

**YOUTH'S EXPERIENCES IN DISCLOSING THEIR HIV POSITIVE STATUS IN  
MALAWI.**

**A DISSERTATION**

**SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR  
THE COURSEWORK MASTERS DEGREE IN NURSING:  
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**BY**


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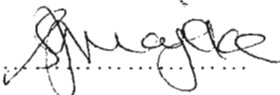
## DECLARATION

I, Mercy Dokiso Chirwa declare that this dissertation entitled “*Youths’ Experiences in Disclosing Their HIV Positive Status in Lilongwe Malawi*” is my own work. I have not submitted this work or any part of it for a degree at any other University within or outside Africa. All the sources used or quoted have been acknowledged by means of complete reference.

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Date: 13 March 2009.

Sisana J. Majeke

## **DEDICATION**

This dissertation is dedicated to my beloved husband Simon Bulukutu Chirwa and our lovely children; Chawezi, Tiwonge, Mercy and Raymond who have been a source of inspiration through their effortless support, encouragement and my all weather friend, without them my academic life was going to be too difficult. You have been a blessing and thank you for believing and trusting me. You are indeed a crown of my joy that I will ever cherish for the rest of my life.

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## ABSTRACT

### **Introduction**

Youth is a group of people which has been greatly affected by HIV epidemic in Malawi. They are vulnerable to HIV infection because they are at a stage where they are beginning sexual exploration. Youth therefore, need a lot of information and support on HIV preventions, and voluntary counseling and testing. They should be encouraged and assisted to disclose their HIV status whether positive or negative for them to access necessary support system.

**Purpose:** The purpose of the study was to explore youth's experiences in disclosing their HIV positive status

**Methodology:** This is an exploratory study that adopted a qualitative approach utilizing the phenomenological design to explore the experiences of HIV positive participants in disclosing their HIV positive status. The study was conducted in Likuni urban and Nambuma areas in Lilongwe district, Malawi. Ten HIV positive participants five males and five females between the ages 19-25 years were purposively sampled half from each area. A qualitative approach to data collection was done through face to face individual in-depth interviews. All the interviews were audio taped and transcribed verbatim using qualitative content analysis.

**Findings:** The following are the four major themes that emerged from the findings of the study: factors leading to and hindering HIV positive status disclosure, disclosure of HIV status, experiences of disclosing HIV positive status, consequences of HIV positive status disclosure. These themes are in line with the objectives and the conceptual framework of the study. The findings of the study have shown that disclosure of HIV positive status among HIV positive youth is difficult and still remains a challenge. The study established that the majority of participants disclosed their HIV positive status due to their deteriorating health status. Stigma and discrimination was found to be the major barrier to HIV positive status while the positive consequences which include: psychosocial care, accessing medical services, safer sex practices and positive living with HIV seemed to be more rewarding because it brought some relief in their lives.

**Conclusion:** Stigma and other hindering factors were found to be the major barriers to disclosure. This therefore, necessitates the need for dealing with barriers to disclosure because the benefits of disclosing HIV positive status are rewarding and outweighs the negative consequences. This study has made some recommendations to promote disclosure of HIV positive status among youth through Ministry of Health, Ministry of Education, National Youth Council, National AIDS Commissions, the Community and further research.

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## ACRONMYS

AIDS	Acquired Immunodeficiency Syndrome
HIV	Human Immunodeficiency Syndrome
MANET	Malawi Net for HIV Support Group
MDGs	Millennium Development Goals
MDHS	Malawi Demographic Health Survey
NAC	National AIDS Commission
NGO	Non Governmental Organisation
NSO	National Statistics Office
PLWA	People Living with AIDS
PMTCT	Prevention of Mother to Child Transmission of HIV
SABC	South African Broadcasting Corporation
TB	Tuberculosis
UNFPA	United Nations Population Fund
UNIADS	The Joint United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
USA	United States of America
VCT	Voluntary Counseling and Testing
WHO	World Health Organisation

## **CHAPTER 1 INTRODUCTION**

### **1.1 BACKGROUND TO THE STUDY**

Human Immunodeficiency Virus and Acquired Immunodeficiency syndrome (HIV and AIDS) continues to be a dire threat to public health globally; 39.9 million people were living with HIV in 2006 (Snowflake, 2006:1). Countries in sub-Saharan region are the ones most affected by the pandemic. According to Joint United Nations Programme on HIV/AIDS (UNAIDS, 2002:1) about 28.5 million people are estimated to be living with HIV in sub-Saharan Africa by 2001. This figure represents 71% of all people living with HIV/AIDS in the world. Approximately 81% of all infected are women and nearly 12 million youth, age 15- 26 years, worldwide are living with HIV and AIDS (UNIADS, 2006:1).

The epidemic is taking an enormous toll on the region's youth, it is further estimated that 9 million of infected youths are from sub-Saharan Africa, (UNIADS, 2006:1). Worldwide HIV Statistics, (2006:1) adds that around 6,000 youths become infected every day and that more than 25 million have already died of AIDS since 1981. In high-prevalence countries of sub-Saharan Africa, the main mode of HIV transmission is heterosexual intercourse. (United Nation Population Fund (UNFPA), 2005:4).

Malawi has one of the highest national HIV prevalence rates in the world, estimated at 15% among adults, 15-49 years of age (National AIDS Commission NAC (2001:1). It has a population of close to 13.6 million people, (Malawi Demographic Health Survey MDHS, 2004:4). Youth, between the ages 15 –24, constitute 2/3 of the population and are

the group which has been greatly affected by the HIV epidemic, accounting for 22%, with 15% in girls and 7% in boys, (MDHS, 2004:4). Since the first case of HIV was discovered in the country in 1985, there has been a relatively high prevalence rate of the infection. About 15% of the population, aged between 15-49 years, is infected and the national prevalence rate is estimated at 8.4 % (MDHS, 2004:1).

The total number of people infected with HIV is estimated to be between 700,000 to 1 million. This figure includes 60,000 – 80,000 HIV positive children under the age of 15 years. This is the group of which 9% are likely to be infected through mother to child transmission. Heterosexual transmission of HIV accounts for 90% of the infection in the country for both the adults and youth in the country (MDHS, 2004:1). Young people remain at the centre of the HIV and AIDS epidemic in terms of rates of infection, vulnerability, impact, and potential for change. Young people should be at the centre of HIV prevention actions (UNFPA, 2005:4).

A well functioning and accessible Voluntary Counseling and Testing (VCT) service is the prerequisite for conducting successful HIV prevention programs (Kebede, 2005:1). Youth should be encouraged to seek VCT and disclose their HIV status. In a study in Kenya on perceptions of youth in VCT, it was found that, although the youth had overwhelmingly positive interactions with their families about VCT, only half of those who were HIV positive disclosed their status to a family member, which proves that disclosing HIV positive status is not an easy task (Niccolai, Dorst, Meyers and Kissinger, 1999:281).

Youth, between the ages 18-24 years are especially vulnerable to HIV infection. Behavioral, physiological and socio-cultural factors make them more vulnerable than adults to HIV infection (UNFPA, 2005:1.) They are at a stage where they are making the transition from childhood to adulthood and are undergoing physical and emotional changes and begin sexual exploration (UNFPA, 2005:1). At this time they take risks in many aspects of their lives, including sexual relationships. Those who have sex may change partners frequently, have more than one partner in the same time period or engage in unprotected sex, which puts them at risk of HIV/STIs (UNFPA, 2005:3).

The higher biological vulnerability of females to HIV infection accounts, in part, for the growing number of young women infected with HIV (UNFPA, 2005:3). Socio-cultural norms that reinforce gender inequalities, such as patterns of sexual networking and age-mixing, are also important factors that leave girls and young women more vulnerable to HIV than their male peers. Worldwide, young women (15-24 years) are 1.6 times as likely as young men to be HIV positive (UNFPA, 2005:3). In Malawi, inadequate reproductive health, lack of information, social-cultural issues and unemployment make youth vulnerable to HIV infection (Lamba, 2002:2).

Despite the fact that youths are vulnerable to HIV infection, closing the Gap (2003:3) states that fewer than one in five young people who are at risk of HIV infection have access to basic prevention and medical care services in developing countries.

Although young people are especially vulnerable to HIV, they have enormous potential for changing the course of the epidemic. Recent data shows that where young people are

well informed of HIV risks and prevention strategies, they are more likely to change their behavior in ways that reduce their vulnerability (Cohen, 2003:2).

Despite more than 1 million people being infected with HIV in Malawi, HIV/AIDS is still a highly stigmatised disease (MDHS, 2004:10). Many people associate HIV infection with illicit behaviors such as promiscuous sex, homosexual contact, or intravenous drug use as such, personal disclosure of HIV status often carries a social stigma that can lead to emotional distress, depression, and isolation.

Only small minorities of people who know that they are infected with HIV have chosen to disclose their status (HIV and AIDS and TB Newsletter, 2001:1). Fear of stigma and discrimination makes people afraid to go for Voluntary Counseling and HIV Testing and keeping, in secrecy, their HIV positive results. However, VCT programs play an important role in helping clients to know their HIV status and adopt HIV preventive behaviors. It is also a prerequisite for conducting successful HIV Prevention of Mother to Child Transmission (PMTCT) Programs (UNAIDS/WHO, 2004:2).

In Malawi there are over 30 centers for Voluntary Counseling and HIV Testing providing Rapid HIV testing and Elisa tests. Overall, 5% of women and 9% of men were tested in 2003; but the majority decline to know their results MDHS, (2004:4). It is further stated that only 14% of the youth were tested for HIV in 2003. Malawi Net for HIV support groups (MANET) (2003:8) agrees with the above findings and states that very few people, including youth, disclose their HIV positive status in the country; this was on the basis of the observations made from their HIV support groups in the country.

Disclosing ones HIV positive status can be an extremely stressful process. The decision to disclose is selective and consists of several steps, including adjusting to the diagnosis, disease progression, assessing one's disclosure skills, deciding whom to tell, evaluating the recipient's circumstance, anticipating the recipient's reaction and having the motivation to disclose. This includes; to whom, when, where, why and how to reveal the HIV positive status Kimberly, 1997 cited in Sowell, Seals, Phillips, and Julious, (2003:2). Paxton, (2002:522) in his study on disclosure of HIV status found that nearly all respondents experienced a period of struggle before disclosure and had taken a period of time (taking up to a few years) to disclose to those closest to them. He explained that some participants described the guilt of this burden because they had not disclosed to their loved ones.

According to WHO, (2004:4) disclosure of HIV positive status is an important factor in HIV /AIDS prevention intervention. It also improves the access to prevention and treatment programs, (including adherence to antiretroviral treatments (ARTs) it provides increased opportunity for risk reduction and help in planning for the future.

A study by Ijumba, Gamiendien & Marron, (2004: 522) in South Africa, showed that knowing someone with HIV was associated with condom use during their last sexual contact. In another study on the benefit of HIV status disclosure, in Thailand, Takai, Akiko, Akabayashi, Ohio and Naka, (1998:483) found that people had more tolerant attitudes and support towards people living with AIDS (PLWA).

In two South African studies, that investigated the consequences of disclosure for women, Sixgashe et. al. (2000) cited in Vetten & Bhana, (2007:3) interviewed 28 women who had been diagnosed HIV-positive at least three months prior to the interview. Fifteen of these women had not disclosed their HIV-positive status, mainly out of fear of being rejected by their partners. Of the thirteen women who disclosed, only seven had disclosed to sex partners. All the women who had disclosed to their partners reported previously trusting and loving relationships, with their partners continuing to be supportive after the diagnosis.

Vetten and Bhana (2007:3) reports of a woman whose husband gradually became abusive after she disclosed her HIV-positive status to him, at first blaming her for bringing the virus into their lives, then beating her and forcing her into unprotected sex. It also reported another woman who was burnt over a primus stove, by her husband, when she disclosed her HIV-positive status. When her four-year-old son tried to stop his father from burning his mother, he was burnt as well. In support of this, Lattene & Lapporte (2004:105) in their study on barriers to HIV status disclosure in South Africa reported that a woman was stoned to death after she had revealed her HIV positive status to the public.

Paxton, (2002:522) however, argues that public disclosure can help to reduce stigma and discrimination. This can also be a powerful tool in breaking the silence surrounding the disease and can help individuals to overcome fear and prejudice (Paxton, 2002:522).

Horizon, (2006: 2) conclude by pointing out that the benefits of HIV positive status disclosures outweigh the negative outcomes.

In Malawi, a study was conducted on the disclosure of HIV positive status among antenatal mothers, to determine pregnant women's perceptions towards the selected potential for HIV prevention efforts for HIV positive mothers who were recruited for the prevention of mother to child transmission of HIV (PMTCT) program. The findings showed that only 64% disclosed their positive status to their partners. The 36% who did not disclose explained that they were afraid of negative reactions from their partners. It was therefore, recommended that programs aimed at the prevention of mother to child transmission of HIV should give serious consideration to these partners. Otherwise this could undermine efforts to prevent HIV transmission from the mother to the child without partner consideration. (Tadesse, Muula & Misiri, 2004:2).

In a study which was conducted by the University of Alabama in USA, at a public health clinic, with HIV-positive women clients, who had experienced domestic violence after disclosing their HIV positive status to their partners, the findings show that women indicated that they were depressed, felt hopeless and too worn down by the negative reactions from their partners (Lichtenstein, 2006:1). Such negative experiences could be a barrier to HIV positive status disclosure. Nations need to deal with such negative experiences in order to promote the disclosure of their HIV positive status, which is a gateway to HIV prevention measures, accessing health care and positive living with the infection.

Malawi is one of the United Nation member states which has demonstrated commitment to fulfillment of the Millennium Development Goals (MDGs), with special emphasis on MDG number six which is about halting and reversing the trend in the spread of HIV/AIDS (UNFPA, 2002:2). Through this commitment, the government of Malawi came up with some of the following initiatives to reduce HIV transmission: Health education campaigns on HIV transmission and prevention, establishment of HIV Youth Clubs, Voluntary Counseling and HIV Testing and Scaling up of Antiretroviral Therapy, inclusion of HIV/AIDS in school curriculums and also by encouraging and supporting research studies on HIV and AIDS (Malawi National AIDS Commission, 2004:4).

## **1.2 PROBLEM STATEMENT**

Since the first case of HIV was discovered in 1985 in Malawi, there has been a relatively high prevalence rate of the infection (Malawi Demographic Health Survey (MDHS), (2004:4). The youths are the most affected with the HIV pandemic, accounting for 22% of all infected cases in the country (MDHS, 2004:4). Youths are the future generation whose health needs to be addressed in order to secure a healthful and productive nation.

Despite the initiatives by the government to reduce HIV transmission, Malawi has experienced ever increasing rates of HIV Infection with the youths being the most vulnerable population (MDHS, 2004:5). According to Population Fund (UNFPA), (2003:2) less than one in five youths, at risk of HIV infection in poor countries, have access to basic prevention services.

In Malawi, only 14% of youths who are sexually active (9% male and 5% female), age 15-24 years, access Voluntary Counseling HIV Testing services, and only 34% of youths involved in high risk sexual behaviors, used condoms to protect themselves (MDHS, 2004:218). According to Malawi Net of People Living with HIV (MANET), (2003:8) reproductive health services are not adequate and not youth friendly in Malawi and further states that medical and social support services for youths living with HIV in the country are limited, which makes youths not value the importance of VCT and disclosure of their HIV positive status.

Disclosure of HIV positive status is a difficult and emotional task for youths as it is associated with other negative experiences including , blame, abandonment, physical and emotional abuse, violence, and depression, discrimination, stigmatization, risk of loosing employment and disruption of family relationships (WHO, 2004:4).

Horizon (2006:1) adds that non disclosure will promote transmission of HIV due to lack of safer sex practices; hinder access to medical care; community and family support services and discourage HIV positive youths to live positively with the infection- a scenario that can lead to unhealthy and unproductive life (Horizon, 2006:1).

Deribe, Woldemichael, Wondafrash, Haile, & Amberbir, ( 2008:1) states that it is important for an individual to disclosure his/her HIV positive status for the following benefits: social and emotional support, ability to access necessary information and treatments including antiretroviral drugs. The add that disclosure of HIV positive status

to one's sexual partner allows them to engage in safer sex behaviours such as using condoms to prevent HIV transmission and encourages partners to go for HIV testing, accessing and adherence to ARVs.

In a study in Uganda found that complete disclosure of HIV status by caregivers to children and strong parental relationships were related to good adherence to treatments (Kajura, Luyirika, Purcell, Kaharuzza, Mermin, Malamba, & Bunnell, 2006:1). The findings underscored the need for providers to support and provide on-going support and maintain open communication with HIV-infected children taking cotrimoxazole prophylaxis and ARTs.

In a study by WHO, (2006:1) found that non-acceptance of positive HIV status and of life-long dependency on ARVs for survival were perceived by many respondents as a major barrier to adherence. When an ARV user is in a state of denial, it is difficult to disclose to others, medicines are hidden from friends and relatives, and when necessary they skip medication to ensure that friends and family do not discover that they are HIV-positive (WHO, 2006:1).

In a study which was conducted in America to examine the extent to which HIV positive young women experienced diverse social and physical consequences with disclosure of their HIV positive status, it was found that 97%, who disclosed their HIV status, experienced negative outcomes; 24% lost friends, 23% were insulted or sworn at and 21% were rejected by family, 13% reported being physically or sexually assaulted as a result of their being HIV positive, and 16% reported having lost economic support (Gielen, Fogarty, O'Campo, Anderson, Keller and Faden, 2006:2).

In Malawi, a study was conducted to determine pregnant women's perceptions towards selected potential for HIV prevention efforts for HIV positive mothers, who were recruited for the prevention of mother to child transmission of HIV (PMTCT) program. The findings showed that only 64% disclosed their positive status to their partners. The 36% who did not disclose explained that they were afraid of negative reactions from their partners.

In another study, which was conducted by Malawi Net for people living with HIV (MANET, 2003:6), on factors that affect people living with HIV, it was found that stigma and discrimination were key factors with significant influence on the ability of PLWHA to live positively with their status. It was further found that people perceive stigma as one of the barriers to HIV positive status disclosure in the country. In another study conducted in Malawi by UNFPA, (2005:8) on perceptions of youth on HIV positive status disclosure among HIV positive youth, it was found that stigma and discrimination were major barriers.

So far no study has been conducted in Malawi to explore experiences of HIV positive youth in the disclosure of their HIV positive status. Given the high prevalence rates of HIV among young people due to their vulnerability, a study on the experiences of HIV positive youth in Malawi is of relevance. There is the need to explore their experiences in disclosing their status to come up with data in this un-researched area in Malawi.

### **1.3 PURPOSE OF THE STUDY**

The purpose of the study is to explore youth's experiences in disclosing their HIV positive status in Malawi.

### **1.4 OBJECTIVES**

- To determine factors that facilitates or hinders disclosure of HIV positive status.
- To describe the experiences of youth in relation to disclosure of their HIV positive status.

### **1.5 RESEARCH QUESTIONS**

- What are youths' experiences on disclosing their HIV positive status?
- What makes youth living with HIV/AIDS disclose or not disclose their HIV positive status?
- What are the outcomes of HIV positive status disclosure among youth who are living with HIV and AIDS?

## **1.6 SIGNIFICANCE AND JUSTIFICATION OF THE STUDY**

The findings of this proposed study will be communicated to the Ministry of Health and other stakeholders in order to provide them with an insight on experiences of HIV positive youths with regard to the disclosure of their status. These findings will be used to contribute to policy and program development that will assist in identifying the appropriate support systems for HIV positive youth post, the disclosure of their status.

Information gained from this study will enlighten and assist National AIDS Commissions in Malawi in their planning and implementation of HIV and AIDS programs for youth in the country.

The findings of the study will be communicated to counselors in the Voluntary Counseling and Testing (VCT) Centers in various Health facilities and education institutions in the country to intensifying the health education messages. These findings will assist counselors to develop strategies that will help to promote disclosure and deal with factors that are barriers to disclosure of HIV status among youth. The findings of the study will provide baseline information for planning strategies and devising measures that will help to deal with the factors that are reported as barriers (eg stigma and discrimination) to HIV positive status disclosure in the community and consequently promote disclosure and positive living among infected youth. It is apparent that the findings of this study will add to the body of knowledge on how to promote disclosure of HIV positive status among HIV infected youth in Malawi and other countries.

## 1.7 OPERATIONAL DEFINITIONS

**Youths:** Are young people in late adolescence stage between the 15-25 years (MDHS, 2004: 8). In this study, youth refer to young people between ages 18 and 25 years who can consent, without seeking parental permission, as would be the case with minors.

**Experiences:** Are defined as narratives of an encounter, or a series of participated in event or lived through. (Morrison, 2006:1) In this study experiences are the negative and positive feelings of HIV positive youth after disclosing their HIV positive status.

**Disclosure:** Is defined as the act of revealing ones HIV positive status to prospective sexual partners or significant others (Serovich, 2005:3). For the purpose of this study, disclosure refers to the ability to reveal ones HIV positive status to others, after an HIV test.

**Human immunodeficiency virus (HIV)** is the virus that causes AIDS (Centers for Disease Control and Prevention, 2007:1). In the study HIV Positive Status is the detection of specific antibody to the HIV blood of youth.

**Consequences:** are defined as the positive or negative outcomes of decisions, events or processes (Serovich, 2005:3). In the study the consequences refer to the benefits and costs of disclosing HIV positive status among HIV positive youth.

**Cost** is defined as a price one pays or the loss of any kind; detriment; pain; suffering (Serovich, 2001:3). In this study cost is defined as any negative consequence of disclosing an HIV positive status.

**Perceptions** - In psychology and the cognitive sciences, perception is the process of acquiring, interpreting, selecting, and organising sensory information (Morrison, 2006:1). In this study, perceptions refer to the thoughts, feelings, views, ideas and opinions about youths HIV positive status disclosure, which could either be positive or negative.

**Discrimination:** is the unfair treatment of a particular race, gender, religion, or group, based on prejudice or bias (Herek & Capitanio, 1998). In the study, discrimination is the unfair treatment of youth who have disclosed their HIV positive status.

**Stigmatisation:** are the negative feelings, beliefs and behaviours directed towards an individual or group, due to a particular label or characteristics (Herek and Capitanio, 1998:3). Stigmatisation, in this study, is the negative feelings and beliefs from people directed towards youths who have disclosed their HIV positive status.

## 1.8 OUTLINE OF THE STUDY

This section has outlined the arrangement of chapters of the study as follows:

**The current chapter: Chapter one is the introduction,** setting out the background to the study. It outlines HIV epidemics, voluntary counseling and HIV testing, disclosure of HIV status. It also has a problem statement, significance of the study, purpose of the study, objectives, research questions and operational definitions.

**Chapter two:** discusses a reviewed literature and findings of the previous studies done on HIV and AIDS, with special emphasis on HIV positive status disclosure that includes

the following: vulnerability of youth to HIV transmission, voluntary counseling and testing prerequisite to disclosure, definition of disclosure, process of disclosing HIV positive status, rate and outcome of disclosure of HIV positive status among people, positive and negative outcomes of disclosure of HIV positive status and a conceptual frame of Consequence Model of HIV status Disclosure by Julianne Serovich, (2001:4).

**Chapter three:** discusses the research methodology of the study. This is an exploratory study that adopted a qualitative approach using the phenomenological design. In this chapter, sampling method, data collection and analysis processes, as well as ethical considerations, have been discussed.

**Chapter four:** includes the presentation of the major findings of the study, according to the following four themes that emerged during the data analysis: factors leading to and hindering HIV positive status disclosure, disclosure of HIV status, experiences of disclosing HIV positive status and consequences of HIV positive status disclosure.

**Chapter five:** discusses the summary of the major findings of the study, and conclusion of the study. This chapter also provides the following recommendations to the stakeholder dealing with youth and adolescent health which includes: Ministry of Health, National Youth Council, Non Governmental Organisation and the community, with an aim to promote HIV testing and disclosure among youth, as well as future research studies in HIV disclosure. The recommendations for further research studies on HIV testing and disclosure have also been provided.

## **CHAPTER 2 LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK**

### **2. INTRODUCTION**

#### **2.1 Literature review**

A comprehensive literature was done on the findings of recent existing studies on disclosure of HIV status and other related information. This literature review assisted in identification of key concepts and other relationships that provided the researcher with a structure for adopting and modifying a conceptual framework of Consequence of HIV Disclosure by Julianne Serovich, (2001:4). The review of literature further helped to build a logical framework and focus for the research study. The details of the conceptual framework are provided in detail later in this chapter.

The literature review will include information and findings of previous research studies focusing on disclosure of HIV positive status, rate and prevalence of disclosure of the HIV positive status, factors that promote or hinder disclosure, experienced outcomes of HIV positive status disclosure of HIV positive status among people and will focus on the disclosure among youths in Malawi, sub-Sahara and worldwide. This chapter has also discussed the conceptual framework for disclosing HIV positive status disclosure.

Muula and Mfutso-Bengo, (2005:1) in their study on when public disclosure of HIV sero-positivity is acceptable in Malawi, explain that HIV is a major public health care problem in Africa. Stigmatisation, discrimination and inappropriate health care services are among the most common challenges that HIV infected people face. They however,

suggest that the tool available in the fight against stigma and discrimination is disclosure. They further explained and warned that disclosure should be accompanied by appropriate individual counseling in order to avoid negative impacts. Knowing the results of an HIV test will help one to make an informed decision as to when, where, who, why and to share the results (Betteridge & Alexandrova, 2004).

### **2.1.2 Vulnerability of youths to HIV transmission**

According to Lopez (2002:2), a large number of young people do not know how to protect themselves from HIV. In his study he found that in sub-Saharan Africa only 21% of young women and 30% of young men (ages 15-24) had the knowledge needed to protect themselves from HIV infection. He further noted that in the same region, only 8% of out-of-school youth (and only slightly more in-school youth) have access to prevention education, and globally, only 44 out of 107 countries failed to include AIDS in their school curricula. In Malawi, youth are at risk of HIV infection because of inadequate reproductive health service and lack of information for the youth to use in order to protect themselves (UNFPA, 2005:5).

### **2.1.3 Voluntary counseling and testing prerequisite to disclosure**

Voluntary Counseling and HIV Testing (VCT) can provide opportunities for people living with HIV and AIDS to explore issues related to disclosure and help them gain insight, skills and confidence to disclose their status in a way that they feel comfortable. In Malawi there are over 30 VCT centers Malawi Demographic Health survey (MDHS, 2004).

Effective counseling can help enable clients to positively integrate life with HIV and address issues of disclosure of their HIV-positive status, including, but not limited to, fulfilling their legal and ethical obligations with regards to the protection of others from HIV infection. Furthermore, HIV infected women who know their HIV status are in a better position to make informed choices about their reproductive lives and, if pregnant, to access specific interventions such as antiretroviral prophylaxis and infant feeding options for Prevention of Mother to Child Transmission (PMTCT) (Advisory Committee on HIV/AIDS, (2001:8).

Joint United Nations Programme on HIV and AIDS (UNAIDS, 2007:2), affirms that comprehensive packages of care, treatment and support, including information provision, education and counseling can enhance HIV prevention efforts, reduce the stigma associated with HIV and AIDS and contribute to the overall physical, sexual, emotional, psychological and spiritual well-being of people living with HIV and AIDS.

#### **2.1.4 Meaning of disclosure**

Disclosure could be defined as the “ability to reveal, while disclosure of HIV positive status is defined as verbally revealing of one’s HIV positive status to a prospective sexual partner or others after an HIV test” (Black, 1999:1). He further states that disclosure can occur in many contexts namely; within personal relationships, family in the work place, to health care personnel, in institutional settings and to the general public. For most people disclosure is a gradual process that happens over time and that raises several

issues, including the rights of People Living with HIV and AIDS to control their own personal information and their right to confidentiality and privacy (Free Term Papers, 2004:2).

### **2.1.5 Process of disclosure**

Free Term Papers, (2004:2) explains disclosure as not a single step, but a process where an individual goes through a series of stages of grieving processes, once an HIV positive diagnosis is made and these stages include; denial, blame, withdrawal, regression and acceptance. For most people, disclosure is a gradual process that happens over time and that disclosure of HIV status raises several issues, including the right of people living with HIV/AIDS to control their own personal information and their right to confidentiality and privacy.

The decision to disclose is one's right, which is selective and consists of several steps including adjusting to the diagnosis that includes denial and acceptance, assessing one's disclosure skills, deciding whom to tell, evaluating the recipients circumstance, anticipating the recipients reaction (experienced outcomes in a form of rewards or costs) and having the motivation to disclose in Sowell et al, (2003:2). He also points out that the decision to disclose one's status is difficult and must include; to whom, when, where, and how to reveal ones status.

### **2.1.6 Method of disclosing HIV positive status**

According to the study done by Serovich, (2006:1) using the findings of her study to test guidelines for clinicians who work with HIV-positive clients to determine the most effective means of disclosing HIV status in different situations. The findings showed that there are two types of methods of disclosing HIV positive status which are: direct and indirect. The direct method, which is referred to as point-blank disclosure, where an individual states that she/he is HIV-positive, either verbally or in writing. The other direct method is stage setting where HIV positive men used techniques such as verbal hints or symbolic hints, such as leaving HIV-related brochures or other materials in plain sight; or insisting on condom usage.

The indirect method of disclosure of HIV positive status is that the HIV positive men would ask for a glass of water to take their medications. Buffering is also another indirect method of disclosure, where a third party is used to disclose the status of the HIV positive man some relied on supportive friends to break the news to potential partners, while other HIV positive men reported positioning themselves where they could easily meet other HIV-positive people, such as support groups or AIDS walks, as their indirect way of disclosing their HIV positive status.

### **2.1.7 Reasons for disclosing HIV positive status**

Greenberg, (2000:1) states that although HIV positive people do not want to disclose their status, they are however motivated to do so because of the following factors: sense of ethical responsibility, concern for partners health, failing health or severity of illness, need for social support to cope with the diagnosis and to alleviate stress associated with non disclosure. A study done by Parsons et al, (2004:461) concurs with the findings of the above study. Their study found that people disclosed their HIV positive results in order to access rewards, which included increased social support and intimacy with partners, assurance, reaffirmation of one's sense of self, and the opportunity to share personal experiences and feelings with sexual partners and to access medical care services.

### **2.1.8 Experienced benefits of HIV positive status disclosure**

Sowell et al, (2003:2) further reports that disclosure of sensitive health information is generally thought to have beneficial effects on an individual's health. He believed that disclosure lowers stress levels and ultimately leads to better psychological health. WHO, (2004:1) observed that, both in developed and developing country settings, HIV positive status disclosure was associated with positive outcomes, including; access to medical care, including antiretroviral treatment, increased social support, acceptance, kindness, decreased anxiety and depression.

UNAIDS, (2007:4) suggest that HIV positive youth who know and share their HIV status have higher self-esteem and less depression than those who do not, Tindyebwe, (2004:2) In his study of outcomes of disclosure of HIV status among women, he found that it helps to create a sense of closeness in the family, reduces feelings of anxiety and isolation, helps build psychosocial support networks and helps them to plan their future reproductive life.

World Health Organisation (WHO, 2004:1) adds that disclosure may also result in less social isolation and the strengthening of relationships by increased opportunity to discuss and implement HIV risk reduction behaviors with partners, increased opportunity to plan for the future and ability to live positively with the virus. Despite these outlined benefits of disclosure of HIV positive status, Silverio, (2003:3), however, points out that the barriers to disclosure include fear of rejection and discrimination.

### **2.1.9 Experienced negative outcomes of HIV positive status disclosure**

Although disclosure is associated with positive outcomes, it has a number of potential risks for the individual, according to WHO, (2004:4) fear of negative outcomes was a major reported barrier. Other negative outcomes include loss of economic support, blame, abandonment, physical and emotional abuse, violence, and depression, risk of losing employment, discrimination, stigmatization and disruption of family relationship. Levy (1999:1) expresses that disclosure does not bring relief and that it may be accompanied by regrets. A study by Simon, Demas, Mason, Drossman & Davis, (2000:147) found that

one in five women, who disclosed her HIV status to her partner, was abandoned and also found that one fifth of women in the study had experienced negative consequences of disclosure that include rejection, abandonment, verbal and physical abuse. In a WHO Report, (2004:3) that looked at violence as an outcome of HIV status disclosure for women who chose to disclose, violent outcomes were reported more often by women in developing countries 3.5-14.6%, compared to women in United States of America, which was 1%-4%. The highest rates of disclosure related violence were reported more among antenatal mothers in developing countries.

#### **2.1.10 Stigma and discrimination**

Theoretically, stigma is defined as imposition of special discrediting and an unwanted mark on the person or specific category of persons in such a way that they are looked at as fundamentally and shamefully different. The label is imposed on people who are or believe they have a distinctive status (UNAIDS, 2002:1).

AIDS-related stigma refers to the prejudice and discrimination directed at people living with HIV and AIDS (PLWHA), and the groups and communities that they are associated with. It can result in people living with HIV/AIDS being rejected by their community, shunned, discriminated against or even physically hurt (AVERT, 2008:1). UN Secretary-General Ban Ki Moon says, cited in AVERT, (2008:2) that “stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. Stigma and discrimination 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".

Research by the International Centre for Research on Women (ICRW), (2005:15) found the possible consequences of HIV-related stigma to be: loss of income/livelihood, loss of marriage and childbearing options, poor care within the health sector, withdrawal of care giving in the home, loss of hope and feelings of worthlessness and loss of reputation. Although the concept is negative, stigma can have positive consequences as it can create a sense of community among stigmatised individuals, motivating them to support each other and make changes that will improve their lives (UNAIDS, 2002:1).

#### **2.1.11 Rate and outcome of disclosure of HIV positive status among people**

The study which was conducted by Lee, Rotheram, Borus and O' Hara, (2004:1) to examine disclosure of sero-status and predictors of disclosure among American – African youth living with HIV, the findings showed that, most youth disclosed their sero positive -status to their families (87%); young men often disclosed to friends. Sixty nine percent of youths disclosed to all their sexual partners. Those who were diagnosed at a younger age were significantly associated with disclosure to the family members. Higher rates of disclosure were to sexual partners.

Although many youth, living with HIV, disclosed their sero-status to their partner, condom use was not increased (Lee, Rotheram, Borus and O' Hara, 2004:1). Kasaye, Lingerh and Dejene, (2005:126) in their study to determine the rate and outcome of HIV

positive disclosure among sexual partners, found that over 69% women reported that they had shared their HIV results with their partners. Among the women who did not share the result, 62.5% said that it was due to fear of partner's reaction (fear of abandonment, rejection and accusation of infidelity). Seventy five percent of those who disclosed their status reported positive partner's reaction. Women who had prior discussions about HIV and HIV testing with their partners had disclosed their results, this accounted for 81.3%.

#### **2.1.12 Rates of disclosure between developed and developing countries**

In a WHO, (2004:2), it is reported that the rate of disclosure, in the developed world, to the sexual partners, ranged from 42-100%, while the rates from developing countries were notably lower than the rates reported in developed world. The rates ranged from 16.7-86% which could be attributed to the high stigmatisation and discrimination rates and lack of adequate health care and of support services for those who make their HIV positive status known.

On average, disclosure to a steady partner was 49% in developing countries and 79% in developed countries. The lowest rate of disclosure was among pregnant women tested in the Antenatal Clinic in sub-Saharan Africa which accounted for 16.7-32% (WHO, 2004:3). Further studies from developing countries showed that women who did not share their HIV test results with anyone, accounted for 10-78% as compared to 3-19% of women in developed countries. (WHO, 2004:3).

Sowell et al, (2003:3), conclude that HIV sero-positive women have greater difficulty disclosing their HIV status to sexual partners than do men. This is because many women in developing countries are not economically empowered, hence depending much on their husband, and the fear to disclose could be due to the anticipated marriage breakdown leading to the loss of financial support. It was also found that in both developed and developing countries, disclosure rates to sexual partners tended to increase over time.

### **2.1.13 Risk of HIV transmission with non disclosure**

In the study done by Stein, Freedberg, Sullivan, Sacvetsky, Lavenson, Hingson, & Samet, (1998:253), to determine the factors associated with the disclosure of HIV positive status to a partner, at Brown University School of Medicine in USA, it was found that individuals with one partner, were 3.2 times more likely to disclose than the one with multiple partners. It was also found that individuals with high spousal support were 2.8 times more likely to disclose than individuals without support. The study concluded that many individuals do not disclose their status to their sexual partner due to fear of negative outcomes. Sexual partners of HIV infected persons continue to be at risk of HIV transmission.

In another study on the disclosure of HIV positive status on individuals on antiretroviral preventive therapy by Gorbach, Galea, Amani, Shin, Celum, Kerndt and Golden, (2004: 2), findings indicated that about 20% did not disclose their status to their regular partners, almost 1/3 did not use a condom during their last sexual encounter with a casual partner.

In a study on men having sex with men, it was found that 42-48% reported not disclosing their HIV positive status for fear of rejection and were practicing unsafe sex, (Gorbach, et al, 2004: 2). The results suggest that ongoing partner notification may be necessary to increase disclosure of HIV status to sexual partners and reduce incidences of HIV transmission. (Niccolai, Dorst, Myers, and Kissinger, 1999:281).

#### **2.1.14 Condom use in relation to disclosure of HIV positive status**

According to Horizon Report (2005:1), HIV care services should include preventive messages that emphasise disclosure of HIV status, partner testing, and consistent condom use with special focus on regular partner relationship. In his study to determine the sexual behaviour, condom use, and disclosure, of HIV status of infected heterosexuals attending an inner London HIV clinic, the results showed that 73% used condoms when they had vaginal sex. The two most common reasons for condom use was that “I did not want to give my partner HIV (39%),” followed by “I did not want to catch another sexually transmitted infection (32%).” While the two most common reasons for not using condoms were “my partner does not like using condoms 13% and I don’t like using condoms” accounting for 6.5%, and “a desire to become pregnant” by only one woman (Stein et al, 1998:1).

Ensuring the prevention of HIV transmission requires a range of protective measures including knowledge of partners HIV status and disclosure of ones sero-status to sexual partners. Disclosure is also fundamental in managing HIV; especially in terms of

adhering to complex treatment regimes. For example HIV positive people have reported that they sometimes skipped doses because they could not take a prescribed medication without being observed doing so (Chesney and Smith, 1999:1163). Disclosure of HIV status has become an entry criterion for many treatment programs in resource constrained settings, access to other forms of care such as home based and specific social support are dependent upon the disclosure of HIV status. It is important therefore, to create an enabling environment by families, health care providers; support groups and communities for people to disclose their HIV status.

#### **2.1.15 CONCLUSION**

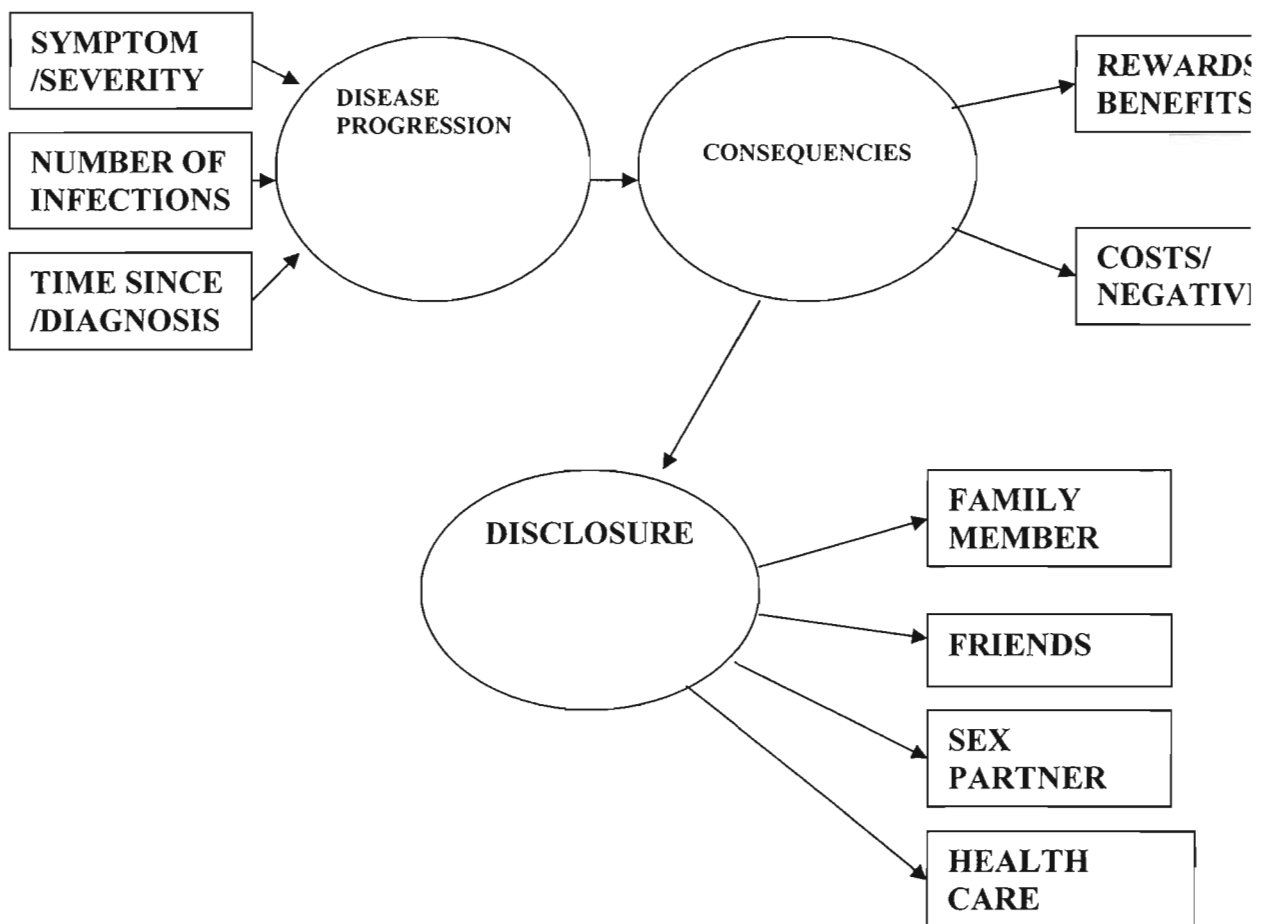
From the literature review, the findings indicate that several studies have been conducted on HIV disclosure among heterosexual, pregnant women, gay partners, HIV positive children, in Malawi and world wide. Studies have also shown that although disclosure of HIV sero-positive status is a difficult emotional task and has negative impacts, beneficial effects are that the individual is able to access medical care and social support and adopts a positive living with the HIV infection.

In most studies conducted in Malawi and elsewhere, the findings are that many people do not disclose their HIV status which is a worrisome situation as far as HIV prevention is concerned. There are studies on youth acquiring the infection through injections and in men having sex with men. All in all, the disclosure rates are very low. Hence the need to intensify studies to discover experiences that will help in efforts to promote the disclosure

of HIV positive status and transmission. Despite the negative consequences of HIV positive status disclosure, most literature still advocates for disclosure of HIV status because benefits of disclosing outweighs the negative implications (Pennbaker et al, 1990, cited in Sowell et al, 2003:2). In view of the above, there is therefore a need to encourage youth to disclose their HIV positive status.

## 2.2 CONCEPTUAL FRAMEWORK

Fig 1 Consequence Model of HIV Disclosure by Julianne Serovich, (2001:4)



## **2.2.1 CONSEQUENCE OF HIV DISCLOSURE MODEL**

Serovich, (2001:3) Consequence Model of HIV Disclosure will be used in this study. This model will help establish youth's experiences with the disclosure of their HIV positive status. This model provides a framework for determining the factors that influence individuals to disclose their HIV positive status and their experienced consequences of disclosure. This model has three main concepts; disease progression, consequences and disclosure as discussed below. Most of the components in this model apply to my study hence the choice to use it.

### **2.2.1.1 Disease progression**

The model describes the relationship between disease progression and disclosure is moderated by the consequences one anticipates resulting from HIV positive status disclosure. That is, as the disease progresses, stress accumulates, which results in the need to evaluate the consequences of disclosure. It also states that the severity of the disease, the number of infections and time since diagnosis, can influence one to reveal to their sexual partners and significant others. The model further states that an HIV positive person will disclose the status once he/she assesses that the rewards for disclosing outweigh the associated costs; Serovich, (2001:3). The model has incorporated social exchange theory.

### **2.2.1.2 Disclosure of HIV positive status**

The Theory contends that individuals who are HIV-positive contemplate the need for privacy in determining whether to disclose an HIV-positive diagnosis or not. They disclose to those who pose little risk while avoiding disclosing to those who could harm them. Persons with HIV are likely to reveal to significant others and sexual partners once the rewards for disclosing outweigh the associated costs.

### **2.2.1.3 Consequence of HIV positive status disclosure**

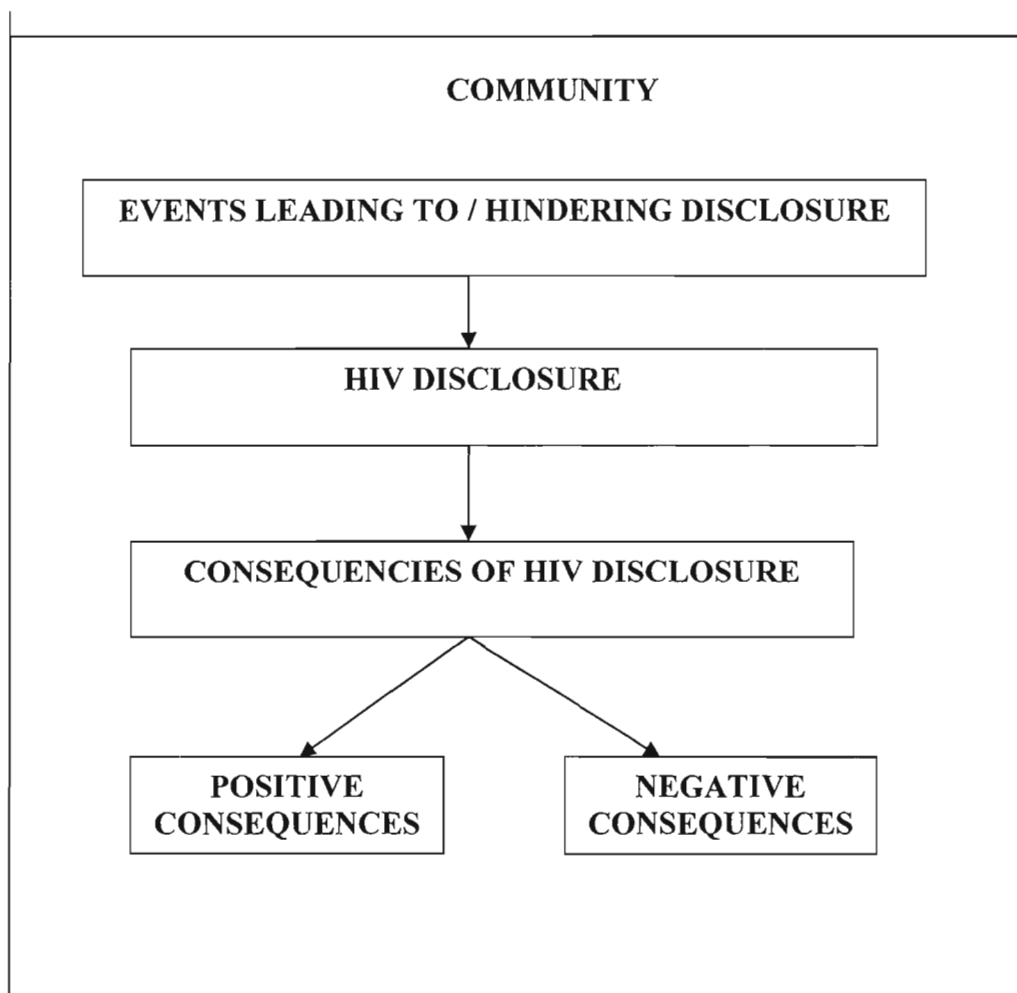
The theory points out that sharing HIV positive diagnosis can provoke a feeling of both relief and anxiety to personal well-being among people living with HIV. According to (Serovich, 2001:3) rewards or positive consequences includes; social, physical, psychological, or emotional dividends that satisfy or please one. Negative emotional consequences of disclosure that have been documented include; rejection, abandonment, and isolation (Serovich, 2005:3). These consequences can be confounded by the fear of, or actual loss of, relationship, employment, insurance, housing, medical services, and the right to education (Serovich, 2001:3).

### **Criticism of the Model of Consequence of HIV disclosure.**

This model has however, been criticised by Serovich, (2001:4), that due to the changes in HIV therapies, individuals are not exhibiting a standard pattern of declining health. For

example, Serovich, (2005:3), in her study did not find any relationship between the severity of physical symptoms and disclosure to sex partners among 129 HIV-positive adults. Thus the disease progression may no longer be the component of the disclosure process. According to the researcher, there are other events that can influence HIV positive status disclosure among HIV positive youth; as such modification of the model would be imperative to suit the study at hand.

**Fig 2: Modified Model of Consequence of HIV Disclosure by Juliana Serovich, (2001:4)**



### **2.3 Modified model of consequence of HIV disclosure**

The researcher has decided to modify the model on the basis that disease progression is not the only event that can influence HIV positive status disclosure among HIV positive youth. The change has been made to the model in order to accommodate the context of my study, which explores the experiences of HIV positive youth in disclosing their status.

#### **2.3.1 Events leading to / hindering disclosure**

Youth living with HIV are members of the community. The perception of the community towards people living with HIV can influence the disclosure of HIV positive status among HIV positive youth. According to Zea, Reisen, Echiverry, and Blanch, (2004:1) there are many events that can influence the disclosure of HIV positive status among HIV positive youth. It is therefore, important to understand events, in order to intervene appropriately. The community can have influence in all four aspects of the model of HIV disclosure.

#### **2.3.2 Disclosure of HIV positive status**

HIV positive youth disclosed their HIV status to those they value and expect rewards and would avoid those who were sources of anxiety or stress to them.

According to Serovich, (2001:3) disease progression is a factor that promotes disclosure among infected individuals.

### **2.3.3 Consequences of HIV disclosure**

#### **2.3.3.1 Positive Consequences**

Youth living with HIV will disclose their positive status if they anticipate benefits or positive consequences. In the study conducted by Horizon, (2004:4) on the benefit of HIV disclosure, it was found that the youth who disclosed their HIV status had a higher self esteem compared to those who did not. According to a study in Uganda by Deribe, Woldemichael, Wondafrash, Haile, & Amberbir, (2008:1), it was found that children who were disclosed to about their HIV positive status showed high access and adherence to antiretroviral drugs.

#### **2.3.3.2 Negative Consequences**

The negative consequences will keep the HIV positive youth from disclosing their HIV positive status. Banerjee and Mattle, (2004:1) in their study, also found that youth who disclosed their HIV positive status were abandoned, discriminated, stigmatised rejected and depressed. WHO, (2006:1) found that when an ARV user is in a state of denial, it is difficult to disclose to others, medicines are hidden from friends and relatives, and when necessary they skip medication to ensure that friends and family do not discover that they are HIV-positive.

## **CHAPTER 3 METHODOLOGY**

### **3.1 INTRODUCTION**

This chapter describes the approach which was taken to explore the experiences of youth Living with HIV, towards the disclosure of their HIV positive status, in Lilongwe, Malawi. The chapter describes the research design, setting, sampling methods and data collection techniques. Ethical considerations and limitations to the study will be discussed further.

### **3.2 RESEARCH APPROACH**

The aim of the study was to explore the experiences of youth living with HIV towards the disclosure of their HIV positive status. To enable the researcher to explore these experiences, a qualitative approach, using phenomenological design was used.

This design enabled the researcher to examine lived experiences of HIV positive youth through the descriptions of views and experiences that were provided by themselves. In an attempt to describe the lived experiences, the researcher focused on what was happening in the lives of the individual youth who were HIV positive and disclosed their status and the importance of the experiences (Brink, 2001:119).

According to Brink, (2006:119) the qualitative approach helped to understand the experiences, attitudes, opinions or views, feelings of the participants in the context in which the action takes place and gives them meaning. Qualitative research uses detailed descriptions from the perspective of the research participants themselves, as a means of

examining specific issues and problem understudy (Brink, 2006:119). Qualitative approach was used to describe the living experiences of the youth living with HIV on disclosure of their status and what meaning these hold for them.

The advantage of using qualitative approaches is that it produces more in-depth and comprehensive information. It seeks a wide understanding of the entire situation (Polit and Hungler, 2000:16). According to James, (1997:1) the disadvantage with qualitative approach however is that, the very subjectivity of the inquiry leads to difficulties in establishing the trustworthiness of the approaches and information. He also explained that it is very difficult to prevent or detect researcher induced bias.

The researcher tried to minimise the bias by avoiding preconceived personal ideas and interest during data collection. According to Brink, (2001:120), bracketing is the identifying and putting aside any preconceived beliefs and opinions one might have about a phenomenon under investigation. The scope of inquiry is also limited, due to the in-depth, comprehensive data gathering approaches which concentrate on deep understanding of only the phenomenon understudy and excluding any other information outside this (Polit and Hungler, 2000:16).

Although a qualitative approach was used in this study to explore the experiences of youth in disclosing their HIV positive status, there was the first part of the individual in-depth interview that had demographic characteristics that were collected with an aim of understanding participant's background using quantitative approach.

### 3.3 STUDY SETTING

Malawi is a landlocked country, south of the equator in sub-Saharan Africa with a population of 13.5 million. It is bordered, to the north and northeast, by the United Republic of Tanzania; to the east, south, and southwest, by the People's Republic of Mozambique; and to the west and northwest, by the Republic of Zambia. It is a small country in the South East of Africa. Its people are known for their cheerful and welcoming nature (Malawi National Statistics Office, (NSO), (2003:1). It is one of the countries which have been greatly affected by the HIV epidemic (MDHS, 2004:2).

**Fig 3: Map of Malawi**



Lilongwe, where the study took place, is the capital city of Malawi and the second biggest city in the country. It has a population of about 1,720,784, (Malawi National

Statistics Office (MANASO), (2003: 1). It is a commercial as well as an industrial city. It has both urban and rural settings.

Lilongwe district has many HIV support groups, including 9 which belong to Malawi Network of People Living with HIV/AIDS (MANET). The study took place at two support groups belonging to MANET+ one in an urban area (Likuni) and the other in a rural area (Nambuma). MANET+ Support groups were elected because they met the set criteria (see map below, fig 4). Participants were drawn from these HIV support groups after obtaining permission. The urban and rural settings were considered in this study in order to obtain different experiences from two diverse communities. This would probably represent the experiences of youth living with HIV on the disclosure of their status in a much broader view.

**Fig 4: Map of Lilongwe Urban and Rural**



### **3.4 POPULATION, SAMPLING METHOD**

#### **3.4.1 Target population**

The target population for this study comprised of all the youth living with HIV, between ages 18-25 years, in Lilongwe District, Malawi. This district has about 343,739 youth aged 15-25 years; of which 4,678 were HIV positive, with females out numbering males (2,558 females and 2,128 male), (Malawi Demographic Health Survey (MDHS), 2004:4).

#### **3.4.2 Selection of Participants**

Purposive, sampling method also known as judgmental was used to sample participants. It is a sampling method in which elements are chosen, based on the purpose of the study. The sampling was based on the researcher's judgment of the participants that were typical of the phenomenon under study, and were especially knowledgeable about the question at hand (Brink, 2001:14).

The advantage of this method is that, it is easy to sample participants and also less time consuming. However, the disadvantage with this sampling method is that it does not give an equal chance for others to participate in the study, as the researcher implies judgment in the selection of the participants. The small sample size also limits generalisation of the findings (Brink, 2001:119). The Malawi net, for people living with HIV support group (MANET+), was contacted to assist with participant recruitment. MANET is a Non Governmental Organisation (NGO) working in the field of HIV/AIDS support groups in

Malawi, an umbrella organisation for support groups and Community Based Organisations for people living with AIDS in the country. It has member support groups in all the three regions of Malawi (Northern, Central and Southern regions), (MANET+, and 2007:1).

There are 225 MANET+ member support groups in nine districts of the central region. Lilongwe District alone has 66 support groups, each having 50 per support group. Out of the 66 support groups, 9 have a total membership of 188 (98 females, 90 males).

Officials of MANET+ were approached and an explanation was given about the study, its purpose, objectives, and all the planned activities. Permission was sought from them to assist with recruitment of participants. This was done to avoid unintended HIV status disclosure of the potential participants, which could violate the right to confidentiality of their HIV support group members. After the participants granted permission and were comfortable enough, the researcher was then introduced to them. Five male and five female participants, who volunteered and met the admission sample criteria, were recruited for the study.

The participants were drawn from these support groups because they were already identified as people living with HIV/ AIDS and had disclosed their positive status. It was also easy for MANET+ to recruit participants because the support groups are within their program.

In qualitative research the researcher does not know in advance the number of participants needed (Brink, 2001:14). Sampling was done simultaneously with data collection. The researcher had in individual in-depth interview with the 10 participants,

until there was data saturation, and no new participants were sought for more information to overcome this bias. An equal number of males and females were included in the study. Considering the sensitive nature of the study (HIV), this method helped to gain access to people who were difficult to find. It is also considered appropriate because recruitment is on a voluntary basis (Polit and Beck, 2006:270).

### **3.4.2 Sample size**

Youth, living with HIV, between the ages 19 -25 years were sampled. The estimated number of participant was 10 and all of them were interviewed with close observation on data saturation.

#### **The inclusion criteria**

- Youth between the ages 19-25 years, both males and females, participated in the study. This age group was chosen because they can make decision whether to give consent to participate in the study or not. According to Malawi Demographic Health Survey (MDHS), (2004:8), 18 years is the minimum age for one to consent to participate in a survey. While under 18 is considered minor and requires a guardian to consent on his/her behalf to participate in the study.
- Willingness and capacity to provide informed consent.
- Willing to have individual in-depth interviews recorded on audiotape.
- Youth who had disclosed their own HIV positive status.

In qualitative research, it is also accepted that research should be evaluated critically and justified in order to ensure that the study was done in an honest manner, to meet the academic requirements as discussed below:

### **3.5 ACADEMIC RIGOR**

According to Brink, (2001:148) qualitative data is assessed for trustworthiness or true value. To ensure the quality of data and findings in this study, the researcher established trustworthiness and true value of data by ensuring the following:

#### **Credibility**

According to Polit and Beck, (2006:332), credibility refers to confidence in the truth of the data and interpretations of them. In this study, credibility was obtained by prolonged engagement in data collection and interpretation. Sufficient time was dedicated for data collection activities. This helped to have individual in-depth understanding of the views of the group as they unfold naturally. The researcher also built trust and rapport with participants. This was achieved by maintaining contacts with the research assistant and participants. Members who participated in the study were provided with feedback on the emerging themes and seeking clarification was necessary in order to have a true reflection of their views. Confidentiality was maintained and unintended disclosure was avoided.

### **Dependability**

Polit and Beck, (2006:335) refers to dependability of qualitative data as data stability over a period of time and over conditions. It is comparable to validity in quantitative studies. This was achieved by keeping detailed records of the research process. This would enable future researchers to repeat the study, in the same context, with the same methods and participants, and obtain similar results. An audit enquiry could be conducted, which involves a scrutiny of data and relevant documents to assess the extent to which proper research practices have been followed.

### **Transferability**

This refers to the potentiality of transferring the findings to other settings (Polit and Hungler, 2006: 430). The researcher achieved this by producing a thick rich detailed description of the methods used in data collection, analysis, as well as the setting where the study took place. This would enable another researcher to apply the findings to another setting and come up with similar results.

### **Conformability**

This refers to the objectivity or neutrality of the data, that is, the potential for congruency between two or more independent people about the accuracy of data (Polit and Beck, 2006:337). Conformability was enhanced by bracketing and maintaining a flexible journal of the study. Although complete conformability is impossible in research, the

researcher made sure that her personal values and beliefs did not influenced the research findings (Polit and Beck, 2006:337).

### **Bracketing**

According to Polit and Beck, (2006:220) bracketing refers to the process of identifying and holding in abeyance preconceived beliefs, opinions or any bias about the phenomena understudy in order to explore the lived experiences of youth living with HIV in its pure form. The researcher put in writing at the beginning of the study any anticipated personal preconceived ideas, beliefs and any presumption for self reflection and external review. She tried to recognize any of these biases and control it. This procedure is intended to facilitate openness and new insight (Burn and Grove, 1997:532).

### **3.6 DATA COLLECTION**

Individual in-depth interviews were conducted to collect data from participants using probes and prompts to obtain reach data from the participants (see appendix 1). This allowed conversation between the participant and the researcher. These are occasionally known as self reports (Brink, 2001:153). Field notes were also recorded to complement the findings.

Data were collected from HIV positive youth between the ages 19 to 25 years by the researcher over a period of 10 days, from 20 to 30 March 2008. These individual in-depth

interviews were conducted at two HIV Support Group Centers where there were youth living with HIV (one from Likuni, a support group in urban and the other one from Nambuma, a rural support group in Lilongwe).

The translated in individual in-depth interview questions with prompts and probes were reviewed by experts at National AIDS Commission in Malawi. The suggestions from this exercise were used to refine the questions, prompts and probes that were further translated from English to Chichewa (see appendix 2) by the researcher prior to data collection. The researcher ensured that expression of experiences and feeling were not lost in translation by ensuring that appropriate Chichewa words were selected that best described the experiences and feelings of the participants. All individual in-depth interviews were conducted in Chichewa for easy communication, since Chichewa is the commonly spoken language in Malawi; this was done to minimize misunderstandings due to the language barrier.

One research assistant was recruited to assist with in logistics for the study, such as: assisting with identification of clients who met admission criteria in to be included in the study. She also helped in identifying private venues for interviews and assisted with serving some snacks and refreshments. The research assistant was working with Malawi Net for People living with HIV and AIDS (MANET+) which also runs the selected sites where the study took place. She was a trained HIV/AIDS counselor and assisted to counsel clients who were emotionally affected during the individual in-depth interviews.

The purpose of the individual in-depth interviews was to gain a thorough understanding of what was going on in the minds of the participants, in this case HIV positive youth, their experiences about HIV status disclosure, attitudes, beliefs, feelings, motives plans, past events, knowledge levels and recall as well as gathering factual information (Brink, 2001:153).

The interviewer encouraged the participants to talk freely on the topic. Probes and prompts were used to solicit more views and clarity from the participants on the topic. About 5 in-depth interviews, each lasting 60-90 minutes were conducted at each of the two selected HIV support group sites. The individual in-depth interviews were tape recorded, after gaining permission from the participants. Data was collected until there was data saturation and when no new information was obtained (Polit and Beck, 2006:267).

After the first interview, the researcher transcribed and analysed the collected data in order to determine if the individual in-depth interview questions would bring out the desired information. It was also for estimating how long it would take to complete each interview and to identify any ambiguities that needed modifications. This data formed part of the report.

### **3.6.1 Data Management and Handling**

Safety was observed for the collected data, by proper storage of the tapes which were used for recoding data. The tapes were well labeled, including identity numbers or codes and dates indicating when the data was collected. Field notes, tapes and tape recorders were kept under lock and key. After data analysis, all the used tapes were destroyed. This helped to ensure confidentiality.

## **3.7 DATA ANALYSIS**

During the period of data collection, the researcher read the transcripts and field notes carefully and repeatedly, 'immersing' herself in the data (Ijumba, & Marron, (2002:522). Immersion allowed the researcher to identify themes, categories and patterns emerging from the data (Marshall, & Rossman, 1999:1). Information in the tapes, from individual in-depth interviews, was transcribed verbatim. Data analysis was done through a series of steps, which includes; coding for themes, patterns, categories, verifying the selected themes with the research supervisor. Data were analysed using content analysis and the transcribed data was read to identify similar issues. Field notes were also read to support important findings obtained during the individual in depth interview.

Codes were developed from the transcribed notes. Major categories and themes and sub-themes were identified and these were put into meaningful groupings for discussion. Data was displayed for the researcher to draw conclusions or meaning. Relationships were

explored between the disclosure of HIV positive status and experiences. Based on the coding system, emerging themes were interpreted and conclusions made on experiences of HIV Positive youth towards disclosure of their HIV status.

### **3.8 ETHICAL CONSIDERATION.**

In order to conform to the ethical and legal standards of a scientific investigation, in this study, the proposal was first presented at University of KwaZulu-Natal School of Nursing for clearance. It was then submitted to the Ethics Committee of Research at University of KwaZulu-Natal and College of Medicine in Malawi for approval and permission to conduct the study. Permission was granted from university of Kwazulu-Natal, (see Appendix 6) Malawi College of Medicine (see Appendix 7), from Lilongwe District Council (see Appendix 8) Malawi Net of People Living with HIV (MANET+) (see Appendix 9) who also liaised with traditional authorities and from the participants. Essential principles underlying the protection of the human subjects are the principles of respect, beneficence and justice (Polit and Beck, 2006:88). In order to conduct the research in an ethical manner, these principles were adhered to throughout the study.

The following were done to ensure that the study complies with ethical requirement of every research: The participants were informed of the study and invited to participate in the study by MANET+. Information sheets about the study, purpose, and significance were read and given to participants to allow them to make an informed decision about their participation in the study both English and Chichewa (see Appendix 3 and 4)

respectively). Participants were informed that participation was on a voluntary basis. They were informed about possible advantages and inconveniences of participating in the study, and that they could withdraw at any time. After the participant agreed to participate in the study, they signed consent forms (See Appendix 5). This was kept by the researcher to ensure that participants remained only known to her.

Information about the participants was kept confidentially as only the person involved in the study had access to it. Individual in-depth interviews were conducted in private rooms. Anonymity was maintained by the allocation of numbers and pseudonyms for each participant instead of using their real names. The risks associated with participating in the study, such as emotional upsets, were kept minimal. In the event of an emotional breakdown during individual in-depth interviews, the research assistant attended to such clients since she was a trained HIV/AIDS counselor. No information was collected that did not relate to the study.

### **3.8 LIMITATIONS OF THE STUDY**

Time frame and inadequate funds were the envisaged constraints in this study; hence the study was done on the homogeneous HIV positive youth, from two HIV support groups in Lilongwe, until data saturation was reached, after individual in-depth interviews of ten participants were done. HIV positive youth in other districts of Malawi heterogeneous HIV positive youth were not included in the study, due to time and financial constraints.

HIV and AIDS is a sensitive area since it deals with sexual issues which are considered private, hence the difficulty in collecting information.

There was the possibility that the researcher felt uncomfortable asking some sensitive questions and even the participants were not comfortable discussing private issues. However, the researcher anticipated this limitation, prior to conducting the study and assured those participants that they could get further assistance with counseling from her as a trained HIV and AIDS counselor.

The other limitation was that the prospective participants were members of HIV and AIDS support groups; the researcher feels that the responses from the participants were influenced by the HIV activities because they were all from the HIV support group which belongs to one organization MANET+.

### **3.9 CONCLUSION**

This chapter has described the research methodology that was used for this study. The research design, the setting, the population, sampling methods, sample size, data collection methods, ethical considerations, data collection and data analysis method that were used as well as credibility and trustworthiness of qualitative data. The chapter concludes by explaining the limitation of the study.

## **CHAPTER 4: PRESENTATION OF RESULTS OF THE STUDY**

### **4.1 INTRODUCTION**

This chapter provides presentation of findings of the study which was conducted to explore the youth's experiences in disclosing their HIV positive status, in Lilongwe Malawi. Data was collected from ten participants, five female and five male, in order to have an equal representation of gender. Written consents were sought prior to the data collection. Individual in-depth interviews were conducted to collect data in order to gain a deeper understating of individual participants views and experiences with the disclosure of the HIV positive status.

Data was collected over a period of ten days from both urban and rural areas in the two selected communities (Likuni and Nambuma) in Lilongwe.

The findings, which will be presented in this chapter, are in line with the purpose of the study objectives and were guided by the conceptual framework of consequences of HIV disclosure by Serovich, (2001:1). The purpose of the study was to explore the youth's experiences in disclosing their HIV positive status. The objectives of the study were as follows:

**Objectives:**

- To determine factors that facilitates or hinders disclosure of HIV positive status,
- To describe the experiences of youth in relation to disclosure of their HIV positive status.

In this Chapter, the findings will be presented in two parts. The first part will be section A, which will give details of the participants' demographic information. The second part, section B, will present qualitative findings of data which included participants' views, thoughts, feelings and ideas that were gathered through individual in-depth interviews from selected youth living with HIV from Likuni and Nambuma, Lilongwe.

The presentation will begin with section A, which are demographic characteristics of the participants in the study.

#### **4.2 SECTION A: DEMOGRAPHIC CHARACTERISTICS OF THE PARTICIPANTS**

The following section of this chapter presents the first part of the findings, which is about participants' demographic characteristic. The aim is to provide a concise description of characteristics of the participants and their possible influence in the study. The information was collected by asking the individual participants about his /her demographic characteristics and tape recorded their responses, prior to individual in-depth interview. This is the only information that was analysed and presented quantitatively. Ten participants were approached and requested to participate in the study, all of them agreed and participated in the study. The demographic profile of the

participants that will be presented in the following section include: gender, age, marital status, place of residence, and level of education, religion and employment.

### **Gender**

There was equal representation of participants in terms of gender, five male and five females. In general there were essentially no differences in the responses to the individual in-depth interviews between male and female participants and both from rural and urban areas. This could be attributed to the fact that they all belonged to support groups and that the HIV activities in the groups could have influenced their responses to some extent. The study included both male and female participants in order to appreciate the views from different sexes and their influence in the study.

### **Age**

The sampled participants' age ranged from 19-25 years, with a mean age of 22 years. There were no significant differences in the views expressed by each individual in this age range on experiences in disclosing HIV positive status.

### **Marital Status**

The participants were asked about their marital status. All of them indicated that they had never been married, except one who was later divorced. Some of the participant had steady sexual relationships (two) while others had casual (two) and the other did not have any sexual partner at the time of the interviews (6). One participant stated that her boyfriend died. All participants stated that they, at some point in time, had engaged in

unprotected heterosexual relationships with their sex partners. This shows that the major mode of HIV transmission in this case was likely to be heterosexual. Heterosexual is the common mode of HIV transmission in Malawi (Malawi Demographic Health Survey MDHS, 2004:12). Marital status did not yield favourable responses in relation to experience of disclosure to spouse in that all participants were not married.

### **Residence**

Half the participants (5) were from an urban area and half (5) from a rural area. The decision was made to have participants from diverse communities in order to determine varied experiences in HIV status disclosure from these areas. This also provided ground for comparing responses as to whether there were any significant differences in the responses of participants from the rural and urban areas. The findings however, showed that the experiences stated by each of them were more or less the same.

### **Educational Level**

Participants' educational level ranged from standard three (primary school) to form four (secondary school) with the majority attempting secondary school level but did not complete. In South African educational system, this level is equivalent to grade three through to grade twelve. There was no participant who achieved a tertiary level of education. The findings have revealed no differences in the responses of participants on their experiences with disclosure in relation to the educational level. All participants experienced difficulties in disclosing their HIV positive status. (Clarification of the educational system between South Africa and Malawi. In Malawi primary school starts from standard one to eight thereafter they are selected to secondary school from form one

to four while in South Africa primary school starts from grade one to seven then thereafter pupils they are selected to high school from grade 8 to grade 12).

### **Employment**

Almost all the participants were not employed except for three who were involved in small scale businesses. In view of this, no participants expressed any experiences of HIV positive status disclosure at work place. Studies show that employed people, who disclose their HIV positive status, are usually discriminated against.

### **Religion**

All the participants belonged to some religious group with the majority being Christians, except for two; one was a pagan and the other a Muslim. The participants viewed religion as an important aspect of their lives, except one who did not believe in God and the church. Those who believed in God and the Church stated that religion plays an important role in dealing with people who have problems, including those who are infected and affected by HIV/AIDS through spiritual counseling and material support.

One participant mentioned that her experience, in disclosing to a religious support group, was positive. This therefore, provides the basis for other people's reasons for disclosing their HIV positive status for them to access this support system. The participants with the above described characteristics provided qualitative data from which the themes, which will be presented in section B below, were derived.

### **4.3 SECTION B: PRESENTATION OF THE RESULTS ACCORDING TO THEMES AND SUB-THEMES**

This section will present the findings of the qualitative data that was collected from the participants through individual in-depth interviews. This study was based mainly on a qualitative approach with an aim of getting a deeper understanding of the youths' experiences of disclosing their HIV positive status.

Data was analysed using content analysis. The findings were grouped into four main themes and their sub-themes in line with conceptual framework that correlated with the purpose and objectives of the study. Some of the participants' views will be presented as direct quotations (excerpts) which reveal the respondent's level of emotion, thoughts, views, experiences and their perceptions about disclosure (Labuschagne, 2003:2).

The following are the four main themes and their sub-themes that emerged from the qualitative data analysis: Factors leading to and hindering HIV positive status disclosure, disclosure of HIV status, experiences of disclosing HIV positive status, consequences of HIV positive status disclosure. The table 4.1 below displays the identified themes and sub-themes.

**TABLE 4.1 IDENTIFIED THEMES AND SUB-THEMES**

No	Theme	Sub-theme
1.	Factors leading to and hindering disclosure of HIV positive status	<p><b>Leading factors:</b></p> <ul style="list-style-type: none"> <li>• Deteriorating health status</li> <li>• Accessing medical care services.</li> <li>• Prevention of Mother to Child Transmission of HIV</li> <li>• Need for emotional and psychological Support,</li> <li>• Benefiting from material supplies</li> <li>• Need for more information about HIV</li> <li>• Promoting HIV /AIDS awareness</li> <li>• To encourage partner to check for HIV Status</li> <li>• To negotiate safer sex</li> </ul> <p><b>Hindering factors:</b></p> <ul style="list-style-type: none"> <li>• Stigma and discrimination</li> <li>• Lack of trust</li> <li>• Denial of HIV positive status</li> <li>• Fear of abandonment or rejection</li> </ul>
2.	<b>The process of Disclosing of HIV status</b>	<ul style="list-style-type: none"> <li>• Method of disclosure, place, and information disclosed</li> <li>• Time taken to disclose</li> <li>• Nature of people disclosed to and rationale</li> </ul>
3.	<b>Experiences of disclosing HIV positive status</b>	<p><b>Positive experience</b></p> <ul style="list-style-type: none"> <li>• Feeling of relief</li> </ul> <p><b>Negative Experiences</b></p> <ul style="list-style-type: none"> <li>• Discrimination and stigmatisation</li> <li>• Receiving unconditional support</li> </ul>
4.	<b>Consequences of HIV positive status disclosure</b>	<p><b>Positive consequences</b></p> <ul style="list-style-type: none"> <li>• Access to health care</li> <li>• Psychosocial support</li> <li>• Living positively with HIV</li> <li>• Safer sex practices</li> </ul> <p><b>Negative consequences</b></p> <ul style="list-style-type: none"> <li>• Stigma</li> <li>• Depression and suicidal ideas</li> </ul>

### **4.3.1 THEME 1: FACTORS LEADING TO AND HINDERING DISCLOSURE OF HIV POSITIVE STATUS**

According to the findings in this study, there are various factors that determine an individuals' decision to disclose their HIV positive status. These factors were divided two subthemes: Leading and hindering factors to HIV positive status disclosure. This section will start by presenting factors that promoted or lead to disclosure of HIV positive and will be followed by those that hindered disclosure amongst the participants as presented below.

#### **4.3.1.1 Sub–Theme 1: Leading factors to HIV positive status disclosure**

Factors leading to disclosing one's HIV positive status include the following:

deteriorating health status, accessing medical care services, Prevention of Mother to Child Transmission of HIV(PMTCT), need for emotional and psychological support, benefiting from material supplies, need for more information about HIV need for more information about HIV promoting HIV /AIDS awareness, to encourage partner to check for HIV status and to negotiate safer sex.

#### **Deteriorating health status and accessing medical care services**

Deteriorating health condition emerged as one of the main sub- themes in this study for participants' decision for having an HIV test and disclosing HIV positive status for most of them. According to conceptual framework disease progression is associated with disclosure. The majority of the participants in this study stated that they decided to go for

HIV testing and disclosed their HIV positive status because of their poor health status. This shows that signs and symptoms of HIV /AIDS was the most common deciding factor for these participants that encouraged them to disclose their HIV positive status they were probably afraid of dying and wanted to access medical treatment. The following were some of the extracts from participants:

*“I became sick now and again, up to the point when I was weak and my hair started changing for the worse, that was the time I decided to have an HIV test, when the results came out positive I decided to disclose my HIV positive status to the health care providers for me to receive treatment” (Participant no. 1).*

*“I told the doctor about my HIV positive status because I wanted him to further examine me and check my immunity level and to give me Antiretroviral drug (ARVs) to improve my deteriorating health condition” (Participant no.7).*

*“I had sexually transmitted infections which were not responding to medications, when I went to the hospital for check up; I was counseled and sent for an HIV test. The results for the test came out positive. I disclosed my HIV positive results to the health provider who was attending to my health problem for better care” (Participant no 9).*

Apart from the deteriorating health status, the participants stated that they also disclosed their status in order to inform those people they trusted for support and reassurance but

also to bring about public awareness of HIV and AIDS in their communities as indicated below:

**Need for emotional and psychological support,**

The findings of this study revealed that almost all participants expressed a high level of anxiety with HIV positive diagnosis. Their anxiety was related to the fear that HIV is a chronic disease that does not have any cure and they were going to die and they also feared a stigma from people who would know their HIV positive status. The need for reassurance and support motivated them to disclose their HIV positive status to other people. Interestingly, it was noted that all participants disclosed their status because they wanted some emotional support from the people they disclosed it to. Most of them indicated that they wanted some psychological support because the HIV diagnosis was devastating to them and therefore needed some reassurance and comfort. The participants expressed the following:

*“I was very anxious, I could not stand keeping the diagnosis from my mother, I wanted her to comfort and reassure me” (Participant no.1).*

*“When I disclosed to my friend he told me not to worry but to be strong” ”  
(Participant no.4).*

*“I had a lot of anxiety after receiving my HIV positive results; I decided to disclose the diagnosis to the health worker who told me not to despair but to accept my condition, I felt comforted by her words” (Participant no.6).*

*“I disclosed to the members of the support group in order to find companionship with those who were already HIV positive and who could understand my problems better as they were also experiencing similar problems with me” (Participant no.1).*

#### **Need for more information about HIV**

The desire to gain more information about HIV and AIDS was also identified in this study as a factor that facilitated disclosure of HIV positive status among participants. They reported that they wanted to learn more about HIV and AIDS for example about medical treatments including ARVs, protective measures and how to live positively with the infection. Some participants explained as follows:

*“I disclosed to my family members because I wanted them to answer some of my worrying questions about HIV and AIDS that I had” (Participant no.5).*

*“I disclosed to the nurse because I wanted her to explain to me more about HIV and AIDS in the following areas: prevention, treatments including ARVs and how I can live healthy and positively with the HIV” (Participant no.10).*

*“I disclosed to one of my friends who was also living with HIV and AIDS because I wanted him to explain to me how he was coping with the infection and the antiretroviral drugs that he was taking” (Participant no.4).*

### **Benefiting from material supplies/donations**

The findings of the study also noted that the majority of participants disclosed their positive status in order to benefit from material supplies that were donated to people living with HIV, by different support groups in the communities. This was possibly related to the fact that all these participants were from low social economic backgrounds, hence needed a material support system for their health.

The participants said this:

*“I am poor and decided to disclose support group so that I can also benefit from food stuff and other material supplies given to HIV positive individuals” (Participant no. 3).*

*“The food that we receive from the support group help us to supplement our diet, but we only receive one in a while, I wish if we were receiving them every month” (Participant no.2).*

## **Promoting HIV /AIDS awareness**

According to the findings of the study all participants wanted to participate in promoting HIV and AIDS awareness to the community on the importance of HIV testing and disclosure. Participants stated that when they accepted their HIV positive status, they decided to publicly disclose their status. This was a striking sub-theme in which participants further explained that they were later not ashamed of their HIV positive status, hence disclosing it openly. They expressed that they viewed their status as part of which they were and wanted other people to follow their example and they said:

*“I disclosed because I wanted people to be aware of HIV transmission, preventive measures, the importance of testing and disclosing HIV positive status for them to access necessary support services and to live positively with the infection” ( Participant no.7).*

*“When I disclosed my HIV positive status to the public, some people were motivated to go for HIV testing after understanding the importance of doing so” (Participant no.10).*

The participants also explained that during HIV and AIDS awareness campaigns by HIV support group members, they learned about the main modes of HIV transmission, including unsafe sex practices, use of contaminated injections and other sharps used by HIV positive individuals as well as mother to child transmission of HIV.

## **Prevention of Mother to Child Transmission of HIV (PMTCT)**

Another theme that emerged from the data was that of participating in PMTCT program. Surprisingly it was found that only one female participant mentioned this as the motivating factor to the disclosure of her HIV positive status. One of the participants narrated that she was pregnant and attended antenatal care where HIV testing was mandatory through provider initiated voluntary counseling and testing in order to recruit HIV positive pregnant women for Prevention of Mother to Child Transmission of HIV program (PMTCT). This female participant explained her reason for the disclosure as follows:

*“when I was pregnant and I went for antenatal care services at a clinic, it was here where the nurse counseled me that I should have an HIV Test so that if am positive I should be given the Antiretroviral drugs to prevent me from passing the HIV virus to my unborn baby. I was sent to the laboratory for the test. When I got my HIV positive results I disclosed them to the midwife who was dealing with me at the antenatal clinic for further management”*

*(Participant no.3).*

This provider initiated voluntary counseling provide an opportunity for HIV positive pregnant women to disclose their HIV status to the health workers in order to access medical care and antiretroviral drugs that prevent the transmission of HIV from mother to the unborn baby during pregnancy, birth and after birth, during breast feeding.

### **To encourage partner to check for HIV Status**

It was noted in this study that risky sexual behaviour was one of the factors that motivated some participants to go for HIV testing and disclosing their positive status. In this study two male participants reported that they went for the HIV test because they considered their sexual behaviours reckless in the past and wanted to know their status before they start presenting signs and symptoms of HIV infection. These participants possibly wanted to be informed of their status and make a decision on their current and future sexual behaviour. They also wanted to assist their partners to go for voluntary counseling and HIV testing to establish their status.

*“I disclosed to my sexual partner so that she can decide whether she wants to go for the HIV testing or not” (Participant no.1).*

*“After I disclosed my HIV positive status, my partner also went for HIV testing where she was also found to be positive” (Participant no. 4).*

### **To negotiate safer sex**

It was also found that some participants disclosed their HIV positive status because they wanted to adopt safer sex behaviour which would prevent re-infection and further HIV transmission among them. They said:

*“After disclosing my status to my sexual partner we decided to use condoms to prevent re-infection” (Participant no.1).*

*“The health provider advised to use the condoms all the time we are having sex after I and my sexual partner tested positive of which we accepted, we also discussed to be faithful to each other to prevent re-infection” (Participant no. 4).*

The study findings discovered that only few participants disclosed their HIV positive status possibly because the majority of participants were single at the time of the study, which could have meant that they were not tied to any marital issues or any serious sexual relationships and therefore; disclosure of their status to sexual partners was presumably of no significance to them. This is however, a high risk group of HIV positive people which could easily transmit the infection to others and should be encouraged to disclose their HIV positive status to their potential sex partners.

Apart from the factors leading to the disclosure of HIV positive status among the participants, the results of the study have also found that there were factors which were hindering disclosure amongst them, as outlined.

#### **4.3.1.2 Sub-Theme 2: Factors Hindering Disclosure of HIV Positive Status**

The findings of the study revealed some factors that were a barrier to the disclosure of HIV positive status which were expressed by the participants. They reported that there were various factors that prevented them from disclosing their HIV positive status to

other people that included: fear of stigma and discrimination, lack of trust, and fear of abandonment by sexual partner.

**Fear of Stigma and discrimination:**

According to the findings in this study, stigma directed at people living with HIV and AIDS not only makes it more difficult for them trying to come to terms with the illness, it also makes it difficult to manage their illness on a personal level. The study findings have revealed that stigma and discrimination were some of the barriers to HIV status disclosure as it was related to negative experiences. The majority of participants, who did not disclose their status to other people, said they did not do so because they were afraid of being stigmatised and discriminated against by some relatives, friends and other people because of their HIV positive status. Participants expressed her fears as follows as follows:

*“I did not disclose because I was afraid I could be labeled and given funny names because of my HIV positive status” (Participant no. 1).*

*“I did not disclose to other people I feared they would stop associating with me because of my HIV positive status” (Participant no. 7).*

*“I have seen how HIV positive people are treated in our community, at first I did no want to disclose because I was afraid people would treat me the same” (Participant no. 2).*

## **Lack of Trust**

The study findings identified that participants tended to disclose to the people they trusted. The findings of the study further, noted that lack of trust was cited as one of the reasons for non disclosure of HIV status by some participants. Two participants explained that they did not disclose their HIV positive status to some family members because they did not trust them in terms of keeping the information confidential. This resulted in the participants keeping the information about their status a secret. A concerned male participant reported his reason for not disclosing to other people:

*“I did not have trust for my mother that is why I did not disclose to her. She does not keep secrets, all her relative and friends would know about my status. I therefore, decided to disclose to someone whom I trusted” (Participant no. 6).*

*“I did not to disclose to any other person because I do not trust them, I was afraid they would break the news to other people” (Participant no. 4).*

Some participants failed to disclose their status due to lack of trust, others stated that they had problems disclosing their status because they were still in denial of their HIV positive diagnosis.

## **Denial of HIV positive status**

Some participants clearly articulated that they were unlikely to disclose their status because they did not want to think about being HIV positive and were in denial about their status. They said they had not yet accepted their diagnosis. The participants expressed themselves as follows:

*“When I got my first HIV positive results I did not accept the diagnosis, I thought the result were wrong and not mine. I did not tell anyone about it, I then went to another clinic after a month to have another HIV test. The results also came out HIV positive. I then decided to disclose” (Participant no 2).*

*“I could not believe my HIV positive diagnosis, I wonder how I got it, I started blaming my late husband for infecting me with virus” (Participant no. 9).*

Denial of HIV positive result could also be related to the fear of negative reactions, like rejection or abandonment from those disclosed to, including sexual partners

## **Fear of abandonment by sexual partner**

The finding of the study showed that the fear of abandonment was one of the hindering factors amongst participants to disclose their HIV status. The fear of abandonment could be attributed to the strong bonds of relationship or the fear of loss of support from the partner. Fear of abandonment was expressed by only one participant. Some participants stated that they did not disclose to their sexual partners because they wanted to maintain

the relationship. They were afraid that if they disclosed, their partners would abandon them. This is what they said:

*“I did not disclose my status to my girlfriend, I was afraid she would terminate the relationship” (Participant no.4).*

*“I feared she would abandon me once she learns of my HIV positive status” (Participant no.6).*

The findings of the study, on factors leading to and hindering disclosure, provide evidence that disclosing ones HIV positive status is a complex process and dependent on various factors that determines an individuals decision, whether to disclose or not disclose his or her HIV positive status to other people. Despite the abovementioned obstacles to disclosure of positive status, all participants mentioned that at some point in time they disclosed their status to someone anyway. The section below will present views of participants regarding the disclosure of HIV positive status.

#### **4.3.2. THEME 2: THE PROCESS OF DISCLOSING HIV POSITIVE STATUS**

The findings of the study established that disclosing HIV status to another person is often difficult, whether disclosing to a sexual partner, a friend, family member, or anyone else.

They said:

*“It took some time for me to gain courage to disclose my HIV positive status to my family members” (Participant no.5).*

*“I felt nervous, confused, I did not know how to start, it was not easy for me to disclose my HIV positive status” (Participant no.4).*

The study also noted that several decisions were made in order to disclose their HIV positive status that included the following sub-themes: the method of disclosing, when to disclose, the right place to disclose and the people to disclose their HIV positive status to. As presented below:

#### **4.3.2.1 Sub-theme 1: Method, Place and Type of Information Disclosed.**

In this section, the method of disclosure, the place where disclosure took place and type of information disclosed will be presented together. Participants in this study were asked how they disclosed their HIV positive status. The findings of this study discovered that two methods of disclosing HIV positive status among participants, these were: direct method where they stated verbally that they were HIV positive. The other method was the indirect one where the participants decided to disclose at the HIV support group, so that if people see them there, they should know that they are HIV positive.

In their responses they explained that, the main method used for disclosing was verbally, through conversation with the people they disclosed to. They all stated that they disclosed specific information about their HIV positive status. They further stated that disclosure was done while in their homes where there was privacy but with familiar space. Some of the participants explained as follows:

*“I told my grandmother verbally that I went for the HIV test because of the frequent illnesses I had been having and that the results were positive, I told her while we were inside our house so that no other person could hear our conversation” (Participant no.4).*

*“I called my mother inside the house and I told her verbally that I have tested HIV positive” (Participant no.2).*

The study findings, however, discovered that the method used by all participants to disclose their HIV positive status was verbal conversation as it was easy and simple for them. Knowledge of a variety of methods of disclosure is important for people to choose the best method that suits their situation.

#### **4.3.2.2 Sub –Theme 2: Nature of People Disclosed To and Rationale**

Deciding whom to tell their HIV positive status was an important consideration that was found in the study for the participants in the process of disclosing their HIV positive status. The study findings further discovered that participants selectively chose to disclose to some people and not others, based on their personal preferences, readiness and rationales. When asked to whom they disclosed their HIV positive status, the participants in the study reported that they disclosed their HIV positive status to people who posed little risk to them like: family members, close friends, health care providers, sexual partners and at a support groups. The majority of the participants however, stated that

they disclosed to their family members including mothers, sisters and grandmother, health provider, followed by close friends, they said:

*“I disclosed to my mother because she is close to me and I stay with her and I wanted to her to know about my status in order to offer me reassurance and other necessary help” ( Participant no.6).*

They further said that their decision to disclose was based on the quality of relationship (accepting versus rejecting) and the perceived ability of those disclosed to, to keep information in confidentiality. They also stated that they disclosed to those who needed to know for medical reasons.

*“After receiving my HIV positive results, I made my status known to any health care provider helping me whenever I went to the hospital for medical review so that I can receive proper care” ( Participant no. 1).*

It was also found in this study that few participants disclosed their HIV positive status to their sexual partners because of the risk of re-infection and wanted to adopt safer sex practices.

*“I disclosed my HIV positive status to my sexual partner so that she can offer me support when I need it, also for her to also have an HIV test and to adopt safer sex by using condoms all the time” (Participant no. 8).*

They further narrated that they disclosed to the people they perceived supportive and accepting and avoided those that did not care. They also indicated that they only told the people that they know will be there for them no matter what. Some of them said:

*“I disclosed to my sexual partner for us to make decision on our sexual and reproductive life for example to practice safer sex and not to have children Participant no.4).*

*“I disclosed to my close friend because I need him to provide me with emotional support for me incase I need help” (Participant no.8).*

This finding of this study has clearly established that these participants had personal reasons on which they based their decision as to who to disclose their HIV positive status. They also decided on the best time to disclose.

The study findings noted that all the participants’ finally made their status known to the HIV support groups; they said the aim of disclosing was to access psychosocial support systems, to relate with fellow HIV positive people, to gain more information on HIV/AIDS and for material gain. One participant said:

*“I disclosed to the members of the HIV support group one month after I had tested hiv positive for me to relate with the members who were also hiv positive and also to gain information on how to live positively with HIV infection but also to access material support” (Participant no.10).*

#### 4.3.2.3 Sub –Theme 3: Time Taken to Disclose

The findings of the study revealed that the time of disclosure varied among the participants with others making it short, while others taking longer to disclose their HIV positive status. All the participants expressed that they disclosed their HIV positive status to someone who was close to them and later to others as well. Time taken to disclose ranged from the same day they received their HIV positive results to some weeks, months and as late as one year with the majority disclosing on the same day and after few weeks of knowing their HIV status. All participants indicated that they at least disclosed to a family members (mother, sister or grandmother), sex partner or their best friends on the same day they received their HIV positive results. They expressed their views as follows:

*“I told my girlfriend about my HIV positive status on the same day I got my HIV positive results” (Participant no.7).*

*“I told my grandmother about my HIV positive diagnosis on the same day I learnt about my status” (Participant no.4).*

*I disclosed my HIV positive status to my family members after some weeks. It took some time for to gain courage to tell them about my status” (Participant no.3).*

It was also noted in the findings of the study that the majority of participants disclosed to health care workers on the same day, with others disclosing after one to two weeks after testing HIV positive. Disclosure to the HIV support groups was the most delayed one, it ranged from two weeks to as late as one year with the majority disclosing after one to three months. Some participants said:

*“At first I did not feel comfortable to disclose my status to many people at the support group but later I joined and disclosed to them after a year after realizing their other HIV positive people were benefiting a lot” (Participant no. 7).*

That findings of the study also found that most female participants disclosed their HIV positive status to their family members on the same day, unlike most of male participants who mainly disclosed to their close friends. Disclosure of HIV positive status by male participants to the closed friends was noted to be done on the same day, but took some weeks and months to disclose to their family members. This shows that male participant felt free to disclose to close friends than to their family member. They said:

*“As soon as I came back from the clinic where I got my HIV positive results, I disclosed to my mother, I did not want to keep this to myself” (Participant no. 2).*

*“I disclosed my status to my close friend that same day I got my HIV positive results” (Participant no. 6).*

## **Summary of process of HIV Positive Status disclosure**

The findings of this study have found that the initial steps of the process of disclosure varied. Some participants required some time to adjust to the diagnosis. Therefore, it took them sometime to disclose. They needed to reach a level of personal acceptance where as other disclose immediately after getting their positive results.

*“I disclosed immediately I came back from the hospital where I received my HIV positive results” (Participant no.2).*

The second step was to decide on the person to disclose to. The criteria were that the person had to pose a low risk. In the context of this study they used mothers, sisters’ grandmother close friends and health care providers.

*“I disclosed to my mother and my sister about my HIV positive status” (Participant no.3).*

The third step was to decide on method of disclosure whether direct or indirect. In this study direct disclosure was the preferred method.

*“I disclosed my HIV positive status verbally” (Participant no.7).*

*“I told them point blank that I was HIV positive” (Participant no.4).*

The fourth step includes: the reactions of persons to whom HIV positive status was disclosed. The reactions varied, they were either accepting or rejecting. One participant said:

*“When I disclosed my family members accepted my HIV positive diagnosis”*  
(Participant no.10).

The last step was learning to live with the reactions of those disclosed to.

*“After I had come to terms with my HIV positive status, I did not care what people said about my status”* (Participant no.2).

The findings of this study have revealed that after the participants have gone through the disclosure process they reported some experiences which they encountered with disclosure of their HIV positive status. These experiences will be present in the next section below:

#### **4.3.3 THEME 3: EXPERIENCES OF HIV POSITIVE STATUS DISCLOSURE**

Despite the encouraging findings of the study, as discussed above, that almost all participants disclosed their HIV positive status to someone, the study findings have further identified that there were varied experiences of HIV positive status disclosure reported by the participants. They expressed that they encountered positive and negative experiences which were emanating from the reactions of their family members, friends, relatives, sex partners, health care providers, support groups and others after they disclosed their HIV positive status to them. They further said that the positive reactions were generally reassuring while the negative ones were demoralising and discouraging.

This section will start by presenting the participants positive experiences to disclosure of their HIV positive status, and will later be followed by negative ones.

#### **4.3.3.1 Sub-Theme 1: Positive Experiences**

##### **Feeling of Relief**

The study findings identified feeling of relief as the major positive experience which resulted after the participants had disclosed their HIV positive status. The study established that all the participants in the study expressed this relief. The participants further explained that they experienced this relief when the people they disclosed to received the news about HIV positive result with positive reactions that included; acceptance, reassurance, and various support systems. The participants also stated that the people who reacted positively after disclosure of HIV positive status was mainly from close family members, close friends, health care workers and HIV support group members. The following were some of the responses from the participants:

*“After I disclosed my HIV positive status to my family members they accepted my diagnosis and reassured me of their help. I felt good, my anxieties and fear that I had about HIV were relieved and was a happy person” (Participant no.6).*

*“I felt relaxed and relieved of the many worries about my HIV status when my sister told me not to worry about the situation in which I was because she promised she will be there to support me when the need arises. She told me this after I disclosed my HIV positive status to her” (Participant no.2).*

*“After disclosing my HIV positive status to my close friends, they reassured me by telling me not to worry or be afraid because I will be given the right treatment since the main health problem was discovered” (Participant no.10).*

### **Receiving Unconditional Support**

According to the findings in this study, some participants received unconditional support, the support which was unrestricted by the people they disclosed their HIV positive status to. This is what some participants expressed:

*“When I disclosed my HIV positive status to a health provider she was positive, reassuring and counseled me on protective measure and how to stay health with HIV, she also provided me with medical support services like medications, information on HIV and AIDS and a supply of condoms. This brought a lot of relief in my life” (Participant no.8).*

*“When I disclosed my HIV positive status to my close friends and family members they told me that they will escort me to the hospital whenever there is a need and that they will be providing me with transport money and other material needs” ( Participant no.4).*

*“After disclosing my HIV positive result to the support group, the members there were welcoming and very supportive. They told me not to worry about my HIV status, they explained how to live positively with the virus. We also prayed together for Gods’ help and at the end we received some maize flour and soya*

*bans. This made me feel relieved and thought that HIV was not the end of the life but a beginning of new life that I have to take on” ( Participant no.2).*

The participants found positive experiences more rewarding than negative ones. The section below will present some negative experiences that were reported by participants in the study.

#### **4.3.3.2 Sub-Theme 2: Negative experiences**

It is worthy to note that, apart from the positive experiences as reported in the above section by the participants, the study findings also discovered that participants had negative experiences with disclosure of their HIV positive status. They stated that the negative reactions from the people they disclosed to lead to negative experiences amongst them. They further described these negative experiences as unpleasant, frustrating and, demoralising. The main sub-theme that emerged from the negative reactions of the people disclosed to was stigma and discrimination, which caused the participants to manifest with shock, denial and anger amongst other things.

#### **Stigma and discrimination**

Most participants reported that before they disclosed their HIV positive status they had fear of being stigmatised or discriminated. They stated that their fears were based on experiences on how HIV positive people are generally stigmatised and discriminated

against by other people in the community. They felt they were not going to be treated equally. They said that this feeling made the majority of them hesitate before disclosing their HIV positive status to other people. While a fear of stigma and discrimination was anticipated by the participants, the findings of the study however, revealed that most participants actually experienced stigmatising and discriminating behaviours from those they disclosed to. Some participant expressed their disappointment they said:

*“I heard them discuss about me in low tones that I suffer from Kawondewonde (a stigmatizing diagnosis for those suffering from HIV/AIDS meaning chronic loss of body weight)” (Participant no.7).*

*“I stopped going to drink beer with my friends. Last time I went there they all left me; they did not want to associate with me because of my HIV positive status” (Participant no.8).*

The study findings provide evident that those who were not close to the participants, were more stigmatising and discriminating than the ones who were closer to them, after they had known the participants HIV positive status. A participant reported this negative and discriminating reaction from friends:

*“My causal friends told me that I was already dead with my HIV and therefore, should not give in suggestions at a community meeting” (Participant no.1)*

Few participants in the study expressed that they avoided experiencing stigma by not participating in social gathering lest people discover their HIV positive status. This is what was said:

*“I avoided places where many people are gathering for a function because I was afraid my friends will discover that I am HIV positive, as such. I also feared they would be saying bad things about me...calling me bad names and pointing at me and saying, see that HIV positive person” (Participant no.6).*

The findings of the study have shown that some participants experienced anger and feeling of guilt after disclosing their HIV positive status. They wondered as to whether those disclosed to were not going to tell their relatives and friends about their status without prior consent. Their anger was related to the fact that, if many people know about their HIV positive status, they would stigmatise them. Some participants said:

*“I felt angry for some days, blaming myself for making my status known to other people which would expose me to stigma” (Participant no.5).*

*“I wish I did not disclose my HIV positive status to them, I feel they will disclose my status to many other people” (Participant no.3).*

Participants stated that the consequences of disclosing their HIV positive status were either positive or negative which will be presented below:

#### **4.3.4 THEME 4: CONSEQUENCES OF HIV DISCLOSURE**

This section will present the consequences of HIV positive status disclosure that participants experienced in this study. Analysis of data revealed a number of negative and positive consequences of disclosing an HIV status to others. The participants reported that they experienced both positive and negative consequences after disclosing their HIV positive status to family members, friends, sex partners, health care workers and HIV support group. The section will start by presenting the positive consequences while the negative consequences will follow later.

##### **4.3.4.1 Sub- Them: 1 Positive consequences of HIV status disclosure**

###### **Psychosocial support**

The results of the study showed that despite the negative experiences that participants had with disclosure of their HIV positive status, most participants however, reported the positive consequences of disclosure of their status which included: accessing psychosocial services from those they had disclosed their status to. The following were some of the responses from the clients when they were asked about the consequences of disclosing their status:

*“After disclosing my HIV positive status, my family member helped me to come to terms with my status through reassurance and for their continued social support” (Participant no.5).*

*“My friends were always there for me and at times they offered me some psychological care when I had worries and was stressed up. This made me cope well with my HIV positive status” (Participant no.7).*

#### **Access to medical care services**

The findings of the study revealed that the majority of the participants had their HIV test secondary to their deteriorating health status and disclosed their HIV positive status to medical care providers in order to access medical care services. The majority of participants expressed the joy of having their HIV test and disclosing their status because they all accessed HIV information, medical treatments including ARVs and free condoms.

*“My health status has greatly improved since I started taking ARVs which they prescribed for me at the hospital with other treatment and free supply of condoms...I feel much better than I was before . . . If I did not disclose my status I would have been dead by now” ( Participant no.9).*

*“The health care provider helped me throughout the Prevention of Mother to Child Transmission of HIV (PMTCT) program and I gave birth to a health child who is free from HIV infection” ( Participant no.3).*

## **Living positively with the HIV**

The study findings showed that HIV support groups in community play a vital role in assisting people to cope with their status, through counseling sessions and material support services offered to people living with HIV. The participants reported that the positive rewards resulting from disclosure of their status to the support groups included: Increased social support and the opportunity to share personal experiences and feelings with others. These made most of the participants accept their HIV positive status and started living positively with HIV infection. They explained as follows:

*“I am not scared of what people say about my status now, I have accepted my HIV positive status, I can disclose it to any one... and I am not worried at all after all I am healthy” (Participant no.10).*

*“At the support group, we share our problems freely and help each other solve these problems; we have spiritual sessions where we dedicate our lives to God trusting that he is with us and will see us through our live. There are health education sessions on HIV that we share at support group. We are also given food stuffs like maize, soya beans, cooking oil and other things to boost our health status.” (Participant no.6).*

The participants describing these consequences often discussed the sense of relief that they experienced by not being rejected, as well as the benefits a positive disclosure

seemed to have on their self- concept and the ability to overcome the stigma associated with being HIV positive and to live positively with the virus

### **Reducing HIV transmission**

From the findings of the study, reducing HIV transmission came out as one of the factors promoting disclosure of HIV positive status among participants. The participants mentioned the following consequences of disclosing their HIV positive status: they gained expanded awareness on measures to decrease transmission of HIV. They participated in HIV counseling sessions, increased opportunities to discuss and implement HIV risk reduction with partners after coming to terms with their HIV diagnosis, increased condoms use and opportunities to plan for the future sexual and reproductive health. They said:

*“Since I was diagnosed with HIV, I discussed with my girlfriend about my status. She accepted my HIV positive status and now we are always using condoms when having sex all the time.” (Participant no.8).*

*“I and my girlfriend started using condoms after I had disclosed to her.... She also went for HIV testing and was found HIV positive.... We were advised to use condoms all the time we are having sex to avoid increasing the number of viruses, we have also planned not to have children” (Participant no.7).*

While the participants in the study appreciated the positive consequences of disclosing their HIV positive results, they also stated that there were negative consequences that they encountered with the disclosure of their HIV positive status, which is presented below:

#### **4.3.4.2 Sub- Theme 2: negative consequences of HIV status disclosure**

The study findings noted that, in spite of the positive consequences of disclosing ones HIV positive status, it was also found that disclosure was accompanied by negative consequences among participants who disclosed their HIV positive status to others. The participant in the study reported that despite the experienced positive consequences of HIV disclosure, they all experienced some forms of negatives consequences after they had disclosed their status to others. The participants mentioned that stigma and discrimination were the most experienced fear of abandonment by sexual partners and threats to personal well-being.

#### **Stigma and Fear of Rejection.**

A highly prominent sub-theme among participants was that of stigma and the fear of rejection. All participants expressed the fear that if they disclosed their HIV-positive status, they would be stigmatised and rejected both on a personal and sexual level by their sexual partners and other people they would disclose their status to. This is what they reported.

*“I did not disclose my status to my girlfriend because I was afraid she would leave me” (Participant no.4).*

Although fear of rejection come out as an anticipated negative consequence of disclosure of HIV positive status from one participant, the study did not identify any theme that

showed that a participant was rejected on the grounds of disclosing his/her HIV positive status.

Participants, who discussed stigma as a negative consequence of disclosure, also suggested that much of the stigma experienced by them was attributed to a lack of empathy and unreasonable fear of HIV positive status on the part of HIV-negative individuals. One participant had this to say:

*“They all left they did not want to eat with me at a funeral, may be they feared I might infect them” (Participant no.10).*

### **Depression and suicidal ideas**

The findings of the study established that stressful life events, like HIV positive status, can increase depressive symptoms. Inability to cope with rising stress and the stigma can also usher in a loss of self-esteem and eventually people can present with suicidal ideas. One participant in the study reported that she was depressed and had ideas of wanting to kill herself after she had disclosed her HIV positive status. She said

*“After I disclosed my HIV positive status, I most of the times felt low and was not interested in anything, I was afraid people will say bad things about me, I preferred to be alone up until I felt like I should kill myself but my family members kept on reassuring me till I accepted my status” (Participant no.9).*

## **4.5 CONCLUSION**

This chapter has presented the findings of the study on exploring the youths' experiences in disclosing their HIV positive status. The findings show that HIV positive status disclosure is a stressful and difficult process for the HIV positive youth. The participants described relief as positive experience while stigma and discrimination as negative experience. The study found that the positive consequences of disclosure included: psychological support, accessing medical care, living positively with HIV, safer sex practices. On the other hand the negative outcomes included: stigma and discriminating, which were discovered to be the major barriers to HIV status disclosure. This chapter concludes by stating that, although disclosure carries with it negative consequences, the benefits of disclosing the HIV positive status outweighs the negative outcomes. As such HIV testing and disclosure should be encouraged.

## **CHAPTER 5: DISCUSSION OF THE MAJOR FINDINGS, RECOMMENDATIONS AND CONCLUSIONS**

### **5.1 INTRODUCTION**

This chapter discusses the findings of the qualitative study, which are in line with the purpose, objectives and the conceptual framework of the study, which was exploring the experiences of HIV positive youth in disclosing their HIV positive status. The major findings that will be discussed are according to the following four major themes that emerged from the findings through the individual in-depth interviews were:

- 1) Factors that lead to and hinder disclosure.
- 2) Disclosure of HIV positive status.
- 3) Experiences of disclosing HIV positive status and
- 4) Consequences of HIV positive status disclosure. Out of the above four themes the major findings of the sub-themes will also be discussed.

Many participants' descriptions of disclosure process reflected weighing the benefits and costs of disclosure similar to that described in Serovich, (2001:4) model of consequences of HIV status disclosure. Many participants however, discussed that there were factors that prompted them either to disclose or not. Their decision to disclose was also based on the anticipated reactions associated with possible positive and negative consequences. Based on this participants selectively choose to disclose to some people and not the others.

This chapter presents a conclusion and recommendations based on the findings of the study, with support from other studies in the area of HIV testing and status disclosure.

## **5.2 FACTORS LEADING TO AND HINDERING DISCLOSURE OF HIV POSITIVE STATUS**

The disclosure of HIV positive status to others is both an event and a process that is not an easy task, considering the stigma and other negative consequences attached to it (UNIADS, 2000:1). This section will discuss the following major findings of the factors that lead to and hindered the disclosure of HIV positive status among the participants.

### **5.2.1 Leading Factors to HIV Positive Status Disclosure**

In the context of this study, the leading factors were those that motivated participants to disclose their HIV positive status. From the analysis of the findings, participants' description of factors promoting disclosure yielded rich data about the decision to, or not to, disclose HIV positive status. The factors described in the study are not uncommon and similar to what has been documented by other research studies within and outside Africa.

The participants cited the following leading factors to HIV positive status disclosure: psychological support and other support services, trust, deteriorating health status, accessing medical care services, Prevention of Mother to Child Transmission of HIV (PMTCT), changing risky sexual behaviour, practicing safer sex, and for HIV/AIDS

awareness. These factors partly concurred with the findings of a study in Pretoria by Mdlalose, (2006:72), in which the frequently reported factors leading to the disclosure of HIV positive status among HIV positive women were to obtain medical care, accessing available support services, and an HIV diagnosis in a child or partner. The findings of a study on Injection Drug Users, in Latino America further agrees with the above findings, where increased social support and intimacy with partners, reaffirmation of one's sense of self, and the opportunity to share personal experiences and feelings with sexual partners and increased utilisation of health care services, were some of the promoting factors to HIV status disclosure (Parsons, VanOra, Missildine, Purcell and Gomez, 2004:459).

#### **Deteriorating Health (Disease Progression) and Accessing Medical Care Services**

According to the conceptual framework there is a relationship between disease progression and disclosure. The findings in this study discovered that deteriorating health conditions was mentioned by the majority of the participants as one of the major factors that facilitated HIV testing and disclosure, for the purpose of knowing their HIV status and accessing medical care services, including antiretroviral therapy.

Many researchers have however, examined the role of disease progression and HIV positive status disclosure as in promoting disclosure, Holt, Verdharma, Nott, Holmes, Snow, (1998:49), Mansergh, Marks and Simon, (1995:639) in their studies found that people who have been living with HIV for a longer period of time and those with increased symptomology are more likely to disclose their HIV status, typically to friends and family, who could serve as a source of support in the face of declining health.

Similarly, a study by Deribe, Woldemichael, Wondafrash, Haile and Amberbir, (2008:7) noted that many HIV-infected individuals delay disclosure until their disease has progressed. This could be due to the fact that as the disease progresses, individuals find that they require emotional or material assistance from family members or others, or it may simply reflect the fact that it becomes difficult to conceal their illness at a late disease stage.

Contrary to these findings in a study by Sowell, et al., (1997:501) symptomatic HIV women were least likely to disclose their HIV positive status to their sexual partners, followed by women with AIDS. Despite medical advances, for most people disease progression is still not a major leading factor for disclosing the HIV positive status, suggesting that disclosure is a difficult event necessitating extensive personal adjustment to the HIV status. However, and interestingly, deteriorating health condition, in this study, was one of the major leading factors to HIV status disclosure. The concept of disease progression is highly reflected in Serovich, (2001:3) model of HIV status disclosure which among other things states that the severity of the disease, the number of infections and the time since diagnosis, can influence one to reveal his/her HIV positive status to sexual partners and significant others.

WHO, (2002:1) concludes that one of the benefits of HIV status disclosure is to access medical health care and other social support services. It is therefore, apparent that people should be advised to seek voluntary counseling and HIV testing and disclosing their positive status, while they are still strong and healthy, rather than having an HIV test when they start manifesting with signs and symptoms of HIV infection. Health education on HIV should place more emphasis on this.

## **Access to Prevention of Mother to Child Transmission (PMTCT) Program**

Accessing PMTCT program was one of the factors leading to disclosure of HIV positive status in this study. Provider initiated voluntary counseling and testing is a current strategy to promote HIV testing and positive status disclosure in health care facilities for patients, including pregnant women attending antenatal care services. Pregnant women who are HIV positive are recruited for Prevention of Mother to Child Transmission of HIV Program in most health care facilities. This program aims at providing information and medical treatments, including antiretroviral drugs, to prevent mother to child transmission of HIV during pregnancy labour and after delivery.

One participant mentioned that she had an HIV test at antenatal care; she disclosed her HIV positive status to health care providers in order to access antiretroviral drugs and other medical care services for prevention of vertical transmission of the virus from her to the unborn baby. In a study by Highleyman (2008:1) the findings showed that the transmission rate of HIV from mother to child fell to 0.8% (40 out of 4864 births) for women who received at least 14 days of antiretroviral therapy, regardless of specific drug regimen or mode of delivery in America. While this study is showing positive and encouraging result there are some barriers to PMTCT program. In line with the findings of this study, a study by Kasaye, Lingerh, Dejene, (2005:127) found that few HIV positive pregnant women in PMTCT program did not disclose their HIV positive test results to their sexual partner for fear of negative reactions. They proposed that men should be involved in PMTCT program so that women are not blamed or isolated when they are found to be HIV positive. A well functioning, appropriate and accessible voluntary counseling and testing (VCT) service is a prerequisite for conducting

successful PMTCT program and services to assist people to make future plans about on safer sex practices and reproductive plans.

### **Accessing Psychosocial and other support services**

According to the findings in this study participants reported that they were motivated to disclose their HIV status because they wanted to access psychosocial and material support services which were offered by family members and support groups in their community mainly in forms of, psychological counseling sessions, reassurance, health education on how to live positively with the virus and being part of the community of people living with HIV, and material gains like food stuffs. These findings concur with those of a study by Hindery, (2004:1) of HIV-positive, heterosexual women from rural Alabama, which showed that support groups helped HIV positive women overcome mental and physical hardships. The support groups can provide help, mutual support and the advice from people who have lived experienced and have coped successfully with the hardships related to HIV and AIDS.

The findings in this study established that participants in the study selectively choose people who were trustworthy and supportive to them, and avoided those that would frustrate them (Serovich, 2001:1). These findings are in line with the results of the study done by , Simoni, Demas, Mason, Drossman and Devis (2000:147) in which they found that HIV positive status disclosure to one's family, friends, and lovers was found to be positively related to social support and the use of more adaptive coping strategies. In another study by (Hindery, 2004:1), in Alabama, on HIV positive women, the findings

showed that HIV support groups helped women overcome mental and physical hardships. Several of support (psychosocial and material) therefore, can form a basis for promoting HIV status disclosure and minimise delays that may lead to deteriorating health condition.

### **Practicing Safer Sex**

Practicing safer sex emerged as one of the reasons for disclosure of HIV status to sexual in this study. WHO, (2004: 1) and the Centre for Disease Control Centre, (2002:1) in their protocols for HIV testing and counseling reported that that HIV testing and disclosing plays a key role in promoting safer sex practices amongst sexual partners. According to the findings of this study, some participants expressed that they disclosed their status to their sexual partners, with the aim of practicing safer sexual behaviours in order to prevent, HIV re-infection they further explained that they adopting safer sex practices by using condoms all the time and being faithful to each other.

Consistent with these findings, a study by Crepaz and Marks, (2003:379) found that HIV positive participants who disclosed their sero-status were more likely to discuss safer sex with their sex partners and had a higher rate of protective sexual behaviour than those who did not. While concurring with the finding from this study, De Rosa and Marks, (1998:224) in their study, discovered that the level of responsibility that participants felt toward their sexual partners, with regard to protecting them from HIV through the use of safer sex practices, had an important impact on their views regarding disclosure and their disclosure behavior. Non disclosure on the other hand may play a central role in promoting HIV transmission.

## **HIV and AIDS Awareness Campaigns**

The findings in this study revealed that some participants disclosed their HIV positive status to make the public aware of HIV and AIDS. Among other HIV activities, the HIV and AIDS awareness campaigns which are conducted by HIV support groups and other clubs in the communities aim at informing the people about the risks of HIV and AIDS, transmission and means of prevention. Their emphasis is mostly on encouraging people to do HIV testing and disclosure. Two participants in the study stated that they were motivated to go for HIV testing and disclosed their status following these campaigns. This helped to bring self awareness about their HIV positive status and how to live with the infection.

At some point in time all participants reported that they made their HIV status known to the support groups and publicly disclosed their status to their communities. According to the findings in this study, participants stated that they wanted to help people in their communities to know the mode of transmissions, prevention measure, HIV testing and disclosure, treatments including ARVS, how to deal with stigma dealing and positive living with HIV infection. In line with these findings, Sandgren, Urazalin, and Andersson, (2007:4) in their study found that due to the HIV awareness campaigns in the community, through mass media and support groups, women were aware of the three main routes of HIV transmission: sexual intercourse without using a condom (89%), sharing needles while injecting drugs (86%) and through mother to child transmissions (68%). These finding therefore, demonstrate the importance of HIV and AIDS awareness

to the community, where people are equipped with information on HIV transmission, prevent, care and mitigating the stigma related to it.

All the participants in this study were from groups. Well supported and functioning HIV support groups, in the community, could be instrumental in dealing with people living with HIV and AIDS. This could be done by providing community awareness on HIV/AIDS through well planned health education activities with active participation of people who are HIV positive and the community at large.

The study also found factors that hindered participants from disclosing their HIV status and the section below will discuss these factors.

### **5.2.2 Factors Hindering HIV Positive Status Disclosure**

#### **Stigma and Discrimination.**

Hindering factors were those factors that made it difficult for participants to disclose their HIV positive status. These factors can affect the successful implementation of HIV prevention and management strategies, as individuals would not be willing to disclose for fear of negative consequences. Some of the major hindering factors cited by participants were stigma and discrimination. According to Serovich and Mosack, (2003:1) people who feel more ashamed about their HIV status are less likely to disclose to casual sexual partners and others. The findings in this study revealed that all participants said that the fear of stigma and discrimination were the most common barriers hindering disclosure of

their HIV positive status. These were manifested through verbal and through actions, by those disclosed to. The study by Petrak, Doyle, Smith, Skinner, and Hedge, (2001:1) agrees with the above findings, which also found that the fear of potential discrimination was often cited as a reason for nondisclosure for injection drug users.

Participants in this study were a mixed group (male and females) and their responses reflected that effects of disclosure affects all irrespective of the gender. Other studies have also shown that stigma has a negative effect on sero status disclosure, particularly among HIV-positive women who fear disclosure to their sex partner for fear of being discriminated against and rejected (Chesney & Smith, (1999); Derlega, Winstead, Greene, Serovich, and Elwood, (2002:1); Van der Straten, Vernon, Knight, Gómez, and Padian, 1998). One other study of sero-positive women also found that fears and concerns about disclosure and stigma were more common than fears of HIV-related death among HIV positive women (Chin and Kroesen, 1999:222). The findings in this study are contrary to the findings from other studies associating negative effects of disclosing mainly with women.

The potential negative consequences that Serovich further described as inhibiting disclosure are extreme anxiety, threats to personal well-being, rejection, abandonment, and isolation. Additionally, Serovich asserted that disclosure is often associated with an undesirable admission of sexual behaviours. Participants were generally unwilling to disclose their HIV because they feared unfavorable consequences. This is possibly the reason why people prefer to keep their HIV status secret. Interventions are therefore,

needed to reduce the AIDS stigma and discrimination, and to assist people with HIV to make effective decisions on disclosure of their HIV positive status for them to access the benefits.

### **Depression and Suicidal Thoughts**

Sharing ones HIV positive diagnosis can provoke anxiety and perceived threats to personal well-being. The participants reported on the potential for self violence and other threats to their personal wellbeing due to high-levels of anxieties, due the negative reactions from those they disclosed to, including stigma. The threat to ones own life was noted in the findings of the study whereby one participant reported that she planned to commit suicide after knowing and disclosing her HIV positive status. In a study by Ross, Sawatphanit, Draucker and Suwansujarid, (2007:1) on the lived experiences of HIV-positive, pregnant women in Thailand, the findings showed that suicidal ideas were common among sero-positive women.

In another study on experiences of HIV disclosure, some women reported verbal and physical abuse from their partners (WHO, 2004:11) which led to depressive behaviours among them. The study by Parsons, VanOra, Missildine, Purcell, and Gómez. (2004:458) also found out that one participant reported witnessing a scene in which an HIV-positive woman was committing suicide after learning of her HIV positive status. In the study, although participants reported fear of threats, none of them experienced any threatening behaviour from those they disclosed to. Their fears were probably based on their previous

experiences of how HIV positive individuals were treated after they had disclosed their status.

There are many factors that can hinder disclosure of positive status among people who test HIV positive, as evidenced in this study and other studies elsewhere. It should be noted that the rewards of disclosing are multiple and can result in acquisition of numerous resources and support systems. It is therefore, apparent that HIV positive individuals should be given information and support for them to make informed decisions on HIV testing and disclosure. The psychological reactions by HIV positive individuals depends on the availability of psychosocial support systems and the individuals patterns of coping with the major stresses. These factors should therefore be taken into consideration by those offering pre and post test counseling in order to limit such negative consequences by HIV positive.

The decision to disclose HIV positive status is dependent on the individuals choice as how to disclose, who to disclose to, when to, what to and where to disclose. The section below discusses participants' process of disclosing their HIV positive status.

### **5.3 THE PROCESS OF DISCLOSING HIV POSITIVE STATUS**

#### **Method of Disclosing HIV Positive Status.**

The findings in this study showed that direct disclosure was the commonly used method for disclosing HIV positive status. In this study, all the participants indicated that the common method they used to disclose their HIV positive status used verbal method to tell

their HIV positive status. They expressed that this was the easiest and simpler method they could have used. This could partly be attributed to their lower levels of education and that of the people they were disclosing to, where writing and reading skills were probably limited.

The findings in this study concurs with findings of a study done by , Serovich, (2006:1) on 'how to tell HIV positive status which found that men who were HIV positive used direct and indirect method to disclose their HIV positive status to their potential sex partners. The direct included: disclosing either verbally or in writing, while in the indirect method they used of symbolic hints, such as leaving HIV-related brochures or other materials in plain sight; or insisting on condom usage, using a third party to assist with disclosure their status. Serovich, (2002:2) revealed that HIV positive individuals choose the method that best suits them and the situation in which they are to disclose their status. Efforts to find studies which found the best method for disclosing HIV positive status did not yield any results. Research studies should therefore, be done to assess the best possible method of disclosing HIV positive status.

### **The nature of People Disclosed and Rationale**

In this study participants reported that they disclosed to people who pose less risk, such as: family members, especially mothers and sisters, close friends, sexual partners, health care providers and support groups. For these participants, disclosure was reported a difficult issue supporting the need for adequate and practical health education and counseling on how to disclose HIV positive status. The findings in this study are in line with the findings in Bairans, (2007:7) study on rate of disclosure, which showed that

disclosure was related to social relations which were categorised as sexual and nonsexual with varying degrees of HIV disclosure depending on the social relationship with the person to whom one did or did not disclose.

For people who are HIV positive, disclosing the HIV positive status could be a stressful event. While people may receive love and support from the people they tell, others may not be as accepting. HIV positive people decide to tell those that will support them throughout this difficult time of telling (Serovich, 2001:4). The decisions about who to tell and who not to, are generally individualistic (Kimberly, Julianne, Serovich and Greene, 1995:1.).

The majority of the female participants in this study mentioned that they disclosed to their mothers and sisters and these findings were consistent with the results of the study by Manson, (1995:1) cited in Serovich, (2000:2) which found that the family members likely to learn of an HIV positive diagnosis were mothers and sisters, while fathers were the least. In the current study, surprisingly, none of the participant reported disclosing to their father. Contrary to these results, Marks et al, (1998:224) in a sample of HIV-positive Latino men living in Los Angeles, found that disclosure of HIV positive status had occurred more frequently to male and female close friends (58% and 43%) than to mothers (24%).

Further analysis of the findings revealed that male participants preferred to disclose to close friends, unlike females who confided in their close family members. These findings collate with the findings of the study by Sowell, Seals, Phillips and Julious, (2003:32)

where HIV positive women reported disclosing to family members and friends selectively, based on who could handle the news positively. The results of study by Sowell et al, (2003:32) further states that participants disclosed to sexual partners because of the risk of infection, this concurs with the findings of this study, where some participants indicated that they disclosed their status because they wanted to practice safer sex behaviors to prevent further HIV transmission.

Disclosure to health care providers was related to accessing information and medical care services including treatment. This was also evident from the report by most of the participants in the study that they decided to go for HIV testing due to their deteriorating health condition, and that they disclosed their HIV positive status to access medical care, including antiretroviral drugs. Consistent with these findings, in the same study by Sowell, Seals, Phillips, and Julious, (2003:32) it was found that the majority of their participants had disclosed their status to health care providers for medical care.

In another study by Sowell et. al, (2002:181), they found that pregnant women, who disclosed their HIV status to health care providers, were recruited for Prevention of Mother to Child Transmission of HIV programme where the mother accessed information, medical services including course of antiretroviral drugs. People who were perceived by participants as close, supportive and accepting were disclosed to selectively, while casual friends were less likely to be informed of the status. From this study, individuals with HIV appear to disclose their status to significant others more frequently than non significant others.

All participants also indicated that they, at some point in time, disclosed their status to the support groups in their communities. They explained that although they disclosed late at the support groups, the support and services they got were worth appreciating, the relationships with fellow HIV positive individual was quite reassuring and supportive. This was coupled with the information and material services they accessed. They even expressed that they will encourage other HIV positive people to disclose their positive status early to support groups in order to get full benefits.

In a study by De Rosa and Marks, (1998:224) found that higher rates of HIV positive disclosure were reported by persons who attended support groups due to the psychosocial benefits they were exposed to. Well organised and functioning support groups would be instrumental in promoting HIV prevention, mitigation of the stigma related with HIV and care. Disclosure to different people was done at varied times, depending on participants' consideration and readiness.

### **Time Taken to Disclose the HIV Positive Status**

Although there was generally no defined right time when one should disclose his or her HIV positive status, HIV positive individuals in this particular study chose to disclose when they felt ready or when they were medically and legally required to do so. Some people take a short time while others take a long time to disclose their HIV positive status after the diagnosis. It is however of concern when disclosure is delayed for a long time,

as there could be high probability of HIV transmission and deteriorating health status during that time. It is advisable therefore, that disclosure should be timely for infected people to access the right services at the right time.

On average, the majority of participants stated that they disclosed their HIV positive status the very same day they got their HIV positive results. The majority disclosed their HIV positive status on the same day. For those who disclosed on the same day, they either disclosed to their mothers, sister, close friends or health care provider. These findings correlate with the results of a qualitative study on disclosure of HIV status by Bor, Plessis and Russel, (2004:167) which showed that people living with HIV disclosed their status immediately after they received their HIV positive results. This study further suggests that various aspects of social support, physical health and psychological wellbeing were positively associated with early disclosure (Bor, Plessis and Russel, 2004:167).

Some participants took a few weeks and some months to disclose to family members, close friends and health providers. Disclosure to the support group took the longest time, with the majority disclosing after one to six months. With one outlier who disclosed his HIV positive status to the support group after a year. In a study by Keogh, (1998:1043) on the social impact of HIV infection on women in Kigali, the period of time that lapsed between diagnosis and disclosure ranged from two months to 13 years.

These findings show that the time for disclosing the HIV status varies with individuals, depending on readiness, preparedness, the reasons for disclosing, anticipated reactions, the nature of relationship and their belief values. The reasons for late disclosure should be considered serious because during this time the people may continue with risky behaviour that will promote transmission of HIV and even delay their access to information and health services as well as other social support services which other HIV positive people are benefiting from. The delay in disclosure may even aggravate their stresses related to the diagnosis, according to the study by Kassaye et al, (2005:129) on the outcome of women who disclosed their HIV positive status, 51.7% received kindness, acceptance and experienced psychological relief unlike those who did not.

### **Summary of disclosure process**

The findings of this study have found that the initial steps of the process of disclosure varied. Some participants required some time to adjust to the diagnosis. Therefore, it took them some time to disclose. They needed to reach a level of personal acceptance whereas others disclosed immediately after getting their positive results. The second step was to decide on the person to disclose to. The criteria were that the person had to pose a low risk. In the context of this study they used mothers, sisters, grandmothers, close friends and health care providers.

The third step was to decide on method of disclosure whether direct or indirect. In this study direct disclosure was the preferred method. The fourth step included the reactions of

persons to who HIV positive status was disclosed. The reactions varied, they were either accepting or rejecting. The last step was learning to live with the reactions of those disclosed to. According to (WHO, 2004:4) the process of HIV disclosure that relates to this study includes: the follows steps: Adjustment to the diagnosis where individuals may need help adjusting to their diagnosis and reaching personal level of acceptance. The other steps involve evaluating the appropriateness of disclosing to potential recipient. This involves decisions on individual basis who should be told taking into account certain criteria such as role. Anticipating the reactions of potential recipients where individuals weigh the anticipated reaction against the anticipated benefits.

### **Reasons for Disclosing HIV Positive Status**

The most prevalent reasons for participants' disclosure of their HIV positive status was the need for expressive support and reassurance. They also stated that they disclosed in order to acquire some instrumental support in form of social support services, medical care and information about HIV and AIDS. Consistent with these findings, a study by Sowell, Seals, Phillips, and Julious, (2003: 32) reported that the majority of their participants had disclosed to health care providers for medical reasons. These findings appear to put health care providers on more of "need to know basis".

Another source of motivation to disclose in this study was a sense of obligation and responsibility to tell their family members, close friends and sex partners about their status. One participant stated that she got a lot of support from her mother and therefore

found it proper to disclose to her, out of a sense of duty. While the other participant wanted to protect her sex partner from the infection by adopting safer sex behaviors, in a study by Parsons et al, (2004:469) on consequences of disclosure, some participants asserted that they owned the responsibility for ensuring safer sexual behaviours.

At this point, people living with HIV need to be assisted to identify persons, organisations best suited for meeting their instrumental and expressed needs. For example, youth may need to identify persons whom they might rely on for emotional social support and for their physical health. This process can help youth in clarifying what they hope to attain from disclosure. It is evident from these studies that for most people facing HIV illness, the family is regarded as the primary source of support. However, access to support services normally requires disclosure of one's health problem to others (Bor, Plessis and Russel, 2004:167).

During voluntary counseling and testing, disclosure is emphasised as one of the major components of HIV prevention and as an entry point to accessing medical and psychosocial support services for people living with HIV (SAFAIDS, 2003:1). Health care professionals therefore, are placed in a unique situation to provide adequate information, health care services and support to assist HIV positive individuals in their decision to have HIV tests and disclose their HIV positive status. The health practitioner should therefore, have greater knowledge of what factors and situations tend to influence disclosure and non disclosure of one's HIV positive status and should develop strategies

to promote disclosure, utilizing Serovich's model of HIV disclosure, which is based on the factors that lead to and hinder disclosure.

#### **5.4 EXPERIENCES OF HIV POSITIVE STATUS DISCLOSURE**

##### **Positive and Negative experiences**

As noted earlier, the decision to disclose is selective and consists of several steps including, among other things, evaluating the recipients' circumstances, anticipating the recipient's reaction and having the motivation to disclose.

This section will discuss the experiences of HIV participants after they disclosed their HIV positive status to family members, friends, health care workers and others. Analysis of data found that the experiences reported by participants were determined by a variety of reactions of the people they disclosed to. The participants reported both positive and negative experiences emanating from favourable and unfavourable reactions from the people who were disclosed to. These reactions were possibly based on how the recipient of the information and the participant perceived HIV, sympathy, their level of understanding of its transmission and its devastating nature of illness, and possibly fear of unknown.

The participants decided to tell people who they anticipated would be understanding and offer them assurance and support and they avoided those that would disappoint them by rejecting and discriminating them. An example of this was reported by one participant who did not want to tell her mother of her HIV positive status for fear of negative

reactions. In the study disclosure of HIV positive status by participants was received with mixed reactions. There were both positive and negative reactions reported by participants after disclosure was made to family members, friends, sexual partners, health care workers and HIV support groups. Participants stated they experienced relief from positive reactions which were reassuring and supportive, while negative experienced were stigmatising and demoralising.

These findings are in agreement with those of a study by Bor du Plessis, and Russell, (2004:167) where a range of initial reactions to disclosure were recorded among family members to the HIV disclosure event which found that thirteen (33%) of the forty family members described themselves as 'shocked' by the disclosure, seven (18%) described 'sadness' and four (10%) said that they were 'not surprised'. A further eight family members went on to describe various additional reactions to the disclosure. These included: 'devastation' 'fear', 'confusion' due to a lack of HIV knowledge; 'disappointment' due to the perceived shortened life. Contrary to these negative reactions, a study by Parsons et. al, (2004:460) found that disclosure was not responded to negatively, but allowed HIV positive individuals to develop a deeper and more intimate connection with their sexual partner.

The study has established that whether participants encounter positive or negative experiences, disclosure of HIV positive status carries with it its own consequences. The section below will discuss these consequences.

## **5.5 CONSEQUENCES OF HIV DISCLOSURE**

### **Positive and Negative consequences of HIV positive Status disclosure**

According to Bor du Plessisb, and Russell, (2004:167) disclosure of HIV positive status is in most case accompanied by both positive and negative consequences because of different perceptions of HIV infections by people in the community. The negative as well as positive consequences of disclosure emerged as sub-themes in this study. The participants reported that they experienced the following positive consequences after disclosing their HIV positive status: social support, reduced levels of their stresses and anxieties, accessing health care services, positive living with HIV infection and practicing safer sex using condoms consistently. Research has shown that positive consequences result from HIV status disclosure to friends and family members, for example disclosure resulted in increased social support and an increased utilisation of health care services as reported in the study done by Simoni, Mason and Marks, (1997:589).

According to a study by Kalichman & Nachmson, (1999: 281) Sero-status disclosure to sexual partners is critical because it facilitates the involvement of both parties in the sexual decision-making process. They further explain that HIV positive individuals who had not disclosed to their sexual partners had shown increased emotional distress. Serovich, (2001:4) also agrees with the findings and states that disclosure can increase self worth and provide emotional release after revealing information which requires

substantial effort to conceal. She further adds that these benefits have the potential to safeguard oneself from the negative risks of disclosing (Serovich, 2001: 4).

While the entire participant appreciated the positive consequences of disclosing their HIV positive status, they inversely stated they also experienced negative consequences after disclosing their status. Among those participants describing potential negative consequences, many expressed that disclosure lead to stigmatisation and discrimination.

The role of stigma and discrimination is an important consideration in the consequences of HIV positive status disclosure. According to Serovich and Mosack, (2003:70), people who are ashamed of their HIV status are less likely to disclose their status. In another study of seropositive women it was found that fears and concerns about disclosure and stigma were more common than fears of HIV related death (Gray, 1999:39). This concurs with the findings of the study where all participants stated that they experienced stigma after disclosing their status. Only two clients mentioned that they were afraid of death from HIV infection, which emphasises the fact that fear of death was not considered a major barrier to disclosure, but stigma.

In most studies, from both developing and developed settings, HIV positive status disclosure to sexual partner was associated with positive outcomes including increase social support acceptance, kindness, decreased anxiety, and depression and strengthening of relationships and practicing safer sex (Serovich, 2006:2).

That findings in this study revealed that while there are many barriers to HIV disclosure, there are also benefits that have both short and long term impacts on people living with

HIV. In line with the findings in this study, Azondekon, (2005:1) revealed that disclosure can help to create a sense of closeness in the family relations, help to reduce the feeling of anxiety, build social support networks, and relieve the burden of living with the secrecy of being HIV positive. Research has further shown that people who anticipate negative consequences from revealing their positive serostatus are less likely to do so (Mansergh, Marks, and Simoni, 1995:1). Similarly Serovich, (2001:4) states that people are not likely to disclose when the costs seem particularly severe and likely to outweigh the potential benefits. The support provided to people living with HIV seems to allay some of the negative consequences associated with disclosure. Disclosure of HIV positive status can therefore help build one's confidence about living with HIV and the stigma and rejection that can come with it. These findings provide further support for Serovich's, (2001:4) claim that people selectively disclose in situations that offer an opportunity for rewards and little risk of harm (or negative consequences).

## **5.6 CONCLUSION**

The findings reported for this study, though based on a small sample of HIV positive youth, have accomplished the purpose of the study, which was to explore the experiences of youth in disclosing their HIV positive status in Lilongwe, Malawi. The study has found that HIV positive youth, both male and females, who participated in the study, had positive and negative experience with the disclosure of their HIV positive status. Their experiences with the disclosure of their status were basically influenced by the reactions of those disclosed to, which were either positive or negative. The positive reaction led to

positive consequences amongst participants that included psychosocial support, medical care and material while stigmatising and discrimination were the most experienced negative consequences of HIV positive status disclosure. Despite the negative consequences of disclosure, it was apparent that the benefits of disclosing HIV positive status outweighed the negative outcomes.

Despite some limitations related to the small sample size and the data collection process, this study offers insightful findings on the experiences of HIV positive status disclosure. This therefore, provides a platform for understanding factors that promote and hinder disclosure among youth and paves a way for planning strategies and interventions that would promote disclosure and deal with those that are a barrier amongst HIV positive youths.

The major findings of this study on disclosure of HIV positive status among infected youth have covered all the major concepts within the conceptual framework of consequences of HIV status disclosure. This model offers some rewards and benefits that assist to promote disclosure among HIV infected youth. The research on HIV disclosure is underexplored among youth living with HIV, especially in Malawi and other African countries. Health care professionals and researchers need to continue to actively pursue measures that would facilitates HIV disclosure to sex partners and significant others. Disclosure of HIV positive status have a variety of benefits such as the potential to provide informed choice, improve well-being of individuals infected and protect life, promote access and adherence to ARVs.

## **5.7 RECOMMENDATIONS**

The recommendations for this study have been drawn from the findings of this study and from other studies which were utilised in the presentation and discussions of the research findings. The proposed recommendations will partly address the proposed significance of the study that aims at bridging the identified gaps and suggested research areas that would promote testing and disclosure of HIV positive status among youth.

### **Ministry of Health and other and other stakeholders**

- There is a need to develop policies and programs that will actively mitigate the stigma associated with HIV testing and disclosure.
- Need for identification and development of appropriate support systems for HIV positive youth post disclosure of their status. For example, strengthening support groups or ongoing counseling. This may help infected youth to overcome barriers to HIV disclosure.

### **Health delivery centers for Voluntary Counseling and Testing**

- Development of a model of HIV disclosure, and strategies with reference to the identified factors that hinder or promote disclosure among youth. The developed strategies to be used by Counselors in all (VCT) Centers in various Health facilities and education institutions in the country to intensifying the health education messages.

- Development of guidelines in relation to a variety of methods of disclosing HIV positive status for youth and other people living with HIV.
- There is need to make HIV testing and disclosure more widely available and more public.

#### **National AIDS Commission -Malawi**

- To continue supporting and strengthening child and youth HIV / AIDS services in the country through sound funding of the programs, initiatives and research activities.

#### **National Youth Council**

- Organisations working with youth and adolescents should apply the Support Group initiative to have more effective and sustainable results in promoting HIV testing and disclosure among youth in the country.

#### **Ministry of Education**

The education sector to incorporate HIV/AIDS information in the curriculum and emphasis on HIV/AIDS education both in primary, secondary and tertiary school where the majority of youth are found.

## **Community Education**

Community based health education programs are needed to mitigate the stigma associated with HIV and consequently promote disclosure and positive living among HIV infected youth.

## **Further research**

There is need to support research activities on HIV testing and disclosure for example on:

- The researcher would like to pursue this study to further explore the possible interventions for promoting disclosure of HIV positive status among infected youth.
- How individuals weigh the negative and positive consequences of HIV sero-positive status disclosure.
- Factors associated with negative outcomes of disclosure in order to develop better screening tools for counselors.
- Exploring best methods of disclosing HIV positive status.

## **5.8 LIMITATIONS OF THE STUDY**

The findings in this report are subject to some limitations, which may limit generalisation of the findings.

- The study was qualitative and comprised a small sample therefore; these findings may not be generalisable.
- The findings may be biased since all participants belonged to some HIV support groups which might have an influence on the nature of the responses and views they expressed during the study. However, these participants were easier to locate and interview.

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**Appendix 1: Individual In-depth interview questions to guide the researcher in sections A and B**

**Title of the Study: Youth's experiences in disclosing their HIV positive status in Malawi.**

Participant Number: .....

Date : .....

Name of interviewer: .....

**Section A: Social Demographic Data**

- Please tell me about yourself

**[Probes: Ages, marital status, residence, educational level, religion, and employment]**

**Section B: Individual in-depth interview questions on disclosure of HIV positive status.**

- What were your experiences in disclosing your HIV positive status?

**[The following probes and prompts were used to solicit more views from the participants on disclosure of HIV positive status:**

Please tell me, what made you to disclose your HIV positive status; explain to me how you disclosed your HIV positive status; how did you feel before, during and after you had disclosed your HIV positive status? How long after knowing your HIV positive status did you take to disclose? What were the reactions of those you disclosed to?

- Is there anything you would like to tell or ask me in relation to the interviews?

**Thank you very for sharing with me this information**

## Appendix 2: Individual In-depth interview questions- Chichewa Version

### MUTU WAKAFUKUFUKU

(Interview Guide translated in Chichewa)

*Kafukufuku wamaganizo a uchinyamata amene anapezeka ndi kachilombo koyambitsa matenda a Edzi ka HIV pa maganizo owulula zakupezeka ndi kachilomboka ku Lilingwe, Malawi.*

Nambala ya otenga nawo mbali mukafukufuku.....

Tsiku la kafukufuku.....

Dzina la wofunsa mafunso.....

Gawo Loyamba: Kudziwa za wotenga mbali mukafukufuku

Fufuzani za zaka zakubadwa, za batja, kumene amakhala, zamaphunzilo, zachipembedzo komanso zamtchilo yomwe anagwirira

**Gawo Lachiwili: Zokambilana pakati pa anthu awiri mozama**

1. Chonde tandifotokuzeleni mwatsatanetsatane chomwe chimpanjitsa kuti inuyo muulule zoti munapezeka ndi kachilombo koyambitsa matenda Edzi ka HIV.
2. Chonde tandiuzani momwe madaululira za kupazeka ndi kachilombo koyambitsa matenda a Edzi ka HIV.
3. Chonde tandiuzani momwe munamvera musaulule, mukulula ndiponso mutaulula za kupazeka ndi kachilomboka.
4. Chonde tandinikirani, kuti panatenga mhawu yayitali bwanjil inuyo mutapezeka ndi kachilomboka ndikuti muululile wina za nkhosya.
5. Chonde tandiuzani mwatsatanetsatane za zomwe anthu amene munawaululira zoti munapezeka ndi kachilomboka anachita atamva za tikhosya.
6. Kodi mukaganiza kuti ndizintho zake ziti zimene zimalephereka kuti anthu anene kuti apazeka ndi HIV?
7. Kodi ndi ubwino wanji umene makuwawona mukaulula kuti mali ndi HIV?
8. Kodi anthu akuganiza kuti pali ubwino wanji kuti kapena kusaulula kuti ndi HIV?
9. Kodi ndi chimbikitsa chanji chimenemungafuze kuti anthu zikulula kuti apazeka, kapena kanansa poyala kuti si ndi HIV?
10. Kodi pali zina zoonjezera pazomwe takambiranazi?

**Zikomo kwambiri chifukwa chakumatsuka kwano ndikuziperka kuti titha kukambirana nanu. Amuye akudalitseni**

### **Appendix 3: Information Document for Participants**

#### **Study Title: Youth's experiences in disclosing their HIV positive status in Malawi**

Dear Participants

My name is Mercy Chirwa; I am a Registered nurse/midwife carrying out a research on Experiences of Youth on Disclosure of their HIV Positive Status in Lilongwe District, Malawi. The study would like to explore the experiences of youth in disclosing their HIV positive status. The findings will help to promote disclosure among youth which will eventually reduce transmission, help HIV positive youth access medical and social support and encourage positive living with HIV. Initially 10 Participants in total will be required, but the exact number will be decided by data saturation. I am therefore inviting you to participate in the research study.

Each in-depth interview will take 60 to 90 minutes. It is estimated that the study will take conducted for two weeks. Information will be sought from HIV positive youth on views, opinions and experiences regarding disclosure of their HIV positive status. The study will be conducted both in urban and rural areas of Lilongwe District (Likuni and Nambuma respectively). Interviews will be conducted in private room. I would like to ask for your permission to tape record the in-depth interviews. The tape will be destroyed after data transcription.

No harm will occur to you as a participant. However, should one of you feel emotionally distressed or uncomfortable, please feel free to inform the researcher or and counseling session will be done by the researcher herself to avoid unintended disclosure of their HIV status to others. Participation is voluntary and you may wish to withdraw from the study if you want. This will not affect the support you are getting from Malawi Net for people living with HIV (MANET). You will not be penalized for not participating in the study.



## Appendix 4: Information Document for Participants Chichewa Version

### Information document for Participant Translated in Chichewa

Dongosolo La kafukufuku Lomwe Otenga Mbali Ayenera Kudziwa Nthitoyi Yisanayambe.

**Mutu wa Kafukufuku: *Maganizo a achinyamata amene anapezeka ndi kachilombo koyambitsa matenda a Edzi ku HIV pa maganizo owulula zakupezeka ndi kachilombo ka ku Lilongwe, Malawi.***

Okondeka Achinyamata wofuna kutenga nawo mbali pa kafukufukuyi lne dzira langa ndine Mercy Chirwa, ndine nam wibe kut anso mzanba. Ndikufuna kupanga kafukufukuyi pofuna kudziwa maganizo a chinyamata omwe anapezeka ndikachilombo koyambitsa Edzi ku Lilongwe m'dziko la Malawi. Cholinga chakafukufukuyi ndikufuna kumva maganizo a a chinyamata pa nkhani yowulula zoti anapezeka ndi kachilombo koyambitsa matenda a Edzi ka HIV.

Maganizo omwe ataperekedwe mu kafukufukuyu adzathandiza kulimbikitsa a chinyamata kuti adzitha kuulula akapezeka ndi kachilomboka, zimenezi zidzathandize kuchepetsa kufalitsa matenda ameneza. Maganizowo azathandizanso akubakuti a zaumoyo kupanga malamulo othandiza anthu amene ali ndikachilomboka kuti adzitha kupiza chithandizo chazaumoyo komanso chisamalire kuchokera m'madera amene akukhala.

Nfundozi zidzathandizanso anthu amene ali ndikachilomboka kuvomeleza zoti ali ndi vutoli komanso kukhala ndi vutoli popanda nkawa zilizonse.

Foyambilira pa kafukufukuyu padzatunika anthu khumi omwe akufuna kutenga nawo mbali komanso nambala yeniyeni yizadziwika pamapeto, mwina anthu ena azidzawonjezekela pamene kafukufuku ali m'kati ndi cholinga choti tipeze njunjo zomwe ana sanathe kudziwitsala.

Kafukufukuyu adzakhala wokambirana pakati pa mwini kafukufuku ndi ena onse wotenga nawo mbali. Kukambiranaku kudzakhala kozama kuti mwini kafukufukuyi amvetsetse za maganizo osiyanasiyana pankhaniyi. Kukambilanaku kudzakhala mu chilankhulo cha chichewa ndipo kudzatenga nthawi yapakati pa ola limodzi ndi theka. Kukambiranaku kudzikachitikila m'malo a chinsinsi. Kafukufukuyi adzafuna kuti ndijambule mumatepi pa wayilesi, choncho ndidzapempha chiloledzo kuchokera kwa otenga nawo mbali kuti nditero. Matepiwo ndizawawononga ntchito yake yikadzatha. Malo a kafukufukuyi ndi ku Likuni komanso ku Nambuma.

Kafukufukuyi alibe zoopsya zili zones kwa otenga nawo mbali. Koma ngati ena atakuzakhudzidwa ndizokambilanazo, mwini kafukufuku adzathandizana nawo. Ofuna kutenga nawo mbali ndi omwe afuna kutero mosaumilidwa ndi wina aliyense ndipo ndiwomasuka kusiya ntchitoyi, akafuna kutero. Akasiya sikuti adzalandila chibalo chirichonse ayi, adzapitilizabe kulandila chithandizo chomwe iwo amalandila ngati membala wa HIV support group wa MANET.

Chinsinsi mu kafukufukuyu chidzasungidwa posatchula maina enieni a omwe akutenga nawo mbali. Manambala kapena mayina oselewula okha ndiwomwe atadzagwilitsidwe ntchito. Mukatenga nawo mbali pa mukafukufukuyi muzathandiza mwini kafukufuku kuti adziwe za maganizo a achinyamata omwe ali ndi kachilombo koyambitsa Edzi ka HIV ponena poyera kuti anapezeka ndi kachilomboka. Ngati muli ndimafunso mukhoza kumuyimbira lamya mwini kafukufukuyi pa nambala iyi; 0731637891 kapena kumulemba kalata pa email address iyi: [mercychirwa@yahoo.com](mailto:mercychirwa@yahoo.com). Ngati mwini kafukufukuyi sanakuthandizeni mokwanila mukhoza kuyimbila a Research Committee pa nambala iyi 031 260 606.

Zikomo



## Appendix 6

### University of KwaZulu-Natal Research and Ethics Committee Clearance



RESEARCH OFFICE (GOVAN MBEKI CENTRE)  
WESTVILLE CAMPUS  
TELEPHONE NO.: 031 - 2633587  
EMAIL: ximibap@ukzn.ac.za

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10 MARCH 2008

MRS. MD CHIRWA (207512616)  
SCHOOL OF NURSING

Dear Mrs. Chirwa

**ETHICAL CLEARANCE APPROVAL NUMBER: HSS/0718/07M**

I wish to confirm that ethical clearance has been granted for the following project:

**"Youth's experiences in disclosing their HIV positive status in Malawi"**

PLEASE NOTE: Research data should be securely stored in the school/department for a period of 5 years

Yours faithfully

  
.....  
MS. PHUMELELE XIMBA

cc. Supervisor (Mrs. S Majeka)  
cc. Mr. S Reddy

Appendix 7

Malawi College of Medicine Research and Ethics Committee Permission Letter



UNIVERSITY OF MALAWI

Principal  
Prof. R.L. Broadhead, MBBS, FRCP, FRCPCH, DCH

Our Ref.:  
Your Ref.: P.12/07/601

College of Medicine  
Private Bag 360  
Chichiri  
Blantyre 3  
Malawi  
Telephone: 677 245  
677 291  
Fax: 674 700  
Telex: 43744

21<sup>st</sup> January, 2008

Mrs M.D. Chirwa  
C/o KCN Bt Campus  
P O Box 415  
Blantyre

Dear Mrs Chirwa,

P.12/07/601 – Youth's experience in disclosing their HIV positive status in Malawi.

I write to inform you that COMREC reviewed your proposal mentioned above which you submitted. I am pleased to inform you that your proposal was approved.

As you proceed with the implementation of your study we would like you to take note that all requirements by the college are followed as indicated on the attached page.

Sincerely,

A handwritten signature in black ink, appearing to be 'E. Borgstein'.

Prof. E. Borgstein  
CHAIRMAN - COMREC

Appendix 8

Lilongwe District Health Office Permission Letter from

December 1<sup>st</sup>, 2007


TO WHOM IT MAY CONCERN

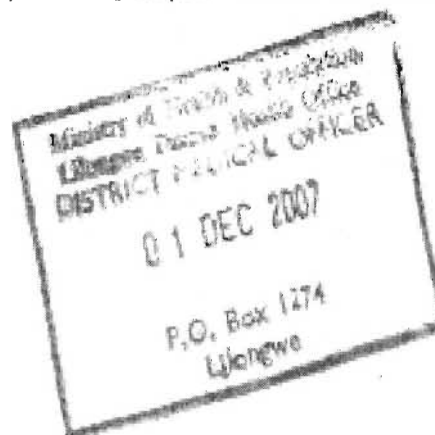
**RE: PERMISSION TO CONDUCT A STUDY IN LILONGWE DISTRICT**

Mrs Mercy D Chirwa, a registered student at University of KwaZulu-Natal pursuing Masters Degree Course in Advanced Midwifery Maternal and Child Health nursing has been granted permission by this office to conduct a research study titled '**Youth's experiences in disclosing their HIV positive status in Malawi.**'

This study will be conducted in Likuni and Namburnu. The study will involve in depth interviews with sample subjects.

Please accord her any help she may require to conduct this study.

  
Dr F. Mhale  
District medical officer



## Appendix 9

### Request for Permission Letter to Lilongwe District Health Office



Faculty of Health Science

School of Nursing

Desmond Clarence Building, 5<sup>th</sup> Building

School of Nursing

**Durban 4041**

**8<sup>th</sup> November 2007**

The District Health Officer

Lilongwe District Office

P.O. Box 1274

Lilongwe, **Malawi**

**Dear Sir / Madam:**

**RE: PERMISSION LETTER TO CONDUCT A STUDY IN LILONGWE DISTRICT.**

My name is Mercy D. Chirwa, a registered student at University of KwaZulu-Natal. I am currently pursuing a Masters Degree course in Advanced Midwifery Maternal and Child Health at the above named University.

As part of the school requirement, I am expected to conduct a research study in an area of interest. My Research Topic is: **Youth's experiences in disclosing their HIV positive status in Malawi.**

I would hereby request your kind approval and permission to conduct the study in your District (both urban and rural Likuni and Nambuma respectively). I will endeavor to

abide by the ethical rules and regulations as laid down by the ethics committee. On completion of the study, a copy of the report findings will be submitted to your office.

Data will be collected by means of in-depth interviews. The selection of participants will be done through purposive sampling. Initially 10 Participants in total will be recruited, but the exact number will be decided by data saturation

All measures will be taken to ensure participants confidentiality and anonymity. The principal investigator will be the only person who will have direct contact with participants unless the participants decide otherwise. No names will be mentioned and the tapes will be destroyed after data transcription. There are no risks involved in this study, however in case of emotions, the researcher will counsel the participants when stressed as a result of their participation in the study.

Copies of the research proposal, the ethical approval from the University of Kwazulu Natal and the information to participants are enclosed for your attention.

Your assistance will be greatly valued.

Yours Faithfully,

Researcher                      **Mercy Dokiso Chirwa**                      Cell: 0731 637 891  
Email: [mercychirwa@yahoo.com](mailto:mercychirwa@yahoo.com)

The Research Supervisor: **Mrs. Sisana Majeke,**                      Tel : 031 260 3317  
Email: [majekes3@ukzn.ac.za](mailto:majekes3@ukzn.ac.za)  
University of KwaZulu-Natal

CC: The Ethics Committee: University of KwaZulu- Natal

## Appendix 10

### Malawi Net for People Living with HIV (MANET+) Letter of Permission



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**Malawi Network of People living with HIV/AIDS**  
All correspondence to be addressed to: The Executive Director

December 3, 2007

Mrs. Mercy D. Chirwa  
University of KwaZulu Natal  
Howard College  
Desmond Clarence Building, 5<sup>th</sup> Floor  
School of Nursing  
**DURBAN, 4041**

E-mail: [mercychirwa@yahoo.com](mailto:mercychirwa@yahoo.com)

Dear Mrs. Chirwa,

**RE: PERMISSION TO CONDUCT RESEARCH STUDY IN MANET+ HIV SUPPORT GROUPS**

We write to acknowledge your letter of November 8, 2007 on the above subject matter and are pleased to inform you that MANET+ will assist you in helping you access two support groups that are registered members of MANET+, one within the Lilongwe City and the other on its periphery.

These two groups will essentially be HIV/AIDS youth support groups that have members that know their HIV status through the proper facilities of HIV testing and counseling that are registered and recognized by the authorities in Malawi.

MANET+ was established on 16 April 1997 as a coordinating and facilitating body with the main goal of promoting effective networking amongst associations and support groups of people living with HIV and AIDS and their collaborators. MANET+ is incorporated under the Trustees Incorporation Act, 1962 (Cap. 5:30) of the Laws of Malawi and as such its rights and obligations are vested in it independently of its officers. The funds and property of the Network are thus vested in its Board of Trustees.

MANET+ coordinates and facilitates the building of capacities of its registered member associations and support groups countrywide with support largely from the National AIDS Commission (NAC), the One World Action (UK), Hivos (Netherlands), the Stephen Lewis Foundation (Canada), the World University Service of Canada (WUSC).

We trust this is in order and should you require any related assistance, please, contact the undersigned through the given contact details and alternatively on [victorkamanga@yahoo.com](mailto:victorkamanga@yahoo.com).

Yours truly,

A handwritten signature in black ink, appearing to read 'Victor Kamanga', is written over a horizontal line.

Victor Kamanga  
**ACTING EXECUTIVE DIRECTOR**

**Appendix 11: Request for Permission Letter to Malawi Net for People Living with HIV (MANET)**



Howard College  
Faculty of Health Science  
School of Nursing  
Desmond Clarence Building, 5 th Floor  
Durban. 4041

8<sup>th</sup> November 2007

MANET

P.O. Box 60

Capital City

Lilongwe, **Malawi**

**Dear Sir or Madam:**

**RE: PERMISSION TO CONDUCT RESEARCH STUDY IN YOUR HIV SUPPORT GROUPS IN LILONGWE, MALAWI**

My name is Mercy D. Chirwa, a registered student at University of KwaZulu-Natal. I am currently pursuing a Masters Degree course in Advanced Midwifery Maternal and Child Health at the above named University.

As part of the school requirement, I am expected to conduct a research study in an area of interest. My Research Topic is: **“Youth’s experiences in disclosing their HIV positive status in Lilongwe Malawi**

I would hereby request your kind permission to conduct the study in your HIV Support groups in Lilongwe District. Further assistance will be sought from your organisation to assist me to recruit participants for this study. This is to avoid unintended disclosure of my prospective HIV positive status participants.



## **Appendix 12: Sample of in-depth interview**

**Participant number: one (Jane –Pseudonym).**

**Sex : Female.**

**Date : March 24, 2008.**

**Residence : Likuni.**

**Venue : Community Support Group Centre Likuni.**

**Interviewer:** Good morning I am Mercy Chirwa as I have already introduced myself to you earlier on. What name do you want me to call you during this in-depth interview? I am requesting you to give me any name that can not be traced by anyone that you want me use when calling you. This will ensure that the information you will give me will be kept secret.

**Participant:** Ehh Call me Jane.

**Interviewer:** Okay thanks, I will call you Jane.

**Interviewer: Jane** Okay thanks you. I will use your pseudonym Jane throughout the interview so that no one will ever know that it was you who said those words. The discussion we have here is all private and confidential although you might see it published in some article, you will not be traced back. All the type of information obtained verbally and recorded in the cassettes will be destroyed afterwards. Is this information clear to you Jane? Do you have any questions or comments?

**Jane:** The information is clear, I do not have any question nor comment now, I will ask when I think of one.

**Interviewer:** Jane, thank you for accepting to participate in this study

**Interviewer:** Is this room comfortable for you to have a conversation with me?

**Jane : Mmmm** yes it is ok; I have no problem with it.

**Interviewer:** Thank you Jane but if you feel uncomfortable at any time please let me.

**Jane : Yaah** I will.

**Interviewer:** okay thank you. (**Participant looked relaxed**). Now before we go further with our conversation, please tell me about yourself (**your age marital status, educational level religion, and employment**).

**Jane : Alright,** I was born on 14<sup>th</sup> June 1985, this year I am turning 24 year old.

**Interviewer:** Okay. Did you go to school? If yes, what level did you achieve?

**Jane** : uhm, yes I did but I did not go far with my education. I only went up to form two but I did not write Junior Certificate either.

**Interviewer: (smiled)** oh! So you say you went as far as form two (grade 9- South African education level) and did not write Junior certificate exams. Explain to me why you did not write the examinations.

**Jane** : well I dropped from school early because I did not have money for school fees. My parents could not afford to pay for me... I wish I could go back to school but I lack financial support.

**Interviewer :( looked unhappy)** Okay thank you Jane. By the way Jane, are you married?

**Jane** : no, I have never been married before and I do not have any children.

**Interviewer** : Okay thanks, Jane; do you belong to any religion? If so what is the name?

**Jane** : Yes I am a Christian I belong to Providence Industrial Mission church.

**Interviewer** : Jane how do you earn a living, are you employed?

**Jane** : Mmmm. I am not working but doing a small scale business. I have a sewing machine and I sew clothes that is what I am doing. But I do not earn a lot of money.

**Interviewer** : Thanks Jane. Mmmm. Now, I want us to talk about your experiences when disclosing your HIV positive status to other people. Is it ok with for us to continue with our interview?

**Jane** : Yes, it is fine I have no problem discussing my HIV positive status with people these days. I accepted my status and I am okay with that.

**Interviewer:** Fine thank you, Jane, please tell me now, what made you disclose your HIV positive status?

**Jane** : It was in May, 2000 when I had an HIV Test. I decided to have the test because of chronic illnesses, I was frequently falling ill from different types of diseases like flue, fever, malaria coughs and loss of appetite and my hair was thin and sparse and people started saying that I have contracted HIV. **(Looked down for a while and Cleared the throat...)** at the hospital, they counseled me before testing, they told me more about HIV, transmission, prevention, ARVs and how to live positively with the

virus. I accepted to have the HIV test. Mhuu, when the result of my HIV test came positive, they also counseled me about the meaning and implications of the HIV positive and negative results. They also stressed the importance of disclosing my HIV positive results

**Interviewer: (Jane was Silent for a while)** okay Jane, please carry on.

**Jane** : Oh yaah, immediately after the HIV positive results, the first thing that came to my mind was not to disclose my status for fear of negative consequences, but after thinking about it for a while, I felt it would be heavy for me to keep this diagnosis in secrecy, after all I told my mother that I was going for an HIV test. Hiding this information from my mother would make me feel uncomfortable. At this point I was very distress with positive result and needed someone to reassure me and this could only be done if I disclose to someone who cares for me. I also valued the advice from the HIV counselor who told me the importance of disclosing for me to access necessary support services from the hospital, relatives, friends and support groups. Mmnn

**Interviewer: (Jane took a deep breath).** Yes, Jane go on, I am following what you are saying.

**Jane** : okay, ahhh thinking about all this, I decided to disclose my status to the people I valued most.

**Interviewer:** Mmmm. So (pause), so how did you disclose your HIV Positive?

**Jane** : Eh hh it was not easy; anyway, I disclosed my positive status on the same day I received my results. I first told my mother who offered me support. I called her inside the house and I kept quiet for some time, thinking what would be best words to use to break the news, I was anxious, I had a lot of fear as to how my mother and other people will react to the news. My mother looked at me and I looked at her but long at last I told her. I am HIV positive and tears rolled on my cheeks, when I was telling her, I could feel that I was shivering within myself. My mother held my hands and said it's okay now that the health problem has been Identified you will be started on treatments. Her words made me relieved and my stress levels went down now that there is my mother who has positively accepted my status.

**Interviewer: (looked sad).** Yes, Jane, please continue...

**Jane** : okay. Mmmm. After some days, weeks, and months, I told others about my HIV positive status including to my sisters, close friends, support group and to the community. As time passed I started accepting my status and felt comfortable to talk about my HIV positive status to other people as well.

**Interviewer** : thank you, Jane, could you please explain what were the reactions of those you disclosed to.

**Jane** : Mmmm, disclosing my HIV positive status was not easy. When I disclosed to my mother, sisters, close, friends they were accepting and offered themselves to help me when need arises. I felt good that there were people who will be there for me in times of need. Disclosure to the medical personnel was also helpful because I was treated accordingly and was offered information and advice every time I go to the hospital and was offered ARVs after assessing that my body immunity was low. I also did not regret disclosing to the support group in our community because they members there were accepting and welcoming, furthermore, all the members in the support group were all HIV positive so we were sharing common problems and offered each other some solutions on how to deal with our problems. At the support group there are also a lot of activities which are psychological reassuring. The other benefit at the support group was to access to donated foods and other items for HIV positive people Disclosure helped me to live positively with HIV.

**Interviewer: (Jane stretched herself).** Okay. Jane please tell me the positive reactions after disclosing you HIV positive status from the people you after disclosing your HIV positive status. Were there any other reactions?

**Jane** : Oh yes, (excited). I observed that after disclosing to some people about my HIV positive status, some of my friends started resenting me, they did not want to mix with me a lot. I also heard that some people were saying bad things about me with my positive status. Some other people said that I had limited days of living because I had AIDS. At funerals, some people did not want to eat with me because I was HIV positive.

**Interviewer:** So how did you feel when other people were showing negative reaction?

**Jane** : At first I used to feel bad and did not want to mix with them, this made me to isolate myself and was getting depressed. I used to feel embarrassed because of my positive status. But the constant reassurance I got from my mother, sisters and close

friends made me to accept my status and not to worry much about what other people say. The situation even improved when I joined the HIV support group where people were free about their HIV positive status and discussed the measures to overcome stigma and discrimination. I also overcame fears eventually.

**Interviewer:** Jane please tell me, what were the benefits of disclosing your HIV status?

**Jane** : OKay, (smiled), Mmmm, HIV diagnosis causes psychological trauma to both the infected and others, the benefits of disclosing my HIV positive status is that, I experienced are: I was reassured about my status by family members close friends and my fellow members of our HIV support group. I started the ARVS because I disclosed my HIV positive status and other people encouraged me to go to the hospital to access ARVS, without that I would have died way back. Disclosure also helped me to adhere to my ARVs regimens because my relatives remind me to take my medications. Without disclosing no body can come to my way like to encourage me to go to the hospital and start using the medicine. Disclosure of my positive status also helped me to access some food staff and other items donated to those infected with HIV at the support groups in order to improve the their lives. The advice that I got from the hospital family members, support group and close friends helped me live positively with HIV infection. I am feeling I much healthier than I was before my HIV test.

**Interviewer** : Thanks. Mmmm, and what are the disadvantages of non disclosure of HIV positive status?

**Jane:** people who do not disclose their HIV positive status are usually depressed, they can commit suicide and not at terms with their status. They can not access ARVs may not take them for fear that people will know that they are taking treatment for AIDS. They can not access some benefits from support groups. Therefore, I feel that those people who do not disclose can die quick. If I did not disclose I would have long died.

**Interviewer:** Ok thank you Jane for you time. Do you have any questions or comments about what we have discussed?

**Jane:** No, thanks.

**Interviewer:** Okay thanks Jane, have a nice day.