

The Impact of  
Structured Support Groups for Pregnant Women  
Living with HIV

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## **Abstract**

In this study, the impact of a structured support group programme developed for HIV-positive women in South Africa is assessed. The programme has been developed to fit the needs of HIV-positive women in South Africa, using an action research approach. The study utilises a quasi-experimental design, with an intervention group and a control group taking part in both a pre- and post-intervention interview. The participant's experiences and the impact of the intervention were assessed using a multi-method approach. The program was assessed quantitatively in terms of its impact on the participants' levels of depression, self-esteem, coping, social support, disclosure, personal stigma, perceived community stigma, coping and knowledge. Qualitatively, participant feedback regarding their experience of the support groups was assessed to provide complementary data to augment the results from the quantitative analyses.

Participants were recruited for the study through the Serithi project, and these women were invited to take part in the support group programme. Over a period of one year, 156 women were recruited for the study, 72 of whom agreed to participate in the groups (intervention group), with the remaining 84 women declining the invitation, forming the control group. Ten support groups were implemented during this time-period. Following the implementation of the program, the results from the pre-intervention assessment were analysed and compared, so as to acknowledge any differences that may have existed between the groups prior to their involvement in the study. Post-intervention results were then analysed and compared, in order to statistically determine the impact of the structured support group programme. Participants' qualitative feedback regarding their participation in the intervention, and their perceived personal benefits from their involvement was analysed using content analysis.

Although some differences were identified between the two groups in the pre-intervention analysis, the control group did seem to be a valid comparison. Findings of the research indicate that the intervention group showed significantly higher positive coping, self-esteem, levels of positive support and HIV-related support, and disclosure compared to the control group. Interesting results were found regarding depression and knowledge levels, although these were not found to be significant. No differences were identified between the groups in terms of negative coping, negative support or the experience of stigma. It was concluded that support groups can be effective in assisting HIV-positive women in their journey toward psychosocial adjustment to their HIV infection. It is important, however, that interventions aimed at HIV-positive individuals in South Africa should be developed to fit the specific needs of the target group.

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## **Chapter 1 – Introduction**

### **1.1 HIV and AIDS: An Introduction to the Epidemic**

It was Friday, the 5<sup>th</sup> of June 1981, when the first case of what would later become known as acquired immunodeficiency syndrome, or AIDS, was reported by the Centre for Disease Control. Nearly three years later, in April 1984, the cause of AIDS, the human immunodeficiency virus, or HIV, was identified, and with this came a newer and fuller understanding of the epidemic (Morin, 1988). There is evidence that HIV infection has occurred in Africa for over 30 years, with antibodies specific to HIV having been identified in stored blood specimens dating back to the 1950s (Gallo, 1991). HIV went unnoticed, however, as it was overshadowed by numerous other illnesses affecting developing countries. Various theories attempt to explain the origin of the HI-virus, but the most widely held view is known as zoonosis, which proposes that HIV developed in humans in Central Africa from a non-human virus. Epidemiological data has provided support for this theory, and similar viruses have also been found in old-world apes living in Africa (Gallo & Montagnier, 1988). Despite the fact that HIV and AIDS has been a shocking reality for more than a quarter of a century, we still have much to learn and research continues to probe deeper into the various dimensions of the epidemic.

Sub-Saharan Africa is severely affected by the HIV and AIDS epidemic, with an estimated 70% of all HIV infections. Recent estimates show that of all the HIV-positive people in the world, estimated by the Joint United Nations Programme on HIV/AIDS (UNAIDS) to be around 42 million in 2002, six out of every ten HIV-positive men, five out of every ten HIV-positive women and nine out of every ten children live in sub-Saharan Africa. In South Africa it is estimated that there are between 5,7 and 6,2 million people infected with HIV (Department of Health, 2005; Dorrington, Bradshaw, & Budlender, 2002). The South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, undertaken in 2005, shows the reality and sheer enormity of the HIV and AIDS problem that this country faces. An estimated 13,3% of women and 8,2% of men in South Africa were infected with the HI-virus at the time of this survey. The survey also shows that prevalence is related to age, from 3,3% in children aged 2-14 years, to 16,2% in adults 15-49 years of age, and dropping again to 5,7% in people older than 50 years of age (The South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005).

In the same survey, the authors state that, in order to properly understand the epidemic, one must have an understanding of the many powerful social, political, structural and economic factors that largely determine the high prevalence and spread of the virus in South Africa. In



summary, the authors discuss six important determinants of the HIV and AIDS epidemics in South Africa. The first five of these determinants are:

- 1) *Labour migration*: The fact that migrants are away from their regular partners for long periods of time, increases the likelihood of infidelity, which increases the chances of exposure to HIV;
- 2) *Occupation*: HIV is not evenly distributed among all occupational groups. Commercial sex workers and long-distance truck-drivers, for example, have been identified as core groups in the spreading of HIV;
- 3) *Culture and religion*: Some cultural aspects inhibit infection rates, such as customs that discourage early sexual initiation and promote abstinence, while others exacerbate the disease, for example rights of passage to adulthood, such as encouraging boys to prove their manhood by losing their virginity after being circumcised. Religion obviously also plays an important positive role in the promotion of marriage and faithfulness between partners;
- 4) *Sexually transmitted infections*: Due to the fact that individuals with STIs have an increased risk of acquiring and transmitting HIV, and the burden of STI disease in South Africa is high, STIs have a large impact on the spread of the disease;
- 5) *Alcohol and drug use*: Both have been shown to be important factors contributing to the risk of HIV infection. One large concern related to this, is the steady increase in injection drug use in South Africa.

The sixth important determinant related to HIV/AIDS in South Africa listed in this survey (The South African National HIV Prevalence, HIV Incidence, Behaviour and Communication Survey, 2005), and the most relevant to this study, are the issues surrounding HIV and women. In 1993 the executive director of the World Health Organization's Global Program on AIDS made the announcement that women accounted for half of the new HIV infections in the world, and made up the majority of people with HIV in sub-Saharan Africa. He went on to attribute women's vulnerability to biological, epidemiological and social inequities, and called out to men all over the world to help eradicate social traditions that subordinate women (Gross, 2004). Ten years later, on International Women's Day, March 8, 2004, the secretary-general of the United Nations, Kofi Annan, expressed his concern on how women are increasingly bearing the brunt of the HIV epidemic, and stated that the reason for this are the societal inequalities which put women at risk, such as poverty, violence and abuse, a lack of information and the infidelity of their partners (Gross, 2004).

Females have been shown to be more vulnerable to HIV infection. Their lower status in the community and disempowerment have been linked to their higher infection rate. Younger

women are especially vulnerable due to the immaturity of their reproductive system and the fact that they are more likely to be exposed to sexual coercion. Another factor, particularly in South Africa, is that of “survival sex”, in which women attempt to overcome immediate needs, such as the issue of shelter, through sex, or “transactional sex”, in which women attempt to gain access to consumer items, such as clothes, in return for sex. The relationship between sex and violence is also an important factor in South Africa, as women are often exposed to HIV through rape (Kim, 2000). The myth that HIV and AIDS is a “gay man’s disease” (Herek & Capitanio, 1999) has been dismissed and it is now an intimidating reality that women, and more specifically low-income women, are a consistently increasing percentage of new HIV cases (Gurung, Taylor, Kemeny & Myres, 2004). Research has also shown that women in minority groups have shown the largest increase in rates of new HIV/AIDS cases. Despite this, both low-income and minority group women have been the least studied HIV-positive population, specifically regarding the improvement of biopsychosocial health following an HIV diagnosis (Ironson, Weiss, Lydston, Ishii, Jones, Asthana, Tobin, Lechner, Laperriere, Schneiderman & Antoni, 2005).

In addition to these six determinants of HIV and AIDS in South Africa, issues such as poverty, power imbalances in relationships, and access to food, medical care and income all add to the effect of the pandemic on societies and economies (Barnett & Blaikie, 1992). Since the 1980s, education programmes informing the public about the dangers of HIV, and about the routes of transmission, have been widespread. Consequently, new cases of HIV infection are now primarily individuals who are unable, or unwilling to follow safe sex practices (Angelino & Treisman, 2001), or do not believe they are vulnerable. The prevalence of HIV has increased throughout the world, especially in the poorer and least resourced communities, such as in South Africa (Lindegger & Wood, 1995). Poverty has been found to be the main contributory factor to many diseases in South Africa (Schoub, 1992). HIV/AIDS has been shown to bring to light, and exacerbate South African political issues such as social prejudices, economic inequalities, discriminatory practices and political injustices that were once the basis of apartheid (Crewe, 1992). “The virus has become a social barometer, highlighting not only the social and economic imbalances within societies, but also between countries and national economies” (Lindegger & Wood, 1995, p7).

Being diagnosed as HIV-positive is a serious life crisis requiring considerable coping resources. When receiving an HIV diagnosis a person has to deal with a life threatening disease, issues such as death, HIV-related symptoms, change in life expectancy, change in body image, decisions about disclosure, mistrust in relationships, stigma and possible social isolation and rejection (Hudson, Lee, Miramontes & Portillo, 2001; Skinner & Mfecane, 2004). HIV infection has a draining effect on intrapersonal, interpersonal and material resources and should be

thought of as an unrelenting force with an uncertain course, and not as a single stressful life event (Kalichman, 1995).

## 1.2 HIV and AIDS: The Ultimate Biopsychosocial Phenomenon

A systems-theory perspective is integrated throughout the course of this study, as it is important to recognise the interconnectedness and the symbiotic relationships existing within the context of the HIV epidemic. According to systems theory, a system is defined as two or more related parts, where a change in one part will have a direct effect on the other parts. Subsystems are related and interact with one another, and this interaction affects the system as a whole (Hanson, 1995). As will be illustrated during this study, many subsystems exist within the context of HIV, and these subsystems interrelate, and should not be viewed as independent entities. This symbiotic relationship can be seen when one examines the effects of the virus for example. “The AIDS epidemic has been constructed as a complex social phenomenon with numerous political, economical, cultural and personal implications” (Rasera, Viera & Japur, 2004). HIV/AIDS has been described as the ultimate biopsychosocial phenomenon, as its impact is not only limited to the immune system, but also to the social network, psychological functioning, culture and religion of individuals (Schneider, 1989). Holland and Tross (1985) described a three-phase model illustrating the factors associated with an HIV diagnosis:

- Medical factors (e.g. symptoms, course and complications)
- Psychological factors (e.g. personality, coping and social support)
- Sociological factors (e.g. stigma, custom, belief and value)

These three factors associated with HIV and AIDS will now be briefly discussed, to give the reader a better understanding of the biopsychosocial aspects of the epidemic.

### 1.2.1 Medical Factors associated with HIV and AIDS

Although this study deals with only the psychological and social factors of this system, and not the biological factors, it is important for the reader to have an overview of the biological aspects of the virus, with special reference to those specifically related to HIV-positive pregnant women who are the focus of this research. Despite the fact that these biological aspects of HIV are not entirely relevant to the study, it is important to acknowledge them as an important part of the HIV and AIDS system. Human immunodeficiency virus (HIV) is the virus that causes acquired immunodeficiency syndrome (AIDS) in humans. The HI-virus is found in blood, semen, vaginal fluids and in breast milk, and is transmitted through sexual contact with an infected person; through mother-to-child-transmission (MTCT) before or during birth, or through breast-feeding; or through contact with infected blood and blood products, for example through the sharing of

needles or through blood transfusions. Once HIV has entered the body of an individual, it begins to infect the white blood cells, known as CD4 cells, which are a marker of the strength of one's immune system. Doctors use these CD4 cells as a measure of how well a person's body is fighting the virus, and also check an individual's viral load which represents the amount of virus in a person's body. As the virus attacks and destroys the immune system, it replicates itself using the CD4 cells as a host, before destroying it, and so, as a person's CD4 count decreases, the viral load increases. Persons with a high viral load are more likely to progress to AIDS, which is when a person's immune system becomes too weak to protect the body, and the person then begins to get sick. There are many diseases and clinical problems common in AIDS patients such as TB, STIs, septicaemia, pneumonia and meningitis. It is usually these illnesses, or opportunistic infections (OIs), that eventually kill an HIV-positive individual.

Mother-to-child transmission (MTCT) can occur before, during or after birth, and it is therefore extremely important for pregnant women to be well informed about the ways in which to reduce the chances of transmitting HIV to their babies. The rates of transmission from mother to child vary, with infection rates as high as 40% in less developed countries. The risk of transmission is also largely associated with factors related to the virus, the mother, the delivery process, the baby and feeding practices, which explain the differences in infection rates between countries. Transmission from mother to child during pregnancy is dependant on the mother's health during pregnancy and the possible disruption of the placental barrier. During delivery, the infant may be exposed to maternal blood or cervical secretions and in this way HIV can be transmitted to the baby. After birth the most important route of transmission is through breast milk. This risk of transmission is higher for mothers who do not exclusively breastfeed. Women who develop cracked nipples due to a poor breastfeeding technique are also at an increased risk of transmitting the virus to their babies. In general, the risk of MTCT is also increased if the woman has a high viral load.

The risk of transmission to the child during pregnancy is reduced by quality prenatal care, such as the treatment of any illness or STIs during pregnancy, the prevention of re-infection and the provision of antiretroviral treatment (ARV). The risk of transmission during labour and delivery is reduced through avoiding artificial rupturing of membranes, minimising the use of forceps and vacuum-assisted deliveries, treating any signs of infection, clamping and cutting the umbilical cord only after it has ceased pulsing, to avoid spraying infected blood, and finally, and most importantly, providing a short course of an ARV drug, if available. In South Africa, the drug used to prevent MTCT is called Nevirapine. It is important for HIV-positive pregnant women and new mothers to understand the risks of breastfeeding their babies, as they have the virus in both their blood and their breast milk, so transmission of HIV to the baby after birth is possible.

Counsellors should give these women all the available options on these risks, and information on alternative infant-feeding options. If alternative options are available, the risks are dramatically reduced, but if these alternative methods are not available or accessible, exclusive breastfeeding has been shown to be the better option. Breastfeeding alternatives include commercial infant formula, home-prepared formula, non-modified cow's milk, modified breast milk, breast milk banks or wet nursing.

### 1.2.2 Psychological Factors associated with HIV and AIDS

The psychological factors associated with HIV and AIDS dealt within this study will be discussed at length in Chapter 2, and therefore just a brief overview of the various psychological factors existing within the HIV and AIDS system will be presented here. The psychological consequences of HIV infection are as diverse as the individuals affected and infected by it, and have a range as broad as the disease process itself (Kalichman, 1995). Feelings of sadness, worry, despair and confusion are just a handful of the assorted reactions to HIV that an individual may experience, and these emotions are often compounded by several other affective, cognitive and behavioural responses (Kalichman, 1995). With the continuing improvement of HIV treatment, and as people infected with the virus are now living longer, it is important to dispel previously held beliefs that receiving an HIV-positive diagnosis is the equivalent of a death sentence. HIV-positive individuals, however, continue to face the prospect of a chronic and potentially debilitating disease, and early death, despite these advances in treatment, and with this, will also face the challenge of coping with the emotional implications of living with the virus (Kelly, Murphy, Bahr, Kalichman, Morgan, Stevenson, Koob, Brasfield & Bernstein, 1993).

For the purpose of this study, the psychological factors, or subsystems, associated with HIV have been divided into three areas of focus, namely emotional well-being (depression and self-esteem), coping (positive coping and negative coping) and interpersonal relations (social support and disclosure). These three areas of focus will now be broadly defined, so as to provide the reader with a brief overview and an understanding of their relevance to the field of HIV, and more importantly, their relevance to this study, before dealing with them in more detail in the following chapter.

#### Emotional well-being

People living with HIV/AIDS (PLWHA) frequently battle with symptoms of depression (Philips, 1998) and a decline in self-esteem (Visintini & Bagnato, 1995). These two factors are used in this study to assess emotional well-being, and more specifically, to assess the impact of the intervention, described in Chapter 4, on the emotional well-being of HIV-positive pregnant

women. HIV presents a multitude of different sources of depression, such as discrimination, stigma, violence, rejection, fear of infecting others, worrying about blood test results, concern about opportunistic infections, and the fear of death. The hopelessness of having an incurable, degenerative and stigmatising disease such as HIV is another important feature of depression in HIV individuals (Kalichman, 1995). In general, people need tremendous courage to deal with the difficulties of everyday life, and when a life threatening disease such as HIV is added to the mix, along with the stigmatisation and uncertainty for the future, one's self-esteem and coping strategies become extremely important.

### Coping

As previously mentioned, the coping strategies employed by HIV-positive individuals also play an important role in the psychological adjustment to HIV infection. Coping has been described as one's reaction to the question: "what do I do?" (Ebersohn & Eloff, 2002). This is another important psychological factor associated with HIV and extremely pertinent to this study. Coping is defined by Lazarus and Folkman (1984) as "cognitive and behavioural efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the individual" (p7). Coping with HIV is largely influenced by a multitude of competing stressors, such as social discrimination, poverty and, of course, the individual's social and coping resources (Kalichman, 1995). Researchers studying coping processes have described how individuals living with HIV endorse various social and psychological strategies in their quest to cope with the illness (Fleishman & Fogel, 1994). Lazarus and Folkman (1984) have described two general coping strategies, namely *problem-focused coping*, which is an active cognitive or behavioural effort to manage stress through behaviour or environmental change, and *emotion-focused coping*, which is the cognitive management and regulation of distressing emotions. Positive and negative coping strategies will be assessed in this research to evaluate the impact of the intervention on the coping strategies of the participants.

### Interpersonal Relationships

Social support is an important factor in the HIV-positive individual's quest towards coping with the psychological implications of living with HIV. There are many factors associated with having HIV that increase the need for social support, but despite this, HIV-positive individuals often lack adequate social support when they need it most (Gill, 1993). Interpersonal relationships have been shown to assist in alleviating psychological distress associated with chronic and life-threatening illness (Cobb, 1976). A person living with HIV/AIDS must first jump the hurdle of disclosing his/her status, before being in a position to receive HIV-related social support (Huber, 1996). Disclosure has been identified as a major psychological stressor for HIV-positive individuals (Semple, Patterson, Temoshok, McCutchan, Straits-Troster & Chandler, 1993), due to

reasons such as the fear of abandonment and rejection, stigma and violence to name a few. Individuals contemplating disclosure may also fear a disruption in relationships, particularly by evoking stigmatising attitudes (Simoni, Mason, Marks, Ruiz, Reed & Richardson, 1995). The levels of disclosure and of social support will be assessed in this study.

It is important to note that while these psychological aspects, which are variables assessed in this research, play a critical role in the life of an HIV-positive individual, the psychological adjustment of people living with the virus is not limited to these factors alone. Other psychological factors co-existing within the HIV and AIDS system, but not dealt with in this particular study, are discussed by Kalichman (1995), and include:

- *Grief and bereavement*, which are the obvious psychological responses to the loss of a loved one, and which have also been shown to be more pronounced in individuals who are infected with HIV themselves. Witnessing the death of a loved one caused by AIDS can prompt thoughts of one's own looming illness. Personal losses such as a loss of activity, mobility and social functioning may also lead to feelings of grief, similar to those associated with bereavement due to death.
- *Suicidal risk*, which has been recognised as an increased risk for people diagnosed with HIV, and is usually spurred on by responses to HIV, such as depression and feelings of hopelessness. PLWHA have higher levels of suicidal ideation and are more likely to attempt suicide than HIV-negative individuals (Zamperetti, Goldwurn, Abbate, Gris, Muratori & Vigo, 1990). Research has also shown that physical symptoms and depression in HIV-positive individuals are significantly associated with suicidal tendencies (Belkin, Fleishman, Stein, Piette & Mor, 1992).
- *Anxiety*, which is the most common response to HIV, and is composed of cognitive, affective, behavioural and somatic symptoms. Similar to depression, anxiety often stems from feelings of vulnerability to the disease, prejudices and concern about the future.
- *Somatisation*, which can be defined as a tendency to attribute somatic symptoms of psychological distress to one's physical illness, despite the absence of any medical explanation. For HIV-positive individuals, physical health can often become an obsession or preoccupation. Illnesses unrelated to HIV, such as a cold or flu, or even something as simple as a headache, can lead to somatisation, causing the individual needless distress over an irrational fear of progressing to AIDS.
- *Anger*, which is a common reaction to any life-threatening illness, and *guilt*, which is often associated with the diagnosis of sexually transmitted diseases, are both regular psychological responses to an HIV diagnosis. Self-blame, shame and self-devaluation are among the first emotional responses to a positive HIV result



(Chuang, Jason, Pajurkova & Gill, 1992). Anger can be directed towards a person believed to have transmitted the virus, caretakers for not being able to cure the disease, or society for not efficiently responding with urgency and compassion. Similar to guilt, anger may also be directed inwardly, originating from the individual's perceptions of either taking irresponsible risks, failing to recognise a risk situation, or trusting a seemingly safe situation. Guilt may fester from social stigmas, discrepancies in behaviour, moral beliefs or social judgements. Anger and guilt both stem from attributions of blame for HIV infection.

Psychological intervention seems to be a necessary step in the HIV-positive individual's journey toward adjusting to their HIV infection, as it would seem that the psychological impact of HIV is just as severe as its physical debilitation. The sociological factors associated with HIV will be discussed in the next section. It is important to note that although these factors are discussed separately, they are intertwined, and work together in either assisting, or hindering the HIV-positive individual's journey towards acceptance of his/her status.

### 1.2.3 Sociological Factors associated with HIV and AIDS

Together with the biological and psychological factors associated with HIV and AIDS, which can be described as micro-systems within the larger system of HIV and AIDS as they are defined by Bronfenbrenner (1989), there are also many sociological factors, or macro-systems, that have played an equally important and, at times, devastating role in the course of the epidemic, and which have great significance for this study. While the psychological aspects of this study will be described in detail in the following chapter, it is important to discuss the sociological factors here, as they create the setting on which this research is based. Stigma has particular implications for South Africa, given the history of racism and other stigmatising beliefs (Skinner & Mfecane, 2004). Research has shown that stigma associated with disease often attaches itself to existing stigmatising frameworks (Sontag, 1988; Van der Vliet, 1996), and in South Africa, where stigma and discrimination played such a large role in the apartheid system, AIDS has now been associated mainly with black people, women and, more specifically, poor black women (Skinner & Mfecane, 2004).

In the media there are various reports of discrimination against people with HIV in different contexts. Examples are the reports on the death of Gugu Dlamini who was killed because she openly stated she was HIV-positive (Baleta, 1999), reports on the experiences of Nkosi Johnson and other children who were prevented from attending school because they had disclosed their status (Streek, 2001), reports about discrimination in the work place (Ngqlyaza, 2000a; Viol,



2000), in the military service (Ngqlyaza, 2000b), and in the health care setting (Krautkammer, 2000) and reports of severe rejection and isolation in families (Altenroxel, 2000). These reports on stigma and discrimination in South Africa can explain why people with HIV have difficulty in accepting their diagnosis and fear disclosing their status.

For all sciences, HIV/AIDS is one of the most complicated and bewildering social challenges faced by contemporary society. Mann (1987) states that there are three phases to the AIDS epidemic. The first two are HIV and AIDS. The third is the phase of stigma, discrimination, blame and collective denial, and it is this phase that makes it so difficult to effectively tackle the first two, again portraying the interconnectedness of factors within the context of HIV. AIDS-related stigma is defined by UNAIDS (2002) as an attribute or quality which in some way significantly discredits an individual in the eyes of others, and should be seen as a process. It would seem that living with the shame and guilt of contracting HIV far outweighs the actual physical effects of the virus. Many women are rejected by their families, abused by their husbands and gossiped about by their neighbours (Chase & Aggleton, 2001). Returning briefly to the psychological factors, it should be noted that while factors such as stigma occur within a sociological context, their effects within the individual context are extremely pertinent, especially to this research, and should therefore be seen as interlinked, and not independent of each other.

The work and research done in South Africa to stem the tide of the epidemic have largely been focused on prevention and medical treatment, but seem to have neglected a rather important aspect, namely the provision of psychological support for those infected, with a proper focus on the effects of the resultant stigma and discrimination (Skinner & Mfecane, 2004). Interventions attempting to combat stigma have not always been tailored to specific cultural settings or populations, which subsequently explains their unexpected failure rate (Collymore, 2002). People are suffering in silence because of their fear of rejection and discrimination, and it is this silence which is doing more damage than the virus itself. In addition to problems within the African context with regard to the limited provision of psychological support, there are also numerous cultural, traditional and religious beliefs about disease and illness that often constitute lay understandings of a complex biomedical phenomenon such as HIV/AIDS (Chase & Aggleton, 2001). Beliefs about the origin, progression and nature of HIV/AIDS are often bound to historical, cultural and political contexts, which are likely to come into conflict with the dominant biomedical model of medicine and disease. The stigma surrounding HIV/AIDS may thus detrimentally affect efforts by individuals and communities to become informed about various aspects of the disease.

Despite the fact that few interventions in South Africa have focused on the reduction of the felt stigma and the psychosocial impact of the virus experienced by HIV-positive individuals, there are

numerous projects in place attempting to reduce stigma through education and awareness campaigns, but altering community attitudes and perceptions is not an overnight task, and this will undoubtedly take time. It has been made clear in various studies, both South African (Cameron 2000) and international (Goldin 1994; UNAIDS 2000b) that reducing stigma is a vital step in stemming the epidemic and it is important that interventions that effectively reduce HIV/AIDS-related stigma be identified and implemented (Brown, Trujillo & Macintyre, 2001). One of the problems in reducing HIV/AIDS related stigma is that many PLWHA reinforce the belief that HIV is something to be ashamed of, by remaining silent and denying their status. This is understandable when one looks at examples of discrimination towards HIV-positive individuals as mentioned earlier.

Stigma is born especially from fear, ignorance, lack of knowledge and social judgment (Parker, Aggleton, Attawell, Pulerwits & Brown, 2002). Different forms of stigma do exist, and for the purpose of this study, Goffman's (1963) classifications of stigma shall be utilised, so as to achieve a comprehensive understanding of the levels, or subsystems, of stigma experiences within the study sample. These different forms of stigma include:

- ❑ Experienced or felt stigma, which is the stigmatised person's experience of or fear of being stigmatised. This is a construction of the person and represents the stigma internalised by the affected person.
- ❑ Perceived community stigma, which is the perception a person has of the community's stigmatising attitudes.
- ❑ Enacted stigma, which refers to the actual experiences of stigmatisation and incidences of discrimination by the affected person.

Scambler and Hopkins (1986) argued that perceived stigma often precedes, rather than results from, enacted stigma. They claimed that many individuals reduce the opportunities for enacted stigma in order to protect themselves from discriminatory actions. People with HIV/AIDS therefore fear to reveal their status and may withdraw from society because they expect that other people will reject them, irrespective of the enacted or real community stigma. It would seem that if we are to eliminate, or at least reduce, the stigma related to HIV/AIDS, there must be not only a communal approach, such as awareness programmes, but also an individual approach, focusing more on the stigma felt by the infected, and empowering PLWHA to take control. One way of dealing with community stigma is to encourage open discussions about HIV by people living with the virus. The empowerment of HIV-positive people to disclose and positively deal with their diagnosis is a step towards breaking the silence and addressing the community attitude, but as has already been discussed, disclosure of one's HIV status seems easier said than done (Semple et al., 1993).

Although South Africa presents with a wide range of cultures, religions, social structures and the HIV epidemic, South Africa allows for a diverse set of lessons to be learned. The opportunities for exchanging experiences and knowledge have now been well established. Many epidemiological, psychosocial and medical characteristics of the spread of HIV have been shared between borders, and therefore intervention approaches can also be transferred, adapted and refined to fit new environments. However, for the most part, interventions that tackle the barriers posed by stigma and discrimination have remained neglected throughout the region, making it imperative to highlight what has been done and what has worked previously. As has been mentioned, women are bearing the brunt of the HIV infection in South Africa (Gross, 2004), and intervention is necessary if the tide of the epidemic is to be stemmed. It is essential for interventions aimed at HIV-positive women to not only learn from past research, but also to be developed to fit the needs and experiences of the women that will be involved, especially within an African context.

### 1.3 Motivation for the study

The majority of the research that has been done in this field has either been done in other countries, or has been conducted in Africa, but from a Western perspective (Van Dyk, 1992). In a country like South Africa, where HIV and AIDS have such an enormous impact, it is important that interventions developed within the context of the African HIV and AIDS epidemic, are developed not from a western perspective, but rather from an African perspective. In addition to this, while several studies have focused on the use of support groups in the context of HIV and AIDS, the majority of the studies have been done using gay male populations, and few have attempted to statistically measure the impact and effectiveness of HIV support groups. As has already been mentioned, research in sub-Saharan Africa to date has tended towards a focus on mainly the prevention of HIV, and not on developing much needed care and support services for those living with the virus (Amon, 2002). There are also very few South African studies that have attempted to explore the actual experiences of PLWHA (Sobo, 1995).

Using both qualitative and quantitative measures, this study attempts to evaluate the effectiveness of a structured support group intervention for HIV-positive pregnant women in the South African context, in terms of its impact on their psychological adjustment to their HIV infection. Support groups bring people with HIV together to share their experiences and provide each other with the much needed support to live with the virus. The implementation of structured support groups takes the focus of providing support a step further, in providing empowerment to these women through knowledge and “breaking the silence”. It is this silence that can make HIV

so deadly, and by giving PLWHA a voice, through the implementation of support groups for example, it becomes possible for the epidemic of stigma to be gradually stemmed. In a study done by El-Sadr (2001), it was found that women who attended support groups were more likely to gain access to treatment. He also found a high correlation between the lack of support and depression. Women who had no social support scored higher on depression scales than women who had a good support base. In another study, conducted by Moskowitz (2003), it was found that participants who scored higher positive affect scores had a significantly lower risk of death from AIDS. A possible reason for this is the impact of positive affect on the immune system. Another reason that was discussed in this study is how positive affect may improve health behaviours. It was found that depressive mood is associated with substance abuse, poor adherence and increased sexual risk behaviour. Social support was also found to have a high correlation with the slower progression of HIV.

This research provides valuable information on the design, implementation and effectiveness of support groups. Support groups provide PLWHA with a safe and non-judgemental environment to voice their worries and concerns. In a time when women are in need of support, sensitivity and understanding, they are often forced to deal with their diagnoses alone. Support groups provide people with HIV a safe environment to talk about the virus, share their experiences, listen to the stories of other infected individuals and access information (Summers, Robinson, Capps, Zisook, Atkinson, McCutchan, McCutchan, Deutsch, Patterson & Grant, 2000). They are able to learn from each other's experiences and provide one another with the support that they do not receive from the community, and often not even from their family and friends. Importantly, interventions such as HIV support groups can also often lead to empowerment. Broun (1999) states, "the greatest challenge, yet the one that reaps the most benefit, is empowering women to become activists for their own health care" (p123). This research study was done as part of the Serithi project, which is described below.

#### 1.4 The Serithi Project

The aim of the Serithi project is to develop an understanding of the experiences of women who test HIV-positive at antenatal clinics in townships in Tshwane, to use this understanding to develop an intervention to support women in dealing with their diagnoses and the stigma the community attaches to HIV/AIDS, and to have an impact on their health choices such as disclosure, condom use and infant feeding. The project started with negotiations with health service authorities on 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 families of a below average socio-economic status. Culturally, African communities are community-oriented, with a focus towards the collective, rather than the individual. 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. Due to the limited number of people who seek testing, it is very difficult to have an accurate prevalence rate of HIV. The estimated prevalence of HIV in childbearing women in Atteridgeville is 33.8% (Local audit data, Department of Obstetrics and Gynaecology, Kalafong Hospital). 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 has formed a very close relationship with the counsellors and the clinic staff, and provide regular counsellor 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 interview 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, the disclosure of her status, and various psychological measures, with the aim of gaining a better understanding of her experiences of living with HIV. Interviews with the first 317 women were done as a baseline study to better understand the experiences and needs of the participants. From these interviews, needs were identified and 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. 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.

### 1.5 Overview of this study

In the following chapter the psychosocial implications of HIV specifically relevant to this study are discussed in detail. This discussion includes a section on the direct effect of psychological functioning on the HI-virus, and more specifically on the human immune system. Following this, an in-depth look at depression, self-esteem, coping and social support related to HIV gives the reader a better understanding of the psychosocial implications of HIV. This is then followed by a

discussion on possible intervention strategies that have been suggested to address the psychosocial needs of HIV-infected individuals, with specific reference to support groups as an intervention strategy for HIV-positive women in South Africa.

In *chapter three*, the theory and practice of support groups are discussed, including a section on the heterogeneous nature of HIV support groups, the theory behind group therapy, facilitation of support groups, and a look at the challenges of running an HIV support group. A section on past research evaluating the effectiveness of support groups follows this.

In *chapter four* the study itself will be described, in which a 10-session structured support group programme is assessed in terms of its psychosocial impact on HIV-positive pregnant women in a South African context. This chapter includes a description of the structured support group programme, a description of the action-research process used to design the programme, methods used in the data collection process, ethical implications, and other methodological issues.

In *chapter five* the results of the study are presented, both quantitative and qualitative, as a method of triangulation has been utilised in the assessment of the groups, meaning that the qualitative feedback from the participants is used to augment the quantitative data, as one cannot solely rely on statistics in person-centred research such as this.

A discussion of the results of the study follows in *chapter six*, and the study is concluded with a summary of the findings and implications of the research, and a discussion on the limitations.

## **Chapter 2 – The Psychosocial Implications of HIV**

### **2.1 An Introduction to the Psychosocial Implications of HIV**

Receiving an HIV-positive diagnosis “is the beginning of a long road of challenging life events and extraordinary personal changes, which can overwhelm even the most psychologically well-adjusted individual” (Joseph & Bhatti, 2004, p30). As was discussed in the previous chapter, HIV/AIDS has been described as the ultimate biopsychosocial phenomenon, as its impact is not limited to the immune system, but also effect the social network, psychological functioning, culture and religion of individuals (Schneider, 1989). With the development of modern, holistic care, the traditional biomedical model that has been utilised in the past has been increasingly replaced by the systems theory based biopsychosocial approach described in chapter one. This approach proposes that disorders, whether medical or psychological, are more complex and multi-faceted than has been thought in the past (Schlebusch & Cassidy, 1995). With the continual increase of HIV infections, research and intervention programmes are progressively focusing more and more on the psychological aspects of the infection, in addition to preventative work (Lindegger & Wood, 1994).

With the emergence of new medical care regimens known as highly active anti-retroviral therapy (HAART), PLWHA have a longer life expectancy and better physical health and quality of life. These powerful ARV medications have transformed HIV from a once acute illness, into a now manageable chronic illness. This does not, however, mean that an individual diagnosed HIV-positive has it much easier now than those before. A chronic illness challenges one’s ability to adapt to environmental stressors, and often obstructs an individual’s attempt to fulfil personal dreams and ambitions, or sometimes even to simply meet basic needs (Hudson et al., 2001). Additionally, a chronic illness is also often accompanied by many other related stressors, such as physical deterioration, role changes, relationship issues, employment concerns and preparing for an uncertain future (Hudson et al., 2001). These advances in HIV treatment over the past few years have generated important changes that one needs to take into account when working in the field of HIV/AIDS. Although the advances in the treatment of HIV have improved the life expectancy and health of people infected with HIV, a cure still remains elusive, and individuals living with the virus have no choice but to face the challenges of living with a chronic medical condition (Tate, Flanigan, Tashima, Nash, Adair, Boland & Cohen, 2003). The continuous improvement of medication, and consequent improvement in life-expectancy, has led to PLWHA becoming more susceptible to multiple emotional and social problems (Kalichman, Sikkema & Somlai, 1996).



Continuing with the systems theory perspective, Schneider (1989) describes the different levels at which a psychologist becomes involved in the fight against AIDS. Psychologists may intervene at the macro-social level, assisting with policy development, or at a preventative educational level, working with educational/awareness campaigns. Psychologists can assist in the training and debriefing of lay counsellors for clinics and hospitals, and can provide psychological counselling for the affected and infected through one on one counselling, therapy groups, self-help groups or support groups. Finally, psychologists can apply their expertise in the research setting, often combining research with one or more of the above aspects of HIV/AIDS. Psychology in South Africa has been criticised because, despite the fact that the country is plagued by numerous health care problems, professional psychological help is limited to the wealthy minority, and the biopsychosocial needs of the HIV-positive people are often left to the non-specialist health care workers (Lindegger & Wood, 1994).

Research has consistently found psychological distress among individuals living with chronic, life-threatening illnesses (Derogatis, Morrow & Fetting, 1983; Katon & Sullivan, 1990; Lyketsos, Hoover & Guccione, 1996). A review on the psychiatric sequelae of HIV infection, conducted by Catalan (1999) in South Africa, shows that HIV is associated with psychiatric morbidity, psychological distress and negative social impact. Psychopathology associated with HIV has been shown to contribute to non-adherence to medical regimes, disease progression and mortality (Evans, Ten-Have & Douglas, 2002), and psychological problems have been documented at all stages of HIV infection (Ostrow, 1989). Due to the stress associated with living with HIV, PLWHA often experience a variety of social and emotional problems (Spirig, 1998). In a study done by Donlou, Wolcott, Gottlieb & Landsverk (1985), the authors suggest that individuals living with HIV are more distressed than other chronically ill people. They found disturbances in mood and self-esteem, illness-related stress and reduced social reactions.

While it is now known that individuals diagnosed with HIV commonly experience symptoms of anxiety and depression, our understanding of the psychological adaptation to HIV and AIDS is mainly based on research conducted with HIV-positive men, which cannot be generalised to women (Simoni & Ng, 2000). There have been very few studies focusing mainly on women living with HIV and AIDS, particularly women from disadvantaged backgrounds. This is disturbing as it has been shown that HIV-infected women generally experience more psychological distress than HIV-infected men (Catz, Gore-Felton & McClure, 2002), and the number of women being infected with HIV are rapidly increasing (Simoni & Ng, 2000). It has been found that anxiety, depression and low self-esteem during pregnancy are all positively related to life stress and inversely related to social support (Tilden, 1983). It is therefore necessary that interventions for women are developed, and developed with the particular needs and experiences of the women in mind.



Although there have been studies which have shown the positive effects of group therapy on depression, anxiety and coping (Emmott, 1991; Folkman, Chesney, McKusick, Ironson, Johnson & Coates, 1991), attempts to assess controlled interventions of psychotherapy aimed at reducing distress and improving coping among women with HIV have been limited, and this is therefore one of the objectives of this study.

In this chapter the impact of HIV on the psychological adjustment of individuals, focusing on the psychological factors described in the previous chapter, namely depression, self-esteem, coping and social support will be discussed. The purpose of this chapter is to provide the reader with a comprehensive understanding of the psychological concepts related to this study, and an understanding of their relevance in the context of the HIV and AIDS system. The second objective of this chapter is to provide the reader with a better understanding of an HIV-positive individual's experience of psychological adjustment following an HIV diagnosis. Finally, this chapter identifies psychological aspects which need to be addressed through intervention, and proposes ways through which this can be accomplished. In the following section, the relationship between the psychological factors and the biological factors is described as a further example of the interconnected subsystems existing within the context of the HIV epidemic.

## 2.2 The Direct Effect of Psychological Functioning on HIV

Research has shown that psychological variables have an effect on how the body combats disease. There has been a growing body of literature since the 1980s, aimed at linking psychological events with immune functions (Kennedy, Kiecolt-Glaser & Glaser, 1988). It has been clinically proven that the way people feel about themselves and their living situation can have direct effects on their immune system, which works to eliminate or incapacitate viruses (Nee, 1995). A wide variety of stressful events have been shown to induce immune suppression, such as examinations (Kiecolt-Glaser, Glaser, Strain, Stout, Tarr, Holliday & Speicher, 1986), losing a loved one (Bartrop, Luckhurst, Lazarus, Kiloh & Penny, 1977), unemployment (Arnetz, Wasserman, Petrini, Brenner, Levi, Eneroth, Salovaara, Hjelm, Salovaara, Theorell & Petterson, 1987) and depression (Schleifer, Keller, Bond, Cohen & Stein, 1989). Kemeny, Weiner, Taylor, Schneider, Visscher and Fahey (1994) have found that a depressed mood has a significant impact on the immune system among PLWHA.

The psychosocial effects of living with HIV seem to work together with the immune system in a vicious cycle. Progressive immune deterioration and the onset of HIV/AIDS-related symptoms, together with the variety of other stressors experienced by PLWHA often lead to psychological stress (Kalichman et al., 1996). It has also been suggested that people's feelings can affect their

immune system (Cohen, 1988; Littrell, 1996; Nee, 1995). As a person, therefore, becomes gradually sicker due to the progression of the virus, psychological distress may increase, and with the onset and progression of such psychological distress, the immune system deteriorates even more.

From research conducted by Goodkin, Blaney, Feaster, Fletcher, Baum, Mantero-Atienza, Klimas, Millon, Szapocznik and Eisdorfer (1992), it has been shown that individuals living with HIV can strengthen their immune system through active and behavioural coping styles. Coping skills such as seeking information about the disease, seeking social support and focusing on the meaning of life have been shown to be associated with lower levels of distress (Littrell, 1996). Insufficient social support (Hedge, 1991) and loneliness (Kennedy et al., 1988) have both been linked to a low CD4 count. Kennedy et al. (1988) conducted a study on the relationship between stress and interpersonal relationships, and found that interpersonal relationships mediated stress and also had a positive effect on physiological immunological outcomes. Symptomatic patients have exhibited more repression, denial and psychological distress, less fighting spirit, and less social support (Hedge, 1991). In a study by Teshima, Sogawa and Kihara (1988), it became clear that stress reduction improved T-cell subsets. Evidence has proven that behavioural and psychological interventions can safeguard against the immune-suppressing effects of HIV testing (Littrell, 1996), and may enhance the activity of the immune system (Fawzy, Kemeny, Fawzy, Elashoff, Morton, Cousins & Fahey, 1990). In the following section, the relationship between emotional well-being and HIV will be discussed with reference to past research focusing on depression and self-esteem.

## 2.3 Emotional well-being and HIV

### 2.3.1 Depression and HIV

In 1995 The World Health Organization (WHO) predicted that by 2020, depressive disorders will have a more harmful effect on people's quality of life than any other condition (WHO, 1995). "Depression is a major mental health problem throughout the world" (Choenarom, Williams & Hagerty, 2005, p18) and has been shown to be a common comorbidity in patients with chronic diseases (Anderson, Freedland, Clouse & Lustman, 2001; Barefoot & Scholl, 1996). HIV is no exception (Bing, Burnam & Longshore, 2001). Research has shown that depression is the most common neuropsychiatric aspect of HIV (Tate et al., 2003) and PLWHA frequently battle with symptoms of depression and anxiety (Philips, 1998). Despite this, "in South Africa, where five-million people are infected, there are few studies investigating the psychiatric morbidity of

HIV/AIDS infection, and potential risk factors of depression in this group remain relatively unexplored” (Olley, Seedat, Nei & Stein, 2004, p482).

Major depression can be characterized by a low mood, in which clients may complain of persistent sadness or flatness of emotional tone, and anhedonia, which is a loss of interest in, and withdrawal from all regular and pleasurable activities. Individuals diagnosed with major depression also experience decreased energy, feelings of hopelessness and despair and a decline in self-esteem, which often lead to feelings of guilt. Problems sleeping, poor concentration and memory, and difficulty producing thoughts are also common (Angelino & Treisman, 2001). Golden, Gersh and Robbins (1992) discuss four interactive dimensions of depression, namely emotional-affective symptoms, such as sadness and crying; cognitive symptoms, such as pessimism; behavioural symptoms, such as diminished motivation; and vegetative symptoms, such as disturbances in sleeping patterns.

In terms of the prevalence of depression in HIV-positive individuals, research has provided non-conclusive data, with results ranging from as low as 0% (Fukunishi, Negishi, Moriya, Hayashi & Matsumoto, 1997), to as high as 47.8% (Dew, Becker & Sanchez, 1997). The discrepancy between the results of these studies could be explained by individual differences. For example, a person’s distress can depend upon his/her health status at that time, their optimism/fatalism, their expectations regarding things such as the success of a treatment regime, their knowledge of HIV disease and associated topics, the presence of adequate social support, presence of other life stressors, and finally the individuals general coping style (Kelly, Murphy, Bahr, Koob, Morgan, Kalichman, Stevenson, Bernstein & Lawrence, 1993; Kelly & Murphy, 1992). Depression tends to occur more frequently at certain points in time, during which people are more vulnerable and which may in themselves be triggers. Examples include periods of initial adaptation or adjustment to HIV-positive status, experiencing rejection, abandonment or discrimination upon disclosure to family, friends and others, and learning of a significant drop in CD4 count or an increase in viral load count.

“Despite the knowledge that depression may contribute to HIV risk behaviours, and that HIV infection may worsen depression, depression remains under-diagnosed and under-treated in medical clinics” (Angelino, 2002, p31). The under treatment of depression can lead to poor adherence (Singh, Squier & Sivek, 1996), and also self-medication with drugs or alcohol, which has also been associated with poorer adherence (Cook, Hunt & Woodward, 1999). It has been shown that major depression is treatable, with more than 80% of people responding to treatment, and returning to normal functioning (Hsu, 2002). The problem seems to be that most people do not seek treatment for depression, with some studies stating that over 50% of people with depression fail to get treatment (Lesserman, Petitto & Perkins, 1997). In the past, depression

has been under-diagnosed and under-treated, possibly because depression has been viewed as an expected reaction to a positive HIV diagnosis (Asch, Gifford, Burnman, Turner, Shapiro & Bozzette, 2003), with overlapping symptoms such as insomnia, diminished appetite and weight loss, a change in taste, decreased libido and decreased concentration and memory, but it is important that people view depression as a separate illness that needs to be treated.

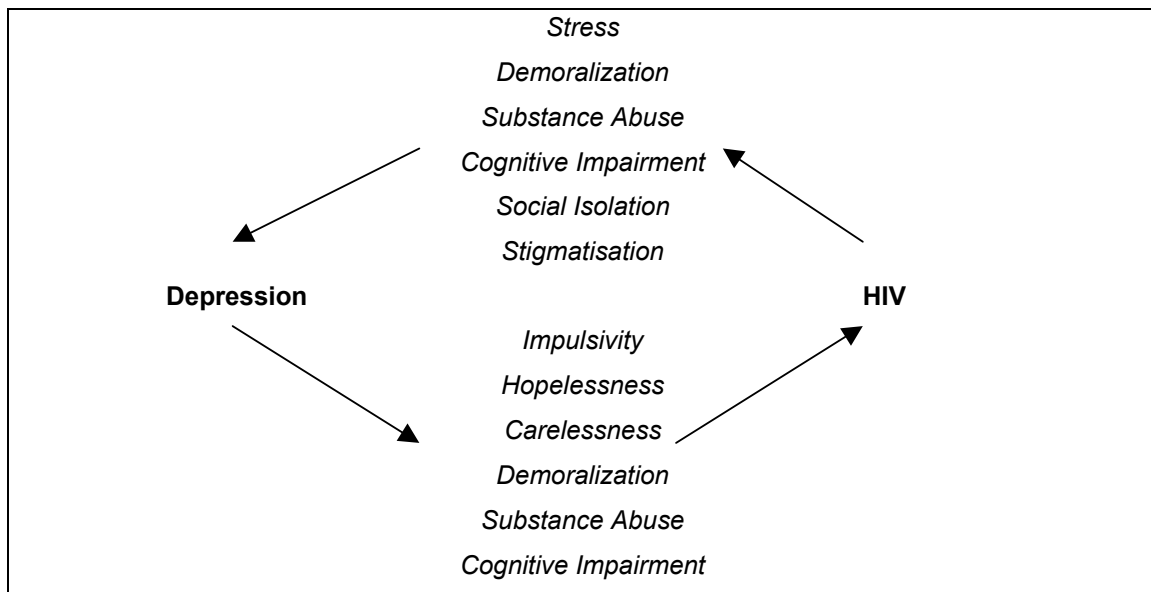
According to Olley et al. (2004), “there is increasing evidence that major depression impacts the course of HIV infection” (p481). Depressive symptoms have been linked with an increased risk of developing AIDS (Lesserman, 2003) and has been shown to directly compromise the immune system, which in turn speeds up disease progression (Evans et al., 2002), positive affect has been associated with decreased disease progression (Moskowitz, 2003). Research (Leserman, Petitto & Perkins, 1997) has shown that depression can limit the energy needed to focus on staying healthy and this may be one of the reasons for the accelerated progression to AIDS. Therefore, the effective treatment of depression in HIV-positive individuals can significantly influence the mental and physical health of these individuals (Tate et al., 2003). According to Tate et al. (2003), “depression should remain the primary mental health concern among practitioners who provide treatment to individuals infected with HIV” (p119).

Research has shown that stress and depression aggravate one another, and so form a vicious cycle (Choenarom et al., 2005). Depression often develops when an individual is under stress, and depression, in turn, inhibits one’s ability to cope with stress. As was discussed in section 2.2, stressors such as receiving an HIV-positive diagnosis are thought to have an effect on one’s health status by causing negative affective states, such as depression, which lead to negative effects on one’s biological processes of behavioural patterns, in turn, compromising health and well-being (Cohen & Williamson, 1991). Depression has been shown to increase with the severity of the disease, and the increasing feelings of hopelessness regarding one’s diminishing health (Belkin et al., 1992). Below is a diagram explaining the vicious cycle of depression and HIV (figure 2.1). As an individual living with HIV becomes sicker, so he or she will become more demoralised, which has further negative consequences on the individual’s health.

Particularly relevant for this study, past research has shown the link between depression and gender (Piccinelli & Wilkinson, 2000; Lichtenstein, Laska & Clair, 2002) and depression and negative life events (Dew, 1997). Various studies have shown that women are twice as likely as men to being diagnosed with major depression (Olley, Gxamza, Seedat, Theron, Taljaard, Reid, Helmuth & Stein, 2003; Pigott, 1999; Penzak, Reddy & Grimsley, 2000; Evans et al., 2002). James (2004) found that HIV-positive women diagnosed with chronic depression were also nearly twice as likely as others to die from AIDS-related illness and that those who had access to mental

health care services had half the death rate of those without. In South Africa it was found that being an HIV-positive woman, who often experiences more serious consequences following stressful life events, was a predictor for a diagnosis of major depression (Olley et al., 2004). Depressive symptoms during pregnancy have been linked to lower satisfaction with social support (Bernazzani, Saucier, David & Borgeat, 1997). The same results were found in a sample of low-income pregnant women (Seguin, Potvin, St.-Denis & Louselle, 1995). In developing contexts, such as South Africa, women with HIV are more prone to stigmatisation (Bennetts, Shaffer & Manopaiboon, 1999), and it has been found that these women face more previous and current negative life events (Lipsitz, Williams, Rabkin, Remien, Bradbury, Sadr, Goetz, Sorrel & Gorman, 1994). It can be concluded that in developing countries, such as South Africa, HIV-positive women are at greater risk of psychopathology, such as depression (Olley et al., 2003), and therefore have a particular need for psychosocial intervention in this country. In the following section, the relationship between self-esteem and HIV will be discussed.

Figure 2.1: The cyclic relationship between depression and HIV



Adapted from Angelino (2002).

### 2.3.2 Self-esteem and HIV

It has become a trend in psychology to study self-esteem as one of many variables making up the personality (Visintini & Bagnato, 1995). According to Kieffer (2001), "the individual self is developed from a network of relationships with other persons, which are internalized and become part of a self-matrix. Self-esteem is an extremely important issue for PLWHA. With the world as it is today, one needs tremendous courage to deal with the burdens and difficulties of every day life.

When an illness such as HIV is added, together with its stigmatisation and the uncertainty, life becomes burdensome. It is at this point when psychological intervention is often necessary (Broun, 1999). Research has shown that individuals living with HIV could have a loss in self-esteem due to social stigma, guilt or self-exclusion feelings or physical deterioration, to name a few (Visintini & Bagnato, 1995).

According to Yalom (1995), there is nothing more important to one's self-esteem and well being, than to be accepted by a social group. One's self is made up of a reflection of appraisals, and the way one regards one's self is determined by the way in which others perceive us, and their attitudes towards us. This is termed "public esteem", and Yalom (1995) notes that people are continuously concerned and influenced by the evaluations of others, especially evaluations from the group to which they belong. Bandura (1995) found that an individual's beliefs about his/her capabilities and potential to meet situational demands (Self-efficacy) influence effort, perseverance, perception of control, personal choices, thought patterns, depression and perceived stress. In terms of individuals living with HIV, high self-efficacy, for instance the strong belief that one has the skills to prevent re-infection or the skills to slow down the development of AIDS, can lead to better biological outcomes (Ironson et al., 2005).

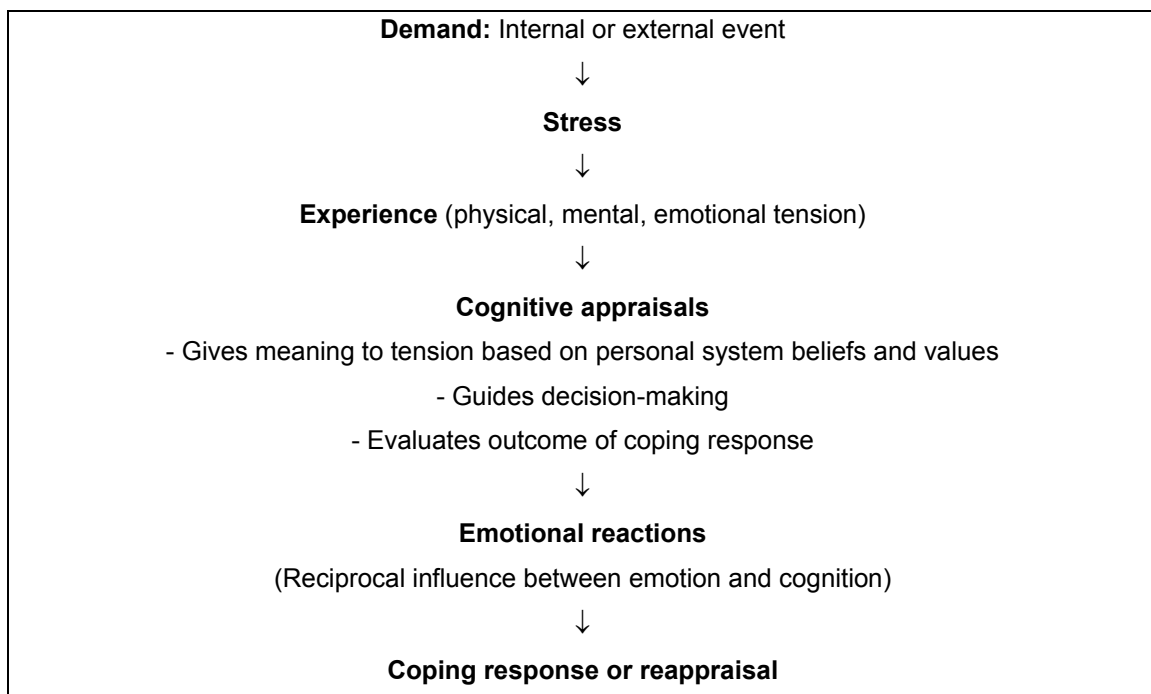
Visintini and Bagnato (1995) propose that it is in fact one's cognitive self-evaluation, and not one's self-esteem that is influenced by HIV. They stress the importance of differentiating between the way one feels about oneself, and what one rationally thinks about oneself. These authors believe that an individual's level of self-esteem is the influencing factor with regard to the individual's psychological reaction to HIV. It has been shown in the past that a perceived inability to cope may lead to a loss of self-esteem and self-efficacy, as well as feelings of helplessness and depression (Ironson et al., 2005). Register (1989) found that changes in physical appearance due to the illness have a dramatic impact on one's self-esteem, as well as on one's interpersonal relationships. Hackl, Somlai, Kelly and Kalichman (1996) showed that, through the process of self-blame, women who had disclosed their HIV status to their family subsequently had a significant decrease in self esteem.

Effective coping strategies are essential in the process of psychological adjustment to an HIV diagnosis. It has been consistently documented that there is a relationship between emotional well-being and coping styles (Clesla & Roberts, 2001; Lesserman, Jackson & Petito, 1999; Commerford, Gular, Orr, Reznikoff & O'Dowd, 1994). In the following section, coping and its associations with HIV and AIDS will be discussed.

## 2.4 Coping and HIV

Since Lazarus (1966) put forward his conceptual analysis of stress and coping four decades ago, the interest in the process by which people cope with stress has grown dramatically. Lazarus described stress as consisting of three separate processes. An individual must first perceive a threat (primary appraisal), and must then decide on his/her reaction to the threat (secondary appraisal), and finally, execute the response (coping). Figure 2.2 shows the universal process that all humans use to cope, regardless of age, gender, culture and socio-economic situation. Coping is defined by Lazarus and Folkman (1984) as “cognitive and behavioural efforts to manage specific external and/or internal demands appraised as taxing or exceeding the resources of the individual” (p7). Researchers studying coping processes have described how individuals living with HIV endorse various social and psychological strategies in their quest to cope with the illness (Fleishman & Fogel, 1994). Carver, Scheier and Weintraub (1989) discuss two possible ways in which individual differences may influence coping. The first of these possibilities is that people do not approach each new coping context with a clean slate, “but rather bring a preferred set of coping strategies that remains relatively fixed across time and circumstances (p270). The second possibility takes the first a little further, in proposing that personality characteristics predispose an individual’s coping style.

*Figure 2.2: Stages in the transactional coping process*



(Ebersohn & Eloff, 2002).



Coping is considered to be an extremely important factor affecting adaptation outcomes such as psychological well being, especially in the long term (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) have described two general coping strategies, namely, *problem-focused coping*, which is an active cognitive or behavioural effort to manage stress through behaviour or environmental change, and *emotion-focused coping*, which is the cognitive management and regulation of distressing emotions. Problem-focused coping is aimed at problem solving, or doing something to alter the source of the stress, while emotion-focused coping is aimed at reducing or managing the emotional distress associated with the situation. Although both types of coping are elicited by most stressors, people tend to utilise problem-focused coping more often when they feel something constructive can be done, while they will more often use emotion-focused coping when the person feels the stressor is something to be endured. Generally, active-coping is associated with more positive affect and higher self-esteem in populations dealing with chronic illness, while negative emotion-focused coping strategies such as denial and avoidance are generally associated with greater depression and distress (Ironson et al., 2005). Despite this, neither of these coping strategies are considered better than the other, as they are rather judged by the effectiveness in meeting the demands of the situation in which it is used (Lazarus & Folkman, 1984). Some strategies seem to be more effective for certain contexts than others, and therefore an individual's coping response may vary across situations and may also change over time (Folkman, Lazarus, Dunkel-Schetter, DeLongis & Gruen, 1986).

#### Problem-focused coping

Kalichman (1995) broadly defines HIV-related problem-focused coping, or active coping, as encompassing strategies such as cognitive coping, which involves creating meaning out of being HIV-positive; the involvement in medical treatment; seeking information; life-style changes such as eating healthier or reducing the consumption of alcohol; and social activism. It has been shown that effective problem focused strategies include help-seeking behaviour, cognitive restructuring, religious activities and humour. These types of coping strategies have been found to lead to lower levels of distress (Kalichman, 1995). Due to the fact that many of the women infected with HIV are from poor areas (Catz et al., 2002), a large amount of their energy is needed to meet the survival needs of their family, and this makes women particularly vulnerable and unprepared when attempting to cope with an HIV infection (Springer, 1992). In their study on the effectiveness of coping strategies used by HIV-positive women, Moneyham, Hennessy, Sowell, Demi, Seals and Mizuno (1998) found "that the use of active coping strategies focused on managing the illness, seeking social support, and spiritual activities may function to protect against emotional distress" (p359). The use of problem-focused coping has been directly linked to the availability of social support (Nyamathi, Flaskerud, Leake & Chen, 1996). It has been



shown that fewer active coping strategies and the perception of less social support contribute to greater anxiety and depression (Catz et al., 2002).

#### Emotion-focused coping

In terms of emotion-focused coping, Kalichman (1995) differentiates between denial, which can occur at various stages of HIV infection; acceptance, which has been described as the natural final stage of coping with a terminal disease (Kubler-Ross, 1981); avoidance, which involves trying to forget about one's status; and the use of distractions. It has been found that the primary coping mechanisms employed by HIV-positive women include denial, concealment of their status, isolation and crying (Hackl et al., 1996). Emotion-focused strategies such as avoidance have been correlated with higher symptom levels (Frazier & Burnett, 1994). Individuals using this strategy will refuse to dwell on thoughts of the illness, and distance themselves from it, by refusing to discuss it. This type of coping mechanism could suggest the individual's inability to deal with the reality of their illness. Namir, Wolcott, Fawzy and Alumbaugh (1987) found that individuals living with HIV who refuse to think about their disease often show a better mood and states that therefore, some forms of denial can be helpful for people with HIV. Broun (1999) states that "denial is a healthy way of coping for the most part" (p123), and there has also been some evidence that emotion-focused coping, such as avoidance, can be beneficial in dealing with a short-term stressful situation, but they do appear to be less effective over the long term (Suls & Fletcher, 1985). Avoidance coping strategies have, for example, been associated with increased psychological distress, including anxiety and depression, and poor adjustment (Moneyham et al., 1998). Similar findings have been found specifically related to individuals living with HIV, and their use of avoidant coping strategies (Fawzy, Namir & Wolcott, 1989). They reported that avoidant coping increased distress levels, as well as negatively influencing anxiety and depression. Fleishman and Fogel (1994) state that women living with HIV are more likely to make use of avoidant coping mechanisms than men, and also reported higher levels of depression. Kalichman et al. (1996) found that individuals who had not attended support groups endorsed avoidant coping strategies. This may explain their reluctance to seek support in the first place.

To conclude this section, research has shown that some coping mechanisms, such as acceptance, humour and positive reframing are associated with a better response to stress, while coping strategies such as behaviour disengagement and avoidant coping have been associated with poorer adjustment (Carver, Pozo, Harris, Noriega, Scheier, Robinson, Ketcham, Moffatt & Clark, 1993). Moore, Schuman and Schoenbaum (1996) found an association between positive coping strategies and fewer depressive symptoms and other research has shown that HIV-positive individuals who deal directly with the stressors associated with their illness experience

better adjustment (Turner-Cobb, Gore-Felton, Marouf, Koopman, Kim, Israelski & Spiegel, 2002). It can thus be concluded that positive coping skills are critical in the psychosocial adjustment to an HIV diagnosis, and so the inclusion of positive coping into interventions for HIV-infected women is also essential. As has been mentioned, using the active-coping strategy of seeking social support has been associated with less emotional distress (Moneyham et al. 1998). In the following section, the relationship between social support and HIV will be discussed.

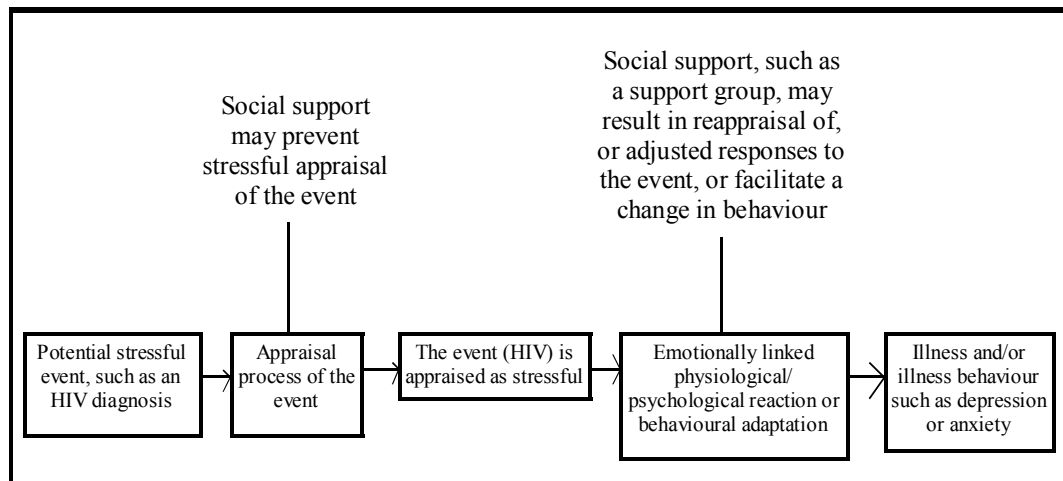
## 2.5 Social Support and HIV

Over the past 20 years, the interest in the role of social support in disease progression and general mental and physical health has increased. Research has shown that social support can have a large effect on protecting individuals in crises from developing pathology, can facilitate compliance with treatment regimens and accelerate recovery (Cobb, 1976). Although links have been found between social support and health (Madge & Marmot, 1987), the pathways that explain these links are still to be discovered (Ashton, Vosvick, Chesney & Gore-Felton, 2005). In Green's (1993) article, the question is posed about whether "good social support promotes psychological well-being which in turn promotes good health, or does good health ease psychological adaptation which in turn attracts a wider support network?" Past research has shown that social support has a large impact in shaping mental health outcomes, however much is still to be understood about the actual nature of this relationship (Schmitz & Crystal, 2000). Social support is defined as emotional, informational, or instrumental assistance from others (Dunkel-Schetter & Bennett, 1990). Cobb (1976) defined social support as information leading the subject to believe that he/she is cared for and loved, esteemed, and a member of a network of mutual obligations.

In their classic work Cohen and Willis (1985) discuss the process by which social support is beneficial to one's well-being. They describe two different models that could explain this process, namely the buffering model and the main-effect model. The buffering model "proposes that support is related to well-being only (or primarily) for persons under stress" (Cohen & Willis, 1985, p310). This means that support acts as a buffer to protect the individual from the possible negative effects of stressful events. This buffering process could occur at two possible stages during a person's reaction to a stressful event (see figure 2.3 below). Support may have a positive effect on one's appraisal or expectation of a stressful event by increasing the individual's perceived ability to cope with the situation. The second entrance point at which this buffering process may occur, and the more relevant for this study, is after the experience of stress, but before the onset of any pathological outcomes, such as depression or anxiety. The introduction of support at this time may have a direct positive influence on the individual's psychological and

physiological processing, and either reduce or eliminate the stress reaction. Support could assist in providing a solution to the problem, reduce the perceived importance of the stressor, or assist in the facilitation of more healthy behaviours (Cohen & Willis, 1985).

Figure 2.3: Two possible stages at which the buffering process may occur



(Adapted from Cohen & Willis, 1985)

The alternative model states, “that social resources have a beneficial effect irrespective of whether persons are under stress” (Cohen & Willis, 1985, p310). This means that if an individual’s social support increases, so will the individual’s level of well-being, irrespective of life-situation or existing social support. An argument in support of this model is that individuals with large social networks, or with available social resources, are exposed to regular positive experiences, and have set roles within the community. This provides the individual with positive affect, and stability, as well as recognition of self-worth. The mere involvement within a social network may also assist in the avoidance of negative experiences, such as economic or legal problems (Krantz & Moos, 1988). Cohen and Willis (1985) conclude their discussion by stating that there does seem to be evidence that supports both models, and it would seem that each represents a different process by which social support may have a positive effect upon an individual.

Social needs are met through much more than just mere interpersonal contact (Cohen & Willis, 1985). Thoits (1995) stated that the most powerful measure of social support was the presence of an intimate, confiding relationship, although it must be understood that social support is multi-dimensional. According to Cohen and Willis (1985), there are four different kinds of support resources, although not independent of each other.

- *Esteem or Emotional Support:* The support shows the individual they are valued and accepted unconditionally, despite any faults. It may counterbalance any threats to the individual's self-esteem, that may have occurred as a response to the stressor.
- *Informational Support:* This kind of support assists the individual in gaining a better understanding and insight into a specific problem, and can also assist the individual in their coping process. This would counter the individual's perception of a lack of control.
- *Social Companionship:* The physical act of spending time with others, thereby reducing stress through either distraction or through the facilitation of positive affective moods.
- *Instrumental Support:* This kind of support involves the provision of financial aid, material resources or other services. This type of support is also often termed material support.

A study undertaken by Smith and Rapkin (1995) showed that more than a third of PLWHA have unmet social needs. There are many factors associated with having HIV that increase the need for social support, and therefore also a need for interventions that encourage supportive relationships between infected individuals. As has been mentioned earlier in this chapter, HIV has been linked to depression, suicidal thoughts, guilt and fears of social isolation (McKeganey, 1990; Platt, 1992). Limited social support can therefore make the process of dealing with one's HIV status even more difficult. An HIV-positive diagnosis can very often lead to disruptions in social functioning. AIDS stigmatisation, for example, can cause the individual feelings of shame, low self-esteem and guilt (Siegel & Krauss, 1991). HIV-positive individuals may also experience relationship conflicts (Turner, Hays & Coates, 1993). For example, an HIV diagnosis can have large implications on an individual's present and future sexual relationships due to the fact that HIV is sexually transmitted (Catalan, 1990). The breaking up of close relationships can often follow a positive HIV diagnosis, regularly due to the discrimination and stigmatising attitudes (Schmitz & Crystal, 2000), therefore limiting the individual's source of social support, when he/she needs it most. Ciambone (2002) stated, "The benefits of social support are particularly important for people with HIV/AIDS because of the concomitant stigma and social isolation accompanying the disease" (p877).

While it is important to recognise the social support needs of these individuals, it is also important, especially for the purpose of this study, to review past research on the benefits of social support. In the same vein, it is also important to not only understand the positive effects of social support, but also the effects of negative support (Schmitz & Crystal, 2000). Much research has focused on the effects of social support on emotional well being. It is important to

note first, that research has shown that the perceived adequacy of support may be more important than the actual availability of support (Lennon, Martin & Dean, 1990). Serovich et al. (2001) found that it is perceived social support that is associated with mental health. Simply the belief that one would have support and help from family, if needed, is comforting, regardless of whether that support is actually available. For the purpose of this research therefore, perceived social support has been assessed, instead of the actual availability of support.

Cohen and McKay (1984) found that social support could help individuals mobilize their psychological resources, which can assist them in managing their emotional burdens, and may also lead to financial or material support, and may additionally provide cognitive guidance to better handle the situation. In other studies investigating the role of social support in the management of long term disease, a positive relationship has also been found between support and psychological resources, which has been shown to help the patient cope with the illness and encourage the recovery (Madge & Marmot, 1987). Related specifically to HIV, studies have shown that:

- Social support is critical for emotional well being of HIV-positive individuals (Crystal & Kersting, 1998),
- Social support has a positive influence on the mental health outcomes of PLWHA (Fleishman & Fogel, 1994; Turner et al., 1993).
- Social support has been shown to be an important aspect of psychological adjustment for PLWHA (Green, 1993).
- Social support has a positive effect on the self-concept of individuals living with HIV and AIDS (Schmitz & Crystal, 2000)
- Social support has been positively associated with coping (Green, 1993), although few studies have looked at the impact of social support on coping behaviours (Schmitz & Crystal, 2000),
- Social support has been linked to the better adjustment to the psychological stress associated with receiving an HIV-positive diagnosis (Schlebusch & Cassidy, 1995).

In addition to the benefits of social support on mental health and emotional well-being, social support has also been linked to better health (House, Umberson & Landis, 1988; Cohen & Wills, 1985); more rapid recovery from illness (Sarason, Sarason & Gurung 1997); a lower risk for mortality (Uchino, Cacioppo & Kiecolt-Glaser, 1996); increased survival time among individuals with HIV and AIDS (Patterson, Shaw & Semple, 1996), and among individuals with other chronic illnesses (Reynolds, Boyd & Blacklow, 1994; Spiegel, 1990; Anderson, Deshaies & Jobin, 1996; Thomas, Friedmann, & Wimbush, 1997; Christensen, Wiebe & Smith, 1994;); the slower rate of

decrease of CD4-count (Theorell, Blomkvist, Jonsson, Schulman, Berntorp & Stigendal, 1995); and a slower progression to AIDS (Lesserman, Petitto & Golden, 2000).

While the research has shown that there are various needs of individuals living with HIV and AIDS, and that the benefits of social support are vast, it should be noted that the trauma that is experienced with an HIV diagnosis will also often depend on factors such as the method of infection; personality characteristics; the degree of support; knowledge and the experience of AIDS related issues (Cartwright & Cassidy, 2002). The social support needs of people with HIV also differ depending on the stage of illness. An individual in the early stage of the disease may appreciate having someone to go out with, while someone already experiencing opportunistic infections will place higher value on physical care (Green, 1993). It is also important to note that there are multiple sources of support that PLWHA make use of (Johnston, Stall & Smith, 1995). In a study by Moneyham et al. (1998), HIV-positive women indicated that there are two types of social support that are important to them, namely family and friends, and other HIV-infected individuals. Interaction with other HIV-infected individuals was especially important for combating the feelings of isolation. Another extremely relevant topic to discuss at this point is disclosure, as one must first jump the hurdle of disclosing one's status, before one is in a position to receive HIV-related social support (Huber, 1996).

An individual recently diagnosed with HIV is often encouraged to disclose their status to appropriate others, such as a partner or close family members (Gielen, O'Campo, Faden & Eke, 2000). Disclosure to sexual partners is obviously important for reasons such as risk of re-infection and risk to others. It is important to disclose to one's partner, so as to encourage him/her to go for testing, if they do not already know their status. Individuals with HIV will often also disclose to family members in the search for support, and in preparation for the future, when they will need assistance, as the virus progresses. The reasons behind the disclosure of one's HIV status can vary greatly, and depend on various factors (Kalichman, DiMarco, Austin, Luke & DiFronzo, 2003). The reason for disclosure could be focused more on someone else than on oneself, such as when disclosing to a sex partner or health care providers to protect the individual from possible exposure to the virus (Jeffe, Kahn, Meredith, Schlesinger, Fraser & Mundy, 2000). Alternatively, the reason for disclosure could be for more personal reasons, such as to maintain honesty in a relationship, stress relief, or to access social support from family or friends (Simoni et al., 1995).

Women have reported that disclosing to family members is an extremely selective process and despite the obvious importance of disclosure, it has been identified as a major psychological stressor for HIV-positive women (Semple et al., 1993), due to reasons such as the fear of

abandonment and rejection, stigma and violence. Individuals contemplating disclosure may also fear a disruption in a relationship, particularly by evoking stigmatising attitudes (Simoni et al., 1995). Gielen et al. (2000) state that HIV-positive women can experience social harms when others learn they are positive. They also found that women experience many other consequences of disclosure such as loss of jobs and rejection from family. Another barrier to disclosure is the fear of unintended disclosure to others, through word-of mouth, and because of this, individuals contemplating disclosure will place trust-worthiness at the top of the criteria list, when deciding to whom to disclose. Very little work has looked at the impact of both intended and non-intended disclosure (Gielen et al., 1997).

Through disclosure, support may be gained, lost or unchanged, and so it is important for an individual considering disclosure to think about the advantages of possibly gaining social support specific to coping with HIV, as well as the disadvantages of possibly losing an otherwise generally supportive relationship (Kalichman et al., 2003). In an earlier study by Gielen et al. (1997), it was found that one in five women who decide to disclose their HIV status experience some kind of negative reaction that ultimately results in a loss of social support. Research has shown that in spite of the reasons for non-disclosure, HIV-positive women do eventually disclose their status, with disclosure rates as high as 98% (Gielen et al., 1997).

Findings from Kalichman et al. (2003) show that disclosure to friends is significantly more common than disclosure to family members, but it was reported that those who had disclosed to family members such as parents or siblings, received more support from those relationships. One can conclude that if disclosure to family and friends leads to greater social support, which in turn may buffer much of the emotional distress of living with HIV/AIDS, interventions focused on education, family counselling and stigma reduction may help to remove barriers to disclosure, and in so doing, indirectly improve the mental health and the quality of life of individuals, and families infected and affected by HIV.

Various research studies have made suggestions for possible intervention strategies that could be implemented to assist HIV-positive individuals in the psychological adjustment to their HIV infection. While it is important in the development of an intervention for HIV-positive individuals to learn from the experiences and the findings of past research, it is also important to develop interventions to fit the needs and experiences of the individuals involved. In the following section, possible intervention strategies, which have been suggested in past research, are discussed, with special reference to support groups as an intervention strategy in a South African context.



## 2.6 Suggested Intervention Strategies

In terms of possible intervention strategies which could be implemented to assist HIV-positive individuals in their psychological adjustment to the virus, various research studies have made some valuable contributions. Angelino (2002), for example, found that HIV-positive patients with major depression could benefit from supportive psychotherapy, including support group participation. Factors such as social support, spousal support and a sense of belonging have all been found to have an influence on the relationship between stress and depression (Choenarom et al., 2005). Often “a listening ear, together with acceptance and reassurance, is exactly what is needed and is more therapeutic than any treatment protocol” (Philips, 1998).

In another study, examining depression in pregnant minority women, it was found that social support satisfaction and active coping were both associated with positive well-being, and it was recommended that interventions for women should promote social support utilization and the use of active coping (Rudnicki, Graham, Habboushe & Ross, 2001). It has been found that people high in self-esteem engage in more positive, active-coping strategies in dealing with stressful situations, while those low in self-esteem may become more preoccupied with the stress, and the related emotions, and become more likely to disengage from their goals when under stress (Carver et al., 1989). Moskowitz (2003) states that interventions should start to focus less on trying to reduce negative affect, and instead attempt to increase opportunities for experiencing positive affect, as it is increased positive affect that will have a larger influence on one's health outcomes. Moskowitz (2003) states that there is a stronger association between positive affect and health outcomes than with negative affect. She proposes that positive and negative affect should be seen as independent constructs, and not opposites. It has been shown that psychological resources such as optimism, social support and coping strategies can reduce the likelihood of depression. Optimism is defined by Carver et al. (1989) as a generalized outcome expectancy that good things, rather than bad things will happen. In the past, optimism has been shown to be related to higher natural killer cell cytotoxicity during stress (Seegerstrom, Taylor, Kemeny & Fahey, 1998) and optimists, in general, show good psychological well-being (Armor & Taylor, 1998), which suggests that optimism could moderate depression in response to a stressor such as being diagnosed with HIV. Optimism has also been linked to lower levels of distress, less avoidance of others and fewer AIDS-related concerns (Taylor, Kemeny, Aspinwall, Schneider, Rodriguez & Herbert, 1992).

In addition to promoting positive affect, supportive interventions can also prompt a sense of belonging in the individual, which has been found to be associated with better psychological and social functioning (Hagerty & Williams, 1999). A sense of belonging can be defined as an



individual's personal experience of involvement within a system, and the feeling of being an integral part of that system (Hagerty, Lynch-Sauer, Patusky, Bouwsema & Collier, 1992). Schmitz and Crystal (2000) found that support influences a person's sense of importance to another person, which in turn has a positive effect on one's self-concept, which "provides the foundation from which coping styles arise" (p678). The findings in this study suggest that interventions such as support groups, which will increase an individual's feeling of being loved and understood, can have a positive impact on mental health outcomes, and coping mechanisms. Interventions that attempt to improve decision-making and communication skills, and more specifically aims at empowering individuals living with HIV with the skills needed for effective disclosure may also be of great benefit (Kalichman et al., 2003). It has been shown that people attending support groups are more likely to disclose their status to family, friends and their church, than those who do not attend support groups (Kalichman, 1996). In the following section, support groups, as an intervention strategy for HIV-positive women will be discussed.

### 2.7 Support Groups as an Intervention for HIV-infected Women in South Africa

As has been discussed through the course of this chapter, PLWHA frequently experience an assortment of complex social and emotional needs while living with their chronic illness (Spirig, 1998). Many studies have emphasized the importance of support groups in providing information, understanding and acceptance (Sandstrom, 1996; Bor & Tilling, 1991; DiPasquale, 1990; Hedge & Glover, 1990; Coleman & Harris, 1989; Gambe & Getzel, 1989), and have emphasized that there is a definite need for support groups as an intervention to assist HIV-positive individuals in adjusting to the psychosocial impact of the virus (Spirig, 1998). Individuals living with HIV have a variety of differences in their HIV-related needs, due to the diversity of the population living with the virus, and Spirig (1998) has emphasized the importance of support groups meeting the specific needs of those it supports. It has been highlighted in several studies that PLWHA hold many specific needs for support groups. For example:

- Living with the uncertainty of HIV/AIDS (DiPasquale, 1990),
- Living with the fear of dying (Duncan, 1998),
- Living with anxiety and hopelessness (Gambe & Getzel, 1989),
- Living with the loss of close family and friends (Bor & Tilling, 1991) and
- Trying to work against the stigma and isolation experienced by people infected and affected (Newmark, 1984; Sandstrom, 1996).

It has been noted in recent literature that it is essential for groups to target specific sub-populations of PLWHA due to their different needs (Spirig, 1998). Returning to the specific

needs of women living with HIV and AIDS, it is therefore important for a support group intervention targeting women to be tailored to these individual needs (Chung & Magraw, 1992). AIDS cannot be viewed as an illness that affects lone individuals, but rather as one that strikes mothers, wives, families and communities (Chung & Magraw, 1992). In her article on the psychosocial issues experienced by women living with AIDS, Broun (1999) states that, "women with AIDS often do not look sick" (p120). They shop for groceries and watch soap operas, and are our sisters, mothers, aunts and grandmothers. The psychological problems that women living with HIV experience are often under recognised, and to confound the matter, the essential economic, personal and social resources provided are often inadequate (Zuckerman & Gordon, 1988). South African women have been shown to usually be the ones in HIV affected homes to take the care giving role (Bennett, 1990). Regardless of HIV status, mothers, wives, sisters and daughters provide their family with care, and very seldom receive the same kind of support in return (Richardson, 1988). Although women are often the primary caregivers for their positive male sex partners, they are rarely assured of the same care and support. HIV-positive widows are often faced with problems of shelter, economic maintenance, their children's welfare and their own health care (Bharat, 1996). Women experience various obstacles in trying to obtain effective and empathetic support and treatment for their HIV infection (Chung & Magraw, 1992).

As has been mentioned, HIV-infected women in South Africa have a great need for psychosocial support. Stigmatisation, social support, depression and anxiety along with psychosocial stressors such as poverty and violence all interact to present a complex picture for women living with HIV and AIDS (Serovich, Kimberly, Mosack & Lewis, 2001). Kneisl (1993) found that, in general, women have fewer resources, more role responsibilities and fewer social and community support resources than men. Hudson et al. (2001) suggest from findings in their study, that the psychological distress experienced by HIV-positive women may be related more to the lack of support, than to the stressors associated with ethnicity and poverty. It has also been found that although both males and females experience feelings of isolation and concerns about confidentiality and access to medical treatment, females are more affected by issues of parenting, role adjustment, isolation and the need for social support (Hedge, 1991). Research has found that, generally, women living with HIV are more frequently abandoned by partners and family, than their male counterparts (Ciambrone, 2002). HIV-infected women have become central in much research, largely due to the fact that they are the primary source of infection to infants, as many infected women do not find out about their HIV status until late into their pregnancy, or sometimes even only after birth (Campbell, 1990). In a study conducted by Joseph and Bhatti (2004), pregnant women were found to live in fear of giving birth to a positive child, and experience feelings of guilt for being the reason for their babies' infection. In Broun's (1999) article on the psychosocial issues experienced by women living with HIV, she quotes one of her

clients as saying “a mother should be able to protect her child. Not only can I not do that, I have killed him simply by bringing him into the world” (p122). For this reason, many HIV-positive women have to deal not only with the consequences of their own illness, but that of their child’s too. (Campbell, 1990).

Women living with HIV in South Africa are often still burdened by their culturally defined roles, and are expected to be responsible for things such as childcare, housekeeping and the health of her family (Bennett, 1990). Quite often the women’s own needs are neglected, not only by her family, but by herself (Broun, 1999). These culturally defined roles, and the increasing difficulty that these women may have in trying to meet her family’s expectations, will often lead to feelings of guilt. “Women living with AIDS also tend to be ostracized by their social and emotional support groups, leaving them isolated with few resources to care for themselves and their children” (Ironson et al., 2005, p223). Similar to the research related to depression and gender mentioned earlier, other research has found that women also experience higher levels of psychological distress than HIV-positive men (Franke, Jaeger, Thomann & Beyer, 1992; Kennedy, Skurnick, Foley & Louria, 1995). These differences have been attributed to factors such as poverty, childcare responsibilities, responsibility to give care to others living with HIV, the differential stigma and social isolation that women living with HIV experience (Ickovics, Thayaparan & Ethier, 2000). Additionally, women have been shown to have shorter survival times than men, and this has been attributed to various influencing factors, including having more advanced disease staging at the time of diagnosis (Chu, Buehler & Berkelman, 1990), lower socioeconomic status (Melnick, Sherer & Louis, 1994), unequal access to HIV treatment (Ickovics & Rodin, 1992) and finally, biological sex differences (Richardson, Shelton & Krailo, 1991). Hudson et al. (2001) found that informational support related to HIV treatment, symptom management and medication adherence is an important link to adaptational health outcomes for HIV-positive women.

It is clear that the need for psychosocial intervention for HIV-infected women is great, and support groups can be an effective and meaningful intervention in addressing their variety of needs (Chung & Magraw, 1992). While past research is an important source of information in the development of new interventions, it must be noted that the majority of this research has been conducted from a western perspective (Van Dyk, 1992). It is therefore important for the relevance of psychosocial support for HIV-positive individuals in an African context to be discussed. Some of the concerns related to this include the question of whether the western concept of high-risk behaviour concurs with the African cultural concept. Additionally, views and understandings of “sickness” may differ and many traditional African cultures view sex as a taboo subject (Lindegger & Wood, 1994). For this sort of intervention to be effective in an African

context, one needs to take the African culture, and the specific needs of the target group, into account (Seeley, Wagner, Kengeya-Kayondo & Mulder, 1991). It is important to understand that HIV and AIDS occur within a cultural context. Psychologists, and health workers in general, must be aware of what it means for someone to be infected within their own culture. For women, one must also become aware of what it means to be women in her culture, and understand that roles for women are often culturally scripted, and this can have a large affect on the way the women experiences the infection (Broun, 1999). It is important for one to be sensitive and culturally appropriate, in order to build a trusting relationship with one's client, or group members. Historical traditions, health practices, social values and political priorities must be considered (Sauka & Lie, 2000). It is therefore important to note that this study, and the intervention that forms the focus of this research, has been conducted within the African context of HIV and AIDS, and developed with the specific needs of HIV-positive South African women in mind.

## 2.8 Conclusion

In this chapter, the psychological aspects related to the HIV and AIDS system have been discussed. As was stated in the previous chapter, while these aspects, namely emotional well-being, coping and social support, have been discussed as separate psychosocial factors, it is important to recognise the complex relationships taking place, not only within the context of these psychosocial factors, but within the larger context of the HIV and AIDS epidemics. It is therefore necessary, when developing an intervention for individuals living with HIV and AIDS that the interaction existing between these aspects is taken into account. In the following chapter support groups as an intervention will be discussed, with special attention to support groups for PLWHA.

### **Chapter 3 – Support Groups**

*There is an old Hasidic story of a rabbi who had a conversation with the Lord about Heaven and Hell. “I will show you Hell,” said the Lord, and led the rabbi into a room containing a group of famished, desperate people sitting around a large, circular table. In the centre of the table rested an enormous pot of stew, more than enough for everyone. The smell of the stew was delicious and made the rabbi’s mouth water. Yet no one ate. Each diner at the table held a very long-handled spoon – long enough to reach the pot and scoop up a spoonful of stew, but too long to get the food in one’s mouth. The rabbi saw that their suffering was indeed terrible and bowed his head in compassion. “Now I will show you Heaven,” said the Lord, and they entered another room, identical to the first – same large, round table, same enormous pot of stew, same long-handled spoons. Yet there was gaiety in the air: everyone appeared well nourished, plump and exuberant. The rabbi could not understand, and looked at the Lord. “It is simple,” said the Lord, “but it requires a certain skill. You see, the people in this room have learned to feed each other!” (Yalom, 1995)*

#### 3.1 An Introduction to HIV Support Groups

In response to the acknowledgment that HIV and AIDS is as much a psychosocial problem, as it is a medical problem, nurses, psychologists, social workers, psychiatrists, health advisors and other health providers have made the development of psychosocial care programmes for PLWHA a top priority (Bor & Tilling, 1991). The need for support groups was identified early on in the epidemic (Mail & Matheny, 1989). Since the late 1980’s, support groups have been proposed as an important intervention for PLWHA in dealing with the changes that come with the illness (Spirig, 1998). Support groups have been formed all over the world (Knox, 1989) and have become the most common social support service available to PLWHA (Kalichman et al., 1996), becoming one of the main intervention strategies used to deal with the variety of emotional consequences of HIV and AIDS over the past two decades (Nokes, Chew & Altman, 2003; Martin, Riopelle, Steckart, Geshke & Lin, 2001; Kalichman et al., 1996, Beckett & Rutan, 1990; Fawzy et al. 1989; Spector & Conklin, 1987).

In a time when PLWHA are in need of support, sensitivity and understanding, they are often alone, and without support. Support groups provide people with HIV a safe environment to talk about the virus, share their experiences, listen to the stories of other infected individuals and access information (Summers et al., 2000). They are able to learn from each other’s

experiences and provide one another with the support that they are unable to obtain from the community, and often even from their family and friends. Due to the stigma associated with the infection, discussed in Chapter one, support groups are necessary to provide individuals living with the virus a safe environment to develop relationships and adjust to the consequences of living with HIV (Brashers, Haas, Klinge & Neidig, 2000).

Support groups have consistently been shown to have positive effects for people with a variety of illnesses and disorders including alcoholism (Kurtz, 1982) and cancer (Cain, Kohorn, Quinlan & Schwatz, 1986). In 1935, Bill Wilson and Dr. Robert Smith initiated what is now viewed as the most influential support group over the past few decades, "Alcoholics Anonymous" (Carlton, Beck & Allen, 1993). It is suggested by Kurtz (1982) that AA has been so successful because it revolves around the following principles:

- The members learn about their finitude as humans and that there are aspects of their lives that they cannot by themselves control ("essential limitation").
- The members find agreement and can put an end to their feelings of isolation in the idea of "mutual limitation".
- Members acknowledge that they stand to gain greater independence through a "limited dependency" on the group and by surrender to a higher power.
- Members learn how to deal with negative feelings, such as guilt and shame, coming clean, making amends and other ways of dealing with these feelings and transcending them.

This paradigm has been repeated in various other groups, and it would seem that the principles which most, if not all support groups share, are that of sanctuary, common identity and vulnerability, anonymity, a sharing of ways of dealing with negative feelings, and the management of a process for which people perceive a need for assistance (Carlton et al., 1993).

An HIV support group is a place where individuals who spend much of their time preparing for death can work together in trying to learn how to live (Beckett & Rutan, 1990). Providing empowerment to someone living with HIV involves assisting him or her in learning to live with HIV. One HIV-positive individual summed up the essence of empowerment, in saying, "I need help to focus on living with AIDS, not dying with dignity" (Haney, 1988, p252). Research has shown that PLWHA are an excellent resource in helping others with HIV/AIDS (Haney, 1988). Peer support is achieved through the sharing of experiences, and importantly, confronting the reality of the illness (Chung & Magraw, 1992). One of the most frequently stated issues of PLWHA is the feeling of isolation. These individuals are often unable to talk about their experiences with important others, and for this reason, group therapy has been found to be especially helpful (Beckett & Rutan, 1990). Individuals often attend a support group when their

regular support system fails to meet their psychosocial needs (Knight, Wollert, Levy, Frame & Padgett, 1980). Support groups make members aware that they are not alone (Ribble, 1989) and facilitate social contact for people who are often feeling cut off from the world, and provide members with an emotional outlet, a space for information sharing, health promotion and the reinforcement of positive living. Support groups are also a time-effective and cost efficient way to provide psychosocial services (Chung & Magraw, 1992).

Individuals with chronic or life-threatening illnesses such as HIV face a number of identity challenges (Ezzy, 2000) such as role ambiguity (Brashers et al., 2000) and stigma threat (Alonzo & Reynolds, 1995). Roth and Nelson (1997) state that one of the ways in which these challenges can be managed is through the interaction with similar others, thereby “providing a less threatening comparison environment and allowing those who are stigmatised the opportunity to be ‘off-duty’ from the attribution ambiguity, stereotype threat, anxiety, and mindfulness that are likely to accompany interactions with the non-stigmatised” (Crocker, Major & Steele, 1998, p524). Individuals living with particularly stigmatised illnesses seek out similar others for support and this is an important opportunity for social network development (Davidson, Pennebaker & Dickerson, 2000). “Being with people who cope with similar problems in their lives to some extent alleviates the sense of loneliness and isolation” (Adamsen, 2002, p226). At the same time, the homogeneity of the group also assists in helping members to appreciate their own uniqueness. Initially, groups will focus on what the members have in common, but over time, the members will also start to appreciate and understand their varied responses and attitudes towards their common dilemma (Beckett & Rutan, 1990).

It was shown by Hays, Chauncey and Tobey (1990) that the involvement in support groups or other related community associations were positively correlated with psychological well being, which led to the hypothesis that in assisting others, individuals with HIV were able to decrease their own feelings of dependence and hopelessness, and promote better self-esteem. A terminal diagnosis such as being diagnosed HIV-positive challenges any future orientated attitudes, and forces infected individuals to re-evaluate and reorder life goals and priorities, and this often involves giving up hopes, fantasies and aspirations, such as a long term, intimate and loving relationship (Beckett & Rutan, 1990). It has been found that individuals living with HIV experience greater psychological distress (Discussed in Chapter 2) in the early stages of HIV infection (Tross & Hirsch, 1988), probably due to the anxiety associated with the uncertainty of the implications that come with receiving an HIV-positive diagnosis.

A support system is the most purposeful area that PLWHA need to connect with, and a support group is one effective support system that is very often underutilised (Haney, 1988). Support



groups for individuals living with HIV provide a setting where mutual assistance and support can be both offered, and accepted (Summers et al., 2000), which, as can be seen from the opening passage of this chapter, is critical in such challenging circumstances. In this chapter, the theory behind support groups will be discussed, and past evaluation research focusing on the effectiveness of support groups will be reviewed.

### 3.2 The Theory and Practice of HIV Support Groups

#### 3.2.1 The Heterogeneous Nature of HIV Support Groups

Support groups for PLWHA can vary greatly and are heterogeneous in both structure and format. Groups can have a limited number of sessions or go on for an indefinite period (Foster, Stevens & Hall, 1994; Land & Harangody, 1990) and can be open or closed to new members (Coleman & Harris, 1989). Ribble (1989) states that time limited groups can be effective for psycho-educational support, “but are not ongoing enough for psychosocial support” (p58). Ongoing groups also have some disadvantages such as the addition of new members at unsuitable or inappropriate times, and facilitator or member burnout. According to Bor and Tilling (1991), support groups do not need to be long term-term endeavours. Brief group therapy has become a widely used form of group therapy. Yalom (1995) states, “a brief group is the shortest group that can achieve some specified goal” (p273). Therefore, depending on the nature of the particular concerns of the group, a brief therapy group can have a wide range of objectives, and can vary from eight sessions, to as much as seventy sessions (Yalom, 1995).

Regardless of differences in the length or concerns of a brief therapy group, all share common features. Brief therapy groups:

- Strive for efficiency
- Contract for a discrete set of goals
- Focus on goal attainment
- Tend to stay in the present
- Attend to temporal restrictions
- Are often homogenous in their composition
- Focus on interpersonal, rather than intrapersonal concerns (Yalom, 1995).

Research has found time-limited group therapy to be effective, and has stressed the importance of clarifying the goals of each session, and to keep the group focused on the goals at hand, which is not always a concern in long-term groups (Yalom, 1995).



Support groups may also vary in being either structured or unstructured. It has been found that unstructured sessions increase anxiety and produce more treatment attrition (Fawzy et al., 1989). Support groups can also differ in that they can be composed of men, women, heterosexuals, homosexuals or people at various stages of the illness, and be directed at individuals, couples or families (Buisson, 1989; Hedge & Glover, 1990; Levine, Bystritsky, Baron & Jones, 1991). Finally, support groups can be facilitated by professionals or by peers (Ribble, 1989). Other types of groups include groups focusing more on prevention, groups for bereavement, significant others, children and groups that have a more political focus (Ribble, 1989).

### 3.2.2 The Theory behind Group Therapy

Group therapy is growth oriented, as the emphasis is on discovering internal resources of strength. A group provides the empathy and understanding that is necessary for creating an atmosphere of trust, which then leads to the exploration of the pressing concerns of the group participants (Corey, 2000). Group therapy can be a vehicle for assisting people in making necessary changes in attitude, beliefs, feelings and behaviours. Corey (2000) summarises the goals that are generally shared by members in a therapy group as follows:

- To learn to trust oneself and others
- To recognise the commonality of member's needs and problems, and to develop a sense of universality
- To increase self-acceptance, self-confidence, self-respect, and to achieve a new view of oneself
- To find alternative ways of dealing with, and resolving conflicts
- To increase self-direction, autonomy and responsibility toward oneself and others
- To become aware of one's choices and to make choices wisely
- To make specific plans for changing certain behaviours
- To learn more effective social skills
- To become more sensitive to the needs and feelings of others
- To learn how to confront others with care, concern, honesty and directness
- To learn to live by one's own expectations, and not merely meeting those of others
- To clarify one's values and decide whether and how to modify them

Group therapists from different schools of thought have attempted to describe the phases involved in group therapy. Kieffer (2001), for example, describes four basic phases in the development of a therapy group, namely:

- (1) The *pre-group phase*, appropriately described as a period of “parallel play” by Levine (1991), as members do not relate to one-another in a psychological sense, and depend on the facilitator to provide self-object functions (a relationship to the group as a whole).
- (2) The *engagement phase*, in which the group begins to develop a group identity and group members begin to develop a sense of belonging.
- (3) The *mutuality and optimal responsiveness phase*, in which much of the group progress and working takes place. In this phase, the group works more autonomously from the facilitator, and is characterized by an increase in responsiveness and tolerance from the members.
- (4) Finally, the *termination phase* is characterized by the group coming to an end, and members exploring their feelings towards their membership in the group, and thinking about what they will take from their experience.

Yalom describes what he terms, the “therapeutic factors” of group interaction, which interact in the complex process of therapeutic change. He divides the therapeutic experience into eleven primary factors, discussed below. The relevance of these factors to this study will also be discussed.

According to Yalom, the *instillation of hope* is one of the most important factors in therapy. Hope is necessary for the client in therapy, and simply having faith in the therapy can be therapeutic in itself. Group therapists and facilitators should do their best to instil feelings of belief and confidence in the group. In terms of HIV support groups, the instillation of hope is of utmost importance, due to the hopelessness so common in newly HIV-diagnosed individuals. Hays et al. (1990) has found that participation in HIV support groups is directly associated with increased feelings of hope. Much of this hopelessness stems from the feelings of isolation often experienced by HIV-infected individuals (Platt, 1992), largely due to the stigmatising attitudes toward the disease, discussed in Chapter one. Yalom states that clients often enter group therapy feeling that they alone are experiencing the “frightening or unacceptable problems, thoughts, impulses and fantasies” that they are facing. In keeping quiet about their status, for fear of discrimination, individuals living with HIV limit their chances of learning about others’ who are experiencing similar problems. In joining a support group, HIV-positive individuals often come in to contact with “similar others” (Roth and Nelson, 1997) for the first time, and this can often eliminate feelings of isolation, learning that these are common feelings, which is described by Yalom (1995) as the concept of universality, which leads to feelings of hope and the relief that they now know that they are not alone.

Yalom describes *imparting of information* as differentiating between didactic instruction and direct advice. The knowledge that is passed on from the group therapist or facilitator is termed didactic instruction. Yalom (1995) states that there has been a steady movement towards incorporating psycho-education, or formal instruction into group therapy. Information on the nature of specific illnesses, disorders or life situations, and possible misconceptions can also be included. HIV support groups are no different. Members of the group should be well informed on issues related to the virus, such as basic information on HIV and AIDS, treatment and nutrition. It is also equally important that the sessions correct any misconceptions or irrational fears that the group members may have. While didactic instruction is often solely the responsibility of the facilitator, direct advice from the members will occur without exception in any therapy group. In HIV support groups, where each member has had their own personal experience of discovering their status, and attempted to deal with this issue in their own way, each member has something different to give to the group.

Group therapy offers its members a unique opportunity to help others living with similar problems. Often members joining a therapy or support group will have the belief that they have very little to offer the others in the group because they have needed so much help themselves. Yalom states that the process of helping others (*altruism*) is a powerful therapeutic tool that can greatly enhance a member's self-esteem and feeling of self-worth. Yalom notes that group members will often more readily accept observations or advice from fellow group members, than from the group therapist or facilitator. For an HIV-positive woman, who has been swamped with feelings of helplessness and hopelessness, being given the opportunity to help other women in similar situations through sharing experiences, or giving advice, can often be what is needed to restore a sense of significance and increase self-esteem and feelings of self-worth (Yalom, 1995).

Many clients who join a therapy group will have had troubled family lives during their formative years. The group will often become a substitute family, consisting of a facilitator (or co-facilitators), evoking feelings similar to those felt toward parents and other group members, substituting for siblings, often vying for the attention and affection from the facilitator (parent), and this Yalom (1995) terms *the corrective recapitulation of the primary family group*. This can give members a chance to correct dysfunctional interpersonal relationships and this can have a powerful therapeutic impact. For HIV-positive individuals, a further benefit stemming from the creation of a new family system is that these individuals often lose the support of their family after disclosure, or are simply too scared to disclose in the first place, and so never get the support they require. A support group becomes a new family, and a much needed source of support.

Yalom (1995) states that social learning or the *development of socializing techniques* will occur in all therapy groups, and is an important therapeutic factor. For HIV-positive women, a support group provides a safe environment for them to speak openly, and socialize with other women in similar situations. This increase in social interaction can lead to improved self-esteem, and may also assist in building up the courage to disclose, through role plays and discussions surrounding the topic of disclosure. Group members also learn from the group facilitator, as he or she often has a powerful influence on the communication patterns of group members by modeling behaviors. The group facilitator models active listening, gives non-judgmental feedback, and offers support, and over time, members will pick up these behaviors and incorporate them into their own behavior, termed *imitative behavior*. In an HIV support group, where one of the co-facilitators is a fellow HIV-positive woman, who is living positively and doing her best to make the most of her life, group members will often look up to the co-facilitator, and view her as a source of inspiration, and a role-model for them all. This relationship, between the group members and the HIV-positive facilitator can be an extremely important factor, through imitative behavior, in striving toward self-empowerment, as well as having a large indirect influence on things such as self-esteem and feelings of self-worth.

Yalom (1995) describes *interpersonal learning* as a broad and complex therapeutic factor. He describes the development of a group into a *social microcosm*, in which group members are able to interact with fellow group members as they would in their own social environment. In a sense, one may argue that this is artificial, as members do not have a choice about who is in the group with them, the group members are not central in one another's lives, they do not live, eat or work together and the end of the relationship is already written into a social contract. On the other hand though, Yalom (1995) feels that "the group can be far more real than the world out there" (p41). The group experience emotions together, and are with each other through difficult life experiences, supporting each other, learning from each other, and being honest with one another. For many HIV-positive individuals, the support group is the only source of support available, and the only place where they really can be open and honest, and so from this perspective, one could conclude that the social microcosm developed in an HIV-support group is in many ways, more *real* for the members, than the real world, where they live in fear and denial.

The success of group therapy depends largely on the *group cohesiveness*. It is imperative for group members to perceive their group as being safe and supportive. There are three phenomena which assist in the formation of group cohesiveness, which include:

- Members may expect the other participants to know and understand important aspects of their life.
- The unspeakable can be more readily spoken

- A shared life dilemma can facilitate the trust and willingness needed to reveal intimate and difficult material sooner than would normally be expected (Beckett & Rutan, 1990).

Catharsis is a powerful emotional experience, defined as a release of conscious or unconscious feelings, followed by a feeling of great relief. It is a type of emotional learning, as opposed to intellectual understanding, that can lead to immediate and long-lasting change. While catharsis cannot be forced, a group environment provides ample opportunity for members to have these powerful experiences. Often, HIV-positive individuals have stored up feelings since their HIV diagnosis, which they have been unable to release because of the absence of a safe environment for such a release.

Existential factors are certain realities of life such as death, isolation and freedom. Awareness of these realities can often lead to anxiety. The trust and openness that develops among members of a therapy group or support group, however, permits the exploration of these fundamental issues, and can help members develop an acceptance of difficult realities. Accepting one's HIV status, and the stigma attached to it, as well as many other associated factors, can be extremely difficult, but through the exploration of these issues, within the safe environment of a support group, acceptance and hope can be achieved.

From this discussion on the therapeutic elements of group therapy, it can be concluded that the majority of these elements can also be present in support groups, depending on how the facilitator directs the groups. Facilitation, therefore, plays a key role in a support groups potential to be therapeutic for participants. The facilitation of HIV support groups will be discussed in the following section.

### 3.2.3 Facilitation of HIV Support Groups

It is important that from the outset, fears and expectation of the group members are discussed (Bor & Tilling, 1991). Rules and norms should be established and discussed at the beginning and respected and adhered to throughout (Bor & Tilling, 1991). The group norms are formed from the expectations of the members and from the direction given by the facilitator. A group contract is often a good idea (Beckett & Rutan, 1990), and can state the rules and agreement made by the members. Rules for support groups should be clear, and should not be too many, as members may tend to forget them. Groups should include rules such as respecting each other, keeping confidentiality, participation, speaking one at a time and to not verbally attack one another

It is the facilitator's responsibility to emphasize the importance of confidentiality in the group (Bor & Tilling). In terms of the physical setting for a support group, Yalom (1995) states that groups should be held somewhere that is private and free from distraction. He also states that the room should allow for the group to sit in a circle. There should be no central obstruction between members, so that each member can see every other member in the group. Most group therapists agree that at least sixty minutes is required to warm up and work through the major themes of a session, and that after two hours, the group will become weary and repetitious, and the positive group process will begin to diminish. It has therefore been a general consensus between therapists and group leaders that an eighty-to-ninety-minute group session is the best (Yalom, 1995).

Support groups can be facilitated or non-facilitated. Groups led by a facilitator have the advantage of having one person responsible for observing group process, providing feedback and helping the group run smoothly if it gets stuck (Ribble, 1989). The facilitator's role is to facilitate interaction among the members of the group, and assist them in learning from one another, in establishing personal goals, and encouraging them to transform their insights into concrete action plans (Corey, 2000). It is important that the approach of the therapist or facilitator be flexible, so as to address the needs of the client, or group (Ruiz, 2000). It is also important for facilitators "to keep a focus on particular topics" (Bor & Tilling, 1991, p51). Facilitators usually use techniques such as reflection, clarification, role-playing and interpretation during this process (Corey, 2000). According to Yalom (1995), the most important aspect of facilitation is to have a basic posture of concern, acceptance, genuineness and empathy. He believes that there is nothing more important than this. In addition to group leadership skills, an HIV group-facilitator should have dealt with his or her own feelings surrounding HIV and AIDS, including issues around sexuality, fears of the unknown, empowerment and death and dying (Ribble, 1989). The facilitator should feel comfortable to openly discuss the topics (Bor & Tilling, 1991). Support group facilitators should view themselves as conductors. Their task is not to dominate the group discussion, but rather to facilitate the process of the group. The facilitator should not be central to the group content, but is central to the group process, and has a large role to play in assisting in the creation of the group cohesion.

#### 3.2.4 The Challenges of HIV Support Groups

Due to the stigma surrounding HIV and AIDS, and the consequent difficulty in disclosing, HIV-positive members of support groups need to feel safe when coming to the group (Ribble, 1989). Many individuals living with HIV also find it difficult to share their fears and feelings, and are therefore unlikely to join support groups, despite their obvious need for social support (Hedge &

Glover, 1990). Confidentiality in HIV support groups is extremely important in ensuring that the members feel free to express themselves and to feel safe and comfortable with sharing their status with the rest of the group. There have been various ways of protecting member's confidentiality in support groups including the use of false names, first names only or using no identification at all. Some groups have developed a telephone tree for people who do not want to come to the groups out of fear of discrimination (Ribble, 1989). A study conducted by Nokes et al. (2003) on a telephone support group for HIV-positive persons aged 50 and older showed that such a group can work, but pointed out several limitations such as not being able to see postures and nonverbal behaviours and cues. This can limit a deeper understanding between members and limit the development of a sense of community (Nokes et al., 2003).

Individuals living with HIV may also become exceptionally aware of their bodily symptoms, and often each new somatic experience raises the question of whether this may be the beginning of the end. Participation in a support group, with other individuals having similar experiences, can be both terrifying and reassuring. Terrifying because one witnesses other members either getting sick or sometimes even dying, but reassuring because often many group members remain in good health for long periods of time (Beckett & Rutan, 1990). Support groups could make people more aware of the reality of the illness, and so by refraining from joining such groups, a sense of false hope is maintained. In the following section, past research, focusing on the effectiveness of support groups will be briefly reviewed.

### 3.3 An Evaluation of the Effectiveness of Support Groups

Although support groups for PLWHA have been formed for many years, there are still only a handful of studies that have attempted to evaluate and compare outcomes of support groups. It has been commonly assumed that support groups for PLWHA are helpful, without really having been specifically evaluated (Spirig, 1998). Spirig (1998) reviewed ten studies attempting to formally evaluate the impact of HIV support groups. A few of these studies made use of both qualitative and quantitative evaluation, but the majority employed either one or the other. The studies varied in many ways, such as the research methodology used, the study focus, group size, participant gender, age and sexual preference. Gay men specifically dominated the samples. Despite these differences, all of the authors stressed the effectiveness and usefulness of support groups. Depending on the focus of the support groups, the following outcomes were reached:

- Increased long-term coping skills (Hedge & Glover, 1990),
- Decreased emotional stress and an increase in social contacts (Kalichman et al., 1996),
- A higher quality of life (Nunes, Raymond, Nickolas, Leuner & Webster, 1995).



- A positive effect on reducing risk behaviour, such as unprotected sexual activity (Martin et al., 2001).

In her conclusion, Spirig (1998) states, “what is missing across all these reviewed articles are in-depth descriptions of the components used” (p. 53), such as actual descriptions on how the groups were implemented. It is difficult therefore, to take much more from these studies than simply the fact that support groups do in fact have an informative and supportive effect. Although it is stated that a mixture between educational and psycho-emotional interventions seem to be the most successful, few other conclusions can be drawn about which programme would best suit which subgroup of PLWHA. Spirig (1998) concluded that “support groups empower people, and provide social contacts, emotional and informational sharing, and education and health promotion. Empowerment is crucial for living with HIV because it focuses on the positive, less fatalistic aspects of the illness” (p45). Empowerment is defined by Ribble (1989) as “a process by which people are supported and valued as they learn about themselves, make decisions, mobilize resources and accept power, control and direction of their lives” (p53). It is a gradual process in which the client or members of a support group steadily move closer toward independence and mobilization of their resources. Empowerment is regarded as crucial in surviving HIV infection (Ribble, 1989).

In a study conducted by Coleman and Harris (1989), it was concluded that a psycho-educational model support group is especially effective for individuals recently testing HIV-positive. The focus of these groups is on education about HIV (Nokes, 2003). Gross et al. (1988) conducted a study on a three-session psycho-educational group for HIV-positive individuals and found that the group not only proved to reduce feelings of isolation, but additionally met their objectives for support and education. The groups reduced HIV-related stress such as issues with disclosure, and feelings of helplessness and hopelessness. The study also showed significant reductions in depression, anxiety and often hostility in a pre- and post-group symptom checklist. There have been some criticisms about the shortness of the programme, as three sessions were not seen as being sufficient to make any reliable conclusions (Ribble, 1989).

From research conducted by Kalichman et al. (1996) it was found that participants in support groups felt that the most common benefits of attending a group include being able to share feelings, the relief from being alone, the opportunity to obtain information on treatments and approaches to care, and being able to have their questions answered. Although there was much positive feedback given in this study about the benefits of support groups, the limited negative feedback included complaints about how the groups are depressing when discussing the illness, and when witnessing fellow group members getting sicker.



Summers et al. (2000) conducted research examining the influence of HIV-related support groups on survival in women living with HIV. In this study, the authors compare two groups of deceased woman. The groups included 10 women who participated in an HIV-related support group after their diagnosis, and 10 women who did not. The discussions in the groups centred around self-image, family/parenting issues, intimacy, collaborating with healers, disclosure and privacy, death and dying, spirituality, humour and relaxation. The group met once a week for approximately 90 minutes, for 12 sessions. The study found that participation in an HIV-related support group could prolong survival of HIV-positive individuals.

In a study by Kelly et al. (1993), investigating the outcomes of a social support group intervention, compared to a cognitive-behavioural intervention, it was concluded that although both interventions had positive outcomes, the social support group “produced favourable change on more dimensions of adjustment for more participants” (p1684). In the groups, participants expressed their frustration, anger and depression stemming from the abandonment by family and loved ones often due to the stigmatising attitudes held concerning AIDS and lifestyle. Participants also expressed their concerns about disclosure, and fears about their future. In the social support group intervention, participants were given the opportunity to discuss these concerns with peers in similar circumstances.

### 3.4 Conclusion

Research has shown that support groups are an effective intervention for assisting HIV-positive women to adjust to the psychosocial impact of the virus (Chung & Magraw, 1992). Very few studies have however attempted to statistically evaluate the impact of these support group interventions, specifically in South Africa (Amon, 2002). Many studies have also documented the under-recognition of the extent to which HIV and AIDS affect women (Anastos & Marte, 1989; Campbell, 1990). As has been discussed, there is a pressing need for psychosocial support for HIV-infected women in South Africa. In this study, a structured support group programme for HIV-positive pregnant women was developed and implemented, and this research focuses on the effectiveness of these groups in assisting women in adjusting to, and living with their HIV-positive status. In the following chapter, the processes of implementing these support groups, and the evaluation of the impact of these groups will be discussed.

## **Chapter 4 - Methodology**

In this chapter, the purpose of this research and the methods used will be described, with a special emphasis on the design of the study, the implementation of the structured support groups, and the process of data collection and analysis.

### **4.1 Purpose of the Study**

In this study, the effectiveness of structured support groups, developed to address the specific needs of HIV-positive pregnant women in South Africa, is assessed using both quantitative and qualitative data. In the quantitative evaluation specific attention is paid to the group's impact on depression, felt personal stigma, perceived community stigma, self-esteem, positive and negative coping, disclosure, HIV-related knowledge and support. In addition to the quantitative assessment, qualitative data collected from the participants will be utilised in augmenting the data, to provide a better understanding of the results.

The following hypotheses were investigated:

- ❑ HIV-positive women participating in support groups will experience a statistically significant decrease in their depression scores, level of felt personal stigma, perceived community stigma and negative coping in relation to the control group.
- ❑ HIV-positive women participating in support groups will experience a statistically significant increase in their self-esteem scores, positive ways of coping, support, level of disclosure and level of HIV-related knowledge in relation to the control group.
- ❑ HIV-positive women participating in support groups will evaluate their participation in the groups as a positive experience.

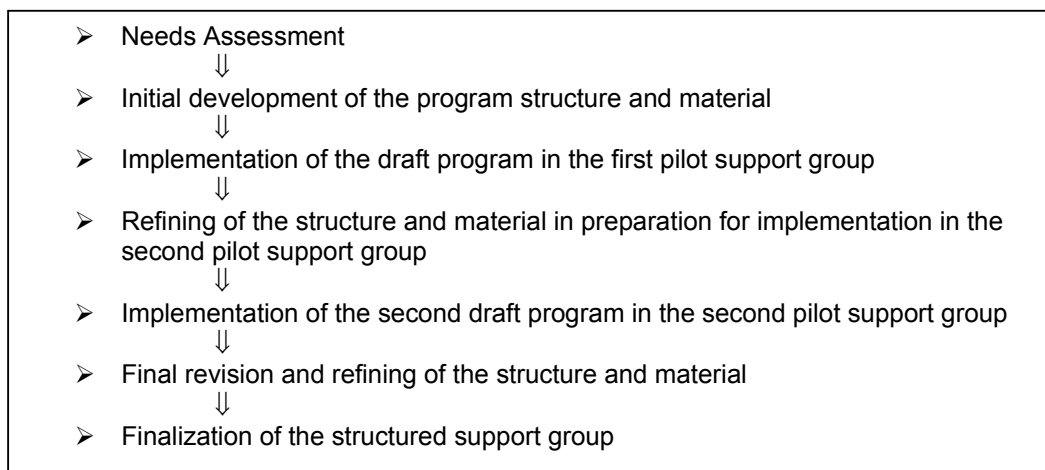
### **4.2 The Development of the Structured Support Group**

An action research approach (Walker, 1998) was utilised in the development of the structured programme for the support group intervention. There are two main characteristics of action research. Firstly, it involves a process of participation of community members in solving social issues (Bhana, 1999; Hollingworth *et al.*, 1997). Secondly it is a process involving a repeating cycle of planning, action, observation and reflecting. Action research is a circular process of feedback used in the planning of each next step of the research. This allows for continuous evaluation and sufficient flexibility to make changes as the process progresses (Hodgkinson & Maree, 1998; Hollingworth *et al.*, 1997; Walker, 1998).

The action research process, and development of the structured group programme are discussed in Visser et al. (2005), and will be briefly outlined here merely as background to the current research. The process started with a needs assessment, in which a focus group discussion was conducted with the eight field workers from the Serithi project. They were retired nurses and graduate students with extensive knowledge of the communities from which the women came. In the discussion they identified the needs they perceived in the group of 317 HIV-positive pregnant women whom they had interviewed as part of the Serithi project. The following perceived needs were identified:

- Information about the disease and treatment
- Information on their rights as HIV-infected women
- Knowledge and skills to assist them in staying healthy
- Knowledge and skills to assist them in dealing with the stress, depression and anger associated with being HIV-positive
- Knowledge and skills to assist them in disclosing to partners, introducing condoms, convincing their partners to test and in dealing with infidelity
- Knowledge and skills to assist them in dealing with HIV in a household where people are scared of becoming infected
- Knowledge and skills to assist them in dealing with stigma and discrimination
- Knowledge and skills to assist them in planning their lives so as to provide support for their children.

The data on the perceived needs were then used to draw up a fourteen-session draft outline of possible topics to address in the support groups, developed around the specific needs of the women. After the needs were identified, and the draft programme had been developed, this draft was then implemented in two Tshwane-township community clinics, with a total of twenty HIV-positive women, used as pilot studies in order to refine the structure and content. During the first session of both pilot support groups the HIV-positive women were asked to discuss what they would like to address in the sessions and what they were expecting. The women in these pilot support groups were invited to give critical feedback which they may have at any point during the groups, if they felt something was missing from the programme, or if something seemed irrelevant. Following the implementation of the two pilot groups, the structured support group programme was finalised. This action research process is represented in Figure 4.1.



*Figure 4.1. The Action Research Process*

### 4.3 The Structured Support Group

The programme consists of ten sessions that were semi-structured so as to encourage group participation and experiential learning through the participation in games, role-plays, exercises, story telling, case studies and the sharing of experiences, feelings and ideas. A conscious effort was made during the design of the intervention to steer as clear as possible from any didactic sessions. Each session began with a different ‘icebreaker’, feedback from the members on their understanding and thoughts on the previous session, and the sharing of experiences and problems encountered during the week. The focus then shifted to the theme of the day.

A systems approach (Capra, 1997; Hanson, 1995) was used to assist in the development of the content of the programme. Various aspects of living with HIV were addressed, namely:

- Facilitating change in the individual,
- Focusing on the individual within the larger contexts, such as intimate relationships and families, and
- The community as a whole, with a focus on community attitudes, stigma and human rights.

Once the process of developing the structured support group was complete, a facilitator manual was compiled (Manual available on request). The manual gives detailed descriptions of each session, consisting of a session outline, explanations of all icebreakers and other exercises, conversation points that should be covered during each session, and background information on each session for the facilitator. A preparation guideline for each session is also included, as well as lists of materials that will be needed. The final structure of the programme is listed below, and is then followed by a more detailed outline of the ten sessions.

*Week 1: Introduction and Orientation*

*Week 2: HIV and access to Treatment*

*Week 3: HIV, Pregnancy and Birth*

*Week 4: The Emotional Experience of having HIV*

*Week 5: The Emotional Experience of having HIV (continued)*

*Week 6: HIV, Disclosure and Stigma*

*Week 7: Coping, Problem Solving, and Stress Management*

*Week 8: HIV and Relationships*

*Week 9: HIV in the household, Human Rights and Stigma*

*Week 10: Life Planning and Goal Setting*

*- Session One: Introduction and orientation*

The first session began with a “getting-to-know-you” icebreaker that served to help the members and facilitators get to know each other. A discussion of member’s expectations then followed in which members were asked to discuss what they were anticipating and what they were hoping to get out of the group. The facilitator then invited the members to discuss what they knew about support groups, and what they felt the meaning and benefits of participating in a support group are. Members were invited to suggest group rules and common objectives for the group, and also discussed what they expected from the facilitator. This session was used to create a relaxed and accepting group environment where participation of members was encouraged.

*-Session 2: HIV/AIDS, treatment and pregnancy*

The next session dealt with information on HIV and AIDS, information on treatment, and a focus on pregnancy with HIV and AIDS. The session began with an icebreaker called “positive names”, which is another exercise aimed at assisting the members in getting to know one another, and becoming comfortable with sharing within the group. The discussion on HIV and AIDS then began with the facilitator asking the group what questions they had on HIV, AIDS, treatment and pregnancy, and these questions were then deflected back to the group, mainly to give the facilitator an opportunity to gauge the level of understanding and knowledge of the group. The facilitator then discussed the different aspects of HIV, AIDS and treatment, including a discussion on the various stages of the illness, ways of transmission and protection, ways in which to stay healthy, and the different types of treatment. HIV and AIDS were explained using the metaphor of body soldiers (CD4 count) and body invaders (The HI-virus).

*-Session 3: Nutrition and living positively with HIV/AIDS*

The focus of session three was on pregnancy and healthy living with HIV, specifically focusing on nutrition and general health habits, such as sleep and exercise, and on how to stay healthy and live positively with the HI-virus. Pregnancy and HIV were discussed, focusing on the risks

associated with mother-to-child transmission, and how to prepare for childbirth. The core message of this session was that HIV is a chronic disease that can be managed through healthy living.

*-Session 4 and 5: The emotional experience of living with HIV*

The focus then shifted to the emotional experience of being HIV-infected. The aim of these sessions was to explain and help the participants understand the emotional experiences of being HIV-positive. At this stage, group members had started to form relationships with the other members in the group, and with the group facilitators. The icebreaker for this session aimed at enhancing group cohesion. The participants were then asked to draw their life-maps, including the role of HIV in their lives. Life-maps are pictures made by the members to represent various aspects of their lives. Members were invited to draw, use pictures from magazines, and write to depict as much as they wanted to share about their lives. The theory behind these life-maps lies in narrative therapy and encourages externalisation. Externalisation assists the client to “stand back from the problem” (Milner & O’Byrne, 2002, p40). In a support group setting, using externalization can assist the members in opening up to the group. By representing their life in a life-map, members can then discuss their picture as something separate from themselves and in so doing, make the process less daunting. Session four was allocated for the creation of the life-maps, and the session was then ended with a discussion on the member’s experience of doing the exercise. The members were then informed that in the following session they would present their life-maps to the rest of the group. The presentation of the life-maps commenced in the following session, with the facilitators reflecting and probing where necessary. Once the presentations were completed, the facilitator asked the group to identify possible problem areas (e.g. depression) and coping techniques (e.g. denial) from their stories, and these were then discussed and explained by the facilitator using the stages in crisis management (Kubler-Ross, 1989).

*-Session 6: HIV, Disclosure and stigma*

In session six, members who had disclosed their HIV-status were invited to share their experience of disclosure with the group, and describe how they had gone about it. The women who wanted to disclose were invited to discuss their feelings about disclosure, and any planned strategies. The difficulties of disclosure were also discussed, with special reference to the negative role of stigma in the community. The group then did role-play exercises to give those who were thinking about disclosing an opportunity to disclose in a safe environment.

*-Session 7: Coping, problem solving, and stress management*

Coping with emotional, social and physical stressors is an important part of surviving and living positively with the virus. The coping skills and stress management session began with a group problem solving exercise. The session theme was then introduced, and each participant was invited to share a positive way of coping with a difficult situation. Each member was also asked to discuss a situation in which she had had difficulty coping. The coping model of Lazarus and Folkman (1984) was used to distinguish between problem focused and emotion-focused situations. Problem solving skills and stress management, rational thinking processes, use of social support and externalization of emotions were introduced as coping skills and applied to the situations with which they had difficulty.

*-Session 8: Intimate relationships*

Session eight dealt with interpersonal relationships. The session began with an icebreaker and discussion on positive and negative experiences in intimate relationships. The members were then invited to discuss the impact HIV had on their relationships with an infected or uninfected partner, and the subject of condoms was also discussed. Role-plays were then done to assist the women in negotiating condom use with their partners. Women's inferior position in the community and violence in intimate relationships were then discussed with a focus on the improvement of relationships.

*-Session 9: HIV in the household, human rights and stigma*

For this session women could bring a family member to join in the group discussion. The aim of involving next of kin in the group was to support family members and strengthen their relationships, as well as give the members of the group a safe opportunity to practice disclosing to people from outside of the group, and from outside of their "sub-system". Following the icebreaker, the group and the visitors introduced themselves. A discussion on safety in the household with regard to HIV, relationships with family members and disclosure to children was then facilitated. A broader community focus was then introduced with a discussion on how to deal with stigma and discrimination, and on the human rights of HIV-positive people. By knowing their rights, women would be able to identify and deal with aspects of discrimination. The members were then invited to share stories of how they feel their rights may have been infringed, or if they had been affected by either stigmatising attitudes or discrimination in the past.

*-Session 10: Life planning and goal setting*

The final session of the programme focused on goal setting and future planning. This included setting short- and long-term goals to assist in giving the members new meaning and hope. This was followed by a discussion on ways in which the members could generate an income to

provide for their families. Members brainstormed on possible means of making extra money, and the option of joining an income –generation project was also discussed.

#### 4.4 Implementation of the Intervention

##### 4.4.1 Recruitment of Participants

Pregnant HIV-positive women were recruited to participate in the study by voluntary HIV counselling and testing (VCT) counsellors in four clinics in Atteridgeville and Mamelodi. The clinics provide medical services to a mainly black, very low to middle socio-economic class urban population (See chapter one for a description of the communities). Following their HIV-positive diagnosis, pregnant women were informed about the Serithi project and were invited to join the support group. They received an information leaflet (See Appendix) about the project. If they agreed to participate, they were then requested to sign a consent form, giving their contact details, and permission for someone from the project to get in touch with them about their participation. The participants were then contacted and an appointment date was made, either at the clinic where the women had been tested, or at the Serithi project offices, based at Kalafong hospital, in Atteridgeville.

At the interview, the women were then given more information about the project and about their possible participation. Once the interviewer was confident that the participant had all the necessary information, she was then given an informed consent form (See Appendix) to sign if she was willing to participate in the study. The women were also informed that they would be subsidized for any travel expenses. The informed consent form is discussed in section 4.4.1. Once the participant had officially agreed to join the project, the first interview then commenced. This interview was used as the pre-test for this study. The scales used in the questionnaire will be discussed in section 4.5.2. The same questions were asked in a similar interview at 3-months post delivery, which was used as the post-test interview (Questionnaires available on request).

Following their first interview, women were invited to join the structured support group. Those that agreed to join the groups were then given an estimated date for the beginning of the next group, and informed that they would be contacted by one of the research assistants a week prior to the first session to confirm their attendance. Women who decided to join the support group formed the intervention group, while women who decided not to participate in the support groups made up the control group (non-intervention group).



It was initially planned that one group would begin in each township every month. This was eventually not possible, as the recruitment rates at the clinics varied. About 50% of the women who joined the Serithi project ultimately joined the support groups. A minimum of ten women would be recruited for each group so as to have an adequate group size. Due to the fact that the groups were being simultaneously run in two townships, a decision was made for a research assistant to phone the prospective participants following the recruitment of every fifty women onto the Serithi project, so as to increase the chances of having at least ten participants in each group. Hence, after every fifty new women had been recruited onto the Serithi project, a starting date for the new groups was made, and a research assistant began with the telephonic confirmation. The research assistant was given a telephone interview (Available on request) to utilise when phoning the women, so as to standardize the recruitment procedure. In this interview, the women were asked if they would like to attend a structured HIV support group that runs for a period of ten weeks, and would begin on the specified date during the following week. Those who declined the invitation to join the groups were then asked a series of questions assessing their knowledge on support groups, and their reasons for not accepting the invitation. The research assistant then compiled a confirmation list of the expected group participants for the first session.

#### 4.4.2 Training and Supervision of Facilitators

The groups were facilitated by psychology Masters students from the University of Pretoria and an HIV-positive woman from the Serithi project. It was felt that having an HIV-positive co-facilitator would eradicate any language and cultural issues, and would also provide a “role-model” for the group members, and present them with a positive view of the virus. In preparation for the intervention, six Masters students and four experienced HIV-positive women (two from each township) took part in a comprehensive training workshop. This workshop was split into four separate themes. These themes included HIV/AIDS knowledge, counselling and group facilitation skills training, training on how to implement the sessions, and finally, the ethics involved in working with HIV-positive women in a group setting and in research. Following the training on these four themes, the facilitators then took part in role-play group sessions.

During the study, the facilitators were supervised by a psychologist and the researcher. Debriefing sessions were held after each support group session. These debriefing sessions included feedback on their thoughts from the previous session, feedback and debriefing on the most recent session, and a discussion on the following weeks’ session material. Any issues that the facilitators may have had in the session were discussed. The facilitators were also required to hand in process notes and register sheets of participants at these meetings. For reasons of

quality control, the researcher sat in on many of the sessions as a co-facilitator, and took notes on the process and content of the groups. These notes were then compared to those of the facilitators so as to ensure that the facilitator's notes were recording all the important data from the sessions. A facilitator assessment form (Available on request) was also completed by the researcher, and feedback was then given to the facilitators during the debriefing session.

#### 4.4.3 Implementation of the Programme

Over a period of one year (02/04/2005 – 31/03/2006), ten support groups, five in each township, were implemented for this study. During this time, a total of 191 HIV-positive pregnant women were recruited into the Serithi project, of which a total of 98 agreed to participate in the structured support group. Of these 98 participants, 72 had returned for their follow-up post-intervention interview at three months post-delivery in time for this study, and these participants make up the intervention group. Of the 95 women who declined the invitation to participate in the intervention, 84 had returned for their follow-up post-intervention interview at three months post-delivery in time for this study. These participants make up the non-intervention, or control group. The total sample for this study is 156 HIV-positive women. The characteristics of the sample population are described in chapter 5.

In Table 4.1, the ten groups that were implemented for this study are presented.

<u>Township</u>	<u>Group Number</u>	<u>Starting Date</u>	<u>Ending Date</u>	<u>Total Number of Participants</u>	<u>Number of Participants eligible for this Study</u>
Atteridgeville	1	01/04/2005	10/06/2005	10	6
Mamelodi	1	02/04/2005	11/06/2005	11	11
Atteridgeville	2	13/05/2005	22/07/2005	11	8
Mamelodi	2	14/05/2005	16/07/2005	10	9
Atteridgeville	3	17/06/2005	02/09/2005	10	9
Mamelodi	3	02/07/2005	09/09/2005	8	4
Atteridgeville	4	29/07/2005	07/10/2005	8	6
Mamelodi	4	16/09/2005	25/11/2005	7	5
Atteridgeville	5	16/09/2005	02/12/2005	11	9
Mamelodi	5	13/01/2006	31/03/2006	12	5
			<b>Total:</b>	<b>98</b>	<b>72</b>

Table 4.1: Groups Implemented

Session attendance was a significant concern in assessing the impact of the intervention. As this study seeks to measure the impact of a structured support group, participants who attended a limited number of sessions could have a considerable influence on the overall outcome of the programme. It was therefore decided that the group of 72 participants would be split into two groups for the analysis:

- The adequate-attendee group, including women who had attended five or more session (N=52).
- The non-adequate attendee group, including women who had attended less than five sessions (N=20).

In the analysis, the impact of the intervention has been assessed by comparing the outcomes of the adequate-attendee group (52 participants) to those of the control group. The outcomes of the total support group sample (72 participants) and of the non-adequate attendees (20 participants) were also assessed, so as to gain a better understanding of the relationship that exists between participating in a structured support group and the number of sessions attended. A summary of the study sample split is presented below in figure 4.2.

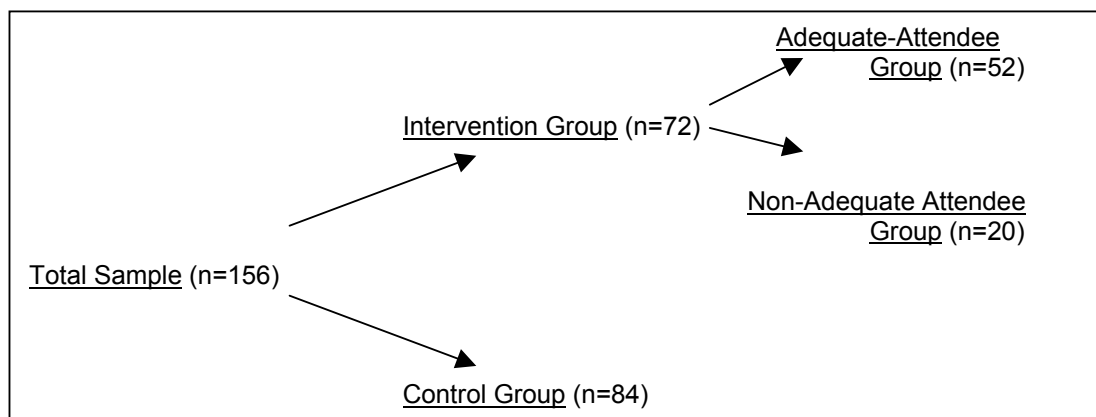


Figure 4.2: Sample Summary

Included in the post-intervention interview were questions assessing the support group participant's reasons for not attending all the sessions. These reasons are discussed in the following chapter. The control group was also questioned on their reasons behind declining the invitation to join the programme.

## 4.5 Ethical Considerations

### 4.5.1 Recruitment Procedures and Informed Consent

The Serithi project recruited pregnant HIV-positive women from four clinics in the townships of Atteridgeville and Mamelodi. During the women's HIV post-test counselling session, following their HIV diagnosis, they were informed by the counsellor about the Serithi project and given an information leaflet (See Appendix). Those who were interested were requested to supply their contact details, and give permission for someone from the project to get in contact with them to make an appointment for an interview. During their first interview the participants were informed about the Serithi project and the structured support group study, and were asked to sign an informed consent form (See Appendix). The women were then invited to participate in the structured support group study. All newly recruited women from the Serithi project were phoned before the start of each new group to confirm the participant's attendance, and those who declined the invitation were asked to answer several questions regarding their reasons for not wanting to attend and to assess their knowledge of support groups.

### 4.5.2 Cultural Considerations

Due to the cultural context of this study, attention was paid to cultural differences between the members of the group and the facilitators. This included language barriers and economic considerations.

#### 4.5.2.1 Language Barriers

All interviews for this study were conducted in the participant's language of choice. The research assistants who interviewed the participants were all fluent in at least five of the official South African languages, and the participant was given a choice of the language of the interview. In the support groups, all groups had at least one co-facilitator who could speak African languages, including an HIV-positive co-facilitator from the same community as the group members. The participants were encouraged during the first session to speak in their home-language, and not to feel pressured to speak in English. The co-facilitator then also acted as a translator for the English speaking facilitator.

#### 4.5.2.2 Economic Considerations

The socio-economic context within which this study took place played an important role in the design of this study. The majority of the participants were unable to afford transport to and from the clinics where the support groups took place, and so financial remuneration was provided at each interview and group session.

#### 4.5.3 Confidentiality

From the time participants were recruited onto the Serithi project, the importance of confidentiality was stressed as a high priority. Confidentiality was mentioned in the first information leaflet the women received from the counsellor, and was then discussed in detail during their first interview. Women were informed that their names would not be used to identify them in the research, and that all of their information would be locked away in a filing cabinet at all times. They were also informed that none of their personal information would be used in the writing up of the data. Confidentiality was also addressed in the first support group session. Participants were informed about the importance of confidentiality in the groups, and that the support group would be a place where they would be able to feel comfortable in speaking freely, and not have to worry about being judged, or stigmatised. Confidentiality was included as one of the rules in all ten groups.

### 4.6 The Evaluation of the Support Groups

#### 4.6.1 The Approach and Design of the Study

To evaluate the outcome of the support group intervention a quasi-experimental design was used as the core of the research. Qualitative data was also gathered so as to augment the quantitative data. The use of multi-methods allows the researcher to get a perspective of multiple understandings of the reality as emphasised in post-modernistic thought. Post-modernistic thought emphasises the importance of multiple understandings of reality (Duncan & Lazarus, 2001). Although assumptions of the positivistic approach have been underlined in the research design, it is acknowledged that many different factors can have an impact on behaviour. To account for some of the variations in the context and the experiential factors involved, qualitative questions have been posed to the participants after taking part in the intervention. These questions on which their experiences of the sessions have been explored serve to augment the results of the quantitative study. The overall approach to the study can therefore be viewed as a multi-method approach, which involves the combination of qualitative and quantitative methods.

Multi-method research takes three forms, which include triangulation, facilitation and complementary (Duncan & Lazarus, 2001). The two set of data were used to compliment each other, as they provide different viewpoints of the outcome of the support groups. This is a strategy for improving the validity and reliability of research findings.

Utilizing this complementary multi-method research strategy, evaluation theory has been employed in the assessment of the impact of the structured support group. A quasi-experimental design was used, which historically dominates evaluation strategy (Trochim, 2001). In this study, summative evaluation has been employed to measure the effects or outcomes of the intervention. Summative evaluation examines evidence relating to indicators of programme effectiveness, and for this reason often utilises quasi-experimental or ex post facto research (Duncan & Lazarus, 2001). The type of evaluation for this study is further defined as an outcome evaluation, which is a sub-division of summative evaluation.

The participants were interviewed on two occasions to gather data for the evaluation of the intervention. Both groups (intervention-group and control-group) were interviewed after recruitment during pregnancy as this served as the pre-test of this study. Participants were questioned on their medical history and demographics, such as their age, gender, race, language, marital status, level of completed education, income, living situation and whether they had disclosed their HIV status or not. Following this, the participants then answered a variety of psychometric scales used in the evaluation of the intervention. The intervention group then took part in the ten session structured support group programme, while the control group did not receive any intervention. Both groups of participants were then re-assessed at about 3 months post-delivery. The results of the two groups were then compared to evaluate the impact of the intervention. This post-test interview comprised of the same quantitative scales as the pre-test interview, and in addition to this, also contained two separate qualitative sections. One aimed at gaining a better understanding of the experiences of the intervention group participants, and the other questioning the control group on their reasons for not deciding to participate in the programme, so as to gain a better understanding of non-attendance. The quantitative scales used as quantitative measures will now be described, followed by a description of the qualitative evaluation.

## 4.6.2 Quantitative Measures

### 4.6.2.1 Depression Scale

Participants in the study completed the Centre for Epidemiologic Studies Depression scale (CES-D, Radloff, 1977). The CES-D has been extensively utilised to describe depressive symptoms among individuals living with HIV. “It taps cognitive, affective and somatic aspects of depression, and it is advantageous because it minimizes confounding of symptoms between HIV and depression” (Catz, 2002, p54). The scale has four separate factors, namely depressive affect, somatic symptoms, positive affect and interpersonal feelings. The scale’s 20 items assessing the experience of depressive symptoms during the previous week are rated from rarely or less than one day in the past week, to most of the time or 5-7 days in the past week. The total scores range from 0 to 60. According to Radloff (1991) a few cut off points were identified from research done in the USA:

- Scores of 16 and above can be used in identifying people with *possible* depression;
- Scores of 23 and above can be used to identify *definite* cases of clinical depression in the USA samples.

Many studies have demonstrated the measure’s validity and high internal consistency and test-retest reliability (Radloff, 1991). Simoni and Ng (2000) found a Cronbach alpha reliability coefficient of 0,90 with an HIV-positive population. In this study a reliability coefficient of 0.88 was found. However, the cut off points have not yet been confirmed in a South African sample.

### 4.6.2.2 Self-esteem Scale

The Rosenberg (1979) Self-esteem Scale (RSE) is a 10-item scale, which includes questions about competence, power or control, moral and social worth, and acceptance and was used to assess self-esteem in this study. The scale attempts to achieve a uni-dimensional measure of global self-esteem, by measuring the extent to which one values and feels content with oneself. The ten question scale has four response choices, ranging from “strongly agree” to strongly disagree”. The scores range from 10 to 40, with 40 indicating high self-esteem. In a study conducted by McCarthy and Hoge (1982), the scale produced an alpha value of between .74 and .77 (N=1852) after a one-year follow-up. Sullivan (2001) found a test-retest reliability of .82 and Cronbach’s alpha of .77. In this study the Cronbach alpha coefficient was 0.75.

#### 4.6.2.3 Coping Scale

Coping skills were assessed by adapting the brief version of the COPE inventory (Carver, 1997; Carver, Scheier & Weintraub, 1989) for HIV-positive people. This questionnaire uses Lazarus and Folkman's (1984) model of coping behaviour. The COPE has been used in a number of health-related studies including a study with HIV-positive men (Antoni et al., 1991). The original Brief COPE is a 14-scale/28-item questionnaire derived from the COPE, which demonstrated good psychometric properties (Carver et al., 1989). Hastings & Brown (2002) found a Cronbach's alpha reliability coefficient of 0.83. In this study the questionnaire was adapted to be used with HIV-positive women. Twelve scales were used assessing active coping, acceptance, planning, positive reframing, religion, using emotional support, using instrumental support, helping others (positive coping) and self distraction, denial, venting, substance use and feelings of no control (negative coping). A factor analysis of the adapted scale was done. Two main factors could be extracted: positive coping and negative coping. Confirmation was also found for 8 of the 12 scales. The reliability of the adapted coping scale as a whole was 0,625. For positive coping reliability was 0.75 and for negative coping reliability was 0.54. This is acceptable if the various ways of coping measured in the instrument is taken into account.

#### 4.6.2.4 Social Support Scale

The Multidimensional Social Support Inventory (MSSI) of Bauman and Weiss (1995) was adapted to assess the perceived social support women experienced. The instrument was developed to assess the five domains of social support among minority women with HIV/AIDS in the USA. For this study, practical, emotional and affirmational support has been combined into a category termed "positive support". In addition, the scale also assesses HIV-related support and negative support. Negative support includes receiving unwanted help and advice, being dominated and not having one's wishes respected. In each domain the respondent indicates the availability and adequacy of support they receive in three specific situations. Answers are coded on a four-point scale (as much as I need, quite a lot, only a little and no support) measuring the perception of the adequacy of the support. It was decided to focus on the perception of adequacy of support because it is perceived support, rather than the actual level of support, that impacts on mental health (Serovich et al., 2001). Bauman and Weiss (1995) reported an internal consistency of 0,84 for the total score. They also reported good test-retest reliability over a two-week period. In this study a reliability score of 0.87 was found for positive support and 0.56 for negative support.



#### 4.6.2.5 Disclosure

The level of disclosure was assessed with a question asking participants if they had disclosed their HIV status to anyone since their diagnosis.

#### 4.6.2.6 Personal and Perceived Community Stigma Scales

The experience of personal and perceived community stigma is assessed using and adapting items from existing questionnaires developed by Westbrook & Bauman (1996). The two scales, consisting of 12 questions each, are similar, however the personal stigma scale focuses on the person's own experience of stigma and internalized blame related to HIV and the perceived community stigma scale focuses on how they perceive most people in the community to react towards HIV/AIDS. The questions asked focus on interpersonal distance, and affective aspects such as tendency to blame. The items are phrased positively and negatively and respondents indicated their level of agreement on a 4-point Likert-type scale (strongly agree, agree, disagree and strongly disagree). Total scores for the scales are calculated in such a way that a high score indicates the experience of high levels of stigma. The reliability of the scales was 0.742 for the personal stigma scale and 0.842 for the perceived community stigma scale.

#### 4.6.2.7 Enacted Stigma Scale

Enacted stigma, or the experience of discrimination, is assessed using 10 questions related to various types of discrimination experienced by HIV-positive women. The participant answers the questions in terms of the degree to which they have had such experience (no experience, little experience, or lots of experience), such as "I have lost friends because I am HIV-positive". A scale score was calculated with a minimum of 0 and a maximum of 20, indicating the level of experience of enacted stigma.

#### 4.6.2.8 Knowledge Scale

A scale of 25 true or false knowledge questions has been used to assess the participant's knowledge of the nature, transmission and diagnosis of HIV. The first 15 true or false questions are seen as general knowledge questions on HIV, such as "A person can have HIV for many years before becoming ill with AIDS". The following 10 questions are more specific to what is discussed in the intervention, such as "A CD4 count measures how well your body can fight off infections". The questions have been split in this way so as to assess the impact of the intervention on the participant's general knowledge of HIV, as well as knowledge specific to the

intervention. General knowledge on HIV is defined for this study as knowledge that the participants should have, regardless of their participation in the intervention. Questions are answered as true and false and a total knowledge score is calculated. The scale has an adequate reliability ( $\alpha=0.65$ ).

#### 4.6.3 Qualitative Assessment

##### 4.6.3.1 The Experience of Participation in the Support Group

Qualitative measures were used in this study to augment the quantitative. In the post-intervention interview, the group participants were questioned on their experience of the structured support group intervention, so as to attain a more comprehensive understanding of the impact of the intervention. The questions focused on their expectations and experiences of the group interaction, the facilitation and the content addressed in the programme. It also included questions on what parts of the programme they learnt the most from, and which parts they felt were not valuable. Finally the participants were asked how their lives had changed since joining the support group intervention.

##### 4.6.3.2 Reasons for not Attending the Group

The control group participants were again questioned on their reasons for not attending the intervention. In addition they were asked whether they felt there was some other kind of support, other than a support group, which would be beneficial for HIV-infected individuals.

#### 4.7 Data Analysis

The data obtained from the pre- and post-intervention interviews were analysed comparing the intervention-group with the control-group to examine statistically significant differences in the outcome. A descriptive analysis of the quantitative data was performed using the SPSS 13.0 for Windows software programme.® Due to the fact that a randomised control group was not utilised, assumptions could not be made with regard to the similarity of the two groups of women. It was therefore necessary to keep in mind that there could be differences in the type of women who would volunteer for a support group and those who do not. The data of the pre-test was therefore compared between the two groups to investigate similarities between the groups at the time of recruitment. An analysis of covariance was utilised in the case of variables that were found to differ at the pre-intervention stage, so as to control for these differences.

To evaluate the effect of the support group on outcome data, data from both groups was analysed through paired t-tests and an analysis of variance (and covariance where applicable) to determine the estimated impact of the support groups. The control group was used to rule out the effect of extraneous variables such as time and giving birth, which could have had an impact on the results of the analysis. An analysis was also undertaken to determine the effect of the number of sessions the women attended on the outcomes. The intervention group was split into an adequate attendee group (attended five or more sessions), and a non-adequate attendee group (attended four or less sessions) (See section 4.4.3 for a summary).

The qualitative questions about the participant's personal experience of the intervention and the control groups' reasons for not attending groups were coded and analysed by myself and a co-researcher using content analysis (Silverman, 2000). Themes emerging from the data were identified and compared by both researchers. These themes were then used to classify the responses.

#### 4.8 Conclusion

In this chapter the methods used to evaluate the impact of structured support groups was outlined. The study was done from a post-modernistic complimentary research perspective, using a quasi-experimental design. This included an experiment and a control group, and pre- and post-test assessments. The intervention was designed with the specific needs of African women in mind. This intervention was developed from a systems theory viewpoint, addressing all levels of the system. In the following chapter, the results obtained from this study will be presented.

## Chapter 5 – Results

### 5.1 Introduction

In this chapter, the results from the data analysis are presented in three sections. First, the sample population is described, followed by the presentation of the results from the pre-intervention analysis. The pre-intervention analysis was carried out, in order to compare the intervention group with the control group, in terms of the outcome variables, prior to the implementation of the intervention. This is then followed by the presentation of the results from the outcome evaluation. The changes that took place between interviews in the intervention group and the control group were compared in terms of the outcome variables, so as to measure the impact of the intervention. The qualitative data on the experiences of the intervention group are also presented. The implications of these results will be discussed in the following chapter.

### 5.2 Sample Demographics

The total sample recruited for this study comprised of 156 pregnant HIV-positive women from the Tshwane townships of Atteridgeville (n=80) and Mamelodi (n=76). The mean age of these participants was 27.08 years, ranging between 18 and 40 years. A large majority of the sample were Sepedi speaking (n=66), followed by Zulu (n=27) and then Setswana (n=23). The remaining 25% of the sample spoke other South African languages, with one of the participants' home language being Shona, which is an indigenous language from Zimbabwe (Table 5.1).

**Table 5.1: Home Language**

	<u>Frequency</u>	<u>Percent</u>
Sepedi	66	42.3%
Zulu	27	17.3%
Setswana	23	14.7%
Tsonga	13	8.3%
Ndebele	8	5.1%
Sotho	6	3.8%
Seswati	6	3.8%
Xhosa	3	1.9%
Venda	3	1.9%
Shona	1	0.6%

Of the 156 women in the study, 88.9% (n=138) had attended at least secondary school, while 11.5% had primary school education or no schooling (Table 5.2).

**Table 5.2: Highest level of education**

	Frequency	Percent
No schooling	3	1.9%
Primary	15	9.6%
Secondary	118	75.6%
Tertiary	20	12.8%
Total	156	100.0

In terms of marital status, the majority of the participants were in a relationship, but not married, with the remaining women either being married or single (Table 5.3).

**Table 5.3: Marital Status**

	Frequency	Percent
Single	13	8.3%
Married	25	16.0%
In a relationship, but not married	118	75.6%
Total	156	100.0

Of the women that were in a relationship, 41.25% (n=59) were living with either their partner or their husband. Participants shared their home with a mean of 2.97 other family members, with a range of between 0 and 15 family members per household, including:

- Parents (37.2%),
- Daughters (27.6%),
- Sons (31.4%),
- Parents-in-law (2.6%),
- Grandchildren (1.9%),
- Siblings (28.5%),
- Grandparents (7.1%) and
- Other relatives (32.3%).

Regarding the participants' HIV status, the majority of the participants had known about their HIV status for less than a month (Table 5.4).

**Table 5.4: Time since Diagnosis**

	Frequency	Percent
1 week or less since diagnosis	67	43.0%
Between 1 week and 1 month	19	12.2%
More than 1 month	63	40.4%
Total	149	95.6%
No date of diagnosis available	7	4.4%
Total	156	100.0

When asked about the HIV status of their partners, 43.6% (n=68) of the participants stated that their partners had never had an HIV test, while 27.6% (n=43) of the partners had been tested for HIV (of which only 16 participants knew of a positive HIV result). The remaining 28.8% of the women were either single (n=13) or did not know if their partner had been tested for HIV (n=32). Aside from their partners, participants also had knowledge of family members and non-relations who had been infected with HIV (Table 5.5).

**Table 5.5: Knowledge of other HIV-infected individuals**

	Frequency	Percent
HIV-infected partner	16	10.2%
HIV-infected family member	45	28.8%
HIV-infected non-relation	47	30.1%

The socio-economic status of the sample exemplifies the disadvantaged situation in which the majority of the participants were living. Just over three-quarters of the sample did not have a regular income. Over 40% of the sample had a monthly household income of less than R1000 (\$161), with the mean monthly household income of R1587.18 (\$255). This monthly income was being shared between a mean of 4.59 people per household. The per capita income was less than R350 (\$56.5) a month. Forty-five percent were living in homes made of material other than brick/cement, such as mud, plastic, cardboard, corrugated iron, prefab and wood. A quarter of the participants (24.4%, n=38) were living in homes that did not have a flushing toilet inside the house, and only 22.4% had piped water inside their homes. From this, it is clear that these women were living in very poor socio-economic conditions. In Table 5.6, the range of monthly household income in this sample is displayed.

**Table 5.6: Monthly Income per household**

	Frequency	Percent
No income	5	3.2
R1 - R999	64	41.0
R1000 - R1999	34	21.8
R2000 - R2999	21	13.5
R3000 - R3999	13	8.3
R4000 - R4999	4	2.6
R5000 - R5999	4	2.6
R6000 and up	4	2.6
Total	149	95.5
Missing answer	7	4.5
Total	156	100.0

### 5.3 Pre-intervention Analysis

Due to the fact that randomised sampling was not possible, differences between the control group and the intervention group were examined, to investigate the comparability of the groups. Analyses were conducted between the entire intervention group (n=72) and the control group (n=84), as well as between the adequate-attendeer group (n=52) and the control group, to improve the validity in assessing the impact of the intervention.

#### 5.3.1 Sample Demographic Differences

Differences were found between the women who decided to attend the support groups and the women who did not, in terms of their socio-economic status. A significant difference ( $p < 0.05$ ) was found between these groups in terms of the monthly household income, with the support group participants having a mean of R1395.2 (\$200) brought into their home per month, compared to a mean of R1685.87 (\$240) per month in the control group. Another interesting difference was that the intervention group displayed lower levels of employment (Table 5.7).

**Table 5.7: Chi-square of Regular income**

	Regular income		Total
	No	Yes	
<b>Control Group</b>	61 (72%)	23 (28%)	84
<b>Intervention group</b>	59 (81.9%)	13 (18.1%)	72
Total	120	36	156

### 5.3.2 Pre-intervention Depression

An independent-sample t-test showed no significant difference in depression between the two sample groups before the implementation of the programme. Although not significant, the intervention group had a higher mean depression than the control group (Table 5.8).

**Table 5.8: Pre-intervention Depression**

		N	Mean	Std. Deviation	t-value	p-value
Depression Score (Pre-intervention)	Control group	84	15.7797	11.69922	-0.853	0.395
	Intervention group	72	17.6062	14.68786		

### 5.3.3 Pre-intervention Self-esteem

No significant difference was found between the groups in terms of self-esteem prior to the implementation of the intervention (Table 5.9).

**Table 5.9: Pre-intervention Self-esteem**

		N	Mean	Std. Deviation	t-value	p-value
Self-esteem Score (Pre-intervention)	Control Group	84	32.3117	3.85792	-0.13	0.990
	Intervention Group	72	32.3077	3.51768		

### 5.3.4 Pre-intervention Coping

Although the active coping score of the entire intervention group was not found to be significantly different to that of the control group, the adequate-attende group did show significantly higher active coping prior to the implementation of the structured support group programme (Table 5.10). No significant differences were found with regard to negative coping.

**Table 5.10: Pre-intervention Active Coping**

		N	Mean	Std. Deviation	t-value	p-value
Active Coping Score (Pre-intervention)	Adequate Attendee Group	52	33.2455	3.42230	-2.370	0.019
	Control group	84	31.7160	3.72235		



### 5.3.5 Pre-intervention Support

No differences were found between the groups in terms of support. Positive support, HIV support and negative support scores were almost identical between the groups (Table 5.11).

**Table 5.11: Pre-intervention Support**

		N	Mean	Std. Deviation	t-value	p-value
Positive Support Score (Pre-intervention)	Control Group	84	20.57	4.778	1.226	0.222
	Intervention Group	72	19.56	5.576		
HIV support score (Pre-intervention)	Control Group	84	5.56	2.304	-0.427	0.670
	Intervention Group	72	5.72	2.445		
Negative Support Score (Pre-intervention)	Control Group	84	2.63	2.683	-1.212	0.227
	Intervention Group	72	3.18	2.980		

### 5.3.6 Pre-intervention Disclosure

Although only approaching significance ( $p=0.077$ ), a difference was observed between the groups in terms of disclosure prior to the implementation of the intervention (Table 5.12).

**Table 5.12: Pre-intervention Disclosure**

	Disclosure?		Total
	No	Yes	
Control Group	36	48	84
	42.9%	57.1%	100.0%
Intervention Group	21	51	72
	29.2%	70.8%	100.0%
Total	57	99	156
	36.5%	63.5%	100.0%

### 5.3.7 Pre-intervention Knowledge

The level of knowledge was also found to be almost identical between the groups (Table 5.13). The difference in terms of the HIV “applied knowledge” was also non-significant, although only 62 participants answered these questions, as they were added to the questionnaire after the recruitment of participants had already commenced.

**Table 5.13: Pre-intervention Knowledge**

		N	Mean	Std. Deviation	t-value	p-value
General Knowledge (Pre-intervention)	Control Group	84	10.7713	2.39312	-0561	0.576
	Intervention Group	72	10.9901	2.47230		
Applied Knowledge (Pre-intervention)	Control Group	29	8.0345	1.52322	-0.345	0.732
	Intervention Group	33	8.1717	1.59887		

### 5.3.8 Pre-intervention Stigma

No significant differences were found between the sample groups in terms of internalised personal stigma, perceived community stigma and enacted stigma/discrimination, prior to the intervention (Table 5.14).

**Table 5.14: Pre-intervention Stigma**

		N	Mean	Std. Deviation	t-value	p-value
Personal stigma score (Pre-intervention)	Control group	84	4.5783	2.64303	1.046	0.297
	Intervention group	72	4.1387	2.53496		
Community stigma score (Pre-intervention)	Control group	84	9.5312	2.67417	1.063	0.289
	Intervention group	72	9.0240	3.26386		
Enacted stigma score (Pre-intervention)	Control group	84	0.2317	.90675	-1.197	0.057
	Intervention group	72	0.7500	2.25020		

### 5.3.9 Reasons for not participating in support groups

Participants who declined the invitation to attend the support groups were questioned on their reasons for not participating. Following the content analysis of these participants’ responses, four themes were identified:

- 1) Work (28%)

- 2) Mind-set (20%)
- 3) Birth of their baby (19%)
- 4) Fear of stigmatisation (10%)

#### Work

One of the primary reasons for declining the invitation to participate in the intervention was that the participant was working. Almost 30% (n=23) of the control group had full time jobs. This was a key restricting factor to the non-attendance, because many of them stated that they would have liked to attend the programme, for example:

- *"I would love to attend, however it clashes with my work schedule";*
- *"I wanted to attend the support group but because of work I was unable to attend".*

#### Mind-set

Others reasons given by the women were associated with their mind-set, or feelings towards participation. Some participants did not have the motivation, or felt they did not need to attend the group or admitted to not yet being ready to accept their HIV-positive status:

- *"There was nothing that I wanted to know or hear. I was just lazy";*
- *"I don't know a reason why I did not attend. I just promised I would come and then never did";*
- *"I felt that I am fine and that I can cope";*
- *"I did not yet accept that I was HIV-positive and that people within the group will see me and talk about my being HIV-positive";*
- *"At the time I did not want to associate myself with anyone, I wanted to be alone".*

#### Birth of their baby

Others declined due the fact that they had just had their baby. Several participants also mentioned cultural beliefs around the baby:

- *"I gave birth earlier than expected and was not able to attend";*
- *"My baby is small. My family believe that if a baby sees many people while still small, the baby cannot sleep and she becomes restless".*

#### Fear of Stigmatisation

Participants also gave reasons stemming from the fear of stigmatisation, with some feeling that the venue was not private and feared identification as an HIV-positive, for example:

- *"Because these people are part of my community and somehow it could reach my family and there is someone in the family who is a loud mouth",*

- *“I’m afraid that I will meet people who know me, find out about my status and tell other people about it”,*
- *“People will see me, I will be uncomfortable when they would ask me why I keep on going in that place”;*
- *“There is a lot of people coming to this clinic and they will find out that I’m HIV-positive if they see me coming here”.*

#### 5.3.10 Summary of Pre-intervention Results

From the analysis of differences between the groups prior to the implementation of the intervention, it was found that the groups were mostly similar. Some differences were found, with regard to:

- Socio-economic status
- Disclosure rate
- Level of active coping

These differences could help to explain why the women ultimately decided to attend the support groups or not. Pre-intervention analysis was also conducted on the control group participants’ reasons for deciding not to attend the support groups, and their reasons were coded into four themes, including work, fear of stigmatisation, mind-set and the birth of their baby. In the following section, the results from the outcome analysis will be presented.

### 5.4 Outcome Analysis

The structured support group programme for HIV-positive pregnant women was implemented over a period of one year, as was discussed in the previous chapter. Following the implementation, the programme was assessed through an outcome evaluation, using a quasi-experimental design. In this section, the results of the outcome evaluation are presented in terms of the quantitative outcomes and qualitative data collected from the participants.

#### 5.4.1 Quantitative Analysis

##### 5.4.1.1 Post-intervention Depression

No significant differences in depression were found between the groups, although the results obtained from the paired-sample t-tests did show some interesting discrepancies between the groups. The control group showed a decrease on the depression scale between the pre- and

post-intervention interview. The intervention group showed a similar result, with a mean decrease in depression, but with a higher mean depression score. Although not significant, the discrepancy between these two mean scores is of interest, and will be discussed in the following chapter. Another interesting result was obtained in the separate analysis of the adequate-attende group, which showed a much small mean decrease and higher mean score on the depression scale between the two interviews. A relatively high standard deviation could, however, explain this discrepancy. The results of the paired-sample t-test analysis are displayed in Table 5.15.

**Table 5.15: Post-intervention Depression**

		N	Pre-intervention	Post-intervention	Mean difference	t-value	p-value
Depression Score	Intervention Group	72	17.6062	14.7865	-2.9029	0.020	0.984
	Control Group	84	15.7797	12.8897	-2.8558		
	Adequate-attende Group	52	15.4446	14.7585	-0.7598	0.0280	0.430

#### 5.4.1.2 Post-intervention Self-esteem

The intervention group's self-esteem score increased significantly more than the control groups self-esteem score (Table 5.16).

**Table 5.16: Post-intervention Self-esteem**

		N	Pre-intervention	Post-intervention	Mean difference	t-value	p-value
Self-esteem Score	Intervention Group	72	32.3194	35.2963	2.9769	-1.930	0.055
	Control Group	84	32.3117	34.1928	1.8203		
	Adequate-attende Group	52	32.3077	35.5641	3.2564	2.176	0.031

Cross-tab chi-square analysis preformed on the individual items of the scale at the post-intervention stage showed differences with regard to:

- A significantly larger number ( $p < 0.05$ ) of participants in the intervention group and the adequate-attende group feel they are able to do things as well as others, with 83.3%

- (n=60) of the intervention group and 90.4% (n=47) of the adequate attendee group strongly agreeing to this item, compared to 67.5% (n=56) in the control group.
- A significantly larger number ( $p < 0.01$ ) of participants in the intervention group and the adequate-attendee group respect themselves, with 80.6% (n=58) of the intervention group and 80.8% (n=42) of the adequate-attendee group strongly agreeing to this item, compared to 59% (n=49) in the control group.

#### 5.4.1.3 Post-intervention Coping

The intervention group scored significantly higher ( $p < 0.01$ ) in terms of active coping, compared to the control group (Table 5.17a).

**Table 5.17a: Post-intervention Active Coping**

		N	Pre-intervention	Post-intervention	Mean difference	t-value	p-value
Active Coping Score	Intervention Group	72	32.6373	35.1389	2.4894	-4.409	0.000
	Control Group	84	31.7160	32.5301	1.0370		
	Adequate-attendee Group	52	33.2455	35.8462	2.5976	4.868	0.000

Due to the fact that a significant difference was found between the groups in terms of positive coping at the pre-intervention stage, an analysis of covariance was also performed, so as to control for this discrepancy. This produced similar results to that of the t-test, confirming a significant difference ( $p < 0.01$ ) between the groups, following the intervention (Table 5.17b).

**Table 5.17b: Post-intervention Active Coping (Covariance)**

	Sum of Squares	df	Mean Square	f-value	p-value
Corrected Model	538.143(a)	2	269.072	22.126	.000
PreActiveCoping	324.966	1	324.966	26.722	.000
SupportGroup	153.101	1	153.101	12.590	.001
Error	1811.955	149	12.161		
Total	176637.000	152			
Corrected Total	2350.099	151			

No significant differences were found between the groups in terms of negative coping, though the intervention group's negative coping decreased more than the control group ( $p=0.204$ ).

Several significant differences were found between the groups in individual items on the coping scale, when analysed independently using the Chi-square test. These analyses showed differences in coping strategies with regard to:

- Talking to someone with similar experiences, with 52.8% ( $n=38$ ) of the intervention group answered "most of the time" to this item, compared to 26.5% ( $n=22$ ) in the control group ( $p<0.01$ ).
- Educating people about HIV and AIDS, with significantly fewer ( $p<0.01$ ) participants from the intervention group (16.7%,  $n=12$ ) and the adequate-attendee group (11.5%,  $n=6$ ) answering "almost never" to this item, compared with 39.4% ( $n=33$ ) of the participants from the control group answering "almost never" to the same question.
- Supporting other people with HIV, with 66.7% ( $n=48$ ) of the intervention group and 71.2% ( $n=37$ ) of the adequate-attendee group answering "most of the time" to this item, compared to significantly fewer ( $p<0.01$ ) participants in the control group (43.4%,  $n=36$ ).
- Receiving comfort and understanding from people, with 73.6% ( $n=53$ ) of the intervention group and 82.7% ( $n=43$ ) of the adequate-attendee group answering "most of the time" to this item, compared with a significantly fewer participants ( $p<0.01$ ) in the control group (51.8%,  $n=43$ ).
- Believing their HIV diagnosis had helped them change their life for the better, with 90.4% ( $n=47$ ) of the adequate attendee group answering "most of the time" to this item, compared to significantly fewer participants ( $p<0.01$ ) in the control group (72.3%,  $n=60$ ).
- Trying not to think about the situation, with 57.7% ( $n=30$ ) of the adequate-attendee group answering "most of the time", compared to a significantly higher percentage ( $p<0.05$ ) in the control group of 78.3% ( $n=67$ ).

#### 5.4.1.4 Post-intervention Support

Regarding the support scores of the groups at the post-intervention stage, significant differences were found related to positive support and HIV support. While the intervention group and adequate-attendee group had shown significant increases in positive support, the control group displayed a mean decrease in positive support. Significant differences were also found between the groups in terms of HIV support scores (Table 5.18).

**Table 5.18: Post-intervention Positive and HIV-related Support**

		N	Pre-intervention	Post-intervention	Mean difference	t-value	p-value
Positive Support	Intervention Group	72	19.56	20.30	0.7746	-2.617	0.010
	Control Group	84	20.57	18.89	-1.7108		
	Adequate-attendee Group	52	19.92	20.38	0.4615	2.192	0.030
HIV-related Support	Intervention Group	72	5.72	6.85	1.1250	-3.637	0.000
	Control Group	84	5.56	5.60	0.0241		
	Adequate-attendee Group	52	5.92	6.90	0.9808	3.380	0.001

No differences were found between the groups in terms of negative support (Table 5.19).

**Table 5.19: Post-intervention Negative Support**

		N	Pre-intervention	Post-intervention	Mean difference	t-value	p-value
Negative Support	Intervention Group	72	3.18	4.11	0.9306	-1.347	0.180
	Control Group	84	2.63	3.39	0.7952		
	Adequate-attendee Group	52	3.44	4.23	0.7885	1.453	0.149

Analyses on the individual items of the support scale showed the following differences between the groups:

- When asked to what extent they would be supported in a time of emergency, 48.1% (n=25) of the adequate-attendee group and 49.3% (n=35) of the intervention group answered “As much as I need”, compared to a significantly fewer participants ( $p < 0.01$ ) in the control group (31.3%, n=26).
- When asked to what extent to which people respect them, 47.9% (n=34) of the intervention group and 50% (n=26) of the adequate attendee group answered “As much as I need”, compared to significantly fewer participants ( $p < 0.01$ ) in the control group (22.9%, n=19).



- When asked whether they know someone that understands what they are going through, 48.1% (n=25) of the adequate attendee group and 45.1 (n=32) of the intervention group answered “As much as I need”, compared to significantly fewer participants ( $p < 0.01$ ) in the control group (22.9%, n=19).

#### 5.4.1.5 Post-intervention Disclosure

Following the implementation of the programme, the intervention group showed significantly higher ( $p < 0.01$ ) disclosure rates than that of the control group (Table 5.20a).

**Table 5.20a: Post-intervention Disclosure**

	Pre-intervention	p-value	Post-intervention	p-value
Intervention Group	51 (70.8%)	0.096	64 (88.9%)	0.009
Control group	48 (57.1%)		59 (70.2%)	
Adequate-attendee group	38 (73.1%)	0.069	46 (88.5%)	0.020

Due to the fact that a significant difference was found between the groups in terms of disclosure at the pre-intervention stage, an analysis of covariance was also performed, so as to control for this discrepancy. This produced similar results to that of the t-test, confirming a significant difference ( $p < 0.05$ ) between the groups, following the intervention (Table 5.20b).

**Table 5.20b: Post-intervention Disclosure**

Source	Type III Sum of Squares	df	Mean Square	f-value	p-value.
Corrected Model	5.019(a)	2	2.509	18.720	.000
PreDisclosure	3.796	1	3.796	28.322	.000
SupportGroup	.693	1	.693	5.169	.024
Error	20.375	152	.134		
Total	123.000	155			
Corrected Total	25.394	154			

#### 5.4.1.6 Post-intervention Knowledge

No significant differences were found between the groups in terms of their general knowledge about HIV and AIDS, following the implementation of the intervention. A difference was noted

between the groups in terms of their “Applied knowledge”, although only approaching significance (figure 5.21).

**Table 5.21: Post-intervention Knowledge**

		N	Pre-intervention	Post-intervention	Mean difference	t-value	p-value
General HIV-related knowledge	Intervention Group	72	10.9901	12.0000	1.0099	0.958	0.339
	Control Group	84	10.7713	12.2410	1.4002		
	Adequate-attendee Group	52	10.6209	12.0192	1.3984	-0.004	0.997
Applied HIV-related knowledge	Intervention Group	72	8.1717	8.3944	0.1313	-0.267	0.790
	Control Group	84	8.0345	7.9620	0.0000		
	Adequate-attendee Group	52	8.1528	8.4615	0.1806	1.860	0.065

Chi-square tests on individual items on the applied knowledge questions showed that the intervention group had more knowledge regarding:

- HIV-positive couples needing to use condoms, with 100% (n=52) of the adequate-attendee group and 98.6% (n=71) of the intervention group answering correctly, compared to significantly fewer participants ( $p < 0.01$ ) in the control group (91.4, n=74).
- CD4 count measuring how well body fights infection, with 100% (n=52) of the adequate attendee group and 98.6% (n=71) of the intervention group answering correctly, compared to significantly fewer participants ( $p < 0.01$ ) in the control group (85.2%, n=69).
- Treatment being provided to HIV-positive individuals once their CD4 count is below 200, with 100% (n=52) of the adequate attendee group answering correctly, compared to significantly fewer participants ( $p < 0.01$ ) in the control group (85.2%, n=69).

#### 5.4.1.7 Post-intervention Stigma

Paired-sample t-tests showed no significant differences across the groups in terms of personal stigma, perceived community stigma or enacted stigma scores. Although not significant, the adequate-attendee group showed the lowest personal stigma level (Table 5.22)

**Table 5.22: Post-intervention Personal Stigma**

		N	Pre-intervention	Post-intervention	Mean difference	p-value	t-value
Personal Stigma score	Intervention Group	72	4.1387	3.5182	-.6132	0.447	0.656
	Control Group	84	4.5783	4.0827	-.4401		
	Adequate-attendee Group	52	4.1055	3.4797	-.6258	-0.430	0.668

Despite there being no significant differences in the personal stigma scores post-intervention, cross-tab chi-square analysis, performed on the individual items of the scale at the post-intervention stage, showed differences with regard to:

- A significantly smaller number ( $p < 0.01$ ) of participants in the intervention group and adequate attendee group feels uncomfortable if people know they are HIV-positive, with 44.2% ( $n=23$ ) of the adequate-attendee group, and 41.7% ( $n=30$ ) of the entire intervention group agreeing to item one, compared to 58.5% ( $n=48$ ) in the control group.
- A significantly smaller number ( $p < 0.05$ ) of participants in the intervention group and the adequate attendee group feels ashamed if someone knows they are HIV-positive, with 17.3% ( $n=9$ ) of the adequate-attendee group and 20.8% ( $n=15$ ) of the intervention group agreeing to item two, compared to 36.6% ( $n=30$ ) in the control group.
- A significantly smaller number ( $p < 0.05$ ) of participants in the intervention group and the adequate attendee group think that HIV is a punishment for bad behaviour, with 11.5% ( $n=6$ ) of the adequate attendee group and 11.1% ( $n=8$ ) of the intervention group agreeing to item twenty, compared to 24.4% ( $n=20$ ) in the control group.

Similar analyses applied to the perceived community stigma scale and the enacted stigma scale showed no significant differences between the two groups.

#### 5.4.2 Qualitative Analysis

In this study, qualitative data was also obtained to compliment the quantitative data. The qualitative data collected from the participants at the post-intervention interview has been analysed using content analysis (Silverman, 2000). In this section, the experiences of the intervention group will be discussed. Data from the participants includes their expectations prior to their involvement, their experiences on how they felt they benefited, feedback regarding the specific sessions and reasons for not attending all of the sessions, where applicable.

#### 5.4.2.1 The Expectations of the Intervention Group

Participants were asked what they were expecting from the programme, prior to their involvement. From the content analysis, six themes were identified (Table 5.23):

**Table 5.23: Expectation Themes**

<u>Theme</u>	<u>Percentage</u>
Advice on how to cope/live positively with HIV	33%
Meet/support other HIV-positive women	30%
Gain knowledge on HIV/AIDS	22%
No expectations	17%
Other expectations	13%
Negative expectations	4%

A third of the participants stated that they were expecting to be *taught how to live positively and take care of themselves*. For example:

- *"I expected support in terms of advice on how to cope with my status";*
- *"I thought I would be supported on how to live with my status";*
- *"I thought I would gain information and learn to live positively with HIV"*

A large percentage of participants (30%) were expecting to *meet and receive support from other HIV-infected women*. For example:

- *"I thought that I was going to find people like me, living with HIV, and we will talk a lot about us living with HIV, so that we won't worry in our lives about it";*
- *"I was going to meet other women in my position and we would talk";*
- *"I thought we were going to share ideas and we will help each other where we can".*

Almost a quarter (22%) of the participants expected to receive *knowledge and information around HIV*. For example:

- *"I thought that I was going to get more knowledge about HIV";*
- *"I thought we were going to be educated on HIV/AIDS and gain a lot of information";*

Several (17%) participants attended the first session of the programme with *no preconceptions or expectations*. For example:

- *"I did not think anything, but I told myself to go and find out what is going on there";*
- *"I just said I will see what happens when I arrive";*
- *"I didn't know what was happening and so I came specifically to find out".*

A small percentage of participants (4%) had *negative expectations* of the programme, expecting “to see very sick people” or worried about discrimination. For example:

- “*I thought that I was going to meet ailing people*”;
- “*At first I thought people were going to undermine me*”.

Other participants responses did not meet the criteria of the above five themes, as their expectations encompassed activities such as “*going to the homes of sick people*”, “*going around disclosing our status to schools*”, “*give health talk from house to house*” or “*expecting to get money, food, and clothing for my baby*”.

#### 5.4.2.2 Personal Gain from Participation in Groups

In the qualitative evaluation of the participant’s experiences of the intervention, four questions were aimed at assessing the participant’s perceived personal outcomes from the programme. The participants were asked how they felt they had benefited from their participation; how they felt their life may have changed since; what it was like interacting with other HIV-positive women; and to describe a situation during their involvement that had helped them in their personal life. These four questions were analyzed using content analysis, so as to assess the participants’ perceived personal gain from the intervention. The analysis showed that the participants benefited from the programme in different areas of their lives:

- Intellectual;
- Emotional,
- Interpersonal
- And behavioural.

##### Intellectual

Participants reported benefiting from the programme in terms of increased knowledge and information associated with HIV and AIDS. The participants’ intellectual gain was divided into three sub-themes:

- 1) The women gained knowledge around the *birth of their child, the risks involved and how to care for the child once delivered*.
- 2) The participants gained knowledge about HIV and AIDS *in general*
- 3) The participants gained knowledge on *how to live a healthy life as an HIV-positive individual*.

For example:

- *"I no longer stress about HIV like I used to because I now have information. I understand that being HIV-positive does not mean that I am going to die soon. I have learnt that eating healthy and condomising can keep me going",*
- *"I learnt that one should not give up, thinking that there is nothing one can do. I learnt that it is not the end of life and one should take care of oneself by eating healthily and exercising",*
- *"It was good because one can always learn something from people who are in the same situation as me".*

### Emotional

The participants benefited emotionally on three levels, in terms of their:

- 1) Their feelings towards themselves;
- 2) Their feelings towards the virus
- 3) And their feelings towards life

*Feelings toward themselves:* Participants remarked that the programme assisted them in gaining self-confidence and self-esteem. For example:

- *"The support group boosted my self-confidence and encouraged me to live my life positively",*
- *"From the group I have learnt that I should trust myself, believe in myself, not look down on myself and how to live a positive life, just like any other person",*
- *"It boosted my self-esteem, and some women gave birth before we parted and I saw that their children were healthy and that encouraged me a lot",*
- *"I'm always happy now especially when it's Thursday because I know that the following day it's support groups".*

Several participants from the intervention group commented on the stigmatising attitudes of the community, and how the programme had assisted them in coping with the shame associated with learning about one's HIV-positive status. One participant commented:

- *"Initially, after finding out about my status, I felt ashamed. However, since the support group I am free of shame".*

Feelings of isolation often stem from the shame and stigmatising attitudes toward HIV and AIDS. Participants commented on how the programme assisted them in realizing they are not alone, and how this realization had ultimately led to acceptance, strength and self-confidence, for example:

- *"It motivated me to accept my HIV-positive status because I realized that I am not the only women living with the virus",*
- *"I have realized that there are others out there who also have the same problems like mine",*
- *"I was strengthened because I could see that I am not alone",*
- *"It was wonderful and I became more confident especially seeing that I was not alone",*
- *"It was great. I looked forward to it and it made me break down the walls of loneliness".*

*Feelings toward the virus:* Participants feelings towards their HIV infection and the stress and coping associated with being infected were also important factors identified in the analysis. Participants commented on how the programme had assisted them in coming to terms with their infection. For example:

- *"I have now accepted my HIV status, and live freely",*
- *"The group has taught me a lot on how to cope with my status and to accept myself as a person living with HIV".*

Participants also remarked on how the programme had impacted on the stress and worry around the virus, for example:

- *"Hearing the experiences of living with HIV and how they got infected with the virus motivated me and gave me strength to go on, and stop worrying about my status",*
- *"I was always stressed out about my status and the support group gave me courage to live my life to the fullest",*
- *"You always find yourself happy and thinking less about HIV".*

*Feelings towards life:* Participants also remarked on how the intervention had had a positive impact on their view of life. For example:

- *"I have learnt to appreciate life more, since being in the group",*
- *"I learned that one should not give up, thinking there is nothing on can do and that it is not the end of the life".*

### Interpersonal

Interpersonally, participants benefited from the intervention in three areas, namely:

- 1) Support
- 2) Freedom to talk
- 3) Companionship/friendship

*Support:* A large factor identified within the theme of interpersonal benefits was *support*. Participants commented on how their participation in the intervention had provided them with much needed support, understanding, comfort and encouragement. For example:

- *"I learned that an HIV-positive person is a human being just like others, I also learned about love, respect and understanding each other",*
- *"This was a good idea to support one another, talking with other people who are HIV-positive, meeting and building a relationship of friends".*

*Freedom to talk:* Participants also remarked on how they had benefited from being given the freedom to talk, and to communicate with others about their status. For example:

- *"It was good as it's not often where you find being able to communicate with people like yourself",*
- *"I learnt that I should feel free about talking and that talking about issues in my life is healthy",*
- *"The support group helped me to open-up freely about my personal problems. During the first session I was shy to talk about my experiences and very quiet, but gradually I gained confidence and now I can talk to anyone about my personal problems".*

*Companionship/friendship:* The idea of companionship and friendship was also raised by many of the participants. Linked with the common feelings of isolation, participants commented on how the support groups assisted them in making friends, or experienced the group as more like family, for example:

- *"It was wonderful. I even made friends and I now have someone from the support group as a friend and she is very supportive",*
- *"It was very good because we were joking and laughing together, we were always happy to attend. I was feeling like I'm having my own family",*
- *"It was exciting and good for all of us because we treated each other like sisters".*

### Behavioural

Behaviourally, participants benefited from the intervention in terms of:

- 1) *Disclosure of their status and disclosure strategies;*
- 2) *And healthy lifestyle changes.*

*Disclosure:* Participants were able to apply much of what they experienced during the intervention in their everyday lives. Many participants commented on how they were able to now more freely disclose their status. Some examples of the participants responses related to disclosing included:



- *“I gained a lot of information about HIV and healthy eating. Moreover, I gained confidence and managed to disclose to others without feeling ashamed of myself”,*
- *“I am no longer scared, I feel that I can disclose to anyone at anytime”.*

*Healthy lifestyle changes:* Participants also remarked about the benefit of the intervention in terms of positive lifestyle changes. For example:

- *“I know what is wrong or right now and my lifestyle has changed completely”,*
- *“I used to drink alcohol, but now I have stopped totally & live a healthy lifestyle”.*

Below is a summary of the themes that were identified during the content analysis of participants perceived personal benefits from the intervention (Table 5.24).

**Table 5.24: Participants Perceived Personal Benefits**

<u>Themes</u>	<u>Sub-themes</u>
Intellectual benefit:	<ul style="list-style-type: none"> <li>• Information regarding the birth of their child, mother-child-transmission and child-care</li> <li>• Information regarding HIV and AIDS in general</li> <li>• Information regarding healthy living</li> </ul>
Emotional benefit	<ul style="list-style-type: none"> <li>• Feelings regarding self (Self-esteem and self-confidence)</li> <li>• Feelings regarding HIV (acceptance, stress, coping and stigma)</li> <li>• Feelings regarding life</li> </ul>
Interpersonal benefit	<ul style="list-style-type: none"> <li>• Support, comfort and understanding</li> <li>• Freedom to talk</li> <li>• Friendship/companionship</li> </ul>
Behavioural benefit	<ul style="list-style-type: none"> <li>• Disclosure</li> <li>• Positive lifestyle change</li> </ul>

#### 5.4.2.3 Feedback on specific sessions

Participant feedback on the specific sessions was assessed through three qualitative questions in the post-intervention interview. The intervention group was asked to give feedback on which sessions they enjoyed the most, or learnt the most from. They were also asked which sessions, if any, they found unnecessary or boring, and were then finally asked what they would have liked to see in the intervention that was not included. From the content analysis that was carried out, the same themes were identified as in the previous section. Participants commented on the intervention sessions on either an:

- 1) Intellectual;
- 2) Emotional;

- 3) Interpersonal;
- 4) Behavioural level.

### Intellectual

A number of participants from the intervention group commented on the group sessions from an intellectual point of view, either in terms of things they had learnt from the programme or in that they had gained knowledge and understanding that had assisted them in coping more effectively with their HIV status. For example, some participants commented on specific content from sessions:

- *“When we were told about healthy eating, as I would have continued in a similar eating pattern, which was unhealthy, and I learned about the importance of exercise”*
- *“We were taught about the immune system, and what makes it drop and also what makes it go high, so I now know how to take care of myself”*
- *“My favourite was the session on how to care for my child as an HIV-positive woman. I didn’t know much as an HIV-positive mother and also as a first time mother, how I was supposed to take care of my child”.*

Other participants commented on how the knowledge they had gained through the sessions had broadened their awareness surrounding the virus. For example, in answer to the question on what they felt was their best session, one participant stated:

- *“The session on stigma, because that opened up my eyes about many things”.*

Participants also remarked on how the information, which they had taken from the sessions, had encouraged and motivated them to make the most of their life. In answer to the same question, one participant answered:

- *“When we were being taught about the virus, I was encouraged that when I’m HIV-positive I can live and become anything that I want to become”.*

In answer to the question regarding which session they found either boring or unnecessary, the majority (90%) of participants answered that there were no such sessions. Examples of these participant’s replies included:

- *“There was never a day that I felt was boring”,*
- *“All sessions were equally informative and helpful”,*
- *“I enjoyed myself. There was never a time I where I felt bored”.*

However, the participants that did provide feedback on this question again replied from an intellectual stand point, in that they found a session boring or unnecessary because they already had the knowledge. For example:

- *“When we spoke about prevention with a condom, because I already knew those things”,*
- *“The one talking about pregnancy, as I already had information on that”.*

### Emotional

Participants also made reference to the emotional content of the sessions, specifically the sessions in which they presented their life maps. These sessions gave the participants the opportunity to disclose in a safe environment, talk freely, and hear the stories and experiences of other women, which were all mentioned as positive factors in their feedback regarding their perceived benefits from the intervention. Several members of the groups commented on the life map sessions, and reported benefiting specifically from those sessions. Referring to the session they enjoyed the most, participants stated, for example:

- *“It was the session when we spoke about being HIV-positive, when we made the maps. This session helped me in the sense that now I feel that I can disclose to more people freely”,*
- *“All sessions were good. When I was at the group I felt less stressed and always felt good about myself”.*

### Interpersonal

From an interpersonal perspective, participants commented on how the session focusing on disclosure had assisted them in disclosing to their family. Referring to the session on disclosure, on participant stated:

- *“These helped me because after them I was able to disclose to my partner”,*
- *“(The session had) made it easier for me to disclose to my aunt, because initially I was afraid of telling her, thinking that she will stop helping me financially”.*

The final session on future planning was also mentioned by several members as important to them. Participants found hope in planning for their future, and for the future of their children. In answer to the question on what the members felt could have been added to the programme, one member felt that it would have been a good idea for the programme to involve the member's partners in some way, and to *“get them to participate”*.

### Behavioural

In terms of feedback on a behavioural level, several participants felt that there could also have been some practical activities include, such as:

- *“A little bit of dress making, cooking and baking”.*

Due to the impoverished nature of the group, participants stated that they would also have like to:

- *“Do something that will help us make some profit or money in the future. Maybe if they can teach us some skills to start a business with us before the programme ends. This will enable us to start our small businesses”.*

In addition to this feedback about the programme, members also stated that they would have liked the programme to have lasted longer than it did. This is illustrated by the following quotes:

- *“I did not wish for the support group to come to an end. I wished we could have another support group”,*
- *“I wished I could see them everyday”.*

#### 5.4.2.4 Reasons for non-attendance

Participants were often unable to attend every session. The session attendance, per session, of the whole intervention group sample is shown below.

Session1 (Introduction):	46 (63.9%)
Session2 (Info1):	42 (58.3%)
Session3 (Info2):	52 (72.2%)
Session4 (Emotional1):	48 (66.7%)
Session5 (Emotional2):	37 (51.4%)
Session6 (Disclosure):	42 (58.3%)
Session7 (Coping & Stress):	45 (62.5%)
Session8 (Relationships):	37 (51.4%)
Session9 (Rights & Stigma):	36 (50.0%)
Session10 (Goals/Planning):	19 (26.4%)

Although the session attendance was a concern, all sessions but one (session 10) were attended by more than half of the participants. Participants were asked about their non-attendance of all sessions. None of the participants indicated that meeting other HIV-positive women, or the content of the sessions as reasons for not attending. The primary reason for non-attendance was due to the birth of the participant's baby. Although the women were recruited as early into their pregnancy as possible, it was often difficult to guarantee that the participant would not

deliver before the completion of the programme. These participants often returned to the group sessions within two to three weeks after delivery. Due to cultural beliefs however, several participants did not return to the group following the birth of their baby, as it is believed that the baby should be confined to the home for a period of between one and two months after birth. Other reasons for not attending the entire programme included:

- Clinic visits (*"I didn't attend once, because I had to take the baby to the clinic"; "I had to go for a clinic check-up so was unable to attend"*);
- The fear of questions from family (*"My partner would visit me everyday and since I have not yet disclosed, it was sometimes difficult for me to attend"*);
- Relocation (*"I moved to my mother's house in Soshanguve"*);
- Health problems (*"I was sick so was unable to attend that session"*);
- Personal problems (*"We were having problems at home"*) and
- Working during the week. Almost 20% (n=13) of the participants that took part in the intervention had jobs, and this therefore made it difficult for them to attend every session. The fact that the majority of the participants were unemployed also served as another hindrance to their regular attendance. Although financial remuneration was provided after each session, participants rarely saved this money for the following weeks' travel expense, as obtaining food for the families was an obvious priority. They therefore did not have money for transport.

## 5.5 Conclusion

In this chapter, the results of the study have been presented in terms of the sample demographics, pre-intervention analysis and the post-intervention analysis. From the outcome assessment of the intervention, participants who took part in the support groups showed significantly higher self-esteem, active coping, positive support, HIV-related support and disclosure. Differences were also noted between the groups in terms of knowledge and depression, while no differences were found regarding stigma, negative coping or negative support. In the following chapter, the results that have been presented in this chapter will be discussed, with a special focus on the programme assessment, implications of the results and their relation to past research.

## **Chapter 6 – Summary and Discussion**

This final chapter gives an overview of the research process, summarizes the results of the study, and discusses the programme evaluation in terms of the significance and the implications of the results. In conclusion, the limitations of this study are discussed.

### 6.1 Overview of Research

In this study, the effectiveness of a ten-session structured support group programme for HIV-positive pregnant women is assessed using a multi-method research approach (both qualitative and quantitative data analysis), with a quasi-experimental design. Quantitatively, specific attention is paid to the programmes' impact on various psychosocial aspects. In addition, qualitative data collected from the participants have been utilised in augmenting the data, so as to provide a better understanding of the results. The following hypotheses were tested:

- HIV-positive women participating in support groups will experience a statistically significant decrease in the depression scores, level of felt personal stigma, perceived community stigma and negative coping in relation to the control group.
- HIV-positive women participating in support groups will experience a statistically significant increase in self-esteem scores, positive ways of coping, support, level of disclosure and level of HIV-related knowledge in relation to the control group.
- HIV-positive women participating in support groups will evaluate their participation in the groups as a positive experience.

Over a period of one year, 156 women were recruited for this study, of which 72 agreed to participate in the structured support group programme, and the remaining 84 declined the invitation, and were used as a control group. The control group, who did not receive any intervention during the time of the study, was used to control for extraneous variables, which could have impacted on the outcomes for this study. The intervention group was split into two groups, namely an “adequate-attende group”, including participants who had attended more than 4 sessions, and a “non-adequate attendee group”, which includes participants who had attended less than 5 sessions. The programme was implemented in two townships in Tshwane, with five groups in each township. All participants were interviewed on their experiences of being HIV-positive, and the specific outcomes were assessed. These interviews were administered prior to the implementation of the 10-week programme, during the participants' pregnancy, and was then re-administered 3-months post-delivery, so as to assess the impact of the intervention.

From the pre-intervention analysis, in which the intervention groups and the control group were assessed in terms of the specific outcomes prior to the implementation of the intervention, it was concluded that the groups were statistically similar in terms of most variables. The groups did however display differences with regard to:

- Socio-economic status: The participants who agreed to take part in the structured support group programme had a significantly lower mean monthly household income and also showed higher levels of un-employment than in the control group.
- Disclosure: More women in the intervention group had disclosed their status than participants in the control group.
- Active coping scores: The intervention group showed significantly higher active coping than participants in the control group.

Following the implementation of the intervention, several significant differences were identified between the groups:

- In terms of active coping, the intervention group were found to have significantly higher mean scores at the post-intervention interview, compared to the control group.
- The intervention group displayed significantly higher mean scores in self-esteem compared to the control group.
- While the intervention group and adequate-attende group had shown significant increases in positive support, the control group displayed a mean decrease in positive support.
- Highly significant differences were found between the groups in terms of HIV-related support, with the participants who took part in the intervention showing significantly higher increases.
- No significant differences were identified between the groups in terms of negative coping at the post-intervention stage.
- With regard to the disclosure of their HIV-positive status following the intervention, participants of the support groups showed significantly higher disclosure rates than the control group.
- Although the groups showed no significant difference in terms of their general knowledge about HIV and AIDS (questions 1-15), following the implementation of the intervention, some differences were noted between the groups in terms of the “applied knowledge” (questions 16-25).
- Participants from the control and the intervention groups both displayed similar decreases in depression, with no significant difference between the two groups.

- No significant differences were found between the groups in terms of internalized personal stigma, perceived community stigma and enacted stigma at the post-intervention stage.

Qualitative feedback from the intervention group was analyzed. The participants perceived various personal benefits from their involvement in the programme. Responses were divided into three areas, namely intellectual (knowledge regarding birth, the risks involved and child care; knowledge regarding HIV and AIDS in general; and knowledge regarding living a healthy life with HIV), emotional (feelings towards themselves; feelings towards life; and feelings towards the virus), interpersonal (support; a freedom to talk; and companionship/friendship) and behavioural benefit (disclosure and lifestyle changes). The participant's feedback regarding the specific sessions in the programme and their reasons for not attending all ten sessions were also qualitatively analyzed. The intervention group's qualitative responses on the intervention were predominantly very positive. The significance of these results and their implications will now be discussed.

## 6.2 Discussion and Implications of the Study

### 6.2.1 Introduction

Returning to the systems approach, and the biopsychosocial model described in the first chapter, the results from this study exemplify the multifaceted nature of the HIV and AIDS epidemic. As has been discussed, the impact of HIV and AIDS is not limited to the biological functioning of an infected individual, despite the fact that it is usually this which will lead to the breakdown of the immune system, and to the individual's ultimate death. The impact of HIV and AIDS stretches far beyond this biological domain, effecting the psychological functioning of individuals, interpersonal relationships and community attitudes, just to name a few. In the same vein, an individual living with the virus, and attempting to come to terms with their infection, must not only strive toward healthy living, but also toward psychological adjustment and healthy social functioning. It is important to note, from the outset of this discussion, that the outcomes of this study should not be viewed as separate and independent of each other, but rather as interconnected and linked to one another within a broader system. Closely related to the biopsychosocial nature of the virus itself, an HIV-positive individual's success in coming to terms with their infection should be viewed as a complex system, in which their biological, psychological and social functioning are all interrelated, and all equally important in their journey toward acceptance, hope and living "positively" with the virus.



From the outcome analysis, assessing the impact of the intervention, several significant differences were identified between the sample groups. In addition to discussing the interconnected nature of these results, and their significance to this particular study, it is also important to note their relation to past research, as a number of these results have confirmed research from previous studies, while others have shown some interesting discrepancies from the work of the past. Due to the fact that this study has focused specifically on the intervention's impact on HIV-positive pregnant women in South Africa, it is important to note that the results from this study cannot be generalized to the broader context of individuals living with HIV, but does hold important significance for HIV-related work with women in Africa. For this reason, this discussion will also focus on the implications of this research for theory and practice in the field of HIV, with specific relevance for South Africa, in which women have become the primary victims to the epidemics, both directly and indirectly.

## 6.2.2 Discussion

### 6.2.2.1 Pre-intervention Analysis

Before delving into the results of the outcome analysis, it is important to first discuss the pre-intervention analysis, which was undertaken to acknowledge sample bias existing between the intervention group and the control group. This was to be sure that the groups were a valid comparison. From the results of this initial analysis, findings seem to confirm that the two groups were reasonably similar. Differences that were found may have been the influencing factors for why they chose to participate in the support group programme or not.

Firstly, the participants who agreed to take part in the programme displayed lower levels of employment and also had a lower mean monthly household income prior to their involvement in the study. It stands to reason that unemployed individuals would be more inclined to attend support groups, due to the absence of work-related time restraints. As the support group programme primarily took place on weekdays, it was understandably more difficult for employed individuals to attend, and it therefore seems logical that a larger percentage of the intervention group was unemployed at the time of recruitment. In assessing the reasons behind declining the invitation to join the programme, work was one of the primary reasons given by the control group to explain their non-attendance, with a number of these participants stating that if it were not for their work, they would have attended. Several participants in the intervention group also stated that they were unable to attend all of the sessions because of work commitments, and it was the unemployed participants who formed the bulk of the adequate-attende group. Another possible explanation for the significant difference in socio-economic status between the groups could be

the motivation behind taking part in the programme. A small number of the participants in the intervention group stated that they were expecting to be taught skills or become involved in some kind of income-generation project during their involvement in the programme. This could therefore partly explain the difference between the groups in terms of the socio-economic status, as individuals with lower monthly household incomes and without jobs would possibly be more inclined to get involved with a programme such as this, in the hope that it may lead to the development of skills, which would ultimately assist them in their financial situation.

The intervention group also showed higher levels of positive coping than the control group, prior to the implementation of the programme. As has been discussed in the literature study, active coping as it is termed by Folkman and Lazarus (1980), is defined as an active cognitive or behavioral effort to manage stress through behavior or environmental change. Individuals using such coping strategies would therefore be more likely to attend an HIV support group to deal with their status than those using negative coping strategies such as denial or avoidance. Although no difference was identified between the groups in terms of negative coping, the fact that the intervention group displayed higher levels of active coping prior to the programme implementation does help to explain their choice to participate. They were more willing to make an active effort to manage the stress associated with their HIV-positive status. From the qualitative assessment conducted with the participants who did not attend the intervention, similar conclusions can be made. One of the main themes identified in their reasons for non-attendance was their "mind-set", in that participants did not feel motivated or did not feel ready to attend the intervention.

The discrepancies between the groups in terms of disclosure prior to their involvement in the study, although only approaching significance, can be explained from the same stance. Disclosure of one's HIV status is inevitable in an HIV support group, and individuals who are not ready to disclose may fear participation in a support group for this reason. This is especially true in a close-knit community such as the communities from which these women came, and so may seem daunting to an individual still coming to terms with their infection. Individuals may also fear the consequences of their disclosure, for fear of their family, friends and the community in general finding out, and for fear of the possible consequent discrimination. This is supported by several statements from members of the control group who mentioned these reasons for not participating in the intervention. Individuals who have already disclosed their status to someone may feel freer to discuss their positive status in a support group, and may feel more confident to disclose their status in the group.

Apart from these differences, no significant differences were found between the groups prior to the intervention, with no difference with regard to self-esteem, depression, support and

knowledge. The groups were therefore relatively similar, and the control group could be used as a valid comparison group in this study.

#### 6.2.2.2 Outcome Analysis

Following the implementation of the support group intervention, an outcome analysis provided an array of interesting results. The intervention group displayed significant increases in self-esteem, active coping, disclosure, and social support, compared to the control group. In terms of depression, no significant differences were found between the groups, although some interesting discrepancies were noted in the mean scores. As was discussed in the first chapter, the psychological factors, or subsystems, associated with HIV have been divided into three areas of focus, namely emotional well-being (depression and self-esteem), coping (positive coping and negative coping) and interpersonal relationships (social support, disclosure and experience of stigma). In this section, the results of the study will be discussed in terms of these outcome variables.

#### Emotional well-being

Following the implementation of the programme, the intervention group displayed significantly higher increases in self-esteem, compared to the control group. These differences in self-esteem can be explained from a number of viewpoints. Firstly, participants in the support groups mentioned feelings of isolation prior to their involvement. The realization of not being alone and meeting other women with similar problems, experiences and backgrounds was a significant factor for these women during their participation. The participation in the groups could have helped discard feelings of isolation and hopelessness, and replace them with feelings of togetherness, support and hope, in realizing that they are not alone (Ribble, 1989).

Past research has shown that the involvement in support groups is positively correlated with emotional well-being. Hays et al. (1990) explained this from the perspective that through supporting and assisting others, an individual is able to diminish their own feelings of dependence and hopelessness. In assessing the participants' perceived personal benefit from the intervention, the majority mentioned the experience of supporting and being supported by other HIV-positive women as a very positive factor during their involvement. The significant differences in self-esteem between the groups could be explained from the stance that through supporting other HIV-positive women with similar problems, the women were able to view themselves as important, or as an integral part of the group, which leads me to my next point. This feeling of belonging, defined by Hagerty et al. (1992) as an individual's personal experience

of involvement within a system, and the feeling of being an integral part of that system, may be another possible reason for the significant difference in self-esteem between the groups.

As was mentioned earlier, Yalom (1995) stated that there is nothing more important to one's self-esteem and well being, than to be accepted by a social group. Yalom states that "acceptance and self-acceptance are interdependent; not only is self-acceptance basically dependent on acceptance by others, but acceptance of others is fully possible only after one can accept oneself" (p56). The results from this study support past research, finding an association between a higher sense of belonging and better psychological and social functioning (Hagerty & Williams, 1999). Participants in the groups described this sense of belonging as an experience similar to finding a new family. Hagerty and Williams (1999) also found a similar relationship between this sense of belonging, and depression, which was not supported by the findings in this research. The data regarding depression will be discussed later in this section.

As was just mentioned, the attendance of a support group may lead to feelings of importance, which may in turn lead to a positive effect on one's self-esteem. Schmitz and Crystal (2000) found that this relationship extended beyond feelings of belonging, as discussed above, but was rather a broader connection between general support and mental well-being. An additional reason for the intervention group's significant increase in self-esteem could therefore be more related to the actual support itself. Past research has shown that support in general has a positive effect on an individual's emotional well-being (Crystal & Kersting, 1998), and this could be the case in this study too. From the qualitative analysis of the women's perceived personal benefits from participation in the intervention, participants stated that they benefited most from feelings of support, companionship, and the freedom to talk. The members became a new system of support for each other, and this may also help to explain the significant increase in self-esteem.

Despite the increase in self-esteem, no significant differences were found between the groups in terms of depression. In fact what seems puzzling is that level of depression of the control group as a whole, had decreased more than that of the adequate attendee group. This does not seem to be congruent with the results obtained from the self-esteem analysis and from past research. Support group participation was found to have a positive effect on levels of depression (Hagerty & Williams, 1999; Angelino, 2002). Other research has also made a link between depression and dysfunctional coping styles (Clesla & Roberts, 2001), which also does not seem to be congruent with the results of this study, as the participants who attended the intervention showed increased positive coping.

In order to explain these seemingly incongruent results (though not significant), one needs to look at the context in which this study took place. Many of the women involved in this study had been recently diagnosed HIV-positive. They live in impoverished homes with little support. Many women use coping strategies such as avoidance and denial to cope with the psychosocial effects of their status. These coping strategies were found to improve emotional well-being, at least over the short term (Namir et al., 1987; Broun, 1999). While the control group may have been able to continue with this strategy, the intervention group was being exposed to the reality of the virus, and had little chance of denying their positive status. It is possible that while the participants from the control group were attempting to deal with their positive status by “trying not to think about the situation”, as was found in the analysis, the intervention group was confronted with a situation where they were exposed to the reality of their diagnosis, which could have contributed to a smaller decrease in depression, compared to that of the control group.

In summary, from the results of this study, it would seem that support groups for HIV-positive women have a positive influence on their emotional well-being, specifically their self-esteem, for the following reasons:

- Realizing that they are not alone
- Feeling accepted
- Feeling important
- Having a safe environment in which to discuss their problems, fears and experiences with similar others
- Having the opportunity to support and be supported
- A sense of belonging
- Through a gradual process of empowerment

### Coping

Participants in the intervention group showed significant increases in positive coping. The intervention group did initially have higher levels of active coping than the control group, and it would seem that their participation in the intervention contributed to it increasing even more. This process began with the women first taking responsibility for their situation, and trying to make an active effort to manage their stress through behaviour or environmental change, namely, deciding to take part in the intervention. Their consequent participation in the support group then led to further positive coping, such as positive thinking (emotion-focused coping) and positive lifestyle changes (active coping), which are reflected in the results from the post-intervention analysis.

With regard to lifestyle changes, many of the participants remarked that their lives had changed for the better, and that they had made positive alterations in the lifestyle, since their involvement in the intervention. Active coping aims at problem solving, or doing something to alter the source of the stress, and many of the participants mentioned positive changes such as healthier living. These positive changes demonstrate how the participants were taking responsibility for their lives. In addition to these changes in their everyday life, significant discrepancies were also found between the groups on several individual items of the coping scale. The intervention group showed significantly better coping in terms of:

- Talking to someone with similar experiences,
- Educating people about HIV and AIDS,
- Supporting other people with HIV,
- Receiving comfort and understanding from people,
- Believing their HIV diagnosis had helped them change their life for the better

These coping strategies are directly related to the safe environment of the support group where they could be open about their HIV status. They were given the opportunity to support and be supported, and receive comfort and understanding from people who understood what they are going through. It stands to reason that the control group would score lower on these positive coping items, and would score higher on items such as trying not to think about their situation, which is a negative form of emotion-focused coping (avoidance). No differences were found though, in negative coping between the groups. In contrast to these findings, Hackl et al (1996) found that the primary coping mechanisms employed by HIV-positive women included strategies such as denial, and Kaplan et al (1997) found that HIV-positive women are unlikely to acknowledge negative coping mechanisms, such as denial and avoidance. It is therefore possible that many of the participants may not have accurately reported their negative coping strategies. This may explain why little discrepancies were found with regard to negative coping in an assessment of the individual items on the coping scale.

It is important to note the relationship that exists between coping and emotional well-being, with special reference to self-esteem, which was discussed earlier. In their study on the effectiveness of coping strategies used by HIV-positive women, Moneyham et al. (1998) found that the use of active coping strategies was positively related to emotional well-being, and this too seems to concur with the results of this research. Carver et al. (1989) found a similar result, finding that those with high self-esteem engaged in more positive coping, demonstrating again the symbiotic, interconnected nature existing between these outcomes. The participants who took part in the intervention already had somewhat elevated levels in positive coping, compared to those of the

control group, and this influenced their decision to take part in the support group, and would also have had a positive effect on their self-esteem, as discussed by Moneyham (1998).

Following from Carver et al. (1989), this elevation in self-esteem, could possibly then have contributed to the participants' further increase in positive coping, which could be seen as part of a larger process of empowerment. Empowerment is a gradual process whereby an individual who is supported, given an opportunity to learn about themselves, and take responsibility for their lives, steadily moves closer towards independence and the mobilization of resources (Ribble, 1989). It would seem that participation in a support group provides an HIV-positive individual with the ideal environment to make this journey toward empowerment, as the results from this study seem to suggest. However, despite the fact that participation in such a group may assist in this journey, it would seem that the individual needs to take the first step themselves, as is portrayed in the results from the pre-intervention analysis. Individuals that took part in the intervention were making an active effort to face the reality of their situation. Active coping strategies such as support seeking were found to have a positive effect on emotion well-being (Moneyham et al., 1998), and these findings seem too, to concur with the results from this study.

Another important step toward psychosocial adjustment to one's HIV-status is acceptance, which is a positive form of emotion-focused coping. Those who took part in the intervention showed significantly higher scores on individual items specifically aimed at assessing acceptance of their HIV status, such as the item asking whether they believe their HIV diagnosis has helped them change for the better. Acceptance has been described as the natural final stage of coping with a terminal disease (Kubler-Ross, 1981). It would seem then, that active-coping may also contribute to better acceptance of one's HIV status, as involvement in a support group may prompt a change in mind-set, changing from a preparing for death, into trying to learn how to live (Beckett & Rutan, 1990). More active coping is also related to more support-seeking behaviour and disclosure, as will be discussed below.

### Interpersonal Relationships

Significantly more women in the intervention group disclosed their status and experienced both positive and HIV-related support compared to the control group. Although it stands to reason that the involvement in an HIV support group leads to increases in social support and disclosure, both these outcomes are important factors in the assessment of the success of the intervention. While the participants have experienced both positive and HIV-related support in the group, and have disclosed their status in the group, the results from the post-intervention assessment were not limited to their intervention involvement. The participants showed significant increases in

disclosure outside of the group. The practice of disclosure in a support group may lead to increased disclosure beyond the group environment. This result concurs with Kalichman's (1996) finding that people attending support groups are more likely to disclose their status to family and friends. The process by which this occurs could be explained in a number of ways. Members of the intervention group mentioned how their involvement in the support groups had given them confidence, and this had helped them disclose to others without feeling ashamed. During their involvement, participants had also dealt with specific issues around disclosure, and many had taken part in role-plays in preparation for disclosing to their family and friends. Participants from the intervention made specific reference to these sessions on disclosure, stating how they had helped them prepare for disclosure.

The improved disclosure rates can also be linked to the increase in active coping, as was mentioned earlier. Huber (1996) stated that disclosure is an important step in HIV-related support seeking, and can therefore also be viewed as an extremely important active-coping strategy, necessary in an individual's journey toward acceptance and psychosocial adjustment. Disclosure was a necessary step for the participants who took part in the intervention, although many of them had already disclosed their status before their involvement in the project, further portraying their already existing active stance in coping with their HIV infection. The use of problem-focused coping has also been directly linked to the availability of social support (Nyamathi et al., 1996), for this very reason. Semple et al. (1993) identified disclosure as a major psychological stressor for HIV-positive women, and it is possible that through the participation in the intervention, and the consequent improvement in self-esteem, feeling of empowerment and a movement closer to acceptance, disclosure became a less daunting task.

Disclosure has been shown to be positively associated with emotional and personal support (Gillman & Newman, 1996), which also seems to support the findings of this study, with significant increases in both disclosure and support in the intervention group. The intervention succeeded in providing the women with much needed support. Participants valued the support, understanding, comfort and encouragement from the group. They also remarked how they had benefited from being given the freedom to talk, and to communicate with others about their status. As has been discussed during this study, HIV-positive women in South Africa need support, and despite this they are often the ones doing most of the supporting, due to many culturally defined roles placed upon them (Bennett, 1990). Interventions such as the one developed for this research can therefore provide women with a much needed support system, to assist them in such trying situations. Participants also commented on feelings of companionship and friendship, which was also seen as important factors during their involvement in the intervention. It is important to note that while the actual availability of support is crucial for these



women, it is the perceived adequacy of support which is associated with emotional well being (Serovich et al., 2001). This may further explain the significant improvement in emotional well-being displayed by the intervention group. The participants' involvement in the intervention, and consequent feelings of importance, acceptance and belonging, discussed earlier, led to a perceived feeling of adequate support. The participants were noticeably more satisfied with the support they were receiving, both HIV-related and generally, compared to that of the control group.

Social support seems to have formed a buffering effect (refer to Cohen & Willis, 1985) for these women. Women experienced an increase in emotional well-being, and a reduction in feelings of stress, as they gradually adjusted to their infection when experiencing increased support. It would also seem that this intervention met the criteria for all four types of social support resources stated by Cohen and Willis (1985). The participant received "esteem support" through their increase in self-esteem, feeling of importance and sense of belonging gained through their participation. Through their involvement, participants gained "informational support", gaining a better understanding of the virus, and also "social companionship", through the forming of new friendships, and a creation of a new system of support. Although the intervention did not directly address the women's needs of "instrumental support", such as the provision of material resources, which is a need, the participants did discuss future goals and possible income generation opportunities.

Research such as Ciambone (2002) stated that social support is particularly important for PLWHA due to the stigma and social isolation associated with HIV infection. As was discussed earlier in this study, stigmatisation and discrimination are daunting realities for people, and especially women, living in South Africa. Despite their involvement in the intervention, no differences were found between the groups in terms of personal, community or enacted stigma. Some discrepancies were found on the individual items of the personal stigma scale pointing to some interesting dissimilarities between the groups. These dissimilarities included:

- Feeling more comfortable if people know they are HIV-positive.
- Feeling less ashamed if someone knows they are HIV-positive.
- Not thinking that HIV is a punishment for bad behaviour.

These results indicate that they feel more comfortable with their HIV status in interpersonal relationships, compared to the control group. Interaction with other HIV-positive women did not have any impact on the way they perceived the stigma in the community. As was discussed in the first chapter, stigma is a social factor of HIV and AIDS. It stands to reason that while involvement in a support group may have an impact on an individuals own feelings towards HIV,

levels of discrimination and the perception of other's attitudes seem to be unrelated to the participant's involvement in the intervention.

### Knowledge

Contrary to expectations and the qualitative feedback of the women, there was no significant difference in knowledge scores between the two groups. The level of general knowledge increased in both groups, and a slight difference was noted between the groups with regard to applied knowledge, although not significant. In the assessment of the individual items on the knowledge scale, the adequate-attendee group showed superior knowledge of re-infection, CD4 count and treatment, which were topics specifically dealt with during the intervention. In their evaluation of the groups, women mentioned that they benefited from the information they had gained regarding the birth of their child, the risks involved and how to care for the baby once delivered, knowledge about HIV and AIDS in general, and knowledge on how to live a healthy life. Gaining information related to HIV was also mentioned as one of the main expectations of the participants who took part in the intervention. Despite this positive qualitative feedback, the quantitative results did not support it. A possible reason for this result is the initial high levels of knowledge displayed by the sample prior to their involvement in the study. In another study assessing knowledge of HIV/AIDS in the communities where these women resided (Visser, de Villiers, Makin, Sikkema, Forsyth, Vandormael & Mundell, 2005), community members displayed high levels of knowledge about HIV and AIDS. Women thus already had basic knowledge of HIV before their participation in the intervention. This hypothesis was therefore not confirmed.

#### 6.2.3 Implications of the Study

The results from this research have some important implications for research and the development of psychosocial interventions for HIV-positive women in an African context. Due to the lack of formalized research done in the area of support group interventions for PLWHA, it is imperative to not only learn from the work that has been done in the field, but also to take from their limitations and to use this to add to current literature. The value of this research study include:

1. This study focuses on much needed care and support services for women living with HIV (Amon, 2002)
2. In this study the specific needs of HIV-positive pregnant women living in disadvantaged communities in South Africa were assessed, and utilised in the development of a structured psychosocial intervention, aimed at assisting them in

adjusting to the various biopsychosocial effects of HIV infection. The content of the intervention is therefore appropriate for women living in an African context.

3. Few studies focusing on intervention strategies such as support groups have actually attempted to statistically assess the impact of these interventions (Spirig, 1998). This study also provides a much needed evaluation of the impact of support groups.
4. This study provides a systems perspective of the HIV and AIDS epidemic, with specific reference to the interconnectedness of the psychosocial aspects associated with HIV infection. The study therefore also has valuable relevance for HIV and AIDS research in general, as these relationships between the bio, psycho and social aspects of the epidemic need to be acknowledged if any progress is to be made in attempts to better understand and deal with the pandemic.
5. There are very few South African studies that have attempted to explore the actual experiences of PLWHA (Sobo, 1995), and this study provides valuable qualitative feedback from HIV-positive women on their needs, experiences and benefits from their involvement in an HIV support group.
6. The process of successfully coping with HIV has been understudied and under-appreciated (Chung & Magraw, 1992), and this study provides valuable information on both positive and negative coping strategies utilised by HIV-positive women in South Africa.
7. Although support groups for individuals living with HIV have been shown to be successful in the past, this study has also attempted to look at the relationship between the number of sessions attended and the psychosocial impact of the intervention. The results seem to suggest that the number of sessions attended is positively correlated with the psychosocial impact of the intervention.

### 6.3 Limitations of the Study

Although much can be learnt from this study, it is important to acknowledge the limitations of the results and the research.

- While this study does contain highly valuable and significant data for HIV in the South African context, participants that took part in this study were pregnant women, of which many were recently diagnosed. This could influence the findings and should be taken into account when attempting to generalise the results.
- The sample used in this research was from disadvantaged backgrounds, and were living in relatively poverty stricken environments.
- Due to the fact that participation was voluntary and therefore a convenient sample, the possible sample bias must be acknowledged. It was women who wanted to deal with

their HIV status who took part in the intervention. It must be noted that women who have serious problems with their diagnosis and are not prepared to join support groups cannot be reached in this way.

- Due to the fact that only one follow-up interview was conducted shortly after the completion of the groups, it must be recognised that the long term effects of this intervention are unknown. This will be addressed in a future study.

#### 6.4 Conclusion

While the western world seems to be gaining a strong hold on the HIV and AIDS epidemics, Africa continues to fight a difficult battle. It is important that as one of the more developed countries in Africa, South Africa take the lead in this battle. Researchers can make use of the lessons learned in developed countries, but the African HIV and AIDS epidemics should be approached from an African perspective. The needs and experiences of infected individuals differ greatly in this continent to others. Therefore interventions aimed at assisting infected individuals in their journey towards acceptance and psychosocial adjustment should be developed around them, and not around the successes and failures in other countries. Although prevention and treatment are essential in this battle, the psychosocial needs of infected individuals cannot be neglected. Just as this study has taken a systems perspective in approaching its outcomes, so must it be taken in the larger context of HIV and AIDS in Africa.

In conclusion, this study has attempted to assess the impact of a structured support group for pregnant HIV-positive women in South Africa. Most of the hypotheses have been confirmed, namely:

- HIV-positive women participating in support groups experienced a statistically significant increase in self-esteem scores, positive ways of coping, positive support, HIV-related support and level of disclosure in relation to the control group.
- HIV-positive women participating in support groups will evaluate their participation in the groups as a positive experience.
- However, knowledge scores did not increase significantly and stigma scores did not decrease significantly.

From the results of this research, it seems evident that the HIV and AIDS epidemics are not limited to affecting only one aspect of human functioning, but should be seen as a smaller part within a much larger system. The outcomes of this study are also all interwoven, and interconnected within a broader system of psychological and sociological adjustment to HIV infection. It seems though, that a psychosocial intervention can assist PLWHA in their journey

toward adjustment and acceptance, if the intervention is developed around the needs of the target group. It is important to address the effects of the epidemic holistically and systemically, if the battle to overcome this ultimate biopsychosocial phenomenon is to be won.

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## **APPENDIX**