AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS OF HIV POSITIVE INDIVIDUALS' EXPERIENCES OF BEING IN A SUPPORT GROUP

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by

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DECLARATION

I Nicole Brink declare that the work contained in this thesis is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before in any other degree at any other institution.

SIGNATURE	**DATE**
(Nicole Brink)	**July 2017**

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ABSTRACT

People who have been diagnosed HIV positive often experience distress and anxiety due to uncertainties pertaining to the implications of an HIV positive status. Research has shown that support groups have always been a way for people to cope with the distress and stressful circumstances associated with health conditions such as HIV. This research investigated the role of face to face support groups in the lives of those living with HIV. The primary focus of this research project is to provide an in-depth exploration of HIV positive individuals' experiences of being in a support group. The study aims to explore the positive and negative experiences of being in an HIV support group and aims to gain an understanding of the role support plays in the lives of those living with HIV.

A qualitative research design was used to explore the above mentioned aim. Semi-structured interviews were conducted with five individuals, (three women and two men) who had experienced HIV support groups. The interviews were transcribed and then analysed according to the principles of interpretative phenomenological analysis (IPA).

The findings of this study revealed five super-ordinate themes, which revealed not only the positive and negative experiences of being in a support group, but also the challenges that the participants' experienced before joining the group. Getting a sense of the participants' experience before joining the group allowed the researcher to get a better understanding of how useful or not the support group has been in helping them deal with the challenges of living with HIV. The themes included: 'struggling to survive after diagnosis', 'struggling to cope: adopting negative coping skills', 'experiencing a turning-point: a will to survive', 'attending support group: a sweet experience' and lastly, 'attending support groups: a bitter experience'. Findings suggest that for these participants, the advantages outweighed the disadvantages of being in a support group. Therefore this study suggests that face to face support groups are a viable and even necessary option for support. These findings support previous research and literature in regards to the importance of social support in the form of support groups in effectively assisting HIV positive people in their journey to adjust to the consequence of living with HIV.

Keywords: HIV Positive, support group, social support, experiences, advantages and disadvantages

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CHAPTER 1

Introduction

The human immunodeficiency virus (HIV) is the greatest epidemic affecting the world today, with South Africa having more people infected with HIV/AIDS than any other country in the world (UNAIDS, 2016). While some progress has been made in preventing new HIV infections and lowering the annual number of AIDS related deaths, through improved access to antiretroviral medication, living with a serious and life-threatening disease like HIV is likely to be stressful and difficult. The impact of HIV and AIDS has had an overwhelming effect on South Africa, carrying with it enormous stress and trauma both for the individual and society at large. On an individual level implications of being HIV positive might lead to disruptions in the person's overall functioning, including social, physical and psychological (French, Greeff, Watson, & Doak, 2015). This epidemic not only effects the person diagnosed, but families as well, family members experience the burden of caring for ill loved ones, and in some cases grieving the death of a breadwinner in the family, and as a result many children are left orphaned (Piennar, 2015). HIV and AIDS also affects the economy as most of government funding has to be spent on healthcare and welfare, it therefore poses a challenge to the economic sustainability of the country (Piennar, 2015). As part of the response to HIV and AIDS, psychosocial support has been seen as a way to help a person adjust to an illness and to improve their psychological well-being, their quality of life and general health. One way of offering psychosocial support is through support groups (Heyer, Mabuza, Couper, & Ogunbanjo, 2010).

The chapter starts by briefly introducing the concepts of HIV/AIDS, HIV challenges and HIV support groups. It then clarifies the rationale for the selection of the research topic. This is followed by the research question, the aims and objections of the study as well as the significance of the study. Finally, this chapter provides an orientating structural overview of the remainder of this research project.

1.1 Defining HIV/AIDS, Challenges and Support Groups

HIV is the acronym for Human Immunodeficiency Virus. It is a virus that is spread through body fluids that affects specific cells of the immune system, called CD4 cells, or T- cells and can lead to AIDS (Acquired Immunodeficiency Syndrome) if not treated (Bartlett, & Finkbeiner, 2006). It can be transmitted in many ways, such as contaminated needles, vaginal, oral and anal sex and can even be transmitted from mother to child during childbirth or breast-feeding (Bartlett, & Finkbeiner, 2006). Both the virus and the disease are often referred to together as HIV/AIDS. No effective vaccine or cure is currently available for HIV, the only treatment means is through antiretroviral treatment (ART), which is lifelong (Hogg et al., 2008). It is therefore apparent that individuals who wish to lead healthier lives must adhere to continuous ART. Living longer with HIV therefore means having to cope with a combination of various kinds of challenges, namely, psychological, physical, financial and social challenges (French et al., 2015; Halloran, 2006; Martin, & Kagee, 2011; Piennar, 2015). In this study a challenge is referred to as something that makes it difficult for the individual to cope with HIV. It is therefore crucial that, different strategies are put in place to deal with this epidemic. Research has shown that people need support when they find themselves in stressful circumstances, for this reason support groups have become the most common and popular way of providing social support services for people living with HIV in resource-limited settings (Visser, & Mundell, 2008). According to Madiba and Kekane (2013), support groups have been used as a key intervention for the past three decades to help people living with HIV deal with the changes that come with their illness.

A support group is a form of social network aimed at assisting an individual to cope with various stressful situations (Roberts, 2008). The support group utilized for this research comprised of men and women, the majority of them women. They were all HIV positive, who participated in group face-to-face meetings for 15 sessions to discuss various themes related to their HIV positive status with the goal of improving their well-being. Literature has shown that participating in support groups enhances the quality of life, improves coping, well-being and mental health (Atanga, Akenji, Atashili, & Nde, 2015). It also lessens feelings of isolation and shame, improves self-care behaviors, and creates mutually beneficial relationships among participants (Mundell, Visser, Makin, Forsyth, & Sikkema, 2012; Roberts, 2008). Despite the fact that support groups are highly recommended as a means of helping HIV positive people cope with their illness, not many studies have focused on peoples overall experience of being in a support group.

1.2 Rationale for this research project

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 the greatest challenges encountered globally and locally and not much research has been published to evaluate the effectiveness of support groups in the lives of HIV positive people.

Another reason that inspired the researcher to embark upon this study is the fact that most literature focus on the numerous positive outcomes of being in a support group (as seen above) instead of the shortcomings; it therefore seems that there is a clear need to conduct research in this area as experiences might not always be positive, and that this fuller understanding may assist those who offer support groups.

The researcher also felt that there was a need to create a platform that would allow participants at the Noordgesig community center to express their thoughts and feelings about HIV support groups. Furthermore, most qualitative research on HIV support groups focus on attitudes or perceptions of support groups whereas there is relatively limited research on the experiences of actually being in a support group (Kekana, 2011; Madiba, & Canti- Sigaqa, 2012). 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.

It is also important to note that most studies on HIV and support groups are about online support groups (Mo, & Coulson, 2008; Van Uden-Kraan, Drossaert, Taal, Seydel, & Van de Laar, 2009). These studies have found that online support groups may be a helpful place for people living with HIV, however in-person or face-to-face support groups have received comparatively less attention. This study will therefore examine the type of support groups where people meet on a regular basis at a specific time and place to talk about their experiences of living with HIV.

1.3 Research Question

The question that is asked in this study is: What are the positive and negative experiences of HIV positive participants who are members of an HIV support group?

1.4 Aims and objectives of the research

The primary purpose of the current study is to provide an in-depth exploration of HIV positive individuals’ experiences (both positive and negative) of being in an HIV support group. The aim of this study was to add to the knowledge base on the understanding of HIV and the usefulness of support groups, In order to achieve the above, three main objectives were developed for this study, as follows:

- To identify the challenges of living with HIV before joining a support group.

- To explore how being in a support group has helped HIV positive people cope with the challenges of living with HIV/AIDS?

- To determine the positive and negative experiences of being in a support group.

1.5 Significance of the study

As mentioned above, the results of the study will add to the knowledge on HIV support groups, which is currently limited in South Africa. It is also envisaged that the results will be used to improve service delivery and aid in the development of policy on support groups. The findings of this study are expected to help ensure that the experiences of the support group members are understood, instead of simply being assumed.

1.6 Structure of the research project

This dissertation is divided into five chapters that explain the execution of the research project on HIV positive individuals’ experiences of being in HIV support groups. Following this chapter which provides the context for the research, the dissertation continues with Chapter Two which provides a review of the pertinent literature related to HIV/AIDS, the challenges of living with HIV and the role of social support in the form of support groups. Chapter Three discusses the research methodology and design employed to answer the research question. The theoretical framework of the research project is explained, as well as the rationale for the choice of methodology. The chapter also discusses the approach adopted to conduct the research project in terms of sampling, interviews and analysis. Criteria concerning quality are also explicated as well as the ethical procedures followed throughout the research project.

Chapter Four contains an analysis of the data that was collected from the verbatim transcripts of the five participants. It includes an interpretation and discussion of the super-ordinate and sub-ordinate themes that emerged from the analysis, and also positions the findings in the larger theoretical context outlined in the literature review. Finally, Chapter Five provides a conclusion of the entire study with a presentation of the limitations, conclusions and recommendations of the study.

CHAPTER 2

Literature Review

2.1 Introduction

The aim of this chapter is to review selected published literature on HIV and support groups and to look at the importance of social support, specifically support groups, in helping people cope with the challenges of living with HIV. In order to gain a clearer understanding of the meaning that HIV support groups have for HIV positive people this chapter will begin by discussing HIV and AIDS in the context of South Africa. The discussion will progress to uncover the challenges faced by those living with HIV as well as uncover the role that social support play in helping HIV positive people deal with those challenges. The chapter will conclude by looking at the impact of HIV support groups and will look at some research on the advantages and disadvantages of being in an HIV support groups.

2.2 HIV and AIDS in South Africa

Human immunodeficiency virus (HIV) infections remain a pandemic that is difficult to comprehend, as is evidenced by statistics indicating that there are currently approximately 36 million people living with HIV worldwide with Sub-Saharan Africa remaining the most affected region (UNAIDS, 2016). South Africa is known as the HIV/AIDS capital of the world (Kauffman, 2004; Simon, Ho, & Karim, 2006) and had an HIV-positive population of approximately 6.19 million in 2015 (1.2 million more than in 2008), with HIV prevalence ranging from approximately 11,2%- 20% of the total South African population (UNAIDS, 2016). This figure, in comparison with the nation’s total population of 54 million indicates a serious problem and proposes major challenges not only for those already infected with HIV, but also in preventing further transmission of the virus. According to Jackson (2002), there are certain overlapping factors that make South Africa more vulnerable to the HIV/AIDS epidemic. These factors include high levels of poverty, cultural norms that accept and encourage men to have more than one partner, resistance to use of condoms, the low status of woman in society and relationships, and the threat of physical abuse that makes it difficult for women to protect themselves from infection.

South Africa makes use of two main approaches in order to manage the HIV problem; the first is preventing further spread of the virus, and secondly to provide care and support to those already infected (Phillips, 2004). Some of the preventative measures that are used to stop the spread of HIV AIDS include HIV/AIDS awareness campaigns, mass condom distribution, sex education in schools, HIV-testing campaigns, voluntary HIV counselling and testing, prevention of mother to child transmission programmes, home-based care, life skills training programmes and peer education within communities, schools and workplaces (Peltzer, & Phaswana-Mafuya, 2008; Phillips, 2004; Schneider, Hlope, & Van Rensburg, 2008). However, recent studies have shown that ART is being recognized as one of the best ways of preventing HIV in South Africa (UNAIDS, 2016; Quaife et al., 2016). Studies found that ART reduces the viral load to very low levels, which reduces the risk of HIV transmission (Quaife et al., 2016; Rodger et al., 2016). Cohen et al. (2011) found that early initiation of ART in people living with HIV reduced HIV transmission to HIV-Negative partners by 96 percent. An extension of this potential is known as Pre-Exposure Prophylaxis (PrEP) which is the use of antiretroviral drugs to protect HIV-negative people from HIV before exposure to the virus (UNAIDS, 2016).

The incidence of HIV is declining, yet the prevalence is increasing due to the fact that more people are now living longer with the disease (Department of Health, 2011; Khumalo, 2012). According to Rhodes, Bernays and Terzic (2009) and Bor, Herbst, Newell, and Barnighausen (2013), persons living with HIV/AIDS in most cases now face life with a chronic medical condition, rather than an acute, fatal disease. South Africa has made positive strides in managing the HIV and AIDS epidemic and people living with HIV have a more positive outlook on their health (Hogg et al., 2008; Montessori, Press, Harris, Akagi, & Montaner, 2004; Samji et al., 2013; Volberding, 2003).

According to the Prevention Gap Report released by UNAIDS (2016), South Africa became the first country in Sub-Saharan Africa to fully approve PrEP in December 2015 as a method to reduce HIV infection. Even though PrEP was only provided to high risk populations such as HIV negative sex workers a great drop in HIV transmission was reported. Between 2008 and 2012, annual HIV testing increased from an estimated 19.9% to 37.5% among men, and from 28.7% to 52.6% among women, causing a drop in the number of HIV related deaths because people who have been tested are more likely to access treatment (Shisana et al., 2014). In addition the rate of mother to child transmission has dramatically decreased to less than 2.6% in 2012 (Bor et al., 2013).

Yet despite the positive strides made, it is also evident, based on the statistics, that HIV/AIDS remains a major challenge in South Africa, which not only affects the people infected, but the community at large. Even though people with HIV live longer they are still faced with many challenges. Khamarko and Meyers (2013, p. 2) explain that, “despite the advances in clinical science, those infected with HIV continue to experience high levels of discrimination and stigmatization in the communities where they live”. Yet, this is not the only challenge that they are facing. Other challenges include mental illness, physical illness, treatment side effects, co-infection and a financial burden (Bogart et al., 2011; Mavhu et al., 2013; Remien, & Rabkin, 2001).

2.3 Challenges of people living with HIV

The various and many psychological, physical, social and financial challenges are discussed below.

2.3.1 Psychological Challenges

Ramine and Rabkin (2001) highlight several negative emotions that are experienced by the HIV positive individual on receiving a diagnosis; these include shock, anger, despair, hopelessness, sadness, fear, guilt, shame and confusion. According to Sherr et al. (2007), the acute response of being diagnosed with HIV may begin with shock and denial, which may then be followed by guilt and anger or sadness. This is followed by a transitional state during which individuals may alternate between anger, guilt, anxiety and denial. These emotions can be particularly distressing and confusing as some people experience changes in self-esteem, identity and even consider suicide (Sherr et al., 2007). Some fear that they will lose their family and friends, lose their life, their ambitions, physical performance and potency, sexual relations, their position in the society, financial stability and independence (Freemon, Nkomo, Kafaar & Kelly, 2007). This confusion might lead to identity crises according to Ciambrone (2001). Studies have shown that there is an increased risk of suicidal attempts among HIV positive people (Kelly et al., 2000). They may see suicide as a way out from pain and difficult situation and a way out of their shame and grief. Sherr et al. (2007) identifies three key psychological stressors that give rise to the common emotional reactions such as anxiety, depression, guilt and anger. This includes medically related stressors, for example illness and CD4 count; life context stressors such as bereavement and relationship difficulties; and disclosure stressors, for example disclosure of sexuality or disclosure of end of life approaching.

Indeed, a diagnosis of HIV in South Africa can result in a major psychological crisis (Kelly et al., 2000), with significant epidemiological consequences (Freeman, Nkomo, Kafaar, & Kelly 2007). Research has shown that there is a higher prevalence of mental disorders in people living with HIV, with the most common being depression, posttraumatic stress disorder (PTSD) and substance abuse (Brief et al., 2004; Freeman et al., 2007; Martin, & Kagee, 2011; Williams et al., 2008). The available evidence demonstrates that people with depression, PTSD and substance abuse problems are less likely to adhere to their HIV treatment (Martin, & Kagee, 2011; Remien, & Rabkin, 2001). It also shows that poor mental health can (independent of adherence) impact on disease progression, as poor mental health increase the immune system functioning declines, making the condition deteriorate faster than it would otherwise (Sherr et al., 2007). Below is a brief discussion of each of the three common mental disorders as it relates to HIV.

2.3.1.1 HIV and depression

Depression is a prevalent yet treatable condition that is commonly comorbid with HIV/AIDS. The common feature in all depressive disorders are the presence of sad, empty or irritable mood accompanied by somatic and cognitive changes that significantly affect the individual’s capacity to function (DSM-5, 2013). Arseniou, Arvaniti and Samakouri (2014), state that depression in people with HIV might arise due to the overwhelming emotional response to HIV as a stigmatized virus. According to Olatunji, Mimiaga, O’cleirigh and Safren (2006), depressive symptoms include persistent sadness, loss of interest, decreased appetite, sleep problems, low concentration, decreased energy, feelings of worthlessness and suicidal ideation. These symptoms have been associated with high risk behaviour and non-adherence to medication (Arseniou et al., 2014). If depression is not treated or recognised, it can profoundly affect the quality of life and life expectancy of people who are HIV positive and therefore may impact on the person infected with HIV as well as their friends and family (Olatunji et al., 2006).

2.3.1.2 HIV and substance abuse

Research has shown that people suffering from depression and HIV might turn to substances as a way to make them feel better or to get rid of negative emotions (Parry, Blank, & Pithey, 2007). There are certain risk factors that make people prone to addiction, including, experiencing discrimination, emotional, physical and sexual abuse, experiencing stress, feeling like they do not fit in socially and a family history of substance use (Herie, Godden, Shenfeld, & Kelly, 2010). Some studies have shown that people living with HIV are most likely to use alcohol, nicotine, marijuana and crystal methamphetamine (Arcavi, & Benowitz 2004; Kalichman, Simbayi, Kaufman, Cain, & Jooste, 2007; Webb, Vanable, Carey, & Blair, 2007). The study by Arcavi, and Benowitz (2004) shows that smoking is more common among people living with HIV compared to the general population (50 percent to 70 percent) and that smoking is associated with respiratory problems, including pneumonia especially among people living with HIV (Webb et al., 2007). According to Ghebremichael et al. (2009), mixing alcohol with HIV medication can make HIV medication less effective and even useless or can make the medication harmful or toxic to the person's body. A study by Phillips and Ogeil (2010) found that excess alcohol consumption impairs thinking and decision making skills, making it difficult to process and evaluate information about risk. This causes a concern for the transmission of HIV. Crystal Methamphetamine also known as "TIK" in South Africa is the main drug of choice for 42% of Cape Town drug users (Watt et al., 2014). According to Health Education, Advocacy and Leadership (HEAL) (2010), crystal meth is appealing for people living with HIV as it helps them overcome fatigue, a low libido and depression and gives them a sense of feeling desirable. A study by Yeon and Albrecht (2008) indicate that recreational drugs such as crystal meth can affect the person's general self-care, weaken the immune system and make people living with HIV more susceptible to other infections.

According to the Ontario HIV Treatment Network (2009), substance use can increase the risk of experiencing or witnessing traumatic events, including physical violence and sexual assault, and can intensify psychological and physical health problems and can cause additional problems such as post-traumatic stress disorder (Ontario HIV treatment network, 2009; HEAL, 2010).

2.3.1.3 HIV and Posttraumatic Stress Disorder (PTSD)

Posttraumatic stress disorder (PTSD) is defined as a psychiatric illness that may emerge after a person experiences, witnesses or is confronted with an event involving actual or perceived threat of death, serious injury or harm to the integrity to self or others (Sherr et al., 2011). Whether or not the diagnosis of HIV qualifies as a traumatic event as defined by the diagnostic criteria for PTSD is continuously debated (Seedat et al., 2009). Important to note is that the most recent version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American psychiatric

Association, 2013) no longer includes the event of being diagnosed with a life-threatening illness as a criterion-A traumatic event required for a diagnosis of PTSD. Nevertheless, the psychiatric consequences and correlates of HIV described by many research studies utilising previous editions remain pertinent.

Martin and Kagee (2011) indicated that 40% of the 85 participants in their study who were recently diagnosed with HIV in South Africa met the criteria for HIV related PTSD. Many studies suggest that PTSD symptoms are often associated with HIV, including symptoms of intrusion, avoidance, hyper-arousal and numbing (Kelly et al., 2000; Seedat et al., 2009; Young, 2011).

A study by Theunick, Lake, & Gibson (2010) surveyed 100 gay and bisexual men in the United Kingdom and found that 33 percent of the surveyed men met the criteria for HIV/AIDS related PTSD, in that they experienced threats to their physical health and witnessed someone else’s death from HIV, and that they had profound feelings of fear and helplessness related to these events. On receiving a diagnosis of HIV/AIDS, infected individuals may experience recurrent, intrusive thoughts or dreams of illness and death and may try and avoid people, activities and places that serve as a reminder of the illness (Olley, Zeire, Seedat, & Stein, 2005; Theunick et al., 2010). Theunick et al. (2010) also found that there are three HIV-related events that most strongly predict developing PTSD, these included; experiencing physical symptoms, witnessing HIV-related death and interestingly, receiving antiretroviral treatment. According to Theunick et al. (2010) receiving HIV treatment was both the strongest predictor and an unexpected finding. The emotional distress evoked by receiving treatment was more highly correlated with PTSD symptoms than any other stressor. They hypothesised that receiving ARV treatment could include catastrophic expectations about the limitations a medication regime may impose on social or occupational functioning thus leading to traumatic fear, or the perceived failure of alternative medicines and lifestyle remedies leading to traumatic helplessness (Theunick et al., 2010).

A study done at a clinic in Cape Town South Africa by Olley et al. (2005) found that 14% of the HIV/AIDS population met the criteria for current PTSD, 36% of the patients experienced trauma due to knowledge of the diagnosis of HIV/AIDS while in other patients it comprised of other events such as rape (5%), robbery/assault (3%), intimate partner violence (2%), serious accidents (2%) and the loss of a loved one (2%).

2.3.2 Physical challenges

The physical symptoms of HIV vary from individual to individual. Worthington, Myers, O”Brien, Nixon and Cockerill (2005) emphasize the fact that HIV affects multiple systems in the body, which may lead to weight loss, problems with the digestive system, impairments of the immune system, lung problems and skin problems. Living with a chronic illness such as HIV, means coping with a range of symptoms related to the infection, comorbid illnesses or side effects from medication (Halloran, 2006; McInerney et al., 2008). Certainly, the physiological effects of HIV/AIDS limit functional activities thereby reducing health-related quality of life for those living with an HIV-positive status (Squire, 2007). HIV also disrupts an individual’s intrinsic immunity thereby making them vulnerable to opportunistic co-infections (Simon et al., 2006). In South Africa the most prevalent opportunistic co-infection is tuberculosis, with 60 percent of those infected with TB having a co-infection of HIV (Daftary, Padayatchi, & Padilla, 2007). Inadequate adherence to ART can result in increased HIV replication, high viral loads, and healing resistance, which can lead to catastrophic consequences (McInerney et al., 2008). Access and adherence to a comprehensive combination antiretroviral therapy is therefore important as it shifts the perception of HIV/AIDS from a terminal illness towards a chronic manageable disease (Jarman, Walsh, & De-Lacey 2005; Kippax, 2006; Nwoye, 2004).

It is interesting to note that various studies have shown that for some people living with HIV, the shame and guilt of contracting HIV is more difficult than the actual physical effects of the virus (Bond, Chase, & Aggleton, 2002; Mburu et al., 2013; Whetten, Reif, Whetten, & Murphy-Mcmillan, 2008). In their study Sowell and Phillips (2010, p. 394) quoted a participant saying “Living with all the infections, diarrhoea and physical pain of HIV/AIDS is overwhelming, but the pain I experience when people discriminate against me is almost worse than the physical pain of the disease”. Below is a discussion of some of the social challenges that those living with HIV experience.

2.3.3 Social Challenges

2.3.3.1 Stigma, Discrimination and Disclosure

HIV-related stigma generally refers to negative and harmful attitudes and beliefs directed to or internalised by people who are living with, affected by, or associated with HIV and its transmission. It can have significant barriers to the success of HIV-related interventions, such as impacting on HIV testing, mental health, antiretroviral treatment adherence, and the willingness to disclose ones HIV status (Deacon, Uys, & Mohlahlane, 2009; French et al., 2015; Kalichman & Simbayi, 2003; Katz et al., 2013).

There are many different views on what stigma means and what it entails. Goffman (1963) was one of the first to define stigma in relation to sickness or disease. According to Goffman (1963, p. 3) Stigma is "an attribute that is deeply discrediting", which he believed leads to two major consequences: loss of status and social rejection. UNAIDS, (2016, p.9) broadly define stigma as "a powerful means of social control applied by marginalizing, excluding and exercising power over individuals who display certain traits". According to Deacon, Stephney and Prosalendis (2005, p. 12) stigma is a "social process by which people use shared social representations to distance themselves and their in-group from the risk of contracting a disease". SANAC (2014) speak about stigma as negative thoughts about a person or group based on a prejudiced position.

Based on the above definitions it is clear that stigma can mostly be experienced in two contexts, the community and family/friends; with gossip and insults coming predominantly from the community whereas neglect, abandonment and abuse predominantly stem from the family/friends (Roberts, 2008). Herek (2002) and The People Living with HIV Stigma Index (2015) identified four different types of stigma namely, external stigma, internal stigma, anticipated stigma and courtesy stigma. In addition to this, Deacon et al. (2009) and Maughan-Brown (2006) identified instrumental, symbolic and resource based stigma. A brief definition of each type of stigma is provided below.

External stigma is displayed through attitudes or actions aimed at people living with HIV including insults, rejection, avoidance, intolerance, stereotyping, discrimination, and physical violence (SANAC, 2014; The People Living with HIV Stigma Index, 2015). This type stigma refers to the experience of unfair treatment by others towards the stigmatized and is also known as enacted stigma. External stigma makes the person living with HIV feel lonely as people avoid contact with them and treat them as inferior (Herek, 2002).

Internalized stigma happens when people living with HIV begin to believe the negative things that those around them say or think (Herek, 2002). It can also be seen as thoughts and behaviours resulting from the person's own negative thoughts about him/herself based on his/her HIV status. This type of stigma revolves around fear and self-blame and feelings of rejection and usually prevents people from talking about their HIV status and stops them from seeking help in terms of medication and support (Hasan et al., 2012; The People Living with HIV Stigma Index, 2015) According Charmaz (2000), internalizing stigma can have a negative effect on the individuals identity. Significantly, a study in Cape Town shows that internalized stigma is strongly correlated with measures of depression and substance abuse (Simbayi, Kalichman, Strebel, Cloete, Henda, & Mqeketo, 2007).

Anticipated stigma is the expectation that one will be treated differently or poorly in the future for being infected with HIV. This is also known as perceived stigma (Herek, 2000; The People Living with HIV Stigma Index, 2015). According to Earnshaw, Quinn and Pak (2012), anticipated stigma is positively related to stress and depression, which may lead people to experience lower quality of life. They also found that those living with HIV believed that they will be terminated from work, be rejected by friends and family and receive poor care from health care workers just because they are HIV positive. A consequence of anticipated stigma therefore is a reluctance to disclose or even, sometimes to seek HIV testing.

Courtesy stigma is the stigmatization a person perceives or experiences due to their association with people living with HIV or their presumed association with cultures and behaviors that are perceived as responsible for HIV transmission (Liu, Xu, Sun, & Dumenci, 2014). For example, simply being a close relative of someone who is HIV positive is enough for people to avoid or treat others cruelly. Those in close relationships with people living with HIV such as caregivers, family members and partners may be discriminated against just because they are friends with them or related to them. This is similar to Symbolic stigma which occurs when people are stigmatized based on their association with marginalized groups or groups that are considered to be at ‘risk’, these people are usually viewed as suspect, morally deficient, or as carriers of HIV transmission, including sex workers, gay men, and people injecting drugs (Herek, 2002; Deacon et al., 2009). These people are often already marginalised and HIV stigma is an additional layer of marginalisation.

Instrumental stigma refers to an individual’s fear of being infected with HIV/AIDS and can be expressed through an individual's concern about his or her risks of contracting HIV through casual contact with people living with HIV/AIDS, such as drinking from the same cup (Deacon et al, 2009).

Resource based stigma refers to the perception that investment of resources in people living with HIV in low-resource settings is wasted because AIDS is both an incurable and deadly disease, while those who are HIV-positive are often cruelly considered responsible for their own infections (Holmes & Winskell, 2013; Maughan-Brown, 2006).

HIV is predominantly classified as a sexually transmitted disease and is perceived by some to be acquired by way of immoral behaviour; this effectively holds the individual with HIV responsible for its occurrence. Pattison (2000, p. 57) explains that "Stigma invokes themes and feelings of humiliation, inferiority, boundary violation, personal anguish and self-devaluation". Having no one to talk to can become an isolating experience as the person feels unable to access social or peer support because of the fear of abandonment or being the subject of gossip (Ssali et al., 2010; Lee, Kochman, & Sikkema, 2002). A horrific example of HIV/AIDS stigma in South Africa is that of Gugu Dhlamini who was stoned and stabbed to death in 1998 for publicly disclosing her HIV status on a local radio station (Jackson, 2002). At the time there was a great animosity towards people who spoke openly about HIV issues because HIV was perceived as a disease affiliated with immorality (Jackson, 2002). Another example of stigma in South Africa is Lorna Mlofana who was a female member of the Treatment Action Campaign from Khayelitsha, South Africa and who was raped by a group of young men who then murdered her after they discovered she had HIV (Almeleh, 2006). A more recent example of stigma in South Africa is the story of a 26 year old man who committed suicide in 2015 after his wife disclosed that she was HIV positive; the man was in shock and disbelief and could not imagine the idea of living with HIV (Modise, 2015).

Despite all of this, research has shown that HIV is becoming less stigmatised and disclosure has become easier due to the wider availability of ARV treatment, reduced fatality rate and an increased number of people, including men, who receive counselling and testing (Denis, 2014; Chan, Tsai, & Siedner, 2015). A large-scale study by Chan et al. (2015), conducted in 18 African countries between 2003 and 2013, found that while a large majority of men and women gave a stigmatising response to at least one of the four questions, these figures declined during the period of significant scale-up of HIV treatment. According to Chan et al. (2015), despite gains, stigma remains deeply entrenched in many African counties.

According to Young (2011) receiving an HIV-positive diagnosis presents challenges which extend beyond medical effects, and directly relate to processes of identity crises for those infected. Typically disclosing a positive HIV status is understood as an analysis of potential benefits and risks (Frye et al., 2009). The benefits of disclosure involves access to institutional treatment, increased health and well-being, relief from secrecy and support opportunities for people living with HIV (Norman, Chopra, & Kadiyala, 2007), on the other hand the risks of disclosure revolve around the stigmatised attitudes and perceptions regarding being HIV positive (Gilbert, & Walker, 2010; Peterson, & Swarts, 2002) and the potential loss of relationships, rejection and exclusion occurring from disclosure (Jarman et al., 2005). Disclosure involves complex continual decisions about who to tell, how to tell them and when to tell them. Norman et al. (2007) describe disclosure decisions as fluid processes which may have multiple rather than one inevitable outcome. However, such risks are necessary for the mobilisation of support and treatment, which requires public disclosure, whether in group settings to access support groups or individual settings to access counselling and treatment opportunities (Poindexter, & Shippy, 2010; Skhosana, Struthers, Gray, & McIntyre, 2006).

Haricharan (2010) identifies two types of disclosure: full and partial. Partial disclosure is characterised by seeking out specific people whom they choose to disclose to. Full disclosure is a public form of disclosure where people living with HIV do not hide their status, and do not selectively disclose to particular people (Haricharan, 2010).

The majority of people living with HIV solved the dilemma of risk and benefit through disclosing partially and managing their disclosure carefully (Kalichman, & Simbayi, 2003). A study by Heyer et al. (2010) found that disclosure was mostly limited to a support group, thus disclosing only to people who were also HIV-positive. Partial and delayed disclosure enables them to minimise the risk of enacted stigma, discrimination and exclusion, while at the same time achieving some of the rewards in disclosure, namely feeling free, improved health and well-being and being able to receive support. On the other hand due to the risks involved most people choose not to disclose at all so they would rather avoid HIV tests and rather keep their status a secret from others hoping that it will reduce discrimination and judgement from others (Jarman et al., 2005).

2.3.4 Financial Challenges

HIV/AIDS, like all transmittable diseases, is linked to poverty. Based on the statistics above it is evident that South Africa is faced with a high incidence of HIV, but in addition to this South Africa also has a high unemployment problem and therefore many of the people living with HIV/AIDS might be faced with various economic disadvantages. Mbirimtengerenji (2007) explains that most people in South Africa lack not only money, but belongings and skills as well, for this reason he defines poverty as “interrelated features of well-being that impact upon the standard and quality of life” (p. 605). According to Piennar (2015) there is a complex relationship between poverty and HIV/AIDS. The relationship is two way, in that poverty is a key factor in transmission and HIV/AIDS can impoverish people in such a way as to intensify the epidemic itself. Piennar (2015) explain that poverty is both a cause and a consequence of HIV/AIDS, for example, poverty is a consequence of HIV because in some cases the breadwinner may be too ill to work or die as a result of HIV/AIDS leaving the family stranded. On the other hand poverty can be the cause of HIV because people who live in poverty strive to get their basic needs met which leads to risky behaviours such as transactional sex for survival, this is further emphasized by a study done by Verheijen (2011, p. 116) when he found that the “direct need for material support plays a role in poor women’s decisions to readily accept sexual proposals from men”.

Mbirimtengerenji (2007) explain that poor people infected with HIV are considerably more likely to become sick and die faster than the wealthy since they are likely to be malnourished, in poor health, and lacking in health attention and medications. The experience of HIV/AIDS by poor individuals, households and communities is likely to lead to an increase in poverty, push some people into poverty and some of the very poor into destitution (Mbirimtengerenji, 2007). High unemployment is combined with the tendency of HIV positive people to lose their jobs as the disease progresses, often as a result of discrimination (Hunt, Jacques, Niles, & Wierzalis, 2003). As seen above in the section on stigma and discrimination people with HIV are rejected by their families, dismissed from employment, denied access to services and excluded from gatherings and events, all as a result of unrealistic fears amongst the public. A study done by Maloon, Crous and Crafford (2004) found that only four out of ten employers were supportive when they found out their employees were HIV positive and as a result HIV positive employees had to face demotion, get fired, look for a new job or refuse to reveal their status to save their job. Maloon et al. (2004) found that on average HIV positive people were absent from work for about 12 days in the last six months due to illness, 20% of HIV positive people reported a loss in income due to their absence from work. Maloon et al. (2004) also explain that having a job is very important for HIV infected people as it gives them secured financial income, a sense of fulfillment and achievement and also helps keep them busy.

In order to assist those who are too ill or weak to work the South African Social Security Agency (SASSA) provides a temporary disability grant to HIV positive people with a CD4 count lower than 200, however once the person begins responding to ART and their CD4 increase the disability grant is taken away (Nattrass, 2006). This provides a challenge as South Africa's unemployment rate is estimated to be at 36.3% meaning there are about 5.7 million unemployed South Africans (Statistics South Africa, 2016). The grant money is therefore important, even to those capable of working because they are usually unable to find a job. Even though ART is provided completely free of charge in South Africa, other costs may force patients to choose between treatment and other immediate needs.

One of the most commonly reported ART-related expense across sub-Saharan Africa is transportation (Nattrass, 2006). The distances that patients must travel to reach hospitals and clinics providing ART are often long. Many South Africans must depend on public transport, in order to reach their destination. The cost of such service ranges widely depending on the total distance traveled, transportation methods available and remoteness of the patient's residence (Hardon et al., 2006). Without the money to travel to hospital or clinic to get ART, patients will not receive the necessary care from their doctor and therefore they will be less likely to adhere to treatment (Mbirimtengerenji, 2007). In addition, because so many people rely on public transport, the reliability of these types of transport can pose a problem. Treatment for HIV is therefore neglected when patients live in poverty and lack such vital necessities as food, or transport money for themselves or family members.

A cross-sectional survey by Amoateng, Kalule-Sabiti and Oladipo (2014) surveyed 728 HIV positive people and their caregivers and found that 70% of the people surveyed experience both food shortage and financial difficulties. ART requires a certain level of nutrition and because poverty is such a serious issue in Sub-Saharan Africa, many people struggle to maintain a steady and healthy diet. Starting ART adds strain for two reasons: appetite increases as health returns and some medications are affected by a patient's food intake (Hardon et al., 2006). Almost half of AIDS-affected households have insufficient food at times (Steinberg, Johnson, Schierhout, & Ndegwa, 2002). As the body regains strength and weight with the initiation of ART, caloric requirements swell and severely resource-limited individuals may default treatment because they cannot afford the additional food they now need. Further complicating the nutrition and treatment relationship, some medications depend on food schedules which may be erratic for those struggling to get enough to eat (Hardon et al., 2006).

As seen above living in poverty further complicates an HIV diagnosis for many South Africans. Bowleg (2012) speaks about the Intersectional Theoretical Framework in order to make sense of the various challenges that those living with HIV experience. Intersectionality was developed roughly in the late 1980s and was first highlighted by a feminist scholar and advocate Kimberle Crenshaw (1989). It is an analytical tool used to understand and respond to ways in which gender identity interacts with other social factor such as race, age ethnicity and sexual orientation (Crenshaw, 1989). Crenshaw (1989) further emphasizes that intersectionality is not merely a multiplying of identity categories such as gender and race; rather, it is meant to provide a means of analysis for how particular identities and conditions are located within structures of power. According to Bowleg (2012) intersectionality is the idea that many parts of a person's identity impact their life at the same time. In most cases some of these aspects lead to oppression. Bowleg (2012) reports that it is important to not only look at just the person's experience of being HIV positive, but to also consider how the persons gender, socio-economic status or race all interact to shape how people with HIV live.

2.4 Coping with the challenges of living with HIV.

Developing positive ways of dealing with the demands of living with HIV can be difficult. According to Moskowitz and Wrubel (2005) the process of coping is triggered by an appraisal. Each situation is assessed based on the apparent threat and/or whether the individual will be able to control it or not (Moskowits & Wrubel, 2005). Thus, if the individual feels that she or he cannot control the threat, he or she may struggle to adjust and cope (Moskowits & Wrubel, 2005). In his study Olley (2006) found that newly diagnosed women tend to adopt problematic coping strategies a result of the shock of receiving a positive diagnosis. Walulu and Gill (2011) found that some HIV positive people coped through caring for their children, keeping busy with the children seemed to be a distraction from the challenges of living with HIV.

Lazarus and Folkman (1984) identified two types of coping styles; emotion-focused and problem-focused. Emotion-focused coping involves trying to reduce the negative emotional responses associated with stressful life events (McLeod, 2009; Lazarus & Folkman, 1984). For example, when someone is diagnosed HIV positive they might feel depressed and anxious and view the diagnosis as a threat that cannot be managed, which may lead most people to adopt emotion-focused coping skills such as substance abuse or blaming and isolating themselves and even denial (Kotze, Visser, Makin, Sikkema, & Forsyth, 2013; Myint, & Mash, 2008; Pence et al., 2008). According to Kotze et al. (2013) emotion-focused coping does not provide a long term solution and may have negative side effects as it delays the person from dealing with the problem.

Another study by Makoae et al. (2008) examined how people living with HIV coped with HIV related challenges. They found seven different strategies that HIV positive people use, with majority (55.1%) of the participants opting for problem-solving coping strategies, such as disclosing their HIV status, speaking to other HIV positive people who share the same problem, getting counselling, helping others to cope with the illness, educating others, learning from others, finding out more about the disease and also joining a support or social group. In addition to this Dagied and Duckert (2008) found that spirituality and religion is a coping strategy used by many people during difficult times. During time of stress and trials people tend to draw nearer to God and pray more as a way of sustaining hope (Dageid, & Duckert, 2008). Studies have shown that participation in a support group enhances problem-focused skills which is more concerned with practical ways of dealing with a problem and aims to remove the cause of the stressor by making use of problem solving skills (Mokhoka, 2000). Problem-focused coping focuses on making positive changes in one’s lifestyle. Being part of the support group facilitates the knowledge that an individual can utilise to modify their lifestyle, providing a long term solution. Pascoe and Richman (2009) and Moskowitz and Wrubel (2005) found that problem-focused strategies are successful in dealing with stressors such as discrimination and HIV infections and therefore support groups help those living with HIV utilise various positive resources as coping strategies to improve their daily lives.

Below is a detailed discussion on social support and support groups as a coping strategy for those living with HIV.

2.5 Social Support

Considering the challenges and complications that people living with HIV/AIDS must deal with, access of care and support are constantly required. Despite all the pessimism surrounding the HIV/AIDS epidemic there are people who are courageous enough to openly disclose their HIV status to family, friends and their communities in order to get support and relief from the stress of secrecy (Mattson, & Hall, 2011; Ssali et al., 2010). Many people who seek support from loved ones do so because they might find it difficult to cope with a crises or problem on their own and therefore when they do not receive the support they long for from family and friends it can be really devastating for them (Ssali et al., 2010). According to Gottlieb (2000, p. 195) social support is a “process of interaction in relationships which improves coping, esteem, belonging and competence through actual or perceived exchange of physical or psychosocial resources”. It is “networks of family, friends, neighbours and community members that are available in times of need to give psychological, physical and financial help” (Mattson, & Hall, 2011, p. 183).

A great deal of research has explored the importance or the effectiveness of social support in the lives of people with chronic illnesses (Freeman et al., 2007; Holt-Lunstad, Smith, & Layton, 2010; Khamarko & Myers, 2013; Vyuvaharkar et al., 2007). Most of these studies have found a positive link between social support and overall well-being, providing evidence that social support is associated with decreased risk of mental illness, physical illness and mortality. A study by Vyuvaharkar et al. (2007) found that people who have social support are less likely to miss medication or engage in unsafe sex; for example, a supportive family member might remind the HIV positive person to take their medication and a supportive nurse at the clinic will educate the HIV positive person and encourage them to stay healthy. Despite the positive effects of social support various studies also indicate that people with HIV experience lower levels of social support after the diagnosis than before and less social support compared with people with other chronic diseases (Klein et al., 2000; Turner-Cobb et al., 2002). Hudson, Lee, Miramontes and Portillo (2001) found that HIV-positive women reported limited social interaction with family and friends and a low level of perceived social support.

Cohen (2004) identifies three types of social support: instrumental, informational and emotional. Instrumental support involves the provision of material aid; for example, financial assistance or help with daily tasks. Informational support refers to the provision of relevant information intended to help the individual cope with current difficulties and typically takes the form of advice or guidance in dealing with one’s problems (Cohen, 2004). Emotional support involves the expression of empathy, caring, reassurance, and trust and provides opportunities for emotional expression and venting (Cohen, 2004).

Mountinho (1990) identified two broad categories of support systems, formal and informal support systems. The formal support system includes provincial hospitals, HIV clinics and primary care practitioners such as doctors, social workers, nurses and other health care workers whereas the informal support network consists of family, friends, partners and support groups. According to Pierret (2003) the primary source of help for most individuals is social support from family members. Familial support is especially common in poorer societies, and is supplemented with religious based organisations and NGOs (Mbilinyi, & Kaihula, 2000). Governmental support in the form of health-care systems is also utilised, especially in societies with inadequate medical resources. 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, access information and learn from the stories of other infected individuals (Summers et al., 2000). Therefore, the aim of this study is to focus on support groups as a means of social support for people living with HIV.

2.6 HIV Support Groups

Early in the HIV/AIDS epidemic before there were prescription drugs to fight HIV, even before a test was available to confirm the presence of HIV, people suffering with HIV/AIDS-related symptoms coped through participation in support groups (Spirig, 1998). Now there is a variety of medications that are used to fight against HIV, yet the importance of support groups for people living with HIV, their families and friends' remains just as critical as it was in the early 1980s (Davidson, Pennebaker, & Dickerson, 2000). Support groups are the most common psychosocial support services available to people living with HIV (Madiba, & Kekane, 2013). In South Africa, most support groups are led by HIV-positive lay counsellors who were trained by non-governmental organizations (Department of Health, 2011). According to Robert (2008), a support group is a place where people with a common situation or illness come together to share their experiences. It is a gathering wherein people with shared challenges, concerns and needs come together to support one another in various aspects of daily living and functioning to share information, knowledge, ideas and experiences without feeling judged (Mundell et al., 2012).

2.6.1 Purpose of HIV support groups

The purpose of support groups includes, providing advice, information, emotional and moral support and to promote awareness about HIV (Davidson et al., 2000; Mundell et al., 2012).

Ultimately the aim of HIV support groups are to provide a safe, confidential environment where people can communicate freely and find the emotional support they need to better normalize HIV in their lives (Family Health International, 2012).

2.6.2 Characteristics of HIV support group attenders

Studies conducted in Sub-Saharan Africa have found that most support group attenders are female who are mothers; usually in their thirties, unemployed and with relatively low levels of education (Shacham et al., 2009; Madiba and Kekana, 2013). Those who attend support groups have also been characterized as experiencing higher psychological distress (Brandt, 2009; Freeman et al., 2007) and reporting lower social support from friends and family (Visser, & Mundell, 2008) than those who do not attend support groups. Men who join support groups are usually older, more likely to be married, and report more physical symptoms and lower CD4 counts than women who join support groups (Madiba, & Kekana, 2013). Numerous reasons have been identified for why HIV-positive individuals join support groups, some include the need for social and emotional support, need for information concerning the illness, being referred by a healthcare worker, access to medication and grants, changing family and friends' attitude towards the illness, dealing with fear of being stigmatized, and making friends (Dageid, 2014; Mkhencele, 2011; Shacham et al, 2009). Visser and Mundell (2008) found that those who seek to attend support groups long to be accepted and loved, to access services such as food parcels and have a desire to disclose their status to loved ones as they do not know how.

2.6.3 Types of Support Groups

Support groups can come in many different forms. Lypen, Lockwood, Shalabi, Harper and Ngugi (2015) speak about four different types of support groups:

Firstly, clinical based support groups. These support groups are offered by Government Health Institutions such as outpatient clinics or hospitals and are often run by a nurse, social worker, psychologist or a doctor. These support groups are directly linked to the patients' medical care and they have a set timetable of when everyone should meet; a folder with the client's history and set program is kept on record. The members are usually people who have been diagnosed in the clinic.

Secondly, faith based support groups. These are usually run by religious leaders. Members include people who have counseling sessions with the church minister or counselor and the members usually attend that specific church. Thirdly, community based support groups. Community based support groups may be organized by a non-profit origination. The support group leaders are usually volunteers who are HIV positive and have personal experience or a family member of someone who is HIV positive. These groups are geared towards interaction and emotional support. Due to the lack of psychological services available to HIV positive people, support groups that form informally in neighborhoods have become the most important sources of support and help for HIV positive people (Forsyth, & Sikkema, 2012).

Lastly, online support groups. This is usually done through internet blogs, online chat-rooms and social media and can be accessed from the comfort of the person's home. This means that people can participate anonymously without showing their faces or revealing their real names. There are no time constraints or set schedule, people are able to access the group or chat to anyone anytime of the day or night. According to Kraan et al. (2006), many people who use online support groups are simply seeking informational support while others are looking for means to feel like they are not alone. For this reason most of people who use online support groups are 'lurkers', these are people who read messages without posting their own comments (Nonnecke, & Preece, 2000).

2.6.4 Advantages of Support Groups

There are many HIV support groups in South Africa, but the question that should be asked is, in what ways are these support groups beneficial or not for those living with HIV. Many studies emphasize the fact that there are various benefits of attending support groups (Atanga et al., 2015; Alemu, Mariam, Tsuli, Ahmed & Shewamore, 2012; Huang et al., 2006; Lee et al., 2002; Lennon-Dearing, 2008; Marino, Simoni, & Silverstein, 2007; Mattson and Hall, 2011; Mundell et al., 2012; Roberts, 2008; Tumwikirize, Torpey, Adedokun, & Badru, 2015; Waltstrom et al., 2013). These benefits include:

2.6.4.1 Reduced isolation

Isolation and loneliness are among the most difficult things for people to deal with when they are diagnosed with HIV. People mainly isolate themselves due to fear of stigma and as a result feel lonely (Jarman et al., 2005). Loneliness is an emotion experienced when someone feels separated from others or unsupported and distressed (Hawkley, & Cacioppo, 2010). Chronic loneliness and feelings of alienation can be extremely detrimental to a person's health; it can induce alcoholism, suicidal ideation, increase the risk of depression and can even lead to strokes or cardiovascular difficulties (Hawkley, & Cacioppo, 2010). Research has shown that people who join support groups experience reduced feelings of isolation and loneliness (Lennon-Dearing, 2008). According to Lennon-Dearing (2008), support groups encourage new friendships and are usually viewed as a place where people socialise (Lennon-Dearing, 2008). Mundell et al. (2012) speaks about the process of ‘Identification’ that occurs within a support group where the members realise that they are not alone and that others have similar experiences, this makes it easier for the members to share they stories and creates a close bond between them.

2.6.4.2 Empowerment

Mundell et al. (2012) found that some members have benefited by giving other members advice in the support group, making them feel empowered. They found that the knowledge they gained was also an important part of empowering them as it gives them a better sense of insight into their situation and allows them to take control of their lives and make positive changes.

2.6.4.3 Enhanced self-esteem and improved quality of life

As seen above, being diagnosed with HIV/AIDS can have damaging effects on an individual’s self-esteem resulting in negative effects on the quality of life of those living with HIV/AIDS. Roberts (2008) reports that HIV positive people develop group norms in a support group which enable the creation of positive self-identities that challenge stigmatising views relating to being HIV positive, he calls this normative support. In addition to this Lee et al. (2002) found that those who attend HIV support groups experience lower internalized stigma. Huang et al. (2006) found that being in a support group motivates and encourages people to participate in productive activities, such as exercising, engaging in hobbies and living a healthy life, but most importantly the support group provides a sense of unity, respect, care, inclusion and support which enables those living with HIV to live fulfilling, healthy, long and productive lives.

2.6.4.4 Improved ART knowledge and adherence

Atanga et al. (2015) found that the knowledge on antiretroviral treatment adherence was quite high among HIV support group members. They found that those who attend support groups had good knowledge on the names of various tablets included in their treatment plan; they are also more familiar with the treatment schedule and facts that could lead to poor adherence (Atanga et al., 2015). Tumwikirize et al. (2015) used a cross-sectional design to compare ART adherence among people living with HIV/AIDS who were in a support group and those who were not. They used self-administered questionnaires and found that those who reported non-adherence had never been in a support group whereas those who were in a support group had better adherence to their HIV treatment.

2.6.4.5 A space to share difficult/negative emotions

Lennon-Dearing (2008) state that a support group allow members to share their personal experiences, fears and concerns which lessons the burden they carry. Members experience a sense of emotional relief from the support of others by just sharing their stories (Tumwikirize et al., 2015).

2.6.4.6 Renewed Hope

As seen above most people experience a sense of hopelessness when they are diagnosed with HIV/AIDS and feel like giving up on life. Studies have shown that support groups are able to restore and facilitate hope, this repair of hope is made possible through the relationships that develop between the HIV-positive support group members (Harris, & Larsen, 2007; Messias, Moneyham, Vyavaharkar, Murdaugh, & Philips, 2009). Witnessing others in the group who are further along their road to recovery and who have made great progress toward having happier and healthier lives show members that recovery is in fact possible, which brings renewed hope for the future (Kylma, Vehviäinen-Julkunen, & Lähdevirta, 2000).

Although many studies have found that HIV support groups are helpful and beneficial in many ways some studies have found that participants view them negatively and report various barriers that hinder participation. Not many studies have focused on the disadvantages or the limitations of being in an HIV support group. This study will therefore not only focus on how helpful support groups have been in HIV positive individuals journey of living with HIV, but also look at the disadvantages or the limitations of HIV/AIDS support groups. Below are some of the barriers and disadvantages associated with being in an HIV support group.

2.6.5 Barriers to participating in support groups

Even though support groups are commonly advocated as one of the best psychosocial support interventions, the participation in South Africa is still poor (Madiba, & Kekana, 2013). This is also evident in the study done by Kekana (2011) in Katlehong Township that found that the majority

(58.06%) of the HIV positive participants never attended a support group. Some people have certain perceptions of support groups that hinder their participation in the groups. According several studies, attendance for most people implies inability to cope or care for themselves, others believe they do not need to attend support groups as they received adequate support from family and friends, while others feared that they would be identified as HIV positive if they had to attend a support group in their area (Heyer et al., 2010; Madiba, & Canti-Sigaqa, 2012; Madiba, & Kekana, 2013). According to Kekana (2011) the main barrier to participation in support groups are the lack of knowledge of the existence of HIV support groups in their areas, they found that 32% of their participants reported that they were not aware of any support groups in their area or nearby. Additionally, Madiba and Kekana (2013) found that it was not so much the lack of knowledge that hindered participation, but rather lack of support groups nearby as people often had to travel long distances to reach a support group.

2.6.6 Disadvantages of support groups

2.6.6.1 Support groups too large

Some support groups are too large which may act as a barrier as it affects confidentiality and inhibits free discussion, it also causes burnout causing support group leaders to lose hope (Heyer et al. 2010). According to Heyer et al. (2010) getting together with strange people may give the person the sense of loss of privacy. Some people may not feel comfortable sharing some past issues, thoughts and feelings with too many people as they might feel like it will break confidentiality of their personal information.

2.6.6.2 Lack of resources

Walstrom et al. (2013) found that most participants in the HIV support group expressed their struggle with poverty and hunger, explaining that the support groups educated them on how health is impacted by stress and proper nutrition, yet the support group is unable to satisfy their needs for income or food sources. A lack of resources seems to be the most dominant reason for people with HIV to stop attending support groups or not attend at all as some participants lack transport and money to get to the group as it is too far to travel (Chazan, 2006; Madiba, & Canti- Sigaqa, 2012). Madiba and Canti- Sigaqa (2012) examined the perceptions of HIV positive men on support groups and explored their reasons for non-participation. They found that the main reason for non-participation was lack of resources such as transport money and food.

2.6.6.3 More women than men

Most support groups are aimed at women and therefore HIV positive men are reluctant to attend (Visser, & Mundell, 2008). In their study Visser and Mundell (2008) found that women outnumbered the men in most support groups. Reece et al. (2007), Ndu et al. (2011) and Mfecane (2011) found that male participants in support groups felt under pressure to conform to a lifestyle that was not consistent with established gender roles. Some men are reluctant to participate in support groups because most of the activities in the group are considered ‘feminine’, whereas men prefer physically demanding tasks that are more ‘masculine’. Mabiba and Kekana (2013) found that the men in their study believed that they are expected to be physically and mentally strong and seeking help or assistance from a support group where there are mostly women will imply that they are weak. Furthermore Rudo (2012) found that the presence of women in the support groups inhibits men from full disclosure of their problems. In the study done by Rudo (2012) men communicated that women are talkative and cannot keep secrets. The perception is that the confidentiality aspect of the support group is compromised by the presence of women resulting in men shying away and not fully expressing their views.

2.6.6.4 Witnessing the decline of fellow members

Heyer et al. (2010) found that some members have a difficult time coping when fellow members drop out or die; they found that experiencing a decline of fellow members can worsen depression or be discouraging for some members. This is further emphasised by Leonard and Ellen (2008) when they found that their participants attended support groups initially, but discontinued due to refusal to engage in issues typically discussed in support groups; fundamentally they found discussing topics related to HIV/AIDS depressing.

2.6.6.5 Time scheduled for meetings

Other studies reported that most participants mentioned that the time scheduled for support group meetings was a reason for not attending support groups. In their study (Chazan, 2006; Madiba, & Canti-Sigaqa, 2012) found that timing mostly affected employed participants; most participants in their study reported that support groups are only during the week in the morning when they are at work. Most participants reported that they were unable to get off work or that they did not ask for the day off because they did not want their employer to know that they are attending an HIV support group.

2.7 Conclusion

As discussed above, HIV/AIDS is not only a medical disease, but it also affects the total person and other spheres of society. Literature has shown that even though there are advances in HIV treatment, those living with HIV still have many challenges to deal with. These include stigmatization, discrimination, issues around disclosure, mental health problems and physical challenges to name a few, but one way to cope with these challenges might be to participate in a support group. Most of the studies on HIV suggest that support groups are generally an effective and useful intervention that increases coping skills, reduces feelings of isolation, and empowers and positively influences quality of life. The literature suggests that a lack of social support can make those that are HIV positive feel anxious and bring about negative emotions and can be an obstacle that hinders people from talking about their HIV status. Even though there are various benefits when attending support groups there are still many people who do not attend support groups. Literature shows that because of nonparticipation in support groups, participants may not fully benefit from the emotional and informational support gained through support groups. However, even though there is minimal literature on the disadvantages of being in a support group, there is indication that support groups are not always beneficial. Some of the disadvantages include being in mixed gender support groups that do not cater for men and women. It also shows that witnessing a decline of fellow member in the group might hinder adjustment. In addition when support groups are to large it may hinder confidentiality. Studies have shown that most people do not attend support groups due to issues pertaining to lack of finances to travel to support groups, lack of support groups in their area and fear that other members might break confidentiality. The reviewed literature has confirmed that getting social support is important to those who are infected with HIV however it is also evident that HIV-related stigma and poverty is a problem in South Africa that has serious repercussions for HIV treatment and prevention.

CHAPTER 3

Research design and methodology

3.1 Introduction

The following section will focus on the research design and methodology. The purpose of this chapter is to present a summary of the research process. The research design used in this study is qualitative in nature and relies on a phenomenological perspective as a research framework. Interpretative phenomenological analysis will be used in order to get an in-depth and holistic understanding of HIV positive peoples experiences of being in a support group because it is a qualitative method of enquiry dedicated to detailed examination of human lived experiences (Smith, Flowers, & Larkin, 2009).

This section will clarify the motivation for choosing a qualitative research design, specifically that of interpretative phenomenological analysis (IPA). The recruitment criteria, along with the manner in which participants were selected, the method of data collection and an explanation of the process of analysis are also outlined. Lastly, issues concerning the quality and ethics of the research project are considered.

3.2 Research Aim

As mentioned in the previous chapter, the aim of this study is to answer the research question: what are the positive and negative experiences of HIV positive participants who are members of an HIV support group? The study aims to gain an understanding of the role support plays in the lives of those living with HIV and to add to the knowledge base on the understanding of HIV and the usefulness of support groups. The main objectives of this study, are to identify the challenges of living with HIV before joining a support group; to explore how being in a support group has helped HIV positive people cope with the challenges of living with HIV/AIDS and lastly, to determine the positive and negative experiences of being in a support group. IPA will therefore be appropriate as it relates well with the qualitative nature of the aim of this study.

3.3 A qualitative approach to research

According Conelly (2007), qualitative research starts from the assumption that one can obtain a profound understanding about people and their world from ordinary conversations and observations. It focuses on the subjective meanings and everyday experiences of people. Unlike quantitative research this research project does not aim to reduce people to numbers, where research participants may be treated as objects to be studied, and where precedence is given to cause and effect relationships, as opposed to the experiential quality of existence (Parker, 2005). Conelly (2007) explains that qualitative research is used to explore and understand people's beliefs, experiences, attitudes, behaviour and interactions. It is concerned with meaning and depth. According to Willig (2001), knowledge gained in a qualitative way refers to knowledge of the world as it appears to each individual as well as how they engage with that knowledge; she states that the knowledge is free of scientific explanations and common sense notions.

Qualitative research does not search for an objective truth; instead it searches for a subjective exploration of the person's perception (Willig, 2001). Therefore, this study seeks neither truth nor objective information, but instead it aims to understand the HIV positive person's subjective experience of how HIV support groups have been helpful or not. Qualitative research is based on the assumptions that each individual is unique, and how people interpret and view the world differs from one person to another and is based on the postmodern belief that there is more than one truth (Conelly, 2007). According to Ritchie and Lewis (2003), the goal of qualitative research is to understand behaviour in a natural setting, to understand a specific situation from the perspective of the research participant and also to understand the meaning that people give to their experience.

Psychology "deals with living subjects who are not simply reacting automatically to external stimuli, but are rather responding to their own perception of what these stimuli mean" (Laverty, 2003, p. 22). Thus a qualitative framework was deemed appropriate for the research project as it is closely aligned with answering the questions "what?" as opposed to dealing with "if" and "then", and allows for the experiences and meaning-making processes of those who have experienced HIV support groups.

There are numerous approaches to conducting qualitative research. However, the methodology selected for this research project is that of IPA, firstly because of the ontological and epistemological position it adopts, and secondly owing to the systematic rigour of the data collection and subsequent analytical process. This will be elaborated on below.

3.4 Interpretative Phenomenological Analysis (IPA)

IPA first made an appearance as a qualitative methodology in the mid-1990s, and was an attempt by its founder, Smith, to find “a middle way between different qualitative methods: an avenue to subjective experiences and the meaning people attribute to these experiences” (Shinebourne, 2011, p. 17). At first glance, this definition would seem to suggest that IPA is merely a descriptive phenomenological endeavour; however, Larkin, Watts and Clifton (2006) explain that the aims of the IPA researcher are twofold. The first aim is to attempt to understand the life-world of the participants – to describe what an experience is like for the participants taking part in the research project. This emphasis results in a view of the participants’ specific experience of a specific event, process or relationship. The second aim of IPA is to create an interpretative reading of the account of an experience that is located in a wider sociocultural, political and theoretical context. This seeks “to provide a critical and conceptual commentary upon the participants’ personal ‘sense-making’ activities” (Larkin et al., 2006, p. 104). The researcher is then able to consider what an experience means for a specific participant in a specific situation (Larkin et al., 2006).

The key theoretical principles of IPA include phenomenology, hermeneutics and idiography. A brief discussion on each of these key principles follows below.

3.4.1 IPA and Phenomenology

The term phenomenology is derived from the Greek words, phenomenon and logos (Priest, 2002). Phenomenon means to appear, to show, or reveal itself or to be made visible or clear and logos refers to thought, oral communication, or the act of reasoning or conveying an idea (Priest, 2002). According to Willig and Stainton-Rogers (2008), Husserl is considered the founder of phenomenology, and was strongly influenced by the philosophers Descartes and Kant. According to Husserl (1999) each human’s existence is unique, he proposed, that in order to understand one’s fellow person, one needs to look at the quality of the experience. According to Priest (2002), phenomenology was not founded, but instead existed, grew and continued changing till the end of Husserl’s life. During the twentieth century several existentialist thinkers used Husserl’s phenomenological approach as a point of departure for their own existential phenomenology.

These thinkers include; Heidegger, Jaspers, Merleau, Ponty and Ortega (Willig, & Stainton-Rogers 2008).

Essentially, phenomenology is the study of experience. A phenomenology researcher examines the qualities and essence of an experience, through interviews, stories, or observations with people who are having the experience of the researcher's interest (Connelly, 2010). According to Polkinghorne (1989, p.4), experience is "the operation of active processes that encompass and constitute the various contents that become present to awareness". This means the phenomenology goes beyond the surface of the expressed behaviour to the underlying meaning and feelings of such expressions (Munhill, 2007). Therefore in this study the researcher aimed to know what the experience was like to live it, not just the person's reactions to the experience.

Husserl (1999) suggested that examination of everyday experiences is characterized through the adoption of "phenomenological reduction". Phenomenological reduction is a technique that allows one to voluntarily sustain judgement about the existence or non-existence of the external world (Giorgi, 1997; Shinebourne, 2011). It requires that one avoids all previous ideas, all theorizing and generalization and involves "redirecting ones phenomenological vision away from the unreflective immersion in experiences of the world towards a focus on "how the object appears to consciousness" (Shinebourne, 2011, p. 17). According to Husserl (1999) there are four levels of phenomenological reduction. This includes bracketing (epoche), the psychological phenomenological reduction, eidetic reduction and the transcendental reduction. Giorgi (1997) explains that the last three forms of reduction serve as a philosophical refinement of the original notion. For the purpose of this study only bracketing will be explained and used.

Willig (2008) and Giorgi (1997) describe bracketing as the suspension of assumptions, judgements and interpretations about the phenomenon as it is lived in the participant's world. It allows the researcher to put aside all biases and enter the research setting without any cultural or religious beliefs and theories. Bracketing (epoche) can basically be viewed as a method in which the researcher is objective and isolated from their experiences in order to prevent these from interfering with the research and the interpretation of the data. The goal according to Giorgi (1997) is to ignore any preconceptions or judgement in order to perceive phenomena directly as they are. Giorgi (1997) explains that during the interview, the researcher may unconsciously bias the interview by allowing his/her preconceptions to filter into the interview through leading questions or non-verbal responses, but this can be avoided by constantly reflecting to check that he/she does not lead the participant or introduce new questions.

The success of bracketing allows for the emergence of the “transcendental ego”, which for Hurssel is pure consciousness that is essential to examine phenomenal experience (LeVasseur, 2003). For Husserl (1999), consciousness is the ability to always be mindful of something, this something refers to the object of which we are conscious, thus there is an intentional relationship between an object and ones awareness of it, whether this is made visible through the perception of a real object in the world or through an act of memory or imagination (Smith et al., 2009). Although Husserl was interested in discovering the essence of experiences, IPA attempts to capture particular experiences as experienced for particular individuals. Within IPA the adoption of Husserl’s phenomenological attitude allows the systematic and attentive reflection of everyday lived experiences (Smith et al., 2009). However in contrast to Husserl’s method of epoche, IPA recognizes the limited nature of knowing in advance the preconceptions which may affect the research process, and insists that the process of determining preconceptions may only be possible within, during and/or after processes of interpretation (Smith et al., 2009). IPA recognizes individuals as involved and rooted within a world of “objects and relationships, language and culture, projects and concerns” particularly within historical, social and cultural contexts (Smith et al., 2009, p. 21). Therefore for IPA the commitment is towards an interpretative and descriptive position within the lived world focusing on understanding “the perspectival directedness of an individual’s involvement in the world” (Smith et al., 2009, p. 20)

Phenomenology remains difficult to be defined. It is a movement that today mean different things to different people. Ultimately it attempts to describe the content in detail and structure of the person’s consciousness with the purpose of grasping the qualitative diversity of his/her experience and to clarify the essential meaning (Shinebourne, 2011). This study is phenomenological in that it wishes to explore the individuals’ personal perception of meaningful events (Smith et al, 2009). The aim is to use the person’s words rather than giving an objective interpretation of the person’s experience.

3.4.2 IPA and Hermeneutics

Hermeneutics is referred to as the theory of interpretation, originally designed to interpret religious texts (Shinebourne, 2011). Hermeneutics involves processes and methods which reveal and make clear the discourse of intersubjectivity, recognizing that meaning is not made explicit but requires illumination (Lopez, & Willis, 2004).

IPA’s hermeneutical orientation demands an interpretation of the participant’s personal and historical context. IPA is hermeneutical in that it recognizes the researcher with in the analytical process (Smith, & Osborne, 2003). This means that IPA considers that one cannot get close to the participants personal world directly as access is dependent on the researchers own conceptions through a process of interpretive activity. For this reason IPA involves a double hermeneutic where the researcher attempts to make sense of the participant who attempts to make sense of his or her own experiences (Smith, & Osborne, 2003). IPA requires that a researcher adopt two positions when interpreting the textual accounts of the participants’ experiences. These positions combine “the hermeneutics of empathy with the hermeneutics of questioning/suspicion” (Smith et al., 2009, p. 36). The hermeneutics of empathy seek to describe the meaning that is present in the transcription as it appears to the researcher and hence examines what is apparent as opposed to latent meanings (Eatough, & Smith, 2008; Willig, 2013). Such interpretation is empathic in that it involves an attempt to understand what an experience is like for a participant (Smith, & Osborn, 2008; Willig, 2013). For example, in this study the researcher assumed an empathic approach and attempted to amplify this meaning first before reading deeper into what the participants are saying concerning their experiences of being in an HIV support group.

Suspicious interpretation involves a more critical stance to the text so that the latent or hidden meanings that are connected to the surface meanings can emerge and can be seen as “akin to detective work where clues are interpreted to find out what ‘really happened’” (Willig, 2013, p. 11). This second level of interpretation aims to give an account that goes beyond the surface description that the participants related, and offers alternative insights and understandings to those of the participants (Eatough, & Smith, 2008). In this study, the process of suspicious interpretation in part involved a process of situating the participants’ experiences and the meanings ascribed to these experiences (their knowledge) in the body of existing knowledge concerning HIV support groups.

The theory of the hermeneutic circle is also important in IPA; this involves moving from the text itself and the apparent meanings to the larger social context, as well to the researcher’s personal foreknowledge, and then back again (Willig, 2013). The researcher therefore maintained an open mind at all times to allow the material to influence prior preconceptions and attempted as far as possible, not to allow any biases to overshadow the meaning that the participants had created out of their experiences while still engaging with a critical stance concerning their stories of being in an HIV support group. Thus, as Willig (2013, p.16) states, the interpretation delivered is “a combination of the old (in the form of the interpreter’s presuppositions and assumptions which are informed by tradition and received wisdom) and the new (in the form of the text) that makes understanding possible”.

Hermeneutics in this study is important as this helped the researcher understand the discursive and subjective knowledge HIV positive people use to make sense of their experiences of being in HIV support groups. Ultimately the endeavour within IPA is towards an interpretative commitment focusing on understanding the relationship between the researcher’s involvement and position within the lived world (Smith et al., 2009).

3.4.3 IPA and Idiography

Lastly, IPA is idiographic, meaning that the focus is the individual rather than large groups of people (Biggerstaff & Thompson, 2008). Idiography is concerned with the distinct experiences of particular people and the particular context in which those experiences occur (Smith et al. 2009). It suggests that everyone is unique and therefore everyone should be studied in an individual way, instead of being generalized. The word idiographic comes from the Greek word “idios” which means “pertaining to self; one’s own, private or separate” (Pagnini, Gibbons, & Castelnuovo, 2012, p.1). It was “developed to allow rigorous exploration of idiographic subjective experiences, and more specifically, social cognitions” (Biggerstaff & Thompson, 2008, p.4). Within IPA there is an idiographic focus on the detailed examination of particular instances and the recognition that individuals can provide unique insight and perspectives in their involvement in a particular phenomenon (Shinebourne, 2011). Interpretative phenomenology employs idiography at two levels: firstly in its depth of analysis and attention to detail, and secondly in its commitment to the subjective experiences for particular individuals in particular contexts (Smith et al., 2009). The researcher therefore placed particular interest in the meanings that the participants ascribed towards their subjective experiences of being in an HIV support group (Langdridge, 2007; Moustakas, 1994; Smith et al., 2009). In this study the researcher captured the participants’ experiences articulated in their own terms, as opposed to pre-existing conceptions of the experience. IPA is specifically interested in this significance, and individuals who place importance upon such experiences have invested extensive amounts of reflection, thought, and emotion into the meaning of the experience (Smith et al., 2009). It is the investment of reflection that IPA is focused upon, in other words attempting to make sense of the participants' own reflection of a particular experience that had specific significance for the participant (Smith et al., 2009).

3.5 Sampling procedure

As discussed above IPA is influenced by idiography, where the aim is to conduct a detailed examination of what a particular experience is like for a particular person (Smith et al., 2009). For this reason, IPA tends to make use of "small, purposively-selected and carefully-situated samples" (Smith et al., 2009, p. 29). This refers to selecting people for whom the research question is significant. There is no definitive answer as to what sample size is ideal, although IPA generally uses small sample sizes in order to understand a particular phenomenon (Smith et al., 2009). Larkin et al. (2006, p.110) argue that a small sample size is justified since "if the objective reality we are discovering is partly dependent on intellectual construction and hence upon our various modes of subjective engagement with the world… then any analysis of our intellectual constructions must also reveal something of the objective reality". Given the scope of this research project and the guidelines offered by IPA as a methodology, five participants were selected, which were deemed sufficient to explore and analyse, in detail, the experiences of HIV positive people who had experienced HIV support groups. Using a larger sample within the scope of this research project may have compromised the commitment to exploring the nuances of personal experiences owing to time constraints (Smith, 2007). The detailed interpretation of such experiences, while not generalizable, served to highlight the subtleties and meanings of the experience of HIV support groups that may have been missed in studies utilising broader samples and statistical measures. Furthermore, using more than one case study enables patterns of divergence, convergence, similarities and differences of the experiences of HIV support groups to be explored (Smith et al., 2009).

In order for the above-mentioned patterns to emerge, this research project followed the recommendation of IPA that a homogenous sample be used. It is important to note that sociocultural and historical contexts occupy a distinct role in the experiences and lives of people in that they can colour the meaning that participants make of the phenomenon being studied

(Eatough, & Smith, 2008). Thus the choice of a homogenous sample ensured that similar participants with similar contexts could be compared, thereby allowing a broader understanding of the specific phenomenon of HIV support groups within the South African context to emerge. In order to select a homogenous group of participants, purposive sampling was employed. This sample therefore included adults (over the age of 18) who were willing to take part in the study. The study included people who have been diagnosed with HIV, who are attending HIV support groups on a regular basis and have been HIV positive for at least one year. The support group was a structured support group consisting of only fifteen sessions per person. People who attended at least ten out of the fifteen sessions were therefore approached. This sample excluded the newly diagnosed members as recently diagnosed people might still be in a state of shock and unable to provide the rich contextualized data that is required.

3.5.1 Data collection

An advertisement was posted on the notice board at the Noordgesig clinic for people to join an HIV support group. The researcher contacted the HIV support group leader by means of the telephone number that was provided on the poster. The researcher then arranged a face-to-face meeting with the support group leader telephonically. During the face-to-face meeting the leader explained that she started the group two years after being diagnosed HIV positive. The group members initially gathered at her home as there were only three people, but due to lack of space she was later forced to find a larger venue as more people started joining. She explained that she struggled to find a support group for herself which motivated her to acquire training and attend workshops at the Red-Cross and the South African Depression and Anxiety Group in order to equip herself and start a support group to assist other HIV positive people who were in need. The support group leader suggested that the researcher join one of the support group meetings in order to present the aims and purpose of the study to the members. The presentation included, the aims of the study, confidentiality, sampling criteria and interview process. A week after the face-to-face presentation the leader called to explain that five participants who met the criteria were willing to participate. The participants were contacted telephonically to schedule the interviews.

The actual data collection process, in the form of individual interviews were conducted in September 2014 (3 participants) and January 2015 (2 participants). All interviews were to take place in September 2014, but due to some participant’s non-arrival the rest of the interviews were rescheduled. The participants explained that they had forgotten about hospital appointments to collect their medication and therefore they were unable to attend the interview. The participants requested that the researcher reschedule the interviews as they were still interested to be part of the project. The interviews took place at the Noordgesig community recreation center, in one of the private rooms where the support group members gather for their meetings.

3.5.2 The Interviews

IPA typically makes use of interviews in order to enable research participants to offer an account of their experiences in their own words (Smith et al., 2009). Because of IPA’s subjective engagement with the world, researchers are able to co-construct meaning in a specific social context with their participants, thereby gleaning an approximate understanding of their perceptions, meaning-making and experiences (Eatough, & Smith, 2008). An interview can therefore function as a means by which researchers are able to begin this journey of bringing that which the participants have experienced to light. With this in mind, a semi-structured interview was selected as the data collection method. Semi-structured interviews are more conversational in nature, containing open-ended questions and allowing the participants to reflect on their experiences in a relatively unimpeded manner without too much imposition from the researcher (Eatough, & Smith, 2008). Eatough and Smith (2008, p. 188) state that “IPA interviews while starting with structure in the form of an interview schedule, can in fact deviate towards what may appear like an unstructured format as researchers emphasise the participants as storytellers rather than respondents”

The interview schedule was constructed in five parts. The first section concentrated on demographic and factual information. This enabled rapport to be built and lead the way for a more in-depth conversation to occur. The second section tried to attain an understanding of the experiences of being diagnosed with HIV, with questions such as “How did you experience yourself after you found out that you were HIV positive?” While not the central aspect of the research project, an understanding of the experiences and meanings attributed to HIV diagnosis was deemed necessary in order to contextualise how HIV support groups was experienced by the five participants. The third section sought to investigate challenges of living with HIV and therefore questions such as “Tell me about the challenges that you are experiencing as a person living with HIV?” were asked in this section. The fourth section focused on social support and questions such as “tell me how your family/friends reacted when they found out that you are HIV positive?” and lastly the fifth section focused on support groups asking mainly about the benefits and disadvantages of being in a support group. In total the schedule consisted of fifteen questions, these questions were designed to elicit responses about the advantages, disadvantages, challenges, expectations and experiences of support group members in relation to the objectives of the study.

During the interviews, the interview schedule was followed loosely, which allowed the conversation to develop a flow. The participants were treated as experts in their own field (Smith & Osborn, 2008) and the researcher, acted in a facilitative role to elicit the experiential accounts with the aim of obtaining a generalised understanding of the phenomenon of HIV support groups from these detailed individual experiences. The content of these interviews were therefore co-constructed between the participants and the researcher. All participants spoke freely without too much distress or discomfort, although there were two instances in which the discussion evoked sadness and tears. However, all five participants indicated that they were happy to continue with the interview despite these emotions.

IPA requires that interviews be transcribed verbatim (Smith et al., 2009). For this reason, the interviews were digitally recorded on a voice recording machine. Taking notes might have posed an obstacle to full engagement with the conversation, and hence recording the interview enabled the researcher to remain fully present with the participants throughout the interview. However, the researcher did make a few notes concerning body language in those instances where non-verbal behaviour was essential to the meaning being conveyed.

3.6 Analysing the interviews

The process of analysis followed the steps recommended in Smith et al. (2009). The method followed is not a sole prescribed system of analysis, as flexibility and creativity is frequently encouraged during the analytic process. This repetitive process of analysis involves flexible engagement with the data, utilizing different modes of thinking as opposed to maintaining a rigid analytic system (Smith et al., 2009). Fundamentally the analytic focus is directed towards the participants trying to make sense of their experiences. The following section outlines the steps that were taken in this process of analysis.

3.6.1 Step One

This step encourages the researcher to be familiar with the interviews by reading and rereading each participant's account numerous times. This process of repeated reading allowed for a representation of the overall interview structure to develop (Smith, Harré, & van Langenhove, 1995). Appreciation of this superstructure allowed the researcher to understand the connections between narratives within the interview; additionally the repeated reading ensured that the participant is the focus of analysis (Smith et al., 2009).

3.6.2 Step Two

This step involved noting anything of interest within the transcriptions, not only to develop familiarity with the text, but also to understand how the participants frame their experiences of being in an HIV support Group (Smith et al., 2009). Langdridge (2007) advises that this stage is merely about stating what is happening in the text, staying as close to the original text as possible with few interpretations. This involved highlighting the language used, and included taking note of repetition, laughter, pauses, tone, and fluency as well as metaphors as it is a linguistic device which links descriptive comments to conceptual notes (Smith et al., 2009).

3.6.3 Step Three

This step involved linking themes and identifying thematic clusters, it basically involved refining, condensing and examining connections between different themes (Arribas-Ayllon & Walkerdine, 2008; Langdridge, 2008; Smith et al., 2009). The purpose of the themes is to show the broader meanings of particular sections of the text (Smith et al., 2009). Fundamentally the themes should reflect the participant's own thoughts and words of the experience under examination, but additionally include the researcher's own interpretation of the participants' experiences (Smith, & Osborn, 2008).

3.6.4 Step Four

The aim of this step was to identify patterns of subordinate themes, which summarises the participants' experiences and that suggest a hierarchical relationship between them (Smith et al., 2009). Abstraction and polarization were used as methods of identifying and linking patterns between emergent themes. Abstraction involves linking similar conceptual ideas across emergent themes (Smith et al., 2009). Polarization involves examining the transcriptions for oppositional relationships across emergent themes, where the emphasis is on noting differences as opposed to similarities (Smith et al., 2009). Biggerstaff and Thompson (2008) suggest that the researcher develop a summary table of the identified themes and the table should be organized in a way that it clearly illustrates the main aspects and concerns acknowledged by the participants. This step allowed for use of examples from the participants, which includes direct quotations from the participants' accounts that provide fundamental features of the participants thoughts and emotions about the experience of the situation being explored (Biggerstaff, & Thompson, 2008; Smith, & Osborn, 2003). After steps one to four were completed for each transcribed interview the final step was undertaken.

3.6.5 Step Five

The final step in IPA involved moving away from the first case, and repeating steps one to four for each subsequent transcribed interview (Smith et al., 2009). The difficulty in this process was removing the influence of analysis from the first and later cases in each interview. Smith et al. (2009) suggest systematically following the outlined steps to ensure consistency and making sure each case speaks on its own terms. During this step the researcher also sought connections across cases (Smith et al., 2009). Here super-ordinate themes were compared between cases, themes directly related to a particular case was shared as a higher order concept between cases (Smith et al., 2009). The researcher used the master list of themes obtained from the first interview to identify more instances of these themes in subsequent interviews, while also being alert to the possibilities of new themes (Smith et al., 2009). These themes were then drawn together into a consolidated list.

3.7 Quality Assurance

Assessing the validity and quality of IPA research necessitates a move away from criterion that typically defines a valid and reliable quantitative research study (Tracy, 2010; Yardley, 2000). A qualitative researcher must be able to demonstrate that his or her research is sound, rigorous and yields results that are valuable in the field of study (Smith, & Osborn, 2008).

The four broad principles by Yardley (2000) were used to assess the quality of qualitative based enquiries in this study. A discussion of each of the four principles follows below.

3.7.1 Maintaining sensitivity to the participants context

Sensitivity to context includes an awareness of the sociocultural environment in which the research project is conducted, the theoretical framework, literature concerning the topic, as well as the accounts that are given by the participants (Yardley, 2000; Tracy, 2010). Sensitivity to context can be accomplished by clearly demonstrating the connections between data, theory and analysis (Henwood, & Pidgeon, 1992). In this study sensitivity was demonstrated in the following ways:

- Throughout the research process, the researcher remained sensitive to the sociocultural environment in which the research project was conducted and ensured that good understanding was gained on HIV support groups in modern-day South Africa in particular, this includes an awareness of the sociocultural context surrounding HIV/AIDS research in South Africa and providing relevant and substantive literature surrounding the experiences of people living with HIV/AIDS in South Africa who attends support groups.
- By ensuring that analytic claims are substantiated through verbatim extracts of the participants' experiences. Verbatim extracts from the interview transcripts were used in order to give the participants a voice, but also in order to assist the reader in seeing how the interpretation was grounded in the context of the interview.

3.7.2 Commitment and Rigour

Rigour describes how thorough the study is and commitment refers to the researcher's ability to be attentive to the participant during data collection, and to the transcripts throughout the analysis of each case (Smith et al., 2009). Yardley (2000) suggests that the study should appear reasonable and appropriate and that the correct methodological procedures should be followed throughout the research process. Rigour and commitment was accomplished in this research project in the following ways:

- In order to assure rigour, the formulation of the research question occurred through consideration of the aims of both the qualitative research process and IPA. Therefore, no hypothesis was generated, but open-ended questions were asked that allowed for the emergence of the participants' experiences and meanings related to HIV support groups.
- The motivation for the selection of the research question was carefully considered and accordingly described in the literature review chapter. The gaps in existing theoretical

knowledge were considered and thus the appropriateness of the research project in contributing to existing knowledge was outlined.

- To further assure rigour, the selection of a homogeneous sample was conducted according to the processes delineated by IPA and the analytical steps prescribed by IPA were followed.
- The researcher showed commitment by being empathic towards the participants and remaining aware of any difficulties that arose throughout the interview process, such as when the two participants became distressed while discussing sensitive information.

3.7.3 Transparency and Coherence

Transparency relates to how well the research process has been described and written up by the researcher and coherence refers to a fit between the research question and the methodology used to answer that question (Smith et al., 2009; Yardley, 2000). According to Henwood and Pidgeon (1992), transparency involves formulating clear documentation that shows how each individual step in the process was followed. Transparency was striven for in this research project in the following ways:

- The steps taken to analyse the data were transparently and coherently described in section 3.6 of this chapter.
- The appendix of this research project contains the invitation letter sent to the participants, as well as the questions asked during the interview.

Another aspect of transparency is reflexivity. This involves discussing the strengths and limitations of the research project, as well as maintaining an introspective stance concerning personal biases and motivations throughout the research process (Yardley, 2000). Reflexivity should not only be involved in the interpretive and analytical aspects of research, but rather in all stages of the research, including the interview (Guillemin, & Gillan, 2004). This was accomplished in the research process in the following ways:

- The strengths and limitations of the research project are clearly discussed towards the end of this research project.
- Throughout the interview process, the researcher maintained a reflexive stance in order to prevent personal biases from overshadowing the participants' descriptions of their experiences.

- The researcher further maintained a reflexive stance throughout the analysis of the verbatim transcriptions, which was accomplished by engaging in the hermeneutic circle (Willig, 2013). The researcher continuously maintained an awareness of the relationship between any fore-conceptions and the accounts offered by the participants.

A final aspect of transparency is the demonstration of coherence, Yardley (2010) recommends that a research project can be considered coherent if it uses methods that are aligned to the research question, and if it connects the relevant literature and underlying theoretical constructs in a meaningful way to the data and to the methodology as a whole. The researcher aimed for coherence by:

- Referring back to the aims stated at the outset of the research project when writing up the analysis. This is further reflected on in the concluding chapter. The description concerning the limitations of the research project was also part of this process, so that the aspects of where the research project might not have lived up to its aims could be transparently revealed.
- The reasoning behind the selection of a qualitative method and the choice of IPA were clearly described in this chapter.
- Clearly demonstrating connections between relevant and underlying theoretical constructs throughout the findings and discussions chapter.

3.7.4 Impact and Importance

This principle refers to the relative value of the research project and focuses on the applicability, significance and practicality of the qualitative research project (Smith et al., 2009). Yardley (2000) states that the real validity of a research project is whether it has something important, interesting or valuable to say, basically referring to how helpful the research is. This research project could be considered to have "heuristic significance" (Tracy, 2010, p. 846) in that it is intended to motivate others to explore and consider not only the positive aspects of HIV support groups, but also the negative aspects in future research endeavours and assists in beginning to understand the phenomenon of HIV support groups better. Most research on HIV support groups mainly focus on online support groups and rely on quantitative analyses thus the impact of this study is enhanced by providing HIV support group members a means of voicing their viewpoints and achieving greater insight into and control over their situations; also providing health care professionals and support group leaders with information on the disadvantages of support groups which in turn will assist them in improving the way HIV support groups are being run.

3.8 Ethical considerations

Ethical considerations are important to qualitative enquiry as the process of in-depth interviewing involves an explanation of the individual's private life towards the public domain (Kvale, 2007). The researcher therefore ensured that the process was conducted with respect for the participant's safety and welfare. Ethical considerations are an essential part of HIV/AIDS research. Given the high levels of stigmatization surrounding HIV/AIDS, there should be a balance between the need for data for prevention and intervention purposes and the integrity and privacy of participants. Thus, the balance between the benefits, such as prevention and intervention, and disadvantages, such as causing emotional distress in research participants while participating in the research, should be carefully monitored when doing research (Ostrow, & Kessler, 1993).

Before the support group was approached, ethical approval was obtained from the Rhodes University Psychology Department's Research Proposal and Ethical Review Committee (RPERC). Once this was obtained, permission was sought from the founder of the support group. Once permission was obtained from the founder, the appropriate candidates were addressed and invited to participate in the research project.

3.8.1 Informed consent

A letter of consent was obtained from all five participants confirming their voluntary participation. The letter informed participants about the aims of the research, its uses and impacts and how the interviews were to be conducted. The letter also included assurances of anonymity, privacy and confidentiality. It further stated that participation was voluntary and that they maintained the right to refuse participation and to termination without prejudice.

3.8.2 Confidentiality

The consent form contained a section concerning confidentiality, in which it was stated that the raw transcript would not be published, but that the research project may appear in a scholarly journal. Accesses to the interview transcripts are limited, and pseudonyms have been used in place of real names. The printed material, except that of the consent form, does not contain any information through which the participants may be identified. The digital recordings were destroyed as soon as the interviews were transcribed (Muthuswamy, 2005). In addition, to insure greater confidentiality of data and protection of participants' identity, the consent forms (which require participants' information) together with the interview transcripts were erased after the thesis was finalised.

3.8.3 Consequences

Consequences are considered as the possible harm or benefits that could occur to the participants as a result of the research project. During the qualitative interview, human experience is examined in detail, giving the researcher access to subjective experiences that are than described and interpreted in a more public sphere (Brinkmann, & Kvale, 2005). While qualitative research claims to avoid the power relations that are encountered in quantitative research between researchers and participants, these relations are more subtle in qualitative research and should not be ignored (Brinkmann, & Kvale, 2005). For example, the interview process can be therapeutic for an individual, but it can also arouse feelings that may not otherwise have been experienced that could re-traumatise an individual (Angell, 1997). Therefore, the interview process itself contains the potential to alter the manner in which a participant feels either about themselves or the situation. In order to address this, at the outset of the interview, the researcher made it clear that the participants could choose to actively proceed or to disengage from the interview at any time. During the interview, the researcher adopted a supportive, non-judgemental manner in order to remain alert to any distress experienced throughout the interview, as well as to avoid eliciting distress (Muthuswamy, 2005). After the interview, the participants were debriefed, and the researcher made contact with them two days later in order to ensure that they were not experiencing any distress as a result of the interview that may have necessitated a referral to a relevant support service such as a psychologist or local counsellor (Muthuswamy, 2005; Angell, 1997). The participants all felt as though they had benefitted from the interview, and stated that it had felt therapeutic for them.

Overall, in this research project ethical principles were adhered to and ethical practice extended beyond procedural ethics by adopting an ethical stance with regard to the participants in order to ensure that no harm would be caused to them and that their voices would be heard throughout the paper at hand.

3.9 Conclusion

This chapter described the research process including selection of participants, data collection, data analysis, issues of quality and ethical procedures in order to gain a clear idea of how the research results were obtained and analyzed.

For the purpose of this study, qualitative research by means of semi-structured individual interviews using the methods offered by Interpretative Phenomenological Analysis was considered an appropriate method for gaining insight into the needs, expectations and experiences of the support group members at the Noordgesig recreation centre.

CHAPTER 4

Findings and discussion

4.1 Introduction

This chapter presents the findings of the study conducted, stemming from the semi-structured interviews of HIV positive support group attendees at Noordgesig Community Centre in Johannesburg. In keeping with the philosophy of IPA, this chapter begins with a brief description of each participant in order to provide insight into the context in which their experiences took place. The chapter will than proceed with a discussion of the findings and the themes that were identified from the interviews. In order to assure that the participant's anonymity is preserved each of the five participants were assigned a pseudonym. The results section is divided into three sections. Firstly, the participant's experiences before joining the support group, secondly, their motivation to join the support group and lastly, their experience of being in the support group which one participant described as "a bitter-sweet experience". Analysis of the verbatim extracts yielded five interrelated superordinate themes. The first theme that was identified is the participants experience of 'struggling to survive after diagnosis', the second theme is struggling to cope: adopting negative coping skills', the third theme is 'experiencing a turning-point: a will to survive', the fourth theme is "attending support group: a sweet experience" and the last theme is "Attending support group: a bitter experience". Direct quotations from the interviews were used as illustrations for emphasis on the themes. The chapter will end with a brief conclusion.

4.2 Participant profiles

These participant profiles describe Thandi, Amanda, Sindy, Rob and Solly as they were at the time of the interview. To protect their privacy, these names are not the participants' real names.

4.2.1 Thandi

Thandi is a 42 year old black woman. She is in a stable relationship and has three children from a previous relationship. She resides in an informal settlement with her boyfriend, his two children and her three children. Her highest level of education is grade eleven. Thandi is unemployed and is dependent on her husband and the children's grant for financial support, which amounts to at least R1500 per month. She discovered her HIV status after being admitted to hospital for a mental illness, while in hospital she was diagnosed with a depressive disorder and with HIV. She suspects that the virus was passed onto her by her ex-boyfriend who is now deceased as a result of AIDS; she describes him as a womanizer. At the time of the interview, she reported that her current partner was unaware of her HIV status. She explained that she was still waiting for the right time to disclose her status as she was afraid of how he might react. Thandi mentioned that since she and her boyfriend met a year ago they have been using condoms. The only people she disclosed her status to were her mother and her sister, who she reported is also HIV positive. Her main source of emotional and social support is her sister and the support group.

4.2.2 Amanda

Amanda is a 36 year old black woman who was single and unemployed at the time of the interview. She resides with her six year old daughter in a one bedroom RDP house. Her highest level of education is grade ten. She discovered her HIV positive status during her first pregnancy at a routine ante-natal clinic checkup. Amanda reports that she had a miscarriage four months into her pregnancy due to stress and depression as a result of her HIV diagnosis. Four years after the miscarriage, Amanda fell pregnant with her second child, but during the delivery her child’s father died after spending a week in hospital with a stomach infection. Amanda reports that she suspects that AIDS killed him as he refused to get treatment. At the time of the interview, it appeared as though Amanda was still grieving and had found it difficult to come to terms with the complications of her first pregnancy and the loss of her partner. Amanda is currently dependent on financial support from her mother, sister and the child grant that she receives for her daughter. Amanda disclosed her status to her mother, sister and her boyfriend before he died. She apparently told her boyfriend during an anger outburst, and while he was angry at first, he later accepted her status. However, her mother and sister were supportive from the beginning. Her source of emotional and social support is her mother, sister and support group.

4.2.3 Sindy

Sindy is a black 30 year old mother of one. She resides with her husband and her ten year old son in an informal settlement. At the time of the interview, she had been married for six years. Her highest level of education is grade eleven. Now unemployed, Sindy worked as a domestic and child-minder, but resigned after her boss requested her HIV results. She reports that finding employment is a challenge, as most of the employers that she approached have request her HIV results before she is allowed cook for them or mind their children. Her husband is a gardener and only earns R500 per week. In addition to this, they get a small grant for their son. Sindy discovered that she is HIV positive while she was pregnant with her son. She reports that she was curious and therefore requested a test during one of her antenatal appointments at the clinic. She expected an HIV positive result as she knows that her husband has been unfaithful. However, she was still shocked and hurt when the results returned were positive. She disclosed her status to her husband, mother, brother and sister during a family meeting and then later to her friends. Her husband also tested HIV positive, but refuses to take his treatment. According to Sindy, he is still in denial. Her mother and husband are supportive, but her brother has rejected her. She experienced mixed reactions from her friends with some being supportive and others rejecting her.

4.2.4 Rob

Rob is a 50 year old black man. Originally from Kwazulu-Natal, he moved to Johannesburg in 2001 for employment opportunities, after his mother had died. He is married to someone he met in a previous support group. At the time of the interview, they had been married for a year. Rob has no children of his own, but is a step-father to his wife's two children from a previous relationship. Rob's highest level of education is grade seven. He was unemployed at the time of the interview. Rob discovered he is HIV positive in hospital after being admitted for dehydration. His HIV diagnosis is as a result of the life he lived in the past, when he apparently abused alcohol and had unprotected sex with multiple partners. Rob seemed to blame himself for his diagnosis and regrets the lifestyle he lived. He has no family in Johannesburg: he has never known his father and he has two brothers who reside in Kwazulu-Natal. Rob has not disclosed his status to his brothers nor his friends as he states that it is still not the right time. His main source of social and emotional support is his wife and the support group.

4.2.5 Solly

Solly is a 43 year old father of two; he has a 17-year-old daughter and a 12-year-old son. At the time of the interview, Solly was divorced and residing with his mother. Solly and his ex-wife separated after she was apparently unfaithful to him. The two children are currently living with his ex-wife, but they visit him on weekends and school holidays. Solly's highest level of education is matric. He was unemployed at the time of the interview, but in the process of seeking employment. Solly worked as a call centre-agent, but was dismissed from work because of his constant absenteeism after his HIV diagnosis. Solly is currently dependant on his mother for financial support and has some money that he received from his work that he is saving for his children's education. Throughout the interview, Solly emphasised his need to find employment again, as if he feels ashamed that he is unemployed and living with his mother. Solly discovered his HIV status while he was in hospital; he was admitted after collapsing and was diagnosed with Tuberculosis and HIV. He disclosed his status to his mother, ex-wife, best friend, sister and his two children. According to Solly his relationship with his best friend has not been the same since he disclosed his HIV status. He reported that he has not disclosed to his brother yet, as he fears his brother would tell other people. Solly's main source of emotional and social support is his mother and the support group.

4.3 Research Findings

It is important to note that the themes presented are one possible construction of the phenomenon of people's experiences of attending HIV support groups. According to Smith et al. (2009), the process of finding themes is based upon the researcher engaging in a double hermeneutic. It is therefore acknowledged that these themes are a subjective interpretation which may have been interpreted in a different way by another researcher.

The five super-ordinate themes together with the related sub-ordinate themes and supporting quotations from the transcripts are presented in the table below.

4.3.1 Table of Super-ordinate and Sub-ordinate themes

Super-ordinate themes	**Sub-themes**	**Indicative quote example**
1) Struggling to survive after diagnosis	The struggle with identity	*"…I was so confused. I didn't know who I was…"* (Amanda)
	Feeling weak: Physically and Emotionally	*"I didn't even go to the gym as often as I use to because I didn't have the energy."* (Solly) *"The pain I felt was horrible, not physical pain emotional pain."* (Amanda)
	The Struggle with Stigma and Discrimination	*"The only problem was to tell my family. I was so scared they would judge me."* (Sindy)
	HIV is not the only struggle	*"Sometimes having no money and being a single mother is worse than HIV".* (Amanda)
	Suicide as a way out	*"I wanted to kill myself..."* (Thandi)
2) Struggling to cope: Adopting negative coping skills	Denial	*"I did not accept my status in the beginning"* (Amanda)
	Substance Abuse	*"…after I found out about my status I drank even worse." (Rob)*
	Avoiding People	*"…I wanted to be alone."* (Amanda)
3) Experiencing a turning-point: A will to survive	The role of social support	*"…just to hear someone say I'm here for you lifted my mood."* (Amanda)
	The role of spirituality	*"So since then I started praying and things started to make sense."* (Solly)
	Children as Motivation	*"…my daughter keeps me going, I need to be strong for her and I need to be healthy so that I can see her grow up*." (Amanda)
4) Attending support group: a *"sweet"* experience	Learning	*"I know more about HIV/AIDS and ARVs."* (Amanda)
	A Sense of empowerment	*"I went to workshops for HIV and I got training on HIV and AIDS, my dream is to educate people on HIV …"* (Sindy)

	Gaining strength back	*"As you can see I'm starting to get it back [lifts arm to show muscles]"* (Solly)
	A sense of hope	*"I am able to dream again."* (Amanda)
	"I am not alone": the power of meaningful relationships	*"Sometimes outside we feel alone like we the only one with the problem, but in the support group I feel like I belong there."* (Amanda)
	"I am free to talk": A non-judgmental space	*"I can talk about anything in the group without being scared"* (Thandi)
	"I am laughing again": Improved quality of life	*"Positive to me now means to stay healthy and be positive in mind so I'm ok and I'm laughing again." (Amanda)*
	Enhanced coping skills: Thinking positive	*I like this positive thinking it makes my mood better, sometimes when you only think about bad things it will make you sick."* (Thandi)
5)Attending support group: a *"bitter"* experience	Mixed gender groups: a struggle for male participants	*"When there are women men are shy to talk about their sex problems."*(Rob)
	Lack of transport money and food	*"Transport is an issue for some of us."* (Sindy)
	One facilitator instead of two	*"…we only have one leader and when she can't make it to the group then we won't have support group that day."*(Amanda)
	Unable to provide indefinite support	*"I think the support group must be longer you know, they mustn't say only 15 sessions."*(Sindy)

Below is a discussion of each of the themes:

4.3.2 Super-ordinate theme 1: Struggling to survive after diagnosis

All participants seemed to think that it was necessary for the researcher to first understand their experience of HIV prior to joining the support group. Getting an understanding of what life was like immediately after diagnosis gave the researcher a broader perspective of how useful or not the support group has been for each participant. Before joining the support group, all five participants struggled to come to terms with their HIV diagnosis. This super-ordinate theme aims to capture participants' experience of the challenges they faced and how these impact on living with HIV.

4.3.2.1 Sub theme 1: The struggle with Identity

Research suggest that being diagnosed with HIV, not only threatens or disrupts the body, but the person's identity as well (Ciambrone, 2001; Roberts, 2008; Sherr et al, 2007, Young, 2011). Receiving an HIV-positive diagnosis alters one's life and future aspirations, while past mistakes are over-emphasised and amplified. All the participants experienced the impact of their HIV diagnosis through loss of certain aspects of their identity. The following description alludes to how Amanda felt she had disconnected from her core identity:

> *"I love people, I used to joke with other people, but when I discovered I was HIV positive it changed everything, I didn't like people anymore… it even changed my behaviour, I was so confused. I didn't know who I was…*" (Amanda)

Amanda expressed immense anxiety and uncertainty about her experience of receiving her diagnosis. The above quote implies that she distinguishes between a former self and her current experience of herself. The changes Amanda reported were associated with significant distress and prompted her to withdraw from social contact. Her account emphasized the distress she felt as she struggled to manage or comprehend her situation of being HIV positive. She seems to view her previous self in a positive light, but she views the self after diagnosis as negative and undesirable. This is similar to what Goffman (1963) described when he said that stigma refers to a spoiled identity.

Just like Amanda, Solly describes how he lost his old self as a result of HIV:

> *"I use to gym a lot and pick up weights so I was built nice, muscles and everything, I was bigger than this. As you can see I'm starting to get it back [lifts arm to show muscles].Then the bad news came, the doctor told me I was HIV positive… So quickly I changed from a fit gym body to a skinny skeleton…"* (Solly)

He further explained how he changed from being an involved father to neglecting his children:

> *"…when my kids come over they would just run into the room with excitement because they have not seen me, I would get so irritated and chase them out. And that's not how I know myself to be, I love spending time with my kids, I was an outgoing person…"* (Solly)

Similarly, Sindy expressed the following:

> *"I'm the type of person that doesn't like keeping secrets, but now I have to keep my status a secret just because people are not educated."* (Sindy)

Based on the above quote it appears as though Sindy felt she had to change a part of her identity as an 'honest person' to accommodate her new identity, that of being HIV positive.

Below Rob also describes how he became "broken" as a result of his HIV diagnosis:

> *"Then the results came back and as I was lying in the hospital bed the doctor told me I am HIV positive. Tjo! I was broken, broken, broken…"* (Rob)

Rob's emphasis on "broken", might signify that he feels like he is not the man he used to be, as if the HIV has damaged him and now he needs fixing or to re-evaluate his identity.

In addition to this, some participants believed that their lives hold little future and opportunities for employment and romantic relationships after diagnosis. According to Maloon et al. (2004) having a job and having goals and future aspirations make up a part of one's identity, therefore the below extracts might suggest that letting go of plans and dreams changes the way in which participants perceive themselves as well as their lives.

> *"When I first found out I was HIV positive, I stopped dreaming, I was just waiting to die, I had no plans for the future."*(Amanda)

> *"…My heart was broken, deep down inside I felt my life was over."* (Thandi)

> "*…they won't give you the job if you are HIV positive."* (Sindy)

Rob and Solly explain how they lost confidence in romantic relationships after diagnosis:

> *"I was always the guy who got the party started and girls were crazy for me, every weekend I would leave with a different girl from the tavern, I thought I was the man, you know girls liked me, but after HIV they run away from me…and because I was so drunk I just slept with*

> *anyone the next morning. I wouldn't even know their names and I won't see them again… If I could take that part of my life back I would [sigh]."* (Rob)

> *"I just believe that I need to be honest with someone if I want to spend the rest of my life with them because that is what I would expect, but I can't be honest, it's difficult… so I don't go on dates that often anymore… My world was crushed*." (Solly)

There seems to be a constant battle between Rob's previous self and his current self. He seems to be proud of his success with women in the past, but at the same time he seems to regret that part of his life and feel shameful, perhaps because he feels responsible for his HIV diagnosis and believes he contracted HIV due to the lifestyle he lived. He therefore perceived his identity after diagnosis as being stained by immoral behavior. There is a sense that he felt distress over his incapacity to get a romantic partner because perhaps this part of his new identity did not fit with his former identity before his HIV diagnosis. Solly on the other hand felt like he could not be his honest 'self' due to fear of rejection and therefore he isolated himself.

The participants also expressed a sense of emptiness after diagnosis, as if they had no self at all. The below extracts reflects a disconnection from identity after diagnosis.

> *"I felt dead, like very frozen, almost like a zombie… I even lost my job."* (Solly)

> *"I became blank as I left the nurses… I did not hear what they said."* (Amanda)

> *"I felt like I could just die there, I felt empty."* (Rob)

Based on the above results it is evident that the reality of testing HIV-positive challenges an individual's self-concept, this is similar to the results found by Charmaz (2000), Ciambrone (2001) and Sher et al. (2007). However the participants in this study seemed to find it difficult to identify themselves as living with HIV. It appears as though they experienced the HIV diagnosis as traumatic. The experiences of identity and the participants' relationship to themselves bear a resemblance to the studies of Kelly et al. (2000) and Young (2011) which found that PTSD symptoms are often associated with HIV. In their Study Kelly et al. (2000) described how traumatised individuals may experience a dissociative state which includes feeling numb or robotic. However, the participants' reactions seem more indicative of complex PTSD in which dissociation is seen to be one of the key symptoms (Sherr et al., 2011). It may be that such feelings were generated as the participants struggled to reconcile who they were with who they had become after HIV diagnosis, which left a sense of being out of control, confused and a need to dissociate from an unknown identity.

4.3.2.2 Sub-theme 2: Feeling weak: physically and emotionally

This sub-theme of feeling weak revealed two experiences. First, the participants experiencing the body as a hindrance and reporting that their bodies were without strength, and that they had lost independence. Secondly, they reported experiencing negative emotions that caused hopelessness and despair. As seen in the literature review chapter, research findings show that the predominant emotions for individuals living with a serious illness are usually morbid and gloomy (Ramine, & Rabkin, 2001). This was certainly true for participants in this study as they reported experiencing sadness, hopelessness, anger, guilt, shame and pain, which as a result made them feel weak emotionally and physically.

Amanda explained how the emotional pain of living with HIV made her feel weak and hopeless:

> *"I really didn't see light at the end of the tunnel. The pain I felt was horrible, not physical pain, I'm talking about the emotional pain. I wanted to give up…"* (Amanda)

For Amanda these negative emotions played a major role in her developing depression, this is evident in her statement below:

> *"I got depression when the doctors told me I have HIV because of all the stress and depression; I had a miscarriage four months after they told me I was HIV positive."* (Amanda)

Similarly, Thandi explained how she too suffered from depression as a result of her HIV diagnosis:

> *"I had a nervous breakdown… I was sick, like mentally ill and then they admitted me into (Ward two at Helen Joseph Hospital)… I was so scared, I cried for many days… I was hurt, so hurt, I kept on asking myself why…I use to cry myself to sleep every night."* (Thandi)

Likewise, Solly also struggled with feeling emotionally weak:

> *"I was diagnosed depressed and the doctor told me to see a psychologist, I was put on medication, went for a month I think and then just stopped going"* (Solly)

Seeing a psychologist, for Solly might have meant that he was too weak to depend on his own strength, rather he had to depend on professionals and medication in order feel better and regain his strength. Leaving therapy prematurely was perhaps a way for him to try and take control instead of feeling dependent or weak.

Solly went on to further explain the physical weakness that he has experienced after his HIV diagnosis:

> *"I didn't even go to the gym as often as I used to because I didn't have the energy. Eih, when I started losing weight, it was worse. I felt very weak… My son said to me daddy why you getting so thin."* (Solly)

As seen previously, Solly took pride in his physical appearance, but due to HIV he started losing weight which made him feel weak and hopeless, as being a body builder was part of his identity. Solly's emphasis on being physically weak might relate to his masculinity, in which men are always viewed as powerful and strong.

Similar to Solly's experience, Robs weakness was also seen in terms of his masculinity:

> *"Tears rolled down my eyes as the doctor spoke to me. You know I never cried as a man, but that day I just cried, because men are not supposed to cry".* (Rob)

Rob crying might represent a sign of weakness as men in most societies are socialized not to show emotions. Men are supposed to stay emotionally strong, but the HIV diagnosis changed that for Rob, making him feel weak and vulnerable. Rob and Solly's experience seem to be similar to what Mabiba and Kekana (2013) found in their study, that the men believed that they are expected to be physically and mentally strong and seeking help or assistance will imply that they are weak.

Solly explained how he lost independence after losing his job as a result of HIV:

> *"…now that I am not working I see how difficult it can be because my mother helps with finances, but I don't like depending on her, I am a grown man who needs to provide for himself."* (Solly)

Perhaps, being dependent on others especially a woman is making Solly feel weak, but also at the same time guilty and shameful as men are usually expected to be the providers. Solly further explains how he thought that he would never contract HIV:

> *"Never in a million years did I ever think I would get HIV, I thought it's only prostitutes and gay people who are at risk, not once did I think it could be me."* (Solly)

It seems as though both male participants felt as though they could not express their distress as they felt that this would be an expression of weakness. Solly's idea that HIV does not infect strong men could also indicate that he did not want to appear as a weak individual, either to himself or to others.

The results indicate that physical health is not the only issue the participants had to deal with. Along with the physical illness are mental and emotional health conditions that may come up, such as depression that made them feel weak, helpless, and sad. Martin and Kagee (2011) also found that there is a higher prevalence of mental disorders in people living with HIV, with the most common being depression. The study by Bond et al. (2002) showed that, for some people living with HIV, the shame and guilt of contracting HIV is more difficult than the actual physical effects of the virus. However, the participants in this study found that both the physiological effects as well as emotional effects of HIV/AIDS limit functional activities thereby reducing their quality of life and making them feel weak or powerless. Hence each participant experienced both psychological and physical negative effects as a result of their underlying distress, which they believed was associated to their experiences of being diagnosed HIV positive.

4.3.2.3 Sub-theme 3: The struggle with stigma and discrimination

One of the other challenges that the participants experienced was stigma. The results in this study indicate that stigma is still a major challenge for people living with HIV and creates a great dilemma when deciding whether to disclose or not. In their study, French et al. (2015) also found that stigma can have significant effects on willingness to disclose ones HIV status. For most of the participants in this study, disclosure appeared to be a stressful event due to fear of anticipated stigma.

Sindy was afraid to disclose her status as she anticipated that her family would be angry and blame her and even reject her:

> *"The only problem was to tell my family. I was so scared they would judge me, but in my heart I knew I had to do it no matter what they said… I knew that my family would be angry… Even though my family knew my husband was sleeping around I thought that they*

> *might think of me as the 'sfebe', you know like a bitch, because my family never really liked my husband they told me many times to leave him, but I didn't listen. So I thought my family would shout me and disown me because of HIV…"* (Sindy)

The other participants also perceived rejections from various sources including family, partners, friends, health care workers, and society in general:

> *"I was so scared, I cried for many days. I told the doctor please don't tell my family, please doctor, that is all I said, because my family will treat me bad they will throw me out."* (Thandi)

> *"My boyfriend… he doesn't know about my status… You see since my last relationship it takes me very long to trust men. I want to make sure that we are serious before I tell him about my status…I think I will tell him one day, but I first need to think nicely before I tell him because I don't want him to leave. Eish! this is so much stress…"* (Thandi)

> *"So many people treat you bad because of your status and I saw how other HIV positive people were treated and that is why not many people know about my status because most people don't even understand the basics of HIV and because they don't understand and know about HIV, they will treat you bad."* (Amanda)

> *"I never told my friends and I don't think I will ever tell them because it's not important for them to know… For me I think it's a personal choice because it can cause many problems for you if you don't tell the right person… People will not treat you the same, family and friends will reject you. They will watch you always to see signs of symptoms."* (Rob)

Some of the participants experienced discrimination which made them feel lonely as people avoided contact with them and treated them as inferior. According Herek (2002), this is also known as external stigma. Amanda reported how she was disrespected by the nurses at the hospital for being HIV positive:

> *"But I have been treated badly by the hospital, the nurses. All HIV patients are being treated unfairly by the hospital, the nurse would scream, if you here to fetch your ARVs than stand on this side, Eish my heart would just beat fast than I just leave and go back later… Is my status not supposed to be secret? At one point I felt like I don't want to go and fetch my medication anymore. The nurses are disrespectful."* (Amanda)

Sindy described how she felt insulted by her siblings' negative reactions when she disclosed her status:

> *"My sister told me she will buy all the medication I need, you know the muti, the traditional medicine to rid me of HIV, I told them no! The muti won't help I'm not bewitched, I am sick, I have a virus… My brother started swearing at me, he said voetsek, you've got AIDS, and you going to give it to us, and you are going to die at any time. I told him I'm not going to die. They were so negative…"* (Sindy)

Solly described how he was hurt by women that he dated due to his HIV status:

> *"The women that I went out with on a date so far would change the topic or leave me at the restaurant when I say I am HIV positive. There's this one woman, we just kissed and touched and I decided to tell her, because she was about to undress me. This was our third date and things were going really well up until I decided to tell her, I was so hurt and felt so rejected."* (Solly)

As a result of past negative experiences, most of the participants chose to disclose partially. However, the partial disclosure presented limitations to the benefits such as social support and a release from the burden of having to keep HIV a secret. For the participants in this study, the risks of disclosure revolved around the loss of relationships, rejection and exclusion occurring from disclosure. These results were similar to what Gilbert and Walker (2010) as well Peterson and Swarts (2002) found.

The accounts below show how Sindy and Solly lost relationships and were rejected by friends and family for being HIV positive:

> *"My brother, he is very distant, we don't have a close relationship like before. I only see him at funerals, he greets me, but we don't talk very much… Only a few of my friends gave me support, and talk to me. Others left."* (Sindy)

> *"I also told my best friend, but he is no longer my friend. Ever since I told him our relationship changed, we spent less time together and so we grew apart. I sent him a message after a while when he stopped answering my calls and I nicely asked him to please not share my status with anyone."* (Solly)

The below extract indicates how for Thandi, being free from secrecy seemed to be a benefit to disclosing, and on the other hand, it appeared to be a risk as she feared that it would result in her experiencing stigma and discrimination. The participants in this study found it difficult to manage this dilemma. Thandi seemed to have a sense that disclosure was the right thing to do, but yet so difficult due to fear of stigma:

> *"You have to worry about what people will say to you when they find out, keeping this a secret is so difficult…my boyfriend does not know. I try to hide my medication from him. Every time when I go to hospital to collect my medication I take it out of the box and I throw the box in the velt so he can't see. I tell him it's my medication for depression." (*Thandi)

When asked if she would ever disclose to her boyfriend, Thandi reported:

> *"Yes, I really want to tell him, but it is so difficult. I think about it every night I can't sleep sometimes because I'm thinking I must do it, it's not fair for him to not know. It's stressing me and eating me up"* (Thandi)

The desire to disclose and the fear of doing so presented a cruel dilemma for the participants. Stigmatisation was the main risk. Consistently, participants feared being spoken ill of, being labeled, being called names, having fingers pointed at them, being gossiped about and sworn at and this prevented them from full disclosure. All the participants feared stigma in the sense that Goffman (1963, p.3) described it: as "an attribute that is deeply discrediting" with the stigmatised person viewed as "disqualified from full social acceptance". As seen in the sub-theme, 'the struggle with identity', being diagnosed HIV positive might lead to the creation of a spoiled social identity, which is dealt with by hiding features which identify the individual as possessing these undesirable differences.

4.3.2.4 Sub-theme 4: HIV is not the only struggle

During the interview process it became apparent that HIV is not the only challenge that most participants experienced. In addition to, struggling with identity, feeling emotionally and physically weak and HIV stigma, participants had to deal with challenges of living in poverty, and being treated unequally due to race, gender and, for one participant, disability. In order to make sense of these interlocking systems of oppression the researcher refers to the intersectional theoretical framework described in the literature review chapter. The intersectional perspective acknowledges that these participants social identities, gender, and being of low social economic status interlock with oppressive forces to create social injustices such as health care inequalities (Bowleg, 2012). It is important to note that all the participants who were interviewed were black, unemployed and reliant on a child support grant or family members for financial support. Also important to note, is that the resources that are needed to improve participants situation are inaccessible to people living in poverty, and may prevent them from living a healthy and productive life. The following description by Thandi alludes to how being a black single mother with no income made it more difficult for her to survive as a person living with HIV:

> *"…the doctor told me I had to swallow my tablets with food and I did not have enough food to eat so I take it when my stomach is empty, I have five children and the little money that I have I make sure they eat first before I eat, eish… sometimes I don't have money to fetch medication than I just stay at home and not fetch it, but then the nurses shout you, they don't understand I don't have money."* (Thandi)

Thandi's poor living conditions make ARV compliance more difficult because she is unable to have proper meals to take her medication or money to obtain transport to attend clinic appointments. Shisana et al. (2014) found that this places HIV positive people at risk of developing AIDS. Similarly Mbirimtengerenji (2007) found that poor people infected with HIV are considerably more likely to become sick and die faster than the non-poor, since they are likely to be malnourished, in poor health, and lacking in medical attention and access to medications.

Amanda privileged her experience of poverty above the effects of HIV. Amanda is a black single mother who lives in poverty and has a disability. For Amanda, being HIV positive is nothing compared to the struggle of being a poor, black, disabled, single mother:

> *"… sometimes having no money and being a single mother is worse than HIV."* (Amanda)

> *"Do you see I'm walking with a crutch now? My pastor disrespected me. He made funny jokes about disabled people. He disrespected me. People cannot see the HIV, but they can see the disability, sometimes I say to myself this HIV is better."* (Amanda)

Below Thandi explains how as a poor, black woman she has little power to negotiate safe sex as her partner is the provider and "man of the house":

> *"He's the only man I had sex with and we did not use condoms because he did not like condoms… I used to tell him that when he goes out he must use condoms because… you know men… when they go away from you for so long they get other women to satisfy them, but he didn't listen when I told him to use condoms, what can I say? Nothing… he is the man of the house*." (Thandi)

Based on the above extract, it appears as though Thandi is financially dependent on her partner and because of this she is engaging in transactional sex as a means to survive. This is similar to what Piennar (2015) found in his study: Often the risk of not complying with abusive men who can withhold critical support is perceived to be greater than the long-term risk of HIV. Piennar (2015) found that poverty plays a major role in influencing sexual decision-making. As seen in the literature review chapter, there is a two-way relationship between poverty and HIV: poverty as a consequence of HIV and HIV as a consequence of poverty. In Thandi's case it appears as though HIV is a consequence of poverty in that she is willing to risk her health in order to survive financially.

Sindy and Thandi also had to endure emotional and verbal abusive relationships in order to survive:

> *"… Even this condom thing we always argue about it because the doctor told me even if we are both HIV positive having unprotected sex all the time can be bad for our health. But he does not want to listen, he starts swearing me so I have no say."* (Sindy)

> *"Sometimes when I go out of my way to cook nice food for him he throws it out and tell me I can't cook. I use to cry myself to sleep every night. Worst of all, he is a womaniser, but I cannot leave you see, because he always tries to make a plan for food for the children, he likes to work hard, even if his job is finished, he will go look for something."* (Thandi)

Based on the results of this study it is evident women have limited economic stability and are more likely to be treated unfairly and as a result, this feeds into the vicious circle of poverty which leads to risk of sexual exploitation and abuse, which consequently leads to greater vulnerability to contracting HIV.

4.3.2.5 Sub-theme 5: Suicide as a way out

With free treatment widely available, HIV is no longer a death sentence, but for most participants in this study thoughts of committing suicide still crossed their minds. Similarly, Kelly et al. (2000) found that there is an increased risk of suicidal attempts among HIV positive people. Perhaps this is as a result of a combination of factors, as we saw above that HIV is but only one of many challenges that the participants seem to endure. Perhaps it is a combination of being HIV positive, struggling with mental health, the associated stigma as well as poverty that play role in the participants' suicidal ideation. This is evident in Thandi's description below when she states:

> "*There was too much things happening*" *"I wanted to kill myself, there was too much things happening. So when I came back from hospital I drank all of my medication at once and I fainted. And before I knew it I was back in hospital again."* (Thandi)

Similarly, Sindy believed suicide will take away not only HIV, but all her other problems:

> *"…I was thinking maybe it was just better if I'm dead, I was thinking maybe it will take away all this problems."* (Sindy)

For Solly it was more about the fear of developing AIDS:

> *"I wanted to die… I didn't want to die of AIDS as I had seen on the TV people in the last stages of the disease. Tjo! They suffer very badly. I felt so much pain, so I thought it will be best if I kill myself. Then I wouldn't have to go through that suffering."* (Solly)

For the participants in this study, suicide can be seen as a way of escaping the uncertainty that comes with living with HIV. They spoke about suicide as a perceived escape from life's difficulties, during a time of great distress. Perhaps thinking about suicide and actually attempting it indicates that the participants struggled to cope. The next theme looks at a related theme, the negative coping skills the participants adopted as a reaction to being diagnosed HIV positive.

4.3.3 Super-ordinate Theme 2: Struggling to cope: Adopting negative coping skills

This super-ordinate theme demonstrate different ways in which participants exemplify their experience of attempting to manage their health and associated changes to their life just after finding out their HIV status. This in turn seems to have implications for their wellbeing. Most of the participants struggled to cope with their HIV diagnosis. Studies found that being diagnosed with HIV can trigger problematic coping strategies (Moskowitz, & Wrubel, 2005; Myint, & Mash, 2008; Pence et al., 2008). For most of the participants in this study it seemed that denial, substance abuse, and avoiding people were the first response to protect themselves against the challenges of living with HIV.

4.3.3.1 Sub-theme 1: Denial

Thandi, Amanda and Solly used denial as a coping mechanism, this is evident in the following extracts:

> *"I refused to accept that I am positive, for many months until I got sick again because of not taking my medication. Not thinking about it made me feel better."* (Thandi)
>
> *"I did not believe it, I remember shaking my head and screaming no, maybe they have the wrong blood results, it can't be mine. There must have been a mistake… It took me a very long time to accept my status."* (Solly)
>
> *"I did not accept my status in the beginning; I was in denial and it was making me sicker and sicker."* (Amanda)

Denial can be helpful if it is short-term as it gives the individual time to adjust to stressful situations, however if not dealt with denial can be dangerous (Lazarus & Folkman, 1984). Based on Solly and Thandi's statements *"it took me a very long time to accept", "for many months"* it is evident that their denial was not short-term. For Sindy and Amanda being in denial was dangerous as it meant not taking their ARV medication as they felt that they were not HIV positive even after being diagnosed and as a result they became more ill. Maybe the participants avoided confronting the reality of being HIV infected in order maintain a sense of 'normalcy'.

4.3.3.2 Sub-theme 2: Substance abuse

Another way of coping for some of the participants involved using substances. As seen in the literature review chapter using alcohol can be viewed as a form of emotion-focused coping (Myint, & Mash, 2008). What was interesting to note in this study is that substance abuse as a coping mechanism was only used by the two male participants. Substance abuse may be an important factor that puts people at risk of HIV infection in the first place and puts them at further risk after being re-infected (Freeman et al., 2007). Rob reported that he was drinking before he was diagnosed which would have placed him at risk of infection. However, he admitted to his drinking escalating after he received the diagnosis:

> *"...I use to drink before, but after I found out about my status I drank even worse but the doctor told me to stop drinking alcohol because it doesn't mix well with the medication. Alcohol has always been my way to escape and run away from my problems, it makes me forget about my problems…"* (Rob)

Below, Solly describes how he not only consumed alcohol, but smoked cannabis as well as a way of escaping the challenges of living with HIV:

> *"I would just stay out of work and go drink myself drunk, I even started smoking weed, something that I have never done in my life, it made me feel more relaxed, you see… So when I pulled my CD4 count the last time I discovered it went down then I asked myself what happened only to find out that I never drank the tablet that day because the weed was playing with my head. So I stopped all together smoking weed just to get my mind in the right gear* [laughs]… (Solly)

Based on Rob and Solly's description above, it is evident that they used substances to help them minimize the pain felt as a result of being diagnosed HIV positive. However, the substances interfered with their treatment adherence. This was also found in the study by Kalichman et al. (2007) when they found that alcohol use is associated with non-adherence to treatment. Literature has shown that alcohol use is a way of life for many and has also been identified a major contributor on the spread of HIV (Kalichman et al., 2007). Thus, it is not surprising that alcohol puts people at risk of HIV and that alcohol is a common but risky way in which people cope with their HIV status.

4.3.3.3 Sub-theme 3: Avoiding people

All five of the participants resorted to isolating themselves from others as a way of coping with HIV. Avoiding others limits the potential benefit of social support and can also be a sign of depression (Flowers et al., 2006). People may isolate themselves for various reasons including feeling overwhelmed by the diagnosis, feeling ashamed for being infected, and a fear of stigma and discrimination as seen above (McLeod, 2009). In this study most of the participants chose to isolate themselves from others to avoid confronting their hurtful negative reactions. Avoiding people according to Myint and Mash (2008) can also be viewed as an emotion-focused coping strategy.

Below Thandi explains that she chose to "stay away" from her mother as a way of protecting herself against negative comments:

> *"My mother is a Sangoma … she says I am bewitched… I try to stay away from my mother, I don't like hearing too much about the ancestors and evil spirits. So I don't visit her as much as I used to."* (Thandi)

Similarly, Amanda expressed her need to avoid people after she was diagnosed HIV positive:

> *"… I wanted to be alone."* (Amanda)

This was echoed by Sindy:

> *"I did not want to see anyone; I just wanted to lock myself away."* (Sindy)

Below, Rob speaks about "hiding" perhaps this indicates that he felt ashamed about his HIV status and in order to cope he had to lock himself in his room:

> *"When you go to your room you alone, there's no one else around you, than you start to think all kinds of nonsense. I felt so alone, because I would hide from my friends and family."* (Rob)

Solly also explained how he too would avoid people at home after he was diagnosed with HIV:

> *"I use to spend a lot of time in my room; I will only come out of my room when I feel hungry… I dodged my friends and family, I just felt like being alone."* (Solly)

The participants' behaviour can be seen as a type of avoidant coping that they adopted after being diagnosed HIV positive. According to literature, avoidant coping involves the selection of behaviours that enable a person to move away from a trauma, and is generally associated with greater negative outcomes (Krause et al., 2008). It appears as though the participants consciously and unconsciously chose strategies to move away from the distress associated with the challenges of living with HIV.

4.3.4 Super-ordinate Theme 3: Experiencing a turning-point: A will to survive

Despite the negative coping strategies mentioned above and all the challenges the participants experienced, they still managed to survive. All of the participants reported that there came a time in their lives when they had experienced a turning-point and this was mainly triggered by social support, spirituality and a need to survive for the sake of their children. Interestingly, these turning-points were the motivations that led the participants to join a support group.

4.3.4.1 Sub-theme 1: The role of social support

Social support can be obtained from family, friends, co-workers, spiritual advisors, health care personnel, NGO personnel, and members of one's community or neighbourhood (Pierret, 2003). Most of participants in this study received only a little social support from their families; most of the support they relied on came from their support group. Each participant in the group had support from at least one family member or friend after disclosing. As seen above in the sub-theme on "the struggle with stigma and discrimination", not all family members and friends were supportive as all of the participants experienced rejection and discrimination for being HIV positive. However, the little support that the participants received seemed more valuable than having no support at all. This was best described by Amanda when she said:

> *"I didn't realise how important support was until I got HIV. Even the smallest thing was good enough, just to hear someone say I'm here for you lifted my mood…"* (Amanda)

Accepting that minimal support and talking to others meant not carrying the weight of the above mentioned challenges alone. This goes back to what Ssali et al. (2010) found when they reported that any people who seek support from loved ones do so because they might find it difficult to cope with a crises or problem on their own and therefore when they do not receive the support they long for from family and friends it can be really devastating for them. It was difficult for Amada to imagine what life with HIV would have been like if she had no support at all, this point is shown in the extract below:

> *"…Yes her presence made me feel stronger, I don't know what I would have done if she wasn't there." (*Amanda)

For the participants in this study social support made them feel loved, understood and valued and seemed to be a protective factor that helped them survive: this is evident in the extracts below:

> *"…thanks for the help of my sister and the support group, they give me good advice… She* (sister) *gives me money when I need money, sometimes she goes to the hospital with me to get my medication or when I'm not feeling well, yah, she is just a good person."* (Thandi)

Below, Amanda explains how her mother's unconditional love and support helped her when she was struggling to survive:

> *"But my mom already knew because she would always visit me, she was there when I was admitted, she never left the hospital room… she was very supportive and told me not to worry… she came to the hospital every day, brought me food and clothes to change. I realise now she didn't have to say anything just her coming to the hospital every day after I told her I am positive showed me she loved me and still cared for me."* (Amanda)

She went on to explain the role of her sister in helping her deal with the challenges of living with HIV:

> *"My sister would send me encouraging messages, every week she brings me to the support group because I don't have a car, I can't take taxi because there's no taxis from my area coming this way, they drop you far than you have to walk down, so my sister helps me with transport to get to the support group every week… she also helps me with money, food and clothes…"* (Amanda)

Sindy also spoke about how her mother's support helped her recover from the challenges of HIV:

> *"…my mom has been the most supportive, she goes with me to doctors' appointments sometimes and she always checks if I have taken my tablets… I could see she was sad and disappointed, but she showed that she loved me irrespective of my status, all she said was, you will remain my child and I'm sure you didn't ask to have HIV. Those words meant a lot and I will always remember it."* (Sindy)

Similar to Amada, Sindy's sister was also supportive. Sindy seems to appreciate the effort that her sister has made in terms of educating herself on HIV, being educated on HIV perhaps means that her sister will understand her better.

> *"My sister is making the effort… she reads a lot about HIV and now she gets it…"* (Sindy)

Solly expresses how his mother's support helped him overcome the challenges of forgetting to take his medication:

> *"…But my mother helps me, she reminds me to take the medication. I really don't know what I would do without my mother's support. Her support makes it easier for me to take my medication and accept my status." (Solly)*

Even Though Sindy's partner was angry and left at first, she accepted his support when he returned; his support meant a great deal to Sindy:

> *"My boyfriend…he was supportive only later on, after many months. He came to visit me. He said to me if you are positive than it means that I'm also positive, we can make it work…"* (Sindy)

Similarly, Rob explains how his wife's encouragement and love has helped him decrease alcohol consumption:

> *"…so I'm drinking less now, it's easier because my wife encourages me, she helps me."* (Rob)

The above extracts indicate that the participants in this study received mostly emotional and instrumental support from their family. As mentioned in the literature review chapter, Cohen (2004) describes emotional support as the expression of empathy, caring, reassurance, and trust. However, despite receiving support from a family member or partner, the participants seemed more hopeful about the support they receive from the support group. The participants seemed to have a better understanding with support group members than they did with their friends and family. According to Amanda her true healing began when she started to attend support group meetings:

> *"First I use to stress a lot, I would cry myself to sleep even though I had support from my mother. It's only when I started the support group that's when I really stopped crying at night and stopped worrying because I was able to see proof.."* (Amanda)

Similar to Amanda, Thandi's turning points seemed to have come from the first day at the support group after being encouraged to join the support group by her sister. Hearing the stories from other members with the same experience as her, made Thandi realize that she needs to survive and change the way she thinks about her situation:

> *"…when I heard other people talking, I asked myself… but Thandi what are you crying for, everyone has problems not only you. Than after that I was comfortable and I was able to share my story."* (Thandi)

For Thandi and Solly support from family was the key in helping them join a support group.

> *"…first I didn't want to come, but my sister forced me because she was in the same support group long time ago and when I came for the first time I saw that it's not so bad and I kept on coming."*(Thandi)

> *"My mother encouraged me; she is very involved in community work so she knew the leader of this group. She said I must meet other people who were in the same position as I… I still cannot believe that I agreed to come."* (Solly)

Indeed, studies have shown that in the context of HIV/AIDS, social support is related to better coping and improved quality of life, and reduced levels of psychological distress (Khamarko, & Myers, 2013; Vyuvaharkar et al., 2007), this is further discussed below in the super-ordinate theme 'experiencing support group: a sweet experience'. Even though the participants experienced social rejection from some people, support from at least one family member helped counteract stigmatising beliefs that they are unacceptable and unlovable due to HIV infection. Social support from a family member or a partner made the participants feel loved and accepted despite their positive HIV status. Interestingly social support from a family member seemed to play a huge role in encouraging HIV positive people to join a support group.

4.3.4.2 Sub-theme 2: The role of spirituality

All of the participants related how their spiritual views changed their perspective concerning why they had been diagnosed with HIV. For these participants, turning to God was a way of maintaining hope. Spirituality is known as a coping strategy used by most people when they are faced with difficult challenges (Dagied & Duckert, 2008). The participants in this study seemed to have turned to God as a way of maintaining hope. For example, Solly had the following to say about how he perceived meaning in his world since adopting a spiritual path:

> *"I never use to go to church, but after I found out about the HIV I was so down and my mother did not like seeing me like that so she forced me to go to church. I went to church, but didn't really listen to the pastor because I didn't want to be there, but there was one thing that really woke me up. He said to me, not me, but when he spoke I felt like it was for me, he said even though you feel like things are too much, like you want to give up on life don't worry, God said he will never leave neither forsake you, you can handle whatever you are going through, just pray and ask God for strength. So since then I started praying and things started to make sense."* (Solly)

Similarly, Sindy believed that turning to God and praying would give her the strength and the healing she needs in order to survive the challenges that HIV presents*:*

> *"…I trust in God and he is my healer that is where I get my strength from… I pray a lot and God answers my prayers… because of church I am able to get better, the pastor preached one Sunday and he said we must stand up and fight and not let the devil get us down. It was that moment when I decided I need to fight back because God has already won the battle."* (Thandi)

The participants also felt that what had occurred in their lives were there in order for them to learn and to grow. For them, the experience had been about evolving or growing as people. Significantly, this growth had a spiritual meaning attached to it and was viewed as God's plan for their lives. This is evident in the extracts below:

> *"I think there is a reason why I have HIV. God knew I could handle it. God says that he will not give you what you cannot bear. My story is supposed to be a testimony for others…"* (Sindy)

> *"But I guess everything happens for a reason, I had to learn something from this experience…somehow somewhere I had to stop this fast life that I was living, and I think. God allowed me to have HIV so I can stop and think about my actions. God wanted me to learn."* (Rob)

Adopting a spiritual framework enabled them to find meaning in their experiences and enabled them to resolve the contrast between feeling 'bad' or perceiving themselves as unworthy individuals deserving of punishment to seeing themselves as more inexperienced individuals who had needed to learn lessons in order to grow. In addition, this enabled them to place their experience of HIV in the larger perspective of their life's purpose, which seems to have enabled them to make a sort of peace with their experiences of living with HIV. This was helpful in aiding the participants in coping as they believe that they are protected and not subject to random acts of misfortune, and that their lives with HIV have meaning. It appears as though the participants used prayer to seek for divine intervention and as a strategy to ease their minds of the challenges they were encountering. Spirituality appeared to provide the most meaningful path to finding answers for the difficulties the participants experienced navigating the uncertainty of their HIV status.

4.3.4.3 Sub-theme 3: Children as motivation

Another factor that encouraged the participants to survive was their children. The participants in this study felt that they needed to be strong and healthy in order to watch their children grow. This result is similar to what Walulu and Gill (2011) found when they conducted a study with mothers to understand the process by which mothers living with HIV manage mothering. This view is evident in Amanda's extract below:

> *"…also my daughter keeps me going, I need to be strong for her and I need to be healthy so that I can see her grow up. I remember I saw the look on her small face when I was so sick and with her small little voice she asked me, mommy are you ok, eih it hurt me and then I decided no I need to be strong for her. She motivates me."* (Amanda)

Interestingly, Sindy's thoughts about her unborn child helped her to remove suicidal thoughts from her mind:

> *"…I thought about my baby in my stomach and she helped me to take those bad thoughts out of my head… I had to accept it for my baby's health… I had to pull myself together because there was a baby coming. I just had to accept it. I had to live for my daughter and take my medication."* (Sindy)

Similarly, Solly's children gave him the motivation to survive, despite the many challenges he experienced:

> *"My kids are important to me so I try my best to stay healthy so that I can see them grow up, get married and have kids, sometimes I look at them and just tell myself, I cannot die now. I pray to God that he helps me."* (Solly)

For these participants it was important not to give up irrespective of the difficulties they were experiencing. For Sindy taking her medication seemed to be a way of not giving up because if she were to default on medication this will mean that she is too weak and therefore unable to care for her child. Solly adopted prayer as a strategy to help him stay strong and look after his children. Seeing her daughter notice her suffering was the causal event that motivated Amanda to change the way she views her diagnosis and to make the necessary choices that enabled her to stay alive. Having children gave these participants a reason to survive. It was interesting to note that not only mothers felt the need to survive for their children, but fathers as well.

4.3.5 Super-ordinate theme 4: Attending support group: *"A sweet experience"*

The participants reported various benefits and disadvantages to attending support group. However, their overall experience appeared to be mostly positive. Solly's statement below indicates both the positive and negative experiences of being in a support group:

> *"To be honest… bitter-sweet. As much as it is amazing it is also difficult."* (Solly)

This super-ordinate theme focuses only on the benefits of support groups as reported by the participants, the disadvantages are discussed in the super-ordinate theme below. These benefits included, learning new lessons, empowerment, renewed strength and hope, feeling of belonging, a platform to share negative feelings and problems without feeling judged and lastly enhanced coping skills.

4.3.5.1 Sub-theme 1: Learning

When asked what makes his experience sweet, Solly responded:

> *"…since I have joined the support group I have stopped smoking weed, I have learned in the group that ARV and weed don't go well together and that is also why I have been so forgetful."* (Solly)

Similar to the findings by Atanga et al. (2015), participants benefited from attending the support group in terms of learning more about HIV and AIDS. In the above extract Solly reveals that gaining knowledge on the effects of mixing ARV and substances provided a turning-point for him to stop using cannabis. Solly was not the only participant who reported better knowledge on HIV.

Sindy explains that the support group has thought her about living a healthy lifestyle with HIV:

> *“We learn about how to live a healthy lifestyle, you know, exercising, eating fruit and vegetables because when you are HIV positive you need to look after yourself.”* (Sindy)

Rob reported that he also gained knowledge regarding his HIV status:

> *“I learned the most about my status, what it means, the CD4 counts and viral load because at first it was very difficult for me to say what the difference was between CD4 count and viral load, but the group explained it nicely, so now I don’t get confused.”* (Rob)

Similarly, Amanda reported learning about ARV medication:

> *“I know more about HIV/AIDS and ARVs, I think I can become a doctor now* [laughs] *no I’m just joking. But sometimes Faith* (support group leader) *brings in some nurses to talk to us about medication and about what this virus is all about.”* (Amanda)

For Thandi the most valuable lesson was that on disclosure because she has not disclosed her status to her partner at the time of the interview. Thandi reported that this knowledge she gained in the support group will make disclosure easier:

> *“I think I will tell him one day, because in the support group we learn about how to tell a loved one and how to deal with different react uhm… what you call it, reactions, so we do things like plays which are very nice.”* (Thandi)

Participants not only learned about HIV, but they also reported learning about forgiveness and gratitude and the value of sharing not only their stories, but other basics such as food and money. This is evident in the extracts below:

> *“…but I have learned to forgive, thanks to the help of the support group*.” (Thandi)

> *“I have also learned to share my things with everyone in the group… When we were talking about healthy eating in the group this one lady said that olive oil is too expensive and she has never tasted it because she can’t afford it, I offered to give her one of the bottles I have in my cupboard that I bought a while ago that I took for granted. People help each other with taxi fair to come to the group. It’s such a nice experience.”* (Solly)

> *"A very important lesson that I learned in the support group is to say thank you for my life. I am grateful, it could have been worse. There are others in the group with worse problems."* (Rob)

4.3.5.2 Sub-theme 2: A sense of empowerment:

In congruent with this study, Mundell et al. (2012) found that the knowledge their participants gained was an important part of empowering them as it gives them a better sense of insight into their situation and allows them to control their lives and make positive changes. For the participants in this study, the sense of empowerment came with the need to help other people who were not in the support group. This sense of empowerment was best described by Sindy when she reported:

> *"So I went to workshops for HIV and I got training on HIV and AIDS, my dream is to educate people on HIV …"* (Sindy)

Sindy goes on to explain that since she has joined the support group she has had a desire to stand up for herself and others and take initiative:

> *"…my goal is to break this stigma, I don't want to keep quiet about HIV anymore, I want to be the voice for many HIV men and women who feel trapped, I want us to be ok with saying: I am HIV positive… My story is supposed to be a testimony for others… to tell people if you are HIV positive it's not the end of the world. I want to motivate people to eat healthy and use condoms and take their medication because I have learned this in the group and it has helped me."* (Sindy)

Amanda also stated how she is transferring the knowledge about healthy eating in the group to her daughter:

> *"I even teach my daughter about healthy eating."* (Amanda)

Prior to joining the support group the participants felt weak and powerless, but the support group provided an opportunity for them to acquire more knowledge about ways of living positively with HIV and that seem to have left them with a sense of empowerment. Through interacting with other HIV positive members in the support group, the participants were able to learn about themselves and HIV, which gave them the courage to accept power, control, and direction of their lives"

4.3.5.3 Sub-theme 3: Regaining strength

As seen in the sub-theme on “feeling weak: physically and emotionally”, participants reported that they had lost their strength after diagnosis; however after joining the support group they reported feeling stronger again. Amanda explained that she felt revitalized and seemed to have more energy after a support group session:

> *“The group helps you to get your strength back when you are sick or weak. When you leave here you have lots of energy, you don’t feel depressed.”* (Amanda)

Similarly, Sindy reported:

> *“I am a stronger person and I don’t let things get me down easily because I have learned how to cope with difficult situations in the group.”* (Sindy)

Solly demonstrated his strength by physically showing off his muscles, his statement, “getting it back” indicates that gaining the strength does not happen overnight, but is instead a process that he is still working on with the help of the support group.

> *“As you can see I’m starting to get it back* [lifts arm to show muscles]*”* (Solly)

The experience of regaining strength has also been identified by Mokhoka (2000), who found that support groups helped participants cope better and the relationships they experienced within the support group gave them the strength to continue with life, no matter how difficult it was. Mkhencele, (2011) found that this renewed strength was as a result of the love, peace and acceptance that the participants experienced in the group.

4.3.5.4 Sub-theme 4: “There is hope”

It appears as though the strength that the participants regained gave them the courage and the confidence to dream again and make plans for the future. For most of the participants, the HIV diagnosis felt like a death sentence, they felt despondent and weak. As reported earlier, some participants thought that suicide was the way out. However, the support group seemed to change this gloomy feeling. For Solly meeting other people who have overcome the challenges he faced was enough to restore the hope that he had lost. In the sub-theme, ‘struggling with identity’, Solly reported: *“I felt dead, like very frozen, almost like a zombie…”* However, Solly also reported that after joining the support group he felt human again. Perhaps feeling human to him means that he has reconnected with his true-self and because of this he is able to live life and plan for the future.

> *"Meeting people who are survivors, it makes me see that there is hope… When I joined I felt like a human again and I had hope again."* (Solly)

Similarly, Amanda Reported*:*

> *"I am able to dream again. When I first found out I was HIV positive I stopped dreaming, I was just waiting to die. I had no plans for the future."* (Amanda)

Based on the extracts above it is evident that the participants' stories changed from that of disappear to that of hope after joining the support group. These findings concur with the studies by Harris, & Larsen (2007) as well as Messias et al. (2009), who indicated that interventions aimed at helping HIV positive individuals, instills a sense of hope as time passes. As individuals gradually accept their status and experience an increase in wellbeing, their stress levels, depression and hopelessness may decrease.

4.3.5.5 Sub-theme 5: "I am not alone": the power of meaningful relationships

For Solly and Amanda interacting with others in the support group allowed them to re-evaluate the severity of their own problems, finding it to be less problematic than their problems which resulted in them feeling more hopeful. This was consistent with the results from the study done by van Uden-Kraan et al. (2008), when they found that members appreciate the opportunity to compare themselves with others and recognize the fact that there are other people who may be worse off than them. This seemed to bring a sense of relief and comfort as participants realise that they too belong. These meaningful interactions between the participants within the support group also make them feel less lonely. Mundell (2012) refers to this as the process of identification. The following extracts confirm the above results:

> *"…hearing the other peoples stories helped me to better myself."* (Solly)

> *"… I had evidence that there are people who are also HIV positive who live long and look just fine, no skin rash, nothing, they were looking nice, I met the most beautiful ladies in the support group. At first I didn't care about myself, but when I joined the support group I*

> *said no man, let me dress up a little bit, let me put on some make-up, I don't have to look like a person who has no purpose."* (Amanda)

The participants in this study reported experiencing reduced feelings of isolation, they were able to build meaningful relationships in the group and at the same time improve their interpersonal skills. Lennon-Dearing (2008) found that support groups encourage new friendships and are usually viewed as a place where people socialise. For the participants in this study, these positive relationships seem to have played an important protective role as it gave the participants a sense of acceptance, identity and belonging. This is conveyed in the extracts below by Amanda and Rob:

> *"… they make me feel like I'm not different you see, sometimes outside we feel alone like we the only one with the problem, but in the support group I feel like I belong there."* (Amanda)

> *"…the group reminds me that I am not alone in this…the people in the group are like my family and when I don't come they will send a message or call me to ask where have I been."* (Rob)

This sense of family spirit that Rob is referring to above was also echoed by Thandi:

> *"I've made new friends and family… this is like my family. I enjoy it very much. I have their numbers and address so I can just call and visit."* (Thandi)

Similarly Rob states:

> *"I became very close with the other two men in the group so we will remain friends. Just getting together every week…laughing…making jokes and having snacks together... the feeling of having a big group of family who understands each other makes me feel happy and relaxed."*(Rob)

Interestingly Rob also met his romantic partner in the group:

> *"… I even met the love of my life in a support group* [laughs]*… We met at the support group, not this one. It was another support group that I went to in 2011. I was diagnosed in February and I joined that group in July and my wife was also there. We were friends we spoke a lot and yah I liked her and she liked me."* (Rob)

The participants' emphasized the power of "togetherness", the power of simply meeting openly together with people who were also HIV positive and had similar challenges to them. This seemed to bring a sense of relief and comfort. This was best described by Sindy in the below extract:

> *"I feel like I can just take off my shoes and talk the whole day. Nobody makes fun of you, they all understand your problems, we laugh together, we even cry together, we do everything together."* (Sindy)

Similarly Rob expressed:

> *"It was good to see that I'm not the only person with HIV, when I was diagnosed in the beginning I felt so alone. Just to get together and hear someone say I'm in the same boat made a difference for me."* (Rob)

Based on the participants' reports it is evident that attending the HIV support group alleviated the sense of loneliness and isolation that they experienced before joining the group. Being able to interact with others who are also HIV positive seems to be a fundamental element for these participants as HIV may begin to be normalized, making them feel more comfortable and at ease with their HIV status.

4.3.5.6 Sub-theme 6: "I am free to talk": A non-judgemental space

It appears as though the bond that the participants created in the group created a platform for them to freely share their negative emotions. The confidence to speak to others was also made possible by creating an atmosphere that is non-judgmental and confidential. This is expressed in the below extracts by Thandi, Amanda and Sindy:

> *"I can talk about anything in the group without being scared…"* (Thandi)

> *"It's nice to have a place to go to talk about your problems, without being judged or people giving you funny looks, I am free to talk."* (Amanda)

> *"I am now able to work better in groups and with different people… I use to be shy, but now I can talk about any problem."* (Sindy)

Just like Lennon-Dearing (2008) and Tumwikirize et al. (2015) found in their studies, this study indicates that a support group allows members to share their personal experiences, fears and concerns without feeling judged. Sharing their concerns with other in the group helps reduce the burden they carry. It is therefore fair to say that members experience a sense of emotional relief from the support of others by just sharing their stories.

4.3.5.7 Sub-theme 7: "I am laughing again" Improved quality of life

Another positive point that was raised by the participants is the fact that they experienced improved quality of life as a result of joining the support group. They reported that they have developed personally and grown since attending the support group. This was similar to what Summers et al. (2000) found, indicating that participation in HIV related support groups may be associated with longer survival, less emotional distress and better overall emotional well-being. The personal growth that the participants experienced as a result of attending the support group may have contributed to the courage they have in conquering HIV instead of the defeat they felt prior to attending the support group.

Thandi explained how her mental health and physical health improved as a result of joining the support group:

> *"Last month I went for a check-up and even my doctor said Thandi you have changed and you look so much better than the last time you were here. It was so good to hear that… you know, I used to have some problems, they used to admit me every second month for depression, but since I've joined the support group I haven't relapsed, my depression is better…"* (Thandi)

Amanda reported overall happiness in her life:

> *"Positive to me now means to stay healthy and be positive in mind so I'm ok and I'm laughing again… I could not have done it alone, Faith and the people in the support group helped me reach that happy place again."* (Amanda)

And Sindy reported feeling more confident:

> *"I am a more confident person and I don't let things get me down easily…"* (Sindy)

Overall, participants reported a positive outlook on life after joining the support group. They reported feeling happier, experiencing less distress and experiencing improved physical and mental health.

4.3.5.8 Sub-theme 8: Enhanced coping skills: "Positive thinking"

Sindy, Solly and Thandi reported how the support group has been helpful in enhancing their coping skills. They reported using strategies such "as positive thinking" which allowed them to experience overall well-being and assisted them to experience growth in their overall lives. According to Makoae et al. (2008) when people have adjusted positively to the diagnosis of HIV they may decide to focus on other important things in their lives, rather than focusing on the impact of the illness itself. The following extracts indicate how the support group assisted the participants to think positively:

> *"…every day before we go to bed we must write down or you can think about it, you don't have to write it down, just think about three things that went good for the day and you must also think why those good things happened today. I like this positive thinking it makes my mood better, sometimes when you only think about bad things it will make you sick."* (Thandi)
>
> *"…everyone must talk about the positive things as well, so every week at the end of the session everyone speaks about something good that happened, it can be about the HIV or just in general. It's so nice to hear people say that they went for a checkup-up and the doctor said the HIV is undetectable, it encourages me."* (Solly)
>
> *"…because I have learned how to cope with difficult situations in the group. I try to think more about the good things in my life instead of crying over the bad things, sometimes you have to accept that we cannot change things."* (Sindy)

For Sindy and Solly the strategy of deliberately choosing to focus on the positive things instead of only negative things seemed to have been useful. In the study by Turner-Gobb et al. (2002), being involved in a support group as part of helping cope with the disease somewhat resolves psychological difficulties related to HIV. Coping literature suggests that focusing on positive things whenever feeling stressed, provided HIV positive individuals with something to distract them from the source of stress and instead allows them to appreciate what is positive (Larazus, & Folkman, 1984). Adopting positive thinking as a strategy helped the participants shift the focus onto something that they can feel grateful for, and because of this they were able to come to terms with the illness part of their identity in a way which feels more comfortable and acceptable. It is clearly evident from the current study, that the participants experienced a healthy shift from emotion-focused to problem-focused coping.

4.3.6 Super-ordinate Theme 5: Attending support group: "a bitter experience"

Support groups have always been known for its advantages, but not many studies looked at the disadvantages. As expected, support groups are not only experienced as positive, there are certain pitfalls that were revealed by the participants in this study. This included men's discomfort with the numerically dominant presence of women in the group, lack of resources, such as transport money and having only one facilitator instead of two and lastly the participants also expressed difficulties with termination of the support group meetings.

4.3.6.1 Sub-theme 1: Mixed gender groups: a struggle for male participants

In terms of the "bitter" aspect of being in a support group, it was interesting to note that only the women reported freedom of expression; as mentioned above, the women reported that they could speak openly about any problem. However, this was not the case for the two male participants. Rob and Solly reported that it was difficult for them to express themselves in the support group as the support group consist mostly of women. The findings of this study show that the presence of women in the support groups inhibits full disclosure of issues for men especially regarding sex. There is a sense that women will not be able to understand men issues or would view the men as weak, the presence of women therefore results in men shying away and not fully expressing their views. This finding was consistent with the results from Rudo's (2012) study as well as Visser and Mundell (2008). However, they found the reasons for men not attending support groups was that they viewed women as talkative which they felt compromised the confidentiality in the group, whereas in this study, it was more about the fear of appearing weak in the presence of women. It is important to note that their results were based on the perceptions of men who never participated in a support group whereas this study examined the actual experience of two men who have attended a support group.

The below extract shows Rob's perception about the disadvantage of being in mixed gender support groups:

> *"When there are women men are shy to talk about their sex problems and all those stuff, but when its only men they are very free to talk."* (Rob)

Similarly, Rob reported:

> *"I will feel more comfortable speaking to a man about certain things. There is stuff that I won't even tell my mother or sister even though we are so close…"* (Rob)

Rob further explained that he investigated the support group before joining and when he saw men existing he felt more comfortable:

> *"I even thought that there were only women, but when I was sitting outside in my car and I saw people coming out I saw men too, but the women were more. I think I wouldn't have joined if I only saw women walking out."* (Solly)

It was also interesting to note that despite this limitation, the men continued to attend the support group meetings, when asked why, Solly reported that he would not have joined if it was not for the encouragement from loved ones, but most importantly what kept them going back was the acceptance and the fact that they had something in common: being HIV positive. This is best described by Rob's statement below:

> *"Even though women are different to men we all have one thing in common, a struggle with HIV."* (Rob)

Perhaps for Rob and Solly, expressing their emotions and speaking about their problems in front of women will indicate that they are weak. As mentioned in the literature review chapter, men are expected to be physically and emotionally strong in society and for this reason they find it difficult to reveal their vulnerability in the support group (Mabiba & Kekana, 2013). Lennon-Dearing (2008) argues that gender homogeneity in the composition of support groups may play a significant part in the outcome of HIV support group participation and is an important consideration for support group planners. Based on the results of this study it is evident that homogeneity is a critical component of successful support group experience for males. Perhaps a remedy would be to encourage more men to join the group or supplement the existing groups with extra men-only support group sessions.

4.3.6.2 Sub-theme 2: Lack of transport money and food

Another limitation of support groups that the participants revealed was lack of resources. This included lack of transport money to get to the support group on a weekly basis. According to Sindy this results in poor attendance:

> *"…also transport is an issue for some of us because many of us don't stay in the community, so sometimes we will only be five in the group because the others don't have fare to come."* (Sindy)

Solly reported that a lack of money was the most important barrier to implementing life skills derived from group involvement. The following statement highlights this point:

> *"…the support group encourages us to eat healthy and exercise, but how can we eat healthy if we struggling to buy bread or meali meal?"* (Solly)

The above extract indicate that although support groups educated participants on how health is impacted by stress or proper nutrition, they were unable to satisfy needs for income or food sources. Similar results were found by Mbirimtengerenji (2007). He found that people often neglect care and treatment when they live in poverty and lack such vital necessities as food, or transport money. This view was described by Thandi when she indicated that she sometimes has to choose between going to the support group and buying food for her children:

> *"…the little money that we get goes for food and other important things in the house and sometimes when I calculate I put support group last on the list even though it helps me so much. So instead of using that money for taxi fare I use it to buy bread then I miss a session with the group."* (Thandi)

This view was shared by Sindy when she stated:

> *"Even when going to hospital sometimes I don't have money to fetch medication or go to support group than I just stay at home and not fetch my medication, but then the nurses shout you, they don't understand I don't have money, but the support group understands."* (Sindy)

> Lack of transport also seemed to be a problem for the reason that some of the participants preferred not to attend support groups in their local communities for fear of being recognised as being HIV positive:

This was indicated by Thandi:

> *"I don't know anyone in the support group and my sister told me most of the people who are in the support group are not from my community."* (Thandi)

Similarly, Sindy stated:

> *"I prefer to go to a different community where no one knows me".* (Sindy)

Based on the background information it is evident that all the participants in the support group are from a low-income background. The results indicate that lack of transportation and money results in missed appointments, poor support group attendance and poor illness management. A solution might be to offer people transport or taxi fare to not discourage them from seeking this support. Support groups should be designed with these issues in mind, so that the lack of resources such as transport and money does not become a burden on the participants' life outside of the support group. This will especially be beneficial for those participants who prefer to attend support groups outside of their communities for fear of unintended disclosure.

4.3.6.3 Sub-theme 3: One Facilitator instead of two

In addition to the above limitations, participants also expressed their frustration with having only one facilitator. Amanda reports that her frustration is mainly related to the cancellation of group meetings as a result of having only one facilitator. This is evident in the extract below:

> *"The only thing I would say is if they postpone a session, sometimes I have made plans already to come, you know… Sometimes because Faith needs to be somewhere else, you see we only have one leader and when she can't make it to the group then we won't have support group that day. She works so hard that lady you know."* (Amanda)

This view was echoed by Rob:

"There is only one leader, so sometimes when the leader cannot make it the group is cancelled. Maybe there should be two leaders so when the one can't make it the group still goes on." (Rob)

Amanda's statement "she works hard" indicates that the facilitator is overworked. As seen in the literature review chapter, burnout of support group leaders can occur when support groups are too large (Heyer et al., 2010). Perhaps recruiting a second facilitator (like Rob suggests) will help overcome this barrier. Based on the results it is clear that facilitators are perceived as a very important part of the support group because they provide guidance and leadership and when the facilitator is unable to make a session it seems to affect the group process. Also, in keeping with the comments above, it is event that the participants make sacrifices to attend these groups, so the support group leaders and organisers need to insure that they follow through with their commitments to those who attend.

4.3.6.4 Sub-Theme 4: Unable to provide indefinite support

Lastly the participants also found that the group meetings ended too early, they reported that they needed the support group to go on continuously and never end as it became part of who they are. The support group is unable to provide indefinite support, which is a concern for some participants as it brought up feelings of sadness and fear. This was mainly due to the strong bond that was created between the support group members during the support group process which made it difficult for most to participants to say goodbye.

This view is best described by Amanda:

> *"I feel sad, very sad… Now I have made friends, I won't get to see them anymore. And sometimes I like being away from home. Now I will have nowhere to go to."* (Amanda)

Similarly, Sindy wished that the sessions would never end:

> *"I think the support group must be longer you know, they mustn't say only fifteen sessions, you should be able to come for as long as you like than you can just stop when you feel like you had learned enough. Even if you learn the same thing over and over* [giggles]*."*
> (Sindy)

For Solly thinking about the ending was difficult, when asked about his feelings regarding termination he responded:

> *“*[Sigh] *eih I don’t know, I still have a few more sessions before it ends so I didn’t really think about it. I come to the sessions not thinking about the last session I only think about what we will be doing for the day…”* (Solly)

He went on to say:

> *“I look forward to come to the support group especially if I had a horrible week, now I won’t have a place to go to on a Thursday to fellowship unless I get a job*, *but like they say all good things come to an end. At least if I have a job it will keep me busy”.* (Solly)

Perhaps not thinking about ending might be a way for Solly to avoid thinking about the negative experience associated with the ending process hence “having a job” would be a coping mechanism to forget about group.

Attending the group meant that the participants had something to look forward to, therefor thinking about ending brought up feelings of sadness and disappointment. The participants feared that they would lose valuable relationships when the support group ends, as seen earlier from what the participants mentioned in the sub-theme on ‘stigma and discrimination’, making friends and meeting with other people takes time due to the fear of being judged and discriminated against by people who do not have the same condition as they do. Therefor the place where they felt they truly belonged was the support group where they could meet and talk to other HIV positive people. Hence, as also seen earlier, they felt like it is easier to form bonds with people who understand them and what they are going through. The participants need for a continuous support group could be indicative of the need for social support by those living with HIV.

4.4 Conclusion

This chapter has explored and described the HIV positive people’s experience of being in a support group. The results indicate that their experiences are both positive and negative with the overall experience being positive. The participants reported their experiences with HIV before and after they joined the support group this was useful as it provided a broader perspective of how useful or not the support group has been. Participants only joined the support group after a turning point which was either as a result of encouragement from a family member, becoming closer to God or motivation from their children. Prior to this, they had attempted to cope by making use of negative coping skills; they were struggling to survive, experiencing difficulties with identity, stigma and discrimination and feeling weak physically and mentally, in addition to struggling with poverty. However, after joining the support group they reported feeling empowered, accepting their HIV status and reported coping positively with the challenges of living with HIV. This is evident in the active role they took in attending the support group, the hope they had, their future outlook and the general emotional adjustment and personal growth. The participants reflected that they felt they had grown and healed considerably at the time of the interview. Although many positive experiences have been cited, some negative experiences from the support group members emerged from this study as well, this included challenges in mixed gender groups, which mostly affected the male participants, other negative experiences included, a lack of resources, overworked facilitators and the inability of support groups to provide indefinite support.

CHAPTER 5

Conclusion

5.1 Introduction

This chapter offers an overview of the research that has been conducted. A summary of the results found in the course of the analysis is presented. Next, the limitations of the research project are considered. Finally, recommendations concerning future research avenues in this field are offered.

5.2 Summary of results

The main aim and the goal of this study was to provide an in-depth exploration of HIV positive individuals‟ experiences (both positive and negative) of being in an HIV support group and to add to the knowledge base on the understanding of HIV and the usefulness of support groups. The study found that before joining a support group, the participants experienced various challenges such as struggling with identity, feeling weak physically and mentally, struggling with stigma and discrimination as well as struggling to cope with the HIV diagnosis while at the same time having to live in poverty. However after joining the support group participants felt more positive about themselves and the diagnosis. The results indicate that they learned new lessons which helped them cope better and gave them a sense of empowerment. The study also found that participants had experienced renewed strength and renewed sense of hope which created a pathway for them to rediscover the self. It also emerged in this study that the participants had changed their perspectives on the future, gaining feelings of confidence and self-reliance and they were able to see alternative possibilities for their futures. The participants also felt less lonely as they met people who experienced similar challenges to theirs; this allowed them to feel a sense of belonging. The study found that the most important element that brought about change in the participants was the meaningful relationships they developed within the support group.

Another interesting finding indicates that having support from at least one family member or friend seemed to have made a difference in the lives of the participants and played a role in them experiencing a turning-point. Receiving social support of any kind has proved to be an important element to those who are infected with HIV/AIDS. Just knowing someone cared was motivation enough for the participants to survive.

For some participants the turning-point arose as a result of talking to a loved one, attending church and getting closer to God and for others it was the motivation from their children.

Generally, the participants had both positive and negative feelings about support groups, but based on the result of this study, the benefits outweighed the disadvantages. Some of the concerns included mixed gender groups, lack of transport money and food, having only one facilitator who was over-worked and lastly struggling with termination of the meetings, as they needed the support group to be continuous, but despite these disadvantages of being in the support group, it was the major source of support and provision of a safe environment where they were able to grow and develop that seemed to have made a difference.

5.3 Limitations

Upon completion of this study, various limitations were observed:

The participants were able to elucidate their lived experiences, although articulated in their second language, English. A limitation exists within the interpretation of experiences not articulated in the participants preferred language even though they were able to understand and speak English it is noted that they would have expressed themselves better if the interview was done in their home language. For this reason a limitation might be that some of the meaning or richness of the data might have been lost or distorted when trying to express their experiences. IPA considers the role of language as important because it shapes experiences and the way the participants express themselves to the researcher (Willig, 2001).

It is also important to bear in mind that members of a specific support group were interviewed, and the group was run according to a specific format therefore participants' views are not representative of all support groups.

Additionally participants in the support group received other interventions such as individual therapy. The impact of the other interventions or their combination may have influenced the results.

Nevertheless, despite the limitations described above, the findings of this study are consistent with other findings reported in the literature and supported by detailed excerpts that suggest that they are valid and meaningful. In addition, by using phenomenology as the major theoretical and methodological framework, the participants own interpretations of their life-worlds were privileged. The focus was on the meanings that they attached to their recalled lived experiences and how this informed their present situations and identities. This understanding is limited in studies which use quantitative methodologies and whose focus is on statistics and not on how the participants experience the phenomenon under study. This study also managed to ascertain the participants' challenges prior to support group participation which is limited in other studies. Therefore, it was easier to determine whether or not the changes in their assumptive worlds did in fact represent a higher level of functioning than before their HIV diagnosis.

5.4 Recommendations

Essentially, the research findings presented in this thesis highlight the benefits of attending support groups for people living with HIV. This study revealed that HIV positive people who participated in the support group were empowered, learned new information, experienced renewed hope, renewed sense of self, sense of belonging and received support from others who were in the same situation as they were. This enhanced their well-being and responsibility for living a healthy life. In noting this, the recommendation is that these groups should be provided and supported. It is also recommended that future interventions should aim at targeting more people especially men to join HIV support groups. In addition, the reasons for non-attendance and disadvantages of the support groups should be explored further so that strategies could be developed to increase the number of people who participate in the HIV support groups and decrease the dropout rate.

Based on the results of this study, one of the disadvantages of support group experience for male participants was being in mixed gender groups. There is a need to consider separate support groups for men and women, since the male participants reported that they find it difficult to express their honest thoughts and feelings in the presence of women. This study consisted of mainly female participants. Further research should consider why support groups are generally used by females. An in-depth qualitative exploration on HIV support group experience should be undertaken, with particular focus on gendered differences. A controlled study of the processes, content and outcomes of support groups for women and men respectively as well as together could provide in-depth knowledge on how to create optimal support systems for people living with HIV.

Owing to the fact that the termination of a support group and the need for on-going support seemed to dominate when it comes to negative experiences, more work should be done to prepare the people participating in such a group for its ending. In addition, the components of equipping the members by using their own informal support structures as well as of strengthening relationships outside the support group need to be closely looked at when implementing HIV support groups in the future.

Further research should also consider the ways in which interventions could be designed to recruit and train 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. In addition, consideration should be given to recruit more than one leader per group in order to avoid missed sessions, absenteeism and facilitator burn-out.

One of the factors that seem to have had a major impact on the participants was poverty. The Department of Health and the Department of Social Development should ensure that there is a budget for support groups to assist with transport money and food parcels as some members are unable to attend support groups due to lack of transport money and unable to take their ARV medication due lack of food. The study was conducted through a Non-Governmental Organisation. The importance of the work that these sorts of organisations do should be recognised, especially in times of economic hardship and funding cuts that put such organisations under severe operating strain.

Finally, this study also highlighted the turning-point that led to support group attendance and the disadvantages of being in a support group which is something rarely documented by other research. Understanding the disadvantages of HIV support groups should assist support group organizers to develop responsive interventions for people living with HIV. Although participants cited a number of disadvantages of being in support groups, they also suggested what would make their experience better. Support group organizers and health care workers should consider this as they have a critical role to play in creating awareness of and education on the role of support groups for people living with HIV.

In conclusion, I hope that this study contributes to the understanding of how these five participants are experiencing HIV support groups. This study adds to the much needed collection of ‘insider’ stories, especially the narratives of the marginalised poor HIV positive people.

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Appendix A: Letter of consent

Rhodes University (Psychology Department)
Consent Form

Please consider this information carefully before deciding whether to participate in this research.

Purpose of research: The study aims to explore the positive and negative experiences of being in an HIV support group and to gain and understanding of the role support groups play in the lives of those living with HIV.

What you will do in this research: If you decide to volunteer, you will be asked to participate in an interview which will take approximately 90 min, with the possibility of a follow-up interview which will take approximately 30 min. You will be asked to answer questions of a personal nature. All interviews will be tape recorded. You will not be asked to state your name on the recording.

Confidentiality

- Your response to the interview questions will be kept confidential.
- At no point will your actual identity be revealed (identity will be anonymous).
- The recordings will be stored on password secure computers and will be destroyed when my final paper has been graded.

Participation and withdrawal

- Your participation is voluntary, and you may withdraw from the study at any time without penalty, however you have to commit yourself to full participation unless some unusual circumstances occur or you have concerns about you participation which you did not originally anticipate.
- You may also skip any questions during the interview, if you feel it is too uncomfortable to answer.

Agreement:

I (participant's name) ____________________ have read and understood the explanations provided to me. The nature and purpose has been sufficiently explained and I agree to participate in this study of (researcher's name) _________________. I understand that I am free to withdraw at any time without any negative consequences.

Signature (participant): ___________________ Date: _______________________

Signature of researcher: __________________ Date: _______________________

Appendix B: Interview schedule
Semi structured Interview Schedule

1. Thank participants for taking the time to be there
2. Introduce myself
3. Assure participants that interview is strictly confidentiality
4. Explain purpose of research study
5. Give approximate time for interview (1 hour)

Demographic information

1. Tell me about yourself (age, marital status, children, family, where were you born, who do you stay with, employment, what do you do to relax)

Diagnosis

1. When did you first find out that you have HIV?
2. Can you take me through that moment how did you feel, what was going through your mind?
3. Can you talk about how you contracted the virus?

Challenges of Living with HIV

1. Describe some of the challenges that you are facing as a person living with HIV
2. How do you cope with these challenges?

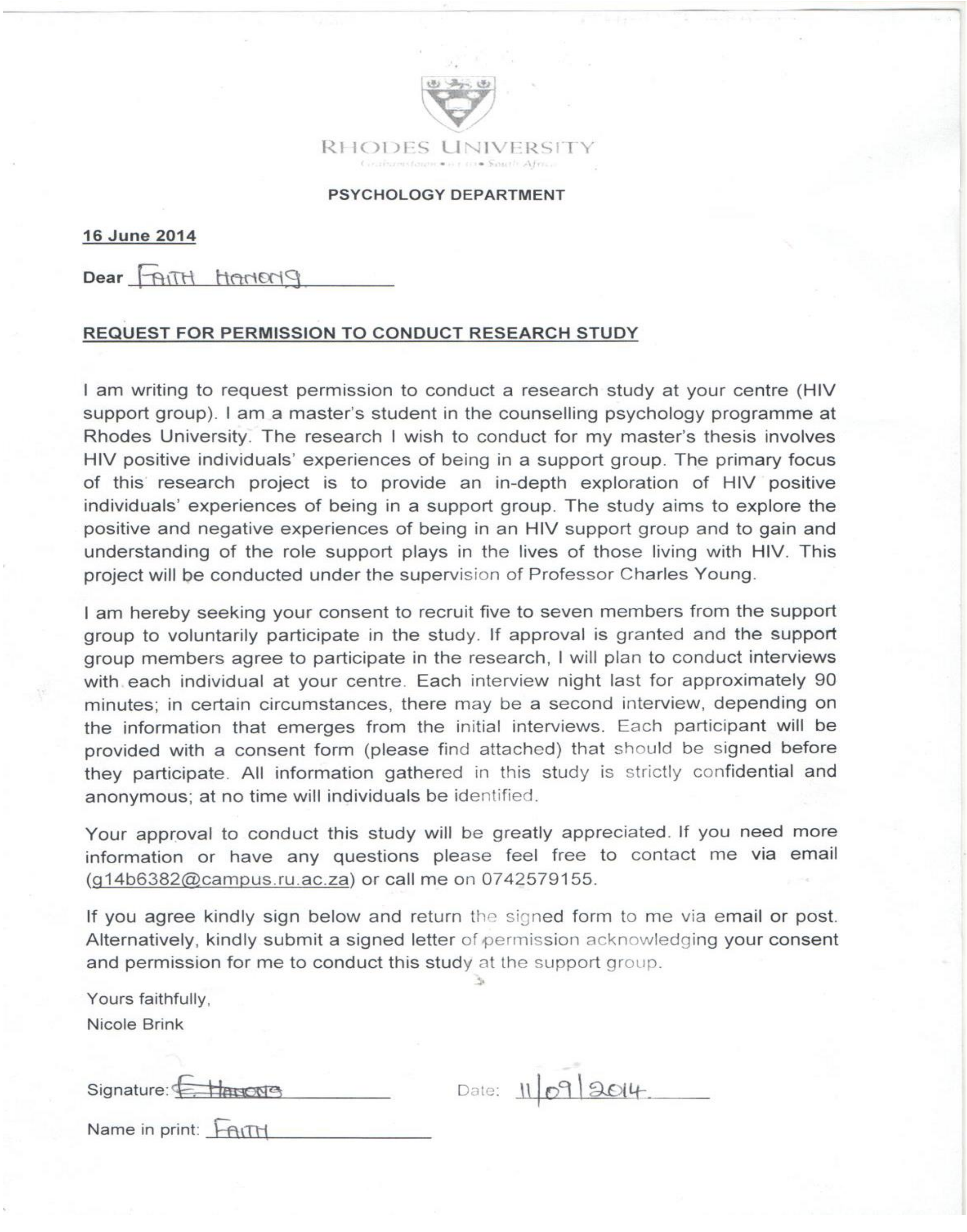
Social support

1. Tell me about family, friends and neighbours and community members (how supportive or not were they?
2. Who were the people that you told first? What was their reaction?

Support Group
1. How did you come to join the support group?
2. Tell me about your experience of being in a support group (what is it like for you)?
3. What were your expectations before joining the group? What was it like to meet other HIV positive people?
4. Has the support group been beneficial for you in any way? If yes, Please explain how it has been beneficial and if no please explain how and why it has not been beneficial.
5. Do you think you have grown or developed since you started the support group? How do you think you have grown?
6. Can you tell me of aspects of the support group that you liked or did not like?
7. How do you feel about support groups ending?
8. Is there anything else that you think is important for me to know about you?

Is there anything else that you think is important for me to know about you?

Appendix C: Permission letter



RHODES UNIVERSITY
Grahamstown • 6140 • South Africa

PSYCHOLOGY DEPARTMENT

16 June 2014

Dear FAITH HAMONG

REQUEST FOR PERMISSION TO CONDUCT RESEARCH STUDY

I am writing to request permission to conduct a research study at your centre (HIV support group). I am a master's student in the counselling psychology programme at Rhodes University. The research I wish to conduct for my master's thesis involves HIV positive individuals' experiences of being in a support group. The primary focus of this research project is to provide an in-depth exploration of HIV positive individuals' experiences of being in a support group. The study aims to explore the positive and negative experiences of being in an HIV support group and to gain and understanding of the role support plays in the lives of those living with HIV. This project will be conducted under the supervision of Professor Charles Young.

I am hereby seeking your consent to recruit five to seven members from the support group to voluntarily participate in the study. If approval is granted and the support group members agree to participate in the research, I will plan to conduct interviews with each individual at your centre. Each interview night last for approximately 90 minutes; in certain circumstances, there may be a second interview, depending on the information that emerges from the initial interviews. Each participant will be provided with a consent form (please find attached) that should be signed before they participate. All information gathered in this study is strictly confidential and anonymous; at no time will individuals be identified.

Your approval to conduct this study will be greatly appreciated. If you need more information or have any questions please feel free to contact me via email (g14b6382@campus.ru.ac.za) or call me on 0742579155.

If you agree kindly sign below and return the signed form to me via email or post. Alternatively, kindly submit a signed letter of permission acknowledging your consent and permission for me to conduct this study at the support group.

Yours faithfully,
Nicole Brink

Signature: F. HAMONG
Date: 11/09/2014.

Name in print: FAITH