HIV-positive pregnant women's experiences of participation

in a structured support group

by

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This dissertation is dedicated to:

My family

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Summary

People who have been diagnosed HIV positive often experience distress and anxiety due to uncertainties pertaining to the implications of an HIV positive status. These individuals are often reluctant to seek counselling and treatment due to the fear of being rejected and discriminated against (Parker, et al., 2002).

There are limited formal networks for HIV support and psychological help in the South African context. Considering this, structured support groups were implemented for recently diagnosed HIV positive pregnant women. These women were recruited from ante natal clinics in Atteridgeville and Mamelodi as part of the Serithi project. Six support groups were implemented and facilitated by various experts including Masters students, of whom the researcher was part.

This project is part of the larger study of the Serithi project in which interviews were conducted with three hundred and seventeen HIV positive pregnant women from disadvantaged locations of Tshwane. Based on these interviews, a support group intervention was developed. This research forms part of the evaluation of the support group intervention. The aim of this study was to explore the experiences of women who attended the support groups. Women who had attended 7-10 sessions were selected and interviewed individually using semi-structured interviews. With the permission of the participants, the discussions were tape recorded and transcribed. The data was analyzed, using qualitative research methods, from an interpretative phenomenological approach. This involved systematically studying meanings, themes and general descriptions of experiences by the research participants.

The main findings in this study showed that women who participated in support groups adopted positive coping and behaviour that is conducive to their livelihood, learned more about HIV and AIDS, seem to have a positive future outlook and are overall empowered. 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 women in their journey to adjust to psychosocial consequence of the disease.

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CHAPTER 1– INTRODUCTION

1.1 Introduction

While some progress has been made in preventing new HIV infections and lowering the annual number of AIDS related deaths, AIDS continues to constitute a major global health priority as the number of HIV-infected individuals continues to increase (UNAIDS, 2009). This reflects the combination of effects of continued high rates of new infections and the beneficial impact of antiretroviral therapy.

The impact of HIV and AIDS is multidimensional. It affects both the individual and society. On the individual level, implications of being HIV positive can be devastating as the individual is impinged on at all levels, namely, socially, physically and psychologically. It also results in a unique community health impact as in most cases, individuals who are infected and affected hail from predominantly impoverished backgrounds (Whiteside & Sunter, 2000). In relation to the social dimension, people who contract the HI virus are mainly economically and socially productive individuals. As a result, the disease poses a challenge to the economic sustainability of a country. In addition, there is a huge growth in the numbers of children who become orphans. Some of these children become instant heads of households if there are no extended family members to take over after the parents have died (Booysens & Bachman, 2002). Another challenge is that older children omit stages of development like teenagerhood to become adults to those of whom they take care of. The same predicament pertains to the elderly since they have to become parents for a second time, in the place of enjoying the time to rest in their elderly years (Booysen & Arntz, 2002; Cross, 2001).

1.2 HIV and AIDS

HIV/AIDS is a disease that was identified in 1981. The HI virus is transmitted through bodily fluids, such as the semen and blood of an infected person. The disease attacks the immune system of the individual infected (Whiteside & Sunter, 2000). The disease may display either slow or fast progression depending on the lifestyle of the individual. When the HIV enters the body, it begins to infect the white blood cells, known as CD4 cells, and attacks and destroys the immune system. It multiplies itself by using the CD4 cells as a host, before destroying the cell. During the progression of the disease, the person infected can remain asymptomatic until he/she reaches the terminal stage. This stage is termed being ill with AIDS (Acquired immuno-deficiency syndrome) due to the opportunistic diseases that can easily attack the body owing to its vulnerability (van Dyk, 2008; Whiteside, 2008).

This section briefly highlights how the virus is transmitted, with special focus on mother-to-child transmission (MTCT) owing to the topic of the study. As discussed earlier, the Human immunodeficiency virus (HIV) is transmitted through bodily fluids and can be found in all bodily fluids including breast milk. It is possible for an infected mother to pass the virus on to the baby during birth, through breast-feeding, or through the child coming into contact with the mother's infected blood or blood products. Owing to the fact that the mother-to-child transmission can occur during or after birth, it is important that the mother is well informed about ways to prevent this from happening. The risk can be significantly reduced by good quality ante-natal care such as prompt treatment of illnesses and the provision of antiretroviral treatment, a careful birthing process to ensure that the blood of the mother does not come into contact with the baby and ensuring exclusive infant feeding, be it breast feeding or bottle feeding (Whiteside, 2008).

1.2.1 The HIV and AIDS pandemic

1.2.1.1 *The Global overview*

The number of people living with HIV continues to grow. The total number of people living with the virus in 2008 was more than 20% higher than in 2000, and roughly three times higher than in 1990. It is estimated that the number of people living with the HI virus worldwide is approximately 33.4 million (UNAIDS, 2009). People newly infected with the virus in 2008 are estimated at around 2.7 million. AIDS accounted for 2 million deaths globally, 1.7 million in adults and 280 000 in children under 15 years every year.

1.2.1.2 *Sub-Saharan Africa*

Sub-Saharan Africa remains the most heavily affected region in the world, with estimates of 71% of all new infections in 2008 worldwide (UNAIDS, 2009). This represents an estimate of 22.4 million people living with HIV, which accounts for 67% of infections worldwide. In this region alone, 2008 witnessed 1.9 million new infections of HIV and 1.4 million AIDS related deaths (UNAIDS/WHO, 2009). The severity of the scourge is closely linked with poverty, the low status of women, and other socio-economic factors facing the region (HIV and AIDS and STI Africa, 2007-2011).

1.2.1.3 *South Africa*

It is considered that South Africa is one of the countries with the largest number of HIV-positive people in the world. The estimated overall HIV prevalence rate is approximately 10.5%. This translates into about 5.24 million people living with HIV in South

Africa (Statistics South Africa, 2010).

South Africa has made some progress in fighting the scourge of HIV and AIDS. Although treatment to manage HIV and AIDS is available in South Africa within the public health system, reports by the Department of Health (2008) revealed that 27% of HIV positive individuals were receiving antiretroviral therapy in the last year. This translate to only 460 000 people receiving antiretroviral therapy instead of the 1 700 000 people needing the therapy (UNAIDS/WHO, 2008).

HIV prevalence varies in South Africa: some provinces are more severely affected than others. The provincial prevalence for 2009 was as follows: Eastern Cape=18.5%; Free State=19.5%; Gauteng 16.6%; KwaZulu-Natal=25.0%; Limpopo=13.8%; Mpumalanga=21.8%; North West=19.2%; Northern Cape=9.3% and Western Cape=6.2% (Department of health, 2010).

1.2.1.4 *Women*

Women and girls continue to be affected disproportionately by HIV as they are twice more likely to acquire HIV from an infected partner during unprotected heterosexual intercourse than men (UNAIDS/WHO, 2009). Globally, HIV and AIDS is the leading cause of death among women of reproductive age (WHO, 2009). In 2007, there were around 12 million women living with HIV and AIDS compared to an estimate of 8.3 million men worldwide. In sub-Saharan Africa, women constitute 60% of people living with HIV (HIV and AIDS and STI Africa, 2007-2011; UNAIDS/WHO 2009). Generally, women have greater physiological susceptibility to contracting the HIV virus, than men. In addition, their economic, social and legal disadvantages place them in a situation vulnerable to

contracting the disease (UNAIDS/WHO 2009). In South Africa, women account for 55% of HIV infection. Teenage girls were found to be five times more susceptible to contracting the virus than boys (UNAIDS/UNFPA/INIFEM, 2004). In the age category of 20-24, males accounted for 5.1%, while females accounted for 21.1% of HIV infections in the same age group. This disparity is largely due to women's biological and social vulnerability (Department of Health, 2010; UNICEF South Africa, no date).

In South Africa, pregnant women are often encouraged to test their HIV status during their routine ante-natal clinic visits. This makes the group central to a statistical analysis of HIV prevalence in the country. During 2009, HIV amongst pregnant women in South Africa was estimated at 29.4% (Department of Health, 2010). The prevalence amongst 15 -24 year old group of pregnant women was 21.7%. This group made up almost 50% of the population of pregnant women living with the virus, while the age group 30-34 comprised 41.5% of the total infection rates among pregnant women. The results in the survey also revealed that, while the 30-34 year old group was the only group where HIV and AIDS cases were increasing, figures from other age groups indicated a stable prevalence over the last four years (Department of Health, 2010; Quintal, 2010).

KwaZulu Natal had the highest prevalence of pregnant women with HIV/AIDS at 39.5%, followed by Mpumalanga and the Free State with prevalence rates higher than 30%. North West, Limpopo, Gauteng and the Eastern Cape had a prevalence rate of 20-30%. Provinces with estimates lower than 20% were Northern and Western Cape (Department of Health, 2010; Quintal, 2010).

Discrimination, stigma, isolation, violence, abandonment, fear of leaving the children behind due to death, as well as self-neglect and sacrifice owing to the expense of taking care of others in the family, are some of the pertinent issues that impact negatively on the

mental wellness of women living with HIV. Turner-Cobb, Gore-Felton, Marouf, Koopman, Kim, Israelski, and Spiegel (2002) indicated that the social support provided for people living with HIV is much less than when they are not diagnosed with the disease. Generally, the psychological consequences of HIV are under-treated as the focus is usually turned to the medical attention to be provided to the individual. The relationship between the biological and psychological implications of the disease should not be overlooked as emotional well-being contributes significantly to the physical well-being of an individual with a chronic disease such as HIV (Angelino & Treisman, 2001).

Support groups have been identified as a basic form of psychosocial support for those living with HIV and AIDS. This form of social support has been proven to be effective in assisting the infected individual to deal with and come to terms with their HIV diagnosis. For women living with HIV, a support group offers several benefits. These include having contact with other women who are experiencing similar challenges, obtaining information and developing different ways of dealing with the demands of the disease. The support group also provides useful information and guidance regarding the illness, dealing with questions pertaining to taking care of oneself and others as well as creating mutual support among the members of the support group (Department of Health, 2010; Visser & Mundell, 2008).

1.3 Background of the Study

This study is undertaken as part of the Serithi project described below. As mentioned, the goal of the study was to explore the experiences of HIV positive pregnant women who participated in the structured support groups offered for them as part of the project.

The Serithi Project

The Serithi project was an NIH funded project, carried out in collaboration between the University of Pretoria and Yale University. Its aim was to develop an understanding of the experiences of women who tested HIV-positive at antenatal clinics in townships in Tshwane. This understanding was then used to develop an intervention to support women in dealing with their diagnoses and the stigma the community attaches to HIV/AIDS. Another aim of the intervention was to exert an influence on their health choices such as disclosure, condom use and infant feeding. The project was begun by negotiations with health service authorities on the provincial and local government level to obtain the necessary permission and support. Four clinics providing voluntary counselling and testing (VCT) services in townships in Tshwane, namely Atteridgeville and Mamelodi, were selected.   Both communities are predominantly black, Sepedi speaking and of below average socio-economic status. People diagnosed with HIV experience a high level of stigma and are tentative in deciding whether to disclose their status, or even in seeking information and support, for fear of stigmatisation by the community. Owing to the limited number of people who seek testing, it is very difficult to establish the prevalence rate of HIV accurately. The estimated prevalence of HIV in childbearing women in Atteridgeville is 33.8% (Kalafong Hospital, Local audit data, Department of Obstetrics and Gynaecology, 2006). The clinic management teams of all four clinics, and the nurses and HIV counsellors providing counselling services, participated in the development of the research protocol. Voluntary HIV counsellors were trained to counsel women on HIV and to refer pregnant women, who tested positive and who agreed to participate voluntarily, to the project. The Serithi Project formed a close relationship with the counsellors and the clinic staff, and provided regular debriefing and training sessions to the clinic counsellors.

Once the women had agreed to take part in the project, an individual interview was scheduled with each of them. This was conducted by a trained research assistant who conducted the interview in each woman's mother tongue. This interview usually lasted between one and two hours, and included questions on the woman's health, demographics, her financial situation, her reaction to receiving her HIV-positive results, disclosure of her status, and various psychological measures. Interviews with the first 317 women were undertaken as a baseline study to better understand the experiences and needs of women living with HIV. From these interviews, women's needs were identified (Visser, Mundell, de Villiers, Sikkema & Jeffery, 2005). This information was used in the development of the intervention used in this research. In the second phase of the project, women were invited to join a structured support group programme, which became the focus of this study. Women who agreed to join the support group attended a 10-session support group programme; the author was one of the facilitators in three support groups. Women who declined the invitation to take part formed the control group for this study. Members from both groups were then interviewed again when their babies were three months old as a post-intervention evaluation (Mundell, 2006).

1.4   Research Question

This research aims to answer the following question: How did HIV positive pregnant women experience participating in the structured support groups presented as part of the Serithi project?

1.5 Aim of the Study

Although HIV support groups are common in communities, very few structured programmes have been implemented in these groups. Even less evaluation has been undertaken to find out how effective they were as a form of intervention. Consequently, as part of the evaluation of the structured support groups, this study explores the experiences of women who participated in them.

1.6 Nature of the Study

This research employs a qualitative research approach using a phenomenological theoretical framework. Phenomenology refers to the study of phenomena. The nature and meanings attached to particular phenomena are understood through the individual's experience. Thus, phenomenology studies human experience and the possible appearances of similar themes amongst accounts from different individuals (Barker, Elliot & Pistrang, 1994). Since the aim of the study is to understand the experiences of HIV positive women who attended a structured support group, the theoretical approach is consonant with this inquiry.

1.7 Key Concepts

1.7.1 Experiences

The phenomenological theoretical perspective refers to participants' expressions of lived experiences (de Vos, Strydom, Fouche, & Delport, 2002). Lives experiences are subjective experiences as understood by each individual participant. The unique subjective

experiences of the HIV positive women who attended the support groups were analyzed from this theoretical stance in order to obtain unique and subjective descriptions.

1.7.2 HIV/AIDS

HIV refers to the Human Immuno-deficiency Virus, while AIDS refers to Acquired Immune Deficiency Syndrome (Dorrington, Johnson, Bradshaw, & Daniel, 2006). This is a virus that affects the immune system. An individual who has contracted HIV might live for a long time without any symptoms of being sickly. However, this varies from person to person, and is dependent on the nutritional, physical, and social support offered to the individual. At the time when the immune system becomes compromised, manifestations of opportunistic infections and malignancies appear. This phase of the disease can be termed as AIDS (Van Dyk, 2008).

1.7.3 HIV positive

Being HIV positive means testing positive for the Human Immuno-deficiency antibodies (Dorrington, Johnson, Bradshaw, & Daniel, 2006).

1.7.4 Pregnant

Being pregnant is the state where a woman has a child growing in her womb. The duration of pregnancy is approximately 40 weeks, divided into three trimesters, each lasting for approximately 12 weeks (Temba, 2008). Louw, van Ede & Louw (1998) describe the stages of pregnancy from conception until birth as the germinal period, embryonic period and the foetal period. The first period, the first one to two weeks, is characterised by

the growth of the zygote and creation of a connection between the zygote and the support system of the mother. The embryonic period lasts from implantation until eight weeks after conception. This stage is characterised by dramatic development. In this time, the developing organism is called an embryo. The last stage, which is the foetal period, is the period where the developing organism is known as the foetus. Differentiation takes place in order for the organs to become functional. This period lasts from about eight weeks from conception (which is the end of the embryonic stage) until birth. Prenatal environmental influences such as the age of the parents, nutrition of the mother, diseases of the pregnant woman, social support and the mental and physical health of the mother have a significant effect on the psychological and physical health of the unborn baby. In this research, pregnancy is coupled with the diagnosis of being HIV positive. As mentioned, the women were recruited from antenatal clinics during their routine visits at about 28 weeks into their pregnancy, and were then referred by HIV counsellors when diagnosed HIV positive to join the support groups.

1.7.5 Support groups

A support group is a form of social network aimed at assisting an individual to cope with various stressful situations (Toseland & Rivas, 2005). In this research, a support group was a group of 10 to 15 women who were all HIV positive and pregnant, who held face-to-face meetings for 10 sessions to discuss various themes related to their HIV positive status with the goal of improving their well-being. The number of participants in each support group meeting varied from time to time due to a number of factors.

1.8   Overview of the Study

This study is divided into the following chapters:

Chapter 1 introduced the study by providing statistics on HIV and AIDS and a brief background of the study.

Chapter 2 is the literature review, which surveys the body of literature on HIV and AIDS and women and support groups.

Chapter 3 reflects on the research methodology of the study, supplying a discussion of the phenomenological perspective as the research framework within which this study is conducted. In order to provide a clear idea of how the research results were obtained and analyzed, sampling, data collection instruments, the context of the research, ethical procedures as well as data analysis are discussed in this chapter.

Chapter 4 presents the research findings based upon the analysis of the data gathered from the participants in the research.

Chapter 5 concludes the study by summarising research findings and discussing these in relation to literature and the research question. The chapter also provides a discussion of the strengths and limitations of the study, and recommendations for future research.

In the next chapter, *Chapter 2*, the researcher will now explore some of the literature dealing with HIV/AIDS, HIV/AIDS and women, and support groups.

CHAPTER 2-LITERATURE REVIEW

2.1   Introduction

This chapter aims at providing an overview of the body of literature related to this study. Women's experience of an HIV positive diagnosis and their need for support will be discussed. The discussion will progress to uncover social support in the form of support groups. The chapter will conclude by presenting some research on the impact of such groups for people living with HIV and the need for support groups for HIV positive pregnant women.

2.2   Women and HIV

2.2.1   Introduction

There is an important difference between the ways in which women are affected by HIV and AIDS, compared to men, due to the underlying consequences of the disease. Women's vulnerability to HIV infection is heightened by their economic dependence on men, lack of access to education, poverty, and exposure to sexual exploitation, coercion and rape. Some women may also be engaging in informal and commercial sex work. When identified as HIV positive, women often face discrimination (WHO, 2010). Through prenatal testing, they are often blamed as the one who brought the disease to the family as they are the first ones to test for HIV.

A number of studies have explored gender inequality and other socio-economic issues that contribute to women's vulnerability to contracting HIV and AIDS. Owing to their

economic dependency, women are not always in the position to protect themselves from HIV and AIDS. The community's acceptance of men having multiple sexual partners increases women's risk. Additionally, there is cultural resistance to condom use, which inevitably contributes to the rising rates of HIV infections and women's risk of contracting HIV from their long-standing partners (Abdool-Karim, 2005; Ross, 2004).

2.2.2 Physiological implications

The leading cause of death in women between the ages of 15 and 44 worldwide is HIV and AIDS. In middle-income countries, for women, HIV and AIDS accounts for 15.4% deaths and 22.3% of deaths in low-income countries (WHO, 2009). Women are biologically more vulnerable than men to all sexually transmitted diseases. Consequently they are twice as likely to acquire HIV from an infected partner during unprotected heterosexual intercourse (UNAIDS, 2008). Their high vulnerability is due to the following physiological reasons:

- The larger surface area of mucus membrane exposed during sexual contact with a man and

- The lining of the vagina which is a large area; hence there is exposure to a larger quantity of HIV infected semen

- Semen contains higher levels of HIV than vaginal fluids do

- More semen is exchanged during sex than vaginal fluids

- Having untreated sexually transmitted infections (STIs) makes it more likely for women to contract HIV since the majority of STIs do not give rise to any symptoms in women. They are then less likely to be recognised and treated.

- HIV levels in vaginal fluids also increase the presence of vaginal yeast infections and

STIs.

- The swelling of the vagina caused by infections causes tiny scrapes and cuts on the delicate skin of the vagina area that can hide HIV. HIV can also increase temporarily after receiving treatment for some of these conditions (WHO, 2003; The national women's health information centre. Office on Women's Health, 2009).

2.2.3 Social implications

Women in abusive relationships are particularly at risk of exposure to HIV infections due to the threat of violence, abandonment or loss of economic support if they negotiate safer sex or refuse sex (UNICEF, n.d).

2.2.3.1 *Social and cultural norms and gender norms*

Men and women are affected by gender norms that define gender roles. Gender roles describe what it means to be a man or woman in a specific culture. In traditional African societies which are mostly paternalistic, men are in a powerful position. The dominant ideology of masculinity characterises men as independent, dominant, invulnerable aggressors and providers, whose key virtues are strength, vitality and courage. In contrast, the dominant ideology of femininity in most societies casts women in a subordinate, dependant and passive position with virginity, chastity, motherhood, moral superiority and obedience as key virtues of the ideal woman. The gender roles are deeply rooted in the socio-cultural context of the society's institutions such as family, school, workplace and even health systems (Rivers & Aggleton, 1999; Tlou, Rantona, Phaladze, 2001). In such a climate, men make the decisions such as whom they would like to marry, and whether they will have more than one sexual partner, while women are expected to be submissive and agree to their decisions. This power imbalance implies that it is more

Women often feel disempowered when it comes to owning their sexuality, so that they are often not able to insist on condom use or on when and how they want to have sex. In addition, the mere fact that the condom, especially the male one, is still the only physical barrier used for prevention of HIV infection, means that the type of prevention becomes useless without male co-operation, leaving women without a choice but to depend on men for their own protection (Department of Health and Human Services: Centers for Disease Control and Prevention, 2007).

Recent studies have shown an increase in new infections occurring in marriage and long-term relationships as a result of partners being unfaithful. For many men, their definition of masculinity is linked with taking risks and being tough, which can increase their vulnerability to HIV infections. Masculinity is also discouraging men from seeking treatment. In some societies, including South Africa, it is perceived as acceptable for men to have more than one sexual partner. Thus, being in a marital or a long-term relationship does not always protect a woman from becoming infected with HIV (WHO, 2007).

Stereotypes in which women are perceived as subordinates to men, socially, psychologically and economically, help shape the way society perceives HIV infected women (Bennett, 1990). As already noted, even women who are sick themselves are expected to take care of their partner and family, resulting in self-neglect (Office on Women's Health, 2009). Many South African women though infected with HIV and AIDS, continue to deal with the day to day struggle of ensuring that their infected and dying partners, parent and/or children are kept clean, and receive their medication and adequate nutrition while their own health continues to fail (Bennett, 1990).

2.2.3.2 *Poverty*

Studies point to a strong link between poverty, unemployment and lack of education as "drivers" of increased risk of HIV infections among women. Generally, people living in poverty receive lower quality health care, which also means that advancing from HIV infection to AIDS takes place quicker (Office on Women's Health, 2009). In addition, women in this position possess limited resources to live a healthy and productive life.

Women account for 30.2% of the total 48.5% of unemployed people in South Africa (Frye, 2006). Often women endure abusive relationships or resort to informal sex work for economic survival if they are desperate.

Although the South African Constitution is clear in protecting the rights of women when it comes to rights to equal opportunities, statistically, men still own the majority of the country's wealth as they occupy senior positions at work. This implies that most women still live in poverty or form a greater proportion of those in informal employment. Their limited economic stability feeds into the vicious circle of poverty which leads to risk of sexual exploitation and violence, which consequently leads to greater vulnerability to contracting HIV (Shefer, Boonzaier, & Kiguwa, 2006;UNAIDS, 2008; UNDAP, 2009).

2.2.3.3 *Violence*

The issue of violence is especially urgent in South Africa in the light of escalating reported incidents of sexual violence. There were 68 332 reported cases of sexual assault between 2009 and 2010 (South African police statistics, 2010). These cases reflect reported incidents only and exclude domestic violence, which may involve sexual assault as well. In a national survey, more than four in ten South African men reported that they

had physically violated an intimate partner (Jewkes, 2009). Over a quarter of men admitted to having raped a woman. Nearly one in twenty men reported committing rape in 2008. This phenomenon is exacerbated by the disempowerment of women in South Africa.

There is evidence that violence against women is an important risk factor for their health. Violence increases the HIV risk factor due to the forced-sex or violent situation (Dunkel, 2004). Forced penetration can cause lacerations that allow easy entry of HIV. In addition, fear of violence keeps some women from insisting on condom use and seeking treatment. Some women fear being tested or do not return for the test results in fear of disclosing to their partners their HIV status as this may also lead to physical violence (UNAIDS/WHO, 2009).

2.2.4 Psychological consequences of having HIV

The psychological impact of HIV/AIDS is important to explore as this has major implications for the manner in which the person affected copes with the disease. After being diagnosed those who have just tested positive experience arrays of emotions. Amongst others, some commonly observed reactions in most individuals are: shock, grief, fear, guilt, anger, sadness, embarrassment and fear. After being diagnosed, most individuals perceive the positive diagnosis as a death sentence (Mokhoka, 2000; van Dyk, 2008). This fear often cripples the individual as he/she becomes pre-occupied with thoughts of death rather than of maintaining a healthy lifestyle to keep him/her alive. Their negative psychological experiences, such as isolation, depression and anxiety are intensified by perceived lack of support from family, friends and society due to the stigma attached to the disease (Mdlalose, 2006). Women often do not know what the reaction of others will be if they disclose their status.

Kübler-Ross (1969) pointed out that these emotions can be divided into different stages of crisis and bereavement. These are outlined as follows: denial, anger, bargaining, and depression. These stages do not necessarily follow in a linear way. Some people may progress from one stage to the other in a timely manner; others may be "stuck" at any of the stages. In other instances, the passage through the stages is not in sequential order as outlined. An individual might move back and forth between stages or go through other stages in a parallel manner, such as being angry and in denial at the same time, depending on the unique circumstances surrounding their crisis. Generally, after going through some of these emotional experiences, acceptance of the positive status might be eventually actualized. It is important for the individual to deal with the negative emotions because burying them may impact negatively on their well-being. Having a strong support system and sharing these negative feelings are some of the tools to enhance well-being in people living with HIV (Logan, 2005; Mokhoka, 2000).

2.2.4.1 *A discussion of the different stages is presented below.*

a. Denial

The first stage of reaction to a crisis is that of denial. Logan (2005) and Mdlalose (2006) point out that this stage is characterized by the refusal to believe what has happened. During this stage, the individual might insist that the HIV diagnosis is incorrect, and may try to seek verification from other health institutions. The patient might also move on as if nothing has changed in their lives and isolate themselves from others due to fear of disclosing their status to their partner, family or friends. This stage is characterised by an initial reaction of shock. Some individuals might feel numb, blank, experience panic attacks,

and an inability to express themselves, while at times they might have disorderly thoughts.

b. Anger

At the onset of a chronic illness such as HIV/AIDS, anger is often a classic reaction. The anger is usually directed towards people who are thought to be responsible for bringing the disease to the individual who has been diagnosed as HIV positive (Mkhoka, 2000). At times, the individual directs the anger at God or oneself, while being aware that it is not their fault (Logan, 2005). At times, the anger towards self might be due to self-blame, accusing oneself of being a bad person or not being careful enough. For women, the feelings of guilt might emanate from a belief that HIV is a result of being promiscuous.

c. Bargaining

The third stage is the bargaining stage. The stage involves bargaining with God, health professionals and family. A person going through a bargaining stage may have thoughts like, "if I hadn't done this, this would not have happened". For a person that is HIV positive, the bargaining process might be, "if I was more careful or if I had tested with my partner" and so on. At times, the individual might bargain for more time, which is asking God to miraculously heal them, or negotiate terms of living a good quality life for an exchange of more days, months or years. As a result, promises are made for an exchange of prolonged life (Logan, 2005; van Dyk, 2008).

d. Depression

The depression stage occurs at the height of the pain, in the form of anger and hopelessness. This is often seen when the immune system has deteriorated, which affords

an easy chance for opportunistic infections to start manifesting themselves. At this point, the individual starts to realise that the disease is not going to go away. Feelings surface such as loss of purpose, guilt regarding not being there for loved ones in the near future, shame at having contracted the virus, as if everything is their fault. Mdlalose (2006) describes how women who had a low self image, lack of financial resources and lack of opportunities to make choices about their lives, suffered depression following their HIV diagnosis. This stage might leave the individual feeling lethargic, tearful and wandering around in a daze. At times, thoughts of suicide are entertained. It is easy for a person to be stuck at this stage, especially when he/she possesses no positive coping mechanisms (Logan, 2005).

e. Acceptance

To complete the process, often people living with HIV and AIDS start to realize that it is possible to live positively with the disease (Logan, 2005; Mokhoka, 2000). The individual starts to act rationally about their status and accepts the help that is available to achieve a good quality of life. This implies that they realize they are in control of their lives and they can make future plans.

2.2.4.2 Shame and Guilt

Common emotions associated with being diagnosed with HIV are feelings of shame and guilt. Most people recently diagnosed with HIV fear disclosing their status, afraid of being stigmatized. They often feel that they will be judged for being HIV positive. In her study, Mdlalose (2006) demonstrates that when HIV positive women perceived the outcome of their disclosure as yielding a positive reaction, they felt more at ease to make their status known, compared to when they anticipated being shamed by those to whom

they wanted to disclose this.

For some women, as indicated, feelings of guilt emanate from a belief that HIV is a result of being promiscuous or entering into a "wrong" relationship. Most women also feel guilty about the potential of passing on the virus to their unborn babies.

2.2.4.3 *Fear*

Fear about the future is one of the common emotions with which HIV positive women have to deal. Their concerns about their families, especially their children, often overcome the immediate need to be well. Women with relatively no social support in a form of family often suffer anxiety as a result of this fear.

2.3   Pregnant Women and HIV

The prevalence of HIV/AIDS among pregnant women is approximately 29.6% in urban areas and 29 % in rural areas (Department of Health, 2010; Quintal, 2010; UNAIDS/WHO 2009). Despite coverage of 92% in antenatal care of prevention of mother-to-child transmission (PMTCT), only 57% of pregnant women living with HIV received antiretrovirals for PMTCT.

The challenges faced by an HIV positive pregnant woman are unique to her, different from those of other pregnant woman without the disease. While being pregnant demands some life adjustments to be made, other demands are added for a woman who is pregnant and HIV positive. In addition to worrying about the unborn child's well-being and future, HIV positive pregnant women often have to think about the chances of transmitting the HI virus to the unborn, and about protecting the baby from contracting the disease

when caring for the child (AIDS Education and Training Centers: National Resource Center, 2007).

Comprehensive care should be at the centre for pregnant women with HIV infection, to achieve a healthy pregnancy, delivery and emotional well-being. The focus must not only fall on the physical health of the mother and the baby, but also on the social, psychological and practical needs. Thus a multidisciplinary approach is the most effective way to address these needs. The pregnant woman may need psychological support through counselling and peer counselling in the form of a support group. Seeing that violence puts women at high risk, women in violent relationships may need legal or police services during and after pregnancy. Thus, cooperation between the different health care workers and social sectors is essential throughout the pregnancy and even when the baby is born (AIDS Education and Training Centers: National Resource Center, 2007).

Women who have been diagnosed with HIV usually need time to come to terms with the diagnosis. For this reason most of them do not disclose their HIV positive status directly after diagnosis. Besides the fear of being discriminated against, some women have reported being rejected, violated, abandoned and shamed as a result of disclosing. This type of reaction provides evidence for issues such as the stigma surrounding HIV (WHO, 2009). Often people with HIV suffer in silence because they are afraid that people will reject or discriminate against them (Parker, Aggleton, Attawell, Pulerwits, & Brown, 2002). This attitude may lead to feelings of helplessness in HIV positive patients. Owing to the fear mentioned above, people living with HIV often do not seek counselling and treatment. This can increase the chances of further transmission of the virus to their partners and re-infection of themselves (Parker et al., 2002).

Receiving the proper support in the form of a support group, friendship and family may therefore help to lessen the burden of being HIV positive. Furthermore, being in a supportive environment can help alter the negative attitude the individual might have about themselves, which could lead to integrating with society and seeking help from others (Turner-Cobb, et al., 2002).

2.4   Social Support

Research has demonstrated that social support is a valuable resource for people who are obliged to deal with an HIV positive diagnosis. Social support has been linked with better physical health as well as greater psychological wellbeing (Turner-Cobb, et al., 2002). Furthermore, counselling people with HIV and providing social support can help them come to terms with their experiences and plan on how they can live healthy and positive lives (Lindegger & Wood, 1995).

According to Dadich (2006) it is the person's cognitive appraisal of the support that they receive from others, and not the mere availability of support, which influences women's adjustment. Social support can enhance positive coping behaviour; consequently, satisfaction with social support is linked to optimal functioning and a positive state of mind. In this regard, HIV positive women with strong links to social support, such as belonging to a support group, having a supportive family and other networks, are more likely to live longer than their counterparts who have fewer or no means of social support (Moskowitz, 2003).

2.4.1 Support groups

Support groups are face-to-face meetings where people with common challenges, concerns and needs come together to help themselves to cope with a stressful event. The group members can help one another in various aspects of daily living and functioning. Some of the needs that such a group addresses include: relationships with others, helping with practical decisions, as well as coping with particular situations as the participants share with one another in a support group setting**.** In the process of helping one another, they share information, knowledge, ideas and experiences (Department of Health, 2005).

These kinds of groups provide a reality check, emotional support, meeting with others and education. In most cases, the group members are people who have undergone the same experience in life, for example, people living with HIV, single parents, new mothers, addicts and so forth. Therefore, participants in a group have the opportunity to share with people who share similar life experiences. The members of the group are usually bound by group norms, goals and objectives based on the agreement of the group. There are different types of support groups namely informal support groups, open or closed support groups, and structured support groups, to name a few (Department of Health, 2005; Toseland & Rivas, 2005; Wood, 2007; Yalom, 1995).

2.4.2 Impact of support groups

In general, HIV positive women who participated in support groups reported the following;

- A significant change in their behaviour, lifestyle, and attitude towards

disclosure (Mdlalose, 2006; Visser, Mundell, Villiers, Sikkema and Jeffery, 2005).

- The participants gain knowledge in relation to the topics covered during the support groups; they became empowered (Mundell, Visser, Makin, Kershaw, Forsyth & Sikkema, in press; Visser, Mundell, Villiers, Sikkema, & Jeffery, 2005).

- Mundell et al. (in press) concludes that their positive coping skills increase and they disclose their status more.

- Their psychological difficulties, such as coping mechanisms, emotional well-being, and inter-personal relationships, will be somewhat resolved (Turner-Gobb et al., 2002).

- They gain a degree of positive self-regard and have learnt constructive means to live a positive life (Dadich, 2006; Lindergger & Woods, 1995).

- They have an overall positive experience during the support groups (Mundell, 2006).

- Summers et al. (2000) demonstrated that women who participate in support groups live an average of 28 months longer than those who do not do so.

In this section, the value of support groups for HIV positive women is discussed:

2.4.2.1 *Help with practical decisions*

Women in the study by Mundell (2006) mentioned benefiting from information that they received regarding taking care of themselves, the baby, the risks involved during birth and obtaining general knowledge about HIV and AIDS.

2.4.2.2 *Disclosure*

Being involved in a support group aids one with the ability to disclose to others

(Kalichman, Sikkema, & Somlai, 1996). In the study by Visser, Neufeld, de Villiers, Makin, and Forsyth (2008): women mainly disclosed to their partners, other family members and friends to gain support for themselves. This further enhances access to social support outside the support group where most women reported they disclosed to relieve the burden of being HIV positive (Mdlalose, 2006). This means they can share this load with many others who are supportive of them. In Levy and Storeng (2007) participants emphasised the importance of disclosure to dispel negative stereotypes about people living with HIV. Publicly opposing the silence surrounding HIV by disclosing to friends, family members, partners or neighbours is seen as dispelling the myth and stigma around the disease.

2.4.2.3 *Social interaction and sharing of information*

As a hub of socialising and meeting with other HIV positive women, support groups have proven to have an impact in regards to emotional relief and confidence. The ability to connect with others who can share similar experiences is particularly important in situations where people have a stigmatising disease or where people are considered to be outcasts from society (Oosterhoff, Anh, Yen, Wright & Hardon, 2008). A greater sense of belonging is closely associated with better psychological and social functioning. Participants in a support group often describe the experience of their interaction with fellow group members as having found a new "family" (Mundell, 2006; Yalom, 1995). This is because the environment in the support group often offers a platform to share without being judged or looked down upon. Furthermore, feelings of self-worth are enhanced in the process.

Research has shown that the involvement in a support group is strongly linked to emotional well-being. In the study by Mundell (2006) women who participated in the support groups reported that being supported and giving support contributed positively. For many people, feeling that one belongs plays a major role in one's self-esteem. Meeting

others who can identify and who are facing similar problems helps the individual in that group feel important (Groomes, 1998).

Other significant changes pertaining to everyday life seen in individuals who participate in support groups are: talking to someone with similar experience, educating others with similar problems, supporting others with HIV, receiving comfort and understanding and believing their HIV diagnosis caused them to change their lives for the better. This is due to the fact that a support group is a safe environment where participants feel that they are free to be themselves.

Being part of the support group seems to provide a defence against stress and depression. As individuals gradually accept their status and experience an increase in well-being, their stress levels, depression and hopelessness may decrease. A number of women who have been part of such groups reported feeling hopeful. From most studies, it emerged that feelings of shame and blame diminish as they found themselves amongst people who are experiencing similar situations (Mundell, 2006).

2.4.2.4 *Coping*

Coping is a collection of actions and thoughts aimed at responding to difficult situations. According to coping theory (Larazus & Folkman, 1984), there are two ways of coping; emotion-focused and problem-focused. Participation in a support group leads to positive coping such as positive thinking and a positive change of lifestyle (Mokhoka, 2000).

Emotion-focused coping - Positive thinking can be associated with emotion-focused coping. This type of coping is used in situations that are perceived as unchangeable. The

purpose of this type of coping style is to reduce the appraisal of the emotional distress or negative emotions to minimise emotional pain. This includes accepting sympathy from others, realising the good and positive in one's life and trying not to think about one's problems as much (Lazarus & Folkman, 1984).

Problem-focused coping - This relates to a positive alteration in lifestyle; being part of the support group facilitates the knowledge that an individual can utilise to modify their lifestyle. Mundell (2006) reported that participants took up healthier living, which demonstrates taking responsibility for one's life.

2.4.3 Structured support groups

In the study by Mdlalose (2006), it was established that upon diagnosis, most women experience negative emotions and thoughts parallel to those of catastrophic stages, namely; shock, anger, denial, bargaining, blame, and depression. These reactions seem to be replaced by positive reactions such as an acceptance of HIV positive diagnosis over the passing of time. There is however marked fluctuation between positive and negative feelings and thoughts throughout the process of coming to terms with the HIV diagnosis (Kubler-Ross, 1981; Logan, 2005).

Considering the importance of social support in enhancing both physical and mental health (Dadich, 2006) and the challenges HIV positive women face, support groups are sorely needed. Due to the lack of psychological services available to HIV positive women, support groups that form informally in neighbourhoods have become the most important sources of support and help for HIV positive women. The Serithi project contributed to this by developing a structured manual, based on the needs of women, to be implemented in

informal support groups. The development of the manual is documented elsewhere (Visser, Mundell, de Villiers, Sikkema & Jeffrey, 2005).

The session outline of the structured support group was the following:

Session 1: Introduction and orientation: Needs assessment, goal setting and group rules

Session 2: HIV and access to treatment: Discussion of information

Session 3: HIV, pregnancy and birth: Knowledge

Session 4: The emotional experience of having HIV: Sharing feeling and building group coherence

Session 5: The emotional experience of having HIV (continued)

Session 6: HIV, disclosure and dealing with stigma: Role plays

Session 7: Coping, problem solving, and stress management: Sharing of coping strategies

Session 8: HIV and intimate relationships: Negotiation of condom use

Session 9: HIV in the household, human rights and dealing with stigma

Session 10: Life planning and goal setting: Planning the future.

It has been indicated that as part of the evaluation of this manual, structured support groups were implemented for recently diagnosed HIV positive pregnant women in antenatal clinics in Atteridgeville and Mamelodi. 145 HIV positive women participated in these support groups. Evaluation was carried out in the form of quantitative research using a quasi experiential design. This research has been reported by Mundell et al. (in press). The current research forms part of the evaluation of the support groups.

While the implementation of support groups for HIV positive women is becoming a popular way of helping HIV positive women, there is limited research that evaluates the impact on the participants of support groups. Because of the informal nature of the groups the experiences of women in such groups are seldom investigated. Hence the current study.

2.5 Conclusion

As discussed above, HIV/AIDS is not only a medical disease, but it also affects the total person and other spheres of society. Recommendations from previous research on impacts of support groups highlighted the need for a qualitative study to explore the impact of structured support groups implemented for HIV positive women in order to apply psychological interventions suitable for women living with this disease.

In the next chapter, description of the research methodology and the phenomenological perspective as the research framework will be presented. Furthermore, the context of the research, the choice of the research participants, data collection, data analysis and ethical procedures will be discussed.

CHAPTER 3 METHODOLOGY

3.1   Introduction

The purpose of this chapter is to present a summary of the research process. A description of the research methodology and the phenomenological perspective as the research framework is given, while the context of the research, the choice of the research participants, data collection, data analysis and ethical procedures are also discussed.

3.2   Research Design

The research design used in this study is qualitative in nature and relies on a phenomenological perspective as a research framework.

3.2.1   Qualitative research

Qualitative research is the method used in this study. The research takes place in a natural context and studies behaviour as it occurs. Owing to the nature of qualitative research in describing social phenomena as they occur naturally, a holistic perspective is gained (Hancock, 1998; Whitley, 2002). The method introduces narrative responses to interview questions which allow for multiple interpretations (Whitley, 2002). It involves exploring, describing and interpreting the social experiences of participants (Smith, 2003).

The research approach emphasizes words, which involves collecting data in the form of a verbal account such as interviews or written reports (Bryman, 2001). The data of this study is obtained through conducting interviews with non-directive questions in order to

gain a rich description of the lived experiences of the participants. The topic requires an

empathic researcher, one who can dwell within the accounts given by the participants. The

researcher was a facilitator of the support groups, which enhanced the empathy and

rapport in the process of data collection during the interviews. She was familiar with all the

research participants as she facilitated the support groups they attended. While the

researcher is not separate from the data collection process, she had to suspend her beliefs

and assumptions in order to explore the full phenomenon as experienced by the research

participants (Barker, Pistrang, & Elliot, 1994; Giorgi, 1989; Shaw, 2001). The researcher did

this by giving attention to and clarifying what the research participants described instead of

assuming she already know what they meant when describing a particular phenomenon.

There are various approaches within the field of qualitative research. Owing to the

nature of this study, interpretative phenomenology is used as a research framework.

3.2.2   Theoretical framework – Interpretative phenomenological approach

The phenomenological approach is rooted in the philosophical tradition initiated by

Edmund Husserl (1859-1938) and Martin Heidegger (1889-1976). The initiative of this

methodology was prompted by the belief that most disciplines lacked a method that

established the nature of their basic concepts (Giorgi, 2008; Koivisto, Janhonen, &

Väisänen, 2000; Smith, 2008).

Phenomenology involves a detailed exploration of the individual´s lived experience

and how the particular individual makes sense of it (Willig & Stainton-Rogers, 2008). The

focus is based on the unique experience of the individual within his/her context, and the

nature of the meanings attached to particular phenomena as understood by the individual (Giorgi, 1989; Smith 2008). A phenomenological study attempts to understand people's perceptions, views and understanding of that particular situation. There is a focus on both the similarities and differences in individual experiences as these are the ways individuals interpret their unique experiences (de Vos, Strydom, Fouche, & Delport, 2002). Instead of attempting to support or refute an established theory, a researcher is able to explore a new perspective by learning from a participant who is experiencing a particular phenomenon (Giorgi, 2008; Shaw, 2001). Such an approach can be helpful in aiding the understanding of everyday experiences (de Vos, Strydom, Fouche, & Delport, 2002).

As noted earlier, phenomenology studies human experience and possible appearances of similar themes between accounts from different individuals (Barker, Elliot & Pistrang, 1994). Individuals who have experienced a specific phenomenon can be identified. Data can be collected from them through systematically studying meanings and themes and a general description of the experience within that particular context amongst individuals.

There are two main approaches to phenomenology, namely descriptive phenomenology which was developed by Husserl and interpretative phenomenology (Koivisto, Janhonen, & Väisänen, 2001). The difference between the two approaches relates to their respective starting points. From Husserl's epistemological perspective, description is primary, while the interpretation is a special type of description.

3.2.2.1 *Descriptive phenomenology*

The descriptive phenomenology was first developed by Edmund Husserl (1965). His philosophical stance was based on the fact that meanings are ideal contents of conscious

acts. He concluded that all mental acts are intentional as they point to something that is not consciousness itself, this including mental objects such as memories (Giorgi & Giorgi, 2008a; Koivisto, Janhonen, & Väisänen, 2001). This method is applicable wherever an experience can be described. The use of psychological reduction in this approach means that whatever is experimentally given to the researcher is considered to constitute a phenomenon. In that, the subjectivity undergoing the experience is considered to be the actual existing psychological subject engaged with the world. Therefore, if there is no psychological-phenomenological reduction that is correctly understood, the procedure in this case cannot be considered to be phenomenological (Giorgi & Giorgi, 2008a).

3.2.2.2 *Interpretative phenomenology*

Interpretative phenomenology is a perspective which converges with hermeneutics. The method requires one to enter into the hermeneutic circle in the proper way and to use the 'fore-knowledge' of the phenomenon that one has in order to determine a proper perspective with which to approach the phenomenon. Once the phenomenon to be studied and the approach are known, analysis to clarify the meanings that emerge can take place. It is then the researcher's responsibility to demonstrate the relevance of these meanings. The goal is not just directed at mirroring reality by describing the experience, but to also change it for the 'better' (transforming the experience) (Giorgi & Giorgi, 2008b). This is gained once the themes have been identified and meanings associated with the themes are clear. The researcher rewrites the participants' account into psychological language, evaluating each theme by comparing the research question with each theme in order to give the theme a psychological significance.

3.3 Research Participants

3.3.1 Selection of participants

In keeping with the research paradigm 5 participants were selected. Owing to the

demanding method of data analysis and the need to explore and integrate different meanings in each interview, a few participants enabled the researcher to better manage the research (Giorgi, 2008). This allowed the researcher the opportunity to capture the depth and richness of data from each participant.

Participants were selected through purposeful sampling. This refers to selecting people for whom the research question is significant. In this research women were selected owing to their participation in the structured support groups. The participants had to be individuals who have experienced the phenomenon studied and who were willing to take part in the study (Giorgi, 2008; Lyons & Coyle, 2007; Smith, 2008). Accordingly, the research participants were selected from the 120 women who had already attended a support group presented as part of the Serithi project. Women who attended more than 7 sessions out of the 10 sessions of the structured support group were invited via telephone to participate in the study. Participants were interviewed until reaching a point of data saturation. That is, when the researcher no longer heard new information from the participants (Whitley, 2002).

The following criteria were used in selecting women to participate in this research:

- Women who had attended more than 7 of the 10 sessions of the structured support group. During each support group meeting, the researcher and two facilitators kept an attendance register, which was filed at the Serithi project offices.
- From the register, women who attended more than 7 sessions were identified and invited via a telephone call to participate in the project.

- Women who agreed to be part of the research project.

- The research began to interview women who already showed interest in participating in the research until information redundancy was reached.

Five women were interviewed individually. They were between the ages of 18-40 years.

3.4   Data Collection

Qualitative methods involve an open dialogue between the researcher and participant (Lyons & Coyle, 2007). In this study, five audio taped individual interviews, with suitable participants, were conducted. Interviewing is a predominant method of data collection when the research aim is the subject's particular account of a phenomenon. This is because the interview can focus its interest on the person's story or narration of a particular subject in their lives.

Interviewing the participant involves obtaining the description of the experience as well as the reflection on what is being described in that experience. Semi-structured interviews were conducted with each participant. This type of interview enables the participants to provide a rich and full account of their experience. An interview guide, which was drafted beforehand, was used as a checklist to ensure that relevant topics were covered during the interview (de Vos, Strydom, Fouche, & Delport, 2002). The interview guide does not dictate the interview; instead, it functions as a guide. This frees the researcher to probe areas which arise in the interview in keeping with following the participant's interests and concerns (Lyons & Coyle, 2007).

The following questions were prepared as the interview guide:

- What were your expectations before joining the group?

- What was your experience of being in the support groups?

- What was it like to meet other HIV positive women?

- How do you think you have grown/developed during the time that you have attended the support group

  o During the support group?

  o After the support group ended?

- How did your behaviour change since you started to attend the support group?

  o During the support group?

  o After the support group ended?

- How have your perceptions of HIV changed through the attendance of the support group?

- What do you remember from the support group?

- How did you feel when the support group sessions ended?

- How did the different aspects of the group processes help you?

  o The interaction with other group members?

  o The interaction amongst facilitators and group members?

  o The interaction amongst facilitators?

- If you were to tell others about the support group, how would you describe it to them in trying to convince that particular person to attend the group?

- Can you tell me about aspects of the support group that you liked?

- Tell me about aspects of the support groups that you did not like?

The research questions were translated into Sotho and the answers were translated

back into English which has not been edited in order to preserve as closely as possible the verbatim nature of the responses.

Participants were invited to the interview by phone. A brief explanation of the study was given prior to the interview and later, before the interview started, the specific core research aims were explained face-to-face. The interview with the research participants was face-to-face. The researcher started the interview by thanking the research participant for her willingness to participate and made sure that they understood the contents of the consent forms fully before signing. The interview started with a focus on issues relevant for the participants before proceeding with exploring the experience of the support group. The practice of focusing on issues relevant to the participant assists in eliminating the researcher's misinterpretation of the core concerns as they are established by the participants during the data collection processes (Lyons & Coyle, 2007).

The role of the researcher here becomes that of a facilitator (Morgan, 1989). This affords the participant an opportunity to expose experiences and perceptions during the interview. The quality of the data depends, inter alia, on the researcher's skills to encourage participants to express themselves freely when facilitating the process (Lyons & Coyle, 2007). In addition, semi-structured interviews involve trust between the researcher and the research participants. The process involves limited boundaries, as the researcher is part of the process and cannot exclude herself from the dynamics of the interview. The researcher needs to build a relationship of trust with the participant that enables her to extend her involvement further than listening and being a passive participant, as it is important to establish a relationship of trust and empathy with the research participants.

Owing to the researcher's involvement in the structured support group, she had already established a relationship and rapport with the research participants during the group sessions. This enabled her to be empathetic, caring and supportive during the process of the interview. The researcher also ensured that the participants were comfortable during the interview by letting them know that they could express themselves in their home language and the approximate time the interview would take. Participants were assured of the maintenance of confidentiality throughout the research process (Lyons & Coyle, 2007).

The use of the participants' home language contributed to the richness and depth of the data obtained during the interviews as this allowed the participants to express themselves freely. The researcher understands that people do not only communicate through using the spoken word. She therefore also noted the participants' non-verbal communication while describing their experiences (de Vos, Strydom, Fouche, & Delport 2002).

Before the commencement of the interview, informed consent from the participants to participate in the research was sought.

3.5   Data Analysis

Interpretative phenomenological analysis (IPA) was used as a method of analysing the data collected for this study. IPA enables the researcher to answer in-depth questions regarding an individual's experience; hence the focus is on the uniqueness of the person's account of the lived experience (Lyons & Coyle, 2007;

Shaw, 2001).

The method is chosen due to the aim of the study. The researcher is interested in the personal perceptions or accounts of the women's experiences in the support group (Smith, Jarman & Osborne, 1999). The data in this study was collected through semi-structured interviews, which assisted the researcher to be actively involved with the material during the data collection process. In addition, the method is relevant to analysing the data as the researcher is already familiar with the data collected from the participants (Lyons & Coyle, 2007; Shaw, 2001). The method of data collection is flexible, allowing participants to discuss aspects of their experiences which the researcher did not anticipate, instead of embarking on confirming or refuting hypotheses. While analysing the data, the IPA enables the researcher to come across unexpected phenomena. IPA is a data-driven approach rather than a theory driven one, which implies accommodating and uncovering constructs from the participants (Shaw, 2001; Smith & Osborn, 2003).

Soon after all the interviews were conducted, the researcher transcribed the audio taped discussion herself. This allowed her to capture the emotions that were present during the interview. It also assisted her to understand the meaning of the discussions in context (Shaw, 2001). The following stages in analysing the collected data were followed (Lyons & Coyle, 2007; Smith, 2008):

Stage 1: Initial reading of the transcripts
The first stage involved several close and detailed readings of the data to obtain a holistic perspective so that future interpretations remained grounded within the participant's account.

The researcher began the process by reading the entire description to discover psychologically relevant lived experiences. This was followed by re-reading the transcripts in order to get a sense of the overall themes. Following the re-reading, wide ranging notes were produced. These were recorded in the left-hand margin of the transcripts. The notes included significant comments and what the researcher regarded as interesting from the interviews. Similarities, differences, amplifications and contradictions in what the participants talked about were highlighted (Giorgi, 2008; Lyons & Coyle, 2007).

Stage 2: Identifying and labelling themes

This stage involved the identification and organising of initial themes into clusters and checking them against the data.

Upon completing the reading of the transcripts, the researcher created a right-hand margin to produce themes using notes that had been made previously in the left-hand margin. This process involved transforming themes, which stem from participants' natural attitudes and expressions, into a level of abstraction which employs psychological terminology (Giorgi, 2008). During this stage, the researcher was mindful not to violate IPA's phenomenological commitments in over-emphasizing the interpretative aspect by neglecting participants' phenomenologies (Lyons & Coyle, 2007).

Stage 3: Linking themes and identifying thematic clusters

The stage involved refining, condensing and examining connections between different themes.

Connections were identified between the first rounds of themes to enable the researcher to integrate the themes. By means of this process, some themes were clustered together while others remained as superordinate themes with sub-themes under them. While the clusters of themes emerged, the transcripts were checked to ensure that these connections had emerged from the actual words of the participants which are the preliminary source.

A table of themes was ordered and produced coherently. Themes for which the researcher could not identify data from the transcript, for support, were disposed of.

Stage 4: Producing a summary table of themes with illustrative quotations
The final stage involved producing a narrative account of the interplay between the interpretative activity of the researcher and the participants' account of their experiences in their own words.

During this stage, the researcher organised subordinate themes into a table together with their respective sub-themes. Once the structure was obtained, the researcher dialogued the themes with the raw data in order to illustrate in full the findings of the study. Thus, it was important to demonstrate the distinction between what was said by the research participants and the researcher's interpretation of the participants' account of the experience.

3.6   Measures to Enhance Research Quality

Validity of research entails how well the research has been carried out and

whether the findings are useful and trustworthy. In a qualitative study, it is acceptable to view all research perspectives as valid and useful. It is not easy to identify criteria that can be applied to the different qualitative approaches with their unique procedures. While measures are not easy in qualitative research, if neglected, they can cause problems in research. Hence, there are reasons to attempt to find common criteria for validity in qualitative research. 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, 2008).

The following guidelines were followed to enhance validity in this study:

- Reliability was enhanced by presenting a thorough description of the methodology of the study, data collection and data analysis process. This was discussed earlier in this chapter.

- Transferability entails that the findings of the research should be transferable to other applications in the field where the context is similar (de Vos, Strydom, Fouche, & Delport, 2002). With this in mind, the researcher provided all information regarding the context of the study (experiences of HIV positive women in a structured support group), with specific biographical, demographic and contextual information.

- During this study, collaboration with a colleague to enhance the quality of the data analysis was undertaken. The colleague was a research fellow on the Serithi project. He completed his masters degree in psychology evaluating the impact of support groups for HIV positive women at the University of Pretoria. The researcher

discussed the themes that emerged with the colleague, who signed a confidentiality agreement within the bigger study (Serithi project); the names of the participants remained anonymous. Possible themes emerging from transcribed data were sent to the colleague to review. The colleague assisted in verifying the logic and validating data synthesis. This also assisted in reducing the researcher's tendency to rely on subjective opinion and/ or preferences when analysing the data.

▪ Transparency - Furthermore a detailed description of how data was initially identified, labelled, and modified through looking at all instances and the discussion with a colleague was provided.

▪ A paper trail involves a clear chain of evidence of how the research process and the final product were produced. For this study, the paper trail included information sources, research notes, hard copies of interviews and electronic mail communications as well as other documents and items created throughout the study.

▪ The researcher's relationship with the participants in the study and the data was intensive and prolonged. This became important in that the researcher was able to establish a relationship of trust and empathy with participants in order to better understand their perspectives when dealing with the data as well.

3.7 Ethical Considerations

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 in this field (Ostrow & Kessler, 1993).

This research is part of the Serithi project. The main project obtained ethical clearance for involving a large number of HIV-positive women in support groups. For this study, the selected participants were informed of the nature of this study, what it entailed and what was expected from them during the interviews. Although all the research participants had signed informed consent forms for participating in the Serithi project, they were requested to give their consent again before taking part in individual interviews specifically for this study. Permission from the project coordinator and manager to use the participant's records, such as obtaining their telephone numbers to invite them to participate, was granted. The Serithi research number was made use of to identify the interviews, as well as for the purposes of data collection (Whitley, 2002). All participants were over 18 years old; thus they qualified to sign their own consent form. Consent was sought to interview the participants, audio record the sessions and publish the findings in the form of a dissertation and scientific journal article.

Confidentiality and privacy - Participants were informed of their right to privacy and confidentiality. This means first that the research participants have the right not to share information if they choose not to do so. Confidentiality in this case secondly means that the researcher withholds information from third parties (de Vos, Strydom, Fouche, & Delport, 2002), and that the research results will be published without referring to specific individuals, but only to reveal general trends. All material resulting from the research

process is kept confidential and safe.

Harm and benefits - Participants were informed about possible adverse effects of talking about their feelings. The researcher offered counselling or debriefing to deal with potential effects; however none of the participants were in need of this service. The participants were informed about the benefit of participating in the study because the interviews served as an opportunity to debrief after the termination of the structured support groups.

3.8   Conclusion

The research process was described in this chapter. Selection of participants, data collection, data analysis and ethical procedures were discussed in order to gain a clear idea of how the research results were obtained and analyzed. The next chapter presents the findings based upon the analysis of the data gathered from the research participants.

CHAPTER 4 RESULTS

4.1 Introduction

The research results will be presented in this chapter. To begin with, a short biographical description of each research participant will be furnished. Subsequently, to introduce the context in which the study was carried out, background information will be briefly discussed. The next step will be the description of the results and themes identified from the interviews. The name of each theme is presented, followed by a short description and a verbatim quote to illustrate it.

Participants

The biographical background of each participant is supplied in order to provide some information concerning certain aspects of their lives. The information was obtained from the Serithi project files from the initial interviews with participants. Careful consideration was given to the amount of information provided owing to the sensitive nature of the study. Pseudonyms were used to protect the identity of each participant.

4.1.1 Desiree

Desiree is a 28 year old woman. She is married with one child. Desiree is living with her husband and their 5 year old child in an informal settlement. They do not have any basic infrastructure in their house; therefore, she collects water from a public tap and uses a pit toilet.

The highest level of education that Desiree has obtained is high school up to

standard 10. She is unemployed and depends on her husband's salary of approximately R3000.00 per month.

She found out about her HIV status during her second pregnancy, which she reported was unplanned. While she was encouraged to test for HIV at the ante-natal clinic, she reports that she too had a desire to know her status. The only person she disclosed her status to report in the initial interview was her husband. Her husband has not yet tested for HIV; thus his HIV status is not known. Although Desiree mentioned that the couple often used contraceptives, they only sometimes use condoms. At the time of the interview, she had not accepted the news about her status and she was still living in denial. Desiree was originally from Mpumalanga and all her family lives there. Whilst living in Gauteng, her main source of emotional and social support is her husband.

4.1.2 Khanyile

Khanyile is a 30 year old married woman. She lives with her husband and their two sons, one 10 years old and one 11 months old. They live in a brick house dwelling with running water and a flushing toilet.

Khanyile is unemployed and reported that she does not have a formal education, while her husband has been educated up to secondary school level. He resigned from his job and receives a monthly pension from his previous work. The family is dependent on the state grant which is approximately R 1280 per month.

She found out about her HIV status during her previous pregnancy when she was encouraged to test for HIV at the ante-natal clinic. She mentioned that she disclosed her status to her younger sister. She disclosed to ease the burden she felt. She believes that it

is not necessary to disclose her status to her husband as the couple use condoms each time they have sexual intercourse. Her husband has not yet tested; hence his HIV status in not-known. At the time of the interview, Khanyile reported that she felt hurt upon receiving her HIV diagnosis; however, she is now doing well emotionally. Her source of emotional and social support is her mother, neighbour, sister, husband and children.

4.1.3 Terries

Terries is a 30 year old mother of two. She lives with her husband in an informal settlement.

Both she and her husband studied until standard 4 at a primary school. She is unemployed while her husband works as a panel-beater. Their household is sustained by a social grant to the amount of R 2180 per month.

Terries reported that she and her husband use condoms all the time. The pregnancy was unplanned. She stopped the use of oral contraceptives because she was not experiencing a regular menstrual cycle. This is when she fell pregnant with their third child. She was curious to know her status, so she decided to test during one of her ante-natal clinic visits. She disclosed her HIV status to her husband to let him know that he may be positive too. The husband reportedly tested negative. Terries, however, reported that he has not shown her the test results. She reported coping well with being diagnosed HIV positive. Her main source of emotional and social support is her husband as her whole family lives in Limpopo.

4.1.4 Thoriso

Thoriso is a 19 year old single mother who lives with her parents, younger sister and

aunt. They live in a brick house with running water and a flushing toilet inside the house.

The highest level of education that she obtained is grade 12. She is unemployed and the household depends on the parents' income for sustenance.

She found out about her HIV status during her routine ante-natal clinic visit. She reports that she tested because the nurse told her it was compulsory. At the time when she learned about her status, she felt hurt and cried uncontrollably. She mentioned that at this time, she often thought of terminating the pregnancy and committing suicide. The only person she disclosed her status to at the time of the initial interview was her boyfriend, with the intention of indirectly letting him know that he too might be HIV positive. He tested and the results were positive. Thoriso mentioned that the couple uses contraceptives regularly, but reported only occasional condom use. Her source of emotional and social support is her mother and boyfriend.

4.1.5 Vanessa

Vanessa is a 33 year old woman. She is married with 3 children. Vanessa lives with her parents who take care of her during the pregnancy and the first few months after her baby has been born. The family lives in a brick house with piped water and a flushing toilet inside the yard.

The highest level of education that she obtained is standard 10. She is unemployed. Vanessa's husband works as a security guard. She also mentioned that her mother works part-time. Since Vanessa is staying at her parents' home, some of the income is used to support her as well.

The couple used the injection as a method of contraception. Vanessa reported that she got tired of using this method when the couple started using condoms on a regular basis. Owing to the fact that the couple has been involved for more than four years, they decided not to use condoms. She decided to test for HIV during one of her ante-natal visits. Although Vanessa reported that she was suspicious of the husband's HIV status due to his frequent sickness, she was shocked to receive a positive diagnosis. Vanessa mentioned that she often thought of terminating the pregnancy after learning about her HIV status. She encouraged her husband to test, but she does not know if he went for testing or the results of his HIV status. Vanessa disclosed her status to her aunt, friend and husband and reported that she was coping well compared to when she initially learned about her status. She receives emotional and social support from her mother, friend and husband.

Context

Most of the women are of low to middle economic status. They stem from various ethnic groups; however, most of them spoke Sotho (Pretoria Sotho) and the ones for whom Sotho is not their first language, can understand and communicate in Sotho. This is also the vernacular of the researcher. As a result, no translation was needed during the interviews.

4.2   Research Results

The analysis was conducted as described in chapter three. The process involved transcribing the recorded interviews. The transcripts were then read several times to obtain a holistic perspective on the participant's responses. This was followed by an initial

identification of themes which were then organized into clusters and checked against the data. The researcher then refined, condensed and examined the different themes for connections between them. Finally, the researcher dialogued the themes with direct quotes in order to illustrate the findings of the study.

The analysis furnished insight into various experiences of the women in the study. A number of themes and sub-themes that emerged are presented in table 4.1.

Table 4.1 Superordinate and subordinate themes

Superordinate themes	Sub-themes	Data extract
1. Importance of support group in facilitating learning	1. Lessons	*"I learned about the CD4 count, how it works, things like the viral load, so by coming to the support group, I learned what I should do"* Vanessa
	2. Information on infant feeding	*"The lessons I have learned, when you are pregnant, to save the child, give the child breast milk for 3 months and not all together (mix feeding), but I decided to bottle feed"* Khanyile
	3. Information about medication	*"I got some advice, if I didn't come, all these things I wouldn't have drank the pills, then the child would have been sick"* Terries
	4. Being HIV positive and handling Pregnancy	*"In the support group, I was happy to see that we are all pregnant. I asked myself, why all pregnant women? I learned that, that means we all have to learn how to handle our pregnancies while HIV positive"* Desiree
	5. Transmission of the virus	*"When I heard that someone has AIDS, I was feeling disgusted. But I learned how you get HIV, not by drinking water from the same glass. Support group gave me this information"* Khanyile
2. Impact on behaviour	1.Lifestyle	*"I grew a lot, even going out (having sex with other man) was not a limit, even while married, I was going out. I have changed my behaviour"* Khanyile
	2. Change of habits -condom use	*"I have changed my behaviour, we use a condom"* Desiree

	-food	*"The knowledge didn't end up at the support group, I got a lot of advice, and they told us to eat healthy food, greens and different things. I see it's important because I have energy when I eat well"* Terries.
	-alcohol use	*"I was even drinking alcohol, but now I left that. I am doing things that are good for my body. When I drew the blood, my CD4 count was four hundred and thirty something, now seven hundred and something"* Khanyile.
	3. Personal growth	*"It helped a lot to have these members, they taught us and helped us to grow"* Desiree
	4. Disclosure	*"...I can now say to someone, I have AIDS, you tell them a lot of things and I am proud to speak about it"* Khanyile
	5. Freedom	*"When I continued not to lock myself inside the house, I couldn't even go to the shops, now I am free, the support group has changed this condition, I felt I am not needed in the community"* Khanyile
3. Inter-personal relationships	1. "I am not alone"/ Sense of belonging	*"When I see another support group, I become happy because I see that I am not alone, I can identify"* Thoriso
	2. Other HIV positive women	*"It was good for me to be amongst other HIV positive women, and it made the stress to go out"* Vanessa
	3. Platform to share	*"What helped is being listened to, my problems realizing that my problems are not bigger than theirs"* Khanyile
	4. Care/Comfort	*"We receive love and that helped us love other. That helped because it felt like all were family members. We were able to love, feel free and share the feelings"*
	5.Role-modelling	*"I liked the fact that the other facilitator was there (She has been living the virus for longer), she kept us going because she's been there. She is in the same situation, her child is healthy"* Thoriso
4. Future perspective	1. Sense of hope	*"When you are HIV positive it doesn't mean it is the*

	-Future plans	*end of the world" Desiree.* *"I started doing a lot of things that I had lost hope in doing" Khanyile"*
	-Life goals	*"Now I am thinking great things, I know that even next year I will still be here. I want to see them(my children) completing school, guiding her and teaching her how to be hygienic as a girl" Khanyile*
5. Effects on emotional outlook	1. Effect on mood	*"I felt that I was relaxed. It made me feel alright" Terries*
	2. Confidence	*"I even spent a month locking myself. Now I am free, I can even tell the ones that I think are having my condition about what we get in the support group" Khanhile*
	3. Sense of control	*"I am going to control HIV. It's been a while, I am not sick, it could be that I have been infected for 5 years, but if you take care of yourself, then you will live" Thoriso*
	4. Coping mechanisms	*"I encourage myself by not thinking a lot, I will sometimes do laundry or clean to get my mind off, or watch TV" Terries*
6. Empowerment		*"Now I am strong, when someone comes with the problem, I can help them where I see I am strong" Vanessa*
7. Termination of support group termination and need of ongoing support		*"Even now when I am getting this call, I thought it means another support group is starting; it will be good to have a support. I miss meeting with people and sharing with others about my life" Khanyile*
8. Feelings of isolation when outside the support group		*" When you get to where you live, you have no one to talk to, it feels like you are in jail, but at least here we talk" Desiree*
9. Facilitator's role		*"I felt to be free with them; even the facilitators were one with us. That made me feel that I was not lost" Desiree*
-Translation		*"The things that we were talking about, I could understand. When things were in English, I was helped by the translation..." Terries*

-Guidance		*"What was important was that everything had leadership guidance, we were taken care of"* Khanyile.
-Creating a warm atmosphere		*"The facilitators helped us feel very welcomed"* Desiree
-Empathy		*"I saw it as a nice thing to have facilitators, but the facilitators are also not the same. We were free. It is because of your being free, the way you introduced yourselves, I felt like understanding you. I think your humanness, you were very patient"* Vanessa.
10. 4. Need to educate and help others outside the support group		*"I share the information with others"* Vanessa

The discussion of each theme follows:

4.2.1 Importance of support group in facilitating learning

This theme was the most prominent throughout all the five interviews. The participants reported that they benefited from attending the support group because they learned more about HIV and AIDS coupled with pregnancy. A number of sub-themes that emerged under this theme are provided below.

Sub-theme - Lessons

Most women found the HIV information that was communicated invaluable in their lives as they continue with the journey of being HIV positive. Information shared during the group sessions helped women to accept their HIV status, to protect others and live a healthy lifestyle.

This is illustrated in the following quotes:" *I understand the different stages, so I have accepted because I know if you're positive, you are positive, this won't change" Terries*

"It is expensive (the effort, time and skills of experts that we do not have to pay for – we get the lessons for) for us to get knowledge, so when getting something like this, you have to grab it" Thoriso

"Firstly when you are hurt, you must not touch the blood, like with my baby. I must always have bandages and gloves so that the child must be safe. That I found knowledge..."Desiree

"I learned about the CD4 count, how it works, things like the viral load, so by coming to the support group, I learned what I should do" Vanessa

Sub-theme-Information on infant feeding

Owing to the fact that all the women in the support group were pregnant, they shared a number of concerns regarding the feeding of their babies considering the fact that they are HIV positive.

"I also learned about breast feeding and bottle feeding. When you get a child, you either give the child breast milk or bottle milk" Desiree.

"The lessons I have learned, when you are pregnant, to save the

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child, give the child breast milk for 3 months and not all together (mix feeding), but I decided to bottle feed" Khanyile.

"Then at Serithi they told me you choose if you want to breast feed or bottle feed. Then I chose to bottle feed" Terries

Sub-theme-Information about medication

The women in the support group expressed concerns about transmitting the virus to their unborn babies to the point where some gave serious thought to terminating the pregnancy. Learning how the baby can be protected gave the participant a sense of relief.

"When you get to deliver without the pill, the child has a chance to be infected, and when the child is born, 2 hours before, you have to give the child drops. It was important because of my pregnancy, especially being a girl and I don't have a daughter" Khanyile.

"What I remember from the support group, the pill Nevarapin, understanding when you are on ARV s, you already have the Nevarapin. But I have learned from the support group that I have to drink the pill. When they give you the pill, to tell them at the clinic that I am on treatment" Desiree.

"I got some advice, if I didn't come, all these things I wouldn't have drank the pills, then the child would have been sick" Terries.

"I thought HIV comes in if you are positive then the child automatically

becomes positive, but now because of the pill, the child can have a

possibility of being negative" Vanessa.

Sub-theme - Being HIV positive and handling pregnancy

The women learned how to handle being HIV positive and pregnant in one of the

lessons during the support group:

"...and the different lessons about when someone is pregnant, how to

handle that. And also how to behave, not to be afraid of others and to

regret living" Desiree.

"The important thing was that I got to know that when I am pregnant,

what I should do" Terries.

"In the support group, I was happy to see that we are all pregnant. I

asked myself, why all pregnant women? I learned that, that means we

all have to learn how to handle our pregnancies while HIV positive"

Desiree.

Sub-theme - Transmission of the virus

Some participants learned about HIV and the transmission of HIV for the first time

when attending the support group.

"It helped because I thought the people were disgusted at her (the

person who is HIV because they avoided the utensils that an HIV

infected person used). But now I know it is transferred through blood.

Now we can live with other people, then when one drinks from the

same cup as me, it will not be transferred to another person" Terries.

"When I heard that someone has AIDS, I was feeling disgusted. But I

learned how you get HIV, not by drinking water from the same glass.

Support group gave me this information" Khanyile.

4.2.2 Impact on behaviour

The majority of women reported some behavioural changes since attending the

support groups. These included lifestyle changes, eating habits, condom use, and change

in perception about their HIV status.

Sub-theme - Lifestyle

The women reported changing their lifestyle to help with lowering their stress levels,

decrease their chances of re-infection and take better care of themselves in order to live

healthy and productive lives.

"I have changed, my life is good. The things I was waiting for was to

have sores and look somehow, but if I take care of myself, I will be

fine" Khanyile.

"Some of the things I can remember are to exercise or to keep myself

busy. When I start thinking a lot, I just do my laundry and my mind is

off the problem. What I thought of is the drawing that we did, or the

relaxation exercises that we did. I felt that I was relaxed. It made me

feel alright" Terries.

"I grew a lot, even going out (having sex with other man) was not a limit, even while married, and I was going out. I have changed my behaviour" Khanyile.

Sub-theme - Change of habits

Condom use

The women gained understanding with regards to the importance of using a condom despite being HIV positive during the support groups. The use of a condom was reported as a habit the women adopted in order to protect themselves from re-infection and to protect their partner.

"When I started, it was not the same. When the support group started, I had an idea of how to behave. I didn't understand when they say when you are a woman and HIV positive, you must use a condom. I didn't understand why I should use a condom, what does it help to do that, but as time went on, I understand why it is important to use a condom" Desiree.

Food

One of the lessons during the support group touched on healthy eating habits. After realising the importance that food plays in their well-being, the women reported eating healthier compared to before attending the support group.

"I was telling myself a lot of things. But the support group helped me to live a good life, even my children are learning from me to eat healthy food" Khanyile.

"Before coming to a support group, I ate just about everything. I didn't think that I have to eat something to boost my body. Now I know that I have to keep stock of vegetables, fruits, things like beans. I was always asking myself, how can I eat beans? Eggs boost your body..." Desiree.

"The knowledge didn't end up at the support group, I got a lot of advice, and they told us to eat healthy food, greens and different things. I see it's important because I have energy when I eat well" Terries.

Alcohol

Some women reported abusing alcohol before attending the support group. After obtaining a lesson on the dangers alcohol posed to their health and well-being, they reported leaving alcohol alone.

"I was even drinking alcohol, but now I left that. I am doing things that are good for my body. When I drew the blood, my CD4 count was four hundred and thirty something, now seven hundred and something" Khanyile.

Sub-theme - Personal growth

Most women reported experiencing life differently after being part of the support group. They expressed that some personal growth took place owing to attending the support group.

"It helped a lot to have these members (to have each other and the facilitators in the support group), they taught us and helped us to grow" Desiree.

"I have grown; I see that I am better. I feel more up; I know that I am better than others. I feel I know more, although they were older, it encouraged me to be involved and motivated" Thoriso.

Sub-theme - Disclosure

As the support group progressed, the women reported gaining confidence in disclosing their status to others. The role plays which were carried out helped in facilitating this.

"I also did not tell others, but from the support group, I got the courage to disclose. Now I am strong" Vanessa.

"Disclosing...I was scared, especially to tell my partner's family. I started telling my family and they were the same. The partner's family, I only told the aunties, but as time goes on, I will be able to tell them" Desiree.

Sub-theme- Freedom

Owing to the stigma surrounding HIV, some women isolate themselves from the society, fearing discrimination. The women in the support group reported that they do not avoid society anymore as they realise that they too belong with others.

"When I continue not to lock myself inside the house, I couldn't even

go to the shops. Now I am free, the support group has changed this

condition, I felt I am not needed in the community" Khanyile.

"When you get to where you live, you have no one to talk to, it feels

like you are in jail, but at least here we talk" Desiree.

4.2.3 Inter-personal relationships

All the women felt that being amongst HIV positive pregnant women gave them a sense of belonging. They expressed the view that realising that they are not alone was comforting to them. In a way it normalised their experience of living with the virus in pregnancy. They felt they could express themselves openly as they did not feel judged. They shared the same problems and could identify with one another.

Sub-theme - "I am not alone"/Sense of belonging

Being with other HIV positive women gave the participants a sense that they are not alone. This seemed to bring a sense of relief and comfort as participants realise that they too belong.

"I felt that I am not alone. I was asking myself, why me, but when I

met other people older than me, I thought I was not alone" Khanyile.

"I found that when we used the game of networking, I felt that I am

not alone. I thought things were over, but I realized that I am not the

only one" Thoriso.

"In the support group we are all the same. It showed me love and that

we are important in the community" Khanyile.

"I felt that I am not alone, when you are sitting alone, you think you

are the only one. When you see others in the same condition, the

stress goes down because of other people's advices" Terries.

"In the support group, I was happy to see that we are all pregnant..."
Desiree.

Sub-theme - Platform to share

The support group was important in providing participants with a platform to share. In sharing, some felt relieved of their burden of the disease, while for some, their problems seemed not as overwhelming as they had perceived them before joining the support group. The confidence to speak to others was also made possible by creating an atmosphere that is non-judgemental and confidential.

"When you get to where you live, you have no one to talk to, it feels

like you are in jail, but at least here we talk" Desiree.

"What helped is being listened to, and someone listening to my

problems and realizing that my problems are not bigger than theirs

(other women in the support group)" Khanyile.

"Confidentiality, to know that if we talk, it will be kept in the group and

not go outside the group" Vanessa

Sub-theme - Care/Comfort

Feeling cared for seemed to play an important role in the way the participants felt about themselves. It also gave them a sense of comfort knowing that they are accepted by others.

"It is like a child sucking her mother's breast; it felt like I am with my mother. When I was sad, I was fine after the support group" Khanyile.

"We receive love and that helped us love others. That helped because it felt like all were family members. We were able to love, feel free and share the feelings...I thought I found brothers and sisters to talk to" Desiree.

"...she kept me going. When greeting me, she showed the vibrancy and the love. Meeting someone like her and maybe I will meet someone like her. Even as a total stranger, being loved and having someone that cares about you" Thoriso.

Sub-theme - Role-modelling

For most women, it was important to see other HIV positive women living positively with the disease as it gave them the sense that it is possible to be HIV positive and live a healthy life.

"Also I saw that they were also pregnant, I thought I will learn a lot from them. What I learned from the women that I was with, I have

learned that they are strong. What they came here for, they were

ready to fight for it. I felt to be free with them" Desiree.

"I liked the fact that the other facilitator was there (She has been living

the virus for longer), she kept us going because she's been there.

She is in the same situation, her child is healthy" Thoriso.

"So in a support group, I learned to express my feelings in front of

other women. I was not aware of the status that I have, others also

have. Now my problem didn't become heavy" Vanessa.

4.2.4 Future perspective

For most of the participants, the HIV diagnosis resulted in feeling that life has ended
and that of their children. The women reported that being part of the support groups
instilled a sense of hope for the future and a new outlook. As reported earlier, some women
thought of committing suicide and/or terminating the pregnancy; however, since their
participation in the support groups, they have a new outlook on life plans as individuals and
for their families.

Sub-theme - Sense of hope

Knowing that there are possibilities for life to be productive and to live healthily as
well as giving birth to HIV negative babies instilled a sense of hope in the participants.

"I used to be very stressed out thinking that I am going to die, thinking

a lot of things. Now when I get sick, I get to the clinic and get some

medication" Vanessa.

"I must be healthy because I have to live for my child. To love someone makes a difference. You don't give up easily, because you don't want to disappoint a person" Thoriso.

"When you are HIV positive it doesn't mean it is the end of the world" Desiree.

Future plans

In one of the sessions, the women started to make future plans that they had lost hope in doing as they though they will be dying soon.

"I started doing a lot of things that I had lost hope in doing" Khanyile"

Life goals

Most of the women expressed the fact that their goal in life is to see their children through school and growing up.

"What motivated me a lot were my children. Thinking about leaving them behind, I decided; let me do this so that I can live, and so that I can see my children finishing school" Khanyile.

"So I thought let me also be strong and I ended up being strong for my children" Vanessa.

"Our children and our families need us. I have the strength to stand

up for my family because of being in the support group" Khanyile.

4.2.5 Effects on emotional outlook

In understanding what they are going through, the participants reported having adopted various strategies that were taught during the support groups, in helping them deal with life stresses, their negative emotions and life in general.

Sub-theme - Effects on mood

Most participants reported a change in and better management of their emotions and mood upon attending the support group.

"I was happy and I had strength...it helped because my mood

changed" Khanyile

"I see that I am better. I feel more up" Thoriso.

"... I was in those stages and ended up in acceptance. The anger is

not there, the fighting, I have changed a lot" Vanessa.

"It was good for me to be amongst other HIV positive women, and it

made the stress to go out" Vanessa.

"When you see others in the same condition, the stress goes down

because of other people's advices" Terries.

Sub-theme - Confidence

Some of the participants reported that being in the support group gave them confidence to share with others and to be strong in who they are.

"I even spent a month locking myself. Now I am free, I can even tell the ones that I think are having my condition about what we get in the support group" Khanhile.

"I have realized being with other HIV positive people; it is good because you can see that you are accepted. When we all stand together" Desiree.

Sub-theme - Sense of control

The information gained from participating in the support group gave participants a sense of control over the disease where they feel as if the disease is not there to control them, but that they will do what is possible to cope positively with being HIV-infected.

"I am going to control HIV. It's been a while, I am not sick, it could be that I have been infected for 5 years, but if you take care of yourself, then you will live" Thoriso.

Sub-theme - Coping mechanisms

The women adopted various coping strategies, Some used distraction as a mechanism, some relaxation, some focused on the solution instead of the problem, some

on sharing with others and others on avoidance.

"When I start thinking a lot, I just do my laundry and my mind is off the problem. What I thought of is the drawing that we did, or the relaxation exercises that we did. " Terries.

"Now when I get sick, I get to the clinic and get some medication. I do not cry that easily. When the anger was coming, I will just cry now and then" Vanessa.

"I encourage myself by not thinking a lot, I will sometimes do laundry or clean to get my mind off, or watch TV" Terries.

"I learned to express my feelings in front of other women" Vanessa.

4.2.6 Empowerment

The women felt that in gaining knowledge and being part of the support group gave them "power". They reported being able to stand up for themselves and take the initiative compared to before they attended the support group. They expressed the fact that they do not shy away from talking about their status and they are able to confront health care workers with confidence because they know their rights.

"When they give you the pill, for a person to tell them at the clinic that I am on treatment, I can now tell the nurse that I am on treatment" Desiree.

"Since joining the support group, I gained a lot of power. I started doing a lot of things that I had lost hope in doing then. I thought I won't get there because I am sick, it is all the same, I am dying soon. But now I got the courage" Khanyile.

"...but since I started to be in the support group, I don' feel like that. I don't feel like HIV can take me down, even if you feel like there is no help, when you go to a support group 2-3 days, you'll feel that there's help" Khanyile.

"Now I am strong, when someone comes with the problem, I can help them where I see I am strong" Vanessa.

"When I came to the support group, my family didn't know, even my boyfriend didn't know. Even myself, I was like that, but I got the courage to talk. It felt good because it was in my heart, but I got the courage to talk" Vanessa.

4.2.7 Termination of support group and need of ongoing support

It seems that the participants needed the support group to go on continuously. The participants expressed a need for ongoing support to help them deal with other challenges they might face in the future in living with HIV. For most of them, this became the most important social support they had accessed without feeling judged, condemned and stigmatised. Being able to relate to others in the support group brought them closer to

each other, and as time went by, they started to get used to the process which became part of them. The end of the support group brought sad feelings for most participants.

"Sometimes I was staying alone the whole day, I got heart broken, I always wished it could run from Monday to Friday. Once a week, when you are alone, wish that it can be the whole week in the mornings" Desiree.

"It was painful when Wednesdays come, I will be thinking, this is what we would have been doing, helping each other with one, two, three. I felt down a lot" Kanyile.

"When they told us it is the last session, I was hurt for two weeks, but went on to be normal" Khanyile.

"I was disappointed to hear that there won't be any more support groups" Vanessa.

"I wish we can have another support group to learn a lot about how we can protect them (the children) even though they are negative, but we can help to protect them" Khanyile

4.2.8 Feelings of isolation when outside the support group

For most participants, being outside the support group made them feel like "outsiders", as if the only place where they can truly feel a sense of belonging is the

support group.

"The support that I get, when I was coming, I was lonely, but I learned…it helped because my mood changed as soon as I got to the support group" Khanyile.

"Meeting with other people, we take a long time not meeting other people" Vanessa.

4.2.9 Facilitator's role

The facilitators in the support group seem to have played an important role in coordinating, setting guidelines, teaching and creating an atmosphere where the women felt comfortable to share with each other.

Translation

Facilitators helped to translate concepts that were taught into the language that the women could understand, be it in their mother tongue or in layperson's terms.

"The things that we were talking about, I could understand. When things were in English, I was helped by the translation..." Terries.

Guidance

The participants reported receiving leadership and being guided through the process of the support group as valuable.

"Facilitators gave us guidance of what to talk about" Desiree.

"What was important was that everything had leadership guidance,

we were taken care of" Khanyile.

Creating a warm atmosphere

The facilitators assisted in creating a warm atmosphere where participants could feel welcomed and comfortable to share with one another.

"The facilitators helped us feel very welcomed" Desiree.

Empathy

The facilitators showed empathy towards the participants which also helped in being integrated into the group.

"I felt to be free with them; even the facilitators were one with us. That

made me feel that I was not lost" Desiree.

"I saw it as a nice thing to have facilitators, but the facilitators are also

not the same. We were free. It is because of your being free, the way

you introduced yourselves, I felt like understanding you. I think your

humanness, you were very patient" Vanessa.

4.2.10 Need to educate and help others outside the support group

The participants not only gave advice to each other in the support group. They also reported that the knowledge they gained, they shared with others who were not part of the support group. Some of them tried to counsel other women who are in a similar position and tell them about the support groups.

"There is a great difference. Sometimes I was able to get home and share about what we talked about and what I have learned. When I shared with my partner, he started to accept. Even when the support group was over, I was able to have courage and had more confidence" Desiree.

"A lot of people do not have knowledge and they are still hiding. At least, when there is a place and tell a person let's go to this place. I have already met people that I have told about Serithi, if she can get other people of her peers" Vanessa.

"I wish there can be a place where women that are HIV positive can meet. A lot of people die because of secrecy. Whom will I tell? They feel they are not anonymous, but if we can all meet about the same thing at least 3 times, get skills to get rid of the stress, they don't know what support group is, they don't know it. But if they can find it, they will enjoy" Vanessa.

"It helped me a lot, because outside, I could advise and teach others

what is a support group. I could explain to someone if you are

positive, you must be tested so that they can also get help. When you

are pregnant, when do you drink the pill, what time and which month

before the child comes" Vanessa.

4.3 Conclusion

In this chapter, background information was presented, followed by a summary of the context of the study. The main themes extrapolated from the analysis were presented, each with a description and verbatim account from the participants. In the next chapter the discussion of the results of experiences of women in a structured support group, integrated with findings from previous research presented in the literature review, will be discussed.

CHAPTER 5 DISCUSSIONS AND CONCLUSION

5.1   Introduction

In this chapter the results of the experiences of the said women, integrated with findings from previous research presented in the literature review, will be discussed. This will be followed by a consideration of the limitations and strengths of the study. Finally, recommendations for future studies will be advanced.

5.2   Main Findings of the Study

5.2.1   Positive outcomes

Knowledge

Similar to the findings by Mundell, et.al. (2005), participants benefited from attending the support group in terms of learning more about HIV and AIDS. Owing to their unique situations, all of the women who participated were pregnant, and found the information valuable in assisting them to manage their HIV status and to care for their babies. Some of the lessons they learned were that their HIV status will not change and that they have to accept living with the virus.

While information about HIV and AIDS is widely available in South Africa, some women appreciated receiving general information about the disease, the transmission thereof, its progression, how it might affect them and their new babies and how they would have to manage the disease. Most of their concerns with regards to feeding their babies were addressed. The feeling of being able to choose which method of feeding to use was

empowering for them. Some chose the type of feeding they would use in terms of their lifestyle, while some did so for economic reasons and others, in terms of what they perceived as being safe for the baby, given the advantages and the disadvantages involved in each method of feeding.

It was a great relief for women to learn that there was a possibility that their babies could be HIV negative. Most of their concerns were about passing the virus to the child. This led to feelings of guilt, despair, and depression. One woman felt that her child (if born HIV positive) would be a punishment for her sins. This also led to some of the women strongly contemplating suicide or/and terminating the pregnancy, as they felt that this was the end of the world for them and that it would be unfair to bring an HIV positive child into the world. Most of them felt that if they had not been part of the support group, they would not have known about the treatment one can take before giving birth. The information obtained gave them power to exercise ownership over the health care they received when giving birth. They were also able to advise the medical staff about the medical attention that was appropriate for their situation.

Being HIV positive and pregnant poses a unique challenge. All the women who participated in the support group learned about their HIV diagnosis during their routine ante-natal clinic visits. Pregnancy, even without any complications, is a major lifestyle adjustment (AIDS Education and Training Centers: National Resource Center, 2007). Being informed, at such a time, that one is infected with HIV, is an added burden. In the support group they learned how to cope with both their HIV status and pregnancy. Some reported changing their attitude, regretting the event of being pregnant as most of the pregnancies were unplanned, to that of embracing the moment.

The results of this study seem to suggest that learning about the different aspects of being HIV positive and pregnant was empowering for the women. Most reported gaining power and re-claiming their lives, while some expressed more determination to continue with life and not to let their feelings weigh them down. Whenever they attended the support group, their outlook on life was different. They experienced more courage and hope and felt that they could face life. Empowerment is a process where an individual, who is given an opportunity to learn as well as the necessary support needed to take responsibility for her life, moves towards mobilization of resources and independence (Ribble, 1989).

Change in behaviour

The women in this study reported changes in some of their behaviour as a result of participation in the groups. One was that of lifestyle. The women came to understand that if they take good care of themselves there is a possibility of living a productive life. They adopted healthy eating habits, limited the drinking of alcohol and adopted methods of relaxation to help maintain an acceptable state of health.

After realising the risks of multiple sexual partners, one woman reported having limited the number of her sexual partners. Before the women attended the support group, they thought using a condom and not using one was all the same, as they had already been infected with the HIV virus. Most of them began to understand the risks of re-infection and realised the importance of using a condom regularly. Those who have been using condoms continue to do so in order to protect their partners, while those who were not regular in their use of condoms began to use them in all their sexual encounters. However, for one woman who has been using condoms as her primary method of contraception, condom use seemed to be a habit. She reported that she did not feel the need to disclose her status to her partner.

One of the behavioural changes that the women adopted is that of healthy eating. A session during the support group was dedicated to teaching the women about health and a balanced diet. Upon gaining knowledge about how eating affects their energy levels, boosts their immune system and enhances their general health, the women started to make choices about the food they eat, to the point of influencing their children to eat healthily as well.

Personal growth

Since attending the support group, the women felt that they have developed personally. The personal growth contributed to the courage they have in conquering the disease instead of the defeat they felt prior to attending the support group. They remained motivated to live for their children and felt more positive. They were proud to talk to others about the disease and the help they could receive upon attending a support group.

Disclosure

The interaction in the support group assisted women to disclose their status. This finding is similar to that of Kalichman, Sikkema, and Somlai (1996). The women in the support group gained courage to disclose their HIV status to others outside the support group. This may be because they observed that other women receive support from others, and not rejection, as a result of disclosing their status (Visser, et al., 2008). Disclosure is important for seeking support from others as the burden of living with the disease is shared with them (Huber, 1996). In addition, one does not feel isolated and lonely, which led to the despair and hopelessness some participants experienced. The participants also shared that they did not feel the shame they used to feel about being HIV positive, which made it easier for them to talk to others about their positive diagnosis. The role-plays that were performed in one of the sessions gave the women the platform to rehearse ways of

disclosing their status as well as to deal with possible reactions from the people to whom they wanted to disclose.

Hope

For most of the participants, the HIV diagnosis felt like a death sentence. As reported earlier, some women thought of committing suicide and/or terminating the pregnancy. However, since taking part in the support groups, they have evidenced a new outlook on life and new vision for their individual lives and the lives of their families. The women reported that the groups instilled a sense of hope for the future. They started making plans for the future, looking forward to raising their children and seeing them through school. Gaining knowledge about HIV, its progression and management contributes towards positive living. The study confirms this as the participants began to realise there is life after an HIV diagnosis. Death does not become an immediate concern compared to the situation prior to attending the support group. Now the women have learned to deal with the disease in a positive manner. These findings concur with a study by Mdlalose (2000), in that women who are involved in interventions aimed at helping HIV positive individuals cope with the disease, arriving in the stage beyond mere acceptance of HIV; instead, hope is instilled as time passes.

Emotional well-being

The participants reported that they began to understand their experiences. This helped them to adopt various coping strategies in dealing with life stresses and their negative emotions related to the diagnosis. This study confirms past research (Mundell, 2006) that being involved in a support group is indirectly related to emotional well-being. Having someone to share experiences with and being listened to contributed to changes in participants' moods. Most reported coming to the support group sad, but leaving the group

feeling happy and "light". Some felt their stress dissolved, while their problems were not as overwhelming as originally perceived owing to the opportunity to relax, receive advice and share openly with other women who are HIV positive.

Coping

Participants in this study reported having adopted various coping strategies to help them deal positively with their condition. 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 a chronic illness such as HIV. Consistent with coping literature which suggests that coping styles within the context of stressful life events are related to an individual's adjustment to their stressful experience, most women mentioned that whenever they felt stressed, they would do something to distract them from the source of stress (Larazus & Folkman, 1984). As discussed earlier, most of the women made lifestyle changes such as healthy eating and stress management. They learned to manage their disease through seeking medical attention and taking the prescribed medication.

Positive thinking was found to be amongst some of the coping mechanisms the women adopted. The participants described how they had battled to come to terms with the HIV diagnosis; however, in the course of the support group, most women accepted the fact that they are HIV-positive and have to find ways to live with the disease. Some demonstrated how they began to think positively about their lives and themselves as discussed above. Expressing one's feelings in front of others is an active effort to cope with stress. For most women, since they trusted the process they shared openly with others.

Educating and counselling others outside the group

While it seemed "doom and gloom" when the support groups ended, most women

took initiatives outside the support group to counsel, educate, and share the information obtained during the time they participated in the groups with others. They encouraged others to test for HIV, to join support groups and seek counselling. One participant described how she led her husband to accept his status by sharing with him what was taught in the support group. Another woman mentioned how she encouraged someone to test so that if she were found to be positive, she could protect her baby. Most of the women felt equipped to counsel and help others. To be able to share this information with others, some had to disclose their HIV status. They reported that because of the courage they gained during the support groups, they were not afraid to tell people about their own HIV status when sharing the information with them. These findings support the notions that individuals who participate in support groups can help each other to come to terms with their diagnosis, which reinforces their courage to tell others about the disease (Lindegger & Wood, 1995).

The women wished there had been more support groups to which they could refer people for help. This is owing to the fact that they expressed that being involved in the support group was a great deal of help in their journey with the HIV virus.

5.2.2 Contributors to positive experience in the group

Interaction between members

Being amongst HIV positive pregnant women gave participants a sense of belonging. The feeling of not being alone was comforting to them. In a way it normalised their experience of living with the virus and going through with the pregnancy. This corresponds with findings from Groomes's (1998) research which established that individuals living with HIV cope better with the disease when they develop relationships

with other people in the same position. They felt they could express themselves openly as they did not feel judged and that the people with whom they were sharing could identify with them.

Feeling isolated often leads to the sense that one is an outsider or lost. In the support group, the women were grateful for the fact that they were not the only ones suffering from this disease. Often, when one does not know that other people are struggling with the same problem as oneself, the problem seems overwhelming. Upon meeting a group of women who were in a similar situation, these women felt a sense of great relief. They realized that even though a person cannot be identified as HIV positive by their appearance, others too might be struggling with the same issues. One participant appreciated the fact that one of the facilitators was someone who has been living with her HIV status for a while. This particular facilitator became a role-model for positive living and a testimony to the possibility of delivering and raising an HIV negative child.

Being able to share with others is a fundamental element for women. It came as no surprise that, when some of the women felt that they could not come together with other people, this felt like being in jail. Instead, sharing brought a sense of freedom and release. Sharing with others was also made easy by the fact that everyone came for the same purpose. At first, most women felt uncomfortable sharing their deepest feelings with people with whom they were not familiar. After a while participants started disclosing personal information in the groups, because they felt the support group was a safe place to share their stories in a confidential, non-judgemental environment where openness was created. Listening to others also made them realise that there were other individuals who were experiencing more problems than they were. The women also reported having benefited from providing others with advice.

The knowledge that one belongs and that someone cares is often perceived as comforting for the participants. Some even expressed feelings of sadness upon the termination of the support group. Members cared for one another, which brought them closer. One woman stated that the group she was in felt like a family where she could openly express her feelings and thoughts. Yalom (1995) defines group cohesion as a condition of members feeling warmth, comfort, belonging, being valued and accepting and supporting other members in the group. The above describes how participations in the support group seemed to draw closer to each other as an indication of group cohesion during their participation in the support group. Coming to the support group was viewed as a special occasion where the participants felt that their mood would be altered for the better. The concern, humility and impartiality in the facilitators also contributed to the feelings of being cared for. Participating in the support group gave the women a sense that they too are welcome in the community.

Facilitation

Facilitators are perceived as a very important part of the support group because they provided guidance and leadership. They also created an atmosphere where the women could feel welcome, supported and free to express themselves. This is owing to the boundaries the facilitators created with the participants with respect to time, confidentiality and not being judgemental of others. While maintaining the role of facilitating the sessions, the women reported that the facilitators' humility and care made them feel like the latter too were part of the group. Facilitators were role models of healthy living. Although the facilitator is not in a position to understand the group members' internal world, he/she makes an effort to forge a close and trusting relationship with participants. Corresponding

with the findings of Yalom (1995), the trust in the relationship between participants and the facilitators in the support group seems to have played an important role in the group process during the support groups. Throughout, participants experienced the facilitators as warm, empathetic, understanding and accepting towards them.

5.2.3 Negative experiences

Terminating the support group

The bond that was created during the support groups was so strong that it became hard for most to part ways. Most women wished the support groups could run the whole week as they felt lonely on the days they were not involved in the support group. The participants felt as if they had lost something when the groups ended. During the interviews, feelings of disappointment, hurt, sadness and loneliness were expressed as a result of the termination of the support group.

Most women expressed the feelings of being an outsider and of isolation when they were not in the group. From what the women mentioned, it also seems that making friends and meeting with other people takes time. The place where they felt they truly belonged was the support group where they could meet and talk to other HIV positive women. This could be the result of the fear of being judged and discriminated against by people who do not have the same condition as they do. Consequently it is easier to form bonds with people who understand them and what they are going through.

Dependency

It seems that the group members became dependent on the social support provided

in the support group. This can be overcome by assisting the women in the groups to develop skills to make friends and strengthen relationships outside the group. Accepting one's status can contribute to leading a "normal" life outside the support group.

Ongoing support

Owing to the need for social support, most women suggested that ongoing support groups be run. One of the participants described how, when she received an invitation to take part in this study, she thought another support group would commence. Some of the ongoing issues the women want to discuss are related to protecting their children from being infected with HIV. Most suggested that, even though the support group could adopt an informal structure a facilitator should be present to facilitate the process. It seems that the suggested support group could be an open one, where people can come in at different stages and stay involved as they need to. This will be a way of meeting people with the same condition to share, as well as to support each other outside the groups when the members are known to each other.

5.3 Summary

Most women were empowered during the process of attending the structured support groups. Referring to literature on social, cultural and gender norms in chapter two, it seems that the women who went through the process of the structured support groups in this study were able to overcome these norms as they were able to negotiate safer sex by using condoms in their sexual relationships. In addition, most of the group members have accepted their HIV status and seem to be coping positively with the disease. This is evident in the active role they took in attending the support group, the lifestyle changes they made, the levels of disclosure, their future outlook and the general emotional adjustment.

While efforts were made to furnish sufficient information regarding the duration and structure of the support group, it seems that the preparation for termination might have been inadequate. This is reflected by the need of the women for a continuous support group and the disappointment they felt upon termination of the support group. This could also be indicative of the dire need for social support by HIV positive women and/or the anxiety due to the fact that the women in the group are ill-equipped to deal with relationships outside the support group.

5.4   Strengths of the Study

The use of the language the women were comfortable with, while conducting the interviews, allowed for freedom of expression and less concern in questioning whether they sounded correct, expressing themselves in English or another language they do not use daily.

The interviews were conducted by the researcher, which gave access to the immediate emotional experience of the participants. Due to the fact that the research is qualitative, the researcher paid attention to considering the body language and emotional state of the participants in order to guide the interview.

A quantitative and qualitative study was conducted by Mundell (2006) to evaluate the impact of a structured group. This study provided a much needed in-depth example of qualitative enquiry being used to gain knowledge of the experiences of the participants in the structured support group, as a tool to evaluate this intervention.

5.5 Limitations of the Study

The researcher's subjective position in the research could have influenced the results obtained. The researcher was part of the support groups as a facilitator, conducted the interviews and was actively involved in the interpretation of the data. The fact that the participants knew the interviewer contributed to the level of empathy in the interviews. The limitation of the involvement of the researcher means that the process depends on the researcher's subjectivity, especially when it comes to transforming themes which are participants' natural expressions of attitudes into an abstract level which evokes psychological terminology (Lyons & Coyle, 2007). This is inherently part of qualitative research and was addressed by various methods to enhance the quality of the data.

Another major implication for the reliability of the data collected is that, through facilitating previous support groups the researcher's established relationships with participants prior to the interview could have inhibited the women from making negative remarks about their experiences in the support groups. This could have hindered their being honest. During the interviews, the participants may not have wanted to disappoint the researcher or attract her disapproval; thus they might have said what they thought she wanted to hear.

The participants in the study represented a selected group of women. They were all black women from disadvantaged backgrounds, living in an urban area. All of them were unemployed with only one source of income, or no income, for the household. This placed them in the low to middle-income class. Therefore, these results cannot be generalized to all South African women of diverse cultures, backgrounds and socio-economic status.

5.6 Conclusion and Recommendations

The study attempted to provide a view of the experiences that HIV-positive pregnant women, who attended structured support groups, underwent. It also afforded an indication of what happened to them in that time and how their participation impacted on their lives. The researcher used a qualitative research method to enter into the worlds of the participants while they shared their experiences through their own descriptions. This provided the researcher with necessary information for the study, while offering the women an opportunity to share their experiences.

The findings were integrated with previous research where the findings of this study concurred with most of the available literature. The findings support the use of a support group for people living with HIV and also speak to the unique needs and challenges of HIV-positive pregnant women as most women only discover their HIV status during their routine ante-natal clinic visits. This means more women in the clinics should be targeted at the stage where they receive the positive diagnosis in order to obtain help in dealing with the disease and its implications for pregnancy and their unborn babies.

In this study, most of the pregnancies were unplanned and all the women were unemployed. This point to a need to further enhance interventions pertaining to family planning, use of contraception, teachings on condom use and the risk of unprotected sex. The issue of unemployment is closely related to the levels of education the women had obtained. Most of them possess a high school certificate while some have received education up to the primary school level. This could be a reflection of the number of women who are empowered to be independent in our society. As long as women are dependent on

men for social and economic support, they will not feel totally empowered to negotiate sexual matters in their relationships. This contributes to the great effort it will take to come out of abusive relationships as well as relationships that are not working.

This study revealed that the women who participated in the groups were empowered, learned new information, shared their experiences and received support from other women 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 implication is that future interventions should aim at targeting more women as not all women who were invited to join the groups, volunteered to become part of the support groups.

While the emotional empowerment process seems to have taken place during participation in the structured support groups, the women in this study have less than or a matric certificate as the highest educational qualification and they are all dependent on their partner and/or family members for material support. As highlighted in the literature section in chapter two, violence, poverty and lack of independence are amongst some of the uppermost elements that drive the spread of HIV in South Africa. It is thus, important to empower women in all spheres of life in order to curb the spread of the disease.

Owing to the fact that the termination of a support group and the need for ongoing support seemed to dominate when it comes to negative experiences, the structured support group manual needs to be revisited to see how to best prepare the women participating in such a group for its cessation. 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 similar interventions in the future.

Overall, the support group seems to have contributed to a positive experience for women who participated. Together with the few adjustments highlighted above, it is suggested that the implementation of structured support groups be rolled out to other contexts similar to the one this study was conducted in.

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University of Pretoria

Pretoria 0002 Tel (012) 4204111

2011/06/27   Faculty of Arts

Agreement to participate in research

Study title

Experiences of HIV positive pregnant women in a structured support group

Introduction

You are invited to take part in a feedback session of your experiences during your participation in the structured support groups which were held as part of the Serithi project. Before you take part in this study, you should fully understand what is involved. If you have any questions, please do not hesitate to ask any of the facilitators of these feedback sessions or the project staff. You should not agree unless you are completely happy about your participation and all the procedures involved.

Purpose of the research

You have been chosen to participate in the study because of your previous participation in one of the support groups that were conducted during this year. The research aims at finding out how you experienced the structured support group sessions.

Description of what is expected in this study.

If you agree to participate, you will be involved in one-on-one interviews. These sessions will be tape recorded with your permission only for research purposes.

What are my rights as a participant?

Your participation on these interviews is voluntary and you can refuse to participate or stop at any time without giving any reason. If you decide not to participate or withdraw from the study this will not affect the care you receive or the relationship with doctors and nurses who provide care for you and your (unborn) baby.

Risk regarding confidentiality

All information obtained during the course of the study is strictly confidential. No information will be communicated to anyone outside the research context. Any scientific reports using data from this study will not include any information that identifies you as a subject in this study.

Benefits

This study will benefit you personally by enabling you to reflect and summarise what you have experienced while you participated in the support group.

If you need any further information about the project you can contact:

Dr Annelize de Villiers at the Serithi project

Prof Maretha Visser, Department of Psychology, University of Pretoria

Nkateko Ndala, 082 5616 324

Informed consent

I_____ hereby confirm that I have been informed by the researcher about the nature, conduct, risk and benefits of the study. I have read (or someone has read to me) the above information regarding the study. I am aware that personal details such as my identity will be anonymous in the process as well as in the reporting. I may at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient opportunity to ask

questions and (of my own free will) declare myself prepared to participate in the study.
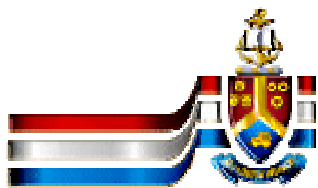
Signed this day of _____   2006/7 in Pretoria

Signature_____   Signature of witness _____

Date _____

University of Pretoria

Enquiry: Ms Annelize de Villiers	Kalafong Hospital
email:	Clinical Building
annelize@kalafong.up.ac.za/	MRC-unit for Maternal and
serithi1@kalafong.up.ac.za	Infant Health Care Strategies
	Serithi Project
or Jonathan Mundell	Private Bag X396, Pretoria,
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	Tel: +((27) 12 373-1077
	Fax: +(27) 12 373-1077

To Whom It May Concern

Re: Permission to use interview data and process notes

This letter serves to confirm that Nkateko Ndala has permission to make use of the Serithi Project interview data that has been collected from the HIV-positive women who participated in a structured support group program. Nkateko also has permission to conduct further interviews with the women from the project.   The Serithi Project will provide the women with financial incentive for their participation in Nkateko's research.

Please feel free to contact me if you have any questions regarding this matter.

Kind Regards,

Jonathan Mundell

Serithi Project

Annexure 3

Interviewing Schedule:

Questions for Individual and focus groups

- What were your expectations before joining the group?

- What was your experience of being in the support groups?

- What was it like to meet other HIV positive women?

- How do you think you have grown/developed during the time that you have

  attended the support group

  - During the support group?
  - After the support group ended?

- How did your behaviour change since you started to attend the support group?

2) During the support group?

3) After the support group ended?

- How have your perceptions of HIV changed though the attendance of the

  support group?

- What do you remember from the support group?

- How did you feel when the support group sessions ended?

- How did the different aspects of the group processes help you?

  - o The interaction with other group members?

  - o The interaction amongst facilitators and group members?

  - o The interaction amongst facilitators?

o If you were to tell others about the support group, how will you describe it to them in trying to convince that particular person to attend the group?

o Can you tell me about aspects of the support group that you liked?

o Tell me about aspects of the support groups that you did not like?