AN EXPLORATION OF THE PSYCHOSOCIAL NEEDS AND CONCERNS OF HIV POSITIVE WOMEN LIVING IN PIETERMARIZTBURG

Sibusiso Dumisani Mhlongo

Submitted in partial fulfilment of the requirements for the degree of Masters of Social Science (Clinical Psychology), in the School of Psychology,

University of KwaZulu-Natal

Pietermaritzburg

March 2004

DECLARATION:

This thesis was undertaken at the School of Psychology, University of KwaZulu-Natal, Pietermaritzburg, and, unless specifically indicated to the contrary in the text, is a product of my work. This work has not been submitted to any other university.

Sibusiso Dumisani Mhlongo

March 2004

ABSTRACT

The study aims to explore women's psychosocial needs and concerns following an HIV positive diagnosis. It also seeks to understand nature and various sources of care and support that women need for learning how to live with an HIV positive diagnosis. Finally, to understand what women need from HIV/AIDS health care and social service providers. In order to achieve these aims, a sample of 12 HIV positive women age between 20 and 40 was approached and interviewed at the Centres for Disease Control Clinic (CDC) in one of the local hospital in Pietermaritzburg. A qualitative research approach using semi- structured in-depth interviews was used in the study. The findings of the study reveal that HIV positive women are still faced with a range of psychosocial needs, different to that of HIV infected men. Their main psychosocial concerns centre on the welfare of their children rather their own health. Women fear rejection from their sexual relationships and as a way of coping with this, they choose to abstain from intimate relationships. Many women receive limited support from their families, health, and social welfare systems.

ACKNOWLEDGEMENTS

CONTENTS

Chapter One

1. Introduction

According to recent surveys conducted by the World Health Organisation, the number of people in the world living with HIV is rapidly approaching 50 million. Currently, it is estimated that in several regions of the world, including sub-Saharan Africa, more than half of the people living with HIV/AIDS are women (Florenza, 2002). This picture is replicated in South Africa where the latest available antenatal survey in 2001 revealed that currently 4.74 million individuals are infected with HIV of which women comprise more than half of this infected group (*ibid.*).

Further, the majority of women diagnosed with HIV, both internationally and nationally fall within the reproductive and sexually active (16-40) age group (Anderson, 2000; Evian, 2000). These epidemiological studies suggest that women in their early twenties are more vulnerable to HIV infection and that women in their late thirties continue to be at risk.

It is widely accepted that women's vulnerability to HIV infection is due to a host of biological, socio-cultural, and economic risk factors (Elias &

Heise, 1993; Van der Vliet, 1993). All these factors singularly or in combination may place women at increased risk for HIV infection (Elias & Heise, 1993). Women living with HIV/AIDS are more vulnerable because they suffer domestic violence and they face an array of psychosocial issues related to the stresses of living with HIV disease and being the primary care provider for their families (ibid.).

In particular, provision of health care services in most parts of the developing world, including South Africa, seem unable to adequately respond to the needs of women living with HIV/AIDS. According to Urlin (1992), HIV/AIDS prevention campaigns have not yet taken into account the cultural, social, and the economic factors that undermine many women's ability to comply with advice to limit their own and their partners use of condoms. Further, public health programmes and interventions within the context of HIV/AIDS are often characterised by a narrow, negative approach that label women as potential transmitters of HIV infection to their children (Urlin, 1992). Currently, there is limited information regarding how women cope with HIV infection and the perceptions and treatment of the health care workers who treat them (Campbell, 2003).

Further, provision of adequate health care to HIV positive women is limited by factors such as social isolation and limited power to make decisions about their lives (Anderson, 2000;Walker & Gilbert, 2000). This is further exacerbated by a lack of money, and transportation amongst other reasons (Mc Namara, 1993).

The needs of women have always presented a unique challenge to health care and service provision systems (Aronstein & Thompson, 1998). The reason being that, women have different issues, problems, and service needs from men (ibid.). Women have to cope with finding out that they are HIV positive in terms of diagnosis. Consequently, HIV positive women are often expected to make a range of complex decisions concerning contraception, pregnancy and abortion. These decisions are likely to be influenced by the relationship of intrapersonal factors, family influences and social pressures (Anderson, 2000).

A review of the literature shows that, since the beginning of the HIV epidemic much has been learned about the mental health and psychosocial impact of the HIV epidemic among gay men, however, less has been done in this region and elsewhere to explore the needs of women in the HIV/AIDS epidemic (Bor & Elford, 1998). As such, the psychosocial impact and the needs of women living with infection appear to be poorly understood and inadequately addressed in the HIV/AIDS literature (Doyal,

Naidoo & Wilton, 1994). This research project is an attempt to address this perceived gap in the literature.

1.1. Significance and aim of this study

The objective of this study is to explore women's psychosocial needs and concerns following an HIV positive diagnosis. More specifically, the study will also aim to:

- ❑ Explore the nature and sources of care and support that women need in learning how to live with an HIV positive diagnosis.

- ❑ Establish what women need from HIV/AIDS healthcare and social service providers.

Women appeared to be a source of strength and the backbone of both the public sector and community-based initiatives aimed at care and protection of those living with HIV/AIDS (Baylies & Bujra, 2000). Therefore, investigating their thoughts, feelings, and experiences of living with HIV infection will provide insight into the cultural, social, and economic factors underlying women's needs for survival after HIV infection.

This study might benefit health care workers who provide primary care to women with information about women's practical needs given the reality of their roles and status. It is possible that the research findings may be of interest to other individuals seeking a more in-depth understanding of how to care for women with HIV/AIDS, and how to provide better services for them. This study might also result in some positive consequences for the women themselves, in that it will provide participants with an opportunity to give a full account of their experiences in a supportive environment.

Chapter Two

2. Literature Review

2.1. Introduction

The needs of people living with HIV infection are to some extent universal, for example the need to work through feelings of guilt, denial, fear, anxiety, and depression are common to both men and women (Doyal et al, 1994). However, differences due to gender seem to exist in all aspects of life, for example, women may find it easier to express their emotional reactions more than men and may perceive the physical changes due to HIV infection as stigmatising (ibid.). This suggests that the effects of an HIV positive diagnosis may have more consequences that are negative for women.

While research in the first decade of HIV/AIDS has increased the understanding of many aspects of HIV, behavioural change still remains the only means of primary intervention (Lindegger & Wood, 1995). Such interventions involve awareness of risk behaviours that might increase the spread of HIV infection. This awareness may be achieved through the provision of adequate psychological services that would allow people in

need to discuss risk factors for HIV disease. According to a study conducted by Duplessis, Bor, Slack, Swash, & Colbelt (1995) people living with HIV expressed a need for assistance with personal issues like food and housing, psychological help for depression, anxiety, sleeping problems, and family relationship problems.

Some researchers viewed HIV infection as having direct impact on women's physical, social, psychological, and emotional aspects of living (Pequengnat & Szapocznik, 2000). This implies that psychosocial interventions can go far in meeting the needs of those living with HIV. Such interventions include support from friends, family members, and support groups that might have a positive impact on the life of those living with HIV.

However, it is important to consider the nature of such services and to find out how HIV positive women understand such services and how they use them to cope with traumatic experiences. This chapter will consist of a detailed discussion about these issues.

It is necessary to begin with an overview of HIV in the world, in the African region, and in the South African context. This will hopefully provide a clear picture of how far South Africa has advanced with regard to prevention of the spread of HIV compared to the rest of the world. This

will be followed by a discussion of the position of women with regard to HIV infection in the South African context. Further, the psychosocial impact of HIV infection on women, such as stigma, isolation, and family disintegration will be examined.

2.2. AN OVERVIEW OF HIV INFECTION IN THE WORLD

Since the start of the HIV/AIDS epidemic, it is estimated that globally 42 million people are living with HIV/AIDS. According to UNAIDS report for 2002, more than 30 million people have died of AIDS since the first clinical evidence of HIV/AIDS was reported in 1981. The current statistics indicated that women constitute 47 percent of the total number of HIV infected persons in the world (UNAIDS, 2002). This figure indicates a slight decline in the rate of HIV infection in women as compared to 50 percent in 2000 (Anderson, 2000).

2.3. HIV infection in the African region

The findings by UNAIDS indicate that at the end of the year 2002, Africa had become the most affected part of the world. It was further estimated that at the end of 2002, about 29 million people in the region were living with HIV. In the following year, this trend continues with the African region still remaining the worst HIV/AIDS affected region when compared with the rest of the world (UNAIDS, 2003). This statistics

includes countries like Botswana and Swaziland where the rate of HIV infection amongst adults has increased to 40 percent. According to the same report, other countries mostly affected in the African region include South Africa with 30 percent of adult living with HIV/AIDS by the year 2003. South Africa is followed by Zambia whereby the latest figures show that HIV has infected between 25 and 30 percent of the adult population (Farham, 2002). In Zimbabwe the rate of HIV infection has increased to 25.06 percent of the adult population in 1999.

In the African region vulnerable groups who are at risk for HIV infection, include young women in the reproductive age between 14-24, and women account for about 60 percent of the population living with HIV/AIDS in this region (UNAIDS, 2003). This is an indication that HIV is affecting most women in their most sexually and economically productive years (Farham, 2003). This is supported by the current antenatal surveys which indicate that one in five pregnant women in some African countries is living with HIV/AIDS (UNAIDS, 2003). In Africa, children born to HIV positive mothers constitute another vulnerable population. This refers to mother-to-child transmission, which accounts for 14 percent of infection in the African region (*ibid.*).

There are a number of factors that place women at increased risk for HIV infection in the African region. Research on HIV/AIDS in Sub-Saharan

Africa reveals that gender inequality and unequal socio-economic status increase women's risks for HIV infection (Awusabo-Asare & Anarfi, 1999). In order for women to survive, some are forced to turn to sex work for financial gains (Farham, 2002). In addition, type of residence, social mobility, and displacement due to war are associated with the spread of HIV/AIDS in the African region (Awusabo-Asare & Anarfi, 1999).

Another important factor leading to the increased rate of HIV infection among women in Africa is the high rate of heterosexual activity (Giese, Meintjies, Croke and Chamberlain, 2003). This is evident in the resent statistics whereby, 86 percent of HIV infection cases are due to heterosexual relationships (Farham, 2002).

2.4. HIV in the South African context

South Africa has a population of approximately 46.6 million people of whom 6.5 million are estimated to be living with HIV/AIDS (Giese at al, 2003). These figures indicate that South Africa continue to feel the devastating effects of HIV/AIDS. Currently, statistics reveal that South Africa has began to experience a drop in life expectancy due to the fact that about 75 percent of people living with HIV are in stage 1 and 2 of disease process (ibid.). This is an indication that South Africa is now facing a high mortality rate due to HIV/AIDS.

The South African HIV/AIDS context mirrors the worldwide pattern of the spread of HIV/AIDS (Shapiro, 2001). According to the Nelson Mandela / Human Science Research Counsel (HSRC) report released towards the end of 2002, adult females accounted for 12.8 percent of HIV infection cases while males accounted for 9.5 percent of the adult population living with HIV/AIDS. Among the youth, females between 15 and 24 years accounted for 12 percent of the HIV infected population. This number is doubled when compared with their male counterparts. When looking at race groups, the report further indicates that the national prevalence amongst Africans is 12.9 percent of adult population living with HIV/AIDS. This prevalence rate has been related to historical factors such as labour migration and relocation as well as the fact that more African people live in informal settlements.

People most at risk in South Africa are those living in areas that are affected by prostitution, crime, a high school dropout rate, and social unrest (Lindegger & Wood, 1995). Further, risks for HIV infection is common amongst those who face deepening poverty, isolation, and the inability to satisfy basic needs such as food and shelter (Campbell, 2003).

In South Africa, HIV/AIDS epidemic reveals that about 3.2 million women are living with HIV/AIDS. Most of these women fall within the childbearing age and many of these women will give birth to children who

will be infected (Giese et al, 2003). Many children are also affected by the epidemic and lose either one or both of their parents to HIV/AIDS. Sloth-Nielsen (2003) predict that, the number of orphans and other vulnerable children in South Africa will double to 800 000 by the year 2005.

2.5. AN OVERVIEW OF WOMEN AND RISK FACTORS FOR HIV INFECTION

One of the key reasons for the rapid spread of HIV/AIDS has been its mode of transmission. In order for the virus to attack a person's immune system it has to enter the bloodstream and there are many different ways in which this can happen for women (Rooth & Dreyer, 2000). There are also other biological, psychological, and socio-economic risk factors that can have an indirect impact on womens' vulnerability to HIV infection. This next session will look closely at these factors.

2.5.1. Biological Predisposition

Women seem to have a biological vulnerability that places them at greater risk for contracting HIV from sexual partners (Doyal, Naidoo & Wilton, 1994). The biological vulnerability stems from the fact that virus appears to be found in a heavier concentration in semen than in vaginal secretions (*ibid.*). In addition, the mucous membranes of the vagina seem to be more permeable than of the penis, and this might facilitate transmission.

Another risk factor is that sexually transmitted infections (STI's) may multiply the risk of contracting HIV especially in women since most STI's cases in women go unrecognised (Adar & Stevens, 2000). Unlike men, sores or other signs are absent or hard to see, and women do not suspect that they are at risk (Rooth & Dreyer, 2000).

Further, a physiologically immature cervix and scant vaginal secretions create less of a barrier to HIV, thus placing younger women at greater risk of HIV infection (Rooth & Dreyer, 2000). There is also a great possibility of HIV infection during forced penetrative sexual intercourse or rape, as it usually results in the tearing and bleeding of the mucous membrane covering the internal surface area of the vagina *(ibid.)*.

2.5.2. Socio-economic position of women

Previous findings reveal that women are at risk for HIV infection because they are poor, unemployed, and they continue to rely on their sexual partners for financial support (Laird, 2001). The fact that most women are economically dependent makes them vulnerable to participating in unsafe sex. As the result of deepening poverty, most women are likely to risk putting themselves and their children at risk because they are unable to demand their partner's practice of safe sex (Foster, 1995). They are also less likely to succeed in negotiating protection, and less likely to leave a

relationship that they perceive to be risky (Gupta, 2001; Rooth& Dreyer, 2000. Even for those who choose not to get married, economic necessities continue to dictate sexual terms between men and women (Laird, 2001).

Gender-based primary intervention programmes seem to have negative implications for women with regard to HIV infection. While gender-based programmes have been very good at persuading women to use condoms, their success has been considerably limited by the attitude of men towards condoms (Adler & Qulo, 1999). The result of the study conducted by PASCA (2002) using a sample of women from the surrounding areas of Pietermaritzburg revealed women's concerns about their lack of power to make decision regarding safe sex. Their powerlessness appears to be due to a lack of co-operation from their sex partners who show an unwillingness to accept HIV/AIDS as reality. As a result, these women end up losing control over their bodies. The study further revealed that, women's lack of education is an important factor that contributes to the lack of awareness about risk behaviour that might lead to HIV infection. According to the PASCA report, any intervention programmes should focus on womens' empowerment about their rights to negotiate safe sex. This can involve assertiveness training that will enhance effective communication skills of HIV infected, thus helping them to talk to their partners and access their rights.

\

2.5.3. Psychological factors

According to Anderson (2000), women who experience emotional difficulties and personality disorders are not likely to engage in safe sex. Secondly, women, more than men usually experience major depressive disorder, post traumatic stress disorders and borderline personality disorders that have an effect on their decision-making processes (ibid.). As a result, these disorders may have an effect on women's decision -making process. In addition, women who have low self-esteem are more likely to have difficulties negotiating safe sex (Lesson & Gray, 1978).

2.6. THE PSYCHOSOCIAL CONSEQUENCES OF HIV INFECTION FOR HIV POSITIVE WOMEN

HIV infection appears to be a social disease more than a biological one. The reason being is that, it affects the social well being of the person in the form of social identity, stigma, rejection, loss of income, isolation and family disintegration (Roux, Venter & Wessels, 2001). These social factors seem to increase the likelihood of HIV infection and reduce the person's physical capability to fight the infection that leads to the development of full-blown AIDS syndrome (Pequengnat & Szapocznik, 2000).

According to Kelly & Lawrence (1998), the psychosocial disruptions that often follow HIV infection are two folds, i.e. emotional and coping mechanism. The emotional upset involves feelings of shock, anger, and denial. Coping with social difficulties depends on the individual style of dealing with social pressure. Most women use avoidance as coping mechanism and this as a result may increases the women's sense of isolation (Kelley & Lawrence, 1988). This may result in poor interpersonal relationships, which contributes towards anxiety, depression, and anger that the women may experience (*ibid.*).

2.6.1. The issue of disclosure

The issue of disclosure is not a simple one, but rather a more traumatising process that involves a number of decisions and commitments regarding when to disclose, to whom, how to disclose, and under what circumstances to disclose (Maman, Mbwambo, Hogan, Kilonzo & Sweat, 2001). These writers argue that disclosing an HIV positive status is a process that challenges the psychosocial well being of the person and those close to them.

The psychosocial challenges regarding disclosure can be more stressful for women than men. Power inequality is one of the reasons that make the disclosure of HIV status a more difficult process for women more than for men (Roux et al, 2001; Stein, 1996; Andries and Novick, 1995; Holt,

Court, Vedhara, Nott, Holmes & Snow, 1998). Other factors that influence disclosure include fear of discrimination and victimisation, rejection and fear of losing economic support (Seidel & Coleman, 1999; Adries & Novick, 1995 & Campbell, 2003). According to Seligson & Peterson (1992) concerns about the reactions of the loved one, including family and friends can hamper disclosure. As a result, many women are afraid that they will loose their support system once they disclose their HIV status (Andries & Novick, 1995). Women also fear that their partner may leave them for someone who is "healthy" and HIV negative.

There are certain psychosocial factors that influence women's disclosure of their HIV status to family members or those close to them. Firstly, if the family member's show empathy and trust then acceptance is guaranteed which will make the process of disclosing an HIV status much easier (Bor & Elford, 1998; Roux et al, 2001). Research on the psychosocial characteristics of disclosure also revealed that, disclosure could be associated with high levels of perceived social support (Holt et al, 1998). Therefore, most women are not likely to disclose their HIV positive status in a situation where there is no perceived support and care (Stein, 1996). This implies that HIV infected individuals are most likely to disclose their HIV status in circumstances where there is perceived personal benefits, which may include social support and economic gains. Their motivation

towards disclosure is simply to access appropriate social support and minimise stress associated with disclosure (Holt et al, 1998).

The consequences of disclosure have some psychosocial implications for the lives of HIV positive women. This relates to the reaction of the family members, partner and friends after disclosing their HIV positive status. Some research findings indicated that social stigma seems to play an important role in influencing partner's reaction following disclosure (Mouyis, Deverell, Mcintuyre & Gray, 2002). Those who disclose their HIV positive status to their partners could face violence and rejection, and possible eviction from their homes (Seidel & Coleman, 1999; Roux et al, 2001; Campbell, 2003).

Past and recent literature has managed to provide insight into the significance of disclosure and factors influencing disclosure (Maman et al, 2001). However, there is still a need for research that will focus on the nature and quality of psychosocial support that HIV positive women need that would help them disclose to their loved ones. This research attempts to explore these issues, which seem to be poorly documented in the reviewed literature.

2.6.2. Social Identity

The loss of social identity and role contributes to a person's decision to isolate themselves from society (Andries & Novick, 1995). The reason might be that, an infected person may see herself as a different and no longer part of her own community. She may regard her diagnosis as the beginning of a new chapter in her life. She may also associate her isolating behaviour with rejection, the desire to protect loved ones, feelings of contamination, and physical and emotional exhaustion (Lewis, 1988; Bor & Elford, 1998).

2.6.3. Stigma

The most devastating effect of HIV positive diagnosis relates to felt stigma, which according to Fitzsimons, Hardy & Tolley (1995) is the fear of anticipated discrimination. It appears that, most women living with HIV will suffer discrimination, stigmatisation, and marginalisation, which the knowledge of HIV infection brings (Van Morrison & Mclachlan, 1992). As a result, infected persons internalise these feelings of self-blame, which are particularly destructive (Duwirkin & Pincu, 1993).

Social isolation due to fear of discrimination also has specific implications for women with regard to treatment access. Because of fear of rejection, people living with HIV/ AIDS are often reluctant to seek out help or access services and they prefer to live without treatment (Lewis, 1998).

The fact that HIV infection is stigmatised socially, maintaining or strengthening women's support systems can be complex and difficult (Gupta, 2001). In addition, avoidance reactions of others can unwittingly heighten distress and leave the HIV positive person feeling shunned, vulnerable, and isolated from the very persons who had previously been a source of support *(ibid.)*.

The stigmatisation of HIV illness seems to be an important factor that leads to an individual's sense of isolation. Part of the social stigma is the person's alienation from the society that she is living in. The meaning that the infected person attaches to being HIV positive may also contribute to social isolation. Self-labelling of oneself as " diseased", "infected " or "contaminated" can foster self-isolation and feelings that the HIV affected persons no longer belong in the mainstream (Kelly & Lawrence, 1998). Previous findings indicate that most HIV positive persons spent more time in solitary activities after they had learned that they were HIV positive, and most feared that their HIV exposure would negatively affect established relationships *(ibid.)*. As Kelley & Lawrence (1988) further note, there are also those people who retreat into self-imposed isolation, either fearing re-exposure to new infections, or out of concern over transmitting the virus to others, or simply because they are stunned by the news of their exposure.

According to Erickson's theory of development, people in their 20's and 30's are working through "intimacy versus isolation" or "generativity versus self-absorption" (Duwirkin & Pincu, 1993). This relates to the most vulnerable group for HIV infection in South Africa that comprised of young women between age 15 and 24 (UNAIDS, 2002). Women at this age are concerned about the need for intimacy of which if not resolved may lead to isolation (Duwirkin & Pincu, 1993. It is difficult for HIV patients to successfully resolve the intimacy versus isolation conflicts during the initial stage of HIV infection (*ibid.*).

Sometimes isolation, as perceived by Andries & Novick (1995) can be indicative of an underlying clinical depression. Isolation in this regard, may be the result of circumstances beyond the patient's control, such as job loss, rejection by friends and family members, loss of income (Durwirkin & Pincu, 1993). As the person enters the final stage of AIDS, isolation may be fuelled by embarrassment about physical changes, such as facial lesions, and physical problems, such as weakness and diarrhoea, that inhibit the patient from being able to participate in social functions. Patients will isolate themselves as the way of defending themselves against anticipated rejection (Andries & Novick, 1995).

There are some cases where women actually experience rejection by family members, partners, friends and co-workers, while many others just

anticipate potential rejection and fear (Lewis, 1988). Furthermore, women who appear to have low status in society are likely to be blamed for failing to protect themselves against HIV infection (ibid.). There is the need for research that will focus on how perceived social discrimination can affect the quality of life for women infected by HIV/AIDS.

2.6.4. The reaction of family and friends

It appears from the literature that, family is regarded as the basic source of physical, economic and social support that plays an important role in taking care of the family members living with HIV/AIDS (Lewis, 1988). Family members not only see one another as well or ill, as helpful and unhelpful, or as responsible and irresponsible, they also see themselves as viewed from the outside as giving aid to the ill member and thus preserving the family or failing to live up to social expectations (Turk & Kerns, 1985). Sometimes there is a shift in the role of family members who have difficulty in setting limits and managing their own needs as they take on the role of caretaker (Lewis, 1988).

Kelley & Lawrence (1988) note that, more than half of women who were in steady relationships hesitated to inform their partner, fearing they would precipitate a break-up in the relationship. In that case, HIV diagnosis has destabilised relationships for approximately one-third of the couples surveyed and couple disruption was equally common among heterosexual

and homosexual couples *(ibid.)*. The findings by Maman et al, (2001) reveal that, a smaller percentage of HIV positive women experience violence from their sexual partners following disclosure of their HIV status. Other studies conducted in South Africa have found that violence, break-up of marriage, being neglected or disowned by their families all took place after women's disclosure of HIV positive status to their sexual partners (Van Dyk & Van Dyk, 2003). This seems to indicate that women are often the ones who have to take the blame for HIV infection.

Chronic illnesses such as HIV/AIDS can lead to rejection of the infected individual by the family while there is increased emotional support from the health care system (Grinstead, Gregorich, Hee-Choi & Coates, 2001). It is further argued that people may reject the HIV patient and family because contact stimulates anxiety about their vulnerability or they may avoid the family because they don't know what to do. According to Lewis (1988), lack of social and economic support also increases the risks of family fracture. The family may lose their sense of unity as the affected person may begin to seek external sources of support.

2.7. THE PSYCHOSOCIAL NEEDS AND CONCERNS OF HIV POSITIVE WOMEN

During the course of HIV infection, a broad range of psychosocial needs and problems are likely to be experienced by the infected person (Mlomo-Ndlovu, 2000). The changing nature of these needs imposes a variety of psychosocial and emotional strains on women living with HIV and those closest to them. Women may have more serious psychosocial concerns because they lack power to make their own decisions and they are often encouraged to be dependent on men (*ibid.*). Below is a closer look at how HIV positive women experience these needs based on previous research findings.

2.7.1. Difficulties in accessing health care services

It appears that, access to health services is one of the most pressing issues facing HIV positive women. In South Africa, where the majority of HIV infected individuals are women from poor socio-economic backgrounds, psychosocial support and care needs remain as a major concern (Adler & Qulo, 1999). Despite a great need for services, women encounter barriers in attaining adequate care and support. These barriers are influenced by gender stereotypes, poverty, lack of education, inferior position in society, and inadequate health systems (Gerntholtz & Richter, 2002; Mc Namara, 1993). In addition, lack of access to resources makes women's style of

living harder and less productive, and contributes to their lower income and their poor health. It is unfortunate that it is primarily impoverished black women who face the majority of these obstacles (Gerntholtz & Richter, 2002).

Despite the existing barriers for women for seeking health care services, other research findings indicate an increased usage of health facilities by HIV positive women living in rural areas of Johannesburg (Modiba, Gilson & Schneider, 2001).

2.7.2. Economic issues

Current research data reveals that an increased number of black women who are HIV positive are living in poverty and struggle with financial issues, homelessness, substance abuse, mental health disorders, and unstable intimate relationships (Anderson, 2000).

In addition, most of these HIV infected women spend their energies in meeting basic needs such as food, housing and employment for themselves and their families. Thus, health care resources become less accessible to these women and less of a priority in the lives of many HIV infected women (*ibid.*).

2.7.3. Women meeting the care needs and support of other family members

Women face a double burden that of being HIV positive and that of taking care of the family members, especially children. As Walker & Gilbert (2002) state, " The predicament of women has a profound effect on the impact of the epidemic on society as a whole. On one level, they carry the burden of the disease, yet they are expected to take responsibility and care for other members of the family who are also HIV positive, thus adding to their disadvantage and depleting community resources to cope with devastating outcomes of the epidemic" (2002: 82). These women may end up losing an opportunity to live their life to the fullest by not focusing on their own illness and on getting better. For many HIV positive women, HIV infection is regarded as a family issue that imposes social, psychological, and economic burdens on their family members (Anderson, 2000).

2.8. RESPONSES TO THE PSYCHOSOCIAL NEEDS OF HIV POSITIVE WOMEN

While different intervention strategies might be available to help those infected in their long and difficult coping process, it is still debatable whether intervention strategies are able to meet the different needs of women living with HIV. It will be very interesting to first look at the

different needs presented by HIV positive women and whether present intervention strategies are able to meet those needs.

Women who are HIV positive need support in terms of adjusting to living with the virus and learning to make personal priorities, as well as making informed decisions about their health care (Dom, Henderson & South, 1992). Social support is therefore crucial in giving those infected women confidence, love, and undivided support as they make decisions that will improve their quality of life (Anderson, 2000). Women's primary needs are to be empowered to define their own HIV related needs and to be able to participate in making the health and social service systems more responsive to their perceived needs (Ostrow, 1990). This suggests that, high quality care for women living with HIV is not best given by addressing medical needs only, but also her social, her relationship and her community needs at large (Anderson, 2000).

Women who are mothers need to know that someone cares what happens to them, not just their children (Ostrow, 1990). According to Anderson (2000), women living with HIV can regain their self-esteem if they are able to care for their children or provide for them as they feel they should. While it is important for women living with HIV to take care of their children, they also need to be encouraged by health care providers to take care of their needs too. Their social position encourages them to care for

others and safeguard their health even when they are ill (Dowling, 1994). Immediate psychosocial concerns, particularly as the disease progresses, increases mother's fear and guilt about leaving their children motherless when they die (Lewis, 1988). Further, some women fear that their children might be taken away through custody or court order as a result of their HIV positive diagnosis (*ibid.*). This is an indication of HIV positive women's lack of understanding regarding their rights as parents as well as insufficient knowledge about their protection from the law.

Women also seem to have specific needs with regards to counselling. According to the Department of Health summary report on HIV counselling (Dom et al, 1992)), women prefer to have a female counsellor as they can easily identify with worries and fears where as a male cannot, and that some mothers, particularly those with young children, may have difficulty leaving the home for counselling unless some form of childcare facility is provided at the centre. Therefore, in this study a home visit was suggested as an alternative form of psychosocial intervention. Other psychosocial interventions are closely examined below.

2.8.1. The nature and effect of psychosocial interventions

According to Linn, Lewis, Lain & Kimbough (1993), there are three functional characteristics of psychosocial support. They include emotional support, informational support and instrumental support. Emotional

support consists of affection, comforting, and encouragement that result in a sense of belonging and personal growth (*ibid.*). Increasing ones knowledge base is one form of information support, while instrumental support involves practical assistance with daily living. Research has shown that emotional, informational, and instrumental support can directly alleviate psychological distress associated with chronic illness, such as HIV/AIDS (Kalichman, Sikkema & Somlal, 1996). The PASCA's (2002) report findings indicate that the majority of HIV positive women living in the surrounding areas of Pietermaritzburg regard the immediate family members as a source of emotional support and home based care. Alternatively, HIV positive support groups offered emotional, spiritual support, and friendship. Husband or partner appeared to be responsible for providing emotional, spiritual and financial support as well as accommodation (*ibid.*).

The previous research findings suggest that adequate social support systems are of primary importance for people living with HIV (Lewis, 1988). One of the most engaging ideas behind the concept of the social support is the notion that interpersonal interactions may in some way influence health and well being (Cohen et al, 2000). This implies that social support has positive impact on physical and psychological well being of individuals undergoing stress *(ibid.)*. This seems to be an

indication that perceived social support more than actual support itself could help reduce stress.

2.8.2. The nature and various sources of social support

The previous research findings suggested that, family members, professional caregivers, home visitors, mentors, lay telephone counsellors, support groups, supervisors at work, friendly companions, network restructuring, and therapeutic allies all form important sources of social support (Cohen et al, 2000; Kalichman et al, 1996). Adjustment to HIV infection is a long process that demands support from family members, work colleagues, spiritual workers, and friends (Mlomo-Ndlovu, 2000). According to the research findings by PASCA (2002), half of their sample indicated that family members have been a basic source of emotional support. However, half of that sample indicated fear of possible rejection by family members should they disclose their HIV status. As the result, this has prevented them from seeking support from their immediate family members.

2.8.2.1. Counselling

Women affected by HIV infection and illness need programmes that will focus on their psychosocial well being and that of their significant others (Ostrow, 1990). This involves high quality, culturally and gender-sensitive HIV/AIDS counselling. Psychosocial counselling of women living with

HIV needs to focus on issues resulting from social isolation and how to deal with unexpected changes in their social roles amongst other things.

Counselling seems to be the most effective form of psychosocial intervention, because it focuses on a person's social environment, her relationships, attitudes, and beliefs about HIV and AIDS, sexual needs, aspirations, and hopes (Mlomo-Ndlovu, 2000). It has been reported to be effective in providing emotional support to HIV positive women, as well as advice about disclosure, facilitating access to community support groups, and welfare grants (McCoy, Besser, Visser & Doherty, 2002). Despite the effectiveness of counselling, Mlomo-Ndlovu (2000) maintains that, counselling can only be effective if the client sees it as acceptable. This suggests that counselling will have a positive impact only if it takes into account social relationships, commitments, and obligations of the individuals. Counselling has also been found to be less effective in the case where pregnant women, immediately after having been diagnosed as HIV positive, are counselled on the risks to the baby, rather than on her feelings (Dowling, 1994).

2.8.2.2. Support groups

Support groups also form part of a range of psychosocial interventions with regard to HIV/AIDS. According to Ostrow (1990), support groups assist group members to enhance self-esteem while benefiting other group

members at the same time. Previous studies, according to Bor and Elford (1988) have found a positive association between support groups and quality of life for those infected by HIV. A support group may also assist group members in coping with difficult medical situations they have just been through by sharing new information or discussing the problems they experience in their daily living with HIV infection (Ostrow, 1990). It also gives members an opportunity to discuss issues and problems related to their condition with others who are experiencing similar problems (Lewis, 1988).

There are a number of factors that make support groups an effective form of psychosocial intervention. In the study conducted in the USA by Crystal (1996), 22 percent of women who attended a support group found it helpful especially when designed for women who are HIV positive.

The PACSA report on the research conducted on the sample of 30 black women from the surrounding area of Pietermaritzburg revealed that, the women who attended the support group were able to disclose their status publicly and coped well with an HIV positive diagnosis. Support groups seem to be more effective when people undergo stressful life events like an HIV positive diagnosis and role transition, because they typically orient themselves to and seek out similar peers who are able to help them integrate their new identities (Cohen et al, 2000). These writers further

argue that peer support groups provide opportunity for members to help one another in a supportive manner.

Results from previous studies seem to indicate that women are still facing a range of unmet psychosocial needs and that few research studies have been conducted that address these needs. While previous research findings have contributed towards our understanding of the psychosocial needs faced by HIV positive people in general, it would be useful to find out, from women themselves, what psychosocial needs and concerns arise for them following a diagnosis with HIV. This study attempts to address this situation.

Chapter Three

3. Methodology

The research method for this study will be discussed. This chapter will involve a brief discussion of the qualitative research methods used, the characteristics of the sample chosen and the procedure for conducting the qualitative research interviews. This methodology chapter will conclude by presenting some ethical issues resulting from the research process, as well as strategies employed to address these ethical dilemmas.

3.1. Qualitative research method

Qualitative research design is often used as an umbrella term for various orientations to qualitative inquiry (Glesne, 1999). This term encompasses in-depth interviews, narrative interviews, focus group, and case studies among others (Hatch & Winiewisks, 1995). The usefulness of a qualitative research methods is that they rely on depth and quality of participant's responses and not necessarily essentially on the number of people who respond in particular way (Silverman, 2000;Miles & Hurbeman, 1994). Qualitative methods aim to understand experiences as nearly as possible as its participants lived it (Miles & Hurberman 1994). In this study, the focus was on eliciting the lived experiences of an HIV positive diagnosis as well

as the resulting psychosocial needs and concerns that emerged for HIV positive women.

3.2. In-depth interviews

The distinctive features of qualitative research method are the use of language in the form of conversation or dialogue (Denzin & Lincoln, 2000). According to Reis & Judd (2000), when conducting in-depth interviews, language becomes a distinctive source of information to reveal innermost thoughts, experiences and cultural conversations. In addition, language is used to transform images, feelings and personal experiences into socially constructed reality.

According to Holstein & Gubrium (1995), interviewing is an effective instrument for systematic inquiry into participant's experiences. This is because interviews provide valuable data with regarding people's beliefs, attitudes, values and knowledge about subjective experiences of the external world (Terreblanche & Durrheim, 1999). Further, by using in-depth interviews one is able to get more substantive information than is possible through the focus groups. Unlike focus groups which concentrate on the imputes generated from group members, in-depth interviews allow for concentration of time spent with each participant and allow for quality of information through the use of probing (Holstein & Gubrium, 1995). In addition, participants may be more willing to share in an individual

interviews compared to group environment of a focus group where confidentiality is guaranteed. For all the above-mentioned reasons, in-depth interviews were considered to be an appropriate method to use given the aims of the study.

3.3. Setting and Participants

Participants for the study were drawn from a group of women who attend the Communicable Disease Clinic (CDC) at a local hospital in the Pietermaritzburg area. The particular hospital was chosen because the majority of HIV positive women often use public hospital and clinics for their health care. The CDC caters mainly for under-resourced patients communities surrounding the city of Pietermaritzburg. The reason for the excessive use of CDC services is due to the fact that most disadvantaged women cannot afford to consult private health care providers. The services provided at the clinic involve medical treatment, counselling, education, and research.

One of the objectives of qualitative research methods is to obtain detailed information from a limited number of participants without making generalisations (Glesne, 1999). Therefore the choice of research participants was based on their ability to participate and give a full account of their own experience (Flick, 1998). This convenience sampling strategy

emphasises the relevance of cases instead of their representativeness (Terreblanche & Durrheim, 1999). Twelve HIV positive women agreed to be participants in the study. The following characterised the sample:

☐ The majority of the sample received their HIV positive diagnosis between 1998- 2001.

☐ The mean age of the sample was 33 years with 10 women in the sample in their mid 30's. Only 1 participant was 40 years old.

☐ About 8 participants were single mothers.

☐ Only 3 women in the sample have matric or grade 12, while 9 of them have below grade 11 in terms of education.

☐ About 10 women in the sample receives a monthly income of less than R700.00

3.4. Procedure

In order to gain entry to the research site and access to the sample, permission to conduct interviews was obtained from the Provincial office of the Department of Health (See appendix, A). After permission was granted the researcher held a meeting with the Superintendent of the hospital. The purpose of the meeting was to brief senior hospital management about the study and to obtain organisational informed consent for the study. The meeting was also helpful as it provided the researcher with information regarding patient profiles and availability.

The sister in-charge introduced the researcher as well as the nature of the study to potential research participants. Those patients who were willing to take part in the study were referred to the researcher in a private room where informed consent to participate in the study was taken before interviews took place.

3.5. Pilot study

Piloting is regarded as the core of an effective research process because it allows for the refinement of the interview and interviewing skills (Temorshock & Baum, 1990). The aim of conducting a pilot study was to find out whether questions were well structured and well understood by participants. The pilot was also done in order to provide the researcher with an opportunity to develop effective interviewing skills. This was achieved as the pilot allowed the researcher to get a feel for the interviewing process (Gillham, 2000). It was anticipated that the pilot study would provide a clear indication as to whether the chosen site was feasible for such an investigation. Further, piloting was done to ascertain whether the interview guide used would be able to cover necessary areas that could yield data regarding the psychosocial needs and concerns of HIV positive women.

Five interviews were conducted during the pilot phase. Following the pilot study and supervision, it appeared that the interview guide was appropriate, however some probes to elicit more data to cover all aspects of the main questions were added.

3.6. Data collection

Participants were approach during their regular visits to the CDC. After the purpose of the study was introduced to the participants (Appendix, B), and as soon as the consent forms were signed, (outlined in Appendix C), the research process began. Interviews were conducted in Zulu (see Appendix .D) and responses were audio recorded.

The interview procedure adopted during piloting was retained for the main study. In order to develop rapport with participants, the researcher presented the interview schedule before the initial interview began. This serves to provide participants with an understanding of what is going to be asked and for what purpose. This was seen as important because, according to Gillham (2000), the crucial part of the research process lies at the introductory phase.

Of the 12 women who participated, only one of them preferred not to give consent for the interview to be audiotaped. With that case, notes of the interviews were taken. Interview schedules consisted of open-ended

questions that probed HIV positive women's psychosocial issues and needs arising from HIV positive diagnosis and throughout the disease process.

3.7. Data analysis

The method used to analyse data in the study was thematic analysis. This method was considered appropriate for the study because the effectiveness of qualitative data analysis can be best achieved by organising data into primary structures and themes (Hatch & Wisniewski, 1995). Therefore, data was closely examined with the purpose of creating common themes and ideas. Since the data had not emanated from a single story, but several stories, it was therefore necessary for the researcher to inspect different interview transcript to discover which themes appeared across all participant's accounts. The thematic method of data analysis used in this study was a combination of the approach outlined in Miles & Huberman (1994) and Da Costa & Donald (2000). The following data analysis steps were taken:

1. The data was transcribed from tape-recorded interviews.

2. The data was translated from Isizulu to English for the purpose of supervision and analysis.

3. With the help of a Zulu-speaking colleague, data was translated back from English to Isizulu in order to ensure efficiency in the translation

process.

4. Broad thematic categories were formulated using the questions from the interview schedule as a guide.

5. In order to ensure validation of the coding schema, another researcher coded the raw data as well. There were strong consensus between the two researchers. Where there were discrepancies, codes were discussed further so that consensus could be researched.

6. Themes were extracted and organised into broad categories as well as sub-categories and analysed accordingly.

3.8. Ethical Issues

In terms of the ethical guideline for the scientific research, quality of relationship should exist between the researcher and the participants from the onset of the research process. Sales & Folkman (2000), suggest that this quality of relationship can be best achieved by researcher's ability to provide care, cultural recognition, warmth, respect, and understanding to participants.

Considering the complex and confidential nature of the disease, measures were taken to ensure confidentiality by asking participants to provide pseudonames. They were also guaranteed that the research information would be kept confidential and that should the researcher wish to publish the information for academic purposes, all identifying information

including the name of the hospital clinic acting as research site will not be used.

The researcher also took into consideration the gender related issues (i.e. the researcher was male, all participants were females) that may have had negative implications for the study. The researcher was aware that women are mostly exposed to male sexual violence, that they experience their partners as being unsupportive and uncaring, and that women generally assume a subordinate position when in contact with men. Every effort was made, as far as possible, to be mindful of these issues by being empathic and by demonstrating unconditional positive regard throughout the research process.

Participants willing to take part in the study were informed about the nature and the purpose of the research at an early stage of the study. They were told about their rights as research participants e.g. the voluntariness of their participation as well as their rights to decline or withdrew from participation in the interview at any time. The purpose of the research and type of question to be asked during the interview process was communicated to all prospective participants. Participants were also informed about their right to give or withhold consent for the interviews to be recorded. There was a case where one participant appeared unwilling to be tape-recorded; therefore, notes were taken during the interview.

Chapter four

4. Results

This chapter presents the results of the study. Some of the main themes will be presented together with supporting data from the transcribed interviews. The main themes that emerged in the study include: psychological reactions as a result of an HIV positive diagnosis, psychosocial needs and concerns following an HIV positive diagnosis, and the nature and quality of psychosocial support received once diagnosed with HIV.

4.1. Psychological reactions as a result of HIV positive diagnosis

The findings of the study indicate that the majority of the women in the sample have suffered emotionally in response to receiving an HIV positive diagnosis. Some of them have not yet recovered from the trauma.

> ...I felt very bad after receiving the news and I was very traumatised. I felt very bad in such ways that even now I am still traumatised and when I tell my husband he was not willing to accept it. I don't have support and I am traumatised because the one who brought this illness to me don't have love... (D.40).. My mind was very confused in such a way that even now sometimes I forget things. (B.31)

One participant reported that her traumatic experience was due to fear of death and concerns about the future of her child.

I was traumatised because I told myself that I will die any time and leave my child, I was very disturbed. (. J.30).

Some women reacted with shock. They were terrified when they heard news of their HIV status, they were confused and did not know what to do. The reaction of shock was mostly because most women in the study believed that their intimate relationship had placed them at high risk for HIV infection.

I was very confused because I recall the manner I have been taking care of myself, now that I had sickness like this it came to my mind that it is due to him failing to take care of himself. (D.40). By that time I was asking myself why me Lord the guy I have been going out with was my first guy, so it was so painful in such a way that I have to ask myself why me, because I have been taking good care of myself all along. (I.22) It was not an easy thing to accept because it was something that shocked me...(F.32)

According to one participant, the experience of shock was so severe that it left her confused and devastated, however she managed to recover from the shock due to family support.

I will say I was shocked in such a way that I never knew whether

to go home or stay in the hospital, after that I phoned my sister...

she said don't worry and don't loose hope...(L.32).

For some participants, an HIV positive diagnosis meant disruption of future goals and aspirations. They lost hope about the future and they eventually changed their life style after receiving news of an HIV positive diagnosis.

It was difficult and it was like the end of the world. I thought I will

die soon, may be within a week...(H.32). My life has changed because

I have told myself that soon I will die, therefore there is no need to

further my education because soon I will die, I don't need to have a

relationship because soon I will die, should I get money I should spend

all of it by that time and save nothing (C.32)... By the time I heard about

my HIV positive status I was at the University and I just dropped out

because I told myself why do I need to study because I will die

soon...(I.22).

It was evident from the participants narratives that few of them had lost hope due to the lack of information about the nature of HIV infection.

It was very painful because with this illness you don't live longer,

you will soon pass away...(G.31)...I had lot of emotional difficulties,

always thinking that may be I will die soon...(L.32) I thought I would

die so soon, may be within a week.... (H.34)

The feelings of fear and devastation appeared to have been experienced by most participants as a result of an HIV positive diagnosis. These feelings seem to have been associated with their concerns about how significant others would react and respond to the news of their HIV status.

I was frightened after receiving the news...(H.34). I thought my

parents would feel bad thinking I was not taking care of myself

because they had never received an explanation, there was fear

that, may be I will not be welcomed. (C.32).. I was traumatised

because I told myself I will die anytime and leave my child, I was

very disturbed (J.30). When I look at my sister's children because I am

taking care of them I just cried. (L.32)

4.2. Psychosocial concerns following HIV positive diagnosis

A number of women's psychosocial concerns appeared among the sample interviewed for this study. Some concerns arise immediately after receiving the news that they were HIV positive, whereas others persisted throughout the disease process.

4.2.1. Disrupted family relationships

An HIV positive diagnosis does not only have a serious impact on the infected person as an individual, but it disrupts the family system as a whole. A limited number of participants reported disturbed family relationships after the news of an HIV positive diagnosis was disclosed to the family. They reported experiences of rejection, isolation, and lack of acceptance from the family system.

> *There is a change with regard to family relationships. .... they*
> *have isolated themselves from me, things are no longer the same*
> *like before, now they have maintained a distance from me...(C.32)*
> *Even now I am alone, all family members are not available. They*
> *never accepted me; they didn't accept me because just now I don't*
> *have anybody I am staying alone.. (E.36) ...At the present moment I*
> *don't feel like a member of the family because that love for the*
> *granddaughter does not exist anymore...(C.32)*

Some participants expected their families to treat them with the love and respect that they felt they deserved. According to them, they felt unwanted in the family and no one in the family was interested in supporting and listening to them. They felt that the family turned against them after they disclosed their HIV status.

> *My friend told her family about her HIV positive status then her*
> *family told us they don't want anything to do with her. (J.30) What*

I expected from my family was love, they had never loved me, instead

I saw them walking at a distance from me...no one has ever come to

check me and to find out how I am feeling...(E.36)

4.2.2. Disrupted intimate relationships

There were a few participants who reported that they have experienced problems in their intimate relationships as soon as they communicated the HIV positive results to their sexual partners. Their partners rejected them or left them as soon as they heard the news of an HIV positive diagnosis.

...I told my boyfriend after that he ran away. (C.32) We broke up

since he found out that I am HIV positive because I was trying to

explain to him what happened but I found that he has kept a

distance from me. (F.32) I broke up with my boyfriend because

he knew that I was HIV positive, they pleaded with him to do blood

test but he refused. (J.30). I told him that I wouldn't be able to make

love to him because I am HIV positive he then left me. (E.36)

It seems that for women in this study that once they recover from the shock of an HIV positive diagnosis, they eventually make a decision to avoid intimate relationships. They seem to do that as a way of coping and to avoid further emotional distress. These feelings of shock intensify as one progress with her HIV positive status.

*.. One of the things that helped me was that I broke up with the
father of my child in 1998, I think that is also helping me to
survive...(E.36)... Even now, I have told myself that I will no longer
have someone to have a relationship. For me, what will make me
survive is not to come closer to men.... (C.32) I used to have a problem
when a man is proposing to me until it reaches the point where I will
tell the person that I can't fell in love with any person because I have
told myself that I will stay like this. (C.32)... to be true I don't need him
near me and I don't hate him, but I don't need him near me...(I.22).*

Some participants eventually developed negative feelings towards intimate
relationships. These feelings persisted even after a person seemed to have
overcome the state of initial shock.

*...It is difficult, there are no more feelings for sexual relationship,
and I don't feel anything...I don't think there is anything further
that will take place between us. (K.34)...There is no feeling for
sexual relationship, I don't feel anything. (crying). (L.32)*

4.2.3. Reactions from partner

Most participants experienced negative reactions from their sexual
partners as soon as they learned about their HIV positive diagnosis.
Women reported that male sexual partners displayed a lack of empathy
and support towards them. Some of the women's worries were that their

partners were either not willing to undergo HIV testing or to accept their HIV positive diagnosis.

.. When I told him that the doctor wants to see him, he said he

will go but up to now I don't know whether he did because he

was the person not showing sympathy to me...(D.40) When I told

my husband he was not willing to accept it...(D.40). but my problem

is that when I told him about taking medication he says he is

fine...(L.32) my boyfriend refused to do blood test and we broke up

and now he has another girlfriend.. (J.30). My boyfriend was made

aware of the situation although he accepted the news but he has

never done anything to find out about his status. (A.29). Although

he knows that I am sick he is still enjoying himself and does not care

what could happen to him.. F.32)

4.2.4. Stigmatisation and victimisation

A number of participants expressed their concern about the need to live without fear and a wish not to be labelled or blamed for having been infected with HIV. There was a feeling amongst participants that other people regard women who are living with HIV as irresponsible people who spread HIV to innocent people. They felt that due to the stigma attached to their condition most people were unable to sympathise with them.

They always point fingers to other people.... like someone

avoiding contact with you assuming that you are no longer healthy

and that because you are a women they will think that you are the

one carrying the virus and spreading it to other people... we are

blamed for that...(E.36). my friend told her family about her HIV

positive status, her family then told us that they don't want anything

to do with her.. (B.31)

4.2.5. Discrimination

Few participants raised their concerns regarding unequal treatment they have received following an after HIV positive diagnosis. Besides family care and support, some participants expressed their need for love and acceptance by their community. They expected other people, including friends to be supportive and not to discriminate against them.

.. They must stop discriminating against us because most of them

they don't know their status. (A.29)...Socially, if they can give us love

so that we feel accepted, this is the only support we need and this

support must come from family and friends. (C.32).. other people

need to treat us well and that we are also human beings.... we

would like them to take care of us and love us, they mustn't hate us

or be scared of using cups that we use...they must know that we are the

same.. (L.32)

4.2.6. Risking unsafe sex

Some women viewed male's reluctance to use a condom as a huge risk for re-infection with HIV. They felt that women's chances of having safe sex are also limited by women's powerlessness in negotiating and/or initiating safer sex.

.. First of all, men do not want to use condoms.... while we hoped

that we have received female condoms, the problem is that they are

very painful when using them...(E.36). my boyfriend sometimes

seems not interested to use condoms; it's difficult, there is no more

feelings for sexual intercourse. (L.32)

This fear regarding re-infection appears to be the motive behind one women's decision to avoid having intimate relationships following an HIV position diagnosis.

.. what I know is that if you end up having a relationship there

will be some carelessness, secondly, if a woman is having sexual

Intercourse there is a great chance for woman to be re-infected.

I don't think is good to get married while you are HIV positive because

one day partner can forget to apply protective measures...(C.32)

4.2.7. Concerns about childrens' care needs

Many participants who have children under their care raised their concerns about financial support for their children during the time when they are sick or when they have passed away. They feared that no one will attend

to their children's school needs and they tended to worry more about children's future than their own.

I think women are affected with regard to their children. you

see it's difficult if you have children while not working and sick (H.34)

there is worry about what will happen to your children when you

get sick. (H.34) My problem is that I am looking after my siblings

after my mother has left us. I had bad feeling that if I die they will

remain destitute no one will support them.. (J.30)...most of the time

we suffer because if you got one or two children going to school may

be the father is not available to provide support. it becomes difficult.

I don't know whether there is any financial support because all

children need to attend school.... so it seems like there is no enough

care...(F.32)...may be I will say that, since I am breadwinner should I

die soon it will be the end of everything. (L.32)

According to one participant, provision should be made for children's care needs even when the mother is still alive and healthy. Furthermore, there should be follow-up in order to maintain effective service for those children in need of support.

As far as I am concerned, I think they must see to it that children

for the one infected with HIV are able to attend school even if

the mother is still alive, they must make follow ups not to wait until

person passed away. (H.34)

4.2.8. Needs for special treatment

Only one participant voiced concerns regarding reduced energy levels that are associated with an HIV positive diagnosis. She believes that an HIV positive person should not be given mentally and physically challenging work to do.

...life is not precious after learning that you are HIV positive, even

if you are working ...its better if your workload is reduced...(C.32)

Another participant expressed her concern about the lack of job opportunities, which makes it very difficult as it has huge financial implications for the women who have been diagnosed as HIV positive. She would prefer that HIV positive women be given special preference when it comes to job opportunities because their HIV positive status places them in huge financial disadvantage.

...Women are not working, it can be better if job opportunities can

be created for them, some have better qualifications but because

there are many people looking for jobs they end up unemployed.

I just think that those who are HIV positive should get special

treatment. (H.34)

4.2.9. Needs for financial support

Some participants reported financial difficulties that have negative implications for treatment as they cannot afford to have money to buy medicine. They regard lack of money as a serious problem facing HIV positive women because they can have limited access to proper food and medication.

I can say we as women in particular have special needs, finance is one of the biggest issue. Because if you want to buy something that will help boost your immune system but one can not afford it due to financial difficulties.... (G.31) Sometimes you can hear about certain herbs that help to improve your condition but you cannot afford them if you don't have money. (E.36) Things are not going well and I can be happy if we can get support. My child is doing grade six.... she might not finish schooling although she wishes because I am sick and I don't have any means. (D.40) I have made an application for disability grant and I don't know whether I will receive it. If the health care system can help us with grants we can appreciate a lot.. (F.32) Government support too plays a role in terms of financial support.. (A.29)

Some participants expressed the need for a financial support grant that will enable them to meet their children's health and school needs. They felt that women are the most affected people in the family because they are expected to provide care for the family as well as themselves.

I think the Department of Health should provide more especially

a grant because women are the most affected ones within the family.

(E.36) If they can have something to help especially as women we

look after children, so if you are sick you end up not knowing what

to do, but if you receive a grant it could be better...(C.32) If there

could be financial assistance to help children who attend

school...(F.32)

4.2.10. Concerns regarding disclosure

One participant voiced her concerns about disclosing her HIV positive status to family members because she feared possible rejection and isolation.

I had never disclosed my HIVpositive nd I don't see whether I will

ever do that. I feel that should I tell my family would hate me, spread

rumours about me and reject me. I am very scared that they can

isolate me and I can have end up having my own eating utensils

My friend told her family about her HIV positive status as a result her

family told us that they don't want anything to do with her. (B.31)

According to some participants, disclosing HIV positive status to non-family members is of great concern because it can result in HIV infected women being singled out. While they realised the need to disclose their HIV status beyond family structures, many women are faced with

unresolved trust issues, which makes disclosure to a non-family member a difficult task.

. it is very important to disclose, although some people are scared that they will be singled out. I think it is a problem to tell someone who is not your relative, may be that person will spread rumours in public, usually this is an issue. (H.34).. My friends and other people I didn't tell them because they will reject me.... For me I cannot tell a person who is not close to me, I can only tell a person close to me (G.31)...I don't see a need to tell all people because other people only know that they must avoid coming closer to a person who is HIV positive...(K.34)

While most women realise the importance of disclosing one's HIV positive status, according to a participant, fear of victimisation can make the task very difficult.

..as far as I am concerned, I believe it is very important to disclose but under the circumstances we are living under, one can put her life in danger, may be a person is not your relative and she/he will regard you as a bad person.... we are very scared to talk about our status because people can kill you like the lady in Durban.. (A.29)

Disclosing one's HIV positive status to one's partner has been regarded by only one participant as a stressful experience. The dominant feeling is that of being scared of rejection.

...Women are facing lots of problems like that you might feel like

telling your partner but you are scared that he will reject you.. (L.22)

There were also concerns about disclosure to the public because according to a certain participant, there is no material benefit gained after she has disclosed her HIV positive status to other people.

...I don't see how disclosing HIV positive status helps, it doesn't help.

If one follows treatment procedures and continues with life because

everybody will die one day, this is what I believe.... I don't see anything

that one can gain after disclosing her HIV positive status. (K.34).... so

it has never come into my mind to disclose my status in public unless if

they say. I will gain something, like I will be safe and not experience

problems, no one will attack you, no one will come to ask you many

questions. (F.32).

One participant felt that disclosing her HIV status to the public would damage the family's reputation and thus, compromise the integrity of the family as a system.

.... I grew up in Pietermaritzburg, so there are so many people who

know me, I can destroy my family reputation, no I am scared, I

don't have guts may be one day I will have a courage. (F.32)

Some participants view disclosure as having a negative effect on the family because, it might cause emotional distress to significant others including children. The main concern about revealing HIV positive status to children is that they might be incapable of dealing with the trauma associated with learning that their mothers are HIV positive.

...first of all I decided not to tell my child because her mind is

already traumatised because of a stepfather. If I tell her about my

status she will be severely traumatised...(D.40) It is not because I

don't trust others, it is just that other people at home are still young,

at the moment I don't think it can be a good idea to let them know

because the way they like me this can destroy them. (I.22)

4.3. The nature and various sources of care and support

Following an HIV positive diagnosis, many women in this study describe being faced with range of needs for care and support. The following section outlines different kinds of support women received as well the quality of such care and support as perceived by women in the study.

4.3.1. Family support

Most women attempted to obtain support from their immediate family members in order to help them cope with stress of receiving the news that they were HIV positive. In most instances, their choice of a person to whom they decided to disclose their HIV positive status seems to have been influenced by the need for care and support during the time of emotional distress.

> *I suppose to tell someone so that I will get support, because by that time I was very ill, so I was supposed to get someone who will take care of me. I told myself that may be I will get help should I tell them. (F.32) The first thing that come to my mind was that I had to tell the whole family because if I hide it from them there will be time when I am sick.. (G.31). They will provide me with support so that they will look after me (C.32). I told my family about my life and the situation I have found myself under. (A.29).. I spoke to my younger sister and she comforted me...(D.40)*

Many participants chose a mother figure as the first person to disclose their HIV status to.

> *I just accepted it and realised that the person to tell is my mother, because the person I had a relationship with has already passed away. (F.32) I was going to tell my mother no matter what, I am her only child. I thought I will need her support because there will*

be a time where I would not be able to do anything. I thought that

it would be better that she (mother) knows that there will be no many

questions.... like why now are you buying lots of immune booster..

.there will be some question therefore I was avoiding such questions

I told my mother...(I.22) I called my mother and told her...(J.30)

In addition, many women regarded a person of the same sex as the best source for emotional support. Participants felt that other women would provide them with an opportunity to share their feelings with ease.

I spoke to my younger sister .I called my younger sister, she is

now 17 years old, then I wrote her a letter and gave it to her, we

get used to it...she said I must tell my mother, I called my mother

and told her. (J.30) After that I phoned my sister who is in

Johannesburg she asked me what are the news, I told her that they

said I am HIV positive. She said don't worry maybe next time they

will say you are HIV negative don't loose hope. (L.32). The only person

who knows is my sister and I will say she is trying. and she has

sympathy. (D.40)

A number of women in the study reported that they received good quality care and support from immediate family members.

I think the support I get from my family is sufficient enough

because there are the people I am so close to. If I have a problem,

there is the one I used to speak to....(F.32). I told my family about the

situation I was in and they don't hate me.. (A.29). I have told all

of them and they supported me more especially my parents and my

brothers.. (G.31) Within the family, only mother who knows, but the

manner she treats me, I can say she do cares for me and that she no

longer have more questions...(I.22).. It was encouragement and

advice, being told that I will survive ...it is just encouragement that

we mustn't put our minds on it...(G.31) The only thing (my mother)

she told me was that we must put trust on God may be I will survive

because I was determined to live, so I put my trust to God. (F.32) My

mother when she got pension money she used to buy me pills. (F, 32).

My parents supported me very well even with prayers and

advises...(G, 31)

However, some women regarded family support they received as being insufficient.

...but within my family I don't get any support, even now I am alone

all family members are not available. even now I have problems if

anything can happen to me I used to think about who is going to help

me, even when I lie down who is going to help me except people from

the community (E.36). There is no support because we are kind of

people who have lost their family members...(D.40) there is no care

and support from family members, partner and friends...(B.31)

4.3.2. Sexual partner

Only one participant reported to have gained financial and emotional support from her sexual partner.

> *My partner was taking good care of me even sending me to the*
> *doctor. (L.32)*

Another participant appeared to be emotionally disturbed because of a lack of financial support from her husband and because she feared that he did love her anymore.

> *My husband does not support me either with money or care when*
> *I am sick. Although he has a well paid job, but he doesn't care about*
> *us.... I don't have support I am traumatised because the one who*
> *brought this illness to me don't have love; even now I am back*
> *home trying to make a living. (D.40)*

4.3.3. Friends

Some participants were able to receive care and support from their friends. This included emotional and financial support as well as physical care.

> *My friends use to nurse me when I am weak. I will say many*
> *friends have helped me. (C.32) I got friends who are social workers*
> *who if they is anything worrying me emotionally, I use to speak to*

them...(I.22) The guy who was proposing love to me we ended up

being close friends and he comforted me and was very supportive to

me. (J.30

4.3.4. Support from church members

Only one participant reported receiving support from church members. She felt that they managed to help her to regain a sense of hope and spirituality.

.. church members used to give me money and they send me to

special clinics to get help and support, they also instil hope in me.

They love me, they visit me and I visit them so they are so close to

me. Spiritually, they make me stronger and stronger. (C.32)

4.3.5. Support groups

One of the participants in the study had access to a support group.

She found the support group beneficial in that it helped to improve her self-esteem.

In the support group you get new family, you get new plans and

being able to sit together. (C.32)

4.3.6. Health care services

Generally, the majority of women reported that they received more care and support at the hospital or clinic than from family members. Many participants regarded the care received from the Department of Health through the clinic CDC as very effective. This care and support mostly consisted of treatment and counselling.

I receive care through medication that we receive here at the CDC. (A.29) I got helped from the Clinic.. (E.36) I can say may be coming here at the CDC for treatment is the only care I got. I got helped at the CDC and they explained to me...(B.31) I used to come here at the CDC.. (L.32)

Many participants regarded the care received from the Department of Health through the clinic CDC as very effective. This involves counselling and medical treatment that has helped patients to regain physical fitness...

It is great, very great, and the Department of Health is worse because after HIV positive diagnosis I lost weight, soon after getting treatment here at the CDC.... I gained weight, began eating, started walking because I was confined in the house because before I was always lying in the bed only wake up when going to the toilet. Really, I got a lot of support from health care system. (F.32). ...at the department of health, I have received great care.. I think for me to

recover I was helped at the CDC because I used to be sick before.

(E.36). attending CDC helped me to survive.. they gave me

counselling. (A.29). I got helped from the CDC as they explained

everythingthat helped me to accept my HIV positive status. (B.31)

Few participants felt that the care and support from the health care system was inadequate and that it failed to meet their expectations.

... I have been coming here at the CDC but have not yet received

any help except that I saw the doctor who told me that my CD-4

count was still high, which means my antibodies are still active,

at the end I don't get anything and they used to say if anytime I feel

sick I can go to the clinic or at the hospital. (H.34) Since I learned

about my HIV positive status, I had never received any care and

treatment, even now I am not receiving any treatment, he (doctor)

said they won't be able to give me medication because I am still alright.

(J.32) I had never received care and support until I went back

home...(L.34)

Most participants expressed their concerns regarding the lack of proper care for those living with HIV/AIDS. While the health care system has offered counselling and medication they believe that this is not enough to help them fight the illness. Their main concern is the lack of food, which makes it difficult to take medication while they are hungry.

...many people are dying because they don't get proper care and

support. They suppose to eat healthy food so that they will take

medication, no one can be able to take medication while she is

hungry.... (C.32) like we have different home background, we get

hungry and it is said that you mustn't take pills before you eat but

you find that you don't have even porridge to eat...(D.40). I think

need for food is a priority.

Some participants complain about unavailability of medication and treatment that would help to boost their immune system.

If Government can provide those drugs in the hospitals that

boosts immune system. because we cannot guarantee to be able

to eat healthy food every day. The immune booster is so helpful

because it provides minerals and other vitamin supplements. If they

can help us by providing medication that will give us energy...(C.32)

One participant expressed the need for home based care that will help those who are sick due to AIDS. She felt that this could be achieved by training home base care providers, and there should be incentives involved that will encourage them to perform at their best.

... The health care system has a lot of things to do.... like those

in the symptomatic stage, they are being refused admission to the

hospitals and they are being sent back home where there is no

sufficient care. Those who volunteer to help need to given salary so

that they will be motivated to provide home-based care because

those people at home need care and support. (C.32)

According to one participant, women need special medical treatment because they are vulnerable to a variety of sicknesses including sexually transmitted diseases that are normally not diagnosed in time. This can affect women even if they use condoms, so there is a need for thorough examination and treatment of women.

The most problem facing women is that they sometimes have number

of sicknesses of which even attending clinic here or referred

somewhere may not get help. may be only if the department of

health can make sure that those living with a virus get care and

treatment on time, because sometimes it can happen that one get

sexually transmitted disease and if not treated they will be a

possibility of re-infection...(I.22)

Chapter five

5. Discussion

5.1. Introduction

This section will examine the findings of this study in relation to previous research findings. Further, it aims to determine the extent to which the study has managed or failed to address its research questions. This study initially had the following questions:

- What psychosocial needs and concerns emerge for HIV positive women that arise as the result of HIV positive diagnosis through to the terminal stages of the disease process.

- What is the nature and various sources of care and support that women need in learning how to live with an HIV positive diagnosis.

- What do women need from HIV /AIDS healthcare and social service providers.

5.2. Psychosocial needs and concerns that emerged as a result of an HIV positive diagnosis

It appears from this study that poor and disadvantaged HIV positive women still face a range of unresolved psychosocial consequences following an HIV positive diagnosis. Some of the psychosocial impacts of an HIV positive diagnosis for women include, disruption of family relations, disrupted intimate relationships, negative reactions from sexual partners, stigmatisation and discrimination, concerns about disclosure, about risking unsafe sex as well as concerns about their children's care needs. These findings are in line with the findings by Roux et al (2001) which indicated that, HIV positive infection has more effect on the psychosocial well being of the person in the form of stigma, rejection, isolation and family disintegration.

5.2.1. Disrupted family relations

The findings of this study show that some women face rejection from their family members when their HIV status is revealed. These women felt neglected, blamed for being infected, and no longer part of the family system. These findings coincide with the results of the study conducted by Van Dyk & Van Dyk (2003) whereby, most women in their South African study faced rejection, neglect and even feelings of being disowned by family members as a result of an HIV positive diagnosis. This is an

indication that for some HIV positive women, their HIV positive diagnosis had a negative impact on the quality of family relations.

5.2.2. Disrupted intimate relationships

The findings also indicated that HIV positive women experience a break up in intimate relationships when their HIV status was disclosed to partners. Some women in the study reported that their sexual partners left them as soon as they told them about their HIV positive diagnosis. They felt rejected while at the same time they reported having no energy to contest the break up as they were still coping with their HIV positive diagnosis. As suggested by Seidel & Coleman (1999), those women who disclosed their status to their partners risk facing rejection and homelessness. This scenario is exacerbated by women's lack of power and economic dependency.

The study has also revealed that some women decided to end their intimate relationships as a way of dealing with traumatic experience of discovering their HIV status. As a way of coping with being HIV positive, many women eventually decided to abstain from relationships in the future. These feelings tended to be persistent even when the person has overcome their initial state of shock following their diagnosis. This is a kind avoidant coping style whereby women withdraw from social contact as a result of an HIV positive diagnosis (Kelley & Lawrence, 1998). In the

South African context, it appears that avoidance coping style is a popular strategy used by a number of people living with HIV/AIDS, and has been perceived by those living with HIV to be effective (Stein, 1996). This kind of coping strategy according to Stein (1996) is not equivalent to denial because HIV infected individuals that use an avoidant coping style are consciously aware about the nature and severity of their illness, but make a decision not to talk or worry about their HIV positive status.

5.2.3. Victimisation and stigmatisation

Some women in the study expressed their fears of being killed or assaulted if they disclose. They reported no actual incidence whereby they experienced harm after they had disclosed their HIV positive status. What this finding illustrates is that perceived stigmatisation rather than actual experience of being targeted may have an equally devastating effect on HIV positive women (Fitzsimons et al, 1995). Further, it seems that fear of adverse events may also influence whether or not women access care and support services, which in most instances would require disclosure of status. As supported by Van Morrison & Mclachlan (1998), stigmatisation has specific implications for women with regard to accessing treatment services. This finding is supported by the results of this study.

5.2.4. Discrimination

Some participants reported their experience of unequal treatment from family members and the health care system because of being HIV positive. They have suffered discrimination as a result they isolate themselves from those whom used to be close to them. Kelley & Lawrence (1988) support these findings and explain that discrimination by others usually heightens distress and leaves the HIV positive person feeling vulnerable and isolated from the very same person who had previously been a source of support.

5.2.5. Risking unsafe sex

The findings of this study suggest that women still lack the power to protect themselves and others from HIV infection and even possible re-infection. Women in this study felt that their chances of having safe sex were restricted because they had limited powers to initiate and negotiate safe sex. Therefore, they unwillingly ended their sexual relationships as a way of protecting themselves. This is supported by Wilkinson & Kitzinger's (1994) study which shows that, women's lack of power also result in constraints on the practice of safe sex and that they have limited control within the sexual situation.

5.2.6. Concerns regarding children's care needs

The findings of this study suggest that women are most concerned about their children. As a result of HIV positive diagnosis, they tend to worry

about their children's care needs rather than their own health. According to Walker & Gilbert (2002), HIV positive women find themselves carrying the burden of the disease, yet they are expected to take care for their children. At the same time they become emotionally disturbed as they contemplate about the future of their children should they get ill or pass away. Women tend to suppress their own physical needs and then feel guilty about expressing such needs. As suggested by Dowling (1994), HIV positive women's social position encourage them to care for others and safeguard their health even when they are ill. These findings are supported by Lewis (1988) who suggested that, the immediate psychosocial concerns particularly as the disease progresses is the mother's increased fear about leaving their children motherless when they die.

5.2.7. Lack of job opportunities

The results of this study reveal that HIV positive women are still faced with unemployment, which makes the process of coping with an HIV positive diagnosis very stressful. Most HIV positive women are still faced with unemployment, which contribute to their low socio-economic style of living. The fact that 95 percent of women who participated in the study are not working, is a clear indication that HIV positive women are part of the increased number of unemployed people living in the country. Adding to that is an increased demand for social grant, which is an indication that women are faced with huge complicating economic challenges in the face

of living with HIV/AIDS. This corresponds with the findings by Laird (2001) whereby, the majority of women have no jobs as thus they still rely on their sexual partners for financial support.

5.2.8. Need for financial support

The majority of women in this study have expressed the need for financial support. They are still faced by unresolved financial difficulties, which limit their treatment options. They cannot afford to buy proper medicines and other food supplements that will help to boost their immune systems. The majority of women who participated in this study are receiving monthly incomes of up to a maximum of 700 rand. This is not enough to meet their daily expenses including food and clothing. Therefore, poverty appears to be an obstacle in accessing adequate resources for women living with HIV/AIDS (Gerntholtz & Richter, 2002). As suggested by Anderson (2000), the majority of black women living with HIV are living in poverty and most of these women spend their energies on meeting the basic needs for themselves and their families and as a result their deteriorating health is of secondary importance. This is further indication of the extent to which HIV takes the path of least resistance (Lindegger & Wood, 1995) and the extent to which poverty and unemployment in many African contexts, increase the vulnerability and ability of many women to "live positively" with infection.

5.2.9. Concerns regarding disclosure

The findings of this study indicate that an HIV positive diagnosis evokes fears regarding disclosure of HIV status to significant others. Some participants in the study decided not to disclose their HIV status because of the fear of possible rejection and isolation. This seems to occur in situations where there has been family conflict prior to an HIV positive diagnosis. Sexual partners rejected some participants after they had informed them of an HIV positive diagnosis. At the same time one participant had not yet disclosed her HIV status to her new boyfriend because of the fear of being rejected.

This is in accordance with the findings by Kelley and Lawrence (1988) which shows that the majority of women who were in steady relationships hesitated to inform their partners fearing they would precipitate a break-up in the relationships. The fear of abuse and neglect has been seen by Maman et al, (2001) as a barrier towards disclosure of HIV status to both family members and sexual partner.

According to previous research findings, disclosing an HIV positive status is not a simple process but a traumatising experience that involves a number of decisions regarding when to disclose, to whom, how to disclose and under what circumstances to disclose (Roux et al, 2001). According to the findings of this study, the majority of women have made decisions to

disclose their status to their intermediate family members because they anticipated care and support from them to help them so that they would deal with the effects of an HIV positive diagnosis.

For many women, their mother is considered a reliable and immediate source of care and support since she is the first person to whom the majority of women in this study decided to reveal their HIV status to. Participants regarded their mothers as source of emotional support and the person with whom they are able to share their feelings. Previous findings also suggested that, disclosing an HIV positive status to family members is more likely because empathy, trust and acceptance are guaranteed (Maman et al, 2001; Roux et al, 2001; Bor & Elford, 1998).

The decision to disclose one's HIV status to non-family members appears to be very difficult because it involves trust issues. The lack of trust intensifies fear of victimisation and discrimination because HIV positive women are not sure what to expect from family members after they have disclosed their HIV status to them. While most women in this study realised the importance of disclosing their HIV status beyond family structures, fear of victimisation make this task very difficult. This is in line with a study conducted in Johannesburg by Stein (1996) where she found that, people who chose to disclose their HIV positive status to other people

found themselves faced with discrimination and disruption in interpersonal relationships.

Disclosing one's HIV status to non-family members can also be made difficult when they are no perceived personal gains. Participants in the study saw no need to disclose their HIV status to persons from whom they have never anticipated receiving any care and support. Similar findings by Holt et al (1998) suggest that, disclosure of ones HIV status appeared to be possible when it is associated with high levels of perceived social support. This implies that HIV positive women are more likely to disclose their HIV status in circumstances where there are perceived personal benefits which might include social support and economic gains.

There are other psychosocial concerns regarding disclosure that women more than men have to deal with. The findings of this study revealed that women choose not to disclose their HIV status to their children for fear that their children might be emotional disturbed after hearing the news. They believe that they have the responsibility of protecting their children from being emotionally disturbed. As suggest by Seligson & Peterson (1992), HIV positive women's concerns about love of their children can hamper disclosure.

5.3. Different kinds of support available for women in reaction to HIV positive diagnosis

The findings of this study suggest that disadvantaged women living with HIV/AIDS in the Pietermaritzburg area have not been exposed to a wide range of social support and care. The majority of women have been attending CDC, which is the most available source of psychosocial support, and care in the Pietermaritzburg area.

Most of them reported receiving only medication and post-test counselling at the CDC. According to Adler & Qulo (1999), the majority of HIV positive women in South Africa are from poor socio-economic background, therefore psychosocial support and care needs remains a major issue.

They were few women in the sample who have received care and support from family and friends. This includes emotional and financial support as well as physical care. Those who did not disclose their HIV positive status had had trouble in accessing care and support from their family members. Some women in the study had never received any care and support from their sexual partners.

5.4. The quality of care and support received.

The nature of care and support available for HIV positive women who participated in the study can be two fold. Firstly, there are those who regard care and support received as very effective, while others regard care and support they received as inappropriate. Those who attended the CDC reported its effectiveness with regard to medication and counselling. The clinic has helped to improve their quality of life and has offered practical support that their families have failed to provide. They have received medication free of charge. This has helped them to boost their CD 4 count. It is through the help from CDC in the form of post-test counselling that many HIV positive women recovered from the psychological effects of receiving an HIV positive diagnosis. The environment itself has allowed HIV positive women to share their experiences.

Those who have access to family care regarded their families as the basis of proper care and support. This is supported by Turk & Kerns (1985) who mentioned that the family is the basic source of physical, economic and social support and plays an important role in taking care of the family members infected with HIV/AIDS. The family support has been affordable because of its availability in times of need.

There are those who reported a lack of effective care and support in order to deal with the effects of an HIV positive diagnosis. Although the CDC is providing medication to those who are sick, others felt sidelined because they are not yet sick and they expected more help than medication. In this case the CDC services only benefited those who were at the advanced stage of HIV infection. Some HIV positive women in this study expected financial support from the health care services but their improved physical condition has disqualified them from receiving a disability grant. For these women there is not enough help. Those who received medication at the CDC also expected the health care services to provide them with food so that they are able to take medication. As suggested by Anderson (2000), high quality of care for women living with HIV is not best given by addressing medical needs only, but also her social needs, her relationships and her community at large.

5.5. Conclusion

The overall objective of this study was to explore the psychosocial needs and concerns of HIV positive women following an HIV positive diagnosis. The findings of this study reveals that HIV positive women are still faced with a range of psychosocial needs due to their socio-economic position. Their main psychosocial concern is that of being unable to take care of others particularly their children. These women tend to worry not about their health but their inability to take care of others. They are more

affected in terms of interpersonal relationships because of rejection by their sexual partners and those close to them. Some HIV positive women have developed negative feelings for intimate relationships, thus resulting in social isolation. This study has also revealed that women still enjoy limited psychosocial support and care from their families.

Chapter six

6. Evaluation and recommendation

An attempt has been made in this study to obtain women's accounts of the psychosocial needs they face following an HIV positive diagnosis. This has been achieved by allowing HIV positive women to express their concerns in their own words. In this case, language has become a distinctive source of information to reveal innermost thoughts and to assist women to express their personal experiences of an HIV positive diagnosis (Reis & Judd, 2000). This study has managed to contribute in a small way towards a better understanding of the psychosocial issues faced by women following an HIV positive and throughout the disease process.

This research study may have contributed towards an improved understanding of the nature and role health care services in meeting the psychosocial needs and concerns for women living with HIV/AIDS. The result of this research revealed that most HIV positive women received counselling at the CDC which has helped them among other things, to disclose their HIV positive status. CDC services have been regarded by most HIV positive women as the treatment of choice. This may have been a potential bias and limitation of the study as the sample was drawn

exclusively from CDC. It is possible then, that women using this service would have a positive view of the service.

While this study can be regarded as having achieved its goal, there are certain limitations due to the nature and size of the sample. First of all, the findings of this study do not allow for generalisation to all women in the Pietermaritzburg area. The sample has been limited to HIV positive women who attended a particular clinic in Pietermarizburg. As a result, not all psychosocial needs and concerns faced by HIV positive women can be established by using such a limited sample. The fact that health care service providers and family members who provide care and support for HIV positive women have been excluded in the study might have been a missed perspective in this study. Both these groups, health care workers and family members, may have offered an additional view on these and concerns of women living with HIV and AIDS.

The findings of this study have direct implications for future studies in the area that deals with the psychosocial impact of HIV positive diagnosis on women. There is still a need for a research that will focus on the psychosocial needs and concerns of HIV positive women as perceived by health care service providers and families who provide care and support to women living with HIV/AIDS. The reason being that health care service providers have vast experience in providing care and support to the

majority of women who attend the CDC clinic. At the same time, they are familiar with the psychosocial needs and concerns faced by HIV positive women whom they meet on daily basis. The research methods should move beyond in-depth interviews and could include case studies and focus groups, as this may yield data of sufficient depth that could increase understanding of the range of psychosocial needs faced by women living with HIV.

The result of this study also seems to have direct implications to those involved in policymaking regarding the development of care and support interventions for HIV positive women. Women still fear and face discrimination due to their HIV positive status within their families and the community. These women need protection from the law in the case they get evicted in their homes. Further, policy makers should ensure that HIV positive women are supported financially by their partners as well their families. This can be done through law enforcement against male partners who run way from their responsibility of looking after their partners.

The findings of this study also have direct implications regarding the role of health care providers and family members towards care and support of HIV positive women. Health care service providers need to extend their services beyond provision of medication but to provide ongoing support

through home visits. Further, provision of food supplies on a regular basis can help those women living in poverty so that they will have something to eat before they take medication. Counselling and education programmes for HIV positive women should focus on life skills, assertiveness and negotiation skills that would empower women and improve their self-esteem. Counselling should involve education about risk behaviours leading to r e-infection. HIV positive women should be provided with information concerning the role of support groups. Those involved in HIV/AIDS counselling can play an important role in facilitating support groups within the communities where most HIV positive women live. However, interventions that focus solely on women and that ignore men and the broader societal conditions that perpetuate the above-mentioned conditions are likely to have limited success. Policy and programme personnel dealing with women should also consider how they could target men in their attempts to improve the condition and circumstances of women living with HIV and AIDS.

7. References

Adar, J. & Stevens, M. (2000). *Women's Health-South African health Review.* [On line]. Available: http//. www SAHR @ hst.org.za.

Adler, G. & Qulo, O. (1999*). HIV/AIDS and STDs*: South African Review: The AIDS Foundation of South Africa.

Anderson, J. (2000). *A guide to the Clinical Care of Women with HIV.* USA. HIV/AIDS Bureau.

Andries, L.J., & Novick, L.B. (1995). *HIV Care A comprehensive handbook for providers*. USA: SAGE.

Awusabo-Asare, K., & Anarfi, J.K. (1999). *Routes to HIV transmission and intervention:* Analytical framework: University of Ghana, Legos and Accra.

Aronstein, D.M., & Thompson, B.J. (1998). *HIV and Social Work. A Practioner's guide.* New York: Haworth Press.Inc.

Baylies, C. & Bujra, J. (2000). *AIDS, Sexuality and Gender in Africa:* Collective strategie and struggles in Tanzania and Zambia. London: Routlegde.

Bor, R. & Elford, J. (1998). *The family and HIV today*: Recent research and Practice. London: Cassel Publishers.

Campbell, C. (2003). *Letting them die:* How HIV/AIDS programmes often fail. South African. Library of Congress Cataloguing.

Cohen, S., Underwood, L.G. & Gottlieb, B.H. (2000). *Social support measurement and Intervention*: A guide for health and social scientists. USA: SAGE.

Crystal, S, (1996). In Kalichman, S.C., Sikkema, K.J.& Somlal, A. *People living with HIV infection who attend and do not attend support groups*: a pilot study of needs, Characteristics and experiences. Aids Care (8) 5, 597

Da Costa, P.C. & Donald, F. (2000). *The experience of a person-role conflict in doctors expected to terminate pregnancies in the South African Public Sector*. SouthAfrican Journal of Psychology. (33), 1.10-18

Denzin, N.K., & Lincoln, Y.S. (2000). *Handbook of Qualitative research*. (Second. ed.) USA. SAGE Publications Inc.

Dorn, N. Henderson, S., & South, N. (1992). *AIDS Women, Drugs and social care*. London: Falmer.

Doyal, L., Naidoo, J. & Wilton, T. (1994). *AIDS. Setting a feminist agenda*. London: Taylor & Francis Publishers.

Dowing, S. (1994) *Women have feelings too: The Mental Health Needs of Women Living with HIV Infection*. In Doyal, L., Naidoo, J., & Wilton, T. AIDS Setting a feminist agenda. (113-119) London: Talor & Francis Publishers.

Duplessis, P., Bor, R., Slack, D., Swash, E., Colbelt, D. (1995). *Assessment of HIV Counselling and Social Care services in a London Hospital*. British Journal of guidance and counselling, 25. 45-51

Duwirkin, S.H., & Pincu.L. (1993). *Counselling in the Era of AIDS.*

Journal of Counselling & Development. Vol. 71. 17-24

Elias, C.J. & Heise, C. (1993). *The Development of Microbicides*: A new

method of HIV prevention for women. New York: Population

Council.

Evian, C.R. (2000). *Primary AIDS Care* .a practical guide for primary

health care personnel in the clinical and supportive care of people

with HIV/AIDS. Johannesburg: Jacana education.

Farham, B. (2002). *What the numbers say.* Perspective. (2), 17-18

Flick,U. (1998). *An Introduction to Qualitative Research.* London: Sage

Publishers.

Florenza, M. (2002). *Womens'Account for half of HIV cases for the first*

Time. [On line]. Available: http://www. Health link.org.za.

Foster, P. (1995). *Women and the Health care industry: "an unhealthy*

relationship?" Great Britain.

Fitzsimons, D. Hardy. V. & Tolley. K. (1995). *The economic and social impact of AIDS in Europe.* London: Cassell productions.

Gerntholtz, L, & Richter, M. (2002). *Young women's access to reproductive health-care services in the context of HIV.* Agenda (52).

Gillham, B. (2000). *The research Interview.* New York: British Library Cataloguing-in-Publishing Data.

Giese, S., Mentjies,H., Croke,R., Chamberlain,R.(2003). *Recommendation for health social services for opharns and other vulnerable children in the context of HIV/AIDS in South Africa.* University of Cape Town: Children's institute.

Glesne, C. (1999). *Becoming Qualitative Researchers:* an introduction. USA: Addison Wesley Longman.

Gupta, G R, (2001). *Gender, Sexuality, and HIV/AIDS: The, The Why, and the How.* Washington DC: British Cataloguing. Inc.

Grinstead, O.A., Gregorich, S.E., Hee-Choi, K., & Coates, T. (2001).

Positive and negative life events after counselling and testing: the Voluntary HIV-1 Counselling and Testing Efficacy Study. AIDS Journal, (15), 1045-1052

Greenbaum, T.L., (2000). Moderating focus group: Apractivcal guide for fascilitation. London: SAGE publication.

Hatch, J.A. & Wisniewski, R. (1995). *Life History and Narratives*. London: The Falmer Press.

Holstein, J.A., & Gubrium, J.F. (1995). *The active interview*. USA: Sage Publications.

Holt, R., Court, P., Vedhara, K., Nott, K.H., Holmes, J, & Snow, M.H. (1998). *The role of disclosure in coping with HIV infection*. AIDS Care Journal, 10(1) 49-60

Kalichman, S.C., Sikkema, K.J. & Somlal, A. (1996). *People living with HIV infection who attend and do not attend support groups*: a pilot study of needs, characteristics and experiences. AIDS Care (8) 5, 589-599

Kelly, J.K. & St. Lawrence.J.S. (1988). *The AIDSHealth care crisis*.

Psychological and social interventions. New York: SAGE

Laird, S. (2001). *AIDS and Gender*: The African reality. Social work. 37(3). 260-267

Leeson, J. & Gray, J. (1978). *Women and Medicine*. London: Tavistock.

Lewis, A. (1988). *Nursing Care of the person with AIDS/ARC*. New York: Aspen.

Lindegger, G., & Wood, G. (1995). *The AIDS crisis: review of psychological issues and implications, with special reference to South Africa*. South African journal of psychology. 25,1-11.

Linn, J.G., Lewis, F.M., Cain, V.A. & Kimbough, G.A. (1993). *HIV-illness, social support, sense of coherence, and psychological wellbeing in sample of help-seeking adults*. AIDS Education and Prevention, 5, 254- 256

Maman, S. Mbwambo, J., Hogan, N.M., Kilonzo, G.P., Sweat, M. (2001) *Women's barrier to HIV-I testing and disclosure: challenges for HIV-1 voluntary counselling and testing*: AIDS CARE, 13, (5), 595-603

Maman, S. Mbwambo, J., Hogan, N.M., Kilonzo, G.P., Sweat, M., & Weiss, E. (2001). *HIV and Partner Violence*: Implications for HIV Voluntary Counselling and Testing Programs in Dar es Salaam, Tanzania. USA: Population Council Inc.

McCoy, D., Besser.m.Visser, R., & Doherty, T., (2002). *Interim Findings on the National Prevention of mother -to- Child Transmission Pilots Sites*: Lesson and Recommendations. Health Systems Trust: Durban.

Mc Namara, R. (1993). *Female Genital health and Risk of HIV Transmission*. New York: United Nations Development Programme.

Miles, M.B., & Huberman, A.M. (1994). *Qualitative data analysis*. California: Sage Publication.

Mlomo-Ndlovu, V.C. (2000). *Living with HIV & AIDS: Beyond Awareness.*University of Zululand Journal of Psychology. 16(1). 27-36

Modiba, P.Gilson.l. & Schneider .H. (2001). *Voices of Service Users.*

Centre for Health Policy: University of Witwatersrand.

Mouyis, E., Deverell, A., Mcintuyre, J., & Gray, G. (2002). *Partner reaction to HIV disclosure.* a paper delivered on the 14th International AIDS Conference, Barcelona: International AIDS Society.

Nelson Mandela HSRC study on HIV/AIDS report (5 December 2002).

Ostrow, D.G. (1990). *Behavioural Aspects of AIDS.* New York: Plenum.

Pequengnat, W., & Szapocznik, J. (2000). *Working with families in the area of HIV/AIDS.* London: Sage.

PACSA report documents conducted by the Gender and Poverty and Economic Justice Desks: November 2002: Mpumuza area. Pietermaritzburg: Unpublished article.

Reis.T.H. & Judd.C.M. (2000). *Handbook of Research Methods in Social and Personality Psychology.* USA: Cambridge University Press.

Roux, A.A., Venter, C.S. & Wessels, C.C. (2001). *A group work*

/

Programme for HIV/AIDS Patients. The social Work Practitioner-Researcher.13 (2). 33-47

Rooth, E. & Dreyer, A. (2000). *The link between Gender violence and HIV/AIDS*. Abstract from the Article on the awareness on the link between gender violence and HIV/AIDS.

Sales, B.D., & Folkman.S. (2000). *Ethics in Research with Human Participants*. USA: American Psychological Association.

Seidel, G. & Coleman, R. (1999) *Gender, Disclosure, Care and Decision Making in KwaZulu-Natal, South Africa*: A pilot Programme using Storytelling Techniques. In Aggleton, P., Hart, H. & Davies, P. Families and Communities Responding to AIDS, p.55. New York: UCL press.

Seligson, M.S. & Peterson, K.E. (1992). *AIDS prevention and treatment*: Hope, Humour and healing. New York: Turck.Inc.

Sloth-Nielsen, J. (2003). *Too little too late*. Child and Youth Care journal. 21, (5), 11-12

Stein, J. (1996). *Coping with HIV infection: First world theory and third*

world practice. African Anthropology, 3(2): 68-85, Centre for AIDS Research and Evaluation.

Shapiro, M. (2001). *HIV testing for insurance purposes: A multi-faceted exploration of the Client's experience and aspects of current practice*. Unpublished Masters thesis in Clinical Psychology. University of Natal, Pietermaritzburg.

Silverman, D. (2000). *Doing qualitative research*. A practical handbook. London: Sage Publications LTD.

Temoshok, T. & Baum. A. (1990*). Psychological Perspectives on Aids. Etiology, Prevention, and Treatment*. London: Erlbaum.

Terre Blanche, M., & Durrheim, K.D., (1999). *Research in Practice.* applied methods for social scientists. Cape Town: University of Cape Town.

Turk, D.C. & Kerns. R.D. (1985). *Health, Illness, and Families*: A life span perspective. New York: Wiley.

Ulin, P.R. (1992). *African women and AIDS*: Negotiating Behavioural Change. Soc.Sc.Ed. Journal, 34(1) 63-73

UNAIDS (WHO) Global estimates. [On line]. Available: http://www.

    Unaids.org/html/pub/media/press releases 01/uniform.

    [2002 May 24].

UNAIDS, Joint Nations Programme on HIV/AIDS. [On line].

    http: www.unaids.org/unaids/en/Resources/Publications/AIDS+

    epidemics.2003, December, 02]

Van der Vliet, V. (1993). *Promotion of HIV/AIDS Research*. AIDS

    Bulletin. 6, (3), 30-31

Van Dyk, A.C., & Van Dyk, P.J. (2003*). Psychosocial barriers to

    HIV/AIDS Voluntary counselling and testing programmes in South

    Africa*. S.A. Journal of Psychology, 33 (2)

Van Morrison.C. & Mclachlan, S. (1992). *Working with women & Aids.

    Medical, Social, Counselling issues*. London: Sage Publications. Inc.

Walker, L.& Gilbert.L. (2002). *HIV/AIDS: South African women at risk.*

    African journal of AIDS Research, (1), 75-78

Wilkinson, S. & Kitzinger, C. (1994). *Women and Health*: Feminist

perspectives. Great Britain: Palmer Press.Inc.

Wilkinson, S. & Kitzinger, C. (1994). Women and Health: Feminist

perspectives. Great Britain: Palmer Press.Inc.

Appendix. A

PROVINCE OF
KWAZULU-NATAL
HEALTH SERVICES

ISIFUNDAZWE
SEKWAZULU-NATALI
EZEMPILO

PROVINSIE
KWAZULU-NATAL
DEPARTEMENT VAN GESONDHEID

NATALIA
330 LONGMARKET STREET
PIETERMARITZBURG

TEL.   033-3952111
FAX   033-3426744

Private Bag   :X9051
Esikhwama Seposi   : Pietermaritzburg
Privaatsak   : 3200

Enquiries: Mr G.J. Tromp
Extension: 2761
Reference: 9/2/3/R

2 4 JUN 2003

Mr S.D. Mhlongo
School of Psychology
University of Natal
Private Bag X01
PIETERMARITZBURG
3209

Dear Sir

APPLICATION TO UNDERTAKE A RESEARCH STUDY

Your letter dated 09 June 2003, refers.

Please be advised that authority is granted for you to undertake a research study to explore the psychosocial needs and concerns of HIV positive women living in Pietermaritzburg, for the year 2003, provided that :-

(a)   Prior approval is obtained from the Heads of the relevant Institutions;

(b)   Confidentiality is maintained;

(c)   The Department is acknowledged; and

(d)   The Department receives a copy of the report on completion.

(e)   That the staff of the hospital are not disturbed and/or inconvenienced in their work and that patient care is not compromised.

Yours sincerely

**SUPERINTENDENT-GENERAL
HEAD : DEPARTMENT OF HEALTH**

Appendix. B

Standard Introduction

Dear Participant

One of the University of Natal's objectives is community outreach through research. To this end, I am conducting a study on the psychosocial needs and concerns facing HIV women in Pietermaritzburg as part of the requirements for the Masters degree in Clinical Psychology. This research is important as an HIV positive women tend to be faced with complex and unmet needs that need to be addressed through appropriate HIV/AIDS prevention and care interventions. We hope that this study will increase our understanding of what women like you need and what are the concerns regarding psychosocial support and care services.

To assist me in understanding needs and concerns faced by HIV positive women, I need to talk to women who are HIV positive. This research will consist of an interview, which will take approximately 1 hour

Should you wish to take part in this research, please note that participation is voluntary and appointments for interviews will be held at a time suitable for you. Furthermore, the research is anonymous and confidential. Should you feel uncormfotable in any way during the interview, please be assured that you can withdraw at any point.

I will prefer to make use of audiotapes during the interview should you agree to that. If you agree to be audio taped, you still have right to switch the audiotape off at any stage of the interview.

The result of the study will be presented in a summarized version with all identifying details including the name of the hospital and clinic concealed. The main research findings and recommendations will be made available to information centers like ATTIC for your information and feedback. The nursing sister and I will also arrange to give you verbal feedback on what we find out from the study. You will also have the benefit of additional counseling should the issues and concerns raised during the interviews prove to be unsettling.

Your contributions will assist towards a better understanding of the psychosocial needs and concerns facing HIV positive women in this country.

Many thanks for your participation

SD Mhlongo

Appendix. C

Appendix. C

Informed Consent Form for interviews (was translated into Zulu)

I, the undersigned

....

agree to participate in the research conducted by Sibusiso Mhlongo, a student doing Masters in Clinical Psychology in the School of Psychology, University of Natal, Pietermaritzburg. I am aware that the research involves interviews about the psychosocial needs and concerns of HIV positive women, like myself. I am aware of the steps that will be taken to ensure confidentiality. I am aware that the data will be used to produce written reports for publication and that these will not contain any identifying information about myself. I also understand that I can withdraw from the research at any point in the research process, should I so choose.

I acknowledge that I gave my consent willingly and without being influenced to do so by the researcher or any other person.

Signed ....

Date ....

Appendix. D

Appendix.D

Interview guide

(translated into Zulu language)

A. **Give an account of your own experience of receiving an HIV positive diagnosis**

   Possible probes

1. What feelings, issues and concerns emerged for you after receiving news that you are HIV positive

2. What sources of care and support have you received since you were diagnosed as HIV Positive

3. What type of care and support did you receive from health care workers, family members, partner or friends

4. How does this care and support correspond with you own needs

B. **Give an account of your experience of disclosure**

Possible probes

1. What are your views on disclosure

2. If you have disclosed, how did you go about doing that

3. What support systems did you need to help you reveal your HIV status

4. Could you tell me about the reaction of family and friends after they received the news that you were HIV positive·

5. How has their reaction or behavior affected you

C. From your own experience, give an account of what women need from health care and social support system

Possible probes

1. What role and/or services do you expect from the health care system

2. What care and support your family and friends have failed to provide you with

3. What care and support do you expect from them