BLACK WOMEN DIAGNOSED AS HIV-POSITIVE: THEIR PSYCHOLOGICAL EXPERIENCES AND COPING MECHANISMS

by

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This dissertation is dedicated to:
my father, Chaka (Nkika)
and mother, Nomkhohlane (Lolo)

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- Moss, today, tomorrow and always.

SUMMARY

Despite the seriousness of HIV and AIDS in women in South Africa, little attention is being paid to special needs of women infected with HIV and the problems they face. Little research that has been conducted on the subject mainly concentrated on the effects of being HIV-positive, emphasising the negative implications thereof. Specific research on how women cope with everyday life, while simultaneously diagnosed with HIV-infection, is still scarce in South Africa. This study investigates how black women who are living with HIV-infection experience and cope with everyday life.

The study was conducted from Lazarus and Folkman's cognitive phenomenological model of coping and Antonovsky's salutogenic perspectives. In the literature study, HIV with specific reference to women was reviewed. The cognitive phenomenological model of coping and the salutogenic theory were also reviewed.

Data was collected by means of unstructured interviews, which were audio-recorded. The research group consisted of four black women who have been diagnosed HIV-positive for at least six months. Three open-ended questions were asked, namely: a) "how have you been experiencing your life since you were diagnosed HIV-positive?" b) "how are you coping with your situation?" and c) "how can you advise other women in the same situation as you?"

A qualitative method of data analysis was used in the study and was described in detail. Twenty-three different categories of experience were identified and further grouped into experiences of being HIV-positive and the ways of coping employed by the women in the study. The categories were then integrated with the literature and theoretical information on coping and salutogenesis.

It was found that the experiences differed from woman to woman. These experiences included experiences in relation to self e.g. emotional experiences; and experiences in relation to others e.g. reactions from other people and problems associated with disclosure of HIV status. All women in this study employed both problem-focused and emotion-focused coping strategies. The context also seemed to play a role in the experiences and the coping strategies used by the women.

KEY WORDS:

BLACK WOMEN, HIV-POSITIVE, PSYCHOLOGICAL EXPERIENCES, PRIMARY APPRAISAL, SECONDARY APPRAISAL, PROBLEM-FOCUSED COPING, EMOTION-FOCUSED COPING, SALUTOGENESIS, GENERALIZED RESISTANCE RESOURCES, SENSE OF COHERENCE.

OPSOMMING

Ongeag die ernstigheid van MIV en VIGS in vrouens in Suid Afrika is daar tot dusver min aandag aan die spesifieke behoeftes van hierdie vrouens en die probleme wat hulle ervaar geskenk. Die beperkte navorsing wat wel daaroor gedoen is het hoofsaaklik gefokus op die effek daarvanom MIV-positief te wees en meer spesifiek die negatiewe gevolge daarvan. Spesifieke navorsing oor hoe vrouens daarby aanpas in die alledaagse lewe is steeds gering. Hierdie studie vors na hoe swart vrouens met MIV-infeksie die situasie beleef en in die alledaagse lewe daarby aanpas.

Die studie is gedoen binne die teoretiese raamwerke van Lazarus en Folkman se kognitief-phenomenologiese model van aanpassing en Antonovsky se salutoginetiese perspektief. MIV met spesifieke verwysing na vroue was bespreek in die literatuuroorsig.

Data is ingesamel deur gebruik te maak van ongestruktureerde onderhoude. Die navorsingsgroep het uit vier swart vrouens, wat vir minstens ses maande HIV gehad het, bestaan. Drie oop-einde vrae is aan hulle gestel, naamlik: a) “hoe ervaar jy jou lewe sedert jy MIV-positief gediagnoseer is?” b) “hoe pas jy aan by jou situasie?” c) “ hoe sal jy ander vrouens in dieselfde situasie as jy adviseer?”

‘n Kwalitatiewe metode van data-ontleding is gebruik in hierdie studie, en dit word in detail beskryf. Drie-en-twintig verskillende beleweniskategorieë is gëidentifiseer en verder gegroepeer in terme van die orvaring om MIV-positief te wees en die verskillende wyses van aanpassing daarby. Die kategorieë is daarna gëintegreer met die bestaande literatuur en die teoretiese raamwerke van aanpassing en salutogenese.

Die resultate het getoon dat die belewenis van MIV van vrou tot vrou verskil. Hierdie belewenisse sluit in die verhouding tot die self, byvoorbeeld emosionele belewenisse; en belewenisse in verhoudings met ander, byvoorbeeld die reaksies van ander mense en probleme geassosieer met die mededeling van 'n positiewe MIV diagnose. Alle vroue in hierdie studie het gebruik gemaak van beide probleem-gesentreerde en emosie-gesentreerde aanpassingstrategieë. Die konteks waarin die vrou haar bevind blyk ook 'n rol te speel in die belewenis en die aanpassingstrategieë wat gebruik word.

SLEUTELWOORDE:

SWART VROUENS, MIV-POSITIEF, PSIGOLOGIESE ERVARINGS, PRIMÊRE BEOORDELING, SEKONDERE BEOORDELING, PROBLEEM-GESENTREERDE AANPASSING, EMOSIONEEL-GESENTREERDE AANPASSING, SALUTOGINESE, ALGEMENE WEERSTANDS BRONNE, GEVOEL VAN SAMEHORIGHEID.

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ERRATA

Change the word "loose" to "lose" on the following pages

p. 10, line 22

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p. 71, line 28

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CHAPTER 1

INTRODUCTION

1.1 INTRODUCTION

Human Immunodeficiency Virus (HIV) is fast becoming the leading cause of morbidity and mortality in South Africa. It has become an epidemic of immense proportions, affecting people of every race, culture and economic status. The complex social, psychological, ethical and physical problems confronting people with HIV-infection set it apart from any other disease. Since shortly after the time when AIDS was first identified, there has been widescale recognition that persons with HIV-infection and AIDS face a range of psychological stressors, potential adjustment difficulties, and coping challenges.

Katz (1997) indicated that early research on HIV portrayed a picture of severe negative emotional consequences for individuals when notified that they were infected with the virus or had an illness indicative of AIDS. These included reports of alarming rates of suicide attempts and suicide completion among HIV-infected persons. Reports of severe depression, anxiety, somatic preoccupation and guilt following the notification of positive HIV serostastus also came about (Kelly, 1998).

Individuals with the poorest long-term adjustment to their HIV status are often those who had the greatest levels of pre-existing psychological difficulties (Kelly, 1998).

HIV treatment seems to be advancing as recently reflected by promising developments in protease inhibitor drug combination therapies. This may be seen as a basis for hope of a longer and healthier life among persons with HIV, and HIV-related illnesses may increasingly resemble other serious and life-reducing but manageable illnesses (Kelly, 1998).

This raises the question of whether coping and mental health issues are different for HIV/AIDS than for other severe life-threatening illness. Groomes (1998) cited factors like social support, coping style, and expectations regarding the outcome of treatment, which predict success in handling stressors related to HIV/AIDS, as the same factors that influence success in coping with other life-threatening illnesses. Due to the above-mentioned reasons, Groomes (1998) thinks that there may be some commonalties between HIV/AIDS and other serious illnesses.

However, there are also contextual differences between HIV/AIDS and other serious illnesses. HIV is an infectious illness that has always generated fear based on myths about casual transmission. To date, there are people who still believe that a person can get infected by sharing things like eating utensils and toilets with HIV-infected individuals.

People contracting HIV are mainly young people and face the prospect of declining health and disability at an age much earlier than most people with serious chronic illnesses. They must also confront the fact that they may have contracted the virus during sex, increasing the sense of responsibility and guilt. What complicates matters worse, is the fact that HIV in South Africa and in many other places in the world, is still perceived to be contracted in specific community segments and social networks, like the poor and the socially marginalised. As a result, these people have often experienced sustained, multiple, and repetitive personal losses of acquaintances, friends, lovers, spouses, and other close social network members to the same disease that they now face. There are few other diseases that entail such issues, which complicates HIV-related coping and creates a unique context surrounding HIV/AIDS (Kelly, 1998).

1.2 WOMEN AND THE HIV EPIDEMIC

Women presently constitute the fastest growing group of people diagnosed with HIV in this country. The infection rate was estimated to have increased four times as fast among women than men in 1993, with more women presently being infected through heterosexual intercourse. A woman is said to be at least ten times more susceptible to contracting HIV during intercourse than a man. This increased vulnerability is thought to be the result of the higher concentration of HIV in semen compared to vaginal fluid and the possibility that labia are more prone to cuts, tears or sores which give infected semen a route to enter the woman's body (Katz, 1997).

According to statistics released by the South African Department of Health in 1999, the HIV prevalence among women who attend antenatal clinics has risen from 7,4% in 1997 to 22,8% in 1998, a 5,2% increase. Women in their twenties have the highest rates at 26,1% for the 20-24 year age group and 26,0% for the 25-29 year age group. The rates in the older age groups seem to be lower at 19,1% in the 30-34 age group and 13,4% in the 35-39 age group. Among older women HIV-infection rates of 10,5% and 10,2% have been found in the 40-44 and 44-49 year groups respectively. Even more worrying is the prevalence among girls aged 15-19 which has risen from 12,7% to 21% over the same period. As can be seen from the statistics, most increase is recorded among women in the childbearing age (Department of Health, 1999).

1.3 MOTIVATION FOR THE STUDY

Women with HIV differ in many important ways from gay and heterosexual men, and intravenous drug users who have been, for the past two decades, the primary focus of HIV/AIDS research (Sempler, Patterson, Temoshok, McCutchan, Straits-Troster, Chandler & Grant, 1993). Gender differences in the course of HIV have also been documented (Strebel, 1995).

According to Katz (1997), women with HIV are generally more likely than men to have a low income, belong to a minority group, and happen to be less well integrated within the community support systems. The relative inaccessibility of the medical care system to the socially disadvantaged women has been demonstrated by the fact that women with HIV are usually diagnosed later than men (Sempler *et al.*, 1993). These delays in diagnosis have been associated with poor prognosis. On average women die two months earlier than men following an AIDS diagnosis (Katz, 1997).

Although women are more vulnerable to being infected than men, as well as the alarming statistics of women with HIV-infection, not much attention is being paid to the seriousness of the problem of HIV in women. The little research that has been conducted in the field mainly concentrated on the effects of being diagnosed HIV-positive, emphasising the negative implications thereof. Berman (1993) is of the view that lives of women living with HIV and those who may be at risk of contacting the virus, depend on greater understanding by the community and more effective responses to women's experiences of HIV. Information on how women cope with everyday life, especially how they manage to stay well despite the diagnosis of HIV, is still very scarce in South Africa.

1.4 AIM OF THE STUDY

The aim of the research is to investigate how black women who are living with HIV-infection experience and cope with everyday life. It will focus on the subjective interpretation of the situation by these women, in an attempt to establish how they manage to adapt to that stressor rich environment.

1.5 AN OVERVIEW OF THE STUDY

The study consists of seven chapters. Chapter two focuses on the literature review on HIV and women. In chapter three, the theoretical approach used in the study is discussed. Chapter four looks at the research process with an emphasis on a step-by-step description of the method of data collection and analysis and chapter five documents the research results. Chapter six contains an interpretation of the study and chapter seven concludes the study.

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CHAPTER 2

HIV AND WOMEN: A LITERATURE REVIEW

2.1 INTRODUCTION

The discovery of the HI-virus is shared between French and American researchers, although it was the team at the Pasteur Institute in Paris who first announced its discovery early in 1983 (Richardson, 1987). HIV attacks the body's immune system. As a result, the body's immune system becomes impaired, leaving the body vulnerable to infections and illnesses which healthy people with intact systems can ward off. These illnesses are sometimes referred to as opportunistic infections, because they take advantage of the opportunity offered by the body's weakened immunity to enter and do the damage (Berer & Ray, 1993).

HIV is not the first virus in the world, or the first fatal one. All the issues which HIV raises about sexuality and relationships, women's health and health care, pregnancy and reproductive choices, and women's personal and professional lives were in existence already. Bor, Miller and Goldman (1992) indicated that HIV adds a new dimension to all these issues, the dimension that must be taken into consideration.

Although all people with HIV-infection share common experiences associated with the knowledge of positive test results, there are a number of biopsychosocial issues specific to women (Berman, 1993). AIDS, a syndrome that is a group of symptoms or illnesses originating from the presence of HIV in the blood stream, was killing women before it had a name and before a cause for it had been found. It had become the leading cause of death among women of reproductive age in many parts of the world by the second half of the 1980s. Yet, it was only on 1 December 1990 that World AIDS Day called the whole world's attention to the extent of a problem women had been living with and dying from for more than a decade (Berer & Ray, 1993).

2.2 HIV TRANSMISSION IN WOMEN

Compared to other sexually transmitted diseases like gonorrhoea, HIV is sometimes poorly transmitted during sexual intercourse (Bury, Morrison & McLachlan, 1992). This is evident in cases of people who are known to have had regular unprotected intercourse with HIV-infected partners for years, without themselves getting infected. Other people however, men and women, have become infected after a single act of vaginal intercourse.

Anal intercourse is riskier for women than vaginal intercourse because the anal canal is more likely to be damaged during penetration than the vagina. Since anal intercourse is a less common sexual practice, more women have become infected through vaginal intercourse (Richardson, 1987). A person with HIV can infect his or her partner at any time during intercourse, although Bury *et al.* (1992) indicate that such persons are more likely to be infectious during seroconversion, which is commonly known as the window period, and later on in the disease as they become symptomatic. There is some evidence that men with HIV-infection are slightly more likely to infect their female sexual partners than women with HIV-infection are to infect their male sexual partners (Katz, 1997; Semple *et al.*, 1993).

Sexual violence plays an important role in the transmission of HIV. Women who are sexually harassed or raped by an infected assailant face the possibility of being infected. Another aspect of violence towards women is with regard to the danger of domestic violence should they refuse sex or insist on condom use or monogamous relationship from their partners. These issues are especially urgent in South Africa in the light of escalating reported incidents of sexual violence (Strebel, 1995).

Unprotected sexual intercourse continues to pose a risk for HIV-positive women whose partners have also tested HIV-positive. Bury *et al.* (1992) assert that such women cannot assume that there is nothing to be gained by using protection since they can be exposed to re-infection by HIV with every act of intercourse. The risk of progression of disease increases in such instances. If a woman did not acquire her infection from her current partner, unprotected intercourse exposes her to a possibility of becoming infected by another strain of virus, which might be more virulent than her own. Other sexually transmitted infections can also result from exposure to unprotected intercourse, resulting in further suppression of immunity in HIV-infected women.

Poverty is thought to be playing a big role in the spread of HIV. Lack of material resources directly affects health status in such a way that malnutrition and susceptibility to tuberculosis lead to reduced immunity. This in turn increases the risk of HIV-infection. Poverty also results in limited access to health care and education, which results in minimal exposure to AIDS education as well as care for those already infected (Mhloyi, 1990). Yet, many studies have pointed to contradictory features of this economic argument being used as a contributor to HIV-infection. They found that it is often women of higher economic status who become HIV-infected. It has been suggested that it is the wives of men who are more affluent, more mobile and thus more likely to pay for sexual favours, who are first infected (Strebel, 1995).

2.3 THE PHYSICAL EFFECTS OF HIV INFECTION ON WOMEN

Around the time that the HIV antibody test becomes positive, which is around six weeks after the time of infection, there may be a short illness like flu or glandular fever. A minority of those infected only experiences this seroconversion illness. The HIV-infected person can then remain well for some years before developing the symptoms of the disease (Faden, Geller & Powers, 1991).

In a study conducted by Semple and her colleagues on the psychobiological stressors among HIV-positive women, fatigue and sleep disturbances were the most commonly reported physical symptoms of HIV-infection. In addition to those general symptoms, women also reported gynaecological problems like chronic yeast infections and irregular menstrual bleeding e.g. amenorrhea for periods lasting up to two months. Other participants reported the presence of abnormal pap smears, which is five to ten times the expected rate. This is perceived as highly stressful because of the possibility of cancer (Semple *et al.*, 1993).

According to Katz (1997), yeast infection (candidiasis) is the most common treatable gynaecological disorder for all women, but it is recurrent and difficult to treat in HIV-positive women. Genital warts, caused by the Human Papilloma virus, is another common symptom in HIV-infected women. The presence of the HIV renders the Human Papilloma virus very difficult to treat, with treatment requiring a long, frustrating course. The recurrence of the viral warts after treatment is much more common for HIV-infected women than for those who are not infected.

Cervical dysplasia, the precursor to cervical cancer, occurs at an unusually high rate in HIV-infected women. The successful treatment of syphilis, herpes and pelvic inflammatory disease is usually close to impossible (Semple *et al.*, 1993). Katz (1997) is of the opinion that HIV-infected women must have regular medical check-ups and pap smears every six months to prevent serious complications.

2.4 HIV INFECTION AND GENDER ISSUES

Women are half of the world's population, receive one tenth of the world's income, account for two thirds of the world's working hours, and own only one-hundredth of the world's property. In Latin America, women head over 50 percent of families in some countries and not less than 40 percent in any country (Paterson, 1996). These figures suggest that in a just society, women can be perfectly capable of taking responsibility for their own lives.

Since most HIV-positive women are known to have been infected through heterosexual intercourse, it is very disturbing to note that most women at risk of infection still find themselves in a position where they can do very little to protect themselves from infection. The condom is still the only physical barrier used for prevention of HIV-infection from male to female. It is commonly known that this mode of prevention is useless without male co-operation, leaving women without a choice but to depend on men for their own protection.

Arguments about human rights have spotlighted the subordinate position of women in most cultures. HIV, however, points the finger at the subordinate role of women and suggests that failure to do something about it will threaten the survival of the whole community. There is no society in the world where you can become gender aware without reaching a conclusion that women are less socially privileged than men, and that men are the ones with the economic, political and commercial power (Paterson, 1996).

Gender awareness also means awareness of traditional and cultural practices, such as polygamy, infidelity, and female circumcision, that make it possible for women to continue to be subjected to situations they find extremely difficult to get out of. Many of these practices have increased the potential for the transmission of HIV and are therefore indirectly responsible for the status of women (Kübler-Ross, 1987).

The World Health Organisation (WHO) is of the opinion that the sexual and economic surbodination of women fuels the HIV pandemic. The fact that a woman in some communities has no effective control over her own body means that she cannot be expected to make responsible decisions about her sexuality. Women may want to stipulate fidelity, safe sex, or no sex at all, but where society defines the male's needs as paramount, it is very difficult for women to negotiate strategies to protect their health (Paterson, 1996).

Many cultures still endorse and encourage infidelity. Paterson (1996) reported from interviews with women in Uganda that some of them reported to have seen their husbands with wives of men who are known to have died of AIDS. These women felt that they did not have power to say anything because of the fear that their husbands will send them back to their parents. Their parents can not let them stay with them either, since it is regarded as a disgrace for a married woman to be sent back to her parents. The women are therefore dependent on their husbands and have nowhere to go.

In other cultures, a widow is obliged to have sexual intercourse with her brother-in-law or a relative of her deceased husband. This practice is called widow cleansing and it adds to risks of HIV-infection should the brother-in-law or the relative be HIV-infected (Edemikpong, 1990).

Mhloyi (1990) pointed out the relationship between HIV-infection and female circumcision. Infabulation, which is the removal of the vulval tissue including the clitoris and the labia, is regarded as the most extreme form of circumcision. After the removal of the tissue, the sides of the wound are sewn together leaving a small opening, almost the size of a matchstick, to be used for urination and menstruation. Sexual intercourse is not possible under the circumstances, unless the vagina is somehow reopened. This is usually accomplished by forcible entry by the husband, which often leads to bleeding. Achieving full penetration can take up to nine months, during which anal intercourse may be an alternative. Anal intercourse and the presence of blood during intercourse further increase the chances of infection in the women.

Women in single-headed households used to be considered to be in a disadvantaged position as far as finances are concerned. This was argued as a reason some of them were not in a position to negotiate safe sex because they could not afford to loose the money, which usually came as a payment for sexual favour. This may no longer be necessarily the case since more women are increasingly choosing not to marry because they argue that this strengthens their economic situation. These women may in fact be in a better position to insist on condom use because they are not forced to submit themselves to their husbands. Despite popular belief, women do not have multiple partners only for material benefits, and it is not numbers of partners but specific sexual practices which increase risk of infection (Strebel, 1995).

2.5 DISCLOSURE OF HIV-POSITIVE STATUS

At the time of positive test results, women are usually advised to notify their partners about their condition. HIV-positive women are also encouraged to obtain regular medical care, to take steps to stay healthy and to make plans about the future of their children as their illness progresses. These women also desire support of family and friends, which they can benefit very much from. The above can only be obtained if they were to disclose their HIV-positive status (Schlebusch & Cassidy, 1995).

Bennetts, Shaffer, Manopaiboon, Chaiyakul, Siriwasi, Mock, Klumthanom, Sorapipatana, Yuvasevee, Jalanchavanapate and Clarko (1999) view disclosure as important in a sense that it may psychologically unburden women and decrease feelings of isolation, by increasing the avenues for social support. A blanket policy of encouraging all women to disclose their status may put some women at risk, but failure to disclose can put others at risk if it means that an uninfected partner will be exposed to the virus or an infected partner does not get tested.

In a study conducted by Gielen, O'Campo, Faden and Eke (1997) on the experiences of HIV-positive women with disclosure of their status, it was discovered that some women are able to disclose their status to other people, while it was still very difficult for other women to do so. Some women reported to have disclosed to several people including close family members, partners, and less commonly to a few friends. A significant number talked to their families only, while a few only told their partners. Most of these women preferred to tell as few people as possible, for reasons such as protection of their privacy and that of their families. Most women reported disclosing their status right away, although some delayed disclosing their test results for periods ranging from a few days to many months.

Reasons for disclosure of HIV status were named as mostly major life events such as the diagnosis of a child with HIV disease and terminal illness in a partner. On the other hand, delaying disclosure was reported to be a result of initial denial about the test results and worry about the impact of the news on others. Fears about disclosure in some women occurred as a result of feared discrimination and rejection, both of which were often attributed to people's ignorance about the disease. A small percentage was afraid to disclose their HIV status because they feared people would react violently. The nature of violence included physical, verbal and emotional abuse from partners as well as from others. Several women reported being beaten by their partners because they blamed them for infecting them with the virus, while one woman related that she was beaten by her friends who attacked her on the street (Gielen *et al.*, 1997).

Strebel (in Berman, 1993) revealed that in her study most women in South Africa did not tell families and friends about their diagnosis, citing lack of understanding from other people as the reason for their fear of disclosure. It was also felt that there was a lack of awareness in the country generally, which is closely tied to the wider process of denial about the presence of HIV in South Africa. Very little has changed since then, people are still generally ignorant and in denial.

Bennetts *et al.* (1999) view stigmatisation of HIV as well known. HIV seems to be stigmatised because it is associated with deviant behaviour like prostitution and it results in changes in appearance such as legions and weight loss (Bury *et al.*, 1992). It is common for a stigmatised person to repress anger about discrimination, which may manifest in self- hatred and shame (Bury *et al.*, 1992).

In a study conducted by Gielen *et al.* (1997), four main themes about how people react to women's disclosure emerged. The majority of women reported experiencing acceptance, support and understanding at some point after disclosing their HIV status. Some reported having been rejected, abandoned, or shamed by someone in response to disclosure. Descriptions of reactions to disclosure often included references to feelings of shock, anger and sadness.

Gielen *et al.* (1997) conclude that studies of the process of disclosure and notification are needed and that an individualised approach to post-test counselling is a must. They further suggest that health workers who have contact with HIV-positive women should ask women about their concerns about disclosure, especially about interpersonal violence from others as a result of the disclosure of the women's status.

2.6 CHILDBEARING AND REPRODUCTIVE ISSUES

The fact that women can transmit HIV to their infants has increased the focus on women as reservoirs of the disease (Strebel, 1995). Before birth, HIV may pass across the placenta to the developing foetus. The virus has been found in organs taken from foetuses as early as 13 weeks of gestation, and therefore it is clear that infection can take place early in pregnancy. HIV may also be transmitted during birth from infected vaginal secretions as the baby passes down the birth canal, or from the mother's infected blood (Katz, 1997).

In the early stages of the epidemic, HIV-infected women were advised to postpone childbearing until more was known about the risk of mother to child transmission and the history of paediatric HIV-infection. Since it became known that advanced maternal HIV disease is associated with increased risk of transmission from mother to child, many women may decide to have children earlier in the course of their disease (Thorne, Newell, Dunn & Peckham, 1996). Katz (1997) is of the opinion that the knowledge of a pregnant woman's HIV status can provide early diagnosis and treatment for mother and child, help a woman make informed reproductive choices, reduce the risk of perinatal transition and provide for referral to vital services.

Factors influencing decisions about childbearing are considered complex (Katz, 1997; Mhloyi, 1990; Strebel, 1995). Many HIV-infected women are faced with the difficulties of deciding whether to fall pregnant in the first place, and if they happen to be pregnant already at the time of diagnosis, the decision to keep the baby or discontinue the pregnancy may still be a very difficult one. Centres for Disease Control and Prevention estimated the risk of transmission from mother to child at 8%. Given the reduced transmission risk, a woman might give birth to a healthy child, but she may die before the child reaches adulthood. There is still a possibility that she can give birth to an infected child, who will be sick and whose mortality is imminent (Bedimo, Bessinger & Kessinger; 1998).

In a study conducted by Bedimo *et al.* (1998) to describe the demographic, clinical, and behavioural factors that influence HIV-infected women's decision-making on childbearing, they found that these women were less likely to get pregnant compared to the same age group in the general population. A woman's fertility was found to be viewed as very significant. Apart from being a source of pride, self-expression and womanhood, women regarded childbearing and mothering as the only way they can rise to the ranks of adult status and accomplishment in the community. Some women expressed the need to leave behind a legacy of themselves to their families.

In the same study, women who were living with a family member at the time of diagnosis, were found to be less likely to undergo sterilisation, possibly because of the knowledge that there will be another family member around to care for a child should a subsequent pregnancy occur. The decision to have sterilisation was found to be associated with a higher CD4 count (a measure of the body's immunity) and having one or more living children. Healthier women were more likely to undergo sterilisation than less healthy ones. The researchers attributed this to the decreasing likelihood of sexual activity as their health declines, thus decreasing their exposure to pregnancy and making sterilisation unnecessary.

When a woman first learns she is infected with HIV, denial is often the first phase of the coping process they usually go through. If a woman is finding it difficult to accept her own infection, it will be more difficult for her to accept the possibility of transmission to her unborn child. The way a woman perceives the risk of perinatal transmission also plays a role in reproductive decision-making. The fact that the risk can be down to 8% with the use of AZT (an anti-retroviral drug) is more than acceptable to other women (Gregson, Zhuwau, Anderson & Chandiwana, 1998).

Sowell and Misener (1997) examined factors that influence the decision to become pregnant and/or remain pregnant using two focus groups with HIV-infected women. A number of women indicated that the decision to have a baby, as well as the HIV status of the baby, was determined by God. Those women also identified ministers and religious teachings as influencing their decision to have the baby if they become pregnant. Only one woman in this study described a belief in a punitive God by stating that HIV was a punishment from God and if the baby was born HIV-infected it was a result of the mother's sins. Knowledge about HIV and beliefs women share about what will happen to them was identified as another factor that helped them make a decision concerning pregnancy.

Women who had babies who had either died or were sick as a result of HIV in this study, indicated that they did not want to be pregnant again. For these women the risk of having another baby with HIV and the pain of watching that child become ill or die overshadowed their desire for a baby. Although most women indicated that they would not have a baby now that they were infected with HIV, some women indicated willingness to become pregnant or continue a pregnancy if it accidentally occurred. This was based on the fact that they had previously delivered a healthy baby after they had been diagnosed with HIV-infection. A woman's state of health was also found to contribute to the decision to have a baby in a sense that some women believed that if they are healthy and take care of themselves during pregnancy, there would be no problems with HIV transmission (Sowell & Misener, 1997).

Evidence from twin studies is that infection can take place during the birth process. Researchers also found that it can also occur postnatally, making breastfeeding one of the things that may place an infant at risk of infection. However, despite this evidence and because of the overall benefits of breastfeeding to the infant, women are generally encouraged to continue breastfeeding even if they are HIV-positive (Strebel, 1995). There is evidence that some women who are conscious of the risk of HIV transmission through breastfeeding have stopped breastfeeding their children. The World Health Organisation issued guidelines recommending that breastfeeding be encouraged in areas where other infectious diseases are common, irrespective of HIV-infection rates (Gregson *et al*., 1998).

Semple *et al*. (1993) conducted a study to identify psychobiological stressors among HIV-positive women. Disclosure of HIV status to the children was found to be the most stressful event experienced by these women. They all felt that they wanted to protect their children from worries about the future, as well as the social stigma associated with HIV-infection. For women with infants, another life stressor involved the fear and uncertainty of having infected their children through pregnancy or breastfeeding. This chronic stress usually continues until the child reaches 18 months when it is possible to establish its HIV status. Caring for a child infected with HIV was also identified as stressful, followed by the issue of deciding on guardianship for young, dependent children.

Childbearing may force HIV into the open if one or both partners are infected with HIV. The whole relationship may be changed by a decision to have or not to have a child. Fear of transmitting the virus or being infected may introduce additional tension into the couple's relationship (Bor *et al*., 1992). Counselling as a standard procedure should include information on childbearing in order to help all HIV-infected women to make their own informed decisions (Bedimo *et al*., 1998). Strebel (1995) indicates strong objection to the fact that most of the debate around reproductive choice focuses only on women and excludes men's responsibilities in decision making.

2.7 HIV AND THE SEX INDUSTRY

Before much was known about HIV and AIDS, the so-called 'risk groups' used to be the focus of attention. As a result, intravenous drug users, homosexuals and prostitutes used to carry the blame as far as HIV transmission was concerned. So much has changed since then, as people become aware of the realities of the disease. When it comes to prostitutes, however, very little has changed.

HIV is sexually transmitted and since sex is an integral part of the sex industry, it is not surprising that HIV is being linked with the sex industry. The disturbing factor is how the media and even some experts in the field interpret this link.

A commercial sexual act is perceived as a high-risk activity because of the inclusion of money as a form of payment. It is usually assumed that a female sex worker is unable to insist on the use of a condom if the male partner does not want to use it, due to the fear of loosing the payment. This assumption does not take into account the risk reduction strategies employed or the HIV status involved. Thomas (in Bury *et al.*, 1992) argues that people should start thinking of prostitution as preventing the spread of HIV, instead of blaming it for the pandemic. He regards the problem as the assumption that all prostitutes are HIV-positive or have Aids, and that if they are not already infected, they are not interested in preventing themselves from becoming infected.

Fear has been generated among members of the public around female sex workers infecting heterosexual males and thereby their heterosexual partners. It would appear that these clients bear no responsibility for their actions and are merely victims of the sex workers, even though they are not forced to have sex, protected or unprotected, with the prostitutes. Threats of or actual, physical violence including rape, in order to obtain unprotected penetrative sex have been reported against sex workers. In those instances where violence occur, it means that the perpetrators of these acts are the ones who don't consider the possibility that they can infect or even get infected by the prostitute (Bury *et al.*, 1992).

The perception that prostitution is directly associated with the spread of HIV persists, despite evidence pointing to the contrary. Anderson and Wilkie

(1992) draw attention to two studies carried out in this subject. In the study conducted by Chaisson and his fellow researchers, no association was found between HIV and prostitution. Another study conducted by Wallace reported an HIV infection rate of 1.1% in a group of men who reported having had contact with a prostitute.

2.8 CONCLUSION

In order to understand the ways in which women infected with HIV cope with the situation, it is important to understand what they go through on daily basis. In this chapter a review of literature on women and HIV/AIDS was presented, with emphasis on what they usually experience. The following chapter consists of a theoretical approach on coping and the salutogenic theory.

ERRATA

Change the word "loose" to "lose" on the following pages
p. 10, line 22
p. 69, line 9
p. 71, line 28
p. 72, line 11
p. 74, line 12
p. 80, line 14 & 15

Change the word "loosing" to "losing" on
p. 17, line 11
p. 72, line 5, 6, 8
p. 80, line 10
p. 82, line 11

p. 11, line 19: "women are" should be "women were"
p. 12, line 21: "legions" should read "lesions"
p. 17, line 25: "reported against" should be "reported by"
p. 17, line 26: "occur" should be "occurs"
p. 25, line 27: "undimensional" should be "unidimensional"
p. 35, line 9: the word "her" should be inserted before "children"
p. 41, line 13: "a individual" should read "an individual"
p. 46, line 6: "a" should be inserted before "friend's"
p. 53, line 10: "hem" should be spelt "them"
p. 63, line 10: the word "a" should be inserted before "few"
p. 71, line 21: "concern and" should read "concern with, and"
p. 85, line 21: "live the way" should be living the way"
p.92, line 6/7: "Hate feelings" should be "Feelings of hate"
p. 96, line 25: "other people" should be "some people"
p. 101, line 7: "a" should be inserted before "daily"
p. 103, line 8: the word "the" should be inserted before "better"
p. 103, line 29: "by another should read "to another"

CHAPTER 3

COPING AND SALUTOGENESIS

3.1 COPING

3.1.1 INTRODUCTION

Individuals are often faced with numerous problems and challenges throughout their lives. These problems and challenges are sometimes referred to as stressors, and they range from everyday difficulties to major crises. Such experiences can not only cause emotional stress, but can also have long-term cumulative effects on physical and psychological health.

Researchers have collected a wealth of information about how people cope with challenges and problems. They have directed their efforts toward answering questions about whether different styles of coping can be identified, whether some coping strategies are more useful for certain problems than others, and how can people learn to cope more effectively with challenges that confront them (Kleinke, 1991).

Before one can embark on the study of coping with stressors, it is imperative that we look at the concept of stress. Hopfoll (cited in Bogle, 1995) describes stress as one of the most complicated phenomena. It involves various systems of the body – cardiovascular, endocrine and neurological; the systems of the psyche – cognitive, emotional and unconscious; and occurs in all social systems - interpersonal, small and large groups. Stress is evoked by such varied stimuli as minor daily hassles, or major life threatening events. It involves our loves, hates, closest attachments, competition, achievements, and every matter in which humans are involved.

According to the biological model of stress that centres on the general adaptation syndrome as formulated by Selye (in Fleming, Baum & Singer, 1984; Monat & Lazarus, 1977), there is a three-stage process that describes how stress affects the individual. The first stage of the process is alarm, in which the organism is mobilised to combat the physical demands of the stressor. The second stage is resistance, in which the organism tries to deal with the still present threat. The third stage is exhaustion, which is brought upon by prolonged exposure to a stressor without resolution. Though there may be no immediate obvious change in environmental conditions, the organism seemingly gives up, and the collapse may result in death. Presumably this only occurs when the threat persists or repeats often enough to overwhelm the organism's ability to resist. The implication of this model is that the effects of stress are cumulative and are involved in serious pathology when they overwhelm one's ability to resist. Stress is not regarded as an environmental demand (which Selye called a stressor), but a universal physiological set of reactions and processes created by such a demand (Lazarus & Folkman, 1984).

The psychosocial model of stress views stress as the reaction of an organism to demands placed upon it. The key focus within this model is upon healthy, usually normal humans and non-physical stressors. The emphasis is on the interaction of stressful agents and the human system of appraisal and evaluation. In this model, stress is conceptualized as a process that involves recognition of and response to threat or danger. Coping, a central part of this process, includes overt and covert responses to threat or danger, usually directed toward overall reduction of stress (Fleming *et al.*, 1984).

3.1.2 THE CONCEPT OF COPING

Historically, coping has been viewed primarily as a response to emotion and was defined as learned behaviour that contributes to survival in the face of life-threatening dangers. These behaviours are initiated by fear, which motivates the behavioural response of avoidance or escape, and by anger, which motivates confrontation or attack (Folkman & Lazarus, 1988).

Within the ego-psychology model, coping includes cognitive processes, such as denial, repression, suppression, and intellectualisation, as well as problem-solving behaviours, that are used to reduce or manage anxiety and other distressing emotional states (Park, 1998).

Moran (1994) states that much has been written on coping, and sometimes the term is used interchangeably with terms like adaptation, mastery and defence. Billings and Moos (cited in Moran, 1994) argue that in many early definitions, coping tended to be viewed as the intrapsychic processes with which a person protects his or her emotional functioning from threat. They go further to suggest that this approach tends to limit the concept of coping to intrapsychic efforts to maintain psychological equilibrium, without taking into account the overt behaviour aimed at solving the problem or at avoiding the threat.

As suggested by Snyder and Ford (1987), the effort at coping should not be required by definition to imply success in protecting people from harm. They propose that any attempt to protect, whether or not it succeeds, should be defined as coping behaviour. Snyder and Ford (1987) therefore define coping as a response whose purpose it is to reduce or avoid psychological stress, pointing out that this definition does not necessitate success in reducing the stress, but is just an attempt to do so.

The literature on coping is quite extensive and has examined a variety of stressful experiences. As reviewed by Lazarus (in Marco, Neale, Schwartz, Shiffman & Stone, 1999) the literature indicates several consistent findings:

1. Coping depends on appraisal of whether anything can be done. If something can be done, then problem-focused coping predominates; if nothing can be done, then emotion-focused coping predominates.
2. Coping acts as a mediator of emotional outcomes.
3. Coping efficacy varies with the type of stressful encounter, the type of personality, and the outcome modality studied.

Folkman and Lazarus (1980) were critical of coping models that focused only on defence mechanisms, intrapsychic processes, and some small segments of the full range of behaviour in the coping process. They asserted that a coping model is not complete if it does not include the many forms of overt actions which people resort to in response to a challenge or threat to their well-being. Lazarus and his colleagues went on to produce such a model, which turned out to be one of the most comprehensive models available.

3.1.3 THE COGNITIVE PHENOMENOLOGICAL MODEL OF COPING

The model is based on the cognitive theory of stress and coping. The theory is said to be transactional in that the person and the environment are viewed as being in a dynamic, mutually reciprocal, bi-directional relationship. Stress is conceptualised as a relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and as endangering well-being (Folkman, Lazarus, Gruen & DeLongis, 1986). Folkman (1984) emphasises the fact that in the definition offered above, stress is not a property of the person or the environment, nor is it a stimulus or a response.

The theory identifies two processes, cognitive appraisal and coping, as important mediators of stressful person-environment relationships and their immediate and long-term outcomes (Folkman *et al.*, 1986a).

3.1.3.1 Cognitive Appraisal

Cognitive appraisal is a process through which the person evaluates whether a particular encounter with the environment is relevant to his or her well-being and, if so, in what way. There are two types of cognitive appraisal: primary and secondary.

> ***Primary appraisals** refer to judgements that a transaction is irrelevant, benign-positive, or stressful. An appraisal that a transaction is irrelevant is a judgement that it has no significant for well-being, and a benign-positive appraisal indicates that a transaction does not tax or exceed the person's resources (Folkman, 1984). Here a person

evaluates whether he or she has anything at stake in the encounter. Examples of this will be assessing whether the situation posseses potential harm to self-esteem, or whether the health of loved ones is at risk or not (Folkman *et al*., 1986a).

Folkman (1984) identifies three primary appraisals, namely harm/loss, threat and challenge. Harm/loss refers to injury or damage already done, as in loss of a limb. Threat refers to potential harm or loss, and challenge to an opportunity for growth, mastery, or gain. McCrae (1984) states that challenges differ from threats in their generally positive tone, although, like any stressor, they require exceptional efforts from the individual. Challenges are also perceived as being often controllable. Challenges and threats are likely to be chronic, whereas losses tend to be acute stressors.

A primary appraisal is shaped by person factors such as beliefs and commitments; as well as situational factors such the nature of the event, whether the event is familiar or not, how is it likely to occur, when is it likely to occur, and how clear or ambiguous the expected outcome is (Folkman, 1984).

***In secondary appraisal** the person evaluates coping resources and options, addressing the question “what can I do?” (Folkman & Lazarus, 1985). Coping resources, which include physical, social, psychological, and material assets, are evaluated with respect to the demands of the situation. Examples of physical resources are the person’s health, energy, and stamina, while social resources represent the individual’s social network and support systems, from which an individual can draw information, assistance and emotional support. Psychological support resources include beliefs that can be drawn upon to sustain hope, skills for problem solving, self-esteem, and morale. Material resources refer to things like money, tools and equipment (Folkman, 1984). The link between these resources and

Antonovsky's General Resistance Resources (GRRs) will be discussed in 3.2.4.

Folkman and Lazarus (1985) perceive the primary and secondary appraisals as working interdependently. For example, if coping resources are adequate for dealing with a threat, the degree of threat is diminished. On the other hand, an event that at first might seem non-threatening can become threatening if coping resources turn out to be inadequate for countering environmental or personal constraints.

3.1.3.2 Coping

According to the theory, coping is seen as the person's cognitive and behavioural efforts to manage, reduce, minimise, master, or tolerate the internal and external demands of the person-environment transaction that is appraised as taxing or exceeding the person's resources (Folkman, 1984; Folkman & Lazarus, 1985; Folkman, *et al.*, 1986a).

Folkman, Lazarus, Dunkel-Schetter, DeLongis and Gruen (1986) identify three features of this definition.

- It is process oriented, meaning that it focuses on what the person actually thinks and how he/she behaves in a specific stressful encounter, and how this changes as the encounter unfolds. Observations and assessments are concerned with what the person actually thinks or does, in contrast to what the person usually does, would do, or should do, which is the concern of a trait approach. The trait approach thus places emphasis on stability rather than change.
- They view coping as contextual, that is, it is influenced by the person's appraisal of the actual demands in the encounter and the resources for managing them. This means that the person and situation variables together shape coping efforts.

- Coping is defined independently of its outcome. It refers to efforts to manage demands, regardless of success of those efforts. Therefore, there is nothing like good or bad coping.

3.1.3.3 Functions of Coping

In this model, coping is viewed as having two major functions, namely, to regulate the emotions or distress and to manage the problem that is causing distress. These functions are also referred to as emotion-focused and problem-focused forms of coping respectively (Folkman, 1984). Both forms of coping are used in most stressful encounters and the relative proportion of each form varies according to how the encounter is appraised.

Examples of problem-focused coping include behaviours like getting a person to change his or her mind, making a plan of action and following it, fighting for what one believes in or wants. The emotion-focused strategies include behaviours such as looking on the brighter side of things, accepting sympathy and understanding from someone, and trying to forget about the problem. Problem-focused coping is found to be mostly used in situations that were appraised as changeable, thereby holding the potential for control, and the emotion-focused form of coping is used in situations that are appraised as not changeable (Folkman & Lazarus, 1985).

3.1.3.4 Coping and Emotions

Much of the research on the relationship between emotions and coping in humans has focused on the ways in which emotion, in the form of anxiety, can interfere with cognitive functioning and hence coping (e.g., Krohne & Laux; Schwarzer & Spielberger, as noted in Folkman & Lazarus, 1988). This research has been criticised by Folkman and Lazarus (1988) for failing to take into account the complexity of emotion and coping processes, when treating emotions as undimensional drives. Here emotions are just seen as affecting coping both by motivating it and impeding it in a unidirectional causal pattern. However, the relationship between emotions and coping in a stressful encounter is bi-directional, with each affecting the other. First, the transaction is appraised as harmful, beneficial, threatening, or challenging. The appraisal of the situation then generates emotions, and the two influence the coping process, which in turn change the person-environment relationship. The altered person-environment relationship is reappraised, and the reappraisal leads to a change in emotion quality and intensity. In this way, coping is a mediator of the emotional response (Folkman & Lazarus, 1988).

Emotions depend on the cognitive appraisals of the significance of the person-environment relationship for the individual's well-being and the available options for coping (Folkman & Lazarus, 1988). Folkman (1984) pointed out that harm/loss and threat appraisals are often characterised by negative emotions, such as anger, fear, or resentment, whereas challenge appraisals are characterised by pleasurable emotions, such as excitement and eagerness.

Emotion-focused coping is mostly used to control distressing emotions, sometimes by altering the meaning of an outcome. The effectiveness of problem-focused coping is said to depend on the success of emotion-focused efforts. If this were not the case, heightened emotions would interfere with the cognitive activity necessary for problem-focused coping (Folkman *et al.*, 1986b).

3.1.3.5 Personal Control and Coping

Among the beliefs that influence primary appraisal, are what Folkman (1984) refers to as generalised beliefs about control. These beliefs have their greatest influence when the situation is regarded as ambiguous or novel. When conditions lack clarity (ambiguous), situational cues regarding the nature of the outcome and/or the extent to which the situation can be controlled are minimal. Under such highly ambiguous situations, a person with an internal locus of control, who has the conviction that events are contingent upon one's own behaviour, might appraise it as controllable. When the situation is not highly ambiguous, it is often expected that judgements about controllability would be influenced more by situational characteristics than by generalised beliefs.

According to Folkman (1984), threat and challenge appraisals, which influence coping, are affected by control appraisals. Threat appraisals seem likely when the desire for control is not matched by expectations for control or when the exercise of control can generate additional distress. On the other hand, challenge appraisals seem likely when encounters that are appraised as relevant to well-being hold a potential for control, and the exercise of control creates little additional distress.

Appraisals of control can shift as an encounter unfolds. Changes in appraisals of control can come about as a result of new information from the environment and coping efforts (Folkman *et al.*,1986a). In real life, control appraisals are viewed as complex, especially in health related contexts. Cohen and Lazarus (in Folkman, 1984) cited the following coping tasks in recovery from illness, each of which refers to an outcome or target of control:

1. To reduce harmful environmental conditions and enhance prospects of recovery.
2. To tolerate or adjust to negative events and realities.
3. To maintain a positive self image.
4. To maintain emotional equilibrium.
5. To continue satisfying relationships with others.

Most research on the relationship between control and stress is based on the assumption that having control is stress reducing and not having control is stress inducing, but Folkman and Lazarus (1985) indicated that the opposite is sometimes true. The way events are connected in real life seems to be the reason behind this observation. An example they give is that of a patient who is told that there is potential for controlling his or her malignancy through chemotherapy. Having chemotherapy may result in malignancy being contained, but at additional cost to the patient's physical and psychological well-being (such as nausea, hair loss, and depression).

Strickland (in Aldwin 1994) pointed out the relationship between control and the type of coping activity. She noted that people with internal locus of control are more likely than people with external locus of control to engage in an information search about disease and health maintenance when it is relevant to their well being. They are also more likely to use more problem-focused behaviours and less emotion-focused behaviour than those with external locus of control are.

Sometimes an experience can be perceived as not reinforcing internal control beliefs. Under such circumstances, an illusion of control can be created through cognitive coping or reappraisal. This can be noticed in a situation where a person takes on responsibility or blame for an event, regardless of the circumstances. Such a reappraisal can make that person to believe that similar events can be prevented in the future, thereby enabling him/her to feel more in control of future events and less threatened (Aldwin, 1994).

3.1.4 PERSONALITY AND COPING

Although the transactional theory of coping holds that the situational appraisals are the key determinants of the coping efforts, another perspective maintains that personality dispositions are also important determinants of coping because they predispose people to use certain coping strategies (Gunther, Cohen & Armeli, 1999). The five-factor model of personality is usually used to look at the relationship between coping and personality since it provides a useful context for assessing individual differences in coping strategy used.

The Big Five is described as a taxonomy of broad, higher order personality dimensions thought to represent the minimum number of traits necessary for adequately describing personality. It includes Neuroticism, Extraversion, Openness to experience, Agreeableness, and Conscientiousness (N, E, O, A, and C, respectively). People high in N are said to normally experience negative emotions such as depression, anxiety, and anger. They are also likely to appraise stressful situations as threats rather than challenges.

Extraverts tend to be energetic and cheerful, and tend to view stressful situations as challenges. People high in O are thought to be untraditional and imaginative, and they are believed to appreciate aesthetic experiences. More agreeable people are likely to be characterised as helpful, trusting, and straightforward, whereas those high in C seem reliable, hardworking, and self-disciplined (Gunther *et al.*, 1999).

David and Suls (1999) noted some links between some of these traits and use of certain coping strategies. People who score high on E should rely more on active, problem-focused coping strategies because of their tendency to see problems as challenges, whereas those high in N should rely more on passive or emotion-focused strategies due to their tendency to interpret problems as threats rather than as challenges. The above expectations were found to be consistent with reports that demonstrated that people scoring higher on N have shown a tendency to rely more on emotion-focused coping strategies and less on problem-focused strategies.

In studies conducted by McCrae and Costa (1986), and Watson and Hubbard (1996) relationships were found between personality traits and coping strategies used. N was found to relate positively to wishful thinking, self-blame and seeking emotional support. People who score high in E were found to be more likely to take action, engage in positive thinking, seek social support and employ more problem-focused coping in general. These people were also associated with less use of emotion-focused coping and avoidance.

Openness to experience related positively to positive reappraisal and use of humour and negatively to use of religious faith as a coping strategy. Active coping and planning, support-seeking, and positive reappraisal are also related positively to A. People with higher C scores tend to use more problem-focused coping strategies like active coping, planning, suppression of competing activities, and restraint coping These people also engage in less emotion-focused coping like drugs, alcohol, denial and accepting responsibility.

Although consistent trends have emerged, David and Suls (1999) pointed out several limitations in the above findings. The majority of studies have been cross-sectional in nature and required participants to recall coping efforts used in the past week, month or more. Reports of coping responses may be subject to memory biases and reflect long term personality dispositions as the time interval between coping efforts and the coping assessment increases. The association between personality and coping may be inflated in such studies. David and Suls (1999) suggest that more accurate reports on this subject can be obtained if the coping strategy used is measured soon after the stressful episode.

3.1.5 COPING WITH HIV

There seems to be a great deal of interest in the possibility that psychosocial factors, and in particular stressful life experiences, psychological distress, and coping resources, are capable of altering the course of HIV-infection by influencing immune functions. The documented association between chronic stress and suppression of immune functions is used as a basis for suspecting that stress and coping might affect the course of HIV infection (Vassend & Eskild, 1998).

Among factors that may serve to buffer the impact of HIV on those infected, coping is considered to be an important factor affecting adaptational outcomes such as psychological well-being, especially in the long term (Lazarus & Folkman, 1984).

Moneyham, Hennessy, Sowell, Demi, Seals and Mizuno (1998) are of the opinion that the choice and effectiveness of the coping strategies used in stressful situations such as illness, should vary over time as a function of changes in the contextual factors like the stage of the disease and related physical symptoms.

Active problem focused coping is found to be effective in some situations and not in others. Although there is some evidence that passive coping strategies, such as avoidance, are associated with positive adaptational outcomes when dealing with short-term stressful situations, their use appears to be less effective over the long term. The use of avoidance coping strategies was mostly found to be associated with increased psychological distress including anxiety, depression and poor adjustment. There is also a possibility that the relationship between avoidance coping and psychological distress is a function of the stage of the disease, since there were instances where avoidance coping was found to be related to positive outcomes (Moneyham *et al.*, 1998).

Although strategies used by women to cope with HIV are likely to differ in different populations and in different situations, studies have found that emotion-focused coping strategies like spirituality or seeking social support, to be positively associated with the psychological well-being of women with HIV (Bennetts *et al.*, 1999).

Most of the research done on coping with HIV has been focusing on the relationship between coping and the adaptational outcomes. The shortcoming of such research is that it fails to consider the role of the context in which coping occurs, and thereby limits the understanding of responses to difficult situations such as illness (Pedersen & Elklit, 1998).

An example is noted by Springer (cited in Moneyham *et al.*, 1998), that the great majority of women infected with HIV are usually poor, from minority groups, and must focus most of their energy on the daily quest of meeting the survival needs of their children. Because of such factors, it has been suggested that women may be particularly vulnerable and unprepared to deal with the demands of HIV-infection due to deficits in the socio-economic resources that support effective coping. Another example is the notion that avoidance coping has been reported to be prevalent among women, minorities, and those with lower education and income. There is, however, little direct empirical evidence that supports the notion that HIV-infected women cope less effectively than other HIV-infected populations (Bennetts *et al.*, 1999).

3.1.6 SOCIAL SUPPORT

It is generally argued that people will fare better when faced with stressful life situations if they have social support (Kimberly & Serovich, 1996). According to Cobb (1976), social support incorporates three components: a) belief by the recipient that he/she is cared for and loved, b) belief by the recipient that he/she is valued, and c) belief by the recipient that he/she belongs to a network of communication and mutual obligation.

Caplan and Killilea (in Santelli, Turnbull, Lerner & Marquis, 1993) defined social support as the attachment among individuals or between individuals and groups which improves adaptive competence in dealing with short-term crises and life transitions as well as long-term challenges, provisions and stresses. This support is accessible to an individual through social ties to other individuals, groups and larger communities (Cobb, 1976). Shumaker and Brownwell (as cited in Zimet, Dahlem, Zimet & Farley, 1988) noted that social support can also be characterised as an exchange of resources between at least two individuals, perceived by the provider or the recipient to be intended to enhance the well-being of the recipient.

Social support is seen to operate as a stress buffer, which moderates the relationship between life events and psychological disorders. It can also be important in the response to both positively and negatively perceived stressors (Bogle, 1995).

Two broad approaches were identified in the assessment of social support. The structural approach looks at some aspects of the structure of the network of relationships. The functional approach, the most commonly used of the two, looks at aspects of the person's relationships, or the ability of those relationships to provide important support functions (Oxford, 1992).

According to Santelli *et al.* (1993), the type of support obtained through support networks varies. Instrumental support, which is sometimes referred to as material assistance, tangible support and aid, is the most common type found. It refers to provision of services and goods that usually assist in solving practical problems. Such support includes things like providing loans and gifts of goods or money (Firth & Rapley, 1990).

Another function of support, which is perceived to form a significant part of social support, is emotional support. It includes listening, showing concern, conveying intimacy (Leavy in Oxford, 1992), warmth, love, caring trust and encouragement (Tolsdorf in Oxford, 1992), empathy and understanding (Santelli *et al.*, 1993). Other components of emotional support are intimacy, attachment, reassurance, and the ability to confide in and rely on one another (Schaefer, Coyne & Lazarus in Oakely, 1992). All the above contribute to a feeling of being part of the group, feeling loved, and cared for.

Thoits (1986) refers to cognitive-informational support, which is sometimes known as advice or guidance, as another function of social support. It basically includes provision of information and advice, which could assist a person in solving problems or giving feedback on how a person is managing his/her life (Schaefer in Oakley, 1992). Solano (in Fehr, 1996) is of the opinion that significant others in an individual's life provide him/her with a frame of reference which may be used to interpret the world and to find meaning in his/her experiences.

Providing company is also seen as another function of social support. Social companionship is defined as spending time with others in leisure and recreational activities. Such activities can be viewed as of help in reducing stress by fulfilling a need for affiliation and contact with others. This can further help in distracting persons from worrying about problems (Cohen & Wills, 1985).

Antonovsky (in Kobasa and Puccetti, 1983) refers to the general resistance resources (GRRs), namely cognitive and emotional, valuative-attitudinal and interpersonal-relational, which could be interpreted in terms of social support since they include the dimensions of understanding, caring and sharing. A lack of support in these dimensions leads to a general resistance deficit

(GRD) and increased levels of stress. A further discussion on the GRRs and GRDs will be given in 3.2.4 and 3.2.5.1.

Being part of a family and having friends does not necessarily mean that one is the automatic beneficiary of support in times of trouble. The degree at which people can draw upon social relations for support depends on more than either the extensiveness of the relations or the frequency of the interaction (Mitchell, Cronkite & Moos, 1984). Support, rather, comes when people's engagement with one another extends to a level of involvement and concern, as is true of family members and close friends, and not when they merely touch at the surface of each other's lives (Pearlin, Menaghan, Lieberman & Mullan, 1981).

Although the availability and provision of social support for people with HIV is perceived to be important (Pedersen & Elklit, 1998; Siegel, Karus, Raveis & Hagen, 1998), there is evidence to the fact that disclosing one's HIV status frequently results in ostracism from family and/or friends (Altman cited in Kimberly & Serovich, 1996). This leads to loss of support.

Because of the physical and psychological stresses on people with HIV, it is crucial for them to establish realistic expectations about who can and will provide support. Providers of support like family and friends may not be available for HIV positive people as for others seeking support because of fear or stigma (Sowell & Misener, 1997). Public opinions and attitudes towards those infected with HIV are based on negative stereotypes, which may lead family members and friends to withdraw support (Kimberly & Serovich, 1996).

Individuals seek social support because they need assistance. People infected with HIV seeking support must disclose their status in order to receive support. The problem comes when they have to decide as to whom they choose to disclose this information. People therefore create boundaries with regard to their perceptions of appropriate targets for disclosure of HIV status. Appropriate delineation of disclosure boundaries in relation to social support is important because the ramifications can either be positive or negative (Schlebusch & Cassidy, 1995).

Family and friends subsystems seem to be the ones, which are perceived to be more supportive when it comes to people with HIV. Family members were found to be likely to buy things, while friends were more likely to run errands and offer moral support for HIV-positive persons (Kimberly & Serovich, 1996).

In a study conducted by Sowell and Misener (1997), they found that for women who have children, the family members most likely to be aware of the woman's HIV-infection are children. This means that a number of minor children are providing support to their HIV-infected mothers. If these women were to disclose to an adult family member, it was most likely the woman's mother. The women reported that their mothers' support had been invaluable in helping them cope with their disease.

The women in the above mentioned study also indicated that they also got support from their peer group of other HIV infected women. After attending a support group organised by the researchers, those women who had not previously been involved with support groups voiced the intent to join a group. They stated that the support they received from the group made them feel that they were with people who really understood them and accepted them unconditionally (Sowell & Misener, 1997).

3.2 SALUTOGENESIS

3.2.1 INTRODUCTION

The salutogenic model as first introduced by Antonovsky (1979) signifies an important paradigm shift from the commonly used pathogenic model by focusing on the origins of health or well-being, instead of examining the causes of disease. The question that is often asked is "why do some people thrive under certain stressful situations when others do not?" The salutogenic approach focuses on persons with an orientation to life that allows them to assess a situation in such a way that they could survive in a situation that others might find psychologically, emotionally, or physically compromising.

There are several salutogenic models in use, but due to the link between Antonovsky's (1979, 1984a, 1984b, 1987) model and coping, only that model will be discussed.

3.2.2 PATHOGENESIS

The pathogenic paradigm assumes that the normal state of affairs of the human organism is one of homeostasis and order (Antonovsky, 1984a). The implication is that the normal state of the human being is a relatively constant condition, which is occasionally disturbed by various pathogens and stressors and maintained by various interacting regulatory mechanisms. Disease comes about as a result of inadequacy in these regulatory mechanisms (Strümpfer, 1990).

Strümpfer (1990) noted that psychology has followed the traditional way of thinking in a pathogenic orientation to psychological problems, thus emphasising the abnormal. The pathogenic paradigm is directed at finding out why people fall ill and specifically, why they develop particular diseases. The information obtained from such findings is then used to find ways of combating and preventing diseases. At the heart of this paradigm is also the assumption that diseases are caused by physical, biochemical, microbiological and psychosocial agents. According to Antonovsky (1979, 1984a, 1984b, 1987) the consequences of pathogenic thinking can be summarised as follows:

- People are classified as either healthy or diseased, implying that the homeostasis of people perceived to be in the healthy category is undisturbed (Antonovsky, 1984a).

- It pressures us to focus on the disease or illness and disregard the sickness. This means that the subjective interpretation of the situation of the person who is ill is usually ignored in favour of the aetiology of the disease. Salutogenesis on the other hand studies everything that may be important about the persons who are ill, including their subjective interpretation of their state of health (Antonovsky, 1979).

- The pathogenic approach focuses on specific illness and it seeks specific immunities and cures, whereas there are factors, both etiologic and symptomatic, that are common to all forms of disease. This specific focus on certain diseases leads to disregard of these common factors (Antonovsky, 1987).

- Pathogenic thinking leads us to believe in a fallacy that all illness will be conquered one day. Antonovsky (1984b) referred to Dobus' argument that disease is an expression of maladaption to the environment, and since the environment is always changing and always producing new threats, the human being's ability to adapt to new threats should always be an important issue to be taken into consideration.

- Placing the focus on causes of diseases leaves little room for looking at coping skills. Antonovsky (1984b, p.115) emphasised this line of thinking by noting: "In other words, prime attention is given to the bugs - as noted earlier, to the specific bugs related to disease X - and not to generalised capacities for coping with bugs".

- Pathogenic thinking leads us to assume stressors are bad. In Antonovsky's opinion, the outcome of this thinking is an attempt to create a sterile environment. The probability of creating the sterile environment is not only very low, but can also be to the detriment of human beings. He suggests that stressors must be seen as having the potential to be toxic, neutral, tonic and salutary or have both positive and negative consequences.

- The pathogenic approach places emphasis on the high-risk group and as a result it tends to ignore the 'deviant cases', i.e., those who do not become sick. Antonovsky (1984a) pointed out that when a positive correlation exists between a stressor (e.g. smoking) and a condition (e.g. lung cancer), only a part of the variance is accounted for even at a high level of probability. Because researchers do not study the deviants, they generate neither hypotheses nor methodologies to create understanding of the full extent of human health (Antonovsky, 1984a, 1984b).

Antonovsky became uncomfortable with the pathogenic paradigm when he realised that it is unable to explain data satisfactory. He pointed out that it does not account for the fact that at any time, at least one-third and possibly a majority of the population of any modern society is characterised by some pathological condition (1984a). He then asked: “How is it that not all people break down?” (Antonovsky, 1979). The above information propelled Antonovsky to formulate the salutogenic model as an attempt to answer the questions he had.

3.2.3 ANTONOVSKY’S SALUTOGENIC MODEL

Strümpfer (1990) refers to Antonovsky as the clearest proponent of the salutogenic paradigm. The word salutogenesis derives from the Latin words *salus* meaning health, and *genesis*, which means origin. This line of thinking therefore leads us to think in terms of factors promoting movement toward the healthy end of a health ease/disease continuum (Antonovsky, 1987). Antonovsky formulated his ideas after making observations of holocaust survivors and wondering how it was possible to live a normal life and keep one’s sanity after such life experiences (Poppius, Tenkanen, Kalimo, & Heinsalmi, 1999).

The findings of the research conducted by Antonovsky went beyond ‘health’ as usually construed. They covered strength to deal with general concerns, like finances, growing old, security conditions in the country and satisfaction with family roles, as well as roles such as being a friend, neighbour, worker or volunteer (Strümpfer, 1995).

There is a generally held view that people can be classified in terms of a fundamental dichotomy of being either healthy or diseased. Those who believe in the former position allocated attention and resources to keeping people healthy and preventing them from becoming sick. The latter view forces the attention to be focused on treating those who are sick, trying to restore health, if possible (Antonovsky in Oelofse, 1996). Antonovsky views this dichotomous classification of people as an oversimplification of health problems. His perspective is that people fall somewhere on a continuum between health and illness.

The salutogenic orientation derives from the fundamental postulate that heterostasis and increasing entropy are core characteristics of all living organisms. In the course of living, people are constantly involved in minor, automatic mechanisms to maintain or restore homeostasis to keep themselves stable, both physiologically and psychologically (Antonovsky, 1979).

A stressor is commonly regarded as a demand made by the internal or external environment of a human being, which upsets the homeostasis to such an extent, that it requires a nonautomatic action to restore it. According to Antonovsky, it is not viable to define all the slight differences in the environment as stressors, since the difference between a stressor and other types of stimuli is a matter of degree. Whether a given stimulus is a stressor depends mostly on the meaning a particular person attaches to the stimulus and the available repertoire of automatic homeostasis-restoring mechanisms (Antonovsky, 1979). This explanation links with primary and secondary appraisal discussed in section 3.1.3.1.

Antonovsky (1979) believed that stressors are omnipresent in the human existence, thus explaining why many of any country's population at a given time is ill to a greater or lesser extent, despite high living standards, environmental control and medical technology. He pointed out that even people in comfortable and favourable environments are continuously exposed to fairly serious stressors.

The distinction between tension and stress is viewed to be of importance for the understanding of the way illness comes about. In Antonovsky's view, stressors are neutral in health consequences, but lead to a state of tension in the organism. If the organism copes well with the tension, the stressor may be tonic. Stress is seen as the result of poor tension management, which opens way for disease (Antonovsky, 1984b).

The characteristics of the salutogenic model (Antonovsky, 1987) are summarised as follows:

- It rejects the dichotomous classification of people as healthy or diseased in favour of their location on the multidimensional health ease/disease continuum.
- It does not solely focus on the causes of a given disease, but on the total human being including his/her sickness.
- The focus is removed from the causes of illness to factors involved in maintaining or improving one's location on the health ease/disease continuum, i.e. coping resources.
- Stressors are not necessarily viewed as pathological, but possibly salutary, depending on the character of the stressor and the resolution of tension.
- It goes further beyond the data obtained from the pathogenic enquiry by always considering the 'deviant cases' found in such an enquiry, i.e. those people who do not become sick.

There seems to be a relationship between Folkman and Lazarus' cognitive phenomenological model of coping discussed in 3.1.3 and the salutogenic paradigm as discussed above since they both look at a person in context, instead of just concentrating on cause and effect.

3.2.4 GENERALIZED RESISTANCE RESOURCES

A generalised resistance resource (GRR) is defined as "any characteristic of a person, the group, or the environment that can facilitate effective tension management" (Antonovsky, 1979, p.99). Antonovsky (1987) also refers to a

GRR as any phenomenon that is effective in combating a wide variety of stressors.

The pathogenic approach is also interested in the study of resistance resources, but only those relevant to particular diseases. The importance of resistance resources relevant to particular diseases is not denied, but Antonovsky (1979) stated that they "are all too often matters of chance or luck, as well as being helpful only in particular situations" (p.99). He gave examples of such GRRs as a certain drug, a telephone lifeline of suicide-prevention agencies, or an understanding look in the eyes of an audience to whom one is lecturing.

Antonovsky (1979) identified eight types of GRRs. They include physical, biochemical, artifactual-material, cognitive, emotional, evaluative-attitudinal, interpersonal-relational and macrosociocultural characteristics of a individual, primary group, subculture and society, that are effective in avoiding and combating a wide variety of stressors. These GRRs can be further related to coping resources like physical, social, psychological, and material assets, which are evaluated with respect to the demands of the situation as discussed under secondary appraisal in 3.1.3.1. The extent to which GRRs are available to a person is perceived to play an important role in determining the person's position and movement towards the healthy end of the health ease/disease continuum (Antonovsky, 1979).

The GRRs can also be divided into three basic categories, namely homeostatic flexibility, ties to concrete other, and ties to the total community. Homeostatic flexibility refers to the ability to accept alternatives to problems and to assess the potential outcomes of such alternatives. Profound ties to concrete others and to the community enable one to more adequately manage tension, by having greater support and stability (Antonovsky in Dohrenwend & Dohremwend, 1974).

A person undergoes life situations or experiences with specifiable characteristics or perceptions, unique to the individual. These experiences generate, over time, a way of seeing one's world, leading us to the concept that Antonovsky called the sense of coherence.

3.2.5 THE SENSE OF COHERENCE (SOC)

3.2.5.1 Definition

While trying to find answers to questions like "whence the strength?" (Antonovsky, 1979, p. 7) and why some people are able to manage stress and stay well, Antonovsky came to the concept of the 'sense of coherence' (SOC). He defined it as:

> A global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that (1) the stimuli, deriving from one's internal and external environments in the course of living are structured, predictable and explicable, (2) the resources are available to one to meet the demands posed by these stimuli, and (3) these demands are challenges worthy of investment and engagement (Antonovsky, 1987, p. 19).

Antonovsky (1979) pointed out that SOC does not refer to any specific area of life or situation or stressor. He sees it as an important component in the basic personality structure of an individual and in the surroundings of a subculture, culture or historical period. He emphasised that having a strong SOC does not mean that a person won't have problems as a result of stressors, but exposure to different stressors can effect a temporary and minor shift in a person's SOC, with changes occurring around a stable location on the health-disease continuum.

GRRs lead one to develop a strong, crystallised, integrated view of the world. Generalised resistance deficits (GRDs), such as low self-esteem, isolation, low social class or cultural instability can lead to a weak sense of coherence. The balance between the experiences provided by these GRRs and GRDs therefore determines an individual's location on the SOC continuum (Antonovsky, 1990).

H. Antonovsky and Sagy (1986) described SOC as an enduring tendency to see one's life space as more or less ordered, predictable, and manageable. Antonovsky and Sourani (1988) view the hallmark of SOC as flexibility in selecting coping behaviours that are judged to be appropriate. A strong SOC leads to the existence of the motivational and cognitive bases for transforming one's potential resources, appropriate to a given stressor, into actuality, thereby promoting health (Antonovsky & Sourani, 1988).

3.2.5.2 Components of SOC

There are three components in the SOC construct, namely comprehensibility, manageability, and meaningfulness. Antonovsky (1987) described these components as follows:

- Comprehensibility

  This component reflects typically solid capacity to judge reality. It refers to a sense that life is ordered, consistent and makes sense. It also refers to the extent to which one perceives the stimuli that confronts one, deriving from external and internal environments, as making cognitive sense, as ordered, consistent, structured, and clear, rather than as chaotic and random. A person with a high sense of comprehensibility sees his/her future as predictable, expecting things to work out as reasonable as can be expected. When things come as surprises like failures or death, such a person can make sense of them. A person with a low sense of comprehensibility on the other hand, will have contrary feelings, thinking that he/she is a loser.

- Manageability

  Manageability is defined as the extent to which one perceives that one has at his/her disposal resources that are adequate to meet the demands posed by the stimuli. Here a person is confident of his/her own resources and he/she can trust others.

A strong sense of manageability makes people to believe that the appropriate resources for successful coping with a given stressor are at their disposal. This has a strong relationship to secondary appraisal discussed in 3.1.3.1. where a person evaluates coping resources and options after appraising the situation. These resources include one's spouse, friends, colleagues, God, the physician, or any other person one thinks is on his/her side. High sense of manageability also protects an individual from feeling like a victim or as if life is treating him/her unfairly whenever he/she is faced with life's unfortunate events (Antonovsky, 1990).

- Meaningfulness

This represents the motivational element in the construct. It refers to the extent to which one feels that life makes sense emotionally, that at least some of the demands posed by living are worth investing energy in, are worthy of commitment and engagement, are challenges that are welcome rather than burdens that one would much rather do without (Antonovsky, 1987, p.18). In case of unhappy experiences, a person with a high sense of meaningfulness will most likely be willingly to take up the challenge, will probably be determined to seek meaning in it, and possibly do his/her best to overcome it with dignity (Antonovsky, 1987).

Antonovsky (1987, p. 22) further elaborated on the components by saying:

> The motivational component of meaningfulness seems most crucial. Without it, being high on comprehensibility or manageability is likely to be temporary. For the committed and caring person, the way is open to gaining understanding and resources. Comprehensibility seems next in importance, for high manageability is contingent on understanding. If one does not believe that resources are at one's disposal, meaningfulness will be lessened and coping efforts weakened. Successful coping, then, depends on the SOC as a whole.

The above indicates that although the three components can be distinguished, successful coping depends on SOC as a whole and not just on a specific component.

The SOC deals with outlook on life. According to Antonovsky persons high on SOC are more likely to stay healthy more often than those low on SOC. Factors affecting SOC are identified as stressors, adaptation and coping. But as Antonovsky's (1987) outlook is salutogenic, the stressors are not always the negative stressors as indicated earlier in this study.

3.2.5.3 SOC and Boundaries

Having a strong SOC does not mean that the person experiences everything in life as highly comprehensible, manageable and meaningful (Strümpfer, 1990). According to Antonovsky (1987) people set boundaries, and what happens outside those boundaries does not matter. This boundary notion suggests that a person need not necessarily feel that all of life is highly comprehensible, manageable, and meaningful in order to have a strong SOC. Some people's boundaries can be wide, some narrow, implying that a person can exclude various spheres of life. Antonovsky (1987) believed that for a person's life to be meaningful, his/her boundaries should never exclude the following spheres:

- a person's own feelings
- his/her interpersonal relations
- the major activities he/she engages in, such as work or being a housewife
- existential issues like death, inevitable failures, isolation, conflict and shortcomings.

Flexibility about areas of life, which a person includes within the boundaries, may be an effective way through which a person with a strong SOC maintains a coherent view of the world. Boundary control (flexibility) can be done by adding or including new areas within the boundaries, or by temporarily or permanently removing from an area where demands are becoming less important and less comprehensible and manageable (Antonovsky in Oelofse, 1996).

Antonovsky (1979, 1984a, 1987) emphasised that acceptance of the salutogenic paradigm does not imply total rejection of the pathogenic paradigm. Antonovsky and Bernstein (as cited in Oelofse 1996, p.13) reflected on a their friend's remark who said: "when I have cancer, I want to be treated for cancer, not for the sense of coherence".

3.3 CONCLUSION

This chapter looked at different approaches to coping with a specific emphasis on the cognitive phenomenological model of coping. The salutogenic orientation, which focuses on finding out how people manage to stay healthy, was also discussed. The next chapter consists of a detailed description of the manner in which the research process was conducted.

ERRATA

Change the word "loose" to "lose" on the following pages

p. 10, line 22

p. 69, line 9

p. 71, line 28

p. 72, line 11

p. 74, line 12

p. 80, line 14 & 15

Change the word "loosing" to "losing" on

p. 17, line 11

p. 72, line 5, 6, 8

p. 80, line 10

p. 82, line 11

p. 11, line 19: "women are" should be "women were"

p. 12, line 21: "legions" should read "lesions"

p. 17, line 25: "reported against" should be "reported by"

p. 17, line 26: "occur" should be "occurs"

p. 25, line 27: "undimensional" should be "unidimensional"

p. 35, line 9: the word "her" should be inserted before "children"

p. 41, line 13: "a individual" should read "an individual"

p. 46, line 6: "a" should be inserted before "friend's"

p. 53, line 10: "hem" should be spelt "them"

p. 63, line 10: the word "a" should be inserted before "few"

p. 71, line 21: "concern and" should read "concern with, and"

p. 85, line 21: "live the way" should be living the way"

p.92, line 6/7: "Hate feelings" should be "Feelings of hate"

p. 96, line 25: "other people" should be "some people"

p. 101, line 7: "a" should be inserted before "daily"

p. 103, line 8: the word "the" should be inserted before "better"

p. 103, line 29: "by another should read "to another"

CHAPTER 4

METHOD

4.1 INTRODUCTION

In this chapter, the research design, the research participants, the method of data collection and the data analysis selected for the study will be discussed.

4.2 RESEARCH DESIGN

The purpose behind the method used in this study is to work from a point where nothing is known about the participants, to a point of understanding the way they experience and cope with their lives. The aim of the study is to gain an understanding of how black women who are living with HIV, experience their lives and make it through life daily. It is important for the purpose of the study for the participants to give descriptions of those experiences in their own words. A qualitative research design was decided upon to gather those descriptions.

Qualitative research designs are investigative methods used to investigate the nature of social phenomena (Maso, 1994). The research design seeks to gain insight by discovering the meanings attached to a given phenomenon. According to Miles and Huberman (1984) qualitative research allows the researcher to focus on the experiences of the participants by means of language. The researcher analyses social settings, motives and meanings, actions and reactions, organisations, culture, individual's daily activities and negotiation of the roles within the context of everyday life (Rothe, 1993)

Creswell (1994) has proposed five underlying assumptions of qualitative research. The first assumption is that the focus is on process and not on product or outcome. Secondly, the interest is placed on meaning, that is, how people make sense of their lives, experiences, and how they structure their worlds. The third assumption is that the mode of enquiry may involve fieldwork, depending on the nature of the study, whereby the researcher physically goes to people, settings, sites or institutions to observe and record the behaviour. Fourthly, the process, meaning and understanding are gained through words and pictures. Lastly, the inquiry is in such a way that a researcher builds abstractions, concepts, hypotheses and theories from details, thus making the inquiry inductive.

The qualitative research design looks at subjective meanings, descriptions, metaphors, symbols and descriptions of specific cases. According to Neuman (1997) the researchers attempt to capture aspects of the social world for which it is difficult to develop precise measures expressed as numbers. In case of the present study, the researcher had an opportunity to interact with the participants as humans, face to face, and the results were not expressed as just numbers.

According to Kvale (1996) qualitative research appears to be particularly relevant for studying the life worlds, lived realities and everyday practices of people in a particular setting. This study attempts to describe the 'life worlds' and everyday experiences of the women as they are. In this study, the qualitative design gave the researcher an opportunity to have direct contact with the women, to enter into their worlds, to listen and follow as they guided her along the journeys of their life experiences. At the end of the day, the researcher ends up attempting to view and understand reality as the participant views and understands it.

Sherman and Webb (cited in Ely, Anzul, Friedman, Garner & McCormack Steinmetz, 1991) analysed what leading qualitative researchers had to say about their work in various fields. Their analysis produced five similar characteristics of qualitative research:

- Events can be understood adequately only if they are seen in context. Therefore, a qualitative researcher immerses her/himself in the setting.
- The contexts of inquiry are not contrived; they are natural. Nothing is predefined or taken for granted.

- Qualitative researchers want those who are studied to speak for themselves, to provide their perspective in which the persons studied teach the researcher about their lives.
- Qualitative researchers attend to the experience as a whole, not as separate variables. The aim of qualitative research is to understand experience as unified.
- Since qualitative methods are tailored according to each specific research question and context, there is no one general method that can be used in all settings.

4.3 THE PARTICIPANTS

The study concentrated on the experiences of black women who were diagnosed with HIV and how they cope with their situation. The literature study looked specifically at the concerns of women infected with HIV. The literature (see chapter 2) indicated that there is research being carried out on how the virus manifests in women as well as the success of prevention methods used by women. Very little research, especially in South Africa, has concentrated on how women actually live their lives and cope, knowing they are HIV positive. Based on this information, it was considered necessary to conduct the study.

4.3.1 RECRUITING OF PARTICIPANTS

The study was conducted at 1 Military hospital in Pretoria. Some of the participants were referred to the researcher by the social worker and the nursing sister from the Infection Control clinic, which is now open everyday of the week. The clinic renders services like family planning, treatment for sexually transmitted diseases, blood testing for HIV, pre- and post-test counselling for HIV, and medical checks and treatment for HIV infected people in the South African National Defence Force (SANDF). The nursing sister referred some participants to the researcher from the Community Centre in Thaba-Tshwane.

While at the clinics, the social worker and the two nursing sisters informed the participants that a researcher would like to see them for an interview. Consent was obtained from the women to speak to the researcher. The women were seen thereafter. The researcher explained to each woman what she was intending to do and gave them time to think about whether they would like to participate in the study.

The number of the participants to be used in the study was not predetermined. It was decided to interview participants until the data becomes saturated and the information starts to repeat itself. Six participants were contacted initially, and they all called the researcher within the following three days to confirm that they were interested in partaking in the research. Subsequent appointments were made, during which the interviews took place. Four women turned up for the interviews, and the fifth woman fell ill before the date of the interview. The sixth woman never came for an appointment. The researcher thought that it was going to be difficult to get women who are HIV positive and would agree to talk about their experiences. To her surprise, all women who were contacted were more than willing to tell their stories for the purpose of this research.

All women were black South Africans. Their educational level ranged from standard eight to matric and none of them had any post matric or tertiary education. They were all working for the South African National Defence Force. All the subjects could speak English, although it was their second or third language. They were given a choice to use their first languages, which were Zulu, Tswana and South-Sotho. Two women chose to communicate in English while the other two alternated between Tswana and South-Sotho and English. All the participants were heterosexual. Detail regarding marital status, children and other biographical information will be provided in chapter 5.

4.3.2 CRITERIA FOR THE SELECTION OF PARTICIPANTS

The participants were chosen on the basis of certain inclusion criteria. These criteria included:

- The participants must be black women who have been diagnosed HIV-positive.
- They must have known of their diagnosis for at least six months to be able to know and describe their experiences and how they have been coping.
- They must be willing to participate in the study and share their experiences and articulate their feelings.
- They must be able to express themselves verbally.
- They must not be mentally retarded, psychotic, or be suffering from neurological disorders e.g. dementia.

All the participants in the study complied with the inclusion criteria above. More detailed background information about the participants will be given in section 5.2.

4.4 DATA COLLECTION

4.4.1 THE INTERVIEW

Since the interview method enables the researcher to study the data as it emerged and not according to pre-selected aspects, the decision was made to use it as a method of data collection (Lee, 1993). The interviews were used to gather descriptions of the experiences of women living with HIV.

An interview is defined as a purposeful conversation usually between two people (but sometimes involving more) that is directed by one in order to get information (Bogdan & Biklen cited in Ely *et al.*, 1991). According to Taylor and Bogdan (1984, p.77) “by in-depth qualitative interviewing we mean repeated face-to-face encounters between the researcher and the informants directed towards understanding informants’ perspectives on their lives, experiences, or situations as expressed in their own words". This means that there is a specific form of interaction in which knowledge evolves through a dialogue (Kvale, 1996). The participants are requested to describe the topic being investigated in detail (Polkinghorne, 1989). As the researcher becomes aware of the meanings, questions are asked and clarifications are sought. An interview is therefore also seen as interwoven 'dances' of questions and answers in which the researcher follows as well as leads (Ely *et al.*, 1991).

The following factors, as proposed by Rothe (1993), motivated the researcher to use interviews as a method of data collection:

- the participants are given the opportunity to express their feelings, knowledge, points of view and beliefs
- an opportunity is given to participants to express themselves in ways that they are unable to do on questionnaires
- room is created for expression of ideas and clarifications
- an opportunity is also created for on-sight verification of answers
- participants may provide insight in terms of how they construct answers and how that construction reflects certain ideologies or interests.

Although interviews can be a very useful method of data collection, Marshall and Rossman (1989) pointed out that they also have their limitations and weaknesses:

- since they must involve personal interaction, co-operation is essential
- participants may not be willing to share all the information with the interviewer
- the interviewer may not ask appropriate questions because of lack of expertise
- the answers to the questions may not be properly comprehended by the interviewer
- participants may not always be truthful

- when interviews are used alone, distortions in data are more likely due to the interviewer's personal biases
- although a lot of data can be obtained through interviewing, such data may be difficult to organise and interpret.

The rationale for the use of the interviews in this study is adequately summarised by Spradley (in Kvale, 1996, p.125) by the following:

> *"I want to understand the world from your point of view. I want to know what you know in the way you know it. I want to understand the meaning of your experience, to walk in your shoes, to feel things as you feel hem, to explain things as you explain them. Will you be my teacher and help me understand?"*

4.4.2 THE INTERVIEW PROCESS

The researcher started by applying for permission to conduct the research project in the SANDF with its employees as participants. Permission was granted without any problems. During the first interview, background information was collected from the participants. The researcher met the participants in her office since it was impossible to meet them anywhere else. The researcher would have preferred to see the participants in their homes in order to get first hand information from the participants' own context. Another purpose of the initial interviews was to establish the relationship with the participants and make sure that they really understood the purpose of the study and what was needed from them.

Informed consent was obtained from the participants. It entailed informing them about the overall purpose of the investigation and the main features of the design, as well as of any possible risks and benefits from participation in the study. The consent further involved obtaining the voluntary participation of the subjects, with their right to withdraw from the study at any point, to avoid potential undue influence and coercion. Participants were then asked to sign a written consent, thus giving their permission to participate in the study.

At the end of the interviews, all the participants seemed relaxed in the researcher's company and were ready to begin telling their stories. One participant asked to start with the next stage of the interview immediately. The next appointments with the other three participants were scheduled for the week that followed.

The researcher decided to use an exploratory interview, which is open and has little structure. In this case the researcher introduced the topic or a problem to be uncovered, which was the way women who are infected with HIV experience their lives and how they cope with their situation. The researcher followed up on the subject's answers to obtain additional information about and new angles on the topic.

Taking into consideration the sensitivity of the topic, the participants were given freedom to express that which they were comfortable with expressing. An understanding was also reached that should any participant experience emotional distress during the interviews, the researcher would refer them for therapeutic support. That did not happen for the whole interview process. To allow the participants to volunteer descriptions and explanations, the researcher asked open-ended questions at the beginning and during the interview (True, 1989). Three open-ended questions were asked namely: (a) "how have you been experiencing your life since you were diagnosed HIV-positive?" (b) "how are you coping with your situation?" and (c) "how can you advise other women in the same situation as you?" All the interviews were audio-recorded and field notes were written during and after the interviews.

4.5 METHOD OF DATA ANALYSIS

According to Dey (1993) analysis involves breaking data down into bits, and then 'beating' the bits together. He further describes it as a process of resolving data into its constituent components, to reveal its characteristic elements and structure. After breaking down data and 'beating' it together, we sometimes end up with something quite different from what we started with. This makes sense since the aim of data analysis is not just to describe, but also to understand the objects and events to which our data refers.

Kvale (1996) is of the opinion that analysis and interpretation of data starts at the beginning of the research process, and not in the final phase of the process. The interviews were transcribed and analysed according to the guidelines outlined by Kvale (1996) and Fiedeldey (1991). The following steps were followed to complete the analysis of the categories of experience:

a. Familiarisation with data

In order to familiarise herself with the information provided in the interviews, the researcher read through the transcripts several times. As it is somehow impossible not to be influenced by one's own frame of reference, it is important to be as aware of one's own ideas as possible. Bearing this in mind, the researcher read the transcripts with the purpose of identifying ideas that were unexpected or new to her. The transcripts were put aside for a week and were then read again, with a view of identifying ideas that may have been missed during the first reading.

b. Developing the categories

The next step was to determine the natural meaning units as expressed by the subjects. This was done by focussing on the meaning of phrases, or of sentences grouped together. Units were identified according to the way they were distinguished from each other on conceptual grounds (Pieterse, 1995). They were then compared by looking at their similarities as well as their differences. Subsequent to this, natural meaning units with similar content and meaning, were grouped together to form categories of experience. This was done separately with every transcript. The researcher then went through all the transcripts together in order to identify common as well as unique categories across the interviews.

c. *Establishing stability*

To establish the intra-observer reliability or stability of the procedure, which will indicate the degree to which a procedure is constant over time, it was decided to start with the analysis of the first transcript. The categories of experience were identified, named and defined. A total of 22 experiential categories were identified. The procedure was repeated again after two weeks, and this time 20 conceptually different categories were identified. The uncertainty regarding the remaining two categories was discussed with a colleague and the decision was made to integrate them into two other already existing categories by extending their definitions. This left the number of categories at 20.

d. *Establishing consensus*

The inter-coder reliability or consensus, which will indicate the degree to which a procedure can be repeated under different circumstances, was established using the first transcript as well. The transcript was analysed independently by a colleague with a Masters degree in Clinical Psychology. She used the same method of data analysis used by the researcher. She identified 18 categories, 17 of which were similar to those identified by the researcher. After discussing her findings with the researcher, they both decided to retain 3 categories initially identified by the researcher, plus one extra category identified by the colleague. This brought the total number of the categories to 21. Categories identified through the process described above were subsequently checked in the remaining three transcripts. Two more categories were identified from the remaining three transcripts, bringing the total number of categories to 23.

e. *Establishing credibility*

The correspondence between meanings the participants attributed to the data they had given and the way in which the researcher portrayed it, indicates credibility of the research. One way of determining this is when the researcher condenses and interprets the meaning of what the interviewee describes and 'sends' the meaning back (Kvale, 1996). This was done during the interview to clarify some points and to ensure that the participants' descriptions were done justice to. The researcher also went back to the participants a week after the categories were identified and described as indicated by Mertens and McLaughlin (1995), to give the participants an opportunity to correct, comment and confirm the results. Every aspect of the study was discussed with the researcher's supervisor to ensure that challenging, disagreeing, and confronting of information takes place. This also helped to ensure the credibility of the research process.

Credibility or trustworthiness of the whole research process is said to be embedded in the skills and sensitivity of the researcher and the way she uses herself as a knower and an enquirer in the study (Reason & Rowan, 1981). The value of trustworthiness in qualitative research is described by the following:

> *"I used to think trustworthiness was pervasive; but after reading Guba and Lincoln, I realise that it is more than pervasive. It's so big that it's bigger than ethnographic study itself. Not bigger in the sense of how much time it takes. But bigger in the sense of how much it has to be thought about – before, during, and after the ethnographic study is done"* (Joan Giansante in Ely *et al.*, 1991, p.93).

f. Description of the categories

After identifying and defining the categories, the next step was to describe them in more detail. Each category was dealt with at a time, taking each woman's description into consideration and making verbatim references from the original transcripts.

g. Interpretation of results

The final step was to discuss the categories and integrate them with the literature and theoretical information provided in chapters 2 and 3.

4.6 CONCLUSION

A detailed account of the research method used for this study was discussed in this chapter. The steps that were followed in the qualitative analysis of data were also provided in detail. The following chapter deals with a presentation of the results.

ERRATA

Change the word "loose" to "lose" on the following pages

p. 10, line 22

p. 69, line 9

p. 71, line 28

p. 72, line 11

p. 74, line 12

p. 80, line 14 & 15

Change the word "loosing" to "losing" on

p. 17, line 11

p. 72, line 5, 6, 8

p. 80, line 10

p. 82, line 11

p. 11, line 19: "women are" should be "women were"

p. 12, line 21: "legions" should read "lesions"

p. 17, line 25: "reported against" should be "reported by"

p. 17, line 26: "occur" should be "occurs"

p. 25, line 27: "undimensional" should be "unidimensional"

p. 35, line 9: the word "her" should be inserted before "children"

p. 41, line 13: "a individual" should read "an individual"

p. 46, line 6: "a" should be inserted before "friend's"

p. 53, line 10: "hem" should be spelt "them"

p. 63, line 10: the word "a" should be inserted before "few"

p. 71, line 21: "concern and" should read "concern with, and"

p. 85, line 21: "live the way" should be living the way"

p.92, line 6/7: "Hate feelings" should be "Feelings of hate"

p. 96, line 25: "other people" should be "some people"

p. 101, line 7: "a" should be inserted before "daily"

p. 103, line 8: the word "the" should be inserted before "better"

p. 103, line 29: "by another should read "to another"

CHAPTER 5

RESULTS

5.1 INTRODUCTION

The research findings will be described in this chapter. To begin with, a short description of the participants will be presented to introduce them into the study. The next step will be the description of the results of the data gathered from the participants, in the form of categories of experience. The definitions of the categories of experience are presented below the name of each category, followed by a short description of the category and the verbatim examples.

5.2 THE PARTICIPANTS

Each participant will be introduced in order to give some background to the reader concerning some aspects of their lives. Careful consideration was given to the amount of background information provided due to the sensitive nature of the study. As a result, the participant's real names and identifying biographical information will not be used to protect their identities.

5.2.1 Charlotte

Charlotte is a 39-year old woman. She is married with two children, a daughter and son aged 17 and 13 years respectively. The two children are still at school in standard 10 and standard 6. Charlotte is presently living with her husband and his brother, whereas her children are staying with her mother in the same township. She said they all thought it was better that way since the children's father is suffering from AIDS. It was very difficult for her to talk to the children about their father's condition. She said she just avoids the subject as soon as it comes up. She described her husband's condition as terminal, saying she believes that he will not live for long. That seemed to be a major cause of stress in her life at the time of the interview, since she was the one who takes care of him most of the time. The husband's brother is very helpful, but he also has to go to work.

She described her relationship with her husband as very close and stated that they spent most of their time together. She also said that the two of them are very close to both their children, even though her husband spent most of the children's growing years in exile. They were married and already had both children when her husband went to exile, only to come back in 1996. He started becoming sick shortly thereafter with ailments like flu and diarrhoea. When his symptoms persisted, blood tests were done and he was diagnosed HIV-positive. Charlotte was diagnosed shortly thereafter.

Charlotte works approximately 80 kilometres from where she lives. Living far from where she works seemed to be another major problem in Charlotte's life. She reported that she wakes up at 03h30 every day to start preparing for work. She boards two taxis, catches a train and a bus to be able to be at work at 07h00. She does administrative work and described her work as not that demanding and not well paying.

5.2.2 Lucia

Lucia is a 28-year old single mother of a 13-year old boy. She and her son are presently living with her parents and her brother. Both her parents are pensioners and her brother is currently employed. She no longer has any relationship with her son's father after the collapse of their relationship soon after their son was born. This didn't seem to pose problems financially because her parents are always helping out with her son. She described her family as close knit and very supportive.

Lucia had been involved with another man for six years, until they broke up in 1998. Three months before they separated, they secretly got married. The relationship did not work out and they divorced three months thereafter. The ex-husband is currently married to another woman. Lucia does administrative work where she is employed. She said she enjoys her work and would like to remain working there.

She described her life as very stable, after many ups and downs. She had been admitted in a psychiatric ward for the better part of 1996 and 1997 for depression. She did not have any symptoms at the time of the interview. She gave a recollection of symptoms like diarrhoea and mouth thrush, which she exhibited a couple of times in the past.

5.2.3 Linda

Linda is a 26-year old woman, who is presently sharing a house with her fiancé whom she is planning to marry. They both tested HIV-positive. Linda said she believes that she was the one who infected her boyfriend after he decided that he didn't want to use condoms any more. By then they both knew that Linda was HIV-positive. Her boyfriend described his actions as a sign of commitment to her even if she is HIV-positive. This is something Linda feels she didn't have control over, even though she tried to talk him out of it.

Linda got infected after she was gang raped by three men. She was tested soon after the incident and the results were negative. She went back for another test after three months, only to get positive results that time. Her rapists were arrested and sentenced to twelve years each. Linda suffered from depression after that incident. She described her life as an uphill battle since then because she had to face so many problems after that incident that changed her life overnight.

Linda and her fiancé have a six-year old daughter who currently lives with Linda's mother. Linda's parents were divorced when she was still little. She hasn't been that close to her father although he always supported them financially. She grew up with six siblings including a sister whom she said she shares almost everything with.

5.2.4 Martha

Martha is a 38-year old mother of two. Her children are aged 17 and 14. She was married to her children's father, but he was involved in a car accident and died about ten years ago. Since then she has been living with her children alone. The eldest, a daughter is in standard ten, whereas the youngest, a son is in standard seven.

Living alone with the two children entails a lot of responsibility for Martha. Martha also does administrative work and complained that she is not earning a lot of money. She however managed to buy a house in a reasonably comfortable area. Both her children are attending good schools and she is making preparations for her daughter to continue with tertiary education next year. She described her children to be all she lives for since she started drifting away from her own family. This happened after her family found out that she was HIV-positive.

Martha had a relationship with a man three years after the death of her husband. She believes that he was the one who infected her since he has died of AIDS. What hurt her most about her situation is the fact that her boyfriend died without telling her that he was suffering from AIDS. She said she found out from his sister after he died.

5.3 CATEGORIES OF EXPERIENCE

From the transcribed interviews with the participants and field notes, categories of experience were identified in terms of experiences of being HIV-positive and the ways of coping with HIV. The same statements at times reflected different meanings and thus certain statements may appear in more than one category. The categories of meaning will follow in no particular order.

5.3.1 REASON FOR TESTING

Definition: References to the reason an HIV test was done were classified under this category. Statements concerning the decision to take or not to take the test were also included.

Description: Each woman felt the importance of stating how it came about that they decided to take an HIV test. Two women had to go for testing because they had physical symptoms like diarrhoea and mouth thrush, as well as swollen glands. Lucia said: *"I had diarrhoea and mouth thrush. They referred* *me to the hospital where they did all sorts of tests".* Her boyfriend also went for testing after Lucia was diagnosed.

Martha's reason for testing was stated as follows: *"I have been going to the sick bay often, complaining about swollen and infected tonsils. So, they finally decided that I must go for an HIV test".*

Charlotte's husband was very sick and his health was declining. He was tested for HIV and he tested positive. Charlotte recalled that time by saying: *"The way he was so ill, he got admitted at Hospice. That was where they suggested that I also go for a blood test".*

Linda was gang raped by three men few years ago. The incident left her with very traumatic memories. She stated: *"They tore our clothes and raped us. Thereafter I consulted and they took blood for HIV testing".* Her results were negative at first. She was given another appointment after three months, and the results were positive. Her boyfriend also tested positive thereafter.

5.3.2 SOURCE OF INFECTION

Definition: Statements referring to possible persons the participants could have been infected by fall under this category.

Description: Three of the women were sure about who they got the virus from. Martha believed that she was infected by the virus as a result of engaging in sexual intercourse with her boyfriend who passed away from AIDS. He told her that he was suffering from TB. She only found out after he died that he had told his family that he was suffering from AIDS. She said:
"It was this guy I've been involved with since I was still staying with my mother".

Linda was raped and tested HIV-positive three months after that incident.
"And sometimes you get infected innocently, like in my case. I was raped, gang raped. Those people were HIV-positive".

Charlotte became infected after having unprotected sexual intercourse with her husband who was sick with AIDS already. She stated that she thought her husband was just joking whenever he told her that he was HIV-positive. She however mentioned that her husband did not insist on using condoms despite knowing for sure that he was really infected with HIV. She stated: *"I wish I'd listened to him when he told me he was HIV-positive, and used condoms".*

Lucia on the other hand was not sure who really infected her between her two ex-boyfriends. Initially she thought that it was her child's father, but later she realised that it was possible that she was infected by her other ex-boyfriend. Her uncertainty is reflected in the following statements:
"My child's father used to have many girlfriends".
"You know, now that I think about it, it is possible that I got it from him, and not my son's father".

5.3.3 REACTION TO TEST RESULTS

Definition: Comments regarding the reaction of the participants to the test results were considered for this category.

Description: The initial reaction of the women was that of shock and denial. When Charlotte was initially diagnosed with HIV she said she couldn't believe it. Her initial reaction was numbness because she thought that she couldn't show a negative reaction in front of her very sick husband. She kept quiet for some time, while she was really suffering inside, dying to tell her news to somebody. She described her reaction in the following sentences:
"I did not take it well, I just couldn't believe it".
"Actually, I suffered from stress".
"Later, after about two weeks I started feeling very bad. I spent the whole week without eating anything. I wished I could talk to somebody".

Lucia was shocked and only started thinking about her test results a few days after the diagnosis. She attributed her reaction to the perception she used to

have those days that HIV was only for homosexuals, prostitutes and foreigners from other parts of Africa. She thought it was absolutely impossible for her to be HIV-positive. She mentioned that she started drinking heavily, trying to forget about what was happening to her. She also said that she couldn't make sense of what was happening to her and she felt like a loser.
"I was shocked".
"I only started thinking about it a few days thereafter".
"There was no way I was HIV-positive".
"Although I could understand the facts, it was difficult to stomach the information when we were now talking about me".
"I was drinking heavily that time, I just wanted to forget"

Linda's first test results came out negative since she was still in the window period. She received counselling thereafter and she understood that the second results could come out positive. When she received them, she was somehow expecting them to be positive, but that did not make things easier for her.
"It was still shocking and difficult to believe".
"It was difficult. I couldn't…actually, I felt like killing myself".

The results didn't come as a big surprise to Martha after knowing that her boyfriend died of AIDS. At the back of her mind she was still hoping that she could be lucky and test negative.
"It wasn't a big shock because somehow I was expecting them to came out that way. I still hoped for a miracle though".

5.3.4 EMOTIONAL RESPONSES

Definition: Any comments about any emotional state at any time since the diagnosis were included in this category. This covers a wide spectrum of emotions e.g. anger, courage, worry, depression, etc.

Description: The emotional responses from the participants will be described below under headings which reflect the various emotions experienced.

a. Anger

Charlotte expressed feelings of anger at her husband for not telling her that he was HIV-positive when he knew about it even before he came back into the country from exile.
"The way I was so very angry with him, I nearly developed hatred for him".

Lucia's feelings of anger started when she started coming to terms with the possibility that she can really be HIV-positive. She couldn't understand why she was angry with almost every person in her life, without knowing who to be specifically angry with. She went for days without speaking to members of her family.
"I was very angry, although I didn't know who I was angry with. I didn't care, I was just angry".

According to Linda, her feelings of anger towards her rapists will stay with her for a long time. She said that she wishes to come face to face with her rapists one day. She also stated that she feels that the prison sentence they received is nothing compared to the physical and emotional scars they left her with.
"I think about them a lot. I am still so angry; I don't think these feelings will ever go away"

The reaction from her family members after hearing about her diagnosis left Martha very angry. She mentioned that she is especially angry with her mother.
"I sometimes feel angry with my mother for treating me the way she does".
Martha also felt angry with her boyfriend for failing to inform her on time about his condition. In this case she said: *"Why didn't he tell me before? I am still angry with him even today".*

b. Hurt

Martha's family's reaction to her diagnosis made her angry, but she also described it as hurtful more than anything that has ever happened to her before.
"They started doing things that hurt me a lot. Nothing has ever hurt me that way before".

Initially, almost everything used to hurt Lucia. Whenever she was thinking about her son, the person she thought infected her, her family and the shame she thought she was putting them through, and the rest of her life thereafter, she felt like her heart was going to break.
"I never hurt like that before. I thought my heart was going to break into small pieces".

Charlotte felt hurt and helpless when she found out that her husband's medical aid was terminated after he was discharged from work due to medical reasons.
"What hurt me most was when I tried to get treatment for him recently, and find out that he had been put off his medical aid".

Talking about the details of the rape incident is something that Linda avoids at all costs because it still hurts very much.
"When I think about it, it still hurts even today".

c. Hate

Charlotte said she nearly hated her husband after learning that she was HIV-positive.
"I nearly developed hatred for him".

Linda is still consumed with hatred towards the people who infected her. Although she described those feelings as something that makes her soul feel

dirty, she also views them as important in that they keep reminding her that she must fight for her life like she did the day she was raped.
"These feelings of hatred makes my soul feel dirty and poisoned, but I also need them to keep me going".

d. Worry

Caring for a terminally ill husband created a huge amount of worry for Charlotte. She said she always has to think about how her husband is doing when she is at work during the day, or whether he'd possibly died when she is at work. She expressed this by saying:
"Sometimes I used to prepare his things for use during the day when I'm at work, thinking that he would be fine, but he would be lying somewhere in the house having fallen and hurt himself".
Financial worry also keeps her awake at night. She had to provide for her family since her husband was laid off. This is a very difficult task for her because she is not earning much. She also spent most of her salary on transport travelling to work.
"I worry so much; I even don't sleep well these days. These financial problems are having a negative effect on me".
"They told us that we must eat fresh vegetables and fruits, but we can't afford them now".

Martha's worry stems from leaving her children behind when she dies. Since the relationship between her and her family of origin had soured, she doesn't know of anyone who can take proper care of her children.
She also said she wants to make sure that her children's educational needs are taken care of in future.
"I worry about my children, especially my son".
"I worry about my children's education".

Linda stated that she worries about her daughter who is too young to understand what is happening. She said that she hopes that her daughter will grow up to reach the age where she can understand what her mother's condition is all about.

"My daughter is too young to understand this. I worry that she will grow up in my absence and will not get to understand what is happening from me, you know, from my mouth".

Lucia's feelings of worry are mostly attributed to the past. Although she still worries about things like her son's future, she emphasised that she no longer allows worry to occupy her thoughts a lot.

"I used to worry a lot and loose some weight, but I no longer allow myself to go through that again".

e. Distress

There were references to depressed mood, sadness, and feelings of hopelessness and helplessness during the interviews with the women. Lucia mentioned that she fell into depression after her diagnosis. She was treated for depression for three years.

"I started getting depressed. Nothing mattered to me anymore".

Linda is still under psychiatric treatment, although she thinks that she is doing very well at the moment. Her doctor had put her off medication for now, but she has to go for follow-up consultations to see if she will stay off for good.

"They admitted me at the hospital for depression".

Charlotte mentioned that she always finds herself feeling sad and depressed whenever her husband is depressed. She mentioned that during these occasions, she becomes filled with feelings of hopelessness and despair.

"My husband has occasions when he becomes very depressed. I always find myself also going into depression, feeling hopeless and helpless".

Lucia, like Linda, had been admitted to the hospital several times as a result of suicide attempts. She attempted suicide five times by drinking an overdose of pills, cutting her wrists and trying to hang herself. Linda took an overdose of sleeping tablets three times.

f. Courage

Linda mentioned that talking to other women in the same situation as she is in, gives her courage to continue fighting.
"I go out and meet people, especially other women with HIV. It gives me courage".

Charlotte said that she gets her courage from her husband. She kept on referring to the fact that the two of them encourage each other.
"My husband and I are best friends. We always encourage each other. I need that courage from him for both our sakes".

g. Feelings of worthlessness

Martha remembered feeling that she wasn't worth anything after the reaction and treatment she received from her family.
"I was very hurt and started thinking that I'm worth nothing".

These feelings were also mentioned by Lucia, who started feeling that way soon after the diagnosis, even before she told anybody. She also mentioned that she felt ashamed of herself for putting her family through that shame.
"I started thinking of myself as someone very dirty and filthy, a prostitute of some sort".
"After a diagnosis I felt like a nobody, a person you can't even classify".
"I felt like it was my fault all this was happening".

5.3.5 PHYSICAL SYMPTOMS

Definition: References to any physical symptom whose presence can be attributed to HIV.

Description: Lucia had to consult a doctor because she was having diarrhoea and mouth thrush repeatedly. She later suffered from pneumonia and vaginal thrush.

"I had diarrhoea and mouth thrush and they were not responding to treatment, so I had to go see the doctor".

"I once had pneumonia, mouth thrush and vaginal thrush".

Linda reported that she only has swollen glands, which seldom become painful. Apart from that she said she never had any other physical symptoms as a result of HIV.

"I have swollen glands, those are the only symptoms I have".

Martha used to suffer from tonsillitis persistently before finding out that she was infected. She never had any symptoms since that time, although she sometimes thinks that people can see through her and conclude that she is HIV-positive.

"I have been going to the sick bay often, complaining of swollen tonsils".

"I'm not symptomatic yet".

"When I wake up in the morning, I sometimes press myself on the neck looking for swollen glands".

"Maybe they can see other symptoms that I'm not aware of".

5.3.6 CHANGES IN PHYSICAL APPEARANCE

Definition: Units that contain comments about a concern and change in physical appearance that were related to being HIV-positive were selected for this category.

Description: The way a person appears physically seems to have a huge significance as far the issue of being HIV-positive is concerned. This seems to be related to weight loss associated with HIV-positive individuals.

Lucia's comments were as follows:

"Sometimes I worry a lot and loose some weight".

"Sometimes I change to such an extent that people become shocked when they see me".

I haven't even lost any weight since I was diagnosed". (Martha)

Charlotte's husband lost weight at some stage and a rumour started that he had AIDS. Charlotte mentioned that she took it upon herself to fight the rumour because it was important to her that people don't talk badly about her husband. She therefore told them that he had been loosing weight because he was drinking too much alcohol. Charlotte is also concerned about loosing weight herself, in case people become suspicious of her status.

"He started loosing weight and people started saying that he had AIDS".

"After he stopped drinking he started gaining weight again and people were convinced that he is not HIV-positive".

"I don't want to loose weight because people will start becoming suspicious".

According to Linda, one cannot tell that she is HIV-positive by merely looking at her body.

"Look at me, no one can tell that I'm HIV-positive. My weight is still OK".

5.3.7 ISOLATION

Definition: Statements reflecting feelings of being alone or feeling like you don't belong, as well as references to people isolating themselves.

Description: Lucia could only be with her family because she felt she didn't have an alternative place to live. Although she was somehow putting herself in that situation, she still felt isolated. Her condition made her want to isolate herself.

"I started feeling out of place, even with my friends".

"I'd stopped visiting people".

Martha never had friends because she said she is too busy with her work and her children. She pointed out that she feels she won't even try to make friends because she fears that people will come to know of her HIV status.

"It sometimes make me feel so alone and isolated".

"I don't really have friends".

Charlotte's sister-in-law and her husband used to be close to them and visit them a lot. After hearing about their condition, they stopped visiting.
"Thereafter they stopped talking to us, avoiding us mostly. It is as if they are isolating us".

5.3.8 REACTION FROM OTHER PEOPLE

Definition: Statements referring to comments, feelings, or actions from other people as a result of one's HIV status, whether positive or negative.

Description: Lucia received many negative reactions from people since she came out and spoke publicly. She had been giving talks trying to educate people about HIV and AIDS. She said that she sometimes feels like people hate her for doing what she is doing.
"I received many negative reactions from people".
"People don't want to hear or listen to talks about HIV. When you talk about it, people start hating you".
"You know, since that day, half of the class were my friends or still talking to me, and half were not".
"People talk badly about me and people with HIV in general".

Lucia's boyfriend left her as a result of her HIV status. She stated that he felt that she was embarrassing both of them by going public with her situation. Since then she had never had one boyfriend for a long time. She felt that men reject her once they find out that she is HIV-positive. She mentioned that some men only want to sleep with her just to experience what it feels like to sleep with a person who is HIV-positive.
"This type of rejection from men always reminds me that I am HIV-positive".
"They sleep with me and thereafter they disappear and say they are no longer interested".
"When they come, they just want to sleep with you to experience how it feels like to sleep with a woman who is HIV-positive".
There were people who accepted Lucia despite her status. She expressed how grateful she is to such people because they helped her accept herself.

"I would not have accepted myself without the help of people who supported me, HIV or no HIV, like my family and friends".
"People began inviting me over for visits".

Charlotte received negative reactions from people after her husband started becoming very sick. She always makes sure that she is not suspected of being HIV-positive herself. Charlotte is specifically concerned about her brother, who is usually drunk and embarrasses everybody.
"He drinks alcohol a lot and is a kind of person who would insult me about my status when he is drunk".
"I would hear that they often gossiped about my husband, but they couldn't face me".
"I always make sure that I eat well so that I don't loose weight because people will start becoming suspicious".
Attending a support group with other HIV-positive women helps Charlotte feel accepted.
"You always come out of there with a feeling that you are not alone, there are many of us out there".

Martha described her family's reaction to her as very negative. She stated that her younger sister washed a cup with bleach after Martha finished drinking water with that cup. She said she is afraid to tell people about her condition in case they treat her like her family treated her.
"They started doing things that hurt me a lot. For instance, when I finished drinking water, my sister would clean the cup I was using with bleach".
"I could see that my sister wasn't really sympathising with me, she was laughing at me inside".
"I'm afraid that my brother will tell me in front of people that I'm HIV-positive and embarrass me".

Martha felt rejected by her family to an extent that she regrets telling them that she was infected.
"I don't want to show them that I'm aware that they've changed towards me".

"These days I can see that my mother is even afraid to hug me. That makes me feel so rejected".

Her sister is starting to show signs of beginning to accept her. This makes Martha happy because she loves her family.

"Lately I've been feeling that my sister is beginning to come around and starting to accept me".

Linda mentioned that the way people choose to treat her after knowing about her condition doesn't bother her. She said that people make their own decisions as to how they treat somebody after they know about his/her condition. She also stated that she always makes it a point that she stays away from people who seem to treat her badly as a result of her status.

"The way you treat me thereafter is up to you".

"If I see that you're not treating me right, I just ignore you and get out of your life".

"I know that there are people who like me and those who don't, and I'm fine with it".

"I sometimes think that people react negatively towards me behind my back, when I'm not there. I don't worry about it that much because they don't face me".

The problem Linda seemed to be having was when people start treating her differently than they used to. She complained that some people treat her as if she has now become special in a way.

"Like my father, he and I had never been close like now. He treats me special and has been very supportive, but I don't want it that way".

Linda experienced rejection from her fiancé, who accused her of knowing about her HIV status for a long time. He also accused her of hiding it from him. After a while, he came back to apologise and Linda felt accepted.

"We had a fight. I felt so rejected".

"He later came back and apologised".

5.3.9 DISCLOSURE OF HIV STATUS

Definition: References to making one's HIV status known, the difficulties thereof, and how other people reacted to the disclosure were included in this category.

Description: The first people all the participants disclosed their status to were the members of their families. Linda and Lucia were fortunate to receive love and support from members of their families immediately after the diagnosis. Martha and Charlotte were not treated in the way they expected to be treated. Linda's family were informed by Linda and her psychologist and they were very hurt by the news. She was disturbed by the fact that her sister was crying all the time after she told her. She said:

"I told my sister that I expect her to be one who supports; the one who gives me strength and courage".

"I then told my mother and the rest of my family through the help of the psychologist. They were all hurt".

Linda then told her boyfriend, who didn't take the news well. This was followed by the disclosure to her friends, the ones she felt she could trust.

"From there I told my boyfriend".

"I told those friends I felt I could trust. Most of them didn't believe me; some of them cried".

Lucia's parents were very sad when they heard the news. She never sensed anything negative from them; instead they stood by her all the way. Her boyfriend was the next person she told. He also didn't react negatively, but he told her not to tell anyone else. It was even difficult to talk about it among themselves because he didn't want to.

"I told my folks, it was a very sad day for all of us".

"I had to tell my boyfriend. I didn't know what to expect, but he didn't leave me".

After living with HIV for two years, Lucia decided to go public and told every person she could tell.

"I usually discuss my situation with a lot of people".

Lucia didn't forget to mention the disadvantages of disclosing one's status. She mentioned how people don't disclose because they fear rejection. She advised that when one wants to disclose his/her status, he/she must be ready for anything.

"Disclosure is still a problem. Sometimes it is good, but it has disadvantages too".

"They don't disclose because they fear rejection".

"When you want to disclose, you must be ready for anything. Some people will accept you, and some will reject you".

Charlotte and her husband disclosed their status together to members of their families. She mentioned that her husband's side of the family initially said that she was the one who infected their son, but her husband told them that he actually was the one who infected her when he came back into the country.

"*They were shocked, they couldn't believe it*".

There was a strong need from Charlotte to keep their status a secret, especially from people at her work place. She also stated that she doesn't want members of her family of origin to know. She only told her sister.

"Only my sister knows because I think she is not judgmental".

She explained that she doesn't have the energy to deal with stigmatisation at the moment, she just wants to concentrate on her husband.

Martha learned from telling her family that disclosing her status is not a good idea. Since they started treating her badly, she'd come to the decision that she will not tell anyone else. The first person she opened up to was her daughter. She, however, said that she feels guilty that she is making her daughter carry her problem as if it was hers, and not Martha's.

"I told my daughter. She was the first person to know".

Martha said she is having fears that as soon as people know about her situation, they'll start to treat her like her family did. She described her fears as follows:

"Stigmatisation will become a problem as soon as people know about my status. You know, people are so insensitive".

"People will start gossiping about me".

"I always avoid the HIV topic whenever it comes up at work".

5.3.10 CONDOM USE

Definition: Statements containing references to the use or lack of use of condoms were considered for this category.

Description: Lucia stated that men don't want to use condoms because they end up concentrating on the condom itself during intercourse. She refuses to have sexual intercourse without a condom, although this makes men suspicious of her condition.

"They don't like the idea of using a condom".

"I always use a condom these days. I even teach those men who don't know how to".

Martha got infected as a result of not using condoms. She said she only started using condoms when everybody started talking about HIV. She mentioned that a nursing sister counselled and told her that the only way she was going to live for long was if she uses condoms. She now insists on using condoms.

"...but I insist on using a condom".

"We only started using condoms when they started preaching about HIV everywhere".

Linda has resigned herself to taking a risk by not using a condom with her fiancé. She said she believes that nothing will change with both of them, as long as they don't sleep with other people without protection.

"We both decided that we will not use a condom and we will stay faithful to one another".

5.3.11 REGRETS

Definition: Those comments that show indications of wishing that one could have done things differently.

Description: Lucia said she has regrets about the way she lived her life after she was diagnosed with HIV. She decided that she was never going to let her life pass her by that way again.
"I spent two years with my life just passing me by".
"I couldn't finish any military course. I dropped out of them all during those two years. What a waste".

Charlotte said she regrets not listening to her husband when he told her that he was diagnosed with HIV when he was still in exile.
"Later on I would think, I wish I'd listened to him when he told me he was HIV positive and used a condom".

Martha also stated that she wished she had used a condom all the time. She also said she regrets the fact that her boyfriend didn't tell her of his HIV status before they started practising unprotected sex.

5.3.12 PERCEPTIONS ABOUT HIV

Definition: Statements about the way people think and talk about HIV and HIV infected individuals were considered for this category.

Description: Martha pointed out that she thinks it is very important that she doesn't worry about her HIV status, fearing that it will affect her immune system and make the virus to be stronger.
"If I dwell on that, I'll be worrying myself and stressing too much. That can affect my immune system and make the virus to be stronger".

She also said she thinks that her mother is reacting the way she is reacting because she is ignorant about HIV.
"I know that this may be because she is ignorant and not knowledgeable enough about HIV".

Lucia commented about the way HIV-infected people don't take care of themselves thinking that they can just take treatment and they will be better.
"People sometimes think that when you take drugs or medication you will be fine and better".

Charlotte found herself defending against the perception that when a person is sick and loosing weight, he/she is HIV-positive.
"I told them that they always conclude that whenever a person is sick, the person is HIV-positive".
At the same time, she found herself reinforcing that perception by doing everything in her power to make sure that she doesn't loose weight in case people become suspicious.
"I don't want to loose weight because people will start becoming suspicious".

Charlotte also emphasised that HIV is not an illness and a person can live for a long time with it. She also mentioned that a person could also get re-infected through sleeping around.
"A person can also get re-infected through sleeping around. This can cause quick and fast progression into an AIDS phase and a person will die".

Linda was concerned about the perception in the society that if you're HIV-positive, you're somehow living a promiscuous life. She also felt the need to point out that she is only HIV-positive and she doesn't have AIDS.
"In our society people think that if you're HIV-positive, you're bad".
"At the moment I'm HIV-positive but I don't have AIDS".

5.3.13 EDUCATION ABOUT HIV

Definition: References to statements about educating people or being educated about HIV.

Description: Lucia reported that she gives talks about HIV and tries to educate as many people as she possibly can. She also talks to her friends with a hope of giving them the facts about the disease.

"I give talks and sometimes interviews on TV".

"I also give talks at colleges and technikons".

"Once I was on a course and I started asking my colleagues if they knew anything about HIV, if they've seen or met someone who is HIV-positive".

Linda said she is trying to educate herself by reading a lot about HIV. She also mentioned that she writes about the daily occurrences in her life for her daughter. She said she wants her daughter to get to know her even when she is no longer alive.

"I read a lot about HIV. I'm also writing daily occurrences in my life".

Charlotte mentioned that she sometimes attends a group where they talk and educate each other about HIV. She said that since she used to work for the Red Cross, she sees herself as somehow knowledgeable about the disease and can therefore share her knowledge with the group members. However, she also mentioned that she feels guilty that she did not divulge her own status.

"In this group we talk and educate each other".

"I also feel free to share the knowledge that I have with them".

"I like to give them facts and teach them about HIV".

She stated her worry about lack of education about HIV, especially to people who are infected with HIV already.

"Education is still lacking on the ground, even with us HIV-positive people".

"We don't get to have seminars and workshops where we get education about HIV".

According to Martha, being HIV-positive made her seek for information about it in order to help herself understand what is possibly going to happen to her. She also realised that her younger sister was looking for information and reading about HIV since she knew that Martha is HIV-positive.

"Being HIV-positive made me take note and start educating myself about the disease. Now I'm able to educate my children and give them the facts about HIV".

"My sister, the one who comes after me, has been reading a lot about HIV and is now beginning to understand things".

5.3.14 LOSS OF A LOVED ONE

Definition: Statements about loosing a person one used to be very close to through death, as a result of being HIV-positive.

Description: Martha lost her boyfriend through AIDS. She reported to have felt terrible mainly because she found out that he died of AIDS. He kept it from her, but his family knew.

5.3.15 FAITH

Definition: Those statements that showed coping with HIV in a religious context were classified under this category.

Description: In an attempt to deal with her situation, Lucia sometimes uses religion. She mentioned that she believes that when the time comes for her to die, it will be the time God has decided for her to die.

"Sometimes I just become too religious and sometimes I just feel. This is not for me. religion, I mean".

Linda said she always listens to gospel music during her spare time and sings along. She stated that she relies on a prayer when there is a need to ask for guidance.

"I pray God to help me live longer for the sake of my daughter".

Charlotte described herself as a religious person. She said she has been praying for God to keep her husband alive and she believes that the fact that he is still alive shows that her prayers were answered. According to Charlotte, God is giving her strength to fight back.
"I prayed and asked God to give me strength to fight".
"If you pray and ask God to look after you, he will"

For Martha, life is just the way God wants it to be. She said she believes that when she dies it will also be God's will. She also mentioned that she hopes that her boyfriend will answer to God one day as to why he deceived her the way he did.
"I told myself that I'll live a normal life until such time when God decides that he wants to take me".
"He'll answer for himself when he meets God".

5.3.16 ACCEPTING ONE'S CONDITION

Definition: Comments regarding a feeling of accepting and coming to terms with the presence of the virus as part of one's life.

Description: Martha decided that there was no use to deny that she is HIV positive, but she must accept it and deal with it.
"Whatever happened, happened. I have to live with this virus inside me".

Charlotte said that she would advise other women in her condition to accept the fact that they have the virus in their bodies. She felt that she owed it to herself to accept her condition since she was the one who used to tell other people to accept it while she was still working for the Red Cross.
"They must accept it and negotiate space within their bodies with the virus".

For one to be accepted by other people, they have to accept themselves first. Linda emphasised that self acceptance must begin with accepting your condition. She attributed the change in her life to accepting herself and expecting nothing from other people. Accepting herself also helped her in a sense that she is no longer ashamed of herself, no matter what people say about her.

"Many people were killed by denial, they didn't want to accept their condition".

"I must be able to accept my condition and myself, before I expect other people to accept me".

Lucia realised that when she accepted her condition, it also meant that she was prepared to face the fact that she will not live for long.

"On the other hand, accepting your condition means that you have to be realistic about your situation".

5.3.17 SUPPORT FROM OTHERS

Definition: Comments regarding the involvement of the family members and other people in an attempt to help deal with the disease.

Description: Martha felt that she needed support from other people who are HIV positive since she doesn't have enough support presently. According to her, the reason may be because she didn't tell or is scared of telling other people about her condition. She gets all the support from her daughter.

"My daughter supported me a lot".

"In that way I can get more support especially from other people or women with HIV".

Lucia's family has been supportive from the beginning.

"They've been very supportive until today. They are always there for me, through thick and thin".

Lucia's boyfriend was also very supportive in the beginning, but he left her later on.

"He didn't leave me, he was very supportive".

She said she finds the support groups she sometimes attends as being very helpful in terms of providing support.

"I attend support groups whenever I can".

"My friends also supported me throughout".

Linda also said that she has a very supportive family, as well as a loving and caring fiancé. She stated that she has a lot of friends she can trust and they've also been supportive. She, however, pointed out the need to attend a support group for more support and information.

"My family and friends supported me throughout".

"At the moment I don't know of any support group in the area I live in. I wish I can attend one".

"The other person I always get support from is this lady I met at the hospital. She is also HIV positive".

Charlotte also mentioned the need for a support group. She used to attend one at a local hospital when she had time. Apart from the group, Charlotte only received support from her husband and her sister. Other members of her family don't know about her condition.

"My husband and I support each other".

"My sister is very supportive".

5.3.18 CONTROL OVER THE ILLNESS

Definition: Comments reflecting a sense of self-mastery or control over the illness.

Description: The participants expressed the feeling that somehow they know about the illness and they are still learning. They also associate the feeling with taking charge of their lives and live the way they want to live.

"If I let myself be weak, the illness is going to defeat me. I must be strong and be in control of my life". (Charlotte)

"I want to have control over my life. I don't want this virus to rule my life". (Linda)

"I read a lot and I'm presently writing about my life story". (Linda)

"If I want to live longer, I must take charge of my life and use condoms". (Martha)

5.3.19 SELF CARE AND KEEPING HEALTHY

Definition: Comments about any activity or behaviour directed towards keeping healthy physically and taking care of oneself.

Description: According to Lucia, eating healthy food and exercising often helps the body to stay strong in order to fight infection. She had started avoiding alcohol because she said it is not advisable for a person in her condition to get drunk. Another way Lucia takes care of herself is by not sleeping around.
"Now I eat healthy food and exercise often".
"I sometimes have a drink, but not enough to make me drunk".
"One may end up making things worse for yourself, if you sleep with someone who is in an advanced stage".

For Martha, taking care of herself means using a condom to avoid re-infection. She stated that keeping healthy would help her live longer. She mentioned that during counselling they teach them to eat right food and keep healthy by exercising to strengthen their bodies.
"Keeping healthy can make me live longer".

Linda mentioned the fact that some people who know about her condition sometimes come to her and ask for advice as to how she continues being healthy. She responded like:
"I take good care of myself. Whenever I'm sick, I consult with the doctor".
"I also eat fruits and lots of vegetables. I exercise, even though it is not regularly".

Charlotte's responses about taking care of herself were as follows:
"They told us to eat fresh vegetables and fruits".
"I participate in sports, especially athletics".
"If a person becomes sick, he/she must take treatment and take good care of him/herself".

5.3.20 AVAILABILITY OF MEDICAL SUPPORT

Definition: Direct references to the availability of medical support were placed in this category.

Description: Charlotte's husband struggled to get treatment at some stage because he was taken out of his medical aid. Charlotte also experienced difficulties making sure that her husband was put under her medical aid. She had been attending counselling at the community centre, where her husband receives food supplements sometimes.

"He couldn't get the treatment he used to get from the clinic and there was no money to take him to the private doctor".

"I usually go for counselling at the community centre where my husband gets his treatment and food supplements".

Linda attributed her recovery partly to the help she received from the hospital in terms of medication and psychological support.

"I wouldn't be here if it wasn't because of counselling and medical support I received from the hospital".

All the women mentioned that they always see the doctor whenever they feel even a little bit ill because they have to take extra care of themselves.

5.3.21 CONCENTRATING ON THE PRESENT AND THE POSITIVES

Definition: Statements regarding the willingness to think about the positive things in a person's life, as compared to thinking about the disease. The category also covered statements regarding living life for the here and now.

Description: Linda stated that she feels better when she concentrates on important people in her life like her family and her fiancé. She mentioned that negative thoughts used to give way to suicidal thoughts in the past.

"I have so much to look forward to; my wedding and a good life ahead. I no longer have time to think about bad stuff".

Linda advised people with HIV to enjoy their lives and live for the present.

"Finally I can say that you must just take life as it comes, one day at a time. Concentrate on what is happening now, and enjoy life".

For Charlotte, taking her thoughts away from her husband's condition used to be an effort. She stated that she forces her mind to think about good things and people she loves, like her children. In her husband's presence, she always tries to help him enjoy himself. She also mentioned that she finds humour very useful for her.

"Although it is difficult sometimes to see the light at the end of the tunnel, I force my mind to concentrate on my children".

"I know that he doesn't have long to live, that is why we take it one day at a time".

"I like making jokes and laughing. Humour works for me".

For Martha, people like her children seemed to contribute in making her happy and positive about her life.

"My children and my work make me happy. At least some things make me positive about my life".

5.3.22 PLANNING FOR THE FUTURE

Definition: Statements containing references to the manner in which the future is perceived, in terms of planning and hopes.

Description: All the participants indicated that they worry about their children's futures and they are making plans to ensure that they are taken care of.

"I worry about my children, that is why I'm saving some money". (Martha)

"This is to ensure that my daughter does not struggle when I'm no longer here". (Linda)

"When I think about the future, I only think about my children and how they are going to survive". (Charlotte)

"If my parents can be around for a long time, they'll take care of my son". (Lucia)

The participants also expressed hope that one-day, there will be a cure for AIDS, even if it will not be in their lifetime.

"Sometime in the future there will be a cure for it. Those of us who have it now may be dead by then". (Linda)

"*They must have hope and tell themselves that one-day there is going to be a remedy or a cure".* (Charlotte)

"I hope for a cure one day". (Martha)

"....maybe there will be a cure one day". (Lucia)

5.3.23 FEAR OF INFECTING OTHERS

Definition: Fear of infecting others, as well as frustration with people with HIV irresponsibly infecting others with the virus were placed in this category.

Description: Linda doesn't live with her daughter, but she said that she fears that she can infect her when she comes to visit her.

"I sometimes think about the possibility of me infecting her".

Charlotte talked about a woman she knew and found out that she had HIV and was spreading it. She took it upon herself to go and talk to her about the consequences of her actions.

"Somebody told me about her condition and that she had become promiscuous".

Lucia stated that she felt hateful after her diagnosis. She thought that by sleeping around, she would get her revenge. She later came to realise that she was only making her situation worse.

"I thought I was spreading the virus, little did I know that I was slowly killing myself".

5.4 CONCLUSION

Background information relating to the participants was presented first. The categories of experience were then presented, each with a definition and the description of that category. The following chapter will deal with the discussion of the results and the integration with the literature.

ERRATA

Change the word "loose" to "lose" on the following pages

p. 10, line 22

p. 69, line 9

p. 71, line 28

p. 72, line 11

p. 74, line 12

p. 80, line 14 & 15

Change the word "loosing" to "losing" on

p. 17, line 11

p. 72, line 5, 6, 8

p. 80, line 10

p. 82, line 11

p. 11, line 19: "women are" should be "women were"

p. 12, line 21: "legions" should read "lesions"

p. 17, line 25: "reported against" should be "reported by"

p. 17, line 26: "occur" should be "occurs"

p. 25, line 27: "undimensional" should be "unidimensional"

p. 35, line 9: the word "her" should be inserted before "children"

p. 41, line 13: "a individual" should read "an individual"

p. 46, line 6: "a" should be inserted before "friend's"

p. 53, line 10: "hem" should be spelt "them"

p. 63, line 10: the word "a" should be inserted before "few"

p. 71, line 21: "concern and" should read "concern with, and"

p. 85, line 21: "live the way" should be living the way"

p.92, line 6/7: "Hate feelings" should be "Feelings of hate"

p. 96, line 25: "other people" should be "some people"

p. 101, line 7: "a" should be inserted before "daily"

p. 103, line 8: the word "the" should be inserted before "better"

p. 103, line 29: "by another should read "to another"

CHAPTER 6

DISCUSSION OF RESULTS

6.1 INTRODUCTION

In this chapter, the researcher will present the discussion of the results and integration with the literature. The discussion will begin with a look at the experiences of being HIV-positive for all the women, and it will be followed by a discussion of the ways of coping with HIV employed by these women.

6.2 THE EXPERIENCE OF BEING HIV-POSITIVE

6.2.1 EXPERIENCES IN RELATION TO SELF

Those categories of experience that relate to the women's feelings about themselves as a result of being HIV-positive were considered for this theme.

After being diagnosed with HIV, the women went through different emotions. The initial reaction was shock and disbelief. It was very difficult for them to accept the fact that they were having the virus in their bodies.

Westbrook and Viey (1982) stated that anger, as a psychological reaction to the onset of chronic illness, is often generated by feelings of frustration associated with the illness. Feelings of anger dominated the responses the women gave. This anger seemed to be mainly directed at the people who were thought to be responsible for infecting the women. The difference in verbalising and admitting to these feelings of anger seemed to be related to the type of relationship between the women and the person who infected them. One of the women could not outwardly blame her present partner for infecting her, even if he was responsible. In cases of the person being a previous partner or the rapists as it was the case with one woman, it seemed easy to put blame without hesitation or looking for excuses for that person. Family members who were not thought to be supportive were also at the receiving end of anger.

When a person is diagnosed with HIV, they immediately think about death. From that moment, that person will also be grieving and mourning some loss, which can be loss of life associated with anticipation of death, or loss of time as a result of the now limited life span. In Martha's case, anger made it difficult to mourn the loss of her boyfriend, who she blamed for infecting her. Simos (1979) sees anger as an integral part of the grieving process. Hate feelings were found to be closely related to anger, with hate also being directed to people who were thought to have infected the subjects.

The emotional reactions also included feelings of self-blame and guilt at being infected. This type of emotional response is common in women, due to the common perception that if they are infected with HIV, they have to be promiscuous (Bennett, 1990). Guilt feelings stem from the thought of dying and leaving one's children behind. These feelings can account for much of the pain of the process of mourning (Simos, 1979). Martha's guilt feelings were mostly related to the perception that she has become a burden to her daughter, who is her only source of support.

Feelings of hurt were also prominent with the participants. Thinking about the children and what will eventually happen to them when their mothers are no longer alive, was very hurtful to the women. The thought of bringing shame to their families when the news becomes known to everybody also hurt. After being raped, Linda couldn't help thinking about that incident. She used to be very depressed whenever she thought about it, but she said lately, it no longer depresses her that much, it only hurts.

Apart from worrying about themselves and their health, these women said they worry about leaving their children behind as well. In cases where there is nobody to take care of the children after the parents have passed away, the children's well-being seemed to be the major thing in the mother's mind. Charlotte's feelings of worry stemmed mostly from her husband's condition, which seems to be getting worse daily. The fact that she also works far from home means that she spends most of her days worried, wondering if she'll find him still alive when she gets home in the evening. Financial factors play a huge role in these women's state of mind. Uncertainty about the future in a sense of not knowing how long they still have to live means they must start saving money for their children. In case of a person like Charlotte, the type of food they are supposed to eat also means proper budgeting in order to afford to cover everything. She has now become the sole breadwinner at home, yet, she spends almost all her salary on transport commuting to work and back.

There were references to sadness and depressed mood during the interviews. All the women did not seem to be depressed during the interviews. They however expressed feeling depressed at some stage or another since they were diagnosed. Two of the women were admitted and treated for depression at least three times since diagnosis, and they also attempted suicide at least twice before. Similar findings were reported by Katz (1997) and Kelly (1998). During these phases of depression they felt hopeless and helpless, and just wanted to end their lives thinking that they were going to die anyway. The knowledge of the facts about the virus and the progression of the disease helped them to understand that they can still live for a long time with the virus, as long as they take proper care of themselves.

Some women mentioned feeling worthless and ashamed of themselves soon after they were diagnosed. The reactions they receive from people further reinforce those feelings. At that stage, all they felt is that they were not worth anything.

People's perception of HIV somehow influences the way HIV infected people perceive themselves (Siegel *et al.*, 1998). The women seemed to be worried about the way they appear physically, trying to maintain weight in an attempt to remove attention from their physical appearance and suspicion about their HIV status. They therefore ensured that they eat enough to be able to retain their body weight. It was important to these women whether people can tell that they are HIV positive by merely looking at them.

6.2.2 EXPERIENCES IN RELATIONSHIPS WITH OTHERS

The themes discussed here relate to the way the women experienced their relationships with partners, members of their families, friends, and members of the public since they were diagnosed.

In the case of HIV-infection, it is important to recognise not only the powerful influence of the individual's immediate familial/social context, but also the broader impact of the larger social climate, and particularly the negative effects of the social stigma, fear of rejection and discrimination (Kaminsky, Kurtines, Hervis, Millon, Blaney & Szapocznik, 1989). The difficulty in sharing the diagnosis with partners was apparent from the women's experiences. It seemed easier if the partner knew about his own status already. In cases where the partners did not know, as it was with Martha, she feared telling him because she was afraid of being rejected.

The common perception from men seems to be that if a woman first tests HIV-positive, she must have contacted it from elsewhere (Paterson, 1996). In Romania, HIV-positive women who had multiple partners were apparently listed as prostitutes in official statistics (Bennett, 1990). When men became the ones who undergo HIV testing first, the women usually find themselves forced to forgive them and stay with them. Paterson (1996) is of the opinion that some women stay with such men because they are dependent on them financially and they sometimes have nowhere to go if they leave them.

Lusakulira (in Bennett, 1990) pointed out that in places like Zaire, HIV-positive women are always blamed for infecting their husbands even though those women suspected that their partners had transmitted the virus to them. In this study, two women are still with the partners they were with before they were diagnosed, one woman's partner left her two years after diagnosis, and the other one has not told anyone she'd been with since the diagnosis about her status.

These difficulties in the relationships seem to be brought about by the changes the diagnosis brings into the way the couples have to live their lives (Walker, 1991). Women mentioned the fact that suddenly they must always have sexual intercourse with a condom, which is difficult in a marriage or a long-standing relationship, where partners didn't use condoms before. The women said they insist on using condoms to protect themselves from re-infection, with an exception of one, who has an agreement with her partner not to use condoms. The agreement had to be accompanied by the commitment from both partners to never have sex outside their relationship.

People living with HIV are better able to live with their condition when they develop or maintain ties with friends, family, and other people living with the virus (Groomes, 1998). The participants' families mostly reacted with shock and hurt. The way they treated the participants ranged from total support to rejection of the HIV-infected person. Rejection from family members hurts most, since they are the people who are thought to be supposed to accept them unconditionally. The decision to disclose the status to family members depended on how much the women trusted their families. In cases where the women felt that they don't trust somebody enough, they kept their diagnosis a secret. Two of the women received love and total support from their families, one woman only told some family members and left others out because she didn't trust them enough to reveal her status to them. She however still got negative reactions from some of those she told. One woman's family rejected her and started treating her badly. She mentioned examples like her sister washing the cup she used to drink water with bleach.

The type of treatment the women received from their families determined the way they related to them thereafter. After Martha's family rejected her, she decided to stop visiting them, unless if it was really necessary. Loss of interpersonal contact, especially with significant people like family members, leaves a person with feelings of isolation (Manuel, Roth, Keefe & Brantley, 1987). This isolation that Martha experienced left her more worried about who is going to take care of her children when she is no longer around.

Although the women expressed their disappointment and hurt as a result of the treatment they got from others, some of them still felt that keeping the diagnosis a secret also contributed to feelings of isolation. They mentioned that when they were unable to talk to other people about their situation, they always felt like they really needed to talk or unload to somebody.

Those who told their friends reported to have experienced nothing but support from them. Being accepted seemed very important to all the women. Although they all feared being stigmatised if their status becomes known, they seemed not to have any problems with disclosure when and if they were ready.

One participant disclosed her status publicly by giving talks in colleges, technikons, and on television. Another participant is now able to tell people at her work place and in her neighbourhood, while two participants still felt that they were not yet ready to tell people outside their families. There was a general understanding that people who are ignorant about HIV are the ones who are making life miserable for people living with HIV. For the participants it seemed that society has concluded that HIV-positive women are promiscuous women or prostitutes.

Groomes (1998) reminded us of the difficulties people with HIV must face when they have to interact among hostile people who perceive them as morally responsible for bringing the disease forward. This perception doesn't help HIV-positive women; it only makes disclosure more difficult. Linda mentioned that she understands that she can't expect everybody to accept her the way she is, with her HIV status. This makes disclosure something she thinks one has to risk when one is ready, conceding that other people will accept and others will reject you.

The only way to remedy the situation described above is through education. The women seem to participate in educating others, each in her small way. They, however, think that not enough is being done to ensure that people become knowledgeable about HIV and AIDS. This experience seems to agree with Strebel's (1992) observation from the study that she conducted on women's disclosure of their HIV status. It was generally felt that there was not much awareness of HIV in the community, which Strebel suggested is closely tied to the wider process of denial about the presence of HIV/AIDS in South Africa (Strebel, 1992).

Although Martha is not yet ready to disclose her status, she said she reads about HIV a lot and teaches her children what they have to know about it. Linda has started telling her colleagues about her condition and educating those who need to know the facts about it. Since Charlotte used to help at the Red Cross, she felt she had the knowledge other people needed about the disease. Although she didn't tell them about her own status, she helped women come to terms with their positive status. She sometimes felt guilty; as if she is deceiving other people, but she said she has a lot to deal with now, with her husband being terminally ill. Being a caregiver to him almost takes all her time and energy. Biegel, Schultz and Sales (1991) pointed out that caregivers to chronically ill individuals also need support and they are often faced with the problem of coping with the lack of support. Charlotte does not have anyone to help her care for her husband, except the husband's brother, who is not always around due to work.

6.3 COPING

According to Ramsey (1989), coping strategies are generally viewed as ways of responding that transcend different situations. Coping is not thought of as a single act but as a constellation of thoughts and acts. This is the reason Lazarus and Folkman (1984) maintained that individuals should not be seen in terms of coping and non-coping but as demonstrating varying degrees of distress and coping over time as they are faced with different situations.

Efforts to change the stressful situation, thus controlling distress, are usually differentiated from responses that alter the cognitive appraisal of stress (Pearlin & Schooler in Holahan & Moos, 1987). Holahan and Moos (1987) mention two coping responses, namely active/approach and avoidance strategies. Style of coping with stress also predicts levels of depression, anxiety, and distress among HIV-positive individuals (Kelly, 1998).

Lazarus and Folkman (cited in Essau & Trommsdorf, 1996) identify two major functions of coping namely, problem focused coping and emotion focused coping. These two functions are explained in section 3.1.3.3. The ways in which the women in the study cope with HIV, will be discussed using the two above-mentioned functions of coping.

Looking at the results of the study, it was clear that the women did not use a single and specific way of coping with their situations. Different ways of coping were used at different stages of experience, like after the initial diagnosis and the time of the interview.

6.3.1 PROBLEM-FOCUSED COPING

This type of coping involves taking a direct action with the purpose of changing the situation through, among other things, decision making, making a plan of action and fighting for what one believes in (Folkman & Lazarus, 1985).

Paterson (1996) reported that women in Rio de Janeiro are involved in educating their communities about living with HIV, using themselves as examples. These women reported that talking about their condition and educating others help them feel better about themselves and cope with the disease. All the women in the study are somehow involved in educating other people about HIV and experiences a person who is HIV-positive goes through. They reported to find talking about the disease, even without disclosing that they are HIV-positive themselves, makes them feel that they are contributing something towards the fight against the disease. Some women have become brave enough over the period since the diagnosis to disclose their status to people outside their families.

Reading and learning about HIV and AIDS most likely helped the women to get a feeling of control over the disease. For example, Martha said that having an idea of what to expect more or less prepares her and makes her know what to do when something happens. This feeling of control is associated with being able to take charge of their lives and live the way they want to live. Actions like making sure that they always use condoms when they are engaged in sexual intercourse in order to avoid infecting others and getting themselves re-infected, are ways of coping with their situation. They also take care of what they eat and keep their bodies fit by exercising regularly.

Taking care of themselves also means that the women have to seek medical help when necessary. They all reported that they make sure that they consult the doctor and seek medical help whenever they don't feel well. They also mentioned that they received counselling after the diagnosis, which helped them understand what having HIV was all about. Some of them are involved in psychotherapy, which helps them accept their condition.

Planning for the future in terms of ensuring that their children are taken care of seems to contribute towards giving them a purpose in life. They reported that they are trying to save some money for their children's education when they are no longer alive. They are also arranging for other people to take care of their children in future.

6.3.2 EMOTION-FOCUSED COPING

As indicated in section 3.1.3.3, emotion-focused coping is usually used in situations that are appraised as not changeable. This type of coping serves as an emotional and arousal oriented coping style with the purpose of reducing negative emotions regarding a situation and preventing further emotional pain (Lazarus & Folkman in Moos, 1992). As Folkman and Lazarus (1985) proposed, emotion-focused strategies include behaviours such as looking on the brighter side of things, accepting sympathy and understanding from others, and trying to forget about the problem.

The women in the study used the following emotion-focused coping strategies:

a. Denial

All women reacted to the results of their tests with shock, disappointment and hurt. The prominent coping strategy employed soon thereafter was denial. Denial is defined as a defence mechanism in which the patient refuses to acknowledge some aspect of external reality that would be apparent to others (Brock, Gurekas & Deom, 1993). Denial can also be when a person totally refuses to accept the diagnosis or admits the diagnosis, denying or minimising the implications. Some participants indicated that they could not believe it was really happening to them and as a result they could not accept the news. They used denial to help shut out awareness of that which would be too disturbing, which in this case was the knowledge that their lives have changed. Mostly disturbing, was the thought that they were going to die and leave their children behind.

Since dealing with a chronic illness is accompanied by feelings of loss (Westbrook & Viney, 1982), women in this study found themselves struggling between letting go or relinquishing what has been lost and holding on to the loss so as to avoid pain experienced due to the loss. Accepting the condition meant accepting the loss, which in turn would mean the ability to deal with the pain of loss. At the time of diagnosis, these women were not ready or able to deal with their loss. Denial was therefore appropriate as it served as a cushion against trauma.

Charlotte's husband told her that he was HIV-positive. She chose to deny the truth and pretended that he was just joking because she was too afraid for both of them. During the period after the diagnosis, Lucia and Martha reported that they convinced themselves that they were just as healthy as everybody else.

b. Avoidance

Talking about being HIV-positive remains difficult for some of the women. Although they were all free to talk about their experiences with the researcher, some of them mentioned that they couldn't talk about it with other people outside their families and close friends. Keeping their status a secret somehow provides them with security against the cruelty HIV-positive individuals seem to live with on daily basis. Charlotte is keeping the truth about her status from her children and she always avoids the topic about their father's illness whenever they raise it. By avoiding to talk about both her and her husband's status with her children ensures that she doesn't have to face the reality of the situation. The fact that she sees her husband's condition as very serious to an extent that she perceives death to be inevitable, only reminds her that she is going to travel along the same route later.

After discovering their HIV status, Lucia's boyfriend at the time decided that she was not allowed to tell anyone about it, including his or her family. They also avoided talking about it among themselves. Pretending as if it didn't happen somehow made it unreal for them. Lucia also started drinking alcohol heavily to avoid thinking about her problem. Martha stated how she always felt uncomfortable at work whenever the subject of HIV/AIDS came up. She avoids talking about it since she fears that people can somehow see through her and conclude that she is infected.

Willingness and making a deliberate effort to think about the positive things in their lives help the women to avoid thinking about the disease and its negative effects. They think about good things in their lives and important people like their children and families who make them feel happy and positive about their lives. Linda added that thinking about her HIV-positive status used to give way to suicidal thoughts in the past. Since she started avoiding to think about her condition and concentrating on important people in her life and how to ensure that she lives for a longer time, she no longer has suicidal thoughts.

Fleishman and Fogel (in Moneyham *et al.* 1998) found that women with HIV used significantly more avoidance coping strategies than their male counterparts. Commerford, Gular, Orr and O'Dowd (in Vassend and Eskild 1998), who also pointed out that these types of coping strategies are significantly related to greater levels of anxiety and depression, also reported similar findings.

c. Religious Faith

All the women indicated that they place God or the higher power in control of their lives. They stated that they see their faith as a source of help in coping with their HIV status. Their belief makes it easier for them to think about death and dying because they put their lives in God's hands. This makes them believe that when they die, it will not be because of HIV or AIDS, but it will be the time God has decided upon for them to die. The belief also helps them perceive their lives as being the same as everyone else's, in a sense that everyone is going to die when their time comes. Kain (in Groomes, 1998) noted that when people infected with HIV are given a chance to pursue spiritual matters, psychological growth often occurs.

Linda mentioned that she listens to gospel music and always sings along. This helps her feel strengthened and good inside. Prayer forms an important part of their daily activities. Martha believes that God has a purpose for every one of us and life is just as God wants it to be. The fact that she also perceives God as being punishing gives her satisfaction when she thinks that the person who infected her will answer to God one day.

d. Acceptance

With acceptance, a person admits the diagnosis and accepts the implications. He/she realistically admits to fears and seeks ways to confront and deal with emotions (Brock *et al.*, 1993). The period it took for the women in the study to come to terms with the presence of the virus in their bodies varies.

The decision to accept the condition meant no longer denying the virus' existence in the women's bodies. All the women had reached a stage where they are able to face up to their fate and accept what happened to them. Linda stated that she has to accept herself first with everything that is happening to her before she expects other people to accept her. To those women who have decided to be open about their situations, talking or telling people about it required self-acceptance first in order for them to be genuine. Accepting the situation generally changed their lives for better, but it also meant that they had to accept the inevitability of death since there is still no cure for AIDS.

e. Social Support

The strategies that a person uses to help him/her deal with difficult circumstances are closely related to the resources available to that person. These resources include financial, social and emotional resources (Antonovsky, 1979). It has already been mentioned that the GRRs can be interpreted in terms of social support as discussed in section 3.1.6. The resources available to the women (GRRs) will be incorporated in the discussion that follows.

All the women in the study received some form of social support from either their spouses, families, friends, or other members of the public. They all pointed out that the support they received assisted them in coping with the difficulties of living with HIV.

Emotional support or emotional GRR is considered important since it gave the women an opportunity to be open and honest about their condition and the associated feelings. This is supposed to be the case especially with people who are perceived to be non-judgemental like family members. Listening, showing concern, warmth, love and understanding provides an opportunity for self-disclosure, which is a process through which one lets oneself be known, either verbally or non-verbally, by another person (Kimble, 1990).

Cohen and Wills (1985) and Manuel *et al.* (1987) describe how perceived support is more important than the support that is actually available. One participant did not receive emotional support from her family, although she expected to get it. The result was fear of disclosing her status to any other person thereafter. Believing that they will be accepted in spite of revealing their imperfections could have enhanced their feelings of self-worth. The confidence that is associated with feelings of self-worth positively influenced the way in which the women managed the challenges associated with being HIV-positive.

Emotional support also includes being in the company of people whom one can relax with and be comfortable. Sharing of personal information and experiences takes place within this context, which is the reason the women felt that they need to belong to a support group. The exchange of personal information in this case can be rewarding for both parties (Kimble, 1990). Support groups also assist group members in arranging their everyday lives outside the group setting so that they receive naturally occurring social emotional, and coping support (Kelly, 1998). Those women who reported to have attended the support groups stated their importance in terms of providing the platform for unloading emotionally.

Provision of counselling and psychotherapy serves as another emotional GRR to HIV-positive women. Some of the women in the study got an opportunity to be involved in therapeutic relationships which are seen as non-judgemental, giving them an opportunity to disclose personal information. The advantages of this disclosure include that it is considered therapeutic when the therapist who is listening accepts the disclosure (Rogers in Kimble, 1990) and that it contributes to self-clarification (Rosenfeld & Kendrick in Fehr, 1996). Prager (1995) noted that lack of disclosure of personal information has been associated with illness and distress.

Informational support and cognitive GRR like provision of knowledge through things like counselling and workshops were viewed by women in this study as important. As described earlier in section 3.1.6, this type of support includes provision of information and advice, which could assist a person in solving problems or giving feedback on how a person is managing his/her life. Sheridan and Radmacher (1992) consider knowledge to be a very important resource. All women in this study viewed exchange of ideas and advice and provision of alternative perspectives as helpful in helping them cope. Sharing information and advice assisted them in solving problems more effectively. An example of this would be sharing information about where to go in case one needs treatment urgently, how to go about disclosing one's status, and how to keep healthy. All this information and advice may contribute to women viewing their problems differently and therefore getting an opportunity to look at their options. This process may lead to a woman to reassess her situation in a more positive way.

Social companionship or just being in the company of other people is seen as another GRR, which is usually provided by friends (Fehr, 1996). This type of support provides company by spending time with others in leisure and recreational activities. Lucia mentioned how she enjoys just sitting and talking to her friends, whereas Charlotte described the time she spent with her colleagues at work making jokes and laughing. This helps facilitate a positive mood, which in turn helps distract a person from worrying about problems.

6.3.3 THE RELATIONSHIP BETWEEN THE SENSE OF COHERENCE AND COPING

The strength of the women's sense of coherence (SOC) is not precisely known since the purpose of this study was not to measure it. Despite this, the components of SOC namely meaningfulness, comprehensibility and manageability can still be generally related to the results of the study. This relationship will be discussed here.

Antonovsky (1979) describes SOC as general and long-term ways in which the person views his/her life, and not only the personal experiences in relation to the current context. According to Antonovsky (1979), an event is interpreted and experienced within the context of the person's SOC.

Health can be promoted when there is motivational and cognitive bases for transforming one's potential resources appropriate to a given stressor (Antonovsky & Sourani, 1988). This implies that a person can be able to deal with a particular stressful situation if he/she is willing and capable of thinking about how to adequately utilise the resources at his/her disposal. In relation to this study, the implication is that those women with a strong SOC will have the ability to utilise GRRs at their disposal.

Antonovsky (1987) refers to manageability as the feeling that one has adequate resources to meet one's demands. A sense of manageability protects an individual from feeling like a victim or feeling as if life is treating him/her unfairly whenever he/she is going through difficult times (Antonovsky, 1990). Manageability also implies being able to trust oneself and others, with a belief that things will work out as well as can be expected. Women in this study have spouses, friends, or family members who are very supportive. Some even have colleagues they can talk to about their problems. They also have access to medical support in a form of treatment, counselling and psychotherapy. Because of the resources they have to help manage their lives, women in this study realised that unfortunate events do occur in life but such experiences can be survived and coped with.

The ability to make sense of the world and judge reality is referred to as comprehensibility (Antonovsky, 1987). Even though some events may not be desirable, people who have the characteristic of comprehensibility expect that they can make sense of them. In the beginning, just after the diagnosis, the women in this study couldn't make sense of what was happening to them and they perceived themselves as losers. Accepting themselves and being accepted by others with their condition helped them have hope that things will work out as reasonable as can be expected. They are also making sense of what is happening to them by thinking of it as God's intention and will.

The motivational element of the SOC, meaningfulness, refers to the sense that life's demands are challenges worthy of investing energy in, rather than burdens (Antonovsky, 1987). The informational GRRs such as giving advice and exchanging personal information proved to play a significant role in the lives of women who are HIV positive since they helped them reappraise their situation, and thereby finding alternative ways of coping. Reappraisal can assist in changing one's perception of events from being seen as threatening, to seeing them as challenges. In this study, HIV-positive women ended up seeing their conditions as challenges worthy of engagement and they decided to take up to the challenge by living their lives to the full. They take each day as it comes and handle daily hassles as they arise. The women in the study also mentioned that they are involved in educating others about HIV and AIDS. They mentioned that it helps them feel that they are contributing towards the fight against the disease. This can also be seen as finding meaning for their lives.

As Antonovsky (1987) pointed out, the SOC is stable on the whole around the age of thirty years. The person's orientation to life, her experiences and her life contexts, however, change. These experiences and contexts interact with and potentially enhance the components of SOC. It has already been stated that although the components can be distinguished, successful coping does not depend on a specific component, but on SOC as a whole.

6.4 CONCLUSION

This chapter provided the discussion of results on experiences of women diagnosed with HIV, and how these women cope with their condition. In the discussion, the results were integrated with the literature and the theoretical approach applied. The following chapter will provide some conclusions drawn from the study.

ERRATA

Change the word "loose" to "lose" on the following pages
p. 10, line 22
p. 69, line 9
p. 71, line 28
p. 72, line 11
p. 74, line 12
p. 80, line 14 & 15

Change the word "loosing" to "losing" on
p. 17, line 11
p. 72, line 5, 6, 8
p. 80, line 10
p. 82, line 11

p. 11, line 19: "women are" should be "women were"
p. 12, line 21: "legions" should read "lesions"
p. 17, line 25: "reported against" should be "reported by"
p. 17, line 26: "occur" should be "occurs"
p. 25, line 27: "undimensional" should be "unidimensional"
p. 35, line 9: the word "her" should be inserted before "children"
p. 41, line 13: "a individual" should read "an individual"
p. 46, line 6: "a" should be inserted before "friend's"
p. 53, line 10: "hem" should be spelt "them"
p. 63, line 10: the word "a" should be inserted before "few"
p. 71, line 21: "concern and" should read "concern with, and"
p. 85, line 21: "live the way" should be living the way"
p.92, line 6/7: "Hate feelings" should be "Feelings of hate"
p. 96, line 25: "other people" should be "some people"
p. 101, line 7: "a" should be inserted before "daily"
p. 103, line 8: the word "the" should be inserted before "better"
p. 103, line 29: "by another should read "to another"

CHAPTER 7

CONCLUSION

7.1 CONCLUSION

The study attempted to provide a view of the experiences that women diagnosed with HIV go through on daily basis. It also gives an indication of how they cope with their lives, considering their situation. The knowledge of being infected with HIV brought many changes in the participants' lives. Bearing this in mind, a deeper understanding of how these women make it through life was found to be necessary.

The study also gave a review of the literature on women with HIV and their experiences. The researcher used a qualitative research design to enter into the life worlds of the women and shared their experiences with them through their own descriptions. This provided the researcher with the necessary information for the study and provided the women with an opportunity to talk about their experiences.

Living with HIV-infection and trying to cope with that situation is made up of diverse experiences for women, such as those set out in the two previous chapters. These experiences differed from woman to woman, but they were also almost similar for all women at different times. After the diagnosis, all women in the study went through almost similar experiences emotionally.

Emotions ranged from anger, sadness, hurt, hatred, and depression to courage. The next difficult experience after knowing the diagnosis was disclosing the HIV-positive status to other people. In general, it looked like family members were more sensitive and supported the women unconditionally, but some women still experienced rejection from their families. Other negative reactions from people in general were verbalised by the women. This brought up the understanding of the difficulties these women go through on daily basis. In the beginning, it seemed difficult for women to even think about making it to the next day, and in two instances the women attempted suicide.

The ways in which the women coped with their HIV status were found to be almost similar for all the women. All women used both problem-focused and emotion-focused coping.

Even though problem-focused coping is said to be mainly used when the situation is appraised as changeable, women in this study still used that type of coping to help them to assess the situation and look at ways of prolonging their lives. Emotion-focused coping continued to be used throughout, that is, from immediately after the diagnosis until the time of the interview. The emotion-focused strategies used included denial, avoidance, acceptance and religious faith. These strategies were used in an attempt to reduce the negative emotions associated with the experiences and to avoid further emotional pain. The context seemed to play a role in the experiences and the coping strategies employed by women infected with HIV.

7.2 LIMITATIONS OF THE STUDY

The four respondents who participated in the study represent a select group of women. They are all black and live in urban areas. They also have access to medical care in the form of medical treatment, counselling and psychotherapy. The respondents' experiences and coping strategies they use to cope with HIV are diverse and rich, but they do not fully represent all women in South Africa. The results are also not representative of all black women, particularly those living in rural areas.

The number of participants used for the study could have been larger. A larger number could have helped in bringing up additional themes and more elaboration regarding the experiences and coping of HIV-infected women.

It is very difficult for HIV-infected women to talk about their experiences. It is even less practical to include their partners and family members in the study.

It will be interesting to know how these people are affected by what the women experience.

All the interviews were audio-recorded. The audio-recorder may have intruded on the interview process, despite reassurances from the researcher that all information will be anonymous and confidential.

The motivation for participating in the study may also have affected the outcome of the study. This motivation could range from genuine interest in helping to an expectation of some sort, e.g. an agreement with the researcher to offer her help whenever it is needed. The researcher's officer's rank in the organisation, may also have contributed in the participants' eagerness to participate in the study. This is still possible even with the participants signing an informed consent.

7.3 RECOMMENDATIONS

This study focused on black women living in urban areas. It is therefore recommended that further research be conducted with women from other race and cultural groups which will make cross-cultural comparisons possible. It is also important to conduct research studies with women in rural areas because it is possible that their experiences and the way they cope with their lives are completely different from those of women in this study, since the context is thought to play a role in experiences and coping. The fact that rural women often come from low socio-economic backgrounds will most likely play a role in the results that can be expected to be obtained.

The study also focused on women who are not having serious symptoms yet. The themes obtained in the study may have been different if the study was conducted on people who are more symptomatic. It is therefore recommended that similar studies be conducted on people who are in advanced stages of the illness, bearing in mind that it is expected that more and more people will be symptomatic in a few years to come. The need for more research on the subject of HIV and AIDS can therefore never be overemphasised.

Women infected with HIV have enough to deal with already without having to also carry around other people's prejudices. More effort should be directed at helping those living with HIV to be able to live without fear of being stigmatised. Various instances have been reported in South African newspapers over time that it even went to an extent of HIV-infected women being killed for revealing their status.

The results of this study have demonstrated that women need access to appropriate information on HIV and how it specifically affects women. Education on HIV should address the type of information that would be of help and how this information can be presented to the different socio-economic groups of women in the country. Alternative methods of education should be looked at in case of many illiterate people, especially in the rural areas. Stage plays and puppets could be used to educate people.

There seem to be too many organisations working on behalf of people living with HIV, and as a result, it becomes difficult for them to get finances. Lack of this type of instrumental support makes it difficult for people with HIV to cope with their everyday lives. A possible approach could be for these organisations to come together and form one big and more organised structure with more power to work on behalf of people infected with HIV. It is very important that HIV-infected people themselves become more involved in the running of such structures because they are the ones who know better about their lives and their condition.

All the women in this study indicated the need to belong to a support group. It is difficult for such groups to be formed because HIV-infected people still find it difficult to disclose their status. Those groups that are in existence are unable to cater for everybody because they may be far from where some people are living. Greatest comfort and sympathy could be gained from other women in similar situations. Worth (1990) has stated that women find it

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p. 103, line 29: "by another should read "to another"

easier to discuss personal issues in groups that consist of women only. A group can either be conducted by a group therapist who has knowledge in the field of HIV/AIDS in a form of group therapy, or a lay person can be trained to run such a group. The primary aim of such a group will be to provide these women with a supportive environment.

Psychotherapy and counselling on an individual level appears to be significant according to the results of the study. The women in this study indicated that they received counselling which helped them to change their initial views on HIV and what to do when you want to live with the virus for longer. It is therefore important for the therapist or the counsellor to be knowledgeable about HIV/AIDS to be able to give valuable information on the subject.

More effort should be placed on preventative measures. The growing rate of infection despite education efforts on the use of condoms and abstinence indicates that something more needs to be done. Provision of female condoms at a reasonable price should be considered in order to give women more control of the situation during sexual intercourse. Education efforts should also be specifically directed to men since they are the ones who can help by taking responsibility for their and other people's lives by making sure that they use condoms.

Although there is some evidence of side effects of the anti-retroviral drugs like AZT, most researchers still believe that they can be useful, especially in reducing the risk of transmission from mother to child in case of pregnant women (Gregson *et al.*, 1998). With the thirteenth International AIDS Conference held in South Africa, the debate around the use of retroviral drugs in the treatment of AIDS will hopefully go a long way towards persuading the government to provide these drugs to pregnant women and rape victims. Resolutions and conclusions reached at this conference will hopefully also help to combat HIV/AIDS.

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APPENDIX A

UNDERTAKING

I, THE UNDERSIGNED (state full initials and surname)

....

DECLARE myself willing to participate voluntarily and without remuneration in the proposed research programme on the experiences and coping of black women diagnosed HIV-positive, which will be undertaken by Ms M D Mokhoka.

This undertaking is subject to the conditions that all information will be treated as confidential and that my identity will be protected at all times.

In addition I undertake that all interviews may be audiotaped and notes may be taken during the interviews. These recordings may not be used for purposes other than research.

Signed at........................on this the............day of...........2000

As witnesses:

1. ....

2. ....

(Signature of participant)

ERRATA

Change the word "loose" to "lose" on the following pages
p. 10, line 22
p. 69, line 9
p. 71, line 28
p. 72, line 11
p. 74, line 12
p. 80, line 14 & 15

Change the word "loosing" to "losing" on
p. 17, line 11
p. 72, line 5, 6, 8
p. 80, line 10
p. 82, line 11

p. 11, line 19: "women are" should be "women were"
p. 12, line 21: "legions" should read "lesions"
p. 17, line 25: "reported against" should be "reported by"
p. 17, line 26: "occur" should be "occurs"
p. 25, line 27: "undimensional" should be "unidimensional"
p. 35, line 9: the word "her" should be inserted before "children"
p. 41, line 13: "a individual" should read "an individual"
p. 46, line 6: "a" should be inserted before "friend's"
p. 53, line 10: "hem" should be spelt "them"
p. 63, line 10: the word "a" should be inserted before "few"
p. 71, line 21: "concern and" should read "concern with, and"
p. 85, line 21: "live the way" should be living the way"
p.92, line 6/7: "Hate feelings" should be "Feelings of hate"
p. 96, line 25: "other people" should be "some people"
p. 101, line 7: "a" should be inserted before "daily"
p. 103, line 8: the word "the" should be inserted before "better"
p. 103, line 29: "by another should read "to another"