

**A SOCIAL WORK INVESTIGATION ON HOW HIV AND AIDS POSITIVE PATIENTS  
COPE WITH THEIR ILLNESS AT KATUTURA INTERMEDIATE HOSPITAL:**

**WINDHOEK, NAMIBIA.**

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**By**

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## **Abstract**

The main purpose of the study was to investigate the coping ability of HIV and AIDS positive patients. The research venue was Katutura Intermediate Hospital: Windhoek. The qualitative approach and phenomenological design was used to gain in-depth information about how participants cope with their illness. Data were collected from 20 respondents using semi-structured interviews. A tape recorder and field notes were used as supportive methods. A content analysis was done to analyze the data.

The findings were based on six sections that were explored during the semi-structured interviews which are as follows: personal information, support networks available, the influence of cultural world views as well as coping mechanisms and counseling needs.

The findings indicated that the participants who receive HIV and AIDS medications left school in Grade 8. They have knowledge about HIV and AIDS which they get from the Radio but still the information is not enough to enable them to cope with their illness.

The findings suggest that people need support from the community, churches and their families but this support network is not sufficient to enable them to cope. They need the support for as long as they live.

The investigation into the cultural world view towards AIDS indicated that community members see HIV and AIDS as a bad disease and view people who have it as bad also. HIV positive people then feel discriminated against and fear that they will experience stigma in the community and that they will be dying soon.

The findings confirmed that the HIV and AIDS participants do not cope with their illness. They will only cope when their needs are

sufficiently met. The patients get counseled by nurses, lay counselors, social workers, psychologists, and doctors. The participants suggested that they need counseling from professionals for as long as they live.

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I give thanks to almighty God for giving me life, hope, good health and the opportunity to accomplish my task. Finally I give thanks to everyone who gave me support directly or indirectly for me to accomplish this task.

### Declaration

I Reagan Maiba Maiba, declare hereby that this study is a true reflection of my own research and that this work, or part thereof has not been submitted for the degree in any other institution of higher education.

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Reagan Maiba Maiba

Signed



Date

23/11/11

## LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency syndrome
CDC	Center for Disease Control
MoHSS	Ministry of Health and Social services
STIs	Sexual Transmission Infections
HIV	Human Immune Virus
PMTCT	Prevention of Mother to Child Transmission
UN	United Nations
UNAIDS	Joint United Nations Program on HIV/ AIDS
UNICEF	United Nations Emergency Fund for Children
UNIFEM	United Nation Development Fund for Women
UNFPA	United Nation Population Fund
WHO	World Health Organization

## CHAPTER 1

### INTRODUCTION AND ORIENTATION TO THE STUDY

#### 1.1. Introduction

HIV and Aids is a major public health problem in Namibia and it affects young and economically active people who are responsible for the care and support of their families. Despite a relatively small population of around two million people and a large geographical area of over 800 000km, Namibia is one of the countries in the world most affected by the HIV and AIDS pandemic (Directorate of Special Programmes, 2005). In 2008, Namibia had an HIV prevalence rate of 17.8 % in adults aged 15 to 49, which is lower than 19.9 % in 2006. However the figure is still quite distressing. In some parts of the country between 50 -70% of hospital admissions, HIV and AIDS is the leading cause of deaths and hospitalization (Directorate of Special Programmes, 2005). In 2007, some 52,000 people in Namibia were receiving anti-retroviral therapy to combat the HIV virus. The 2008 crude HIV prevalence among pregnant women was estimated at 17.8% (UNAIDS, 2009). Just like any other country in southern Africa, the impact of HIV and AIDS extents upon all levels of the Namibian society, from increasing morbidity and mortality rates, increasing numbers of orphans, economic erosion due to the decreased size and efficiency of the labor- force and an increasingly overwhelmed health sector.

According to UNAIDS, 33.4 million people in the world were living with HIV and AIDS in 2009. Sub- Saharan Africa is the region with the highest burden, constituting 22.4 million of people living with HIV and AIDS. In 2007, Southern Africa accounted for almost a third (32%) of all new HIV infections and AIDS related deaths globally, with a national adult HIV prevalence exceeding 15% in eight countries. These countries are Botswana, Lesotho, Mozambique, Namibia, South Africa, Swaziland, Zambia and Zimbabwe (UNAIDS, 2008).

The epidemic remains extremely dynamic, growing and changing its character as the virus exploits new opportunities for transmission. Virtually no country in the world remains unaffected, therefore some countries that have let down their guard see a renewed rise in

numbers of people infected with HIV. Industrialized countries such as United States of America , widespread access to antiretroviral medicines is fueling a dangerous myth that AIDS has been defeated. In Sub- Sahara Africa, the overall percentage of adults with HIV infection has remained stable in recent years, but the number of people living with HIV is still growing (UNAIDS, 2004 Report on the Global AIDS Epidemic).

The total number of patients who enrolled at Katutura Intermediate Hospital on HIV care, both patients on treatment and those who were not on treatment was 11819 since 2003. The total number of people who were on pre care, in other words people who were not yet on treatment but actively coming for checkups of CD4 cells was 5222. The patients who were on antiretroviral treatment since 2003 were 6597. The number of patients who were on first line medication for HIV and AIDS were 3831 and those who were on second line medication were 4128. Lastly the number of defaulters on medications was 581 and those who were not on medications and who were supposed to come for checkups of CD4 cells was 857 (Antiretroviral Clinic Data Base, Katutura Hospital Clinic, 2010).

HIV and AIDS can have a major impact on many parts of a person's life and thus people with HIV and those close to them are subjected to psycho-social factors that affect their mental health conditions such as a person 's moods, emotions and behavior. Many people are surprised when they learn that they have been diagnosed with HIV while some feel overwhelmed by changes that they will need to make in their lives. It is normal to have a strong reaction when a person finds out that he/she is HIV positive, including feelings such as fear, anger and a sense of being overwhelmed. And in most cases people feel helpless, sad and anxious about their illness.

This proposed research on how HIV and AIDS positive patients cope with their illnesses was never been studied in Namibia before and thus people living with HIV have great emotional concerns that require support for coming to terms with their infection. Other concerns were shock, fear over how the disease will progress, and fear of isolation by families and friends and also worry about infecting others. Stigmatization and discrimination were major problems that prevented HIV and AIDS patients from coping well with their illnesses (UNAIDS, 2006).

The purpose of this study was to investigate how HIV and AIDS positive patients who were receiving HIV and AIDS treatment at Katutura Intermediate Hospital cope with their illness.

### **1.2. Statement of the problem**

The problem experienced was that HIV and AIDS positive patients were finding it difficult to cope with their illness. People living with HIV had great emotional needs that required support for coming to terms with their infection. Addressing people's emotional needs have positive outcomes on individuals and communities, serving to improve overall health, strengthening preventive behavior, and improving life changes on a range of different criteria. In a survey of women in the United States, psychosocial intervention (a term often used to describe the range of emotional, mental health and psychological support) measures were most frequently mentioned as those which would help them live with HIV (UNAIDS, 2006).

The need to deal with the connection between mental health and HIV was emphasized in a study of Tanzanian women, which found that depression was associated with disease progression and death. A similar relationship was found in America where a third of HIV-positive women were assessed as chronically depressed. Furthermore, the AIDS related mortality rate of those women with chronic HIV was found double than that of women who had only little or no signs of depression (UNAIDS, 2008).

The social worker was more concerned about how HIV and AIDS patients cope with their illness because most patients were experiencing some difficulties in coping when they were diagnosed with HIV and some even ended up in committing suicide, living in isolation, leaving their jobs, neglecting their families, abusing alcohol, infecting other people who were not infected with HIV, and lastly defaulting their HIV medications.

The researcher has been applying social work counseling with HIV and AIDS positive patients for the past two years and in the case work files of the social workers at the Katutura State Hospital in Windhoek, it was found that these patients develop mental conditions. These conditions were fear, anger and a sense of being overwhelmed and they often felt helpless, sad and anxious about their illness.

The following variables were influencing the research problem:

People with HIV and AIDS were normally labeled with names and were also told that they were going to die soon, and they were isolated from people with other illnesses. They lacked knowledge on how to cope with HIV and they were not taught how to cope or live positively with it. Patients, culture made it difficult for them to cope because some cultures viewed HIV as a punishment from God and in such cases HIV positive people felt guilty and started to prepare themselves to die. Some of the HIV patients were not financially stable and they could not afford to buy themselves healthy and nutritious food. They experienced lack of support in the community and most of them were not supported fully by their families in their communities. There was a lack of resources in the community to help AIDS patients to cope such as home based care, recreation facilities and income generating projects for people with HIV. There was lack of networking between supportive agencies and the HIV patients.

### **1.3. The goal of the study**

The overall goal of this study is to investigate the coping ability of HIV and AIDS positive patients to their illness and this will be a baseline study to support other research to develop a program that will empower AIDS patients to cope with their illness.

The specific objectives for this study are as follows:

- To explore whether HIV positive patients are receiving assistance from the resources available at the hospital and the community.
- To investigate whether the counseling programs given to AIDS patients are sufficient enough to enable them to cope?
- To investigate which support systems such as family, friends and community projects are suitable for these patients and how effective these systems are?

#### **1.4. Significance of the study**

The findings of this study will help AIDS patients to cope better because health workers who will receive these results will be able to develop support programs which will help patients to come to terms with their illness. The topic has not been studied in Namibia yet and the findings will serve as a guiding tool to medical social workers of Katutura Intermediate Hospital and also to upgrade the existing knowledge, policies and practices for them.

#### **1.5. Limitations of the study**

The research will only focus on how HIV and AIDS patients cope with their illness at Katutura Intermediate Hospital and the information will be applicable in other hospitals and New Start centers in other regions.

#### **1.6. Research methodology**

This section includes the research methodology to be followed.

##### **1.6.1 Research design**

The researcher will use the qualitative approach and the phenomenological design because this design allows for in-depth investigation into the coping strategies, coping needs and coping abilities of HIV and AIDS patients and is also holistic in nature and allows understanding of the whole phenomenon by discovering, capturing and interpreting the meaning of respondents. The researcher wants to understand how the patients make sense of their lives under distressing circumstances of being ill. The researcher will describe as accurately as possible the phenomenon, reframing from any pre-given framework, but remaining true to the facts. The researcher is also concerned with understanding social and psychological phenomena from the perspective of people involved.

### **1.6.2. The population of this study.**

The target populations of this study are patients who are receiving treatment and who are living with HIV and AIDS and have coping problems. These patients are registered clients of the social worker at Katutura Intermediate Hospital.

### **1.6.3. Sampling method.**

Purposive sampling will be used because it provides a clear identification of the selection of respondents (De Vos et al., 2005, p.329). Twenty participants who are HIV positive and receiving treatment at Katutura Intermediate Hospital will be selected. These will be registered clients of the social workers and each client will have a file from which the researcher can work. The participants will be selected purposively in the sense that they have to be HIV positive and experience coping problems. The participants will also be requested to participate in a research on voluntary basis.

### **1.6.4. Methods of data collection**

A semi-structured interview schedule for in-depth interviews will be used to collect data in this study. A tape recorder and field notes will also be used as supportive methods. To ensure reliability of the interview the research will be consistent and neutral. Consistency will be obtained through a description of method of data collection, analysis and interpretation, the use of a coding-recoding process and "the use of colleagues and methodology experts to examine the research plan and its application" (Rothmann, 2000). Neutrality of the research will be obtained through confirmability of the data and its interpretations.

The focus points of the schedule will be stigma, isolation, cultural perspectives that influence patients' ability to cope with AIDS, lack of family support, lack of skills and lack of networking.

The validity of the research will be ensured through credibility and transferability. To ensure credibility of the interviews the researcher will spend sufficient time with the participant to establish rapport, to facilitate comfort and to increase the willingness to make known sensitive information (Rothmann, 2000). The researcher will rephrase and repeat questions to the

participant so as to gain credible information. Reflexive analysis will be taken into account to prevent close relationships between the researcher and the participant which can possibly have an effect on the interpretation of findings. The researcher will ensure that there are no inconsistencies between the data and the interpretations thereof.

#### **1.6.5. Procedures**

The researcher will invite people who normally receive HIV medications and who have difficulties in coping with their HIV illnesses at Katutura Intermediate Hospital to participate in this study. This process will take place at the Antiretroviral Clinic (Centre for Disease Control). Permission from patients who will participate will be asked and the interviews will last approximately 45 minutes per patient.

The researcher has already asked permission from the medical superintendent of the hospital and the permission was already granted. The semi structured interviews will be taking place in an office whereby the participants will be allowed to go for individual interviews.

#### **1.6.6. Data analysis**

The analysis procedure that will be applied will be content analysis. Answers will be categorized into different types and the number of each type will be added up. This means, identifying the general themes mentioned in the interviews and then counting the number of times they are mentioned (Hayes, 2000). Themes (topics or ideas) which occur recurrently will be recorded. This will assist in determining dominant and sub- themes. The themes will be used to understand the experiences of HIV and AIDS patients. Each interview will be transcribed by the researcher. Tape recordings will be analyzed by using external microphones for clarity and the tape will be transcribed for close analysis. The researcher will also transcribe and analyze the interviews while they are still fresh and preliminary coding will be used (De Vos et al, 2005).

### **1.7. Ethical issues**

The following ethical issues will guide this research. Respondents in this study were informed about the nature of the study and after that the respondents decided to continue. The respondents were assured that the study will do no harm to them; respondents were informed that participation in the study was voluntarily, so whenever they want to withdraw from the study they were free to do so.

The participants were given information about the study so that they could choose whether to participate in the study or not. They were assured of their right to privacy, anonymity and confidentiality. The information will only be revealed with the participant's consent. The researcher was competent and adequately skilled to undertake the study and the supervisor guided the researcher in the entire research. The researcher was objective in making value judgment and acknowledgement was given to each participant's contribution in the research or study. The feelings from the participants were respected (De Vos et al., 2005, p.58)

### **1.8. Summary**

The problem that was experienced was that HIV and AIDS positive patients were finding it difficult to cope with their illness. The social worker was more concerned about that issue. The specific objectives of this study were to explore whether HIV and AIDS patients are receiving assistance from the resources available at the hospital and the community, to investigate whether the counseling programs given to AIDS patients are sufficient enough to enable them to cope and finally to investigate which support systems are suitable for these patients and how effective these systems are. The findings of this study will help AIDS patients to cope well because health workers who will receive these results will be able to develop support programs which will help patients to come to terms with their illness. The study focused on how HIV and AIDS patients cope with their illness at Katutura Intermediate Hospital. Qualitative approach and phenomenological design was used. Ethical issues that guided this research were discussed.

## **OUTLINE OF THE REPORT**

The thesis is organized in the following chapters:

### **CHAPTER 1**

This chapter presents the introduction and orientation to the study, which includes the aims and objectives of the study. The ethical issues of the study are also presented.

### **CHAPTER 2**

The chapter presents the literature review, which is divided into three sections namely: Section A, Putting HIV and AIDS in context; Section B, Factors contributing to the stress of HIV and AIDS patients; Section C, Coping with HIV and AIDS.

### **CHAPTER 3**

This chapter outlines the research design and methodology.

### **CHAPTER 4**

Chapter four presents the study findings

### **CHAPTER 5**

The conclusions and recommendations are presented in this chapter.

## CHAPTER 2

### HOW HIV AND AIDS POSITIVE PATIENTS COPE WITH THEIR ILLNESS

#### SECTION A

##### Putting HIV and AIDS in context

###### 2.1 Introduction

HIV and AIDS have rapidly emerged as one of the greatest threats to human health in the 21<sup>st</sup> century. There were an estimated 4.3 million new infections in 2006; about half of those newly infected were people living with HIV and AIDS. HIV prevalence was estimated at 39.5 million, close to two thirds of who were living in sub-Saharan Africa (UNAIDS, 2006). Women who were accounted for was 48% of those living with HIV and over 25 million people have died since the beginning of the AIDS epidemic. Currently, over 7.500 people die from AIDS each day and about five people every minute (UNAIDS, 2006).

Every second years the Ministry of Health and Social Services (MoHSS) tests pregnant women for HIV as part of the routine antenatal clinic visits. This is done anonymously, which means that nobody can link the result to the person. This survey helps the MoHSS to monitor how HIV is spreading in Namibia over the years. This allows the Ministry to see the trend of HIV prevalence and the results are used for planning HIV programs and activities.

Namibia's prevalence rate which was recorded on the HIV sentinel surveillance in 2008 was 17.8% which made it very high in the world. Katutura Intermediate Hospital recorded 21.4% which made it one of the highest statistics in the country (MoHSS, 2010). In 2010 the overall HIV prevalence among pregnant women is 18.8%. The results show a slight increase in the overall HIV prevalence and there is no significant difference compared to 2008. The highest age specific prevalence was observed among 30-39 years with 29.6% in the age group 30-34 and

29.7% in the age group of 35-39 years. While the prevalence in adult age groups (30-39 years) was approximately 30 %, the prevalence in youth (15-19 and 20-24 years) was 6.6% and 12.5% respectively. HIV is the highest in Katima Mulilo (35.6%) and the lowest (4.2%) in Rehoboth (MoHSS, 2010).

## **2.2. Preventing the spreading of HIV and AIDS**

In this section attention will be paid to the variety of prevention strategies for spreading HIV and AIDS such as personal and social group efforts, positive prevention strategies and the prevention of the re-infection of people living with HIV and AIDS.

### **2.2.1. Social and behavioral determinants for HIV and AIDS prevention**

In Uganda a variety of social and behavioral factors such as age, gender, peer influence and social environment were taken into account when they designed and implement programs for HIV and AIDS prevention (UNICEF, 1998). This approach will also be of importance for Namibia and therefore attention is being paid to the following factors:

#### **2.2.1.1. Age**

There is unanimous recognition of the fact that HIV and AIDS vulnerability and needs differ across age groups. Most HIV and AIDS interventions among young people have targeted six to 14 years old and fifteen to twenty five years old age groups as distinct cohorts with specific HIV and AIDS related needs and risks. The six to 14 years old age group constitutes children who may not yet perceive their potential risk of HIV infection. Most children in this group seem aware of the existence of HIV and AIDS, either through school, the media, or by direct observance of their parent's close relatives' HIV and AIDS related illness and death. Most children infected during birth will have become symptomatic by this age and therefore have to deal with social stigmatization and curious questioning from their school mates. At the same time, six to 14 year old children have to deal with uncertainty surrounding the health of their parents and relatives. These children are vulnerable to HIV infection mainly through sexual abuse and early marriages. School going children especially girls, are vulnerable to sexual abuse

by some male teachers and administrators ( Morisky, Jacobs, Nsubunga& Hite, 2006). Given that the majority of six to fourteen year olds are enrolled in schools, early interventions targeting this age group were implemented through school based programs such as health education networks and the save the youth from AIDS initiatives and building the capacity of teachers to address issues related to HIV and AIDS. Currently most HIV and AIDS interventions try to raise awareness in this age group about issues of sex. The fifteen and twenty four year old age group includes adolescents and young adults, most of whom are not currently enrolled in school. The HIV prevalence rate was the highest in this age group. Between 1992 and 1998, several innovative peer support based interventions were implemented mainly in secondary schools and tertiary institutions. These programs emphasized formation of AIDS challenge clubs, holding interschool debates on HIV and AIDS topics and providing youth friendly information, education and communication materials and training of peer leaders and counselors. Most of these programs generally sought to enhance youth skills in communication, sex negotiation, response to peer pressure, and development of rational and positive relationships with members of the opposite sex (Morisky et al, 2006).

#### **2.2.1.2. Gender**

HIV prevalence varies widely between men and women in different age groups. In the age group of 25 and below, females are two to three times more likely to be infected than males. In the 15 to 19 years old age group, females are five to six times more likely to be infected than males. The physical and contextual aspects of culture, power relations and economics at domestic and national levels are among the major factors increasing the vulnerability of women to HIV infection. For example, girls are less likely to enrol in school, complete primary school, attend secondary education, or enter institutions of higher learning. A good number of girls are often forced into early marriages and have less power in sexual relationships, because of their subordinated status, women often cannot insist on condom use or successfully resist sexual demands, especially from older men. Married women are generally unable to stop their husbands from having multiple sexual partners or from marrying other wives, even when they know that their husbands are HIV positive or has engaged in multiple sexual relationships.

There are also significant negative repercussions in sexual relationships from stereotyped roles that encourage submissiveness on the part of girls and aggressiveness on the part of boys (Morisky et al., 2006). Several attempts to make HIV and AIDS programs in Uganda more gender sensitive have been instituted. These attempts include improving access to care and prevention services, involvement of women in advocacy, direct provision of HIV and AIDS services to women, and raising the visibility of women in political and socioeconomic affairs from grassroots to the national level. In addition to general policy wide activities, many contemporary HIV and AIDS programs such as microenterprise development, school based HIV and AIDS activities, and skill development, prioritize women in their design and implementation. The involvement of community based institutions like traditional birth attendants, traditional healers, religious leaders and other civil society organizations in HIV and AIDS activities has been another critical factor in improving access to HIV and AIDS services by women in Uganda.

#### **2.2.1.3 Peer influence**

A third factor in the formation and change of behavior is peer influence. Because peer influence has proven to be a significant influence in behavior, it has become a major consideration in the design of most HIV and AIDS interventions targeting young people. The success of peer influence is based on the function of shared interests and beliefs that young people cherish. These cherished interests and beliefs form the basis of peer norms and values that enhance the attainment of common interests. Compliance to values and norms is critically monitored and provides an impetus for empathy and concern about others. In general, people living in communities such as a school for young people or a rural village for adults share information through a complex web of social networks. These networks include community groups, church activity groups, funeral gatherings and various forms of interpersonal relationships. Many HIV and AIDS organizations have taken advantage of these strong community linkages and networks to provide HIV and AIDS related services aimed at changing perceptions and practices regarding high risk sexual behavior. Peer groups comprising people living with HIV and AIDS have been used to offer support, counseling, and friendship. These programs and activities provide

powerful evidence about the existence of HIV and AIDS and produce positive influences within the communities. They also give hope to those already infected that it is becomes possible to live a normal life. More so, peer influences and programs encourage those not yet affected to engage in safer sexual practices (Morisky et al., 2006).

#### **2.2.1.4 Social environment**

Another important determinant of successful intervention is the social environment in which young people live. Since behavior formation and change are both products of the individual's psychological and cognitive factors and interpersonal interaction, an enabling and supportive social environment is critical to the success of any behavioral intervention. Many HIV/AIDS programs targeting young people recognize that most young people live in social environments at home, or in the community that are not conducive for adolescent sexual and reproductive health positive decisions. For the most part, children do not receive adequate family life education in the home; hence cultural norms often prevent parents and other adults from discussing sex with children and youth. Religious leaders too often discourage the provision of adolescent sexual and reproductive health information or services to adolescents. Consequently, in an effort to avoid conflict and breach long established cultural norms, teachers and health workers are reluctant to provide adequate adolescent sexual reproductive information and services to adolescents. Many young people lack critical life skills because most homes and schools do not create environments conducive for adolescents to develop these skills. Non conducive environment results primarily from traditions which do not encourage children to express their own opinions, question the views of others, or make their own decisions. In this regard, a number of adolescent HIV and AIDS programs are aimed at changing this situation by promoting open discussions of adolescent sexual reproductive health issues between teachers and their pupils as well as parents and their children. Many programs attempt to stimulate active support for adolescent sexual reproductive health services among policy makers (Morisky et al., 2006).

## **2.2.2. Personal and social group efforts to prevent HIV infection**

A comprehensive public health approach to cause, prevention and cure is needed to control the spread of HIV infection.

### **2.2.2.1. Health promotion**

Knowledge of exposure to HIV disease and the factors that potentiate disease expression can assist health professionals in planning health care activities that individuals and their partners, families, and friends can implement on their own behalf or with the assistance of the health care workers. These take the form of health promotion, disease prevention, and harm reduction activities. Health promotion strategies pose few risks, have a positive effect on well being, and may contribute to slowing disease progression. Health promotion behaviors and activities are also applicable to all persons, regardless of their HIV status (Ungvarski&Flaskerud, 1999).

### **2.2.2.2. Diet**

Malnutrition is the major cause of immune-suppression worldwide. The impact of specific nutrients on immune status has been documented, for example deficiencies in calorie-protein intake have consistent and profound effects on cell –mediated immunity, antibody response and antibody affinity. Currently, a health promoting diet that promotes optimal immune functioning consists of a variety of foods from each of the seven food groups and is composed of 50% to 55% calories from carbohydrates, 15% to 20% calories from protein and 30% or fewer calories from fat. Two or three servings of food from each of the protein and dairy groups are recommended for each day, seven to twelve servings from the starch grain group, two servings of vitamin C rich fruits and vegetables, one serving of vitamin A rich fruits and vegetables, and three servings of other fruits and vegetables (Ungvarski&Flaskerud, 1999).

### **2.2.2.3. Micronutrients**

Vitamins and minerals are essential for optimal immune functioning. A diet rich in micronutrients should supply the vitamins and minerals essential for immune functioning. The addition of a multivitamin mineral supplement to the diet provides sufficient essential nutrients. Recent reports have suggested that enhanced immune response may be related to adequate amounts of vitamins A and E, beta carotene, zinc and selenium. Researchers at Johns Hopkins Medical Centre have been studying the use of vitamin A, B, C in doses larger than the recommended amount with twenty eight HIV positive men for up to six to eight years. In an interim report these investigators found that micro nutrients intake for at least two years, started early in the course of HIV infection seemed to slow the onset of AIDS (HIV frontline update, 1994). However, it should be noted carefully that mega doses of vitamins and minerals may be dangerous. Mega doses can create nutrient- nutrient or nutrient medication competitive environments, cause toxic effects and neurologic damage, and result in a weakening of the immune system. Information on nutrition and meal planning is an important aspect of health promotion education. Special attention may be required for some groups. Some homosexual men and heterosexual women may have eating disorders or may diet excessively in an effort to be exceptionally thin to enhance their physical attractiveness (Ungvarski&Flaskerud, 1999).

### **2.2.2.4 Regular Exercise**

Physical exercise is recommended as a health promoting activity because it increases lung capacity, muscle to fat ratio, endurance, energy, flexibility and improves circulation. It also improves sleeping, appetite, and regular bowel activity and decreases stress. Solomon and Colleagues (1993) proposed a relationship between psychosocial factors, exercise, and immunity based on studies of athletes, elderly persons and people living with HIV. Currently, an exercise program of thirty to forty five minutes, four or more days per week, is recommended. Exercise should use muscle groups in both the arms and legs, should be fitted to personal endurance, should not be painful or boring. Acceptable and feasible exercise programs must be

designed specifically for individual interest, physical capabilities, financial restrictions and other personal characteristics. Walking is an exercise available to all that is not overly taxing and may be done in the company of children or other adults. The benefits of exercise are not readily apparent to some people, such as the urban poor or mothers with young children, who may believe that it is too expensive and will make them more tired and pressured for time. Balancing the need for regular exercise is the need for adequate, regular rest and sleep. For some persons, sleep programs must be designed that will allow them to fall asleep and may stay asleep. Others need education on the negative effects of sleep deprivation. Sleep deprivation is associated with fatigue and clinical depression. Taken together, these represent added strains, which may facilitate symptom expression (Ungvarski&Flaskerud, 1999).

#### **2.2.2.5. Stress and emotions**

Reduction and control of stress is the goal of stress management programs. Stress may be associated with immune suppression and may increase a person's vulnerability to disease. Sympathetic nervous system response may influence immune system function and viral replication through alterations in cytokine production. Adequate sleep and rest and regular exercise are important stress reduction activities. Mental exercises, such as meditation, visualization and biofeedback, are all types of relaxation techniques that may reduce stress. An adequate coping response has been suggested as a means of moderating stress. Active or involved coping is believed to have beneficial health effects. Active coping includes problem solving activity, increased expression of emotions, seeking advice and information, altering one's lifestyle, taking control of one's health and well-being , and having a sense of purpose and commitment to life. Active coping seems to work best in situations of specific, highly stressful personal events, such as at the time of notification of HIV infection, the occurrence of AIDS onset, or bereavement, rather than being related to a general state of mind and behavior. Studies of active coping as a general state of behavior have found associations with poorer rather than better health status (Ungvarski&Flaskerud, 1999). To date, the relationship of most of these behaviors, attitudes and values is a hypothetical stage of research and should not be promoted with clients as preferable to other forms of coping. Rather, a repertoire of coping

behaviors seems to offer the most useful approach to life events and stress. Other stress reduction techniques involve social group relationships. These include being involved in altruistic ways with other persons and groups, providing and receiving social support, involvement in spiritual and religious activities, taking part in recreational activities and play, taking breaks at work and vacation, and being involved in committed relationships. Avoidance of stress producing situations has also been recommended. However, it should be noted that avoidance of stress is almost impossible in today's world, and using it as a health promotion strategy may produce guilt. Special attention is given to the benefit of emotional expression. In several studies, strong sympathetic nervous system reactivity to the expression of basic emotions such as fear, anger, surprise, disgust, happiness and sadness was related to increased immune function and enhanced mental and physical health ( Ungverski&Flaskerud,1999).

#### **2.2.2.6. Recreational drug use**

The overuse of chemical stimulants, alcohol and recreational drugs such as tobacco, marijuana, and "speed" may have an immunosuppressant effect and these substances are associated with a variety of physical and mental health problems. Avoiding or limiting their use should be part of health promotion activities. Several self-help programs, as well as professional programs, exist to assist persons who wish to modify their substance use behaviors. These substances in addition to their possible immunosuppressant characteristics limit or interfere with the health promotion activities and behaviors. These substances suppress appetite, irritate the gastrointestinal tract, lead to impaired absorption of food, and damage liver cell. All these consequences reduce the health promoting benefits of nutrition and they also interfere with regular exercise, sleep and rest may therefore exacerbate distress indirectly, direct exacerbation of distress may come from their effect on personal and social relationship (Ungverski&Flaskerud, 1999).

#### **2.2.3. Prevention of re-infection for people living with HIV and AIDS**

For the first two decades of the HIV and AIDS epidemic, HIV prevention interventions mostly encouraged uninfected people to adopt safer sex and avoid drug using behaviors, so that they would not get HIV (Office of AIDS, 2003). HIV positive people were not a focus of prevention

efforts for several reasons. Among the public, there was reluctance to acknowledge that HIV positive people have sex. There also was a perception that it was contradictory to try to prevent a disease among people who already had it. In addition, there was concern that such a focus would be perceived as blaming HIV positive people for the epidemic. More recently, researchers, governments and health care providers are recognizing that HIV positive people need prevention from re-infection (Kelly & Kalichman, 2002). These secondary preventions are sometimes called positive prevention. Positive prevention is important because HIV is transmitted by HIV positive people. From an epidemiological and public health perspective, HIV positive people make up the most important group to address with HIV prevention strategies (DiClemente, Wingood, Del Rio & Crosby, 2002; International HIV and AIDS Alliance, 2003). A change in the risk behavior of an HIV positive person will on average and in almost all affected populations, have a much bigger impact on the spread of the virus than the same behavioral change in an HIV negative person (King-Spooner, 1999; Vernazza, Eron, Fiscus & Cohen, 1999). Many HIV positive people use condoms more regularly and adopt to safer sex and drug use. Prevention interventions may help HIV positive people sustain healthy behavior changes (DiClemente et al., 2002).

Living well includes having a healthy sex life. This means protecting HIV positive people against super infection for example re-infection with a different strain of HIV and against new sexually transmitted infections (International HIV/AIDS Alliance, 2003, Wolitski et al., 2005).

Over 70% of HIV positive people continue to be sexually active after they learn that they are infected (Office of AIDS, 2003). Although many engage in safer sex practices, empirical evidence suggests that some HIV positive people continue to have risky sex. HIV positive people who have unprotected sex tend to know less about HIV and AIDS, its transmission and its effects on their health. They believe that safer sex is less pleasurable than unsafe sex, they lack commitment to practicing safer sex, they lack confidence in their ability to practice safer sex, they perceive that they have little control over whether condoms are used, they have problems in communicating with partners about safer sex and finally, they perceive more barriers to use condom.

Unprotected sex cannot only transmit infection to uninfected partners but it also increases HIV positive people's risk of getting sexual transmitted infections (STIs). STIs are serious health conditions that may accelerate AIDS in HIV positive people. They also can make HIV transmission to uninfected people more likely because STIs can increase the number of CD4 positive cells near the genitals because HIV attaches to CD4 positive cells. People with both STIs and HIV often have more HIV particles in their semen, vaginal secretions, anal mucus, and in the blood circulating near genitals. They are also more likely to have open sores or injured skin, making direct transmission of HIV through blood more likely. Even more serious than the threat of STIs is the threat of super infection, which happens when an HIV positive person becomes infected with a second strain of HIV. Second infections are more resistant to antiretroviral therapy (Colen, Morin, Shriver and Coates 2000). This is because many HIV positive people take their antiretroviral drugs incorrectly, which allows the HIV to mutate into drug resistant strains (International HIV/AIDS Alliance, 2002, 2003). Indeed, even recently infected people who have never taken antiretroviral therapy themselves sometimes have already drug resistant strains of HIV, which they acquired from people who did not adhere to their Antiretroviral regimens (Center for Disease Control, 2003). Moreover, research shows that people who have unprotected sex are less likely to take their antiretroviral drugs correctly.

HIV prevention, testing, treatment, support is interrelated. People living with HIV need medical treatment, psychological care, and social support, not just for their own disease but also to prevent spreading HIV to others (International HIV/AIDS Alliance, 2003). Combining HIV prevention with testing and treatment services has number of advantages. According to the International HIV/AIDS Alliance (2002) Providers can screen HIV positive patients for behavioral risk factors and address them through counseling and referrals they can also screen HIV positive patients for clinical risk factors, such as STIs and administer treatments and vaccinations. Additionally they can also teach recently diagnosed HIV positive people how to protect their sex and drug use partners. Finally, they can also teach HIV positive mothers how to reduce their chances of giving HIV to their children. In the United States, public health initiatives for people already infected with HIV aim to increase access to HIV testing, access to quality medical care, use of quality medical care, adherence to HIV therapy and the adoption and maintenance of

HIV risk reduction behaviors. Despite these efforts, HIV positive individuals still face unique challenges in preventing the transmission of HIV. First, they face embarrassment, discomfort, and fear of rejection surrounding disclosure of their HIV 'sero-status' to sexual and drug use partners. In some cases, the desire for trusting sexual relations outweighs fears of transmission, and thus reduces condom use (CDC, 2003).

#### **2.2.4. Positive prevention strategies**

HIV transmission is influenced by a myriad of individual, community, and societal factors. Thus, like prevention efforts for HIV negative persons, prevention efforts for HIV positive individuals must be deployed at multiple levels (DiClemente et al., 2002). Over the past decade, an increasing number of individuals and small group level behavioral interventions have shown to reduce HIV risk behaviors among HIV positive persons (Kalichman, 2005). In particular, several interventions that targeted HIV positive men and women have improved their consistency of condom use and also increased their perceptions of the advantages of condom use. These have also increased their confidence that they can use condoms consistently and correctly. Other interventions for positive injection drug users have reduced their instances of needle sharing and unprotected sex and some social support and counseling programs have reduced the number of HIV positive men's sexual partners. Lastly a number of brief safer sex counseling interventions have decreased the number of unprotected sexual acts among HIV positive people, increased consistent condom use, and increased sexual abstinence.

Prevention strategies for HIV positives focus on improving treatment and care for HIV and AIDS associated opportunistic infections, mobilizing communities to help reduce risk factors for HIV transmission, and changing policies that affect HIV positive person's access to and use of prevention and treatment services ( International HIV/AIDS Alliance, 2003).

##### **2.2.4.1 Individual level intervention strategies**

Individual level interventions strategies include voluntary counseling and testing for persons whose HIV status is unknown and post-test and ongoing counseling for HIV positive people. Counseling efforts are designed to build the knowledge, skills, self efficacy, and motivation

needed to reduce or eliminate risky behaviors that can lead to HIV transmission. According to the International HIV and AIDS Alliance (2003), these strategies can also encourage beneficial disclosure, which involves the voluntary and often confidential disclosure of HIV positive people's sero-status to other people and organizations, so that the HIV infected person will feel comfortable accessing HIV services. Beneficial disclosure also reduces the secrecy and stigma surrounding HIV and AIDS. It can also encourage ethical partner notification, which involves the voluntary and often confidential notification of HIV positive people's sexual and drug use partners, so that they will get tested and take precautions.

Clinics are a key setting for such interventions, as HIV positive people need frequent medical care to monitor antiretroviral effects and to treat opportunistic infections as HIV disease progresses. A study of 839 HIV positive men and women at six public HIV clinic in California found that 50% had never discussed disclosure with a provider at their clinic, and 29% had never spoken with a provider at their clinic about safer sex (Marks, Richardson, Crepaz, Stoyanoff, Milam & Kemper, 2002). Thus, training clinic staff to deliver individual level prevention interventions effectively should be a prevention priority.

Improving treatment of and health care for HIV positive persons may include making available voluntary counseling and testing programs, integrating behavioral prevention counseling with HIV and AIDS treatment in clinical settings, and providing antiretroviral treatment as prevention for further transmission, including parent to child transmission. It also may involve reducing stigma and discrimination toward HIV positive persons in health care settings (International HIV/AIDS Alliance, 2003).

#### **2.2.4.2 Community mobilization**

People living with HIV are a part of broader communities and also influence those communities. They need the support of their communities and their broader environments to implement the risk reduction behaviors promoted by individual health promotion strategies. Community mobilization efforts may have a variety of positive prevention objectives. Some seek to involve communities in positive prevention programs by developing peer support groups for HIV

positive persons. Others have trained people with HIV as peer outreach workers, to increase the visibility of positives and reduce HIV and AIDS stigma (International HIV/AIDS Alliance, 2003). Other community level interventions implemented focused on communication campaigns that raise awareness of the important role of HIV positive people in reducing transmission.

#### **2.2.4.3 Advocacy and policy change**

The success of positive prevention efforts depends crucially on laws and policies, such as those concerning HIV and AIDS related prevention and treatment funding, informed consent and confidentiality laws for HIV testing, and restrictions on school based sexuality education curricula. Advocacy and policy change strategies involve HIV positive people in the development of HIV related policies and programs, including those that target HIV positive people for prevention efforts, address stigma and discrimination against positives, and increase access to treatment among all HIV positive people (International HIV/AIDS Alliance, 2003).

#### **2.2.4.4 Antiretroviral Therapy for positive prevention**

When antiretroviral therapy is taken dramatically it lengthens the life span and improves the physical well-being of people living with HIV and AIDS. Although it is true that living longer and healthier lives gives HIV positive people more chances of transmitting the virus, antiretroviral therapy also lowers the amount of HIV shed through blood, genital and anal secretions. With fewer viruses in their body fluids, HIV positive people are less likely to transmit HIV (Centre for AIDS Prevention studies, 2003).

### **2.3. A Medical perspective on HIV and AIDS.**

People living with HIV and AIDS may suffer psychological distress as a result of the many physical, social and economic effects of the disease on their lives. Among the various stressors are chronic physical pain, physical disfigurement, the possibility of infecting other people, and discrimination, abuse, and loss of fundamental human rights. Other factors include changes in lifestyle to accommodate the illness itself and the financial burden that treatment brings for

oneself and one's family. HIV positives are simultaneously coping with grief from already having lost loved ones to AIDS (Cline, 1990). As a result of these many stressors, people diagnosed with HIV infection often suffer from a number of psychological symptoms such as anger, frustration, anxiety and depression (Kelly, Murphy, Barh, Kalichman, Morgan & Stevenson, 1993).

### **2.3.1. Psychological benefits and challenges of HIV and AIDS therapy**

The advent of Highly Active Antiretroviral Therapies (HAART) for treating HIV infection was a major breakthrough in the managing the HIV and AIDS crisis. This combination of drugs target different stages of the HIV replication cycle, slow HIV disease progression, and prolongs life. Many HIV positive people who have been diagnosed with HIV and are on HAART became healthy enough to return to work or school. Returning to work or school is often considered the benchmark of successful HIV treatment (Brooks & Klosinski, 1999).

HAART also may give hope and optimism to HIV positive people. Researchers have found that having hope and an optimistic outlook, in return, improves people's physical health, decreases their levels of depression, and even extends their life spans (Low-Beer, Chan, Wood, Yip, Montaner & O'Shaughnessy, 2000). Despite these benefits, however, Antiretroviral Therapy can present significant psychological challenges to both those who respond well to the treatment and those who do not (Brashers, Neidig, Cardillo, Dobbs, Russell & Haas, 1999).

### **2.3.2. Challenges for people who do not respond well to HIV treatment**

Although Antiretroviral Therapy makes many HIV positive people healthier, between 15% and 35% of research participants did not improve with antiretroviral therapy, and even more people who are not research participants do not respond well to the treatment (Kelly & Kalichman, 2002). In addition, some people's health may improve with therapy, but then quickly deteriorate (Stone & Smith, 2004).

People whose treatments fail may feel a sense of personal injustice, as if they were cheated, betrayed, or misled about the effects of antiretroviral therapy. They also may engage in self-blame for not having been able to tolerate a potentially effective treatment, especially when

they had to discontinue therapy because of severe side effects. A sense of hopelessness and unwillingness to try new therapies are also common ( Rabkin&Ferrando, 1997).

### **2.3.3. Meeting HIV positive people's needs helps everyone**

There is a clear need for services that will improve the psychological health of people with HIV and AIDS. Improved psychological services for HIV positive people not only help them but also may help the general public (Kelly et al., 1993). High levels of depression and maladaptive coping with HIV infection have been associated with substance use and risky sexual activities, which put others at risk for acquiring HIV (Kelly et al., 1993).

### **2.3.4. Support groups**

The stress of HIV and AIDS can be reduced by social support provided by support groups (Green & Smith, 2004). In a study of HIV positive men who were experiencing moderate depression, 86% of participants who attended a social support group showed improved mental health, whereas about 67% of the participants who did not attend the social support group showed worsened mental health (Kelly et al., 1993). Support groups that target specific sources of emotional distress improve the number and quality of friendships, and also give health information ( Kalichman, Sikkema& Somlai,1996).

## **2.4. Living with the uncertainty of HIV and AIDS**

HIV and AIDS is increasingly treated as a long term, chronic illness. People who live with chronic illnesses such as HIV and AIDS often face uncertainty in the medical, personal and social aspects of their lives (Brasher et al., 1998). Such uncertainty is stressful and can impair HIV positive people's quality of life. To maintain a good quality of life, people living with HIV and AIDS must learn to cope with this unpredictability and uncertainty (Murdaugh, 1998).

### **2.4.1. Medical uncertainties of HIV and AIDS**

Medical uncertainties include uncertainties about diagnosis, symptom patterns, treatments and care, and disease progression in a human body.

#### **2.4.2. Unclear diagnoses**

CD4 positive counts raise and fall, so that people diagnosed with AIDS in the past, based on their low CD4 positive counts, can recover and have CD4 positive counts that do not meet the Centre for Disease Control's diagnostic criteria for AIDS. This can be confusing for HIV positive people, both psychologically and financially. In addition, the various numbers used to monitor HIV positive people's health, including the CD4 positive count and viral load, can be difficult to interpret (Card, Amarillas, Conner, Akers, Solomon & DiClemente, 2007).

#### **2.4.3. Ambiguous symptoms**

All people get aches and pains. HIV positive people face the uncertainty of not knowing whether these aches and pains mean that their illness is worsening. In addition, HIV positive people have many different symptoms that change often, making it difficult for them to plan for the future. HIV positive people are also likely to get opportunistic infections that take advantage of their weakened immune systems. However, they do not know which of the many infections they will get, and often worry about the symptoms and consequences of the different infections (Card et al., 2007).

#### **2.4.4. Complex and uncertain treatment**

Antiretroviral Therapy usually requires taking three or more drugs at different times of the day. For examples some patients take these drugs on empty stomachs. Therapies often change, so HIV positive people may worry about taking their drugs correctly. In addition, many medical treatments are experimental, and so people using them are not knowledgeable about their safety or effectiveness. People's bodies also vary in their responses to different therapies. It is therefore impossible to predict whether different therapies will work or what their side effects will be. For HIV positive people, it is difficult to know which preventative measures to take against opportunistic infections and when to take them. However, they are advised to be vigilant about food and water safety and about being exposed to other viruses (Card et al., 2007).

#### **2.4.5. Personal uncertainties**

Personal uncertainties include uncertainties about one's personal identity, as well as about one's financial challenges and the future (Brasher et al., 2003). During the asymptomatic stage of HIV disease, people feel well but know that they are HIV infected. This can cause them to feel tension between their roles as a sick person and a healthy person. In addition, HIV positive people are often married to, friends with, or related to other HIV positive people, so that they often become caregivers. At the same time, these people also need care. This can cause tension between the caregiver and care receiver roles. Financial uncertainties are also a significant challenge for HIV positive people. Many face uncertainties about when to claim disability status. On one hand, claiming disability means that insurance companies or social security organizations will help pay for treatment. On the other hand, however, claiming disability limit employment options. Additionally, HIV treatments are expensive. HIV positive people often feel that they are trading off their own and their family's financial well being for their health. Finally, because of the wide variability in the course of HIV, People have difficulty knowing how much money to budget for their treatment and for how long (Card et al., 2007).

#### **2.4.6. Social uncertainties**

Social uncertainties include uncertainty about how other people will react to the news that one is HIV positive, how old relationships will change, and how new relationships will develop (Brashers et al., 2003). In particular, HIV and AIDS is a stigmatized illness because it has been associated with homosexuality and drug use. When people let others know that they are HIV positive, people face the prospect of social isolation, since families and loved ones may not react well to their illness. HIV positive people also face much uncertainty in dating and long term relationships, especially because they run the risk of infecting others.

#### **2.5. HIV and AIDS related grief**

Most people living with HIV and AIDS have lost a family member, friend, or associate to the HIV disease ( Sikkema, Kalichman, Hoffman, Kob, Kelly & Heckman, 2000). Coping with a loss as a result of HIV and AIDS may differ from coping with losses to other diseases in several ways.

Many people who die from complications of HIV disease die at a relatively young age (Kain, 2004). Although survivors may have anticipated an HIV person's death, they still find it difficult to reconcile the fact that the life of a young person was cut short. In addition, the stigma associated with HIV may prevent those who survive from freely mourning or acknowledging the cause of a friend or loved one's death (Mallinson, 1997).

## **2.6. Depression in patients with HIV and AIDS**

Depression is extremely common in patients with chronic medical disorders, life threatening diseases and disease affecting the central nervous system, all of which are characteristics of HIV disease. Persons with depression are commonly seen in primary care situation and often present with somatic complaints, memory and concentration problems, insomnia and low energy. Among people living with HIV (PLWH), the prevalence of depression has been estimated at 10% to 25%. Depression is a psychological illness that is quite treatable if diagnosed accurately. Therefore a person who is suffering from the diagnosable disease of depression will experience depressed mood, low energy, sleep disturbance, inability to concentrate, loss of libido, weight changes and possible menstrual irregularities. The major risk factor for depression is a history of depression, substance abuse or both and a family history of the same (Ungavarski&Flaskerud, 1999).

A study that was done at Kasturba Medical College India (2007) found that depression is one of the major problems in any chronic illness. The diagnosis and optimal treatment of depression in HIV and AIDS patients is complicated. HIV infection is a condition where the disease itself may cause many symptoms resembling those of depression. On the other hand, several psychiatric conditions including depression may trigger individuals to acquire HIV infection as a consequence of their influence on behavior. Treatment of depression in HIV and AIDS patients is jeopardized not only the inability to diagnose the condition specifically but also by poor adherence to treatment, which has social, medical and non-medical factors.

Several barriers exist in diagnosis of depression in HIV and AIDS patients. Patients may be unwilling to discuss their moods and emotions with health care providers for fear of being stigmatized further (Reeves, 2001).

For the health care provider diagnosis of depression in HIV and AIDS patients is not an easy task as the depressive symptoms such as fatigue, insomnia and weight loss may be taken as part of the disease itself, and serious thought to diagnose a separate psychiatric disorder is not entertained. The diagnosis may be further complicated by the presence of substance abuse and the use of multiple drugs including antiretroviral drugs that are known to cause depressive symptoms as side effects. Importance of diagnosis of major depression in HIV and AIDS patients is as good as in uninfected persons and when recognized it has a negative impact on adherence with medical treatments, quality of an overall outcome, therefore to overcome the diagnostic barrier. Murdaugh (1998) recommends that health providers should encourage expression of emotions in clinics and non-special specialists need training in the assessment of psychiatric syndromes in HIV patients.

The Kuwait Medical Journal (2007) further suggests several types of clinical rating scales that could be used for diagnosis as well as rating of depression. Studies has also shown that in otherwise asymptomatic HIV infected patients physical symptoms of fatigue insomnia, weight loss are related to psychological disturbances possibly major depression. HIV and AIDS is not only responsible for individual morbidity and mortality but also is a familial and social burden by itself. Treatment of HIV infection is costly and complicated. High incidence of depression and anxiety further increase the complications. Besides "pharmacotherapy", supportive "psychotherapy" has an important part to play in the treatment of those patients who interpret their symptoms to be reaction to diagnosis of HIV infection. Other forms of useful psychotherapy are 'interpersonal psychotherapy' and 'cognitive behavioral psychotherapy' and they are more effective when combined with 'pharmacotherapy' for treatment of severe depression.

Finally, diagnosis and management of depression is an important factor for optimal outcome of HIV and AIDS patients. Safe and effective treatment of major depression, one of the most common conditions in individuals infected with HIV significantly lowers morbidity and mortality of HIV disease. While possibilities of under diagnosis and over diagnosis exist, optimum management should be guided by correct diagnosis. To avoid these consequences therapy

should be undertaken in a specialty clinic whenever possible and alternatives proper antidepressants should be considered in moderate depression particularly for debilitated patients when the antidepressants are less likely to be tolerated (Pratt, 2003).

### **2.7. Psychological and social challenges of living with HIV and AIDS**

Attempts by psychologists to reduce the risk for HIV infection have fallen into six main preventative strategies. Firstly, broad HIV-related education and especially education around the use of condoms is common. Psychological research has attempted to investigate the conditions associated with condom use and other safer sex strategies, or absence of use of these strategies. Secondly, clinical intervention with individuals or groups, for example, educational groups, assertiveness training, social skills training help in reducing HIV and AIDS. The need to develop positive aspects of safer sex has been recognized. Thirdly, counseling and testing also helps people to know information on HIV and AIDS as well as to know their results. Fourthly, encouraging partner notification of HIV status, in other words the therapist should encourage partners to inform each other in case if someone have tested HIV. Fifth, counseling by health care providers, Lay counselors, social workers, psychologists, doctors and nurses provides HIV counseling to patients. Finally, broad community based intervention, in the community there are social support programs and home based care for people with HIV, which they can utilize. Three behavioral change approaches which have shown considerable merit for HIV prevention are; cognitive behavioral skills training, interventions to change social norms around risk behaviors and multifaceted community approach (Eagle, 1994).

### **2.8. Psychological responses to HIV among uninfected persons**

HIV disease occurs in society that disapproves of homosexuality, drug use, and sexual promiscuity. This disapproval is accompanied by fear of contagion, prejudice, discrimination, and stigmatization, and in extreme cases, hatred and violence. It is within this social context that psychological responses to HIV infection occur. It occurs in both persons who are infected and persons who are not infected. Many people who are not infected also are not worried about being infected. The major psychological responses of this group are denial and dissociation (Van Dyk, 2001).

Some heterosexuals practice denial by underestimating their vulnerability to infection, although they are very much aware of AIDS, they do not consider it a threat to themselves. This underestimation of vulnerability is evidenced in the lack of behavioral change among heterosexual adolescents and young adults. Dissociation from the AIDS disease occurs among heterosexuals both by a physical separation of themselves from the so called risk groups and by a psychological dissociation with sexually transmitted diseases, drug use and male to male sexual contact. Many people think that these conditions are morally reprehensible that they would consider it an extreme insult to question a sexual partner about his or her history of sexually transmitted disease, drug use, and sexual practice (Van Dyk, 2003).

## **2.9. Sex, gender, culture and HIV and AIDS.**

Sex describes a biological distinction between men and women. A person's sex is defined by physical features, including a person's genes, internal and external anatomy. Gender is a social categorization that is learned, rather than inherent. Gender defines the roles, responsibilities, rights and obligations of men and women as well as those of boys and girls. Gender roles are defined differently across cultural groups. They are a very powerful feature of social organization, as they not only describe how males and females are expected to behave but also influence power relations, decision making authority and individual responsibility. Gender determines to a great extent how people think, feel and what people believe they can and cannot do as women and as men (Feinstein and Prentice, 2001). Within a given culture, gender roles may differ across the life cycle of men and of women. Moreover, like other social roles and relationships, gender roles can change over time in response to shifts in educational opportunities, economic circumstances, and technology. The biological state of being male or female influences the degree and nature of HIV risk. For example, HIV has an easier time surviving in the vagina than it does on the surface of the penis, making it easier for HIV to be transmitted from a man to a woman than from a woman to a man during heterosexual vaginal sex. However, gender also plays a significant role in HIV risk for both men and women. Gender norms influence the psychological state, sexual and drug use behaviors and economic circumstances these in turn determine men and women's vulnerability to infection, access to

HIV and AIDS treatment services. Gender norms can also help people sustain themselves economically when they or a family member is diagnosed with or dies of AIDS (Feinstein & Prentice, 2001; UNAIDS, 1999; WHO, 2000, 2002).

### **2.9.1 The relationship between culture and HIV and AIDS**

People never have just one cultural background. Instead, people are defined by a wide variety of cultural categories. Examples of cultural categories include ethnicity, race, national origin, religion, geographic region, political orientation, sexual orientation, age differences and disability status. Gender is also an example of a cultural category. People in some cultural groups become infected with HIV and develop AIDS at higher rates than people in others. For example, according to a study of U.S. Job Corps applicants, HIV prevalence among African American adolescent girls were higher than those of white and Hispanic adolescent boys (Valleroy, MacKellar, Karon, Janssen & Hayman, 1998). Culture plays a significant role in these issues, it helps to shape many individuals, communities, and societal level risk and protective factors for HIV infection, as well as access to HIV and AIDS related prevention and treatment service (Wilson & Miller, 2003). In particular, cultural beliefs and norms shape definitions of health and illness, beliefs about what causes AIDS and how to prevent HIV transmission, attitudes toward communicating about HIV related behaviors, and attitudes towards risky behaviors. In many cultures, men may seek many sexual partners and women may feel unable to insist on safer sex practices, such as condom use with male partners. Cultural values, including racism and sexism, also affect individual's ability and motivation to access and use HIV prevention and treatment services. In addition, culture influences the way communities respond politically, socially and financially to the threat of further spread of HIV and AIDS (Hoban & Ward, 2003).

### **2.9.2 Women and HIV and AIDS**

In most societies, girls and women face greater risks of HIV infection than men not only because of biological differences between them (NIAD, 2004), But also because in many societies women's diminished economic and social status compromises their ability to choose safer and

healthier life strategies (UNAIDS, 2001). The epidemic's impact on women has become more pronounced over time. In 2005, an estimated 17.5 million women were living with HIV. Women also comprised of an increasing share of new HIV and AIDS cases reported each year. Specifically, as of the end of 2005, women accounted 48% of adults aged 15 and over living with HIV and AIDS worldwide. In 1997, 41% of HIV positive adults were women (UNAIDS, 2001). This trend also impacted children, as the increase in HIV infection among women of childbearing ages increases the potential risk for vertical transmission of infection to their unborn children and infants. In certain parts of the world, the rate of HIV and AIDS among women has come to equal or exceed that of men. Women represented at least 50% of the adults living with HIV in sub Saharan African, Oceania and the Caribbean as of 2005 (UNAIDS 2006).

Teens and young adults, particularly girls and young women aged 15-24, are particularly hard hit by the epidemic. In sub Saharan Africa, on average, three young women are infected for every young man. In Caribbean, young women are about twice as likely to be infected as young men (UNAIDS, 2005).

#### **2.10. Poverty, economic inequality and HIV and AIDS**

Many communities worldwide are locked in a vicious cycle in which poverty helps to drive the HIV and AIDS epidemic. The epidemic in turn forces the communities into greater poverty. Poverty contributes to rising HIV and AIDS rates by fuelling migration by men, women and children to areas with greater economic opportunities. Migration disrupts marital and familial ties and leads to sexual networks in urban areas where there is an unequal ratio of men to women and sero-prevalence is likely to be high (UNFPA, 2002). Migrating men are more likely to visit sex workers, putting themselves and other families at risk when they return home (Brummer, 2002). Migrating women often have sex with multiple partners for economic gain or protection. The risk of infection for migrating women is further increased when they are forced to submit to unwanted sex, for example, at border crossings or in exchange for physical protection.

In addition, people who live in poverty are also less likely to have information about how HIV and AIDS is transmitted and how to protect themselves than those from higher income levels (WHO, 2002). They are more likely to focus on day to day survival, and not on the reduction of risk for disease that may not manifest themselves for years and once people become ill from HIV and AIDS, insufficient resources often prevent them from obtaining medical care. At the same time, HIV and AIDS also contribute to poverty in various ways. In particular, when the primary household breadwinner becomes ill with AIDS and can no longer work, household income drops. In countries where women cannot inherit or own land, the wife and children of a man who has died from AIDS may lose access to their only source of livelihood. The number of AIDS orphans is expected to reach 25 million by 2010. When one or both parents dies from AIDS, their children are left in the care of already overburdened relatives or in overcrowded orphanages, or they must fend for themselves in child headed households or in the streets. The cost of HIV and AIDS treatments and treatment for opportunistic infections also can bankrupt those who are ill and their friends and extended families who try to assist them (Global AIDS Alliance, 2005).

#### **2.10.1. The feminization of poverty**

Women and girls are disproportionately impacted by poverty, representing 70% of the 1.2 billion people who live in poverty worldwide. Women receive an average of 30-40% less pay than men for the same work (WHO, 2000). This economic inequality may influence their ability to control the timing and safety of sexual intercourse. Specifically, economic dependence on men forces some women to remain silent about HIV risk issues and to stay with partners who refuse to engage in safer sex practices. International research shows that women in monogamous relationships who are vulnerable to HIV infection perceive the negative economic and potentially violent consequences of leaving high risk relationships to be far more serious than the health risks of staying in the relationship. Poverty also leads to greater HIV risk among women by leading women to barter sex for economic gain or survival. Commercial sex work is the most well-known way for women to exchange sex for money, but many women exchange sex for comfort or goods as a rational means of making ends meet. In addition, there is

evidence that girls and young women may willingly initiate relationships with “sugar daddies”, much older, relatively well off and usually married men who support them in exchange for sex. Some girls may also exchange sex for money for school fees or to help their families. Once in these relationships with teachers, drivers, shopkeepers, or even policemen, girls have little power to negotiate the use of condoms (UNFPA, 2003).

### **2.10.2. Educational inequality and HIV and AIDS.**

Women make up almost two thirds of the world’s 876 million illiterates. Worldwide , there are 90 young women in secondary school for every 100 young men, although in some countries, including Bangladesh, Yemen, Chad and Niger there are fewer than 60 young women in secondary school for every 100 young men. In some societies, girls are not able to continue with their education because they are taken out of school by their families to care for sick family members or to perform other household tasks (United Nations, 2000).

Educational inequality contributes to women’s HIV risk directly, by making information on HIV and AIDS less accessible to them, and indirectly by increasing their economic dependence on a male partner. In particular, studies shows that more educated women are likely to know how to prevent HIV transmission, delay sexual activities, to use health care services, and take other steps to prevent the spread of HIV. Education also reduces poverty and affords women greater decision making power. Many cultures value ignorance about sex as a feature of femininity and many young women are prevented by husbands, fathers or other family members from obtaining education about HIV and AIDS. Others decline to seek such information out of fear for their reputations, and those who do learn about HIV and AIDS may hide HIV related knowledge. Lack of education about the causes, prevention and treatment of HIV and AIDS contributes to high transmission rates and low treatment seeking and adherence, and perpetrates stigma and discrimination toward people with HIV and AIDS (Feinstein & Prentice, 2001).

### **2.10.3. Gender based violence and HIV and AIDS**

Gender based violence is rooted in the historically unequal power relations such as social, economic, cultural, political and sexual abuse between males and females. Such violence

increases women's vulnerability to HIV and AIDS. These abuses may include such acts as use of coercion and threats to get one's way such as threatening to leave a relationship, to take the children away, to commit suicide, or to report the victim to welfare authorities. It can also involve destruction of personal properties, displaying of weapons, abuse of pets, thus making the victim feel guilty, worthless, or even isolating the victim from sources of social support, denying the abuse of blaming the victim for it and keeping the victim economically dependent by blocking employment opportunities or access to family income. Although both males and females can suffer from gender violence, studies show that women, young women and children of both sexes are most often the victims of such violence, particularly sexual abuse. Available data suggest that at least one in five of the world's female population has physically or sexually abused at some time in their lives. Sexual violence does not have to include direct physical contact between perpetrator and victim, sexual threats, humiliation, intimidation may be considered sexual violence when they are used to demonstrate power over, or inflict pain and humiliation on another person (Gordon & Crehan, 1999).

Violence against women, in particular forced or coerced sex increases a women's vulnerability to HIV and AIDS. The proportion of HIV infections around the world that are attributable, directly or indirectly, to gender based violence is unknown but, existing evidence suggests that it is likely to be significant. For example South African women who have been physically abused, or whose partners have excessive control in the relationship, have a 50% higher rate of HIV infection than other women. Gender based violence also can compound the barriers to HIV positive women obtaining medical care. Conversations about safer sex, HIV status, or HIV risk reduction are unlikely to take place in situations of rape, particularly when the rapist has a woman. Violence between intimate partners often contributes to HIV transmission by harming the ability of partners to communicate openly with each other about safe sex, their HIV status, or ways to reduce the risk of infection (Feinstein & Prentice, 2001).

#### **2.10.4. Non consensual sex**

Although some forms of gender based violence are region specific such as female genital mutilation, most are universal. One ubiquitous manifestation of violence toward women is non-

consensual sex. In situations of rape or coerced sex, a woman is more likely to experience bleeding and tearing of the genital area. This can create passage ways for HIV to enter the blood stream. In addition, conversations about HIV status, HIV risk reduction, and condom use are unlikely to take place in forced sex situations. These problems are especially acute in conflict, post conflict, and refugee situations, where women and girls are subjected to high rates of sexual assault (UNIFEM, 2001).

#### **2.10.5. Unequal legal status of women**

Around the world, men and women have different status in society, which usually limits women's access to productive resources such as land, property, credit, employment, training and education. Women's subordinate role are often reinforced by laws and policies that, for example, prohibit women from owning land, inheriting property, asking for divorce, participating in democratic processes, protecting themselves from forced marriages and making decisions about their children's education. These discriminatory laws and policies not only deny equal access to resources but also fail to provide women with the opportunities to realize the full benefits of economic and social development. Such legal inequalities increase women's vulnerability to HIV and AIDS in number of ways (UNAIDS 1999).

#### **2.10.6. Property rights**

In many countries, women's rights to land and property are attained primarily through marriage. If marriage ends, women's rights to land or home may end as well. Unequal rights and access to property perpetuate women's dependence on men and undercut their social and economic status. Studies from all over the world, developed and developing countries alike, have found that some women believe that the economic consequences of leaving a high risk relationship are far worse than the health consequences of staying with their partners. In addition, a woman who has been widowed by HIV and AIDS risks losing her land and all her belongings to her husband's family, this situation can force her into commercial sex work or a risky sexual relationship with another man so that she can feed herself and her children (Lewis, 2003).

## 2.11. Summary

This section highlighted the comprehensive public health approach to cause, prevent and cure HIV and AIDS that is needed to control the spread of HIV infections. Depression in patients with HIV and AIDS is one of the major problems in any chronic illness. Diagnosis and optimal treatment of depression in HIV and AIDS is complicated by interactions between the disease conditions. Attempts by psychologists to reduce the risk for HIV infection have fallen into six prevention strategies. Firstly, broad HIV related education. Secondly, clinical intervention with individuals or groups and finally, encouraging partner notification.

People living with HIV and AIDS suffer psychological distress as a result of the many physical, social and economic effects of the disease on their lives.

Highly Active Antiretroviral therapies give hope and optimism to HIV positive people.

Social and behavioral factors such as age, gender, peer influence and social environment were taken into account when they designed and implement programs for HIV and AIDS prevention.

People living with HIV need support of their communities and their broader environments to implement the risk reduction behaviors promoted by individual health promotion strategies.

Antiretroviral therapy lengthens the life span and improves the physical well being of people living with HIV and AIDS when taken drastically.

In societies, girls and women face greater risks of HIV infection than men not only because of biological differences between them.

## SECTION B

### Factors contributing to the stress of HIV and AIDS patients

#### 2.12. Introduction

Stress in HIV and AIDS patients is associated with immune suppression and increases a person's vulnerability to HIV. Stress also can prove detrimental to people with HIV, enabling the virus to spread more quickly and prevent antiretroviral drugs from restoring immune system function. Dealing with stress, taking a realistic view of one's health and having good self-esteem might slow the progression of HIV and AIDS. Adequate sleep, rest and regular exercises are important stress reduction activities in HIV patients (WHO, 2000). In this section, factors contributing to the stress of HIV and AIDS will be highlighted.

A variety of reactions to an HIV positive diagnosis form part of the normal and expected range of responses to news of a chronic, potentially life threatening medical condition. Many patients adjust extremely well with minimal intervention. Some will exhibit prolonged periods of distress, hostility, or other behaviors which are difficult to manage in a clinical setting. Serious psychological maladjustment may indicate pre-existing morbidity and will require psychological assessment and treatment. Depressed patients should always be assessed for suicidal thoughts (Card, Amarillas, Conner, Akers, Solomon & DiClemente, 2007).

Effective management requires time for the shock of the news to sink in; there may be a period of emotional ventilation, including overt distress. The counselor provides an assurance of the strict confidentiality and rehearses, over time, the solutions to practical problems such as who to tell, what needs to be said, discussion around safer sex practices and adherence to drug therapies. Clear information about medical and counseling follow-up should be given. Counseling may be of help for a patient's partner and other family members too. Partners and family members sometimes have greater difficulty in coming to terms with the knowledge of HIV infection than the patients do themselves. Individual support counseling is often required to manage this, particularly role changes within the relationship and other adjustment issues that may lead to difficulties. This forms part of a holistic approach to a patient's overall health

care. In many cases the need for follow-up counseling may be episodic and seems appropriate given the long term nature of HIV infection and the different challenges a patient may be faced with. The number of counseling sessions required during any of these periods largely depends on the individual presentation of the patient and the clinical judgment of the counselor (Van Dyk, 2001).

### **2.13. HIV and AIDS stigma and discrimination**

The stigma and discrimination of HIV and AIDS will be discussed under the following sub-headings;

#### **2.13.1. The origin of stigma and discrimination**

Originally, the word stigma meant a visible mark, such as a brand or tattoo, which was used to disgrace, shame, and condemn a person. Now stigma is used as a mean to reduce a person from a valued, respected person to a discounted one. In some cultures, being female, or black, is considered stigmatizing. Many cultures, which do not understand the biological origins of mental illness, stigmatize the mentally ill (Card et al, 2007).

HIV and AIDS is one of the most stigmatizing medical conditions in modern history (Kalichman, 2004). Many communities direct unfavorable attitudes, beliefs, and policies toward people who have or who are associated with HIV and AIDS and it includes their loved ones, family members, close associates, and social groups (Brimlow, Cook & Seaton, 2003). However some communities are less prejudiced toward people with HIV and AIDS than others.

#### **2.13.2. Causes of stigma and discrimination**

Stigma against HIV positive women is particularly strong. HIV and AIDS is misperceived in many parts of the world as a "promiscuous woman's disease" or a "prostitute's disease". Women are often blamed for the spread of HIV and AIDS to their families because they were the first ones in their families to be tested, as testing during pregnancy or just after childbirth are common. In reality, most HIV positive women in the world contracted HIV from their husbands. HIV positive

women may be expelled from their households, fired from jobs and shunned by their communities.

### **2.13.3. Results of stigma and discrimination**

Some advocates of women's rights point out that a vestige of the blame and stigma against women is manifest in the fact that the infection of newborn babies is still often termed "mother to child transmission" and not parent to child transmission". The stigma of being HIV positive and the social and economic consequences of being labeled HIV positive cause some women to refrain from being tested for HIV and seeking out care (Albertyn, 2000).

In many industrialized nations and developing nations alike, homosexual intercourse is highly stigmatized and in some cases illegal, forcing men who have sex with men to keep their relationships secret. Men who have sex with men are often targets of intolerance and hate crimes. As a result of these norms and legal circumstances, government officials and the general public may refuse to admit that homosexual transmission occurs and not allocate funds for HIV and AIDS prevention among men who have sex with men. Men who have sex with men may in turn, feel compelled to keep their sexual behavior secret, deny their sexual risk, and avoid HIV testing and treatment. This increases their own risk as well as the risk of their partners, female or male (Aggleton & Parker, 2002).

In an analysis of several studies involving more than 4,500 people with the HIV infection, women were 33% more likely than men to die within the study period (NIAID, 2006). This disparity appears largely because of differing access to and use of treatment services, along with domestic violence, homelessness, and lack of social support among women, rather than the biological differences between men and women. In many countries, women with HIV infections are also more likely than men to suffer from malnourishment, which accelerates disease progression. Women whose HIV infections are detected early and receive appropriate treatment have been shown to survive as long as infected men. Even in areas where high quality HIV and AIDS care is available to women, there is evidence that they wait longer than men before seeking care and are less likely to seek care at all. Women are traditionally responsible for the wellbeing and health of their families. When a husband or children are sick,

women are expected to care for them. This often leaves little time for women to attend to their own health needs. Within a family, men's illnesses are often perceived as more important because they tend to have a greater impact on wage earning. Women's work is usually undervalued, and women's illnesses may be ignored until women are unable to perform daily tasks. When a woman is unable to care for her family because of her own illness, she may experience feelings of failure and decreased self-esteem. This low self-esteem is another factor that makes a woman less likely to seek out care for herself (NIAID, 2006).

Goffman (1963) was a sociologist who originally developed the idea of "social stigma" In his work; He identified six dimensions that influence whether a person's quality or condition is stigmatized. Due to the fact that HIV and AIDS is a stigmatizing condition, and because people do not want to be discriminated against, many people are hesitant to find out what their sero-status is to seek treatment for the HIV disease.

UNAIDS (2008) states that, AIDS related stigma and discrimination refer to prejudice, negative attitudes, abuse and maltreatment directed at people living with HIV and AIDS. They can result in being shunned by family, peers and wider community, poor treatment in health care and education settings and an erosion of rights. Psychological damage can negatively affect the success of testing and treatment. AIDS stigma and discrimination exist worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals. They occur alongside other forms of stigma and discrimination, such as racism, homophobia and can be directed towards those involved in what are considered socially unacceptable activities such as prostitution. Stigma not only makes it more difficult for people trying to come to terms with HIV and manage their illness on a personal level, but it also interferes with attempts to fight the AIDS epidemic as a whole. On the national level, stigma associated with HIV can deter governments from taking fast effective action against the epidemic, whilst on a personal level it makes individuals reluctant to access HIV testing, treatment, care and to cope well with their HIV illness.

UN secretary general Ban Ki Moon (2008) says: *"Stigma remains the single most important barrier to public action. It is the main reason why too many people are afraid to see a doctor to*

*determine whether they have the disease, or to seek treatment. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world”.*

HIV and AIDS related stigma is not a straightforward phenomenon as attitudes towards the epidemic and those affected vary massively. Even within one country reactions to HIV and AIDS will vary between individuals and groups of people. Religion, gender, sexuality, age and levels of AIDS education can all affect how somebody feels about the disease. AIDS related stigma is not static. It changes over time as infection levels, knowledge of the disease and treatment availability vary. In 2003, when launching a major campaign to scale up treatment in the developing world, the World Health Organization (WHO) claims that “as HIV and AIDS becomes a disease that can be both prevented and treated, attitudes will change, denial, stigma and discrimination will rapidly be reduced.” A number of small scale studies have been conducted, with fairly positive results. A study of 1,268 adults in Botswana found that stigmatizing attitudes had lessened three years after the national programme providing universal access to treatment was introduced. The study concluded that although improving access to antiretroviral treatment may be a factor in reducing stigma, it does not eliminate stigma altogether and does not lessen the fear of stigma amongst HIV positive people.

AIDS related stigma has had a profound effect on the epidemic’s course. WHO (2008) cites fear of stigma and discrimination as the main reason why people are reluctant to be tested, disclose their HIV status or to take antiretroviral drugs. One study found that participants who reported a high level of stigma were more than four times more likely to report poor access to care. These factors all contribute to the expansion of the epidemic as a reluctance to determine HIV status or to discuss or practice safe sex, means that people are more likely to infect others resulting in a higher number of AIDS related deaths. An unwillingness to take an HIV test means that more people are diagnosed late, when the virus has already progressed to AIDS, making treatment less effective and causing early death. The widespread fear of stigma is held accountable for the relatively low uptake of prevention of mother to child transmission

(PMTCT) programmes in countries where treatment is free. In the case of Botswana, for example, despite the fact that services are available at every antenatal Centre in the country, only 26% of pregnant women availed themselves of the opportunity to protect their unborn children. Over half refused to take a test, and nearly half of those tested positive did not go on to accept treatment( UNAIDS, 2006).

AIDS related stigma leads to discrimination such as negative treatment and denied opportunities on the basis of their HIV status. This discrimination can occur at all levels of a person's life, for example, when they wish to travel, use healthcare facilities or seek employment. A country's laws, rules and policies regarding HIV can also have a significant effect on the people living with the virus. Discrimination practices can alienate people living with HIV, reinforcing the stigma surrounding the disease (UNAIDS, 2008).

#### **2.13.4. Relevant legislation**

In 2008, UNAIDS reported that 67% of countries now have some form of legislation in place to protect people living with HIV from discrimination. However Ban Ki-Moon, Secretary General of the United Nations, believes that 'almost all of these countries permit at least some form of discrimination'. There are many ways that government can actively discriminate against people or communities with or suspected of having HIV and AIDS. Many of these laws have been justified on the grounds that the disease poses a public health risks. President Museveni of Uganda supports the national policy of dismissing or not promoting members of the armed forces who test HIV positive and the Chinese government advocates compulsory HIV testing for any Chinese citizen who has been living outside of the country for more than a year. Furthermore, the United Kingdom's legal system can prosecute individuals who pass the virus to somebody else, even if they did so without intent.

Lack of confidentiality has been repeatedly mentioned as a particular problem in health care settings. Many people living with HIV and AIDS do not get to choose how, when and to whom to disclose their HIV status. Studies by World Health Organization (WHO) in India, Indonesia, the Philippines and Thailand found that 34% of the respondents reported 'breaches' of confidentiality by Health Workers. Doctors in health care settings in resource poor areas with

limited or no drugs have reported a frustration with the lack of options for treating people with HIV and AIDS and who were seen as doomed to die. This frustration can mean that AIDS patients are not prioritized or are actively discriminated against. Fear of exposure to HIV as a result of lack of protective equipment is another factor fuelling discrimination among doctors and nurses in under resourced clinics and hospitals. Stigma and discrimination in health care settings are not confined to developing countries.

In the workplace, people living with HIV may suffer stigma from their co-workers and employers such as social isolation and ridicule or experience discriminatory practices. For example, termination or refusal of employment is not uncommon. Fear of an employer's reaction can cause a person living with HIV some anxiety. Many countries have laws that restrict the entry, stay and residence of people living with HIV. Almost sixty countries, territories and areas have restrictions that specifically apply to HIV or AIDS based on positive status alone. This number does not include those countries where legislation uses language such as "contagious" or "transmissible disease." (UNAIDS, 2008).

UNAIDS identified around a dozen restrictions applying to HIV positive people regarding entry, stay and residence and five require a declaration of HIV status which can result in HIV positive people being denied entry, stay or the need for discretionary approval. Until the 4<sup>th</sup> of January 2010, the United States restricted all HIV positive from entering the country, whether they were on holiday or visiting on a longer term basis. Twenty two countries including Egypt, Russia and South Korea deport foreigners based on HIV positive status alone (UNAIDS 2008).

#### **2.14. Psycho-social stressors on persons within the spectrum of HIV and AIDS.**

Persons who are infected with HIV have a variety of psychological and social stresses that may differ in degree of severity, the stage of illness and whether or not symptoms have appeared. The stressors associated with HIV disease are compounded by the age of the population affected, the high mortality rate and accompanying anxiety and depression, the social stigma, fear, ostracism and discrimination associated with diagnosis of the disease and symptoms of

the disease and its contagious nature (UNAIDS,2006). These psycho-social stressors will now be discussed.

#### **2.14.1. Psychosocial assessment**

Gathering information about persons across the spectrum of HIV infection in various categories of psychosocial adjustment can help the health care professional anticipate reaction, needs and vulnerability to psychological dysfunction and aid in designing an appropriate psychosocial intervention plan. Psychosocial assessment should be conducted frequently with persons who have HIV infection, especially at the various crisis points in the disease spectrum(United Nations, 2000).

#### **2.14.2. Social and psychiatric history**

The person's history of interpersonal relationships, education and career can provide insight into vulnerability to psychological dysfunction. Use of non-prescribed drugs and alcohol, prior psychiatric care, and pre-existing mental illness are other indicators of possible psychological dysfunction. Psychologically healthy people usually have stable jobs and stable interpersonal relationships while psychologically vulnerable HIV infected persons may have pre-illness behaviors that include drug use and multiple sexual contacts. The presence of a personality disorder or of a previous depressive, anxiety or thought disorder is more likely to result in severe psychological symptoms and also maladaptive response to the stresses of illness(UNAIDS, 2008).

#### **2.14.3. Current distress and crisis**

What specific threats and losses are HIV positive people experiencing currently? What aspect of the illness is the most distressing and bothersome to the person at the present time? The person's level of anxiety, fear and behavioral disorganization will change from time to time and will relate to the duration, intensity and precipitant of the current crisis (UNAIDS, 2006).

#### **2.14.4. Coping abilities**

The person who is facing HIV disease will call into action previous patterns of understanding problems and methods of resolving them. Knowing which approaches have been successful for this person in the past and which approaches are currently being tried will give an indication of how he/she will attempt to cope with the illness and how successful that attempt might be and it will also give directions for providing support to the person's coping responses ( Pratt, 2003).

#### **2.14.5. Social support available**

Gender, age, ethnicity, and route of exposure all affect the amount and kind of social support available and needed by people living with HIV and AIDS. Fewer organized resources are available for women. The needs of different groups differ from one another and from those of gay white men. The following questions should be asked: what types of support and assistance do people living with HIV need? What practical assistance do they need? Do they interact with other people socially? Do they have emotional support? And how can assistance be provided?( Reeves, 2001)

People have different goals, resources, skills and social roles, depending on their age. The majority of people living with HIV are in their twenties, thirties and forties. Young adults are not developmentally prepared to confront their mortality. Those in their twenties have fewer resources and skills than those in their forties. The former are involved in the psychosocial tasks of establishing independence, autonomy and adult identity. At times of illness this age group typically becomes intensely re-involved, emotionally and financially, with the family of origin. Older persons (those in their thirties and forties) have more resources such as money, housing, insurance and have established independent adult roles. At times of illness they are more likely to depend on a spouse or lover and friends for support (UNAIDS, 2006).

People's needs for psychosocial support differ according to the phase of their illness. Stresses on the person are different in HIV testing, AIDS diagnosis, treatment and after treatment phases. They also differ according to the person's clinical syndrome and opportunistic infections. Therefore people living with HIV fear central nervous system disease more than

other clinical syndrome, the associated memory loss and mood changes result in depression, anger and strain on their social network. Emotional reactions and methods of coping differ in response to their phase of illness and the clinical syndrome( Pratt, 2003).

A person's personal identity also affects his or her reaction to a life threatening illness. Sources of self –esteem, valued achievements and future goals makes up that person's identity. His or her orientation to living and search for meaning all play a role in determining how the person perceives and combats the illness and what kind of social support is needed (Pratt, 2008).

The losses that the person has had, is currently having, and anticipates having as a result of the illness determine the kind of psychosocial support needed. Persons may be currently grieving a loss and going through the grief and feel some recognition and equanimity toward a process. They may have had previous experiences with loss and grief and feel some recognition equanimity toward the process, or they may have had no previous experience and are anxious and fearful about anticipated losses and the grieving process. An assessment in these various areas will provide the health care professional with the information needed to design psychosocial intervention plan for the person with HIV disease. This plan can be individualized to meet the specific needs of person as they move through the various phases of the disease spectrum and of their emotional and social responses to the illness. The common psychosocial crisis that occurs in people living with HIV and have been identified and intervention strategies have been designed to support them during these crises (Van Dyk, 2000).

#### **2.14.6. Psychological stressors**

The major psychological stressors on people living with HIV is the knowledge that they have a fatal disease with the potential for a rapid decline to death. Most frequently, psychological reactions are those of fear, anxiety and depression, which are compounded by the uncertainty of the course of the disease. Social stresses on people living with HIV include exposure, stigma, rejection, abandonment and isolation. Common psychological reactions are guilt, fear, anger and suspicion (Brasher et al., 1998).

#### 2.14.7. Crisis points

Certain crisis points in the course of the disease cause intense anxiety, fear and depression. The initial intense crisis is at the time of confirmation of HIV sero-positivity. For symptom free persons who are sero-positivity, significant adverse reaction in the form of depression, anxiety and preoccupation with AIDS are commonly reported. Suicide risks have been reported to be higher in persons recently infected with HIV than in the general population. The devastating effects of sero-positive test results may include feelings of panic, depression and hopelessness (Brasher et al., 1998).

Interpersonal and social responses may also be devastating. Many persons lose their sexual partners because of disclosure of sero-positive test results. In addition, discrimination in employment and housing and loss of insurance benefits may occur. Persons who receive HIV positive test result may require prolonged counseling and also need a variety of social, medical and psychiatric support services. Counseling during the HIV testing process provides an opportunity to identify those most at risk of psychopathological abnormalities and those with history of current depression, anxiety, cognitive symptoms and drug use. During the long asymptomatic phase of HIV infection, many persons do not experience severe distress but, instead, become actively involved in managing their illness and engaging in health promotion activities. Those who do experience sustained psychological problems have been identified as those who, at the same time of HIV testing, demonstrated depression, anxiety and cognitive symptoms within clinical ranges and as those who use drugs. When HIV infected person begin having symptoms of disease, they may experience all the psychological and social stresses associated with AIDS. Each development for instance the appearance of symptoms that signals to a person further deterioration towards AIDS and eventually death has the potential of stimulating a psychological crisis. The same existence issues that accompany a diagnosis of other life threatening illnesses occur with AIDS. One set of responses to an AIDS diagnosis is characterized by denial, followed by anger, turmoil, and disruptive anxiety, a feeling of being already dead and depressive symptoms. Another coping response may be a period of problem

solving during which people living with HIV focus on adhering to a medication regimen and on health promoting lifestyle changes (Brasher et al., 1998).

The treatment phase may be accompanied by weakness, depression and alienation. Patients fear disfigurement, debilitation and pain. Treatment may include isolation procedures that make patient feel alienated and socially abandoned. The termination of treatment often brings on increased anxiety and fears of renewed disease progression. Hyper vigilance about body functions and the appearance of new symptoms can result in hypochondriasis, demanding behavior toward medical personnel, and excessive dependence on caregivers. Recurrence or relapse of disease is often accompanied by feelings of hopelessness, helplessness, sadness, low self-esteem, and discouragement, loss of control, dependence, isolation and suicidal ideation. Patients fear being abandoned by loved and caregivers who might decide that continued treatment is futile. At this point, some persons may seek medically assisted suicide (Brasher et al., 1998)

#### **2.14.8. Suicide assessment**

The potential for suicide has been recognized at several crisis points in HIV infection and disease. Increased risks of suicide are associated with any aspect of HIV disease that may cause psychological distress. HIV antibody testing and learning of a sero-positive status, appearance of an AIDS indicator disease, a drop in CD4 positive cell count or an increased in viral load, pain treatment regimens and dementia. People living with HIV who are more likely to take their own lives are those with previous depressive episodes, adjustment disorders, personality disorders, alcohol abuse, high level of environmental stress, inadequate counseling before and after the HIV antibody test, and poor support networks. Several groups whose behavior puts them at risk of acquiring HIV infection are also at greater risk of committing suicide (Brasher et al., 1998). People with HIV contemplating suicide may have made suicide pacts with friends and loved ones, and may be grieving the loss of friends who died of AIDS. They may be experiencing the loss of independent function accompanied by loss of self-esteem. They may also be facing an existential crisis in which life has ceased to have meaning. Any or all of these factors may be

motivation for suicide. Persons who are males, white, advanced in age, and living alone are more likely to commit suicide (Brasher et al., 1998).

#### **2.14.9. Crisis intervention and support**

People living with HIV need a full range of psychosocial interventions, including immediate crisis intervention, individual therapy, or both, to deal with feelings of extreme anxiety, fear and anger and with impulsive behavior and suicidal thoughts. Persons with HIV should be encouraged to express their anxiety, fear, sadness and anger and to grieve with the understanding that grief can be a healing process. Pharmacotherapy should be used for intense anxiety, depression, hopelessness, and insomnia. Clients also need ongoing psychosocial support in the form of support to dispel self-blame and guilt, provide reassurance, share information and experience, and reduce feelings of isolation and loneliness. Infected persons need education regarding the disease and its treatment, liaison with community resources to help them resolve practical problems and instruction in techniques of reducing stress and anxiety, such as relaxation. They also need supportive intervention from a social network that includes family, friends, health care professionals, volunteers and an attorney. These people can offer encouragement, comfort, concern, compassion, affection, legal and spiritual assistance. All these interventions play a role in the treatment of people living with HIV during crisis points in their disease. This will take priority at any given time depending on individual response and can be determined by psychological assessment of the person at various points. If possible, the HIV infected person should be assigned a primary care giver or a case manager who will coordinate services needs and provide a central and familiar person the client can see to ensure continuity of care throughout the course of the illness, hospitalization, community care and friends ( Ungavarski&Flaskerud, 1999).

#### **2.14.10. Psychological conflict**

People with HIV disease are subjected to an unusual number of psychological or internal conflicts. Some of these conflicts revolve around transmission of the disease from whom the person got it or to whom he or she might have transmitted it. People may also experience guilt over their previous lifestyles, especially if they have had a number of anonymous sexual

partners or have used injection drugs or other recreational substances. Strong feelings of guilt and self-blame among people living with HIV may cause them to internalize society's prejudicial attitudes toward the groups to which they belong and lead them, in turn, to stigmatize others (Grossman, 1995).

#### **2.14.11. Social stressors**

Persons with HIV disease are subject to an unusual number of social and societal stresses. The first of these may involve public identification as a member of a highly stigmatized group (Grossman, 1995). Social stigmatization is attached to both of the largest transmission groups for HIV infection, men who have sex with men. Persons who have considered their sexuality or drug use to be private matters are subject to exposure and possible rejection by family and friends. At a time when people most need social support, comfort, compassion and closeness, they might be left alone and isolated. Persons with asymptomatic disease are faced with dilemma as whether to confide in family, friends and health care providers because stigmatization and social rejection are likely to result from divulging this information. People living with HIV have been confronted with a variety of problems involving employment and insurance. Some have been fired from their jobs because employers and co-workers feared that they will contract HIV and in some cases, this discrimination has extended to the families of people living with HIV. Others have had to leave their jobs because of physical disability and in many instances health insurance is lost when the job is lost. Many people living with HIV are without financial security, material resources and insurance. Many people living with HIV have limited societal support networks for example; the family may not be involved with the person or may live in distant places. The reason could be alienation from the family because of lifestyle or relocation by the people living with HIV to a large urban area. Therefore, some families abandon a relative with HIV infection when they learn of the diagnosis and this action could be the result of a desire to avoid social stigma, fear of contagion, or a belief that the disease is a just retribution for homosexuality, drug use, or having multiple sexual partners. Such a situation leaves the infected person without a social network to assist with basic physical needs and to provide emotional support at a crucial time, and it forces greater dependence on a single family

member, lovers, friends and sometimes children. Community resources can help meet basic physical needs of people living with HIV at home through practical services such as shopping and housekeeping. Some churches help visiting parents and siblings find places to stay when from out of town. In the United States of America, the gay community and gay service agencies have organized a variety of supportive services for persons with limited or distant social support networks and these services include case management which provides social services, nursing services, insurance counseling, client advocacy, emotional and physical support (Ungavarski&Flaskerud, 1999).

### **2.15. Summary**

The stressors associated with HIV disease are compounded by the age of the population affected, the high mortality rate and accompanying anxiety and depression, the social stigma, fear, ostracism and discrimination associated with diagnosis of the disease and symptoms of the disease and its contagious nature. HIV and AIDS is one of the most stigmatizing medical conditions in modern history. Many communities direct unfavorable attitudes, beliefs and policies toward people who have or who are associated with HIV and AIDS and it includes their loved ones, family members, close associates and social groups.

Sixty seven percent (67%) of countries in the world have some form of legislation in place that protects people living with HIV from discrimination.

Persons who are infected with HIV and AIDS have a variety of psychological and social stressors that differ in degree of severity, the stage of illness and whether or not symptoms have appeared.

## SECTION C

### Coping with HIV and AIDS

#### 2.16. Introduction

This section highlights the importance of counseling and the coping mechanisms that HIV and AIDS patients use in order to come to terms with their illness. Counseling is needed before and after the test is done. HIV and AIDS counseling has two general aims which are the prevention of HIV transmission and the support of those affected directly and indirectly by HIV. The importance of encouraging and working towards coping strategies involve active participation to the extent that the patient can manage in planning for care and in seeking appropriate social support.

#### 2.17. HIV counseling and psychosocial management of patients with HIV and AIDS

Counseling in HIV and AIDS has become a core element in a holistic model for health care, in which psychological issues are recognized as integral to patient's management of the disease. (UNAIDS, 2006).

It is important that HIV counseling should have these aims because the spread of HIV can be prevented by changes in behaviors. Face-to-face counseling has a particular contribution, in that it enables good communication of sensitive issues of a client's life. Communication can be hampered due to a client's concern for confidentiality or anxiety about a judgmental response. When patients know that they have the HIV infection, they suffer great psychological stressors due to fear of rejection, social stigma, disease progression, and the uncertainties associated with future management of HIV. Good clinical management requires that such issues be managed with consistency and professionalism, and counseling can both minimize morbidity and reduce its occurrences. All counselors in the field of HIV must therefore have formal counseling training and receive regular clinical supervision as part of adherence to good standards of clinical practice (Chippindale & French, 2001).

### **2.17.1 Different types of HIV counseling programs and services**

Counseling is needed before the test is done as well as after the test for those who are HIV positive or negative; when risk reduction assessment is done to help prevent transmission; family and relationship counseling is needed outreach counseling; crisis intervention and structured psychological support for those affected by HIV and support groups (Van Dyk, 2001).

#### **2.17.1.1. Pre- test discussion**

A discussion of the implications of HIV antibody testing should accompany any offer of the test itself. It is done to ensure that principle of informed consent is understood and to assist patients to develop a realistic assessment of the risk associated with testing HIV positive. The process includes accurate and up to date information about transmission and prevention of HIV and other sexually transmitted infections. Patients should be made aware of the "window period" for the test (the period of 12 weeks since the last possible exposure to HIV should have elapsed by the time of the test).

Patients present for an HIV and AIDS test for a number of reasons ranging from a generalized anxiety about health to the presence of HIV related physical symptoms. For patients at minimal risk of HIV infection, pre- test discussion provides a valuable opportunity for health education and safer sex messages to be made relevant to the individual. For patients who are at risk of HIV infection, the discussion is an essential part of post-test management. These patients are particularly appropriate to refer for specialist counseling such as done by a social worker. The importance of undertaking a sensitive and accurate sexual and injecting drug risk history of both the patient and their sexual partners cannot be overstated. If patients feel they cannot share the information with the social worker or a counselor then the risk assessment becomes meaningless. Patients may be inappropriately reassured and be unable to disclose the real reason for testing. Counseling skills are an essential part of establishing an early picture of the patient and his/her history and of how much intervention is needed to prepare him or her for positive results. Reinforcement of prevention messages is also necessary. It is therefore at this stage that potential partners at risk are identified and they will become an important part of the patient's management of HIV (Van Dyk, 2001).

### **2.17.1.2. Post –test counseling**

HIV results are given in person. For negative patients the information which is given is about risk reduction. One to one group interventions considered for risk reduction strategies. The window period of 12 weeks is checked again and the decision taken about whether further tests for other sexual transmitted infections are appropriate. Thereafter, HIV positive patients should be allowed time to adjust to their diagnosis. Coping procedures rehearsed at the pre-test discussion will need to be reviewed in the context of the patient's here and now situation. Practical arrangements including medical follow- up visits should be written down. Overloading the patient with too much information about HIV should be avoided. Therefore counseling support should be available to the patient in the weeks and months following the positive test results. Significant developments in antiretroviral therapy have had led to a surge of optimism about long term medical management of HIV infection, and people are now living much longer with HIV. Patient adherence is an important factor in the efficacy of drug regimes. However, taking large numbers of tablets several times a day is a constant reminder of HIV infection. The presence of side effects can often make patients feel unwell and some may be unable to cope with the side effects. Counseling may be an important tool in determining a realistic assessment of individual adherence and in supporting the complex adjustment to a daily routine of medication (Van Dyk, 2001).

### **2.17.1.3. Coping strategies for HIV and AIDS positive patients**

The importance of encouraging and working towards coping strategies involving active participation to the extent that the patient can manage in planning for care and in seeking appropriate social support which has demonstrated clinically and empirically. Such an approach includes encouraging problem solving, participation in decisions about treatment and care, emphasizing self-worth and the potential for personal control over manageable issues in life. Many patients diagnosed with HIV some years ago are now feeling well enough to return to work and to study and are learning to readjust to living, as they had formally adjusted to the possibility of dying. Patients also have to deal with the uncertainty which remains about the long term period of current medical treatment, and there are some who fails on the

combination therapy. Even with the significant medical advances in patient management, counseling remains an integral part of the management of patients with HIV, and their partners and families (Walensky&Paltiel, 2006).

#### **2.17.1.4. How individuals cope with HIV and AIDS by using the internet**

Although identified 20 years ago, HIV and AIDS remains among the most serious disease epidemics of modern times, because of the stigmatization associated with infection. No health crisis has rivaled HIV and AIDS in underscoring the need for emotional, informational and instrumental support (Reeves, 2000). The most important role that support plays in coping with HIV and AIDS is that adults with HIV and AIDS have utilized traditional means of support which are families, friends and community based service organizations in coping with their illness. Recently, the internet has been recognized as a potential avenue for support. Although the internet may prove promising, little is known about how the wide array of resources available via the internet is used (Reeves, 2000). It is however a helpful resource to be considered and to be brought under attention of post –modern patients. Individuals living with HIV and AIDS have social reactions in group settings, such as chat rooms and on a one- to- one basis. The salient feature of online connection was that it linked participants with other individuals living with HIV and AIDS as one participant describes that ‘the neat thing about internet is that a person can actually hook up with people that have gone through the same experiences, that understands what a person is talking about and that have been there’. Making social connections on the internet allows a person to receive ‘input or feedback from people that are in similar situations for example people living with HIV and AIDS, but that have had different experiences with doctors and with treatments. Making social connections over internet generates an ‘encouraging effects’ because it puts a person in contact with men and women who have become infected and who have somehow decided to take the illness as a challenge , instead of some kind of personal embarrassment or defeat (Reeves,2000).

The use of internet for advocating makes people excited and when advocating with other people things are done through education. Reeves (2000) states that people have to be informed in order to care and try to effect change’. In other words advocating is used in

allowing people's voices to be heard on a particular issue and the internet was an efficient forum for advocating. One participant said that advocating is as 'getting involved and having her voice to be heard , speaking up, raising concerns, raising questions and being noticed as a person that has concerns that are important not just for one person but for a group that a person is a member of'.

The Internet as a place to get information can also allow for a certain amount of escapism. Individuals also use the internet to relieve the pressure associated with their illness. Most people with HIV and AIDS use the internet for meditation, lowering stress, things that do not matter and also connect to other events that make them happy (Reeves, 2000).

#### **2.17.1.5. Coping and stress management programs**

Coping and stress management programs that are based on cognitive and behavioral theories and delivered to small groups can positively affect the mental wellbeing of people living with HIV and AIDS ( Kelly & Kalichman,2002). These interventions first teach people how to tell the difference between stressors that can control or change and stressors that they cannot control or change. In response to the controllable stressors, these interventions then teach people how to address their problems in constructive and efficient ways. In response to the uncontrollable stressors, these programs teach people how to view their situations more positively and to deal with their negative emotions (Chesney, Chambers, Taylor, Johnson &Folkman, 2003). Some of these interventions also teach people how to relax and avoid anxiety.

#### **2.18. Nutrition for HIV and AIDS patients**

Nutrition plays an important role in helping the immune system of people's bodies. The immune system is a natural part of people's body that fights of germs, viruses, bacteria and other disease causing organisms that people can come in contact with every day. When a person is infected with HIV, his /her immune system is being damaged. Therefore eating right can help a person's body to stay stronger during any medical treatments that a person may need to have. When people feed their bodies well, they feel better and have more positive attitudes about life. Eating tasty meals with people who care about other people is a wonderful

"medicine" for a person's emotional health. There is no single "right " way of eating. In the absence of a cure, it is important to control symptoms, support the immune system, and lower the levels of HIV circulation in the blood. To lower the level of HIV in the blood, patients take a prescribed combination of antiviral drugs. The role nutrition plays will vary along the disease continuum, with consideration given to the patient's age, gender, behaviors, current medication, drug history, socioeconomic status, and associated health concerns. In all cases, adequate fluid intake and increased calories and proteins intake are necessary to fight the infection. Proper nutrition must begin immediately to support nutritional deficiencies including vitamin A and E, the B vitamins, magnesium and zinc that occur early in the disease process. These nutritional deficiencies contribute to increased immunity and disease progression (Lehman, 1997).

Mazo and Berndtson (2002) suggest that once the patient has been diagnosed with HIV infection, more protein and complex carbohydrates, along with moderate amounts of fats, should be consumed. The diet should include lean meat, fish, beans, seeds and nuts, whole grain breads and cereals, fruits and vegetables. Moderate amount of fat for energy and calories can be acquired through foods such as nuts, avocado dip, peanut butter, and seeds. The diet should include each of the five major foods groups (dairy, vegetables, meat, fruit and bread). Patients with poor appetite should eat six or more smalls throughout the day, rather than three large ones. In prolonged cases of appetite depression, a physician may prescribe an appetite stimulant and it is important to keep all food refrigerated to avoid eating rare meats.

### **2.19. Preventative educational campaigns**

Instead of one broad preventative strategy for HIV prevention, a variety of educational campaigns have been mounted to educate the general public about HIV. These educational campaigns have been informed by a variety of educational models, ranging from traditional humanistic models, to radical structuralism models. There have also been a variety of modalities used for education, from didactic, through participative to dramatic methods. Educational campaigns aimed at improving knowledge of HIV and AIDS and self-protective behavior seem to have had varied impact. Some studies have found relatively little

impact of broad educational campaigns. On the other hand, a number of large surveys have found changes in HIV risk factors following educational programs, especially in homogenous communities. In order to succeed upon the pandemic, sex and sexuality need to be openly addressed. In South Africa, there is still a great deal of opposition from churches and educational departments. For example, initial AIDS education programs were to be based on cultivating a lifestyle based on high moral standards, chastity and being aware of the ideal sexual relationship, one man with one woman. The overall message was that condom promotion encourages promiscuity, a belief inherent in many South African schools today. The correctional services still do not allow condoms to be distributed in prisons and the legal system still outlaws homosexual practices and prostitution, making interventions with people who engage in these sexual practices very difficult.

#### **2.19.1. Cognitive behavioral skills training**

With the realization that knowledge of HIV and AIDS is itself not sufficient for decreasing rates of HIV infections, especially because of the frequent failure to translate knowledge into self-protective behavior, greater emphasis have been placed on teaching skills to make risk reduction behavior changes. Many of these interventions have been based on social learning models, as have interventions based on social learning models, like intervention in other areas of health risk behavior (Eagle, 1994).

#### **2.19.2. Social norm change project**

Health related psychological research has shown that in considering modification of personal risks for disease, perception of peer norms regarding risk behaviors plays an important role as a modifying variable. This has also been found to be the case for HIV and AIDS where condom use or other safe sex practices are expected to be endorsed and supported by peer groups, there is a greater likelihood of these safe behaviors being practiced by members of the peer group (Eagle, 1994).

### **2.19.3. Community intervention projects**

Multidimensional, grassroots, community based campaigns have been recognized as important vehicles of intervention in the HIV epidemic, especially to ensure sustained and supported risk behavior change. It has been shown that sustaining behavior changes to reduce HIV risk also requires an appraisal of values, goals, social networks and personal relationships, as well as community networking, consulting and involving local community members, leaders and organizations. Unlike many of the approaches that rely on clinical or counseling type intervention models, using face to face individual or group counseling, community based approaches have the potential for developing community specific interventions reaching far greater portions of the population (Eagle, 1994).

### **2.20. Summary**

The most important role that support plays in coping with HIV and AIDS is that adult with HIV and AIDS have utilized traditional means of support which are families, friends and community based service organizations in coping with their illness. Recently, the internet may prove promising, little is known about how the wide array of resources available via the internet used (Reeves, 2000). Social connections, advocating and escaping has been used on internet as a means of coping.

Partners and family members sometimes have greater difficulty in coming to terms with the knowledge of HIV infection than the patients do themselves. Individual counseling support is often required to manage HIV. The importance of encouraging and working towards coping strategies involves active participation to the extent the patient can manage in planning of care and in seeking appropriate social support. Nutrition plays an important role in helping the immune system of people's bodies. The immune system is a natural part of people's body that fights germs, viruses, bacteria and other disease causing organisms that people can come in contact with every day. Furthermore, antiretroviral therapy, when taken drastically lengthens the life span and improves the physical well-being of people living with HIV and AIDS. Although it is true that living longer and healthier lives gives HIV positive people more chances of transmitting the virus, antiretroviral therapy also lowers the amount of HIV shed through blood,

genital and anal secretions. With fewer viruses in their body fluids, HIV positive people are less likely to transmit HIV (Centre for AIDS Prevention Studies, 2003).

### 1.1. Introduction

This chapter discusses the research methodology which includes research design, population of the study, sampling method, research instruments, procedures, and data collection method and data analysis.

### 1.2. Research design

The researcher used the qualitative approach and phenomenological design because this design allows for in-depth investigation into the coping strategies, coping needs and coping abilities of HIV and AIDS patients and is grounded in nature and allows for the understanding of the whole phenomenon by discovering, capturing and interpreting the meaning of respondents. The researcher wanted to understand how the patients make sense of their lives and discovering characteristics of being ill. The researcher described as naturally as possible the phenomenon and he also refrained from any pre-given framework, but he remained true to the facts.

### 1.3. Population of the study

The population of this study was patients who were receiving treatment and who were living with HIV and AIDS and having coping problems. These patients were registered clients of the social work at Ndabulana Intermediate Hospital.

### 1.4. Sampling method

Purposive sampling was used because it provides a clear identification of the selection of the respondents (De Vos et al., 2003, p.179). Twenty participants who were HIV positive and receiving treatment at Ndabulana Intermediate Hospital were selected. These people were registered clients of the social workers and each client had a file folder which the researcher could work on. The participants were selected purposively in the sense that they had to be HIV positive and experience coping problems. The participants were requested to participate in the research on a voluntary basis.

## CHAPTER 3

### RESEARCH METHODOLOGY

#### 3.1. Introduction

This chapter discusses the research methodology which includes research design, population of the study, sampling method, research instruments, procedures, and data collection method and data analysis.

#### 3.2. Research design

The researcher used the qualitative approach and phenomenological design because this design allows for in-depth investigation into the coping strategies, coping needs and coping abilities of HIV and AIDS patients and is also holistic in nature and allows for the understanding of the whole phenomenon by discovering, capturing and interpreting the meaning of respondents. The researcher wanted to understand how the patients make sense of their lives under distressing circumstances of being ill. The researcher described as accurately as possible the phenomenon and he also reframed from any pre –given framework, but he remained true to the facts.

#### 3.3. Population of the study

The population of this study was patients who were receiving treatment and who were living with HIV and AIDS and having coping problems. These patients were registered clients of the social worker at Katutura Intermediate Hospital.

#### 3.4. Sampling method

Purposive sampling was used because it provides a clear identification of the selection of the respondents (De Vos et al., 2005, p.329). Twenty participants who were HIV positive and receiving treatment at Katutura Intermediate Hospital were selected. These people were registered clients of the social workers and each client had a file from which the researcher could work on. The participants were selected purposively in the sense that they had to be HIV positive and experience coping problems. The participants were requested to participate in the research on a voluntary basis.

### **3.5. Method of data collection**

A semi structured interview schedule for in-depth interviews was used to collect data. A tape recorder and field notes were also used as supportive methods. To ensure reliability of the interview the research was consistent and neutral. Consistency was obtained through a description of the method of data collection, analysis and interpretation. The use of coding-recoding and "the use of colleagues and methodology experts to examine the research plan and its application" (Rothmann, 2000). Neutrality of the research was obtained through conformability of the data and its interpretations.

The focus points of the schedule was knowledge about HIV and AIDS, community support, spiritual support, family support, resources, fear, stigma and discrimination, cultural perspective that influence patients' ability to cope with HIV and AIDS, coping skills, losses and gains.

The validity of the research was ensured through credibility and transferability. To ensure credibility of the interviews the researcher spent sufficient time with the participants to establish rapport, to facilitate comfort and to increase the willingness to make known sensitive information (Rothmann, 2000). The researcher rephrased questions to the participants so as to gain credible information. Reflexive analysis was taken into account to prevent close relationships between the researcher and the participants that could possibly have an effect on the interpretation of the findings. The researcher ensured that there were no inconsistencies between the data and the interpretations thereof.

### **3.6. Procedures**

The researcher invited people who normally receive HIV medication and who have difficulties in coping with their HIV illnesses at Katutura intermediate Hospital to participate in the study. This process took place at Antiretroviral Clinic (Center for Disease Control). Permission from patients was granted. Semi-structured interviews took place in an office whereby the participants were allowed to go for individual interviews.

### **3.7. Data analysis**

The analysis procedure that was applied was content analysis. Answers were categorized into different types and the number of each type was added up. This means, identifying the general themes mentioned in the interviews and then counting the number of times they were mentioned (Hayes, 2000). Themes that occurred recurrently were recorded. This assisted in determining dominant and sub-themes. The themes were used to understand the experience of HIV and AIDS patients. Each interview was transcribed by the researcher. Tape recording was analyzed by using external microphones for clarity and the tape was transcribed for close analysis. The researcher also transcribed and analyzed the interviews while they were still fresh and preliminary coding was used (De Vos et al., 2005).

### **3.8. Summary**

This chapter discussed the research methodology that was employed in the study. Qualitative approach and phenomenological design was used. The population of this study was patients who were receiving treatment and who are living with HIV and AIDS at Katutura Intermediate Hospital. Purposive sampling was used and twenty participants were sampled. A semi-structured interview schedule was used to collect data. Tape recorder and field notes were used as supporting documents. The interviews took place at antiretroviral clinic and the analysis procedure that was applied was content analysis.

## CHAPTER 4

### DATA ANALYSIS AND DISCUSSION OF RESEARCH RESULTS

#### 4.1. Introduction

This chapter presents and discusses the results of this study. The specific objectives for this study were to explore whether HIV and AIDS positive patients are receiving assistance from the resources available at the hospitals and the community. To investigate whether the counseling programs given to HIV and AIDS patients are sufficient enough to enable them to cope and finally to investigate how effective the systems are for the patients.

#### Section A:

#### 4.2. Personal information

The personal information of the participants was explored to get a holistic understanding of their lives.

##### 4.2.1. Category 1: Marital status

The marital status of patients was included to get a clear understanding of which category of people are most affected by HIV and AIDS for example married, single, cohabit or divorced.

**Themes:** Marital status.

**Patterns:** The participants were in relationships but their relationships were not successful and they started to live alone. This resulted in them to get partners who satisfy them sexually and financially for example a one night stand for sex only.

**Quotes:** Participant 1: "I am single"

Participant 2: "I am divorced."

Participant 3: "I stay with my boyfriend."

Participant 4: "I just have one night stands for sex to get money."

**Professional interpretations:** Single people within the Namibian society seem to be the most vulnerable of contracting HIV and AIDS because of their lifestyle and relationships.

#### 4.2.2. Category 2: Education

Education was explored to get an understanding of the patient's level of education, and to understand in which level people are most affected by HIV and AIDS.

**Themes:** School drop- out.

**Patterns:** Most of the female participants dropped out in Grade 8 because they were pregnant.

**Quotes:** Participant 5: " I left school in grade 8 because I was pregnant."

Participant 6: "I left school in grade 8 because I was no longer interested."

Participant 7: "I left school in grade 8 because I was the bread winner of the family."

Participant 8: "I left school in grade 8 because I wanted to support my kids."

Participant 9: "I left school in grade 8 because my boyfriend said he was going to marry me."

**Professional interpretations:** Females with low a level of education are more likely to get HIV and AIDS. They don't see the importance of education and at the end they live without jobs and finally they find themselves in poverty that will lead them into practicing prostitution.

#### 4.2.3. Category 3: Knowledge about HIV and AIDS.

Knowledge about HIV and AIDS was included in order to find out whether HIV and AIDS positive patients have information about their illness.

**Themes:** How knowledge is disseminated.

**Patterns:** People listen to the radio and that is where they get the information about HIV and AIDS but they still need more information in order for them to cope with their illness.

**Quotes:** Participant 17: "Knowledge about HIV and AIDS helps me to live positively with the virus".

Participant 18: "Knowledge about HIV and AIDS helps me to feel better and it encourages me to stay positive".

Participant 19: "Knowledge about HIV and AIDS helps me to know how to deal with HIV positively".

Participant 20: "Knowledge about HIV helps me to take care of myself".

Participant 4: "Knowledge about HIV and AIDS helps me to understand how to take medication correctly".

**Professional interpretation:** HIV and AIDS patients have knowledge about HIV and AIDS but they still need more information in order for them to cope well with the disease. Since HIV and AIDS have changing symptoms, patients need to be equipped with new knowledge about the disease. Ungvarski and Flaskerud (1999) confirms that knowledge of exposure to HIV and AIDS as a disease and the factors that potentiate disease expression, can assist health professionals in planning health care activities that individuals and their partners, families and friends can implement on their own behalf or with the assistance of the health care workers. This takes the form of health promotion, disease prevention and harm reduction activities. Health promotion knowledge poses few risks, have positive effects on well-being and contribute to slowing down the progression of the disease.

## Section B

### 4.3. Support

#### 4.3.1. Category 4: Community support

HIV and AIDS patients need community support in order to cope well with their illness.

**Themes:** Sources of community support.

**Patterns:** People want this support so that they can live positively with HIV and AIDS. When there is no support they go to church and become part of the church community and some patients isolate themselves which influences their ability to cope.

**Quotes:**Participant 10: "Support will help me to live without problems."

Participant 11: "Support will make life easier in terms of collecting medications."

Participant 13: "Support will help me to live positively."

Participant 14: "Support will help me to cope with HIV and AIDS."

Participant 12: "Support will help me to forget about HIV."

**Professional Interpretation:** People have support from their family members such as sisters, parents, brothers and spouses but the support is not sufficient enough for them to cope with HIV and AIDS. They want support such as care, love, counseling, encouragements from anyone who is willing to give support. Brasher (1998) confirms that people living with HIV and AIDS need a full range of psycho-social interventions including immediate crisis intervention, individual therapy or both to deal with feelings of extreme anxiety, fear and anger. Clients also need ongoing psychosocial support in the form of support to dispel self-blame and guilt, provide reassurance, share information and experience and reduce feelings of isolation and loneliness.

#### 4.3.2. Category 5: Spiritual support

Spiritual support helps people to come to terms with their HIV illness for example HIV positive patients feel emotionally better when they get spiritual support from their churches.

**Themes:** Churches provide support.

**Patterns:** People go to church and pray whenever they are stressed about thinking that they are going to die soon. Church members pray with them all the time and people feel relieved when they go to church and pray.

**Quotes:**Participant 3: "Networking helps me to feel good because there is some support group."

Participant 8: "When I go to church I get some encouragement from the Word of God."

Participant 1: "I feel relieved from problems when I pray."

Participant 7: "Praying helps me to forget about my problems of HIV."

Participant 9: "I get supporting information about HIV and AIDS."

**Professional interpretation:** People are aware that churches in their community provide them with support so that they can cope with HIV. People normally interact with each other at church, they socialize even though these services are not enough for them, therefore they need lot of support from people and more organization that can provide them with counseling. Reeves (2000) confirm that people with HIV and AIDS have to get involved and have their voice heard. They have to speak up, raise concerns, raise questions and be noticed as people that have concerns that are important not just for one person but for a whole group of people. HIV positive people need to network with other people in order to exchange views about HIV and AIDS. By doing this it will help them to cope with HIV and AIDS.

#### 4.3.3. Category 6: Family support

HIV positive patients need support from their family members in order for them to cope with their illness. Support from family members is very important because patients will feel loved and wanted.

**Themes:** Support from family members.

**Patterns:** Most people need support such as spiritual support, counseling, encouragement, advices, love and care. Also they need new information on HIV and AIDS and they need this information as long as they live.

**Quote:**Participant11: "Support will help me not to worry about HIV."

Participant 19: "I will feel loved if I have support."

Participant 16: "I will start with the normal life and not be depressed by HIV."

Participant 17: "I will feel part of the community when I am supported."

Participant 20: "When I get financial support I will buy food for myself and my family so that we can live healthy."

**Professional interpretation:** People get support from family members but this support is not enough for them to live positively and they need it as long as they live. Ungarvaski&Flaskerud (1999) confirms that family support is important for HIV positive people to cope with their illness. The family of an HIV positive patient is very important to a patient. Patients need love and care from their family members and in most cases when HIV positive people start to get sick they are more likely to depend on a spouse and their families for support.

#### 4.3.4. Category 7: Assistance from resources available to make a living

Resources are very important in a patient's life because it helps to make life easier, for example when an HIV patient has a stable job he/she will not worry much because she will have a stable home which meets his/her own needs.

**Themes:**How to make a living.

**Patterns:** Most of the people are working and some are self-employed doing small businesses of selling food.

**Quotes:** Participant 14: "I need resources so that I can help myself to live longer."

Participant 18: "I need resources so that I can forget about HIV and AIDS."

Participant 10: "I need resources so that I can live without stress."

Participant 7: "I need these resources for myself and my children so that our immune system can be prolonged. "

Participant 2: "I need these resources to gain a living."

**Professional Interpretation:** People have knowledge of what resources are and they interpreted resources as something that helps a person to gain a living such as money and work. Most of them are working and some are self-employed. People normally get assistance from resources available in the hospital and in the community. The assistance from resources available in hospital and the community is not enough for them and that makes it difficult for them to cope with HIV and AIDS. Therefore they need money and food so that they can have a balanced diet and any form of assistance is also needed for them to cope. Ungvarski and Flaskerud (1999) states that a health promoting diet that promotes optimal immune functioning is needed for the body in order for an HIV infected person to live long. Therefore, work, money and food is needed for HIV positive people so that they can help themselves.

## Section C

### 4.4. World view

#### 4.4.1. Category 8: Cultural perspective

Culture influences how patients cope with their HIV illness and people who are discriminated and stigmatized don't cope with HIV. Some cultures say that HIV is a punishment from God and a person who gets it is a prostitute.

**Themes:**How HIV and AIDS are perceived.

**Patterns:** When people of the community say that those who have HIV are bad people and HIV is a bad disease, they usually separate themselves from such people. HIV positive patients find it difficult to cope because of what people say about them.

**Quotes:**Participant 16: "When people say that HIV is a bad disease I feel bad."

Participants 9: " When people say that HIV is a bad disease I feel unwanted."

Participant 17: "When people say that HIV is a bad disease I cry."

Participant 15: "When people say that HIV is a bad disease I keep quite."

Participant 1: "When people say that HIV is a bad disease I pray to my God."

**Professional Interpretations:** The community interprets HIV as a bad disease and people who are living with HIV and AIDS feels bad about how people view and say about it. Most of HIV people with AIDS isolate themselves from the people who talk about HIV as a bad disease. HIV positive people usually isolate themselves from the community and pray to God and some even cry. Cultural beliefs and norms shape the definition of health and illness. In many cultures men may seek many sexual partners and women may feel unable to insist on safe sex practices such as condom use. Culture influences the way communities respond politically, socially and financially to the threat of the spread of HIV and AIDS.

#### 4.4.2. Category 9: Fear

HIV positive people have fear of dying and fear of being victimized. They find it difficult to come to terms with it especially when someone who they know has AIDS and dies.

**Themes:** Fear of death.

**Patterns:** Most people reacted with shock when they were told by the HIV counselor that they are HIV positive.

**Quotes:** Participant 3: "When I learnt that I was HIV positive I was shocked."

Participant 9: "When I found out that I have HIV I felt bad."

Participant 8: "When I find out that I have HIV I kept quite."

Participant 2: "When I find out that I have HIV I started crying."

Participant 10: "When I find out that I have HIV I prayed."

**Professional interpretation:** People are no longer scared of HIV and AIDS, even though when there were first diagnosed they were scared. People pray to God when they are scared and they feel better. Brasher et al (1998) states that major psychological stress and fear on people living with HIV is the knowledge that they have a fatal disease with the potential for rapid decline to death. Most frequently, psychological reactions are those of fear, anxiety and depression which are compounded by the uncertainty of the disease.

#### 4.4.3. Category 10: Stigma

HIV positive people are being stigmatized in the community, work places, and schools in spite of the appeal to stop discriminating against HIV positive people.

**Themes:** People are being stigmatized because they have HIV, and they are being discriminated against by their own family members.

**Patterns:** When HIV positive patients are stigmatized people start to laugh at them and they say that they have a disease that is not curable and they are going to die very soon. HIV positive people feel bad and go away from those people, and that makes it impossible for them to cope with HIV.

**Quotes:** Participant 18: "I feel bad when I am stigmatized."

Participant 19: "I keep quiet when I am stigmatized."

Participant 12: "I pray to my God when I am stigmatized."

Participants 11: "I go away from the people who stigmatize me."

Participant 5: "I cry when am being stigmatized."

**Professional Interpretations:** People do not cope well with HIV because they are being stigmatized. They say the government should educate the public about HIV and AIDS. HIV is not only transmitted through sexual intercourse but also through other methods such as exchange of bodily fluids and breast feeding. Most people said the government should emphasize the issue of eradicating stigma and persecute those who stigmatize others about HIV and AIDS.

Kalichman (2004) says that many communities direct unfavorable attitudes, beliefs and policies toward people who have or who are associated with HIV and AIDS and it includes their loved ones, family members, close associates and social groups. Stigma against HIV positive women is particularly strong therefore HIV and AIDS is misperceived in many parts of the world as a promiscuous women's disease or a prostitute's disease. Women are often blamed for the spread of HIV and AIDS to their families because they were the first ones in their families to be tested during pregnancy or just after child birth.

#### **4.4.4. Category 11: Discrimination**

Discrimination is one of the biggest problem in Namibia and HIV positive people are been discriminated against because they have HIV and AIDS despite of the government policies which stress about zero tolerance towards discrimination against people with HIV and AIDS.

**Themes:** The source of discrimination and people's reaction to discrimination.

**Patterns:** People laugh at AIDS patients and they say that they have a disease that is not curable and that they are going to die soon. In such cases, HIV positive people isolate themselves from those who discriminate against them.

**Quotes:** Participant 9: "I keep quite when I am discriminated."

Participant 4: "I cry when I am discriminated."

Participant 16: "I pray when I am discriminated."

Participant 20: "I feel bad when I am discriminated."

Participant 7: "I think of committing suicide when I am discriminated."

**Professional interpretation:** HIV positive patients do not cope well with their illness because they are being discriminated against by their family members. They have guilt feelings and they also start to blame themselves for contracting HIV. These people are being laughed at, being talked about and being mocked in public. As a result, discriminated HIV positive people go away from those people who discriminate against them and pray to God.

UNAIDS (2008) clearly states that discrimination occurs at all levels of a person's life for example when they travel, use health care facilities or seek employment. A country's laws, rules and policies regarding HIV can have a significant effect on the people living with the virus. Discrimination practices can alienate people living with HIV, reinforcing stigma surrounding the disease. Many of these laws have been justified on the grounds that the disease poses a public health risk. President Museveni of Uganda supports the national policy dismissing or not promoting members of the armed forces who test HIV positive and the Chinese government advocates compulsory HIV testing for any Chinese citizen who has been living outside of the country for more than a year. Furthermore, the United Kingdom's legal system can prosecute individuals who pass the virus to someone else even if they did so without intent.

## Section D

### 4.5. Coping skills and counseling

#### 4.5.1. Category 12: Counseling which fosters coping

HIV and AIDS positive patients need coping skills and counseling to cope with their illness.

**Themes:** Counseling needs.

**Patterns:** Most people listen to radios and this is where they find the information on HIV and AIDS and how they can live positively even though they find it difficult to cope.

**Quotes:** Participant 6: "I can learn coping skills from the church."

Participant 1: "I can learn coping skills from a friend who is HIV positive."

Participant 2: "I can learn coping skills from the hospital and clinics."

Participant 5: "I can learn coping skills from a support group."

Participant 8: "I can learn coping skills from the radio."

**Professional interpretation:** Most people said that they can only cope with HIV and AIDS if their needs are met. HIV and AIDS positive patients get counseled by either Nurses, HIV lay counselors, Social workers and Doctors. They also get therapeutic counseling, supportive counseling as well as problem solving counseling but this counseling is just for a short period of time. HIV positive people need support; care, no stigma and discrimination as well as information and counseling programs that will help them cope with their illness. Currently they struggle to cope because the counseling is not sufficient enough for them to cope.

HIV positive people are not coping with their illness because the counseling that they get is not enough and they have many problems that need to be addressed in order for them to cope with their illness. Walensky & Paltiel (2006) says that, it is important to encourage and work towards coping strategies such as active participation to the extent that the patient can manage

in planning for care and in seeking appropriate social support. Such an approach includes encouraging problem solving and participation in decision making about treatment and care.

#### **4.5.2. Category 13: Losses**

Loss and bereavement are an integral part of working with HIV and AIDS patients . This category explored loss in the life of the participants and how it affected their ability to cope with it.

**Themes:**People have lost their friends when they were diagnosed with HIV and AIDS. Their friends left them because of their HIV status.

**Patterns:**Most HIV positive patients said they can only overcome these losses when their friends come back and have a good relationship again.

**Quotes:**Participant 16:“I lost a job”.

Participant 9:“I lost my friends”.

Participant 17:“I lost my family”.

Participant 15:“I lost my girlfriend”.

Participant 1: “I lost a daughter”.

**Professional interpretation:**HIV and AIDS patients lost their friends when they were diagnosed with HIV and AIDS. These people can only cope with HIV when their friends come back to them and have a good relationship again. Kelly, Kalichman, Morgan & Stevenson (1993) says that people living with HIV and AIDS may suffer psychological distress as a result of the physical, social and economic effects of the disease on their lives. Among the various stressors are chronic physical pain, physical disfigurement, the possibility of infecting other people and discrimination, abuse and loss of fundamental human rights. Losses that the person has had, or is currently having and anticipates having as a result of the illness, determine the kind of psychosocial support needed. Persons may be currently grieving a loss and going through the grief and feel some recognition and equanimity toward a process. They may have had previous experiences with loss and grief and feel some recognition toward the process, or they may have

had no previous experience and are anxious and fearful about anticipated loss and the grieving process.

#### **4.5.3. Category 14: Gains**

In spite of the obvious losses unexpected gains such as a change in mind set which sees an individual as worthy in the eyes of God and getting a job, learning about the Holy Spirit and being a role model have been gained by HIV positive patients.

**Themes:** Types of gains.

**Patterns:** Knowledge about God has helped HIV positive patients to live positively for a while, but they have not yet learned to cope with it. Most of the participants go to church and also advice other people about HIV and AIDS.

**Quotes:** Participant 7: "I have gained nothing at all".

Participant 2: "I have gained the Holy Spirit".

Participant 4: "I became a taxi driver".

Participant 9: "I gained a job".

Participant 8: "I am now a role model for others".

**Professional interpretation:** People have gained spiritual but it is not enough for them to cope with HIV and AIDS. Reeves (2000) states that, the most important role support plays in coping with HIV and AIDS is that adults with HIV and AIDS have utilized traditional means of support which are families, friends and community based service organization such as churches in coping with their illness.

## CHAPTER 5

### CONCLUSIONS AND RECOMMENDATIONS

#### 5.1. Introduction

The main purpose of this study was to investigate how HIV and AIDS positive patients who are receiving HIV and AIDS treatment at Katutura Intermediate Hospital cope with their illness. The conclusions and recommendations based on the research results will be provided. The results will be presented according to the individual items of each section.

#### Section A

#### 5.2. Personal information

##### 5.2.1. Marital status

**Conclusion:** People who are HIV positive are single and vulnerable and could be re-infected because they are looking for someone to satisfy them sexually and financially.

**Recommendation:** HIV positive single people need health support systems such as churches that will support them.

##### 5.2.2. Education

**Conclusion:** Due to the low educational level of grade 8, the patients find it difficult to get employed and they find themselves in poverty that leads to practice prostitution. Apart from the fact that they are HIV positive, they are affecting other people with HIV.

**Recommendation:** Alternative options of job creation should be developed. HIV positive patients should be empowered with knowledge not to spread the virus, in other words they must be empowered so that they can become change agents.

### 5.2.3. Knowledge about HIV and AIDS

**Conclusion:** People have knowledge about HIV and AIDS but, they still need more knowledge and information to be able to promote health programs which prevents the spread of the disease and reduces harmful activities.

**Recommendation:** HIV and AIDS patients, families and friends should assist health care workers in health promotion programs in order to slow down the progression of the disease.

**A profile of the personal information of an HIV positive patient is that the person is single, dropped out of the school and has limited knowledge of HIV and AIDS.**

## Section B

### 5.3. Support

#### 5.3.1. Community support

**Conclusion:** They need professional psychosocial intervention which takes care of their anxiety, fear and anger as well as self-blame and guilt.

**Recommendation:** Psychosocial support programs need to be made available by professionals who are able to help the HIV and AIDS patients to deal with extreme feelings of isolation and loneliness.

#### 5.3.2. Spiritual support

**Conclusion:** HIV and AIDS patients know about the services and groups that are available and that give support to people with HIV and AIDS. These groups include churches in the communities and patients make use of them in order for them to cope. Despite of that, the support is still not enough for them to cope, therefore, they need continuing support from people and any organization that can support them to build their ego-strength.

**Recommendation:** HIV and AIDS patients should interact with each other either at church or in their communities and they need to speak up, raise concerns, raise questions and be noticed as people that have concerns that are important not just for one person but for the group of people that they represent and they also need to network with other people in order to exchange views about HIV and AIDS.

### **5.3.3. Family support**

**Conclusion:** HIV and AIDS patients get support from their close family members such as brothers, sisters and spouses but the support is not enough for them to cope with HIV. The support can be in the form of love, counseling, encouragement and care.

**Recommendation:** Family support should be given to HIV and AIDS Patients. Relatives are the most important people for HIV and AIDS patients. Therefore, close relatives should give support such as counseling, encouragement, love and care. By doing so, HIV positive patient will have hope for life. When HIV positive people start to get sick they are more likely to depend on a spouse and their family. It is therefore recommended that families should be very close to HIV and AIDS positive patients.

### **5.3.4. Assistance from resources available**

**Conclusion:** HIV positive people have knowledge about HIV and AIDS and resources available at hospitals and communities but these resources are not enough for them to cope with HIV and AIDS.

**Recommendation:** Opportunities need to be developed in communities whereby HIV patients can participate in work, be paid for it and buy food that they need in order to live positively.

**According to the results in this section it seems that support is available but not sufficient to live positively with AIDS.**

## Section C

### 5.4. World views

#### 5.4.1. Cultural perspective

**Conclusion:** Most of the communities view HIV and AIDS as a bad disease in the society and view people who have it as bad. Therefore HIV positive patients feel bad about what the community say about them and this makes HIV positive patients unable to cope with their illness.

**Recommendation:** Culture that discriminates against people with HIV and AIDS should be challenged so that it becomes responsive to HIV and AIDS patient. Societies should be educated about HIV and AIDS and the government and non- governmental organizations that are in the field of HIV and AIDS should take the leading role.

#### 5.4.2. Fear

**Conclusion:** HIV positive people are no longer scared of HIV and AIDS as they were when they tested positive for the first time. The issue that scared them most was the fact that they were going to die soon. These patients normally pray to God whenever they are scared and after praying they feel better but the fear does not go away permanently.

**Recommendation:** Churches should provide counseling that is based on fear and they should also provide information on hope to people living with HIV and AIDS so that these people can have a better quality of life. The government and non -governmental organizations that deal with HIV and AIDS should provide information on how to handle fear.

#### 5.4.3. Stigma

**Conclusion:** HIV positive people are being stigmatized by their own family members despite the information provided by the government and other organizations. It is being said that it is a prostitute's disease and women are being blamed for it.

**Recommendation:**The government of Namibia and other relevant stakeholders should emphasize the issue of eradicating stigma and persecute those who stigmatize others about HIV and AIDS. Educational programs based on eradicating stigma should be developed and disseminated to families of HIV positive people and the community at large in order to educate them on the harm that is caused when they stigmatize people.

#### **5.4.4. Discrimination**

**Conclusion:**HIV positive people are been discriminated against by their own family members and also by their employers on the notion that they are HIV positive. This makes it difficult for HIV positive people to cope with their illness.

**Recommendation:** Education programs and policies which targets families and communities should be implemented by the government of Namibia to educate them on the harm they cause to HIV positive people when they discriminate against them. Laws and regulations that discriminate against people with HIV and AIDS should be abolished.

**This results indicate that the world of Namibian families discriminate against AIDS patients.**

### **Section D**

#### **5.5 Coping and counseling**

##### **5.5.1. Coping**

**Conclusion:** HIV positive patients do not cope with HIV and AIDS. They can only cope if their needs are met. These patients are normally counseled by nurses, HIV lay counselors, social workers and doctors.

**Recommendation:** Health programs for coping such as stress reduction awareness should be introduced to HIV positive people so that they can cope with HIV. Therapeutic counseling, supportive as well as problem solving techniques should be given to HIV positive patients for as long as they live so that they can cope with HIV and AIDS.

### 5.5.2. Losses

**Conclusion:** HIV positive patients lost their friends when they were diagnosed with HIV. Their friends left them after they learnt that they were HIV positive. These friends thought that they were going to get HIV or be labeled as well when they are seen with HIV positive patients. Loneliness contributes to a lack of ego- strength which makes coping with AIDS more difficult.

**Recommendation:** Psychosocial support programs should be established to help HIV and AIDS patients who are experiencing loss to come to terms with it and cope with loss.

### 5.5.3. Gains

**Conclusion:** HIV positive patients gained knowledge about God and they trust in Him. Despite the spiritual gain that they have, HIV positive patients still struggle to cope with HIV and AIDS.

**Recommendations:** Community based service organizations such as churches should work closely with people who are HIV positive to encourage them so that they can adapt to their illness. The Ministry of Health and Social Services should provide churches with information on HIV in order for these churches to incorporate it in their church programs.

**These results clearly indicate that HIV patients do not cope.**

### 5.6. Recommendations for future social work research

The following recommendations should be considered by social work students for future research in the area of HIV and AIDS:

- An almost similar study with a broadened scope, in terms of geographical coverage and sample would need to be done before the generalization of results to the population of Namibia.
- Conduct qualitative research to understand what enables people to cope with HIV and AIDS.

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# A social work investigation on how HIV and AIDS positive patients cope with their illness at Katutura Intermediate Hospital

HIV and AIDS positive patients at Katutura Intermediate Hospital should complete this questionnaire.

## Instructions

1. Make a tick ( ) next to the correct answer in the box, unless otherwise indicated.
2. Boxes with the word "other", requires you to specify your answer.
3. Remember that information provided will be treated with confidentiality and no references will be made to individuals.

### Section 1

#### Background information

##### Category: 1. Marital status

The following information will be used as identifying particulars

1. What is your marital status?

Married	
Divorced	
Widowed	
Single	
Co-habiting	

**Category 2: Education**

2. What is your level of Education?

None	
Grade 1-5	
Grade 6-7	
Grade 11-12	
Tertiary education	
Other.....	

**Category 3: Knowledge about HIV and AIDS**

3. Do you have HIV?

.....  
.....  
.....

4. What do you know about HIV and AIDS?

.....  
.....  
.....

5. Where did you get the information about HIV and AIDS?

.....  
.....  
.....

6. What more information about HIV and AIDS do you need?

.....  
.....

.....  
.....  
7. How does information about HIV and AIDS help you to cope?

.....  
.....  
.....  
.....

**Section 2**

**Support**

**Category 4: Community Support**

8. What support is available for you to cope with HIV and AIDS?

.....  
.....  
.....  
.....

9. Is that support sufficient enough?

.....  
.....  
.....

10. What support do you need?

.....  
.....  
.....

11. Why do you need that support?

.....  
.....  
.....

12. How will that support help you to cope?

.....  
.....  
.....

13. Whom do you want to support you?

.....  
.....

14. Why do you want those people to support you?

.....  
.....  
.....

**Category: 5. Spiritual Support**

15. Do you know about services, groups, medication in your community?

.....  
.....

16. What networking is available for you in your community?

.....  
.....  
.....

17. Do you know how to utilize a resource/ network?

.....  
.....  
.....

18. How do you think can this help you to cope?

.....  
.....  
**Category : 6.Family support**

19. Do you get any support from your family?  
21. What is your understanding of a support?

.....  
.....

20. Who in your family is supporting you?  
22. What resources are you have available?

.....  
.....

21. Who do you want to support you?  
24. What resources do you know about?

.....  
.....

22. What kind of support must they give you?  
23. Why do you need these resources?

.....  
.....  
.....

23. How often do you need support?  
25. Are there resources available at the hospital?

.....  
.....  
.....

24. How will support help you to cope?  
26. Are there resources available in your community?

.....  
.....  
.....

25. For how long do you need these support?  
27. Do you get assistance from resources available in the community?

.....  
.....  
.....

.....  
.....  
.....

**Category: 7 . Assistance from resources available**

26. What is your understanding of a resource?

.....  
.....

27. What resources do you have available?

.....  
.....

28. What resources do you know about?

.....  
.....

29. Why do you need these resources?

.....  
.....  
.....

30. Are there resources available at the hospitals?

.....  
.....

31. Are the resources available in your community?

.....  
.....

32. Do you get assistance from resources available in the community?

.....  
.....  
.....

33. How will this assistance from the hospitals and community help you to cope?

.....  
.....  
.....

**Section 3**

**World view**

**Category: 8. Cultural perspective**

34. What is your cultural perspective of HIV and AIDS in your ethnical group/ village /neighborhood?

.....  
.....  
.....

35. How does that makes you feel?

.....  
.....

36. What do you do in such meetings/gatherings/ groups?

.....  
.....

37. How is that perspective influencing your coping?

.....  
.....  
.....

**Category: 9. Fear**

38. Are you scared of HIV and AIDS?

.....  
.....

39. What frightened you when you were diagnosed with HIV?

.....  
.....  
.....

40. How did you react when you learnt that you are HIV positive?/ what did you do?

.....  
.....  
.....

41. Are you still frightened?

.....  
.....

42. How are you dealing with your fear?

.....  
.....  
.....

43. Is that influencing your ability to cope?

.....  
.....

**Category: 10. Stigma.**

44. Are you being stigmatized because of HIV and AIDS?

.....  
.....

45. Who is stigmatizing you?

.....  
.....

46. What do people do when you are stigmatized?

.....  
.....  
.....

47. How do you feel when you are stigmatized?

.....  
.....  
.....

48. What do you do after being stigmatized?

.....  
.....  
.....

49. How is that influencing your ability to cope?

.....  
.....  
.....

50. How can stigmatization be changed?

.....  
.....  
.....

**Category: 11. Discrimination**

51. Are you being discriminated because of HIV and AIDS?

.....  
.....

52. Who is discriminating you?

.....  
.....

53. How do people discriminate against you?

.....  
.....  
.....

54. How do you react to discrimination?

.....  
.....  
.....

55. How is that influencing your ability to cope?

.....  
.....  
.....  
.....

**Section 4**

**Coping**

**Category: 12. Coping Skills**

56. What skills do you think does an HIV patient need?

.....  
.....  
.....

57. What skills do you have at present?

.....  
.....  
.....

58. Do you think you need to learn new skills?

.....  
.....

59. What have you learned in a meanwhile?

.....  
.....  
.....  
.....

60. Do you get counseling?

.....  
.....

61. Who counseled you?

.....  
.....

62. What type of counseling did you get?

.....  
.....  
.....

63. Is the counseling given sufficient enough to enable you to cope with HIV?

**Category : 13. Losses**

64. What have you lost since you have been diagnosed with HIV?

.....  
.....  
.....  
.....

65. Can you overcome these losses?

.....  
.....  
.....

66. How will you overcome them?

.....  
.....

.....  
.....

67. Will this growth empower you to cope with HIV?

.....  
.....  
.....

**Category : 14. Gains**

70. What have you gained?

.....  
.....  
.....  
.....

71. Has this helped you to cope better?

.....  
.....  
.....

72. Are you able to help other people and to be a changed agent?

.....  
.....  
.....  
.....

**Thank you very much for completing this Research Questionnaire**