

**EXPERIENCES OF STUDENTS LIVING WITH HIV AND AIDS (SLWHA) REGARDING
SUPPORT GROUP IN A SELECTED UNIVERSITY CAMPUS, EASTERN CAPE
PROVINCE**

BY

MATONA PRUDENCE KALIPA

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School of Health Sciences, Department of Nursing Science

University of Fort Hare

Supervisor: Mrs. J.E. Bereda-Thakhathi

Co-Supervisor: Dr. N. Tshotsho

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DECLARATION

On this Day.....of.....
2014, I.....declare that this research is my
original work, unless stated otherwise and that it has never been published before.

Signature..... Date.....

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ABSTRACT

Background: South Africa has one of the highest HIV and AIDS epidemic statistics in the world, especially people under 25 years of age (Department of Social Development, 2002:11). Some university students are implicated, thus Support groups in this context are crucial to help them cope with their unique circumstances.

Purpose: of this study was to assess the effectiveness of support groups for SLWHA within a university campus in the Eastern Cape Province.

Method: Interviews were used to explore the experiences and challenges of SLWHA.

Results: The study shows that support groups are pivotal in the wellbeing of SLWHA in meeting diverse needs such as sense fo belonging, emotional, psychological, information and knowledge,socio-economic as well as health and physical needs. Support group members experience relatively similar living experiences, dynamic as their various lives are, they are able to share their emotions and problems arising from their HIV statuses, thereby lessening their burdens. Some negative experiences were observed, like issues of confidentiality, depression and stress.

Conclusion: University support groups can be improved through structured programs that includes various stakeholders like health professionals (wellness centre), university management, and others including academics within the university. Also, expanding their borders via the use of social networks, and expanding their activities to include music, sports, vegetable gardening, group visitations, skills training, and other useful projects shall help to improve lives of victims and fight against the infection of other community members.

CHAPTER 1

BACKGROUND AND CONTEXT OF THE STUDY

1.1 INTRODUCTION

South Africa is said to have the highest prevalence of HIV/AIDS compared to any other country in the world with 5, 6 million people living with HIV, and 270,000 HIV related deaths recorded in 2011, AIDS Foundation South Africa, 2013. There is an estimated prevalence rate in the general population of 10.8% (Shisana, Rehle, Simbayi, Parker, Zuma, Bhama, Connolly, Jooste & Pillay (2005: 115). To date, South Africa is estimated to have the most People Living With HIV and AIDS (hereafter, PLWHA) globally and a significant minority of PLWHA in South Africa are still engaging in risky behavior of not using protective measures to avoid infection thereby posing a big threat against all the efforts being made to prevent the spread of HIV and AIDS. Support groups in this context play a huge role in educating people about means of living healthy and creating a safer environment for those around them.

Support groups are a mechanism based on group theory which has proven overtime to be effective in assisting people to make necessary changes to attitudes, beliefs and behaviors Visser, Mundell, De Villers, Sikkema, and Jeffery (2005:339). Furthermore, support groups offer a helping hand to HIV positive people and enable them to face the world with a positive attitude. However, it is important to note that a uniform approach or a one glove fits all support group approach may not be useful for the unique challenges faced by HIV positive students.

Spirig, (1998: 43-45) supported the advocacy for tailor-made support groups to accommodate specific needs of different groups, for example they maintain that men living with HIV/AIDS need a tailor made support group made for them. It is thus understood that this would be the case with the assistance offered to students. The emphasis in the study was on the unique needs like facing the fear of dying, dealing with the stigmatization and trying to beat it, living with the uncertainty of HIV and AIDS and living with anxiety, fear and hopelessness (Spirig, 1998:43-45).

Globally, a lot has been said around issues of HIV and AIDS. The following subsection reviews what other scholars have said on HIV and AIDS and support groups. People living with HIV and AIDS suffer a lot of complex emotional and social challenges that ultimately affect their physical wellbeing. Thus support groups have become a crucial part of the strategies that health care givers and advocacy groups offer to address these complex challenges faced by PLWHA. A study conducted by Mundell, Visser, Makin, Forsyth, and Sikkema, (2012:178), highlights that PLWHA join support groups with expectations to; learn to trust oneself, find new solutions to a universal problem, create a sense of belonging and identity, to discuss problems and create innovative ways of dealing the problems, to learn how to comfort others with love, care and honesty etc. An understanding of these expectations is essential in the success of the support groups as they determine the attendance and satisfaction of the clients that could easily be the difference between attending and not attending to gain information to assist in the change of behaviour and being determined to engage in positive, positive living.

In a study conducted in Zimbabwe on HIV prevention-related risk factors among University of Zimbabwe students, the results indicated that there is high risk behaviour among university students. The study results revealed the use of condom as 4% for female students and 15% for male students out of 933 interviewed students (Terry, Mhloyi, Masvure & Adlis, and 2006:40). In South Africa, a study was conducted in Cape Town to investigate the challenges faced by people living with HIV and AIDS (PLWHA), and some of the findings indicated that AIDS-related stigma is still pervasive in local communities, though in other communities it is rife with open stigmatisation of people living with HIV and AIDS (Cloete, Strebel, Simbayi, Van Wyk, Henda, and Nqeketo, 2010:3).

In terms of support groups in higher learning institutions in South African universities, a study revealed that the fear of stigmatization forced many students to live in the closet and not seek required help to improve their positive living, Nowell, (2012:468). The study showed that 38% of students felt that their friends would support them if they disclose their status to them; this means that 62% are afraid of stigmatization. Moreover the study revealed that 18 % felt that the university is an unsafe environment for them. These act as an indication that there is a need for support groups in universities to come up with a tailor made approaches in order to help students regarding their challenges while living with HIV and AIDS within the campus (Nowell, 2012: 468).

The Eastern Cape has not been spared by the pandemic disease and among university students, the risky behaviours is also evident as has been observed in our own

university campus. The HIV statistics continue to grow regardless of the availability of a support groups like SAVE act, which is like a stokvel, has assisted people living with the virus to disclose their status and its effort to reduce the spread of HIV. Amidst all the other efforts by clinics and individuals, there is still a dire need for a tailor made approach to assisting HIV students on campus. In this case students need help which is relevant to their needs given that they live in a university environment which has lots of learning demands.

Since the late 1980's in Eastern Cape support groups have been proposed as an important intervention for PLWA in dealing with challenges and changes coming with illness. These support groups can be made up of strictly men, women, heterosexuals, homosexual or they can be mixed. They can also comprise of people at various stages of HIV disease, and can be directed at individuals, couples or families as well as students. Mundell (2006:14) stated that in response to the acknowledgement that HIV and AIDS is as much a psychological problem, as it is a medical problem, nurses, psychologists social workers, psychiatrists, health advisors and other health providers have made the development of psychological care programmes, in the form of support groups for People Living With HIV and AIDS a top priority.

Being HIV positive is traumatising enough even to adults who live at home with support. What more students that have worse yet unique challenges given that they are away from home, alone with various challenges and learning demands. Presently there is a local support group within the campus hence the need for the researcher to assess its

effectiveness. Given the researcher's background and experience as a nurse, the challenges students face can be stated as the difficulty of disclosing their status, the stigma related challenges, difficulties of dealing of dealing with reality of being HIV positive, thereby affecting their ability to maintain a good health.

According to Spirig, (1998:45), group support is often one therapeutic intervention offered for PLWA. Group support usually means particular interventions provided to a specific group of people by professionals, peers, or both, over a limited time. Visser, Mundell, Villiers, Sikkema & Jeffery (2005: 335) says that sometimes a listening ear is all that one needs to be re-assured that life is worth living. Based on the findings of the studies mentioned above, the main challenges faced by PLWHA, include: HIV and AIDS-related stigma, fear of death, the "othering tendency" where one is blamed for the spread of HIV.

1.2 PROBLEM STATEMENT

South Africa has the highest prevalence of HIV/AIDS compared to any other country in the world with 5,6 million people living with HIV, and 270,000 HIV related deaths recorded in 2011 (AIDS Foundation, 2013). One group that is severely affected by the disease is that of young people, "with approximately 60% of all adults who acquire HIV becoming infected before they turn 25" (Department of Social Development, 2002: 11).

This alone, stipulates that more research needs to be done about the unique challenges faced by young people, especially those that are of school going age seeing the family, community and sometimes the government invests a lot in them in the belief that they are the future leaders.

Moreover, many studies have been done on HIV/AIDS, covering a vast number of different issues, with minimal focus on the fact that HIV also affects university students in a way that is unique to their own circumstance as learners away from home. Some issues covered by other studies before, include, stress, and coping strategies of PLWHA, done by Lazarus and Folkman (1984); issues on social support among people living with HIV/AIDS, done by Kimberly and Serovich (1996); and challenges faced by HIV positive women, concerns on Prevention of Mother-To-Child Transmission (PMTCT), stigma, discrimination and the implications for PLWHA services done by Sanders (2008) and various other studies.

However, very little work has been done with specific attention on the effectiveness of support groups for university students, given their unique challenges. Besides the usual challenges faced by PLWA, HIV positive students in universities are even more burdened because of their unique settings on university campus and campus-life related challenges. Thus the researcher seeks to assess the effectiveness of support groups in the Eastern Cape Province for SLWHA within the university campus.

1.3 THE PURPOSE OF THE STUDY

The purpose of this study was to explore the experiences of students living with HIV and AIDS regarding support groups in a selected university campus in the Eastern Cape Province. The researcher sought to describe and recommend ways of rendering the best support to SLWHA for the betterment of their academic performance and their overall lives.

1.4 SIGNIFICANCE OF THE STUDY

This study attempted to expose the unique challenges faced by HIV positive students and influence the nature of support groups formulated to support them for the utmost effectiveness. The study will recommend strategies for support group formulation and their approaches to assisting HIV positive university students so that these support groups are more effective. This study will also assist in fighting the continuous spread of HIV generated by ignorance or the feeling of helplessness to a point of wanting to vent of frustration by spreading the disease to unsuspecting students. It will also influence the work of university clinics as well as university policy formulation around issues of HIV and AIDS management and support systems.

1.5 THE OBJECTIVE OF THE STUDY

- The objective of this study was to explore experiences of students living with HIV and AIDS regarding the support system in a selected university campus in the Eastern Cape Province.

1.6 RESEARCH QUESTION

The research question was:

- What are the experiences of the SLWHA regarding the support group in a selected university campus in the Eastern Cape Province?

1.7 DEFINITION OF CONCEPTS

- **Student**

A student is a person who is studying at a university or college, furthermore a student is a person who is a learner and interested in particular subject (Wikipedia, Retrieved: 21.02.2013). Students used in the context of this study are HIV positive and are registered at the university of Fort Hare.

- **University Campus**

A University Campus is an institution at the highest level of education where you can study for a degree or do research (Wikipedia, Retrieved: 21.02.2013). In this study a campus will be referring to a selected campus designated for this study. The university

campus where this study is carried out is the University of Fort Hare Main Campus, which is in Alice Town.

- **Support**

Is help that is being offered to a person who needs help, it can be psychological, emotionally or spiritually (Uys and Cameron, 2003: 82). Support in this study refers to the help offered directly or indirectly to the student living with HIV and AIDS.

- **Support Group**

Is a group of people who gather to help each other and also sharing a common problem for example a group of students who are living with HIV/AIDS they meet to support and encourage each other because they are allotment same problem (Uys and Cameron, 2003:81). 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).

- **HIV**

HIV refers to Human Immunodeficiency virus. This is a lent virus (slow virus) that belongs to a group of viruses known as retroviruses and causes AIDS in humans (Weller, 2005:189). Thus this study focuses only on the students who have been tested for HIV and were found to be positive, and are now part of a support group.

- **AIDS**

Acquired Immunodeficiency Syndrome is the late symptomatic stage of chronic disease caused by human immunodeficiency virus infection which progressively impairs the body's cell-mediated immune response to infections and cancers (Weller, 2005: 13). In the context of this research, it is key to note that none of the participants were at AIDS stage; however they were all HIV positive students.

- **Students Living with HIV and AIDS (SLWHA)**

This refers to a student who is infected with HIV/AIDS and is aware of their status. During the whole process of illness they need spiritual and emotional support, and often also economic support (Uys and Cameron, 2003: 4). The students that participated in this study included first year students up to fourth year level. Some of them had known their status prior to registering at the University of Fort Hare, however, some students only volunteered to get tested after registration and discovered their status.

1.8 RESEARCH METHODOLOGY

1.8.1 Research Design

In this study, the researcher used the explorative and descriptive qualitative research design. Qualitative research design is a systemic, interactive, subjective approach used to describe life experiences and give them meaning (Burns & Groove, 2009: 717).

Furthermore Hancock (2002:2) defines qualitative research as that which is concerned with the opinions, experiences and feelings of individuals producing subjective data a lived experience. This study was exploratory and descriptive in nature because it sought to find out lived experiences of SLWHA are getting along in their support groups, what challenges concern them and how best to improve the positive impact of support groups.

1.8.2 Population

The population refers to the larger group of people that can be studied for a particular research. According to Burns & Groove (2009:714), a population is described as all elements (individuals, objects, events or substances) that meet the sample criteria for inclusion in a study. In this study the population comprised of SLWHA in one of the University of Fort Hare campuses within the Eastern Cape Province.

1.8.3 Sample and Sampling Method

A sample refers to a subset of the population that is selected for a study and sampling includes selecting groups of people, events, behaviours, or other elements with which to conduct a study Burns and Groove (2009:721). Burns and Groove (2007:330) defines sampling as a sampling plan or method outlines strategies use to obtain a sample for a study. Purposive sampling method has been used where the researcher used a conscious selection to identify the students that are relevant for the study Burns &

Groove (2009:716). Given the fact that the participants have to be SLWHA, purposive sampling has been used for selecting participants for this study.

1.8.4 Sample Size

Sampling reduces the likelihood of information overload which would result in inaccuracy; this is so because, with a sample; time money and efforts are focused on a manageable size of participants. Sample size means the number of units and individuals that will be used in the study. De Vos, Delport, Fouche, and Strydom: (2005: 328), further explains that the sample size is determined by what the researcher wants to know and the purpose of the study. The size of the sample for this study was determined by data saturation.

1.9 DATA COLLECTION METHOD

Data collection methods refer to the tools used to extrapolate answers to questions asked at the beginning of this study. This means that the key research question determines the kind of research instrument used to collect relevant information (De Vos et al, 2005:292). The researcher primarily used personal interviews to collect data. A tape recorder was used as well as field notes which were then transcribed verbatim. Personal interviews provided a secure, comfortable environment, which facilitated openness and encouraged elaboration to deepen the data.

1.10 DATA ANALYSIS

Data analysis is explained as the sifting out from all the data collected, only that information that is worth telling to others (Hancock, 2002: 27). The data gathered was analysed qualitatively based on the key themes that emerge following the carrying out of interviews with SLWHA within the university campus. This section was guided by the key guiding research questions to organize the collected data, breaking it into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned.

1.11 PILOT STUDY

A pilot study is understood to be a trial study which enables the researcher to test their data collection method and also to test the researcher as a data collection tool. A face to face interview was conducted in that regard to check and improve the researcher's skill to interview as well as the probing skill for more depth.

1.12 ETHICAL CONSIDERATIONS

Ethical considerations are an important aspect of research because there are so many pitfalls which may occur when one draws up a research proposal to research a nursing problem with human participants. To protect the human subjects and avoid some of these pitfalls, ethical considerations are followed. Below is a list of some of the ethical considerations followed in this study:

- Informed consent
- Voluntary participation is encouraged
- Participants were protected from harm
- Confidentiality was observed and anonymity maintained
- Honesty was encouraged or the benefit of the study
- Trustworthiness of the study was placed as a priority.

The above listed ethical considerations are discussed in detail later in chapter 2.

1.13 CONCLUSION

This chapter has successfully introduced the topic, motivated its need and importance, and explained the background to this study. Furthermore, this section also outlined what various other scholars have said and done in previous related studies and finally explained how the research is going to be conducted, as well as listed the ethical principles to be considered for this study.

CHAPTER 2

RESEARCH METHODOLOGY

2.1 INTRODUCTION

Research is a structured enquiry that uses acceptable scientific methodology to investigate problems with the intention of solving them or creating new knowledge. This chapter thus seeks to explain the research methodology used by the researcher in investigating the effectiveness of Support Groups for SLWHA. There are mainly two kinds of research which is quantitative and qualitative research. For this study a qualitative approach has been selected. Qualitative research is an umbrella phrase which covers an array of interpretative techniques which seek to describe, decode, translate, and otherwise come to terms with the mutual meaning of the phenomena under study, Al-Busaidi (2005).

Research can be classified according to purpose, e.g exploratory, descriptive, analytical, or predictive. Due to the nature of the key guiding research questions for this study it can thus be categorically viewed as explorative and descriptive study of the use of support groups in dealing with HIV and AIDS. Research can be classified according to its applicability thereby making it either applied research or basic research (Hussey & Hussey, 1997:86), because this is an academic research it therefore follows that it is basic research.

There are five sub sections on research methodology, the setting, the research design, sampling and population sample, data collection methods, data analysis and the key ethical considerations for this study.

2.2 RESEARCH DESIGN AND METHODOLOGY

2.2.1 THE SETTING

The setting refers to the context in which the study is conducted. Sometimes this is referred to as the background surrounding the study. This study is conducted in a University of Fort Hare Main Campus. The Main Campus has the highest number of students compared to all the three university campuses of Fort Hare. Some of these students are struggling with HIV/AIDS. Of these students, only those that had already tested and knew their status and were already part of a support group. In an education setting, there are already other challenges faced by the student, even worse if the student is HIV and living on campus away from the family.

2.2.2 DESIGN

In this study, the researcher used qualitative research design which has been both explorative and descriptive in nature. This is so, because this study answers the questions of 'who is infected and receiving support', and 'how they feel about the support groups and what challenges they have'. Qualitative research is concerned with the opinions, experiences and feelings of individuals producing subjective data.

This approach thus allowed the researcher to collect data in the form of written or

spoken language. The intent of this qualitative research was to understand a particular social situation and effectiveness of support groups and the interaction within. The research design entailed the researcher being involved in an investigative process where the researcher had to gradually make sense of a the experiences and challenges faced by SLWHA, through the use of contrasting, comparing, replicating, cataloguing and classifying the object of this study. This entailed the researcher entering the participants world and through interviews and observation as is stated by Creswell, (2005:161). The qualitative approach is appropriate and relevant to this research as "it is concerned with the meanings people attach to their experiences of the social world and how people make sense of that world," (Pope and Mays, 2000: 3).

Given the purpose of this study the key guiding research question for this study was:

- What are the experiences and challenges of the SLWHA regarding the support they receive from the existing support groups within a university campus?

2.2.3 POPULATION

According to Mouton (1998: 83) population is the sum total of all the people and their characteristics about which a conclusion is to be drawn, a sample of participants to some degree must share common language, culture and views, as suggested by Leedy and Ormrod (2005: 60). In this study the population included all students living with HIV and AIDS in a selected University Campus. To make the study feasible a population sample was selected out of this larger population.

2.2.4 SAMPLING

A sample refers to a small portion of the total set of objects, events, persons that together comprise the subject of a study (De Vos et al, 2005: 104). This can be understood as the selection of those individuals representing the entire population. In this study purposive sampling was used. Purposive sampling refers to a sample that is formed based on the judgment of the researcher, (Rosnow & Rosenthal, 1991:65). In purposive sampling, individuals are sampled based on the notion that they are likely to possess useful information for the purposes of the study. One of the disadvantages of purposive sampling is that it does not allow for random sampling, therefore all persons in a given category are not given an equal chance of being sampled. Using this sampling procedure, participants were sampled for both the pilot study and the final interviews. Given the fact that the participants have to be SLWHA and be a part of a support group, it thus follows that purposive sampling was used for selecting participants for this study.

- **Sample Size**

Sampling reduces the likelihood of information overload which would result in mistakes or inaccuracy resulting from large amounts of data. Sample size can thus be understood as the number of units and individuals that will be used in this study. The sample size for this study was 15 SLWHA and are part of a support group.

- **Inclusion and Exclusion Criteria**

For the participants to be included in the study they had to meet the following criteria:

- They have to be students at the university of Fort Hare, staying in residences. This means that all non-resident students are excluded from this study.
- The students have to have been HIV positive for at least 6 months and are part of a support group. This means that even if students are resident students and have been HIV positive for longer than 6 months but they are not members of any support group they are naturally excluded on that basis.
- Finally, the students must be willing to freely participate in the study. This means that if students are resident students, HIV positive for longer than 6 months and are part of a support group, but if they are not willing to freely participate in the study, they are excluded.

2.5 PILOT STUDY

Prior to the final field work and data collection, a pilot study was conducted where a trial study was done on two prospective participants who were not part of the larger population sample. The pilot study enabled the researcher to test the data collection tool. In this study that meant that the researcher created the interview guide and used it on two prospective participants emanating from the research questions to check and improve the research interview skills.

2.6 DATA COLLECTION METHODS

Data collection methods can be understood as the tools used to extrapolate answers to questions asked at the beginning of this study. This means that the key research question determines the kind of research instrument used to collect relevant information. Data was collected through individual interview supported by tape records and field note. The experiences of SLWHA in a selected university campus was used as a backbone of this study. While recorded personal interviews are the core research instrument, supplemental observations were made to compliment the findings of interviews. While other researchers have used focus group discussions where experiences and understandings are shared, this is not ideal for this study as it is a very sensitive issue. Student environments, where there is a slight chance of discomfort, can jeopardize the results of the study. The personal interview provided a secure, comfortable environment, which facilitates disclosure, and encourages elaboration (De Vos et al, 2005: 328). The face to face individual interviews were rather time consuming but they were more advantageous as they allowed follow up questions and rendered unexpected information following observations made during the interviews.

Prior to the interview the venue was made to make the participants comfortable. Before recording anything, the participants were told that the interview shall be recorded, as a way of getting their consent. On tape, greetings were done to establish rapport. The signing of the Consent Letter was confirmed by both. The introduction was done on the

topic and focus of the study so that the participant was fully informed. Key to the interview's success was the application of various communication skills such as asking questions with clarity, probing and listening. In respect of key ethical considerations, openness and honesty was encouraged, also the participants were advised that should they want to stop at any given time they should go ahead and state. Moreover, confidentiality was assured by explaining to them that their name will not be divulged nor published. At the end of the interview, the participants were thanked and the interview was properly closed.

2.7 ETHICAL CONSIDERATIONS

Ethical considerations, as introduced in chapter 1, are an important aspect of research because there are so many pitfalls which may occur when one draws up a research proposal to research a nursing problem. Some of these pitfalls are administrative in nature, economic, social and even psychological in nature. Among the remedies to these pitfalls, ethical considerations are key. Ethical considerations are established in order to protect the individuals from any physical harm or mental harm in anyway. Furthermore, it is to respect the moral, cultural values, religious and philosophical convictions, and other fundamental rights including respect for privacy and also maintain the highest level of confidentiality. The researcher ensured that the ethical principles met the national and international standards governing research of this nature with human participants (Murray and Beglar, 2009:32). Therefore, various ethical principles were considered in this study to safeguard the dignity, rights, safety and well-

being of the all the participants in this research study. The point of departure was soliciting approval from the University of Fort Hare Research Ethics committee for this study.

2.7.1 Informed consent

By informed consent, it means that the participants must be told prior to the research what the nature of the study will be and what the procedure will entail and furthermore they may cease participation in the study at any time without penalty as the study is voluntary. The participants for this study were notified prior to the interviews as to what the study entailed. On the day of the interviews the topic, focus and intentions of the study were explained. The participants were notified that the interviews were being recorded prior to the recording of the interviews. Finally, they were given a chance to read a consent letter and authorize the researcher to go ahead with the interview by signing the consent letter.

2.8.2 Voluntary participation

Babbie (2004: 63) asserts that social research represents an intrusion into people's lives, thus an encouragement of voluntary participation is crucial to avoid infringing on people's rights and privacy. The researcher thus encouraged the participants to participate out of free will, first and foremost via a letter of information on the study topic and soliciting consent. Participants were also reminded that they have a right to stop the interview at any given point.

2.8.3 Protection from harm

In this study, dangers such as physical, emotional or psychological harm were closely guarded against and thoroughly examined. Babbie (2004: 64) indicates that social research should never injure the people being studied, regardless of whether they volunteer for the study or not. Research participants for this study were not exposed to undue physical or psychological harm hence the interviews were conducted at a place of their choice and the interview time duration was kept minimal less than 30 minutes. The researcher ensured that reasonable efforts were made to minimize the discomfort and loss of self-esteem, as suggested by Babbie (2004: 64).

2.8.4 Confidentiality and anonymity of the participants

Given that the researcher used interviews to assess a sensitive personal issue, it thus becomes crucial that the participants be assured that their identity will be kept confidential and that their responses shall be kept anonymous. No names were attached to the data given. The research participants' right to privacy was thus respected and under no circumstances will the research report be presented in which the participants are identified or any personal data of the research group is revealed. All data obtained has been treated in the highest ethical and confidential regard.

2.8.5 Honesty

Research findings were reported in a complete and honest fashion without fabricated data to support a particular conclusion. Full acknowledgement of all material belonging to another person is mandatory to avoid plagiarism and documentary theft (Leedy and

Ormrod, 2005: 60). In this study all sources have been acknowledged. In carrying out the interviews, the participants were encouraged to be as honest as possibly can. Even the environment where the interview took place encouraged honesty as the participants were free and open.

2.8.6 Measure to Ensure Trustworthiness

Trustworthiness is key to this study as it its key purpose is to support the argument that the study's findings are "worth paying attention to" (Lincoln & Guba, 1985: 290). As explained earlier in chapter 1, trustworthiness is corner-stoned on credibility, transferability, dependability and confirmability of a particular study. Lincoln & Guba (1985: 296) explain that credibility is an evaluation of whether or not the research findings represent a "credible" interpretation of the data drawn from the participants' original data. They further explain that transferability is the degree to which the findings of a study can apply or transfer beyond the bounds of the project. Dependability is explained as an assessment of the quality of the integrated processes of data collection, data analysis, and theory generation. Finally, conformability is a measure of how well the inquiry's findings are supported by the data collected, by Lincoln and Guba, (1985: 296).

2.9 DATA ANALYSIS

Data analysis was done by sifting out from all the data collected, only that information that was worth reporting in line with the key research questions for this study was used. This section was guided by the key guiding research questions to organize the collected data, breaking it into manageable units, synthesizing it, searching for patterns,

discovering what is important and what is to be learned. This systematic approach to organizing data enabled the researcher to formulate themes that helped to organize data presentation. Thereafter, these themes were interpreted and explained to gain meaning. Gibbs (2002:56) further asserts that the explanations given are a reflection of the interpretation or understanding of the people or situations under study. In short, the data gathered was analysed qualitatively based on the key themes that emerged following the recurrence of certain related answers from SLWHA from the university of Fort Hare.

2.10 DELIMITATION OF THE STUDY

The study focused strictly on University of Fort Hare HIV positive students who are part of a support groups. Moreover, the researcher is aware of possible concerns of confidentiality from participants leading to low participation or misleading answers for that matter. Thus the issue of confidentiality was highly stressed and participants approached individually to encourage open conversations and true answers.

2.11 CONCLUSION

This chapter has successfully laid out how the answers to the key research concerns of this study shall be found. The sampling procedure has been explained, data analysis outlined and finally the ethical considerations key for this study are discussed. The next chapter is on the data collected and analysis.

CHAPTER 3

DISCUSSION OF RESULTS AND LITERATURE CONTROL

3.1 INTRODUCTION

The focus of this chapter will be the discussion of results following data analysis and literature control thus sifting out only that information worth telling others as stated by Hancock (2002: 27). The data gathered was analysed qualitatively based on the key themes that emerge following the carrying out of interviews with SLWHA from the university of Fort Hare. This section was guided by the key research questions that were used to organise the collected data, breaking it into manageable units, synthesizing it, searching for patterns, discovering what is important and what is to be learned.

The researcher further gave explanations as a reflection of the interpretation or understanding of the responses given by SLWHA. To begin with, the researcher exposes the unique needs of PLWHA; this is what necessitates the very presence of support groups. Having understood the latter, the researcher then gave an overview of what happened in the interviews, followed by gender issues observed in support groups, subsequent to that the researcher covers experiences and challenges and finishes off with an evaluation of the effectiveness of support groups as is reflected by the perceptions of the SLWHA.

The support group for SLWHA at university of Fort Hare, is mixed both females and males. Other studies have shown a support for this kind of support groups. This finding is in contrast with recent findings from a study on participation in support groups conducted with HIV positive men, participants felt strongly about having men only support groups Canti-Sigaqa (2010:68). This is natural for men as they tend to strongly influence each other's preference once put in a group. While acknowledging that men have a tendency to shy away from sexual discussions amongst women, this finding can not be accepted as objective as it predetermined the outcome by asking a group of men already involved in a related study, this would be the same if women were to be grouped together on a related subject, they would tend to support a women only support group. It can be argued that the gender homogeneity influences group cohesion and may play a significant part in the outcome of HIV support group participation (DiPasquale 1990:279). We can however take cue from this aspect and introduce age sensitive support groups, whereby 1st years are grouped together and led by a mature 3rd year or 4th year student. Then on the 2nd year they join the larger group so that they are readyied for the dynamics in older groups. Another key finding in this study, is the constant referal to a need for the support groups to be facilitated by professional persons, various literature maintains that the professional leader must continue to be deeply involved in the dynamic life of the group, this is also supported by Woods (2007;9-28).

3.2 AN OVERVIEW OF THE INTERVIEWS

The section above shows that PLWHA have unique needs and it is these unique needs that the Support Groups for SLWHA seek to address. The key concern of this study was the effectiveness of support groups in helping SLWHA. To answer this question, the researcher conducted 15 interviews with SLWHA in the University of Fort Hare, these students are part of a support group for PLWHA.

Prior to the final interviews a pilot study was carried out on 2 participants. The observations made during the pilot study clarified the questions and led to follow up questions to further probe areas which participants proved to struggle with. Thereafter the researcher conducted 15 interviews over a period of one week. There were 5 male participants and 10 female participants. The interviewees were between 1st year and 4th year of their study at the University of Fort Hare. At the time of the interviews in 2012, the majority (9 out of 15) participants were senior students between 3rd year and 4th year of their study. Only two of these were first year students, then the other four were second year students.

To ensure consistency all interviews were guided by an identical interview schedule which the researcher read and understood before administering the interview. The interviews took the form of an open-ended questions whereby participants were asked the same questions. A list of issues for investigation was drawn up prior to the interview, as encouraged by Denzin and Lincoln (2000:46). These interviews were conducted

during the holidays to ensure that the students' university time tables were not interfered with. Minimal time was spent on each interview thus they took about 8-15 minutes. The interview questions are on **Appendix A** at the end of this study.

RESULTS AND LITERATURE CONTROL

The recorded interviews were transcribed over a period of one week.

The table below outlines the themes and sub-themes that emerged during data analysis. These include positive drive of SLWHA as a result of attending support group and negative experiences of SLWHA as a result of attending support group

TABLE 3.1: THEMES AND SUB-THEMES

Themes	Sub-themes
Positive drive of SLWHA as a result of attending support	<ul style="list-style-type: none"> • Increased skills to accept and live with HIV, • A positive drive for leading a better life that protects the life of others, • Means to establish friendships and family ties, • Optimistic positive living, • Finally attending support groups for SLWHA leads to one experiencing a reduction of stress and thus leading an active life.
Negative Experiences of SLWHA as a result of attending support group	<ul style="list-style-type: none"> • Stigmatization, name calling, and rejection, • Being judged and discriminated, • Stress and depression.

3.3 THEME ONE: POSITIVE DRIVE OF SLWHA AS A RESULT OF ATTENDING SUPPORT

Visser, Mundell, Villiers, Sikkema & Jeffery (2005: 335) says that sometimes a listening ear is all that one needs to be re-assured that life is worth living. Based on the findings of the studies mentioned above, the main challenges faced by PLWHA, include: HIV and AIDS-related stigma, fear of death, the “othering tendency” where one is blamed for the spread of HIV.

The results show that support groups are pivotal in the wellbieng of SLWHA as they help to meet the diverse needs such as belonging needs, emotional needs, psychological, informational and knowledge needs, socio-economic, health and physical needs of SLWHA. Emotional benefits reflected in the results of this study include boosted confidence, a sense of belonging, comfort and encouragement when they felt like giving up. Also the members reported relief from stress or depression which challenged them after discovering their positive HIV results. In this theme, the following subthemes emerged;

- **Increased Skills to Accept and Live with HIV regardless the stigma ad discrimination**

Below are some examples of how the participants felt the support groups helped them with regard to a higher quality of life, one participant said they felt they “... **get a lot of help because we are able to disclose and share experiences. It is an open environment where everyone feels free to talk, we feel united so we can live better...**”

The participants felt that attending support groups increased their knowledge about HIV and living positively. Being together in a group enables them to learn and observe from each other and gives one encouragement and skills to accept and live with HIV regardless the stigmatization and discrimination.

- **A positive drive for leading a better life that protects the life of others**

With regard to increased social contact and decreased stress, one participant said, **“we meet different people... we advise each other and enable each other to live with our status. We tell each other that all is our dreams are still possible... we help each other to live healthy...”**

- **Means to establish friendships and family ties**

Attending support groups becomes a point of social contact, especially for those that are newly diagnosed and are living in the closet. Support groups become means to establish friendships and family ties as they all identify with each other’s problems. There is lot of sympathizing and empathy amongst the group as they all identify with each other’s pain.

- **Optimistic Positive living plus a positive drive for leading a better life that protects the life of others**

With regard to living a less risky lifestyle, others were encouraged to disclose to their families and gain strength from the support group so that they own their status and choose an optimistic positive living. One participant said **“...Yes we get a lot of support... when I joined the support group it became a lot of help to me because I met others that**

are like me and they have been living with HIV. We shared experiences and feelings, this strengthens me, for example I did not know how to tell my mother but the group gave me ways to disclose...”

- **Finally attending support groups for SLWHA leads to one experiencing a reduction of stress and thus leading an active life.**

Attending a support group increases social contact and decreased stress of most participants. One participant felt “...**We meet different people...we advise each other and enable each other to live with our status. We tell each other that all our dreams are still possible...we help each other to live healthy...”**

Support groups are a mechanism based on group theory which has proven overtime to be effective in assisting people to make necessary changes to attitudes, beliefs and behaviors Visser, Mundell, De Villers, Sikkema, and Jeffery (2005:339). Furthermore, support groups offer a helping hand to HIV positive people and enable them to face the world with a positive attitude

3.4 THEME TWO: NEGATIVE DRIVE OF SLWHA AS A RESULT OF ATTENDING SUPPORT GROUP

According to the 2012-2016 National Strategic Plan, it is further indicated that from the beginning HIV has been regarded s a human right issues, and denial of human right regarding care and support of people living with HIV and AIDS is regarded as human right violation. It is crucial for all humanity to approach health issues with respect of

human dignity. This theme is indicative of constraints that SLWHA had while attending the support group within the university campus.

Though some participants indicated that attending a support group equips the SLWHA with courage to disclose, three sub-themes emerged indicating the negative drive of SLWHA as a result of attending the support group;

- **Stigmatization, name calling, and rejection**

Also, pertinent in the findings of this research study is that SLWHA face a lot of stigmatization at their homes, communities and even at the university. The act of stigmatization takes many forms such as getting judged, being discriminated, people avoiding a certain topic when you are around, and being called degrading names. The different forms taken up by stigmatization are discussed below.

One participant stated that **“Firstly I get stigmatized everyday by my peer and other members of Fort Hare community. But fortunately for me I am living beyond HIV positive status so that does not affect because I decided to own my HIV status. Also I was rejected by my boyfriend...”**

One female participant felt that the support group enabled her to disclose to her parent, though for a long time she was hiding it because she feared that her father would victimize her mother as he would blame the daughter’s HIV status on the mother. She

says “it was not easy to disclose to my parents particularly to my mother since I knew that my father would blame her...”

She further said that: **“...Even at home my mother’s reaction was negative to a point I lied to her and said I was joking but she finally discovered and accepted it. Other people are always judging you...”**

SLWHA are faced with vast and diverse challenges. It is not all rosy, the SLWHA share a vast number of negative experiences associated related to prior to attending the support group. At the very same time they revealed negative challenges associated with attending a support group. The challenges faced by SLWHA take various forms ranging from emotional, health, socio-economic and psychological. Yalom (1995:56) states that one’s emotional state is related to one’s ability to accept one’s status. It is then indicative that once one suffers rejection and emotional stress, these problems directly interfere with their ability to accept and cope with their status.

One of the key emotional challenges is that of rejection, as shown by the extracts below:

“...my boyfriend rejected me. Then when I met another partner when I disclosed he didn’t accept me, ...People could not accept me and they called me names...”

- **Being judged and discriminated,**

One participant indicated that, “...**Sometimes you lose your friends as far as losing my girlfriend due to my disclosed status. Other people go around talking about you being HIV positive,after I told my friends I started losing them one by one...**”

While she had good intentions by sharing her status with her mother soon after being diagnosed positive, that did not have good results hence she said she was joking and continued to hide her medication and results from her family. The above situation made her hide her status from her mother for a long time before the support group gave her the courage to disclose again. Unlike in a situation whereby one is still hiding and they are forced to play ‘hide and seek strategies’ that affect their times of taking medication. Some people don’t take medication because they are at work or on the way or some family members are around. Let us consider the most popular one of mothers who ends up breastfeeding in public in fear of selling their status away.

The majority of participants attested to being victim of stigmatization whereby once one is seen with a group of HIV positive students, immediately they are “othered” and name calling takes its toll. Due to the existence of misconceptions and stereotypes about HIV, many people in society tend to avoid mixing with the group. In fact, the support group is seen as only being for HIV positive people, whereas the group can be useful for both infected and affected people who need to know more about HIV or who would like to share information to reduce the burden of those infected. One participant said,

“...There are quite a number of challenges I went through after I find out about my HIV status...but the only one that I will mention, that I experienced at the University of Fort Hare is that many people still talk bad about HIV especially about those people that are infected. Also some people like your friends they withdraw from the friendship...”

Other participants attested to being victims of name calling whereby one's status becomes a point of insult by the family, friends and community at large. One of the participants said,

I would say it's the reaction that I get from the other family members as well as the community at large...I would say the stigma is a main problem. Immediately you have been diagnosed positive whenever you disclose you get that negative reaction

Name calling in itself is an act of discrimination and rejection. Due to their status, the participants confessed to being discriminated against by their friends and family. Community members end up avoiding social contact for fear of being infected. This on its own, point

back to the issue of stigma, where people continue to hold stereotypical views and myths about the transmission of HIV.

One participant said, **“I would say, firstly... for example people talk negatively about you or they address you in a negative way or even insult you about your status, I have experienced that...”**

Another participant also stated that, **“...You get stigmatized or you are called names such as ‘lantombazana enalanto’ (that lady with that thing). Also my boyfriend rejected me when I told him about my status...”**

Another participant also stated that, **“...People could not accept me and they called me names...”**

Rejection is a popular issue amongst people living with HIV. Rejection could be from family, friends or community. Of the 15 participants, 3 females were rejected by their boyfriends after they disclosed their status and one male was also rejected by his girlfriend.

One participant said **“...my boyfriend rejected me. Then when I met another partner when I disclosed he didn’t accept me.”**

Some participants complained of experiencing being judged as being loose or having been promiscuous. This kind of judgment leads to more discrimination and name calling. All of the above discussed sub-themes contribute to the rise in stress and depression amongst SLWHA. The group itself also becomes a source of stress sometimes because, when a member falls sick and perhaps passes away, some of the participants tend to begin speculations about their own health.

One participant explained that,

“After I told my friends I started losing them one by one. Even at home my mother’s reaction was negative to a point I lied to her and said I was joking but she finally discovered and accepted it. Other people are always judging you.”

Many a times, the hiding stage is detrimental to others, like the breastfed children. Moreover, it makes life a whole lot difficult for one to live an open life, as a nurse in the field I normally say that this is a stage where one actually stigmatizes oneself by excluding themselves from the larger world, by living in fear that they may be called names before they are even known to be HIV positive. For example, if people are in the house one will avoid being seen with medication and always want to act all strong. Optimistic positive living entails accepting one’s status and learning to live with it. Being in a group of HIV survivors that continue to have a wonderful life regardless of their status makes one look forward to each day with excitement and hope.

The information shared, skills attained, and hope given, one begins to aspire to help others lead a better life by protecting the life of others through being an ambassador or when in a relationship with others, they actually take it upon themselves to engage in protected sex and healthy living for all around them. It was discovered that there were more women than men in support groups. These women were in relatively good health compared to their male counterparts. This finding is consistent with the findings of a study conducted by Summers, Robinson, Capps, Zisook, Atkinson, McCutchan, Deutch, Patterson, and Grant (1999: 234- 237) where the participation in HIV related support groups for women living with HIV was associated with longer survival.

- **Stress and depression.**

Socio-economic challenges are difficult to engage on as they do not easily come out, one would have to observe the home settings or university room and daily routines of the SLWHA to get an understanding of this. However, in this particular study issues of socio-economic issues came up through one participant who said;

“...I am from a poor family hence I usually need someone to help me get to the clinic so that I can get help from the clinic to get food parcels that I can eat so that I can eat my medication...”

Stress and depression is another challenge faced by SLWHA. Yalom (1995:56) states that the emotional state is related to one's ability to accept one's status. Other participants stated that **“I became stressed and depressed.....I became depressed...”**

“...It was not easy to disclose to my parents particularly to my mother since I knew my father would blame her.....It was a challenge disclosing my status to me peers and my girlfriend...”

Due to stress and depression some participants struggled with accepting their HIV status. Furthermore Yalom (1995:56) elaborates that acceptance and belonging to a social group also plays a big role in enabling further self-acceptance of one's status. However, some of the SLWHA even battled with the mere task of disclosing their status to impossible family members. Others feared the victimization of their mothers by their fathers as the fathers normally blame HIV of their daughters on the mother's lack of

discipline. Rejection, thus, in any means, has a negative impact on the road to health for any SLWHA.

It is key that while most of the challenges faced by SLWHA are outside the group, the group itself does offer its own challenges for some SLWHA. A few participants reported little discomforts “the confidentiality in the support group is a bit shaky, meaning that it makes other people in the support group a little bit uncomfortable.” Moreover, if not handled properly the support group becomes a double edged sword in that it can have adverse effects on the members. In the event where one member dies, there are complications where members 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.

Furthermore, the researcher found out that due to the open interaction and the sharing of information, the participants had less emotional stress and they decreased their own feelings of dependence and hopelessness, and they felt that the support group promoted better self-esteem after which they are ready to help the rest of the world by fighting against the spread of HIV. This finding is consistent with another comparative study conducted by Kalichman and Sikkemma (1996:131) 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.

3.5 AN UNDERSTANDING OF THE GENDER ISSUES IN SUPPORT GROUPS

The results of the study show that the support group for SLWHA at university of Fort Hare, is mixed both 10 females and 5 males. Other studies have shown a support for this kind of mixed support groups. However, this finding is in contrast with recent findings from a study on participation in support groups conducted with HIV positive men, participants felt strongly about having 'men only' support groups, Canti-Sigaqa (2010:68). This is natural for men as they tend to strongly influence each other's preference once put in a group. While acknowledging that men have a tendency to shy away from sexual discussions amongst women, this finding can not be accepted as objective as it predetermined the outcome by asking a group of men already involved in a related study, this would be the same if women were to be grouped together on a related subject, they would tend to support a women only support group. It can be argued that the gender homogeneity influences group cohesion and may play a significant part in the outcome of HIV support group participation (DiPasquale 1990: 279). We can however take cue from this aspect and introduce age sensitive support groups, whereby 1st years are grouped together and led by a mature 3rd year or 4th year student. Then on the 2nd year they join the larger group so that they are readyied for the dynamics in older groups. Another key finding in this study, is the constant referal to a need for the support groups to be facilitated by professional persons, various literature maintains that the professional leader must continue to be deeply involved in the dynamic life of the group, this is also supported by Woods (2007;9-28).

3.6 AN UNDERSTANDING OF THE EXPERIENCES OF SLWHA

Cognizant of the unique needs of PLWHA as discussed earlier in this chapter, this section and subsequent sections explore the experiences of SLWHA according to their own words. The results show that some of the participants knew their status prior to registering at the university, whereas the others only tested positive after they had registered at the university. These results show that the university environment encourages students to get tested and know their status. Another reason is the high level of awareness campaigns carried on campus from Orientation day and all year round.

In such an environment, the essence of Support Groups cannot be downplayed; it actually gives more of a reason why the effectiveness of these support groups should be strengthened. The results also show that most students do not join the support group immediately after being diagnosed positive, only a few of the participants joined the support group immediately. Most of these SLWHA take between 3 months and 3 years to join Support groups. This is a worrying factor, since during the time when one is not a member of a support group they are likely to be living an uninformed positive life that could be detrimental to themselves and others. Others who were diagnosed prior to coming to the university even took longer than 4 years, others as long as 8 years before they could become part of a support group. Other participants are living positive for many years and only become part of the support group after they join the university, this means that the university's support group needs to be a highly effective one as it may

be the only mechanism of support that students may ever enjoy during their student days.

The results further show that males have a tendency to take longer to join support groups than their female counterparts. This creates a gap or a need which is later raised by one of the female participants, a need for a strategy to increase male participation in support groups. This finding is could be used to explain why there is 10 females in and fewer man in the support group at the university. These observations are consistent with Viadro, Stratton, Asfaw and Shibru, (2008: 2), when they state that HIV is still seen as largely a “female thing,” and thus women’s attendance of HIV support groups is relatively higher than their male counterparts.

It is imperative that people understand that HIV/AIDS is not a women problem only but rather a whole humanity problem that demands the response and reaction from all females and males alike to ensure an HIV free generation. It is encouraging to note that in men in some parts of the world are beginning to take responsibility for their contribution in HIV/AIDS pandemic. Men now participate in a drive to reduce HIV/AIDS; one key example is the increased participation in voluntary circumcision, especially in Eastern Cape South Africa where circumcision has always been a part of their African traditional practices. According to UNAIDS (2013), It is projected that circumcising 80% of all uncircumcised adult men in the countries with high HIV prevalence and low prevalence of male circumcision by 2015 would avert one in five new HIV infections by 2025, with long-term prevention benefits for women as well as men. If men are more

involved in Support groups then they can discuss such issues in these groups to a point where they can become ambassadors or champions in the adoption of HIV reduction and elimination strategies. In fact, with men's help, medical male circumcision shall assist in the roll out of medical circumcision for newborn males (UNAIDS, 2013).

Finally, SLWHA saw value in the support groups, all SLWHA that participated in this study attested to getting value from the support groups. The findings of this study support Carter's findings as he views support groups as providing 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" Carter (1994:76).

According to the results of this study the kinds of help they get from support groups varies from emotional support, knowledge sharing, experience sharing, advices on how to handle the issues of stigma and discrimination, how to handle rejection, how to disclose, how to own one's status and live positively. The results show that due to the fact that these SLWHA in support groups share a common denominator they openly share their problems. Some of their responses are reflected below;

"...One becomes comfortable with people sharing because we speak, in a way, the same language because of the relationship between us... The confidentiality in the support group is a bit shaky, meaning that it makes other people in the support group a little bit uncomfortable..."

“... I get a lot because I communicate with them about things that I can’t discuss with my family...”

“...Yes I do get the help I need from the support group, for instance now I can be able to own my HIV status... Now I can know what to do and what not to with my status and I am comfortable with the fact that I am HIV positive...”

“...I get help from the support group because we share so many experiences as SLWHA and those personal experiences generate different ideas, updated information which helps us to be strong every day. Sometimes we also invite the experts that are more knowledgeable about HIV pandemic, to those support groups, so we get more information...”

“...sometimes when I am feeling with depressing moment the support group strengthens me to stand firm again and feel like any other normal person...”

“...Yes, we get a lot of help because we are able to disclose and share experiences. It’s an open environment where everyone feels free to talk we feel united so we can live better...”

“...We meet different people...we advise each other and enable each other to live with our status. We tell each other that all our dreams are still possible...we help each other to live healthy...”

“... Yes we get a lot of support... when I joined the support group it became a lot of help to me because I met others that are like me and they have been living with HIV. We shared experiences and feelings, this strengthens me, for example I did not know how to tell my mother but the group gave me ways to disclose...”

“...A lot mam, because the people in the support group know better. Their experiences are sometimes even worse than what I know so we console each other and encourage each other to fight and live on...”

“...I used to struggle with taking my medication now I get constant support from other students in similar situations. I also get a lot of information regarding certain illnesses and challenges and how to deal with them...”

The interaction in support groups is rated highly open. While a few reported little discomforts **“the confidentiality in the support group is a bit shaky, meaning that it makes other people in the support group a little bit uncomfortable.”** The majority mostly stated that due to the fact that they were all sharing a similar problem they tended to see each other as family, thereby making it easier for them to openly interact with each other. Thus they felt they are safe and free from being judged since in the support group they met other people who were also living with the virus and this inspired them to want to own their statuses and live positively. These results are further supported by an earlier study done by Mundell’s study conducted in 2006. Mundell revealed that support groups were like family, this is further supported in a study conducted by Gaede, Majeke, Modeste, Naido, Titus and Uys (2006:362-368). Mundell (2006: 46) states that for HIV positive individuals, a support group becomes a new family and a much needed source of support. Some participants for this study mentioned that the support group had given them the courage to disclose their HIV status to their mother, someone at home and that the support group had also helped to be consistent with their medication, this finding is also evident in Heyers, Mabuza, Couper and Ongunbajo (2010: 234).

Moreover, the participants stated that the open interaction in the support group enabled them to withstand the stigma from society. As a result of the kind of interaction and information shared at support groups, all the participants attested to being able to face any name-calling, negative comments and other challenges. This view is supported by Visser, Mundell, de Villiers, Sikkema & Jeffery (2005:335) who states that the interaction amongst HIV positive people is an important component in the success of the support groups, because members could share experiences and learn from each other. Resulting from this interaction, some participants were strengthened to disclose to their families and community. In some cases some even went as far as becoming champions in the fight against HIV as they began to teach openly about how to live positively and share the information from the support groups with other people in their communities.

In summary it can be asserted that the positive experiences within the support group results in boosted confidence, a sense of belonging, comfort and encouragement when they felt like giving up. Also the members reported relief from stress or depression which challenged them after discovering their positive HIV results. In short the benefits of support groups can be summarized as seen in the next section.

3.7 CONCLUSION

This chapter has successfully discussed the results and provided supporting literature to provide clarity and understanding of the findings. This chapter, guided by the research questions has explored and described the experiences of SLWHA, the challenges faced

by SLWHA and finally reflected how the SLWHA view the kind of support they get from the support group. It is quite clear from the participants' responses that, for the most part, support groups are pivotal in the physical, psychological, social and academic lives of SLWHA. This is more important taking into account that the support groups are the closest kind to family support that the SLWHA get while they are at the university campus. All the participants, SLWHA, have attested to experiencing various benefits of belonging to a support group and are willing to extend their support to fight HIV/AIDS and support other students still living in the closet regarding their status. The subsequent chapter presents the conclusions made from these findings, recommendations, implications and limitation of the study.

CHAPTER 4

CONCLUSIONS, RECOMMENDATIONS, IMPLICATIONS AND LIMITATIONS

4.1 INTRODUCTION

Chapter 4 is the final chapter where the researcher gives conclusions based on the findings, gives recommendations for the betterment of support groups for SLWHA, and outlines the implications and limitations of this study.

4.2 CONCLUSIONS DRAWN FROM THE RESULTS, DISCUSSION AND FINDINGS OF THIS STUDY

Cognizant of the role played by the support group in encouraging the SLWHA and in improving their self esteem and self-acceptance, together with its offer of group belonging, the support group can thus be seen as playing a pivotal role in the wellbeing of SLWHA. Study findings suggest that the challenges faced by SLWHA can be better served if improvements are made to the nature of Support Groups. This can accelerate the ability of SLWHA to better cope with life's little challenges by building a family away from home, in the physical and online. The results also suggest that if not properly handled Support Groups can be more harm than good in that they become detrimental to the very own people that they are meant to strengthen. Some of the negatives (resulting from the support group itself) to look out for are:

- Issues of confidentiality

- Reverse effects resulting from seeing sick members or even a bereavement within the group
- **Discussions regarding positive drive for attending support group**

According to findings of this study one can conclude that members of a support group experience relatively similar living experiences, dynamic as their various lives are, they are able to share their emotions and problems arising from their HIV statuses, thereby lessening their burdens. The participants of this study expressed that they freely interacted amongst each other, things that they cannot openly discuss with their family members with confidence; they share and resolve their problems in the support groups.

Other people's positive living becomes an inspiration, other people come to understand that other members experience bigger challenges yet live with them successfully, thereby undermining their own problems and being challenged to deal with them since others deal with bigger issues. Similarly in a study conducted by Heyers, Mabuza, Couper and Ogunbajo (2010: 234 -239), 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 Spirig (1998:45) suggests 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, 2005:234). Based on the above discussion, clearly support groups have unlimited benefits to help SLWHA thus the improvement of support groups becomes crucial for the future. The section below gives recommendations to help improve the effectiveness of support groups.

- **Discussions pertaining to the negative drive of attending support group**

Initially when support groups were established there was a lot of sensitivity around the issue of open disclosures, over the years these have worn out and more and more people are welcoming the idea of open positive living, and the issue of stigma is slowly being addressed. Participants indicated that support groups are good to strengthen openness but on the other hand it is difficult to be open to people who are close to you. This then is indicative of gaps that are seen by the participants regarding areas that are not handled in most of the deliberation agendas, like relationships, religious issues that are also sustaining them to deal with life and health issues, as well as being a parent of an infected child as a SLWHA.

In view of these developments, there is a need to adopt the suggestion from some of the participants that support groups be made open to both infected and affected people not only the infected. This shall quicken the fight against HIV and further ease the

stigma about HIV as more and more people will be getting firsthand information from the SLWHA.

4.3 RECOMMENDATION AND MEANS TO IMPROVE THE EFFECTIVENESS OF THE SUPPORT GROUPS FOR SLWHA

The following recommendations are based on the results of the study:

- **Religious impact, relationships and having children with HIV and AIDS as a SLWHA should be taken into consideration in support group activities.**
- **Broadening the support group horizon of care**

Support groups can be improved by expanding their borders via the use of the readily available social networks. Support groups can simply send each other messages or links via email or face book.

- **Establishment of a structured programme to guide the support group**

It is a key for the improvement of support groups is the establishment of a system with a structured program for the support groups. The support groups need systematic not sporadic support to successfully maintain effective impact on its members and the community. It is also suggested that support groups should be flexible and allow members to exit when they have been empowered to manage their statuses and

possibly continue the support only via social networks. This shall ensure groups to remain small and manageable as there shall be in and out not only incoming numbers.

4.4 SUMMARY OF THE IMPACT OF THE STUDY

- ***Students Living with HIV/AIDS***, the results have implications for SLWHA, both those living on campus and off campus.
- **Other universities**, the results of this study have such great potential benefits of Support groups, especially for those universities that predominantly black, universities such as university of Fort Hare. They could benefit from their implementation on campus, this is based on the understanding that Africans are community driven people where family support and extended family plays a crucial role in the wellness of the individual and society as a whole. This is especially correct, considering the current approach already much practiced in African societies, with other problems like bereavements, orphaned children or neglected children etc. In such cases the problems is taken care of by the family, whereby each aunt, brother, mother or grandparent pitches in to help whoever is in distress.
- **The Health Care Centers in university campuses**, the results have implications for University Health care centers as they can learn a lot on how to run support groups on university campus.

- **The community at large**, the results have implication for the community at large as they learn more on the plight of SLWHA and learn how the community can become part of the solutions for the Support Groups for SLWHA.
- **The University top management** can learn from the document how to tap into the activities of the SLWHA support groups for the benefit of the victims and the institution at large. Their support to the health care centers in this regard means better service to their students; a happy student is a productive student and thus great ambassador for the university. Thus the management need to support the Health Care Centers and policies to make better the plight of SLWHA
- Government Policy Makers, as they are seen as prospective stakeholders in collaboration with institutions to push health programs that supports the plight of SLWHA on university campuses.

4.5 LIMITATIONS OF THE STUDY

The study focused strictly on SLWHA within one main campus of the University of Fort Hare in the Eastern Cape Province, hence cannot be generalized to the larger population. This means that the study findings cannot contribute to the management of HIV/AIDS in academic institutions, hence the recommendation that follows below.

Finally, to address the methodology limitations of this study, it is recommended that future research should use a wider population sample that can have a control and

experimental group to confirm the results of this study in a situation where results can be generalized to a larger population.

4.6 FINAL CONCLUSION

The study provides a description of experiences, challenges and perceptions of SLWHA on issues of effectiveness of their support groups. The SLWHA studied in this case comprises of students that are already members of a support group. The thesis provides introduction and background in chapter 1, followed by research methodology in chapter 2, consequently giving a discussion of results in chapter 3, and rounding off with conclusions, recommendations in chapter 5.

Given the key research question of this study, the findings are thus summarised up below. The positive experiences of SLWHA include information, increased skill to live positively, social contact, formation of 'new families,' and resultantly encouraging a positive drive to lead a better life that protects self and others. Furthermore, the study successfully reveals the challenges faced by SLWHA, these include: stigmatization, name calling, rejection, being judged, discrimination, stress and depression. Finally, this research gives a clear indication on how SLWHA perceive the role played by support groups in their lives, in essence this reflects the effectiveness of support groups in addressing the unique needs of PLWHA, with special focus on SLWHA.

The study has revealed interesting results that show a high level of appreciation of support groups amongst university populations, with all of the participants attesting to a need for a support group and having gotten emotional, mental or psychological, physical, informationl and social help from a support group on campus. The only need faced by SLWHA but is not met by support groups is the economical challenges. Furthermore, the study exposes the various other areas that a support group can cover, this includes extending the borders of support groups from physical contact to cyber contact thereby creating virtual support systems via social networks like facebook, whatsapp, twitter, Chat or a website presence. Also on the same point, support group activities can be extended to cover the out of the box activities that are normally no covered in suport groups but are a neccessity in the lives of SLWHA, these include music, gardening, short term projects, community outreach, motivational book reading, sharing, and writing where resources permit because a story shared is a problem solved, and many other activities . Finally suggestions are made for the improvement of the effectiveness of the support groups.

The results also revealed an important pattern of more students getting to know their status after registration, thereby putting more demand for effective support groups, for the likely to grow number of students who are aware of their status and need this kind of support. These findings have implications for the nature of activities involved at orientation to thus encourage early testing and healthy safe living to prevent HIV spread on campus. The results further imply that the university management ought to be more visibly involved and render support in the fight against HIV/AIDS. It also implies that all

the departments in the university can play a crucial role in a university wide campaign against HIV/AIDS and support for those infected and affected students and staff.

The importance of support groups must not be downplayed given the fact that there are signs of an increase in risky sexual behaviors in several countries like Burkina Faso, Congo, Cote d'Ivoire, Ethiopia, Gabon, Guyana, Rwanda, South Africa, Uganda, the United Republic of Tanzania and Zimbabwe where more people are involved in multiple partner practice, as well as a decline in condom use in Cote d'Ivoire, Niger, Senegal and Uganda, (UNAIDS, 2013). In a country where promiscuity is on the rise and Sex Workers are fast becoming popular in our little towns, Alice Town included, University of Fort Hare implicated one way or another, people cannot afford to bury their heads in the sand and wish things away. Instead people need to get up and be part of a support group as one of the many mechanisms needed to enable the country to beat HIV/AIDS. We still dream of an HIV free generation.

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APPENDIX A: CONSENT LETTER

Title of The Study: An assessment of the effectiveness of support group for students living with HIV and AIDS (SLWHA) within the University of Fort Hare, Eastern Cape Province.

Investigator: Ms M. P. Kalipa

Organization: University of Fort Hare

Phone : 082 356 7659

E-mail: mkalipa@ufh.ac.za

Background

You are being invited to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear of if you need more information.

The objectives of this study are to:

- To assess the effectiveness of already existing support groups for SLWHA within a university campus in the Eastern Cape Province.
- To recommend strategies that can influence the support groups to be impactful and effective towards the support of SLWHA.

The key research questions are:

- What are the experiences of the SLWHA regarding the support they receive from the existing support groups within a university campus?
- What could be the possible strategies that can influence the effectiveness of the support groups for SLWA in a university campus setting?

Ethical Guidance

I guarantee that your name shall be kept confidential by using a pseudonym instead. By the same token, we request you to be truthful and honest when responding to any of our questions.

If you agree to participate in this study please sign below to show that you are making an informed consent to respond to this interview.

Signature:

Date:

APPENDIX B: INTERVIEW GUIDE

SECTION A: DEMOGRAPHIC INFORMATION

1. Male Female
2. Level of study
3. How long have you known your HIV status
4. How long have you been part of a support?

THE EXPERIENCES OF THE SLWHA REGARDING THE SUPPORT THEY RECEIVE FROM THE EXISTING SUPPORT GROUPS WITHIN THE UNIVERSITY OF FORT HARE

- What are the challenges you experience as a result of your HIV status?
- Do you feel you are getting help from the support group?
- Are you free to interact with other support group members?
- Do you think your being part of this support group has enabled you to deal with the negative comments from society or stigma about HIV and AIDS?

AN EVALUATION OF THE STRATEGIES THAT CAN INFLUENCE THE EFFECTIVENESS OF THE SUPPORT GROUPS FOR SLWA IN A UNIVERSITY CAMPUS SETTING

- Mention any sections of your life where you feel the support group is not touching?
- What do you think should be done to improve the strength of your support group?

APPENDIX C: ETHICAL CLEARANCE CERTIFICATE



University of Fort Hare
Together in Excellence

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: THA01 1SKAL01

Project title: **An assessment of the effectiveness of support group for students living with HIV and AIDS (SLWHA) within a university campus in the Eastern Cape Province**

Nature of Project: Masters

Principal Researcher: Matona Prudence Kalipa

Supervisor: Ms JE Bereda-Thakhathi

Co-supervisor:

On behalf of the University of Fort Hare's Research Ethics Committee (UREC) I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instrument(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the UREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

The Principal Research must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

The UREC retains the right to

- Withdraw or amend this Ethical Clearance Certificate if
 - Any unethical principal or practices are revealed or suspected
 - Relevant information has been withheld or misrepresented
 - Regulatory changes of whatsoever nature so require
 - The conditions contained in the Certificate have not been adhered to
- Request access to any information or data at any time during the course or after completion of the project.

The Ethics Committee wished you well in your research.

Yours sincerely



Professor Gideon de Wet
Dean of Research

27 November 2012