An evaluation of the role of support groups in the lives of HIV positive people at Nontyatambo and Empilweni Gompo Community Health Centres in East London, Eastern Cape.

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Declaration

I, Nontando Precious Mkhencele declare that, the research reported in this dissertation, except where otherwise indicated, is my original work. This dissertation has not been submitted for any degree or examination at any other university. This dissertation does not contain other person’s data, writing, pictures, graphs or other information, unless specifically acknowledged as being sourced from other persons.

Signed………………………………..
Abstract

South Africa has the highest number of people living with HIV/AIDS in the world. The estimated 5.7 million South Africans that are living with HIV need comprehensive and holistic care. Psychosocial support is a vital aspect of care for HIV positive people. Support groups have been identified as a basic form of psychosocial support. The aim of this study was to evaluate the role of support groups in the lives of HIV positive people in East London, Eastern Cape. A qualitative study design was implemented using focus group interviews to explore the role of HIV support groups. The research questions were designed to elicit responses pertaining to the needs, expectations and experiences of HIV positive support group attendees. Activities conducted in support groups as well as the attitude of support group members towards recruiting other HIV positive people to join the group were also explored. Findings revealed that the benefits of attending a support group included emotional and psychological support, sense of belonging to a “family”, assistance with disclosure issues, gaining information about HIV and treatment as well as material benefits such as food parcels and job opportunities. The greatest need of support group attendees was assistance in obtaining a Social Support or Disability Grant. A few negative experiences were reported which included: unfulfilled promises by people outside of the group, unfair allocation of grants and food parcels, as well as negative group dynamics at times. Support group members agreed that even though there were few negative experiences, the benefits clearly outweighed the negative experiences. Most participants agreed that they would recommend the support group to other HIV positive people so that they could also enjoy the stated benefits. In summary, the study concluded that support groups are very helpful in the lives of HIV positive people.
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CHAPTER 1

INTRODUCTION

1.1. Background
The primary goal of this study was to examine the role of support groups as a form of social support for HIV positive people. This topic was of interest to the researcher because HIV/AIDS is one of biggest challenges that we are faced with globally and locally. According to UNAIDS (2008) it is estimated that about 33.4 million people were living with HIV/AIDS globally at the end of 2008. Out of this number, about 22.4 million are in Sub Saharan Africa. An estimated 2 million deaths due to AIDS related illnesses occurred worldwide in 2008. The UNAIDS (2009) Report states that with 22.4 million HIV positive individuals, Sub-Saharan Africa remains the most heavily affected region, accounting for 67% of all HIV infections worldwide, 68% of new infections among adults and 91% of new HIV infections among children. Sub-Saharan Africa also bore the brunt of the world’s AIDS-related deaths, at 72% of AIDS deaths worldwide (National Antenatal Sentinel HIV & Syphilis Prevalence Survey, 2008). According to Campbell, Nair, Maimane and Sibiya (2007), HIV/AIDS is currently the chief cause of death and illness in Sub-Saharan Africa.

South Africa has the highest number of people infected with HIV/AIDS globally. An estimated 5.7 million people were living with HIV/AIDS in South Africa in 2009 (HIV and AIDS in South Africa (2010). The UNAIDS 2009 Global Report Epidemic Update estimated that in 2008, 310 000 people died from AIDS in South Africa. South Africa is regarded as having the most severe HIV epidemic in the world. The Eastern Cape province, where the study was conducted, has the third largest number of HIV positive people in the country. According to Nicolay (2008), 1.4 million people (15% of the population) and one in every 5 adults in the Eastern Cape, were HIV positive in 2008. The statistics clearly show that HIV/AIDS is a huge problem globally and even more so in our country. It is therefore crucial that, as a country, we have different strategies in place to deal with this epidemic.

Kalichman and Sikkema(1996) stated that social support groups offer a means of addressing the support needs of people living with HIV/AIDS. According to India
HIV/AIDS Alliance (2007), a support group is a group where members provide each other with various types of non-professional, non-material help for a particular shared burdensome characteristic. The help may take the form of providing relevant information, relating to personal experiences, listening to others’ experiences, providing sympathetic understanding and establishing social networks. Social Tract (2010) describes a support group as a structure or meeting wherein people with common challenges, concerns and needs come together to support one another in various aspects of daily living and functioning—emotional, spiritual, physical and psychological; to share information, knowledge, ideas and experiences. Members of the group are bound by group norms, goals and objectives as agreed upon by the group. Mundell (2006) states that support groups for people living with HIV/AIDS can vary greatly and are heterogeneous in both structure and format; groups can have a limited number of sessions or go on for an indefinite period and can be open or closed to new members.

HIV support groups are based in Government Health Institutions like hospitals, health care centres and clinics, as well as in the communities. They are often run by health care workers, people living with HIV/AIDS (PLWHA), Non Governmental Organizations (NGOs), Faith Based Organizations (FBOs), and individuals who want to make a positive difference in the lives of HIV positive people. With the shortage of skilled professionals such as social workers and psychologists, health care workers usually recommend support groups as a form of social support to HIV positive people. A study conducted by Heyer, Mabuza, Couper and Ogunbanjo (2010) revealed that most HIV positive people attended support groups because they were referred by a health care worker. Despite the fact that support groups are highly recommended as a means of helping HIV positive people cope with their illness, not much research has been published in the Eastern Cape Province to evaluate the effectiveness of support groups in the lives of HIV positive people. This is what inspired the researcher to embark upon this study.
1.2. Problem Statement

It is commonly assumed that support groups in general are helpful to people living with HIV. Health care workers usually recommend and refer newly diagnosed HIV positive people to a support group with the assumption that joining a support group will benefit the client. There is usually no follow-up review afterwards, to see whether the support group really had a positive impact in the lives of the clients. This is why the researcher felt it necessary to investigate the nature and extent of the role played by support groups in the lives of HIV positive people in the Eastern Cape Province.

1.3. Purpose

The purpose of this study was to evaluate the role of HIV support groups and their effectiveness as a form of social support for HIV positive people.

1.4. Research Question

What is the role of support groups in the lives of HIV positive people at Empilweni Gompo and Nontyatyambo Community Health Centres in East London, Eastern Cape?

1.5. Objectives of the study

The objectives of this study are to:

1.4.1. Identify the needs and expectations of support group members.
1.4.2. Determine whether the support group meets these articulated needs.
1.4.3. Establish an inventory of activities undertaken by these particular support groups.
1.4.4. Document both positive and negative experiences of support group members at Empilweni Gompo and Nontyatyambo Community Health Centres.

1.6. Significance of the study

The researcher felt that there was a need to examine the role of support groups in the lives of HIV positive people. There is a general perception that support groups are helpful for HIV positive people. By conducting this study, the researcher wanted to explore the needs, expectations and experiences of HIV positive people attending a
support group. The study also endeavoured to explore the activities carried out by support groups and evaluate whether these activities are helpful to the support group attendees.

The researcher felt that there was a need to create a platform that would allow participants at Empilweni Gompo and Nontyatyambo Community Health Centres to express their thoughts and feelings about HIV support groups. The findings of this study are expected to help ensure that the feelings of the support group members are understood, instead of simply being assumed. The health care workers who refer clients to a support group should know exactly what the advantages and disadvantages of being in a support group are.

1.7. Summary
This chapter has indicated the significance of conducting this study to explore the perceived benefits of HIV support groups, if any. The background, problem statement, purpose and objectives of the study have been laid out. The next chapter addresses the literature review.
CHAPTER 2

LITERATURE REVIEW

2.1 Introduction
This chapter informs the reader about previous research conducted on HIV support groups. The review reveals that there is not much published research on HIV support groups in South Africa. Most of the studies were carried out abroad. The few studies conducted on support groups in South Africa, were in Gauteng, KwaZulu-Natal, Western Cape and Mpumalanga and not in the Eastern Cape. In this chapter, the existing literature on HIV support groups will be reviewed looking at the following aspects:

i) Support groups for people living with HIV/AIDS
ii) Needs of HIV positive support group attendees
iii) Activities at support group meetings
iv) Positive experiences associated with attending a support group
v) Negative experiences associated with attending a support group

2.2. In-depth literature review

2.2.1. Support groups for people living with HIV/AIDS (PLWHA)
According to Carter (1994), “Support groups provide a nonjudgmental environment where people with similar experiences vent their feelings; work on their day to day problems; explore issues that concern them, including spiritual issues, and widen their base of friends”. Mundell (2006) states that support groups for PLWHA can vary greatly and are heterogenous in both structure and format; groups can have a limited number of sessions or go on for an indefinite period, and can be open or closed to new members. He further states that time-limited groups can be effective for psycho-educational support, but are not ongoing enough for psychosocial support; whereas ongoing groups also have some disadvantages such as the addition of new members at unsuitable or inappropriate times, and facilitator or member burnout.
According to Carter (1994), four general types of support groups exist - groups that:

(i) Follow a suggested, often ritualistic, format; have established written guidelines but use rotating facilitators

(ii) Use rotating facilitators or no designated facilitators. They follow either a loose regular format or are “free form”

(iii) Are facilitated by trained volunteers. These groups usually have some kind of verbal or written agreement about the format of the meetings and the ground rules for the group

(iv) Are facilitated by trained professional. The format and guidelines of these groups vary with the professional’s style of leadership and the purpose of the group.

Walch, Roetzer and Minnett (2006) state that support groups are among the most widely available and widely used psychosocial interventions for persons with HIV. According to Gaede, Majeke, Modeste, Naidoo, Titus and Uys (2006), in the context of the person living with HIV, social support and health behaviour play a large role not only in the HIV progression, but also in the quality of life. One of the key elements in HIV/AIDS care and support as recommended by WHO and UNAIDS, is the provision of psychosocial support. Support groups have been identified as a basic form of psychosocial support for those living with HIV/AIDS (Social Tract, 2010).

According to Carter (1994), support groups are especially important to persons who are HIV positive because, after being diagnosed, they are confronted with a wide range of emotions. She further explains that as HIV positive people face changing social support and financial situations, they can become frightened, bewildered and worried. When others reject them and treat them inappropriately they can become depressed, angry and isolated. In support groups PLWHA meet others who have had similar experiences.

There may also be support groups for loved ones and caregivers of people living with HIV/AIDS (Carter, 1994). Carter further explains that loved ones benefit from special support groups to deal with their issues, including their feelings about care giving, fear of contagion and infection, grief, changed social conditions, health concerns and obsessive thoughts, while support groups also help caregivers meet the challenges of
social isolation and lack of support system and reduce stress, enhance coping skills and avoid burnout.

2.2.2. Needs of HIV positive support group attendees

Hogan, Linden and Najarian (2002) cite three main types of support needs for support group attendees, namely (i) emotional support, (ii) information support and (iii) instrumental support.

(i) Emotional support involves verbal and nonverbal communication of caring and concern and is believed to reduce distress by restoring self esteem and permitting the expression of feelings. (ii) Information support, which involves the provision of information used to guide or advise, is believed to enhance perceptions of control by reducing confusion and providing patients with strategies to cope with their difficulties. (iii) Instrumental support involves the provision of material goods such as money, transportation or food and may also help decrease feelings of loss of control (Hogan, et al, 2002).

According to Carter (1994), support groups help meet the needs of persons living with HIV/AIDS. A study conducted by Ndlumbini (2009) revealed that one of the major concerns of HIV positive support group attendees was the need to gain access to social grants. This is supported by Heyer et al (2010) who stated that new members of the support group expected the support group to assist them with accessing grants and were disappointed when their needs were not met. Goudge, Ngoma, Manderson and Schneider (2009) argue that government grants play a crucial role in bolstering social support from family and neighbours, providing financial access to basic requirements such as rent, food and clothing for the unemployed, and meeting the costs of transport to the clinic, so facilitating adherence. According to Cloete, Strebel, Simbayi, van Wyk, Henda and Nqeketo (2010), in the context of unemployment, poverty and lower socioeconomic status, HIV status becomes a secondary concern to PLWHA. Poverty is a powerful variable in the rapid progression and dissemination of HIV in communities (Gaede et al, 2006). If we are to win the fight against HIV/AIDS, poverty needs to be addressed.
Support group attendees also need to feel safe when they attend the support group meetings. It is usually the only place where they do not feel judged by society. Due to the stigma surrounding HIV and AIDS, and the consequent difficulty in disclosing, HIV positive members of support groups need to feel safe when coming to the support group (Mundell, 2006). According to Hudson, Lee, Miramontes and Portillo (2001), people living with HIV/AIDS have psychological stressors that include fear of disclosure, stigma, social isolation and fear of death. After discovering their HIV status, they need a great deal of social support to help them cope with the physical, emotional and psychological impact of the illness. According to Gaede et al, (2006) support groups have been shown to be an important source of social support.

2.2.3. Activities done at support group meetings

Visser et al (2005) state that, although support groups are becoming a popular way of providing the needed support for people living with HIV in a resource-limited environment such as South Africa, very few structured programs have been developed to be used in support groups, and even less evaluation has been carried out regarding the effectiveness of support groups as a psychological intervention in this context. The HSRC provides guidelines for support groups, listing 12 points such as confidentiality, responsibility, acceptance, don’t give advice, one speaker at a time, giving attention, avoid interruptions, sharing, questions, be in the present, discussion, begin and end session on time. The HSRC guidelines also state that a support group usually follows a structured format to open and close the meetings. The facilitator gives a welcome and asks the attendees to give their first names and give a special welcome to first time attendees. The facilitator generally suggests a topic for the meeting but also gives the group permission to share anything that they desire.

In HIV support groups, different issues pertaining to HIV, treatment adherence, disclosure, coping mechanisms and other relevant issues are discussed. According to Hemphill (2004) an enormous amount of education about HIV takes place in support groups; people learn from each other how to select and communicate with medical providers, how to navigate social and medical services and how to deal with medication side effects. Discussions about safer sex and other transmission reduction techniques also take place and beliefs about prevention and HIV are explored and evaluated. Hemphill (2004) also states that, in support groups, adherence issues are
often explored as members share concerns about maintaining their confidentiality while taking their medication around other people, the role of recreational drugs in compromising effective treatment and making self care a priority are discussed.

2.2.4. Positive experiences associated with attending a support group

**Improved quality of life**

Social support has been shown to have a positive association for improved quality of life in PLWHA. Support groups are believed to have a positive impact in the lives of HIV positive persons. A review of the literature indicates that, to a large extent, support groups have a positive influence on the lives of HIV positive people.

A study conducted by Summers et al (1999) indicates that participation in HIV related support groups for women living with HIV may be associated with longer survival. In this comparative study, the HIV positive women who attended a support had an increased survival period compared to those who did not attend. Another comparative study conducted by Kalichman et al (1996) reported that people who attended support groups had less emotional distress and more social contacts than those who did not attend support groups, who were lonely and depressed. According to Mundell (2006), the involvement in support groups was positively correlated with psychological wellbeing, which led to the hypothesis that in assisting others, individuals with HIV were able to decrease their own feelings of dependence and hopelessness, and promote better self esteem. The same study concluded that attendance of a support group resulted in: i) increased long term coping skills ii) decreased emotional stress and increase in social contacts, iii) a higher quality of life and iv) a positive effect on reducing risk behaviour such as unprotected sexual activity.

**Sharing of emotions and problems**

In a support group, members share their problems with one another, therefore the emotional burden is lessened. In a study conducted by Heyers et al (2010), participants mentioned that they benefited emotionally through sharing their experiences, through identifying with other peoples’ experiences and through forming new friendships in the support group. This is supported by Mundell (2006) who stated that participants in support groups felt that the most common benefits of attending a support group include being able to share feelings, the relief from being alone, the
opportunity to obtain information on treatments and approaches to care, and being able to have their questions answered. A review of literature by Spirig (1998) suggested that support groups empower people, and provide social contacts, emotional and information sharing as well as education and health promotion. In the absence of support of family and friends, support groups can provide recently diagnosed people a safe environment to talk about the virus, share their experiences, learn from the stories of other infected individuals and access information (Visser, Mundell, de Villiers, Sikkema and Jeffrey, 2005). The benefits of belonging to a support group include having contact with others who are experiencing similar challenges in their lives, obtaining useful information and developing different ways of dealing with the demands of HIV/AIDS (Social Tract, 2010). According to Hemphill (2004), many people living with HIV comment that, above all, their participation in a support group gave them hope. The hope that is regained through support group participation is very crucial because, according to Maneesriwongul, Panurat, Putwatana, Srirapong-nam, Ounprasertprong and Williams (2004) after patients knew they had HIV infection, they were so depressed that they felt like going off to die and had no hope in their lives and some had suicidal intentions. Support groups play a crucial role in restoring hope and the will to live in these individuals.

**Information sharing and education**

In a study conducted by Heyers et al (2010), focus group participants mentioned that they benefited from information received in the support group such as basic HIV facts, transmission, prevention and treatment in support group meetings and had not had accurate or adequate knowledge about HIV before they joined the support group. They felt that the knowledge gained about nutrition and the detrimental effects of smoking and alcohol use helped them to maintain their health. The support group members also felt less anxious because they understood the virus better and they knew what to do, what to avoid and when to access health care.

**Reduction of stigma and isolation**

People living with HIV/AIDS often suffer in silence because of their fear of rejection and discrimination. According to Mundell (2006), one of the most frequently stated issues of PLWHA is the feeling of isolation. This silence can contribute to the development of depression and hopelessness, reduce the likelihood of one’s seeking
information and treatment and increase the chances of transmitting the virus (Visser et al., 2005). Support group members have taken the first step in breaking the silence, by joining the support group. Mundell (2006) states that being with people who cope with similar problems in their lives, to some extent alleviates the sense of loneliness and isolation.

Due to the stigma associated with the infection, support groups are necessary to provide individuals living with the virus a safe environment to develop relationships and adjust to the consequences of living with HIV (Mundell, 2006). Stigma, according to Liamputtong, Haritavorn and Angsulee (2009), is a “process of devaluation” associated with stereotyping and prejudice. It is employed by individuals to define certain attributes of others as “discreditable or unworthy, resulting in the person stigmatized becoming discounted or tainted. Castro and Farmer (2005) state that AIDS, stigma and blame have been intertwined since the start of the epidemic and that one of the characteristics of AIDS stigma is that from the onset, this disease has been associated with a lifestyle that society attributes to being shaped by “voluntary acts”. Stigmatized individuals are subject to feelings of shame and guilt. According to Goudge et al. (2009), AIDS-related stigma has highly damaging consequences, limiting the impact of public health interventions through delays in testing and poor treatment adherence. They further argue that the result of stigma, is a greater number of new infections, poorer health and occasionally suicide. Meeting other people who share the same concerns and fears concerning the disease can reduce the power of HIV-related stigma. According to Mundell (2006) individuals living with particularly stigmatized illnesses seek out similar others for support and this is an important opportunity for social network development. HIV support groups therefore play a crucial role in this regard.

**Assistance with disclosure**

This support becomes very useful to HIV positive people as they sometimes find it difficult to disclose their status to family and friends due to stigma and fear of rejection. According to Cloete, Strebel, Simbayi, van Wyk, Henda and Nqeketo (2010) reluctance and anxiety to disclose HIV positive status, and fears of being rejected and discriminated against are evidence of the persistent nature of AIDS-related stigma in communities and households. A support group then becomes the
only place where HIV positive people feel safe to talk about their status. For many people living with HIV, a support group is the first place where they acknowledge to another person that they are infected and where they come face to face with other people who are positive (Hemphill, 2004). In a study conducted by Heyer et al (2010), some participants mentioned that the support group gave them the courage to disclose their illness or assisted with the disclosure of their HIV status to someone at home.

2.2.5. Negative experiences associated with attending a support group
In a study conducted by Heyer et al (2010), participants mentioned that when the support group is large, this affects confidentiality and inhibits free discussion especially about sensitive topics. Support group leaders also felt overwhelmed and burnt-out, which caused them to lose hope, to become less sympathetic and to quarrel with each other.

The same study revealed that potential negative experiences of attending support groups are concerns around confidentiality and open communication in groups, worsening depression when group focuses on illness, witnessing the decline of fellow members or experiencing members leaving, negative group dynamics and the presence and influence of disruptive members. This is also echoed by Mundell (2006) who states that individuals living with HIV may become exceptionally aware of their bodily symptoms, and often each new somatic experience raises the question of whether this may be the beginning of the end. Participation in a support group, with other individuals having similar experiences, can be terrifying because one witnesses the other member getting sick or even dying.

2.3. Summary
This chapter has explored existing literature on HIV support groups. In conclusion, the literature suggests that support groups are very helpful to HIV positive people, helping them to cope with the illness. Although there are few negative experiences associated with support group attendance, the benefits of belonging to a support group clearly outweigh the disadvantages. The next chapter presents the research methodology followed in this study.
CHAPTER 3

RESEARCH METHODOLOGY

3.1. Introduction
The purpose of this study was to evaluate the role and the effectiveness of HIV support groups which are an essential aspect of planning social support for HIV positive people. This chapter outlines the methodological framework used in conducting this investigation. A qualitative research design was chosen as the appropriate method to explore the role of support groups in the lives of HIV positive people. According to Burns and Grove (2001), qualitative research is a systematic, subjective approach used to describe life experiences and give them meaning. It is also a way of gaining insights through discovering meanings.

Spirig (1998) cautions that it is commonly assumed that support groups are generally helpful as a way of supporting people living with HIV/AIDS, without specifically having been evaluated. In this study, focus group interviews were used to explore the nature and extent of the role played by support groups in the lives of HIV positive people attending support groups at Nontyatyambo and Empilweni Gompo Community Health Centres.

In this chapter, the following will be discussed: research design, population, sample, research instruments, inclusion and exclusion criteria, data collection, ethical considerations, data analysis and limitations of the study.

3.2. Research Design
This is was a descriptive qualitative study that endeavoured to explore the needs, expectations and experiences of support group members at Empilweni Gompo and Nontyatyambo Community Health Centres in East London, Eastern Cape. According to Mack, Woodsong, MacQueen, Guest and Namey (2005), qualitative research methods provide valuable insights into the local perspectives of study populations; it also produces culturally specific and contextually rich data. The researcher conducted two focus group interviews; one at each of the above mentioned institutions. The
researcher chose this method because Macket al (2005) state that the principal advantage of focus groups is that they yield a large amount of information over a relatively short period of time. They are also effective in exploring an in-depth and broad range of views on topics such as those explored in this study.

### 3.3. Population

The population from which the sample was chosen was from the Buffalo City Municipality, located in the Amathole District of the Eastern Cape Province. The Eastern Cape Province has the third largest number of HIV positive infections in the country, namely 11% or 730,000 of the general South African population (BCM Integrated Development Plan Review, 2010). Buffalo City has a population group of about 880,000 people, a third of which live in Mdantsane, South Africa’s second largest township (buffalocity.gov.za). There is a combination of both urban and rural areas within the Buffalo City Municipality. The support groups from the CHCs, where the study was conducted, are located in Mdantsane and East London, within the Buffalo City Municipality.

### 3.4. Sample

The researcher used purposive sampling of HIV positive people attending support groups at Empilweni Gompo and Nontyatyambo Community Health Centres. According to Mack et al (2005), purposive sampling groups participants according to preselected criteria relevant to a particular research question. Purposive sampling is therefore most successful when data review and analysis are carried out in conjunction with data collection (Mack et al., 2005). The study focused on support group members who had known their status and had been in the support groups for more than six months; therefore it excluded the newly diagnosed members. In accordance with the requirements of the study, all participants had known their status for more than 6 months and had been members of the support group for more than 6 months.
3.4.1. Inclusion and Exclusion Criteria

3.4.1.1. Inclusion Criteria
To be included in the study, the participants had to meet the following criteria:

- HIV positive
- Adult (minimum 18 years of age, no maximum age limit)
- Both males and females
- Have known their HIV positive status for more than 6 months
- Have been attending the support group for more than 6 months

3.4.1.2. Exclusion Criteria
All newly diagnosed support group members who have known their HIV status for less than 6 months were excluded from the study.

3.5. The research instruments
Two focus group interviews were conducted by the researcher. The questions asked were meant to elicit responses in relation to eight questions asked, namely:

- Please explain your needs as an HIV positive person attending this support group.
- What were your expectations when you first joined the group?
- So far, do you think the group has managed to meet these expectations? Yes or No. Please explain.
- Describe all the activities of this support group?
- How are these activities helpful to you?
- Please share your positive experiences of being a member of this support group.
- Describe the negative experiences of being a member of this support group.
- Would you advise another HIV positive to join a support group? Yes or No. Please explain.

These research questions are attached as Annexure G (English) and Annexure H (Xhosa).
3.6. Data Collection
The actual data collection process, in the form of focus group interviews was conducted in August 2009. The interviews took place at the above mentioned institutions, in the private rooms where the support groups gather for their meetings. Permission to use these rooms was granted by the site managers of the two institutions where the study was conducted. See Annexure C and Annexure D for the approval letters from site managers. The researcher asked eight questions from the participants during the focus group interviews. Research questions are attached as Annexure G and Annexure H. These questions were designed to elicit responses about the needs, expectations, experiences of support group members in relation to the objectives of the study. The research participants were also asked about activities of the support group, as well as their attitude towards recruiting other HIV positive people to join the support group. Questions relating to the respondents’ age, gender and period since they have known their HIV status were also asked. After informed consent, attached as Annexure E, was granted and signed by the participants, interview data was collected by the researcher, in the form of field notes and audio taped interviews, which were later transcribed for use in data analysis. These were semi-structured in depth interviews of about one to one-and-a-half hours for each support group. The researcher ensured that all the participants had a chance to respond to the questions by probing responses from those who were seemingly quiet during the interview. As the interview continued, there was active participation by all the support group members.

There was a potential for bias in data collection, as the participants knew the researcher who used to work in the institutions mentioned above, from which the sample was taken. To try and minimize this, the researcher explained the study purpose fully to the participants and urged them to respond freely and as honestly as possible to the questions.

3.7. Ethical Considerations
All ethical considerations were observed during the study. The research was cleared with the University of Fort Hare Ethics Committee first before it commenced. See Annexure A for an approval letter from the Ethics Committee-UFH.
conducted the study was also granted by the Epidemiological Research and Surveillance Management Unit of the Eastern Cape Department of Health, attached as Annexure B.

The researcher was truthful and straightforward in explaining to the participants the objectives of the study and the anticipated risks and benefits to the individual participants and community. Before conducting the focus groups, the researcher obtained informed consent individually from the participants. (See Annexure E and F, for copies of the consent form in both English and Xhosa). A consent form, which clearly stated what the study was all about and that the participants were free to discontinue the study at any time they wished to do so, was obtained from each participant. The consent forms were written in both English and Xhosa to accommodate those participants who did not understand English. Explanations were also given in Xhosa as well, as most of the support group members were Xhosa speaking. This was done to ensure that the support group members had a clear understanding of what they were participating in. Confidentiality was maintained at all times by the researcher and the names of the participants were not used in the study. This was done to ensure that the information shared in the focus group, did not leak outside of the group, especially because HIV is still a sensitive issue surrounded by stigma. Members of the focus group were also advised to respect each other’s privacy and keep everything shared in the group confidential.

3.8. Data Analysis
Field notes were expanded by transforming shorthand into a narrative and elaborating on non-verbal observations made during the focus group interview. All expanded notes were then transcribed and typed into a computer in English for analysis. Analysis included careful checking of all data collected as well as attentive listening and analysis of the audio tape. The transcript was read through thoroughly with the aim of interpreting the responses of the participants. The qualitative feedback of the participants was interpreted by identifying themes in response to each question asked by the researcher. The researcher was guided by the study supervisor from the University of Fort Hare in this process, in order to enhance the trustworthiness of the themes identified. The supervisor is highly experienced in research. It was really beneficial for the researcher to have the supervisor’s guidance in this regard, to make sure that the data was analyzed accordingly.
3.9. Limitations of the study
As far as fieldwork is concerned; the researcher conducted the interview and also took notes, as there was no note taker due to budget limitations. However, the audio tape helped to ensure that everything that had been said by the participants was captured.

3.10. Summary of the chapter
This chapter presented the research methodology. For the purpose of this study, qualitative research by means of focus group interviews, was considered an appropriate method for gaining insight into the needs, expectations, experiences as well as the activities undertaken by the support group members at the above mentioned institutions.
CHAPTER 4

ANALYSIS AND DISCUSSION OF FINDINGS

4.1. Introduction
This chapter presents the findings of the study conducted, emanating from the two focus group interviews of HIV positive support group attendees at Nontyatyambo and Empilweni Gompo Community Health Centres. Eight questions were asked of the focus group participants, which were mainly meant to explore the needs, expectations and experiences of support group members. The questions also endeavoured to gain insight into the activities undertaken during support group meetings as well as to explore the attitudes of support group members towards recruiting other HIV positive to join the support group. These questions can be viewed in Annexure G and Annexure H.

4.2. Presentation of the findings
The total number of participants was 35, comprising 29 females and 6 males, between the ages of 26 and 54. At Nontyatyambo, there were 18 participants whilst at Empilweni Gompo there were 17. In each support group, there was a peer educator who was also part of the support group. Peer educators are people living with HIV who are employed to educate other HIV positive people about HIV and treatment. The majority of the participants (83%) were females, but this was not intentional on the part of the researcher; it is because there are fewer men in these support groups than women. This is in line with existing literature that states that women are more likely to attend support groups than men do. According to Cloete, Strebel, Simbayi, van Wyk, Henda and Nqeketo (2010), once diagnosed HIV positive men avoid seeking help, treatment or support for fear of stigma. Cloete et al(2010), further explained that such behaviour was seen as related to the male “macho” culture and needing to be seen to be strong, while HIV was still seen as largely a “female thing” and thus it was mainly women who attended support groups. This fact was found to be true in both of the support groups studied.
Table 1: Distribution of the participants according to age and gender.

<table>
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<th>Age range</th>
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<tr>
<td>Total</td>
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<td>100%</td>
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</table>

4.2.1 Needs of HIV positive support group attendees

Seven themes emerged from question 1:

(i) Need for love, peace and acceptance;
(ii) Need for interaction with other HIV positive people;
(iii) Need for accessing HIV/AIDS grant;
(iv) Need to access social support services such as food parcels
(v) Fulfillment of treatment related needs;
(vi) Need for education and training, and
(vii) Disclosure related needs. It was an interesting observation to note that these themes emerged repeatedly across the responses from both support groups, and they spoke mainly to needs relating to basic needs. The themes are discussed below:

Need for love, peace and acceptance.

According to Maslow’s hierarchy of needs, the need for love and belonging is the third most important need for human beings. “Maslow states that people seek to overcome feelings of loneliness and alienation. This involves both giving and receiving love, affection and a sense of belonging”

HIV positive people attending support groups at Nontyatyambo and Empilweni Gompo Community Health Centres expressed a common need for love, peace and acceptance. It came out strongly in the discussion that they had a need to feel loved and accepted by fellow group members, to make up for the rejection and abuse that
they sometimes receive from family and friends because of their HIV positive status. Support group members indicated that they needed to find ways of how to live peacefully with HIV despite the discrimination that they sometimes suffer in their communities. Below are some of the extracts from the support group members’ responses that expressed these needs:

One person stated:
“I need advice on how to live peacefully with HIV - my family does not want me.”

Another study participant stated:
“I need love, I get love from the group and they give me strength. We come from different homes, some are abused at home and we get help in the support group.”

Yet another participant supported this view stating:
“At home we often don’t get accepted. When we join the group we need love and acceptance.”

These expressions are clear indications that love, as Maslow stated, is an important need that ought to be fulfilled. The above extracts are also an indication that the support groups led to the fulfilment of human needs such as love, peace and acceptance that were not being fulfilled in their homes. Carter (1994) generally agrees with this view, and regards HIV support groups as a major source of love and acceptance for HIV positive people.

**Need for interaction with other HIV positive people.**
One of the needs of HIV positive people is to interact with other HIV positive people when they join a support group. The responses of the support group members indicate that, as individuals, they need someone who understands what they are going through, to listen to their problems and comfort them in difficult times. They also need to have a sense of belonging, as they are sometimes discriminated against in their communities. Some participants indicated that some group members also need encouragement from the group when they feel like giving up.
These needs were expressed in the following responses:
“I need to learn more about HIV and to interact with other HIV positive people.”
Another participant stated:
“The things that I need are love and for my fellow group members to listen to my problems.”

Clearly the above statements indicate the need for interaction with other HIV positive people is a major need. According to Hemphill (2004), “support groups reduce isolation, physically and emotionally, while enhancing empowerment. For many people living with HIV/AIDS, a support group is the first place where they acknowledge to another person that they are infected and where they come face to face with other people who are HIV positive”. A support group therefore seems to be a place of comfort and safety for HIV positive people where they can share their problems with people who understand what they are going through, without the fear of being judged or discriminated against.

**Need help for accessing HIV/AIDS grant**

The Social Support Grant emerged as one of the major needs for HIV positive support group attendees. According to the Department of Social Development(2009), the amount of the disability grant is R1010.00 per month and only persons who are unable to work due to mental or physical disability qualify to get a disability grant. HIV positive people don’t automatically qualify for a disability grant if they are not physically disabled. They need to be very ill with a clinical stage 3 or 4 disease (according to World Health Organization clinical staging criteria) in order for them to qualify for a grant. Even then, the grant is usually temporary; lasting for a period of 6 months to a year, when they get better it is withdrawn. This criterion does not fit the majority of support group attendees as they are generally not very sick to the point of being physically disabled. The majority of support group members are unemployed and they see the “disability” grant as a form of poverty alleviation. According to SouthAfrica.info (2009), about 24.9% of South Africans are unemployed. The total number of unemployed people stood at 4, 16 million in the last quarter of 2009, (Mail & Guardian, 09 February 2010, p.1). In the Buffalo City Municipality where the study was conducted, there are high levels of poverty. According to the BCM Integrated Development Plan Review (2010), approximately 70% of the households in Buffalo City have an income of less than R1500 per month and about 28% of all households
have zero income. Looking at these statistics, it is understandable why one of the needs of support group attendees, was to gain assistance on how to access a grant when they joined the support group. The statements below speak to this need:

One group member stated:

“I need to get help on how to access a grant.”

Another support group member stated:

“I am disappointed that my grant was taken - I feel like stopping ARVs.”

The above statements indicate the frustration that HIV/AIDS positive people experience with regard to the issue of accessing the grant. Some participants also felt that it was unfair for the government to withdraw the disability grant when a person improves whilst on ARVs. The expressions that are cited below, demonstrate that HIV positive grant holders develop a dependence on it.

One participant stated:

“What do you do when your grant is taken away because your CD4 count is high? I need the grant. My grant was taken away because my CD4 count was high but I’m still in pain - my feet are painful.”

Yet another participant said:

“I used to get a grant before, but when my CD4 count went up it was stopped. I appealed but it was declined again.”

“The perception of social grants in people living with HIV/AIDS meant receiving disability grant is having money to buy food so that they can be able to adhere to their treatment” (Ndlumbini, 2009). In the absence of a social grant or food parcels, some find it hard to adhere to treatment.
Need to access social support including food parcels.
The participants felt that the government should supply them with food parcels consistently so that they can take their treatment well. According to some group members, at times they don’t have food to eat due to poverty and this affects their adherence to treatment. According to Schwabe (2004), approximately 57% of individuals in South Africa were living below the poverty income line in 2001. Limpopo and the Eastern Cape had the highest proportion of poor people with 77% and 72% of their population living below the poverty income line, respectively, (Schwabe, 2004). This explains why some group members feel that they are entitled to social support from the government.

Relating to the issue of food parcels, one participant stated:  
“I need the government to help us with food - the treatment makes us hungry.”

One of the respondents felt that everybody in the group should get food parcels irrespective of whether they receive a grant or are employed. Currently only people who do not receive a disability grant and those who were unemployed qualified to receive food parcels. The group felt that this was unfair as they were all part of the group.

The expression that follows indicates that the group members felt strongly about the equal distribution of food parcels:  
“We want everybody to get food parcels irrespective of whether they get a grant or not. The peer educators in the support group should also get food parcels and any other sponsorships that we get, like t-shirts, because they are also part of the group.”

The peer educator in one of the support groups felt strongly about the fact that they needed to be formally registered as a support group so that they can obtain direct funding and help from the government to avoid the exploitation that they currently experience from people who pretend to have their best interest at heart when in fact they do not.
The statement below speaks to this point:

“My need is for this support group to be registered so that we can get funding and help from the government. I don’t like the fact that we become victims as HIV positive people, to people who take our IDs with the pretence of getting funding for us and they never come back. Even at churches they use our status for their own benefit.”

This view was echoed by yet another participant who felt that the government should assist them and involve them in decision making,

“We need government to make projects for us so that we can do something and not feel useless. When decisions are made about us HIV positive people we should be involved, not decided for.”

The statements above express the frustration of some support group members concerning their perception of being used by some people including churches, for their own benefit. The group also feels that being formally registered would assist them to secure funding that will enable them to embark on income generating projects.

The entire group alluded to the fact they wished they could receive visits from a social worker in some of their group meetings, to listen to their problems and try to assist them, as this has not happened yet. The above discussions tried to bring to the fore the participants’ expectations pertaining to the issue of social support, grants and food parcels.

**Fulfilment of treatment related needs**

More than half of the support group members, from both support groups, are on antiretroviral treatment. This medication does not cure HIV, but helps to suppress it in the body so that it does not totally deplete the immune system. For this medication to work it needs strict adherence to treatment. HIV positive people on ARVs are faced with the challenge of having to take lifelong treatment without missing doses. If they do not adhere to their treatment properly, they run the risk of developing resistance to treatment, which will mean that the drugs no longer work for them. Literature supports the view that adherence to HIV/AIDS medication can be a challenge. According to Hemphill (2004), “Medication regimens for controlling HIV can be
complicated and taking medication according to schedule can be difficult for a multitude of reasons”. The support group members stated that they needed advice on how to overcome this challenge.

The expression below speaks to this point:
“I need advice on how to take treatment correctly and not miss a dose.”

The peer educator in the group also shared that being part of a support group has helped some members to improve adherence to their treatment. The group members also expressed the need to be knowledgeable about their disease and treatment. The group seems to be dealing well with this aspect as they also have a special support group specifically for members who are on ARVs, which meets on Fridays. Some group members also highlighted the fact that they used to fear taking ARVs before joining the group, but now they don’t fear this requirement anymore as the support group has empowered them by providing information.

The statement below affirms this point:
“I used to be scared of ARVs before I came to the group. After I joined the group I didn’t have a problem with my treatment anymore. I take it well.”

The preceding discussion is an illustration that support groups have an important role in promoting adherence to HIV treatment.

Need for education and training
The support group members expressed the fact that they would like to be equipped with training and skills that can assist them to get a job so that they can provide for their families. Besides the need for formal education and training, they also stated that they need to learn more about HIV so that they can help other people.

The statements below support this point:
“I need to get education and training so that I get skills that will enable me to get a job and work for my children, not leave them on earth with nothing.”
Another group member stated:

“Our need as people living with HIV is to get education about HIV so that we can help to educate other people. In a support group we do learn about HIV.”

The responses above clearly point out the need that HIV positive people have for ongoing education and training.

**Disclosure related needs.**

Due to the stigma surrounding HIV/AIDS, it is still not easy for some group members to disclose their status to family and friends. According to Goudge, Ngoma, Manderson and Schneider (2009) “AIDS related stigma can cause delays in testing, poor treatment adherence and greater numbers of new infections”. The stigma is not always external; there is also internalized stigma imposed by HIV positive persons on themselves which prevents them from disclosing their status to their families as well as accessing HIV/AIDS care. Some of them would really like to disclose to their families and loved ones but they do not know how to. They need the support group to assist them in this regard as they don’t feel strong enough to do this.

The statements below express this point:

“I need help to be stronger and learn to talk about my status. In the communities we get rejection, in the group we get encouragement that HIV is not the end of life.”

The view was also echoed by another participant who said:

“I need to get strength to talk about my status.”.

The discussions above highlight the fact that the support group members have a desire to talk about their status but lack the strength to do so. It is therefore important that HIV positive persons are assisted through disclosure issues, so that they can be able to disclose their status to the relevant people.

4.2.2. **Expectations of support group members when they first joined the group.**

This particular question attempted to elicit information on the expectations of the support group members when they first joined the group. It was established that support group members had different expectations when they joined the group.
These expectations were based on their understanding and/or assumptions of what a support group is and should do, as well as myths and misconceptions that they had gathered from the communities. Some expected to see very thin and sick people in the support group, because that’s how HIV is perceived in the communities, but they were encouraged when they saw healthy, beautiful people.

One group member stated:
“I expected to see thin people but I saw healthy ones and got encouraged”.

Four themes emerged from question 2:
(i) Expectations of encouragement;
(ii) Expectations of assistance with grant;
(iii) Expectations on gaining knowledge;
(iv) Expectations of disclosure
The expectations are discussed in detail below. Most of the expectations seem to have been met by the group except the one pertaining to the disability grant.

**Expectations of encouragement**
It emerged from the interview that one of the great expectations of HIV positive individuals when they joined the support group, was to receive encouragement. Some of them were abused at home and they came to the group with heavy emotional burdens, expecting to receive encouragement and help from the group. They expected to be accepted by the group and not discriminated against, as these were also other HIV positive people like themselves.

This expectation appears to have been met, as can be seen in the following statement:
“I was abused at home because of my status. I got comfort and encouragement when I came to the group. We have fun and share jokes in the group.”

HIV infected people also need encouragement in taking their lifelong treatment and the group helps a lot in this regard. Within the group there are other group members on treatment, and they encourage each other on treatment compliance. The point below bears testimony to this fact:
“I expected encouragement, there’s a lot of it in the group. We encourage each other with taking treatment and personal issues at home.”

A similar statement was echoed by another group member who stated:

“The first thing I expected the day I came to the support group was to get encouragement as a person living with HIV. When I came I got the encouragement I needed. I will never leave the support group.”

According to Visser et al (2005), “Often a listening ear, together with acceptance and reassurance, is exactly what is needed and is more therapeutic than any treatment protocol”. The support group members expect to be listened to with understanding and to get encouragement from the group. The expectation for encouragement seems to have been met by the support group as all the participants agreed that they get encouragement from the group, which is why they keep on coming to group meetings.

**Expectations of assistance with grants**

As the majority of South Africans live in poverty, the need for the social support emerged quite strongly from the group discussion. Many of the participants felt that they are entitled to a disability grant because they are unemployed and are infected with HIV. According to a study conducted by Ndlumbini (2010), 90% of the participants believed that having a social support grant is a motivating factor for taking treatment. Some of the support group members thought that joining the support group would increase their chances of accessing a grant. They were disappointed when they did not get the grant they expected, but they still remained in the group as it helped them to cope with the illness.

The statement below supports this view:

“Can people in power please advocate for us to get grants because we’ll have HIV forever, we’ll die with it.”

The support group members also expected to have support from asocial worker who would listen to their problems. They have had some visitations by a professional nurse to educate them about HIV related illnesses and treatment, but not once has a social worker ever visited the group, which they found disappointing.
**Expectations of gaining knowledge**

The third theme pertaining to expectations of support group members is that which relates to gaining knowledge. The support group attendees expressed the view that they expected to gain knowledge about HIV and treatment when they joined the group. They get this knowledge from the peer educators in the group, as well as the professional nurse who sometimes visits and educates them about HIV related conditions.

One of the respondents stated:

“We also have knowledge now and know our rights.”

In a study conducted by Liamputong, Haritavorn and Angsulee (2009), when the participants were asked what benefit they received from joining the support group, most referred to the knowledge they gained. Most of the support group members in this study shared that their expectation of gaining knowledge was met by the group. It seemed that whilst the support group members agreed that their level of knowledge about their condition had increased since joining the group, there were still some gaps regarding knowledge on how to get better.

The following quotation indicates that there might still be a gap in knowledge:

“I expected to get advice on how to get better; I have a problem with health. I expected to hear new things that I did not know. I got some information but not everything.”

A qualitative analysis of the in-depth interviews conducted by Kalichman et al (1996) suggested that “support groups currently available to people living with HIV may be meeting the needs of some, but many others have not experienced these benefits”.

**Expectations of disclosure**

The last theme pertaining to expectations that support group members had before joining the group relates to disclosure. Due to the stigma associated with HIV/AIDS, many HIV positive individuals are understandably fearful of disclosure and of seeking support and information about HIV (Visser, Mundel, de Villiers, Sikkema and Jeffrey, 2005).
The respondents in this study shared the point that one of their expectations when they joined the group was to learn how to talk about their HIV status to others. Some of the attendees communicated the fact that joining the support group had helped them to be stronger and able to disclose their status to others.

The statements below illustrates this point:
“*When I joined the group I was still fragile. I had just found out about my status. I got comfort when I joined, I felt better. I can disclose now, I have accepted my status*”

Another respondent stated:
“I used to hide my folder when coming to the clinic but now I don’t hide it anymore. I want other people to come so that they get help. I also got motivated to take my treatment.”

Yet another group participant stated:
“I wanted to be bold about my status and defend myself from other people discriminating me. I got the confidence I needed from the group.”

The above views demonstrate the fact that the support group has helped the participants to accept their status and become more confident in accessing care as well as withstand discrimination.

4.2.3. Support group activities
When support groups meet there are certain activities that they do which range from physical, psychological and income generating activities. The respondents explained that they meet to talk about issues affecting them as HIV positive people, as well as to educate each other about the virus and treatment. They get physically active through sport and gardening. As a form of income generation, they do beadwork and nurture pot plants which they sell to the community. Music is also part of their recreational activities, and is also a form of alleviating stress. The discussions presented below pertain to the frequency and types of group meetings held by the group, as well as the different activities done by the group:
Support group meetings

The support group meets on different days of the week to address the different needs of the group. At Empilweni Gompo, the support group for HIV positive people meets on Wednesdays only. At Nontyatyambo the support group also meets on Wednesdays for HIV positive people and on Thursdays there is a support group for the family members of HIV positive people attending the support group. According to Carter (1994), loved ones of people living with AIDS (PLWA) can also benefit from special support groups to deal with their issues, including their feelings about care giving, fear of contagion and infection, grief, changed social conditions, health concerns and obsessive thoughts. At Nontyatyambo there is also a support group that meets on Fridays which is exclusively for support group members who are taking antiretroviral treatment. Due to the requirement of a lifelong commitment to treatment, HIV positive persons on ARVs need the support to ensure continued adherence. The response below expresses this point:

“Can’t wait for support group day, we have different support group days. Wednesdays we have support group for HIV positive people only. Thursday we have support groups for our family members. Fridays we have ARV support group- for people taking ARVs, who are also part of the Wednesday support group”.

The preceding discussion indicates that the support group caters for the different needs of the members and their families. The statement also highlights the excitement that group members have about group meetings.

The next theme that is presented discusses the different recreational activities that the support group embarks on.

Recreational activities

The range of recreational activities that were identified by the support group members included music, sports, artwork, gardening activities as well as educational and motivational activities.

Music

Both support groups explained that they have a gospel choir which sings at community functions and churches. When one of them dies or is bereaved, the choir also sings at the funeral to show support to their fellow group member.
**Sports activities**
The support group at Nontyatyanbo has a soccer and a netball team which helps them to exercise and stay fit. They train on the health centre grounds and play sport with other teams from the community.

**Beadwork activities and pot plants**
Both support groups have income generating projects like beadwork and pot plants. They mainly do beadwork of HIV badges which they sell (especially during the World AIDS Day activities) to make a profit. They also engage in rearing pot plants as a group and selling them to the staff in the health centre and to the community as a form of income generation. In a study conducted by Visser et al (2005), support group attendees shared the fact that they needed to have ideas about income generating activities while conversations regarding their problems take place. This fact was found to be true in these groups.

**Gardening**
The support group at Empilweni Gompo has a garden which they work on to produce vegetables which they consume and also sell to the health care workers for income. At Nontyatyanbo they do not have a garden because the soil is very hard and they don’t have proper gardening equipment.

**Educational and motivational activities**
In the groups they have educational sessions and talk about HIV. They sometimes have a professional nurse to come and present HIV related topics to them.

One of the participants stated:

“*We have education sessions and talk about HIV. Before we joined the group we could not even differentiate between HIV and AIDS*”

Both support groups are also involved in community outreach programs. They do HIV education and awareness campaigns through talks, drama and music. They reach out to the communities, schools and churches, to warn people about HIV and to show them that there is life after an HIV positive diagnosis.
Sharing of personal stories and advice

Another theme that emerged in relation to support group activities was the sharing of personal stories and advice regarding HIV. The respondents stated that in the group they share their personal stories to motivate each other on how to overcome challenges such as disclosure, stigma and discrimination. They also advise each other on how to cope with HIV both physically as well as emotionally.

The statement below speaks to this point:
“We advise each other, like when someone who has just joined the group who is not well; we advise them what to do.”

Through support and motivation they build each other’s confidence, as stated in the following quotation:
“We build each other’s confidence so that we can stand on our own”

The experience of the support group members in relation to this theme is supported by Carter (1994) who stated that support groups can provide people with HIV a relaxed and informal place to share their experiences and build new friendships.

4.2.4. How are the activities helpful to you?

By exploring this question, the researcher wanted to ascertain whether the activities carried out by the group were of value at all to the support group members. The participants were of the view that for the most part, these activities help them to relieve stress and get their mind off their HIV positive status. Discussed below are the perceived benefits of a range of recreational and other income generation activities.

According to the support group members, drama helps them to tell a story and to give a message to other community members. The statement below speaks to this point:
“Drama helps us to tell a story and give a message, for example the importance of acceptance, especially for religious leaders. They must know that HIV is real. They should not lie to people and say if they get saved, they will be healed. There is no cure, just treatment.”
They expressed the fact that sport helps their bodies stay fresh and it refreshes their minds. It helps them not to think of HIV all the time. Beadwork also helps to get their minds off HIV. They learn fine motor skills through beadwork. They also sell the beadwork for income:

“Beadwork helps us to concentrate on other things, other than the virus”.

Being part of a choir helps to refresh their minds. The quotation below speaks to this point:

“Choir- helps us a lot, keeps our blood fresh, you feel the virus has run away. When we sing our minds get refreshed.”

Activities such as gardening help to keep the support group members active and promote teamwork. It also helps to generate income as they sometimes sell the vegetables:

“Gardening helps to build teamwork as we work together on the garden. We get income as we sell the vegetables and we also share them among us to eat at home.”

The activities discussed above, seem to have a positive impact in the lives of the support group attendees. The participants all agree that these activities add value in their lives and lessen the HIV related stress.

4.2.5. Positive experiences associated with being a member of the support group. In exploring this issue, the researcher wanted to explore whether there were really positive experiences associated with being a member of a support group or not.

According to Spirig (1998), “It is commonly assumed that support groups in general are helpful for people living with HIV/AIDS without that fact having been specifically evaluated”.

Support group members expressed the fact that they have fun in the support group. They also reported that they share jokes and laugh together. Sometimes they go out to gospel shows together.

The following statement supports this point:

“When I came to the support group I realized that people have fun.”
Another positive experience that was cited was that the support group has assisted the members with disclosure issues. They had gained confidence because of the support group; and they can now stand boldly and talk about their HIV status.

The statement below supports this point:

“I used to be scared to talk in front of people about my status. Now I have confidence to talk about my status.”

Another constructive aspect associated with being a support group member was that the experience had helped them with adherence issues as well. They stated that they did not have fears of taking their ARV treatment anymore. According to the support group members, the support that they get from the group, made it easier for some of them to start ARVs and adhere to them.

The statement that follows highlights this point:

“I used to be scared of ARVs before I came to the group. When I joined the group I didn’t have a problem with my treatment, I take it well.”

This point was also echoed by another participant who stated:

“The group helped me to get information about ARVs. I used to fear them.”

Some participants viewed the fact that they sometimes get social support in the form of food parcels positively. This helps them a lot, as most of them are unemployed. The following statement brings this point out clearly:

“There are benefits like food parcels that we get from the group”

The fact that they care for each other was viewed positively by group members. It was stated that support group members sometimes have candlelight ceremonies to remember those who passed away due to HIV/AIDS.

“Candlelight ceremony makes me feel good that people who died of AIDS are not forgotten.”
Most group members stated that the candlelight ceremonies also help them to celebrate the fact that they are still alive because of ARVs. The following statement speaks to this point:

“During candlelight ceremony, I remember the first time I knew about my status. I like it because you get revived and appreciate the fact that you are still alive and taking treatment.”

The experiences cited in this study add to the positive perceptions that the members have in relation to the support groups. It was also interesting to note that the group members get encouragement from the group and realize that life goes on despite the HIV infection.

The following statement affirms this point:

“From the group I learned that life goes on. HIV is not the end of life.”

An additional aspect that was raised as a positive factor was that through being members of the group, some have had learning opportunities which resulted in employment within the Eastern Cape Department of Health.

This point is significant indeed and is supported by the following statement:

“I got a job as a caregiver through being a support group member.”

A further positive point that was raised by the support group members was that the group members have a sense of belonging to the group. The group is viewed as being like family to some of them.

The following statement expresses this point:

“We build families; older mamas treat us like their own children.”

The views of the support group members on the issue of belonging are also affirmed by Liamputong, Haritavorn and Angsulee (2009) who stated that becoming a member of a PLWHA support groups is a form of belonging, and it is a strategy that the women in this study used in order to deal with their HIV status.
4.2.6. Negative experiences associated with being a member of this support group

Although many positive experiences have been cited, some negative experiences from the support group members emerged from this study as well. The responses of the participants in this study demonstrated that the negative experiences could be classified into three sub-themes that fell into this category namely:

(i) The experience of unfulfilled promises;
(ii) Unfair allocation of grants and food parcels;
(iii) Dynamics within the support group.

The experience of unfulfilled promises.

Some support group members expressed the view that they are tired of people who come and listen to their problems, take their ID numbers and promise them things but never come back to deliver. They have been promised things like gardening tools, a fridge, a stove, a computer, crèche for their children, sewing machines and equipment. None of these things were delivered and the people who made these promises disappeared. This was really disappointing to them as they really needed the assistance. They feel that HIV negative people take advantage of them and use them for their own benefit.

The point expressed below supports this view:

“People without HIV exploit us, they use us as ladders. They think the virus is in our heads. They think we’re stupid.”

Some support group members also feel that some HIV negative people come to the group just to see who is there and take the information to the community. Some support group members feel that there should be no HIV negative person coming to the group.

The following statement highlights this point:

“HIV negative people sometimes attend the group and take information outside. I don’t like HIV negative people to attend this group.”

The discussion above points out the fact that the support group is sometimes used by some community members for their own benefit under the pretence of wanting to help
the group members. It also implies that some group members do not trust HIV negative people.

**Unfair allocation of grants and food parcels.**

According to the support group members in this study, there is inconsistency in the allocation of benefits. They expressed the view that there is unpredictability in the allocation of food parcels; and were not happy with the fact that they sometimes get food parcels and sometimes they don’t. They also feel it is unfair that the peer educators in the group don’t get food parcels when the rest of the group does. Peer educators in the group do not get a grant or food parcels because they are employed by the government. The statement below expresses this perceived unfairness:

“Our peer educators are not getting food parcels, because they get paid. This is unfair; they should get them as well.”

The support group members also stated that they felt sad that not all of them were getting a disability grant in the group. All of the above aspects are viewed as negative patterns in the allocation on grants.

**Dynamics within the support groups**

Another factor that was associated with negative experiences within the support group was associated with group dynamics. As an illustration of this point there were feelings of disappointment as new group members got jobs as peer educators and lay counsellors, while long standing members did not. They felt that the members who have been there for a long time should have been considered first.

The statement that follows expresses this view:

“For job purposes, new people from the group were employed and we didn’t get jobs.”

Another point which was raised by one of the participants was that, there is a support group committee, which some of the group members feel is biased when dealing with issues and this hurts some group members. Some feel that there is jealousy among group members, that some members are denied food parcels because of the perception
that they have money. Some group members claim that there are members within the group who sometimes gossip about other members to people outside of the group.

The statement that follows expresses this view:

“Support group members sometimes gossip about each other to people outside of the support group”

There are also group members who feel that there are those who think they are better than others and undermine others within the group.

As expected, when a diverse group of people come together, conflict is usually inevitable due to group dynamics. Support groups are no exception. Sometimes negative experiences are associated with support groups. The causes of these negative experiences can be external, that is caused by people outside of the group, or internal where they are caused by conflicts between support group members. A survey of the literature indicates that not all of the perceptions of support groups are positive. Kalichman et al (1996) discovered that it was common for people to have had adverse experiences in support groups, including complaints that groups were depressing when they focused on illness and when participants witnessed the physical decline of fellow members.

4.2.7. Attitudes towards recruiting others to join a support group.

A positive point that emerged from the study was that, many respondents agreed that they would advise other HIV positive people to join the support group because they would get knowledge, help, support, acceptance and encouragement. They stated that they would encourage others to join the support group so that they could see that there is life after an HIV positive diagnosis, just like other chronic conditions.

The statement below brings this point out:

“Yes I would encourage others to join. I’m a living example; I tested in 1997 and didn’t accept my status. I felt exposed even before disclosing, it was like people can see that I’m positive. I joined the group in 1998 and I got encouraged when I saw healthy happy people. My stress levels came down. I gained knowledge. I also got a job as a peer educator through a support group.”
The participants in this study, agreed that they would recruit all HIV positive people, especially the newly diagnosed ones to join the group so that they could learn how to cope with HIV.

The statement that follows supports this view:
“Yes I would recruit others to join. When you are newly diagnosed it is very difficult to cope, you need to join the support group. That’s how I got help to cope; I also recruited others to join the support group.”

The four responses below are some of the reasons why support group members felt that they will definitely recruit other HIV positive people to join the support group:
“I gained a lot of knowledge. I tested myself in privacy and didn’t tell anyone, in 5 months time I got very sick. That’s when I joined the support group, I got help and knowledge.”

Another respondent stated:
“I was sick at home, had a visit from support group members and they carried me to the clinic to get help. When I felt better I wanted to be part of the support group to help others.”

Yet another support group member remarked:
“People should join the support group and get education on how to live positively and comply with treatment.”

Supporting the recruitment of HIV infected people to join a support group one respondent stated:
“In the support group they will get encouragement and see that they are not alone with HIV. They will also get help with disclosing their status.”

One member, however, felt that she was not sure whether she would recruit others to join because some people just come to look who’s in the support group and they never come back again. This action upsets the group members.
The statement below expresses this view:

“Sometimes we invite people to the support group but they don’t stay, they just come to look who is here and they don’t come back.”

Another member also shared the view that she was not sure if she would recruit other HIV positive people to join the support group, because according to her, support groups are not what they used to be. She had the perception that people come only for what they can benefit from the group.

The statement that follows supports this view:

“Support groups were good at first when there were no benefits, but now it’s about what people can get out of the support group. Sometimes people undermine each other in the support group; there are people who think they are better than others. This makes me feel bad.”

An analysis of the discussions in the theme pertaining to the attitudes towards recruiting other HIV positive people to join the support group demonstrated that the positive experiences of being a support group member clearly outweigh the negative views. This is evidenced by the fact that almost all support group members agree that they would definitely invite other HIV positive people to join the support group because of the said benefits.

4.3. Summary
This chapter has presented the analysis and discussion of the study findings. It is quite clear from the participants’ responses that, for the most part, support groups are indeed helpful in the lives of HIV positive people. Support group members have experienced the benefits of belonging to a support group and would recommend the support group to other HIV positive people so that they can also experience these benefits. The next chapter presents the discussion, implications for practice, limitations of the study, conclusion and recommendations.
CHAPTER 5

DISCUSSION, IMPLICATIONS, LIMITATIONS, CONCLUSION AND RECOMMENDATIONS

5.1. Introduction
This chapter presents the discussion of the findings in relation to earlier studies, the implications for practice, limitations of the study, conclusion and recommendations.

5.2. Discussion
This study explored the role of support groups in the lives of HIV positive people. The study findings reveal that support groups are indeed helpful for HIV positive people. The support groups help to meet the emotional, psychological as well as physical needs of HIV positive people. There are multiple benefits associated with being a member of a support group such as emotional benefits, information benefits, instrumental benefits and material benefits. A study conducted by Gaede et al (2006) also revealed that the benefits of attending a support group included emotional and information support, tangible support affectionate support and positive social interaction. The participants of the study shared the fact that to them, the support group was like family. Mundell (2006) stated that for HIV positive individuals, a support group becomes a new family and a much needed source of support. In this study, support group members expressed the feeling that they had received love, acceptance, peace and courage from the group. When they felt like giving up, the group gave them the strength to carry on. According to Carter (1994), HIV support groups often become a major source of love and acceptance as well as courage for HIV positive people. Most of the support group attendees had fears of disclosing their status to their loved ones before joining the group, but the group had helped them to overcome this fear. Other group members had fears of taking antiretroviral medication because of lack of knowledge, but the adherence counselling they received from the group had helped them to overcome this fear. This is similar to findings of a study conducted by Heyers et al (2010) where participants mentioned that the support group had given them the courage to disclose their HIV status to someone at home and that the support group had also helped them to adhere to their medication.
Emotional benefits reported by group members included a sense of belonging and relief from stress. In the support group, the members felt safe and free from being judged, they met other people who were living with the virus and this helped them to realize that they are not alone. This view is supported by Visser et al (2005) who stated that the interaction with other HIV positive people was an important component in the success of the support groups, because members could share experiences and learn from each other.

It surfaced from the findings that there were also socioeconomic benefits associated with support group membership. Some members became employed as peer educators while other group members also made some money by selling vegetables that they had produced from the garden, as well as some beadwork that they did as part of the support group activities. The food parcels that were sometimes distributed within the groups, as well as disability grants that some members received from the government, also helped to alleviate poverty.

Concerning the issue of disability grants, however, very few support group members were receiving grants as the majority did not qualify according to the criteria set by the Department of Social Development. This was a major cause of frustration for the support group attendees, as they felt that they needed the disability grant to survive, as most of them were unemployed and living in poverty. Goudge et al(2009) stated that government grants play a crucial role in bolstering social support from family and neighbours, providing financial access to basic requirements such as rent, food and clothing for the unemployed, and meeting the costs of transport to the clinic, and in so doing facilitating adherence to medication regimens.

Besides the material help, it also emanated from the group that the other important aspect that they gained from the group was the knowledge that they received about HIV and how to live positively with the disease. This assisted them to be knowledgeable about their disease and treatment. According to Heyer et al (2010), gaining information about HIV and how to remain healthy was an important reason for participants to continue attending the support group. Because of the said benefits, most of the support group attendees were confident that they would definitely recruit
other HIV positive people to join the support group so that they could receive the help they need and also experience these benefits.

Although there was a lot of positive feedback from the participants concerning the support group, there were also a few negative experiences as well. There was some dissatisfaction concerning unfair allocation of food parcels and grant, dynamics within the group and experiences of unfulfilled promises. Support group members shared the feeling that they were tired of people from outside the group who come and promise them things, but never come back to deliver on their promises. Both support groups shared that they had been promised material things by people outside of the group who wanted their ID numbers, but the promised items were never delivered.

Concerning the activities that are conducted by the support groups, besides the music, sport, gardening, beadwork and community outreach, there was no structured program for the support groups. They did not have a set plan that they were following. Members only got together to talk and share experiences. This could be attributed to the fact that there was no trained professional to conduct the group sessions. The group sessions were conducted by a support group chairperson, who is also living with HIV, with no formal training on how to conduct the group sessions. The support group members also shared that they need to be trained in skills that can help them to get jobs so that they can take care of their families, as most of them were unemployed and living in poverty.

The findings of this study also revealed that, the support groups were not getting as much assistance and support as they would have liked to get from the relevant professionals within the multidisciplinary team. They sometimes had a nurse to educate them on HIV and health issues, but they never had visits from a social worker, which they felt was crucial as they had many social problems.

5.3. Implications for practice

It is envisaged that after the findings of this study are shared with the Department of Health, the health care workers should be motivated to refer every HIV positive client to a support group to experience all the benefits shared by participants in this study.
The need for a social worker by support group members came out strongly from the participants. The Department of Social Development in collaboration with Department of Health may need to respond with strategies as to how to meet this need of HIV positive people attending support groups in the Eastern Cape Province.

5.4. Conclusion
In conclusion, this qualitative study aimed at exploring the role of support groups in the lives of HIV positive people. The emphasis was on identifying the needs, expectations and experiences of support group attendees as well as establishing an inventory of activities carried out in support group sessions. The attitudes of support group attendees towards recruiting other PLWHA to join the support group were also investigated.

The first finding of this study is that support groups can assist members in coping with the various challenges associated with living with HIV/AIDS through offering structured emotional, informational, instrumental and material support. Even though there were few negative experiences cited by the support groups interviewed for this study, the benefits clearly outweigh the negative experiences. The members also generally agreed that they would definitely invite other PLWHA to join the support groups.

The second finding is that there is a need for a structured program to be followed in our local support groups as this seemed to be lacking in the support groups studied. Since one of the main concerns of the participants was access to social grants, the proposal is that social workers should be more involved in support groups as well as in facilitating access to appropriate social assistance. The third finding is that there is a need for support-group leaders to receive appropriate training and support in order for them to run the groups effectively.
5.5. Recommendations
Support Groups are an essential element of psychosocial support and should be researched thoroughly in our country if we are to offer our HIV positive population comprehensive HIV care. The following recommendations are made in relation to two spheres of practice namely: Proposed intervention and recommendation relating to further research.

5.5.1 Proposed interventions
(i) The Department of Health and the Department of Social Development should develop a structured program that can be followed by all support groups in the Eastern Cape Province. This would help support group members to be better organized and to make the most out of their group sessions. This program could also include skills training which could help support group members in seeking employment.
(ii) The above mentioned departments and supporting NGOs in the province should ensure that there is training of support group leaders on how to facilitate support group meetings effectively. This would ensure that the group leaders have the necessary skills to maximize the benefits obtained from attending support groups.
(iii) The Department of Social Development should deploy Social Workers to visit the support groups, even if it is only once a month, to listen to the social problems experienced by support group members and assist where they can. The social workers could also impart skills such as stress management and coping skills to the support group members.
(iv) The Department of Agriculture should strengthen the gardening activities done by support groups by providing proper gardening equipment and training to the support group members. If this area can be strengthened, it will ensure that the nutritional needs of HIV positive people are met as well as assist with poverty alleviation.

5.5.2 Recommendations for further research
(i) It is proposed that a further study should be conducted to assess support group attendance versus the number of HIV positive people accessing health services. The reasons for non attendance of the support groups should be explored so that strategies could be developed to encourage support group participation for all PLWHA.
(ii) A further study should also be conducted to assess whether all HIV positive people require/need support groups. Can some people cope without support groups?
REFERENCES


ANNEXURES:

ANNEXURE A

APPROVAL LETTER FROM ETHICS COMMITTEE, UFH.

OFFICE OF THE DEPUTY VICE-CHANCELLOR:
ACADEMIC AFFAIRS AND RESEARCH
Private Bag X1314, Alice 5700
Tel: 04060 22403
Fax: 066282944
tsnyders@ufh.ac.za

Application for clearance from the University of Fort Hare’s Ethics Committee

Project Title: Various applications in the Department of Nursing Sciences as below:

Date of application: 1 December 2008

Having consulted the Dean of Research, I hereby grant permission to conduct the research outlined in the schedule below.

<table>
<thead>
<tr>
<th>Name of student</th>
<th>Proposal title</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr. E.M. Yako 200605058</td>
<td>Adherence to pre-selected infant feeding practices among mothers on the prevention of mother-to-child transmission (PMTCT) of HIV/AIDS programme in the Amathole Region, Eastern Cape, South Africa.</td>
<td>Approved.</td>
</tr>
<tr>
<td>Mrs. N. Mkhencele 200605055</td>
<td>An evaluation of the role of support groups on the lives of HIV positive people at two Community Health Centres in East London, Eastern Cape.</td>
<td>Approved with corrections. Supervisor to oversee.</td>
</tr>
<tr>
<td>Mrs. R. Durrheim 200605060</td>
<td>The study of self-esteem among patients diagnosed with schizophrenia in the East London Hospital Complex, Eastern Cape province, South Africa.</td>
<td>Approved with corrections. Supervisor to oversee.</td>
</tr>
<tr>
<td>Mrs. N. Qomofo 200605064</td>
<td>Community Based Education: The perception of the 2008 first year B. Cur students of the University of Fort Hare.</td>
<td>Approved with corrections. Supervisor to oversee.</td>
</tr>
<tr>
<td>Ms. N. Jora 8421725</td>
<td>Perceptions of final year nursing students of the University of Fort Hare in the Eastern Cape towards the Objective Structured Clinical Examination during the year 2008.</td>
<td>Approved.</td>
</tr>
</tbody>
</table>
ANNEXURE B

APPROVAL FROM THE EASTERN CAPE DEPARTMENT OF HEALTH

Eastern Cape Department of Health

Enquiries: Zonwabale Merle
Tel No: 083 376 1202

Date: 02nd January 2009
Fax No: 046 606 1177
E-mail address: zonwabale.merle@impilo.eoprovd.gov.za

Dear Ms NP Mkhencele


The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.

2. You are advised to ensure you observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants. You will not impose or force individuals or possible research participants to participate in your study. Research participants have a right to withdraw anytime they want to.

3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.

4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.

5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

[Signature]

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT
ANNEXURE C

APPROVAL FROM EMPILWENI GOMPO COMMUNITY HEALTH CENTRE

PROVINCE OF EASTERN CAPE

Department of Health

BUFFALO CITY LSA

Isebe Le Zempilo

EMPILWENI GOMPO COMMUNITY HEALTH CENTRE

Private Bag X 9047, EAST LONDON, 5200

Tel: (043) 733 1289

Fax: (043) 733 9211

Enquiries: Dr. E. Anderson

Date: 01 July 2009

Dear Mrs. Mkhencele

Re: An evaluation of the role of support groups in the lives of HIV positive people at Empilweni Gompo Community Health Centre.

This serves to inform you that you have been granted permission to conduct the above mentioned study at Empilweni Gompo Community Health Centre.

Thank You

[Signature]

Chief Medical Officer: Empilweni Gompo Community Health Centre
ANNEXURE D
APPROVAL FROM NONTYATYAMBO COMMUNITY HEALTH CENTRE

Dear Mrs. Mkhencele

This is to inform you that you have been granted permission to conduct the study of: An Evaluation of the role of support groups in the lives of HIV positive people at Nontyatyambo Community Health Centre.

Yours Faithfully

Mr. P. Yose

[Signature]

2/07/2009

Middle Manager Health: Nontyatyambo Community Health Centre
ANNEXURE E
SAMPLE OF CONSENT FORM (English)

STUDY TITLE: An evaluation of the role of support groups on HIV positive people at Empilweni Gompo and Nontyatyambo Community Health Centres in East London, Eastern Cape.

Mrs. Mkhencele is a registered nurse studying the Role of Support groups on HIV positive people at the above-mentioned institutions. Although the study will not benefit you directly, it will provide information that might motivate other HIV positive people to join a support group, enable health care workers to refer clients in need to a support group and also increase your sense of well-being, arising out of participating in the study.

The study and its procedures have been approved by the appropriate people and review board at the University of Fort Hare in East London. The study procedures involve no foreseeable risk or harm to you or your family. The study procedure will include responding to interview questions, which will take about one-and-a-half to two hours. There will be a note taker and a tape recorder, to capture all your responses to questions. You are free to ask any questions about the study or being a participant and you may call Mrs. Mkhencele on 0844079208 if you have further questions.

Your participation in this study is voluntary; you are under no obligation to participate. You have the right to withdraw at any time and your care and that of your family members and your relationship with the health care team will not be affected. The study data will be coded so they will not be linked to your name. Your identity will not be revealed while the study is being conducted or when the study is reported or published. All study data will be collected by Mrs. Mkhencele, stored in a secure place and not shared with any other person without your permission.

I HAVE READ THIS CONSENT FORM AND VOLUNTARILY CONSENT TO PARTICIPATE IN THIS STUDY.

Subject’s Signature:                                                                         Date:

I HAVE EXPLAINED THIS STUDY TO THE ABOVE SUBJECT AND HAVE SOUGHT HIS/HER UNDERSTANDING FOR INFORMED CONSENT.

Researcher’s Signature:                                                                  Date:
ANNEXURE F
SAMPLE OF CONSENT FORM (XHOSA VERSION)
IPHEPHA LEMVUME YOKUZIBANDAKANYA NESIFUNDO
SOPHANDOLWAZI (RESEARCH)

Esi sisifundo sokujonga indima edlalwa liqumrhu labantu abaxhasanayo (support
group) kubomi baba baphila nentsholongwane ka gawulayo. Oluphando lolwazi
luzobe luqhutywa kumaziko empilo ase Empilweni Gombo nase Nontyatayambo,
Emonti, Empuma Koloni.

U Mrs Mkhencele ngumongikazi oqhuba ufundo lokuphandulwazi ephonononga
indima edlalwa zii support group kubomi babantu abaphila nentsholongwane ka
gawulayo kulamaziko empilo angasentla. Nangona olufundo lusenongancedi wena
ubuqu, kodwa luzoveza ulwazi olunokukhuthaza abanye abantu abaphila
nalentsholongwane ukuba bazibandakanye ne support group.

Uhlobo oluzoqhutywa ngalo olufundo lulphononongiwe lwafunyanwa lungenasiphako
ngabasemagunyeni kwi Dyunivesi yase Fort Hare, Emonti. Olufundo
alunakukwenzakalisa wena nosapho lwakho kwaye ungayeka ngalo neliphi na ithuba
uziva ufuna. Akusosinyanzelo ukuzibandakanya kwakho nolufundo, uqhutywa
yintliziyo. Akuzokusetyenziswa igama lakho kolufundo, ngoko ke akunobakho ndlela
yokuba kwazeke ukuba impendulo zemibuzo zisuka kuwe. U Mrs uzakuqinisekisa
uba lonke ulwazi alufumana kolufundo ulugcinagcina kwindawo efihlakeleyo,
lungadibani nabanye abantu. Uhlobo oluzoqhutywa ngalo olufundo lolokuba
uphendule imibuzo, into leyo enothatha ixesha elingange yure enesiqingatha ukuya
kwi yure ezimbini. Ukuba unento ongayiqondiyo okanye imibuzo ngolufundo
lokuphanda ulwazi, qhagamshela u Mrs Mkhencele kule nombolo: 0844079208.

Ndiyifundile lenkcazelol ingasentla kwaye ndiyavuma ukuzibandakanya kolufundo.

Tyikitya apha: 
Umhla:
Ndimcacisele waqonda lomntu ungasentla yonke into emalungu nolufundo.
Researcher’s signature: Date:
ANNEXURE G
SAMPLE OF INTERVIEW QUESTIONS

1. Please explain your needs as an HIV positive person attending this support group?
2. What were your expectations when you first joined the group?
3. So far, do you think the group has managed to meet these expectations?
   - If YES, how so?
   - If NO, why not?
4. Describe all the activities that you do as this support group?
5. How are these activities helpful to you?
6. Please share with me your positive experiences of being a member of this support group?
7. Describe the negative experiences of being a member of this support group?
8. Would advise another HIV positive person to join a support group? Yes or No, please explain.
ANNEXURE H
SAMPLE OF INTERVIEW QUESTIONS (XHOSA).
IMIBUZO YOFUNDO LOPHANDOLWAZI.

1. Nceda uchaze izidingo zakho njengomuntu ophila nentsholongwane ka
gawulayo ohamba le support group?
2. Wawulindele ntoni uqala kwakho ukuzibandakanya nale support group?
3. Ingaba uzokutsho ngoku le support group iyifezile iminqweno yakho?
   - Ukuba kunjalo, cacisa?
   - Ukuba akunjalo, cacisa?
4. Chaza ukuba zintoni eniye nizenze xa nihlangene niyi support group?
5. Ingaba ziluncedo kanjani ezizinto kuwe?
6. Nceda undichazele zeziphi izinto ezintle ezikweleleleyo ngoba ulilungu le
   support group?
7. Nceda undichazele zeziphi izinto azimbi ezikweleleleyo ngoba ulilungu le
   support group?
8. Ingaba ungamcebisa omnye umuntu ophila nentsholongwane ukuba
   azibandakanye ne support group? Ewe okanye Hayi, nceda ucacise.