

**BEING WOMAN
AND LIVING WITH HIV/AIDS
IN NEW ZEALAND:
A FEMINIST PERSPECTIVE**

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Abstract

HIV (human immunodeficiency virus) and AIDS (acquired immunodeficiency syndrome) was first diagnosed in the early 1980s. It was constructed in the western world as a 'male disease' affecting predominately gay men. At the same time women were identified as having HIV/AIDS. They, however, have figured very minimally in the unfolding discourse surrounding HIV/AIDS.

Nine New Zealand women took part in this study which explores and describes their experiences of being HIV positive. Participants described feeling 'invisible' within a 'male disease', and a sense of not being taken seriously. Participants felt they were influenced by the social construction of women with HIV, which defines them as 'carriers' of the virus to men and 'transmitters' to the 'innocent' unborn foetus. Women's role in society, and gender social and power inequalities have led these participants to believe that HIV/AIDS is experienced as a different disease for women than it is for men.

Nursing discourse related to HIV/AIDS in the early 1990s supported the notion that HIV/AIDS patients were people who were deviant and/or addicted. Nurses were influenced by the social and medical construction of HIV/AIDS and many have contributed toward negative attitudes with bias and prejudice and lack of understanding. This attitude in turn has contributed negatively to the quality of care given to women with HIV/AIDS.

Women's stories have yet to emerge as a significant contribution to the HIV/AIDS issue. This thesis plays a part in the beginning of that contribution.

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CHAPTER ONE: Introduction

1.1 Introduction

Nine New Zealand women discussed their experiences of living with a diagnosis of being HIV (human immunodeficiency virus) positive. This research, which tells aspects of their stories, brings into focus a poorly explored area in women's health experience. It is argued that there is a dearth of information for women and society regarding women's place within an epidemic such as HIV and AIDS (acquired immunodeficiency syndrome). HIV/AIDS, historically, has not been perceived as a significant problem for women. It was defined in the early 1980s as a 'gay man's disease', (Doyal, 1994; Fee & Fox, 1988; Green & Miller, 1986) and a disease of the third world (Long, 1996; Treichler, 1999). By the mid 1980s women were presenting with HIV/AIDS; the women most likely to be diagnosed as having AIDS were black, intravenous drug users, partners of drug users, or prostitutes (Doyal 1994; Fee & Fox, 1988; Kendall, 1996; Kitzinger, 1994; Long, 1996; Schneider & Stoller, 1994; Treichler 1988). The resulting discourse created a culture of silence and invisibility for many other women who also were or became HIV positive. This thesis makes a small contribution to breaking that silence.

Feminist theory is utilized within this thesis to examine issues of gender, power, subordination and women's positioning in society in relation to nine HIV positive women. Data was analyzed following a thematic analysis incorporating a feminist process. This process most usefully explores and describes issues affecting women living with HIV in New Zealand.

1.2 Aims of the Study

The main aim is to: -

1. Explore and describe women's experience of being HIV positive in New Zealand in the year 2001.

Secondary aims are:

1. To provide information to health professionals to enable them to have an understanding of the issues experienced by HIV positive women.
2. To share the information gained with all women, with special emphasis on women who are HIV positive.

1.3 Background to the Study

The history of AIDS dates back to the early 1980s. A New York Medical Center identified a group of patients suffering from a rare form of skin cancer, Kaposi's sarcoma (KS), along with further cases of pneumocystis carinii pneumonia (PCP) in seemingly otherwise fit young men. KS and PCP are conditions usually manifested only in individuals with depressed immune systems (Fee & Fox, 1988; Gilman, 1993; Green & Miller, 1986). The one thing these young men did have in common was that they were all homosexual (Fee & Fox, 1988; Gilman, 1993; Green & Miller, 1986; Treichler, 1999; Watney, 1993). The central issue surrounding this disease, in the early 1980s, focused on sexual orientation and this can be further confirmed by the designation the disease was given in the early stages. The term GRID (gay-related immunodeficiency) was identified and this label structured an understanding that people with GRID not only carried an infectious disease, but also belonged to a specific group (Gilman, 1993; Green & Miller 1986; Grover, 1993).

As the disease progressed and more cases were identified, the disease became known as AIDS (Gilman, 1993; Green & Miller, 1986; Grover, 1993). By 1982, not only were more gay men being diagnosed but also women and babies were presenting with the classified symptoms of AIDS. This forced the Center for Disease Control (CDC), a body responsible for collecting data and defining categories for specific infectious diseases to broaden the categories of those classified as being at risk of contracting AIDS to include women (Buzy & Gayle, 1996; Esu-Williams, 1994; Schneider & Stoller, 1994). The CDC definition included the '4 H- Club' described as homosexuals, heroin addicts, Haitians, and haemophiliacs (Gilman, 1993; Green & Miller, 1986). When women were included as part of this list they were identified as 'hookers' (Gilman, 1993; Green & Miller, 1986; Treichler, 1999). It was further revealed within this period, that women could also become infected if they were intravenous drug users or sexual partners of intravenous drug users (Fee & Fox, 1988; Green & Miller, 1986). By 1985 the human immunodeficiency virus (HIV) had been identified as the virus which causes AIDS (Fee & Fox, 1988; Green & Miller, 1986).

Reviewing the literature in the early 1980s it becomes clear that women in both developed and developing countries played little role in the unfolding dialogue of issues surrounding HIV infection (Preble & Siegel, 1996). Some feminists noted that because AIDS was constructed as a 'gay men's disease', and there was a dearth of information and lack of any discussion about women and AIDS, they did not at first identify AIDS as a women's issue (Richardson, 1994a). Other feminist scholars agree that women did not have a voice; the dialogue surrounding HIV/AIDS was led by well educated, economically advantaged and white homosexual men (Preble & Siegel, 1996; Treichler, 1999).

When feminist authors did examine the issues surrounding women and HIV/AIDS they commented that the message from the medical literature for women was confusing (Doyal, 1994; Treichler, 1988). It was acknowledged as early as 1982 that women could not be excluded from contracting the disease, but women were considered not to be at risk if heterosexual, white, and a non-drug-user (Bury, 1994; Schneider & Stoller, 1994; Treichler, 1988). Africans, Haitians, drug users and prostitutes were blamed as seemingly responsible for the spread of the disease (Bury,

1994; Schneider & Stoller, 1994; Treichler, 1988). So it appeared that for women to contract HIV/AIDS they needed to be involved in a certain behaviours and therefore also guilty of spreading the disease. In marked contrast there was a discourse of 'innocence' around victims of the epidemic who became infected because they were either recipients of infected blood or HIV infected babies (Bury, 1994; Treichler 1999).

Although the early messages for heterosexual women may have been contradictory and at times confusing, for women who had sexual relationships with women there was even less information. The risk of HIV transmission for lesbians was first thought to be so small that information for this group was not available in the early 1980s (Hollibaugh, 1994; Hunter & Alexander, 1996; Stoller, 1994). CDC did not record mode of transmission to include lesbian as a category until 1993 (Hunter & Alexander, 1996).

Available literature, also written by feminist authors in the mid 1990s reports that by the mid to late 1980s, when infected women began to look for support and information, the information and services for them had not been established (Ankrah, Schwartz, & Miller, 1996; Kendall, 1996; Preble & Siegel, 1996). From early on, as already highlighted, the emphasis was that HIV/AIDS was for male homosexuals and caused by penetrative sex. This concept extended into the health care objectives. Research targeted male populations, clinical definitions were driven by the experience of male patients, and all the education and the prevention programmes were male centered (Doyal, 1994; Pinch, 1994; Richardson, 1994b). The bias in the system towards men had implications for the health care of women, in terms of access, acceptance and appropriate health care services (Ankrah, Schwartz, & Miller, 1996). It can be demonstrated within the literature that doctors and other health professionals were unprepared for the particular issues that women would raise (Bury, 1994; Preble & Siegel, 1996; Treichler, 1999).

1.4 Feminist Critique of HIV/AIDS

Many feminist writers today believe that there are very clear explanations for the androcentric emphasis of HIV/AIDS in the literature. Women have been left behind in the epidemic and feminist theory provides potential explanation for this phenomenon (Kitzinger, 1994; Long, 1996; Schneider & Stoller, 1994).

Firstly, feminist theory comments on the position of women in society. Feminist scholars believe that women are positioned as socially, politically and economically subordinate in the structure of society (Acker, Barry, & Esseveld, 1983; Beasley, 1999; Lather, 1991; Maynard & Purvis, 1994; Reinhartz, 1992). This position, feminists believe, places women in a vulnerable position when it comes to a disease such as HIV/AIDS (Schneider & Stoller, 1994; Treichler, 1999). When HIV/AIDS was no longer constructed as just a 'gay man's disease' and it was finally acknowledged that HIV could be transmitted through heterosexual intercourse, women were placed in an extremely vulnerable position (Pinch, 1994). Reasons for this vulnerability included issues around the inequality of women in almost all societies, through power imbalance and the economic dependence of women (Pinch, 1994). For example feminists scholars have argued that heterosexual relationships are constructed hierarchically where key roles of dominance and submission are acknowledged and accepted. Therefore when issues arise over who has control over sexual decision making, a man may refuse to use a condom as a form of disease prevention and a woman's position, in a vast majority of cases, is powerless (Holland, Ramazanoglu, Scott, & Thomson, 1994a; Sosnowitz, 1994; Wilton, 1994a; Wilton, 1994b). It is also acknowledged that men, along with the power they have in sexual decision making, provide the presumed or actual economic stability many women still rely on to maintain their families' existence (Cash, 1996).

1.4.1 Feminist critique of HIV/AIDS prevention programmes

This powerlessness, argue feminists, also extends into the design of prevention programmes to stop the spread of the HIV (Holland, Ramazanoglu, Scott, & Thomson, 1994a). Prevention programmes which encourage the use of condoms, assume that women have the power, or can attain the power, to change the outcome of sexual encounters (Preble & Siegel, 1996). Many feminist scholars believe that focusing on women to encourage condom use misses the opportunity to challenge masculine sexual and cultural norms and supports the perception that men do not need to take responsibility for the spread of HIV/AIDS (Preble & Siegel, 1996; Treichler, 1997; Wilton, 1994a). Therefore there is support amongst feminists for more development in appropriate gender based programmes, which they believe has been lacking in schools, and adolescent health programmes (Gupta, Weiss, & Mane, 1996; McCarthy, 1994).

1.4.2 Feminist critique of women and pregnancy

The one issue surrounding HIV/AIDS and women that did attract the attention of the medical profession, early in the debate, centered on pregnancy and HIV/AIDS. Abercrombie (1996) feels there has been a disproportionate emphasis on pregnancy and perinatal transmission which she reports has resulted in additional "stigmatization of HIV-positive women" (p.102). This writer goes on to say that women have been constructed as 'vectors' of the disease, or transmitters of the virus, rather than treating them as individuals with a life threatening disease. Other feminist scholars believe that women have suddenly become visible within the HIV/AIDS debate only in their function as breeders, and that more effort needs to be put into understanding the whole HIV infected family rather than place judgement on women (Auer, 1996; Bury, 1994; Pinch, 1994).

Still the research on women and pregnancy continued and early studies suggested that pregnancy was actually dangerous for women with AIDS, causing rapid progression of the disease (Bury, 1994; Buzy & Gayle, 1996). Along with this, the risk of the baby being infected with HIV was put at around 50% to 60% (Auer, 1996; Bury, 1994).

These studies have now been superseded, but it is possible these initial reports are still having an impact on women. The myths persist. A report in 1996 produced from a focus group of HIV positive women to study the reproductive decision making in the United States, commented on one major finding (Sowell, Moneyham, & Aranda-Naranjo, 1999a). They found that many woman had limited or inaccurate information concerning the potential transmission of HIV from mother to baby and even less information on treatment options for reducing perinatal transmission (Sowell, et al.).

Studies now show that perinatal transmission rates can be as low as 8% in women who follow a protocol of zidovudine (AZT) therapy during pregnancy, as compared to 25% to 30% transmission rate in women who do not take AZT (Abercrombie, 1996; Buzy & Gayle, 1996; O'Gara & Martin, 1996). Latest medical research also indicates that further reduction of HIV transmission to the foetus can be achieved through a choice of mode of delivery indicating birth by elective Caesarian section and breastfeeding alternatives (White, 1999; Ministry of Health, 1999).

But the biomedical determinants for women are not the only influencing factor when it comes to a decision around childbearing (O'Gara & Martin, 1996). For many women in many societies childbearing and rearing are important for social value, self-esteem, cultural perspectives and survival (Auer, 1996). In other words a woman's decision to have a baby does not just relate to one factor but involves a multitude of issues. Many women may feel unfulfilled if they do not have children, others may feel it is their role. In some societies adults depend on their children to provide for them in their old age, while in other cultures having children holds a high value within their society (Auer, 1996). These reasons often out weigh the knowledge that a women is HIV positive and the possibility that she may pass the infection on to her child (Ankrah, Schwartz, & Miller, 1996; Auer, 1996; O'Gara & Martin, 1996).

Feminist scholars would comment that emphasis and focus on women with HIV and pregnancy has been to the detriment of other research for women (Abercrombie, 1996). Ironically pregnancy is a reason why many women have been excluded from drug trials and other research, due to potential foetal damage (Kendall, 1996). Trials with female condoms or vaginal viricides seem small in comparison.

These themes are explored in greater detail in the following chapter but feminist literature as previously cited, generally concurs that because HIV/AIDS has been constructed as a 'gay man's' disease this has led to a lack of information directly for women. The effect of this lack of access to clear information means in the past that women have been unable to make informed choices concerning health issues directly relating to them (Lather & Smithies, 1997). In the year 2001 as research continues women still appear to lack clear information surrounding women's experience of being HIV positive and consequently lack subject positions, narratives, and identities that can make sense of information and act upon it (Treichler, 1997).

1.5 Justification for the Study

To date there is only one research report that addresses women and HIV/AIDS in New Zealand (Brander & Norton, 1993). Research on men and HIV/AIDS in New Zealand cover a report on Maori men and HIV in 1994 published by Te Puni Kokiri, and a nationwide demographic survey of men who have sex with men (MSM) in 1997 (Worth, Saxton, Huges, Reid, & Segedin, 1997). The most recent research in 1999 focused again on MSM covering socioeconomic and cultural issues which may place men at risk of HIV (McNab & Worth, 1999).

Admittedly the proportion of men who are HIV positive in New Zealand is higher than for women, but statistics also suggest that the numbers of women are steadily increasing each year (AIDS Epidemiology group, 2001). Recording of HIV infections in women in New Zealand began in 1985 where there were no confirmed cases. By the end of 1992, there were 35, at the end of 1997 100, at the end of 1999 130, by the end of 2000 183, and 202 by June 2001 (AIDS Epidemiology group, 2001). These figures indicate a rising number of women diagnosed with the virus, and since 1992 the numbers have more than tripled. The proportion of females diagnosed with HIV has risen from 8.4% in 1986 to 14.3% in 1992 (Worth, 1998). The most recent report (June 2001) puts the percentage of women with HIV to be 32% of the total (AIDS Epidemiology group, 2001).

Along with the statistics showing an increase in women with HIV internationally there is a corresponding lack of social research and information for women surrounding HIV/AIDS. As previously indicated it was not until 1994 that feminist scholars applied feminist theory and analyses to the debate around HIV/AIDS and women (Doyal, 1994; Lather & Smithies, 1997; Schneider & Stoller, 1994). Consequently no feminist analysis has been produced in New Zealand to date, nor has there been any nationwide published reports or research since 1993. A dissertation as part of a Masters of Social Science was completed in 1999, (Rogers-Hayden, 1999) which looked at 'Women and HIV/AIDS in New Zealand' and focused on the development of Health Policy in New Zealand. This dissertation used feminist principles to analyze policy development and the purchasing of services for women with HIV and AIDS. This provided a very worthwhile window into this area of social policy. My intention is to apply feminist theory, and engage in conversation with women who are HIV positive.

In justifying this study I also had personal correspondence at the gender studies department with Dr. Heather Worth at Auckland University. Dr Worth has extensive knowledge in HIV/AIDS in New Zealand. She has been involved in numerous reports and research studies involving HIV/AIDS, including the nationwide demographic survey of MSM in 1997 and the most recent report of MSM in 1999. Dr. Worth has also applied for funding to the Health Research Council of New Zealand in 1997 and 1998, for funding to complete nationwide research on women and HIV/AIDS in New Zealand. Both applications to date have been turned down (personal correspondence 2000).

1.6 My Position in this Study

My personal interest in HIV/AIDS began in the 1980s when I was working as a public health nurse in a rural part of New Zealand. Part of my job description as a public health nurse in secondary schools was to assist and act as a resource person for the sexual health curriculum. HIV/AIDS education was in the context of a sexually transmitted disease, a new topic for most teachers who looked to health

personnel such as public health nurses, to provide the resources. My involvement also extended into the community where in 1989 I was employed as a community development nurse, working with community health workers. I assisted them in bringing this information to their various community groups amongst isolated rural communities. Finally it was during my two-year assignment in Zimbabwe, in the mid 1990s working exclusively with HIV/AIDS that I became acutely aware of the impact of this disease. In a country such as Zimbabwe HIV/AIDS was not a 'gay man's disease'. In fact any display of homosexuality is not only a form of self-imposed discrimination, but also is against the law. And so from a culture and a construction of HIV/AIDS as a 'gay man's disease' I was confronted daily with the another face of HIV/AIDS which consisted of men, women and children being equally infected. Part of my job was to access and then suggest, in conjunction with other health workers, an appropriate health care service for HIV positive people in a very rural and economically poor area of Zimbabwe. This was a challenging mission and an experience I value very much. Official statistics estimate that 25% of the adult population of Zimbabwe were HIV infected 600,000 men and 800,000 women at the end of 1999 (personal correspondence AIDS Epidemiology group 2001).

On my return to New Zealand I gained employment within the HIV field, I was back in a culture where HIV/AIDS remained predominately a 'gay man's disease'. But within this culture and working in the field I also realized there were women in New Zealand with HIV, they just seemed small in numbers and nearly invisible.

In 1999 I enrolled in a Women's Health paper, which enabled me to study in-depth local and international issues, which surrounded women and HIV/AIDS. Thus the idea of this research topic was formed. Although my enthusiasm for the topic was high I realized the many ethical and emotional dilemmas a sensitive issue such as this could produce. Working in the field as a nurse I knew the statistics of HIV positive women in New Zealand and felt a viable research proposal could be formed within the boundaries of a Master's thesis.

But as a nurse working in the field it could be also seen as a disadvantage. I felt I could not interview women whom I had already nursed; I knew some of their stories and recognized that this might bias the research analysis and outcomes. The question

of how to access women that I personally did not know was of some concern as I was also aware of personal and professional protectionism within the field which kept access to HIV positive women minimal. An even bigger concern for me was would women be willing to share and record their stories on such a sensitive issue. The project, I felt, needed doing however difficult. This became my task and this thesis describes and analyses my findings.

1.7 Conclusion

The exploration and description of women's experience of being HIV positive in New Zealand is the main aim of this research. Traditionally HIV/AIDS has been constructed as a 'gay man's' disease and still is in many developed countries. Women with HIV were traditionally constructed as prostitutes intravenous drug users and women of colour. Along with this construction women were also seen as 'vectors' and 'transmitters' of the virus to men and 'innocent' unborn children.

Feminist scholars believe women are disadvantaged in society being socially, politically and economically subordinate and therefore placed in a vulnerable position in a disease such as HIV/AIDS. This vulnerability is described in terms of power imbalance, where men hold power over sexual decision making and in many circumstances hold economic power over women as they rely on male economic potential to maintain the family existence.

The reading of this literature was my inspiration to follow this topic and being a nurse and feminist and working amongst people with HIV/AIDS both in New Zealand and internationally gave me the experience and background. Despite the difficulties I thought I might encounter in accessing women with HIV in New Zealand who were willing to tell me their stories, this did not deter me from my goal. I felt their stories needed telling, as there was a dearth of published literature in New Zealand which highlighted this area of research from a feminist perspective.

The following chapter will provide a more detailed critique of the literature surrounding women and HIV from the early 1980s to the present day at a local and international level.

CHAPTER TWO: A literature Review

2.1 Introduction:

As the purpose of this study is to explore women's experience of being HIV positive this literature review will cover readings with specific references to women and the way women have been constructed in the HIV/AIDS debate. The critique of this construction will include medical, feminist and nursing discourse.

The literature will also be reviewed with an international perspective, as there is a dearth of literature from New Zealand, which addresses issues surrounding women and HIV/AIDS.

2.2 International Statistics

Globally statistics indicate 34.7 million adults are thought to be infected with HIV (AIDS Epidemiology group, 2001). Today women comprise 47% of the total adults infected with HIV (AIDS Epidemiology group). These figures are almost 50% higher than the estimates projected by the World Health Organization (WHO) in 1991.

International statistics demonstrate that there are more men infected with HIV and dying of AIDS than women in all parts of the world except sub-Saharan Africa (Buzy & Gayle, 1996). In sub-Saharan Africa 55% of HIV positive adults are women (AIDS Epidemiology group, 2001). This is in contrast to East Asia and Pacific where it is estimated that 13% of HIV positive adults are women (AIDS Epidemiology group, 2000). Although statistics report that the majority of people living with HIV live in the developing world, it is also reported that the rate of new HIV infections in some countries is rising faster in women than in their male counterparts (Buzy & Gayle,). Adolescent girls are at greater risk of acquiring HIV than any other group (Buzy & Gayle). Concern has been expressed internationally that HIV infections in woman are increasing in the age group of fifteen to twenty-five (Ankrah, Schwartz, & Miller, 1996; Auer, 1996; Buzy & Gayle, 1996). This is

ten years younger than the average age of HIV infected men (Buzy & Gayle, 1996). Reasons for this age difference vary, but feminist scholars believe young women are becoming increasingly infected in the developing world as men seek out younger women who may not be infected with HIV (Buzy & Gayle).

Globally HIV/AIDS is primarily a heterosexual disease (Buzy & Gayle, 1996). It is also reported that for women the mode of transmission is predominately through heterosexual contact (Bury, 1994; Buzy & Gayle, 1996; Doyal, 1994; Schneider & Stoller, 1994; Treichler, 1988). Some estimates put heterosexual transmission for women at 90%, compared to 60% for men (Buzy & Gayle, 1996; Doyal, 1994).

2.2.1 New Zealand Statistics

When data collection first commenced for women in New Zealand (1985) there were no reported HIV infections while for men there were 63 HIV infections (Ministry of Health; 1999). Since the first woman was diagnosed with AIDS in New Zealand in 1986, a total of 45 females have been notified with AIDS (6% of the total) (AIDS Epidemiology group, 2001). During that time 202 females (10 girls and 192 women) have been diagnosed with HIV infections and the number of females being diagnosed has been increasing since the early 1990s (AIDS Epidemiology group,). A record 26 HIV infections (32% of the total) diagnosed among females during 2000 (AIDS Epidemiology group,). One-third of the 48 infections diagnosed during the first half of 2001 have been in females (AIDS Epidemiology group,).

Men who have sex with men (MSM) have been, and still are, the main mode of transmission of HIV in New Zealand, but since the early 1990s there has been a decrease of HIV cases in MSM. In 1997 there were 65 new HIV infections in MSM, compared with 1996 when there were 95 new infections (personal correspondence with New Zealand AIDS Foundation (NZAF).

Mode of transmission for New Zealand women is most common through heterosexual contact. Since the start of 1996 when the AIDS Epidemiology group began to collect detailed information on the circumstances of new HIV infections

80% of all female infections arose from heterosexual transmission (AIDS Epidemiology group, 2001).

All but 20 of the new HIV infections in females (82%) of the total were thought to have occurred overseas, with 51 of the cases (45%) acquired in Africa and 22 cases (19%) acquired in Asia (AIDS Epidemiology group, 2001). Of the 20 females whose infections occurred in New Zealand, 19 were infected by heterosexual means and one was infected perinatally (AIDS Epidemiology group).

The sex shift has changed both here in New Zealand and internationally and should be cause for concern .

2.3 Medical Discourse and HIV/AIDS

Medical science is described as a powerful discourse. For many decades society has trusted medical science to provide researched data to explain disease etiology, treatment and cure. Medical science has provided the world with information and research-based evidence of HIV/AIDS for over two decades. It is therefore appropriate to review the history of the construction of women within the medical discourse in order to identify women's position today in this epidemic.

2.3.1 The first decade; 1980 to 1990

Documentation surrounding the history of AIDS refers to the first medically diagnosed cases in 1981 (Fee & Fox, 1988; Green & Miller, 1986; Tulloch & Lupton, 1997). The Centers for Disease Control (CDC) in America, (which monitors the spread of diseases), received reports of cases where chest infection, pneumocystis carinii pneumonia (PCP) along with a rare form of skin cancer, Kaposi's sarcoma (KS) appeared in young men (Fee & Fox, 1988; Green & Miller, 1986; Treichler, 1988; Watney, 1993). These conditions, according to biomedical science, usually appear in people whose immune systems are weakened in some way, by drugs, malnutrition or by age. These young men did not appear to fit within this profile. The one thing that did link them together was that they were all male homosexuals (Fee & Fox, 1988; Green & Miller, 1986; Treichler, 1988; Watney, 1993).

Scientists wanting clues in disease etiology observed homosexual lifestyles, including sexual behaviour and use of recreational drugs. Anal intercourse was a behaviour common to gay men, and this was thought to be a contributing factor in disease transmission (Fee & Fox, 1992; Green & Miller, 1986; Watney, 1993). But it was also discovered that the use of stimulant drugs was widespread amongst this community and it was suggested that a particular supply of amyl nitrate (or 'poppers') might be contaminated causing the immune system to collapse (Fee & Fox, 1992; Green & Miller, 1986; Watney, 1993). Scientists based in America then informed the world that this disease was particular to gay and bisexual men. They named the syndrome GRID translated to gay related immune deficiency syndrome (Fee & Fox, 1992; Green & Miller, 1986; Watney, 1993). This labeling led people to believe that only men who had sex with men were associated with contracting this disease.

Early medical literature with reference to the developing world and HIV/AIDS is more difficult to locate. Patient testimony, media observation and journalistic reports were more wide spread, but medical scientific data is concentrated within the developed world and has contributed to the construction of who was considered to be at risk of contracting HIV.

By mid 1982 the picture was changing and the disease was more commonly known as acquired immune deficiency syndrome or AIDS. People with AIDS now included intravenous drug users who shared needles, Haitians, hemophiliacs and others who had received infected blood or blood products (Fee & Fox, 1992; Green & Miller, 1986; Treichler, 1999; Watney, 1993). As early as 1983 it was reported that a small number of women were also being diagnosed with AIDS, and it was thought that the mode of transmission was via intravenous drug use, transfusions with contaminated blood, and eventually through male sexual partners who also had AIDS (Treichler, 1999). By 1985 the human immunodeficiency virus (HIV) had been identified (Fee & Fox, 1992; Green & Miller, 1986; Watney, 1993). Also by 1985 AIDS was seen in babies born to women who had been infected heterosexually or through needle sharing (Bury, 1994; Doyal, 1994; Green & Miller, 1986; Schneider & Stoller, 1994; Treichler, 1988).

It was now difficult to ignore that women were at risk of developing AIDS, but medical literature constructed women with AIDS in a particular way. The CDC definition of who was at risk of contracting HIV described the '4 Hs', that is homosexuals, Haitians, hemophiliacs and hookers (Fee & Fox, 1988; Gilman, 1993; Green & Miller, 1986; Treichler, 1999). Heroin addicts were added in 1986 (Fee & Fox, 1988; Gilman, 1993; Green & Miller, 1986; Treichler, 1999). From this definition women were constructed as being capable of becoming HIV positive if they were Hispanic, prostitutes, commercial sex workers, hookers or drug addicts (Long, 1996; Lupton, 1998; Treichler, 1988; Tulloch & Lupton, 1997).

Along with this construction there was also another dialogue concerning women's anatomy. An article by John Langone in 1985 (cited in Treichler, 1999) suggested that the virus entered the blood system by way of the 'vulnerable anus', and this was in contrast to the 'rugged vagina'. Presented with scientific drawings, the article stated that the anus was more vulnerable to a virus and the body was not built for men to have sex with men. The so-called 'rugged vagina' could tolerate the virus as the vagina provided too tough a barrier for the AIDS virus to penetrate (cited in Treichler, 1999). The tone of this article appeared to have two messages. One was for society, which said that AIDS was the fatal price paid for anal intercourse. The other message was that women need not concern themselves as the 'rugged vagina' could tolerate the virus. The vagina was built to withstand being abused by blunt instruments such as a penis and the birth of babies (Treichler). This message for women over the next decade, according to feminist scholars, was the "contradictory messages women received about their biological vulnerability" (Treichler, 1999 p.17). AIDS could not be a threat to the vast majority of heterosexual women. It was only for those who practised anal intercourse. Scientific discourse continued to construct women as 'inefficient' and 'incompetent' transmitters of HIV. A woman's uterus was constructed as a passive receptacle, without the projectile capacity of a penis or a syringe (Fee & Fox, 1988; Treichler, 1999).

How then did this explanation fit with the construction of women as prostitutes who were seen as the 'vectors' of the disease? The medical literature explained that there were exceptions and as Treichler, (1999) comments prostitutes were seen as "so contaminated their bodies are virtual laboratory cultures for viral replication" (p.20). Prostitutes were seen as exceptions along with African woman, who seemed to have different sexual practices or exotic bodies, but these were 'other' women (Ruangjiratain & Kendall, 1998; Sosnowitz, 1994; Treichler, 1999). Along with this, HIV was often described as a virus that originated elsewhere. This was perhaps because the vast body of the medical literature originated predominantly in North America and Britain.

Although medical literature admitted that a cure for the virus was not immediately forthcoming, they could detect early signs of the virus. The CDC role and responsibility was to set out a list of diagnostic conditions for infectious diseases such as HIV/AIDS, and this was set in the early 1980s. As the disease progressed this list of conditions was broadened but it was not until 1993, more than a decade into the disease, that any gynaecological conditions were included in this list (Lather & Smithies, 1997; Schneider & Stoller, 1994). The revised classification for HIV since 1993 now includes cervical dysplasia, cervical carcinoma in situ, pelvic inflammatory disease, and recurrent vulvovaginal candidiasis (Abercrombie, 1996; Buzy & Gayle, 1996; Lather & Smithies, 1997).

This raises important issues for women. It took over ten years to identify conditions specific to women, and only now is it formally recognized that "HIV positive women do experience sex specific medical problems" (Lather & Smithies, 1997 p.35). Clinical characteristics of men did not accurately reflect the clinical manifestations of HIV in women. In a study of deaths of women with HIV/AIDS in the US it was found that 48% died of conditions not listed in the CDC definition (Bury, 1994). It was also reported that when the CDC did expand the case definition of AIDS, there was a 151% increase in the number of AIDS cases in women (Abercrombie, 1996).

This lack of medical information has also directly affected women in terms of misdiagnosis and a lack of early detection of HIV (Doyal, 1994; Lather & Smithies, 1997; Schneider & Stoller, 1994). Feminist scholars believe that many women would have died from HIV associated conditions without a diagnosis of AIDS, therefore statistically women have been underrepresented in the AIDS epidemic since the mid 1980s (Bury, 1994; Lather & Smithies, 1997).

2.3.2 The 1990s and masculinist bias in medical research of HIV/AIDS

Feminist scholars would argue that male bias in clinical medicine is not unusual, and there has always been a prevailing androcentric dominance in clinical research and medical practice (Ankrah, Schwartz & Miller, 1996). But feminist scholars believe that male bias was particularly dominant within HIV/AIDS research (Ankrah et al., 1996; Pinch, 1994; Schneider & Stoller, 1994; Treichler, 1988). Winifred Pinch (1994) comments that the history of the epidemic was framed in androcentric terms, male homosexual incidence was emphasized, and research targeted male populations

It would be reasonable to assume that if HIV/AIDS continued to affect one population group then research in that area would have been appropriate. But as previously explained while in 1983 women were identified as HIV positive, it appears that research remained male dominated. Ankrah, Schwartz and Miller (1996) point out “women’s experience with the disease was largely ignored by the health care system for an entire decade”(p.270). This view is also supported by Hankins and Handley (1992), who comment that “seemingly little attention has been paid thus far to the unique features of HIV infection in women” (p.957).

Others feminist scholars believe that power and politics have an influencing factor on male dominance in HIV/AIDS medical research. Doyal (1994) states that gay men, especially in developed countries such as the USA, were involved in the many aspects of funding, organization of research treatments and prevention facilities concerning HIV/AIDS. Lupton (1998) also agrees, commenting that gay men in wealthy industrialized countries possessed political motivation, experience and organizational capacity to sway government funding in supporting HIV/AIDS medical research, treatment trials and prevention programmes.

Investigation of HIV/AIDS as a different disease for women than for men, did not occur until the mid 1990s (Abercrombie, 1996). One of the first medical studies which describes the natural history of HIV in women was conducted in Rhode Island in 1991(Abercrombie, 1996). It included a cohort of 200 women and the findings were compared with the known clinical manifestations of men. Women were reported to have a greater incidence of candida infections, a greater incidence of chronic or recurrent herpes simplex infections and a lesser frequency of *Pneumocystis carinii* pneumonia (PCP), and an absence of Kaposi's sarcoma (KS) in comparison to men (Abercrombie, 1996).

Then in the late 1990s more studies were conducted with specific emphasis on women and gynecological manifestations and these findings have influenced the management of women with HIV. It has been acknowledged that women who are immunosuppressed report an increased incidence of cervical cancer and cervical cancer in HIV positive women has been reported to be rapidly progressive (Abercrombie, 1996). Therefore clinical practice guidelines, such as those released by the American Department of Health, recommend regular cervical smears for detection of cervical disease in women with HIV (Abercrombie, 1996).

Still the medical research with specific reference to women is small. For example studies exploring the effects of HIV and menstruation appear a low priority. These studies have been done but have been small, not well controlled and have yielded conflicting results (Abercrombie, 1996; Buzy & Gayle, 1996).

There is also a lack of research on women and antiviral (AVR) treatments. A recent survey in Australia revealed that there was a greater uncertainty or distrust among women towards AVR treatments (McDonald 2000). Women believed (46%) that combination AVR drugs are harmful to women and were unsure whether HIV treatments will stop them dying from AIDS (McDonald). Research into the effects of medications on women being different to that of men have yet to reveal results (Ankrah Schwartz, & Miller, 1996).

There is also a lack of commitment to research, to produce safe measures of chemical or physical barrier protection which women could control. Ankrah, Schwartz and Miller (1996), argue that the development of virucides and the use of the female condom could be increased and made available to women, especially those who are unable to negotiate consistent condom protection from their partners.

Feminist analyses of the amount of medical research with specific reference to women and HIV comment that there needs to be a greater emphasis on women's clinical manifestations (Abercrombie, 1996; Buzy & Gayle, 1996). Cohorts are small and there needs to be multi-centered, longitudinal, prospective studies with large cohorts before clinical manifestations of HIV disease in women can be more accurately defined (Abercrombie, 1996; Buzy & Gayle, 1996)

2.3.3 Medical research of women and pregnancy and HIV/AIDS

In comparison there has been a large focus within medical research on women and pregnancy and HIV, and many contend that there has been a disproportionate emphasis on pregnancy and perinatal transmission (Abercrombie, 1996; Pinch, 1994).

Medical research established early that women were able to transmit the infection to the foetus and so place the unborn child at risk for HIV infection (Ankrah, Schwartz, & Miller, 1996; Auer, 1996; Bury, 1994; O'Gara & Martin, 1996; White, 1999). Transmission from an infected mother to her infant can occur in utero, during birth and via breast milk (Abercrombie, 1996; Auer, 1996; Bury, 1994; Pinch, 1994; Treichler, 1999; White, 1999). As women are given this information they are then placed in the position of making decisions regarding reproduction. Feminist scholars believe that immediately tensions existed between what was expected of a woman in cultural terms, along with a woman's role in society and social pressure on what was deemed acceptable (Auer, 1996; Kendall, 1996). Cultural issues and women's role in society, placed against the knowledge that transmission could occur, places women in a position of being made to feel morally responsible for making decisions concerning reproduction (Abercrombie, 1996; Pinch, 1994). Medical advice to women who were HIV positive and pregnant early 1990s strongly advised abortion

of the foetus and you were seen as 'illogical' or not clear in moral thinking if you displayed other behaviour (Bradley-Springer, 1994). Women who were HIV positive were also encouraged not to become pregnant. Some feminist scholars believe that statements from medical science suggesting abortion and no pregnancy were based more on health goals to reduce infections along with patriarchal repressive strategies without consideration for women's self determination and reproductive rights (Bradley-Springer, 1994; Pies, 1994).

Early studies also produced conflicting evidence surrounding perinatal HIV transmission rates. According to some African studies up to 40-50% of infants born to HIV infected women may become infected (Auer, 1996). Transmission rates from European studies in 1991 were estimating the rate to be about 30% (O'Gara & Martin, 1996; Pinch, 1994).

Those early studies have since been superseded and medical research now has a focus on interventions to reduce the perinatal transmission of HIV. Three main issues involve breastfeeding, mode of delivery and antiretroviral therapies. Current research recommends the introduction of a range of these interventions suggesting that they can reduce transmission rates to less than 2% (Ministry of Health, 1999; White, 1999).

Medical research has hailed the antiretroviral drug as the biggest success story in the field of HIV/AIDS. One of these drugs AZT (or zidovudine) has become a major focus of discussion concerning mother-to-child transmission of HIV. Antiretroviral drugs work by blocking the function of a crucial enzyme (reverse transcriptase) and this action has the effect of disrupting an early stage in the replication of the virus.

Studies carried out in France and the United States, in the early 1990s, gave the drug AZT to pregnant women and to the baby for six weeks. In a group in which the mother and baby were given AZT the risk of transmission was reported to be only 8.3%, as compared to another group of mothers and babies who were given a placebo, the rate of transmission was reported to be 25% (White, 1999). All babies in this study were formula feed. This study was referred to as the most important study to date and it revolutionized the recommended treatment of pregnant HIV positive

women. Further studies are continuing with AZT and pregnant HIV positive women, which include women being treated with oral AZT, but then breastfeeding (White, 1999). The results of these trials have yet to be released.

The mode of delivery has also been addressed within medical research. In Geneva, at a World AIDS conference in 1998, a compelling picture was painted of elective caesarian section contributing to reducing the risk of transmission. A European study of 235 mother-infant pairs reported a transmission rate of 2% to 3% for infants delivered by elective caesarian section compared to 11% of those delivered vaginally or by emergency caesarian section (Ministry of Health, 1999). Studies in Switzerland reported that no transmission occurred in babies delivered by elective caesarian whose mothers had received AZT during pregnancy (White, 1999). While women who received elective cesarean delivery, but no AZT, the rate of transmission was 8% (White, 1999).

The convincing evidence of these reports continues, but along with the support for these studies comes the controversy. The long-term consequences of possible adverse effects on children receiving AZT has yet to be studied. There is also the concern that the early use of antiretroviral drugs may increase the odds of drug resistance. This could reduce treatment options for a mother or her child if exposed to AZT as a foetus (White, 1999). The use of placebo trials on HIV positive women concerns many women debating the ethics of the use of placebo. Medical researchers argue that research with placebos is the fastest way to find answers and the sooner the better (Ankrah, Schwartz, & Miller, 1996; White, 1999).

The mode of delivery of elective caesarian section can only take place in countries which provide safe and effective surgery. But along with the information confirming caesarian births comes a belief that this may not always be indicated as some doctors are advocating returning to vaginal births as they consider other low risk factors of individual women (personal correspondence with HIV/AIDS specialist 2001).

Of all the medical literature concerning transmission of HIV from mother to child the most controversial is that involving breastfeeding. Although researchers are able to state that breastfeeding can transmit HIV to an infant they are still unable to say how likely it is that transmission occurred solely through breastfeeding (O'Gara & Martin, 1996; White, 1999). When the child of an HIV infected mother is also infected, it is still not certain whether the child became infected during pregnancy, during the birth process, or while the mother was breastfeeding (White, 1999).

Nevertheless breastfeeding is now not recommended for mothers who are HIV positive (Ankrah et al., 1996; Auer, 1996; O'Gara & Martin, 1996; White, 1999). Current knowledge suggests rates of transmission among breastfeeding mother-infant dyads vary from 18% to 53% (O'Gara & Martin, 1996). Rates among bottle-fed infants in the same studies vary from 25% to 33% (O'Gara & Martin, 1996). Other studies conducted in Rio de Janeiro with children of infected mothers who were breastfeeding found 49.3% of the children became infected. This is in comparison to bottle-fed children, same city, where it is reported that 18.8% of the children became infected and their mothers were also HIV positive, (White, 1999). Similar studies have also been carried out in Soweto, in South Africa, where comparisons were made between breastfeeding and formula-fed infants. Results indicate that breastfeeding more than doubled the risk of HIV transmission to the child (O'Gara & Martin, 1996).

Although the threat of HIV is serious, the other important issue is that bottle-feeding in some circumstances also poses risks for babies. A great majority of infants in developing countries have a possible better survival rate with breastfeeding than with bottle-feeding (Auer, 1996; O'Gara & Martin, 1996). Breastfeeding has been promoted by many organizations, such as the World Health Organization (WHO) as a way to minimize infant morbidity and mortality, especially in developing countries. Breastfeeding is the best infant food in any society, it is the least expensive, enhances infant and maternal interaction, and is understood to reduce maternal fertility (O'Gara & Martin, 1996; White, 1999). The WHO issued a statement in 1992, which states that a baby's risk of dying of AIDS through breast-feeding must be balanced against its risk of dying of other causes if not breast-fed (cited in White, 1999).

This information fills women with uncertainty. Most women wish to do what is best for their infant, but in many ways this information is essentially instructing poor women to breastfeed and wealthy women to bottle-feed. Also, considering the fact that it is still not possible to distinguish babies infected during birth, women are left with an extremely difficult choice (O'Gara & Martin, 1996; White, 1999).

Studies into more affordable interventions to decrease transmission from mother to child seem few and far between. But considerable interest has emerged recently regarding the use of Vitamin A. A study in Malawi found women with severe vitamin A deficiency to have transmission rate of 32.4%, compared to 7.2% for women with high vitamin A levels. (White, 1999). Low cost Vitamin A supplements given routinely to all pregnant women to reduce the transmission of HIV may appear to be cost effective and convenient. As yet the use of Vitamin A is not scientifically proven and so the vitamin is not administered.

2.4 Feminist Discourse of Women and HIV/AIDS

Feminist theory critiques mainstream thought. Although there is considerable agreement amongst all feminists that traditional mainstream thought is inadequate, feminists differ over what to do about the inadequacy (Beasley, 1999). Feminist scholars believe that women are positioned as socially, politically and economically subordinate to men in the structure of society (Acker, Barry & Esseveld, 1983; Beasley, 1999; Lather, 1991; Maynard & Purvis, 1994; Reinharz, 1992). This feminist theory is arrived at through analysis of the relative valuing of masculinities and femininities, identifying a power imbalance and inequality, which profoundly effects many women in society (Beasley, 1999; Maynard & Purvis, 1994; Sarantakos, 1998; Sigsworth, 1995). In other words feminist theory posits that socially constructed masculine characteristics are more valued than feminine characteristics; this places women in a subordinate position. Feminist scholars therefore argue that women are extremely vulnerable in an epidemic such as HIV/AIDS, due to their social, sexual, political and economic subordination (Long, 1996; Pinch, 1994; Schneider & Stoller, 1994; Seals, Sowell, Demi, Moneyham, Cohen, & Guillory, 1995; Treichler, 1999). This vulnerability to the HIV epidemic

can best be described through the lens of feminist analysis (Doyal, 1994; Lather & Smithies, 1997; Pinch, 1994; Schneider & Stoller, 1994; Treichler, 1988; Treichler, 1999). This vulnerability will be explained in more detail by reviewing the literature on a number of areas vital to understanding women's experience of being HIV positive.

2.4.1 HIV/AIDS education programmes

Feminist scholars have analyzed the educational message surrounding HIV/AIDS. They argue that HIV/AIDS education programmes ignore gender and social constructs and little has been done to educate women specifically (Cash, 1996; Doyal, 1994; Gupta, Weiss, & Mane, 1996; Kendall, 1996; Sosnowitz, 1994; Treichler, 1999; Wilton, 1994a).

The delivery of educational material is heard on radio and seen on television. It appears in newspapers and magazines and posters are also distributed to health facilities and community notice boards. Early efforts of HIV/AIDS education in the Western world focused on gay men (Treichler, 1997; Tulloch & Lupton, 1997; Watney, 1992). The early 1980s message was 'warn and inform' (Cash, 1996; Tulloch & Lupton, 1997). As campaigns focused on gay men and their lifestyles, the general public was presented with concepts of deviant behaviour of homosexuality, promiscuity and drug taking behaviours (Treichler, 1999; Tulloch & Lupton, 1997; Watney, 1993). HIV/AIDS was portrayed as a disease of death for sinful behaviour (Lupton, 1998). This discourse invoked stigmatization, discrimination, advocating moral meanings and metaphors associating HIV with the plague, leprosy and sin (Fee & Fox, 1988; Lupton, 1998; Tulloch & Lupton, 1997).

In the mid 1980s HIV/AIDS became reframed as a heterosexual disease (Lupton, 1998; Treichler, 1999; Tulloch & Lupton, 1997). From 1986 advertisements and television health promotions portrayed an increased sense of urgency as a threat was now posed by HIV/AIDS to heterosexuals (Tulloch & Lupton, 1997). Education programmes set out to reach this new and larger mass audience (Cash, 1996; Tulloch & Lupton, 1997).

America launched a campaign emphasising personal responsibility, 'anyone can acquire AIDS' (Tulloch & Lupton, 1997). Advertisements emphasized the negative outcomes of being involved in 'at risk' behaviours, such as, sharing needles and having multiple sex partners (Cash, 1996; Lupton, 1998; Tulloch & Lupton, 1997).

Britain's campaign in 1986 said 'don't die of ignorance', forbidding images of coffins and tombstones were utilised (Tulloch & Lupton, 1997). Images also appeared of a seropositive person who had progressed to AIDS with Kaposi's sarcoma lesions (which do not appear on all people) and the emaciated body (Lupton, 1998; Tulloch & Lupton, 1997).

In Australia the image of a 'grim reaper' advertisement became well known. This image of AIDS was a medieval figure of death, a skeletal and scythe-carrying grim reaper swathed in swirls of mist (Lupton, 1998; Tulloch & Lupton, 1997). He was shown bowling a ball at collections of people representing middle class Australia. The bowling ball knocked people down as the grim reaper raised its arm in victory celebrating its strike (Tulloch & Lupton, 1997). The message within this image is that prevention is the only way to stop the spread of AIDS and if you have sex, 'have just one safe partner', or 'always use condoms' (Lupton, 1998; Tulloch & Lupton, 1997; Watney, 1993).

Essentially the educational message was, and in many ways still is, use condoms and refrain from multiple sex partners. Feminists argue that these messages are not only inappropriate for most women but fail to take into consideration the social and political construction of gender and sexuality (Pinch, 1994; Taylor, 1995; Treichler, 1997). They argue that the promotion of condom use for women encompasses an inherent fundamental problem (Doyal, 1994; Gorna, 1996; Taylor, 1995; Treichler, 1997).

Feminist scholars believe men have the power to choose or reject sexual partners and to insist or demand sexual gratification to fulfill their 'natural' needs (Sosnowitz, 1994; Wilton, 1994a). Feminists believe that women in submissive roles are placed in positions of powerlessness and have in many cases, little or no say in the negotiation regarding sexual decision making (Kline, Kline, & Oken, 1992; Pinch,

1994; Sowell, Moneyham & Aranda-Naranjo, 1999a; Zierler & Krieger, 1998). Studies also indicate women who challenge the power of men who demand sex may place themselves at risk (Schneider & Stoller, 1945; Sherr, Hankins, & Bennett, 1996; Treichler, 1997).

Secondly the condom has been promoted and represented as a protective measure against sexually transmitted disease, including HIV. But as Taylor (1995) explains, condom use has in the past been associated with illicit sex, sex with prostitutes, one night stands and sporadic sexual encounters. Therefore condom use is seen by many as a sign of mistrust which requires justification (Cash, 1996; Maxwell & Boyle, 1995). For many women in positions of powerlessness, negotiating safe sex or condoms for protection is not only difficult but places them in positions of risk, including rape (Maxwell & Boyle, 1995). Studies have shown that condom use for many women challenges issues of trust, fidelity and intimacy, and brings a fear of violence and the risk of economic dependence (Cash, 1996; Kline, Kline, & Oken, 1992; Paul, et al., 1995; Pinch, 1994).

Research also indicates that for women who have one lifelong partner or lifetime serial partners, condom use has no bearing at all (Cash, 1996; Gupta, Weiss & Mane, 1996). Education campaigns promote women as safe if they stay in long term relationships. Therefore, most of the world's women who are in monogamous relationships may not consider themselves at risk within their relationships with male sexual partners (Cash, 1996; Gupta, Weiss, & Mane, 1996). The condom message, and refraining from multiple partners does not inform women in monogamous or serial monogamous relationships that they too are at risk (Cash, 1996). The message both conveys and maintains a message that only promiscuous women get AIDS; this in turn, reinforces existing stigma and adds to misinformation (Schneider & Stoller, 1994; Treichler, 1997).

Prostitutes who do have multiple partners are said to have in general a heightened awareness of unprotected sex (Gorna, 1996; Gupta et al., 1996). They know the risks of not using condoms (Alexander, 1994; Cash, 1996; Gupta et al., 1996). But prostitutes are reported to forego the use of condoms with trusted regular non-paying clients and lovers (Cash, 1996). Sex workers may therefore believe that they are not

at risk with regular partners or they have trust in their partners (Cash, 1996; Gorna, 1996; Gupta et al., 1996). Research also indicates that prostitutes are in a better position to negotiate condom use when the commercial nature of the relationship is known to both parties (Cash, 1996; Gupta et al., 1996).

These assertions demonstrate that women are vulnerable in many situations. Research also indicates that even though women may be aware of their male partner's infidelity many still feel unable to change behaviour as it could jeopardize physical safety and economic stability (Cash, 1996; Gupta Weiss, & Mane, 1996; Pinch, 1994; Schneider & Stoller, 1994; Wilton, 1994(a); Zierler, 1998). It is the belief of many feminist scholars that when a woman insists on using a condom she must weigh up the possibility of personal rejection, violence, or withdrawal of economic dependence, whatever her occupation or circumstances (Doyal, 1994; Gorna, 1996; Schneider & Stoller, 1994; Treichler, 1999).

Feminist scholars therefore believe that advising women in AIDS prevention to use condoms and refrain from multiple sex partners assumes that women have the power, or can attain the power, to change the outcomes of sexual encounters (Doyal, 1994; Gorna, 1996; Schneider & Stoller, 1994; Treichler, 1999). Men still hold the decision making power about sexual activity in most societies and many feminists believe that targeting women advocating condom use, and reducing sexual partners, misses the opportunity to challenge masculine cultural and sexual norms (Alexander, 1994; Cash, 1996; Gupta, Weiss & Mane, 1996; Pinch, 1994; Sowell et al., 2000; Zierler & Krieger, 1998). Other feminists comment that targeting heterosexual and bisexual men in prevention measures also poses risks (Preble & Siegel, 1996). Preble & Siegel (1996) comment that targeting men not only means relying on men's dubious compliance but also misses the opportunity to empower women (Preble & Siegel, 1996). To date effective AIDS prevention programmes for women in New Zealand are yet to emerge.

2.4.2 HIV/AIDS and androcentric research

Feminist analysis of research on women and HIV/AIDS as previously indicated noted the lack of medical quantitative research with a focus on women. But there is also a lack of social and qualitative research explaining women's experience with the disease (Ankrah, Schwartz & Miller, 1996; Kendall, 1996; Pinch, 1994).

Quantitative research on HIV/AIDS remained male dominated until the late 1980s when women and pregnancy became a focus (Doyal, 1994; Gorna, 1996; Kitzinger, 1994; Schneider & Stoller, 1994; Sherr, Hankins, & Bennett, 1996; Treichler, 1999). When qualitative research became an accepted form of research, men were still the major focus of HIV research (Kendall, 1996). Recommendations from research studying men's behaviour supported STD programmes for men, condom programmes for men and prostitutes, and partner reduction programmes for men (Kendall, 1996). Feminist scholars argue that women were only targeted in research for the roles they play, as 'vectors' of the disease i.e. sex partners of injecting drug users, prostitutes or perinatal transmissions (Gorna, 1996; Kendall, 1996; Pinch, 1994; Treichler, 1997).

Research on women and HIV increased in the late 1990s, but feminists comment that there is still an urgency to focus on women's expressions of their experience of being HIV positive. They argue that there is a need to incorporate women's subjective experience on the multiple facets of their lives and roles along with the cultural and social structure of their particular society (Preble & Siegel, 1996; Schneider & Stoller, 1994; Sherr Hankins, & Bennett, 1996). This research would include special emphasis on sexual roles and power relationships (Taylor, 1995; Treichler, 1997; Weeks, Schensul, Williams, Singer, & Grier, 1995; Withell, 2000). Feminists acknowledge that in the late 1990s women's vulnerability has been recognized as an issue, but much more needs to be done to address gender issues, social justice and human rights. Preble, & Siegel (1996) believes that there is an absence of research that analyses the negotiation and decision making process between heterosexual partners.

It is the belief of many feminist scholars that one way of achieving more women focused research is by using a qualitative research approach, conducted in an atmosphere supportive of women's points of views (Harding, 1987b; Maynard & Purvis, 1994; Patton, 1990; Reinharz, 1992). This could be achieved by conducting interviews that are culturally and politically sensitive to particular women's environments (Kendall, 1996; Maynard & Purvis, 1994; Reinharz, 1992). Sensitive issues such as privacy should be particularly emphasized in the context of HIV (Kendall, 1996; Lather & Smithies, 1997; Lee, 1993). Same sex interviewers are seen as imperative, along with ethnographic and participant observation research methods (Lather, 1991; Lee, 1993; Maynard & Purvis, 1994; Reinharz, 1992). Focus groups are also espoused by feminist researchers but they have the potential to reduce privacy in the case of HIV/AIDS issues.

Although qualitative research has become increasingly popular as a form of social research for women, it would appear that in New Zealand that we have followed similar trends in terms of androcentric research for HIV/AIDS. Nationwide surveys and research reports funded by government have focused on men and HIV/AIDS. Realistically, in the late 1980s, the population of HIV positive people was predominately male and this research would have been considered appropriate. But as previously stated, statistics now indicate that despite the increase in women with HIV men and HIV remains the research focus. In 1994 Te Puni Kokiri, (the Ministry of Maori Development) produced the report concerning HIV/AIDS and Maori. In 1997 *Male Call / Waea Mai, Tane Ma* was produced researching men who have sex with men (MSM) and funded by the New Zealand Health Research Council. This was followed up by a further report in 1999 again on MSM covering socioeconomic and cultural issues which may place men at risk of HIV (McNab & Worth, 1999). As previously stated there has been only one nationwide report on women and HIV in New Zealand produced in 1993 (Brander & Norton, 1993). This report included demographic data along with identifying issues and resources needed and available for women who were HIV positive. It also included issues and resources for women who care for people with HIV/AIDS.

One of the most recent research projects in New Zealand is under way at present and is coordinated by the La Trobe University in Melbourne Australia in collaboration with the New Zealand AIDS Foundation. Its aim is to recruit 300 people living with HIV/AIDS in New Zealand to complete a questionnaire, the outcome of which is to study nationwide the social and clinical experience of living with HIV/AIDS. The promoters of the survey hope that women will take part.

2.4.3 HIV/AIDS and paternalistic health care

Feminist literature not only critiques the androcentric nature of research and HIV/AIDS but it also has focused its attention on a critique on health care services provided for people living with HIV/AIDS. It is suggested that the health service provided to HIV positive persons necessitates a rethink to ensure that women have greater access and quality of care (Meredith, Delaney, Horgan, Fisher, & Fraser, 1997)

Until recently most medical care and support service programmes for HIV/AIDS in the developed world have been geared towards white homosexual males (Ankrah, Schwartz & Miller 1996; Meredith et al., 1997; Sowell, Moneyham, & Aranda-Naranjo, 1999a). Research indicates that not only do women present late to these facilities, but they often feel uncomfortable in the provided environments and are consequently less likely to use the services (Meredith et al., 1997; Sowell et al., 1999a). Research also indicates when women do confront the health care systems in many instances they are ignored or made to feel marginalised, and are recognised only in their roles as mothers or prostitutes (Ankrah et al., 1996; Sowell et al., 1999a). Studies in America have shown that as more women attended health services they not only had to confront issues of being pregnant or a prostitute, but faced issues surrounding class, race and gender (Ankrah et al., 1996; Kline, Kline, & Oken, 1992; Pinch, 1994; Sowell et al., 1999a; Zierler & Krieger, 1998). A recent survey in America of 939 HIV positive clients from an AIDS health service found women and minorities used the services at a significantly lower rate than men and whites (Sowell et al., 1999a). The authors of this report suggested that social, racial and ethnic differences may make minority women feel uncomfortable and less likely to use available services (Sowell et al., 1999a).

Overall research on the most appropriate health care for women with HIV infection reports that much must be done to increase the acceptability of health care facilities for women and to challenge existing care models (Ankrah Schwartz, & Miller, 1996; Meredith, Delaney, Horgan, Fisher, & Fraser, 1997; Sowell, Moneyham, Aranda-Naranjo, 1999a).

In New Zealand identifying available resources and resource requirements formed part of the aims of the Ministry of Health report in 1993 involving HIV positive women (Brander & Norton, 1993). Fifteen HIV positive women were interviewed and results indicated 'some women' (percentage not supplied), experienced instances of 'mistreatment' and a complete absence and or refusal of support, while others felt satisfied with the service provided (Brander & Norton). Within this report, providers of some key services also identified the lack of appropriate information available to offer women at the time of testing (Brander & Norton.). A more recent study of New Zealand health services and their appropriateness for women has yet to be conducted, but it is hoped a survey underway at present will provide gender specific data to analyse.

2.4.4 Lesbians with HIV/AIDS

Lesbians are largely absent from the literature on HIV/AIDS and an education campaign for them is a very recent initiative. It would appear that research into the vulnerability and risk of transmission of women who have sex with women is an extremely low priority (Hunter & Alexander, 1996; Richardson, 1994b; Stoller, 1994).

Early literature assumed that lesbians were not at risk of HIV infection, but as feminist scholars point out there is a lack of epidemiological data to either confirm or deny this claim (Richardson, 1994b; Treichler, 1997). The CDC data did not ask women if they had sex with women, therefore if women did not identify as lesbian they were presumed to be heterosexual (Richardson, 1994b). It was not until 1993 that CDC had a classification as lesbian, for women who were HIV positive (Hunter & Alexander, 1996; Stoller, 1994; Treichler, 1997).

Another complicating issue is the definition of the term lesbian. The simplest term suggest that lesbian means a woman who has sex with women. However as with most other social groups lesbians live a range of lives, identities and behaviours (Gorna, 1996; Hunter & Alexander, 1996; Richardson, 1994b; Stoller, 1994). A growing number of studies suggest that there are heterosexual behaviours among women who have sex with women (Hunter & Alexander, 1996). Lesbians also marry and have children, while others are involved in the sex industry as this is a major source of income for poor women in developed and developing countries (Gorna, 1996; Hunter & Alexander, 1996). Still others live in heterosexual relationships for fear of discrimination and stigma (Hunter & Alexander, 1996; Richardson, 1994b; Stoller, 1994).

This evidence indicates that the risk for lesbians and bisexual women of HIV infection, in the industrial countries, is the same as those described for heterosexual women. Risks include injecting drug use, unprotected vaginal or anal intercourse with a man, and unscreened blood transfusions (Hollibaugh, 1994; Hunter & Alexander, 1996; Stoller, 1994).

Some lesbian health workers and feminists believe there are other reasons why lesbians have been left out of the HIV debate. Richardson (1994) comments that the dominant construction of lesbian, in the sexual sense, means that essentially lesbians do not have 'real' sex and therefore cannot transmit the virus (Richardson, 1994b). This reflects in part the attitude of the phallocentric view that 'real' sex has to include the act of placing a penis in the vagina (Gorna, 1996; Richardson, 1994b).

Statistics suggest that there have been five possible cases of women to women transmission since 1984, but none have been confirmed through virus matching determining if the strain of one virus passed to another is genetically identical (Treichler, 1999). Therefore little is known about HIV transmission risk between women. A study is reported to be in progress, funded by the CDC which will assess the risk of women to women transmission and identify the types of sexual behaviours of lesbians who are HIV positive (Treichler, 1999).

Feminist scholars argue that women who have sex with women need information on how to protect themselves and their partners from HIV infection. Lesbian activists continue to advocate for increased research on lesbian transmission rates (Hollibaugh, 1994; Hunter & Alexander, 1996; Richardson, 1994b; Stoller, 1994). HIV positive lesbians have been invisible with very little information available regarding the risk of transmission to other women.

2.5 Nurses' Discourse of HIV/AIDS

Nurses have been provided with the etiology, epidemiology and details of transmission of HIV/AIDS from the start of the epidemic through to the present day. But research also indicates that HIV/AIDS brought with it a complexity of issues that has challenged nurses' ability to provide quality and equity of care (Hodgson, 1997; McCann, 1997; McHaffie, 1994; Robinson, 1998).

In the 1990s, almost ten years into the epidemic, research into nurses' attitudes related to HIV/AIDS became a focus. Research has emerged from the United States and the United Kingdom and more recently in Australia, and similar findings have emerged (McCann, 1997; McHaffie, 1994; Robinson, 1998; Valimaki, Suominen, & Peate, 1998).

Many nurses studied in the early and mid 1990s were reported to have fears and negative attitudes towards people with HIV/AIDS (Hodgson, 1997; McCann, 1997; McHaffie, 1994; Robinson, 1998). Homophobia, dislike of intravenous drug users, and fear of AIDS were attitudes expressed by many registered and training nurses (Valimaki et al., 1998). Hodgson (1992) reports that research also indicated that drug users tended to produce negative attitudes because they were seen as untrustworthy and irresponsible. Nurses identified issues concerning fear of infection for themselves and beliefs about the right to refuse to care for HIV positive patients (Robinson, 1998). Religious attitudes and reports of describing people with AIDS having only 'got what they deserved' were also highlighted (Robinson, 1998; Valimaki et al., 1998).

Since the 1990s education programmes have improved. Studies have recommended that it is essential that both nursing students and qualified staff gain insight into their own values and prejudices thereby identifying areas of concern and educational need (McCann, 1997; McHaffie, 1994; Robinson, 1998; Valimaki et al., 1998).

Nursing educators believe that HIV and AIDS education should be set in the context of sexuality, infection control, palliative care and nonjudgmental attitudes to lifestyles (McHaffie, 1994; Robinson, 1998). Studies also indicate a clinical component is important, indicating that positive attitudes are associated with the direct experiences of knowing or caring for people with HIV/AIDS (McHaffie, 1994; Robinson, 1998).

New Zealand research into nurses' attitudes and concerns surrounding issues of HIV/AIDS was published in 1993 and 1994 (van Wissen & Siebers, 1993; van Wissen & Woodman 1994). The findings did emphasise the need for further education with respect to nursing care of HIV positive patients, and more awareness of universal precautions along with the genuine risk of HIV/AIDS transmission.

The most recent review of the literature contends that a shift is being made towards a more positive attitude (Witt Sherman & Ouellette, 1999). It found that the majority of nurses had tolerant attitudes towards individuals with HIV (Witt Sherman & Ouellette,). These authors feel that education, national awareness and the increase of AIDS in the heterosexual population and children may be responsible for increasingly positive attitudes. Missing from the literature is the attitude nurses have regarding women and HIV.

Educating nurses about HIV and AIDS and facilitating the process of exploring student attitudes and values requires a skilled teaching staff. Finding staff with these skills, plus opportunities for nurses to care for patients in countries where the prevalence of HIV/AIDS is low, can be problematic.

2.6 Conclusion

The literature has identified areas of HIV/AIDS research where there is a lack of reference to women and their unique features both clinically and socially. Feminist literature maintains that initially there was a male dominated discourse surrounding HIV/AIDS which may have been appropriate at the time, due to the discovery on HIV in gay males. But as women also became identified as HIV positive, medical and social research remained focused on men. Feminist scholars believe that medical interest in women only became a feature when it was discovered women could transmit the virus to the 'innocent' foetus. The aim then became to lower the rate of transmission to infants by encouraging women with HIV to avoid pregnancy and offer abortions to HIV positive women who were pregnant.

Two decades into the epidemic feminist scholars believe women still remain invisible in medical research. Information for women about different tolerance levels to new antiviral drugs is lacking along with any clear indications of differences in clinical manifestations. Research into women controlled protective methods such as physical and chemical barrier methods remain minimal also.

Gender sensitive research into social issues relating to different experiences for women have only recently been recognised as it was assumed women and men would have similar experiences in living with HIV. As gender issues surrounding HIV/AIDS have only lately been debated this has resulted in many women not identifying with a disease constructed essentially as a 'male disease'.

The following chapter outlines the methodology and method used to conduct this research.

CHAPTER THREE: The Research Methodology and the Research Method

3.1 Introduction:

This chapter describes the methodology and the method chosen to conduct this research. Methodology is described by Harding (1987b) as “a theory of analysis of how research does or should proceed” while the method is a “technique for gathering evidence” (p.2).

Qualitative research is explained in this chapter along with feminist methodology, which has been chosen as the theoretical underpinning of this research. The data was collected using semi-structured interviews and data was analyzed using thematic analysis.

3.2 Qualitative Approach

A qualitative approach implies a focus on human experiences in naturalistic settings (LoBiondo-Wood & Haber, 1994). The qualitative researcher is reported to have less concern for the objective and is more interested in how people make and understand the world (Kellehear, 1993). Qualitative researchers believe the lived world is a social construction and people have an understanding about the world which can be interpreted through stories or narratives (Kellehear, 1993). This interpretation is also shaped by the social, cultural and physical world that surrounds people and the energies and influence that comes from their stories becomes the dominate narrative (Kellehear, 1993; Olesen, 1994). Kellehear (1993) explains that the main aim of the qualitative researcher is to ‘rewrite the narrative’. By this he means to uncover or deconstruct the narrative thereby revealing meanings that people have unconsciously internalized in the course of their daily lives.

This research was undertaken to explore and describe women's experience of being HIV positive in New Zealand. To explore and describe the unique meaning of that experience required a methodology where individuals could contribute their stories in natural settings and explain their reality of that lived experience.

Within this research I am positioned as a woman, a registered nurse working in palliative care, and a feminist. I also have the advantage of working within the only residential environment in New Zealand set up especially for HIV positive people. Within this environment I am aware that few HIV positive women use the provided service. I was curious to find out why. Also in my position as a registered nurse I was very aware of nurses' attitudes and the limited knowledge they had of women and HIV. This research could enable health professionals to have an understanding of the issues experienced by HIV positive women in New Zealand.

Carrier (1995), states

For knowledge to have value to nursing it must offer explanation or illumination of the human experience in ways which allow growing reflection on the quality and applicability of our practice (Carrier, 1995, p.180-181).

3.3 Feminist Research

Theories of knowledge and the way knowledge is constructed have underpinned feminist debate for many decades. Who knows what about whom, who can know, which questions are studied, and how is knowledge legitimized are important questions for feminist scholars (Code, 1995; Maynard & Purvis, 1994; Thorne & Varcoe, 1998).

Theories of knowledge as a primary feminist concern not only address issues of who conducts research and which questions are asked, but also examines to what extent power inequities are embedded in research (Thorne & Varcoe, 1998). Many feminists believe that mainstream research has provided insufficient knowledge about women's health for decades (Reinharz, 1992; Mies, 1991). Therefore feminist

research methodologies are a response to the need for more appropriate approaches to knowledge development (Maynard & Purvis, 1994; Mies, 1991; Reinharz, 1992; Schneider & Jenness, 1994; Thorne & Varcoe, 1998).

Most scholars of feminist research agree there is no 'one' method that can be termed 'the' feminist method. Nevertheless, although there is no clear definition of 'one way' to do feminist research many feminists believe there are some basic principles that determine what is feminist research (Maynard & Purvis, 1994; Mies, 1991; Reinharz, 1992; Thorne & Varcoe, 1998). I have chosen three major feminist research principles to explore and describe women's experience of being HIV positive in New Zealand. These principles are: the validation of women's experiences, the method of research should not be oppressive, and interpretations of observations by the researcher should be discussed and shared with participants so they may benefit from the research (Campbell & Bunting, 1991; Hall & Stevens, 1991). These are elucidated in the following sections.

3.3.1 Validating women's experience

Feminist researchers believe validation of women's experience and ideas should be acknowledged and become a basic and important principle of feminist research (Hall & Stevens, 1991; Harding, 1987a; King, 1994; Sigsworth, 1995). In other words women's experience should be validated and be a legitimate source of knowledge with women as the 'experts' on their own lives (Campbell & Bunting, 1991). Feminists would purport that for too long there has been an ideological belief that masculinity emphasis is the 'norm' (Tong, 1998; Weedon, 1997). Glass & Davis (1998) acknowledge that women's voices are particularly vulnerable to silencing and suppression and comment that exposing women's voices allows them to break free from dominant discourse. Lather (1991) agrees, saying that revealing women's previously invisible experience is one step towards equity in women's social position. Lather (1991) believes that this exposure is the "overt ideological goal of feminist research" (p.71). Most feminists argue that the examination and exposition of the female experience also exposes the social construction of male power in the delivery of knowledge (Glass & Davis, 1998; Hall & Stevens, 1991; Lather, 1991; Maynard & Purvis, 1994).

Women's stories of being HIV positive in New Zealand have yet to be explored. Men's stories and their experience are more readily available. Treichler (1997), in her work with women and HIV/AIDS, comments that if women's voices are not heard, then women lack clear information, narratives, subject positions and identities. Treichler adds that without these identities women cannot make sense of HIV/AIDS information or "act upon it" (p.375).

3.3.2 Non-oppressive Research

The second feminist principle I followed was that research should not be oppressive or harmful to participants (Carryer, 1995; Hall & Stevens, 1991; King, 1994). In other words feminist research should be as meaningful for participants as it is for the researcher. In order to achieve this tenet of feminist research the concept of reciprocity should be integrated into the research process (Acker, Barry, & Esseveld, 1983; Edwards, 1993; Harding, 1987a; Reinhartz, 1992). Being able to reciprocate is seen as not only of benefit to the research and the researcher, but more importantly being useful to the researched (Carryer, 1997; Glass & Davis, 1998; Lather, 1991; Maynard & Purvis, 1994). A reciprocal process involves the researcher contributing something of themselves to the research. A woman as a researcher, researching other women, is said to have experiences and knowledge to share (Glass & Davis, 1998). Feminists believe that this process of sharing allows women to uncover oppression through promoting equality and sharing (Glass & Davis, 1998). Sharing information also encourages an interactive approach which attempts as much as possible to create a non-hierarchical atmosphere, and establishing an equal partnership with participants (Carryer, 1995; Hall & Stevens, 1991; King, 1994).

More recently though, some feminists believe this concept of sharing information is naïve. They state that this special nonhierarchical women-to-women link may not apply in all situations (Acker et al., 1983; Edwards, 1993). Most feminists have now acknowledged that there are structurally based divisions between women on the basis of class, race, education and power differences (Acker et al., 1983; Edwards, 1993). Acker et al explain that while conducting feminist research, they found some women were uneasy when being interviewed. The explanation given by women participants

for their unease was they thought they might not give the 'right responses' especially as the interviewers were from a different class, being from a 'university' (Acker, Barry & Esseveld, 1983).

I also had concerns around this particular issue as I had positioned myself to participants as a white middle-class registered nurse, completing a Masters Degree through a University. As I strove to enhance non-hierarchical research concepts one participant encouraged me with her feedback. After an interview said she was very nervous in the beginning thinking that she would not be able to answer the questions. Her next comment was that she had worried needlessly as she had really enjoyed the interview concerning her life, and living with HIV. I also noticed that during interviews, participants knowing I was a registered nurse and my past experience with HIV often asked for my opinion. More interestingly questions were infrequent around medical treatments or interventions, as many participants knew more about their medications and physical symptoms than I did. Moreover, the questions were around what were the opinions of the other women interviewed and did they have similar issues. I was willing to share this information. Skeggs (1994) concurs with other feminist researchers commenting that she found that by providing answers to questions raised within the research process understanding developed between the participants and the researcher.

There was one further concept I was determined to follow to ensure the research was non-oppressive. I was aware of projects where the researcher achieves their goal, mostly their degree, but the researched are left feeling alone, or having no greater understanding of their particular issues or any greater insight. Therefore as the research continued and I interviewed more women, being able to pass on their concerns and issues appeared to reassure participants they were not alone, that others had similar concerns and ways of coping.

Women asked me why I was doing this research. I explained because of my practical and hands on experience in Africa and also a vast amount of background reading that I had completed the previous year in a university paper concerning women's health, I was now interested in women who were HIV positive and their issues. Being able to explain my reasons, combined with my experience within the field, appeared to

enable women to openly share their experiences. I also felt some form of interaction, sharing and equality had occurred when two participants in particular felt comfortable enough to agree to share the second interview within an environment unfamiliar to them, namely my own home.

Feminists, believing this reciprocal process is part of feminist research, also believe it should be written into the research report providing added interpretation of the data (Harding, 1987a; Lather, 1991). Throughout this report I reveal issues that I shared with participants along with acknowledging my own learning process surrounding issues concerning women living with HIV.

3.3.3 Interpretations discussed and shared with participants.

Hall and Steven (1991) believe that feminist inquiry is done for the purpose of finding answers for women and to assist in the explanations of their own lives, therefore gaining in some way from that knowledge. These authors go on to say the feminist research should be *for* women and not just for health professionals or health agencies who use this information for other purposes. This is in contrast to health research *on* women, which is for the purpose of providing answers *about* women for the medical or health professionals who may use the information as they desire (Hall & Stevens, 1991).

One main aim was that this research would be helpful for participants. A question that was asked of me by one health professional when first attempting access to participants was ‘would this research be of help for participants?’ Not only did I hope that the participants would find the research helpful and the outcomes meaningful for them, but I also hoped that the outcomes of the research would be of value to other women who were HIV positive. Carryer (1997), researching women’s lives and their experiences of embodied largeness, comments that in her research the results were for women to “understand and perhaps transform their own lives” (p.56).

I like Carryer (1997), also had a wish that the research would be thought provoking for health professionals. Carryer explains that not only did she hope that her research

would give an insight into participants' lives, but also nurses who read their stories may use this knowledge as a guide for practice. I also hoped that nurses and other health professionals would read the research even though I admitted I could have no control over how they used this information.

3.3.4 Reflexivity

While adhering to the three principles already discussed to determine what is feminist research, feminist researchers also believe in the concept of reflexivity. Harding (1987), describes reflexivity as the 'what is going on while researching'. Feminists believe researchers need to reflect upon and examine critically the research process, and position themselves within the moral and sociopolitical context of the research (Harding, 1987b; Lather, 1991; Maynard & Purvis, 1994; Stanley & Wise, 1983). Koch & Harrington (1998) explain that reflexivity is characterized by ongoing self-critique and self-appraisal. Examining what is going on while researching means stating your processes, biases and position and identifying this within the research (Harding, 1987). Examining critically and exploring analytically the research process is seen as an essential part of reflexivity and of feminist research (King, 1994).

3.3.5 My Position

Examining my position and biases within this research process, I reflected on my initial contact with HIV/AIDS. This was in the education field as a public health nurse working in secondary schools as a resource person within the sexual health curriculum. At this particular time, in the 1980s, HIV/AIDS in New Zealand was constructed first and foremost as a 'gay disease'. The educational message concerning who was most vulnerable in contracting HIV was gay men, intravenous drug users and prostitutes. This message I took into secondary schools along with videos and written education material. My second contact with HIV/AIDS was in a position in Africa for two years working alongside HIV positive people and setting up support services to assist with the care and wellbeing of all people identified as HIV positive. This experience in 1994 and 1995 changed my perception of HIV. In Zimbabwe being HIV positive included an equal proportion of women and men. On my return to New Zealand in 1995 I decided to increase my involvement in HIV, and worked within the only residential environment for HIV positive people. In New

Zealand there appeared to be no change in the construction of HIV/AIDS. The stereotypical concepts of who was HIV positive were still, in general, gay males, drug users and prostitutes. My enrolment in a woman's health paper in 1999 enabled me to read overseas literature concerning women and HIV/AIDS. Working in Africa and working in New Zealand with HIV positive people enabled me to have two completely different experiences. But one issue I felt needed inquiry was the place of women in HIV discourse. I was interested in women's stories living with HIV/AIDS within New Zealand. Aware of my biases, position and interest in women and HIV, my research topic was formed.

3.3.6 Gender

One final overriding principle that is central to feminist research is gender. Gender is the "basic organizing principle which profoundly shapes/mediates the concrete conditions of our lives" (Lather, 1991, p.71). Most feminists believe that gender is the main focus of feminist inquiry and gender is described as a lens through which an understanding of social order is viewed (Lather, 1991; Reinharz, 1992; Stanley & Wise, 1983).

Feminists believe that there is gender inequality within society and seek to offer a range of different explanations of how femininity is disprivileged and thus women are oppressed (Stacey, 1993). Feminist theory is described generally as a body of knowledge, which seeks to explain women's subordination and oppression in society.

Feminists seeking answers to inequality have developed various 'schools' of thought and feminism can be described as complex as there are a number of explanatory theories. Early feminist theory commencing in the 1960s, attempted to explain reasons for women's oppression. The theoretical range included liberal feminist, radical feminism and socialist feminist theory. Further on in the development of feminist theory psychoanalytic and existentialist feminism developed while today postmodern feminist thought is discussed (Tong, 1998; Weedon, 1997).

Describing each feminist theory is a complex process, but there is a central debate to feminist theory and that is the issue of gender, which offers a challenge to masculine bias. Many feminists believe that social and political thought, even today, marginalises and makes trivial accounts of women's experiences (Beasley, 1999). Beasley (1999) believes that one major problem with mainstream social and political thought is that the experiences of men or a description of men's experience, is presumed to be common to all humans and is therefore universal. Or in other words man is the 'norm' or becomes the standard model, the most dominant, while women are different. Simone De Beauvoir an influential French feminist in one of her major works 'The Second Sex' summed up the difference between men and women. She describes men and women's hierarchical relationship, as 'he' is the subject or absolute, whereas 'she' is the other that is 'not man' (Beasley, 1999; Tong, 1998). Feminists believe therefore that there is assumption of things male being not only 'norm' and 'absolute', but also superior (Beasley, 1999).

Gender is also described in the form of masculinity and femininity within feminist theory. Masculinities and femininities are described as social constructs or in other words patterns of sexuality and behaviour imposed on us by social and cultural norms, of what it is to be male or female (Moi, 1997). Characteristics of femininity are constructed as subservience, humility, modesty, caring for others and dependence, while masculinity has constructed characteristics of assertiveness, independence, rationality and being analytical (Holland, Ramazanoglu, Sharp, & Thomson, 1994b; Moi, 1997). Feminists believe that a patriarchal society defines masculinity as the dominant culture, and society places greater value on masculinity and its characteristics (Beasley, 1999; Evans, 1995). Feminists therefore believe that not only is the concept of masculinity dominant and of greater value within western culture, but it is also perceived as the mainstream of social and political thought and the presumed natural order of society (Beasley, 1999; Evans, 1995; Stacey, 1993; Tong, 1998).

This gender debate is continued into feminist theory and HIV/AIDS. Feminist analysis of HIV/AIDS and gender consider that the social, sexual, political and economical subordination of women has structured the vulnerability of women to this epidemic (Doyal, 1994; Schneider & Stoller, 1994). Feminist thought concerning

women and HIV is that male dominance has prevailed in the construction of this disease and this is reflected in the emphasis of male dominated research, representation and analysis (Treichler, 1997). This dominance therefore perpetuates a view of AIDS as a 'man's disease'; it also means that women are positioned as the 'other'. If the experience of men can be described as universal and common to all humans it is my view that this concept of men as norm and universal discourages a focus on women's issues surrounding HIV and AIDS.

3.3.7 Reliability, validity and rigour in feminist research

Reliable and valid research findings in feminist research have been frequently challenged and criticized especially from the conventional empirical studies. In the positivist empiricist era, reductionism and objectivism was espoused (Hall & Stevens, 1991). Qualitative feminist researchers argue that feminist and qualitative research requires a paradigmatic shift along with new ways of evaluating and conducting rigour (Carrier, 1997; Hall & Stevens, 1991; Webb, 1993). Lather (1991) also argues for the need to go beyond empirical efforts, revise concepts and find more appropriate ways to include interactive dialogue and to capture the objective inquiry.

Reliability, in the traditional sense, is said to be the repeating of an experiment in a different setting and yielding the same results (Hall & Stevens, 1991). Feminists argue that human experiences are unique, particular to context and therefore women's experiences cannot be standardized or tested for repetition (Carrier, 1997; Hall & Stevens, 1991; Webb, 1993). Hall & Stevens (1991) consider that feminist research is best evaluated "by standards of rigour that reflect the adequacy of the whole process of inquiry" (p.20). In other words standards should focus on the whole process of inquiry ensuring outcomes are well grounded, justifiable, meaningful and relevant, which Hall & Stevens (1991) describe as adequacy.

Other feminist researchers have also suggested criteria by which researchers can apply validity and rigour to feminist research. Acker, Schwartz, & Miller (1983) uses the term 'worthwhile' and 'adequate' in terms of validity. This concept is

concerned with the emancipatory goal of the research or in other words the researcher should ask to what extent does the research have an emancipatory emphasis. Also the voices of participants are heard, does the researcher demonstrate a reflective approach and does the analysis of the research reveal the social influences of those being studied.

Hall & Stevens (1991) in a discussion on rigour in feminist research, describe criteria involving reflexivity, credibility, rapport, coherence, complexity, consensus and relevance. These authors believe that if these criteria can be identified within the research then reliability and validity can be measured. Although I could not immediately identify each criteria in isolation I was particularly aware of the issues of reflexivity and constantly considered my own values, assumptions and motivation. To be completely without bias in feminist research is considered impossible, and feminist researches comment that bias should be acknowledged within research and addressed through the process of reflexivity (Carryer, 1997; Lather, 1991; Webb, 1993).

Lather (1991) offers guidelines by which validity may be evaluated using criteria such as construct validity, catalytic and face validity. I have used these criteria as guidelines to evaluate the validity, reliability and rigour within this research project and these are discussed below. An analysis of these follows.

3.3.7.1 Construct Validity

Construct validity can be evaluated by means of reflexivity. In other words this construct asks the researcher to make clear and report on throughout the research, the decision-making processes reflected in the content and the process (Lather, 1991). Hall & Stevens (1991) comment that construct validity is a reflective approach that “fosters integrative thinking, appreciation of the relativity of truth, awareness of theory as ideology and willingness to make values explicit” (p21). If the researcher can report on her research critically and analytically in a step by step process, addressing her own beliefs and values, which are outlined in the research report, this is considered to be reflective of a process (Maynard & Purvis, 1994). From the very beginning of the research process, in a personal journal, I made documentation of the

step by step process, including my feelings and thoughts before and after interviews, and my changing thoughts based on participants stories. This journal was referred to constantly especially during data analysis, and the decision trail and actions are highlighted throughout the research report.

3.3.7.2 Face Validity

This concept is described as important for confirmation of emerging data (Lather, 1991). It requires the researcher to return the emerging analysis, data, and tentative conclusions to participants for their comments and reactions, then to refine it according to their reactions (Lather, 1991). Most feminist researchers would agree that good feminist research involves getting back to the participants with tentative results and refining results in light of their reactions (Acker, Barry, & Esseveld, 1983; Hall & Stevens, 1991; Lather, 1991; Reinhartz, 1992; Webb, 1993). After considerable reading and rereading of the data and the tentative establishment of four themes, I returned the themes to all participants for their comments. Written comments returned within one month, many with confirmation of themes and how relevant they were, along with added comments to reinforce the emerging ones.

3.3.7.3 Catalytic Validity

Lather's definition of catalytic validity is:

The argument for catalytic validity lies not only within recognition of the reality altering impact of the research process, but also in the desire to consciously channel this impact so that respondents gain self understanding and, ultimately self determination through participation (1991, p.68).

This form of validity is concerned with the notion of the change promoting aims of feminist research. This way of validating feminist research is to ensure a focus on the participants and their full involvement in the research process. Not only should the interview process itself be seem as interactive, but also an awareness of participants knowing their own reality in order to transform it (Lather, 1991). As much as possible I tried to be collaborative in the research process with each participant.

I was also aware during the interview process and sometimes after the interviews of participants' sense of their own reality. Participants' sense of their own reality is demonstrated in the following two chapters where I discuss data analysis. Some participants felt that taking part in this research may in some way may help change the social construction of women and HIV.

3.3.8 Nursing and feminist research

Speedy (1991) reports that nursing and feminism have had an uneasy past, with nursing historically shunning the principles of feminism. Qualitative research on the other hand has gained support from nursing scholars as it is reported to be more appropriate towards understanding an individual's lived experience in the natural world (LoBiondo-Wood & Haber, 1994). It is only in the past decade that there has been, amongst some nursing scholars, a belief that by adopting feminist concepts and qualitative feminist research the development of nursing theory and practice will be enhanced (Carryer, 1995; Glass & Davis, 1998; Hall & Stevens, 1991). Feminism has much to offer nursing today as it questions the appropriateness of the traditional 'scientific' modes of research, especially surrounding a topic describing women's experience of being HIV positive.

Nursing is described as a discipline of 'caring' or assisting people through life and death processes (Speedy, 2000). However, especially today, nursing cannot practice in isolation away from the sociopolitical and economic influences affecting the health status of those for whom they care. Carryer (1995) believes nursing must offer explanations, or at least insights of the human experience, in order to reflect on the quality and the appropriateness of nursing practice.

Speedy (1991) also argues that feminist principles are congruent with nurses' integral concept of caring and feminist research offers alternative paradigms in studying women's health issues looking beyond the disease oriented medical model. Qualitative research along with feminist principles searches for the subjective and

reflective approach challenging previous knowledge patterns of objectivity and statistical data.

Although not all research within nursing would be considered to be appropriate for feminist research, an awareness of the existence of a methodology to seek out subjective knowledge agrees with the ethic of 'care' central to nursing care (Carryer, 1997; Speedy, 1991).

Up until recently nursing has been slow to acknowledge its sociopolitical role and feminist research principles, which address issues of race, class and gender oppression. Feminist nursing researchers comment that feminist research enables nurses to examine prior knowledge for androcentric and ethnocentric aspects of social construction (DeMarco, Campbell, & Wuest, 1993). Nurses who have been involved with feminist nursing research believe concepts of patriarchy, misogyny, power relationships and relationships amongst nurses can all be addressed with feminist insights and analyses (Bunting, 1994; Campbell & Bunting, 1991; De Marco et al., 1993; Parker & McFarlane, 1991; Speedy, 1991). It is therefore argued that following feminist principles within nursing can offer alternative paradigms to a dominant patriarchal view (Carryer, 1995; Glass & Davis, 1998; Parker & McFarlane, 1991; Speedy, 1991).

Embedded in the opposition to the suggestion of feminist research, is the mythical concept that feminism is against men and could damage women and children as well. Feminist scholars reply to this criticism by pointing out that feminist research has a focus on the critique of domination and exposes existing structures that repress or alienate all people (Speedy, 1991). Speedy (1991) believes feminist principles allow for an examination of women's experience from a woman's perspective for all women, enabling nurses to develop more understanding of the women's experience and equip nurses with new knowledge. It is therefore suggested that feminist research within nursing can address structures of exploitation of all people, not only women. Finally I believe feminist research has the potential to create a paradigm shift, an alternative framework for nursing theory and practice and has the potential for new knowledge to support and enhance nurturing which is the centrality of nursing care.

3.4 Research Method

With consideration of the above methodological issues this section describes the method undertaken in this thesis. Uppermost in my mind were the principles of feminist research including reciprocal and reflective processes.

3.4.1 Participant Selection

Following full ethical approval of two ethic committees, Massey University and Auckland Ethics Committee, along with the support of the New Zealand AIDS Foundation (NZAF), participant access was the next step. I approached a support centre for HIV positive people in one city region, which included a network of social workers, counselors and volunteers. Explaining my research outline to this particular support network was initially met with some concern. Their concerns arose around maintaining confidentiality for the target group, who the research was for, and would women be willing to take part in research and talk with a researcher they did not know. After some discussion a meeting was set up with the part-time coordinator of 'Positive Women' a network for HIV positive women. The support of the proposed research was demonstrated when she agreeing to post my flyers to all women on her list.

I approached the editor of a local magazine, which publishes monthly information specifically for all HIV positive people and asked it they could place the flyer within the next posting. Although the magazine goes to male and female HIV positive people, within a selected geographical area, it also has a distribution to institutions, caregivers and people supporting people with HIV. I also approached the only inpatient unit, specifically for HIV positive people in New Zealand. The staff placed a flyer on their notice board.

Women interested in taking part in the research were able to make contact by cell phone. As only three women made contact within the first four weeks of the release of the flyers, I decided to widen my area of contact. With the support of the editor of a New Zealand nationwide HIV magazine, I wrote a small article about myself, and my intended research, which was included in next month's issue. This resulted in the

biggest response and although it meant more travelling it enabled me to meet the initial number of women I intended to interview. A bonus was that the cohort included women living in rural areas of New Zealand.

3.4.2 The Participants

Nine women participated in this research. In geographical terms three women lived in cities, the other six women lived in rural or semi-rural areas of New Zealand. Their ages ranged from 19 to 45 years old. One out of the nine women did not have children. One participant was pregnant at the time of interviewing, and three women had grandchildren. Two participants were in paid part-time employment, while another was studying to finish her degree. One participant identified as Maori, seven as New Zealanders and one as Australian. The length of time participants had been HIV positive ranged from one to thirteen years.

I interviewed nine women out of a possible 192 (AIDS Epidemiology group, 2001). The findings cannot be generalized as representing all HIV positive women. Qualitative feminist research does not speak for all women and works from the premise that woman is not a universal category (Olesen, 1994). Feminist scholars reject conceptions of women as a homogeneous category and recognise and emphasis differences in terms of power, culture, race and education (Beasley, 1999). In other words a qualitative feminist researcher acknowledges differences amongst women, and recognises their differences within contextual and historical settings (Carrier, 1995).

3.4.3 Ethical Issues

The flyer only briefly outlined my research intention and so it was suggested by the 'Positive women's' coordinator that we also include the information sheet in the mail-outs so that women had as much information as possible as to whether or not to take part. This was also the format requested by a social worker in another city area assisting in a mail-out. Therefore, in some circumstances, women who made the initial contact already had a more detailed outline of my research intent. When women made contact by cell phone I again outlined the purpose of the research and

made a time and date to meet. On the first visit I once again went over the information sheet, especially with women who had not seen it initially, and explained they may still decline to be interviewed if they wished. All women, after the first meeting, consented to be interviewed and signed a consent form. One woman asked if a social worker could be present during the interview, which was agreed between all parties. The other eight women preferred to be interviewed alone. All women also agreed to being audio-taped and were aware they had the right to have the audio-tape turned off at any time during the interview.

The participants were asked to use a pseudonym by which they would be known throughout the study in order to maintain their anonymity. Seven women chose their own pseudonyms and two women requested that I choose a name. A pseudonym was agreed upon for these women at the end of the interviewing process. All transcripts were sent to the participants by post for verification and clarification. At this stage participants were asked to make alterations to their transcripts if they felt they had changed their minds over some statements or wished to expand on some dialogue. This is in keeping with a feminist approach to the research process, which enables the participants to have some say over the emerging data. Information that may identify women, such as place names and names of friends or relatives were removed from the final transcripts in keeping with the ethical requirement of anonymity.

One of the biggest ethical issues for myself as researcher was approaching a research topic, which is considered by many as a 'sensitive topic'. A 'sensitive topic' is described by Lee (1993) as any research which poses an intrusive threat, that is, "dealing with areas which are private, stressful or sacred" (p.4). This same author goes on to say that 'sensitive topics' also relate to the study of possible deviance, which may involve revealing information that may be stigmatizing or discriminating. Sensitive topics are also said to include those which impinge on politics, in the widest sense, controversial issues, and topics causing social conflict (Lee, 1993). All of these aspects could be inherent within this particular research.

One further ethical issue was that I also felt I could not interview women who were HIV positive that I had nursed. I was concerned that my role as nurse and the new role of researcher would be confusing and could involve a power imbalance.

Holloway and Wheeler (1996) comment that if the nurse is confronted with the dual role of nurse and researcher and this distinction is not clear it may affect the essential character of the research topic.

3.4.4 Interviews

All interviews were conducted at a site requested by participants and all but two chose their own familiar home environment. Two women preferred my home for the second interview. Interviews were semi-structured to ensure as much as possible a relaxed atmosphere where these women's stories could be explored creatively without a set of ordered questions disrupting the flow of conversation. Feminist researchers support the use of semi-structured interviews commenting that this method allows women's voices to be heard within their particular context, allowing them to choose their style of language rather than the researcher's and allows reflective involvement of both parties (Hall & Stevens, 1991; Oakley, 1981; Reinharz, 1992). Oakley (1981) suggests that traditional paradigms of interviewing, which included a one-way process of the interviewer eliciting information and not responding to questions asked by the participants, creates problems for feminist interviews when looking for validation of women's subjective experiences.

The timeframe for interviews and the number of interviews was a question asked by most participants. My response to the timeframe was approximately one hour but I remained unsure, as I needed to take into consideration the participants' health status. I was unsure about the number of interviews, considering two to be appropriate. The length and number of interviews is debated within qualitative and feminist research and Burnard (1997) comments that we do need to acknowledge that we cannot claim to have an intimate understanding of the ways in which other people live and think after one hour of discussion. Although I understood I could not claim to have absolute understanding of participants' life worlds, I felt that I could gain some insight, even after only one, one- hour interview. Burnard (1997) comments that what also needs to be taken into consideration is that, in principle, we are faced with "the next account from this person of the same events may be different" (p.255). After each interview and the return of the transcripts participants were asked if they wanted another interview. Five women elected two interviews, the other four women

chose to be interviewed only once commenting they felt they had covered all, or most, of what they wished to say.

Asking women about their private lives and a topic considered as 'sensitive' such as HIV/AIDS (Lee, 1993), placed myself as the researcher in a position of being intrusive. My position as a nurse and feminist researcher was explained to the participants, along with my experience working in Africa with HIV/AIDS and my present working position as a palliative care nurse. I wished to inform participants of my life experiences to enable interviews to be as reciprocal as possible, in line with suggested feminist principles of feminist research (Maynard & Purvis, 1994; Reinharz, 1992).

Transcription of the tapes was performed by myself. Transcription consisted of listening to small segments of the tape, pausing the tape recorder and typing directly into a computer. Observing medical secretaries at work typing letters with the aid of headsets and dictaphones I felt I could transcribe all my interviews more efficiently with this added device. This involved borrowing the machine from medical records in the weekends when the typists were not using them, and returning the machine Monday morning. It was a long process at the time, with that added disadvantage of time restraints of equipment, but the advantage was it allowed me to become very familiar with the data.

On a cautionary note here, it is essential to have interviewing equipment in full working order with backup equipment should something fail. In one interview, where I thought I had recorded our hour long interview, when I played it back it contained only very undistinguishable sounds. This particular participant amazingly understood and agreed to be interviewed again, at a later date, but this time I was equipped with a new, up to date, recording machine.

3.5 Method of Data Analysis

Thematic analysis was used as the method for analysis as it is said to be applicable to qualitative research and it makes sense of data from semi-structured interviews (Burnard, 1991).

Morse and Field (1995) describe thematic analysis as: -

The search for and identification of common threads that extend throughout an entire interview or set of interviews. Themes are usually quite abstract and therefore difficult to identify. Often the theme does not immediately ‘jump out’ of the interview but may be more apparent if the researcher steps back and considers ‘what are these folks trying to tell me?’ (p.139-140).

DeSantis & Ugarriza (2000) comment that themes emerge from the data and are not superimposed on the data by the researcher. In other words the researcher does not impose her/his ideas of themes, and then set forth to seek out supporting evidence of their existence. DeSantis & Ugarriza (2000) explain that themes may be “explicitly expressed and openly promoted” (p.363) by participants, but that in the majority of cases themes tend to be more implicit or embedded. The skill of the researcher is to extract the inferred data converting them from emic-implicit to etic-implicit meaning (DeSantis & Ugarriza, 2000).

Burnard (1995) describes thematic analysis as a representation of participants’ feelings, beliefs, thoughts and utterances in an organized and systematic way.

Theme definition as described by DeSantis & Ugarriza (2000) is:

an abstract entity that brings meaning and identity to a recurrent experience and its variant manifestations. As such, a theme captures and unifies the nature of basis of the experience into a meaningful whole (p.362).

While collecting the data and at its completion I was careful not to assume what would emerge as themes within the research. Instead I looked for themes that maybe more hidden, but captured meaningful experiences for the participants

Researchers using thematic analysis comment that to find and identify themes certain criteria should be followed (Boyatzis, 1998; Burnard, 1991; DeSantis & Ugarriza, 2000; Kellehear, 1993; Parahoo, 1997). Kellehear (1993), comments that as thematic analysis is subjective, this means it is more demanding on the individual researcher to analyse the data, especially when themes do not emerge immediately. In identifying themes within this research I have followed criteria suggested by Boyatzis (1998), Burnard, (1991), DeSantis & Ugarriza (2000), Kellehear (1993) and Parahoo (1997).

There is a general consensus amongst researchers using this method that one of the first steps is to read and read again the transcripts and become immersed in the data (Burnard, 1991; Kellehear, 1993; Parahoo, 1997). This process is described as an attempt to become more aware of the world of the participant and look inside another person's world (Burnard, 1991). Boyatzis (1998) describes this stage as trying to make sense of data developing codes and being open to all information. This same author goes on to say that it helps to have excitement and an interest in the raw data information, but adds researchers should overcome the tendency to impose or read into the raw data their own values and biases.

The next suggested step is while reading the data to look for recurring experiences, topics or events and write down headings or categories, or general sets of ideas or terms as they emerge (Burnard, 1991; Kellehear, 1993). Burnard (1995) describes this step as 'open coding' where categories are freely generated. DeSantis & Ugarriza (2000) describe categories as a general set of ideas that convey a wholeness, pattern or repetition. Boyatzis (1998) adds that research using this method requires long hours of information analysis before interpretation.

As I typed the transcripts repetition of single words and groups of words emerged and I quickly wrote them down. I then reread each transcript as a whole making

notes and then compared them to the initial repeating words or groups of words I found while transcribing. Twenty-five headings were found at this point.

Following this the next step is described as narrowing the themes down into a more manageable sense with accompanying statements (Burnard, 1991; DeSantis & Ugarriza, 2000). In other words there is now a sense of reductionism as the number of categories are 'collapsed' down into ones that are similar (Burnard, 1995). I had at this stage reduced the headings or categories to ten, which I considered was still too many and looked for themes that appeared similar. Researchers familiar with this method of analysis advise that it is important to have multiple copies of transcripts, which allow for sections to be cut out and labelled, but also maintain a single complete copy of each transcript for reference (Burnard, 1995; van Manen, 1997). Although I was cutting and pasting excerpts of dialogue from transcripts I did have locked away securely in my filing cabinet full complete copies of each participant's transcript.

It is also pointed out at this stage that merely to cut out strings of words devoid of context is to "risk altering the meaning of what was said" (Burnard, 1991 p.463). Not only did I have in mind the relevance of context while I cut and pasted excerpts of transcripts I also felt I was making decisions about what was to stay in the analysis and what would be omitted. What stays in and what does not is also an issue debated by qualitative researchers. Burnard (1995) suggests at this stage that the researcher has an option of just presenting the raw data and allowing the reader to seek their own meaning. This option seemed pure, but hardly practical, given the amount of data gathered. Sandelowski (1993) states that in qualitative research no two researchers will arrive at the same result given the same data. The concern over whether a text has 'true' interpretation has irked those of the positivist quantitative traditions who feel that this ambiguity undermines the issue of reliability and validity. Kellehear's (1993) view of interpreting data says that this means reading the data several times and looking for repetition or themes that make sense to you. Then the interpretation is defended by the supporting references within the text. Although this was of some encouragement I had to acknowledge that the analysis up to this point was my own. With this in mind I kept re-reading the texts from each

participant making sure to retain women's stories as a whole and replaying the tapes as necessary for more clarification.

One of the final steps for establishing themes is to select or ask some participants to check the appropriateness of emerging themes (Burnard, 1991). At the time I felt some degree of certainty regarding the accuracy of four main emerging themes, reduced from ten, and so I wrote to each participant with these themes, along with some of their explaining data.

Seven women responded, five by letter and two by telephone, with affirming comments such as: -

I thought the themes showed a good understanding of women's issues with HIV (Paula Letter returned p.2)

I do like your titles they make perfect sense to me (Mungu Letter returned p.1)

Narrowing all that information down to four themes must have been hard work...but you have done wonderfully well...great name themes (Jose letter returned p. 2).

I agree wholeheartedly that they [themes] are issues that desperately need addressing (Margo letter returned p.1).

3.6 Conclusion

This chapter presented the research outlines of qualitative and feminist research. It presented the rationale for engaging in this form of research to best explore and describe women's experiences of being HIV positive in New Zealand. The reflective and reciprocal approaches were highlighted throughout this chapter promoting as much as possible an equal partnership between myself as researcher and those participating in the research.

The 'sensitive' nature of the topic and my expressed concerns surrounding this research were acknowledged, along with the idea that this research would be of some benefit to the participants.

This chapter has addressed the methodological basis for this project and explained the method used to collect and analyse data. In the following chapter the data will be presented and an interpretive process will be extended to incorporate the lens of gender and feminist theory.

CHAPTER FOUR: Our Daily Lives with HIV

4.1 Introduction:

The previous chapter explained the methodology underpinning this study and the method used. In this chapter and the following, the data will be analyzed and discussed. Excerpts from participants will be provided to enhance explanation of the four emerging themes.

Throughout this study two main issues emerged when talking with the participants. One issue pertained to their day to day living with a chronic illness that has no cure, and the techniques they used in coping. The second issue was one that involved politics, and social attitudes, and the impact that gender has on women's lives.

The first two themes, presented in this chapter, are 'To reveal or conceal' and 'What do I have to do or say to be taken seriously?' The two themes presented in the following chapter are 'The invisibility of women in a male disease', and 'Women's experience of being HIV positive mirrors women's place in society'. Although I have separated the four themes, they should not be seen in isolation as they frequently overlap.

4.2 To Reveal or Conceal?

Meeting each participant for the first time I was aware that all but two women looked physically well. I had a sense that for all these women they were endeavouring to get on with their lives, which in most instances involved caring for their families. While talking about their families and discussing demographic data the conversation flowed into the subject of how to tell others about their seropositive status, who to tell, and for what reason. For the majority of these women keeping their seropositive status to themselves meant they could pass as seronegative, because they looked fit and well. But also for most of the women to conceal an identity of being HIV positive was concealing a secret, which if exposed could be discrediting. Simultaneously women also felt to reveal an HIV positive status involved an element of risk, a risk that involved being judged, discriminated against and stigmatized. This dilemma of

whether to reveal or conceal a seropositive status was an ongoing concern for all participants, and it created tension and stress within their lives.

To fully explain this theme the following sub-headings highlight some of the very complex issues facing participants in revealing or concealing their HIV status.

4.2.1 Stigma

Research indicates that being diagnosed with HIV is to know that you have one of the most stigmatized health conditions known (Green & Sobo, 2000). Many of the participants expressed the concept of stigma and admitted that the thought of stigma and its implications had a great deal of bearing on individual decisions to reveal or conceal.

I do feel it [the stigma] I must do because I am not open about... I don't tell people until they have got my trust completely (Joy In 1: p.3).

HIV is not exactly something that is flavour of the month. It is not like...breast cancer or cervical cancer...it has stigma around it, which makes it doubly hard (Rita In 1: p.4).

Margo worries about how a small community such as the one she lives in, would cope if someone found out she was HIV positive.

If someone found out here [I was HIV positive] I would be mortified because I don't know how people would cope in such a small community (Margo Int: 1 p.18).

The modern dictionary definition of stigma is a 'distinguishing mark burned or cut into the flesh' (Delbridge, 1986). Green & Sobo (2000) comment that in certain historical settings stigma carried a positive meaning as in some religious settings stigmatic markings could signify special grace. In more modern times and in many social setting and cultures, stigma is a negative construct and is described by Goffman (1963) as an individual's failure to live up to social and cultural ideas

within which they live. In other words stigma has its roots in the failure of an individual to fulfill one's ascribed role, he or she is tainted or discounted (Bunting, 1996). Goffman (1963) comments that an individual failure to live up to social and cultural ideas may take the form of a physical blemish or some deformity, or by a state of identity. Also within this idea of stigma is the idea of 'otherness' or a distancing of a stigmatized person, i.e. he or she is not like me or, that could never happen to me so we assume that the stigmatized person is very different from ourselves (Bunting, 1996). It has been well documented throughout history that some diseases are more stigmatized than others; leprosy and tuberculosis are examples of recorded stigmatized diseases (Fee & Fox, 1988; Watney, 1993). Sontag (1991) suggested that the most dreaded and stigmatized diseases are those which are the most disfiguring. AIDS has images of skin lesions and extreme weight loss, which qualifies the disease as a stigma.

Green & Sobo (2000) argue that stigma is a socially constructed label and also comment that what is stigmatizing in one place and time may not be in another. In other words stigma is not only socially constructed but also a culturally relative construction (Green & Sobo, 2000). Today the term stigma has a meaning understood by all and the knowledge that AIDS carries stigma appears to be commonplace in all parts of the world. My personal observation of the concept of stigma was very real. When I was working with people who were HIV positive in Zimbabwe, everyone knew the shame and stigma of HIV/AIDS. The relationship between AIDS and the presence of stigma is commonly understood, but generally left unsaid (Green & Sobo, 2000; Lather & Smithies, 1997; Schneider & Stoller, 1994; Treichler, 1999).

Joy expressed her feelings of stigma by identifying it with a physical deformity and symbol dating back to the era of leprosy.

If I was a leper you know in the old days the lepers had the bell I would have quite happy have worn a bell. I just felt so dreadful (Joy Int 1: p.3-4)

It is unclear whether women with HIV are more or less stigmatized than men, due to the limited scholarly attention that has focused on gendered differences concerning

issues of stigma and discrimination (Green & Sobo, 2000). Green (1995) reported that women felt or perceived themselves to be more stigmatized than men and were more likely than men to assess the attitudes of the general public to be hostile towards them. This report goes on to say that women felt a greater sense of shame and stigma and felt tarnished by the 'dirty' image they felt others held of people who were HIV positive (Green, 1995). Perceived stigma was raised by participants as one factor to take into consideration when thinking about revealing or concealing your HIV positive status. But along side this was the issue of being seen as tarnished, dirty and contagious.

4.2.2 Dirt and contagion

Words used to describe how participants felt about themselves, such as dirty and contagious, were reason enough not to reveal an HIV positive status to others.

I felt just so dirty and so contagious, so contagious, I didn't like people touching me (Joy Int 1: p.3-4).

Feeling dirty and contagious by revealing also meant the risk of being ostracized, which meant even more of a reason not to tell.

You don't want to tell anybody you don't want anyone to know...it is a dirty disease, you are looked down on, you are ostracized (Margo Int 1: p.10).

Fear of being ostracized from society and people wanting to steer clear of me because they are going to catch a contagious disease...so I keep it to myself (Lydia Int 1: p.2).

The feeling of being unclean was not only internalized by Jose but it was also reinforced in the language used by a health professional to describe Jose's condition when she went for treatment of her symptoms.

It is morally devastating you just feel so grubby...I was told I was full blown...when you think blown or fly blown what do you think of...maggots...I feel grubby, you can't wash it out...people touching me I don't like it (Jose Int 1: p.5).

Feeling contagious and whether or not to 'tell' was certainly uppermost in the mind of Kyle when she went to visit a friend and she was asked to hold a new baby. Even though Kyle knew she could not pass her virus to the baby in this circumstance, the feeling of being contagious was still an inner fear. Should she tell, but what would people think?

I didn't really want to hold it...I know I couldn't give it HIV [by just holding the baby], but I feel a bit contagious...I wonder what other people think (Kyle Int 1: p.17).

Paula explains a similar experience

The only thing I sort of feel uncomfortable with is if I am hugging a friend...who doesn't know about me...it is sort of like you know don't touch me. I know she can't get it...but I sort of feel like I am lying to her by not telling her (Paula Int: 1 p.17).

By not revealing Paula feels that she is keeping a secret. She implies she does not wish to keep secrets from her friends by concealing her identity but it seems the only way.

The internalized feeling of being unclean dirty and contagious felt like a lifetime sentence for one woman.

I just cannot imagine myself ever being involved with another man...it is too scary...it comes back to this 'not clean' ...I am a leper (Joy Int: 1 p.16).

Feelings of being contagious, not clean, and implications of stigma, were not the only reasons participants expressed anxieties around the decisions to reveal or conceal. There was also the fear of being judged for deviant behaviour.

4.2.3 Deviant behaviour

Individuals who have HIV/AIDS are socially constructed and understood as predominately someone who has engaged in deviant behaviour (Butcher, 1994; Green, 1995; Kline, Kline, & Oken, 1992; Treichler, 1988; Watney, 1993). Deviant behaviour associated with HIV/AIDS is defined as being involved in homosexuality, sharing needles to inject drugs, prostitution or sleeping with a person who uses intravenous drugs (Bury, 1994; Doyal, 1994; Fee & Fox, 1992; Green & Sobo, 2000; Schneider & Stoller, 1994; Treichler, 1988; Watney, 1993). Therefore to be HIV positive means at least to have had a past history of deviant behaviour.

Within deviant behaviour there is also the socially constructed perception that you are responsible for your own behaviour. In other words if you have contracted HIV you are responsible for your behaviour and therefore for your condition, or in other words you got what you asked for (Green & Sobo, 2000).

Therefore revealing your status puts you at risk of being judged for your behaviour and participants expressed this risk as part of the decision making process.

When I tell people I am positive I get I'm either a prostitute or a lesbian or drug addict and if I am really lucky I am all three of them [laughter] (Jose Int 1: p.4).

The fear of being judged was also a concern for Mungu early in her diagnosis and she explained that she just went away and hid. Thirteen years on Mungu has revealed her HIV positive status to family and some friends and feels more confident in doing so. During the second interview with Mungu I shared with her how so many participants felt afraid of revealing their HIV positive status and that this fear included being judged or labeled as either bad, a prostitute, a drug user or even colored. Mungu quickly replied

What is wrong with those things? (Mungu Int: 2 p.24)

Although we shared laughter at her quick response I reflected that I had just made a judgement based on the social construction of HIV. But Mungu did agree that women are going to be judged once they have revealed.

Yeah it is very sad...I believe it [fear of being judged] is one of the major reasons why we don't stand up...because it is too hard and the support is not there (Mungu Int: 2 p.24).

As already mentioned it is unclear whether women with HIV are more stigmatized for deviant behaviour than men, although as reported by Green & Sobo (2000), it is common for women with the virus to *feel* that they are seen as more stigmatized and promiscuous, (my emphasis). Rita feels she is being judged every time she reveals her seropositive status to others.

People ask how did you get it...and they look at you and think...you must have got it through being a prostitute or a drug user...if you don't fit into these categories...which ironically few women do...you have to deal with that. Why should you have to justify yourself? (Rita Int: 1 p.13).

Deviant behaviour for women implies a 'bad' woman, someone involved in prostitution. Prostitution and HIV became synonymous when HIV was discovered in the female population. The idea that prostitutes spread diseases dates back to the nineteenth and early twentieth centuries (Alexander, 1994). Historically prostitutes have been positioned as responsible for the spread of sexually transmitted infections (STI), and images of women as dispensers of infection date back to VD campaigns in World War Two (Butcher, 1994). This pattern has emerged with the AIDS epidemic and women are seen as the carries or 'vectors' of HIV (Treichler, 1988). The fact that research indicates in most western countries that professional prostitutes have a very high awareness of the dangers of unprotected sex, and do use protection, seems to be forgotten when identifying blame for the spread of HIV amongst the heterosexual population (Treichler, 1999). Research also indicates that if prostitutes test HIV

positive they are more likely to have contracted HIV from partners outside of work who insist on condom-free sex (Alexander, 1994; Butcher, 1994). The myths surrounding prostitutes being seen as responsible for infecting men persist, even though evidence now indicates that transmission from women to men is twenty times less likely than transmission from men to women (Bunting, 1996). If women feel that they will be judged for deviant behaviour they are less likely to reveal being HIV positive.

Although prostitution is seen by many as deviant behaviour for women, Green & Sobo (2000) report that women may be considered even more socially deviant than men if they use injected drugs. This behaviour is seen as not only deviant, but also irresponsible and therefore avoidable (Green, 1995). Mungu states this is one reason why she does not always reveal how she believes she contracted HIV.

If I said I got the virus because I was an injectable drug user they would just switch off (Mungu Int: 2 p.25)

Mungu feels by revealing a past history with drug use people feel she either deserves the disease or they place her as 'other' increasing the stigma and discrimination reason again for not revealing an HIV positive status.

But there was one area where participants felt it was important to consider in more detail revealing, as it had implications not only for themselves but for others close to them. Revealing to close family members and their children was felt to be important to participants, but it still held elements of social risk for themselves and their significant others.

4.2.4. Significant others

Eight of the nine participants had children and three participants were grandmothers. Each woman discussed how revealing or concealing from family members caused a great deal of anxiety.

I don't want people labeling me with something, I don't like that label...also my children (Lydia Int: 1 p.2)

Women, they protect their children...they are scared that if anyone finds out [their HIV positive status] it is the children that are going to get punished (Margo Int: 2 p. 17).

Paula lived in a small rural area and was most concerned when starting her HIV positive child at school. She was worried about the school keeping it confidential.

We lived in the country...a small community I didn't really have much faith in the principal up there keeping it confidential...(Paula Int: 1 p.6).

The need to protect their children from stigma was discussed by many of the women. Research indicates that women are more concerned than men about revealing their status where issues surrounding children are concerned (Green & Sobo, 2000). A recent study in Scotland carried out by Green & Sobo confirmed that all the women in the survey raised stigmatization as an issue when they came into contact with children of friends and relatives, whereas less than half the men in the survey raised childcare as an issue. The men were not involved in childcare. Reports of friends or relatives not allowing their children to play with the child whose mother was HIV positive have been reported (Green, 1995). Green & Sobo claim that incidents involving friends and their children can fundamentally change the nature of a relationship once it is realized that a member of that family is HIV positive. Revealing your status puts you at risk of losing friendships especially for women in their child caring role.

Perhaps even more distressing for participants was revealing their status to their own children and grandchildren. Joy is a solo mother with three young children.

I haven't actually told them that I am HIV positive...I have told them that I have got a bug in me and they know that I take medicine everyday...I will tell them...I will put a name to it one day (Joy Int 1: p.4)

Paula, along with her partner, is HIV positive. They have three young children

None of our children know, we sort of decided that it is not fair to let them know...got to let them be kids I think (Paula Int 1: p.5)

Research also indicates that women fear telling their children because children being children they might tell their friends at school. Mothers then fear the children may be stigmatized, isolated or even asked to leave the school (Bunting, 1996).

A more encouraging comment came from Paula who had shifted her family from one area to another in an effort to find a school for her children which she felt would be more supportive than the previous one. Paula has one child who is HIV positive.

The school is pretty good actually...I told the principal and he's a pretty 'new age' type. I had requested that not all the teachers know...he said they have got policies and procedures...when dealing with first-aid that all the children get treated like they have an infectious disease (Paula Int: 1 p.5).

The age of the children and their perceived ability to understand the concept and the perceived consequences was part of the decision process for most of the women interviewed when deciding whether to reveal or conceal their HIV positive status.

I have told my daughter [daughter was married with own children] but my son doesn't know. My son would come home from school...they would have health education now and then and HIV would come up and he would come home with these statements and I would think that is really good he is informed perhaps I should tell him now. But I never had the courage...I still

haven't told him...I have been humming and haring for the last year because he has grown up a lot and he is a responsible kind of caring person (Margo Int 1: p.7).

Parents and bothers and sisters were also amongst the significant others to be told, which created stress and worry.

Kyle was 19, pregnant and living in rural New Zealand with her male partner. When she became pregnant she immediately informed her mother of the pregnancy, but was unable to reveal her HIV positive status until she was more than half way through her pregnancy.

I didn't tell her [mother] until I was five months pregnant...she already knew I was pregnant, but she didn't know I actually had HIV...I had to keep it a secret from her (Kyle Int 1: p.3)

Kyle's reason for not disclosing was fear of her mothers' reaction and to give herself time to come to terms with her situation.

Joy described her relationship with her family as good and told her sister straight away along with her parents, and wrote to her brothers. Joy reported their responses were mostly supportive as they expressed concern for her and her children. With friends she still feels the stigma and has been reluctant to reveal. This has cost her their continued friendship. She also has been reluctant to reveal to friends, especially those associated with the children, fearing stigma and isolation for herself and her children.

I haven't told any friends connected with the children...A lot of friends that I had prior, [to living overseas] I didn't get back in contact them, or if they made contact with me I didn't let them into my life. So I lost their friendship (Joy Int 1: p.3-4).

One woman found some positive aspects in the experience of telling her family. Mungu has four children and one grandchild.

I think in terms of my being HIV positive it has woken some of my family up into their own behaviours and their own safe sex, or lack of. So that has been a positive thing (Mungu Int 1: p.16).

Reasons for revealing to family and friends come with risk, but also to be taken into account by participants were those who ‘needed to know’ due to being at risk of HIV transmission, by virtue of their relationship. With few exceptions, participants expressed an obligation to reveal to long-term sexual partners, enabling them to make informed decisions regarding their sexual relationship.

Although this ‘need to know’ information and revealing to significant others was deemed important, revealing or concealing became more of a concern and problem when the idea of forming new relationships was considered.

4.2.5 Forming new relationships

Joy explains that she thinks she is an honest person but being HIV positive is something she is not always willing to share. This is because revealing her status affects the kinds of relationships she has with others.

Basically I like to think I am an honest person, and it [being HIV positive] is part of me that I am not willing to share, you know I won't share. It is [HIV] definitely part of me, and it is not going to go away...it is a fairly big part of me...it is part of the baggage. So a lot of my friendships are sort of superficial really because that part has not been shared (Joy In 1: p.9).

Being HIV positive means in reality the taking on of a new identity. Green & Sobo (2000) believe this new identity takes time and involves a process of adjustment. Most research on adjustment to a new identity concerning people with HIV has been conducted on homosexual or bisexual men (Green & Sobo, 2000; Wilton, 1994b). Such reports claim that there are phases or processes people go through in

establishing their new identity which involve periods of denial, anger, depression, suicidal thoughts, fears of others' rejection and feelings of self-loathing and shame (McCain & Gramling, 1992). These authors go on to say that once a person has come to terms with some of these issues the next phase is one of 'fighting the sickness'. This includes a process where HIV positive people focus on locating and establishing friendships with supportive people and they have concrete goals for developing a level of wellness (McCain & Gramling, 1992).

A more recent study has been done (Barroso, 1997), on living with HIV involving 14 men and 6 women. Five themes were identified as people came to live with their HIV identity. These included normalizing, focusing on living, taking care of oneself, being in relation to others and triumphing (Barroso, 1997). The study also revealed that being HIV positive and adopting a new identity is not a linear process. In other words the process is not along a line in simple planned out steps (Barroso). Forming this new identity involves periods of anger, and shame followed by a period of steady calm then the person may return to periods of depressive thoughts and isolation (Barroso, 1997; Green & Sobo, 2000). Research also indicates that when you feel more confident about yourself and your identity you will feel more confident around disclosure.

Becoming confident with a new identity and the ability to tell others has come slowly to Kyle. She reports adjusting has been more possible with the support of her male partner who is also positive, but adds they recently moved to a new area and she and her partner did not know many people. Forming new relationships is part of living in a new area and Kyle explains that they have had mostly good experiences with telling people but also adds some caution.

People that aren't close to us we don't tell and like we are careful who we make friends with...I mean anyone who wouldn't accept us, and we know wouldn't, we don't bother with, because they are not very nice people (Kyle Int 1: p.2)

Paula reports she could not tell anyone for a while due to her sense of shame and stigma. Her husband took on that role with her consent, especially in the early stages of her diagnosis.

I am getting better and better at telling people...and letting them know whereas before I use to just let [name of partner] do it. Like when we first found out, he told my family (Paula Int 1: p.5).

Revealing or concealing within new relationships also involves new sexual relationships and for some of the women this was a topic of stress and a constant concern. Margo talks of an experience she had in telling a new partner.

One guy...I did tell him pretty well straight away...he said it didn't bother him...I found out from a friend he was only hanging around because he thought I was going to die quickly and could inherit everything. When I confronted him...he admitted it...I said you might as well pack your bags and go because I am not going to die (Margo Int 1: p.24).

Research on disclosing an HIV status within a new relationship has been carried out mostly on gay men. New research by Green & Sobo (2000) conducted in New Mexico and North-West England and Scotland involved both men and women and they asked HIV positive people for their opinions re self-disclosure with new sexual partners. A higher proportion of participants reported that in new relationships non-disclosure was the preference in conjunction with safe sex practices. The report went on to say that participants felt that only when a relationship had time to build and a sense of commitment was established was there any need to reveal your status (Green, 1995). This report did not reveal any breakdown of difference of opinion between male and female.

However feminist scholars argue that women are disadvantaged in sexual negotiations and have less power over sexual safe practices (Butcher, 1994; Kendall, 1996; Kitzinger, 1994; Treichler, 1997). Women's ability to negotiate sexual choice and safe sex practices are issues that will be discussed in more detail in the following chapter.

For one woman forming new sexual relationships was described as too difficult and she had chosen the option of celibacy. She described the fear she had around passing on the virus and her decision around celibacy meant she did not have to confront the issue of revealing her HIV status to sexual partners.

Huge amounts of stuff around these issues and I just thought this is too big and I can't cope with it and I am not having sex (Mungu In 1: p.14).

One further and final issue to be discussed with participants around the theme of revealing or concealing, concerned issues regarding work environments and employment.

4.2.6 Employment and work environments

Some participants were seeking work and others had previously been in paid employment but had decided to seek other options for health reasons or childcare concerns. The issue surrounding revealing or concealing your HIV status to your colleagues and or your employer was a constant dilemma expressed by many of the participants.

Kimberly believes it is only important for her to reveal her status once she has established a relationship with work colleagues, thereby attempting to avoid stigma and discrimination.

With me a lot of the time when I am working I don't tell people I am positive. It's only at certain points where it is important that they suddenly realize, because otherwise they see me as deviant or they pre perceive what kind of person I am at that point. So it is better that they actually understand that I am educated...I have a life, I am a human being...and yes I have a virus (Kimberly Int 1: p.9-10).

Discrimination in the workforce against HIV positive people has been documented and gay men report that discrimination does exist (Green & Sobo, 2000). It is possible that revealing an HIV positive diagnosis may mean job termination. In New Zealand it is illegal for employers to ask 'are you HIV positive' but reference to health issues is included in questions asked by employers. Research indicates that some HIV positive men did disclose their seropositivity; if their occupations put others at risk they felt it their duty to stop working or change jobs (Green & Sobo, 2000).

Mungu has worked in paid employment for indefinite periods over the past few years depending on her health status, but fears applying for jobs.

I had this idea that no one will hire me... who wants to hire someone that is HIV positive when you don't know if they are going to show up to work today? (Mungu Int 2: p34).

Mungu went on to say she enjoys working, and she wants to work, but she has fears around health related questions.

I make it a policy if they don't ask don't tell, but I won't lie if they do ask I won't give them false information (Mungu Int: 2 p.34).

Margo felt she had been unfairly dismissed from her previous job due to her HIV status, but was unable to prove it in court and an out of court settlement was agreed upon by both parties. Margo is determined to work and keeps applying for jobs.

I have applied for a lot of jobs... and got to the stage where I actually had interviews and filling out forms and they ask do you have an illness? If I say no and they find out six-month later...there are reasons to dismiss me...because I wasn't honest. If I say yes, well kiss the job goodbye they are not going to employ me...I wasn't going to put myself in a position like that anymore (Margo Int 1: p.19).

4.3 Summary

All participants had issues concerning revealing or concealing their HIV status. Being selective about disclosing hinged on, in most cases, the fear of being discredited by others. The majority of participants sustained non-HIV linked public identities, but within their personal social networks they identified as HIV positive.

All participants went through a process of risk assessment related to revealing their HIV positive status and talked about the cultural and moral issues that underlie their disclosure decisions.

Whether it is more difficult to reveal or conceal your HIV positive status due to being female has not been fully researched but participants expressed their perceptions of being more stigmatized because they were women. Participants suggested they *felt* the 'dirty' and 'tarnished' image more than men did especially due to societal attitudes surrounding promiscuity.

Participants also felt that by disclosing they were putting their children at risk of being stigmatized and discrimination. This was an added vulnerability that men were less likely to experience, due to not being involved in childcare.

The following theme introduces a concept the participants had about not really being taken seriously in the context of 'you cannot be serious, you cannot have HIV, you are a woman'.

4.4 What do I have to do or say to be taken seriously?

The previous theme dealt with the difficult decisions the participants felt they had to confront around revealing or concealing their diagnosis. This new theme arises from situations where participants felt they were not heard or not believed because of their sex and wondered what they had to do as HIV positive women to be taken seriously. Again sub headings are used to emphasize issues frequently mentioned by participants as areas to be addressed.

One area where women felt unheard and not taken seriously was in their contact with the medical profession.

4.4.1 The medical profession

Biomedicine and science have hegemonic authority as the assumed providers of the most accurate answers to the etiology, treatment and cures to all forms of illness. Theirs is a powerful and often unchallenged discipline, but it is the knowledge that is relied upon by the general public to be the most accurate and up dated scientific knowledge.

For many of the participants, local doctors or general practitioners (GPs) were their first contact for health and medical advice. Rita decided she had some health concerns and went to seek medical advice. Rita considers herself well educated and so already had a good sense concerning health knowledge and kept up with regular health checks. But due to a recent traumatic sexual encounter she went to a GP for advice and support.

I had to ask three different GPs to have an HIV test. I was told that as I was certainly somebody who had regular smears and looked after my gynecological health and had no previous sexual diseases or anything of the usual nature that one stereotypically thinks an HIV person should be, then I wouldn't be at risk at all (Rita Int 1: p.2).

Rita was asking specifically to be tested for HIV and had to visit three GPs before one finally agreed to test. The test revealed a positive result. Not only was this news devastating to Rita, but Rita also explained how her GP expressed surprise and astonishment at her positive diagnosis.

Joy 39, and mother of three children, had a similar reaction when she visited a local GP and requested she be tested for HIV. Joy informed her New Zealand GP she had been living and working in Africa and wanted a test before she returned just to be sure, as she had been feeling tired and run down lately. Joy also informed her GP she had cut herself while working in a nursing environment in an African country. The GP was reluctant to test and reassured Joy that the test was unlikely to be positive.

Joy reflects on why her GP might have been reluctant to test.

You know I was a mum, white, middle class. It was because I had cut myself and I don't know if it was one of those medical things of you know you won't get positive because of that...sort of mentality...I possibly didn't look like what an HIV positive would look like, or what you normally see (Joy Int 1: p.12).

Her test came back positive and Joy reports her doctor was also surprised and shocked.

White middle class women asking for HIV tests could appear unusual to many New Zealand GPs and Rita and Joy may not have been seen as being at risk. Even after Rita explained her concern around a recent sexual experience, and Joy's experience of living and working in Africa for the past two years, this still did not seem indication enough for these GPs to test either Rita or Joy for HIV.

Medicine is constructed as an 'objective' scientific discipline and doctors are trained to think in an objective and scientific way. The 'objectivity' of medicine means that doctors are presumed to be able to rise above value judgements (Lupton, 1994). At present in New Zealand and possibly worldwide, there is a socially embedded construct of who is an HIV positive women, i.e. women who engage in prostitution,

drug addiction, or women of colour. Perhaps naively we presume that doctors are not influenced by this social construct and are objective in their scientific investigations. Joy and Rita were outside the social construction of women who might be HIV positive and so were not taken seriously when they asked to be HIV tested. The positive result was not expected from women who presented as educated, white middle class and informed.

Other examples of doctors' construction of which women might be HIV positive was experienced by Margo while in hospital for a surgical procedure. She was visited by a doctor who expressed his surprise at her seropositivity. Margo was also a woman in her 30s, educated, white and middle class.

I remember one doctor...he said I just have to ask you how did you get infected you don't seem the sort (Margo Int 1: p.18).

To this particular doctor Margo did not seem the *sort*, as she did not present as someone who is morally deviant, addicted and lacking self-discipline or a woman of colour. Doctors are not immune to the everyday rhetoric such as 'bad women' and HIV and this doctor felt Margo needed to explain herself to him because her source of infection was unclear and seemed not to fit his preconceived image of a *sort* of woman. It would appear that in these circumstances in order to be taken seriously HIV positive women are expected to explain their source of infection to medical staff if they are perceived to be outside of the stereotypical construct.

Joy explained her experience when she visited a doctor for an eye infection. Joy was discussing with the doctor her reason for referral when the doctor suddenly read the referral form with HIV positive written on it. The reaction of the doctor was not one that Joy would have expected from a medical professional.

She turned around and put gloves on...to talk to me, to talk to me not even touching me, to talk to me. She knows she cannot pick it [HIV] up from talking to me she knows that in her head...they have got knowledge in their head...but...it has not stuck into her consciousness... it happens (Joy Int: 1 p.17)

Being taken seriously also means for Joy being treated appropriately by a medical professional who should have advanced knowledge. She felt that medical personnel should not react with fear and should not take inappropriate protection from infection.

Jose also describes her experience with the medical profession. As I listened to her story I was beginning to feel a little uneasy at being part of a health profession, which is reported to offer unbiased care and support. Jose's past life experiences had put her at risk of HIV, and her specialist knew this lifestyle. Jose's visit to her specialist was after commencement of a combination of relatively new drugs, which the specialists explained could lengthen her life span and also give her more quality of life. But Jose's health did not improve and she actually felt she was becoming more unwell, with symptoms of nausea and diarrhoea and a slight skin rash. He went on to explain these were new drugs and she needed to continue with her treatment and she would eventually get used to them. Still Jose felt she had tried long enough on these drugs, she was not well, and her specialist was not taking her seriously. So Jose decided to take a more extreme approach to make the specialists listen.

I had taken a gun, it wasn't a real gun it was an imitation gun...and I said to him right you are now going to listen to me...he wet his pants and he listened to me. But I got arrested and they charged with me threatening to kill and they put me in jail for six months...I got sick...so most of the time I wasn't in jail I was in hospital (Jose Int 1: p.6).

Jose's decision to make a doctor listen to her may have been extreme, but she felt that was the only way she could deal with a situation to be heard and taken seriously.

Further examples of participants feeling that doctors did not take them seriously occurred when they were told of the diagnosis and immediately afterwards. After being informed of their positive results participants felt that they were left feeling unsupported, not fully informed and offered no additional resources, as if women with HIV did not really exist.

To be told sitting in the waiting room...that was the way I was told. After it happened I was given another blood test and was told to come back and given a book and some really banal and inane and ineffective post and pre test counseling which didn't do anything (Rita Int 1: p.2).

This was Valentines Day...he didn't know how to handle it and he apologized for the way he had handled it. Then for the weekend I was totally left...there was no support there was nothing (Margo Int 1: p.3).

It was at a meeting with lots of other people...he [name of health professional] just slipped me this piece of paper that is folded over ...I just opened it...it said your test was positive. Well I didn't know what to do with it. Things are a lot more together now I think...that was back in the 80s (Mungu Int 1: p.2-3).

Participants had the feeling that because women with HIV were small in numbers compared to men it meant they were not really taken seriously. So GPs were unaware of the skills required informing women of their diagnosis and the follow-up that was required. Participants felt that, especially in rural areas, GPs are not being fully informed, and many of them did not have up to date information. This left women with HIV in rural areas often feeling unheard and not taken seriously when wanting support and understanding.

Doctors need to be educated...as a service, GPs are not aware (Kimberly Int 1: p.16).

I just go to him, [GP] for physical things...we don't talk about anything deep...you know any the issues around HIV (Mungu Int 1: p.4).

They [GPs] sign their name on the dotted line once a year when I need to get my disability allowance, sort of thing, that is all I see them for...they don't really offer me anything (Lydia Int: p.6).

Margo also notes the lack of experience and knowledge of GPs, and adds that in her particular area there are few HIV positive patients. Her GP admits he has no other HIV patients and Margo feels he is not keeping up to date with new research. Her needs go unmet when she visits and this increases her feelings of isolation and stigma. Being not taken seriously she feels almost as if she does not exist.

I said [name of GP] you really don't know what to do with me do you? He said no you are an exceptional patient that I have got...and I thought right ok I am his only HIV patient...his patients don't have things like that here (Margo Int 1: p.6).

Along with statistics that indicates that HIV is increasing in the female population worldwide, medical research now indicates that women may present with different symptoms than those of men (Lather & Smithies, 1997; Treichler, 1999). In 1993 the Centers for Disease Control (CDC) formally recognize that HIV positive women experience gender-specific medical problems (Lather & Smithies, 1997; Treichler, 1997). Possible correlates of seropositivity include invasive cervical cancer, severe and recurrent vaginal yeast infections, and pelvic inflammatory disease (Abercrombie, 1996; Lather & Smithies, 1997). Participants felt that if GPs remained uninformed of the HIV process and its signs and symptoms, women continued to believe that they were not being taken seriously. It could also mean that women presenting with for example, reoccurring gynecological conditions could be misdiagnosed.

Two women expressed feelings of support and having their voices heard and taken seriously.

She [GP] was wonderful...I was lucky...she knew what resources were available she had dealt with two other HIV positive women (Joy Int 1: p.2)

I had a home birth and a really good doctor supporting me (Lydia Int 1: p.13)

As discussions with participants continued around things medical, contact with nurses became a focus⁴. Participants did not seem to hesitate when discussing the nursing profession knowing I was one. Their conversation which was open and frank may be have been in the hope that the information given would assist nurses in their understanding of HIV positive women.

4.4.2 The Nursing profession

Participants had similar experiences with nurses where they were not taken seriously. Nurses are influenced by the biomedical model for information concerning HIV. But nurses are also assumed to be historically and contemporarily embedded in the practice of holistic care, duty to care, and intention to care (Hodgson, 1997; McCann, 1997). In other words nurses work with moral obligations to unconditionally provide care in a non-discriminate, non-judgmental way respecting individual needs, values and culture in the provision of nursing care (McCann, 1997). But research carried out on nurses' attitudes towards people with HIV/AIDS indicates that amongst nurses there are negative attitudes (Hodgson, 1997; McCann, 1997; Robinson, 1998). McHaffie (1994) examines the results of a survey carried out in the United Kingdom in the late 1980s and early 1990s, which indicated some nurses did have negative attitudes towards homosexuals and individuals who use intravenous drugs. These attitudes were found to inhibit the giving of good quality care, and nurses needed to gain insight into their own values and prejudices (McHaffie, 1994). Other reports indicate that negative attitudes not only affect the quality of patient care but also result in refusal to care (Robinson, 1998). A notable gap in the literature was nurses' attitudes to women who were HIV positive and people from ethnic minorities.

Margo found some nurses displayed negative attitudes, which may have affected her quality of care, while others were more willing to take the time to talk and listen.

The nurse she leant against the doorway...and I said to her you can't get it...and she said no I know...but I just wanted to talk with you because you look like a normal woman. She was honest... others thought let's clean this up quickly...lets take her temperature and get out...I felt like I was a real contaminated freak (Margo Int 1: p.14-15)

As the AIDS epidemic becomes a reality for an increasing number of countries in the world more nurses will be exposed to people with HIV/AIDS. A report from Germany suggests nurses' attitudes towards people with AIDS were more tolerant and positive and homophobia was only found with a small minority (Lohrmann, et al, 2000). The most recent report on New Zealand nurses' attitudes towards people with HIV was in 1994. The report identified that nurses' attitudes were varied, and depended on social influences, personal experiences and the extent of knowledge regarding HIV/AIDS (van Wissen & Siebers 1993; van Wissen, & Woodmam, 1994).

The experience of nurses appeared limited when Mungu was admitted to an outpatient department after breaking her leg. Not only did she feel on display but also that she was just not taken seriously.

I broke my leg once...I got to A and E ...I was like a monkey on display...and nobody would touch me...they just stood there...because they hadn't seen anyone that was HIV positive...it took a long time to get treated (Mungu Int 1: p.17).

Research into nurses' attitudes has not been sex specific. It is therefore difficult to establish if there is a different attitude to women who are HIV positive than there is to men.

Other research concerning nurses' attitude to HIV patients concerns infection control. Some research indicates that the precautions taken by health care workers often far outweighs the risk of potentially acquiring the virus. It was found that nurses need more education in infection control procedures and had misconceptions regarding disinfecting and precautionary measures for people with HIV (Lohrmann et al., 2000; McCann, 1997; McHaffie, 1994; Robinson, 1998).

Margo experienced this misconception regarding infection control when she went into hospital for a routine small surgical operation.

I was given my own room there was a notice on the door that I was in isolation. Right next door to where I was, there was bathroom facilities...but I wasn't to use those...I had to walk down to my own toilet and my own showers, no one else was to use them either. The nurses put gloves on, double gloves on when they took my temperature (Margo Int 1: p.14).

This incident highlights nurses' need for improved education concerning accurate precautions for infection control in HIV patients. Fear, rather than care, was operating in the support of Margo where the nurses' need to protect themselves from infection overrode their compassionate care. This in turn indicated to Margo that they operated from a sense of fear and appeared not to take time out to talk with her and take her seriously.

To not be taken seriously by health professionals is one area of concern for participants, but this concern carries over to other services such as social welfare services.

4.4.3 Social services

For various reasons there was a need for most of the participants to access social services for support. Access was usually through Work and Income New Zealand (WINZ), but many participants felt judged by this institution. Participants expressed feeling of stigmatization, along with perceived feelings that they did not portray the appropriate images of illness for an HIV positive person. This left participants feeling that they were not being taken seriously by WINZ and had to prove constantly that social support was necessary for them. Rita comments on her experience and the feelings of once again being judged.

The whole experience ...going into places like Income Support looking physically well, and because you look ok they say oh she doesn't look like she has got that. Which is great on some levels of not looking like you have something, but there is no way that someone in a WINZ office can make a judgement. They do make judgements...like oh they do not look sick then they don't deserve this (Rita Int 1: p.9).

Joy had a similar experience of not being taken seriously when informing WINZ that she was going to increase her hours at work for a short time and needed to adjust her benefit. Her caseworker congratulated her and felt that she should continue with more work, which may enable her to come off the benefit. Joy tried to explain that due to her illness she would become unwell if she maintained full-time work. Her caseworker at WINZ thought differently and said so.

She told me to change my lifestyle...but what do I change...I don't want to rip off the system...I know what I can cope with and what I can't. You try to do your best and you try not to live off the state...I have been up front and I have said...I am HIV positive (Joy Int 1: p.20).

Joy and Rita felt the image of someone who is HIV positive, in the eyes of an institution such as WINZ, is of someone who presents physically as very unwell. Media and medical construction reinforce this perception. Medical discourse predominates and strongly influences other disciplines and agencies. This hegemonic authority often goes unchallenged. The image of someone with HIV is still understood by many as a physical image of wasting and skin lesions. To be HIV positive, working, and a woman, may mean, to some administrators of social welfare benefits, that you are not HIV positive because you look physically well. Therefore women such as Rita and Joy may not be taken seriously and may not be allowed to continue their benefit.

Other judgments may also be made based on the notion of deviance thus supporting the belief that HIV positive people 'get what they deserve' and may not deserve public money to support them.

Paula wonders why every time she goes for a renewal of her benefit she has to go and get a medical, as if the diagnosis is going to change.

We get a disability benefit...I get annoyed with WINZ...you go for a renewal and they want you to go through all your stuff again [i.e. going to GP again for confirmation of diagnosis]. I just wrote on the form I am tired of going through my personal stuff with you...you can keep it [the benefit] (Paula Int 1: p.7).

Paula believes she is being judged by institutions such as WINZ who continued to demand documentation for a chronic and terminal illness such as HIV/AIDS. She indicated that going through her 'personal stuff' just reinforced the stigma. Lupton (1994) believes that medical science is such a powerful discourse, that it can also dictate which disease is the result of individual lifestyles thereby establishing blame with the individual. An epidemic such as HIV/AIDS is particularly open to panic, irrationality and stigmatization accompanied by attempts to appropriate blame (Lupton, 1994). This powerful discourse is embedded into institutions where they are unable to think independently of medical influence.

4.4.4 Public perception

To not be taken seriously by health professionals and social service professionals was of concern to all participants, but another area where they felt their opinion was not taken seriously was in the eyes of the general public. They felt that within the public there was little perception that women and HIV existed and they wondered what they had to do inform people that they were real and needed to be taken seriously.

Two participants expressed great concern that even women close to them, a daughter and a close girlfriend, still did not get the message that women were vulnerable to HIV.

My own daughter has sex, not using a condom...you know it takes five minutes to pause and put a rubber on...I am dying of AIDS and she never thought of it (Jose Int 1: p.8).

I've got friends out there who are white middle class friends who still have unsafe sex knowing that one of their closest friends has HIV. I mean how long do they need for a wake up call to start thinking and asking the right questions and talking to the right people (Rita Int 1: p.5).

Not to be taken seriously was a great concern to all participants, not only because they themselves have been misunderstood, but also because they had concerns for other women who were unaware of the risk and their vulnerability.

Perhaps the last word in this section belongs to Jose, who wrote back to me with her comments on the proposed themes and under this theme she added another comment.

Jill are women ever taken seriously? I truly believe that until HIV in women reaches epidemic proportions then and only then will we be taken seriously (Jose p. 1 returned letter of proposed themes)

4.5 Summary

In this chapter participants have expressed concern that health care workers (trained in biomedical knowledge and holding a legitimated position of expertise) were judgmental towards women who are HIV positive. Not to be taken seriously by the very profession who should be in full support of them is of great concern for these participants. Nurses and doctors need to examine and gain insight into their own values and prejudices, which can result in negative attitudes and may inhibit the giving of good quality care.

The socially embedded construct of the 'sort' of women who is HIV positive has influenced not only the general public but also colonized other institutions that seem unable to think independently of medical influence. Participant experiences indicate they felt judged by professionals in social service positions and they frequently had to explain or justify their position. This increased their feeling of stigmatization and not been taken seriously.

In summary not be taken seriously, combined with issues surrounding revealing or concealing an HIV positive diagnosis contributed to some of the stress facing participants living in their day to day lives. But contained within this way of living were wider issues involving politics, power and continued gender differences and inequalities. The following chapters will explain two further themes.

CHAPTER FIVE: Observe our Gendered lives

5.1 Introduction:

This second data chapter presents the two final themes, and concerns a sociopolitical view of the impact that gender has for participants in living with HIV. An overriding issue for that encompasses both themes is that living with HIV for women is different than it is for men, and these differences have not been fully acknowledged or acted upon.

The two themes 'The invisibility of women in a 'male disease' and 'women's experience of being HIV positive mirrors women's place in society' are discussed under sub-headings.

5.2 The invisibility of women in a 'male disease'

Gay-related immunodeficiency (GRID) was the first terminology used to describe a sexually transmitted infectious disease now known as HIV/AIDS (Fee & Fox, 1988; Gilman, 1993; Green & Miller, 1986). This disease was structured as belonging to a specific group and even as the disease progressed and the title changed to HIV/AIDS in the early 1980s it still belonged predominately to 'gay men' in the western world. Modes of transmission were also broadened in the early 1980s to include intravenous drug use and contaminated blood. In 1982 women could not be excluded as the virus was identified internationally in women of colour, intravenous drug users, prostitutes or women having partners who were also involved in intravenous drugs (Fee & Fox, 1988; Gilman, 1993; Green & Miller, 1986; Schneider & Stoller, 1994; Treichler, 1988).

As previously stated New Zealand's first recorded statistics concerning HIV positive women was in 1986 where five women were reported to be HIV positive (Shew, Say, Ellis-Pegler, & Thomas, 1995). Since then there has been a steady increase in women with HIV. Statistics gathered to end of June 2001, indicate 202 females (10 girls and 192 women) have been diagnosed with HIV infections (AIDS

Epidemiology group, 2001). Women now represent 32% of the total. One of the most significant statistics emerging this year is that one-third of the 48 infections diagnosed during the first half of 2001 are female (AIDS Epidemiology group).

Internationally the rate of new HIV infections is rising faster in women than in their male counterparts, and today women make up 47% of the 34.7 million adults thought to be infected with HIV (AIDS Epidemiology group, 2001). Globally, HIV/AIDS is primarily a heterosexual disease and for women heterosexual transmission accounts for 90% of all HIV infections compared to 60% for men (Buzy & Gayle, 1996). In New Zealand 80% of HIV infections in women arose from heterosexual transmission (AIDS Epidemiology group). The sex shift of HIV/AIDS has changed and the increase in women with HIV is predicated to continue (Buzy & Gayle).

Rising HIV statistics for women receives little attention here in New Zealand as the public profile of HIV/AIDS still refers to 'gay men'. Participants commented on the invisibility of women with HIV many times and I will discuss their perceptions of this invisibility. Lydia sets the scene for this theme as she describes her experience when she attended a support group meeting for HIV positive people. She talked of being lost and lacking identity, along with a feeling of invisibility.

I never [prior to diagnosis] had anything to do with homosexual men...and here I was in an environment with hundreds of them and my reality was being a mother with a whole bunch of kids and I just didn't feel like we had a whole lot in common. Apart from the fact that we had this little virus crawling around in our blood that was supposed to make us kind of like have this strange connection...a strange kind of denominator (Lydia Int: 1 p.4).

This 'little virus crawling around in our blood' appears to these women to be where the similarities stop and where gender defines HIV/AIDS as a different disease.

One area of invisibility for these participants was in education and the prevention of the spread of HIV. Without an immediate foreseeable cure for this disease in terms of drugs or vaccines, large educational programmes to prevent the spread of HIV/AIDS has become the main focus internationally and here in New Zealand.

5.2.1 The educational message for women and HIV/AIDS prevention

Within the first educational messages in the early 1980s, the dominant discourse involved the 'gay male'. Gay men were constructed as being involved in deviant sexuality and injecting drugs, and the prevention message was to use condoms and avoid needle sharing (Lupton, 1998). Jose and Margo express how this message was interpreted within their minds, which essentially rendered women invisible.

To me it was a thing that men who had sex with men get...it didn't cross my mind I was a high risk factor...I just thought I am not a man so I am not at risk. I am a drug user but I didn't think I would get it because I didn't know anybody with it (Jose Int 1: p.4).

It was gay...I got the information that was coming to me through different media...it was really a gay orientated disease...not a white middleclass women who didn't sleep around (Margo Int: 1 p.5).

Here in New Zealand the director of the New Zealand AIDS Foundation (NZAF) believes that the prevention message amongst 'gay men' has been one of the most successful educational campaigns in New Zealand (personal correspondence with Kevin Hague, 2001). Hague reports that new HIV infections in men in 1997 were 65 compared to 95 new infections in 1996.

As the disease progressed and HIV/AIDS was identified in the heterosexual population a shift in the educational message became apparent in advertisements and health promotion programmes (Lupton, 1998). Mass campaigns began in America, Britain, and Australia with the message saying 'anyone can die of AIDS' and 'don't die of ignorance'. Images of coffins and tombstones, were marketed, and from Australia the 'grim reaper' was profiled 'he' was skeletal and carrying a scythe (Lupton, 1998). One participant remembers this image well but explains it only instigated fear tactics, increasing stigma and provided little information for women.

Remember the grim reaper? I mean what tactics...people were terrified...but no knowledge...I remember that period (Kimberly Int: 1 p.10).

Lydia recalls her first HIV/AIDS media images and recalls it was of young men thin and skeletal.

I knew the word AIDS and I depicted someone who was extremely ill and about to drop dead...a living skeleton walking around (Lydia Int: 1 p.3).

Essentially the message within these images of the late 1980s and early 1990s was that prevention is the only way to stop the spread of AIDS. Already condoms were promoted within the gay community and this message was extended to everyone, male or female, who was sexually active. Included in this message, which is the same message for 2001, is not only to use condoms but also refrain from multiple sex partners (Doyal, 1994; Lupton, 1998; Treichler, 1997).

All participants knew the educational message of condom use and refraining from multiple sex partners, and were aware of the continued increase of HIV amongst women. Essentially participants felt women were not getting the message and they expressed concerns at the phallocentric nature of the educational message, which was seen as rendering women invisible.

Women are not being educated on their vulnerability...there is no education going on (Kimberly Int: 1 p.13).

It scares me in a way that there is not much education [for women] on how to prevent HIV...to me it just doesn't exist, or at least it is very hard to see. Doctor's clinics you never see posters...I still think that there is a lot of attitude, that it couldn't happen to me and it is still a gay thing (Joy Int: 1 p.6).

I think there is a lot of women out there who are infected and don't know it...I don't think there is enough education there for women, it is all oriented towards gay men (Margo Int: 1 p.16).

The majority of the general public don't perceive it [HIV/AIDS] as something women can have...or associate it with women at all...there is very little education or information or awareness out there for the rest of the women population of New Zealand (Mungu Int 1: p.6).

Participants agreed that a specific message for women and HIV prevention was not visible. The educational message espoused was still directed towards gay men, and some women felt powerless and frustrated by this. Other participants who felt confident enough, were actively involved in the educational message, but their experience often left them angry and even more concerned that women remained invisible.

Mungu took the opportunity offered to her to talk to a women's group where she and a gay male counterpart were asked to speak about their experience of being HIV positive.

One of the guys came along and we both talked...he talked about what it was like [to be HIV positive] for him being a man, and I talked about what it was like for me being a woman. At question time...they all asked questions about him being gay, nothing about HIV nothing about HIV and women... (Mungu Int 1: p.12).

Joy mentioned her experience when she was involved in working amongst adolescent boys at one particular school.

I used to be in a boys' school and we got into [talking about] HIV...just chatting and these senior students...the attitudes came across...just blew me away...stereotype gay...and really negative (Joy Int 1: p.9-10).

Kimberly mentions her experience believing young people today still have the concepts of gay men and HIV while women are not mentioned and therefore remain invisible.

I speak to young people in rural areas...they know nothing, they still talk about it as if it is a gay virus (Kimberly Int: 1 p.4).

The participants felt that the invisibility of HIV positive women just reinforced the public perception that HIV was not amongst the female population. Participants believed strongly that adolescents, especially young women, needed to be informed.

It is something kids today need to hear about...[it] needs to come from a women...it needs to come from a heterosexual person...I am a grandmother...it doesn't happen to grandmothers (Margo Int: 1 p.23).

Kyle was also concerned about the educational message for young people and felt even though some media did give a message it was still essentially a gay message.

I think younger people have to be educated about it...they have a lot of young TV shows...the only place I hear about HIV is on queer nation which is a programme for gay people...not just centre it around being gay. All those music programmes...[could include the HIV prevention message]...but not make it all informative and boring...but actually get a point across (Kyle Int1: p.13).

Rita is involved in sex education in schools and believes that young women are still given some very confusing messages surrounding the use of condoms. The main message for women and condoms, she suggests, is that they are used to stop getting pregnant. Rita reflects on her own education in schools surrounding condom use.

My education [at school] you were basically taught what to do to stop getting pregnant...nothing about asserting yourself...[young women] they are not given skills about how to say no and they are not given skills about assertiveness (Rita Int 1: p.5).

A specific message for protection against HIV spread amongst women is invisible (Kitzinger, 1994; Treichler, 1999). The only message women do receive is to use

condoms, but feminists argue that if condom promotion is the educational message, it cannot be effective unless issues surrounding sexual negotiations are addressed, issues which take into account men's power in sexual encounters (Taylor, 1995). Feminist scholars argue for greater development in gender based education programmes in schools, where young women are not just offered education on the mechanics of reproduction, but are also provided with opportunities to learn about concepts of masculinity and femininity (Holland, Ramazanoglu, Scott, & Thomson, 1994a; McCarthy, 1994).

Rita reflects on her early education around sexuality.

As a young person my belief system was that sex was something you kind of gave to get love and intimacy really...you should be a virgin before you marry...but you have to protect yourself against pregnancy...really confusing (Rita In 1: p.7)

Feminists and sociologists argue that femininity and masculinity are socially constructed (Holland, Ramazanoglu, Sharp, & Thomson, 1994b). In other words most of the behaviours, attitudes, desires and thoughts arise from social learning or are socially 'acquired' rather than from any biological state of being born male or female. Feminist scholars believe that socially constructed concepts of femininity for young women mean that as young women they must be acceptable to men, and in order to do that they should control their bodies in particular ways (Holland et al., 1994a). Being desirable to men, means your body is free of fat, spots and surplus hair (Holland et al., 1994b). But feminists also believe that embedded within this message for young women is the notion of male control over sexuality. Young women may not recognise that their constructed femininity contributes to their own subordination in sexual encounters (Bartky, 1990; Holland et al., 1994a; Preble & Siegel, 1996; Treichler, 1997).

Rita again reflects on her perception of what it is to be female.

It was about what women should always be, you know, seen as feminine...pretty...and men have the power really (Rita Int: 1 p.6).

Feminist scholars have analyzed the educational messages preventing the spread of HIV where the use of condoms and refraining from multiple sex partners is promoted for women. The promotion of condom use for women encompasses an inherent fundamental problem (Gorna, 1996; Taylor, 1995; Treichler, 1997). It is argued that women are disadvantaged by forms of social relating which give men greater power and leave women with little or no say in negotiating sexual decision-making (Kline, Kline, & Oken, 1992; Pinch, 1994; Sowell, Seals, Moneyham, Guillory, & Mizuno, 1999b; Zierler & Krieger, 1998). Studies also indicate that women who do challenge men over sexual encounters, or challenge the power of men who demand sex, may place themselves at risk of violence or of economic dependence (Cash, 1996; Kline et al., 1992; Paul et al., 1995; Pinch, 1994).

Many participants expressed feelings of invisibility as they confronted issues surrounding the negotiation of using condoms in sexual encounters. Participants saw this as a major concern in the prevention of HIV spread for women. They were particularly concerned when it came to long term relationships and condom use.

Most women won't even think about asking her husband to wear a condom...and it is quite possible that the guy would get very defensive and...you know would deny things (Joy Int: 2 p.19).

How can you ask a long term partner that shouldn't you use a condom...it says that I no longer trust you to be monogamous...a lot of women will be beaten up by their partners for that sort of thing, or raped (Mungu Int: 2 p.24).

Participants appeared to have a very clear idea of the risk women took in condom negotiation and clearly felt education for women specifically needed addressing, to break the invisibility of women in a 'male disease'.

The emphasis of women refraining from multiple sex partners to avoid the spread of HIV was also of concern for these participants. They felt women in monogamous relationships or serial monogamous relationships did not get the message that they

too may be at risk. Paula explains her situation and feels other women may also be in a similar situation. She had been in a relationship for many years before she was diagnosed.

People think that if a women gets it, [HIV] it is because she is promiscuous...you know I had been with the same partner for many years before I contacted it and so that is quite a big misconception (Paula Int: 1 p.14).

Feminist scholars also believe that inherent within the message of refraining from multiple partners in that only promiscuous women get AIDS (Schneider, & Jenness 1994; Treichler, 1997). For women who do not have multiple partners this message is invisible to them, as they do not consider themselves to be at risk.

Women had ideas of their own to address the invisibility and as previously mentioned some of the women were involved in education identifying more emphasis on women's HIV stories. While some felt it was their role to educate others participants felt that this was a difficult thing to do given the public perception of HIV, especially the perception of the 'sort' of women who is HIV positive.

I don't think I am quite confident enough to do it really [give education in a public forum]...I would rather just get on with my life. I am not just that confident to stand up and be able to talk to people like that...it would be quite scary (Kyle Int 1: p.16).

While Kyle was not prepared to be that visible Paula felt she could speak publicly as a married woman with a partner and three children.

I don't have a problem with that [education for women as a role model]...people need to see what someone looks like that is HIV...and to realize that it could happen to them as well (Paula Int 1: p.14).

Rita was also involved in public speaking as an HIV positive woman and belonged to a group of 'positive' women. However, few of these women would speak publicly.

Rita felt that women's voices did need to be heard, to become more visible, but also stressed too much public profile has its drawbacks. A public profile could become a sole identity and this could make a person incredibly vulnerable.

I am kind of visible, but not wanting to become too visible...just because I am afraid that it becomes all my identity (Rita Int 1: p.16).

Rita then adds

There is not a lot of support for you if you do that...[become publicly HIV positive] it is such a small country and once you are sort of out...you have to be really out to be effective. I have tried to be just visible...in a simple way...but I find it really confronting and I am just tired now you know (Rita Int 1: p.12).

Although being invisible in a 'male disease' was thought by participants to be inherent in the educational message for the prevention of HIV/AIDS this was not the only way they felt invisible. Many participants mentioned male dominated research and HIV/AIDS. All participants were concerned that most research was carried out on men, especially surrounding new drug administrations, and this knowledge was then automatically transferred to females. This once again left them feeling vulnerable and invisible.

5.2.2. Sex specific research

All participants felt there has been advancement in medications for HIV positive people, but expressed uncertainty and distrust when considering the benefits of these combination treatments for themselves and their children. Their reasoning focused on the fact that much of the research had been carried out on men. They also expressed concerns about the side effects of drugs on women.

Most of the testing and treatments have been done on males, and this is odd...hence why I don't go on drugs...I believe they are really toxic (Kimberly Int: 1 p.7).

The majority of research looks at men, all the drug research looks at men...I mean our bodies are not the same as men, everybody knows that (Mungu Int 2: p.29).

In the magazines they send us all their drug trials...they are done on men...they don't put enough into the women (Jose Int: 1 p.26).

Women are something the drug companies just don't want to know the whole issue is just fraught (Rita Int 1: p. 4).

Recent research carried out in Australia reveals there are differences in the attitude of women and men towards antiviral treatments (ARV). Fewer women (60%), than men (70%), believed that antiviral drugs meant better prospects for most people (McDonald, 2000). In this survey 42.1% of women believed combination AVR drugs were harmful and nearly one half of women 45% were unsure whether HIV treatments would stop them dying from AIDS (McDonald, 2000).

Concerns surrounding male specific research continued to be expressed by participants and feminist scholars agree that male bias in clinical medicine is not unusual, but add that male bias is particularly dominant within HIV/AIDS research (Ankrah, Schwartz, & Miller, 1996; Pinch, 1994; Schneider, & Stoller, 1994).

Realistically, with HIV/AIDS being first identified within the male population, men became the research focus. But it is also noted that HIV/AIDS has been amongst women since 1983, but the amount of research carried out on women specifically has been slow in coming. Ankrah, Schwartz & Miller (1996) and Hankins & Handley (1992) agree that women have been largely ignored for an entire decade, and any unique features of HIV infection for women have been paid little attention. One of the first studies describing the natural history of women and HIV was carried out in 1991 where clinical manifestations of HIV were compared between women and men

(Abercrombie, 1996). But it was not until the mid-1990s that specific emphasis on women and gynecological manifestations were studied which formed the clinical practice guidelines for doctors for detection of cervical disease in women with HIV (Abercrombie, 1996). The medical research with specific reference to women remains small and research into the medication differences between women and men have yet to reveal results (Ankrah, Schwartz, & Miller, 1996).

Kimberly offers her view of why women need greater access to research drug trials as she believes she has observed women who have reacted to combination AVR drugs and feels there is a difference between men's and women's bodies.

They are over drugging them [women] they are giving them far too much for their body weights and they are not associating them [drugs] with the size of women (Kimberly Int: 1 p. 8).

There is a need for commitment to research, which will produce safe protective measures for women, that women can personally control. Elias & Heise, (1996) believe research on the female condom should receive greater input along with a safe and effective intravaginal microbicide. Ankrah, Schwartz, & Miller, (1996) also comment that if these methods of protection could be further developed women who were unable to negotiate consistent condom use with their partners would be advantaged. In order to reduce women's invisibility within HIV discourse there needs to be greater emphasis on sex specific clinical manifestations and drug trials along with psychological and social issues, so that women can be more accurately defined and visible (Abercrombie, 1996; Buzy & Gayle, 1996).

All participants wanted more sex specific research to raise women's profile and to inform other women of their stories. As one participant pointed out, you only need to look at how many research projects have been carried out on HIV positive women in New Zealand to realize that they remain invisible. As previously noted in the literature review there has been one official report concerning women and HIV/AIDS in New Zealand published in 1993 by the Ministry of Health.

5.3 Summary

Participants expressed their feeling of invisibility in a disease discourse that was constructed by men and for men. The sense of women being invisible within a construction of HIV/AIDS as a 'male disease' was exacerbated by the phallocentric nature of the educational message. Inherent within the educational message of using condoms to prevent the spread of HIV/AIDS is the belief that women can control men's power over sexual negotiation.

Concern was also expressed that young women were particularly at risk with the 'use condoms' message. Participants believed young women might be unaware of the socially constructed concepts of femininity and masculinity that exist in society, which gives men control over sexuality issues. Participants wanted more gender based education programmes in schools to enable young women to acquire knowledge of positive and affirmative concepts of women's culture, along with skills in sexual negotiation.

Participants also felt that due to a lack of sex specific research, women continued to remain invisible. Women felt much of the research had been carried out on men and felt uncertain and distrustful of research on drug trials that focused exclusively on men. Feminist scholars also believe there is a lack of commitment to research, which would enable women to control their own protection against HIV including intravaginal microbicides and the female condom. Sex specific research therefore has the potential to enable HIV positive women to become visible within the HIV/AIDS discourse.

Participants were aware that globally and within New Zealand there is a gender shift of HIV/AIDS infection that will continue as long as women remain invisible within a 'male disease'.

5.4 Women's experience of being HIV positive mirrors women's place in society

This is the fourth and final theme of the data analysis.

As participants continued to describe their lives living with being HIV positive, their perceived feeling of invisibility were further expanded into feeling of powerlessness and a sense of frustration in being considered as the 'other' within HIV. Some participants felt being treated as the 'other' within HIV, that is not male, was similar to the way women were treated in society, meaning they felt powerless to change a structure made by men for men.

Feminist scholars have developed theories which explain women's powerlessness their sense of 'other', in society, and these theories have become an increasingly accepted part of social and political discourse. Feminist theory critiques traditional social and political thought where there is an assumption of male superiority and centrality along with a commonly accepted and confirmed women's subordinate position (Beasley, 1999). A major emphasis of mainstream social and political thought is that it tends to universalise experiences, meaning that experiences associated with men are thought to be common to all human beings (Beasley, 1999). Overall, most feminist theory positions women as socially, politically and economically subordinate in the structure of society (Beasley, 1999; Evans, 1997; Maynard & Purvis, 1994; Tong, 1998; Weedon, 1997).

Women's subordinate role in society was brought into context as participants described their experience of being HIV positive in a male dominated society. Examples of this subordination are described.

5.4.1 Support services for people living with HIV/AIDS

Support services worldwide have been set up to assist people affected with HIV/AIDS. Support services vary internationally depending on financial, political and social circumstances. Here in New Zealand support services for people living with HIV consist of counseling, assistance with benefits, needle exchange centers, information libraries, support groups, medical advice and hospice care. The amount of support available also depends on location, as city areas have more resources than those in rural areas, and there is only one residential facility here in New Zealand providing medical and social support for anyone who is HIV positive. Support services was a topic raised by participants and although it was agreed that services were available, the appropriateness and the extent of the service was contentious and gaps were identified.

I think for me, I am a solo mother...I see a lack of support in that area...there are some good support services for people who are really sick (Lydia Int: 1 p.5).

I think people with children...they need more support...especially if they are alone and they haven't got support...you know support of children...helping to care or getting time out. I would have liked more help in that area, especially initially when you are coming to terms with everything (Joy Int: 1 p.7).

Would be better to have something like the Karitane kind of idea...someone to come into the house and look after the kids while they go out for the day...for a break. It is really trying bringing up children...and having HIV (Rita Int: 1 p.9).

Childcare support was an area participants felt needed addressing and research indicates that one of the most important issues impacting on women with HIV/AIDS was in their role as mothers and caregivers (Sowell, Moneyham, & Aranda-Naranjo 1999a). As well as childcare, women are caregivers to partners and other extended family members. A woman's role in society is frequently constructed as a caring

role. Research indicates that women as caregivers often view their own health problems and needs as having a low priority relative to the needs of others, especially their children (Sowell et al., 1999a). Many women find it difficult to ask for assistance when caring for others for fear of being judged as not coping (Sowell et al.,).

Kimberly concurs with research findings as she explains

You are looking after the kids, you are worried about your husband, you are worried about a relationship. You are trying to make sure the family is not too worried about you, you cannot verbalize anything to anyone, because you are female in the home, and you are there to keep it together. You can't ask for help because women don't ask for help (Kimberly Int: 1 p.7).

Mungu also explains women's roles as mothers where they address first the needs of their children, then their own health as secondary. This manifests particularly when there are financial restraints.

The question is do I go to the doctors today or do I feed the kids tonight...the kids will get fed (Mungu Int: 1 p.10).

Childcare was also an issue for Rita who argued that facilities and resources to provide childcare for women are not available. Here she explains why this might be.

It is not an issue for gay men [caring for children] they have no inclining of that...or if they do they are not living with them [children] on a day to day basis. They have no inclining, they do not have children...HIV...it can't be looked at separately (Rita Int: 1 p.10).

Facilities and resources have not been an issue within HIV as the majority of men do not physically care for children, and therefore resources run by men for men have not addressed issues around childcare.

But for women with HIV/AIDS the welfare of their children and other affected family members is of paramount concern (Sowell, Moneyham, & Aranda-Naranjo, 1999a). Once again, until recently much of what was written or discussed about HIV/AIDS was heard from gay or bisexual men, and resources set up for men have been transferred to services for women. Internationally in western countries there is now growing evidence to suggest that existing support services set up for men fail to supply the needs of women. Growing evidence has led to the recognition of woman's experience of HIV as different to that of men's and a realisation that existing services need review. Women's subordinate role in society has been a contributing factor in the lack of appropriate services for women with HIV (Ankrah, Schwartz, Miller, 1996; Auer, 1996; Sowell, Moneyham, Aranda-Naranjo, 1999a).

Participants expressed anxiety surrounding the seeking of support from some existing HIV support services. They had visited sites that offered advice and support on HIV/AIDS in the form of social services, counseling and information. For many women this experience resulted in their needs being unmet.

I walked in there [name of counseling service] and requested that I see a counsellor. The initial reaction was which group are you from...what research are you doing?. I looked at them and said...I have just been diagnosed...that was my first recognition of prejudice...I realized I didn't fit the criteria...I wasn't a gay male...I didn't have HIV/AIDS tattooed across my forehead (Kimberly Int: 1 p.2).

We do have centers but they do not do anything directly or specially targeted at women...they are not interested (Rita Int 2: p.19).

I have made contact with the center...but I found most of them [at the center] were older than me...let alone women...most of it seems to be gay oriented (Kyle Int: 1 p.5).

Paula decided to visit a center for HIV positive people along with her male partner who is also HIV positive. She explains her feelings of being uncomfortable.

My partner and I don't have much to do with the [name] center...we just find it too gay oriented for us...that is what puts us off the most...we both feel that a lot of the support goes to the gay community. I am not sure the center has women counselors (Paula Int: 1 p.10-11).

As previously explained there is one residential center in New Zealand which provides medical and social support for anyone who is HIV positive. Jose decided she was in need of medical attention and respite care, as coping with three children on her own was proving difficult. Travelling to the center required a long journey but Jose thought the trip would be worth it, and although Jose enjoyed her stay she also commented on the male atmosphere.

I would like to see more places that are for HIV women to go to...more places that accept women [name of facility] it is full male orientated...like they forget women can get it (Jose Int 1: p.9).

The reference to 'gay' facilities was repeated many times by all participants and women felt unsupported by a service which seemed unaware of women's needs. Recent research indicates that women who feel uncomfortable in the provided environments are consequently less likely to use the services (Meredith, Delaney, Horgan, Fisher, & Fraser, 1997; Sowell, Moneyham, Aranda-Naranjo, 1999a).

One service specifically set up for all HIV positive women was a three-day retreat. This concept follows the success of men's experience with a three-day retreat which has been reported to have assisted men with increased knowledge of their disease, the opportunity to form bonds, networking with others, and affirmation of self.

Participants found these three-day retreats in women only environments to be extremely beneficial but commented that it was only a once a year facility. They inferred that it was not quite enough.

We have had three years in a row a retreat, which I go to organized by the women, and this is just awesome...but it is only once a year (Lydia Int: 1 p.6).

[The retreat] it is something that every women should have the opportunity to go to...it is nice to know that you are normal and that there are women out there who have the same problems as you do. You realize that are not alone, it is not a gay issue, that it is a wider issue than that (Margo Int: 1 p.18).

I have certainly found the women's retreats really helpful...simply because you come into contact with other women and you realize that you are normal (Paula Int 1: p.9).

The retreat has become more of a focal point for HIV positive women...it is a very effective dynamic way...they are taking time out from their families, it is free, and there is a real network built up on the spot (Rita Int: 2 p.14).

All women spoke of the retreat as good experience, but many felt it was only once a year, in one part of county, and some women found the organization and personal funding it took to get there, difficult.

I would have to find baby sitters...and having to pay for that...becomes expensive...it is where to put the children where they will be happy (Joy Int 1 p.10).

The experience of women-only environments was unfamiliar to many participants. Many women felt more supported and empowered in an environment with other women, to whom they could relate and share experiences. Being seen and made to feel normal, providing an opportunity to discuss with other women similar problems taking time out from their families, and realizing you are not alone, are experiences many women may not have had. Their roles as mother and caregiver within society were changed for a few days and many participants felt empowered by this. Treichler (1997), comments that women need narratives and identities to make sense of a disease and give direction for an epidemic that has been influenced by prevailing stereotypes and ongoing confusions that this disease is a 'gay male' disease.

Women's position within HIV/AIDS internationally has been constantly confusing for women. Images that do exist have positioned women who are HIV positive, as

where, bad mother and promiscuous, which femininity places women as powerless, submissive and subordinate. This position mirrors women's place in society, which oppresses women socially and politically. Treichler (1997) believes that AIDS is a paradigm for the condition of women within our society and feels it is imperative that we look closely at the AIDS environment as a useful commentary on gender. A women's position is needed within HIV discourse to form appropriate social policy and awareness (Treichler, 1997).

An attempt to provide a supportive environment for women only has been created by the formation of 'Positive Women' established in one city area of New Zealand. This group has a part-time coordinator who is in touch with HIV positive women through letters and mail outs and provides a facility for support group meetings. The focus of the group is on support, and as Rita explains it has potential as a wellness tool.

I think it has huge potential to be really successful...I think it only exists for women who are positive...I don't see it as a preventative tool...it is about people who are positive...increasing their sense of wellness. It is grueling to live with [HIV] and there is no going back on that...and I think [the group] lessens this for women, it certainly does it for me (Rita Int: 2 p.16).

Although many women felt the group had potential, rural women felt that due to its city location they had limited access, and leaving messages on an answer phone monitored once weekly was not always adequate to their needs. Some participants felt the group went only part way in providing support for women. Mungu comments that assisting women in their day to day lives is to be commended but nothing really changes in the larger context of social and political change.

A small group of women who are positive get together and talk about the same thing every time, about the risk factors for women and how nobody in society is aware. All those kinds of things, and nothing changes...it is not going anywhere (Mungu Int: 2 p.20).

Other participants also felt this group was important but lacking in a more political voice, which could influence societal attitudes towards women living with HIV. However, some participants felt even more concerned that there was even less support for women from the strong New Zealand AIDS Foundation (NZAF) body which coordinates the HIV/AIDS social and political environments.

5.4.2 Political environments for women and HIV/AIDS

The New Zealand AIDS foundation (NZAF) was set up to assist and monitor people with HIV/AIDS. Included within its many roles is providing an extensive amount of resource material for people and their families with HIV/AIDS, counseling and social support services, initiating and creating education campaigns along with supporting and coordinating research projects involving HIV/AIDS. All participants were aware of the NZAF but some participants saw the organization as predominately supporting men.

The AIDS foundation doesn't receive funding for women...and while they have just written it into their new constitution that...we will do things to benefit women...it was only after pressure. Their core group is men who have sex with men and I think women are quite threatening to them...they might be gay men...but they are still men...they don't want to loose their power base (Rita Int: 2 p.14).

The AIDS foundation...the money goes towards gay men, there is nothing for women (Margo Int 1: p.17)

Mungu, while collecting money for AIDS awareness day in December, was endeavoring to inform others of her perception of women's position within HIV/AIDS.

I did tell some people my close friends...that none of the money you give the AIDS foundation gets to any of the women (Mungu Int: 2 p.23).

Funding continued to be an issue for some participants who felt the NZAF could be more forthcoming in supporting initiatives for people with HIV/AIDS. Rita felt the success of the women's retreat needed acknowledgment and required funding from a reliable source. The current method of funding for the retreat was canvassing for money from other organizations willing to support women who are HIV positive.

I think [the retreat] really needs to be acknowledged, it needs funding every year. I hate the whole sense of fund raising ...it could take up almost six months of the year...[to find sufficient funding] (Rita Int: 2 p.15).

Mungu also had issues around the funding of the retreats. She implied that the men could fund raise without too much effort, inferring that men had better access to financial resources.

I met this guy, he was organizing the funding for the new men's retreat...80 registrations...he has all the confidence in the world that he will be able to raise the funds in such a short time, in a matter of three months. The positive women's group, have an enormous problem raising the funds for 20 women (Mungu Int 2: p.27)

This perceived confidence to locate extra funding might be explained in terms of male power, and men's political knowledge. An example of male power and privilege is explained by Lupton (1998) who believes that around the time that HIV/AIDS was identified in the gay community, the gay liberation movement was also emerging in many western countries as a growing political force. Lupton (1998) reports that, in Australia, gay men possessed within their group many organizational and political skills and they lobbied Governmental bodies for funding for HIV/AIDS around prevention and treatment options (Lupton, 1998).

The submissive roles of women and their perceived powerlessness and lack of political skills was often brought to my attention when talking with participants and listening to their stories. This sense of powerlessness reflected in my mind women's submissive and subordinate position within society. Some participants accepted the

position as the norm while other participants, although aware of women's subordination, felt powerless to change the situation.

Rita demonstrated an understanding of her political position when she expressed her frustration and her lack of skill when confronting Accident Compensation Corporation (ACC) for compensation. She felt there needed to be a law change for women in her position but felt she lacked the skills, knowledge and societal support for change.

How does one get involved in lobbying around those law issues...those kinds of issues are really important (Rita Int2: p.17).

Mungu was also aware of political issues that affect all HIV positive women but she also found the situation difficult. She continued to ask herself if she should encourage women to become involved, does she even have the right to influence others, but also she felt if women did not get involved then the situation might not improve.

The majority of them [HIV positive women] are unaware of the issues because they are not political or they don't perceive themselves to be political and they are just ordinary people who carry on their lives even though they have HIV. They miss issues...and there is a dilemma there for me...do I give them a little bit of a shake up and say look there is an issue here? I don't think I have the right to do that to people...but at the same time...how do things change, so it is a dilemma (Mungu Int: 2 p.31).

When Mungu was offered a place on the board of trustees in the NZAF she was aware of opportunities this may present for women, but on reflection she felt she could not participate due to a culture of misogyny and a feeling of tokenism.

There is a huge culture of misogyny amongst the AIDS foundation and if you are unaware you miss it. I was invited on the board of trustees for the AIDS foundation...and the misogyny was just so bad I thought no. I think the only reason why they wanted me was because they could fit three caps with the

one person. I was a woman, I was Maori and I was HIV positive...they didn't have any of those on the board (Mungu Int: 2 p.22).

Many of the participants felt intimidated by the strong male culture leading the politics of HIV/AIDS and felt powerless to initiate change.

One further issue that concerned participants and also reflects women's subordinate position in society was the debate surrounding pregnancy and HIV/AIDS. As previously indicated women's early position within HIV/AIDS was someone who was described as a 'reservoir' 'vessel' 'vectors' or carrier of a disease infecting her male victim (Treichler, 1997; Treichler, 1999). When in the early 1980s it was revealed that children were presenting as HIV positive, pregnant women became the subjects of extensive research as the quest to reduce transmission to the 'innocent child' became the objective (Bury, 1994; Pies, 1994; Treichler, 1997).

5.4.3 Women and pregnancy and HIV/AIDS

The discovery that a woman could transmit HIV to the foetus and place the child at risk constructed women, not only as 'vectors' of the HIV, but now also as a transmitter. Feminist scholars believe that greater attention to women and HIV did not come about because there was an increase in women contracting HIV, but because there was an increase in paediatric AIDS cases (Pies, 1994). The focus became the pregnancy as women were seen as childbearers rather than women with a serious disease. The discovery that women could transmit the virus increased the stigmatization of HIV positive women as they were now seen as transmitting a virus to an 'innocent victim', the unborn child (Abercrombie, 1996; Bury, 1994; Kitzinger, 1994; Pinch, 1994; Treichler, 1999).

Pregnant women with HIV were placed in a subordinate and submissive role confronting a system, which interpreted them as possible transmitters. This perceived perception is internalized by Joy as she expresses her embarrassment when she attended a doctors clinic realizing she was pregnant for a fourth time. She was newly diagnosed as HIV positive and a recent solo mother.

Can you imagine the embarrassment of going to your doctor and saying you are pregnant [three children at home] It is bad enough being HIV positive but pregnant and HIV positive was just too much (Joy Int: 2 p.14).

Confirmation that HIV could be transmitted to the foetus followed a statement from the Centers for Disease Control (CDC). It recommended that women who were infected with HIV, or had AIDS, should be advised to delay pregnancy until more was known about transmission (Pies, 1994; Pinch, 1994; Treichler, 1999). This message suggests that discouraging women from becoming pregnant or carrying their infant to full-term (abortions were also advocated) would prevent the births of many, or most, of the HIV positive infants (Bradley-Springer, 1994; Pies, 1994; Pinch, 1994). The American College of Obstetricians and Gynecologists went so far as to strongly advise their colleagues that HIV infected women be counseled about the risks and advised about abortion options (Bradley-Springer, 1994). Early studies suggested that pregnancy was dangerous for women with AIDS and the presumed risk of the baby becoming infected was high, 50% to 60% (Bury, 1994).

Medical opinion that possible transmission to the infant was high and the prospect of reducing the births of HIV positive infants placed women in a difficult position. Preventing a birth, or the abortion option, was seen to be 'logical' behaviour for any woman (Pies, 1994). Any other behaviour, such as carrying on with the pregnancy or choosing to become pregnant, knowing you were HIV positive was constructed as being 'illogical' or not clear in moral thinking (Bradley-Springer, 1994; Pies, 1994). But as Bradley-Springer (1994) points out these recommendations did not address the loss of reproductive opportunity this would pose for many women. Also this statement was seen as a patriarchal repressive strategy which oppressed women's self determination and reproductive rights (Bradley-Springer, 1994).

Margo was faced with this decision when she found out she was HIV positive and pregnant. She based her decision on the information she was given at the time, which included the possibility of transferring the virus to the baby, but finally decided that because she may not be able to care for the child she would have an abortion.

When I found out that I was positive there was no way that I was going to have the baby...I had an abortion...I had made up my mind. I thought I am not bringing up someone in the world who I might never be able to look after...I had my tubes tied (Margo Int: 1 p.11).

Women's position in society as 'good' and 'moral' positioned pregnant women with HIV who risk infecting their child as being selfish, irresponsible, or immoral (Bradley-Springer, 1994). There is evidence that health professionals, influenced by medical discourse, had a tendency to coerce HIV positive women into having abortions (Auer, 1996; O'Gara & Martin, 1996; Schneider & Stoller, 1994).

Paula found out she was pregnant at the same time she found out her HIV positive status. She explains her dilemma and her emotional state as she endeavored to make a decision that would benefit all concerned. Paula was advised to consider an abortion, but although she had some reservations about aborting her baby, felt powerless and under pressure.

Complete upheaval you know one minute your life is normal and next you are dealing with this big issue ...we were also having our other two children tested, so there was so much going on. I didn't really want to go through the termination...but...the pressure was certainly there you know...I just felt there was a huge amount of pressure from the doctor (Paula Int: 1 p.2).

Joy also had a very difficult decision to make and consulted her GP about her pregnancy. She was advised it would not be a wise decision to carry on with the pregnancy considering she was having twins and was already a solo mother of three children. Joy decided after much deliberation that to carry on with pregnancy was the right decision for her.

I spoke to my GP [re abortion] she said...it is not very wise...[to carry on with the pregnancy] ... I wasn't going to let anyone bully me into anything. I came to the conclusion that if I aborted these little people HIV would win...because I would have given up...all that I hold as value, my values over done...I would have lost and HIV would have won. I came to the conclusion

that...I cannot abort even though you know it is going to be hard...for me as a person and what I hold dear I couldn't (Joy Int: 2 p.14-15).

A decision to abort a child for any women comes as an extremely difficult option, but the advice and therefore pressure to abort by health professionals is a strong influence to ignore. A woman's self-determination, validation, acknowledgment and an identity as a pregnant woman have been ignored within a medical discourse which advises women to avoid pregnancy or to abort.

Women's position with HIV and pregnancy mirrors women's position in society, where there is continued pressure to consider others before themselves. Mungu explains that the pressure for women to consider abortion without consideration for the women's self-determination may still exist.

Everybody has the right to have a child...whether they are HIV positive or not. New Zealand doctors were, in the early 1990s, advising women who were HIV positive not to get pregnant or to abort...but not only just advising but putting immense amounts of pressure on women to abort (Mungu Int: 1 p.7).

As research continues and new findings emerge, advice to pregnant women is changing. Women who are HIV positive and pregnant are in a position of immense tension within a decision making process. There is the tension between what is expected of a woman in her role of reproduction, and her own values of wanting to give birth and what is deemed socially acceptable or morally right (Abercrombie, 1996; Auer, 1996).

New medical research now indicates that transmission to the foetus can be reduced markedly by a combination of three methods of intervention: the mode of delivery is by caesarian section, the administration of antiretroviral drugs to mother and baby, and the withholding of breastfeeding (Ankrah, Schwartz, Miller, 1996; Auer, 1996; O'Gara & Martin, 1996; White, 1999).

As I continued to ask participants views on pregnancy and HIV I gained a sense of how difficult this decision was. I was also becoming aware of how participants made choices and what factors influenced their final decision.

Kyle was a young pregnant woman, newly diagnosed, and had been advised by the latest medical research.

They told us what we could do, they told us the chances of the baby getting HIV...and like with the new medications they have...it reduces it by I can't remember how much, but lots. We went on the Internet...saw some things...about women who have had children and their children haven't got HIV (Kyle Int: 1 p.3).

Kyle appeared well informed and ready to live with the experience of becoming a mother. She had been advised not to breastfeed and would have the baby by elective caesarian section. Kyle reports she felt encouraged with this information to keep the baby and was looking forward to fulfilling her new public role as mother of a young infant. Although Kyle felt encouraged and comfortable with her advice to carry the pregnancy she seemed not prepared to face public scrutiny of her HIV status and perhaps face public attitude of stigmatization towards women who were HIV positive.

I didn't like going to antenatal classes...we stopped going...I just felt too different...they were all having natural births...they were talking about breastfeeding and all these things that didn't apply to me. I didn't feel comfortable...to tell the other groups of people expecting a baby that I have got HIV...it kind of pointed us out (Kyle Int: 1 p.18)

Kyle's role as a young mother who could not breastfeed, and a mode of delivery that was going to be caesarian section, made her feel uncomfortable. Her choice of withdrawal left her feeling isolated and different.

For Paula being HIV positive and pregnant was also a dilemma and although she sought medical opinion, her personal feelings towards what is still unknown in

medical research was of concern. She took zidovudine (AZT), had a caeserean section, and decided not to breastfeed, but was left with a feeling of powerless and coercion.

I didn't breastfeed ...they gave me AZT...and I had a caeserean section and they were pumping AZT into me. There is so much controversy like when I was trying to make a decision of whether to have a natural birth or a cesarean section...they just don't know (Paula Int: 1 p.10).

Personal correspondence with medical specialists (November 2001) indicates that birth by caeserean section is no longer considered necessary in all women who are HIV positive.

Medical research has identified drugs such as AZT to be one of the biggest success stories in the field of HIV/AIDS, especially with regard to pregnant women. As previously noted research indicates that AZT in combination with birth by caeserean section and avoiding breastfeeding can reduce transmission rates to the foetus to 2% to 3% (White, 1999). What is not known is the long-term effects of AZT on mother and child. This lack of knowledge is of great concern to many HIV positive mothers.

Paula expresses her concern once again at the feeling of the unknown and the influence of a powerful discourse which advises drug administration. Paula has one son who is HIV positive.

He has been on dideoxyinosine (ddI) since he was a baby, since he was 18 months. I don't really know if I am ready to put him on the next process that of the protease inhibitors medications...I just wonder what other damage it is doing (Paula Int: 1 p.4).

Medical research is difficult to challenge especially when you are HIV positive and pregnant and want to breastfeed. Current knowledge suggests rates of transmission amongst breastfeeding mother-infant dyads vary from 18% to 53% (O'Gara & Martin, 1996). Studies in South Africa where comparisons were made between breastfeeding and formula-fed infants indicated that breastfeeding more than doubled

the risk of HIV transmission to the child (O'Gara & Martin, 1996; White, 1999). As already discussed women are positioned as illogical, immoral and irresponsible if they defy such medical advice and research. Still Lydia felt very uncomfortable when she was advised not to breastfeed and looked for her own alternatives to medical advice. She did extensive research and was interested in a study in Malawi concerning vitamin A levels. The study indicated that if she took vitamin A, this would lessen the chance of transmission and she decided to follow this advice. This study did find that breastfeeding women with a deficiency of vitamin A had a transmission rate of 34.4% compared to women in the same area with high vitamin A levels who had a transmission rate of 7.2% (White, 1999). This research was not considered scientific by medical advice and Lydia decided to bottle-feed.

I didn't breastfeed. I did bottle feed and it was horrible, I hated it...the most awful experience of my life, to have my breast swelling up with milk and my baby grieving for my comfort. That is the normal thing to do [breastfeeding] and I couldn't...it was so stressful...so I got a breast pump and I pumped out the milk and I heated it up...which kills off the nasty virus...and gave it to the baby through the bottle (Lydia Int: 1 p.14-15).

This method of feeding the infant also became stressful over time and Lydia returned to bottle-feeding with infant formula. The issue of pregnancy and HIV affected all nine women and the only participant who, as yet, does not have a child explains her dilemma around a decision for the future.

I am not sure what the drugs do long term...on an unborn child in the last trimester...I am only 31 I have still got the ability to wait a few years to make that decision finally...I don't know if I particularly want a child of mine facing that possibility [of their mother dying]. It is not based on my identity feeling any less as a person or a women that you have to have a child...however it does kind of impact when my peers start [having children] it does bring up stuff for me (Rita Int: 1 p. 11).

As previously stated many women in society feel validated, acknowledged and identified when they become pregnant and bear children. Rita felt this identity issue

was not important for her, but a woman's decision to have a child is considered fundamental to women's role in many countries (Auer, 1996). Women who are HIV positive and pregnant have been made to feel irresponsible, morally wrong and stigmatized.

Participants' experience of being pregnant and HIV positive has demonstrated some mirroring effects as to women's position in society where women are subordinate and their submissive roles render them less able to challenge a dominant medical patriarchal discourse where women's self-determination is difficult to assert.

One final issue that was identified within this theme was referred to with frequency amongst participants. This was the idea that participants felt they were to blame for their HIV positive statuses. As I listened to their stories of perceived blame I was often overcome, not only that these women had a terminal chronic illness, but also by their belief that contracting HIV was entirely their fault.

5.4.4 Blame and shame

Shame and blame were two words participants used when exploring and describing experiences of living with HIV. Their sense of blame and shame was expressed when they discussed how they thought they contracted HIV. Concepts of gender identity and what it is to be feminine were described by participants. Sex refers to the biologically given state whereas gender refers to a social construction of characteristics which are defined as masculinities and femininities (Jones, 1994). Gender identity is said to be learnt early in life as young girls are taught to be pretty, sweet, modest and subservient, while boys are expected to display toughness, strength, independence and assertiveness (Moi, 1997).

The perception of what it is to be masculine or feminine has been brought into debate since feminist theory began to challenge male power. Western cultures produce a hegemonic masculinity constructed in the image of a white middle-class heterosexual male who is seen as virile, successful, powerful, competitive and aggressive (Holland, Ramazanoglu, Sharp, & Thomson, 1994b). This powerful male aggressive behaviour is constructed by society not only as dominant but also as being of more

value, this therefore places women in a subordinate position. Women's femininity is constructed as submissive, caring towards others, nurturing and warm, an emblem of cleanliness and community (Kitzinger, 1994). Constructed also within masculinity is men's sexuality and to be a 'real man' means not only being dominant but also having desires and needs of a sexual nature (Kitzinger, 1994). One demonstration of potency, which is shown amongst peers and society, is to have sexual encounters with females thereby showing a true sense of masculinity (Holland, Ramazanoglu, Sharp & Thomson, 1994b). Feminist scholars argue that for women to behave in a similar manner positions women as 'bad' 'slut' 'whore' or 'temptress' (Gorna, 1996; Kitzinger, 1994).

Participants' feeling of blame and shame arose from their perceived role in society and what it is to be female and feminine, inferring that due to 'behaving badly' they deserved to be HIV positive.

I do blame myself...I have some guilt around that because [of] the way that I contracted the virus, I was married and it was an extra martial affair or was more of a rape than anything, but I still blame myself. If I hadn't done it or having a little freedom fling then it wouldn't have happened... it is all my fault (Lydia Int: 1 p.8).

If anyone is to blame it is myself, I can't blame anyone but myself...I didn't take precautions, my fault...a women has to take responsibility (Margo Int: 1 p.22-23)

Initially yes I felt I was to blame and had shame that is why it was so hard for me to tell people about it (Paula Int: 1 p.9).

I certainly felt blame, I always thought I was to blame...I trusted that person...I was being feminine...pretty (Rita Int: 1 p.6).

Lydia felt she was to blame as she internalized what it is to be female 'having a little freedom fling' was not what women do so therefore she perceived she got what she deserved. Margo thought she should be held responsible placing all the blame on

herself while her male partner was proving his masculinity *'I didn't take precautions, my fault...a women has to take responsibility'*. Rita perceived a feeling of trust, and wanted to be seen as pretty and feminine and available.

The social conditioning of what it is to be female are learned concepts of femininity. Feminist scholars argue that the hegemonic heterosexual masculinity of being a 'real man' positions men with considerable power, the latter is more valued by society which places women in a submissive role (Holland, Ramazanoglu, Sharp, & Thomson, 1994b).

What it is to be feminine was perceived by Rita as something women just have 'put up with' in society. Rita explains she does not blame herself for her HIV positive status, but she did initially believe in her learned social skills of what it is to be female. She acquired this learning at an early stage of her life.

I was basically raped and got HIV from my boss...despite the fact that I did have consensual sex with him twice that wasn't the point...that type of abuse is rife out there...I thought that was just what you had to put up with (Rita Int: 1 p.6).

This sense of blame is present amongst some participants who believe that they deserve a terminal disease due to their actions of being 'bad' women. Participants' experience of being HIV positive mirrors women's role in society where concepts of femininity and male power make sexual negotiation not only difficult but often almost impossible due to messages surrounding femininity.

5.5 Summary

Participants often felt subordinate, submissive and powerless in describing their experience of living with HIV. Participants explained their feeling of subordination when their needs went unmet as they accessed resources for HIV people. They found the service catering more to the needs of 'gay men'. Policies and strategies contained within HIV/AIDS resources remain essentially for men and some participants felt frustrated by their inability to influence policy services for women.

A sense of subordination was also felt by participants who were pregnant as they felt powerless and coerced when seeking advice on issues surrounding their pregnancy and their options. Women who are HIV positive and pregnant, or thinking of pregnancy, are constructed as illogical, immoral and selfish, rather than being seen as pregnant women with a terminal illness who would normally be tragic figures evoking enormous sympathy. Extensive research surrounding women and pregnancy constructed women as transmitters of the virus. The focus of research and pregnancy was more about protecting the 'innocent' child and reducing the paediatric AIDS rate, rather than about women with a terminal illness. Women's position in society leaves them less able to challenge a system of power contained within a patriarchal medical discourse.

Many women describing their experience of becoming HIV positive felt a sense of shame and blame. Concepts of femininity and masculinity were acknowledged where women felt it was their role in society to be there for men especially in relation to sexual demands. This subordinate position in society renders women powerless to challenge the masculine construction of what it is to be male and the resulting power imbalance is inevitable. This situation renders women especially vulnerable to a disease such as HIV/AIDS.

The following and final chapter will encapsulate and discuss the findings of this research.

CHAPTER SIX: Discussion and Concluding Statements

6.1 Introduction:

In the two previous chapters the four emerging themes were analyzed and in this final chapter I discuss what has emerged from the research. My comments also include implications for nursing practice, the limitations of the research and recommendations for further study.

6.2 Restating the Aim

The overall aim of this research was to explore and describe women's experience of being HIV positive in New Zealand. I particularly focused on New Zealand women, to make this inquiry unique to the New Zealand experience, acknowledging the dearth of research within this population of HIV positive people. My second aim was to provide information to health professionals to enable them to have an understanding of the issues which HIV positive women experience.

6.3 New Identities and the Risk of Disclosure

The acceptance of the new identity of being HIV positive took time for participants. Most women felt that the longer they lived with HIV the more accepting they became. This enabled them to have more confidence in living with HIV, gave them more ability to cope with the revealing or concealing of their identity. Even with self-acceptance all participants agreed that considering to reveal or to conceal a diagnosis of being HIV positive involved risk. The risk associated with disclosure involved being exposed to stigma and being judged as having a past history of deviant behaviour. Concealing an HIV positive diagnosis meant living a life of secrets which was described as dishonest and made participants feel uncomfortable. At times however, this seemed the only option available.

As previously discussed HIV/AIDS has been constructed as one of the most stigmatized health conditions known. This created image draws a distinctive line

between the 'healthy' and the 'other'. The 'other' is portrayed as contagious, sexually deviant and addicted (Fee & Fox, 1992; Green & Miller, 1986; Treichler, 1999; Watney, 1993). Participants perceive that not only is HIV/AIDS associated with deviant behaviour, but this deviant behaviour was also viewed as the responsibility of the individual (Green & Sobo, 2000). Therefore being labeled as unhealthy, 'other', contagious, and culpable, creates a social construct of stigma. But participants felt that being female and HIV positive is possibly more stigmatizing for women. Women with HIV were constructed as 'vectors' of the disease and were blamed, mostly through prostitution, for spreading and passing the virus onto men. Women were also seen to be the transmitters who pass the virus onto the 'innocent' unborn child. These two constructs were internalized by many participants and this became apparent when participants described their lives and living with HIV.

Participants found that decisions regarding whether to reveal or conceal their HIV positive status added to the stress of living their day to day lives. Disclosing not only meant the risk of being judged but also women felt once they revealed they were not always taken seriously. Participants felt institutions such as social welfare services did not take them seriously when they applied for benefits. This was especially noticeable if they appeared fit and well, or were working part-time. Justifying their seropositive status with medical records was needed constantly, along with explanations of their perceived continued wellbeing. As institutional bureaucrats these workers were using medical records to deal with, and justify, their perception of someone with HIV positive. Institutional workers appear to have a perception of someone who is HIV positive as being physically unwell, presumably deviant, addicted and male.

Participants also felt that when they disclosed to friends or to professionals in many circumstances it was assumed that they were a 'sort' of women whose source of infection occurred through prostitution or intravenous drug use. Not only did participants feel this concept was assumed, but also when participants did not look like the 'sort' of women with HIV they were asked to explain themselves. Ironically, in many circumstances, medical and nursing professionals demanded this explanation. This is of concern because their supposed objectivity along with their

legitimated positions of expertise should have meant that they avoided passing judgements on an already vulnerable population such as women with HIV.

Participants argued that revealing a positive HIV diagnosis was different and more stigmatizing for women than it was for men due to their different roles in society and the different responsibilities they had in their lives, especially involving their role with children. For many women fear of the effect an HIV positive status could have on their children, spouse and extended family, was of particular concern. As explained by some participants, family cohesion and childcare tended to be the responsibility of women and disclosure of seropositivity affects every family member, not just her alone. Participants were concerned that their children may be affected in their social relationships outside the home when it was established that a child had a mother who was HIV positive. Women feared it could hinder a child from socializing with other children outside the family environment. Research also indicates the social stigma associated with HIV/AIDS can arouse fears of shame within the extended family (Green, 1995). Women must face this risk when and if they reveal (Ankrah, Schwartz, & Miller, 1996; Green, 1995; Green & Sobo, 2000). For these reasons and others some participants with children kept their seropositivity status confidential.

In summary, participants felt that there was significant gender difference concerning issues of disclosure, in particular involving stigmas and a woman's role around the care of children. These were specific issues that men were less likely to confront, and they placed extra stress on women living with HIV.

6.4 Prevention of HIV/AIDS and the Messages for Women

A further finding within the data was participants' concern, surrounding not only the increasing spread of HIV amongst women, but also the lack of a preventative educational messages aimed specifically at women. Participants believed that education was one way to combat the spread of HIV, because there was no cure or vaccine in the foreseeable near future. They were most concerned about the phallogentric nature of the prevention message. Participants felt that the preventative message towards gay males and the use of condoms was appropriate, but the

message of using condoms within the heterosexual population, was translated as a message which assumed women had the power to negotiate sexual encounters. The interviewees felt that women did not always have the power to say no to sexual advances from men, especially when those men were also their partners and where condom negotiation could involve threats of violence.

The fact that most participants described the power men held over sexual negotiation and condom use was interesting. I assumed that many women would be unaware of male power over sexual contacts, as there is anecdotal evidence to suggest many women do not challenge men's authority and power over their right to demand sex from women. As intimated previously, within the data analysis, feminist scholars believe unequal power relationships make condom negotiation difficult and that women who challenge the power of men demanding sex may place themselves at risk of violence and economic instability (Cash, 1996; Kline, Kline, & Oken, 1992; Pinch, 1994).

Participants also worried that the HIV prevention message of using condoms and refraining from multiple partners failed to inform women who were in serial or monogamous relationships that they too are at risk. Participants felt this message did not reach women in monogamous relationships who felt they were safe with one male partner and as one woman explained she had been with the same partner for many years before she became HIV positive. Condom use messages can be ineffective if women do not feel safe enough to request that their partners use them.

Some participants were unable to find solutions to the power men held in these situations. Participants involved in education suggested that more input into schools with specific emphasis on gender differences could be one approach. Participants felt sex education should start with adolescents within schools, and that education should not be based around reproductive biology but more around gender education with concepts of femininity and masculinity exposed.

Participants did feel they had been, and still were, influenced by the social construction of what it is to be feminine. Images of 'good girls' and 'bad girls' were evoked by some participants believing that the 'good girl' image involved being

pretty, submissive, moral, and available for men. Other participants sensed that women who have sex out of marriage, have multiple partners and do not take responsibility for their actions are 'bad girls' and therefore perhaps deserve what they get. Current constructions of femininity places women in vulnerable positions and contributes to their risk of contracting HIV/AIDS from men (Bury, Morrison, & McLachlan, 1992; Kendall, 1996; Treichler, 1997).

The educational message for adolescents and the prevention of HIV/AIDS should contain scenarios that challenge predominant concepts of masculinities and femininities (Holland, Ramazanoglu, Sharp, & Thomson, 1994b; Preble & Siegel, 1996). Feminist scholars also believe there is a lack of general education which needs to address the gender and social inequalities within society. These inequalities are currently ignored within the HIV/AIDS prevention message (Cash, 1996; Preble & Siegel, 1996).

Changing societal attitudes and behaviour is a daunting challenge for any educational programme but education on sexually transmitted infections (STI) and AIDS prevention which aims to influence people's most intimate, secret sexual behaviour requires well considered strategies. According to these particular participants strategies to educate women concerning the spread of HIV/AIDS have yet to be effective. They feel there is no specific education at present which addresses the needs of women in the HIV/AIDS prevention context.

The early educational prevention design messages surrounding HIV/AIDS were initially based on generic and fear-based messages (Lupton, 1998). Since then research has indicated that positive constructive AIDS prevention messages give people a more informed message, along with prevention messages tailored to target populations (Preble & Siegel, 1996). In other words there is a need to target education with a specific emphasis on gender, culture, ethnicity and religion surrounding HIV/AIDS prevention (Kitzinger, 1994; Preble & Siegel, 1996; Treichler, 1999).

Participants' ideas surrounding education of women and HIV/AIDS was on my mind as I attended a recent HIV/AIDS workshop (November 2001). I asked a representative from the New Zealand AIDS Foundation (NZAF) if there were any future plans for HIV/AIDS education programmes to target women specifically. His reply was that they had no funding to start such a programme, but they would be willing to assist other organizations or institutions that thought an educational message was necessary. The implication was that he felt there was no immediate need to commence such an educational campaign. The New Zealand Family Planning Association (NZFP) also replied to the same question by commenting they had no budget for such an undertaking and no future plans to address this issue.

6.5 Social Service Provision for Women with HIV/AIDS

Participants all expressed concern over the services provided for people living with HIV/AIDS.

Gay men were, and still are, the predominate users of existing New Zealand health care services for HIV/AIDS. These services were originally set up for men, and by men. The data analysis revealed that some women were attending and using the provided service. But participants using these services reported feeling uncomfortable in the existing environments and intimated their reluctance to attend a service that did not meet their needs. It would appear that the existing models of care to support people with HIV/AIDS have not changed significantly enough to address models of care for women.

There is international evidence to suggest that any service providing for women needs to include support for the family as a whole, especially as women are often caring for a spouse or children who are also HIV positive (Sowell, Moneyham, & Aranda-Naranjo, 1999a). Whole families can be disrupted when the woman is HIV positive, as she is usually the principal caregiver. Participants requested that more support be given from existing services to facilitate this need, especially for single parents where the issue of childcare was a concern, along with assistance in caring for children when the mother is unwell.

Psychological services were also deemed an important part of a social service. Some participants felt unsupported especially when there were no women counsellors available. If they were available they were difficult to access or were not available during specific times of need.

There is one provision that has been specifically set up for women. A national support group for all positive women is a provision which participants were aware of and had access to. But there were also some participants who felt that due to its location, many women could only communicate via mail or phone. It also only had a part-time coordinator and answer phone communications, which was limiting when women required a quick response to requests for support. Although this group was small it did appear to meet the needs of some women who wanted group support. Others felt the group did have potential but at present it was only a support group missing a branch which could be further developed into a political or social voice of change for women with HIV.

The provision of appropriate services tailored to the needs of HIV positive women in specific areas with specific needs is requested by these participants, but their voices appear small when they challenge the well established patriarchal knowledge base within HIV/AIDS discourse.

6.6 Male bias research

Most participants acknowledged the male bias within HIV/AIDS research. Current literature supports this claim contending that women's experience of the disease has been largely ignored (Ankrah, Schwartz, & Miller, 1996; Bury, 1994; Kendall, 1996; Pinch, 1994; Schneider, & Jenness, 1994; Treichler, 1997).

Participants were particularly concerned regarding the use of the more recently discovered antiviral drugs, which some women felt uncertain about using. They felt the drugs were too toxic with many side effects, and participants commented on the lack of research carried out on females, and drug intolerance. Some participants felt that women's bodies were different and were unprepared to accept an explanation

that medications would have the same effect on women as they would on men. International research indicating any differences has yet to emerge.

I also questioned a researcher at the same HIV/AIDS workshop previously mentioned. I asked if he thought there were any differences in tolerance levels between women and men's reactions to drug administration. His response was that testing had mainly been restricted to men.

Participants were unaware of research for women in microbicides and barrier methods for HIV/AIDS protection. This is an area which has not been treated as a priority by pharmaceutical companies resulting in a failure to produce safe protective measures that women can control (Ankrah, Schwartz, & Miller, 1996). Several authors argue strongly for the development of HIV prevention technology controlled by women, which they believe would fill an important gap in the global response to HIV infections (Ankrah et al., 1996; Auer, 1996; Cash, 1996; Elias & Heise, 1996).

The only area participants agreed had been researched at great length was pregnancy and HIV. Although participants appeared grateful for this research, there was a perception that at times some women felt coerced and pressured in certain circumstances. Some participants felt their self-determination and personal belief systems were not considered. They felt a sense of powerlessness against a strong medical scientific discourse. A general feeling amongst participants was that a woman had a right to have a child and for many women pregnancy is a time where they are validated and acknowledged. The privilege of bearing a child seemed to be dismissed when advice was given by medical professionals advocating abortion. This was a difficult perception for these women to come to terms with.

Participants felt they were being judged adversely if they were pregnant and had chosen to follow the pregnancy through. Research indicates that women are constructed as illogical or immoral if they risk passing the virus to the 'innocent' child (Bradley-Springer, 1994; Pies, 1994). This concept may have influenced one participant who was not prepared to reveal her HIV status to others within a group of pregnant women, for fear of perceived immoral behaviour and discrimination.

Participants seemed well informed of the risk of transmission to the foetus and many had followed medical advice, although with some reservations. Participants expressed concerns about unanswered questions surrounding medications such as AZT, and the long-term effects. Others had reservations about intervention methods such as caesarian section deliveries, and the debate concerning breastfeeding verses bottle-feeding options.

As with most research, long-term effects do not become evident immediately and participants did express concerns in this area that not enough was known especially surrounding the drug AZT. More recently evidence has emerged which suggests there may be concerns about the effects of AZT on both pregnant women and their babies (Preble & Siegel, 1996). One participant posited that there be more research into vitamin A supplements for breastfeeding mothers. This has not been fully researched in a scientific manner but there is some evidence to suggest that women with high vitamin A levels have less transmission rate than do mothers with low vitamin A levels (White, 1999). If this was proven it may be a safe and more cost-effective way of reducing transmission through breast milk, especially in developing countries.

The level of research on women and HIV is not responding to the increase of HIV in women. The focus continues on pregnancy and the foetus, and decreasing the infant rate of HIV infection rather than on the women with a serious illness (Auer, 1996). Other feminist literature states that too much research on pregnancy has been to the detriment of other research on women (Abercrombie, 1996). Differences in clinical manifestations in comparison to men, along with the already mentioned chemical and physical barrier methods of protection, could be given priority (Abercrombie, 1996; Auer, 1996; Batten, 1993).

In one area of New Zealand there are plans to introduce an HIV screening programme for all pregnant women. This is aimed at detecting HIV during the antenatal period with the intention of offering treatment that will reduce the possibility of transmission of HIV to the foetus (Coney, 2001). The blood test will be carried out as a matter or routine screening with counseling only proposed if a positive result ensues (Coney, 2001). This proposal raises issues around ethics and

consumer rights where a positive result could lead to compulsory treatments of mother and baby.

There is one new survey at the present moment being carried out in New Zealand concerning HIV/AIDS. La Trobe University in Melbourne Australia, with the support of the NZAF, has recently launched a nationwide survey to study the social and clinical experience of people living with HIV/AIDS in New Zealand. Women will be included amongst the participants and there is some expectation that this survey will help develop and provide educational and support services for men and women living with HIV/AIDS in New Zealand.

Despite the increased recognition that women will comprise a growing number of new HIV infections in New Zealand there has been little effort to enlist women in research agendas and policy agendas for effective prevention and control efforts. The central argument here is that women's stories have not been taken seriously and women's lives and their experiences have been ignored in research, policies and programmes. Women need a stronger voice in determining the agenda for this HIV/AIDS epidemic if the programmes are to become more effective in reducing the spread and identifying areas of need and effective research.

6.7 Implications for Nurses

Nursing has been described for decades as the caring profession. Nurses are seen to encompass a philosophy of care which is holistic and non-judgemental, respecting individuals needs values and culture (Schietinger, & Daniels, 1996; Witt Sherman, & Ouellette, 1999). New Zealand has led the way in aspects of cultural safety, acknowledging differences and outlining a model of care determining biculturalism (Ramsden, 1990). Cultural safety is a process of delivering care that is both mindful and respectful of any difference between health professional and client in terms of ethnicity, sexuality, gender, poverty and other criteria. The concept of cultural safety has been adopted by all nursing schools in New Zealand as an effective and important part of nursing education. But a culture of acceptance of difference and non-judgemental practice by nurses was not the experience of some participants.

Women expressed feelings of being seen 'like a monkey on display' (Mungu Int. 1: p.17) or 'a contaminated freak' (Margo Int 1 p. 15).

Other participants experienced feelings of isolation as nurses used excessive and inappropriate methods of protect themselves from the risk of infection. There is scope for nurses to focus their attention on developing a relationship with HIV positive women rather than focus on the disease or the transfer of fear. Providing supportive caring and safe environments and maximizing the potential nurses have for providing holistic health care, should be an aim for all nurses. Accepting diversity and the acceptance of cultural competence, which includes the acceptance of a persons diverse lifestyles, is part of the ethic of care.

Caring for people with HIV/AIDS also involves significant issues surrounding confidentiality. Nurses need to be aware that an HIV/AIDS diagnosis remains confidential to the patient. Family members and friends should only be informed with the patient's consent. The issue of confidentiality would provide rich territory for a further related research topic.

One participant described an instance where there was a major confidentiality breach, which at the time caused me to have great concern as a researcher. The participant stated she had gone into hospital for a minor operation. Just before she returned to work her employer made telephone contact to inform her that she had been dismissed for stealing money from her workplace. Her home was searched and at the following court case, the court could find no evidence to support the claim. The court declared she could return to work, but this participant felt wrongfully accused and did not return. It was later revealed that the wife of her former employer had nursed her and although the participant could not prove this was the reason for her dismissal she could find no other reason, as her work record was excellent (Margo Int 1 p 11-12).

Another comment from a participant expressed her extreme sense of powerlessness once her seropositivity was known to any one health professional. She felt this information could be passed on to others in a professional capacity without her consent (Mungu letter returned p.1).

Health professionals do not always need to know if a person is seropositive if universal precautions are in place and practiced. Nurses need to ensure they are up to date with universal precautions against all infectious diseases when caring for women who are HIV positive. Over protection and displays of fear and discrimination may interfere with quality nursing care. Participants expressed concern that over protection against transmission increased the stigma and discrimination felt by women as they continued to live with the stress of being HIV positive.

In summary participants expected but did not find the very qualities which nursing espouses as characterizing good nursing practice. This is an irony for a client group who are especially vulnerable and most particularly in need of high quality, non judgemental, confidential and informed nursing care.

6.8 Limitations of research

The sample of nine participants could be considered small, however it is nine of a possible 192 HIV positive women in New Zealand in 2001. These stories are essential and need to be acknowledged as having significant value in contributing to women's experience of being HIV positive in New Zealand.

Interviews could be seen as limited as some researchers may question the quality of data in which four participants were interviewed for only one hour and five participants for two hours. More data may have been collected which reinforced the already established themes, or new themes may have emerged. As Burnard (1997) suggests we do need to acknowledge that we cannot claim to have an intimate understanding of the ways in which people live and think about their lives after a one-hour discussion. However it is also suggested by Burnard (1997) that we may gain some insight as to this person's interpretation of their lives at that particular time. Nonetheless, within the collected data across the nine participants there were remarkable consistencies.

The nine women interviewees do not represent all women in all areas of New Zealand. Nevertheless participants did come from a large geographical area of New Zealand including both the North and South islands, rural, semi-rural and city areas.

6.9 Recommendations for Further Research

The topic of women and HIV/AIDS in New Zealand deserves a more extensive inquiry. One report in (Brander & Norton 1993) seems within the present climate of the increasing numbers of HIV positive women to require an update. In 1993 women represented 5% of the total HIV infections. In the year 2001 it is reported that women represent 32% of the total HIV infections (AIDS Epidemiology group, 2001). It also has to be acknowledged that one-third of the 48 infections diagnosed during the first half of 2001 have been in females (AIDS Epidemiology group). Providing appropriate resources for these women seems imperative, and only with adequate research will all their needs be identified. Similarly it seems vital that we address the rapid rise in numbers of HIV positive women.

Overseas studies indicate a great deal needs to be done to improve the health and welfare of women with HIV (Ankrah, Schwartz, & Miller, 1996; Auer, 1996; Sowell, Moneyham, & Aranda-Naranjo, 1999a). New Zealand is lacking clinical and social research to identify the unique features of women living with HIV/AIDS. There is a need for more information on the social experience of women with HIV in New Zealand to ensure adequate education and social support service to fill gaps identified by these nine participants.

A woman's place in society and socially constructed concepts of femininity and masculinity have contributed to women's vulnerability to HIV (Abercrombie, 1996; Cash, 1996; Green & Sobo, 2000; Treichler, 1997). Issues surrounding sexual encounters and sexual negotiation, power and gender issues, require more research to highlight and address areas of inequality.

That women appear reluctant to adhere to taking antiviral medications is indicated in recent research from Australia (McDonald, 2000). Until research produces gender

specific data that women can interpret, women's uncertainty and distrust of medications will continue.

Women with HIV/AIDS have not benefitted from the extensive social and clinical research that men who have sex with men have. The time is now well overdue for an extensive nationwide survey focused on the particular needs of women and how they live their lives. It is time to end the gendered neglect and the consequent stigma and discrimination.

6.10 Concluding Statement

Few countries of the world remain untouched by this disease which affects men, women and children. In the western world HIV/AIDS was once considered a disease of men, particularly gay men, and gay men still constitute the majority of cases in developed countries. Since then, internationally and within New Zealand, HIV/AIDS has shifted to more vulnerable populations as this epidemic has increasingly become a disease of girls and women. Women are exposed to social and gender inequalities and their role in society has fatal implications for women and HIV infection. Education is the only tool of prevention at present and participants in this research believe that the educational message is not reaching all women.

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NURSING RESEARCH

PARTICIPANTS REQUIRED

Women and HIV/AIDS

I am a registered Nurse carrying out research for the completion of my Master of Arts Degree

My area of interest is HIV and woman. In the past stories of men's experience have predominated. These stories are important but women may have different information to contribute.

If you are HIV positive, a women, and would like more information on how to take part in the research just let me know. Because the research involves conversation between yourself and me as the researcher it is necessary that you be able to speak easily in English.

The research will involve private interviews with me only, and your confidentiality and privacy is assured.

PLEASE CALL:- JILL TELEPHONE NUMBER 

Just leave a contact phone number along with a time which would be convenient for me to contact you and we will talk some more.



WOMEN AND HIV/AIDS

CONSENT FORM

I have read the information sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand that I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I agree to provide information to the researcher on the understanding that my name will not be used.

(The information will be used only for this research and publications arising from this research project).

I agree \ do not agree, to the interview being audio taped.

I also understand that I have the right to ask for the audio tape to be turned off at any time during the interview.

I agree to participate in this study under the conditions set out in the information sheet.

Signed: _____

Name: _____

Date: _____

INFORMATION FOR INTENDING PARTICIPANTS

HIV/AIDS AND WOMEN

My name is Jill Bennett and I am a registered nurse doing research in order to complete my Masters of Arts degree (nursing) at Massey University. This research is a requirement of this degree, and I am at present employed as a palliative care nurse at St Joseph's hospice, caring for people with terminal illness.

My supervisor for this research topic is Dr. Jenny Carryer who is a Professor of Nursing at the School of Health Sciences at Massey University. The study has ethical approval from the Massey University Human Ethics committee and the Auckland Ethics Committee.

I invite you to consider being a participant in this study, which is outlined below, and you are free to ask as many questions as you wish. If after you have read this information you are still unsure, you are then under no obligation to take part. In order to be able to participate easily in this research, you need to be able to converse easily in English.

STUDY OUTLINE

HIV was once considered to be a disease of gay men and drug users. It is now obvious that this is no longer the case and it is my intention for women who are HIV positive to have the opportunity to describe their own experience. I am keen to explore your experience of being HIV positive here in New Zealand, and to ask what impact this is having on your life. I believe women's stories of being HIV positive have yet to be told, and with your help the telling of your story would not only assist other women, but also provide more understanding for health professionals who are attempting to provide a service for HIV positive women.

YOUR PARTICIPATION

Should you agree to participate in this study, your involvement would consist of one, or up to three meetings with me only. The first meeting would be to discuss the study and gain your written consent, then we could continue with a discussion lasting up to one hour. Follow up meetings, one or two, may be necessary to clarify some discussion points, and this would also provide you with an opportunity to discuss some issues in more detail or retract information you feel is not required. Interviews will be taped with your permission, and then typed up. You would then be offered the chance to read your transcript and to comment further on its accuracy, once you have had time for reflection.

CONFIDENTIALITY

At your first interview, I will ask you to choose a different name by which you will be known throughout the study. At no time will your real name, or any other information be used which would enable you to be identified. Selected excerpts of your words will be printed in the written thesis document, but I would delete any identifying features, in order to protect your anonymity. Once the tapes have been transcribed and typed onto paper, they will be kept locked away until the thesis has been marked. You will then be offered your tapes to keep, or if you do not want to keep them yourselves they will be destroyed. Only myself and Dr Jenny Carryer, the typist, (who will be required to sign a confidentiality agreement), and possibly the examiners will read the transcripts, which will be kept under lock at my home office at all times.

CONSENT FORM

- ❖ Before the study commences, I will ask you to sign a consent form, which states that you have agreed to participate, and you fully understand what is required of you by your participation in this study.
- ❖ It will also state that you have the right to withdraw from the study at any stage without fear of coercion or disapproval, or affecting in anyway your access to care and treatment.
- ❖ You may refuse to answer any particular question at any time throughout the study.

Should you agree to participate I will endeavor to keep you fully informed throughout the course of the study, and at the conclusion a summary of the research findings will be available to you. I will also keep you informed on how I intend to publish the research findings. You will be able to contact either my self or my supervisor at any time throughout the research study.

Jill Bennett [REDACTED]
[REDACTED]

You may contact the Health and Disability Advocates Trust if you have any questions re yours rights as a participant in this research, or you wish to make a complaint.

Phone 0800 205 555. This number includes Northland to Franklin areas.

In the unlikely event of a physical injury as a result of your participation in this study, you will be covered by the ACC legislation with limitations. If you have any questions about ACC please feel free to ask for more information before your agree to take part in this research.