Three: Methods and materials ........................................ 14
3.1. Study design ................................................................. 14
3.2. Study setting and population ................................................ 14
3.3. Study sample and recruitment .............................................. 14
3.4. Data collection .............................................................. 15
3.5. Validity and reliability ....................................................... 15
3.6. Bias .............................................................................. 16
3.7. Data analysis plan .......................................................... 16
3.8. Ethical considerations ....................................................... 16

Chapter Four: Findings ............................................................ 18
4.1. Introduction ..................................................................... 18
4.2. Section A: Socio demographic information ................................ 18
4.2.1. Gender distribution of study participants .............................. 18
4.2.2. Age distribution of study participants ................................. 19
4.2.3. Marital status ............................................................. 20
4.2.4. Educational level ........................................................ 20
4.2.5. Employment status ...................................................... 21
4.2.6. HIV profile of participants ............................................ 21
4.2.6.1. Categories of people participants disclosed to ............... 22
4.2.6.2. Reported time participants have known about HIV diagnose ............................................. 22
4.2.6.3. HIV treatment staging ............................................. 23
4.2.6.4. Participation in HIV support groups .............................. 24
4.2.6.5. Participation in other support groups .............................. 24
4.3. Section B: Reasons for non-participation in HIV support groups ... 25
4.3.1. Personal and social issues ............................................. 26
4.3.2. Access issues ................................................................. 26
4.3.3. Service issues ............................................................ 26
4.4. Section C: Perceptions of HIV support groups ................. 26
4.4.1. Participants’ perceptions about support groups ............ 27

Chapter Five: Discussions and recommendations ................. 29
5.1 Introduction ...................................................................... 29
5.2 Demographic characteristics of the participants .............. 29
5.3. HIV profile of participants ............................................ 30
5.4. Participation in support groups ..................................... 31
5.5. Reasons for participation .............................................. 32
5.6. Barriers to participate in support groups ...................... 34
5.7. Perception of support groups ....................................... 35
5.8. Conclusion ................................................................... 36
5.9. Recommendations ....................................................... 38
5.10. Limitations ................................................................. 39
6. References .......................................................................... 40

Appendix 1: Structured questionnaires - English version .......... 46
Appendix 2: Structured questionnaires - Setswana version ......... 51
Appendix 3: Structured questionnaires - IsiZulu version .......... 55
Appendix 4: Consent form - English version .......................... 59
Appendix 5: Consent form - Setswana version ....................... 60
Appendix 6: Consent form - IsiZulu version ........................... 61
Appendix 7: Permission letter to Ekurhuleni South Regional Manager.. 62
Appendix 8: Permission letter to Chief clinic head and facility manager. 63
Appendix 9: MREC Clearance Certificate ............................... 64
**List of Figures**

- Figure 1: Gender distribution of study participants.................................18
- Figure 2: Age distribution of study participants......................................19
- Figure 3: Marital status...........................................................................20
- Figure 4: Educational level.....................................................................20
- Figure 5: Employment status.................................................................21
- Figure 6: Categories of people disclose to.............................................22
- Figure 7: Reported time participants have known about HIV diagnosis........22
- Figure 8: HIV treatment staging..............................................................23
- Figure 9: Participation in HIV support groups..........................................24
- Figure 10: Participation in other support groups........................................24

**List of Tables**

- **Table 1**: Barriers for non-participation in HIV support groups.................25
- **Table 2**: Participants’ preference of support groups..............................26
- **Table 3**: Perceptions of HIV support groups........................................27
Chapter 1: Background and Introduction

1.1. Background on HIV support groups.
The rapid spread of HIV and AIDS worldwide has placed a great burden on the public health care system as well as for people living with HIV and AIDS (PLWHA) and their families. In response HIV support groups have been established as an alternative health care and support for PLWHA by governmental, nongovernmental officials, local communities and the PLWHA themselves (Lyttleton 2004). And for more than a decade, support groups have been proposed as a key intervention PLWHA with the organization and self-support for PLWHA regarded as the mainstay of responses to HIV all over the world (De Barros et al. 2004). Support groups have been proposed as an important intervention for PLWHA in dealing with changes that come with the illness. A support group is defined as a structure or a meeting wherein people with common challenges, concerns and needs come together to support one another in various aspects of daily living and functioning, such as emotional, spiritual, physical and psychological needs. Support groups are composed of men, women, heterosexuals, homosexuals or can be mixed. In South Africa, most support groups are led by HIV-positive lay counselors who were trained by Non Governmental Organizations (National Department of health 2003).

1.2. The importance of support groups.
Support groups are an informal resource that attempts to provide healing components to a variety of problems and challenges. An informal support outside of family, friends, or professionals often provides greater understanding, more similarity, an opportunity for empathy and altruism, and a sense of identity for participants (Encyclopedia of mental disorders 2011). Support groups for PLWHA are usually formed to provide care and support to people infected and affected by HIV and AIDS (Cohen in Mundell 2006). Support groups for PLWHA’s help with support, care and treatment and in advocacy to tackle stigma (De Barros et al. 2004). In addition, support groups educate people and create awareness of HIV and AIDS, and work towards reducing new infections, stigma and discrimination for PLWHA. Visser et al. (2005) sums up the functions of support groups for PLWHA as providing PLWHA with a safe environment to talk about the
virus, share their experiences, and learn from stories of other infected individuals. Learning new ways to handle challenges, cope with changes in their lives, and maintain new behaviors (Encyclopedia of mental disorders 2011).

1.3. The benefits and effectiveness of HIV support groups.
There is evidence that participating in support groups for PLWHA benefits the individual, according to Simbayi (2008) several studies have shown that support groups are effective in reducing psychological distress both in PLWHA and in other chronic illnesses, Support groups have also been found to be effective in improving coping styles and psychosocial adjustment of PLWHA. Sikkema (2002) also maintain that support groups for PLWHA is able to assist its members in working through their difficulties associated with being HIV positive, provided an opportunity for the participants to give and receive meaningful support. In a study conducted in South Africa, Visser et al. (2005) showed that support groups provide PLWHA a relaxed platform to share their experiences about HIV and AIDS and build new friendships, love and acceptance, suggesting that the formation of support groups can be a source of valuable support for people living with HIV and AIDS.

1.4. Barriers preventing participation in HIV support groups.
Regardless of social and psychological benefits that HIV support groups bring to an individual PLWHA, still organizations are experiencing poor participation in support groups for PLWHA. There may be barriers that prevent PLWHA from attending their support groups. Stigma and discrimination are the major factors that PLWHA faces on daily bases and they affect participation in HIV support groups. Holzemer & Uys (2004) showed that PLWAs and their families are subjected to prejudice, discrimination, abuse, and hostility related to stigma associated with HIV. Could there be other barriers that affect PLWHA from participating in HIV support groups? That is what this study is determined to find out.
1.5. Problem Statement
In response to the acknowledgement that HIV and AIDS is as much a psychological problem as it is a medical problem, all members of the multidisciplinary health team (nurses, psychologists, social workers, psychiatrists, health advisors) have made the development of psychological care programmes for PLWHA a top priority.
Similarly in 2004, Ramokonopi Health Care Centre introduced Voluntary Counselling and Testing (VCT) as well as HIV support group as a comprehensive management of HIV and AIDS services. When the support group for PLWHA was launched, initial attendance was good but with time, members began to drop out of the support group. This resulted in the termination of the support group as members gradually decreased; currently there is no HIV support group at the health centre. This is despite evidence showing that support groups for PLWHA provide diagnosed people with a safe environment to talk about the virus, share their experiences, and learn from stories of other infected individuals and have access to information (Visser et al. 2005).
Furthermore support groups for HIV positive has been used as strategy to enhance their quality of life, decrease isolation and feelings of shame, improve self-care behaviors, and create mutually empathetic relationships (Lennon-Dearing 2008).

The health centre has recently started with the with roll out of antiretroviral treatment (ARVs’) program and health workers think its important to restart the HIV support group for PHWA again. However, the challenge is that the reasons why PLWHA using this health facility do not want to participate in support groups are not known. One of the motivations why the health providers want to reinitiate support groups is because support groups are a popular way of providing the needed support for PLWHA in many resource limited environments and need very little resources. Mundell (2006) states that support groups offers group therapy which can be a vehicle for assisting people in making necessary changes in attitude, beliefs, feelings and behaviors. Various studies show that PLWHA experience lower levels of social support after diagnosis and need social support after having learnt of their HIV positive status. Support groups have also been found to be effective in improving coping styles and psychosocial adjustment of PLWHA (Simbayi 2008).
In a study conducted among men LWHA in the Eastern Cape, Sigaxa-Canti (2010) reported that access to support groups, days and times of the support group meetings, issues around gender in the support groups, confidentiality and stigma were found to be barriers to attend support groups. This study will investigate why PLWHA in this community do not participate in support groups for PLWHA.

1.6. Study Aim
The aim of the study was to determine what HIV positive people perceive as barriers to participate in HIV support groups.

1.7. Research Objectives
The objectives of the study were;
1. To identify HIV positive people’s perceive barriers to participate in HIV support groups
2. To determine attitudes of HIV positive people towards HIV support groups
3. To determine the proportion of HIV positive people who participate in HIV support groups

1.8. Research Questions
The study questions were;
1. What are HIV positive people’s perceived barriers for participation in HIV support groups
2. What attitudes do HIV positive people have towards HIV support groups.
3. What is the proportion of HIV positive people who participate in HIV support groups?

1.9. Study significance
The results of the study will add new knowledge on support groups, which is currently limited in South Africa and Sub Saharan Africa.
It is also envisaged that the results will be used to improve service delivery and aid in the development of policy on support groups.
Chapter 2: Literature Review

2.1. Introduction

This chapter provides background about support groups and various facets of HIV/AIDS support groups. It reviewed several key studies on HIV/AIDS support groups throughout the world.

2.2. Overview of HIV support groups

Support groups have been regarded as a key intervention for people living with HIV and AIDS for more than a decade Sprigs (1998) and De Barros et al. (2004) and are among the most widely available and widely used psychosocial interventions for persons with HIV and have been around for many years (Davidson et al. 2000; Kalichman et al. 1996). Group support usually means particular interventions provided to a specific group of people by professionals, peers, or both over a limited time and often one therapeutic intervention offered for PLWA (Yalom 1995). One other characteristic of Support groups is that they are member-centred, supportive and empowering and participation has been linked with reducing depression, anxiety and isolation and improving survival time and mental health (Lennon-Dearing 2008). The organization and self-support for PLWHA regarded as the mainstay of responses to HIV all over the world (De Barros et al. 2004). According to Siebert & Dorfman (1995) in most literature support groups have been recognized as a valuable and a readily available source of support for people infected with HIV. Spirig (1998) conducted a review of literature that concluded that support groups can be useful, effective, and helpful in intervening with people with HIV/AIDS. While Lennon-Dearing (2008) argues that support groups may prove to be the single most powerful psychosocial intervention for women living with HIV.

2.3. Purpose of HIV support groups

The primary purpose of support groups for PLWHA is to provide emotional and/or psychological support, to provide PLWHA with information, and for the members to potentially develop coping skills (Schopler & Galinsky1993; Spirig 1998). According to Wood (2000), the purpose of support groups is to help members cope with stressful events. Furthermore support groups provide reality testing, emotional support,
socialization, and education to PLWHA. While Lennon-Dearing (2008) see support
groups for HIV-positive women as a strategy to enhance their quality of life, decrease
isolation and feelings of shame, improve self-care behaviours, and create mutually
empathetic relationships. In addition, support groups provide mutual aid and self-help for
people facing chronic disease, life-threatening illness and dependency issues (Cline
1999). Lyttleton (2004) argues that a very powerful function of Thai support groups is
that they allow their members to challenge the dominant trope of becoming HIV infected
and or ill with AIDS as a social trauma.

Several studies are in agreement that support groups are necessary for PLWHA due to
the nature of illness and associated factors of social stigma, isolation, living with anxiety,
and hopelessness, the fear of dying, living with bereavement, loss of intimacy and
changes in sexual relationship (Bell et al. 2007; Coleman & Harris 1989; Spirig 1998). In
addition, support groups can provide an ideal forum for individuals to understand facts
about their health and ways to manage HIV/AIDS with information on topics such as
treatment options and proper nutrition (Coleman & Harris 1989). A lack of knowledge
about the disease may lead an individual to feel desperate and hopeless (Manchester
2004).

2.4. Benefits of HIV support groups.
Several researchers has articulated the benefits of support groups and currently the focus
was on the benefits of women only support groups for HIV infected women. Support
groups are regarded by patients as less stigmatizing and by health care providers as more
cost effective and more beneficial than individual therapy (Moosa 2009). Outcomes of
HIV support group attendance have shown that members become empowered to value
themselves and make small steps to better their lives both physically and emotionally
(Lennon-Dearing 2008). Support groups are also known to decrease social isolation and
create a sense of belonging, which may enhance self-esteem and lead to greater self-
protective behavior for women at highest risk for disease (VanDevanter 2000). Joining a
support group assist in feeling of belonging and equips the PLWHA with skills to
improve their quality of lives and prolonging their lives. Visser et al. (2005) reported that
support groups provide PLWHA a relaxed platform to share their experiences about HIV and AIDS and build new friendships, love and acceptance. The impact of the group on their lives was that support groups had made a difference in their lives, they did not feel alone anymore, they gained self-acceptance and confidence, learned to talk about their problems and how to cope with the diagnosis. Lennon-Dearing (2008) also reported that participation in HIV support groups offer women with an improved medication compliance and decreased risk behavior for re-exposure and reduced feelings of shame. Support groups provide substantial services addressing a range of acute needs, including medical, material, and emotional assistance. They also challenge social discrimination and the anxiety, fear, guilt, sadness, ignorance, blame, and anger that those with HIV confront by offering a very specific way of being publicly positive. Many Thai HIV infected feel people strongly that belonging to a support group reduces psychological morbidity and prolongs one’s life (Lyttleton 2004).

Heyer et al. (2010) showed that perceived benefits for attending HIV support groups included receiving psychological support, accepting one’s HIV status, reducing stigma and isolation, increasing hope, forging new friendships, helping others, obtaining HIV-related information, developing strategies to change behavior, gaining access to medical care at the adjoining HIV clinic and receiving food donation.

**Reasons for joining and participating in HIV support groups.**

The literature report different reasons for joining HIV support groups. Some of the reasons found in the literature includes; mentioned monetary incentives support group size, salience of the group content, geographic access, consistency of group leadership and use of peer leaders along with professional facilitators, support for participation, self-initiation of the participant (Van Devanter et al. 1999). Wong-Rieger & Lindee (1992) found that the motivating factors for participating in support groups were different for men and women. Men were influenced by the information exchanged, especially on medical trials and safer sex; while women were influenced by the testimonials and participation in focus groups. For both groups, there was a clear distinction between factors related to giving support and those promoting the desire to seek support. It
demonstrates the differential impact of information exchange and emotional sharing and suggests that different strategies need to be pursued in setting up men's and women's HIV support group.

Funck-Brentano et al. (2005) did a study on HIV infected adolescents peer support groups. They found that at baseline, adolescents who chose to join the support group were experiencing significantly more difficulties with their parents’ over protective behavior than those who refuse to participate. Those participating were also motivated to share their difficulties with HIV infected peers and find relief by sharing their experiences with their peers.

In a study conducted with mentally ill HIV positive people in South Africa, Moosa (2009) found that most of the members joined the support group with the expectation of receiving emotional support and education. Similarly Liamputtong (2009) found that HIV positive women in their study were seeking knowledge, sense of belonging, emotional support from support groups. The authors also argue that joining AIDS support groups was used by some women as a strategy to counteract stigma of their conditions and lives in Thai society.

2.6. Characteristics of attenders and non attenders of support groups.

Characteristics of attenders and non-attenders may vary according to the type of support group or problem they face Lyttleton (2004) reported that middle- or upper-class men and women with financial security and access to high quality medical assistance, coupled with a concern for status, are likely to remain outside the umbrella of PLWHA groups communal services.

Davidson et al. (2000) and Kalichman et al. (1996) also found that HIV support group attenders were more likely to have greater education and a longer time since diagnosis than non-attenders. These authors found greater psychosocial distress and more avoidant coping among non-attenders. Other psychosocial differences have also been found. Lower internalized stigma has been found for HIV support group attenders in comparison to non-attenders (Lee et al. 2002).
Kalichman et al. (1996) examined differences in psychosocial functioning among HIV-seropositive men and women who have and have not attended support groups and examined the utilization of support groups for meeting support needs among people living with HIV infection and AIDS.

Results showed that those who attended support groups knew they were HIV-seropositive for a longer time, reported less emotional distress, and had more social contact than did non-attenders. However, non-attenders endorsed avoidant coping strategies to a greater extent. Analyses showed that time since testing positive accounted for differences between groups in social connectedness but not differences in anxiety, depression, or avoidance coping. Thus, HIV-seropositive persons become socially re-connected with time, but individuals with avoidant coping styles experience greater emotional distress and are unlikely to seek support groups.

2.7. Barriers affecting participation in HIV support groups.

Walch et al. (2006) study results showed that respondents who showed interest in the participation of HIV support groups were diagnosed more recently than those who did not express interest and respondents who had never attended any other type of support groups. Also those who had never attended any type of support reported more perceived barriers to participation in an HIV support group than those who had previously attended some type of support group.

Van Dervanter et al. (1999) study examined the factors that may influence participation among women in a weekly support group. Qualitative data indicated that although monetary incentives play some role in the woman's decision to participate, other factors are also important. These include program outreach, support group size, salience of the group content, consistency of group leadership from the intervention to the support group, and use of peer leaders along with professional facilitators. Clearly not everyone with HIV infection joined support groups for PLWAs. The findings of Lyttleton (2004) showed that there were many reasons for not joining HIV support groups. Examples of the reasons are: personal disinclination, and/or practical constraints presence of existing family support or the financial means for alternative help strategies.
Heyer et al. (2010) results about negative aspects of attending the support group included the large size of the support group, long queues at the HIV clinic, concerns about confidentiality and negative staff attitudes towards the participants. Leaders were concerned about conflict, burn-out and impractical protocols. Access to disability grants was also a concern.

Research has found that HIV-infected adults age 50 and older are more socially isolated than younger HIV-infected individuals. Scrimshaw & Siegel (2003) examines the perceived barriers to obtaining emotional and practical social support from friends and family among 63 older adults (age 50+) living with HIV/AIDS. Many reported they did not receive enough emotional support or practical assistance. Barriers to obtaining support included: (1) nondisclosure of HIV status; (2) others’ fear of HIV/AIDS; (3) desire to be self-reliant and independent; (4) not wanting to be a burden; (5) unavailability of family; (6) death of friends to AIDS; and (7) ageism. These barriers may explain the greater social isolation of HIV-infected older adults and inform interventions targeted at reducing these barriers.

2.8. Gender aspect of HIV support groups.
According to Siebert and Dorfman (1995) literature show that group composition of support groups is a relevant issue to the group treatment of PLWHA. Homogeneous HIV support groups are likely to develop group cohesion faster and stronger than heterogeneous groups. The literatures further show that the majority of HIV supports groups are composed of members who are homogeneous for risk group, stage of illness, or gender.
As already mentioned the composition of support groups for people with HIV are often homogeneous for gender, stage of illness, risk group for contracting HIV Lennon-Dearing (2008) also argue that gender composition of support groups is important because it enhances cohesiveness and maximize interpersonal interaction Gender homogeneity in group composition may play a significant part in the outcome of HIV support group participation and is an important consideration for support group planners (Yalom 1995; Lennon-Dearing 2008; DiPasquale 1990).
According to Siebert & Dorfman (1995) the poorer attendance of women in mixed gender support groups was the impetus for women only supports groups which may offer women greater benefits from the curative factor of group cohesion. Research further shows that mixed-gender groups do not provide an adequate opportunity for women to use or benefit from their unique communication styles, or to address their greatest concerns (Woods 2000). Literature also shows that group therapy research suggests that women do better in all-female groups (Siebert & Dorfman 1995). Most agency staff decided to provide female only support groups because HIV-positive women may seek the company of other women like themselves to have role models of other women living with HIV. And women only HIV support groups provide members role models of women living with HIV that normalize and destigmatize members’ situations (Lennon-Dearing 2008).

Furthermore Lyttleton (2004) and Whetten et al. (2004) found that women outnumbered men in most mixed gender HIV support groups. In addition, Lyttleton’s (2004) findings are that gender and social identity are significant factors that influence the benefits to be gained from belonging, and that women markedly outnumber men in most Thai groups, and many people living with HIV and AIDS regard masculinity as a constraining factor on male participation to support groups. Lyttleton (2004) further argues that, gender not only structures vulnerability to HIV infection but it also plays an important part in self-management of HIV and AIDS, particularly in the way it influences disclosure and channels benefits to be derived from belonging to support groups.

2.9. Disclosure and support groups

According to the WHO one of the benefits of support groups, is that they may help PLWH develop the confidence to disclose (UNAIDS/WHO, 2000). In a study conducted with HIV positive women in Kenya, Gillett & Parr (2010) found that women gained confidence to disclose to relatives and partners after meeting other people living with HIV at their support group. Similarly, findings from multi-country study carried out in sub-Saharan Africa also showed that interaction with other people living with HIV gave women more courage to disclose their HIV status (Gillett & Parr 2010). However when
PLWHA are not in any support groups literature has shown that disclosure is associated with social support. According to Kalichman et al. (2003) the decisions to disclose HIV-status depend on the barriers and needs associated with specific types of relationships. Disclosure to family members and friends are focused more on oneself to maintain honesty, relieve the stress of concealing one’s HIV-status, or to access social support. Kalichman et al. (2003) reported that in his study with HIV positive men and women, results showed patterns of selective disclosure, where most participants disclosed to some relationship members and not to others, disclosure was associated with social support, friends were disclosed to most often and perceived as more supportive than family members, and mothers and sisters were disclosed to more often than fathers and brothers and perceived as more supportive than other family members. Participants who had fully disclosed to immediate family members, specifically parents and siblings, reported more social support from those relationships.

According to Serovich et al. (2008) the emotional benefits of disclosure include social support, relief that comes from sharing a burdensome secret, and the built-in reward of educating others about HIV. Similarly findings from Kalichman et al. (2003) suggested that people living with HIV-AIDS who have disclosed their HIV status to family and friends enjoy greater social support from those relationships and that social support may buffer emotional distress in people living with HIV-AIDS. While Gillett & Parr (2010) found that women’s motivations to disclose were strongly influenced by access to food, medicines, and ability to pay their children’s school fees. The author further argue that social support for HIV positive women in their setting has some economic context, suggesting that initiatives aiming to promote disclosure, such as support groups, should be adapted to the specific needs of those they serve. Kalichman et al. (2003) also speaks to efforts to improve HIV-status-disclosure decision-making skills and communication skills for effective disclosure which may include identifying safe situations for disclosure, assuring a safety net in case disclosure is met with rejection or other adverse outcomes.

In a study conducted with HIV positive men on ART in South Africa Canti-Sigaqa (2010) reported that men disclosed their HIV positive status to people close to them, either the parents, partner or siblings. The main reason for disclosure among men in this
study was for the purpose of making the family member a treatment partner. In South Africa, enrollment in the ART programme is dependent on the HIV positive person having a treatment partner, it is assumed that the treatment partner will enhance adherence to ART (National Antiretroviral Treatment Guidelines 2004). The occurrence of disclosure prior to joining a support group was also reported by Moosa (2009) who found that most of the members of their support group had already dealt with the issues of disclosure of their HIV status either to a family member or a friend prior to joining the group. The author further argues that the reason for the higher rates of disclosure may be attributed to the likelihood that because most of the members of this support group were mentally ill patients. Families and caregivers were involved in the process of consenting for the HIV test or involved in the post test counselling as a requirement from national department of health guidelines. In Thai HIV infected people, the decision to reveal to others depends on many factors and is often determined by the perceived benefits of disclosure outweighing the disadvantages of a loss of privacy and occurs in stages, beginning with partners and or family. Majority Thai HIV infected people access to treatments, knowledge sharing, and emotional intimacy appear to be key factors for disclosure (Lyttleton 2004).

2.10. Management of HIV stigma
People living with HIV (PLWH) and their families are subjected to prejudice, discrimination, abuse, and hostility related to stigma associated with HIV (Holzemer & Uys 2004). A descriptive, qualitative research design was used to explore the experience of HIV-related stigma of PLWH and nurses. In describing incidents of stigma, respondents reported strategies used or observed to cope with those incidents of stigma. Seventeen different self-care strategies were identified: restructuring, seeing oneself as Ok, letting go, turning to God, hoping, changing behavior, keeping oneself active, using humor, joining a support or social group, disclosing one’s HIV status, speaking to others with same problem, getting counseling, helping others to cope with the illness, educating others, learning from others, acquiring knowledge and understanding about the disease, and getting help from others. Coping appears to be self-taught and only modestly helpful in managing perceived stigma (Makoae et al. 2008).
Chapter 3: Methods and materials

This chapter presents the methods, target population and instruments used to carry out the study.

3.1. Study design
The type of research that was used for the study is quantitative descriptive research.

3.2. Study setting and population
The study was conducted at Katlehong Township at Ramokonopi Health Care Center. It is located in Region B, Ekurhuleni Southern District, Gauteng Province– South Africa. The target populations were adults living with HIV/AIDS, males and females who are on the wellness clinic and ART program at Ramokonopi Health Care Center. Some patients are the down referrals from Natal Spruit Hospital, while others are the new initiations from the clinic- current enrollments. The total population size is 700 according to the hospital and clinic patients’ registers.

3.3. Sampling
Sampling method for this study was simple random sampling. Using Epi –Info statistical software, a sample size was calculated based on a study population of 700, with the estimated proportion of 50% and the worse value of proportion of 55%. At a 95% confidence level a total of 248 participants have to be recruited. A random number table (Dawson& Trapp, 2004, p 362) was used to select the 248 participants needed for the study. This was done by selecting only three digit numbers that are not above 700 from the table.

Sampling frame for this study was the patient register, all patients who have tested HIV positive and who attend the follow up visits for prophylaxis treatment and of ARV treatment at Ramokonopi Health Care Center are listed in this register. This patient’s register was used to randomly select the participants for the study.

Participants have been informed that they have being selected randomly according to way they are numbered in the patient register for the study when they came for the follow up
visits at the clinic and when they came to attend the adherence classes at the clinic. The researcher called the participants separately, they had been informed about the research study and its purpose, and the researcher determined at that moment whether the selected participants were interested or not.

3.4. Data Collection
The technique used to collect data were structured questionnaires, which were in English (Appendix 1), Setswana (Appendix 2) and Isizulu (Appendix 3) languages. The study questions were divided into three sections. Section A consisted of demographic data, section B consisted of multiple choice questions and section C are perceptions questions. It was self-administered questionnaires. The questionnaires had been administered at Ramokonopi Health Care Centre when participants came for their follow up visits clinic and adherence classes. To complete the questionnaire it took each participant approximately 20 minutes.
To ensure anonymity, participants had been informed not to write their names on the questionnaires and a private room was used when participants were responding to the questionnaires to ensure their privacy.
To ensure confidentiality of the data the research assistances assured the participants that the information given will be treated with confidentiality that means the data collected will only be used for the stated purpose of the research and no other person will have access to the data collected.

3.5. Validity
To ensure validity (accuracy) in the study, pre-testing was done. The instrument use to collect data (structured questionnaires) was pre-tested to clarify questions asked so to ensure that both the research assistances and participants have similar understanding of the structured questionnaires. Twenty participants took part in pre-test and their results were not included in the study.
This pre-test took place during the training of the research assistances and pre-test for participants were done in the field before the study was conducted. If it happened that
during the pre-testing the participants were having difficulties in understanding the questionnaires then the tool was going modified.

3.6. Reliability
To measure reliability of the study, an item analysis was used. It is a more detailed method for estimating the internal consistency of an instrument (questionnaire). The researcher identified those items within an instrument which were not providing useful information about the subjects or which are actually confusing the data. The researcher removed these troublesome items from the instrument and replaces them with better items to increase the overall reliability of the instrument (Bless & Smith 2000).

3.7. Bias
Bias could be introduced if the researcher collects the data, because the participants are patients at the clinic were the researcher is rendering health care services. In other words the researcher was familiar with the participants of the study. To minimize bias in the study, research assistances collected the data for the researcher. Due to the simple random sampling and by increasing the sample size bias was minimized.

3.8. Data Analysis Plan
Raw data was coded and captured in Microsoft Excel. The data was analyzed by importing it in the statistical software package STATA, Summary statistics was used to calculate and interpret the mean, median, and range of continuous variables under investigation and to obtain frequency tables for discrete variables like gender.

3.9. Ethical Considerations
A clearance certificate was obtained from the Medunsa Research and Ethics Committee (MREC) before the data was collected. Permission to conduct the study was sought from the Ekurhuleni southern regional manager (Appendix 4), permission letter to the chief clinic head and facility manager of Ramokonopi Health Care Centre (Appendix 5).
Informed consents English version (Appendix 6), Setswana version (Appendix 7) and Isizulu version (Appendix 8) were obtained from all participants of study before the data was collected from participants because all participants have right to privacy and voluntary participation. Participants were ensured confidentiality been informed that the information given was going to be treated with confidentiality and the data collected was going to be used for stated purpose of the research only.
Participants were informed that participation was voluntary and that they can withdraw from the study at any time. Participants were told not to write their names on the questionnaire to ensure anonymity. A private room was used when participants were responding to the questionnaire to ensure their privacy. To ensure confidentiality of the data the research assistances assured the participants the information given will be treated with confidentiality that means participants were assured that the data collected will only be used for the stated purpose of the research and no other person will have access to the data collected.
Chapter 4: Findings

4.1. Introduction
This chapter presents results from a sample of 248 HIV positive adult participants from Ramokonopi Health Care Centre at Katlehong Township. The format of data presentation will be divided into three sections. Section A is socio-demographic data as well as the HIV profile of participants. In section B, the reasons for non-participation in HIV support groups is presented, while in section C perceptions and opinions about HIV support groups are presented.

Section A: Socio-demographic

4.1.1. The study recruited both male and female participants in the study and both genders had equal opportunity to participate. The gender distribution of study participants is shown below in percentages.

Figure 1. Gender distribution of study participants (n = 248)

Figure 1 shows the gender of participant in the study. The results show that there are more female participants in the study than male participants with female representing 63% participants and male representing 37% of participants.
4.1.2. Participants were asked to give their age by years in the study and participants aged 15 years and above had an equal opportunity to participate in the study. Participants’ ages are categorized in five groups: 15-20, 21-30, 31-40, 41-50 and 51-60 as presented in figure 2.

Figure 2. Age distribution of study participants

![Age distribution](image)

Figure 2 shows the age distribution of participants. The age group between 31-40 are in the majority (39.68%) in the study followed by age group 21-30 with 34.41%, then age group 41-50 with 19.03%, then age group 15-20 with 3.64%. The age group 51-60 was the least represented with 3.24%.

4.1.3. Participants also provided information on marital status as shown in the figure below. Marital status is categorized into five groups: single, married, widowed, separated and divorced.
Figure 3 shows that, single people are more represented in the study compared to other marital groups. Majority are single with 52.63%, followed by married participants with 24.7%, the widowed participants are 9.72% while the separated participants are 6.88% and divorced participants are 6.07%.

4.1.4. Participant also provided information on their educational level in the study. The educational level was divided into four categories, uneducated, primary level, secondary level and tertiary level.

Figure 4. Educational level
Figure 4 shows that participants in the study mostly had a secondary level education, compared to the primary, tertiary and uneducated participants. Participants with secondary education were 52.02%, followed by 30.65% participants who ended their education at primary level. Participants with tertiary education were 12.9% and the uneducated were less with 4.44%.

4.1.5. Participants also provided information on their employment status. The employment status results are shown in figure 5 below in percentages.

**Figure 5. Employment status**

![Employment status](image)

Figure 5 shows that 60% of participants in the study were unemployed as compared to 40% who were employed.

**HIV profile of participants**

Information on the HIV profile of participants was also gathered; participants provided information on who they disclosed their HIV status to, period of time since they were diagnosed with HIV as well as HIV treatment staging.

4.1.6. One of the key was to determine disclosure of HIV status to other persons by participants the study. Figure 6 show that most participants disclosed to more than one person.
Figure 6. Categories of people participants disclosed to

![Bar chart showing categories disclosed to](chart.png)

Figure 6 indicated that majority (35.8%) of study participants disclosed their HIV status to their partners more than a third (33.7%) of the participants reported that they disclosed their HIV status to their friend. 26.4% of the participants disclosed to their parents while only 4.1% disclosed their HIV status to their colleagues.

4.1.7. Participants were asked indicate the period they have known about their HIV status. The periods were divided into four categories: Less than 1 year, 1-5 years, 6-10 years and more than 10 years.

Figure 7. Reported time participants have known about HIV diagnosis

![Pie chart showing time since diagnosis](chart.png)
Figure 7 shows that participants who knew their HIV status for 1-5 years are in majority (52%) in the study, followed by 37% participants who knew their HIV status for less than 1 year. Participants who knew their HIV status for 6-10 years were 9% and only 2% of the participants knew their HIV status for more than 10 years.

4.1.8. Participants further indicated their HIV treatment stage. The stages were divided into three, HIV positive not on treatment, HIV positive on prophylaxis treatment and HIV positive on ARV as presented in figure 8.

**Figure 8. HIV treatment staging**

![HIV treatment staging](image)

Figure 8 results show that 48% of the participants in the study were on ARV followed by 42% participants who were on prophylaxis treatment and only 10% of the participants were not on any treatment.

4.1.9. Participants were asked about their current and previous attendance of HIV support groups. Participation of HIV support groups was categorized into six stages as showed in the figure 9 below.
Figure 9. Participation in HIV support groups.

Figure 9 results shows the majority (58.06%) of participants had never participated in HIV support groups. About 20.56% participants attended 1-2 meetings but did not continue. About 9.68% participants attended HIV support groups once a while. Participants who attended for several weeks and several months have equal percentage of 5.24. Lastly, participants that attended for more than 1 year are only 1.21%.

4.1.10. Participants were also asked whether they had participated in other support groups, for example support group for medical health problems, mental illness and drugs and alcohol support groups as presented in figure 10.

Figure 10. Participation in other support groups.
Section B: Reasons for non-participation in HIV support groups.

The table below present participants responds about the barriers that prevent them from attending support groups.

Table 1. Barriers for non participation in HIV support groups

<table>
<thead>
<tr>
<th>Why are you not participating in an HIV support groups?</th>
<th>Freq/Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have concerns about my privacy in a support group</td>
<td>74 (29.84)</td>
</tr>
<tr>
<td>I do not want people to know that I am HIV positive.</td>
<td>52 (20.97)</td>
</tr>
<tr>
<td>I do not like talking in a group.</td>
<td>21 (8.47)</td>
</tr>
<tr>
<td>I do not understand the language spoken by others in support group meetings.</td>
<td>8 (3.23)</td>
</tr>
<tr>
<td>I do not need a support group right now.</td>
<td>17 (6.85)</td>
</tr>
<tr>
<td>I do not like the environment where the support group meetings are held.</td>
<td>10 (4.03)</td>
</tr>
<tr>
<td>I am not able to attend a support group because of my illness.</td>
<td>14 (5.65)</td>
</tr>
<tr>
<td>Support groups are held within my working hours.</td>
<td>13 (5.24)</td>
</tr>
<tr>
<td>My home schedule prevents me from going to a support group.</td>
<td>9 (3.63)</td>
</tr>
<tr>
<td>My work schedule prevents me from going to a support group.</td>
<td>36 (14.52)</td>
</tr>
<tr>
<td>My school schedule prevents me from going to a support group.</td>
<td>2 (0.81)</td>
</tr>
<tr>
<td>I have enough support already.</td>
<td>12 (4.84)</td>
</tr>
<tr>
<td>I cannot join a support group because my parents /partner refuse that I attend.</td>
<td>6 (2.42)</td>
</tr>
<tr>
<td>I do not know that support groups are available for HIV positive people.</td>
<td>33 (13.31)</td>
</tr>
<tr>
<td>Support group meetings are hard to find in the area where I live.</td>
<td>45 (18.15)</td>
</tr>
<tr>
<td>I do not have transportation to and from a support group.</td>
<td>21 (8.47)</td>
</tr>
<tr>
<td>There’s no food in support groups.</td>
<td>1 (0.40)</td>
</tr>
<tr>
<td>I’m afraid.</td>
<td>1 (0.40)</td>
</tr>
</tbody>
</table>

Table presents participants respond to questions on why they were not participating in support groups for PLWHA, participants were give a change to selected from a list of reasons which comprised of questions related to personal and social issues, service related issues and access issues.
Personal and social issues

The majority of participants (30%) are concerned about their privacy in support groups, 20% don’t want people to know that they are HIV positive, 12% don’t need a support group because they have enough support, 8% don’t like talking in a support groups, while 5% cannot attend support group because of their illness.

Access issues

About 18% of participants said support groups are hard to find and 8% have transport problems to take them to and from support group meetings. Furthermore, 24% of participants are unable to attend HIV support group because of their work, school and home schedules.

Service issue

About 13% of participants stated that they don’t know that support groups are available for people living with HIV and AIDS and 4% don’t like the environment where support groups are held.

Section C: Perceptions of HIV support groups.

In addition participants were requested to indicate their preferences of how support groups should be conducted. Table 2 indicates participants’ preferences on support groups.

Table 2: Participant’s perceptions about support groups

<table>
<thead>
<tr>
<th>Preference of support groups</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq/Percent</td>
<td>Freq/Percent</td>
<td>Freq/Percent</td>
</tr>
<tr>
<td>Prefer separate support groups for males and females.</td>
<td>93(37.5)</td>
<td>11(4.44)</td>
<td>144(58.06)</td>
</tr>
<tr>
<td>Prefer to attend support groups with my peer group.</td>
<td>155(63.01)</td>
<td>15(6.1)</td>
<td>76(30.89)</td>
</tr>
<tr>
<td>Prefer to attend small sized support groups.</td>
<td>187(76.02)</td>
<td>18(7.32)</td>
<td>41(16.67)</td>
</tr>
<tr>
<td>Prefer to attend support groups facilitated by professionals.</td>
<td>201(81.71)</td>
<td>8(3.25)</td>
<td>37(15.04)</td>
</tr>
</tbody>
</table>
More than half (58.06%) of the participants would prefer mixed gender support groups. While 63.01%, prefer to attend with their peer groups in support groups. The majority prefers to attend small sized support groups and to attend support groups facilitated by professional person (76.02% and 81.71% respectively).

Participants were also asked about their perceptions of support groups, table 3 show the responses of participants.

Table 3. Perceptions of HIV support groups.

<table>
<thead>
<tr>
<th>Opinions of a support group</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Freq/Percent</td>
<td>Freq/Percent</td>
<td>Freq/Percent</td>
</tr>
<tr>
<td>Support groups are only for people who cannot cope with their HIV status</td>
<td>167 (67.61)</td>
<td>15 (6.07)</td>
<td>65 (26.32)</td>
</tr>
<tr>
<td>Support groups are for people who lack knowledge about HIV/AIDS.</td>
<td>146 (58.87)</td>
<td>26 (10.48)</td>
<td>76 (30.65)</td>
</tr>
<tr>
<td>Support groups are for people who seek love, support and acceptance.</td>
<td>197(80.08)</td>
<td>20 (8.13)</td>
<td>29 (11.79)</td>
</tr>
<tr>
<td>Support groups sometimes turn into quarrels.</td>
<td>72 (29.03)</td>
<td>121 (48.79)</td>
<td>55 (22.18)</td>
</tr>
<tr>
<td>Support group meetings are too long.</td>
<td>46 (18.55)</td>
<td>135 (54.44)</td>
<td>67 (27.02)</td>
</tr>
<tr>
<td>I do not like support groups.</td>
<td>19 (7.79)</td>
<td>46 (18.85)</td>
<td>179 (73.36)</td>
</tr>
<tr>
<td>I don’t like to be stigmatized; hence I don’t attend HIV support groups.</td>
<td>64 (26.12)</td>
<td>54 (22.04)</td>
<td>127 (51.84)</td>
</tr>
</tbody>
</table>

Table 3 shows that majority of participants (67.67%) think that HIV support groups are for individuals who cannot cope with their HIV status, as compared to 26.32% who think differently about the issue.
Majority (80.08%) reckons that support groups are for people who seek love, support and acceptance. About 58.87% of participants reckon HIV support groups are for people who lack knowledge about HIV/AIDS.

About 73.36% participants did not support the issue of not liking support groups. Majority (51.84%) believe that being stigmatized is not the reason for non-attendance of HIV support groups. The participants’ were unsure about support group meeting being long and turning into quarrels because majority haven’t attended support groups.
Chapter 5: discussion

5.1. Introduction
The aim of the study was to determine what HIV positive peoples perceive as barriers to participate in HIV support groups. This chapter discusses the findings of the study presented; first, the demographics and HIV profile of the participants are discussed, followed by detail discussion of participation support groups. The chapter concludes with a presentation of concluding statement, recommendation and limitations of the study.

5.2 Demographic characteristics of the participants
The study was conducted at Ramokonopi Health Care Centre at Katlehong Township, Gauteng province with people living with HIV/AIDS and enrolled in an ART program. The majority (63%) of participants in the study were female as compared to (37%) males. The high representation of females in this study is consistent with previous studies that identified unequal medical utilization patterns among women with HIV infection when compared with men with HIV infection (Whetten 2004).

The participants’ ages ranged from 15-50 with only 3% of the participants falling within the age range 51-60. The age category 31-40 was in majority (39.68%); more than a third (34.4) of the participants were between ages 21-30. Though not so highly represented, about 20% of the participants were aged between 41-50. National HIV Survey study estimated HIV prevalence among South Africans, by age and sex and the results indicated that among females, HIV prevalence is highest in those between 25 and 29 years old; among males, the peak is in the group aged 30-34 years (South Africa HIV & AIDS Statistics 2008).

The results further show that more than half (52.63%) of participants were single and about a quarter (24.7%) were married while a small number (9.7%) of the participants were widowed and about 12% were either divorced or separated.
The literacy level of the participants was high with more than half (52.02%) of participants having attained a secondary education and about 13% of the participants had attained tertiary education. Only a small number (4.4%) had no education at all and a third (30.6%) had a primary education.

The unemployment rate among the participants was high with 60% of participants reporting to be unemployed. The high unemployment rate is not unique to the participants of this study but a possibly a reflection of the high unemployment rate of the general population from where this sample was obtained. The unemployment rate in South Africa was last reported at 24 percent in the fourth quarter of 2010 (South Africa Unemployment Rate 2010).

5.3. HIV profile of participants

The results show that for majority of participants (52%) have been living with HIV between 1-5 years while for more than a third (37%) of the participants the period since diagnosis was less than a year, a small percentage (9%) of participants have been living with HIV for 6-10 years. The maximum period since diagnosis was 10 years, with only 2% of the participants falling into this category. The period of diagnosis is in line with the HIV treatment stages of the participants. The results shows that about half (48%) of the participants in the study were on antiretrovirals (ARVs) while almost the other half (42%) being on prophylaxis treatment and only 10% of the participants were not on any treatment. The results further show that the majority (80%) of the participants have been on ARVs for more than 1 year but less than 6 years, whilst 18, 3% have been on ART for a period of between 1-12 months.

The results show a very high disclosure rate among the study participants, all participants reported that they had disclosed their HIV status to one of the following persons, sexual partners, friends, parents and colleagues at work. The most person disclosed to were the sexual partners and friends at 35.8% and 33.7% respectively. Less than a third (26.4%) of participants disclosed to parents. Our study findings are consistent with previous studies, Kalichman et al. (2003) also reported that majority of people living with HIV/AIDS disclosed their HIV to friends significantly more often than family members. The study results further show that disclosure of HIV positive status among the study
participants was mostly to people close to them. Canti-Sigaxa (2010) reported that the main reason for disclosure among participants in their study was for participants to get a treatment partner. The authors found that often close family members of partners argues that disclosure decisions for many HIV positive people must balance the need for social support specific to coping with HIV-AIDS were disclosed too, to become treatment partners. Kalichman (2003) argues that disclosure decisions for many HIV positive people must balance the need for social support specific to coping with HIV-AIDS.

There are several possible reasons that may explain the high rates of disclosure among the participants in this study. Currently in South Africa enrollment in the antiretroviral program is depended on the HIV positive person having a treatment partner (National Antiretroviral Treatment Guidelines 2004). It is highly likely that the need for a treatment partner could be associated with the high level of disclosure among participants in this study. However the results also show that 62% of the participants have not yet been initiated on ARVs, therefore the high level of disclosure cannot be attributed to a need for treatment partner. Moosa (2009) reported a high disclosure rate among participants in their study and suggested that the knowledge of HIV status for more than six months might have afforded the participants sufficient time to deal with issues of disclosing to family members. Similarly in this study time since diagnosis for participants ranged from 6 months to 10 years. As already mentioned there is close association between disclosure of HIV status and perceived social support. According to Kalichman et al. (2003), participants who had fully disclosed specifically parents and siblings in their study reported more social support from the people they disclosed to. The other reason for high disclosure rates in this study could be attributed to good counselling and also to participants’ better understanding of a HIV diagnosis and disclosure.

5.4. Participation in support groups
With regard to support group participation, majority (58.06%) had never attended HIV support group before. Of the participants who had participated in HIV support groups only 1.21% reported participation of more than 1 year, about 10.4% reported participation ranging from several weeks to several months, about 9.68% participants
participated once a while and the majority (20.56%) reported that they attended about 2 support group meetings. The poor attendance of support groups in this setting cannot be explained from this data however Lyttleton (2004) argues that perceived reluctance for individuals to come out and join support groups could be attributed with levels of community acceptance of HIV.

Data was also collected on participation in other support groups like support groups for medical health problems, for mental illness and for drugs and alcohol and majority (87.85%) reported no participation in other support groups. The most common support group that participants reported to have attended was medically related support groups (8.1%), very few participants reported attending support groups for mental illness and drugs and alcohol abuse.

The results further showed that participants who were currently on HIV treatment (prophylaxis and ARV) has attended HIV support groups before at one time in their life while participants who were not on any treatment formed the majority of participants who have never attended HIV support groups. This invariable mean that the majority of participants who were recently diagnosed in this study were more likely to form the majority who were not on treatment yet, suggesting that time since diagnosis was associated with non participation in support groups in this study. These findings are consistent with previous research Kalichman et al. (1996) reported that in their study people who did not attend support groups had known their HIV status for a shorter time than participants who attended support groups. The results further show that participants who has taken part in HIV support groups had also attended other support groups for medical and mental health problems. Participants who never attended HIV support group also never attended other support groups.

5.5. Reasons for non participation
The main reasons that participants gave for not attending or participating in HIV support groups was that they are concerned that their HIV status will be known by others. The results further show that concern for privacy was one of the major reason participants did not participate in HIV support groups. These findings are consistent with current findings
from Heyer et al. (2010) where participants of a hospital based HIV support group reported being concern about the large size of their support groups which they felt will affect issues of confidentiality. According to the authors the large support group size and the open nature of the support group prevented people from opening up and sharing their experiences. Concerns about confidentiality was reported by Morrow (2001), that participants in her emphasized the importance on the confidential nature of the group in order to engage freely, they were concerned that other members of the support group might discuss issues raised within the support group outside.

It is however interesting to note that about half of the participants in this study did not mention stigma as a reason for not participating in support groups, this is despite their concern for privacy and confidentiality. This is in contrast with recent data from Canti-Sigaqa (2010) who reported that participants in their study were reluctant to attend support groups for fear of being recognized, participants felt that participating in support group in their communities is like disclosing their HIV status and most did not want their status known by people in their communities because of stigma and social rejection. Morrow (2001) also reported that because of the fear of stigma attached to HIV/AIDS some women in her study feared that their attendance of the support group would reveal their HIV status to others people they would prefer not to know. It should also be noted that none of the participants in this study disclosed to people outside of their close family or friends. Liamputtong (2009) found that most women in their study would keep the illness secret by not telling people outside their immediate families because HIV/AIDS still carries a stigma among Thai people, women were not willing to disclose their HIV status within a social climate where PLWHA are stigmatised.

Majority of participants in this study also indicated that they would prefer to attend small-sized support groups. Heyer et al. (2010) also reports that previous studies with cancer patients has recommended that support groups limit their size to a maximum of 12 members.

In addition for the concern for confidentiality and privacy, participants reported that they do not like talking in a group which is in line with the need for small group size which
according to Heyer et al. (2010) will foster open communication and sharing of experiences

Heyer et al. (2010) also reported that negative group dynamics and disruptive members can deter patients from attending support groups. Participants in their study reported that support group leaders felt overwhelmed and burnt-out, which caused them to lose hope, to become less sympathetic and to quarrel with each other. Similarly participants in this study had negative perceptions about support groups and reported that support groups sometimes turn into quarrels, it was however not determined whether this is based on experience or perceived perceptions of support groups. Walch (2006) reported that in their study participants who had never attended support group reported more perceived barriers to participation in an HIV support group than those who had previously attended some type of support group.

One other reason given by participants for non participation in HIV support groups was that participants don’t need support now and that they have enough support. Similar findings were previous reported that non participants of support groups reported being healthy and receiving other support (Kalichman et al.1996). Majority of participants in this study were of the opinion that support groups were only for people who cannot cope with their HIV status. Similar findings were reported by VanDevante (2000) that both participants and non-participants of support groups viewed those attending support groups somewhat negatively, they describe participants as less self sufficient, needing more help and lonely. The author further argues that attending a support group was thus mildly stigmatized in their study.

5.6. Barriers to participate in support groups
Access to support group was one of the reasons participant did not attend or participate in support groups. Participants reported that support groups are hard to find in their communities, work schedules prevents them to attending support groups meetings, lack of transport money to travel to and from support groups. Similar reasons for non participation to support were reported (Canti-Sigaqa 2010). They reported that for most
participants in their study support groups were not available in the local communities
where the participants resided. Most participants were unemployed and did not afford
transport to and from support group meetings. Issues of money, transport problems, time
and distance were also reported as barriers to participate in support groups (Morrow
2001, Visser et al. 2005). There are many reported reasons for non participation in
support groups by Thai people infected with HIV, including personal disinclination,
practical constraints, lack of family support lack of financial assistance, lack of time,
work, while others were not interested. And there were those who had no one to leave
their children with (Liamputtong 2009).

5.7. Perceptions of support groups
Participants were asked to give their opinions about HIV support groups and majority of
were not in favor of gender based support groups; they would prefer to attend mixed
gender support groups. This finding is in contrast with recent findings from a study on
participation in support groups conducted with HIV positive men, participants felt
strongly about having men only support groups Canti-Sigaqa (2010). Traditionally
support groups for HIV was mainly for men, the debate on the gender homogeneity of
support groups began when women became infected with HIV. The argument was that
women only support groups would benefit women Lennon-Dearing (2008). Women
could become aware and informed of HIV-related complications and interventions
specific to women (Siebert 1995). According to Kalichman et al. (1996), findings from
interviews with women in their study suggested that support groups designed for women
can be helpful. It is also argued that gender homogeneity influences group cohesion and
may play a significant part in the outcome of HIV support group participation
(DiPasquale 1990). It should however be noted that almost two thirds of the participants
in this study were female, suggesting that majority do not see the need for women only
support groups.

The study results further show that though gender homogeneity was not important
participants preferred to attend support groups with their peers. Literature shows that
ethnicity, race, gender, age, or sexual orientation has been considered as themes for homogeneity. Furthermore call for culturally homogeneous groups has also appear in the literature (Wood 2007). In this study where the age ranges from 15-60 there is meaning to the need for age sensitive support groups. Culturally a 15 year old would not be able to discuss sexually related issues in the presence of a 60 year old. Siebert & Dorfman (1995) maintain that there are some advantages of homogeneous groups, and that group composition should provide members with people similar to themselves.

Furthermore participants in this study desired to attend support groups facilitated by professional persons. Literature show that traditionally support groups were facilitated by professionals. There have been debates about this role over the years but, group experts maintain that the professional leader must continue to be deeply involved in the dynamic life of the group (Woods 2007; Schopler & Galinsky 1993).

5.8. Conclusion

The study provides a description of people with HIV infection who had not attended support groups and those who had previously attended support groups. The study has revealed disturbing results about participation in HIV support groups in this setting and the results show that none of the participants whose time since diagnosis ranged from 6 months to 10 years were attending any HIV support groups at the time the study was conducted.

The results also revealed an important pattern about disclosure of HIV status among study participants. Though the disclosure rate in very high, only about a third of the participants disclosed to their sexual partners. These findings have implications for early testing, condom use and prevention of infection re-infections among the study participants. This data further suggest that there is still poor communication, fear of rejection and non disclosure among partners. Consistent with other studies majority of people living with HIV-AIDS disclosed their HIV to friends significantly more than to family members.
This study further revealed important information about barriers to participate in support groups, consistent with other studies one of the key reasons for not participation in support groups were concerns for privacy and confidentiality. Also consistent with previous and current data are the barriers to participate in support groups, participants reported that support groups are hard to find in their communities, work schedules prevents them to attending support groups meetings, lack of transport money to travel to and from support groups. These barriers should be viewed in the context that majority of the participants had never attended any support group did not personally experience some of the barriers with the exception that support groups are hard to find. This researcher is inclined to agree with Walch (2006) that non participants have a tendency of reporting more perceived barriers than participants of support groups.

Of concern is the perception that support groups are for people who cannot cope with their HIV status. VanDevante (2000) also reported similar statements from participants in their study; he observed that attending a support group was thus mildly stigmatized. This attitude has implications for the success of support groups in this setting, if this is a popular perception, even newly diagnosed people will be socialized to view support groups negatively.

Stigma was not mentioned as a reason for not participating in support groups in this study despite participants concern for privacy and confidentiality being the main reason for non participation in support groups. Our study findings are in contrast to other studies conducted with PLWHA on support groups where participants feared that attendance of the support group would reveal their diagnosis leading to stigma and social rejection (Canti-Sigaqa 2010, Morrow 2001).

With regards to the homogeneity of the support group, the study is not conclusive. Though majority of participants would prefer mixed gender support groups, about a third of the participants desired gender homogeneity in support groups. The differences in support group need are an indication of diversity of the people living with HIV/AIDS who utilizes public health institutions in the country. It is therefore obvious that a one
size fits all approach to support groups is not going to work, it is important that the support group be designed to meet the needs of PLWHA, this will require a greater involvement of PLWHA in the development of support groups. In this study participants expressed the need that group composition to be of people similar to themselves with regard to age.

5.9. Recommendations

Even though it was only a small percentage, some participants did not know about HIV support groups, PLWHA should be educated about the benefits of support group attendance, preferably at the time of their diagnosis. Because if people living with HIV are unaware of services meant for them they will not be able to benefit from those services.

Of high concern is the high number of PLWHA who do not view support groups as an important service for PLWHA. Further exploration studies should be conducted to better understand this phenomenon and to examine ways acceptable for providing support for PLWHA.

Innovative support groups that take into consideration issues of group size, group composition, homogeneity, timing for group meeting, and professional facilitation should be the way forward, this study findings should form the basis for the development of support groups that could be piloted in this health facility.

It is also recommended that support groups should be designed in a way that they allow PLWHA to exit when they have been empowered to manage their HIV diagnosis. With people surviving longer and experiencing good health while on ART, it would make more sense to newly diagnosed people that membership of the support group is not lifetime
5.10. Limitations
The study can only describe participants who had not attended support groups and those who had previously attended support groups and cannot compare them because none were attending any support groups at the time of data collection.

One other limitation of the study is that the study did not determine why participants who previously attended support groups stopped attending. Qualitative research to explore factors that support or prevent long-term participation in such support groups will mitigate this limitation.
References


*Encyclopedia of Mental Disorders*, viewed 2007-2011, from
http://www.minddisorders.com/Py-Z/support-groups.html


KALICHMAN, S.C., SIKKEMA, K.J. & SOMLAI. 1996. A. People living with HIV infection who attend and do not attend support groups: A pilot study of needs, characteristics and experiences. AIDS Care. 8, 589-600.


MUNDELL, J.P 2006. The impact of structured support groups for pregnant women living with HIV. University of Pretoria. South Africa.


Appendix 1: Structured Questionnaires English Version

Perceived barriers to participation in an HIV Support Groups among People Living with HIV and AIDS at Katlehong Township - South Africa

Section A: Demographic Data.

Please mark appropriate box with an ‘X’

1. Age in years
2. Gender
   - Male
   - Female
3. Marital status
   - Single
   - Married
   - Separated
   - Divorced
   - Widowed
4. Education level reached
   - Never went to school
   - Less than standard 5 or grade 7
   - Less than standard 10 or grade 12
   - Tertiary or college
5. Employment status
   - Working
   - Not working
6. To who have you disclosed your HIV status
   - Friend
   - Parent
   - Partner
   - Colleague
7. Period known about HIV status
   - Less than 1 year
   - 1-5 years
   - 6-10 years
   - More than 10 years
8. Where do you fall in the HIV stages?

<table>
<thead>
<tr>
<th>HIV positive not on treatment</th>
</tr>
</thead>
<tbody>
<tr>
<td>HIV positive on prophylaxis treatment e.g. Bactrim tablets, Vitamin B Co and Folic acid</td>
</tr>
<tr>
<td>HIV positive on Anti-Retro Viral (ARV) treatment</td>
</tr>
</tbody>
</table>

9. Previous HIV support group participation

| Never attended an HIV support group |
| Attended an HIV support group for 1-2 meetings but did not continue |
| Attended an HIV support group once a while |
| Attended an HIV support group regularly for several weeks |
| Attended an HIV support group regularly for several months |
| Attended an HIV support group regularly for one year or more |

10. Other support groups attended

| Never attended other support group |
| Attended a support group for other health problem e.g. cancer, stroke, diabetes mellitus |
| Attended a support group for mental health problem |
| Attended a support group for drugs or alcohol problem |

**Section B: Multiple choice questions**

**Please mark appropriate box with ‘X’. You may select more than one answer.**

**Why are you not participating in an HIV support group?**

| 1. I have concerns about my privacy in a support group |
| 2. I do not want people to know that I am HIV positive. |
| 3. I do not like talking in a group. |
| 4. I do not understand the language spoken by others in support group meetings. |
| 5. I do not need a support group right now. |
| 6. I do not like the environment where the support group meetings are held. |
| 7. I am not able to attend a support group because of my illness. |
| 8. Support groups are held within my working hours. |
| 9. My home schedule prevents me from going to a support group. |
| 10. My work schedule prevents me from going to a support group. |
| 11. My school schedule prevents me from going to a support group. |
Section C: Perception questions

Please mark the appropriate box(s) with ‘X’ to indicate your response. Only one response per question is needed.

<table>
<thead>
<tr>
<th>How would you prefer the support groups to be?</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Unsure</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I prefer support groups that are separated into male and females.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. I prefer to attend with my peer group in support groups.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I prefer to attend a support group with a small group size.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I prefer a support group that is facilitated by a professional person.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is your opinion of a support group?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Support groups are only for people who cannot cope with their HIV status.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Support groups are for people who lack knowledge about HIV/AIDS.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Support groups are for people who seek love, support and acceptance.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Support groups sometimes turn into quarrels.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Support group meetings are too long.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. I do not like support groups.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I don’t like to be stigmatized; hence I don’t attend HIV support groups.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I have enough support already.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. I cannot join a support group because my parent/partner refuse that I attend.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. I do not know that support groups are available for HIV positive people.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Support group meetings are hard to find in the area where I live.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. I do not have transportation to and from a support group.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. State any other reason(s) not listed above why you do not want to participate in a support group.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 2: Dipotso Setswana Version

Tse dingwe tse di thibelang go tsea karolo mo mekgatlong ya tshegetso ya batho bao ba ka mogare wa HIV/AIDS kwa lekeisheneng la Katlegong- South Afica.

Section A: Demographic data
Ka kopo tshwaya lepokisi le le maleba ka ‘X’

1. Bogolo ka dingwaga
2. Bong
   Monna
   Mosadi
3. Boemo ba nyalo
   Mongwe
   Nyetswe
   Kgaoagane
   Thhadile
   Motlhogadadi
4. Maemo a thuto a o a fitlheletseng
   Ga kea ya sekolong
   Kwa tlase ga standard 5 or Grade 7
   Kwa tlase ga standard 10 or Grade 12
   Thuto e e kwa godimo kgotsa kholetshe
5. Boemo ba tiro
   Dira
   Ga o dire
6. O boleletse mang boemo ba gago ba HIV
   Tsala
   Motsadi
   Molekane
   Modira-mmogo
7. Nako e o itsiseng ka boemo ba HIV
   Ka fa tlase ga ngwaga
   Dingwaga di le 1-5
   Dingwaga di le 6-10
   Go feta digwaga di le 10
8. O wela mo maemong a mafe a HIV?
   Tshwaetso ya HIV empa o se mo kalafing
   Tshwaetso ya HIV, mo kalafing ya prophylaxis e.g. Bactrim tablets, Vitamin B Co and Folic acid
   Tshwaetso ya HIV, mo kalafing ya di Anti-Retro Viral (ARV)
9. Mekgatlo ya tshegetso ya HIV ya pele eo o tsereng karolo

<table>
<thead>
<tr>
<th>Ga ke is eke tenele mokgatlo wa tshegetso</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Tsenetse kopano ya mokgatlo wa tshegetso wa HIV gangwe-gabedi empa ka se tswele pele</td>
<td></td>
</tr>
<tr>
<td>Tsenetse mokgatlo wa tshegetso wa HIV gangwe morago ga lobaka</td>
<td></td>
</tr>
<tr>
<td>Tsenetse mokgatlo wa tshegetso wa HIV dibeke tse mmalwa</td>
<td></td>
</tr>
<tr>
<td>Tsenetse mokgatlo wa tshegetso wa HIV dikgwedi tse mmalwa</td>
<td></td>
</tr>
<tr>
<td>Tsenetse mokgatlo wa tshegetso wa HIV ka tatelano ngwaga kgotsa go feta</td>
<td></td>
</tr>
</tbody>
</table>

10. E mengwe ya mokgatlo ya tshegetso e e tsenetsweng

<table>
<thead>
<tr>
<th>Ga ise ke tenele mokgatlo wa tshegetso</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Tsenetse mokgatlo wa tshegetso wa mathata a boitekanelo e.g. cancer, stroke, diabetes mellitus</td>
<td></td>
</tr>
<tr>
<td>Tsenetse mokgatlo wa tshegetso wa bothata ba bolwetse ba thalagonyo</td>
<td></td>
</tr>
<tr>
<td>Tsenetse mokgatlo wa tshegetso wa diritibatsi kgotsa bojalwa</td>
<td></td>
</tr>
</tbody>
</table>

**Section B: Multiple choice questions**

*Ka kopo tshwaya lepokise le le tshwanetseng ka‘X’. O ka kgetha dikarabo go feta e le nngwe.*

**Go reng o sa tsaye karolo mo mekgatlong ya tshegetso ya HIV?**

<table>
<thead>
<tr>
<th>1. Ke na le matshwenyego ka bosephiri mo mokgatlong wa tshegetso</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Ga ke batle batho ba itse gore kena le mogare wa HIV</td>
<td></td>
</tr>
<tr>
<td>3. Ga ke rate go bua mo bathong</td>
<td></td>
</tr>
<tr>
<td>4. Ga ke utlwisiuse leoleme le le dirisiwang ke ba bang mo dikopanong tsa mokgatlo wa tshegetso</td>
<td></td>
</tr>
<tr>
<td>5. Ga ke batle mokgatlo wa tshegetso gona jaanong.</td>
<td></td>
</tr>
<tr>
<td>6. Ga ke rate maemo a dikopano tsa mokgatlo wa tshegetso di tshwarelwang mo teng</td>
<td></td>
</tr>
<tr>
<td>7. Ga ke kgone go tsenela mokgatlo wa tshegetso ka lebaka la bolwetse ba me.</td>
<td></td>
</tr>
<tr>
<td>8. Mokgatlo wa tshegetso o tshwarwa ka diura tsa tiro</td>
<td></td>
</tr>
<tr>
<td>9. Thulaganyo ya kwa lapeng e nthibelela go ka tsenela mokgatlo wa tshegetso.</td>
<td></td>
</tr>
<tr>
<td>10. Thulaganyo ya kwa mosebetsing e nthibelela go ka tsenela mokgatlo wa tshegetso</td>
<td></td>
</tr>
<tr>
<td>11. Thulaganyo ya kwa sekolong e nthibelela go ka tsenela mokgatlo wa tshegetso</td>
<td></td>
</tr>
<tr>
<td>12. Ke sets eke na tshegetso e e lekaneng</td>
<td></td>
</tr>
</tbody>
</table>
### Section C: Perception questions

*Tshwaya lepokise/mapokise le le maleba ka ‘X’ go bontsha karabo ya gago. Go batlega karabo e le nngwe mo potsong nngwe le nngwe.*

<table>
<thead>
<tr>
<th>O rata mokgatlo wa tshegetso o be jwang?</th>
<th>Dumela thata</th>
<th>Dumela</th>
<th>Ga ke itse</th>
<th>Ga ke dumele</th>
<th>Gana thata</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ke rata mokgatlo wa tshegetso o o kgaogantsweng ka basadi le banna</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Ke rata go ka tsena le balekane ba ka mo mokgatlong wa tshegetso</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Ke rata go ka tsenela mokgatlo wa tshegetso le sethopho se sennyne</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Ke rata mokgatlo wa tshegetso o o tsamaisiwang ke moitseanape</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Monagano wa gago kamekgatlo ya tshegetso.</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Mekgatlo ya tshegetso ke ya batho ba ba sa kgoneng go ka lepalepana le maemo a bona a HIV</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Mekgatlo ya tshegetso ke ya batho ba ba senang kitso ka HIV/AIDS</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Mekgatlo ya tshegetso ke ya batho ba ba batlang lerato, tshegetso le go amogela</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Mekgatlo ya tshegetso ka nako dingwe e fetoga go nna dikomano</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Dikopano tsa mekgatlo ya tshegotso ke tse telle</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Ga ke rate mekgatlo ya tshegetso</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Ga ke rate go mamaretswa, ke ka moo ke sa tsamae mekgatlo ya tshegetso</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 3: Structured Questionnaires Isizulu Version

Perceived barriers to participation in an HIV Support Groups among People Living with HIV and AIDS at Katlehong Township - South Africa

Section A: Demographic Data.

Bhala isiphambano ‘X’ empendulweni yakho.

<table>
<thead>
<tr>
<th>1. Iminyaka</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Ubulili</td>
<td></td>
</tr>
<tr>
<td>Indoda</td>
<td></td>
</tr>
<tr>
<td>Umfazi</td>
<td></td>
</tr>
<tr>
<td>3. Isimo somshado</td>
<td></td>
</tr>
<tr>
<td>Awushadanga</td>
<td></td>
</tr>
<tr>
<td>Ushadile</td>
<td></td>
</tr>
<tr>
<td>Uhlukanisile ngokuhlala</td>
<td></td>
</tr>
<tr>
<td>Uhlukanisile Umshado</td>
<td></td>
</tr>
<tr>
<td>Umfelokazi</td>
<td></td>
</tr>
<tr>
<td>4. Ufunde wagcinaphi</td>
<td></td>
</tr>
<tr>
<td>Awufundanga</td>
<td></td>
</tr>
<tr>
<td>Ngaphansikwa standard 5 or grade 7</td>
<td></td>
</tr>
<tr>
<td>Ngaphansikwa standard 10 or grade 12</td>
<td></td>
</tr>
<tr>
<td>Infundo ephakeme</td>
<td></td>
</tr>
<tr>
<td>5. Isimo somsebenzi</td>
<td></td>
</tr>
<tr>
<td>Uyasebenza</td>
<td></td>
</tr>
<tr>
<td>Awusebenzi</td>
<td></td>
</tr>
<tr>
<td>6. Ushele bani ukhuthi u HIV</td>
<td></td>
</tr>
<tr>
<td>Umngani</td>
<td></td>
</tr>
<tr>
<td>Umzali</td>
<td></td>
</tr>
<tr>
<td>Umlingani</td>
<td></td>
</tr>
<tr>
<td>Osebenzanaye</td>
<td></td>
</tr>
<tr>
<td>7. Uqale nini ukwazi ngegciwane le HIV</td>
<td></td>
</tr>
<tr>
<td>Ngaphansi konyaka</td>
<td></td>
</tr>
<tr>
<td>Unyaka owodwa noma emihlanu</td>
<td></td>
</tr>
<tr>
<td>Inyisithupha noma ishumi</td>
<td></td>
</tr>
<tr>
<td>Ngaphezu kweshumi</td>
<td></td>
</tr>
</tbody>
</table>
8. Ungaphansi kwaliphi izinga?

<table>
<thead>
<tr>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>U HIV awuthathi mapilisi</td>
</tr>
<tr>
<td>U HIV uthatha Bactrim tablets, Vitamin B Co and Folic acid</td>
</tr>
<tr>
<td>U HIV u thatha ama Anti-Retro Viral (ARV)</td>
</tr>
</tbody>
</table>


<table>
<thead>
<tr>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awuzange ube nenhlango</td>
</tr>
<tr>
<td>Uyile kanye noma kabili awabe usaphinda</td>
</tr>
<tr>
<td>Uyile kanye nje</td>
</tr>
<tr>
<td>Uyile amaviki amalingana</td>
</tr>
<tr>
<td>Uyile izinyangana</td>
</tr>
<tr>
<td>Uyile unyaka noma ngaphezulu konyaka</td>
</tr>
</tbody>
</table>

10. Enye inhlangano okewayo kuyo

<table>
<thead>
<tr>
<th>Condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Azange ngiye neydwa</td>
</tr>
<tr>
<td>Uyile enhlanganweni nge sinye sezifo e.g. cancer, stroke, diabetes mellitus</td>
</tr>
<tr>
<td>Uyile enhlanganweni ye nkinga yengqondo</td>
</tr>
<tr>
<td>Uyile enhlanganweni yezidakamizwa nophuzo</td>
</tr>
</tbody>
</table>

**Section B: Multiple choice questions**

**Bhala isiphambano ‘X’ lapha ufaka impendulo. Ungakhetha impendulo engaphezu kweyodwa.**

**Kungani ungayi enhlanganweni ye HIV?**

<table>
<thead>
<tr>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ngiyakhathazeka ukukhipha imfihlo yami enhlanganweni.</td>
</tr>
<tr>
<td>2. Angifuni kwaziwe ukuthi ngi HIV.</td>
</tr>
<tr>
<td>3. Angithandi ukukhulumza enhlanganweni.</td>
</tr>
<tr>
<td>4. Angiluqondisisi ulwimi olukhulunya ngalo enhlanganweni.</td>
</tr>
<tr>
<td>5. Angiyidingi inhlangano.</td>
</tr>
<tr>
<td>6. Angiyithandi indawo okuhlanganelwa kuyo.</td>
</tr>
<tr>
<td>7. Angisabikhona enhlanganweni ngenxa yo kugula.</td>
</tr>
<tr>
<td>8. Angikhoni ukuya enhlanganweni ngoba ngisuke ngise msebenzini.</td>
</tr>
<tr>
<td>9. Imisebenzi yasekhaya iyangivimba ukuya enhlanganweni.</td>
</tr>
<tr>
<td>10. Uhlalo lomsebenzi luyangivimbela ukuya enhlanganweni.</td>
</tr>
<tr>
<td>11. Uhlalo lwesikolo luyangivimbela ukuya enhlanganweni.</td>
</tr>
</tbody>
</table>
### Section C: Perception questions

**Bhala isiphambano ‘X’ ebhokisini elifanele ukubonisa impendulo yakho. Kube yimpendulo eyodwa.**

<table>
<thead>
<tr>
<th>Uthanda inhlangano ibe kanjani?</th>
<th>Vuma kakhulu</th>
<th>Vuma</th>
<th>Angazi</th>
<th>Angivumi</th>
<th>Angivumi Neze</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Ngithanda inhlangano ehlukaniye ubulili.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Ngithanda inhlangano enabantu abangangami.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Ngithanda inhlangano yabantu abayidlanzana.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Imibono yakho ngenhlangano.</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Inhlangano eyabantu abanga khoni ukumelana nesimo se HIV.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Inhlangano eyabantu abangenalo ulwazi nge HIV/AIDS.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Inhlangano eyabantu abadinga uthando, ukunakekelwa okwamukeleka.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Enhlanganweni kxesinye isikhathi kunokungaboni ngasolinye.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Imihlangano yakhona ithatha isikhathi eside.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Angiyithandi imihlangano.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Angithandi ukubandululwa yingakho ngingayi emhlanganweni.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX 4: English consent form

UNIVERSITY OF LIMPOPO (Medunsa Campus) ENGLISH CONSENT FORM

Statement concerning participation in a Study.

Study Title
Perceived barriers to participation in an HIV Support Groups among People Living with HIV and AIDS at Katlehong Township- South Africa.

I have read the information on the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I understand that participation in this study is completely voluntary and that I may withdraw from it at any time and without supplying reasons. This will have no influence on the regular treatment that holds for my condition neither will it influence the care that I receive from my regular doctor.

I know that this study has been approved by the Medunsa Campus Research and Ethics (MCREC), University of Limpopo (Medunsa Campus) and Ramokonopi Health Care Centre. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to participate in this study provided my privacy is guaranteed.

I hereby give consent to participate in this study

_________________________________________  ___________________________________________
Name of patient/volunteer                      Signature of patient or guardian.

________________________  ______________________  ______________________
Place.                     Date.                      Witness

Statement by the Researcher

I provided written information regarding this study

I agree to answer any future questions concerning the study as best as I am able.

I will adhere to the approved protocol.

_________________________________________  ______________________  ______________________
Name of Researcher                      Signature                     Date
APPENDIX 5: Setswana consent form

UNIVERSITY OF LIMPOPO (Medunsa Campus) SETSWANA CONSENT FORM

Seteitemente se se ka ga go tsaya karolo mo Patlisisong

Leina la Patlisiso

Tse dingwe tse di thibelang go tsea karolo mo mekgatlong ya tshegetso ya batho bao ba ka mogare wa HIV/AIDS kwa lekeisheneng la Katlegong- South Afica.

Ke buisitse tshedimosetso mo ke utlwile maitlhomo le maikemisetso a patlisiso e e tshitshintsweng mme ke filwe tšhono ya go botsa dipotso le go fiwa nako e e lekaneng ya go akanya gape ka ntlha e. Maitlhomo le maikemisetso a patlisiso e a tlhaloganyega sentle. Ga ke a patelediwa ke ope ka tsela epe go tsaya karolo.

Ke tlhaloganya gore go tsaya karolo mo patlisiso ke boithaopo le gore nka ikgogela morago mo go yona ka nako nngwe le nngwe kwa ntle ga go neela mabaka. Se ga se kitla se nna le seabe sepe mo kalafong ya me ya go le gale ya bolwetsi jo ke nang le jona e bile ga se kitla se nna le tlhotlheletso epe mo tlhokomelong e ke e amogelang mo ngakeng ya me ya go le gale.

Ke a itse gore patlisiso e e rebotswe ke Patlisiso le Molao wa Maitsholo tsa Khampase ya Medunsa (MCREC), Yunibesithi ya Limpopo (Khampase ya Medunsa) Cliniki ya Ramokonopi. Ke itse ka botlalo gore dipholo tsa Patlisiso di tla dirisetswa mabaka a saentifiki e bile di ka nna tsa phasaladiwa. Ke dumelana le seno, fa fela go netefadiwa gore se e tla nna khupamarama.

Fano ke neela tumelelo ya go tsaya karolo mo patlisiso e.

_____________________________  ________________________________
Leina ka molwetse/moithaopi  Tshaeno ya molwetse kgotsa motlamedi.

_________________________
Lefelo.

_________________________
Letlha.

Paki

Seteitemente ka Mmatlisisi

Ke tlamatsetse tshedimosetso ka molomo le/kgotsa e e kwadilweng malebana le patlisiso e.

Ke dumela go araba dipotso dingwe le dingwe mo nakong e e tlang tse di amanang le patlisiso ka moo nka kgonang ka teng.

Ke tla tshegetsa porotokolo e e rebotswe. 

_________________________
Leina la Mmatlisisi  

_________________________
Tshaeno  

_________________________
Letlha  

_________________________
Lefelo
APPENDIX 6: Isizulu consent form

UNIVERSITY OF LIMPOPO (Medunsa Campus) ISIZULU CONSENT FORM

Isitatinende esiphathelene nokuhlanganyela ukuthola ulwazi esifundweni.

Isihloko sesifundo:
Izinto ezivimbela ukuthi abantu bangahlanganyeli ezinhlanganweni ezisiza ngokufundisa ngegcwane le HIV/AIDS elokishini lase Katlehong e-South Africa.

Sengifundile ngokwanele ngezinhloso zemfundiso, ngithole nesikhathi esanele sokubuza imibuzo manje ngiyaqondisisa ngaphandle kwempoqo.

Ngiyaqondisisa ukuthi ukuhlanganyela kwami kulesifundo kwakwemphamba kumahalakanti futhi nginelungelo lokuyekela ngesikhathi engifuna ngasokubonisa ngaphandle kwempoqo.


Ngiyavuma ukuthi ukuhlanganyela kwami kulesifundo kwakwemphamba kumahalakanti futhi nginelungelo lokuyekela ngesikhathi engifuna ngasokubonisa ngaphandle kwempoqo.

Isitatimende somfunisini

Nginikela ulwazi olubhalwe phansi ngalesifundo.
Ngiyavuma ukuphendula imibuzo yangomuso mayelana nesifundo.
Ngizimisele ukuhambisana nemigomo yesifundo.

<table>
<thead>
<tr>
<th>Igama lomfunisisi</th>
<th>Sayina</th>
<th>Usuku</th>
<th>Indawo</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix 7: Permission Letter to Ekurhuleni Southern Regional Manager

2 Selkirk Mansion
Selkirk Street
Germiston
1401

Dr Ronnel Kellerman
Ekurhuleni Health District
40 Catlin Street
Germiston
1401

Dear Sir/Madam

Permission to conduct a study at Ramokonopi Health Care Centre.

Please consider my request to undertake a study in determining barriers for non participation of HIV positive people in support groups for people living with HIV/AIDS (PLWHA).

I am currently enrolled for a Master of Public Health (MPH) Degree at the School of Public Health, University of Limpopo (MEDUNSA Campus), and am therefore required to submit a research report in partial fulfilment of my degree. The title of the study is: **Perceived barriers to participation in an HIV Support Groups among People Living with HIV and AIDS at Katlehong Township - South Africa** and the study aims to determine perceived barriers that can lead to no participation in HIV support groups and to find out if there is still individuals interested in joining HIV support groups.

My protocol has been reviewed by the MEDUNSA Research and Ethics Committee.

I hope that the findings from the study will assist in understanding the barriers for non participation of people living with HIV/AIDS in support groups and assist in initiating support groups for people living with HIV/AIDS.

Yours faithfully

Mamma Olga Kekana (Miss)
Mobile: 0780646244
Work: 0119057519

Appendix 8: Permission letter to Chief Clinic Head and Facility Manager
The Chief Clinic Head and Facility Manager  
819 Sontonga Street  
Katlehong  
1431

Dear Madam

Permission to conduct a study at Ramokonopi Health Care Centre.

Please consider my request to undertake a study in determining barriers for non participation of HIV positive people in support groups for people living with HIV/AIDS (PLWHA).

I am currently enrolled for a Master of Public Health (MPH) Degree at the School of Public Health, University of Limpopo (MEDUNSA Campus), and am therefore required to submit a research report in partial fulfilment of my degree. The title of the study is: Perceived barriers to participation in an HIV Support Groups among People Living with HIV and AIDS at Katlehong Township - South Africa and the study aims to determine perceived barriers that can lead to no participation in HIV support groups and to find out if there is still individuals interested in joining HIV support groups.

My protocol has been reviewed by the MEDUNSA Research and Ethics Committee. I hope that the findings from the study will assist in understanding the barriers for non participation of people living with HIV/AIDS in support groups and assist in initiating support groups for people living with HIV/AIDS.

Yours faithfully

Mamma Olga Kekana (Miss)
Mobile: 0780646244
Work: 0119057519
RESEARCH ETHICS
CLEARANCE CERTIFICATE

Research Project Title: Perceived barriers to participation in HIV Support Groups among People Living with HIV and AIDS at Katlehong Township – South Africa.

Research Project Number: 30/12/2010-1

Name of Researcher(s): Olga Mamma Kakana

Division/Institution/Company: MPH degree at School of Public Health; University of Limpopo

DECISION TAKEN BY THE EKURHULENI HEALTH DISTRICT ETHICS PANEL (EHDEP)

- THIS DOCUMENT CERTIFIES THAT THE ABOVE RESEARCH PROJECT HAS BEEN FULLY APPROVED BY THE EHDEP. THE RESEARCHER(S) MAY THEREFORE COMMENCE WITH THE INTENDED RESEARCH PROJECT.

- NOTE THAT THE RESEARCHER WILL BE EXPECTED TO PRESENT THE RESEARCH FINDINGS OF THE PROPOSED RESEARCH PROJECT AT THE ANNUAL EKURHULENI RESEARCH CONFERENCE HELD IN JULY/AUGUST.

- THE ETHICS PANEL WISHES THE RESEARCHER(S) THE BEST OF SUCCESS.

CHAIRPERSON: Gauteng Department of Health (Ekurhuleni Region)
Dated: 30/12/2010

DEPUTY CHAIRPERSON: Ekurhuleni Metropolitan Municipality
Dated: 30/12/2010
UNIVERSITY OF LIMPOPO
Medunsa Campus

MEDUNSA RESEARCH & ETHICS COMMITTEE

CLEARANCE CERTIFICATE

MEETING: 09/2010
PROJECT NUMBER: MREC/H/2008/2010: PG

PROJECT:
Title: Perceived barriers to participation in HIV support groups among people living with HIV and AIDS at Katiegong Township - South Africa

Researcher: Ms O. Kakana
Supervisor: Ms S. Madiba
Department: Public Health
School: Health Care Sciences
Degree: MPH

DECISION OF THE COMMITTEE:
MREC approved the project.

DATE: 04 November 2010

PROF G. OGUONJU
CHAIRPERSON-MREC

Note:
1) Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee.
2) The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES.