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"