EXPERIENCES AND COPING STRATEGIES OF WOMEN LIVING WITH HIV/AIDS DIAGNOSIS: A CASE STUDY OF MASERU, LESOTHO

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<u>Declaration</u>

I hereby declare that this thesis is my own work, that it has not been submitted or part of it for any degree or examination in any other university and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

M J Diaho

Abstract

Several studies have reported that thirty million people are living with HIV/AIDS in sub-Saharan Africa. Fifty percent of the infected adults are women aged between 15 and 49 years. In Lesotho, HIV/AIDS has also been declared a national emergency and an estimated 180,000 women out of 330,000 adults, and 27,000 children are living with HIV/AIDS. Statistics have shown that the majority of AIDS cases occur in adults aged 15 and 49 years in Lesotho. Presently women are the fastest growing infected population in Lesotho. Regardless of the growing numbers of women infected with HIV/AIDS, experiences of women living with HIV/AIDS have received little attention in Lesotho. Qualitative research in this area is necessary to gain access to women's perceptions of their HIV positive status. In this study, the experiences and coping strategies of Basotho women living with HIV/AIDS were investigated. The study used a feminist approach to research. Feminist research stresses the multiplicity of knowledge and it is useful to understand the subjective experiences of women. In-depth, face-to-face interviews were conducted with five women ranging between 29 and 46 years, purposefully drawn from Positive Action Society Lesotho (PASL). Grounded theory was used to analyse the data. Findings indicate that women's risk for exposure to HIV is related to their ability to protect themselves by negotiating a safe sexual relationship. Women who feel powerless in their relationships are less likely to protect themselves against HIV exposure. These perceptions of powerlessness are the result of a broad array of experiences that may include exposure to gender-based violence and restricted economic opportunities. The results show that it is common for women to be shocked, depressed, and discouraged when they find that they are living with HIV/AIDS as can be expected. It is also difficult for women to disclose their HIV positive status to family, friends and community members because of stigma attached to HIV/AIDS. Participants developed different ways of coping with their status such as religion, healthy life style, AIDS counselling and social networks. There was a profound sense of anxiety about the future care of children. The study concludes with a number of recommendations to promote an environment that will make it possible for women living with HIV/AIDS to cope with their illness.

Opsomming

Studies het bevind dat daar ongeveer dertig miljoen mense in sub-Sahara Afrika is wat met MIV/VIGS leef. Vyftig persent van geinfekteerde volwassenes is vroue tussen die ouderdom van 15-49 jaar. In Lesotho is MIV/VIGS as 'n nasionale ramp verklaar en daar word beraam dat 330,000 volwassenes, 180,000 vroue en 27,000 kinders MIV/VIGS het. Statistiek het ook getoon dat die meerderheid VIGS gevalle in Lesotho voorkom by volwassenes in die ouderdomsgroep 15-49 jaar. Vroue is tans die vinnigste groeiende groep. Ten spyte van die groeiende getalle vroue wat met MIV/VIGS geinfekteer is, het die ervaringe van vroue in Lesotho wat met MIV/VIGS saamleef tot dusver relatief min aandag geniet. Kwalitatiewe navorsing in hierdie verband is nodig om toegang tot vroue se persepsies te verkry rakende hul eie MIV positiewe status. In hierdie studie is die ervaringe en hanteringsmeganismes van Basoetoe vroue wat MIV/VIGS het, ondersoek. Die studie het 'n feministiese benadering gebruik, wat die multiplisiteit van kennis en die subjektiewe ervaringe van vroue beklemtoon. In-diepte aangesig-tot-aangesig onderhoude is met vroue tussen 29-46 jaar gevoer. Gegronde teorie is gebruik om die data te analiseer. Bevindinge dui aan dat vroue se risiko vir blootstelling aan MIV verband hou met hul vermoë om hulself te beskerm deur te onderhandel vir 'n veilige seksuele verhouding met 'n maat. Vroue wat magteloos in hul verhoudings voel, is waarskynlik minder suksesvol om hulself teen MIV blootstelling te beskerm. Hierdie persepsies van magteloosheid is die resultaat van 'n breë spektrum ervaringe wat sekondêre status, blootstelling aan geweld, en beperkte ekonomiese geleenthede insluit. Soos wat verwag word, toon die bevindinge dat dit algemeen vir vroue is om geskok, deppressief en ontmoedig te wees wanneer hulle uitvind dat hul MIV/VIGS het. Dit is ook moeilik vir vroue om hul MIV status aan familie, vriende en gemeenskapslede bekend te maak weens die stigma wat aan MIV/VIGS kleef. Respondente het verskeie wyses ontwikkel om hul status te hanteer, soos godsdiens, 'n gesonde leefstyl, VIGS raadgewing en sosiale netwerke. Daar was ook 'n intense bekommernis by vroue oor die toekomstige sorg vir hul kinders. Die studie sluit af met 'n aantal aanbevelings om 'n omgewing te promoveer wat dit vir vroue wat met MIV/VIGS leef moontlik sal maak om hul siekte te hanteer.

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Contents

<u>Key Words</u>

HIV/AIDS

Lesotho

Gender

Feminism

Feminist research

Vulnerability

Experiences

Coping strategies

List of acronyms

AIDS-Acquired Immunodeficiency Syndrome

GOL-Government of Lesotho

HIV-Human Immunodeficiency Virus

IEC-Information, Education and Communication programmes

LAPCA-The Lesotho AIDS Programme Coordinating Authority

MOHSW-Ministry of Health and Social Welfare

NAP-National AIDS Programme

NASP-The National AIDS Strategic Plan

NGOs–Non-Governmental Organisations

PASL–Positive Action Society Lesotho

PLWAs-People Living With AIDS

UNAIDS–Joint United Nations Programme on HIV/AIDS

CHAPTER 1: INTRODUCTION

1.1   HIV/AIDS in Lesotho

The first case of AIDS in Lesotho was reported in 1986 and there has been a rapid increase of HIV/AIDS cases since then (NASP, 2000). For instance, a survey done in five districts of Lesotho, Maseru, Mafeteng, Leribe, Quthing and Maluti, showed a high prevalence of AIDS in these areas (cited in NASP, 2000). The geographic distribution of HIV/AIDS by district is shown in Figure 1 below.

Figure 1: Distribution of HIV/AIDS by district in Lesotho (1998)

New AIDS Cases in Lesotho by District (1998)

Butha Butha 191
Leribe 225
Berea 154
Mokhotlong
Thaba Tseka 151
91
Maseru 1671
Mafeteng 356
Qacha's Nek 114
152
Mohale's Hoek
Quthing 137

○ = Confirmed reported AIDS cases

DISEASE CONTROL ; STD/AIDS UNIT ; Ministry of Health ; LESOTHO.
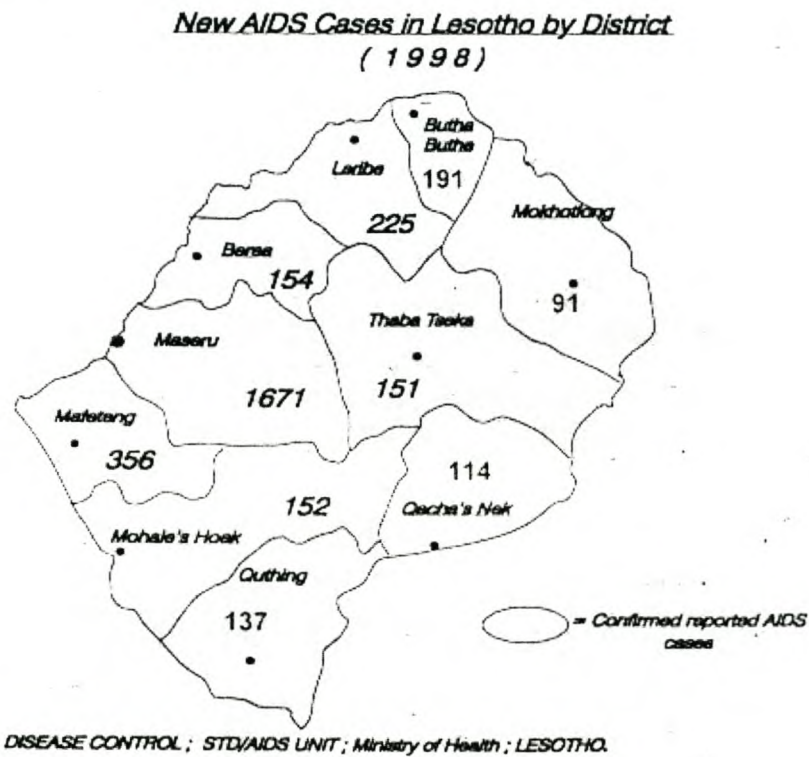
In Lesotho the major route of the AIDS epidemic is heterosexual intercourse. For example, the majority of people living with HIV/AIDS either had multiple sex partners or a history of sexually transmitted diseases. Only a small percentage had a history of blood transfusions (NASP, 2000). It is estimated that there are more women living with HIV/AIDS (54.2%) than men and that the progression from HIV infection to full-blown AIDS is faster in women than in men (Strebel, 1995a; Moe,

1998; NASP, 2000, Positive Action Society Lesotho). Figure 2 below shows the estimated number of adults and children living with HIV/AIDS at the end of 2001.

Figure 2: Number of adults and children living with HIV/AIDS (2001)

These estimates include all with HIV infection, whether or not they have developed symptoms of AIDS, alive at the end of 2001:		
Adults and children	360,000	
Adults (15-49)	330, 000	Adult rate (%) 31.0
Women (15-49)	180, 000	
Children (0-15)	27, 000	

From: Epidemiological fact sheet produced by UNICEF, WHO, UNAIDS, 2002.

Some of the factors which have contributed to making women vulnerable to HIV infection are migration, urbanisation, gender inequalities and cultural practices.

1.1.1 Migration

Lesotho's economy is characterised by a high degree of labour migration to the Republic of South Africa. The migrant labour system exposes and increases women's chances of being infected with to HIV/AIDS (Abdool et al, 1992; Vetten & Bhana, 2001). For instance, it encourages a system of informal polygamy, with some Basotho men having female partners both in South Africa as well as in Lesotho. The high levels of male migration often disrupts marital ties and encourages the growth of sex work, leading to risk for male migrants, sex workers and the partners of male migrants who become infected on their partner's return home. This migration can bring HIV into previously untouched areas and homes because there is also a reluctance to use condoms both with casual or regular partners.

1.1.2   Urbanisation

In the same way, when women migrate from rural communities to urban environments, the shift is more than simply geographic; it can also change the form of their relationships. For example, in rural areas social relations are likely to be expressed in terms of family relations, whereas in urban areas social relationships are more contractual and sexual relations may become a mechanism for social mobility (Webb, 1997 cited in Vetten & Bhana, 2001; Doyal, 1994; Laird, 2001). Several studies (Kethusegile et al, 2000; Vetten & Bhana, 2001, Nashandi, 2002; White, 2001) have shown that women use sex as a commodity to obtain presents, clothing and food from older men.

1.1.3   Gender inequalities

More men have multiple partners in comparison with women and they assume a dominant role in intimate relationships by their ownership of women's bodies (Letuka et al 1997; White, 2001; Baylies, 2000; Bridge, 2000; Collins & Rau, 2000; UN Division for the Advancement of women, 2000; Hannan, 2003). For example, the majority of women are disempowered in families. This control of the sexuality of women has resulted in women not being able to negotiate for condom use in these relationships. For instance, a married woman cannot refuse her husband sex or suggest a condom even if she knows that he has extra-marital affairs, which could expose him to the risk of HIV and endanger her life and health (Letuka et al, 1997; Kethusegile et al, 2000).

1.1.4   Cultural practices

In a society where lobola is accepted as in the case of Lesotho, women are more vulnerable to HIV/AIDS (Pietersen, 2000, cited in Vetten & Bhana, 2001; Reinwick, 2002) because lobola encourages some men to regard women as their property because they have been paid for. There is a tendency to regard men's sexual needs as paramount. This reinforces existing patterns of gender discrimination.

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Moreover, the Sesotho culture does not permit adults to talk about sex with youngsters and this inhibits sexual behavioural change among the youth. For instance, the older and more traditional Basotho are reluctant to discuss sex and sexuality (Moe, 1998; NASP, 2000). Another problem is that people no longer conform to cultural and religious codes of conduct, for instance the taboo on sex before marriage, and as a result they are more exposed to HIV/AIDS. There is pressure on younger women to get married and they are expected by society to stay married at all costs. This has resulted in the majority of young women accepting unprotected sex with men they do not know.

1.1.5   Economic factors

Most women are economically dependent on men. For instance, older and more economically powerful men have been reported to attract poor women and younger girls with promises of wealth. For example, "with promises of economic benefit, younger women, often teenage girls, engage in unsafe sex with these older men (the so-called sugar daddies) running the risk of becoming infected with HIV/AIDS" (Letuka et al, 1997:34; Moe, 1998). The following section looks at what the government in Lesotho has done to address the problem of HIV/AIDS.

1.2   National responses to HIV/AIDS in Lesotho

The government of Lesotho (GOL) has responded to the AIDS epidemic by introducing strategies for preventing and curbing this disease. One of these strategies has been to adopt a multi-sectoral approach in an attempt to deal with HIV/AIDS (Moe, 1998; NASP, 2000). It has achieved this through the Ministry of Health and Social Welfare (MOHSW) by initiating a task force consisting of selected principal secretaries, the civil society and youth to organize and supervise HIV/AIDS control activities. For instance, there are Information, Education and Communication (IEC) programmes which are meant to provide accurate information and educate people about HIV/AIDS. These programmes also encourage people to communicate about safe sex. All these are achieved through the media.

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1.2.1 The National AIDS Strategic Plan (NASP)

The National AIDS Strategic Plan (NASP) was adopted in 1999 and it is a key document which tabulates the operations of the revised National AIDS Programme (NAP). The Policy Framework requires that the human rights of every individual should be respected and protected and prioritises privacy for People Living with AIDS (PLWAs). It also recognises the social, cultural and religious contexts of people in Lesotho. Its overall objective is to create an enabling environment for the prevention of the further spread of HIV/AIDS and other STDs, and to lessen the impact of HIV/AIDS on the infected and affected individuals, families and communities (Government of Lesotho, 1999). The Lesotho AIDS Programme Coordinating Authority (LAPCA) was established as the national coordinating structure to institutionalise the co-ordination with the Prime Minister's office.

1.2.2 AIDS Task Force

There is also an AIDS Task Force whose role is to provide technical support to the National Aids Committee, which comprises of ministers of all government ministries, representatives of selected NGOs, the private sector, donor agencies and individuals in their own private capacity (Government of Lesotho, 1999 cited in NASP, 2000). The AIDS Task Force consists of technical experts from the following fields: health, education, social science, religion, law, human rights, economic development and social welfare.

1.2.3 Non-Governmental Organisations (NGOs)

NGOs and the private sector are also playing an important role in combating this disease through interventions. One such NGO is Positive Action Society Lesotho (PASL). It was introduced in May, 1999 as an HIV/AIDS support group. Its overall objective is to encourage people to be involved in the fight against HIV/AIDS. It also tries to empower the volunteers by involving them in income-generating activities. Some of the volunteers that are living with HIV/AIDS are provided with

psycho-social support, medical care and advice, nutritional care and advice and are encouraged to educate others about HIV/AIDS.

1.3   Problem statement

This study investigates the experiences and coping mechanisms of women who are living with HIV/AIDS in Lesotho. Studies (Moe, 1998; NASP, 2000) have shown that there are more women than men living with HIV/AIDS in Lesotho. For instance, "of all AIDS cases in Lesotho so far, 45.1% were male and 54% were female" (NASP, 2000:7). Studies (Moe, 1998; NASP, 2000) on HIV/AIDS in Lesotho have focused on the epidemiology of this disease and have ignored the impact on people living with HIV/AIDS. It is therefore important when researching the impact of HIV/AIDS to identify the experiences and coping strategies infected women use in dealing with their situation. The goal of this study is to provide relevant information to organisations dealing with HIV/AIDS to assist them in develpoing policies that are more cognisant of women's needs and experiences.

1.4   Significance of the study

There is a large and continually growing body of research done on gender and AIDS (Berer & Ray, 1993; Doyal, 1994; Lorber, 1997; Foreman, 1999; UNIFEM, 2000; UNAIDS, 2001a) but there are few studies considering the experiences and coping strategies of women living with HIV/AIDS (Dorn et al, 1994; Bury, 1994; Dowling, 1994; Crossley, 1998; Catala'n, 1999; Dane, 2000; Nashandi, 2002; De Capua, 2003; Ninan, 2003). This study focuses on women in Lesotho since there are no studies which are located in Lesotho with this particular focus.

1.5   Paradigm

This study used a feminist approach, which stresses the multiplicity of knowledge and the subjective experiences of women (Maynard, 1994; Devault, 1999a; Owen, 1996). Feminist researchers emphasize that researchers should be aware of the existing power relations between the researchers and the researched (Oakley 1981:41 cited in Jayaratne & Stewart, 1991; May, 1993).

1.6   Research design

This study adopted the case study design. The participants were recruited from Positive Action Society Lesotho (PASL). Five participants were chosen through purposive and snowball sampling techniques. Semi-structured interviews were employed as the method of data collection. An interview guide was developed and observations made during the course of the interview were recorded.

The interviews were analysed using grounded theory methods. Tape recorded interviews were transcribed and the themes that emerged were clustered under four main themes: experiences of women living with HIV/AIDS, concerns of women living with HIV/AIDS, coping strategies and arrangements for children.

1.7   An outline of the chapters

Chapter 1 presented an introduction to this study and set out the study problem and its significance. It further described the paradigm and research approach utilised in this study. In **chapter 2** key concepts were reviewed and an overview of literature on women and HIV/AIDS is presented. **Chapter 3** gives an overview of the research design used in this study. Motivation is given for using qualitative research approaches. Different stages in the research are discussed: sampling techniques, data collection methods, ethical considerations and data analysis. The chapter concludes by discussing the researcher's encounters with HIV positive women in Lesotho. In **chapter 4** the experiences and coping strategies of participants are discussed within the framework provided by the relevant literature. **Chapter 5** concludes the study and suggests some recommendations for future studies

CHAPTER 2: LITERATURE REVIEW

2.1   Introduction

This chapter reviews key concepts that are employed in this study. An overview of HIV/AIDS in Africa and factors influencing women's vulnerability are presented. The impact of HIV/AIDS on women is discussed with reference to the impact of HIV diagnosis on women, the social attitudes to women living with HIV/AIDS within families and communities. The chapter concludes with a description of how women living with HIV/AIDS cope with their situation and it identifies various support options available to and utilised by these women.

2.2   Key concepts

2.2.1   Gender

Gender refers to relationships and decision making opportunities associated with being male or female (Hannan, 2003). Gender relations are based on power whereby men exert control over women in a number of spheres (Strebel, 1995). In this study, the researcher looks at the relationship between men and women in relation to decision making on sexuality, because men use violence to control women's sexuality. The term is also used to challenge the idea that social interactions between men and women are determined by biology or nature (Strebel, 1995; Rivers & Aggleton, 1999).

2.2.2   Vulnerability

Vulnerability refers to the fact that women lack the power, opportunities and abilities or skills to make decisions that can impact on their own lives (Tallis, 1998). In this study, it is used to refer to factors that expose women to the risk of acquiring HIV/AIDS.

2.2.3 Experiences

O'Sullivan (2000) points out that there is a tendency of representing HIV positive women as 'other' and to overlook the fact that their experiences are different. In this study, 'experiences' refer to research participants' individual experiences of living with HIV/AIDS within each woman's broader social context. The feminists assumption that there are multiple realities is implied in the use of the plural term 'experiences'.

2.2.4 Coping strategies

The Oxford Advanced Learner's Dictionary defines 'cope' as a person's ability to deal with a difficult situation whether successfully or unsuccessfully. In this study, this term is used more broadly to refer to women's efforts to manage their HIV/AIDS status. According to Carson & Butcher, an individual's ability to cope is determined by her perception of her own competence (1992).

<u>2.3   HIV/AIDS in Africa</u>

HIV/AIDS is currently the leading cause of death in sub-Saharan Africa and the fourth-largest killer globally (UNIFEM-SARO 2002; UNAIDS, 2002b). For instance, out of 24.5 million people living with AIDS, 53% are women, representing 82% of the world's women with HIV/AIDS (White, 2001). In sub-Saharan Africa, 30 million people are living with HIV/AIDS (Dworzanoski, 2002, White, 2001; UNIAIDS, 2002). African women particularly are infected with HIV/AIDS. For instance, about half of the infected adults are women between ages 15 and 49 (Secure the future; UNIAIDS, 2001; Steinberg et al, 2002). The following figure shows HIV prevalence rate by age and sex in different African countries.

HIV Prevalence rates by Age (15-24) and Sex
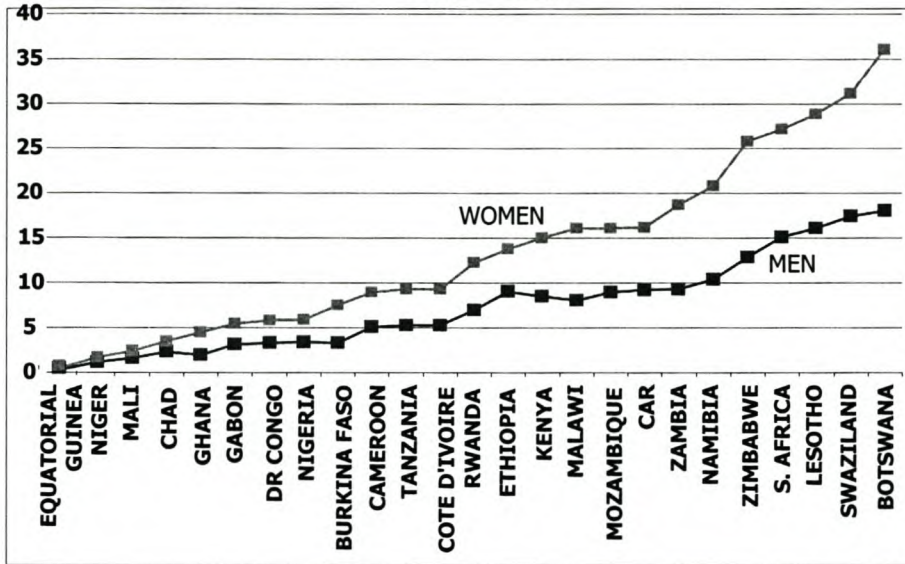
Adapted from White, 2001

The above figure shows the estimates of between 20 and 26 percent of women living with HIV/AIDS aged between 15 and 24 years in Namibia, Zimbabwe, South Africa, Lesotho, Swaziland and Botswana.

2.4   Factors influencing women's vulnerability

Factors that contribute to women's greater vulnerability are ideologies of masculinity, biological vulnerability, economic vulnerability and violence against women. (Doyal, 1994; Lorber, 1997; Tallis, 1998; Rivers & Aggleton, 1999; Vetten & Bhana, 2001; Nashandi, 2002; UNIFEM-SARO 2002,).

2.4.1   Masculinity

This study adopts Connell's definition of masculinity; "[it]...is simultaneously a place in gender relations, the practices through which men and women engage ... and the effects of these practices" (Connell, 1995: 71). In societies where ideologies of masculinity encourage men to have multiple sexual partners, both men and women are in danger of contracting HIV infection (UN Division for the

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Advancement of Women, 2000; Hannan, 2003; Rivers & Aggleton, 1999). Moreover, the assumption that men are knowledgeable prevents them from accessing information on HIV/AIDS. As a result, conforming to stereotypes about masculinity makes both men and women susceptible to HIV infection (Rivers & Aggleton, 1999).

2.4.2   Biological vulnerability

Women are more likely than men to become infected with HIV infection during vaginal intercourse because of the large area exposed to contact (Strebel, 1995; O'Sullivan, 2000; Mutangadura, 2001, Goldstein, 2003) and because they sometimes bleed during sexual intercourse (White, 2001; Hannan, 2003).

2.4.3   Economic vulnerability

Several studies (Amaro, 1995, Strebel, 1995; Moe, 1998; Tallis, 1998; Laird, 2001; Vetten & Bhana, 2001; Nashandi, 2002;) have shown that the majority of women being infected are poor minority women because they do not have resources of their own and are economically dependent on men. These women find it difficult to negotiate for safe sex because of the likelihood of being abandoned if they insist on condom use. In such cases, marriage provides forms of economic and social support that would not be available to them if they were to remain single. For example, a member of the parliament of Uganda explains,

> The women tell us they see their husbands with the wives of men who died of AIDS and they ask, 'what can we do? If we say no, they'll say: pack up and go. If we do, where do we go to?' (Matembe, 1993 cited in Laird, 2001:124)

Poverty also reduces women's access to treatments for opportunistic infections and dietary supplements required by the immune system (Strebel, 1995; UN Division for the Advancement of Women, 2002; Collins & Rau, 2000; White, 2001). Poverty can also prevent women from accessing information on safe sex and this exposes them to HIV infection (Hannan, 2003). This unequal access to prevention methods, information and care constitutes human rights aspects of HIV/AIDS.

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2.4.4   Violence against women

Male violence against women is based on the existing inequalities in societies. For instance, in violent relationships, some women lack power to protect themselves from HIV infection. Under these circumstances, these women usually put themselves under the risk of infection instead of facing violence (Hannan, 2003). This was the case in Zimbabwe where women reported that they feared being beaten or abused if they confronted their partners about their extra-marital affairs (Meursing & Sibindi, 1999; Vetten & Bhana, 2001; Gupta & Weiss, 1993 cited in Hannan, 2003). As a result, women live in fear of violence and of not being able to say no to unprotected sex. Therefore, we see men having considerable power over women because of the threat of violence. The above examples from Uganda and Zimbabwe illustrate that women have very little control over their own sexuality (Dolphyne, 1991 cited in Laird, 2001; UNAIDS, 2001a; Tallis, 1998, Rivers & Aggleton, 1999). Even in a more global context, as feminists have pointed out,

> using or not using a condom is not a simple, practical question about dealing rationally with risk. It is the outcome of negotiation between potentially unequal partners…In many sexual encounters women have little choice about whether or how to engage in sexual activity with men, the option being physical injury or more subtle forms of sanction (Holland et al 1994:5).

Given that there are no studies done in Lesotho on the experiences and coping strategies of women living with HIV/AIDS, the study will make reference to studies done in other countries.

2.5   Experiences of women living with HIV/AIDS

The way women living with HIV/AIDS cope is shaped by their initial reaction to the HIV positive diagnosis, social attitudes to HIV positive women, medical experiences, access to health care, their roles as care givers, their reproductive roles, desire to have children and AIDS care policies.

2.5.1   Initial reaction to HIV positive diagnosis

The initial reaction of women to an HIV positive diagnosis is usually an experience of shock. Common to both men and women is the need to work through possible feelings of guilt, denial, fear, anxiety and depression (Dowling, 1994; Crossley, 1998; Olley, 2003). The shock may lead to feelings of hopelessness. In some cases, shock may act as a defence mechanism, blocking the news of their HIV status until sufficient time has passed to come to enable them to terms with their diagnosis. Shock may be expressed by withdrawing from others.

Several studies (Crossley, 1998; Dane, 2000; Feldman, 2000) have reported that women diagnosed as HIV positive usually experience fear because of the stigma attached to this disease. Anxiety symptoms have also been reported which are the result of their uncertainty of HIV disease progression (Hays et al, 1998). This could be explained by inadequate health education (Olley, 2003).

Furthermore, because of public debates about responsibility, control and morality in relation to HIV/AIDS, women with HIV/AIDS make decisions which reconstruct intimacy and sexuality in the context of HIV/AIDS (Adam & Sears, 1998). For instance, a number of participants in Adam & Sears' study reported celibacy after learning of their status.

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2.5.2   Social attitudes to HIV positive women

Women are being held responsible for the heterosexual transmission of HIV/AIDS (Bury, 1994; Wilson, 1994; Laird, 2001, Nashandi, 2002). For instance, women are seen as the 'carriers' of disease, the group that is most likely to be infected, as well as to infect others (Tallis, 1998:11; De Bruyn, 1992 cited in Baden, 1992). In some cases, husbands blame their wives who are HIV positive, even if the husband had transmitted the virus to her (WHO, 2000). As a result, these women are often abandoned or divorced.

In societies where HIV is seen as a sign of sexual promiscuity (Dowling, 1994), gender norms shape the way men and women infected with HIV are perceived. For example, in Lesotho HIV positive women face far greater stigmatisation than men do. This means that women who are HIV positive often encounter negative experiences from their family and friends, broader community and health care providers (Tallis, 1998).

Women widowed as a result of AIDS and infected single women may be particularly vulnerable. For instance, infected single women are unlikely to find a partner. In South Africa, widowed women lose social support from their family and face ostracism by the community. This is because many traditional families become extremely suspicious when their son or brother dies and widows are frequently blamed and resented for surviving their husbands (Ndlela, 2002).

The fact that women living with HIV/AIDS are blamed by their communities has an enormous impact on their lives. For instance, where blame for the epidemic has explicitly or implicitly been placed on women, violence and abuse have been reported. Violence against women has also been reported when women living with HIV/AIDS disclose their status to partners or communities (UNIAIDS, 1998, Vetten & Bhana, 2001).

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2.5.3   Medical experiences

A culture of blaming women for the epidemic has led to particularly hostile reactions to infected women by health care providers (Nashandi, 2002; Dorn et al, 1994; Manchester & Mthembu, 2002). In some instances, the issue of confidentiality has been overlooked. For example, Fako-Falten explained,

> I don't think I wanted to but I was keeping a public secret, you know. Like when I was given my results everyone was there, everyone was listening. It was a room full of people. So, I was told what the results were. So for me to keep quiet it was like, anyway everyone knows, so, why keep quiet about it (cited in De Capua, 2003:1).

Several studies (Kuyoh & Best, 2001; Ninan, 2003; De Capua, 2003) reported discrimination by health care providers on the basis of a positive diagnosis. For instance, they reported that women living with HIV/AIDS said doctors and dentists avoided treating them after they disclosed their status. This was also the case in India, both in government and private hospitals, where doctors admitted that they did not treat people with HIV positive diagnosis (Ninan, 2003).

Women with HIV positive diagnosis are often excluded from drug trials for fear that they may become pregnant during the treatment and that the drug might damage the foetus (Bury, 1994; Hannan, 2003). At the end of 1999, women made up only 12% of trial participants (BRIDGE, 2002). Women who are already pregnant when they are diagnosed, or who become so afterwards, may find that counselling focuses on the risk to the baby, rather than on the mother's needs and feelings (Dowling, 1994).

2.5.4   Access to medical care

There is also a tendency to see women living with HIV/AIDS as prostitutes. As a result, women in general may avoid seeking early treatment, for fear of being labelled as prostitutes. This puts them and others at risk of early death (De Bruyn, 1992: 251 cited in Baden, 1992).

Most women living with HIV/AIDS do not have adequate access to care and treatment for opportunistic infections (Vetten & Bhana, 2001) or to food supplements to strengthen their immune systems. For instance, poor, minority women are unlikely to receive ongoing preventative medical care and they are also unlikely to go to the doctor when they are sick. Often they do not enter the health care system until the disease has progressed to the point where treatments are less effective (Bury, 1992:37; Strebel, 1995; Olley, 2003). The women's poverty (Sy, 2001) as well as a government's policies regarding health care for women living with HIV/AIDS, as in the case of South Africa (Vetten & Bhana, 2001) are the root of the problem.

An early diagnosis is crucial to managing the disease successfully. Unfortunately, health care providers overlook women's symptoms. As a result, some women do not find out about their status until they are ill. The longer a person has HIV without being tested and treated, the quicker the disease progresses. UNDP also confirms that of the handful of women who seek care, only two out of three are adequately treated (UNDP, 1998:58; cited in Crothers, 2000). In some cases, women postpone seeking help from clinics because of the indistinctness of their symptoms in terms of menstrual cycle and pregnancy (Strebel, 1995; Crothers, 2000). Disclosure is very difficult for women living with HIV/AIDS and their access to care and support is further hampered as a result.

The high expenses of health care often reduce already limited resources for the payment of children's education, food, housing, basic utilities and home maintenance causing economic losses extending well beyond the affected women's death.

2.5.5 Women as caregivers

The impact of AIDS on women has been termed 'triple jeopardy' because it affects women as individuals, mothers and caregivers. Not only are women affected because of their vulnerability to HIV infection, all women, regardless of their HIV status are affected as a result of the burden of care for their children and extended family (Vetten & Bhana, 2001). HIV/AIDS is being dealt with around the world by the largely invisible expertise and energies of women carers (Wilson, 1994). For instance, many women experience their own infection, while worrying about possible infection of their children and looking after other infected people as in the community who need home-based care (Dowling, 1994; Hannan, 2003).

Moreover, women are the main carers when people become ill. For example, they support orphans and provide the backbone for most voluntary efforts to raise awareness and change behaviour. According to UNIFEM, the responsibility of home-based health care is being passed on to women. Thus, with little or no information and training, women caregivers look after HIV positive family members at great risk to themselves. Women are bearing the load of AIDS care either as formal or informal carers (Tallis, 1998; UNIFEM-SARO, 2002). For instance, traditional birth attendants (TBAs) and midwives are clearly at risk. Informal caregivers in Home Based Care (HBC) are on call 24 hours a day and are typically emotionally close to the patient. These factors result in enormous stress on the women.

2.5.6 Women's reproductive roles

Most women living with HIV are mothers. Motherhood adds to the dimension of fear, anxiety and loss for women living with HIV/AIDS. For instance, the demand for childcare can be overwhelming in the context of grief and illness (Berer & Ray, 1993; Foremen, 1999; Dane, 2002). In addition, women living with HIV/AIDS feel a great responsibility for the ways in which children will be affected by being informed of their mother's HIV positive status. Henderson (1992:14) found that

Choosing the right time to burden them with the responsibility of keeping quiet to avoid harassment, of often facing the dire consequences of public knowledge, or of fearing for their mother's health and possible death was no simple or straightforward task.

Other studies have found that informing children about a parent's status can be constructive in that it enables children to understand HIV/AIDS and its impact on the sick person (Nashandi, 2002).

Women living with HIV/AIDS also have to contend with the worry of who will look after the child if the child seems likely to outlive them. Relatives may be unwilling to look after children whose parents died of HIV, particularly if the children are HIV positive (Nelson et al, 1994 cited in Dane, 2002).

Several studies (Vetten & Bhana, 2001; Sy, 2001) have revealed that when women become ill, household members may be unwilling or unable to care for them and that children have to fulfil the role of caregiver. For example, young girls are more likely to be pulled out of school to cope with a mother's illness, or adolescent girls may be forced into early marriage or sex work to support families (UNIFEM-SARO, 2002).

2.5.7 Desire for children

Some women in African countries regard childbearing as important for self-esteem and economic survival (Strebel, 1995; Nashandi, 2002). For instance, in Lesotho, the desire for children is rooted in the need for find personal satisfaction and financial security, especially where women are economically vulnerable. A 27-year-old Kenyan housewife for instance, explained her desire to have a child regardless of her husband's and her HIV positive status.

> My husband doesn't want any children. But I want a child. I cannot live without kids. I am always alone and I am not barren. If I have a child, I will take care of my child and I will be active. I can work because I know I have somebody to take care of. I will have a responsibility (Kuyoh & Best, 2001).

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Several researchers (Kuyoh & Best, 2001; Lutalo et al, 2000) have reported that women living with HIV/AIDS desire to have children regardless of the risks involved. For example, Feldman & Maposhere's (2000) study in Zimbabwe found that 16 out of 52 HIV positive women interviewed became pregnant after their diagnosis, with 7 of the 16 pregnancies desired. This desire for children reduces HIV-infected women' acceptance of family planning methods as was shown by the study done in Zimbabwe (Lutalo et al, 2000).

2.5.8   AIDS care policies

AIDS care policies have tended to rely on individual patients to notify their partners of their condition. Mandatory partner notification has been suggested in some contexts although this may have severe negative consequences for women. MRC research on STD clinic attendees, found that men were hesitant to attribute their STDs to their own sexual activities and they instead held women responsible (Reddy & Meyers-Weitz; cited in Crothers, 2000).

Policies regarding pregnancy and childbirth in the light of HIV have been prescriptive and often unsupportive of women. For example, because of the fears of transmission to the foetus, HIV positive women are usually advised to avoid or terminate pregnancies. Some women find out about their HIV positive status when they are pregnant. As a result they have to consider abortion or face the possibility that their child may be infected, which may not be apparent for many months after the birth. Recent studies have shown that with medical intervention like antiretroviral therapy, which should be administered during the birth, the unborn children have a better chance of survival.

Studies have also shown that breastfeeding mothers with a HIV positive diagnosis can pass the virus to their babies. HIV positive women have as a result been discouraged from breastfeeding despite evidence that the risk of transmission is low. This poses a great problem to mothers who are impoverished and cannot afford to buy milk for their babies. These policies are problematic in a context where

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childbearing is an important indicator of women's status and access to resources and where it is difficult to provide safe alternatives to breast-milk.

2.6   Coping strategies

There are various studies on coping strategies employed by women living with HIV/AIDS. Because HIV/AIDS is stigmatised, affected women are often prevented from gaining access to some of the few social support mechanisms for which they might be eligible (Lovelife, 2001). Some HIV positive women feel frightened, ashamed and isolated by their HIV status, even if they are in support groups. In such cases these women become frustrated and are not able to exchange information on HIV/AIDS with other women. Some fear disclosing their HIV positive status to friends, family and colleagues because nobody in their areas is open about being HIV positive. Without any previous efforts to counter the myths about HIV/AIDS, these women are understandably afraid of what people may think of them.

Nevertheless, some women living with HIV/AIDS are coming together to discuss their common concerns and have started to make use of the support systems that are available in different countries. Some of the strategies that women living with HIV/AIDS use are religion, informal support and adopting a healthy lifestyle.

2.6.1   Religion

Spirituality and religion are important in helping women living with HIV/AIDS to cope. For example, a number of women living with HIV/AIDS reported that HIV/AIDS made them return to their previously neglected religious roots in order to find meaning, spiritual support and a deepening of faith (Siegel, 2001:126; Nashandi, 2002). Women living with HIV/AIDS also make use of hospices because they provide support and promote Christian principles. These help them to face death as the only way that they will be united with God (Dworzanoski, 2002).

Christian counselling falls under helping profession and it is used to alleviate suffering for people living with HIV/AIDS. It creates a positive anticipation that God will heal them.

2.6.2 Social support

Family support enables women living with HIV/AIDS to accept and deal positively with their status. For instance, emotional and financial support from family members reduces fear, stress and depression leading to suicidal thoughts (Dworzanoski, 2002; Parry, 1990). Social support can also be provided by friends, the community, social workers and psychologists.

Informal networks provide yet another form of social support. At these informal groups, women living with HIV/AIDS provide support to each other. They also become socially active. For instance, they join NGOs that cater for people living with HIV/AIDS and they seek information about HIV/AIDS. According to Siegel (2001), the women in her study reported that HIV/AIDS enabled them to value life more and thus appreciated life even more. As a result, they focused on helping others through advocacy, education and care provision. Researchers like Henderson argue that, although informal networks are helpful, they need to be used in conjunction with other support structures in order to enable these women to avoid overloading each other (Henderson, 1992).

2.6.3 HIV/AIDS counselling

HIV/AIDS counselling is another form of support given to women living with HIV/AIDS to assist them to cope with their status. Dworzanoski contents that counsellors can "help PLWAs to cope with the loss of their autonomy, privacy, control; aid patients to vent anger; and teach patients coping mechanisms to combat anxiety, depression and suicidal tendencies" (2002: 426). Through counselling, an individual can develop a sense of responsibility in meeting problems posed by the infection (UNAIDS Technical update, 1997). HIV positive women are provided with supportive or problem solving counselling or both.

2.6.4   A healthy lifestyle

A healthy lifestyle curbs the development of the disease and prolongs a person's life, and is especially important for people living with HIV/AIDS because their immune systems are weak (Dworzanoski: 2002). Some women living with HIV/AIDS have been reported to make healthy changes in their lifestyle. For instance they stop substance abuse, smoking and risky sexual behaviour (Siegel, 2001). They also seek medical care. For instance, most of them cope by enrolling in clinical treatment trials, go to clinics and consult traditional healers.

2.7   Conclusion

The literature illustrates that HIV/AIDS is increasing at an alarming rate in Africa and that women are particularly at risk because of reproductive roles and the gender oppression resulting from these roles. Shock, anger and denial are the most common reactions to HIV positive diagnosis. Family, friends and the community form the support structure for women living with HIV/AIDS. Religion, AIDS counselling, a healthy lifestyle and social support are the coping strategies used by women living with HIV/AIDS.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

3.1   Introduction

This chapter is a presentation of the various research methods and techniques that were used to carry out this study. It opens with a discussion of feminist methodology, the sampling techniques that were used and the interviews that were conducted. The chapter concludes by discussing the method used to analyse the data.

3.2   Conceptualisation

3.2.1   Feminism(s)

Several feminist scholars (Mama, 1995; Kolawole, 1997) in Africa have introduced alternative terms like African feminism and Womanism to white feminism. These terms have been introduced because of a history of Black women in the African countries. For instance, poverty, religion, problems with the extended family and cultural heterogeneity are regarded as important factors in the lives of African women. African feminism will be used to explain the experiences of women living with HIV/AIDS in Lesotho.

3.2.2   Feminist research

Research becomes feminist when the researcher puts the social construction of gender at the center of her investigation (Lather, 1991). In this study, the researcher looks at the ways in which gender socialisation shapes the experiences and coping strategies of women living with HIV/AIDS in Lesotho.

3.3   Methodological framework

Feminist researchers have argued that women's perspectives have been silenced and that their experiences in traditional social science have been used for men's benefit (Schoepf, 1991; Devault, 1999). As a result, feminist theorists have challenged this positivist understating of social relations. For example, Devault

> Pointed to the omission and distortion of women's experiences in mainstream social science, the tendency to universalise the experience of men (and relatively privileged women), and the use of science to control women, whether through medicine, psychiatry, or through social scientific theories of family, work, sexuality, and deviance (1999:26).

Feminist researchers are committed to research about women and their concerns (Devault, 1999:30; Olsen, 1994, cited in Neuman, 1997). They seek to empower women and to produce research grounded in participants' experiences (Owen, 1996; Maynard, 1994; Ramazanoglu & Holland, 2002, Neuman, 1997; Lather, 1991; Jayaratne & Stewart, 1991). A case study design can be used to gain understanding of the participants' experiences within this paradigm.

3.4   Case study design

Feminist researchers use a case study approach to gather detailed information about a specific person, a particular social setting, event or group to effectively understand how it operates or functions (Berg 1998:212; Hakim, 1987, Dixon et al, 1987; Neuman, 1997; Yin, 1984; Zucker, 2001). For instance, case studies are commonly used to study minority groups who are usually excluded in large studies, to understand their experiences, for instance case studies of delinquents. The following section discusses the sources of errors typical of this design and some ways of addressing them.

3.4.1 Sampling and Data collection

Case studies do not offer information that can be seen as useful beyond the individual case. Furthermore, ethical issues can also arise in case studies in that "there may be practical difficulties in combining sometimes conflicting roles of team members and researcher" (Hakim, 1987:74). Another important practical difficulty with case studies has to do with choosing a research team that has the appropriate experience and skills (Hakim, 1987). In such cases where the research team is not equipped with interviewing skills, and skills to analyze and interpret interview transcripts, the researcher should consider additional training to improve their skills.

Reliance on memory has also proved problematic for both the researchers and respondents. This is because what respondents remember is "systematically incomplete" (Stern, 1979:75). Participants tend to be selective in what they report and sometimes do not disclose all information. The researchers can address the problem of reliance on memory by seeking information from other sources. These sources can be the respondent's family, neighbours or friends who maybe able to verify what the participant has disclosed. Other alternatives that the researcher can use are non-participatory observation (Hakim, 1987) and archival records (Stern, 1979). They are reliable because they do not depend on memory.

3.4.2 Data analysis

There can be too many subjective decisions made by the researcher to offer genuinely objective results. As a result, the researcher ends up reporting her conclusions instead of presenting carefully selected themes from the data in conjunction with the research questions (Hakim, 1987). An alternative could be to give respondents the opportunity to review and to comment on the draft report as a validating procedure (Yin, 1984 cited in Hakim, 1987).

Some data collecting methods used in case studies are personal documents, participant observations, interviews and third person reports. The following section will discuss one type of interview, semi-structured interviews.

3.5   Semi-structured interviews

Semi-structured interviews gather data in which participants are able to tell their own stories and thus facilitate the breakdown of power relations between the researcher and participants. Feminists have emphasized "the importance of listening to, recording and understanding women's own descriptions and accounts" (Maynard, 1994:12). The following section discusses the steps that researchers follow in an interview.

3.5.1   Co-operation

Before an interview can take place, it is important for the researcher to ask for co-operation from people that are to participate in the study. This is important because a field interview "involves a mutual sharing of experience" (Neuman, 1997: 372). Once the people have agreed to participate in the study, then the researcher should consider ethical issues. Participants should be assured of anonymity and confidentiality and the researcher should consider the consequences of the research interaction for the subjects.

3.5.2   Interview context

It is important that the researcher conducts the interview where the participants feel comfortable. This could be in the participant's home or office.

3.5.3   Rapport

In order to encourage the participant to open up, the researcher starts by building rapport. Participants should first be engaged in a semi-formal chat to try to make them feel at ease. "Rapport established in the interview situation may well have a direct impact on how forthcoming respondents are and hence the quantity (if not the quality) of data collected" (Phoenix, 1994:50). Building rapport may also require

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the researcher's sharing of personal experiences with the participants to get them to trust her.

3.5.4   Ethical Issues

Neuman (1997) cautions that, because social researchers transgress the privacy of subjects in order to study social behaviour, they must take precautions to protect the subject's privacy. This is done to enable respondents to give honest answers. Researchers like Singer, Von Thurn and Miller found that assuring confidentiality modestly improved responses when researchers asked about highly sensitive topics (1995, cited in Neuman, 1997).

Confidentiality entails protecting the information on a research subject's identity after the information is gathered. The participants engaged in the research should voluntarily sign the contract (see Appendix A) that should be prepared prior to the interviews. The contract is a written agreement to participate should be signed after the research process has been adequately explained. According to Neuman, "a fundamental ethical principle of social research is: never coerce anyone into participating; participation *must* be voluntary" (1997:450; Willig, 2001; Kvale, 1996). Real names should not be used when reporting the interviews.

3.5.5   Interview relationship

Feminist researchers are committed to reducing unequal power in the research relationship. They maintain that research relationships should be such that the researcher does not objectify research participants but allows them to voice their own lives (Beoke-Betts, 1994). One frequent source of enthusiasm for qualitative methods stems from their potential to offer a more human, less mechanical relationship between the researcher and 'the researched' (Jayaratne & Stewart, 1991:90). Oakley maintains that

> The goal of finding out about other people through interviewing is best achieved when the relationship of interviewer and interviewee is non-hierarchical and when the interviewer is prepared to invest his or her own personal identity in the relationship (1981:41 cited in Jayaratne & Stewart,1991).

In cases where the participants are not forthcoming with information, the researcher can encourage them to speak but should refrain from using force or leading questions. According to Neuman, the researcher "avoids probing inner feelings until intimacy is established, and even then the researcher expects apprehension" (1997: 372).

Once the interview has started, it is important that the researcher avoids interrupting the participant too frequently and that she does not finish the respondent's sentences. Scholars like Kohler have also pointed out that the researcher will "hear" nothing in the process of data collection and analysis unless he or she allows the narrators to speak for themselves, takes cues from them, and listens with a minimum of interruption (1991:234-35). Mishler maintains that,

> The interviewer's presence and form of involvement-how she or he listens, attends, encourages, interrupts, digresses, initiates topics, and terminates responses – is integral to the respondent's accounts (1989:82 cited in Neuman, 1997:371)

3.5.6 Objectivity

According to Acker, the ideal of objectivity is to remove the particular point of view of the observer from the research process so that the results will not be biased by the researcher's subjectivity (1991; Smith, 1983; Woods & Trexler, 2001; Mouton, 1996). Kirk & Miller maintain:

> The assumptions underlying the search for objectivity are simple. There is a world of empirical reality out there. The way we perceive and understand that world is largely up to us, but the world does not tolerate all understanding of it equally (1986:11 cited in Silverman, 2001).

Researchers like Carr and Kemmis (1983) point out that in order for the researcher to understand the motives and intentions of participants; she must grasp the "subjective meaning" the actions have for them.

Feminist research addresses this concern with objectivity in social science. Feminist researchers attempt to maintain a critical perspective towards the assumption that the researcher must, and can, strive to be a neutral observer standing outside the social realities being studied. This assumption is challenged by the feminist critique of social science that documents research, which has previously been taken as the neutral account of human society. Feminist researchers seldom ask objective survey questions, collect the answers of many people, and then claim to have something meaningful (Neuman,1997). Instead, feminist researchers consider social context as central because it shapes the participant's interpretation (Woods & Trexler, 2001; Henwood & Pidgeon, 1993).

Feminist research does not claim to be value free. Instead, feminist researchers make their values explicit and do not regard one set of values as better or worse. For instance, Lather does not support the notion of value-free, objective social science. She argues that complete value freedom is impossible and that scientists and other professionals use the term to hide their own feelings (Lather, 1991; Neuman, 1997). Furthermore, some studies have indicated that conventional methodological approaches that apply objectivity and ethical neutrality in field research fail to come up with data which adequately reflect the experiences and standpoints of historically marginalized groups (Beoku-Betts, 1994).

Babbie & Mouton also explain that, within this paradigm, objectivity is understood in two ways: In qualitative research, the researcher is regarded as the most important instrument of the research process. As a result, the researcher is faced with the challenge to be unbiased in the description and interpretation of data (2001:273). The other challenge facing the researcher is to build a relationship with the subjects of the study in order to come up with truthful 'insider' descriptions. Therefore objectivity means gaining trust and building rapport.

Feminist researchers believe that data must be both valid and reliable. Validity and reliability are the two central concepts in any discussion within a qualitative research. The rest of this section will discuss each concept in turn, examining what each concept means in practice in feminist research.

3.5.7 Reliability

Reliability refers to the "degree of consistency with which instances are assigned the same category by different observers or by the same observer on different occasions" (Hammersley, 1992:67 cited in Silverman, 2001:225). However, qualitative researchers are less concerned with reliability and are more interested in exploring the specific problem in detail (Willig, 2001). Furthermore, they believe that qualitative methods can generate reliable results if applied appropriately (Silverman, 2001; Willig, 2001).

There is also an assumption in qualitative research that reliability has more to do with low-inference descriptors. This involves:

> Recording observations in terms that are as concrete as possible, including verbatim accounts of what people say, for example, rather than researcher's reconstruction of the general sense of what a person said, which would allow researcher's personal perspectives to influence the reporting (Seale, 1999: 148 cited in Silverman, 2001:227).

When reporting on interviews, qualitative researchers address the need for low-inference descriptors by using an audio tape for all face-to-face interviews, take care to transcribe the tapes carefully and present their research report (Silverman, 2001).

3.5.8 Validity

Validity is defined as the extent to which research describes, measures or explains what it was designed to describe and measure (Willig, 2001). It has become a common practice for social researchers to use the notion of truth instead of validity and goodness of fit. According to Mouton, the terms validity and goodness of fit "capture the idea that a statement or collection of statements can be more or less truthful" (1996:30). Feminist researchers use terms such as credibility and plausibility instead of terms like validity and goodness of fit.

The question of what is true or valid is one that feminist research have in common with all social scientists but there is an obvious difference in how they conceive of

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this truth. Feminist researchers are not interested in prediction, but aim to show that the results accurately reflect the aspects of social life that they claim to represent.

Qualitative methods are flexible and open-ended, allowing for the evaluation of what is considered to be valid. Respondents can for instance challenge the researcher's assumptions about the meaning and relevance of concepts and categories (Willig, 2001). Thus the great strength of qualitative research is "the *validity* of the data obtained: individuals are interviewed in sufficient detail for the results to be taken as true, correct, complete and believable reports of their views and experiences" (Hakim, 1987:27).

In addition, a qualitative researcher can get feedback on her findings from the participants. If the study or findings make sense to participants, then it seems to have some validity (Willig, 2001). Lastly, the fact that qualitative researchers are always reviewing their own roles in the research process and do not impose their own views or meanings on participants promotes validity. However, reactivity is the biggest threat to the validity of research findings when human behaviour or characteristics are the sources of information (Mouton, 1996).

Some ways of enhancing validity and reliability are triangulation, extensive field notes and member checks.

3.5.9 Triangulation

Triangulation is used to see whether different methods work together. These methods can be interviews and observations which can be used to complement each other. Through these methods, the qualitative researcher makes the most of the strength of each and minimizes weaknesses inherent in a single strategy (Woods & Trexler, 2001). Denzin points out:

> Triangulation, or the use of multiple methods, is a plan of action that will raise sociologists [and other social science researchers] above the personal biases that stem from single methodologies. By combining methods and investigators in the same study, observers can partially overcome the deficiencies that flow from one investigator or method (Denzin, 1989:236; quoted in Babbie & Mouton, 2001:275).

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3.5.10 Extensive field notes

Here the researcher is required to have at least two sets of notes. One set should be to describe the area of study and non-verbal communication, while the other set should be for recording what actually happens during the interviews. This is to make it possible for the researcher to make necessary changes as the research proceeds (Babbie & Mouton, 2001).

3.5.11 Member checks/ respondent validation

This entails taking interview transcripts or written material and analyzed data back to respondents to give them an opportunity to confirm that what the researcher has written is actually what they said (Lincoln, 1985; Babbie & Mouton, 2001; Silverman, 2001). The participants' comments on the experience of being researched tell the researcher a great deal about the validity of the interview data.

3.6   Grounded theory

Grounded theory methods are used to analyse and understand a set of qualitative data. Grounded theory methods are techniques for collecting and analysing data that are meant to develop a theory (Charmaz et al, 1995; Lacey & Luff, 2001). Thus these methods are inductive because the results lead to an evolutionary body of knowledge that is grounded in data (Neuman, 1997; Stauss and Corbin, 1990; Charmaz et al, 1995; Lacey & Luff, 2001). The resulting theory is an explanation of categories, their properties, and the relationships among them. As Strauss and Corbin put it, grounded theory is:

> Inductively derived from the study of the phenomenon it represents. That is, discovered, developed, and provisionally verified through systematic data collection and analysis of data pertaining to that phenomenon. Therefore, data collection, analysis, and theory should stand in reciprocal relationship with each other. One does not begin with a theory, then prove it. Rather, one begins with an area of study and what is relevant to that area is allowed to emerge. (1990:23)

The procedure of doing grounded theory is mapped below:

Procedures of doing grounded theory

- Open coding (initial familiarisation with the data)
- Delineation of emergent concepts
- Conceptual coding (using emergent concepts)
- Refinement of conceptual coding schemes
- Clustering of concepts to form analytical categories
- Searching for core categories
- Core categories lead to identification of core theory

Testing of emergent theory by reference to other research and to social cultural/economic factors that affect the area of study.

Adapted from Lacey & Luff (2001:7).

3.6.1   Coding

All grounded theory studies use a data coding scheme. Qualitative grounded theory coding means "*creating* the codes as you study the data" (Charmaz et al, 1995:37; Hancock, 1998; Neuman, 1997). Qualitative methods use codes to categorize data rather than to quantify it. Therefore, the number of times an individual comment is categorized is not important.

Coding is always guided by the research question to enable the researcher not to lose the focus of the study. Coding also makes it possible for the researcher to come up with a theory. One way of identifying the themes is by categorizing components or fragments of ideas or experiences, which often are meaningless when viewed alone (Leininger, 1985 cited in Aronson, 1994). Then the researcher can be able to interpret the data and come up with a broad picture of participants' collective experiences (Aronson, 1994; Neuman, 1997).

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3.7   Self-reflexivity

Feminist researchers emphasize self-reflexivity (Lather, 1991) which means that the researcher reflects on her social identity, her role in the research process and the relationship between the researchers and researched. Reflexivity may also serve as a method of validating research findings (Lather, 1991).

3.8   Procedure

3.8.1   Study area

Lesotho has ten districts, however this study covered only Maseru, which is the capital town of Lesotho (See a map below showing the study area). All ten districts have reported HIV/AIDS cases; however, the lowlands are the more affected areas than the highlands (Moe, 1998).

A map of Lesotho showing the study area-Maseru

3.8.2 Participants and sampling technique

The participants for this study were recruited from Positive Action Society Lesotho, one of the NGOs dealing with HIV/AIDS in Lesotho. The population for my study can be broadly defined as all women with HIV diagnosis, aged 26 to 50 years volunteering at Positive Action Society Lesotho. Both purposive and snowball sampling methods were used to secure a sample of five women. Purposive sampling was chosen because it uses the judgement of an expert in selecting cases, or it selects cases with a specific purpose in mind (Neuman, 1997). It also enabled the

researcher to use an organisation catering for the needs of HIV positive people to identify a sample for inclusion in the study.

3.8.3   Semi-structured interviews

The venue for the interviews was the Positive Action Society Lesotho offices. The interviews were semi-structured and the researcher considered the fact that interviews would offer opportunities for direct interaction with participants (Devault, 1999). Unlike the researchers within a positivist paradigm, we (feminist researchers) do not pursue the notion of objectivity. Instead we believe that the researcher should interact and work together with the participants (Neuman, 1997).

Participants were first involved in a semi-formal chat to try to make them feel at ease. Establishing rapport and the researcher's willingness to answer questions that the respondents may have can convince respondents that the researcher does not want to exploit them (Phoenix, 1994; Maynard, 1994).

With their permission, the cassette recorder was turned on and the interviews started. A set of themes was produced as an interview guide. These covered: experiences of living with HIV/AIDS, concerns of women with HIV/AIDS, their coping strategies and arrangements for children where applicable.

Semi-structured interviews were preferred to other techniques like questionnaires because of their ability to explore mainly those areas where the researcher perceives gaps and difficulties (Banister et al, 1994, Smith & Van Langenhove, 1995; Willig, 2001). The interviews were semi-structured to add flexibility (Smith & Van Langenhove, 1995). Unlike a questionnaire, the interviews facilitated the participants' insight into their own developing awareness of the scope of the problem. The interviews ranged in duration from forty five minutes to one hour.

The participants received money for transportation costs, a lunch and a small gift, and these incentives played a definite role in inducing participants' participation.

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3.8.4   Data Analysis

Data was processed and analysed manually after the interviews. This included translating the interviews from Sesotho to English and transcribing the interviews verbatim. The interviews were analysed by using grounded theory. Grounded theory relies on coding and categorising data into meaningful sets, to facilitate easy analysis (Aronson, 1994). This involves summarising the collected data and presenting the results by putting emphasis on the most important information. Grounded theory uses the constant comparative method to analyse data. This is where comparisons between data are made after all primary documents are completely coded to generate grounded theory (Wolcott, 1994, Glaser and Strauss, 1967, Neuman, 1997; Hancock, 1998; Lacey & Luff, 2001). It is important that the researcher continues with the process of constant comparison until 'theoretical saturation' is reached.

3.8.5   Self-reflection

This section of the study is about my experience of conducting the interviews. I found it a great challenge to gain access to these women. What I did to gain entry, or some measure of cooperation, was to explain my research intentions to them after I had located them through Positive Action Society Lesotho. The fact that all participants in my study were situated at Positive Action Society Lesotho was an advantage for me because it saved time and also meant they were easy to find.

In retrospect, I realize that at first the women were less receptive to participate in the study than I had expected. This realization made me anxious because I had assumed that they would readily cooperate. People living with HIV/AIDS have been researched over the years in Lesotho although it is still difficult to gain entry for research purposes. Some of these women hesitated to participate because they said that past relationships with researchers have been exploitative and that they do not benefit from being research participants. In one journal entry I noted the following:

Date 01/04/03: some women claimed that other researchers either from South Africa or abroad had requested them to participate in their studies without necessarily explaining how they would benefit from such studies. These women also stated that they were 'tired' of outsiders speaking for them and so resisted research. They thought the fact that they are uninformed made them vulnerable in that they were being used to further other people's careers.

Questions about representation have been raised by a number of feminists (Funani, 1993; Fouche, 1993; Gouws, 1993; Maqaqi, 1996), both internationally and in South Africa. These questions were raised as a result of white feminists doing research on black women. Feminist researchers asked: who has the right to represent, speak on behalf of and do research on whom? These questions were raised out of the realisation that Black women have always been objects of speculation and inquiry with little or no agency afforded to them. The commonality of experience of black women is their status as objects of research or as marginalized voices in the global systems of knowledge (Hendricks & Lewis, 1994). Brink maintains that

Certainly, it would seem that where power acquires a stake in representation, an invisible boundary is crossed, and the adoption of another's voice comes to be perceived as an act of appropriation. Such a situation can all too easily become just another instance of the powerful exploiting the weak (Brink, 1998 cited in Fester, 2002).

Unlike researchers with outsider status, I was accorded insider status as a black researcher and as somebody who comes from the same culture and place as the respondents. I assured these women that I would bring a special sensitivity and engagement to the research process. Occupying an insider status meant that I was less likely to generate distrust and hostility from research participants, or exclusion from particular types of information (Baca Zinn, 1979). Beoku-Betts found in her study of African American women that some of them preferred a black scholar like her conducting research in their community. As one participant put it, "black scholars have a sense of soul for our people because they have lived through it" (1994:417).

Despite some women's hesitation to participate in the study, 5 women were interested in the study and encouraged me to return. The rest refused outright to be

interviewed. I guess that they were suspicious and less accepting of my intentions. Or perhaps they were sceptical that the research would produce anything worthwhile for women living with HIV/AIDS in Lesotho. This resistance made me aware that the fact that I was a woman discussing 'women's issues' was not enough for the establishment of rapport and the uninterrupted flow of an interview (Phoenix, 1994).

Nevertheless, the study was informative and challenging because of the different views presented by the participants. I was entrusted with a lot of information about their lives and experiences. According to Shaffir,

> Successful entry to the research setting, and securing the requisite cooperation to proceed with the study, depend less on the execution of any scientific canons of research than upon the research's ability to engage in sociable behaviour that respects the cultural world of his of her hosts (1991:73)

Conducting all the interviews in Sesotho was time-consuming and some words or questions seem to lose their essential meaning when translated into English, when interviews were transcribed. Overall, while it was beneficial to conduct the interviews in the participants' favoured language, it also meant the meaning might be altered during the process of translation. I have tried to remain as true as possible to my understanding of the original meaning. Dane explains that the "use of interviewers whose ethnic origins are the same as those of the study population, where possible, is an additional step that can be taken to secure translations that accurately reflect the content" (2000:6).

3.9   Conclusion

In summary, the feminist paradigm was reviewed and the emphasis in this chapter has been on semi-structured interviews as a method that feminist researchers use to gather data/ information. Some principles of doing interviews were discussed. What emerges clearly is the view that data collection is not an objective, neutral process of identifying the truth about subjects. Instead emphasis is put on subjective experiences of the participants rather than the frequencies of events (Strebel, 1995)

within the feminist paradigm. The chapter concludes with the researcher' reflections on her experiences during data collection.

Chapter 4 presents the verbatim transcripts of the interviews with the participants. These transcripts show the experiences and coping strategies employed by the participants.

CHAPTER 4: CASE STUDIES

4.1 Introduction

This chapter is a presentation of interview transcripts. The researcher conducted two sets of interviews and the second set of interviews served as a follow-up to fill the gaps evident in data gathered during the first set of interviews. The interviews were edited to clarify and present the data more systematically according to themes that emerged from the transcripts of the interviews. The translation process of interviews from Sesotho to English proved complex, the translated interviews are presented verbatim with every attempt made to represent the original Sesotho.

4.2 Case 1: Alice

4.2.1 Background

Alice was born 32 years ago at Mafeteng and she is the second of four children. At the time of the interview she was staying at Ha Pita with her two children, a boy (7 years) and a girl (9 years). She was married but her husband passed away in 2000. She has COSC and did a dressmaking course, but had to stop when her health deteriorated. She is not formally employed and volunteers at PASL.

4.2.2 Transcribed interview

4.2.3 Reactions of participant to diagnosis

Researcher: I would like to thank you for allowing me to interview you. Should you feel uncomfortable or that you want the interview to stop at anytime please let me know. When did you know about your status?
Participant: in 2000.

Researcher: What were your thoughts then?

Participant: I thought that it wasn't a problem because I was already a volunteer here at Positive Action long before I was diagnosed as HIV positive. I volunteered because I enjoy working with my hands and like to work in a group. At that stage I didn't even think that I could be sick. I started to lose weight and I wasn't eating properly, so the founder of PASL suggested that I should go for tests. An AIDS counsellor who worked here then explained everything before the test. The only problem was that they just tell you that you are living with HIV/AIDS and I wasn't given my results. The fact that I was already in contact with HIV positive people on a daily basis helped me a lot. When I was told about my HIV positive status, I had hope that I would survive just like those people I was meeting on a daily basis. What gave me hope is seeing those people surviving and living with this disease for a long time.

4.2.4   Reactions of family and friends

Researcher: Does your family know about you status?

Participants: Yes most of them know because I told them. Generally, I'm getting a lot of support from my mum, dad and sisters, my mother-in-law and brothers- in-law. My mum is always concerned about my health, I guess it's because she works at the Red Cross. My three sisters buy me immune boosters and garlic. Even when I used to go to Bloemfontein once a month, the other one and her husband used to take me. My in-laws on the other hand have also been supportive emotionally and are always checking on me. I guess it's because I have always confided in them when my husband was cheating on me. When I told my husband's younger brother, he was very touched and he asked, why you? I guess that he ask me that question because he know that I never cheated on my husband.

Researcher: You have mainly talked about your family members, what about your friends?

Participant: Most of them support me but I get worried when I don't see them sometimes.

4.2.5   Concerns of women living with HIV/AIDS

4.2.5.1 Finances

Researcher: Apart from volunteering here (at Positive Action Society Lesotho), what else do you do to earn a living?

Participant: I am just working here as a volunteer. I don't earn money on a monthly basis like people working for the government. At least in the past I was staying nearby, but now I have to take a taxi and sometimes I don't even have money for transport.

4.2.5.2 Heterosexual relationships

Researcher: Have you ever thought of how you could have been infected?

Participant: To be honest, it was my husband who infected me. I have always been a faithful wife, so I don't see how I could have infected him. I learned that I was sick when I was still mourning his death.

Researcher: How does it make you feel, the fact that he infected you as you put it?

Participant: At first, I used to be very angry and I had a lot of questions for him concerning my sickness. One time I discovered that he kept his medical card from me and the doctor had diagnosed him with sexually transmitted diseases. I asked him why he was losing weight and looked pale but he said nothing was bothering him. I remember, one night he came home very drunk and forced me to have sex with him. I was reluctant because he had been drinking and when I looked at his penis, I realized that it had sores. Regardless, he forced himself on me and even beat me. I told his mother and aunt about this incident. I was reluctant to tell my family to avoid family quarrels. I guess not telling them was my way of protecting them because I knew they wouldn't take it very well. Afterwards I had vaginal thrush and I was treated for it.

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Researcher: How did these experiences make you feel?

Participant: I have stopped dwelling on the past because he's no longer around. I learned about it after his death, so in a way I couldn't ask him anything. I remember that I used to talk to him about his behaviour and pleaded with him to change. He used to work at LHDA as a driver. He was earning around R2000 and he used to give me R700 to spend on food, children's needs and his transport. I had to work hard to come up with my money when he was still alive. He used to spend most of his salary on alcohol and women.

Researcher: You mentioned that you husband passed away, so have you tried to have relationships with men after his death?

Participant: I have decided to take a five-year break from relationships with men. I feel that I need to rest for some time. Even before I got married, I wasn't very interested in sexual relationships. Apart from that men can be problematic because it would mean that I would have to take care and I feel I wouldn't be able to do it.

4.2.5.3 Reproductive role

Researcher: Would you say that being HIV positive has influenced your reproductive role?

Participant: No, because even now it's very difficult to raise my 2 children. It's not the sickness as such that prevents me from having more children but financial constraints.

4.2.6   Coping strategies

Researcher: You said that you used to be angry with your husband. Would you say that has changed over time?

Participant: At the moment, I'm over that anger and I have tried to continue with my life. I think that it is better when one has accepted one's status because that way you learn to take care of yourself. The fact that people always worry what other people will say when they learn of their HIV positive status is the issue that needs our attention. It's just that today, I'm not feeling very well, I'm having stomach

cramps and my stomach is also running. Apart from that I know some women who are living with HIV/AIDS that I usually speak to. However, I can't invite them to join Positive Action because even for people who are volunteering, the R10 that we are given everyday for lunch is now a problem. I also think that it is easier to speak to a male if you are one and a female if you are a woman concerning these issues. Overall, women are worried that they are getting HIV/AIDS from their male partners.

Researcher: You said that you are not working. So what do you do to look after yourself?

Participant: I used to go to Carewell clinic whenever I could afford it. Sometime when I am very sick it is a problem because you find that I do not even have enough money to go and see the doctor. I haven't actually gone for vaccine trials because I'm not that sick. Even when we were given a chance to go for vaccine trials by Positive Action, I suggested that some people who were sicker than I was should go in my place. Of late, I was introduced to a man who specializes in traditional herbs and I think they help me a lot in that they help me pick up weight and especially with depression. However, sometimes I judge myself and have less confidence because of some symptoms. Look at my face now, I am reacting to a TB treatment. Most of the time I try not to compare myself to others.

Researcher: What else do you do?

Participant: I come from a family of Christians. I believe that God is protecting me because I'm still alive. I also get a small amount here but somehow I get by. I'm also getting a lot of support from our pastors in that they prayed for me when I disclosed my status to them and they continue to pray for us.

Researcher: Would you say volunteering here has helped you to cope?

Participant: Initially we were sharing offices with men who are volunteering, but we now have a separate office for women because of lack of respect from some younger boys. As older women, we didn't feel free to discuss our symptoms in their presence. Since our separation, I feel happier and there are few confrontations. We work very well as women and work very hard to make beads on a daily basis. I

enjoy our little space because we support each other and we don't discriminate against each other.

4.2.7 Arrangements for children

4.2.7.1 Disclosure to children

Researcher: You mentioned that you have children, how many are they?

Participant: I have two children.

Researcher: Do they know that you are sick?

Participant: They are still very young, so I haven't told them. But my assumption is that they have heard about AIDS from TV and radio. Imagine if I were to tell them that their father died of AIDS, I think that they wouldn't understand because the one is 9 years while the other one is only 7 years.

Researcher: I hear that your concern is to do with their age; if they were older, what would you say to them?

Participant: Since nowadays children can watch all programs on television, I think that it would have been easier. I guess that I would have told them in the same way as I told my family and friends.

4.2.7.2 Welfare of children

Researcher: You mentioned that you have two small children, who do you think will take care of your children when you are no longer able to do so yourself?

Participant: I know we'll all die regardless of our status. When it comes to my children's welfare I worry a lot. You can never be sure because at the moment they are being treated very well by everyone, but who knows what will happen once I'm gone? Moreover, like I said earlier we are given R10 here on a daily basis. You can't open insurance with that kind of money. There is nobody with insurance among people who are sick. The issue of my children's education and food worries me the most. My mother is still working and she helps me financially whenever she can, so I should think she will take care of my children.

Researcher: Is there anything that you would like to add?

Participant: No.

Researcher: Thank you very much for your cooperation.

4.3   Case 2: Lineo

4.3.1   Background

Lineo was 46 years old and lived at Stadium Area. She was a widow and had two children, a 24-year-old son and 19-year old daughter. She did the first year of a degree at National University of Lesotho (NUL) but had to apply for an official withdrawal because of her health. At the time of the interview, she volunteered at PASL and was also involved in media projects, which aimed to educate people about HIV/AIDS.

4.3.2   Transcribed interview

4.3.3   Reaction of participant to diagnosis

Researcher: I would like to thank you for allowing me to interview you. Should you feel uncomfortable or that you want the interview to stop at any time please let me know. When did you know about your status?
Participant: In June 2002.

Researcher: How did you feel when you were told?
Participant: You know…since there were things that I was observing on my body, I had a feeling that those symptoms would lead to something serious. I had even thought of testing for HIV/AIDS at one stage, but I was scared that the tests might not come out as negative. I had a severe vaginal thrush and other signs. In June last year, I became very sick and I was diagnosed with tuberculosis. At the stage, I asked my doctor to take my blood to do a HIV test. He did and I was told that I'm HIV positive. I must say that I was shocked because part of me expected the results to come out as negative, do you get what I'm saying? My biggest fear was that people would link my sickness to extra-marital affairs. You know I'm a Christian, so my concern was that people would think that I was sleeping with this and that man. I was reassured by the fact that people who are close know me very well and that I wouldn't behave in that fashion. People should learn that one can get it in

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other ways and this will help people to stop blaming themselves and other people for that matter.

Researcher: Would you say your feelings have changed over time?

Participant: Yes, I'm always encouraged by the saying that the fact that you see other people as healthy does not necessarily mean that they are actually healthy. I am saying this because there are some few cases when I met the person today and tomorrow she is gone. This somehow reassured me that being HIV positive is not a death sentence because people are also dying from other causes. My doctor told me that my concern should be with looking after myself and eating properly. After speaking with my doctor, I was able to talk about the issue of AIDS generally although I was very worried about my children.

4.3.4 Reactions of family and friends

Researcher: Have you told your family about your sickness?

Participant: Yes and they support me all the time. Even when I don't have medication, I know that I can always count on them. They are always concerned about what I eat. What amazes me is the fact that if you were to visit my home, you wouldn't even think that there is an infected person from the way they are doing things. Perhaps it has more to do with the fact that I am fine at the moment, even my daughter and my mum wear my clothes sometimes, they are not even concerned about sharing the bathroom with me. I have taught them about the HIV/AIDS and the ways in which it can be transmitted.

Researcher: Are there other family members that you told about your status?

Participant: When I told my children, I wasn't sure whether to tell my brother because I wasn't sure how he was going to react. At the end I decided to tell him because I didn't want him to hear it from other people and I think he is dealing with it fairly well. Even my in-laws know about my status. Yes, I got a sense that even among my friends and in-laws there are some who still don't get this talk about AIDS. I am saying this because there are instance when some said it publicly that I'm HIV positive, a few months back, I would be very worried but now I'm not concerned about who knows and who doesn't anymore. Some of these people who

are always concerned about some people's HIV status do not even know theirs themselves, so I pity them.

4.3.5   Coping strategies

Researcher: I hear that you are getting a lot of support from your family. Would you say they are the only people that are helping you to cope?

Participant: I must say, at times I feel very confused and sad and this is usually the time when I prefer to be in the company of other people who are also infected. Ever since I was diagnosed as HIV positive, I sometimes become very moody, I'd be shouting at everybody for no particular reason; at times I just break down and cry.

Researcher: You mentioned earlier that whenever you are feeling down, you prefer to be in the company of other people who are living with AIDS. How does that help you?

Participant: At times, I don't even have to go searching for these people because some of them come to my place. They know that I'm very involved around the issues of AIDS so they come to listen to my story. I was practically dead, I always tell them, but look at me now. I don't just talk to people living with HIV/AIDS but also talk to those who say they do not have it.

Researcher: I hear that your family is assisting you in terms of getting your medication and eating properly. What are you doing to earn a living?

Participant: I was studying at the National University of Lesotho but I had to apply for official withdrawal because of my health. I hope that I will still go back to school but in the meantime, I am involved in a project that is aimed at people living with HIV/AIDS. We are interested in teaching them some ways of making a living, so we are targeting those who are not working.

Researcher: You say 'we' when you talk about this project. Who are these other people who are involved with you on this project?

Participant: Some of them are my friends. I am very open about the issue of HIV/AIDS.

Researcher: So what kind of response are you getting from your audience?

Participant: Yes, people's perceptions differ and there are still some who are scared to discuss the issue of AIDS, they still feel that they can't discuss it openly. Regardless, I just talk about it. I even have a slot on radio and every opportunity I get I talk about it.

Researcher: Which other strategy to you use to cope?

Participant: I did Christian counselling but whenever I'm motivating or counselling people, the Bible is not my only source of inspiration. I feel that sometimes if I'm speaking to the person and going through the bible to look for some scriptures, they end up not focusing on what I would be saying.

Researcher: You mentioned earlier that you are on medication. Where do you get that kind of medication?

Participant: I have been getting the medication from my doctor here in Maseru and they are around R400. However, I thought of checking the prices in Ladybrand, and I was surprised to get them at R80. It is a combination of anti-biotics and I feel they are working.

Researcher: Would you say volunteering at Positive Action has helped you to cope?

Participant: Yes I think so in that it gave me an opportunity to meet other women like myself and to learn how they are also fighting this disease. However, we feel that we need an organization that caters specifically for women because right now we don't have privacy to articulate our fears as women.

4.3.6   Concerns of women living with HIV/AIDS

4.3.6.1 Heterosexual relationships

Researcher: Have you ever thought of how you could have been infected?

Participant: My husband passed away some time back and after that I had been involved with other men; so in my case I can't really say so and so infected me because I might have been the one who infected them. In order to live with it I just take it for granted that it was my fault that I have it.

Researcher: You mentioned that your husband passed away and that you have been having a few relationships after that. So is there someone in your life presently?

Participant: I'm not involved at the moment (laughs). Some friends and family members are concerned and feel that I should have one. I guess what prevents me to have one is the issue of being a Christian because as a Christian one is expected to behave in a certain way. But I feel that I can still marry if I want since I'm a widow.

4.3.7   Arrangements for children

4.3.7.1 Disclosure to children

Researcher: How many children do you have?

Participant: I have two adult children, a boy and a girl. The girl is a student at the National University of Lesotho. The nice thing is that the other one, the boy, was already involved with the NGOs dealing with the issue of HIV/AIDS in Lesotho. Even so, it came as a shock to both because they never expected that it would actually be somebody in their family.

Researcher: Would you say that telling your children about your status has benefited you?

Participant: Yes, because ever since I told my children about my sickness, I have been feeling better; it was as if a weight had been put off my shoulders.

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4.3.7.2 Welfare of children

Researcher: You said that you are staying at your parents' place with your children. Have you ever considered who will take care of them when you are no longer able to do so yourself?

Participant: We felt that it would be more practical for my children and me to stay at my parents' place because I'm not working. So I think that when I'm no longer able to be with them, then my parents will carry on with supporting them as they are doing now.

Researcher: To conclude, we talked about the fact that you only knew about your status in June 2002. And also about the issue of support, how your family assists you with medication and healthy food. You also mentioned that most of your friends know that you are living with AIDS and that you do not have a problem with other people knowing about your status. You are very active in the issues of HIV/AIDS and you are engaged in a project around this issue; you even have a slot on radio which gives you an opportunity to teach people about this disease. However, you also said that even through you are open about it, there are times when you just break down. You mentioned that you are a Christian counsellor and mentioned your role very explicitly. Does that cover all the areas that we touched on today?

Participant: Yes, I think it does.

Researcher: Thank you very much for your cooperation.

4.4   Case 3: Lieta

4.4.1   Background

Lieta was 40 years of age. She lived at Ha-Motloheloa. She was married but had separated from her husband. She had four children, three sons (20, 17, 13 years) and a 10-year-old daughter. She only stayed with her two youngest children while her mother-in-law stayed with the other two. She went up to Form D and went to South Africa in search of a job. At the time of the interview she was volunteering at PASL.

4.4.2   Transcribed interview

4.4.3   Reactions of participant to diagnosis

Researcher: I would like to thank you for allowing me to interview you. Should you feel uncomfortable or that you want the interview to stop at any time please let me know. When did you know about your status?

Participant: In June of 1999. I came back in 1998 from South Africa where I was working.

Researcher: What were your thoughts then?

Participant: Since I was having vaginal thrush all the time, I suspected that it could be a symptom of HIV/AIDS.

4.4.4   Reactions of family and friends

Researcher: What makes you think that your father and mother do not believe you?

Participant: I can just tell from their reactions. My sister even tried to explain to them that I'm living with this disease, but it seems like they are taking it lightly and this in a way discourages me. Sometimes, I feel like I'm not part of the family because they discuss things behind my back. It's as if my younger brother is their

only child. Perhaps it is because I disappointed my parents when I separated from my ex-husband. My sister, on the other hand, is very supportive.

Researcher: Apart from family members, who else have you told about it?

Participant: I have my two male friends. One helps me with traditional herbs and helps me financially whenever he can. The other one was very supportive when I found out about my status. He told me that it was not the end of the world. He is my source of inspiration. Apparently he has been involved in one of the organizations catering for people living with HIV/AIDS. He has even helped me find a house where I'm staying now for free and I rely on him when I don't have money.

4.4.5   Concerns of women living with HIV/AIDS

4.4.5.1 Heterosexual relationships

Researcher: Have you ever thought of how you could have been infected?

Participant: The problem is that men think it is women who are more likely to get sick. Yet if one looks at HIV transmission, you find that it is mainly men who are infecting women. I know a number of women, their partners died before them and they also reported that if it hadn't been because of the partners they wouldn't be sick. I know of a number of stories. I have thought of how I could have contracted this disease, definitely it was not from my ex-husband because we separated a long time ago. I used to stay with my ex-boyfriend in Gauteng and I was aware that he was having a number of relationships. I sometimes blame myself for not leaving him before I contracted this disease. I remember that I used to have vaginal thrush and I would go to the clinic all the time. I even suggested that they should take my blood to check if I had AIDS.

4.4.5.2 Medical experiences

Researcher: You said that you asked the doctor to do HIV/AIDS test; then what happened?

Participant: The sisters at the clinic were reluctant to do the tests. At times they would check me and then tell me not to worry. I ended up being confused because I wasn't quite sure what was wrong with me, and I somehow had a feeling that I might be HIV positive. In 1998, I went back to Lesotho and at that time the thrush was not that severe and I only went to see a doctor once in a while. After some time, it became severe again; I went to see a doctor and asked for some HIV tests. Even here the concern was that I didn't have signs for HIV/AIDS and they asked me why I wanted to be tested. I explained that it would put me at ease because then I would know what I'm dealing with. So they agreed. I went for the test in June 1999 and they did two tests and both were positive. However, the doctors and nurses were surprised by my reaction. I was calm because I had anticipated it. There was even this lady who had just been given her results and they encouraged me to talk to her because of my positive reaction.

Researcher: You said that you separated from your husband some time back. So have you considered engaging in other relationships?

Participant: Ever since I learned that I'm sick, I haven't had any intimate relationship. I just don't feel like being involved with anyone. Again I think it has more to do with the reactions that I sometimes get from some men when I tell them that I'm sick when they want to be involved with me. They just laugh, which is a sign that they do not believe you. So I have decided to be celibate and it has been some time now. At first I didn't think I would still be around, but I guess it's because I'm taking care of myself now. I'm doing very well without a man in my life, yes I must say some people have shown concern and are even asking which church I'm attending because of this change in my behaviour.

4.4.6   Coping strategies

Researcher: You mentioned earlier that there are 2 male friends that you told about your sickness. Are they the only people that you feel understand what you are going through?

Participant: Yes, but there are also some people who are very supportive here at Positive Action where I'm volunteering. I learned about Positive action when I was attending support groups at Queen Elizabeth hospital and then I decided to join it. I can say that discussing it with them is not a problem, and I never stop to think whether they are positive or negative. However, here it is quite different because you know that you are talking with people who are also sick, so you are not scared that you might be judged based on what you disclose. And then there is an issue of confidentiality here unlike at other places. We sometimes discuss the problems we face as a result of disclosing our status but we don't just focus on that; we also discuss some ways of making a living since all of us are not formally employed. I even think that if we had financial support, nobody would even think that we are living with HIV/AIDS. If only we could separate from men because most of them are very young and sometimes dominate us in that when we make suggestions, they are not taken seriously because we are women.

Researcher: Apart from support groups, which other strategies do you use to cope?

Participant: I have gone for vaccine trials in the past with the help of Positive Action. It even provided us with transport whenever we had to go for these trials. At the moment, I'm not using any form of medication because I'm not working. I mainly use traditional medicines. I am also getting a lot of support from the pastors in my church. They have told me that this AIDS is an evil spirit and that it can be defeated by prayer. Whenever I don't feel well I pray with them and their prayers really help me.

4.4.7   Arrangements for children

4.4.7.1 Disclosure to children

Researcher: You mentioned that you accepted that you would be living with the disease when you were first told. Would you say the way you saw it has changed over time?

Participant: My major concern is my children. I have thought of telling them but I don't know how I should tell them. The other issue is that we have separated from my ex-husband and the children are in his care. Our families are still discussing the issue of our separation and I haven't told him about my sickness because I feel that he doesn't have time for me. This puts a lot of stress on me and even if I were to get sick tomorrow, it will be mainly because of this issue.

Researcher: You stated that you have children. How many do you have?

Participant: I have four children and like I said, they do not know about my sickness. I have asked for advice from here (Positive Action), and they suggested that since I wanted the eldest one to know, that it would be wise to first of all come with him to some workshops on AIDS so that he can be able to deal with it when I tell him, instead of being shocked.

4.4.7.2 Welfare of children

Researcher: You said that your children are staying with your ex-husband. So do you think that he would continue to take care of them when you are no longer able to do so yourself?

Participant: To be honest, I don't know and I don't like to think about it. The thing is I'm getting more support from friends than my family. For instance, if some of my male friends do not see me for some time, they become concerned and even come to my place to see if I'm fine. Even when they hear about a certain doctor they tell me.

Researcher: I would like to conclude. But before I do so, is there anything that you would like to add?

Participant: Not really.

Researcher: Thank you for your cooperation.

4.5 Case 4: Mary

4.5.1 Background

Mary was 29 years old. She had her first child when she was 14. In 1990, she got married and the marriage lasted for four years. At the time of the interview, she had separated from her partner. She lived at Ha-Thamae with her 2 daughters, 13-years and 11-years old. She had completed standard 7. She worked at Positive Health and was also a volunteer at PASL.

4.5.2 Transcribed interview

4.5.3 Reaction of participant to disclosure

Researcher: I would like to thank you for allowing me to interview you. Should you feel uncomfortable or that you want the interview to stop at any time please let me know. When did you know about your status?

Participant: In 1994. Early January 1994 I used to have this big pimple under my armpit and I went to Lesotho Defence Force (LDF) clinic to see a doctor. He injected me and I was given some medication for it. But in March 1994 the problem was still persisting and I went back to the doctor again. He suggested that he should take my blood to run some tests. I said that he should also include the HIV/AIDS test. After some time, my result came back positive.

Researcher: What were your thoughts then?

Participant: My fear was to die and leave my children; I even heard people saying people living with AIDS do not live for a long time. This used to frustrate me a great deal. Sometimes, I became angry when I thought of this disease and how it has changed my life. My lips were red and I lost weight.

Researcher: Has that changed over time?

Participant: I must say I'm quite well at the moment even though I must admit that whenever I think of my children and their welfare, I end up depressed and having these headaches all the time.

4.5.4 Reactions of family and friends

Researcher: Does your family know about your sickness?

Participant: Yes, my mum knows and I think that she has accepted it. However, she is a very loud person and she takes alcohol all the time and she shouts for no particular reason. That is the reason why I left her because I was staying with her.

Researcher: Apart from your mother, have you told other people about your status?

Participant: I have a lot of support from my three brothers, especially the eldest because he was recently diagnosed with HIV/AIDS. I am also getting support here at Positive Action and even from some of my friends. However, some people are still very ignorant, like those that I have told about my sickness, they just don't believe me! I have told the person that I'm involved with at the moment and that it is important that he should know his status and use protection all the time. He seemed very shocked and scared, perhaps it's because there are no signs at the moment that might suggest that I'm sick in any way.

4.5.5 Concerns of women living with HIV/AIDS

4.5.5.1 Heterosexual relationships

Researcher: Are you still involved with him?

Participant: Yes, I don't have a problem with having an intimate relationship as long as the person agrees to use protection. However, you find that there are still guys who are still willing to risk and I get discouraged by that kind of mentality because I wouldn't want to infect anyone. I have been seeing my present boyfriend for sometime now but he still doesn't believe that I'm living with AIDS. He said that he would believe me if we could go together for HIV test.

4.5.6 Coping strategies

Researcher: How have you coped with your status up to this point?

Participant: Immediately after receiving my results, I was introduced to one lady who was helping people living with HIV/AIDS. This lady was from an organization called Helping Other People Everywhere (HOPE) in South Africa. We met with others on Thursdays to talk about our fears. She even provided us with food to keep our immune systems going. At a later stage I learned that that lady left and I never saw her again.

Researcher: Which other coping strategies do you use?

Participant: I always say, people should learn to live with this disease; I know it is not easy but we should trust in God. Because He can never let us down if we ask Him for help. In order to go on I rest a lot, especially when I have a headache because I think that I should take care of myself. Pastors at Universal Church believe that I'm already cured because they say nothing is beyond God.

Researcher: Would you say that volunteering has helped you to cope with HIV/AIDS?

Participant: Yes, it has although we encounter a number of problems on a daily basis. For example, we feel that some men in the organization dominate us in that we can't even borrow money from the organization while they can. Again they come with their girlfriends to the offices after working hours and we know because they leave used condoms on the floor.

4.5.7 Arrangements for children

4.5.7.1 Disclosure to children

Researcher: Do you have children?

Participant: I have two children. They just know that I'm always feeling sick, the headache; but they don't actually know what I'm suffering from because they are still very young. I don't know what to say to them. The older one heard me one time

when I was speaking with my mum about AIDS and she asked me what it is but I could not respond.

Researcher: I hear that your concern is to do with their age; if they were older, what would you say to them?

Participant: I would just tell them that I'm living with HIV/AIDS. Then it would mean that they would be able to care for me. Even now whenever I'm having a headache, I can see that they worry; perhaps it is because I'm having it almost every day.

4.5.7.2 Welfare of children

Researcher: You said that your children are staying with you and your mother and that she is drinks and shouts all the time. So do you think that she would continue to take care of them when you are no longer able to do so yourself?

Participant: Yes, I think so since even now we are depending on her for shelter and food. There is no one else that I can turn to, so I guess then that it will have to be her.

Researcher: Before I conclude, is there anything that you would like to add?

Participant: No, I think we have covered about all I wanted to say.

Researcher: Thank you for your cooperation.

4.6   Case 5: Diana

4.6.1   Background

Diana was 44-years-old and the sixth of seven children. She lived at Ha-Seoli with her 72 year old mother. She never married and had been a nun before she had a son (10 years). She completed COSC as an adult and worked before volunteering at PASL. She was a survivor of rape.

4.6.2   Transcribed interview

4.6.3   Reactions of participant to diagnosis

Researcher: I would like to thank you for allowing me to interview you. Should you feel uncomfortable or that you want the interview to stop at any time please let me know. When did you know about your status?
Participant: I found out about my HIV positive status on the 15 March 1999.

Researcher: What was your first reaction then?
Participant: In a way, I used to be in denial when I was told about my sickness. That put a great deal of stress on me in a way. I even thought that maybe the doctor didn't do the test properly. Pre-test and post test counselling were not offered. I was just told that shingles was a symptom of AIDS. I took the test and they told me I'm living with this disease; nobody ever showed me my results.

4.6.4   Reactions of family and friends

Researcher: Have you disclosed your status to your family?
Participant: When I found out about my status I decided not to tell my family because I wasn't sure how they would react. I was also not sure how to go about it. My biggest fear was that they would judge me and even mention it whenever we disagree about something. Again I never got married; in fact I used to be a nun but left when I felt I wasn't fulfilled as one. I had thought of confiding in my mum, but then I thought that she would tell my sister-in-law. This would have been a problem

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because we are not on good terms because they feel that I should have married and left my family. I thought that my mum would take it in a bad way because already I had a baby out of wedlock, then I'm diagnosed with HIV/AIDS.

Researcher: Do they still not know about your status?

Participant: It was only in 2000 that I decided to tell my mum, brothers and sisters. At that stage, I had decided to go public about it and I even started teaching people about it and speaking during conferences. So I thought it would be decent if my family heard it from me instead of hearing from somebody else or on the radio for that matter. They did not believe me because there were no signs that suggested that I could be sick. Maybe if I had been sick when I told them, they would have believed me. So it took them a while to get used to the idea that I'm living with AIDS. After some few months, I became very sick and it was only then that I could see from their faces that they saw that I'm sick.

Researcher: You said that you decided to disclose your status publicly; how did people react?

Participant: I remember that when I first went public about my status, I lost some friends and some people used to hate me. Those people wouldn't even communicate with me. After several workshops, some of them changed their minds and realized that anybody can have this disease. So they started asking me for advice, what I did to take care of myself and this encouraged me a lot because it gave me a space to articulate my fears. Most of them were women. On the other hand, there were still people who felt that if I hadn't left the convent, I wouldn't be having it. They went to the extent of suggesting that it is a punishment from God. I was expected to rest and not be active in committees at community level; they just didn't see how an AIDS victim could ever be a leader.

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4.6.5 Concerns of women living with HIV/AIDS

4.6.5.1 Medical experiences

Researcher: You mentioned earlier that you thought that your doctor did not do the test properly, why was that?

Participant: Because even before I took the test, he said he suspected that I had HIV/AIDS. After the test, he asked me how many sex partners I had in the past. He also told me that I did not have much time left. He suggested that I should start making funeral arrangements as soon as possible. You know…I actually believed him. I ca not say shingles was painful as such. It used to be very itchy and it was only when I scratched it that I would start having a severe pain, sometimes I would not even sleep.

4.6.5.2 Heterosexual relationships

Researcher: Have you ever considered how you could have been infected?

Participant: I guess that I can't say exactly who infected me because most men that I was involved with looked healthy. There were these two who started losing weight and were sick all the time. So I should think that maybe I got it from one of them. The other boyfriend died before I knew that I'm sick whereas the other one died after I had discovered. I even went to see him when I heard that he was sick and even asked him whether he knew his HIV status. He wasn't open with me but he said that he didn't care whether he had it or not. At that time he had lost a lot of weight and was in pain. I somehow got a feeling that he knew that he was HIV positive.

4.6.5.3 Violence against women

Researcher: How did that make you feel?

Participant: I wasn't blaming him as such since I have also been raped. I was coming from evening classes; you know I did my COSC when I was already an adult. This person who raped me also cut me on the head and I lost a lot of blood and felt very dizzy. The injury was dressed at the hospital. Sometimes, I think that it must have been that person who infected me.

Researcher: What were your thoughts then after being raped?

Participant: I'm still traumatized by that rape incident. I didn't become pregnant because I was injecting. Apparently, the rapist already had six cases of rape before he raped me. He was not prosecuted because there was no evidence.

4.6.6   Coping strategies

Researcher: How do you cope with your diagnosis?

Participant: I decided to join Positive Action and rather focus on getting well. Sometime in the year 2000, I was included in a vaccine trial, but I became very sick and people who were administering it suggested that I should leave the treatment. At the moment I'm not using any form of treatment and even with that treatment, we had been informed that if we left it then we would die, that we should take them all the time.

Researcher: Would you say that joining Positive Action has helped you?

Participant: Yes, although it also has its disadvantages. The young men in this organization do not consider our age differences; they are very noisy and make nasty comments. I have also observed that most of the work is done by women.

Researcher: You mentioned that you are not taking any form of medication at the moment. So what do you do to boost your immune system?

Participant: At the moment I don't want anything to do with medicines. But I try to look after myself by engaging in protected sex. I have decided to continue having

intimate relationships because I discovered that being with somebody at the level really helps me, especially when I'm having stress. But in some cases we fight about protection, some men do not like a condom. I avoid things like alcohol or to be with somebody who has taken alcohol because I feel that I have to be in control all the time.

Researcher: Apart from engaging in sexual relationships, what else do you do?

Participant: If I am staying at home, I go to church or see some friends. I always tell my friends that they should not lose hope even if they were to live with this disease. I tell them about myself, how I had been told several times that I wouldn't live but I have survived for a number of years now.

6.6.7   Arrangements for children

6.6.7.1 Disclosure to children

Researcher: You mentioned earlier that you never married. What about children do you have them?

Participant: I have one child and he is 10 years of age. He knows about my status and even goes with me to workshops. I also encourage him to speak openly about my sickness.

6.6.7.2 Welfare of children

Researcher: Who do you think will take care of your child when you are no longer able to do so yourself?

Participant: I think in the case when I'm no longer able to care for him, my family will take over, especially my brother.

Researcher: Before we conclude the interview, is there anything that you would like to add?

Participant: I would like to point out that my main concern is with women. I believe that they need to be educated about it and how it can affect their lives. I believe that we have a big role to play in this AIDS era.

Researcher: Thank you very much for your cooperation.

Chapter 5 will present the analysis and discussion of participants' experiences of living with HIV/AIDS and their ways of coping with their status.

CHAPTER 5 – RESULTS AND DISCUSSION

5.1   Introduction

The general objective of the study was to investigate the experiences and coping strategies of women living with HIV/AIDS in Lesotho. This objective was achieved by looking at the participants' reaction to their HIV positive status, the responses of families, friends and the community, and the women's experiences of interpersonal relationships. The study explored the structures that are in place and the personal coping strategies participants have used.

A number of interrelated themes emerged from each interview, which will be discussed in turn: demographic details, experiences of living with HIV/AIDS, concerns of women with HIV/AIDS, coping strategies and arrangements for children. The complex intersections between gender, sexuality and the various oppressions that keep the women interviewed for this study marginalised, silenced and at risk are explored.

Case studies methodology has been criticised as not representative because the researcher only focuses on a few cases. This study is not nationally representative of all Basotho women living with HIV/AIDS and may be seen as an under representation of the reality because there were only five participants. Moreover, the participants could be seen to be in a better position than many other women living with HIV/AIDS by virtue of their access to some form of support at an organisation where they are volunteering. Nevertheless, the study does document the real life circumstances of a section of women living with HIV/AIDS. The study serves as a record of how women infected with HIV/AIDS are responding to the epidemic.

5.2   Demographic details

The ages of participants ranged from 29 to 46 years. Alice was 32 years, Lieta was 40, Lineo was 46, Mary 29 and Diana was 44. All participants had a relatively low level of formal education. Alice completed COSC and studied a dressmaking course before she volunteered at PASL. Lineo did the first year of her studies at National University of Lesotho (NUL) but had to apply for official withdrawal because of her health, and afterwards she joined PASL. Lieta went up to Form D and then went to South Africa in search of a job before volunteering at PASL. Mary did Standard 7 and worked at Positive Health. Diana completed COSC and worked for some time before joining PASL.

Although participants in this study were 29 to 46 years old, the majority of women living with HIV/AIDS in Lesotho are between ages 20 to 39. (Moe, 1998; NASP, 2000). This could mean that older women living with HIV/AIDS are in the minority. All participants in the study had a relatively low level of formal education. This corresponds to findings in South Africa and Lesotho which suggest that women living with HIV/AIDS are mostly uneducated women (Kethusegile et al, 2000; Letuka et al, 1997; Vetten & Bhana, 2001). Regardless of their low level of education, it seems that doing volunteer work helped them to have knowledge about HIV/AIDS.

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Descriptions of participants

Participant	Age	Marital status	Level of education	Religious Affiliation	Occupation	Number of children
Alice	32	widow	High school	Evangelical	Volunteer	2
Lieta	40	Separated	High school	Universal Church	Volunteer	4
Lineo	46	Widow	Tertiary	Born-again Christian	Volunteer	2
Mary	29	Divorced	Primary	Universal Church	Volunteer & Positive Health	2
Diana	44	Never married	High school	Catholic	Volunteer	1

5.3   Reactions to diagnosis

Participants' knowledge of their own HIV status ranged from one year to nine years. Diana went through a period of denial when she first learnt of her positive status. She used denial as a defence mechanism that protected her from facing her positive status in that she tried to convince herself that the doctor had made a mistake. Lineo experienced shock at being diagnosed as HIV positive. This is because she had not expected the results to come back positive. Mary also felt afraid when she was told about her status. She was scared that she was going to die and leave her children. This was perpetuated by a misconception that people living with HIV/AIDS do not live for a long time.

Implicit in the discussions during the interviews is the fact that some women with HIV diagnoses adjust to the process of living with HIV/AIDS better than other do. For instance, Alice and Lieta readily accepted their status and seemed to be in

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control and this assisted them in terms of preserving their mental and physical health. For instance, Lieta already suspected that she could be HIV positive because of symptoms like vaginal thrush, which she observed. As a result, HIV positive results confirmed her suspicions. Alice mentioned that she was already a volunteer before she knew her status. The knowledge about HIV/AIDS helped her to cope better than those who were not informed. What emerged from this study is that the more knowledge women have about HIV/AIDS the better they cope with their HIV positive diagnosis. That is why it is important for the government to encourage women to do volunteer work on HIV/AIDS.

5.4   Deciding whom to tell of their HIV positive status

Although all participants disclosed to their families and friends, they initially, grappled with the question of to whom they can disclose their HIV diagnosis with minimal risk of negative consequences. This suggests that the disclosure of HIV diagnosis raises issues around stigma and isolation. Most participants were selective in deciding to whom to disclose their status. This is because they feared being rejected, wanted to spare loved ones emotional pain and were also concerned about discrimination. For example, Diana and Lineo feared rejection by family and friends. Diana said that she did not tell her family when she first found out about her status because she anticipated that they would judge her. She also wanted to avoid the extreme emotional distress she felt it would cause them. Lieta thought that her parents would regard her as a disgrace because she had separated from her ex-husband. Lineo, a born-again Christian, also anticipated that her friends and people in the community would link her status to extra-marital affairs. These explanations that participants gave for not disclosing their status or postponing to do so suggest that they knew that their communities had internalised the myth that women are to blame for AIDS.

Some children were told that their mothers had HIV/AIDS and were given additional information about the mothers' health, including prognosis of potential death. Participants reported many reasons for disclosing their HIV infection to their children, including wanting to educate their children about HIV, wanting their children to hear it from them, wanting their children to know before they became

very ill, and wanting to be honest with their children (Schrinshaw & Siegel, 2002; Dane, 2000). Of the children who knew their mother's HIV status, all had been told by their mothers and were not asked to keep disclosure secret. Most participants reported a significant increase in their children's understanding of HIV/AIDS, but no significant behavioural changes. These findings are consistent with research on disclosure reporting that the relationships between the mother and children become closer following disclosure (Nashandi, 2002; Schrinshaw & Siegel, 2002). However, these findings contrast sharply with experiences of some mothers, who reported a significant increase in child behaviour problems and a decrease in mother-child relationship quality from pre- to post-disclosure. After disclosure, significantly more positive changes were reported by participants than negative ones. The study revealed that disclosure of HIV has a significant impact on the family in terms of relationship changes and provision of social support.

5.5   Social reactions to HIV infection

5.5.1   Reactions from family members

The informal support system is defined as a close relationship from which women derive social support. As a group, participants' informal support network comprised the family and friends. However, the composition of individual women's support systems varied. Most families supported the participants, both financially and emotionally, and this was important for participants. For example, Alice, Lineo, Mary and Diana reported that their families supported them by providing medication and a balanced diet whenever they could. Diana and Lineo mentioned that their children also supported them. Stigma from family was however also reported. For instance, Lieta reported that her mother and father were in denial when she disclosed her status. They did not support her in seeking health care and excluded her from family affairs. This is consistent with past research on the experiences of stigma by women living with HIV/AIDS in Thailand (Dane, 2000).

Consequently, she felt that she relied more on support from her two male friends than her family. This finding that male friends were available for support is very important because literature on social support for women living with HIV/AIDS has

not explored the role of men as friends, not sexual partners, in the process of support. It also suggests a shift in gender hierarchies because men take on the role of care giving, which is predominantly women's domain. These men's knowledge and experience with HIV/AIDS could be utilised by NGOs to educate other men.

5.5.2   Reactions from community

Isolation by people in their communities was one form of discrimination against women living with HIV/AIDS that was reported. For instance, Diana said that when some friends and people in her village heard about her status, they became hostile to her. Lineo mentioned that some of her friends and her in-laws were not supportive when they found out. Diana also indicated that people in her community were judgemental and less sympathetic towards her. They even said God was punishing her. In her community, HIV/AIDS was regarded as an illness attacking people who violate the moral code, a punishment for sexual irresponsibility (Gilman, 1988; Sontag, 1991). This shows a tendency of judging women living with HIV/AIDS as guilty and therefore deserving of the disease (Dansky, 1994 cited in Goldstein et al, 2003). This attitude reinforced the stereotypes, stigmatisation and isolation of women living with HIV/AIDS (Maja, 2001).

Religious traditions also complicated reactions to HIV/AIDS as was the case in communities where HIV/AIDS was regarded as a punishment from God. This implies that religious organisations are often a source of stigma. It is clear that the social construction of HIV/AIDS shapes the personal circumstances of these women. This tendency to blame the women made participants feel uneasy whenever they disclosed their status.

5.5.3   Reactions of health care providers

Some health care providers played an important role in uplifting the spirits of these women by strengthening the social support resources available to them. For example, Lineo's doctors gave her hope after disclosing her HIV status and emphasised the importance of emotional and physical wellbeing for people living with HIV/AIDS and provided information on nutrition. Alice said that her AIDS

counsellor provided her with information on how to live positively after disclosing her status. Immediately after receiving her results, Mary was introduced by her doctor to an AIDS activist from an organization called Helping Other People Everywhere (HOPE) in South Africa.

However, some doctors tended to be hostile to some participants. For example Diana explained that her doctor asked her about the number of sexual partners she had had. Afterwards, the doctor suggested that she should make funeral arrangements as she did not have much time left. Lieta was told to talk to another patient who had just found out about her HIV positive status. These examples suggest a lack of information about HIV/AIDS. Stigmatisation by health care providers was reported in a number of studies which showed that PLWAs were refused services at clinics (BRIDGE, 2002; Hannan, 2003). Therefore, there is a need to educate health care providers about the referrals of people, who have just learned of their HIV positive status, to counsellors, psychologists and social workers for more information on HIV/AIDS.

5.6   Challenges

The women cited the following challenges that they face on a daily basis: sexual relationships with men, sex after testing HIV positive, access to medical health, disclosure to children, reproductive role. The need for special organisations for women also emerged very prominently in the interviews.

5.6.1   Sexual relationships with men

Alice mentioned that lack of communication, alcohol abuse and male violence against women were some of the problems that she experienced in her marriage. These factors contributed to her vulnerability to HIV/AIDS. For instance, she explained that her husband failed to inform her when he had STDs. In one incidence, he went out and came back drunk, forced himself on her even though he knew that he had sexually transmitted infections. This example illustrates a case where a married woman could not protect herself from the threat of STDs and HIV/AIDS because of physical violence. Past research indicates that there is a

strong relationship between violence against women and HIV/AIDS because violence against women can increase the risk of acquiring HIV infection (Strebel, 1995; Vetten & Bhana, 2001, Nashandi, 2002, McFedden, 2003).

It is clear that inequality between men and women when negotiating sexual relationships makes women vulnerable to HIV/AIDS. Women's roles as wives, and the subordination of their sexuality to that role, deprive them of their right to control their own bodies. The issue of sexual choice for women has been raised by a number of feminist scholars (Chowbhury, 1991; Miles, 1992; McFadden, 2003) who agree that sexual freedom can transform the social spaces of women.

Some women in this study were survivors of rape by strangers. Even beyond the private sphere of the home men use violence to control women's bodies (Strebel, 1995; McFadden, 2003) to prove their manhood. Rape is used as a weapon against both single and married women. This suggests that some men view women's bodies as completely unimportant. One idea for future research would be to explore the motives of husbands or male partners who use violence against women to gain sexual access to women.

5.6.2 Women as caregivers

Women's roles as caregivers expose them to life threatening situations when partners become ill (Strebel, 1995; McFadden, 2003). For example, Alice was in a situation where she had to care for an HIV infected partner, but she did not know about his status. As a result, she thought that she could have acquired HIV infection as she was nursing him. She explained that she learned about her status after he had died. She thought that her husband got infected through extra-marital affairs. Furthermore, she had to deal psychologically and emotionally with death of partner.

5.6.3 Sex after testing HIV positive

Testing HIV positive raised many issues for participants. However, all participants were able to work through these issues and reconstruct a sex life after testing positive. Alice, Lieta and Lineo decided to be celibate after testing positive. Some of the reasons for being celibate were loss of interest in sex, anger and distrust of men and the desire to focus on their own lives separate from men. Anger was mentioned by participants who stated that their partners infected them. This anger resulted in distrust of men. Consequently, they stated that they did not miss relationships and sex with men.

HIV/AIDS was not a factor in their decision to abstain from sex; rather their reasons for adopting celibacy were based on emotions and fear (Siegel & Schrisma, 2003). From their narratives, it was clear that they did not plan to be with a man in the future. This means that these participants socially isolated themselves and their resentment was generalised to all men. Past research has shown that celibacy was prevalent in men and women following diagnosis of HIV/AIDS (Siegel & Schrisma, 2003; Adam & Sears, 1994). The reasons that the participants gave for their choice call for future research to examine in detail the adoption of celibacy among women living with HIV/AIDS.

Some participants reported their fear of transmitting HIV to their partners, commented on the complexities of negotiating safer sex, and explained changes in sexual desire linked to their health status. Mary and Diana disclosed their status to their partners and developed ways of initiating safer sex. They expressed fear of transmitting HIV/AIDS to their partners. However, adopting safer sex was not easy for them. For instance, Mary remarked that her boyfriend was in denial and even said they should go for HIV tests together. This shows that the responsibility for safe sex fell more heavily on them as women living with HIV/AIDS. This responsibility extended to protecting partners willing to expose themselves to HIV infection. The participants attributed men's unwillingness to use condoms to ignorance. This is consistent with findings that suggest that safe sex has been regarded as the responsibility of women, even though they have little power in this

domain (Strebel, 1995b). As a result, radical feminists have called for greater equality between men and women to enable women to adopt alternative sexual practices, like non- penetration and masturbation (Miles, 1992).

5.6.4 Accessing medical care

Gaining access to adequate medical care was a pressing concern for most participants. HIV/AIDS retroviral treatments were beyond the reach of these women (Maja, 2001) and this resulted in minimal care for them (Strebel, 1995). Traditional healers provided primary health care for them. This was exacerbated by the fact that four participants were not formally employed. All participants only benefited from income-generating activities, which were done at Positive Action Society Lesotho (PASL). The participants received R10 on a daily basis that they used for lunch and sometimes transport or the clinic.

5.6.5 Disclosure to children

Most of the children were not aware of their mother's HIV status; however, most mothers planned to disclose eventually. Some of the reasons participants avoided disclosure is their fear of the negative impact on the child and family that the stigma associated with AIDS can bring, believing that their children were too young or immature, and that it would be too much of an emotional burden for their children (Bury, 1994, Dane, 2000). What was interesting was that when these women worried, their worry was more likely to be for their children than for themselves.

5.6.6 Economic circumstances

Although all participants did not want more children, they thought that their poor economic circumstances could be one of the reasons influencing their decisions not to have more children. For instance, they said they were already struggling financially with the children they had. This shows that the participants did not think that their status influenced their decision not to have children in any way.

5.6.7   Sexism in NGOs

The participants complained that PASL did not contribute to reducing their vulnerability within the organisation. This means that PASL did not integrate an awareness of how gender inequality could contribute to subordination of these women. As a result, participants called for an establishment of special HIV/AIDS organisations that could increase their participation in decision making. Some of the reasons that they cited were: they were mixed with younger men who did not give them space and respect as older women; men generally dominated them in that women did all the work and they could not borrow money from the organisation, yet some men could. They also complained that some men use the offices at the organisation to have sex with younger girls. The women's tolerance of these circumstances shows the domination of male power in organisations that are meant for PLWAs. This calls for structural changes in order to prevent the marginalisation of women.

5.7   Coping strategies

All participants explained that they used several strategies to cope with their status. They used social networks to share information and experiences with people living with HIV/AIDS, and they relied on medication and religion to cope with HIV/AIDS.

5.7.1   Social networks

The findings indicate that women rely on other women who are living with AIDS and on NGOs catering for people living with HIV/AIDS to cope. As a way of coping they reported a number of networks and groupings formed with the aim of sharing experience and information among women living with the virus. For example, Lineo was involved in projects which were meant for people living with HIV/AIDS to help them generate money and live positively. She also presented educational programmes on AIDS on radio. For her, helping others gave her a sense of purpose. The participants found that sharing their experiences with others was

helpful, comforting and healing. This confirms the literature reviewed with respect to the argument that social support and the presence of confiding relationships are associated with low levels of psychological distress (Kelly et al, 1993; Catal'an, 1999; Hayes et al, 1998; Parry, 1990).

5.7.2   The need to take control of one's health

All participants repeatedly expressed the need to take control of their own health. Taking control meant seeking medical treatment. Although all participants accepted the value of some medical treatments, most participants could not afford them. As a result, they used alternative medicines. For instance, Alice and Lieta used traditional medicines because they believed they helped them with depression and weight loss.

Taking control also meant taking responsibility to follow a healthy life style, getting adequate rest, avoiding drugs and eating well. Alice adopted a positive outlook as a way of dealing with her status. She identified the acceptance of her status as the most important decision and looked after herself and did not compare herself to other people. Mary used resting as one of her coping strategies. Diana avoided alcohol and partners who took alcohol. This is consistent with past research that has shown that maintaining a positive self image is important for PLWAs. Siegel and Krauss' study of women living with HIV/AIDS reported that they avoided risky behaviour like taking drugs and unprotected sex and adopted healthy lifestyles (Siegel & Krauss, 2000).

5.7.3   Religion

All participants said that they were Christians. Lineo had done Christian counselling and counselled other people who were living with HIV/AIDS. All of them said that praying helped them a lot, especially when they were depressed. Diana said she attended prayer meeting and also prayed a lot on her own. Mary said she was getting a lot of support from spiritual leaders at Universal Church. Overall, they all believed that God protected them. Religion played an important part in participants' lives after they learned that they were living with HIV/AIDS. All

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participants engaged their religious leaders on issues of HIV/AIDS. This has been confirmed by other studies (Nashandi, 2002; Siegel, 2001; Dworzanoski, 2002), which reported that women returned to their religious roots after being diagnosed as HIV positive.

5.7.4 AIDS counselling

Alice mentioned counselling as the strategy that she used to cope with her status. This counselling component was established within the organisation to provide support for PLWAs and it was provided by village-based counsellors. AIDS counselling was also used by other participants as a coping strategy. A number of studies have suggested that counselling can help people living with AIDS to make informed decisions and to cope better with their status (UNAIDS Technical update, 1997; Dworzanoski, 2002).

5.8   Arrangements for children

Alice had two children, a 7-year-old son and 9-year-old daughter; Lineo had two adult children; Lieta had four children, three sons (20, 17, 13 years) and a daughter who was 10 years; Mary had two daughters, one was 13 years while the other one was 11 years and Diana had a 10-year-old son.

Planning for the future should include provisions for children's welfare. Generally, all participants avoided the subject of death for fear of becoming upset. As an example, Lieta explained that she did not want to think about death and the future arrangement for her children. All participants stated that facing death and making future arrangements for their children with family members was difficult for them. Diana, Mary, Alice and Lineo reported that they had made future arrangements for their children, while Lieta had not made any arrangements. They all feared that their own dying process would be a burden to their families. It is clear that families were trusted with future care of children even though discussions on the plans about their children had not taken place. These findings validate the cultural value of family support in Lesotho.

5.9 Conclusion

Gender specific violence, such as rape, emotional abuse and physical violence, contribute to the risk of acquiring STDs and HIV/AIDS. Negative reactions to HIV diagnosis were predominant although acceptance of HIV positive status was also adopted. Stigmatisation by family, friends and the community impacted negatively on the women. Helpful behaviour, like financial and emotional support, were mostly provided by family, friends and PASL (Hays et al, 1998, Nashandi, 2002; Parry, 1990).

Finances, disclosure and negotiating safe sex were some of the challenges that these women faced. They were however not silent victims in this struggle against HIV/AIDS. For example, they demonstrated great agency and coping strategies. Some became involved in media projects and all participants relied on formal and informal networks and religion to cope with their HIV positive status. Although some had been exposed to sexual violence, they joined an NGO catering for PLWAs in order to access information on how to live positively with their status. With an increasing numbers of women living with HIV/AIDS, there has been a greater focus on women's empowerment economically and socially. In Lesotho, this was evident in PASL running income-generating projects. All the participants were concerned about the welfare of their children since four of them were not employed. However, they all felt they can rely on their families to care for the children when they died.

5.10 Recommendations

A number of suggestions based on the findings of the study should be made, to help HIV positive women cope with the disease. This study may serve as the basis for providing other intervention or social actions in the future. The results will be beneficial to NGOs dealing with HIV/AIDS to assist women in dealing with their HIV positive status. The following recommendations can be adapted to effectively intervene and support women with HIV diagnosis.

- There is a need to address the issues of power, human rights and socio-cultural expectations in an attempt to address HIV/AIDS. Definitions of masculinity and femininity should be questioned.
- There is a need to question whether programmes address the specific needs of women and men. NGOs need to revisit their goals, strategies and resource allocations from a gender perspective.
- There is a need for financial and medical resources to address the issue of HIV for women.
- It is important for health care professionals to recognise their potential to intervene when approached by HIV women.
- People in different communities need to be educated in overcoming the myths about HIV/AIDS and women.
- AIDS prevention programmes aimed at women who are at risk of contracting HIV/AIDS should not decontextualise risk factors from the women's social and economic environment.
- There is a need for more research to address the issue of women and AIDS because it has not been explored sufficiently in Lesotho.

References

Abdool, K. Q. (1998). Women and AIDS: The Imperative for a Gendered Prognosis and Prevention Policy. *Agenda.* 39:15-25.

Abdool, K. Q, Abdool, K. S, Signh, B, Short, R. & Nqxongo, S. (1992). Seroprevelence of HIV Infection in Rural South Africa. *AIDS.* 6: 1535-1539

Acker, J, Barry, K, & Esseveld, J. (1991). Objectivity and Truth: Problems of Doing Feminist Research. In Fonow, M A & Cook J. *Beyond Methodologies: Feminist Scholarship as Lived Research.* Bloomington: Indiana Press.

Adam, D. B & Sears, A. (1998). Identifying Helpful Behaviours of Loved Ones: the PWA's Perspective. In Bor, R & Elford, J. *The Family and HIV Today.* London: Cassell.

Amaro, H. (1995). Reproductive Choice in the Age of AIDS: Policy and Counselling Issues. In Squire, C. *Women and AIDS: Psychological Perspectives.* London: Sage Publications.

Aronson, J. (1994). A Pragmatic View of Thematic Analysis. *The Qualitative Report.* 2 (1). Online. www.nova.edu/ssss/QR/BackIssues/QR2-1/ aronson.html.

Babbie, E. (2001). *The Practice of Social Research.* USA: Wadsworth Thompson Learning.

Baca, Z, M. (1979). Field Research in Minority Communities: Ethical, Methodological, and Political Observations by an Insider. *Social Problems.* 27.2: 209-19.

Baden, S. (1992). *Women, HIV/AIDS and Development: Towards Gender Appropriate Strategies in South East Asia and the South Pacific.* Asia: Institute of Development Studies.

Baylies, C. (2000). Perspectives on Gender and AIDS in Africa. In Baylies, C, Janel, B. & The Gender and AIDS Group. *AIDS, Sexuality and Gender in Africa: Collective Strategies and Struggles in Tanzania and Zambia*. London & New York: Routledge.

Bell, J. (1993). *Doing Your Research Project: A Guide for First-Time Researchers in Education and Social Science*. Buckingham: Open University.

Beoku-Betts, J. (1994). When Black Is Not Enough: Doing Field Research among Gullah Women. *NWSA Journal*. 6(3):413-433.

Berer, M. & Ray, S. (1993). *Women and HIV/AIDS: An International Resource Book*: London: Pandora Press.

BRIDGE. (2000). *Gender and HIV/AIDS*: Overview report. Sussex: Institute for Development Studies.

Bury, J. (1994). Women and HIV/AIDS: Medical Issues. In Doyal L, Naidoo J & Wilson T. *AIDS: Setting a Feminist Agenda*. London: Taylor and Francis Publishers.

Carr, W. & Kemmis, S. (1983). *Becoming Critical: Knowing Through Action Research*. Canada: Deakin University.

Carson, R. C. & Butcher, J. N. (1992). *Abnormal Psychology and Modern Life*. New York: Harper Collins.

Charmaz, K. (1995). Grounded Theory. In Smith, J. A., Hare, R. & Langenhoven, L. *Rethinking Methods in Psychology*. London: Sage.

Catal'an, J. (1999). *Mental health and HIV Infection: The Psychological and Psychiatric Aspects*. London: UCL Press Limited.

Chowbhury, A. (1991). Reproductive rights of women and AIDS. *Journal of the Indian Medical Association.* 89:185- 186

Collins, J. & Rau, B. (2000). *AIDS in the Context of Development.* Geneva: United Nations Research Institute for Social Development (UNRISD) & UNAIDS.

Connell, R. W. (1995) *Masculinities*, Oxford: Polity Press.

Crossley, M. L. (1998). Women Living with a Long-Term HIV Positive Diagnosis: Problems, Concerns and Ways of Ascribing Meaning. *Women's Studies International Forum.* 21(5):521-533.

Dane, B. (2000). Disclosure: The Voices of Thai Women Living with HIV/AIDS. *International Social Work.* 45 (2): 185-204.

Davies, L. (1994). *Qualitative Approaches in Educational Research.* Birmingham: University of Birmingham.

De Capua, J. (2003). *Voice of America: AIDS in Lesotho.* Washington: UTC.

Denzin, N. K. (1994). *Handbook of Qualitative Research.* Thousand Oaks: Sage.

Devault M. L. (1999a). On Authorship and Authority in Feminist Writing. *Liberating feminist Method and Social Research.* Philadelphia: Temple University Press.

Devault M. L. (1999b). Talking Back to Sociology: Distinctive Contributions of Feminist Methodology. *Liberating feminist Method and Social Research.* Philadelphia: Temple University Press.

Dorn, N, Henderson, S & South N. (1994). *AIDS: Women, Drugs and Social Care.* London: Falmer Press.

Doyal, L. (1994). HIV and AIDS: Putting Women on the Global Agenda. In Doyal, L, Naidoo, J & Wilson, T. *AIDS: Setting a Feminist Agenda.* London: Taylor and Francis Publishers.

Dowling, S. (1994). Women Have Feelings Too: The Mental Health Needs of Women Living with HIV Infection. In Doyal, L, Naidoo, J & Wilson T. *AIDS: Setting a Feminist Agenda*. London: Taylor and Francis Publishers.

Feldman, R. & Maposhere C. (2000). Voices and Choices: A Participatory Research and Advocacy Study of Reproductive Health and Rights of HIV Positive Women in Zimbabwe. *The XIII International AIDS Conference*, Durban, South Africa, July 9-14.

Fester Gertrude. (2002). *Women Writing for their Rights*. Online. http://www.wworld.org/programs/regions/africa/gertrude_fester.htm

Fouche, F. (1993). Nigerian Conference Revisited. *Agenda*. 16: 39-41.

Funani, L. (1993). The Great Divide. *Agenda*. 16: 55-57.

Foreman, M. (1999). *AIDS and Men: Taking Risks or Taking Responsibility*. London: The Panos Institute and Zeb Books.

Gilman, S. L. (1988). AIDS and Syphilis: The Iconography of Disease. In Crimp, D. (Eds). *AIDS: Cultural Analysis, Cultural Activism*. Cambridge: Massachusetts Institute of Technology.

Goldstein, N, Pretorious, H. G & Straurt, A. D. (2003). The Social Construction of HIV/AIDS. *Health South African*. 8(2): 14-22.

Gouws, A. (1993). The Angry Divide. *Agenda*. 16: 67-70.

Gupta, G, R. & Weiss, E. (1993). Women's Lives and Sex: Implications for AIDS Prevention Culture. *Medicine and Psychiatry*. 17 (4): 399-412

Hakim, C. (1987). *Research Design*. London: Allen & Unwin Inc.

Hancock, B. (1998). *An Introduction to Qualitative Research*. University of Nottingham: Trent Focus Group.

Hannan, C. (2003). *Women and HIV/AIDS*. New York: Division for the Advancement of Women.

Hays, R. B, Magge, R. H. & Chauncey, S. (1998). Identifying Helpful Behaviours of Loved Ones: The PWA's perspective. In Bor, R & Elford J. *The Family and HIV Today*. London: Cassell.

Hendricks, C & Lewis, D. (1994). Voices from the Margins. *Agenda*. 20: 61-75.

Henwood, K. L. & Pidgeon N. F. (1993). Qualitative Research ad Psychological Theorizing. In Hammersley, M. *Social Research: Philosophy, Politics and Practice*. London: Sage Publications.

Holland, J, Ramazanoglu, C, Scott, S. & Thomson, R. (1994). Desire, Risk and Control: The Body as a Site of Constestation. In Doyal, L, Naidoo, J & Wilson, T. *AIDS: Setting a Feminist Agenda*. London: Taylor and Francis Publishers.

Jayaratne, T, Epstein, J. & Stewart, A. (1991). Quantitative and Qualitative Methods in the Social Sciences: Current Feminist Issues and Practical Strategies. In Fonow, M. A. & Cook, J. *Beyond Methodologies: Feminist Scholarship as Lived Research*. Bloomington: Indiana Press.

Kelly, J, Murphy D, Bahr G, Stevenson, L, Brasfield, T, Bernstein, B. & St Lawrence, J. (1993). Factors associated with severity of depression and high risk sexual behaviour among persons diagnosed with Human Immunodeficiency Virus (HIV) Infection. *Health Psychology*. 8:221-238.

Kethusegile, B, Kwaramba, A. & Lopi Barbara. (2000). *Beyond Inequalities: Women in Southern Africa*. Zimbabwe: Cannon Press

Kitzinger, J. (1994). Visible and Invisible Women in AIDS Discourses. In Doyal, L, Naidoo, J. & Wilson, T. *AIDS: Setting a Feminist Agenda*. London: Taylor and Francis Publishers.

Kohler, R. C. (1991). When Gender Is Not Enough: Women Interviewing Women. In Lorber, J. & Farrell, S. A. *The Social Construction of Gender*. Newbury Park: Sage Publications.

Kolawole, M. (1997). *Womanism and African Counsciousness*. Africa World Press.

Kuyoh, M. & Best K. (2001). HIV-positive Women Have Different Needs. *Network* 20(4). Online. **http://biblioline.nisc.com/scripts/login.dll?login**

Kvale, S. (1996). *Interviews: An Introduction to Qualitative Research Interviewing*. London: Sage.

Lacey, A. & Luff, D. (2001). *Qualitative Data analysis*. University of Sheffield: Trent Focus Group.

Laird, S. (2001). AIDS and Gender: The African Reality. *Social Work*. 37(2): 122-127.

Leask, L, Elford, J, Bor, R, Miller, R. & Johnson, M. (2003). Selective Disclosure: A Pilot Investigation into Changes in Family Relationships Since HIV Diagnosis. *Journal of Family Therapy*. 19(1): 59-69.

Letuka, P, Matashane, K. & Morolong, B. L. (1997). *Beyond Inequalities: Women in Lesotho*. Zimbabwe: Cannon Press.

Lincoln, Y. (1985). Establishing Trustworthiness. *Natural Inquiry*. New Park: Sage.

Lindlof, T. R. (1995). *Qualitative Communication Research Methods*. Thousand Oaks: Sage.

Lorber, J. (1997). *Gender and the Social Construction of Illness*. London: Sage Publications.

LoveLife. (2001). *Impending Catastrophe Revisited: An Update on the HIV/AIDS Epidemic in South Africa*. South Africa: The Henry J Kaiser Family Foundation.

Lutalo, T, Kidugavu, M & Wawer, M. (2000). Contraceptive Use and HIV Testing and Counselling in Rural Rakai District, SW Uganda. *The XIII International AIDS Conference*, Durban, South Africa, July 9-14.

Maja, N. (2001). HIV/AIDS: Traditional Healers, Community Self-assessment and Empowerment. *Indigenous Knowledge (IK) Notes*. 37:1-3.

Mama, A. (1995). *Beyond the Mask: Race, Gender and Subjectivity*. London: Routledge.

Manchester, J. & Mthembu, P. (2002). *Positive Women: Voices and Choices. Brief*. Brighten: University of Sussex.

Maqaqi, S. (1996). Who Theorizes? In *South African Feminisms: Writing, Theory and Critism, 1990-94*. London and New York: Garland Publishing Inc.

May, T. (1993). Interviewing: Methods and Process. *Social Research: Issues, Methods and Process*. Buckingham: Open University Press.

Maynard, M. (1994). Methods, Practice and Epistemology: The Debate about Feminism and Research. In Maynard, M. & Purvis, J. (Eds). *Researching Women's Lives from a Feminist Perspective*. London: Taylor & Francis Ltd.

Meursing, K. & Sibindi, F. (1999). *Condoms, Family Planning and Living with HIV/AIDS in Zimbabwe*. (Online). Available
www.hivnet.com/genderaids

Miles, L. (1992). Women, AIDS, Power and Heterosexual Negotiation: A Discourse Analysis. *Agenda*. 15: 14-27

Moe, A. M. (1998). *AIDS Epidemiology in Lesotho*. Lesotho: Ministry of Health and Social Welfare.

Mouton, J. (1996). *Understanding Social Research*. Pretoria: Van Schaik Publishers.

Mutangadura, G. B. (2001). Women and AIDS in Southern Africa: The Case of Zimbabwe and its Policy Implications. *Jenda: A Journal of Culture and African Women Studies*. 1 (2): http//www.jendajournal.com/jenda/vol1.2/toc1.2.htm

Nashandi, J. C. N. (2002). *Experiences and Coping Strategies of Women Living with HIV/AIDS: Case Study of Khomas Region Namibia*. Unpublished Masters Thesis. Cape Town: University of the Western Cape.

National AIDS Strategic Plan (NASP) 2000/2001/2003/2004. (2000). *A Three-Year Rolling Plan for the National Response to the HIV/AIDS Epidemic in Lesotho*. Lesotho: Government of Lesotho.

Neuman, L. W. (1997). *Social Research Methods: Qualitative and Qualitative Approaches*. London: Allyn and Bacon.

Ndlela, S. (2002). The AIDS Widows. *True love*. 283: 123-124

Ninan, A. (2003). Without My Consent-Women and HIV-Related Stigma in India. *Population Référence Bureau*. Online. http://207.86.25.61/scripts/hl.exe?13944118|5C4F6D42454A7C53_1&URL=http:// www.prb.org/Template.cfm?Section=PRB&template=/ContentManagement/Conten tDisplay.cfm&ContentID=8278^~!netscape=0

Olley, B. O. (2003). *Psychoimmunology and HIV/AIDS: Implications for Care in Women in Nigeria*. Cape Town: MRC Research Unit on Anxiety and Stress Disorders.

O'Sullivan, S. (2000). Uniting Across Boundaries-HIV Positive Women in a Global Perspective. *Agenda*. 44: 25-31

Owen, J. (1996). Childish Things: Men, Ageing and Violence. In Pilcher, J. & Coffer, A. *Gender and Qualitative Research*. (Eds). United States: Avebry.

Parry, J. K. (1990). *Social Work Practice with the Terminally ill*. United States: Charles Thomas Publishers.

Phoenix, A. (1994). Practising Feminist Research: The Intersection of Gender and 'Race' in the Research Process. In Maynard, M. & Purvis, J. (Eds). *Researching Women's Lives from a Feminist Perspective.* London: Taylor & Francis Ltd.

Positive Action Society Lesotho. (2003). Online. wwwposite-action.org/std/hivlesotho_en.php

Reinwick, N. (2002). The Nameless Fever: The HIV/AIDS Pandemic and China's Women. *Third World Quarterly.* 23(2): 377-393.

Richardson, D. (1994). AIDS: Issues for Feminism in the UK. In Doyal L, Naidoo J & Wilson T. *AIDS: Setting a Feminist Agenda.* London: Taylor and Francis Publishers.

Rivers, K. & Aggleton, P. (1999). *Men and the HIV Epidemic, Gender and the HIV Epidemic.* New York: UNDP HIV and Development Programme.

Rweyemamu, C. (1999). Sexual Behaviour in Tanzania. In Foreman M. *AIDS and Men: Taking Risks or Taking Responsibility.* London: The Panos Institute and Zeb Books.

Schoepf, B. (1991). Ethics, methodological and political issues of AIDS research in Central Africa. *Social Science and Medicine*, 37(11). 1401-1413.

Secure the future: AIDS in Africa. (2002). Online. http://www.securethefuture.com/aidsin.data/aidsin.htm

Siegel, K. (2001). Women with HIV/AIDS Described Several Forms of Positive Change Resulting from their Illness. *Qualitative.* 126 (4). Online. http://www.evidencebasedmursing.com

Siegel, K. & Schrimshaw, E. W. (2003). Reasons for the Adoption of Celibacy Among Older Men and Women Living with HIV/AIDS. *The Journal of Sex Research*. 40(2): 189-200.

Seidel, G. & Coleman, R. (1999). Gender, Disclosure, Care and Decision Making in KwaZulu Natal, South Africa: A Pilot Programme Using Storytelling Techniques. In Davies, Peter; Aggleton, Peter and Hart, Graham. *Families and Communities Responding to AIDS*. London: UCL Press Limited.

Silverman, D. (2001). *Interpreting Qualitative Data: Methods of Analysing Talk, Text and Interaction*. London: Sage Publications.

Shaffir, W. B. (1991). Managing a Convincing Self-Presentation: Some Personal Reflections on Entering the Field. In Shaffir, W. B. & Stebbins, R. A. *Experiencing Fieldwork: An Inside View of Qualitative Research*. London: Sage Publications.

Smaling, A. (1992). The Pragmatic Dimension: Paradigmatic and Pragmatic Aspects of Doing a Qualitative or Quantitative Method. *Quality and Quantity*. 20:233-249.

Smith, J. A. (1995). Semi-structured Interviewing and Qualitative Analysis. In Smith, R. H. & Van Langenhove, L. (Eds). *Rethinking Methods in Psychology*. London: Sage.

Smith, J. K. (1993). Quantitative versus Qualitative Research: An Attempt to Clarify the Issue. *Educational Research*. 12: 6-13.

Smith, D. E. (1987). Women's Perspectives as a Radical Critique of Sociology. In Harding S. (Eds). *Feminism and Methodology*. Bloomington: Indiana University Press.

Sondag, S. (1991). *Illness as Metaphor*. New York: Penguin.

Steinberg, M, Johnson, S, Schierhout, G. & Ndegwa, D. (2002). *Hitting Home: How Households Cope with the Impact of the HIV/AIDS Epidemic.* California: The Henry J. Kaiser Family Foundation.

Stillwagon, E. (2001). AIDS and Poverty in Africa. *The Nation.* 22-25.

Strebel, A. (1995a). Whose epidemic is it? Reviewing the Literature on Women and AIDS. *S.-Afr. Tydskr. Sielk.* 25 (1): 12-19.

Strebel A. (1995b). Focus Groups in AIDS Research. *Journal of Community and Health Sciences.* 2(2):59-69.

Sy, E. (2001). *Gender, HIV/AIDS and Human Security.* Online. http://www.un.org/womenwatch/daw/csw/sy2001.htm

Tallis, V. (1998) AIDS is a Crisis for Women. *Agenda.* 39: 6-14.

Terre Blache, M. & Durrheim, K. (1999). *Research in Practice: Applied Methods for the Social Sciences.* Cape Town. University of Cape Town Press.

UNAIDS. (2001a). *HIV Infection in Women.* Online. www.niaids.nih.government/factsheets/womenhiv.htm

UNAIDS. (2001b). *World AIDS Campaign Fact sheet.* Online. www.unaids.org

UN Division for the Advancement of Women. (2000). *The HIV/AIDS Pandemic & its Gender Implications.* Namibia: Windhoek

UNIFEM. (2000). *Gender and HIV/AIDS: Women's Human Rights.* Online. www.uniferm.undp.org/hiv_aids/hiv_facts.html

UNIFEM-SARO. (2002). *Gender and HIV/AIDS in Zimbabwe : A Community Based Research.* Zimbabwe: Cannon Press.

Vetten, L. & Bhana, K. (2001). *Violence, Vengeance and Gender: A Preliminary Investigation into the Links Between Violence Against Women and HIV/AIDS in South Africa*. South Africa: Centre for the study of violence and reconciliation.

White, A. C. (2001). *The Gender Dimensions of HIV/AIDS*. Bridge Town: World Bank Institute.

WHO. (2000). *Human Rights, Women and HIV/AIDS*. (Online). www.who.int/inf-fs/en/fact247.html

Willig, Carla. (2001). *Introducing Qualitative Research in Psychology: Adventures in Theory and Method*. Buckingham: Open University Press.

Wilson, T. (1994). Silences, Absence and Fragmentation. In Doyal, L, Naidoo, J. & Wilson, T. *AIDS: Setting a Feminist Agenda*. London: Taylor and Francis Publishers.

Woods, M. & Trexler, C. J. (2001). Linking Interpretative Theory to Practice: Examining an Underused Research Tool in Agricultural Education. *Journal of Agricultural Education*. 42 (2): 68-78.

Wolcott, H. F. (I994). *Transforming Qualitative data: Description, Analysis, and Interpretation*. Thousand Oaks, CA: Sage.

APPENDIX A: Consent to be a research participant

Mahlao, Judith Diaho, a researcher from the University of Stellenbosch in South Africa is conducting a study on "Experiences and Coping Strategies of Women Living with HIV/AIDS Diagnosis: A Case Study of Maseru, Lesotho".

If I consent to participate in this study, I understand that:

❖ I will be interviewed.

❖ The interview will be tape-recorded. The tapes will be destroyed when the study is completed. In the interim, only the researcher and the transcribers will hear the tapes. They will never be played publicly.

❖ My participation in the interview is entirely voluntary. I may at any time refuse to answer a question or stop the interview without any consequences to me.

❖ I may choose to have my identity kept confidential in any report, article, or text, which results from this study. I will indicate to Mahlao Diaho my choice to have my identity kept confidential at the beginning of the interview. I may decide at a later date to keep my remarks confidential as well. I will then contact Mahlao to inform her of my decision.
(+27-0839667819/ +266-88710190; Mahlao@mailfly.com)

❖ There may be some risk to me- psychologically, emotionally, perhaps physically- in talking about the subject of HIV/AIDS

❖ The benefits of participation are indirect, that is, further understanding of HIV/AIDS may help to protect women.

❖ The interview and the products of the research are the sole property of the researcher.

I understand the conditions of my participation in this study.

I voluntarily agree to participate.

Signature ……………………..

Date …………………………

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APPPENDIX B: Demographic questionnaire

Strictly confidential

1. District: Maseru

2. Residential area……………………………………………………………

3. Age (tick one only)

15-20	
21-25	
26-30	
31-35	
36-40	
41+	

4. Marital status (tick one only)

Never married	
Married	
Co-habiting	
Divorced	
Separated	
Widowed	

5. Levels of education (tick one only)

None	
Primary	
Secondary	
Tertiary	

If primary, secondary or tertiary specify…………………………………….

6. Are you employed? (Tick one only)

Yes ☐   No ☐

If yes specify……………………………………………………………………….

7. Do you have children?

Yes ☐   No ☐

If how many children do you have?..