

EXPERIENCES AND COPING STRATEGIES OF WOMEN LIVING  
WITH HIV/AIDS: CASE STUDY OF KHOMAS REGION, NAMIBIA

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## KEY WORDS

Namibia

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Coping

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Reproductive-role

Violence

Socio-cultural



## DEDICATION

This study is dedicated to all the women who are living with HIV/AIDS in Namibia,  
and those supporting and caring for them.

## ABSTRACT

This study focuses on the impact of HIV/AIDS on women in Namibia. Namibia, with a population of only 1.7 million people, is ranked as the seventh highest country in the world in terms of HIV/AIDS infections. The percentage of women living with HIV/AIDS in Namibia accounts for 54 % of the total number of 68 196 people in the country living with the virus. Women are also diagnosed with the disease at a younger age (30) in comparison to their male counterparts (35 years). Despite their needs, women living with HIV/AIDS bear a triple burden of caring for those living with HIV/AIDS, caring for themselves and coping with the responses to their infection. There are few focused intervention strategies to support and care for women living with HIV/AIDS in Namibia.

The review indicates that women are in most cases shocked when they find out about their infection and experience economic, emotional, physical, social and spiritual difficulties as they often have little or no form of support or have not disclosed their status in order to enlist support from friends or family. The literature ascribes these responses to be contributed by the blame women experience at a personal, societal and program level. According to the literature women's coping with HIV/AIDS is influenced by socio-cultural expectations and especially exacerbated by the reproductive demands in the African context as motherhood is accorded social status and value. Absence and awareness of formal and informal support systems also makes it difficult for women to enlist support from organizations. Violence as a consequence of HIV infection further emerged to act as a barrier in terms of disclosure, enlisting support and negotiating safe sex practices. The primary concern for women living with HIV/AIDS was found to be care and survival of their children.

The aim of this study is to explore the experiences and coping strategies of a group of women living with HIV/AIDS in Namibia. The study utilized qualitative research methods. The data was collected through 2 focus group discussions with a total of 12 women in the Khomas region, between the ages of 15 to 49 living with HIV/AIDS. The in-depth interviews were held with 5 key informants drawn from institutions working with HIV/AIDS issues in Namibia. Qualitative thematical analysis was used to analyse and interpret the data.

Based on the findings of the study, it is evident that the participants are mostly concerned about the future and care of their children. They indicate that social and cultural expectations, violence as a consequence of their infection, lack of social and personal support and skewed gender relations are major barriers to their ability to cope adequately with their illness. Despite the presence of HIV/AIDS in the country for 11 years, it appears that HIV/AIDS is still highly stigmatized, with women often being blamed for the spread of the disease. Due to the stigmatization and negative responses from close family members and society as a whole, participants experience, among others, feelings of loneliness, anger, anxiety and depression. As a result, they are afraid to enlist support by disclosing their status, fearing abandonment and rejection by their partners, family and society, as well as violent reactions from partners if they inform them (partners) of their HIV status. It was also found that there are misconceptions of being pregnant as women seek social validation and acceptance through motherhood as a result of social or family pressures. However the misconception surrounding pregnancy can also be ascribed to the announcement of the mother-to-child-transmission programme by the Ministry of Health and Social Services early this year (2002).

The findings of the study further confirm and found that coping strategies of women in Namibia were primarily influenced by socio-cultural expectations. Women cope better at organizational level than personal levels. At the same time women's willingness to cope with the disease was found to be dependent on male partners cooperation as disclosure of a persons status could be accompanied by violence. The main coping strategies utilized are support groups and religious solace, as rejection or blame of infection is not experienced. Support systems have also been found to be more prevalent at organizational than personal levels as family members have in most cases ostracized persons living with the virus. Other participants have however experienced support at personal levels especially from grandmothers in the form of childcare.

The study makes a number of recommendations, among others the inclusion and education of men in reproductive health issues, as it will encourage shared responsibility. Women and people living with HIV/AIDS should be educated about the services and support systems available including positive aspects of utilizing

support services. Marketing strategies of HIV/AIDS issues thus need to be restructured in order to reach all people. The needs and issues affecting people living with HIV/AIDS should also be exposed in order to encourage positive thinking, break down the stigma and lobby family and social support. These recommendations will assist us to create an enabling environment where responses to women living with HIV/AIDS are more sensitive and their needs more visible.

## DECLARATION

I hereby declare that "*Experiences and Coping strategies of women living with HIV/AIDS: A Case study of Khomas region, Namibia*" 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 I have used or quoted have been indicated and acknowledged by means of complete references.

Johanna Christa Ndilimeke (Shapaka) Nashandi

August 2002

Signature: .....



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## LIST OF ACRONYMS

AIDS	-	Acquired Immunodeficiency Syndrome
CAA	-	Catholic Aids Action
CCN	-	Council of Churches in Namibia
DFID	-	Department for International Development
DWA	-	Department of Women Affairs
HIV	-	Human Immunodeficiency Virus
MOHSS	-	Ministry of Health and Social Services
MTCT	-	Mother-to-Child Transmission
MWACW	-	Ministry of Women Affairs and Child Welfare
NACOP	-	National Aids Coordination Program
NANASO	-	Namibia National Network Services
NANAWO	-	Namibia National Women's Organisation
SADC	-	Southern African Development Community
UNAIDS	-	Joint United Nations programme on HIV/AIDS
USA	-	United States of America
CEDAW	-	Convention on the Elimination of all forms of Discrimination Against Women

## CHAPTER 1 - INTRODUCTION

According to the Government Institutions Pension Fund (GIPF), HIV/AIDS amongst communities in Namibia is still a mystery despite the continuing increase of HIV/AIDS infections. Many people believe that the disease is caused by "witchcraft" (GIPF, 2000:3). Others in various Namibian communities speak of ancestral spirits that are not at peace. Another factor that encourages ignorance according to GIPF is the fact that people do not acknowledge the cause of death of people living with HIV/AIDS. Some families claim that the person died of pneumonia, tuberculosis (TB) or malaria. Later it becomes known that the person died of AIDS-related illness. Despite prevalent ignorance about the disease within Namibian communities, the number of funerals held per week has increased awareness about the disease (GIPF, 2000; Maletsky, 2002; Meursing & Sibindi, 1999).

The position of women in recent HIV/AIDS discourse has become increasingly prominent. While there is a large body of research on women and HIV/AIDS that reflects on women's vulnerability to the illness for example, (Skjelmerud and Tusubira, 1992; de Bruyn, Jackson, Wijermars, Knight and Berkvens, 1998; Department for International Development, 1998; Tallis, 1998; Take Control, 2001b) there is still little work that explores women's experiences of living with HIV/AIDS, particularly in Namibia. Despite the fact that HIV/AIDS does not discriminate based on color, wealth or class of persons, there is evidence that certain people are more vulnerable to infection than others. This can be seen in demographic characteristics, geographic distribution and access to resources of those infected (Strebel, 1993; Burry et al, 1992).

The needs and role of women are also not adequately addressed in Sub-Saharan Africa and Namibia specifically. Many women who are infected and affected by HIV/AIDS are often characterized by their relation to the disease in terms of condom use and high rate of infection. Women have thus in the process been branded as transmitters of the disease, both to their children and to their male partners (Squire, 1993; Skjelmerud & Tusubira, 1997; Department for International Development (DFID), 1998). The implementation of strategies and plans formulated to address the HIV/AIDS pandemic has also not succeeded in addressing how women are affected by the disease. The strategies tend to focus more on educational and preventative aspects, with minimal focus on women living with HIV/AIDS, particularly in Sub-Saharan Africa (Take Control, 2001b; Burry et al, 1992; Long & Ankrah, 1996).

Cultural, legal and economic factors in societies where there is a history of discrimination have not accommodated women's needs (Take Control, 2001b). Countries have not sufficiently addressed the complex web of cultural, economic and structural constraints for women. Women's lack of access to information, knowledge about their sexuality and lack of power to discuss and negotiate safe sex have made them more vulnerable to HIV/AIDS. Most women don't feel they can discuss condom use with their partners due to the risk of the negative and sometimes violent reactions that may occur. Women often become infected with HIV/AIDS as a result of continuing unsafe sexual practices (Vetten & Bhana, 2001; American Public Health Association, 1991; Long et al, 1996; DFID, 1998).

It is important to consider the difference in the experiences of men and women who are HIV-positive. While men living with HIV/AIDS also need assistance, support and



care, the low social status of women and socially constructed barriers further infringe on their access to health care and their ability to effect changes in their sexual behavior. At the same time, women often bear the responsibility of caring for the family and often neglect their own health problems (Richardson, 1989; Take Control, 2001b; Long et al, 1996; de Bruyn, Jackson, Wijermars, Knight & Berkvens, 1998).

This study focuses particularly on women living with HIV/AIDS, since knowledge about the resources available to such women in Namibia is limited. The study will elucidate and offer an in-depth understanding of the experiences and coping strategies of the participants of this study living with HIV/AIDS in the Khomas region, Namibia. Based on the information obtained, the study anticipates suggesting possible ways in which women living with HIV/AIDS can be supported and how their needs can be facilitated. The study further seeks to serve as a guideline for the implementation of focused intervention strategies and service delivery, especially for use by the media, NGO's and policy formulators. The National Aids Coordination Program (NACOP) is identified as the main body that could utilize findings of the study. The study recommends how existing policies can be implemented in order to reach women in rural and urban settings. It is also anticipated that the study will contribute to the various efforts to counter the spread of HIV/AIDS and serves as a platform to give a voice to women living with HIV/AIDS.

### **1.1 General Overview of Aids in Africa**

Over the past ten years, HIV/AIDS in Africa has come to represent a complex set of challenges. The disease has destabilized community and institutional support

structures and broken down family ties. African extended family relations and communities that traditionally served as a foundation and support system for needy family members have been severely undermined (Rugalema, 1999; Barnett and Blaikie1992). Many children are being orphaned due to HIV/AIDS when their parent(s) die, and are in many instances left in difficult circumstances. Women, who in many cases do not have stable employment, are also left without breadwinners. Evidence shows that adult males thus far form the majority of victims of adult mortality. Women are as a consequence expected to play the role of mother, caregiver and breadwinner (UNAIDS, 2000a; Take Control, 2001c).

In 1993 it was estimated that 5 million women were infected with HIV/AIDS. Currently, 36.1 million people are living with HIV/AIDS globally, of which women represent 15.7 million. One tenth of the adult population in Africa aged between 15 and 49 years are living with the virus. Amongst the ten highest affected countries in the world, seven are in the southern cone of the African continent. Namibia is ranked 7<sup>th</sup> in the world. Yet the threat of HIV/AIDS has not made a serious impact on perspectives and patterns of people's sexual behaviour especially in the Southern African Development Community (SADC) where HIV prevalence remains high. The SADC region currently has the highest infections of 25.3 million in the world (Buzy & Gayle, 1996; UNAIDS, 2000a; UNAIDS, 2000b)

Even though the disease is concentrated in certain regions of the world, various countries have experienced either a decrease or stagnation in rates of HIV/AIDS infections. West Africa, for instance, has experienced relatively stagnant prevalence rates, remaining below 3% in some countries, whilst Sub-Saharan countries have been

experiencing increasing rates. These stagnant rates indicate that some countries are hard at work in reducing HIV infections, giving hope to other countries experiencing increasing rates (UNAIDS, 2000a & 2000b).

In Namibia and also neighbouring Zimbabwe, HIV/AIDS is considered rooted in socio-cultural factors (Meursing & Sibindi, 1999; Take Control, 2001b). Among these are traditional factors, marital separation caused by migrant labour systems that results in casual relationships, and urbanization, which has reduced social control over sexual behaviour of both men and women. Other social factors also include the low status of women and lack of education, information and skills training for employment purposes (Take Control, 2001b; Meursing et al, 1999).

## **1.2 Women and HIV/AIDS**

It is estimated that women in Africa make up half of the known number of HIV/AIDS infections, occurring mainly among the productive age group, people living in urban areas and who are sexually active. The largest portion of women infected with HIV is concentrated in Sub-Saharan Africa. It is estimated that for every 10 men in the Sub-Saharan region, 12 women are living with HIV/AIDS (UNAIDS, 2000a). Social and economic factors such as migrant labour systems (that still exist), inaccessibility to health facilities, urbanization, poor living conditions, and cultural aspects such as female circumcision exacerbate the spread of HIV infections (de Bruyn et al, 1998; Take Control, 2001b; Doyal, Naidoo & Wilton, 1994). Women who migrate either to escape unemployment or simply to experience city life, find themselves in difficult situations i.e. prostitution or continuous unemployment. This also contributes to the



problem of HIV/AIDS. Such conditions create opportunistic environments for the spread of the disease, as women's autonomy in most societies are limited. Many African countries have thus adopted programs to help control the spread of the disease. However, some have not implemented these programmes where people need it most, e.g. in rural settings (Buzy et al, 1996; Meursing & Sibindi, 1999; Richardson, 1992).

Evidence indicates that HIV/AIDS prevention and intervention programmes have not adequately accommodated women's particular needs and circumstances. This is because preventative strategies and messages have mostly targeted men and have not benefited women. Such messages include “stick to one partner”, “abstain” and “condom use” (Skjelmerud & Tusubira, 1997:127). However, these have changed internationally, though in some countries these messages are only now attempting to include both men and women (Skjelmerud et al, 1997; Meursing et al, 1999).

In Namibia, HIV/AIDS has become the leading cause of death since 1995, and is determining macro-economic, human welfare and poverty levels. Of the population of only 1.7 million people in 1999, 68 196 (laboratory reported cases) people are living with HIV/AIDS and almost every family in Namibia is either infected, or affected. It is further estimated that 190 000 people are living with HIV/AIDS, of which over 10 000 are children. Women account for 54 per cent, which is more than half of the population. They are on average diagnosed at a younger age (30 years) in comparison to men (35 years). At the same time, it is estimated that 1 in 3 infants born from HIV positive mothers will be HIV positive (Ministry of Health and Social Services, 2000; CAA, 2002 Online; Take Control, 2001b; Take Control, 2001c).

The Ministry of Health and Social Services (MOHSS) study, which is carried out every two years amongst pregnant women at antenatal clinics, indicates that there has been an increase in HIV infection of women from 1992 to 1998. In Oshakati, where the highest occurrence of HIV infections in the country are found, rates amongst women have increased from 4 % in 1992 to 34 % in 1998. In the 2000 survey, 3 890 samples were tested between August and November, of which one out of every five women were HIV positive. The highest prevalence rate was in the age group 24 to 29 years at 25% (1 in 4 women). These results suggest that even though the incidences indicate a high level of stagnation, there is no evidence of a reduction in the rate of infections. As a result, there is a need to make women's infection visible (MOHSS, 2000; Take Control, 2001c).

What is most frightening about the position of women in Namibia are the projections of infection amongst young girls. According to the current statistics, for every one hundred 14-year-old girls, 60 will have become infected by the age of fifty years; 25 will die by age thirty; and 48 will die of AIDS by the age of forty (Steintz in Otaala, 2000b).

HIV/AIDS in Namibia also remains a highly stigmatized disease and strongly associated with notions of promiscuity. There also strong gender barriers impacting on safe sex practices, as women who carry condoms are referred to as “loose”, while it is accepted for men to carry condoms (Nasheya in Otaala, 2000b:36). The skewed power relations have not only facilitated women's vulnerability, but also their reluctance to openly discuss ways of protecting themselves from HIV infection, negotiating condom use, and their experiences of living with HIV/AIDS. Preliminary

studies in Namibia further indicate that urban-based women are more likely to negotiate safe sex than women in rural areas (Take Control, 2001b). It is also argued that women in non-committed relationships are able to more easily insist on safe sex in comparison to women in committed relationships (Richardson, 1989; Meursing & Sibindi, 1999; de Bruyn et al 1998). Sex workers in Namibia, who are women in most cases, find it difficult to insist on safe sex, mainly because prostitution is illegal in Namibia and they fear violent behaviour by their clients. As a result they find it difficult to seek help, treatment or protection (Take Control, 2001b).

### **1.3 National response to HIV/AIDS in Namibia**

Since the first four HIV/AIDS cases reported in Namibia in 1986, the disease has been increasing at a speed that has become difficult to keep track of. During 1989, 129 cases of HIV/AIDS were reported, while in 1993, 2 517 cases were reported. Over the period of 1998 and 1999, 27 567 cases were reported, 12 701 cases for 1998 and 14 866 cases for 1999. The number of people infected every year has thus tripled (MOHSS, 2000; Take Control, 2001b).

The HIV/AIDS pandemic in Namibia has therefore reached the stage where it has been acknowledged that policies should not only focus on ensuring that people are knowledgeable about the disease, but must also take a holistic approach. Non-governmental organizations have been complementing government efforts to address HIV/AIDS issues by setting up programs that assist people living under various conditions. The government, through various Ministries, has also developed instruments to address the challenges of HIV/AIDS in Namibia.

The government of Namibia first established the National Aids Control Program (NACP) within the Ministry of Health and Social Services (MOHSS) as a response to the increasing number of HIV/AIDS infections. However, due to a deficiency in coordination and decision-making, the program was unsuccessful (Ministry of Health and Social Services (MOHSS), 1998). A second national response was thus formulated and launched by the Namibian President, Hon. Sam Nujoma, in 1998, namely the National Aids Coordination Program (NACOP). The primary goal of the program is to coordinate HIV/AIDS activities. Even though the program falls under the auspices of MOHSS, it functions independently, and is the highest decision-making body on issues pertaining to HIV/AIDS. All ministers, regional governors and the Secretary General of the Council of Churches in Namibia (CCN) are members of the committee, which is spearheaded by the Namibia National Women's Organisation (NANAWO) (MOHSS, 1998).

The National Gender Policy was also adopted in 1997 and specifically outlines the need for the "protection, promotion and maintenance" of women's health and the implementation of strategies for both men and women to have equal access to health care services, especially with regard to HIV/AIDS and family planning (Department of Women Affairs, 1997:14). The policy also emphasizes the enactment of legislation to protect women against discriminatory socio-cultural practices that contribute to the spread of HIV/AIDS (Department of Women Affairs, 1997).

One of the instruments that have been developed and adopted to protect the rights of people living with the disease is the HIV/AIDS Charter of Rights Policy. It includes gender dimensions, such as the position of women and the girl-child; provision of



counselling services for women; and adequate information for women with HIV regarding reproductive health (Legal Assistance Centre Report, 2000).

An HIV/AIDS document on Policies and Guidelines for Support and Care is also in place. The document aims to serve as a technical support system in developing HIV/AIDS related strategies and approaches both on primary and secondary levels. The document further emphasizes the responsibility of individual and societal care management and support for those living with HIV/AIDS.

There are also additional policy documents and guidelines that have been adopted under NACOP since 1990 to address various issues pertaining to HIV/AIDS. Other documents are, however, being reviewed or finalized. Among these are the Policy on HIV/AIDS: Confidentiality, notification, reporting and surveillance; Policies and Guidelines for HIV/AIDS prevention and control; National Code on HIV/AIDS and employment; STD management guidelines; National Guidelines on HIV/AIDS home based care and Guidelines for breastfeeding of infants of mothers infected with HIV/AIDS (Office of the President, Online).

The above-mentioned policies acknowledge that HIV/AIDS remains volatile and that there is a need to be flexible and adapt to changes. The government further recognizes that even though HIV/AIDS is still not a notifiable disease partner notification is an important component. This is due to the stigma attached to HIV and the unequal relations between men and women.

## 1.4 Problem Statement

It is evident that the Namibian government and NGO's have carried out various activities and research over the past eleven years to reduce the rate of HIV/AIDS infections. There have however been few direct attempts to adequately meet the needs of people living with the illness. Women, who are mostly affected, have been focused on primarily in terms of their role in transmitting the disease and there has been little focus on intervention strategies and support for women living with HIV/AIDS. Existing intervention strategies focused on women have thus tended to be vague. Policy documents and programs also lack focus on issues of care and support for those living with HIV/AIDS and do not ensure proper implementation and monitoring instruments. Due to the large population of women infected with HIV in Namibia and their complex web of needs, it has become a necessity to document women's experiences and coping strategies with regard to the disease.

In an attempt to contribute to the debate on the change of attitudes and provision of services, and to fill the gap in the literature about women living with HIV/AIDS, *the study will focus on women's experiences and the varied ways in which they are coping with living with HIV/AIDS in Namibian society.*

## 1.5 Outline of Thesis

**Chapter 2** presents a review of the literature, highlighting contemporary debates on the experiences and coping strategies of women living with HIV/AIDS. The chapter

mainly focuses on the position of women and how various contextual factors impact on their experience of living with HIV/AIDS.

**Chapter 3** provides an overview of the study and how it was conducted. It presents the methodology, methods and procedures utilized in the study.

**Chapter 4** and **Chapter 5** present the analysis and discussion of the findings of the study. Common themes are extracted to indicate the various experiences and coping mechanisms of the participants. **Chapter 4** focuses on the experiences of the participants when they found out about their HIV status, including the challenges they face in living with the stigma. It discusses the reported responses that they encounter in their attempt to enlist support from partners, siblings, parents and institutions. It further highlights the demands participants perceive as challenging and barriers that socio-cultural expectations create for women living with HIV/AIDS. Finally, the chapter focuses on the link between violence resulting from HIV/AIDS disclosure and negotiation of condom use. It explores the sexual freedom and power that men in society enjoy over women and the consequences of increased infection and re-infection.

**Chapter 5** discusses the coping strategies and support mechanisms that exist and are used by participants in the Namibian context. It highlights the personal coping strategies that participants utilize in dealing with their situation, such as spiritual solace, counselling and keeping busy. The chapter then deals with the efforts of the Ministry of Health and Social Services, the Ministry of Women Affairs and Catholic Aids Action in supporting women, including any other responses by the government.

The views of the three institutions on why there is a need to target women and the importance of male involvement are also discussed.

**Chapter 6** will present the conclusions and recommendations that emerge from the study and suggest possible future research needs.



## CHAPTER 2 – LITERATURE REVIEW

### 2.1 Introduction

HIV infection presents a triple burden for women as they frequently have to care for themselves, care for other people living with the disease and cope with the negative responses and blame for their infection. It is widely recognized that women, particularly those living in deprived socio-economic contexts are more vulnerable to HIV/AIDS (Vetten & Bhana, 2001; DFID, 1998; Outwater, 1996; Strebel, 1993; de Bruyn et al, 1998). This vulnerability "...encompasses both the risk of infection and the experiences of the disease such as progression...and access to care." (DFID, 1998:42). Women's vulnerability is mainly entrenched in their "social, sexual and economic" position (de Bruyn et al, 1998:10). Various factors leading to women's increased vulnerability include issues such as the lower status of women, lack of care and support for those infected or affected, rejection and discrimination (UNAIDS, 2000a; Strebel, 1993, Take Control, 2001b).

The literature on women living with HIV/AIDS will highlight how women's experiences and coping strategies are influenced by conditions such as the above-mentioned triple burden, and their vulnerability in terms of their low sexual status in society. Other relevant factors are lack of support, subordination and cultural and societal barriers to HIV/AIDS prevention. Given the shortage of primary sources relating to women's experiences and coping strategies in Namibia, the study relies primarily on work carried out in other countries.

### *2.1.1 Women's vulnerability and risk of infection*

Even though this study's focus is on the experiences and coping strategies of women living with HIV/AIDS, it is important to contextualize the study in a broader understanding of women's vulnerability to infection. It has been widely documented that there are multiple biological, environmental, economic and socio-cultural factors that make women particularly vulnerable (Buzy et al, 1996; de Bruyn et al, 1998; Take Control, 2001b; Long & Ankrah, 1996; Outwater, 1996).

Estimations are that women's infection due to unprotected sex is "at least twice than that of men" (de Bruyn et al, 1998:10). The infection rates among African young girls are also higher than their counterparts, with their infection rates being five times higher than that of teenage boys (UNAIDS, 2000a). Young girls are thus at greater risk, as they are more likely to be "coerced", "raped" or "enticed" into sex by someone older, stronger or richer (UNAIDS, 2000a:47; Take Control, 2001d; Vetten & Bhana, 2001). In many instances, social pressures force girls to engage in unprotected sexual relationships at an early age. In Tanzania, for example, 17% of unmarried teenagers reported having sex with men 10 years older than themselves (Barnett & Blaikie, 1992; UNAIDS, 2000a; Outwater, 1996).

Commonly, women have a lower status in society and in sexual relationships in particular. This vulnerability is exacerbated by "cultural practices" in which male sexual needs and pleasure are defined as paramount (de Bruyn et al, 1998:10). Women are seen to be the property of their husbands in many societies, making them economically dependent, and facilitating their subjugation to men sexually (Meursing

& Sibindi, 1999; Outwater, 1996). In Uganda, for example, women experience seeing their husbands with widows of men that have died of HIV, yet are not able to do anything about (Patterson, 1996). Women in Zimbabwe are also said to be unable to question their husband's extramarital affairs, as they may risk being beaten or subjected to other forms of abuse (Meursing et al, 1999). Similar incidences are also evident in Namibia, as women are accorded lower status and are commonly economically dependent on men (Take Control, 2001b). Becker (2001), in a paper examining masculinity among young men in Namibia, explains that HIV/AIDS has intensified masculine power over women. Due to women's limited ability to protect themselves against HIV infection, they are put at risk as women don't have control over their sexuality. This is because; their sexuality is socially controlled. According to the male participants in the Owambo tribe, women are expected to act shy and should not initiate sex (Becker 2001). Even though women are willing to negotiate condom use (for safe sex), they find it difficult due to "reasons related to gender and power" (Becker, 2001:2). These limitations according to Becker (2001:10) place women at risk of being labeled "cheap," "first time girl", or "*oshikumbu*"<sup>1</sup>. They are at the same time accused of being unfaithful or having affairs because they carry condoms or initiate safe sex (Becker, 2001). This subordination of women makes them vulnerable and powerless to adequately protect themselves from HIV infection, which has become an urgent threat to public health (Long & Ankrah, 1996; Take Control, 2001a).

Mann and Tarantola (in Tallis, 1998:93) categorize women's vulnerability to HIV/AIDS infection in three categories as follows:

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<sup>1</sup> Derogatory term usually applied for single mothers or otherwise used as bitch.

- *Personal vulnerability*: This encompasses an individual's lack of access to information; personal characteristics such as individual attitudes and perceptions of personal risk; and lack of skills such as the ability to negotiate safer sex.
- *Programmatic vulnerability*: This refers to the contribution of HIV/AIDS programmes to reducing or increasing women's vulnerability. For the most part, the omission of issues of gender inequality in awareness campaigns fails to challenge women's vulnerability to HIV/AIDS.
- *Societal vulnerability*: This refers to the larger framework in which women operate on a day-to-day basis. It includes "the political situation, culture, tradition, gender relations, attitudes towards sexuality, religious beliefs and poverty" which all contribute to women's heightened vulnerability to HIV/AIDS.

## **2.2 Experiences of women living with HIV/AIDS**

HIV infection has exposed women to various negative experiences, largely as a result of environmental responses that are not only intensified by socially constructed ideas, but also institutional responses of, for example, NGOs or Ministries. These responses have created an enormous gap between women's lived experiences and an enabling environment that addresses women's needs in relation to HIV/AIDS. The experiences of women living with HIV/AIDS are impacted on by responses at personal, societal and program level.



### *2.2.1 Psycho-social experiences in living with HIV/AIDS*

It is argued that since HIV/AIDS is severely stigmatized, women infected with the disease face negative responses (Richardson, 1989; Burry et al, 1992; Long & Ankrah, 1996; Meursing & Sibindi, 1999). These include health officers not wanting to provide medical care and insurance companies being unwilling to provide cover. Refusal to treat, and avoidance of HIV patients by general practitioners and dentists has led to women often not wanting to disclose their status to health workers. Children may also be excluded from schools due to their parents being infected (Dom et al, 1994; Richardson, 1989).

Women living with HIV/AIDS thus experience “emotional, physical, social and spiritual” difficulties due to the often-negative responses that they are confronted with from family members, friends, health professionals and community members (Tallis, 1998:89). They have to deal with complex social issues such as rejection by partners, isolation from community members, financial constraints and psychological concerns such as low self-esteem and emotional insecurity (Auer, 1996). Serious prevention and support measures and counselling that take into account women’s contradictory conditions (socio-cultural expectations and economic conditions) are thus called for (Strebel, 1993).

It has been widely documented how HIV-positive people fear the discovery of their HIV status, given the disadvantages associated with this. They fear that they will be “stigmatized and rejected by partners, family, friends and workmates...” and that they will be branded as “immoral” (Meursing & Sibindi, 1999:3; Government Institutions

Pension Fund (GIPF), 2000:3). They may also feel embarrassed by their physical appearance (Richardson, 1989; Burry et al, 1992). Women living with HIV/AIDS further find it difficult to access care and treatment due to their personal constraints such as economic constraints and also due to certain government policies (Vetten et al, 2001; Tallis, 1998; Berer & Ray, 1993; Burry et al, 1992). In Namibia and South Africa, women who have narrated their stories speak of how their HIV infection has often left them without employment and support as well as being emotionally depressed (Tallis, 1998; Vetten et al, 2001; GIPF, 2000). Family members were reported to respond furiously, throwing women out of the house when they find out about their HIV status. Family rejection may be so strong that family members are not willing to contribute or to pay for funeral expenses (Tallis, 1998). A 51-year-old Namibian woman explained that her mother was furious and was only concerned about the loss of income. She posed the question: if family members are not willing to accept and support women living with HIV/AIDS how are community members expected to respond (GIPF, 2000)?

An AIDS diagnosis for many women thus comes as a shock even if they suspected it. They may enter into a denial stage when they find out their status and experience feelings of anger, suicidal feelings, anxiety, isolation, betrayal and fear of losing control of their lives or mental faculties (Richardson, 1989; Buzy et al, 1996; Burry et al, 1992; Dorn et al, 1994; Squire 1993). Richardson (1989) suggests that women living with HIV/AIDS should be made aware how HIV infection occurs as feelings of depression may progress their status. At the same time they should be made to understand how HIV is spread and should have access to accurate information rather than myths or assumptions (Long et al, 1996). Such measures will result in women

knowing what precautions to take to prevent infecting others (Take Control, 2001b; Burry et al, 1992; Buzy et al, 1996; de Bruyn et al, 1998).

HIV infection has also sparked a new form of oppression for women, as they are often blamed for the rapid spread of HIV/AIDS. Children's views on HIV transmission also seem to apportion blame on women (de Bruyn et al, 1998; DFID, 1998; Richardson, 1989). In Uganda for example according to Barnett et al (1992), a group of children expressed the view that women are seen to be a danger as they (women) are responsible for the spread of HIV and survive longer than men. This tendency of women to be constructed as scapegoats for the spread of the disease has become a daily experience. Even if women want to tell their partners in order to enlist support, they fear the possible risks of disclosure. Indications are that socially constructed ideas and the messages of HIV/AIDS carried by the media have contributed to women being viewed as the primary transmitters of HIV/AIDS (DFID, 1998, Burry et al, 1992).

In a South African study, Strebel (1993) found that HIV/AIDS is depicted as "a silent and invisible disease" (Strebel, 1993:194). Participants in Strebel's (1993) study aired the same view as stated in the GIPF Forum (2000) by a Namibian women that, if people are not comfortable with informing families close to them about their HIV status due to their fear of social rejection, it will be difficult to bring about behavioural change (Tallis 1998). Women are thus often dependent on the sympathy of support groups, if they are referred by health officers to social workers or support organizations.

### *2.2.2 Experiences in relation to women's reproductive role*

Even though there is no conclusive evidence that pregnancy encourages the progression of HIV, evidence worldwide shows that a woman's immune system is weaker after pregnancy. Because a woman's immunity is depressed during pregnancy, it is argued that the disease will progress rapidly. Others suggest that it has no impact (American Public Health Association, 1991; Auer, 1996). There is, however, general consensus that early or late medical intervention can influence the survival time of a person (American Public Health Association, 1991:4; Auer, 1996; Cullinan & Thom, 2002; Take Control, 2001b). In countries where medical intervention has been implemented and accessible, women have better options as their babies have a better chance of survival. Evidence in the USA, for example, indicates that infection rates have been significantly reduced in children of women who are given antiretroviral therapy during pregnancy, and where such therapy is administered to the baby six weeks after it is born (American Public Health Association, 1991).

In South Africa and Uganda where the programme is still being piloted, studies found that anti-retroviral drug therapy reduces the risk of transmission to babies to one in six (Cullinan & Thom, 2002). In Namibia, medical intervention through the mother-to-child transmission (MTCT) programme was announced early this year (2002). However, none of the MTCT programme activities have been implemented at the time this study was conducted (Maletsky, 2002). Researchers suggest that studies of progression of HIV among women should consider underlying conditions that affect health, such as demographic indicators of those infected and access to health-related resources (Buzy et al, 1996; American Public Health Association, 1991). Conditions



that affect the health of women will assist researchers to better understand situations women find themselves in and evaluate the progression of HIV/AIDS in pregnant mothers.

As motherhood reflects social status and represents a central identity for women in most societies, many women, upon being informed of their HIV status, experience a deep sense of loss (Burry et al, 1992; Dorn et al, 1994; O'Gara & Martin, 1996). This is so because society reinforces perceptions that child bearing and rearing is the key to "self-esteem, social value, strategic action, economic viability and survival" (O'Gara & Martin, 1996:220). The desire to have children for women, who are HIV-positive, has been found to be greater than for those who are not infected (Were, 2000; Auer, 1996; Buzy et al, 1996; Dorn et al, 1994). In the African context, children are considered as a "symbol of wealth, investment and social security" (Were, 2000:2). In-laws are said to push for grandchildren, as it is perceived as a way of strengthening the family name and growth thereof. In some cases, it is seen as compensation for the bride price "lobola" (Meursing et al, 1999:6).

However, motherhood is only one of the multifaceted reproductive decisions that women are expected to take. Breastfeeding also forms part of motherhood as it minimizes infant mortality and under-nourishment, especially for women who live in poor socio-economic circumstances. It is also least expensive. Yet, through breastfeeding mothers can transmit HIV to their babies. As a result infants born to HIV-positive mothers in impoverished circumstances are infected more frequently than those with higher incomes (O'Gara et al, 1996). Due to the abovementioned

socio-cultural expectations, HIV-positive women experience difficulties in coping with cultural and societal pressures (de Bruyn et al, 1998).

According to Berer and Ray (1993), a primary concern expressed by women living with HIV/AIDS is how to care for their families, particularly their children. Since many women find out about their own infection when they learn that their baby is infected, they are faced with many obstacles. These obstacles and issues include dealing with the infection, planning for the care of their children after their death and consequences of their own infection for their children. They fear that their child/children will be branded due to their infection (Auer, 1996; O'Gara et al, 1996; Richardson, 1989). Various studies report how grandmothers, aunts and the girl-child in the home are increasingly taking over the reproductive roles of mothers (Rugalema, 1999; Barnett et al, 1992; Take Control, 2001b; UNAIDS, 2000a; de Bruyn et al, 1998). As is often the case, no one else in the extended families are willing to assist children orphaned by HIV/AIDS, or whose parents are living with the disease (Meursing et al, 1999; Were, 2000; CAA, 2001; Barnett et al, 1992; Burry et al, 1992).

Women who are living with the disease also at times experience negative responses from health professionals towards their pregnancy, particularly with regard to termination, family planning and information (Dorn et al, 1994; O'Gara, 1996). Because of the preconceived notion that a baby born to an HIV-positive mother has no chance of survival, women are pressurized not to have children. In other countries, where abortion is legal, women are often pressurized to terminate their pregnancy (Dorn et al, 1994). Termination of pregnancy has often been performed without

women making an informed choice. It is in most cases also not explained to women why it is advisable not to have children (Berer & Ray, 1993; Dorn et al, 1994; Auer, 1996). Women living with HIV/AIDS may also experience maltreatment with after-birth care (Dorn et al, 1994; Berer & Ray 1993). Women living with HIV/AIDS need more information and care than women who are not living with the disease. This includes information on breastfeeding and bottle-feeding, nutrition for the baby and services provided (Vetten & Bhana, 2001; O'Gara et al, 1996; Meursing et al, 1999).

Because of the discriminatory practices that children are often exposed to as a result of their parents being infected, women are many times put under pressure to disclose their illness to their children at an early stage. Researchers have found that there are positive and negative aspects about informing children. Disclosure allows for the children to understand the illness better and also why people's behavior may change towards them. On the other hand, they are burdened with the responsibility of secrecy, fear for their mother's health, consequences of public knowledge and possible loss of their parent (Dorn et al, 1994).

There is also growing evidence of great stress associated with giving care, particularly for women. The burden of HIV/AIDS on both women who are positive and those who are not is heavy and affects all aspects of their lives (de Bruyn et al, 1998). While women who are HIV positive often carry their burden alone, they are normally expected to ignore their own health due to cultural obligations to care for their families. Instead of caring for themselves, they care for their "spouse or partner, HIV positive baby", as well as "having to provide care and support to the sick and to orphans" (Were, 2000:3).

### *2.2.3 Violence against women and HIV/AIDS*

In Namibia, "...one in five Namibian women has been beaten, raped or sexually abused by a man." (Take Control, 2001a:1). Violence directed at girls and women makes them not only more vulnerable to HIV infection but also impacts on women's experiences of living with the virus (UNAIDS, 2000a). Violence reduces women's control, as they often feel less able to question men about their extramarital affairs (Take Control, 2001a; Meursing et al, 1999). In Uganda, for example, a husband assaulted his wife because she refused to have sex with him after he had affairs with other women (Doyal et al, 1994;).

Negotiation for safe sex by women has also been found to spark physical violence. This is because men traditionally have greater control over "when, where and how sex takes place" (Vetten & Bhana, 2001:10). Women as a result avoid discussing condom use as they fear "violence or rejection" and of being accused of cheating by their partner (Vetten & Bhana, 2001:10; Take Control, 2001b). Even if women want to tell their partner in order to enlist support, they fear the possible risks of disclosure. Violence is thus found to be a barrier to HIV prevention, as the use of sexual contraceptives, such as the female condom, requires the cooperation of men. The only protective measure women can control is saying "no" (Burry et al, 1992:39).

Violence as a consequence of HIV infection puts a great strain on women when their male partners first receive confirmation of their status or where the man is infected and the woman not (Dorn et al, 1994). A man will often express anger through physical abuse of the woman, even if there was no quarrel before the abuse, as he



feels betrayed (Dorn et al, 1994; DFID, 1998; Vetten et al, 2001). Violent threats by men to both married and single women have also surfaced as a result of HIV infection (Meursing et al, 1999). The threats encompass withdrawal of material or financial support, desertion and condemnation by family members. Berer and Ray (1993:179) state that the "imbalance in power between men and women" is responsible for the lack of safety in sexual relationships.

Further arguments are that women's disclosure of their status or suggesting condom use can also provoke violent behaviour by men (Vetten et al, 2001; Take Control, 2001; Becker, 2001; de Bruyn et al, 1998). This behaviour includes blaming women for bringing the virus into their lives, abandonment or rejection and women being thrown out of their homes. Men have both sexual freedom and power in relationships (Vetten et al, 2001; Burry et al, 1992; Richardson, 1989). Similar responses from men in Namibia have also been reported (Take Control, 2001a). A Zimbabwean study reported that a wife who informed her husband about her test results responded that "he told her not to believe the doctor, Aids did not exist..." (Meursing et al, 1999:6). The study further showed that some husbands wanted more children after an HIV diagnosis and reacted violently or fled when the wife did not want more children in an attempt to protect their husband from infection. As a result, women fear the above-mentioned responses and prefer to keep quiet (Meursing et al, 1999; Vetten et al, 2001). Women would also rather comply with their partners' demands, even if it is a threat to their health, instead of giving up the relationship. Such compliance would involve engaging in unsafe sex, breastfeeding or having children whilst they are aware of the consequences. These responses are found to have become major barriers to the



control and prevention of HIV infections (Vetten et al, 2001; Burry et al, 1994; Meursing et al, 1999; Take Control, 2001b).

### **2.3 How women cope living with HIV/AIDS**

Coping is seen as a dynamic process that is influenced by a person's environmental and social position (Barnett et al, 1992; Melnick, 2001). People need to feel secure in their social and natural environment in order to cope with a new threatening disease. It is argued that in order for coping strategies to be enhanced, messages regarding HIV/AIDS should be incorporated into cultural engagements and presented in culturally appropriate languages of local people (Barnett et.al, 1992; Strebel, 1993; Long & Ankrah, 1996). If no guidelines are offered within social frameworks and at an individual level, people affected may reject the strategies and support systems that are introduced (Barnett et al, 1992). The level of awareness and knowledge and the accuracy of information on how to cope with the illness, as well as the services provided are thus important (Barnett et al, 1992; Richardson, 1989; Burry et al, 1992).

The most effective coping strategy that is commonly utilized in stressful situations according to Melnick (2001), is positive self-expression based on internal or personal strengths. This is because coping becomes problem focused and emotion focused, which encompasses positive thinking, social support and acceptance. Coping can occur at an individual and organizational level (Melnick, 2001).

Strebel (1993) found that economic and emotional support is central to women's coping strategies, as they are mainly concerned for their future employment prospects and fear of being abandoned. Support and care for a person living with HIV/AIDS is thus important, as coping with any terminal illness instills fear (Richardson, 1989; Burry et al, 1992). People develop fears of isolation, rejection and an inability to cope. This affects women's physical and emotional health. Some women experience suicidal thoughts due to their financial and social difficulties (Richardson, 1989; Buzy et al, 1996; Burry et al, 1992).

Since an individual will develop different symptoms of the disease according to the various stages of HIV/AIDS, support and coping strategies will also vary (Department for International Development (DFID), 1998). Thus, the support and care needs should be determined according to the stage of the individual's disease (DFID, 1998; Burry et al, 1992). According to various authors, women cope in various ways. This encompasses, among others, adopting a healthy lifestyle, i.e. a healthy diet, regular exercise, safe sex or changing sexual behaviour and cutting down on alcohol and cigarettes (Richardson, 1989; CAA, 2001; DFID, 1998). A healthy life style restricts the development of the disease and can prolong a person's life (Richardson, 1989; CAA, 2001). While denial is a common phase that HIV positive people go through, it is also used as a coping strategy for some (Burry et al, 1992). Some women want to be alone so that they can put things into perspective, while others however appreciate having someone to talk to (Burry et al, 1992; Barnett et al, 1992). At the same time persons living with the disease in many cases prefers not to leave their protective environment (homes) for fear of questions that might arise due to their physical appearance (Richardson, 1989; Buzy et al, 1996).

There are various support systems that have been shown to assist women living with HIV/AIDS to cope better, as detailed below.

### *2.3.1 Family support and Care giving*

Coping strategies, according to Parry (1990:105), are influenced by “cultural and communication” practices. These practices are able to positively support women and families living with HIV/AIDS. Where grandparents, aunts, uncles, and cousins characterize the family system known as the extended family, the institution plays a major role in assisting people to cope with terminal illness (Parry, 1990; Rugalema, 1999; Barnett et al, 1992). The extended family mainly assists by way of material and supportive exchanges, of which the family or individual in need can expect cooperation and emotional assistance in times of stress (Parry, 1990). In Africa especially, extended families have been able to assist the increasing numbers of orphans. However, the numbers of potential caregivers are shrinking as the traditional coping mechanism is stretched to the limit (Take Control, 2001c; Rugalema, 1999). Vetten and Bhana (2001:7) also indicate that when the woman (as caregiver) becomes ill, household members may not “be willing or able to care for them”. This is as a result of frequent deaths in families that reduce adult caregivers (Take Control, 2001c; UNAIDS, 2000a; Rugalema, 1999). Individuals are reluctant to accept financial responsibility for children, as a result of fear for the stigma attached to people living with HIV/AIDS. Another factor that fuels this reluctance is the absence of financial and practical assistance from the State (UNAIDS, 2000a).

Despite the fact that orphans are not taken into households they still receive financial and material support from paternal or maternal relatives. Rugalema (1999) explains



that extended families' decision not to take in AIDS orphans is due to economic constraints in their own households. Extended families prefer to avoid dependency of the orphans on them (Barnett et al, 1992). School attendance for children orphaned or affected by AIDS thus becomes sporadic as they occupy themselves with economic or survival activities. Elderly households that take in AIDS orphans are also dependent on their adult children for support (Take Control, 2001c; Barnett et al, 1992; Rugalema, 1999). In countries like Namibia and South Africa grandparents mainly depend on a pension from the State.

Caring as an activity is seen to be a natural duty for women, performed both in the family and society as a whole (Richardson, 1989; Burry et al, 1992). But due to the intensity of the activity it has stretched women's coping and caring skills more than anticipated. Caring involves emotional, physical and mental strength, creating problems for women who don't have access to community, regional or national care programmes (Richardson, 1989; Burry et al, 1992; DFID, 1998).

### *2.3.2 Spiritual and Psychological care*

It is widely argued that family members, representatives of religious communities, health-care providers and counsellors are important sources of psychological and spiritual support for people living with HIV/AIDS (Parry, 1990; Barnett et al, 1992; Rugalema 1999; UNAIDS, 2000a:93). Spiritual counselling enables people with HIV/AIDS to cope better with their infection, as HIV often creates feelings of shame, guilt, suicidal thoughts and loneliness (CAA, 2000; Burry et al, 1992). Most people living with HIV/AIDS have turned to religion for comfort. They find the role of

religion to be very strong as they are able to find their balance, encouragement and self-empowerment (CAA, 2000; Burry et al, 1992).

Since a person living with HIV/AIDS can be bedridden for a long period, economic resources can be critically exhausted (Barnett et al, 1992; Richardson, 1989). Because of the number of deaths experienced in many communities, funeral practices have changed. In many societies mourning periods have been reduced from a week to one and a half or two days in order for economic activities to continue (Barnett et al, 1992; Rugalema, 1999). Barnett et al (1992:107) refers to an author who commented that '...death had become so common that if one misses work for one day to attend a funeral, one can easily end up losing a month's work'. People as a result prefer to work during the day and attend mourning sessions in the evenings as a coping mechanism (Rugalema, 1999). Women who are bereaved or living with HIV are also said to be listening to each other be it at roadsides or markets in an effort to support each other and economic activities to continue. Those who work full time meet to talk about general or comic issues of AIDS as a way of reliving stress and coping with the situation (Barnett et al, 1992; Rugalema, 1999). Religious solace thus plays an important role for many people living with HIV/AIDS as it serves as a source of strength and hope. A woman in Northern Namibia reported that she regained hope and strength when a pastor in church preached, "God loves all of us, no matter who we are" (CAA, 2000:47). An established relationship with God and the church is reported to give people living with the virus a feeling of belonging. The church has therefore a contribution to make by putting people in touch with their beliefs and help them cope with their anxieties (Gyssler and Huber, 2000).



There are however instances where people's beliefs may themselves become a "source of great pain" (Gyssler et.al, 2000:1). This occurs when people with HIV/AIDS blame themselves and feels as if they deserve the illness on the basis of religious scriptures and interpretations (Gyssler et.al, 2000).

### *2.3.3 Social support systems*

Social support is not a single concept but refers to the "interpersonal aspects" of a person's life (Gottlieb, 1981:119). It encompasses any input that is provided by an individual or group, and includes a wide range of experiences such as; emotional and psychological health; the development of self-esteem in being valued; and network support that develops mutual obligation for the individual. Networks and support groups for women in various societies have been on the increase as they aim to share experiences and information among women affected and infected with the virus (Barnett et.al, 1992; Richardson, 1989).

Formation of specific social support groups and care for caregivers, and those living with the virus has been found to be essential in order to deal with feelings of isolation and frustration (Dorn et al., 1994; CAA, 2001). Support groups create an environment in which women can cope and thrive as the spirit of support among group members reduces the stigma that goes with self-disclosure and other negative consequences of being positive (Dorn et al., 1994; Were, 2000). Support groups are a way for people with a common problem to talk and help each other, providing an opportunity to learn from the experiences of others (CAA, 2001; Richardson, 1989). Group gatherings may further encourage people to seek counselling or any other

support services that might further help them cope (UNAIDS, 2000a; Dorn et.al, 1994). Another advantage is that support groups enables people to meet others without being rejected and getting advice from people who are going through the same difficulties. An important quality of support groups is that people don't feel alone and experience some relief when attending the meetings (CAA, 2001; Richardson, 1989). Support groups are thus seen as an important strategy in coping with terminal illness.

Burry et.al (1992) indicate that support services focused on women should be appropriate for their needs and developed accordingly. Women should be content and able to use them. As women are in most cases occupied with solving their social problems such as "housing, financial or legal difficulties" they often don't get time to visit support services (Burry et.al, 1992:66). Involvement in-group and educative activities, will benefit the women, as well as professionals and most importantly family. Attendance of support group meetings may distract their minds by keeping them busy; offer advice, and facilitate their ability to access services and support systems better (Dorn et al. 1994; Burry et al, 1992).

#### **2.4 Summary**

The experiences and coping mechanisms that are indicated in the review show how negative responses, the low status accorded to women, social and cultural demands and stigmatization of the disease influence a person's positive living with HIV/AIDS. The review indicates that women are in most cases shocked when they find out about their infection and enter into a state of denial categorized by feelings of shame. They

experience economic, emotional, physical, social and spiritual difficulties as they often have little or no form of support or have not disclosed their status in order to enlist support from friends or family. The literature ascribes these responses to be linked primarily with the blame women endure at a personal, societal and program level as a result of their infection, children and partners infection. This has encouraged skewed gender relations at household and community level.

The review further illustrates that the experiences of African women living with HIV are particularly exacerbated by the reproductive and domestic demands in the African context as a consequence of the social and cultural expectations women have to fulfil. Because of the social status and value that is accorded to child bearing and rearing, women's desire to have children is stronger when they test positive. However women find it difficult to cope with these pressures as motherhood, which encompasses breastfeeding, is believed to contribute to the progression of the disease or infection of babies. Also the slim survival rate of babies born to HIV positive mothers, especially in countries where there is no medical intervention and where many women live in poverty, creates a traumatic experience of having a baby.

A major concern for women who test positive after they have had children is the future and care taking of their children and the consequences of their infection on the children, as assistance is not readily available. In Africa especially where the extended family plays a major role in taking care of children it has become a difficult process due to the high adult mortality rates. Grandmothers have become caretakers of children orphaned by HIV/AIDS or whose parents are living with HIV who are unable to care for them due to constraints in many African societies. Rugalema (1999) and

Barnett et.al (1992) explain that extended relatives want to avoid financial obligations, dependency from children and the stigma that goes with HIV. The emerging trend is thus for children-headed households.

The review further indicates how violence against women has become a barrier in disclosing HIV status, negotiating safe sex practices and condom use, resulting in infection and continued unsafe sex practices. The writers explain that the imbalance of power, improper policy implementation and little or no support systems for women living with HIV/AIDS create a lack of safety for these women. The review concludes that support systems and structures are key to enabling women living with HIV/AIDS to cope better with their infection at a personal, community and social level.

While there is an indication of much work being carried out on the experiences and coping strategies of HIV/AIDS for women elsewhere, there is a gap in Namibian literature, with little literature on women's experiences and coping strategies.

Chapter 3 will introduce and explain the methodological framework in which the study was carried out. It will also indicate the procedures and instruments utilized to carry out the study.



## CHAPTER 3 - METHODOLOGY OF THE STUDY

In this chapter, the process and methods used to conduct the study will be explained. The chapter deals with the framework of the study, the procedures in selecting the participants and setting up of the focus groups and interviews. Finally, it sets out the method used to analyze the data.

### 3.1 Methodological framework

Various authors on qualitative and quantitative social research methodology have conveyed their views on which methodology is more useful. However, they also acknowledge that each methodology has “strengths and limitations” in its aim to clarify human actions. This study is based within a qualitative methodology, in which the data was collected through in-depth interviews and focus group discussions (see appendix3).

Qualitative research methodology encompasses the usage of multiple methods to collect data that informs an in-depth understanding of issues. It aims to “...make sense of, or interpret, phenomena in terms of the meanings people bring to them” (Denzin & Lincoln, 1998:3). Qualitative multiple methods include a study of empirical materials, case studies, personal experiences, interviews and other methods. One of the research methodologies that utilize multiple methods is the feminist approach (Neuman, 2000). Feminist methodology defines the world as a “web of interconnected human relations” and thus sees researchers as “gendered beings ” (Neuman, 2000:83). It is argued that qualitative methods are an “appropriate vehicle for...feminist inquiry” (Marshall, 1986:207) as they are suited for understanding



gender relations, since gender influences "...culture and shapes, basic beliefs and values" (Neuman, 2000:83). Feminist research thus allows flexibility, the investigation of sensitive subjects and is able to reflect on complex issues of people's experiences (Griffin, 1986). Feminist research also encourages debates on sexuality. As a result, qualitative methods can be used to research sensitive issues such as sexuality and domestic violence (Strebel, 1993; Condor, 1986).

When conducting research, feminists explore the "awareness of knowledge and power" (Devault, 1999:187). Researchers frequently assume the "power to define and represent others" (Devault, 1999:188). In the research process, however, researchers fail to recognize the power and influence research participants can bring to the process. As such, researchers should be aware of the inherent power relations existing between researchers and researched. This process of becoming aware of power relations constitutes the outsider/insider phenomenon and is referred to as self-reflexivity within qualitative methodologies (Devault, 1999; Naples, 1996). The outsider/insider phenomenon has been widely used in feminist research methodologies in an attempt to acknowledge and deal with power relations (Devault, 1999). Naples (1996:84) describes the outsider/insider phenomena as the "...masked power differentials and experiential differences between the researcher and researched". These differences in experiences and power over data should make researchers constantly aware of their position and representation in the process. Researchers should therefore not focus on the separation of the insider or outsider position. They should rather focus on the sensitivity of issues of power and control and should reflect on their own actions. This encourages researchers to be open-

minded during interactive processes, for example in focus group discussions (Naples, 1996).

Researchers should also bear in mind that the outsider and insider positions are not “fixed or static” (Naples, 1996:84). They are considered to be flexible positions that are spread throughout social locations. Researchers are thus never fully outside or inside the environment of those being studied (Naples, 1996).

During this study, I located myself in a learning position, both as an insider and outsider. This is because as an insider, I have first hand experience in working with people living with HIV/AIDS in the Katutura Hospital, Windhoek, for a period of one year. At the same time, I have some knowledge about the dynamics and culture of the communities from which the research participants come, since I live in and am familiar with the region studied. Yet, I am also an outsider, since I am a graduate student studying in a foreign country and in a relative position of power to the participants. I am also an outsider to the participants’ experiences of living with HIV/AIDS.

### **3.2 Research aims**

The broad aim of the study is to investigate how a group of Namibian women in the Khomas region experience and cope with living with HIV/AIDS. The study is based on the following central questions:

- (i) What are the participants’ experiences of living with HIV/AIDS in terms of:
  - Domestic and reproductive roles;
  - Community and interpersonal relationships;

- Responses to participants' illness;
  - Social and emotional demands.
- (ii) How have participants responded to living with HIV/AIDS in terms of:
- What support structures they have utilised and are in place?
  - What personal coping strategies they have developed?

### **3.3 Selection Criteria and Research Participants**

Sampling refers to "the process of selecting things or objects ..., which involves some form of...selection of elements from a target population" (Mouton, 1996:132). I used convenience sampling in which already established groups of participants are drawn on. Focus group participants and key informants for the in-depth interviews (discussed under 3.4) were recruited on a voluntary basis.

The target population of this study for the focus groups was women living with HIV/AIDS and who are between the ages of 15 and 49 years in the Khomas region of Namibia. The target population for the in-depth interviews was key informants working with women with HIV/AIDS. Seventeen respondents formed part of the research population, of which 12 are HIV-positive focus group participants and 5 are key informants working with HIV/AIDS issues.

### *3.3.1 Focus groups*

The 12 participants were recruited for the focus groups through Catholic Aids Action, which is an NGO, where people living with HIV/AIDS attend support group meetings and other activities. Letters were written to the line ministries (MOHSS and MWACW) and support agencies (CAA and Namibia Network of Aids Service Organization (NANASO)) to inform them about the study and the recruitment of participants. I requested a platform to inform and invite possible participants to participate in the discussions. Only CAA was able to assist. A meeting was held with the National Coordinator to establish support, to network and outline the purpose of the study and to explain the category of research participants needed (to ensure correct information is conveyed). The national coordinator expressed great support for the study on condition that a copy of the study is submitted to them. I was put in contact with the regional representative that would assist with recruitment of participants and any other assistance needed. Next, a meeting was held with the regional representative to make arrangements for recruitment. She preferred the organization itself to recruit the participants in order to protect the identity of women who decline. She explained that some of the women have not publicly disclosed their status and as a result their identity has to be protected. We agreed upon a date and venue where discussions will be held and also discussed transport arrangements. The practical arrangements were time consuming due to staff shortage and the reopening of schools (January). Therefore, flexibility was vital.



### 3.3.1.1 Demographic information

The participants come from the same residential area, which is Katutura, Windhoek in the Khomas area. Five sections in Katutura where 5 of the participants come from are dominated by informal settlements that constitute shacks. Two of the other participants stay in shacks that are added to a formal house. The settlement can thus be classified as a poverty-stricken area. The ages of the women who participated in the focus groups range between 21 and 42 years and are presented in Table 1.

*Table 1: Age of Focus group participants*

<b>Age</b>	<b>Number of participants</b>
21 – 25	1
26 – 30	3
31 – 35	6
36 – 40	1
42	1

Six of the women have attended primary school and the other six have progressed to junior secondary school. None of the participants have progressed beyond Grade 9. Eight of the women have never been married, with three cohabitating and one separated from her husband.

Concerning the employment status of the participants, ten of them are unemployed with only two of them being employed. These two participants are employed as domestic workers and earn N\$140 and N\$80 respectively per month. Whilst most of the women are unemployed all of them including those employed receive assistance



in the form of food parcels from CAA every Friday, because of their involvement with the centre.

The numbers of children the women have ranges from 0 to 5 children, as presented in Table 2. It cannot be stated, however, whether the women included their children who have died. 4 of the participants were diagnosed with HIV after their pregnancy and the other 6 due to persistent ill health. 3 of the participants' babies died between 1-3 months after birth.

*Table 2: Number of children born to each participant*

No. of Participants	No. of children
3	1
4	2
2	3
1	4
1	5
1	0

Most of the participants have been living with the disease for two years as they were tested between 1999 and 2001. Only one woman indicated that she was tested in 1986, which implies that she was probably one of the first four cases of HIV/AIDS reported in Namibia. Migration patterns also emerged during the discussions as 8 of the women migrated from the places they originally call home in search of a better life. Six of the women are from one of the four northern regions, which are Oshikoto, Oshana, Ohangwena and Omusati regions. Two are from the southern regions, that is

either Hardap or Karas regions. The women are thus trying to survive in an environment where personal support is minimal or absent.

Even though the women share almost similar backgrounds, the results from the focus group discussions indicate inherent differences such as personal support level that influences their circumstances. Economic circumstances and institutional support influences women's lives differently. The participants reported how their contact with CAA has positively changed their lives (Chapter 4).

### ***3.3.2 Key informants***

Five key informants were recruited for the study and are key people working with HIV-positive people in their respective organizations.<sup>2</sup> The informants include 2 males and 3 females. The institutions that participated are Catholic Aids Action (CAA), Ministry of Health and Social Services (MOHSS) and Ministry of Women Affairs and Child Welfare (MWACW). They form part of the various key stakeholders and government ministries dealing with HIV/AIDS in Namibia and also formed part of an HIV/AIDS reporting and disclosure task force in 1999 (MOHSS, 2000).

Communication with the informants was established through formal letters and followed-up by telephone and facsimile. The key person in MWACW was unable to meet with me due to other commitments. I used personal contacts to set up appointments telephonically with other staff members who work with HIV/AIDS

issues in the same ministry. The MOHSS was very enthusiastic about the study and gladly participated.

### **3.3.3 Research Assistant**

I utilized a research assistant in the data collection process. This person, recruited through CAA, provided counselling needs and assistance that arose during the focus group discussions. During the follow-up meeting with the regional representative, I requested her to suggest someone who is familiar with the dynamics and needs of HIV-positive people. I also explained to her that the person should be a woman, resident in the region and attached to the centre on a part-time or full-time basis to ensure confidentiality. The presence of women researchers in groups of women participants is said to create a sense of shared experiences among the participants (Finch in Strebel, 1995).

The assistant is a member of CAA and is a trained counselor and was also very helpful in translations when it was needed.

## **3.4 Methods**

As discussed before, both focus groups discussions and in-depth interview techniques were used in order to collect in-depth information.

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<sup>2</sup> The job titles of informants cannot be disclosed due to confidentiality.

### *3.4.1 Focus groups*

Focus groups are seen as "...a way of listening to people and learning from them...." (Morgan in Madriz, 2000:835). They have been frequently used in HIV/AIDS research with women. It is a technique that allows collective rather than individual participation. Focus groups enable research participants to interact and give a collective understanding and meaning to topics being researched (Strebel, 1995; Wilkinson, 1998). Two focus groups consisting of a group of 6 women each was set-up in Windhoek.

During the initial stage of the groups, a vignette was used (read by the researcher) to introduce the topic. The story dealt with the experiences of a woman (Margaret from Kwazulu-Natal in South Africa) after she found out that she was HIV-positive and how she learned to cope and live with HIV/AIDS (see Appendix 1). Vignettes are used to enable participants to explore their own experiences and relate to the person(s) in the story (Strebel, 1993).

A demographic questionnaire was also constructed to gather demographic data on the participants' lives. The questionnaire included questions on the women's educational level, number of children, age, etc. (see Appendix 2).



### *3.4.2 Interviews*

Interviews are methods utilized to maintain conversations with people and develop theoretical interpretations thereof. This method is based on a series of questions that are relevant to a topic, asked by a researcher to an informant. The informant's answers constitute the data. Interviews are used in four ways: structured, semi-structured, focused and unstructured focused interviews (May, 1993).

Since the aim of the study was to collect detailed information, I used the semi-structured interview method to collect the data for the key interviews. Semi-structured interviews are open-ended questions that enable the researcher to gain detailed understanding of a respondent's perception of a particular topic (Smith, 1995). It is flexible as it allows the researcher to seek elaboration and clarification on important themes that emerge from an interview. The informant is also able to give a fuller understanding and perception of a topic (Smith, 1995).

The sessions allowed the researcher to ask about the informant's personal experiences in working with HIV-positive women. The informants also elaborated on the strategies and intervention methods that are in place to support women living with HIV/AIDS in Namibia.

### **3.5 Procedures**

I telephonically contacted the regional representative of CAA three days before the group meetings confirm the date, time, and venue of the focus groups. The first group

was held on 6<sup>th</sup> February 2002 and the second group on 13<sup>th</sup> February 2002. The groups consisted of 6 women each and started at 4 o'clock the afternoon. The meetings were held at the CAA premises in Katutura, Windhoek. Most of the participants were recruited either a day before the group discussion or on the same day. Even though the women come to the same centre, not all of them knew each other in the group. Both groups were co-facilitated by the assistant and myself. This is because we had a mixture of people who did not speak the same language. The participants spoke Afrikaans and Oshiwambo. As a result I asked the questions in Afrikaans to the Afrikaans speaking participants and the research assistant would repeat them in Oshiwambo. Both groups were conducted in the same manner. The arrangement for me to speak Afrikaans was made because the assistant could better express herself in Oshiwambo. This proved to be time-consuming but very effective as the women could express themselves better. Each group lasted for about 1 hour and 20 minutes instead of the proposed 45 minutes. Some of the participants (3) also had speech disability, which slowed down the discussion.

At the beginning of the sessions I welcomed and thanked the participants for volunteering to participate. I introduced myself and explained the purpose of the study and meeting to ensure that there was no confusion. An explanation was also given on the process of the discussion and I asked their permission to use the tape recorder. There was no uncertainty from the participants about the tape recorder being used.

I further explained the confidential manner in which the discussions will be treated and that they should not use their names during the discussions. The demographic

questionnaire was filled in at the beginning of each group session. As the questionnaire was in English, my assistant and I grouped the participants in the same language group for the purpose of the demographic questionnaire only. Each one took the group of participants who speaks the same language and translated the questions while they filled in the questionnaires.

The group discussions officially started with a vignette that I read in Afrikaans and Oshiwambo. Thereafter, the discussion followed, directed by the interview schedule. A finger lunch and drinks were served to the women at the end of the discussions. The arrangement to have the snacks at the end of the discussion was made by the participants themselves. Finally, each participant was given N\$25,00 as a token of appreciation. I also transported the participants staying 1 to 3 kilometers away from the Centre back home.

The interviews with the 5 key informants were held at each individual's office after contact was made through facsimile and telephone. The time and date of the interview was in most cases determined by the informant. Permission was sought to use the tape recorder, explaining why it was required. The interviews lasted between 25 and 40 minutes and were conducted from 7<sup>th</sup> January to 16<sup>th</sup> February 2002.

### **3.6 Data analysis**

Qualitative thematic analysis was used to interpret the data. It is believed that there is no one correct way to employ qualitative thematic analysis. Rather, each project creates the appropriate manner for the employment of thematic analysis (Smith,

1995). It is however important that researchers give meaning to the participant's interview and engage in an "interpretative relationship with the transcription" (Smith, 1995:18). Themes are seen as "...abstract constructs investigators identify before, during and after data collection" (Ryan & Bernard, 2000:780).

After the data collection process was completed, I transcribed the discussions from the audiotapes into English. Next, I checked that the transcriptions correlate with the discussions by listening to the tapes and reading through the transcriptions simultaneously.

Themes were then formulated from the transcribed text. Williams in Ryan et al (2000) suggests that researchers start with general themes from the literature review and add more themes as they progress.

The participants' and informants' statements were sorted into thematic piles and sub-themes. The statements within the themes and sub-themes were then sorted if they indicated coherence with other participant's statements. The themes identified served to structure chapters 4 and 5. Quotes from participant's statements are used to illustrate and support findings of the study.

Chapter 4 will present an analysis and discussion of the participant's experiences in living with HIV/AIDS and the responses that they encountered based on the empirical findings in the Namibian context.



## **CHAPTER 4 - EXPERIENCES of WOMEN LIVING with HIV/AIDS**

### **4.1 Introduction**

In this chapter, I present a discussion and analysis of the main findings that emerged from interviews conducted with a group of women living with HIV/AIDS in central Namibia. The chapter focuses on the experiences of participants, in particular the responses of family and society at large. The data collected from both the focus group participants and interviews with key informants draws attention to the daily difficulties participants have experienced since confirming their HIV status.

The findings are discussed within three main themes that are further divided into sub-themes:

- 1) Experiences of living with HIV/AIDS;
- 2) Reported demands on participants in their role as women, mothers and wives;
- 3) Violence and HIV/AIDS

The data collected from the focus groups and key informant interviews are both presented under these main themes and sub-themes.

### **4.2 Living with HIV/AIDS**

#### **4.2.1 *Experiences from day of confirmation***

The participants spoke of how they experienced various feelings after receiving confirmation of their HIV status. They expressed feelings of shock, numbness, fear, guilt, anger, confusion, shame and suicidal thoughts when they found out about their

status. They were concerned about their children and what people, especially family members, would say about their infection. Such feelings are common experiences for women living with HIV/AIDS as it has been widely reported in the literature on women's responses to living with HIV/AIDS, particularly their inability to continue the needs of their dependents (Dorn et al, 1994; Tallis, 1998; Richardson, 1989). Burry et al (1992) attributes this failure to the difficulty women face providing for both their own needs and those of their family.

The participants shared their reactions to finding out about their HIV status:

*I felt a bit funny that time and I felt weak and was numb. I came home and I went to sleep and after I woke up. I decided I would not talk ...*

*It was written HIV positive. I started shivering...*

*...I have to accept it and I ask the Lord to help me so that I cannot be overpowered by suicidal thoughts...*

*Since I had many unanswered questions. People started asking at home what it is? But I did not say...*

*She said, mom you know that these are your results, however your results show that you have been diagnosed with an infection of that illness of now a days. Do you know about it? I said yes. So that means you have been tested positive. So, she started talking about various and many other things. After that, I came out of the room. When I came out, I walked around and around. From there, I sat near the entrance of the hospital door. Then I started thinking to myself what will I do? I said to myself, no I just have to go home...*

*I felt ashamed to talk on the phone...*

A 42-year-old participant who lives in a shack with her children shared how she felt numb and thought she would only live a few days or months and then die. Richardson (1989) reminds us that women need to have access to accurate information. They need to know about and have access to the various options and support systems available. Such reactions and thoughts of immediate death may be attributed to misinformation of the public or lack of media exposure on living with HIV/AIDS.

These feelings led the participants through stages of denial and a search for answers. They experienced feelings of loneliness, depression, isolation, shame and self-blame. As a result, participants found it difficult to disclose their status to family members, as they feared rejection and blame.

*My grand father also said to me, ya you have AIDS, what are you looking for at my house, go away. When he said that to me, I started crying and asked him why are you saying I have AIDS? Then I told him, yes I told you I have AIDS but why are you teasing me with it, with that illness ...*

Even though the participants speak of having accepted their status, they are still not able to say that they are infected with the HIV virus. This is evident in the way they refer to and talk about the disease. Most of the participants spoke about the disease as “this” or “it”, instead of “HIV/AIDS” or “virus”. This indicates that the participants are still not comfortable with the illness. Another example is the way in which the following participants explain the relationship between themselves and their family members and how they refer to HIV/AIDS:

*Yes, they know now. I first felt shame and I did not tell anybody. But when I started communicating with the CAA people, (name) and (name) came with me to tell my aunty...  
I later started accepting, I accepted. I do not have problems anymore with this illness and so on. So many people know about it, that I am like this (HIV positive). And they don't give me problems when we meet. They just greet me and they don't show that I am like this. But afterwards, they talk about me. I hear the stories afterwards but I don't care with them...*

#### 4.2.2 Negative Community Responses

The participants explained that the negative responses they experience on a daily basis have become a part of their lives. "Teasing", "gossip" and questions about their health and physical appearance are common responses they are confronted with from the general public. For some of the participants, the teasing has resulted in physical fighting with family members. One participant explained how she and her four siblings live with their mother. She and her brother fight because he would talk about her HIV infection as though she 'looked for it'. She moved away and is now staying alone with her two children. She said that she is at peace on her own. Another participant also explain the results of teasing between her daughter and niece:

*I have an older sister from my father's side and she has a daughter who drinks. If she is drunk, she comes and tries to pick a fight. She says things like skeleton ghost etc. Once my eldest daughter fought with her because she was referring to me. But since that incident, she rarely comes there.*

The same participant who physically fought with her brother explained that her ex-boyfriend enquired whether she had died. She elaborated that he was aware of her status but wanted to make her feel guilty:

*I met one of them and he asked, oh I thought you have died already. I understand you have AIDS. Then I answered him, it is because of you that I have AIDS today, so I am still alive...*

At the same time, the participants - including the informants - expressed the view that women are blamed for various things that go wrong because of their infection. Many reported how families blamed them for their boyfriend or husband's possible infection, for example:

*His cousin later came to me and she said Ya you are the one who infected the men with illness, if my brother die then you must know. Then I said oh, but I know and God also know it was not me who gave that man the illness. Because when I took him to the clinic that Monday none of his family members were there. I was the only one who cared for the man until the day he died.*



The participants who informed their family members about their status explained that they are also blamed for the loss of financial income to the household, because they may be unable to provide financial assistance to the household anymore. One participant, who is in her early 30's, stated that since her only daughter stays with her mother, her sister accused her of neglecting her child since she does not provide financial support to the child anymore.

The informant from MOHSS explained that since women are in many cases the first to know their status because "they are the ones that get pregnant" and often visit health facilities, their families can easily reject them. Husbands therefore assume that their wives brought the disease into the house. As a result, MOHSS and CAA has intervened in cases where women have been forced to leave their homes and are physically abused when their HIV status becomes known. The CAA informant explain:

*The husbands are sometimes not friendly in working with CAA. You find that beatings are happening in households then we intervene by talking to the parties involved... (CAA)*

According to the participants, they disclose their status to family and friends as a way of seeking support and care. Their disclosure has however led to negative responses from those close to them. They are often ostracized, excluded, chased away and despised by family members. One participant explained that she felt "thrown away" in hospital by her family members, since they never came to visit her. She told them not to come again, as she had established a family of her own in hospital. Another participant felt that she became a person in another circle, "...because people don't want to associate with you anymore".

One participant explained how her mother's behaviour changed:

*... My sisters and mother all know, because I went back to Gibeon (southern Namibia). But my mother's behaviour showed. It was as if I am dirty because if I maybe drink out of something then, I must use my own cutlery and if I bath in a bath tub, no one else is suppose to use it again. They treated me like that. (A participant who informed her family that she is HIV positive)*

A similar incident was also cited in the GIPF Forum (2000:3) in which a 51-year-old woman was thrown out of the house in northern Namibia after telling her mother about her HIV status. The woman felt that if family members are not prepared to support women living with HIV, how could it be expected from the general public to care. These responses, according to the participants, contribute to people living with HIV/AIDS not wanting to publicly disclose their status, especially when they don't feel secure in their own families. One participant related her experience of deciding whether or not to inform her grandmother:

*You think to yourself, oh! My Lord what will I do because I will leave my kids behind and they don't even know me well. Maybe the Lord has the power. Then you think maybe if I tell my grand mother, she might just say I don't care you went to look for it. You just keep quiet, and decide not to tell anything because you are scared. You again think to yourself, what should I do is it possible that I don't even tell someone at home.*

Health institutions – that are expected to instill hope in people - also appear to aggravate such stressful situations. One participant, who is 35 years old and originates from the Oshikoto region in northern Namibia, spoke of ill treatment by a nurse at the Onandjokwe Hospital in Ondangwa, as a result of her HIV status. She explained that:

*...I detected fault in a nurse in the hospital when her colleague was putting me on the drip for strength, she said that, I must not be put on the drip I will be found dead anyway. She continued to say (the nurse) there is no blood in that person, Will she not die if you put her on the drip like that?*

She checked out of the hospital and attended the Windhoek hospital where she received adequate treatment.

The participants concluded that their main concern, in terms of the responses they encountered, is the experienced of being referred to as “suffering from Aids”, and thus not feeling valued and respected. They said that they just want to be treated the same as other sick people, while receiving adequate support in living with HIV/AIDS.

*Since I had developed pimples, they said that the reason why I look like that is because I have AIDS. You know these people that are saying these things to me, are not even my friends, but they are saying these things as if I have told them something. They just see because I am ill, they say that she is falling ill because she is suffering from AIDS...*

#### 4.2.3 Challenges

Informants indicated that, in general, women living with HIV/AIDS have multiple negative experiences. The participants explained that as a result of their HIV infection, they are faced with challenges that impact on their daily lives. Apart from the stigmatisation and social isolation that they endure, their means of survival is limited as employment opportunities are slim. All the participants indicated that it was difficult to keep a job, even if they wanted to. This is because of the physical weakness and poor health that hinders their ability to do strenuous. One participant shared her experience of working for seven years, and then being laid off because of her health: “...anyway the whites I worked for did not want me anymore because I was always sick”. Another participant also explained why she does not look for a job:

*No, since I started falling ill I have not looked for a job. Because even if you get a job, the problem is today you are feeling healthy, tomorrow you are not okay. So it is not possible...*

While it is true that HIV/AIDS weakens the body and impacts on work performance, opportunities for uneducated people with HIV/AIDS seem to be absent in the Namibian context. Despite the provision made in the Charter of Rights for people living with HIV/AIDS, the reality for especially domestic workers and other general workers is different at grassroots level. According to the GIPF Forum, a woman interviewed reported that, when he heard she was HIV positive, she was fired without her employer asking "her exact diagnosis" (GIPF, 2000:3). The participants therefore expressed feeling pessimistic about work opportunities as they might continuously be on sick leave.

*I feel that my body is always weak because of my health, so I can't do work that demands hard work or long hours...*

*I think if you are infected with HIV it is difficult to look for a job or be employed because you cannot do heavy work. So you can end up being fired because you are not performing or you are always sick...*

Participants also encounter questions from their children and family members with regard to their health and physical appearance. Explaining to the children why these changes occur presents a challenge to the participants. They explained that their children seem not to understand why their mother is not working or why she is always sick. This inability to provide for the family causes distress and pain. One participant explained that children's demands are the major problem. She said:

*... we suffer a lot because my children is the biggest problem. I don't want to say they are a problem but I have to ...*

The questions asked by the participants' children and family members therefore cause them to be uncomfortable at home. They are indirectly forced to disclose their status, even though they are not emotionally ready, for example:

*... my sister said I should tell my child because she maybe knows about the illness.... So I told the child but she said she does not know about the illness. ...She is 10 years old but maybe she was ashamed of me or didn't really know about the illness. I don't know...*



*My only problem is questions from the child. He is always asking why are you just lying in bed and not going to hospital if you are sick? So you just ignore the child because you don't know what to say...*

*On a later stage I started feeling ill and weak, my children started asking, mommy what is it? What is it mommy? ... I said, oh my children I really want to, but I don't have the energy right now. But they would not have understood because it was the first day... so I told my children that there is a problem. The whole time that mommy was sick, mommy did not know that I have such a illness.*

Some of the participants felt that it is best not to tell children anything as their health might be affected. This, according to one participant, may lead to feelings of guilt and self-blame. She feels that it is better not to bother their children.

*Even the children who are bigger, you can't tell them. They will feel bad and because of you the child might fall ill because he or she knows. It is not possible to tell them, you just have to stay there with your lifestyle putting your trust in God.*

The informants representing the various institutions working with people living with HIV/AIDS acknowledge that they are aware of negative responses to people living with HIV/AIDS, such as unfair dismissals and refusal of insurance policies. The informant from MWACW pointed out that she heard people talking about insurance companies that do not grant policies to HIV-positive people or that lower the value of the policy. The informant from the CAA also explained that the fact that an employer is aware of an employee's HIV-positive status is enough reason to fire the person. She stated that:

*... bosses actually, even though there is nothing wrong they find reasons to fire you as an infected employee ...*

Despite the knowledge of the above-mentioned incidences, only the MOHSS has received complaints of ill treatment resulting from a person's HIV status. The informant explained that women in Namibia find it harder to resolve the challenges that they face, since the options and opportunities are limited.

This, according to the informant, is because of the low status women enjoy in Namibia.

*Women who for instance have no resource persons in rural places where they can try and go for counselling or advice for guidance... You know these kinds of people are not there. It does not even reach them so you kind of in a situation of ah, these women being vulnerable by virtue of where they are and by virtue of that, I mean, nothing significant has been done... They need to know about condoms they should be having condoms, we are talking about female condoms now, and I mean ,... so many rural places is not even thousands of women like Namibia in rural settings did not even see this condom (female condom) ... They need to be educated on that, for them to appreciate the female condom if they have to put it in and so on. And that's the only time I mean we can really kind of have positive results in terms of women being able to cope with the situation they face (MOHSS)*

### **4.3 Demands on women living with HIV/AIDS**

#### **4.3.1 Socio-cultural demands and Positive Living**

According to the informants, the domestic and reproductive roles of women in Namibia are commonly influenced by cultural and social expectations. As a result, women are expected to fulfil various demands. A woman who is married or is in a committed relationship that is traditionally accepted, is, for example, expected to satisfy her husband sexually and support and care for him (MOHSS). The participants and informants felt that there is a need to review policies and guidelines in relation to socially constructed ideas.

An informant from MWACW explained that even though a woman is willing to use a condom to prevent HIV infection, the husband or boyfriend is likely to refuse to do so. This behaviour, according to the informant, is due to the cultural belief that "...it is taboo for a woman to say no..." or to suggest using condoms.

Women living with HIV/AIDS, according to the participants and informants, are culturally and socially expected to perform their domestic or reproductive roles and care for the family with no consideration for their own health. They are expected to bear children especially if they are married, and to have sex without demanding safe sex, even though they are aware of the consequences.

*Yes, women can't make choices; men are having the upper hand because they can have someone else. In the domestic set up there are still pressures and your pain as a woman is not acknowledged but you are expected to still console. It is also expected from you to clean and not to take care of yourself... (CAA)*

As a result, there is indirect conflict between efforts to prevent the spread of HIV/AIDS and socio-cultural demands, as these demands act as barriers to preventing HIV infection. One participant explained that even though they are aware that HIV infection involves both partners "...you cannot transfer our (your) pressure". She feels that as a woman "...you must be strong for anything". Women themselves seem to accept the responsibility for their partners' infection. An informant explained the difficulties women living with HIV/AIDS experience due to socio-cultural pressures:

*The, status of women in our society is a different tribal and cultural setting... that is double trouble for women ... women have to take care of their husbands, who infected them, who in most cases are the first ones to fall sick and by the time he is gone, or he has passed away, there's no one to look after the women. You see, in times the family members will even blame her for infecting their son. And her own family members may even reject her. So that makes triple trouble for women... we kind of get into a situation where I mean there are... social pressures, which are tied to the women. The fact that she's married, (uhh), there is no way that she can refuse sex, (uhh) the fact that she's married, she's suppose to have children. Some of the women would even knowing that their husbands are HIV positive because of the social pressure go into unprotected sex with the husband to satisfy their communities, in-laws and so on. (MOHSS)*

The informant from CAA further explained that women in Namibia would rather put their lives at risk than act against socio-cultural expectations. She explained that a mother might choose not to breastfeed her baby due to her infection. But because her family, including her in-laws, might ask questions, she'll breastfeed her baby even



though she knows this may be dangerous for her baby. A woman's concern, according to the informant, is that "people" might notice her not breastfeeding. Becker (2001) states that women living with HIV/AIDS find it difficult to adopt the correct lifestyle when living with HIV/AIDS, as they are likely to run the risk of being beaten because they are considered to be an embarrassment.

The participants also indicated that there are emotional demands from their children and partners to constantly receive love and attention. These demands are difficult to fulfil as women constantly feel guilty about their infection and envious towards those who are healthy. One participant explained that:

*... You feel hatred towards certain people but they are not the ones who gave you the disease ...*

The participants thus feel that counselling services and caring friends or people are needed to deal with emotional, cultural and social demands. At the same time, the support and care will allow them to be conscious of their behaviour.

*The problem is that most of the time we need to have a sister or friend or neighbour whom you can rely on. Someone who cares i.e. if you did not come out of the house for the day, the person will come and check what is going on. But most of the times you must remain inside the house while others are laughing outside. You feel bad and lonely...*

*...You need a counsellor who will counsel you, so that even if someone does not know or knows about your illness, will be able to help you ... you also have to think about what to say to anyone. Because you have to assess whether people are contributing to your problems or how they have assisted you. As a woman you should always be conscious of your lifestyle and think of how you should behave and stay...*



### 4.3.2 Reproductive demands

There was general consensus amongst the participants that women in general have become “the main victims of the disease”. They felt that as young women, their reproduction is slowed down or even cut off in some instances, because there is no medical intervention. The participants further explained that even if they never had children before, there is a slim chance to have children because of their infection. They therefore choose not to have children at all because of the limited chance of having an uninfected baby. They are often “...waiting for the worse to happen”.

*We feel very bad because we women have become victims of this illness like we women are the most infected with this virus. While this is your peak period to have children, we are unable to.*

The participants and informants explained further that since they are HIV positive, there is a likelihood that their babies will die after three months. The informants indicated that in their work with women living with HIV/AIDS in Namibia, the main impact of HIV/AIDS on women is on their reproduction. Because if a woman decides to have a baby, it is likely to die after a few months since the mother-to-child transmission programme announced early this year (2002) by MOHSS has still not been implemented. The measures that have to be taken in order to prevent HIV transmission, e.g. not breastfeeding, are thus not an option for many of the women. This is because many women live in poverty (all 12 participants are dependent on other people). One participant, in her early twenties, who has only one child, explained that her son always asks when he will have a sister. But she knows it will not happen.

*It is also difficult for you to have children because the child is likely to die after two months or so... Pregnancy has also become a problem because even if you have a child it will die after 3 months or so. Reproduction is as a result cut off.*

They further explained that not having healthy children and the slim survival chance of the baby are not the only limitations. Even if the baby had a better survival chance they are still unable to care for the child emotionally and financially due to their economic status and possible early death. They explain as follows:

*Because you will not be able to care for them (Hum) you just comfort yourself by using family planning ... and at the same time you have to look after yourself so that the children you have can grow up. Because you can die while your children are not grown.*

*For me it is a heavy risk. The risk that I am in is, due to my illness. I lost my job. I have been trying to get money, so that I can make sure my children go to school. I have been running around from here to there, and through that, friends of mine give me clothes, food and a little money. So that is what I occupy myself with during the day ...*

The participants pointed out that despite the above-mentioned difficulties, there is still social pressure to have children.

Other women have however been found to become pregnant for the wrong reasons, according to the CAA informant. Women choose to fall pregnant in order to show that they are not HIV-positive. She explains:

*... I think we still (hum) embark on more education.. Educating (uh) women on HIV/AIDS. (women think) I should get pregnant; ... some women still wants to show the world that I am not HIV positive you know, because I don't know why they think that if you have a baby you are not HIV positive. But those (hum) ideas are still out there...(CAA)*

The participants also expressed concern about the welfare and victimization of their children as a result of their infection as a parent. Some of the participants have thus informed their children, in order for them to understand the changes that might happen in their lives. They are also able to make plans for the care of the child. One participant explained that her fear is that people will taunt their children because their mother died of AIDS.

*... when they are among people once you die, people will refer to them that your mother died of AIDS. So you are not waiting for something else its only death that you are waiting for...*

*... I spoke to my child... I told her that I am sick and can't work for us as I use to do. So there is also nowhere to go for us. Since your father work, you must get to know him so that you establish contact with him. Because I don't know where I should leave them and in whose care I have to leave them...*

Since participants are not able to exercise proper control over their children when they become physically weak, they sometimes find it difficult to discipline their children (Rugalema, 1999). This is because children start fendng for themselves. As a result, parental responsibilities are taken over by grandmothers or the children themselves.

*...My mother is the most important one because she takes care of my child and all other brothers and sisters...*

#### **4.3.3 Domestic Demands**

The participants explained that their HIV-positive status has constrained them in performing their domestic roles with ease because of their deteriorating health. This is because they (the participants) could provide or “struggle” for their children better before the illness, but are unable to do so now as most of them are unemployed, single and too weak to do odd jobs. One participant explained that even if she sells sweets and fruit in the street, people don't want to buy because they suspect you have HIV/AIDS due to your physical appearance, i.e. rashes and pimples. The girl-child and grandmothers thus take over the domestic responsibilities. According to one participant, she is preparing her 6-year-old daughter to survive in the event of her death:

*My daughter is now the one in charge of the domestic affairs she cleans and so on. I feel my child of 6 years must be prepared for life in case I die. She will know how to at least care for herself*



Another participant also explained how children are taking charge:

*So I tell them that I am ... sick and cannot work any more. Cooking has also become difficult because sometimes I have to cook on the fire. Because of the smoke I sometimes faint. It is difficult to have children. Because they obviously have to care for you and take over everything in the house, cleaning and so on*

An informant from MWACW further explained:

*...I hear about households where only grandmothers are taking care... of the orphans (and) the burden of the sick. I mean all these; most of them or all are on women. If they die (mothers of children) then, they have to take care of the orphans under really difficult circumstances. (MWACW)*

The participants explained that their parenting role diminishes while they are still alive, because the children are required to become adults at an early age and to take care of themselves due to the circumstances. Such trends, according to an informant from the CAA, have resulted in children losing control and becoming ill-disciplined, as there is no parental control and supervision. He further explained that these conditions make children vulnerable to bad influences and they may drop out of school at an early age (Rugalema, 1999).

*HIV normally weakens people (immune system) and constrains them in production, resulting in health that deteriorates e.g. terminally ill and can't control children (discipline). I have also observed the terminally ill, who have children that has lost control e.g. school attendance. This makes children vulnerable to bad influences from others. Since women are mostly looking after the house, they worry over children's action. (CAA)*

*Because we are, we are having these houses; younger children now head some of the houses, because their parents died of HIV/AIDS. (MWACW)*

*All the time you are waiting for the worst to happen. There is a change in ones life, because you don't work the same way that you use too and you don't walk the distance as it is too long and you get tired easily. Because you are weak (Participant)*

Participants explained that since most of them have not informed their immediate family members of their HIV status, there are expectations to still provide for their families. As most of the participants' children are either staying with their parents or other extended relatives, continuous financial support is expected by their parents or



those they had given assistance to. These expectations have created feelings of hopelessness for them, as their ability to provide has been limited due to their health. The participants stated that this has resulted in them having to pretend to be healthy yet unemployed, to avoid questions. They explain how difficult it is:

*... You can't even afford to work, because how many times will you go to work. You at least want to send your kids even soap to make them feel good, so that they can at least see that their mother is in Windhoek (for work). But they don't understand life and don't know how you are doing. You think to yourself, oh! my children think they have a mother that is alive, but they don't know I am sick ...*

*The way I look at it from my side, I only think about my mother and my child. Because I think to myself, I have this illness and if I die what will happen. My mother is in poverty meaning my child will also stay in poverty and he is still small. I don't know whether he is infected or not, I don't know...*

*All I wish for is a job or help with money. Because your children keep asking for things and that is the thing that one has to struggle with all the time. You feel bad...*

*In my family, I am the eldest and earlier I use to give something each month. I use to send my step mom something every month. But up to now, when she comes I still give her \$10,00 or so... I still try to work because the others are not working. They now realize that I can't give them anymore. I can't walk long distances.*

#### **4.4 Violence and HIV/AIDS**

##### **4.4.1 Disclosure and Asking**

Another common negative response that women living with HIV/AIDS are confronted with is physical violence, emotional abuse or financial abuse as a consequence of their HIV status. Even though the number of participants is too small to draw a conclusion about the risks of disclosure, it is important to acknowledge the presence of such incidences in their communities.

The participants indicated that, as women, they are scared to reveal their status to their partners. This is because of the risk of being beaten. The participant who was tested positive in 1986 explained that she tore her clinic card into pieces because she was afraid her boyfriend would find out. She further explained:

*...I told the people that the Dr's said I was just very ill ... So I stayed and while we were like that, that man (boyfriend) use to beat me a lot, beat and beat and beat me a lot. I started thinking to myself, I must make a plan to leave this man. I left him and started staying alone as I was working for myself I could struggle for myself...*

Despite having a current boyfriend who does not physically abuse her, she had not told him about her infection when she was tested again in the year 2000.

*Like now the boyfriend that I am staying with now does not know anything. Even here at the CAA, I always lie to Faith. I told her that she must please not tell my boyfriend for now. He also went for a blood test so when he gets his results, only then will he know what is going on. And so the men does not know...*

As such they prefer to keep quiet until their partners find out for themselves. Some women, according to one participant, are threatened by their male partners who discover that they are sick. She said that the boyfriend or husband would tell his partner:

*... If I hear you are HIV positive and I am diagnosed with HIV I will kill you...*

Obviously such a response is terrifying to anyone who has just received news that will change their lives forever. Vetten et al (2001:19) explains that women who keep their status secret experience "stress and guilt", since they are aware of the consequences of their secrecy. According to an informant, the secrecy can also lead to a "quicker progression in the illness".

Another participant, who is 24 years old, related that she and her husband separated because she asked him about an affair that he had. He responded that if she is aware of him sleeping around “why is she still staying with someone who had slept with an HIV-positive person” and “why did she not go back to her family”. She had later on found a note saying:

*“Just take your things and leave because I am tired. I am not tired of you but by what you said to me with someone who has died of AIDS”.*

Her inquisitiveness thus resulted in her separating from her husband, because she had asked him about an affair that he had.

The participants expressed that they don't feel pressure in revealing their status to their partners, but instead to family members. They prefer their partners to find out themselves, in order to avoid physical violence or emotional abuse. The participants also explained that they don't want to feel responsible for their partners' actions. One participant related how she is aware of cases where a woman says that she feels sorry to tell her husband or boyfriend about her HIV status, because he might commit suicide.

Four of the participants who have informed their partners about their HIV status have found them to be cooperative and supportive of them:

*I told him that they found I have HIV, but they told me that the person whom I stay with (sleep) should also go for testing. Okay, then he also went for the test.*

One of the four participants, however, explained that her partner rejected the information and did not believe that they are HIV positive:



*I told my boyfriend that it seems they found me HIV positive. Then he said nurses like lying. I said, do you think computers lie? It is true because machines just don't show anything. But he said, no nurses like lying.*

#### 4.4.2 Condom use

The participants had different opinions on the attitudes of men in Namibia towards condom use. Seven of the twelve participants felt that men are aware of the dangers of HIV/AIDS but still don't want to use condoms. They explained that a man would rather use condoms with his casual girlfriend but not with his steady partner. The participants considered this approach to hinder their efforts to introduce condoms to prevent infection.

*The men are not behaving well, because one will just answer you and say, you know the story already. I will not use a condom. But in the mean time his sexual behaviour is not good. You on the other hand want to protect yourself but he does, one day he uses a condom the other he does not. You don't know how life is. They are really not behaving.*

*You know you can find someone walking with condoms in his pockets, but he maybe use it some place else. But with you he will not use it. Whether you live together or you live separately and he only comes to your room. You will find maybe he does not sleep at your place and he comes there in the morning. He will take his clothes off, put it here and go in the shower. You may find condoms in his pockets, but he will not use it on you ...*

Participants also felt that their partners are always suspicious of them when they ask to use condoms, and often think that they are unfaithful. Their partners would in most cases ask why they are introducing condoms if they have not been doing so before. Other men would not use condoms because they believe that they will be infected with HIV one way or the other and that there is no need to protect themselves. The belief that a person will be infected even if condoms are used might be ascribed to the fact that men do not trust condoms or belief that they burst. The participants blame this attitude on the disrespect men have for women.



*... You see these men actually are just disrespectful... The other one will maybe say, if we are infected I don't care because both of us will have it...*

Some participants felt that men have an understanding of why condom use is important and are willing to do so. They said they could introduce the topic with ease due to the public exposure of HIV/AIDS issues. Men however will still decide whether they will use condoms or not.

#### **4.4.3 Negotiation for safe sex**

Participants felt that men have an understanding of why condom use is important and some men are willing to do so. They said that they could introduce the topic due to public exposure of HIV/AIDS issues. They were however of the opinion that women still find it difficult to negotiate safe sex practices. Negotiation was found to be difficult as men still decide whether they will use condoms or not. An informant from MOHSS explained that women would knowingly engage in unprotected sex with their HIV-positive husband. He said: "It is like taking poison".

The participants indicated that men always want to show that they are in a superior position and therefore do not listen to their women. The men would rather listen and take advice from their male friends.

*You do tell them but also with difficulty and he will agree. You want to go on with you life and your children are small. Someone does not even have any children, there is just nothing. So you really want to move on, but your partner doesn't want to support you. If you tell him something he doesn't want to but he will only accept it if it is coming from his friend.*

Some men boast to their male friends about their dominance over their women. Such behavior, according to the participants, reflects the social acceptance of male dominance.

*...because they would say things like, she just know that if I tell her I am not using a condom, that is the way she knows me...*

The participants pointed out that even if they themselves explain the danger of HIV/AIDS and the possibility of infection to their male partners, they still do not cooperate. The boyfriend or husband would rather respond: "...you already have the illness what will it help to use a condom". Other participants agree that:

*It's just the way the others are saying if you tell them to use a condom they don't want to. He will just say, you already have the illness, what will it help to use a condom. While you at least want to really take care of yourself, so that you can go forward.*

As such, the participants felt that men are jealous and feel threatened by women. Men have the perception that they don't want to die alone and thus have to take their women with them, by infecting them deliberately.

*At the same time it seems as if they are jealous. Men are now a day's jealous of their women. If they see their lives are not prosperous they don't want to leave you behind. He wants to abuse you so that you can also die with him if he has to die. (Hum) Even if he is using condoms he still uses alcohol. But alcohol will kill you quickly, because it breaks your immune system down. But he use condoms but he drinks far, far too much and one is not suppose to drink.*



#### 4.5 Summary

The results indicate that due to the stigma attached to HIV/AIDS, women living with the illness encounter various pressures, reactions and difficulties because of their infection. As a result, their main fear is of being rejected or abandoned by their partners and family members. Women who have disclosed their status in an effort to enlist support have been abandoned and rejected by either partners or family members, as they are blamed for their infection for the loss of household income. In fact, women seem to assume responsibility for their partners' infection.

The results further show that motherhood, children's welfare, diminishing parental roles and possible victimization of children are major concerns for women living with HIV/AIDS. However, they choose not to have children because of the consequences of their infection, especially with regard to the chances of survival of the baby, and the emotional and financial care they need. At the same time, others choose to have children due to misconceptions about what it means to be HIV-positive. Furthermore, children who are born before their mothers are infected are confronted with becoming adults at an early age, because they take charge of domestic responsibilities. This makes them vulnerable to bad influences, and in many cases they become school dropouts.

Socio-cultural expectations, violence and reproductive and domestic demands are also difficulties that participants in the study are confronted with. This has resulted in indirect conflict between living with HIV/AIDS and socio-cultural expectations, since women would rather put their own lives at risk in order to satisfy society, family and

their partner. The participants felt that even though they are able to talk about safe sex practices, their partners still made the decision on the usage of condoms. It can be concluded, based on the results, that the main challenge for women living with HIV/AIDS is the limited options and opportunities available to them, including the ability to protect themselves from HIV infection. The participants felt that there is a need for adequate support and counselling services in order to cope with the various expectations and demands.

Chapter 5 will discuss the empirical findings related to the coping strategies that women living with HIV/AIDS use and the support systems that have been developed.



## CHAPTER 5 - COPING STRATEGIES AND SUPPORT SYSTEMS FOR WOMEN LIVING WITH HIV/AIDS

*HIV/AIDS support should be a commitment "...to reach a consensus on meeting the needs and expectations of people with HIV that is perceived as equitable and responsive to other equally important needs" (UNAIDS, 2000a:88).*

### 5.1 Introduction

In this chapter, I will present an analysis and discussion of the coping strategies utilized by the group of participants living with HIV/AIDS. I will also show what support systems the various institutions interviewed have developed to assist women to cope better with the disease.

Since all the participants are attached to the CAA Centre, their coping strategies are influenced by the CAA. The coping strategies they use are mainly at organisational level and are therefore based on external resources. Even though internal support resources are present, including family support and personal resources, the participants have not used these abundantly as a way of coping. The results show that participants mainly utilize spiritual consolation and group support meetings as ways of coping. Most of the participants have not established community-based support groups outside of CAA support, as they have not publicly disclosed their HIV status.

The support systems provided for women in Namibia range from educational programs, policies and projects. There are also social welfare grants that women can access in order to get financial assistance. Even though the above-mentioned support services do exist, access to these services for women living with HIV/AIDS is not

guaranteed. Most of the participants are not aware of all of the services at their disposal.

## 5.2 Coping strategies

The participants and informants indicated that coping with HIV/AIDS in Namibia is a difficult experience. This is because of socio-cultural expectations that include reproductive and domestic demands on women. At the same time, they have to care for themselves. One participant explained that a women's willingness to live positively greatly depends on her male partner. She explained that:

*... You as the woman behave yourself, but the men no, he just behaves as he wants. The person drinks (alcohol) and then he wants to force you to drink, drink you use to drink, even if you don't take the alcohol what will happen. If you have to die you will just die. But I don't want to die like that; I don't want to die.*

The participants stated that while they would have preferred to receive support from their partners, brothers, sisters etc. to cope at home, they cope better away from home through the support of organizations. This is due to them bearing the blame of infection; pressure to disclose their HIV status and men's unwillingness to cooperate.

Reported personal coping strategies that the participants use are 'keeping busy' at the CAA Centre; attending support group meetings; speaking informally to fellow women who are also HIV-positive; and spiritual counselling and religious activities.

The participants indicated that they go to the Centre everyday to work on a Beads Project. This keeps them busy and enables them not to think about their social or economic problems.



The support group meetings at the Centre are a major source of support, according to the participants. They feel comfortable in the groups as all of them are at the same level of understanding. One participant explained that:

*...You can talk about anything or can be given advise on what HIV/AIDS is ...how HIV/AIDS influence or can impact on your children and all your family members*

Even though bible studies are also held in support groups, spiritual counselling and informal conversations are utilized at a personal level as a coping strategy. The participants have prayer sessions where they read the bible and pray for each other. They explained that hope in God is all they have. Other participant's felt that what happened to them has been determined by God and as a result felt that God will also find a way out for them. One participant used the phrase *Weshipewa ku Mpamba taamba owala*<sup>3</sup>.

With regard to informal discussions, the participants share information on where assistance is rendered to people living with HIV/AIDS, including which tablets or vitamins are available on the market. The participants further advise each other on how to negotiate for safe sex and how to live positively with HIV/AIDS.

*We tell each other where you can get help or where HIV assistance can be found. We also tell each other where we can get tablets when one of you learn about new drugs, especially vitamins that can boost your immune system. ... Since we are now many, each one tries to buy medicine...*

These strategies help them to make sense of their circumstances and to learn more about the disease and living positively with it.

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<sup>3</sup> Phrase in Oshiwambo (local language) What God gives you accept with both hands

### 5.3 Support systems

#### 5.3.1 Personal support and care

Participants explained that the personal support systems have not worked for all of them. Personal support includes support from family, extended family and friends. The first institutions that participants seem to seek support and disclose their HIV status to are assistance-rendering institutions. Participants explained that they knew they would get help and would not be rejected. During the focus group discussion, five participants explained that they came into contact with the centre through referrals from nurses in hospital and friends that are also HIV-positive. Family members on the other hand were frequently informed about their HIV status when the women's health deteriorated or after several sessions with counselling services. The participants further explained that despite the fact that they do not feel comfortable in disclosing their status to family members, but they felt pressurized to do so because of the expectations that family members have on them. Their experience was also made worse by negative comments made and questions asked about their physical appearance for example:

*My family for example, I am staying with my brother and I have not told him about it, because I am staying with them but they are not treating me well. I have not told him. ...I have not told anybody, because the person that I actually have to tell is in the north (northern part of Namibia)*

*I did travel twice to the north but when I arrived at home I did not say anything. If I look at the person whom I think I can tell. I just can't and I feel as if life is not fair. I look again to the next person, so that I can tell them but up to today. But now I pray to my Lord that he must help me, because he will be the only one to know that I am HIV.*

Seven of the participants that have informed their children, partners, parents, siblings, friends or others, revealed that they have received mixed responses. One participant



shared that after she told her Aunt and the rest of the family, they started ignoring her. She would meet with them in public but they would pretend not to see her. If she attempted to draw their attention, they would look at her and walk away. Other participants however feel that their families have been very supportive. A participant, who informed her mother, was for example taken for registration to the CAA so that she could receive counselling services and any other assistance. Her mother also takes care of her by providing her with vitamin tablets and other forms of care.

Most of the participants however are not currently living with their families or in the same towns. As a result familial support is limited or completely absent. Grandmothers, however, seem to be the greatest internal support system for women. Of the 11 women who have children, five live with their children while six of the women's children are either living with their grandmothers or extended family.

The research participants indicated that they have not individually or collectively established support structures in the community to assist each other. They have however, through support group gatherings at CAA and assistance from counsellors at the Centre, established activities that they actively participate in at group level.

*We have support groups in which you can talk about or can be given advice on what HIV/AIDS is about and what alcohol can do to your body. How HIV/AIDS influence or can impact on your children and all your family members. Also that it is better to behave and stick to one partner because HIV/AIDS can also contribute to you losing your job...*

Participants also reported on the assistance and services that they received from health officers. Only one participant reported a bad experience as discussed in chapter 4. All the other participants tested in other parts of Namibia reported that they have received adequate treatment with regard to pre- and post-counselling. They received sufficient

information and explanation on possible life changes if they were found to be HIV-positive. They were then given an option to proceed with the test or decline to be tested.

### *5.3.2 Agent-specific support structures*

The informants from the institutions interviewed indicated that various support systems to meet the needs of people living with HIV/AIDS in general have been introduced and set up in Namibia. These systems also cater for the needs of women, even though they are not specifically developed for women living with HIV/AIDS.

The support services that are currently provided by MOHSS, CAA and MWACW for women living with HIV/AIDS are based on the mandate and objectives of the service-rendering institution. As a result, institutions offer various activities that are currently available for people living with HIV/AIDS in Namibia. In the interviews, these emerged as follows:

#### *5.3.2.1 Catholic Aids Action (CAA)*

The CAA has developed support groups where women meet to share their difficulties, advise and encourage each other, pray and have bible studies. Home-based care and counselling training is also provided for volunteers, especially women, as they are the major caregivers. The training enables the women to assist others who are also HIV-positive in their communities or homes. According to the CAA informants, home-based visits assist the counsellors to identify households that need additional



assistance in understanding the disease or that need spiritual assistance. CAA provides support in terms of providing school accessories through a program for orphaned and vulnerable children. Children who are vulnerable, such as orphans and unemployed children of single parents, are given a voucher of N\$250.00, made out in the name of a local shop to acquire school accessories such as uniforms.

The CAA has further developed educational programs for the youth in general and specifically for women living with HIV/AIDS. The youth program is called "Stepping Stones" and focuses on awareness raising, sexuality and spiritual growth. Gatherings are held for the youth at the Centre where they come together for discussions. The program for women is aimed at women who are living with HIV/AIDS. It focuses on empowering women with the tools on how to live with HIV/AIDS, the consequences of choices made, e.g. sex without a condom, pregnancy etc. and the options and services available.

The Centre also has a Beads Project that the participants volunteer to work on as a way of keeping busy. They are thereby given a small amount of money occasionally to help themselves. Since the project is not profit-driven, it serves as a financial support system for the women. Another support system that participants believe is significant are the food parcels that they receive every Friday from the CAA. These food rations ensure that they have food at least every Friday and don't need to "beg" for food.

### 5.3.2.2 Ministry of Health and Social Services (MOHSS)

The informant from MOHSS explained that their focus is on coordinating and monitoring HIV/AIDS activities in the country. As a result, they monitor HIV/AIDS activities that are conducted and assess the growth or stagnation of HIV/AIDS infections. The Ministry also serves as technical advisor to companies or institutions that seek to develop and implement HIV/AIDS programs in the workplace or communities. They have no programs that specifically target women living with HIV/AIDS.

### 5.3.2.3 Ministry of Women Affairs and Child Welfare (MWACW)

The informants from MWACW indicated that it is a newly established ministry (2001), and has not developed multiple programs to address the needs of women living with HIV/AIDS. The Ministry has, however, recently launched and implemented the Femidom (female condom) Project on 20<sup>th</sup> April 2001. The project aims to empower women in safe sex practices. It also serves to give women an option of using the male or female condom.

The Ministry also networks with various ministries and NGOs to support people living with HIV/AIDS on a national and regional level. As such there are plans to develop programs to support women living with HIV/AIDS.

*Actually... the ministry is in a process of coming up with an action plan for the ministry. We are still in a process where we have just put up a task force to work on our own action plan... be able to identify whether we are going to ... only concentrate on the Female condom, we might also have this home based care... to assist those who are caring for the infected (MWACW)*



#### 5.4 Policies and strategies

The informants explained that Namibia has adequate instruments that specifically deal with the elimination of gender-based discrimination and HIV/AIDS discrimination for people both living with and without HIV/AIDS. The informant from MOHSS explained that it is no use adopting or developing new policies if they are not adequately implemented. The informant further suggested that there is a need for NGO's to assess and monitor whether everybody is aware of the services. The policies that are currently in place are:

- i) The National Gender Policy of 1997
- ii) Namibian HIV/AIDS Charter of Rights of 2000, and
- iii) CEDAW document of 1995

There are also other policies for the aforementioned services that women living with HIV/AIDS can access. These include social welfare grants, which constitute school care, foster care and disability grants. The following programs have also been proposed but have not been implemented yet:

- (a) Prevention of Mother-to-Child-Transmission (MTCT) programme and
- (b) An HIV/AIDS Orphan Fund

The informant from CAA explained that even though the MTCT programme has been proposed and has received publicity, nothing has been implemented. There has been misunderstanding and confusion, because women believe that pregnancy will give them access to the drugs and will cure them. Men, on the other hand, according to the informant, have the perception that the programme is intended to cure women only.

## 5.5 The need for women-only approaches

According to the informants, the need for women-only approaches is essential because of the difference between the needs of women and men that are influenced by socially and culturally constructed expectations that still dominate Namibian society.

One informant explains:

*... I don't think that much is being done for them. You get the women who have lost their husbands... They are working, they need to look after their children, they (women) don't even come for counselling, and there is no time. They work from Monday to Saturday. So there is no support. Women need... to be strong to hang in there for the sake of the children and for her sake... So the one option for her (women) is telephone counselling... if that women... is not working with a phone... what happens then? How does she cope? She has that fear ... to go to work tomorrow, taking my children to school so that they can maintain the life that my husband had for my children... how do I console them (the children) in a way that they don't hate their father... I mean, even some of them... you get married women, they find out they are HIV positive when the husband is being buried... (CAA informant)*

The informants further explained that while there is a need to formulate programs that target the needs of women, these should also include men. It was felt that men should be included in women's activities to stimulate collaboration amongst partners or between husbands and wives. Another informant cautioned that reverse discrimination should be avoided in which HIV/AIDS assistance only focuses on women and excludes men. This is what two of the informants had to say in justifying why approaches that focus on women are needed:

*Now even when we went for the female condom we were saying that... is a partner issue when it comes to sexual intercourse. So you cannot just target women only. Because you might target a women and then when she go back home, then the partner might refuse to use the condom. So we were saying that lets... bring them both on board. So that, they can have the same level of understanding and then, it will be better. It will even be better for us. Because you know in our cultures, it is sometimes taboo for a woman to say no ... (MWACW informant)*



## 5.6 Access to information and services

Accessibility of services has been found to be a problematic area. All the institutions acknowledge that nothing has been done to secure services for people living with HIV/AIDS and specifically women living with HIV/AIDS. As such they felt that unless marketing strategies and priorities are changed to cater for women with HIV/AIDS, their needs would remain invisible. At the same time, support structures will also remain inaccessible. One informant explained what should be done:

*They need to know about condoms they should be having condoms, we are talking about female condoms now, and I mean, so many rural places is not even thousands of women like Namibia in rural settings did not even see this condom... They need to be educated on that, for them to appreciate the female condom if they have to put it in and so on... And that's the only time I mean we can really kind of have positive results in terms of women being able to cope with the situation they face... So we need a whole kind of a market education, public awareness not only for women services but all the services that we suppose to get is offered. And I think that is basically a challenge. (MOHSS)*

Access to health services and other resources for HIV/AIDS was also believed to be based within health institutions only. However, not all these institutions are within walking distance of some areas. Informants suggested that an extensive campaign should be launched around the services available for people living with HIV/AIDS with a particular focus on women.

*I think maybe we have to do a lot so that the rural community has also access to condoms especially both male and female condoms. For them is just when you are going to a hospital at a certain town. That is where you are getting condoms. (MWACW)*

## 5.7 Summary

Results presented in this chapter indicate that women living with HIV/AIDS find it difficult to cope, particularly with respect to fulfilling social and cultural expectations. Because HIV/AIDS influences sexual relations, the participants felt that women's willingness to cope with the disease depends on male cooperation, which is not always available.

The results further found that because of the blame, pressure and negative responses, participants experience at home disclosure of HIV status was found to be difficult for them. The participants depend more on the organizational support systems available to them. The results show that the first institution to be informed about a person's infection tends to be the assistance-rendering institutions and organizations. Families are informed after a few counselling sessions or attendance of support groups at the Centre.

One of the positive aspects of the results is the role that health officers play. The results show that pre- and post-counselling was consistently offered to the participants. They were also referred to an institution where they can receive further counselling services and any other additional services that are provided. One incident of ill treatment has also been reported in the study.

While some of the support systems, such as the income-generation activities have been found to be useful, there is a general feeling that the support systems and services available are still limited, inaccessible and not focused enough. There has



also been some misunderstanding and confusion arising from the announcement of the MTCT programme, since it still has not been implemented. Both participants and informants suggested that it is essential to differentiate between female and male needs, although men should not be forgotten in the interventions

It is evident that an understanding of the status of women in society and the need for the inclusion of men to guarantee understanding and cooperation needs to be seriously addressed. Although the results show that the government has adopted significant instruments to meet the needs of women living with HIV/AIDS, not enough is being done to ensure that women claim their fair share of services available.

Chapter 6 will conclude and provide a summary of the findings.

## CHAPTER 6 - CONCLUSIONS and RECOMMENDATIONS

### 6.1 Introduction

This study focused on a group of women living with HIV/AIDS within the Namibian context. It dealt with the experiences of the participants from the day their HIV status was confirmed and the coping strategies they reported utilising. The study also attempted to explore the nature of support systems that are in place to support such women living with HIV/AIDS. This final chapter aims to highlight the major issues that emerge from the empirical findings. I will explore the implications of the study for support of women living with HIV/AIDS and offer recommendations derived from the study, including possible future research activities.

### 6.2 Summary and conclusions

This study has offered a perspective on what a group of Namibian women living with HIV/AIDS experience. The results clearly indicate how complex HIV prevention and coping strategies are for women within societies driven by various social expectations and cultural values and where gender relations are imbalanced. It is hoped that such findings will provide a source of information to the Ministry of Women Affairs and NACOP on the conditions tolerated by women living with HIV/AIDS and their need to be supported.

The literature reviewed indicates that women all over the world experience some degree of difficulty as a result of their HIV infection, given that the illness is

entrenched in women's social, sexual and economic status (de Bruyn et al, 1998; UNAIDS, 2000a). In most African societies, HIV/AIDS has sparked a new form of oppression due to the triple burden on women, women's limited knowledge of their own sexuality and personal/political rights, and the limited provision of services (Tallis, 1998; Berer & Ray, 1993). At the same time, focused support services that aim to sufficiently address the needs of women living with HIV/AIDS are inadequate. This is unfortunately still the case in the face of the HIV/AIDS pandemic, as many African countries have not improved access to services and their awareness of women's needs (Barnett, 1992; Meursing & Sibindi, 1999; Rugalema, 1999). The findings of this study confirm that women in Namibia experience similar difficulties in accessing services related to HIV/AIDS, since they are either limited or absent.

The results further indicate that women in Namibia experience various pressures, negative responses and especially economic difficulties as a result of the stigma attached to HIV infection, the low status accorded to women and gender power imbalances. Women are blamed for their own infection and that of their partners and children. They are also blamed for the loss of household income. As a result, women find themselves being ostracized, rejected, unemployed and abandoned. This has led to women themselves feeling responsible for the disease. The participants in this study confirmed the argument that there is no shared responsibility created or encouraged in public messages about HIV/AIDS but that women are by nature made accountable for the disease (Richardson, 1989; Burry et al, 1992).

At the same time, the impact of skewed gender relations in society indicates how women are expected to be passive and subordinate to men because of certain aspects of socio-cultural expectations that act as barriers to enlisting support and ensuring prevention of HIV/AIDS (Becker, 2001; Vetten & Bhana, 2001; Burry et.al, 1992). The results also indicate that women in Namibia experience these barriers as it is socially accepted and enforced through male dominance (Becker, 2001). The demands and expectations thus seem to be a dual problem for women living with HIV/AIDS. This urgently requires a gendered approach, given that there is a conflict between positive living and socio-cultural expectations of women living with HIV/AIDS. As in Strebel's study (1993), the participants in the study appear to have adequate knowledge on HIV prevention in order to protect themselves. The problem however remains how they would achieve this when they do not have adequate personal support and cooperation from their male partners.

A major concern that has been identified in the literature review and confirmed by the results are the domestic and reproductive dilemmas of HIV-positive mothers. These mothers are concerned about the welfare of their children as they are in most cases left unemployed and are not financially and often physically able to care for the children. But due to the participants' desperate need to care for their children, they seek help from assistance-rendering institutions or friends, instead of family members, because of the negative responses they encounter from their families. Women are thus frequently dependent on the support of people outside of their families, which is exacerbated by the finding that they often lose their jobs because of their infection. This indicates that people living with HIV/AIDS experience very limited job security



even though the Charter of Rights for HIV-positive people protects the employment rights of people living with the virus.

Women are also concerned that their children will carry the legacy of being born to an HIV-positive mother and have sometimes, in an effort to protect them, opted not to inform their children. The literature however indicates that there are positive and negative aspects in informing children. For some it may allow better understanding of the illness to children and why people's behaviour may change. On the other hand, children are burdened with the responsibility of secrecy, fear for their mother's health, the consequences of public knowledge and possible death of their mother (Dorn et al, 1994).

Whilst many women choose not to have children due to their infection (even though they are socially pressurized to do so), the study found that there are also misconceptions about being pregnant. Some women use pregnancy as a way of seeking social acceptance and validation and to show that they are not HIV positive. Socio-cultural pressures further exacerbate this social validation because it is attached to motherhood. The social value attached to motherhood is confirmed in the literature (O'Gara et al, 1996; Burry et al, 1992; Dorn et al, 1994; Were, 2000; Meursing et al, 1999). The study further shows that women may also be using pregnancy as an attempt to show that they are not HIV positive, indicating that there is little understanding of how the virus manifests itself. Women thus need to be educated. Further evidence of the study is the confusion and misunderstanding that emerged from the announcement of the MTCT programme early this year. Many people have not grasped what the MTCT programme entails, because women view the

drug as a cure and become pregnant in order to have access to anti-retroviral drugs. Unless awareness campaigns are carried out and understanding of the drugs is created, Namibia will be confronted with another problem of further animosity between men and women, as communities will view the government as supporting women only.

A serious concern that has been pointed out in the literature and confirmed by this study is the link between violence and HIV/AIDS (Vetten et al, 2001). Violence has been found to be part of the barriers to women disclosing their HIV-status and negotiating safe sex practices. Violence is perpetrated in various forms such as emotional, economic and physical abuse. Women living with HIV/AIDS thus fear to disclose to their male partners, possibly resulting in infection of partners, as they are scared to be “killed” or physically abused. This has been said to be a result of the jealousy men feel towards women and the disregard of women’s opinion. As Becker (2001) shows, women are expected to ‘act shy’. It is evident that women thus have limited control over their sexuality and prevention of infection or infection of others, as they would rather risk being infected or infecting others than lose out on a relationship or disrespect their partners. The decision for many women to stay in abusive relationships with men may be because of their need to survive as indicated in the study. The participants explained that due to their unemployment in most cases and limited support, women “use” their partners to provide them with basic necessities such as shelter, food and clothing. On the other hand men who violate their women due to their HIV infection are indirectly contributing to their own infection, since their women knowingly infect them. Violence therefore has serious implications for government’s efforts as women are made to take responsibility for the spread of the disease despite not having social power. Becker (2001) explains that

HIV/AIDS has intensified masculine powers over women as men attempt to enforce their power.

Due to the difficulties, negative responses, concerns, demands, expectations and barriers women experience, the results confirm the literature reviewed with respect to the argument that support systems and services are key to women coping with their infection at a personal, community and social level (Strebel, 1993; Richardson, 1989; CAA, 2001; Burry et al, 1992). The participants however find it difficult to gather support from family and to utilize support systems at organizational level. While familial support does not appear to be available for most women, they do appear to receive positive support at an organizational level. The personal support systems found to be supportive are mainly grandparents as they assist with taking in and caring for children. Families are thus more concern about the children as they are most vulnerable under the circumstances. This is understandable as most families struggle economically to sustain their households and thus prefer to assist those most vulnerable, in this case children. Rugalema (1999) and Barnett et al (1992) confirm that life can become difficult for children affected by HIV/AIDS, including school attendance, as they don't have parental control or guidance. The limitations on support systems, options and opportunities for women and their children is thus a great concern as women often don't have the means to support their children.

The findings further indicate that people living with HIV/AIDS mainly rely on religion as a coping strategy and support system. This has been confirmed by other studies in Namibia where spiritual solace has been found to be a primary support system and coping strategies. Counselling services and support groups have been

found to be a major support for participants, as in other literature, who feel that they are together with others who are going through the same experiences, and are therefore able to learn more about HIV/AIDS (Dorn et al, 1994; Were, 2000; Richardson, 1989). A major support system is the income-generating project run by the CAA. The study found that participants felt a sense of worth to themselves and society as a whole.

Coping strategies for women living with HIV/AIDS has particularly been a challenge, as women's willingness to cope with the disease heavily depends on the cooperation of their partners. In the event where the woman is single, her ability to cope depends on extended family and community support. Negative responses make participants feel guilty and violent relations are often kept secret by women. Participants who, for example, choose not to have children due to their infection are coerced through social values to do so in order to be valued by their partners, in-laws or society. These participants, like women elsewhere, are thus not secure in their social environments. Such security is considered to be essential in order to cope with a threatening disease (Long et al, 1996; Barnett et al, 1992).

Even though the results show that Namibia has adequate policy instruments to address HIV/AIDS, the study also indicates that the needs of women living with HIV/AIDS have not been clearly defined and addressed. Although informants agreed that approaches and programs focused on women are needed, there is a lack of programmes targeting women. The work of the Ministries of Health and Social Services and Women Affairs and Child Welfare does not appear to be visible at a local level for women living with HIV/AIDS. Whilst the mandates of Ministries



allow them to carry out specific tasks, the major line Ministry, that is MWACW, has limited services that focus on women despite their high infection rates. A further support service that has been announced by MOHSS is the MTCT programme, but this has not yet been implemented. It is suggested that this lack of implementation may be influenced by current debates taking place in South Africa.

### **6.3 Recommendations**

The objective of the Namibian government includes reducing or keeping stagnant the rates of HIV infections through prevention, control, awareness raising and support to people living with HIV/AIDS. This study is a challenge to all stakeholders and most of all line Ministries, churches and women's organizations to recognize and address the needs of women living with HIV/AIDS. As findings of the study indicate, women's infection needs to be understood within a complex web of factors, which is heavily influenced by socio-cultural factors. Responses at community, national, organizational or personal levels also have much to do with how women understand and cope with their infection. The following recommendations regarding necessary policy and practical interventions, based on the findings of this study, are thus made:

- Due to the limited options and opportunities available to women living with HIV/AIDS in terms of reproductive health, properly focused implementation and monitoring of existing strategies needs to take place in order to facilitate an enabling environment for women living with HIV/AIDS.
- Support services for women living with HIV/AIDS in terms of counselling, support groups and planning for their children's future should be adequately

implemented and accessible to all women in this situation at a grassroots level. For this to be effected, community members should be given the skills and tools to provide such services. Educational interventions to provide a community understanding of the needs of women and the complex nature of their infection, should be undertaken in order to encourage community initiatives. These community members, including HIV-positive women themselves, should receive guidance from trained HIV/AIDS counsellors to ensure that the skills are applicable and presented in culturally appropriate language. Barnett et al (1992) explains that if guidance is not offered within social frameworks, communities and people affected might reject the strategies.

- Since violence has been found to be a barrier to the prevention and control of HIV infection, there is a serious call for interventions, which deal with violence against women and male control over women's sexuality in communities. Furthermore, men need to be educated and included in reproductive health issues. They need to be made aware of the needs of women and the consequences for them and their children if no support is rendered to women. This will encourage shared responsibility for HIV infection.
  
- Whilst prevention of infection is key, awareness campaigns need to present messages that expose the issues and needs of people living with HIV/AIDS in order to make the disease a visible one, and in the process, challenge the stigma that is still attached to HIV/AIDS. And since socially constructed ideas

of what constitutes “bad and good” women will not be changed overnight, it remains a challenge to society at large to change the perceptions of how men and boys think about girls and women. Tertiary institutions and schools are important components of change.

- Women and people living with HIV/AIDS should be educated about the services and support systems available in their regions and towns, and the positive aspects of utilizing these services. As suggested by the MOHSS informant, marketing strategies need to be restructured in order to reach all people, especially those in rural areas and people living with disabilities, because they are often bypassed. This will encourage positive thinking and community involvement. HIV/AIDS should become a disease ‘spoken about’ and ‘not whispered about’. Regional governors and councillors should be held accountable by presenting bi-annual reviews on HIV/AIDS services in their regions.
  
- Since health officers and caregivers are important support systems for people living with HIV/AIDS, the disease has without any doubt also added to their workload. Therefore, health institutions need to give support to caregivers and equip them with technical resources in order to provide better care for those who are ill.



#### 6.4 Limitations of the Study

This study centered on how various responses influence the experiences of a group of women and the coping strategies they utilize in living with HIV/AIDS. The study thus serves as a mouthpiece for a group of women who have lived with HIV/AIDS for 2 years or more. The intention of the study is not to draw conclusions representative of the situation of all women living with HIV/AIDS in Namibia. It merely aims to give an indication of the situation women are faced with in Namibian society and the issues they are confronted with.

As such, the study has limitations due to the sample it utilizes. The study was only based in one urban-based region and does not give account of rural settings. This is attributed to time constraints and funding limitations. As a result, the findings might not be representative of the experiences and coping strategies of women in rural settings. The region used as a case study is also one of the most advantaged regions in terms of access to information and availability of services. However, the results indicate that the operational levels of institutions and agencies that provide HIV/AIDS-related services are believed to be inadequate in both rural and urban settings, as is shown in Chapter 5.

Since none of the women have finished their basic education, are unemployed and seven of the women live in shacks, their experiences are different to women who are employed and have completed their secondary or tertiary education. The findings of the study are thus influenced by the education level and economic standards of the participants. A more comprehensive study, looking at women across the different



regions, including rural and urban areas, and all levels of education and class, would be necessary to provide a more representative picture of Namibian women living with HIV/AIDS.

## **6.5 Recommendations for Future Research**

Given the strong influence of social and cultural expectations on how communities and family respond to women living with HIV/AIDS, including the impact of violence on HIV/AIDS, extensive national research on the needs and experiences of women living with HIV/AIDS is essential in order to inform national support services. At the same time, an assessment of current messages aimed at women living with HIV/AIDS (and those who are not) should be considered to see whether they are culturally appropriate and accepted within the Namibian context.

A further recommendation for research is an investigation into men's understanding of the needs of women and perceptions of condom use, negotiation for safe sex and violence. This should include how they (men) can contribute to HIV prevention and facilitating disclosure of HIV status. Addressing the myths and perceptions of what constitutes an HIV-positive woman in the Namibian context is also needed in order to facilitate sensitive responses from community and family. Finally, an evaluation should be done to determine which regions have support services and where services need to be established to ensure that the whole country is provided with support services.

In spite of the limitations of the study, it is evident from this small sample that there is a long way to go in meeting the needs of HIV positive women in Namibia. Nonetheless, these women illustrate an ability to utilize whatever they can to survive and to support or find support for their families. It remains an important challenge for communities and the state to more adequately provide for women living with HIV/AIDS in Namibia.

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## APPENDIX 1- VIGNETTE

This is the story of Margaret, who comes from Kwa-Zulu Natal in South Africa, she has been living with HIV/AIDS for three years.

Margaret told that she is certain her ex-boyfriend infected her. "He told me that I was mad and that there was no way he could have infected me, he said that it was a women's disease and that this must be God's way of punishing women. "But it could only have been from him, he was my first boyfriend and the first and only person that I have had sex with. I didn't really want to, but he kept telling me that if I loved him I would and my friends kept saying that if I didn't he would leave me. So I did."

Margaret comes from a low income family only her mother works and then her grandmother helps by giving them some of her pension money each month." She has two younger siblings, a brother aged 14 and a sister aged 11. "When I first found out I was HIV positive I did not know what that meant. I thought okay, so I am going to die tomorrow. I felt alone and scared and ashamed because people might think that I was sleeping with all the boys," she said. "For a long time I couldn't tell my mother I was scared that she would chase me away, but eventually I did and my mother just looked at me and cried. She also said that I would die the very next day."

Eventually she and her mother were put in contact with a NGO that was counselling people. "They helped us understand what HIV is and that I could live for a long time. They explained everything to us and then we went home and explained to my family." When people first found out, they cursed her and some called her "the devil". Her mother and family were also targeted, and at school her younger siblings were teased and told that they had to keep away from the other children.

But it was the isolation from the community and her extended family that was often worse. "One minute I was part of them and the next they wouldn't even walk on the same side of the road as me. I couldn't understand that and at that time I didn't know anybody else that was living with the disease. I was alone." Through a nurse in another area Margaret was able to link up with an organization for women that are living with the disease. "In the group we are all the same, nobody is better than the other, we share our experience and find ways of living with the disease.

She adds: "I am sad because I know that if I have a child it could have HIV/AIDS so I choose not to have children because I don't want them to go through what I am going through. Margaret says one of the hardest things is not having the medicine that she needs to take care of her. But Margaret says her biggest fear is that her sister will follow in her footsteps. "I tell her everyday about the dangers, that she can say no at anytime to sex".

Source: [www.relief.int/irin/hivaids/](http://www.relief.int/irin/hivaids/)



## APPENDIX 2 - DEMOGRAPHIC QUESTIONNAIRE

Strictly confidential

1. Region: Khomas

2. Residential area \_\_\_\_\_

3. Age (circle one only)

15 - 20	1
21 - 25	2
26 - 30	3
31 - 35	4
36 - 40	5
41 +	6

4. Levels of Education completed (circle one only)

None	1
Primary	2
Secondary	3
Tertiary	4

5. Marital Status (circle one only)

Never married	1
Married	2
Co-habiting	3
Divorced	4
Separated	5
Widowed	6

6. Are you employed? (tick one only)

Yes

No

7. Do you receive any kind of grant or any other assistance?

Yes  No

If yes, explain \_\_\_\_\_  
\_\_\_\_\_

8. Do you have children?

Yes  No

9. If yes, how many children do you have? \_\_\_\_\_

THANK YOU



## **APPENDIX 3 - SCHEDULE QUESTIONNAIRE**

### **FOCUS GROUPS**

1. What are the general experiences of women living with HIV/AIDS, from the time of receiving confirmation of their status until present?
2. What have the various responses been from family, community, health officers and spiritual leaders to their status?
3. How does HIV/AIDS influence their reproductive and domestic role?
4. What are the emotional, social and physical demands that they are confronted with?
5. What support structures and coping mechanisms have women developed?

### **KEY INTERVIEWS**

1. In terms of policies, what strategies and intervention methods are in place to support women living with HIV/AIDS?
2. Is there a need to set-up approaches that only deal with women?
3. What support structures and coping mechanisms have your agency/organisation set-up in various regions?
4. Are you aware of any negative practices by institutions against women?
5. What are the experiences on the impact of HIV/AIDS on women's reproductive and domestic role?
6. How is accessibility of women who cannot afford services ensured?

