

**THE UNIVERSITY OF ZAMBIA**  
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**DISSERTATION**

**Difficulties of Disclosure of HIV Status to Sexual  
Partners among Expectant Women in Selected  
Clinics in Lusaka Urban**

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**2009**

**Difficulties of HIV Status Disclosure to Sexual  
Partners among Expectant Women in Selected  
Clinics in Lusaka Urban**

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**A DISSERTATION SUBMITTED IN PARTIAL  
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HEALTH**

**THE UNIVERSITY OF ZAMBIA  
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## Abstract

HIV disclosure and nondisclosure may have positive and negative impact on HIV positive clients and their sexual partners, family, and friends but very little was known in Zambia on the types of disclosure and its determinants. This study sought answer two research questions; what risks or rewards do expectant mothers anticipate when considering disclosing their HIV status to their male partners? And why do they choose a particular pattern of disclosure?

**Research design:** A cross sectional explorative descriptive and mixed study was employed driven by the deductive and abductive strategies based on the philosophy of realism and interpretivism. The study was done in four clinics in Lusaka urban. A simple random sampling (lottery) method was used to select the four clinics and a disproportionate sample of 260 women was primarily sampled. A survey questionnaire and 22 one-to-one in-depth interviews were the main source of the data. Qualitative data was coded and analysed using content analysis and quantitative data was analysed using SPSS software version 14.

**Findings:** The findings showed that decision making to disclose is a selective process and it consists of several steps, including arriving to the diagnosis, to disclose or not to disclose, when and to whom. It was evident that just after counseling, the participants were willing to disclose mostly to their partners irrespective of what risks there were. Disclosure is more unlikely to take place within distant, casual, uncommitted, and short-term sexual relationships but with husbands or within close family and/or friends in nonsexual relationships. Disclosures were done on the first day after being diagnosed with HIV infection. This study supports past research that has argued that women's concern about stigma, rejection and violence related to disclosing their HIV-seropositive status are unwarranted. However, negative reactions to disclosure were common, including betrayed confidence and abandonment but we did not find it to be significant in this study.

**Recommendations:** It is recommended that nurses and other primary health care workers need to be open and supportive in caring for the HIV+ client, discussing the advantages of disclosing one's HIV status to sex partners, but, at the same time, respecting the rights of clients to make their own decision about disclosure. Nurse midwives will need to have greater knowledge of what factors and situations tend to influence disclosing and not disclosing one's HIV+ status, especially to sexual partners. There is need to develop intervention strategies that could include support and open discussions with HIV+ clients, even role-playing disclosure conversations- assuming that clients are interested in disclosing. As for HIV research, various types of social relationships associated with HIV disclosure are under-explored and future research may have to explore this. Researchers need to continue to actively pursue clues as to what facilitates HIV disclosure to sex partners, because disclosure has the potential to improve well-being, provide informed choice, and protect life.

## DECLARATION

This dissertation is the original work of Lentisha Muyanza. It has been prepared in accordance with the guidelines for MPH dissertations of the University of Zambia. I hereby declare that this dissertation has not been submitted for a degree in this or any other university.

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## Certificate of Approval

This dissertation of Ms. Lentisha Muyanza has been approved as partial fulfilment of the requirements for the award of the Master of Public health (MPH) by the University of Zambia, Lusaka.

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## **Dedication**

This work is dedicated to my children Patricia, Gae, Mutinta and Nicholas.

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### **List of abbreviations**

AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal care
CDC	Centre for Disease Control
CSO	Central Statistics Office
HIV	Human Immunodeficiency Virus
PMTCT	Prevention of Mother to Child Transmission
SPSS	Statistical Package for the Social Sciences
STIs	Sexually Transmitted infections
UNAIDS	United Nations Programme on HIV/AIDS
UNICEF	United Nations Children's Fund
WHO	World health Organisation

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## CHAPTER ONE - INTRODUCTION

### 1.0 Background

HIV/AIDS is an ongoing global pandemic. It is a major health problem in many countries causing psychological and physical pain, suffering, social and economic costs to society. AIDS is the leading cause of death in sub-Saharan Africa. According to 2001 estimates, there were 28.5 million people living with AIDS in Africa, comprising >70% of the world's HIV-infected population. Since 1981, when the first AIDS cases were identified in the United States followed by Africa the next year, there has been a growing understanding of the HIV/AIDS epidemic's trajectory and the toll it has taken across the globe. Last year (2007), there was another major revision in the data compared to prior published figures. Better data provide a clearer picture of trends over time. The latest estimates from UNAIDS and the WHO (2008a, b) indicate that:

- § The number of people living with HIV/AIDS globally rose from 28.5 million in 2001 to 33 million in 2007 due to continuing new infections, people living longer with HIV, and general population growth;
- § The global prevalence rate (the percent of the population aged 15–49 with HIV), 0.8% in 2007, has levelled off since 2000;
- § Annual deaths increased from 1.7 million in 2001 to 2.0 million in 2007, but have declined in the last couple of years due in part to an antiretroviral treatment scale up;
- § New HIV infections are believed to have peaked in the late 1990s and declined between 2001 and 2007 from 3.0 million to 2.7 million. This decline is attributable to natural trends in the epidemic itself and to prevention efforts. Still, there were more than 7,000 new HIV infections each day in 2007;
- § Women represent half of all people living with HIV/AIDS, as they have in recent years;

- § HIV is among the leading causes of death worldwide and the number one cause of death in sub-Saharan Africa;
- § Most people with HIV are unaware that they are infected.

These most recent trends, and the snapshot provided below, represent significant revisions by UNAIDS/WHO based largely on improved methodology and better data availability from countries over time. Importantly, methodological changes have led to revisions in earlier published estimates including significant reductions between 2006 and 2007. For example, the current estimate of the number of people living with HIV/AIDS is a reduction of about 6 million from the 2006 published estimate. Most of the reduction (70%) is explained by revisions to prevalence estimates in India and five sub-Saharan African countries. Both incidence and mortality estimates are impacted by these changes and also reflect an increase in the estimated survival time for a person living with HIV (increasing from 9 to 11 years) (UNAIDS/WHO, 2008; a, b, d; UNAIDS, 2007).

### ***Current Global Snapshot***

HIV/AIDS cases have been reported in all regions of the world, but most people living with the disease (more than 95%) reside in low and middle-income countries, where most new HIV infections and AIDS-related deaths occur. Sub-Saharan Africa has been hardest hit, followed by the Caribbean; there is also concern about the epidemic in parts of Eastern Europe and Asia. Worldwide, HIV is primarily transmitted heterosexually, although risk factors vary within and across populations. In many regions of the world, men who have sex with men, injection drug users, and sex workers account for significant proportions of infections (UNAIDS/WHO, 2008a,b,c,d).

### ***Sub-Saharan Africa***

Sub-Saharan Africa, the hardest hit region, is home to two-thirds (67%) of people living with HIV/AIDS, or 22.0 million people, but only about 11–12% of the world's population. Most of the world's children with HIV/AIDS (90%) live in the region.

Almost all nations in this region have generalized HIV AIDS epidemics-that is, their national HIV prevalence rate is greater than 1%. In 9 countries, more than 10% of adults are already estimated to be HIV positive. South Africa is estimated to have 5.7 million people living with HIV/AIDS, the highest in the world, and almost one in five South African adults is HIV positive. Swaziland has the highest prevalence rate in the world (26.1%). However, the latest data are promising-in many countries, national HIV prevalence has either stabilized or is showing signs of decline (UNAIDS/WHO, 2008a).

### ***Zambia's Profile of HIV/AIDS***

Zambia's population is estimated at 10.4 million of which it is estimated that 14% are HIV positive (CSO, 2007) and at the moment, she is currently experiencing a myriad of crises because of the HIV/AIDS epidemic. Zambia, in southern Africa, has one of the world's most devastating HIV and AIDS epidemics. One in every six adults in Zambia is living with HIV and life expectancy at birth has fallen below 40 years. This has compounded Zambia's existing economic problems. In four decades of independence, Zambia has found peace but not prosperity and today it is one of the poorest and least developed nations on earth. Although Zambia has received hundreds of millions of dollars from rich country governments toward HIV programmes, prevalence rates are not dropping and have remained more or less stable since the nineties, at as high as 25% in urban areas (UNAIDS/WHO, 2006).

Although declining HIV trends have been observed in young people since 1998, HIV/AIDS in Zambia is still a major threat to the lives of women in the reproductive age group and their children. Approximately one in five expectant women in Zambia is infected with HIV. In Zambia, PMTCT services were implemented in October 2001 as part of Ministry of Health routine prenatal care in two Lusaka district clinics. Services were scaled up to all 24 Lusaka District clinics and the University Teaching Hospital by December 2003. The current number of PMTCT sites nationwide are 66 out of which 25 are in Lusaka Province (Sinkala et al. 2005). The Zambian Ministry of Health PMTCT programs ensure that all expectant women are provided HIV testing and counselling as part of routine antenatal care. One of the thrusts of PMTCT has been motivating HIV status disclosure to partners among expectant



mothers; drawing heavily from enunciations contained in The Power of Partnerships: The U.S. President's Emergency Plan for AIDS Relief (PEPFAR, 2008).

## **CHAPTER TWO - LITERATURE REVIEW**

### **2.0 Introduction**

This chapter will review the literature related to disclosure and HIV status. Since studies in disclosure are yet to gain momentum in this part of the world, most of the literature discussed here will be mainly based and informed by researches conducted in the West and some parts of Africa and Asia. This literature review provides the reader with an overview of major academic works concerning disclosure and HIV status. This is not a comprehensive review of the available literature, and it is not a meta-analysis (a synthesis of research results using various statistical methods to retrieve, select, and combine results from previous studies). In this section, previous studies examining the dynamics of HIV status disclosure are reviewed.

The literature review on HIV status disclosure has been arranged classified according to their focus on one of the following themes: the ethical dynamics of status disclosure, the rates of Partner notification in expectant women with HIV, the experiences of expectant mothers in calculating the risks and benefits of disclosure to their partners, the prevailing disclosure and types of social relationship the impacts of such disclosure and the best or ideal model of HIV disclosure we could use in Zambia. This thematisation serves as a heuristic device, a convenient way of organizing the work in building answers to the research question.

Since the author is trained in public health and nursing, the emphasis of this literature review takes a medical orientation rooted in public health and nursing. Nevertheless, examples outside these areas are provided to show that the analytic framework offered can easily be applied to studies of HIV status disclosure from a wide range of disciplines.

## **2.1 Definition of Key Concepts**

Below are definitions of key concepts that have been used in this study:

- Disclosure - The revelation of information that was previously kept secret.  
Disclosure in the context of HIV occurs when a person's HIV test result is revealed to another person.
- Difficulties - A troublesome or embarrassing state of affairs especially to do with issues of sexuality and subsequent infections such as HIV
- Partner - An established couple in a sexual relationship
- Pattern - The regular or repetitive form of behaving
- Benefits - What might accrue to one following disclosure in view of positive effects.
- Challenges - A test of one's abilities to disclose their HIV status in view of negative effects
- Stigma - A negative social phenomenon which occurs when someone is evaluated as possessing an undesirable trait or behaviour and thus deemed imperfect in regard to the standards of society

## **2.2 Benefits of PMTCT and Counselling**

When women were compared, it was noted that the lowest rates of HIV status disclosure were among expectant women tested in antenatal care in sub-Saharan Africa (16.7% to 32%). Additionally, larger proportions of studies from developing countries reported women that did not share their HIV test results with anyone (10% to 78%) as compared to women in developed country studies (3% to 10%) (Suzanne, 2004). HIV testing and counselling within PMTCT programmes provide a useful setting for discussing barriers to HIV status disclosure that individual clients may perceive. Data from pilot PMTCT programmes supported by UNICEF between January 2000 and June 2002 showed that of more than half a million women who attended clinics in twelve countries, only 71% received counselling; of those counselled, only 70% took an HIV test; among women who tested HIV positive, only

49% received preventive drugs. Assuming that HIV prevalence among all women was similar to the rate among those who were tested, fewer than one in four HIV-infected women who attended a clinic went on to receive the drugs that they needed. The same study further illustrated that among expectant women who do take a test and are found to be HIV positive, a high proportion (sometimes up to 70%) choose not to tell their partners (Noble, 2007). In Zambia, from October 2001 to March 2005, 188,027 expectant women were counseled for HIV out of which 137,007 (72%) were tested for HIV and 31,565 were diagnosed as HIV infected (23%) with 10,276 of them testing RPR positive. Of these women, 26,666 received Nevirapine prophylaxis (84%) but only 10,247 babies were documented to have received the Nevirapine at birth (38%) (Sinkala, et al. 2005). This signifies a very high drop out rate and has implications on the efficiency of counselling and inevitably PMTCT service provision. Improving efficiency means looking at various issues and one of the main issues is disclosure. Women who disclose their status to partners may be more likely to participate in programmes for prevention of HIV transmission from mothers to their infants. Most are afraid of violence or abandonment. In many societies, it is common for men to blame their partners for being infected even if they too have HIV. An HIV positive, expectant woman who has not disclosed her diagnosis to her partner, family or friends is generally less likely to accept preventive drugs and to practise unconventional methods of infant feeding, for fear of revealing that she is infected (Sinkala et al. 2005). Health care practitioners in PMTCT programmes are in a vital position to assist and support HIV positive mothers in their HIV disclosure decisions. But for Health care practitioners to accomplish this, they need to understand the complexity and dynamics surrounding HIV disclosure and nondisclosure and also the impact that such decisions can have on HIV positive clients and their sexual partners, family, and friends. To be able to do this there is need for a body of knowledge on the various factors that influence disclosure or non disclosure of one's HIV sero-status to their sexual partner. With this information, health workers may identify and assist those women who wish to avoid or delay disclosure. This is the main purpose of undertaking this study in the selected PMTCT centres in Lusaka Urban.

## **2.3 Ethical Dynamics of Status Disclosure**

The position regarding the ethics of disclosing HIV seropositivity to partners is full disclosure. Disclosure is advocated using time-honoured adages such as, 'honesty is the best policy' and 'do unto others'. This seems to reflect enduring influence of basic moral socialisation agents such as family, school and church (Rier, 2007). We are taught that honesty is extremely valuable to a relationship and as such couples should be up front with their status. Women often frame disclosure as vital for a healthy relationship and as a test of commitment. As a result of PMTCT programs, women are often the first member of a relationship to reveal their HIV status. PMTCT programs advise women to disclose their HIV test result to their partner and to encourage him to have an HIV test. But for many women, particularly those who are HIV-positive, talking to their partner about HIV/AIDS is hard because of fears of rejection (which could mean loss of housing and food) and accusations of infidelity. Health care providers too face an ethical challenge: how to address the issue of negative consequences following disclosure, while, at the same time, promoting disclosure, given that most women report positive outcomes (Rier, 2007).

## **2.4 Rates of Partner Notification**

Literature tends to show that the rates of partner notification of HIV status are higher in developed countries than in developing countries. Some of the reasons that have been advanced are affluence, legal demands where failure to disclose could subject those who are positive to criminal prosecution. Though actual convictions are not particularly frequent (Bray 2003) and yet non-disclosure is common (Ciccarone *et al.* 2003, Parsons *et al.* 2005, Wolitski *et al.* 1998, Stein *et al.* 1998; Garbach *et al.*, 2004). In the US, the rate of disclosure of their HIV serostatus is higher among women than among women in developing country studies, with rates of 42-100 percent in the U.S. compared with 16-86 percent in developing countries (Simoni, 2000; Armistead, 1999; Sowell, 1997; Lester, 1995; Rotenberg, 1995; Simoni, 1995; Kilewo, 2001; Nebie, 2001; Antelman, 2001; Issiaka, 2001; Pool, 2001; Farquhar, 2000; Gaillard, 2000; Sigxaxhe, 2000; Bennetts, 1999; Rakwar, 1999; Ladner, 1996; Van der Straten, 1996). Defeu *et al.* (1994) reported that 89% of the participants spoke about their condition with at least one person; 82% informed their

partner(s) within the month following the diagnosis. This was traumatic for half of them whose confidence was betrayed and for 30% who received negative reactions from their partners, as well as for 21% who were abandoned. Moore and Padian (1994) showed that on entering the longitudinal study, only 31% of the 130 seropositive heterosexual men with partners who were not infected had revealed their condition. Hays et al. (1993) exposed the reasons for keeping silent about seropositivity-fear of rejection, professional discrimination, partner's anxiety, loss of freedom and trust within family relationships, and revulsion of being gay-without suggesting that these reasons might hide other deeper issues. Klitzman (1993) defined five types of attitudes toward sex partners: revelation, concealment, indirect revelation (e.g., mentioning that a lover has just died of AIDS), giving false information, and complete sexual abstinence.

Caution should be exercised, however, in comparing results across these studies, as there were differences in how rates of disclosure were measured and in the timeframes. Some studies looked at disclosure two weeks after testing, and others were almost four years after testing. Although direct comparison is therefore difficult, it is possible to identify trends. The lowest rates of disclosure in all the studies are among expectant women tested during antenatal care (ANC) in sub-Saharan Africa (16.7 – 32%) (Kilewo, 2001; Nebie, 2001; Antelman, 2001; Gaillard, 2000). In most settings, there is a core group of women who choose not to disclose their serostatus to anyone: 3-10 percent in the U.S. and 10-78 percent in developing countries (Kilewo, 2001; Nebie, 2001; Antelman, 2001; Gaillard, 2000).

## **2.5 Benefits of Status Disclosure**

Theoretically, rewards of disclosing are multiple and can result in the acquisition of numerous resources. These resources may be emotional, physical, and social in nature. For example, emotional benefits might include the acquisition of social support, relief from sharing a burdensome secret, and the intrinsic reward of educating others about HIV or the risks of having sex (Siegal et al. 2005). Furthermore, disclosing one's serostatus eliminates hiding complicated adherence rituals from friends, family, and co-workers. Disclosure of one's HIV positive status to sex partners has been found to lower infection rates as persons may be motivated

to engage in or adopt safer sex practices (Sturdevant 2001). And, it has been proposed that nondisclosure may play a central role in HIV transmission (De Rosa and Marks, 1998) and is associated with greater sex risk taking (Hyde et al., 2005). De Rosa and Marks found that higher rates of HIV positive disclosure were reported by persons who attended support groups and also received post-test counselling. Another study suggests that HIV positive participants who disclosed their serostatus were more likely to discuss safe sex with their partners than those who did not disclose (Crepaz and Marks, 2003). Participants who disclosed and discussed safe sex with their partners also had a higher rate of protected sexual behaviour than did those who disclosed to their partners but did not discuss safer sex. In another study, HIV 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 (Simoni et al., 2000).

It has been shown that HIV positive persons want to disclose their condition because they may need instrumental support (e.g., help in grocery shopping or meal preparation, transportation to and from appointments with health care providers) and or socio-emotional support (e.g., an opportunity to discuss their feelings about the condition). Some researchers (Kalichman, et al., 2003; Stein et al., 1998) have found that HIV positive persons who believe that their spouse is very supportive are more likely to disclose to them. Individuals who want to disclose often need time to make personal adjustments before sharing the information with others. This is because revealing one's serostatus often indicates that the individual has come to terms with the disease (Holt et al., 1998). Although the amount of time needed to adjust to the diagnosis varies from one person to another, research has shown that the longer individuals live with HIV, the more likely they are to have disclosed their status to other persons (Mansergh, et al., 1995; Mason et al., 1995).

## **2.6 Reasons For and Against Disclosure**

As for the complexity of disclosing one's HIV positive status, there are many reasons given for and against HIV positive persons disclosing to sexual partners, friends, family, employers, strangers, and healthcare providers. Reasons for disclosure include the following: it is the right thing to do to protect others, reaffirmation of self,

increased social support, catharsis, desire to educate others, seeking help, desire to test someone's reaction, being in a close or supportive relationship, and a mechanism for dealing with the disease (Derlega et al. 2002; Holt et al., 1998; Parsons et al., 2004; Serovich and Mosack, 2003; Wolitski et al., 2003). However, the reasons for not disclosing include the following: stigma, need for privacy, fear of rejection by sexual partners, threats to personal well-being, potential loss of income, substance use, difficulty in communicating, denial, low viral load, type of sex, location of sexual encounter, legal reprisal (fear of arrest), and condom use (no need to disclose) (Carr and Gramling, 2004; Derlega et al.; Garbach et al., 2004).

Personal characteristics may also influence disclosure decisions. Persons who disclose their HIV status are typically younger, are females, have high ethical and moral standards, are more spiritual, and are in a serodiscordant relationship, have participated in interventions that teach techniques for disclosing, or have advanced HIV disease (Best, 2002; De Rosa and Marks, 1998; Knight et al., 2005; Simoni et al., 2000; Wolitski et al., 2003). Additionally, respondent's education is included in our analysis. However, only a limited body of research has reported on the impact of education on disclosure. Bor and du Pleiss (1997) found that adults with higher levels of education were reluctant to talk about their HIV status with family members because they had higher levels of shame and preferred to cope on their own. It may also be that those with lower educational attainment have fewer socioeconomic resources available to cope with their illness and may need economic support from their family of origin. Thus, education may influence disclosure through its impact on felt shame and need for support.

Overall, it is clear that no one set of factors predominantly influences disclosure of one's HIV serostatus. Parsons et al. (2004) found that responsibility was an important consideration in HIV disclosure patterns. Some participants said that responsibility was the primary reason for not disclosing to casual sex partners, explaining that disclosure was not necessary because they used safer sex (condoms) and did not put their partners at risk.



## **2.7 Calculating the Risks and Benefits of Disclosure**

Learning that one is HIV-infected creates an internal struggle about whether or not to disclose one's HIV-seropositive status (Marks et al., 1992). The decision to disclose is selective and consists of several steps, including adjusting to the diagnosis, assessing one's disclosure skills, deciding whom to tell, evaluating the recipient's circumstances, anticipating the recipient's reaction and having a motivation to disclose (Kimberly et al., 1995). The decision to disclose one's status is a difficult one, and must include to whom, when, where and how to reveal one's status to others. The decision to tell one's family members may be especially difficult (Kimberly et al., 1995; Serovich et al., 1998; Sowell et al., 2003).

Black and Miles (2002) found that; once women learned they had HIV, they were faced with feelings of shame about having HIV and an immediate concern about being stigmatized. As a result, they were confronted with issues related to disclosure and had to determine "what is at stake" in telling. However, the women also faced the concurrent need for support and tangible assistance. To protect themselves, the women determined a calculus of disclosure. To calculate is to reckon or determine by reasoning and evaluating (Neufeldt and Guralnik, 1996). Thus, this calculus involved a careful, reasoned evaluation of the risks and benefits for oneself and significant others when disclosing one's diagnosis of HIV. The goal of the calculus was to disclose the diagnosis in situations where the risk was minimized and the benefits were maximized.

The women's perceived risks of disclosure were closely linked to personal feelings of shame and the threat of being stigmatized by individuals or the entire community. These threats were fuelled by observations of stigmatizing statements and behaviours in their social world and by their direct experiences being stigmatized. As a result, most women carefully controlled information about their HIV positive status to others (Herek and Capitanio, 1999).

Stigma, a negative social phenomenon, occurs when someone is evaluated as possessing an undesirable trait or behaviour and thus deemed imperfect in regard to the standards of society (Goffman, 1963; Lewis, 1995). Stigma is a powerful social

label that discredits and taints a person's image, changes his or her self-identity, and can lead to self-hatred and shame (Alonzo and Reynolds, 1995; Goffman, 1963). Because stigma is so closely associated with interpersonal relationships, people who feel they have a stigmatizing characteristic can become withdrawn, isolated, and lose social and emotional support. Few illnesses in modern times have been associated with the high levels of stigma and resulting social isolation that accompanies a diagnosis of human immunodeficiency virus (HIV). Transmission of the virus is commonly associated with social and sexual behaviours such as prostitution (Pryor et al., 1999). Because these behaviours violate the moral standards of many, a resulting infection with HIV may be seen as the responsibility of the individual (Alonzo and Reynolds, 1995; Herek and Capitanio, 1999). Individuals with HIV may be stigmatized because HIV is infectious, poses a threat to the health of others, and is fatal (Crandall, Glor, and Brit, 1997; Herek and Capitanio, 1999; Pryor et al., 1999). Understandably, HIV-positive individuals are fearful of being gossiped about, labelled, and discredited, and as a consequence struggle with issues of disclosure, secrecy, and social isolation (Alonzo and Reynolds, 1995; Barroso and Powell-Cope, 2000; Fife and Wright, 2000; Moneyham et al., 1996).

From the afore stated, the calculus to reveal ones status is a recursive process, with decisions made and remade over time, depending on the situation and the needs of the women. Even in situations in which the decision is not to disclose, the women often anticipate a future time when they would tell someone or everyone. Disclosure often occurs "at the right time," meaning a time when the women need additional support, or "on a need to know basis."

## **2.8 Patterns/Types of Disclosure**

Black and Miles (2002) developed a typology of disclosures among women. In their study, they found that a small group was categorized as secretive disclosers and an even smaller group as full disclosers. However, most of the women were categorized as selective disclosers. The typology is described below.

### **2.8.1 Secretive Disclosers**

Secretive disclosers are committed to maintaining their diagnosis as a secret to all but a few select trusted individuals. Most tend to tell only one other person, typically their husband or partner or their mother. Such women often limit their social lives to reduce the risk of being found out and report feeling lonely and isolated. One participant reported this feeling :

“Angry and not able to tell anyone what is making me so mad”. (Black and Miles 2002 p.692)

Although these women are committed to keeping their diagnosis a secret for as long as they possibly could, they also examine the reality that sooner or later they would reveal their diagnosis to others. Their calculus of risk is that disclosure would almost certainly result in punitive or discrediting actions by others. Thus, what is at stake for them is the maintenance of current relationships.

### **2.8.2 Selective Disclosers**

Most women tend to describe a calculus of disclosure that includes elements of selectivity in determining whom to tell and not to tell. Typically, women tell close family members, such as their partners, mothers, and sisters, and occasionally, all older members of the immediate household, but were highly selective as to whom to tell outside of the household. Some would support the posture that disclosing within the family was acceptable and allowed the women to live openly in the intimate confines of their homes, while protecting themselves from stigmatization in the community. Determining another's “need to know” the HIV diagnosis was in some women's disclosure evaluations. The decision is often made to tell others, particularly family members, who were in positions to provide assistance and support. One woman described choosing to tell her mother about her diagnosis because she needed child care for her daughter during her frequent clinic visits:

She's really come through for me, but I know that she is really upset and worried. (Black and Miles 2002 p.693)

Another woman, although ambivalent about disclosing, chose to tell her aunt about her diagnosis when she became ill with a severe urinary tract infection and needed help:

She's always been good to me. . . . I just wanted to tell her. She was really disappointed, she said, and didn't talk for awhile, but she said she loved me and would do all she could to help me out, and she did. (Black and Miles 2002 p.693)

For both of these women, being selective about disclosing resulted in positive outcomes in which trusted others rendered important support.

It could be inferred that selective nondisclosure is a variation of selective disclosure and involves making a conscious decision *not* to reveal the diagnosis to specific individuals or groups. Because they recognise the stakes as high when disclosing to individuals not trusted to maintain their secret, many women develop a calculus of disclosure that eliminates certain persons who "don't need to know" from being told about the diagnoses. Surprisingly, this selective nondisclosure sometimes involved sexual partners, some of whom may not be infected.

#### *Full Disclosers*

This entails being completely open about the HIV diagnosis within the confines of adult relationships. Women who are full disclosers have differing reasons for their openness. One woman was an AIDS activist who wanted others to know about HIV in order to be more supportive of people with HIV and to help prevent HIV from spreading. She said,

"all my family knows, my mama, my sister, my brother, my cousins, my neighbours." (Black and Miles 2002 p.694)

She had told them for a number of reasons, which she had carefully evaluated. One reason was a desire to get even with the man who gave her the infection.

"I do think my friend had AIDS. I couldn't believe it when he told me I needed to get checked. I know I told some people to get back at him." (Black and Miles 2002 p.694)

Having contracted HIV from a single sexual encounter with an HIV-positive man, this woman felt compelled to let everyone know because “people need to know it can happen to anybody.” She also noted the benefits of telling as therapeutic:

“I can’t live holding something like that inside.” The benefits included gaining future support: “When I get sick, I know I’ll need people to help me. It ain’t about being too shamed. I ain’t had no problems with nobody.” (Black and Miles 2002 p.694)

These three types of disclosures can be diagrammatised as shown in figure 2.1.

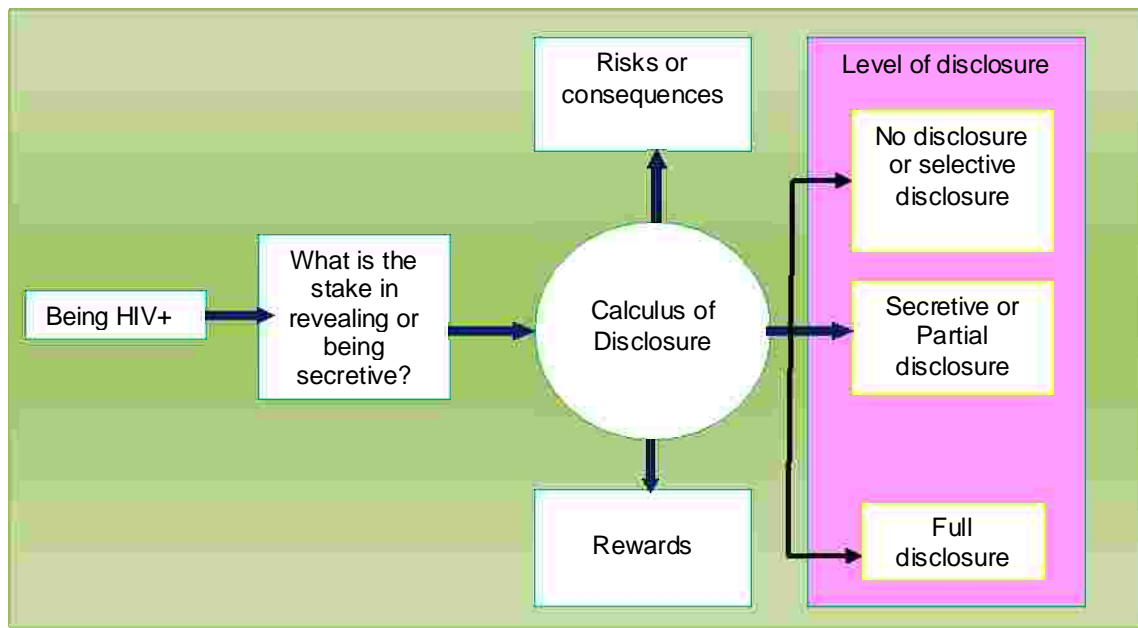


Figure 2.1 A model of the disclosure calculations to ascertain the risk-to-benefit ratio of revealing or keeping secret of HIV diagnosis. (Black and Miles 2002 p.691)

## 2.9 The Problem of Disclosure

There have been noted problems of disclosure among people who have been HIV positive. For HIV positive individuals, disclosing their seropositivity is often tantamount to admitting behaviours, such as prostitution, homosexual relations or injection drug use that – though opposition and stigma may have declined with time (Herek *et al.* 2002) – remain widely stigmatised. Disclosing seropositivity to a sexual

partner implies that that partner, too (and that partner's other partners) might be infected. Disclosure may cause rejection, and emotional and even physical abuse (Maman and Medley 2004). Yet disclosure can also bring emotional support, instrumental assistance, and relief at being able to be candid with friends and family (Greene *et al.* 2003, Klitzman and Bayer 2003). AIDS 'risk-management' decisions such as those involving disclosure are often emotionally fraught, placing trust, intimacy, and risk in tension with one another (Rhodes and Cusick 2000). Seropositives carefully weigh whom, when, and how to tell, and often experience disclosure as a process, not an event (Cusick and Rhodes 1999). As we will see below, relationship type and social setting can be significant influences on disclosure decisions.

In public health terms, disclosure enables partners to notify their other partners, and to adopt precautions to avoid transmitting the virus further. Disclosure to seronegative partners can correlate with increased practice of safer sex (DeRosa and Marks 1998). Since the arrival of powerful antiretroviral therapies (HAART) in the mid-1990s, disclosure can also help infected partners postpone progression to AIDS.

Klitzman and Bayer (2003) interviewed 77 individuals about HIV/AIDS disclosure attitudes and practices. Responses ranged from those claiming that they always disclosed to partners, even when taking precautions, to those claiming that they seldom disclosed even when engaging in high-risk activity. Commonly-reported themes in that study (and in others, such as Sheon and Crosby (2004) included: disclosure associated with feelings of moral responsibility and the desire to preserve trust in relationships; more disclosure to primary than to casual partners; everyone is responsible for their own protection; 'safer sex' as a substitute for disclosure; and, in high-risk venues, 'burn-out' with safer sex messages combined with mutual presumption of seropositivity resulting in a 'don't ask/don't tell' or *caveat emptor* ethos justifying unprotected relations.

Moral and ideological discourses on practices such as HIV disclosure have shifted with the AIDS epidemic. Tensions between civil liberties and prevention marked its early years, when stigma and discrimination sparked powerful concerns to safeguard

privacy (Shilts 1987, Bayer 1989). The discourse of individuals' responsibility towards partners was often considered hostile moralising and victim-blaming; partly for these reasons, prevention efforts often emphasised self-protection, rather than disclosure (Bayer 1996). By the mid-1990s, however, when AIDS was already evolving from an acute new public health emergency to somewhat more manageable, better-understood chronic disease, some activists (e.g. Mass 1995, Rotello 1995, Signorile 1995) and researchers (e.g. Danziger 1996, Bayer 1996) were advocating a new focus on individuals' responsibilities towards others in areas such as disclosure. All this parallels – and may partly reflect – wider trends, in which the 'new public health' highlights individual responsibility (Dodds, 2002, Petersen 1997, Nettleton 1997).

It has been established that the quest to compel persons who are HIV positive to disclose is beneficial and yet disclosure's actual value is controversial. When asked, seropositives may mistakenly declare themselves seronegative: their HIV test may have been performed during the post-infection window period when the virus was not easily detectable, or prior to subsequent infection. Clearly, the many seropositives unaware of their status (CDC, 2006) are ill-equipped to disclose. Moreover, as the data below indicate, seropositives may knowingly deny their status when asked. Also, though those who consistently disclose may engage in fewer high-risk activities, this relationship is complex (Parsons *et al.* 2005). If both partners are HIV positive, for example, disclosure can be used to justify unprotected relations, despite the risk of re-infection or other sexually transmitted infections (STIs) (Simoni and Pantalone 2004, Sheon and Crosby 2004, Serovich and Mock 2003). Some thus conclude that disclosure should not be the centrepiece of prevention messages (Simoni and Pantalone 2004, Sheon and Crosby 2004). Instead, many AIDS service organisations (ASOs) (Adam 2005, Duffin 2004) and others (e.g. Frascino 2005) still hold that each partner (*regardless* of serostatus) is responsible for practising risk-reduction. Also, given the potential for violence or criminal prosecution, some hesitate to press vulnerable individuals to disclose (Gillins *et al.* 2000).

## 2.10 Disclosure and Types of Social Relationships

While there are some of these problems highlighted above around disclosure, researchers (e.g. Chervenak and Weirs, 1989; Marks et al., 1992; Hays et al., 1993; Mason et al., 1995) cite disclosure to be a complex phenomenon. There are many reasons given for the complexity and one such reason relates to varying types of sexual relationships. The complexity of this disclosure theme of social relationships can be simplified into a model that displays two categories of social relationships (sexual and nonsexual) relative to disclosure or nondisclosure of one's HIV positive status. This would include the following types; not disclosing in "anonymous, casual, or short-term sexual relationships" to disclosing in "long-term, non-casual, committed sexual relationships." (Bairan et al 2007 p. 70)

Findings indicate that seropositive men and women are more likely to inform intimate lovers, spouses and close friends than to tell casual sexual partners, immediate family members or co-workers. In addition, disclosure is likely to increase with deterioration in physical health, independently of the length of time since testing HIV seropositive. Most of the findings are consistent with a Reasoned Action perspective (Fishbein and Ajzen, 1975) which emphasizes that decisions about disclosure are influenced by a person's perception of the social, psychological and material consequences of informing others (Mason et al., 1995; Leask et al., 1997).

A qualitative inquiry by Bairan et al (2007) attests to some of the reasons for a particular position to disclose depending on how close people are;

One participant stated,

"...Being a sex worker, I have relations with people that I don't even know. I don't want to know your name. So I don't tell them [disclose] right the bat... And if I don't say that [I'm HIV+]". (Bairan et al 2007 p. 79)



Participants in all focus groups declared that HIV positive people were unlikely to disclose their HIV status to casual sex partners. The consensus was that they are not going to tell. One stated,

"They [casual sex partners] don't even exchange names, much less status." (Bairan et al 2007 p. 84)

Another said,

"So if you don't expect to see them again, you wouldn't disclose." (Bairan et al 2007 p. 84)

Not only do HIV positive persons generally not tell their casual sexual partners, most participants in all the focus groups were in agreement that people often lie in these situations. One said,

"You got a lot that does that [lie]. They'll tell you they don't have it. Ain't nothing wrong with me. I don't use no condoms." (Bairan et al 2007 p. 93)

The main reason given for not disclosing was that the HIV positive person wanted sex. Another stated,

"Most people I know, they would [lie]. Cause basically they want what they call a quicky... They just want to have a quick sex and go on." (Bairan et al 2007 p. 95)

Another said,

"The reason I think that they lie like that is because they want to get their sexual appetite, you know, fulfilled!" (Bairan et al 2007 p. 95)

One participant stated that they lie by omission; they just don't tell, whereas another inferred that they use deception versus outright lying.

"You can give them an honest answer, and ... never once tell them I have HIV!" (Bairan et al 2007 p. 99)

## 2.11 Theories and Models in Disclosure Relationships

Research in disclosure has relied on several theories but the notable ones include: Lazarus and Folkman's theory of stress and coping, health belief model and the theory of planned behaviour. The last two are used in making predictions of a particular event happening or the likelihood of a particular action. Below we present the theories that have been cited frequently in such studies.

### 2.11.1 The Health Belief Model

The health belief model (figure 2.2) was developed initially by Rosenstock in 1966 and further by Becker and colleagues throughout the 1970s and 1980s. Their aim was to predict preventative health behaviours and the behavioural response to treatment in acutely and chronically ill patients. According to the model, ways of behaving are based on subjective schemata (beliefs). Depending upon an individual's subjective cognitions, being informed by the health worker that one is HIV positive may signal an opportunity to be secretive, despite having been counseled. Over recent years, the model has been used to predict many other health-related behaviours. According to the health belief model, behaviour for instance to disclose or not is a product of a set of core beliefs. The original five core beliefs that are at the centre of disclosing or not are the individual's perception of:

- § *The susceptibility* to illness – 'My chances of getting more and more infected are high';
- § *The severity* of the illness – 'HIV/AIDS is a serious illness';
- § *The costs* involved in carrying out the behaviour – 'Telling my partner that I am positive will make him reject me';
- § *The benefits* involved in carrying out the disclosure – disclosing that I am positive will make me be supported and
- § *Cues to action*, which may be helpful (e.g. counselling information and health education leaflets).

The health belief model suggests that these core beliefs are used to predict the likelihood that behaviour (disclosure or non-disclosure) will occur. The model can be diagrammatised as follows:

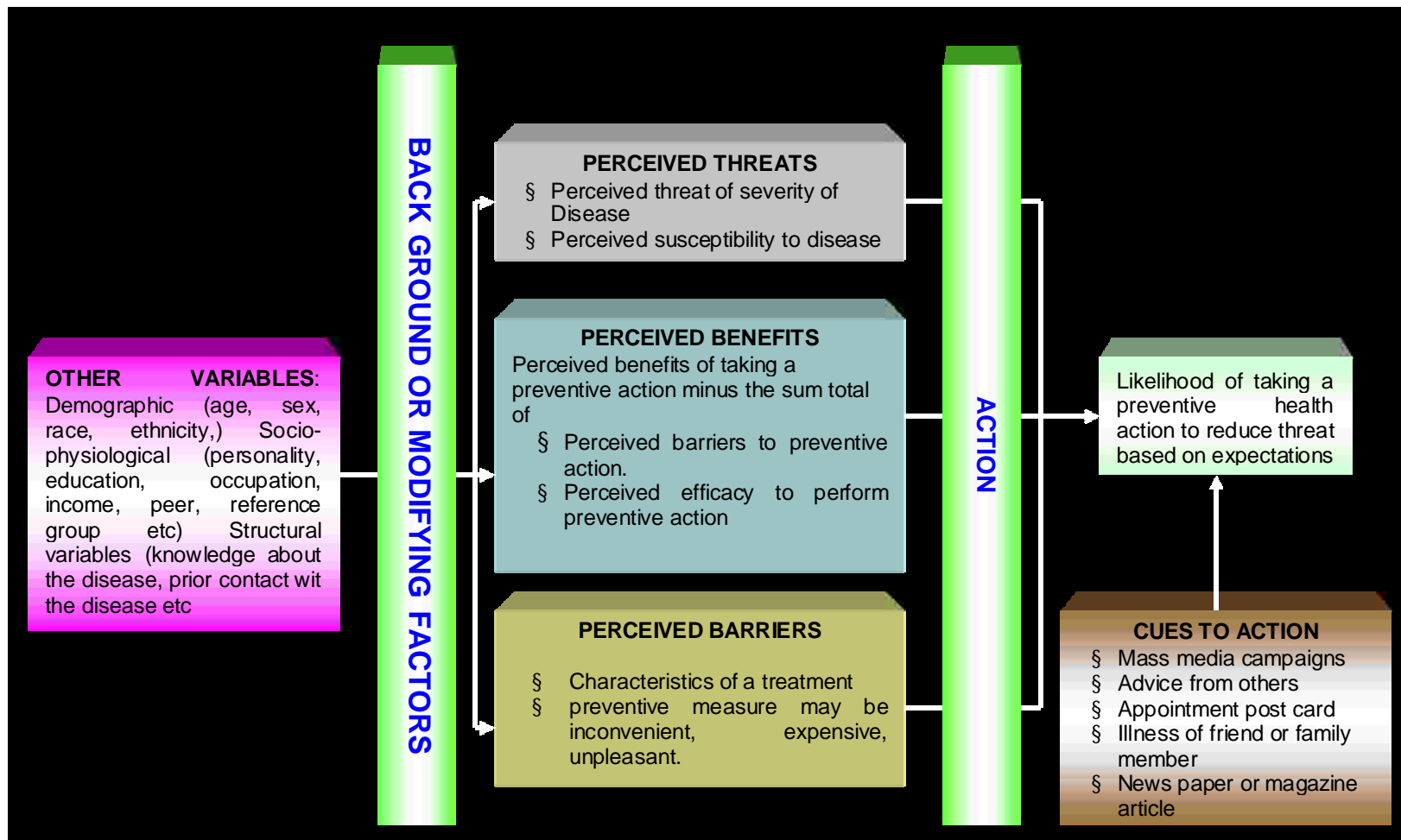


Figure 2.2 Health Belief Model (Rosenstock 1966)

### 2.11.2 The Theory of Planned Behaviour

The theory of planned behaviour (figure 2.3) was developed by Ajzen and colleagues (Ajzen, 1985; 1988; Ajzen and Madden, 1986). It emphasizes behavioural intentions as the outcome of a combination of several beliefs. The theory proposes that intentions (about disclosing) should be conceptualized as 'plans of action in pursuit of behavioural goals' (Ajzen and Madden, 1986), and that these are a result of the following composite beliefs:

*Attitude towards a certain behaviour (to disclose)* – These are composed of a positive or negative evaluation of a particular behaviour, and beliefs about the outcome of the behaviour ('Disclosing will be harmful and will lead to rejection).

*Subjective norm* – this represents the beliefs of important others (partner, counsellors, parents, pastors) about the behaviour, and the individual's motivation to comply with such beliefs ('People who are important to me will approve if I disclose my positive status').

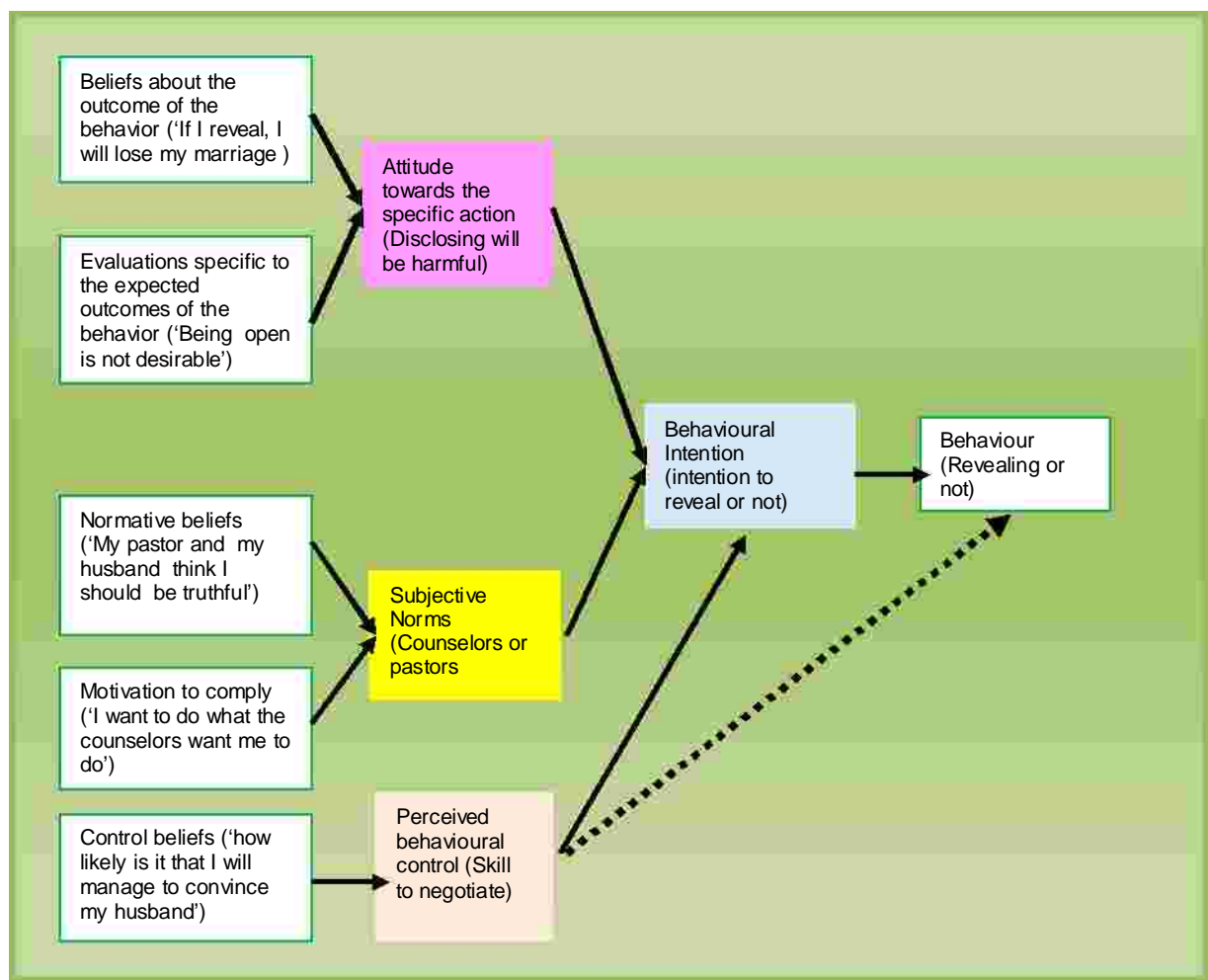
*Perceived behavioural control* – comprising a belief that the individual can carry out a particular behaviour (to tell or not to tell) based on a consideration of internal control factors (e.g. skills, abilities, rightness of information) and external control factors (e.g. obstacles, opportunities) – both of which are related to past behaviour.

These three factors predict behavioural intentions, which are then linked to behaviour (to tell or not to tell). The theory of planned behaviour also states that perceived behavioural control can have a direct effect on behaviour without the mediating effect of behavioural intentions. Applied to this study, the theory would predict that someone will have high intentions to reduce the chances of being rejected in marriage (behaviour intentions) if she believes that:

Revealing one's status will reduce the chances of re infection and be beneficial to her health (attitude to the behaviour); or will make one lose her marriage.

The important people in her life (partner, parents, pastors,) want her to be open (subjective norm); and she is capable of negotiating her seropositive status due to her past experiences and evaluation of her husbands position (high behavioural control).

The model also predicts that perceived behavioural control can predict behaviour without the influence of intentions. For example, a belief that the individual would not be able to exercise because they are physically incapable of doing so might well be a better predictor of their exercising behaviour than their high intentions.



**Figure 2.3 Theory of Planned Behaviour** (Ajzen and Madden, 1986)

### **2.11.3 Lazarus and Folkman's Theory of Stress and Coping**

Lazarus and Folkman's theory of stress and coping provides an appropriate physiological perspective for study (Lazarus and Folkman, 1984). This theory proposes that a person's cognitive appraisal of a situation or event will determine if that situation or event is viewed as a threat, as well as determine the person's response. Stress theory indicates that a person's view of the world and their assessment of how they are able to respond to difficult situations are critical for successful coping (Lazarus and Folkman, 1984; Lazarus, 1991). Because of the stress associated with disclosure of HIV infection, women's ability to effectively cope may be strained, especially in the context of a relationship where the women may be at risk because of pregnancy. While it may be necessary for women to disclose their HIV infection to obtain needed resources and support, negative consequences may be associated with such disclosure. Therefore, women's decisions related to disclosure of their HIV status (e.g. if to disclose or how to disclose) are likely to be influenced by their appraisal of the positive or negative consequences of disclosure.

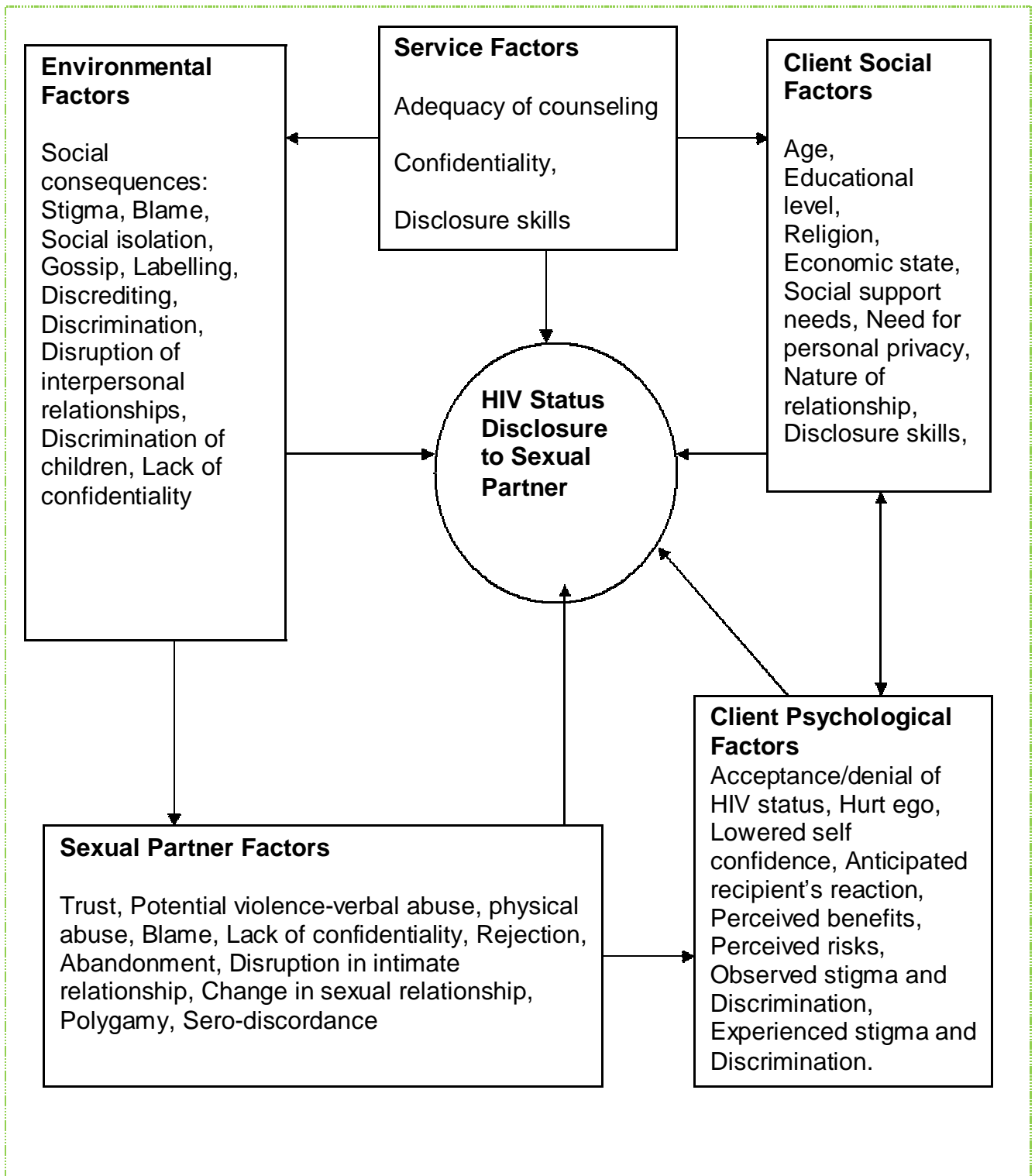
In this study, we are going to use Lazarus and Folkman's theory of stress and coping. This is appropriate in situations where an event has already happened (status was revealed and clients were counselled) than in circumstances when HIV status is unknown and the researcher wants to make predictions as to what would be the case. The later situation is more likely to elucidate experiences in real life situations than the former in hypothetical situations.

### **2.12 Summary**

The literature has shown that choosing to disclose one's HIV status is a serious decision that involves calculating what is at stake in telling or concealing the diagnosis. The decision to tell or not to tell has benefits and risks. For an HIV-positive woman, the calculus of disclosure includes determining the risks of losses vis-a-vis gains. When one decides to disclose, there are quite a number of reasons

for disclosure and these include: it is the right thing to do to protect others, reaffirmation of self, desire for increased social support, catharsis, seeking help, desire to test someone's reaction, being in a close or supportive relationship, and a mechanism for dealing with the condition. However, the reasons for not disclosing include: stigma, need for privacy, fear of rejection by sexual partners, threats to personal well-being, potential loss of income, substance use, difficulty in communicating, denial, low viral load, type of sex, location of sexual encounter, legal reprisal (fear of arrest), and condom use (no need to disclose).

## 2.4 Conceptual model of Difficulties of disclosure of HIV status to sexual partners





## **CHAPTER THREE - THE RESEARCH PROBLEM**

### **3.0 Statement of the Problem**

An opt-out antenatal HIV testing policy is currently in place in all clinics in Lusaka for pregnant women. However, this policy does not extend to their male partners. PMTCT guidelines recommend that all HIV-positive expectant women be encouraged to disclose their HIV infection to their partner. Disclosure may enable women and their partners to negotiate HIV prevention practices such as condom use and post-exposure prophylaxis, as well as securing important psychological and social support. The PMTCT program in Zambia emphasises partner notification and awareness of this on the family has been seen to be very helpful. Although there is an increased awareness of the impact of HIV on the family there has been little systematic research in the area of partner notification especially in Zambia.

While HIV disclosure and nondisclosure may have impacts on HIV positive clients and their sexual partners, family, and friends, very little is known in Zambia on the determinants of disclosure. The HIV AIDS counselling guidelines from all training institutions recommend that all HIV positive expectant women be encouraged to disclose their HIV infection to their partners and that this should be viewed as a process rather than an event.

At the moment, we cannot account for (a) the ethical dynamics of status disclosure (b) the rates of partner notification in expectant women with HIV, (c) the experiences of expectant mothers in calculating the risks and benefits of disclosure to their partners, (d) the prevailing disclosure and types of social relationships, (e) impacts of such disclosure and (f) what the best or ideal model of HIV disclosure we should use in Zambia.

These concerns show a large gap in our prevention strategies and if we do not undertake this study, we may not achieve the desired millennium development goals.

### **3.1 Research Question**

This study sought to answer two research questions;

1. What risks or rewards do expectant mothers anticipate when considering disclosure of their HIV status to their male partners?
2. Why do they choose a particular pattern<sup>1</sup> of disclosure?

### **3.2 General Objective**

To determine factors associated with disclosure or non-disclosure of HIV status to male partners among expectant women on the PMTCT programs in selected clinics in Lusaka Urban.

### **3.3 Specific Objectives**

1. To describe the rate of disclosure.
2. To explore the time it takes expectant women to disclose to their partner after learning about their HIV positive status.
3. To explore the anticipated risks associated with disclosure of HIV status to their partners.
4. To explore the anticipated rewards/benefits associated with disclosure of HIV status to their partners.
5. To determine whether the nature of sexual relationship has an effect on disclosure of HIV status to their partners.
6. To describe the patterns of HIV status disclosure to their partners.

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<sup>1</sup> Full disclosure, partial disclosure and no disclosure at all.

## **CHAPTER FOUR - METHODOLOGY**

### **4.0 Dimension of study and Design**

This was a cross sectional explorative descriptive and mixed study. The study was driven by the deductive and abductive strategies as constructed by Blaikie (2000) based on the philosophy of realism and interpretivism. This realist and interpretive research is set to rely on studying predefined dependent and independent as well as the full complexity of human sense making as the situation emerges (Walsham 1993; 1995; Kaplan and Maxwell, 1994; Johnson, 2000). This called for the researcher to collect quantitative and qualitative data.

### **4.1 Study Site and Sampling Procedure**

The study was done in Lusaka urban. The site has twenty three clinics offering PMTC services across four sub districts. The study was conducted in four clinics, one from each sub district and these were Kanyama, Matero Reference Centre, Chelstone and Chilenje clinics. A simple random sampling (lottery) method was used to select the four clinics.

#### *Quantitative Data Sampling*

In order to determine an ideal sample for this study,      used the statistics given to us by the district health management team. There are about 250 expectant mothers who are HIV positive in an antenatal setting within Lusaka urban over a period of 3 months. This gives us a population of about 750 in three months (The period we intend to do the study). In order to yield an adequate sample from a known population, Yamane formula (below) which is appropriate in such cases will be used. This gives a sample of 260 women. To draw the sample elements for the study, we used the formula below:

$$n = \frac{N}{1 + N(e)^2}$$

Where:  $n$  is the desired sample size

$N$  is the known population size and

$e$  is the precision set at .05

Each clinic proportionately rendered a sampling frame of the following proportion 0.2 for Chilenje, Chelstone and Matero while Kanyama will render 0.4. In total, we drew 52 from Chilenje, 52 from Chelstone, 52 from Matero, while Kanyama gave us 104.

#### *Inclusion Criteria*

Only HIV positive expectant women who were attending antenatal clinics and whose names appeared on the PMTCT programme register in the previous two months at the selected centres were included in the study. In this way the researcher had an opportunity to include women who may or may not have revealed their status. The rationale was based on Sherr et al.,'s (1977) who argue that it takes a woman no less than two and half months to reveal her status to closer relatives.

#### *Qualitative Data Sampling*

Purposive maximum variation non-probability sampling was used to draw mothers who meet the inclusion criteria. Purposeful sampling is the dominant strategy in qualitative research (Lincoln and Guba, 1985; Patton, 1990) and in this study, it was chosen because the researcher was seeking a wide range of information and cases which could be studied in depth on disclosure patterns. The sample to yield

qualitative data was determined after the preliminary quantitative analysis. This was preferred because the researcher wanted to seek representative experiences by including a wide range of extremes. The method sounds odd, but it worked as an extension of the statistical principle of regression towards the mean - in other words (Dennis, 2004). But by seeking maximum variation, average people were automatically included. To determine which mothers needed to be interviewed, the researcher picked mothers who fell into extreme and central categories. The aim was to try as much as possible to obtain as representative a picture as possible of the extent to which particular experiences occur, and which categories of mothers. The principle is that the researcher wanted to aggregate answers to be close to the population's answers as would be elicited from the survey. When using purposive maximum variation non-probability sampling, it is not possible to ascertain the sample size beforehand. However, a rule of thumb says that when the survey sample size is less than 30, the minimum purposive sample is 12. Any sampling units that may be included beyond 12 will have to be determined by saturation<sup>2</sup> of categories according to Glaser and Strauss (1967:65).

## 4.2 Data Collection

For this project, the researcher collected data using survey questionnaire and one to one in-depth interviews.

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<sup>2</sup> In their seminal text *The Discovery of Grounded Theory: Strategies for Qualitative Research*, Glaser and Strauss (1967:65) declared that saturation refers to when no additional data are being found whereby the researcher can develop properties of the category. They submitted, "as he sees instances over and over after they have seen coded incidents for the category a number of times

### 4.3 Key variables

Dependent variable	Independent Variables
Disclosure of HIV status to sexual partner	Rate of disclosure: The number of disclosures made out of the total number of participants in percentages.
	Time and Disclosure: Time it takes to disclose- 0 day to 365 days
	Calculating risks: (i) intending to reveal ones serostatus as one adjusts to the diagnosis, (ii) assessing one's disclosure skills, (iii) evaluating the recipient's circumstances, (iv) anticipating the recipient's reaction, (v) when and where to reveal one's status
	Benefits: (i) emotional support - relief from sharing a burdensome secret. (ii) social support - e.g., an opportunity to discuss their feelings about the disease and educating partner about the risks of having un safe sex (iii) eliminating complicated adherence rituals from partner (iv) instrumental support - e.g., help in grocery shopping or meal preparation, transportation to and from appointments with health care providers
	Nature of Relationship: Casual sexual relationship, Short- term sexual relationship, Long -term sexual relationship, Cohabiting, Married, Divorced and single, Widowed and single.
	Difficulties of disclosure: (i) Psychological - denial, fear of triggering violent episodes, accompanied by regrets, fear of rejection by sexual partners, Personal feelings of shame and the threat of being stigmatized (ii) Social - difficulty in communicating, potential loss of support, abandonment, need for personal privacy.
	Pattern of disclosure: (i) Secretive disclosure - whereby the woman does not reveal to the partner or any one. (ii) Selective disclosure - where the woman reveals to relatives only or to nearly everyone but not her partner or to significant others including the partner.

#### **4.4 Operationalisation of Variables**

This study tested the hypothesis, which was:

There are no difficulties experienced by expectant mothers in disclosing their HIV status to their male partners.

The key variables of the study were: Disclosure, patterns of disclosure, difficulties, benefits, the right time of disclosure, nature of relationship and calculating risks.

These variables were operationalised as follows:

1. Rate of disclosure was operationalised as the number of disclosures made out of the total number of participants and was measured in percentages.
2. Time and disclosure were operationalised as the right time in terms of the period a woman takes to make personal adjustments before revealing her serostatus to the partner or others and these were measured on a numeric scale using the values: 0 day (still waiting for the right time up to day) or 1 day or 7 days or 30 days or 90 days or 365 days.
3. Calculating risks as a moderator or process variable was operationalised as intending to reveal one's serostatus as one adjusts to the diagnosis, assessing one's disclosure skills, evaluating the recipient's circumstances, anticipating the recipient's reaction, when and where to reveal one's status. These were measured on a 5 point numeric scale.
4. Benefits as factors motivating one to reveal the serostatus was operationalised as rewards accruing to one. These rewards are: desiring to obtain (i) emotional support (relief from sharing a burdensome secret) (ii) social support (.g., an opportunity to discuss their feelings about the disease and educating partner about the risks of having unsafe sex (iii) eliminating complicated adherence rituals from partner (iv) instrumental support (e.g., help in grocery shopping or meal preparation, transportation to and from

- appointments with health care providers). These were measured on a 5 point numeric scale.
5. Nature of relationship was operationalised as the degree of sexual relationship in which one is involved and it was measured on a nominal scale as casual sexual relationships, or short-term sexual relationships or long-term sexual relationships, or cohabiting (*living as married*) or married or divorced and single or widowed and single. These were measured on nominal scale.
  6. Difficulties as negative consequences of disclosure making one silent about the serostatus was operationalised as biological ( Low viral load, advancement of disease) psychological (denial, fear of triggering violent episodes, accompanied by regrets, fear of rejection by sexual partners, Personal feelings of shame and the threat of being stigmatized) and social (difficulty in communicating, potential loss of support, abandonment, need for personal privacy) .These were measured on a 5 point numeric scale.
  7. The patterns of disclosure as revelation of serostatus was operationalised in two ways as (i) secretive disclosure whereby the woman does not reveal to the partner or any one (ii) selective disclosure where the woman reveals to relatives only or to nearly everyone but not her partner or to significant others including the partner. These were measured on a nominal scale.

#### **4.5 Data Collection Techniques and Application**

In-depth interviews and a survey structured questionnaire were used to obtain information in this study.

##### *Development of the Questionnaire*

The disclosure questionnaire (Appendix I) was developed and validated using the guidelines of developing a new research instrument by *Guillemin et al.*, (1993) and Burns and Grove (1997) approaches. The development was based on



theoretical knowledge in the domain of disclosure. After reviewing relevant literature, key concepts that were thought to be reflective of HIV/AIDS and disclosure behaviour were identified. This was followed by identification of variables and their operationalisation. In this way, it was then possible to cast the variable items into questions relying as much as possible on what authors in various literature applied meaning to the terms.

Some of the questions were constructed on an ordinal scale, in order to eliminate social desirability biases. Social desirability according to Smith (1981:300-302) are tendencies by most participants to give answers that present a favourable self concept to make them appear “well adjusted, or unprejudiced or democratic or open minded or rational.” In this study, social desirability was controlled for by providing in some questions examples as enhancement in order to provide extra contextual information to participants so as to make it easy for them to give honest answers (Neuman, 2000:258).

When the instrument was developed, what was needed was to accord them measures of validity and reliability. The approach, used in this study, was based on the Delphi technique (Bernard, 2000:247) and the recommendations by Oberle *et al.*, (2000). The process involved content validity check and reliability check. These were applied as follows:

#### *Content Validity Check*

Before introducing an instrument for pilot testing, the developed instrument was validated in terms of content (Bernard, 2000:48). An informal think-aloud session was organised to guarantee content validity to the questionnaire. Content validity was examined at the level of the entire instrument and at that of the individual items. The questionnaire was examined to see if the variables fitted with the theoretical concepts. Content validity was also examined at the item level to determine the extent to which each item was to be measured. To achieve all these, the questionnaire was reviewed by staff at Kara Counselling and staff in the School of Humanities and Social Sciences,

who are all researchers as well as teachers of academic disciplines in psycho social counselling. This was done in order to obtain expert opinions on the relevance of items to the purpose of the study and whether the test items would provide answers to the raised research questions. Other areas included checking, possible wording problems, and clarity of instructions. Wording and conceptual problems were discussed, and additional ideas were invited in order to ensure that sufficient issues relevant to the inquiry were covered. Following comments raised, the draft instrument was revised eliminating irrelevant items, collapsing related statements, and addressing a number of wording problems. This helped to eliminate totally irrelevant items from the instrument (Chaiyawat, 2000), and to re-phrase or supply new wordings for items related to the measured constructs where it was pointed out (Hughes, 1998; Aminzadeh *et al.*, 1999).

### *Reliability<sup>3</sup> Check*

Although validation of data collection instruments is a necessary step in research (and this is emphasised in research manuals e.g. Seliger and Shohamy, (1989), Hatch and Lazaraton, 1991), there is little detail and practical guidance on how validation should be conducted. As Converse and Presser (1986:52) point out, discussing the issue of pre-testing questionnaires, there are no general principles of good pre-testing, not even systematisation of practice, not even consensus about what is expected; regrettably, researchers do not leave any records for each other. Alderson and Banerjee (2002) make similar arguments and the researcher's own readings confirm that few studies actually report validation data processes. This makes it practically difficult to obtain information about commonly accepted practices and standards in the field. The decisions made in the validation process in this study were therefore based partly on the literature, and largely on the researcher's sense of plausibility regarding situational analysis and making decisions in dealing with practical constraints.

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<sup>3</sup> The reliability of an instrument refers to its consistency. There are two aspects of reliability. The first one is called external reliability. This refers to the degree of consistency with which an instrument gives one a correspondence between two interval tests. This is achieved by a test and retest. The second one is called internal reliability. This refers to a scale of measurement whether it is measuring a single idea and whether the items that make up the scale are consistent (Bryman and Cramer, 1990:70-73).

Seliger and Shohamy (1989), Hatch and Lazaraton (1991) and Alderson and Banerjee (1996) guided the process of reliability that was used in this study. From the methods that these authors recommend, for establishing the reliability of data collection instruments, which are applicable to new questionnaires, the researcher did not use the *Cronbach alpha* coefficient. This was not done because it was going to be of limited value for nominal and ordinal scales upon which the SASSQ was framed. In addition, *Cronbach alpha* coefficient does not reveal whether the obtained quantitative value is an indicator of item heterogeneity<sup>4</sup> or unreliability. Furthermore, Alderson and Banerjee (2002) point out that internal consistency may not be a good check of questionnaire reliability since questionnaire items in research, unlike items in a test or examination, are usually not intended to measure one thing but many things. In order to be sure, it was necessary to look into individual items. To do this, the researcher chose the test–retest method measure of external reliability as an appropriate way of guaranteeing reliability for this study. The test–retest method was chosen as the main reliability check method because it enabled the researcher to establish the reliability of the questionnaire for stability over time and, because it is a relatively feasible method to apply. Two considerations were taken to be important to bear in mind when using this method: first, the variables measured could be subject to significant change over time, and second, a repeated administering of the same questionnaire may result in the sensitisation of the participants to the issue being researched. Both concerns are related to the time between the test and retest, which implies that the decision about the appropriate length of time is crucial; however, little information is available on this issue in the literature. So to overcome this limitation, we chose to pilot test the instrument at Chainama Clinic that will not be part of the study.

This pilot testing served two purposes. The first purpose was to let the researcher have an experience of how to go about interviewing respondents. The second one was to test the data collection tools with a view to perfecting them. The details of the process appear below.

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<sup>4</sup> Diverse in character or varied in content.

Twenty-two participants participated both in the interviews and the test and retest of the questionnaire. Participants were asked by the researcher to seek clarification in case of difficulties in understanding or interpreting items. The first questionnaire had 36 items. Two pilot tests were done on the same participants over four weeks. On the first occasion, the general feedback was positive. It was surprising that participants were interested in the topic and the study itself. However, on the second occasion, some of them were irritated about having to fill the questionnaire for the second time. The researcher, however, explained the purpose of the second test and asked for their cooperation. Their cooperation was in turn obtained.

After the retest, a qualitative analysis was done (not to aggregate the data) to compare individual responses on each item by looking for consistency between the initial responses and the second responses. This was done to see how the participants kept on picking the same answers. Some questions that gave inconsistent and ambivalent responses were dropped whereas others were revised. In the end, the items in the questionnaire were reduced from 36 to the present 32 items (Appendix I).

### *Administering the Questionnaire*

All expectant mothers who met the inclusion criteria attending any one of the PMTCT sessions were approached to take part in the study. Before being seen by a doctor, or clinical officer or nurse they were handed a questionnaire. In order to maintain some control over the completion of the questionnaires, the researcher alone was responsible for distributing them. Completed questionnaires were put in envelopes provided and deposited by the women in a box within the clinic. Those who were not able to read or write were assisted by the researcher and trained research assistants to answer the questionnaire in a private room that was made available.

### *In-depth Interviews*

Noting that the researcher wanted to seek representative experiences by including a wide range of extremes of participants and experiences that were churned from the preliminary descriptive analysis, only participants who fell into extreme zones and those around the mean were interviewed thematically (Appendix II). The reasoning behind starting with the survey questionnaire informing the in depth interviews were informed by sequential paradigm crossing. This is where one paradigm is used initially to create grounds for the next. Sequential paradigm crossing is the researcher wants to overcome the deficits in one paradigm and enrich the research in an attempt to confirm or corroborate findings or cross validate findings. The idea of having these phases is to allow the researcher make well informed interpretations of the quantitative data to inform or enrich the qualitative data. This variant augments the generalisation of qualitative findings to different samples which would be the case in pure idiographic inquiries.

## **4.6 Data processing and Analysis**

### **4.6.1 Qualitative Data Analysis**

The first step in analysis was coding which entailed reading through the data several times to identify common ideas and develop categories, patterns or themes. Most of the categories emerged from the types of questions that were asked and also while examining the data.

The data was then analysed using content analysis to show how women make disclosure decisions. This occurred six weeks after the preliminary quantitative descriptive analysis. In this study, data was left at a thematic level of analysis. This means that what a respondent said was usually taken as an accurate reflection of what her experience was really like (lived experience).

#### **4.6.2 Quantitative Data Analysis**

Quantitative data was analysed using SPSS software version 14.

#### **4.7 Ethical considerations**

A written consent was obtained from the women after explaining the purpose of the research and ensuring that they understand clearly the issue at hand. This took place after clearance by the UNZA research ethics committee      permission obtained from the Lusaka District Health Management. The details appear in the Appendices.

Information obtained from the women during the study shall be kept strictly confidential as it borders on personal information which most people would rather keep to themselves. A private room was made available for answering the questionnaire. Envelopes were provided for the women to put in their completed questionnaires. The answered questionnaires will be kept by the researcher in the strictest of confidence for only six months after which time all the responses will have been examined. There were no names written on the questionnaire.

The possibility of emotional distress to the participants that may be evoked by discussing this emotive subject was a risk which was addressed by selecting research assistants that were equipped with psychosocial counse      skills to address this, (the researcher too is a trained and practicing psychosocial counselor). The women were informed that they will benefit more information on HIV transmission, prevention, coping skills and communication skills.

A token sum of money was given to each participant as transport reimbursement and as an expression of gratitude for availing time and information.

## **CHAPTER FIVE – RESULTS**

### **5.0 Introduction**

In this study, the research findings are presented using themes and de Vaus's (2001) guide. The results chapter is divided into sections as follows: (i) descriptive demographic findings, (ii) position just after counselling, (iii) Period of time taken to disclose (iv) rate of disclosure to partner, (v) Pattern of disclosure, and (vi) reasons (factors) for choosing a particular pattern of disclosure.

Data for this analysis was drawn from 260 HIV + expectant women and the results are from a cross sectional study carried out in the antenatal clinics of four urban health centres in Lusaka urban in the months of April, May and June 2009. All participants were volunteers and signed a written informed consent statement prior to taking part in the study. The total number of patients who were approached for the study who satisfied the inclusion criteria was 260, of which none declined, leaving the study population sample of 260.

## 5.1 Descriptive demographic findings

Parameter		
<b>Age</b>		
Mean	26.0	
Standard Deviation	5.3	
<b>Occupation</b>	<b>Frequency</b>	<b>Percent</b>
Student at Secondary School/Primary	2	.8
Sales and clerical job	13	5.0
Professional	8	3.1
Business	95	36.5
Home maker	142	54.6
<b>Total</b>	<b>260</b>	<b>100.0</b>
<b>Client's Educational Status</b>		
Never been to school	1	.4
Primary school	135	51.9
Lower secondary school	95	36.5
Lower secondary school	22	8.5
College/University	7	2.7
<b>Total</b>	<b>260</b>	<b>100.0</b>
<b>Client's Religion</b>		
Christian but a Catholic	51	19.6
Christian but a Pentecostal	110	42.3
Christian but of another faith (Seventh Day, New Age)	99	38.1
<b>Total</b>	<b>260</b>	<b>100.0</b>
<b>Marital Status</b>		
In a casual sexual relationship	6	2.3
Married	221	85.0
In a short-term sexual relationships	9	3.5
In a long-term sexual relationships	7	2.7
Cohabiting (living as married)	4	1.5
Divorced and single	6	2.3
Widowed and single	7	2.7
<b>Total</b>	<b>260</b>	<b>100.0</b>

**Table 5.1.1 Respondents' demographic profile**

Participants were predominantly Zambian black women of reproductive age with no incomes. Within the sample, the majority  $n= 221$  (85 %) were married and very few  $n = 39$  (15%) either led a solitary life of being single, divorced or widowed or cohabiting or having short term relationship or were in a casual relationship. Generally, the expectant mothers were not educated. Just about half of these expectant mothers  $n = 134$  (51.5%) had attended primary school,  $n = 95$  (36.5%) attended lower secondary education,  $n = 22$  (8.5%) attended upper secondary education completed their senior secondary education,  $n = 7$  (2.7%) had gone as far as college or university whereas only  $n = 1$



(0.4%) had never been in school. Concerning their religious faith, all of them claimed that they were Christians. Majority of them  $n = 150$  (57.7%) were non Pentecostals Christians as compared to  $n = 110$  (42.3%) who claimed to be Pentecostal Christians. It was surprising to note that though everyone was a Christian; their degree of religiosity in terms of reading the bible or praying was extremely low. In terms of reading the bible, only  $n = 7$  (2.7%) read the bible frequently as compared to  $n = 253$  (98.3%) who read it poorly (as either often, rarely or not at all). Concerning praying, only  $n = 3$  (1.2%) always prayed,  $n = 90$  (34.6%) prayed frequently and  $n = 167$  (64.2%) prayed but poorly (as either often, rarely or not at all). Table 5.1.1 shows this profile.

## **5.2 Position Just After Counselling**

Figure 5.2.1 Frequencies of women who participated in interventions that teach techniques for disclosing.

When the expectant mothers were asked as to how long ago they knew their status, the range was wide - 2 months to 84 months. The mean was 4.3 months (SD  $\pm 8.5$ ). In spite of the fact that these expectant mothers were counseled before and after HIV status assessment, very few expectant mothers  $n = 8$  (3.1%) actually had participated in interventions that teach techniques for disclosing (Figure 5.2.1).

### 5.3 Period of time taken to disclose HIV status

Figure 5.3.1 Period it took or will take when found to be HIV + and counseled to reveal serostatus

Nearly all participants  $n = 190$  (73.1%) took one day to disclose their status to their partners and the rest were dragging or would drag for some time, when they were found to be HIV + and counselled (figure 5.3.1).

The narratives below (using initials) attest to the types of disclosures and the motives for the stand taken to disclose or not to.

“Ah that is a difficult matter to handle. I have not disclosed to anyone yet. Intend to disclose to my husband only. When the time is right. I may only inform him six months after the baby is born, i.e., 10 months from now. One year-but for as long as I may postpone it. I will pretend I have not been tested before.

I will tell him to accompany me to the antenatal clinic for information about the baby. Then, have the test done for both of us-‘know our status at the same time’. I don’t even know how to start, how to put it to him for him to agree to come to the clinic with me. Since he is married, perhaps his wife may have let him know about PMTCT.”

M. K. 23 Unmarried and was in an unfaithful relationship

“I have disclosed to my spouse, his brother, my mother and my close friend. It only took one day. I just handed him the new start card for him to go and use on same day and explained the result. I had told him that I was going for test earlier. “

O. M.

“I have disclosed to my husband only- our own secret. I told him after one week of the test. I was told so at the clinic- so he also gets tested but he has refused, says he doesn't work so it's ok.”

I. C. M.

“I have disclosed to my husband and elder sister. I told my husband so that he may know, so that he may go for testing too, so that if need be we may start treatment together. I told my sister so that she may know and so that she may not blame me in future for hiding. I love my husband. I respect my sister. Actually, I told my husband the same day. I told my sister one week later. I was direct. I told him after dinner while resting; he asked how my visit to the clinic was. That was when I explained everything.”

A. M. C.

“I have informed my aunt and not my husband (cohabiting). It took me one day to tell my aunt. I will never tell my partner because we are not married. Our relationship was a casual one. It took me one day to inform my aunt. I had only one partner and I do not intend to reveal my status to him.”

G. M. L.

#### **5.4 The rate of HIV status disclosure**

The disclosure rate to sexual partners in this study was extremely high  $n= 148$  (56.9%) with only  $n= 10$  (3.8%) having declined to reveal their status to their sexual partners (Table 5.4.1).

**Table 5.4.1 Rates of disclosure**

Disclosure Rate	Frequency	
	n	%
I have been secretive and have not revealed my sero-status to my partner	10	3.8
I have been secretive and have not revealed my sero-status to any one	36	13.8
I have been selective and have revealed my sero-status to my partner only	148	56.9
I have been selective and have revealed my sero-status to my relatives only	10	3.8
I have been selective and have revealed my sero-status to nearly everyone but not my partner	3	1.2
I have been selective and have revealed my sero-status to nearly everyone including my partner	53	20.4
<b>Total</b>	<b>260</b>	<b>100.0</b>

## **5.5 Pattern of disclosure**

The pattern of disclosure of HIV status was influenced by the difficulties, anticipated risks and anticipated benefits on an individual.

### **5.5.1 Difficulties and Disclosure**

There were more participants experiencing difficulties on the right of the midpoint “somehow” than on the left for each variable except for self denial (I disagreed that I was positive) as evident from frequency table 5.5.1.1. 52.7% had fear of triggering violence, 54.2% had fear of rejection by partner, 79.2% had personal feelings of shame, 86.6% had fear of being stigmatized, 55.4% had fear of being abandoned by partner and 55.0% had a desire for personal privacy.

### 5.5.1.1 The Fears or Difficulties Considered in Disclosing Their HIV Status

Position After Counsel	Frequency and Level of difficulty					Total
	Not all	Very little	Somehow	Much	Very Much	
I disagreed that I was positive	157(60.4%)	28(10.8%)	37(14.2%)	10(3.8%)	28(10.8%)	260(100%)
I had fear of triggering violent episodes	63(24.2%)	23(8.8%)	37(14.2%)	29(11.2%)	108(41.5%)	260(100%)
I was filled with regret	5(1.9%)	2(.8%)	21(8.1%)	24(9.2%)	208(80.0%)	260(100%)
I had the fear of rejection by my partner	61(23.5%)	20(7.7%)	38(14.6%)	31(11.9%)	110(42.3%)	260(100%)
I had personal feelings of shame	15(5.8%)	3(1.2%)	19(7.3%)	28(4.2%)	195(75.0%)	260(100%)
I had the fear of being stigmatized	5(1.9%)	6(2.3%)	19(7.3%)	11(4.2%)	219(84.2%)	260(100%)
I had the fear of being abandoned by my partner	56(21.5%)	22(8.5%)	38(14.6%)	33(12.7%)	111(42.7%)	260(100%)
I had the desire for personal privacy	58(22.3%)	20(7.7%)	39(15.0%)	32(12.3%)	111(42.7%)	260(100%)

The narratives below attest to the difficulties and risks related to disclosure

“Ah that is a difficult matter to handle. I have not disclosed to anyone yet. Intend to disclose to my husband only. When time is right. I have a lot of things on my mind: I am afraid that he may accuse me of infecting him and his wife since I am younger. Still trying to adjust to crisis. I have no desire to tell him about my status but for my baby’s needs later after birth-formula. I don’t know exactly how I will ever start to tell him- I am hoping I will find a way, the right words but I don’t know how.”

M. Z. 23

“At first I hesitated not to disclose to him. I thought ‘He will think I brought it as I was sickly since I got pregnant and he was healthy’. To adjust was not easy but I desired to tell though it was not easy                      se he was well. Any way I did have much fear. I said to myself, he would understand since we both were in other relationships before we got married.”

I. C.

“I am able to disclose when I decide on whom to tell.                      now, I cannot tell just anyone else other than my aunt. There is no                      Why should they know? They will just make me a topic for discussion especially that I

am not married and I am still young. I have no consideration for my partner's circumstances because our relationship was casual. I am and have not even tried to figure out what his reaction would be because we are not together."

G. M. L. 32 Years

"I am failing to accept that I am HIV positive. I am filled with a lot of regret because he had told me that he was HIV positive but I went ahead and entered a relationship with him. I would like to tell my elder sister who is my guardian but I am filled with a lot of fear."

L. L. B. 19, un married but in a steady relationship

Now Lydia broke down and started crying. It took almost an hour of counselling, consoling and encouragement for her to calm down. From this time through the end of the interview, she kept breaking down and sobbing- from anger at herself and fear and she continued...

"I don't know how to break the news to my sister. I live with her, she looks after me and she will look after me in the event that I fall ill. In case my spouse does not marry me, I may not be able to buy for my baby. I may be forced to breastfeed my baby with the risk of transmitting the virus to the baby. I know I must tell my sister but I am afraid, I don't know how to do it. Even my spouse, I was only able to tell him over the phone and not face to face."

### **5.5.2 Risks and Disclosure**

Though most of the participants revealed their status to their partners within the shortest possible time, disclosure was a risky venture to the majority across the six risks variables while to some it was not (table 5.5.2.1.). 3 out of 4 indicated that it was a risk to disclose their HIV status.

**Table 5.5.2.1 Calculating the Risks of Disclosure**

Calculating the Risks of Disclosure	Frequency		
	Yes	No	Total
I was trying to adjust to the diagnosis	194 (74.6%)	66 (25.4%)	<b>260(100%)</b>
I was trying to assess my disclosure skills	196 (75.4%)	65 (24.6%)	<b>260(100%)</b>
I was trying to assess my partner's circumstances	195 (75%)	65 (25%)	<b>260(100%)</b>
I was trying to figure out my partner's reaction	196 (75.4%)	65 (24.6%)	<b>260(100%)</b>
I was assessing when to reveal my sero-status	195 (75%)	65 (25%)	<b>260(100%)</b>
I was assessing where to reveal my status	194 (74.6%)	66 (25.4%)	<b>260(100%)</b>

The narratives below attest to some of the statistics presented above.

I disclosed to my husband and children. I did so to strengthen and prepare them for eventuality. So they understand and not question the home visits from clinic staff when they bring food supplements. My husband has left me for dead.

M. N. (Abandoned by Husband 3 Months ago for disclosing)

Before deciding to tell him, I was afraid that he was ing to be angry and start heaping the blame on me. But I was surprised that he was not. I then went on to explain that I was told to go with him to the clinic for VCT, but he declined and just said let's wait and see, maybe the result may have been false. After all, I still look very healthy and he too is healthy. There is no need to start looking for what is not there.

M. M. H. 21yrs old

### **5.5.3 Rewards to Consider in Disclosing Their HIV Status**

Though the participants considered status disclosure risky, they however found it to be very beneficial to do so. A cursory look at the frequencies and taking “somehow” as the midpoint and the discriminatory zone, there are more participants who considered disclosure to be beneficial than those who did not. 89.2% indicated that they disclosed their status because they desired to obtain emotional support, 93.1% desired to obtain social support, 92.3% desired to eliminate complicated adherence rituals from partner and another 92.3% desired to have instrumental support. (Table 5.5.3.1.).

**Table 5.5.3.1 Rewards to Consider in Disclosing Their HIV Status**

Benefits of Disclosure	Frequency and Level of Benefit					Total
	Not at all	Very little	Somehow	Much	Very Much	
I desired to obtain emotional support (relief from sharing a burdensome secret)	5(1.9%)	1(.4%)	22(8.5%)	18(6.9%)	214(82.3%)	<b>260(100%)</b>
I desired to obtain social support (e.g., an opportunity to discuss your feelings about your sero-status and educating your partner about the risks of having un safe sex)	5(1.9%)	1(.8%)	12(4.6%)	22(8.5%)	220(84.6%)	<b>260(100%)</b>
I desired to eliminate complicated adherence rituals from partner (going to ng'angas).	5(1.9%)	1(.8%)	14(5.4%)	20(7.7%)	220(84.6%)	<b>260(100%)</b>
I desired to have instrumental support (e.g., help in grocery shopping or meal preparation, transportation to and from appointments with health care providers).	5(1.9%)	1(.8%)	14(5.4%)	21(8.1%)	219(84.2%)	<b>260(100%)</b>

There were varied reasons for disclosing and not to do so among the respondents. Below, we provide a profile of some common ones;

“I went on to disclose because I wanted to obtain support from my husband for both me and the baby. I also wanted to obtain emotional support and encouragement from my friend. You see you need physical, emotional and financial support in this situation.”

O. M.

“I decided to reveal my status because I felt that my aunt whom I consider like my mother deserved to know because she is the one who will look after me if and when I eventually fall very ill.”

G. M. L.

“I told my parents because they are the ones (especially my mother) who advised me to go for the test in the first place. I revealed my status to my relatives because they are family, they were looking after me in my illness and were giving me all the support and encouragement during my illness. I told my in-laws just for them to know for future support just in case we will need it.”

M. Y.



### **5.6 Reasons (Factors) For Choosing a Particular Pattern of Disclosure**

We attempted to assess the probability of association between the type of disclosure and the degree of risk faced or rewards considered. The test statistic was set at  $\alpha = 0.05$ . If the observed value was less than or equal to the probability of the alpha error rate, we were going to reject the null hypothesis and conclude that our data supports the research hypothesis. We then conclude that there is a relationship between the variables as long as at least 5 cells are found and have zero counts. A cursory view shows that among the three variables that influenced the type of disclosure (fear or difficulties, risks and rewards) there was no association at all except only fear attribute and self-denial. This was not present in the sample and as such, it played no role in influencing the type of disclosure.

## **CHAPTER SIX DISCUSSION OF FINDINGS**

### **6.0 What This Study Shows**

This cross section study shows the following answers to the two research questions

To the first research question: What risks or rewards do women use when considering disclosure of their HIV status to their male partners? Before we could establish the risks and rewards of disclosure, the the study shows that decision to disclose is a selective one and consists of several steps, including adjusting to the diagnosis, to disclose or not to disclose, when and to whom, is a difficult one however, it was evident that just after counseling, the participants were willing to disclose mostly to their partners irrespective or what risks there were. This implies that they looked at disclosure as a must because it was after all beneficial. It is not surprising to note that most women initially disclosed their HIV status to their partner and then friends and other relations. To show that disclosure was not a hassle in this sample, one would be surprised that the vast majority of these initial disclosures were done on the first day after being diagnosed with HIV infection.

To the second research question: Why do they choose a particular pattern of disclosure? This was in essence an answer based on the hypotheses that were derived from Lazarus and Folkman's theory of stress and coping and the theory of planned behaviour.

Concerning Lazarus and Folkman's theory of stress and coping, the participants' cognitive appraisal of testing positive and their reaction to it (Lazarus and Folkman, 1984 ) showed that fear was a factor to disclosing and they however made their decisions after calculating risks that were involved (including adjusting to the diagnosis, assessing their disclosure skills, their partners' circumstances and reaction as well as

revealing their sero status. After weighing the risks, participants in this study described disclosure processes that, for the vast majority, reflected need for immediacy based on their appraisal of the negative consequences associated with disclosure.

With regards to the theory of reasoned action , nearly all participants scores and descriptions of their decision processes reflected weighing benefits and costs of disclosure similar to that described in theories of reasoned actions (Ajzen, 1985; 1988; Ajzen and Madden, 1986; Fishbein and Middlestadt, 1994 ) as well as ways to apply criteria regarding the appropriateness or not of disclosure. However, when the participants were interviewed, their decisions were based on their emotional and intuitive processes as their sole criteria for disclosure more clearly reflected by their personal appraisal of the positive consequences than negative consequences associated with disclosure than reasoned actions. These participants were more likely to tell their partners than non-partners of their HIV infection.

## **6.1 Synthesis of Findings**

The current study represents the first to explore disclosure of HIV status in Zambia and in a sample of predominately-African women of reproductive age residing in the city. The sample was recruited from clinics, and is representative of women receiving care and of similar demographic background. It is not surprising to note that most women initially disclosed their HIV status to their partner then friends and other relations. To show that disclosure was not a hassle in this sample, one should not be surprised that the vast majority of these initial disclosures were done on the first day after being diagnosed with HIV infection. The decision to reveal one's HIV-positive status is psychologically significant. This finding relates to Defeu et al. (1994) who reported that 89% of the participants spoke about their condition with at least one person; 82% informed their partner(s) within the month following the diagnosis.

The women in this study described disclosure processes that, for the vast majority, did not reflect any hesitancies to disclose based on their appraisal of the negative consequences or risks associated with disclosure and this is at variance from what has

been established in other studies. Many women's descriptions of their decision processes reflected weighing benefits and costs of disclosure similar to that described in theories of reasoned actions (Fishbein and Middlestadt, 1994 ) as well as ways to apply criteria regarding the appropriateness or not of disclosure. However, very few women discussed making decisions based on their emotional and intuitive processes as their sole criteria for disclosure more clearly reflected their personal appraisal of the negative consequences associated with disclosure than reasoned actions. These women were less likely to tell partners of their HIV infection. This study supports past research that have argued that women's concern about stigma, rejection and violence related to disclosing their HIV-seropositive status are unwarranted. Defeu et al. documented that negative reactions to disclosure are common, including betrayed confidence (50%), negative reactions from partners (30%) and abandonment (21%) (Defeu et al., 1994 ) and yet we did not find it to be significant in this study. In a study by Zierler et al., 45% of the adults who had experienced relationship violence reported that it was the result their HIV infection (Zierler et al., 2000 ). While the above-cited research documents women's concerns about negative responses such as rejection, abandonment and violence primarily within the context of women's relationships with husbands and sex partners are unsupported in this study, women may also not fear similar negative consequences associated with disclosure to relatives and friends.

A small group of women felt uncomfortable disclosing their HIV status to their partner and all others had markedly different appraisals of the consequences associated with disclosure as compared to women who had no hesitations. These women described a belief that in order to overcome societal stigma associated with HIV disease, it was not important for others to be made aware that someone they know is HIV-infected. These women seemed afraid of potential negative consequences of disclosing their HIV-seropositive status and a number of the women resigned to keep quiet about HIV in their communities. However, the reasons for not disclosing are similar to some notable studies elsewhere and include: stigma, need for privacy, fear of rejection by sexual partners, threats to personal well-being, potential loss of income, substance use, difficulty in communicating, denial, low viral load, type of sex, location of sexual

encounter, legal reprisal (fear of arrest), and condom use (no need to disclose) (Carr and Gramling, 2004; Derlega et al.2002; Garbach et al., 2004; Parsons et al.2004; Serovich and Mosack, 2003).

Further, reasons for non-disclosure have been cited as probability of disruptions in interpersonal and intimate relationships (Black, 1993; Yep, 2000), abandonment and rejection (Mooney *et al.*, 1992; Black, 1993), and discrimination (Yep, 2000). Simoni et al., 1995) found that one in five women who disclosed her HIV to her partner was abandoned (Simoni et al., 1995). A woman's disclosure of her HIV infection to sexual partners may trigger violent episodes (Rothenberg and Paskey, 1995; Zierler, 1997; Zierler et al., 2000). Gielen et al. (1997) found that one-fourth of women in their study had experienced negative consequences of disclosure that included rejection, abandonment, and verbal and physical abuse (Gielen et al., 1997).

This belief in the risks or losses arising from openness and/or confrontation of HIV-related stigma may have served as a resource for these women, maintaining the fear of disclosure (Lazarus and Folkman, 1984 ). Women described as 'full' disclosers were much more likely to tell 'all' across categories, although significantly higher levels of disclosure were only found for partners. Perhaps relatives and friends are more on the periphery of one's social network—this is where full disclosure would make the most differences. Because these women seem afraid of being 'out' about their HIV infection, they may be the persons in the community whom people 'know' have the disease. Clinically, avoidant behavior is associated with a host of negative outcomes including depression and anxiety (Folkman *et al.*, 1991). From a public health perspective, Kalichman and Nachimson found in their study of disclosure that women who did not disclose their HIV status to their sexual partners also did not practice safer sex, particularly condom use (Kalichman and Nachimson, 1999 ). Hence, the group of women in this study who did not disclose may be more likely to place partners at risk of HIV infection. This risk of infecting partners without notification takes on greater significance for women in this study.

There are also similarities in reasons that have been revealed in this study with those documented elsewhere that advance reasons of disclosure to anyone, including sex partners, family and friends. Women have appraised the disclosure process to be too difficult or risky to undertake and engaged in avoidant behaviors to hide their illness. There are many reasons given for and against HIV+ persons disclosing to sexual partners, friends, family, employers, strangers, and healthcare providers. Reasons for disclosure include the following: it is the right thing to do to protect others, reaffirmation of self, increased social support, catharsis, desire to educate others, seeking help, desire to test someone's reaction, being in a close or supportive relationship, and a mechanism for dealing with the disease. (Holt et al., 1998; Derlega, et al., 2002; Parsons et al., 2004; Serovich and Mosack, 2003; Wolitski et al., 2003).

Because of the complexity and the on-going nature of HIV-infected women's struggle with disclosure issues, counseling support from health educators is critical to help women realistically appraise their concerns related to disclosure so that they can access needed support and services. Even though a majority of the women described the importance of disclosing in order to maximize life and health care options, the few women who did not disclose require support to successfully assess the benefits of disclosure and cope with the stress of the disclosure ss. These women may have a critical need for stressing health education counseling in order to develop a plan for disclosing and coping with reactions of people with negative attitudes about individuals with HIV infection.

The theories presented earlier suggest that a better understanding of HIV-infected women's decision-making skills, and the potential reactions of partners, family, friends, and sexual partners, is a key to maximizing positive health outcomes and access to needed services. The nurse midwives working with HIV-infected expectant mothers need to be aware of the wide range of decision-making criteria that women use to decide how to disclose to a variety of people and routinely assess concerns about the disclosure processes. Nurse midwives may be in a unique situation to intervene to assist women, in understanding the importance of disclosure in making long-term plans

for their children. By being aware of and sensitive to conceptual linkages proposed by stress and planned behavioral theories, nurse counselors could more effectively counsel women in the benefits of disclosure to select those sitting on the fence or the hardliners as well as assist the women to develop plans for disclosing. Our findings underscore the need for counseling to be culturally and personally sensitive in order for disclosure to be as positive and successful experience as possible. Additionally, the nurse health educator who understands cognitive processes is better prepared to respond effectively to a range of women's decisions in order to provide appropriate counseling to reduce unsafe and unhealthy behavior.

## **6.2 Recommendations**

Though disclosure seems not to be a problem as shown in this study, this study offers significant implications for healthcare providers including nurses, in clinical practice, education, and research particularly for those situations when disclosure is not possible.

Primary prevention of HIV transmission from HIV+ persons to HIV negative persons is even more important today, now that drug therapy allows many HIV+ persons to live and be sexually active longer. It is recommended that nurses and other primary health care workers need to be open and supportive in caring for the HIV+ client, discussing the advantages of disclosing one's HIV status to sex partners, but at the same time, respecting the rights of clients to make their own decision about disclosing.

If clients choose not to disclose their HIV status, Nurses should be nonjudgmental of their decision. But at the same time, Nurses should continually reinforce the use of condoms during all sexual encounters. If HIV+ clients wish to disclose to family and/ or friends, techniques could be utilized such as role-playing disclosure conversations, along with counseling and support.

Ideally, women and their partners should go through the whole pre-test counselling, testing procedure and post-test counselling together. However, since

men very rarely accompany their wives or partners at reproductive health facilities, this is unlikely to happen unless efforts are made, where culturally appropriate, to make reproductive health-care settings male friendly. It is recommended that counsellors discuss the benefits of couple counseling with women during pre-test counselling sessions. Those women who would like to be counselled and tested together with their partners should be catered for or referred to specialized counselling and testing services. In the latter situation, a mechanism must exist for communicating test results to the original service providers, with the consent of the couple and without breaching confidentiality.

As for HIV research, various types of social relationships associated with HIV disclosure are underexplored but yet have the potential for increasing HIV disclosure, decreasing unsafe sex, and reducing the number of new HIV infections. “Health care professionals and researchers need to continue to actively pursue clues as to what facilitates HIV disclosure to sex partners, because disclosure has the potential to improve well-being, provide informed choice, and protect life” (Sullivan, 2005: 45).

### **6.3 Limitations and Strengths of the Study**

Like all studies, this cross sectional non comparative and non experimental study has limitations. Caution is warranted in the interpretation of data based on only subjects who are confined to Lusaka and expectant mothers. The participants attending antenatal clinic are not representative of all HIV infected female patients attending treatment centres in Lusaka and as such the sample limits the generalisability of the findings. In addition, the female population here excludes those in rural areas. Studies without mixed demographics tend to show similar rather than important differences according to the social, cultural and sexual characteristics of the subjects and the stage they have reached in their HIV disease. This study has failed to point towards the need for more information about such differences in relation to the impact of HIV on the family in a locality like Lusaka. Ideally, a control group with another disease like a sexually transmitted infection like gonorrhea could be used for comparison. However, at present



there is no comparable group of patients who do not have a terminal illness with a similar need to disclose a health condition and compare difficulties, risks and rewards on account of disclosing.

However, this study is of great significance. The study indicates that research into HIV disclosure patterns could be investigated in a clinic setting. The disclosure of one's HIV status to the partner, 'close family' and friends opens up the opportunity to receive social support. Research has shown that people with HIV infection who have their status disclosed are easily integrated into social networks and have higher levels of psychological wellbeing than those who are not (Kelly et al., 1993). Clinicians and managers should avoid interpreting these findings as 'league table' results but instead use them to demonstrate that they are working collaboratively to respond to patients' health dilemmas and communication concerns. This survey is credible because it describes disclosure from a quantitative point of view and from a lived experience and points to factors behind disclosure. It is also credible because the sample size is very adequate and in addition, subtleties of the complex process of disclosure have been captured, as the questions focused on the disclosure process - the disclosure of HIV infection itself have been answered.

## **6.4 Conclusion**

The disclosure rate to sexual partners in this study was extremely high with very few (3.8%) having declined to reveal their status to their sexual partners. Additionally, women that did not share their HIV status with anyone at all were 13.8%. The majority of these women disclosed their status to their partners within the same day of learning of their status. There were no differences in the types or rates of disclosure according to age, education and marital status.

Three variables influenced disclosure (fear or difficulties, risks and rewards). The difficulties or fears that led to non-disclosure cited were denial that one was indeed HIV+, fear of triggering violence, fear of rejection and abandonment and a desire for

personal privacy. The risks that the women in this study had to consider before deciding whether or not to disclose their HIV status were not being able to tell how the partner would react to the news, not knowing the right time or place to undertake the seemingly huge burden of disclosure. The rewards to consider were the factors that favoured disclosure which ultimately led to the high rate of disclosure in this study and these were mainly a desire to obtain support from the partner for the women themselves and for their prospective baby in form of physical, emotional and financial support.

The pattern of disclosure shows that most women initially disclosed their HIV status to their partner and then friends and other relations. The vast majority of these initial disclosures were done on the first day after being diagnosed with HIV infection. The women in this study described disclosure processes that, for the vast majority, did reflect any hesitancy to disclose based on their appraisal of the negative consequences or risks associated with disclosure and this is at variance from what has been established in other studies. Many women's descriptions of their decision processes reflected weighing benefits and costs of disclosure similar to that described in theories of reasoned actions as well as ways to apply criteria regarding the appropriateness or not of disclosure. However, very few women discussed making decisions based on their emotional and intuitive processes as their sole criteria for disclosure. They more clearly reflected their personal appraisal of the negative consequences associated with disclosure than reasoned actions. This study supports past research that have argued that women's concern about stigma, rejection and violence related to disclosing their HIV-seropositive status are unwarranted.

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# **APPENDICES**

## Appendix I Survey Questionnaire

You have been selected by chance with 260 other people to help us know what may relate to you and other people. Please read /listen to each item carefully and decide to what extent it is characteristic of you. Give each item a rating that applies to you by using a scale that is given for each question. Please remember to respond to all items. There is indeed no right or wrong answers. Your answers will be kept by me in the envelope that I have given you in the strictest confidence for only six months after which time I shall have examined all the 260 responses. There after I shall destroy them. There will be no identification mark that relates to you on the questionnaire. I am sure that you will be open in responding to these statements.

1. Age -----
2. Age range: sixteen to twenty five----- twenty six to thirty five..... thirty six to forty five .....and over forty six.....
3. What is your occupation?

Occupation	Tick only one
Student at College/University	
Student at Secondary School/Primary	
Administrator	
I am in a sales and clerical job	
I am a professional	
I am in business	
Farmer	
Driver/Conductor	
I work for sex	
I am a home maker	

4. How far have you gone in school?

Level of Education	Never	Primary	Lower Secondary	Upper secondary	College /University
Tick					

5. If you have some one in a sexual relationship, what applies to you?

sexual relationship	Tick only one
I have some one in a casual sexual relationship	
I am married	
I am in a short-term sexual relationships	
I am in a long-term sexual relationships	
I am cohabiting ( <i>living as married</i> )	
I am now divorced and single	
I am now widowed and single	

6. What is your religious faith?

Religious faith	Tick only one
I do not have a faith	
I am Muslim	
I am Hindi	
I am a Christian but a Catholic	
I am a Christian but a Pentecostal	
I am a Christian but another (Seventh Day, New Apostolic etc)	

To what extent do you adhere to the commandments of your religious faith?

7. Reading the religious book- like the Bible or Koran?

	Not at all	Rarely	Often	Frequently	Always
Tick					

8. Praying?

	Not at all	Rarely	Often	Frequently	Always
Tick					

9. Have you participated in interventions that teach techniques for disclosing? Yes-----  
No-----

10. How long ago where you found to be HIV +? ----- months

11. When you were found to be HIV + and counseled, it may have taken some time as the right time to reveal your serostatus to your partner. hat time interval applies to you?

- a) I am still making personal adjustments but waiting for the right time to date.
- b) I took one day
- c) I took /am taking 7 days
- d) I took /am taking 30
- e) I took /am taking 90 days
- f) I took/am taking 365 days.

12. When you were found to be HIV + and counseled, you mig be in one position below which one?

- a) I have been secretive and have not revealed my serostatus my partner-----
- b) In have been secretive and have not revealed my serostatus to any one -----
- c) I have been selective and have revealed my serostatus to my partner only-----
- d) I have been selective and have revealed my serostatus to my relatives only-----
- e) I have been selective and have revealed my serostatus to nearly every one but not my partner-----
- f) I have been selective and have revealed my serostatus nearly every one including my partner-----



Before deciding to reveal ones serostatus, people may consider calculating risks and whether to tell or not to tell their partner. Please read each item carefully and decide to what extent it is characteristic of you. Assign marks from 1 to 5 to each of the items as a way you agree with yourself = " 1 extremely agree and 5 = "extremely disagree" by stating what was going on or is going on in your mind?

- 13. I was trying to adjust to the diagnosis-----
- 14. I was trying to assess my disclosure skills-----
- 15. I was trying to assess my partner's circumstances-----
- 16. I was trying to figure out my partner's reaction-----
- 17. I was assessing when to reveal my serostatus-----
- 18. I was assessing where to reveal my status-----

After calculating risks, you may have decided to reveal or are going to do so or will not at all. Look at the response in question 17 above and answer the following questions.

If you faced difficulties as negative consequences of disclosure and you decided to be silent about the serostatus to your partner, read each item carefully and decide to what extent it is characteristic of you. Assign marks from 1 to 5 to each of the items as a way you agree with yourself = " 1 extremely agree and 5 = "extremely disagree" by stating what was going on or is going on in your mind?

- 19. I disagreed that I was positive

	Not at all	Very little	Somehow	Much	Very much
Tick					

- 20. I had fear of triggering violent episodes

	Not at all	Very little	Somehow	Much	Very much
Tick					

- 21. I was filled with regret

	Not at all	Very little	Somehow	Much	Very much
Tick					

- 22. I had the fear of rejection by my partner

	Not at all	Very little	Somehow	Much	Very much
Tick					

- 23. I had personal feelings of shame

	Not at all	Very little	Somehow	Much	Very much
Tick					

- 24. I had the fear of being stigmatized

	Not at all	Very little	Somehow	Much	Very much
Tick					

25. I had the fear of potential loss of support

	Not at all	Very little	Somehow	Much	Very much
Tick					

26. I had the fear of being abandoned by my partner

	Not at all	Very little	Somehow	Much	Very much
Tick					

27. I had the desire for personal privacy

	Not at all	Very little	Somehow	Much	Very much
Tick					

If you felt that there were rewards following revelation to your partner, read each item carefully and decide to what extent it is characteristic of you. Assign marks from 1 to 5 to each of the items as a way you agree with yourself = " 1 extremely agree and 5 = "extremely disagree" by stating what was going on or is going in your mind?

28. I desired to obtain emotional support (relief from sharing a burdensome secret)

	Not at all	Very little	Somehow	Much	Very much
Tick					

29. I desired to obtain social support (e.g., an opportunity to discuss your feelings about your serostatus and educating your partner about the risks of having un safe sex)

	Not at all	Very little	Somehow	Much	Very much
Tick					

30. I desired to eliminate complicated adherence rituals from partner (going to ng'angas).

	Not at all	Very little	Somehow	Much	Very much
Tick					

31. I desired to have instrumental support (e.g., help in grocery shopping or meal preparation, transportation to and from appointments with health care providers).

	Not at all	Very little	Somehow	Much	Very much
Tick					

## Appendix II - Schema of In-depth Interview Questions

**I would like to find out a few things about HIV in your household and I would be happy to hear your views or comments.**

### **Theme I: Patterns of HIV disclosure**

1. Please tell me about whom you disclosed to /intend to disclose your status to.
2. What made /will make you decide to tell those people?
3. What value do you attach to these people?

### **Theme II: Extent of partner notification among expectant women**

4. How long ago were you found to be HIV?
5. How long did /will it take for you to reveal your status?
6. What time interval applies to you?
7. How many partners do you have and to how many did you /do you intend to reveal your status to?

### **Theme III: Ways that expectant mothers go about revealing their status.**

8. What was /is happening in you before you decide (d) to reveal your status?
9. How did you /will you/ finally reveal your status?

### **Theme IV: What goes on cognitively in calculating the risks and benefits of partner disclosure?**

10. What was /is going on in your mind before you decided to reveal your status?
11. Please tell me about how you tried /are trying to adjust to the diagnosis and desiring to reveal your status?
12. Please tell me about how you tried /are trying to assess your disclosure skills
13. Please tell me about how you tried to /are trying to assess your partner's circumstances.
14. Please tell me about how you tried to /are trying figure out your partner's reaction
15. Please tell me about how you tried to /are trying to select the best time to reveal your serostatus
16. Please tell me about how you tried to /are trying to select the best place to reveal your status.

### **Theme V: Why do expectant mothers select a particular type of disclosure?**

17. Why did you decide to reveal your status?
18. Please explain the motive for your selected choices and persons.

### **Summary**

Let's summarize some of the key points from our discussion. Is there anything else?  
Do you have any questions?

*Thank you for taking the time to talk to us!!*

## Appendix III - Consent Form

### CONSENT TO PARTICIPATE IN A RESEARCH STUDY

#### **Title of the Research study**

Difficulties of HIV status disclosure to Sexual Partners among Expectant Women in Selected Clinics in Lusaka Urban

#### **Investigator**

Lentisha Muyanza, MPH student, School of Medicine, UNZA, Lusaka. Cell no. 097 7 753 355.

#### **Purpose and Background**

This is a research relating to HIV/AIDS and problems of disclosure. This study is exploring this issue from the women's point of view because literature in public health has persistently shown that more women than men are experiencing disclosure problems. The main purpose of this study is to explore and understand HIV/AIDS and disclosure behaviours which will help us find ways of how we can fortify counselling.

#### **Procedure**

If you agree to participate, the following things will happen:

1. You will be asked questions on the difficulties of disclosure of your HIV status to your partner that you are/were experiencing since you were found to be HIV positive.
2. Your name will not be written on the questionnaire.

#### **Benefits**

You will benefit more information on HIV transmission, prevention, coping skills, communication skills and psychosocial counselling.

#### **Risks**

There are no envisaged risks to me that may ensue from participating in the study.

#### **Reimbursement**

You will be paid a token sum of Kwacha thirty thousand only (K30 000.00) as transport reimbursement and as an expression of gratitude for availing time and information.

#### **Confidentiality**

A private room shall be made available for answering the questionnaire.

An envelope will be provided for you to put in your completed questionnaire.

Your identity will be kept confidential in so far as the law allows.

Your answers to the questions will be kept confidential and will only be used for research purposes.

The answered questionnaire will be kept by the researcher in the strictest of confidence for only six months after which time all the responses will have been examined. There after it shall be destroyed.

#### **Questions**

....., the research assistant will discuss this information about this study with you and answer your questions. If you have further questions, you may contact her on phone no. .... or Lentisha Muyanza the researcher of the study on 097 7 753 355.

#### **Right to refuse or withdraw**

Your participation in the study is entirely voluntary and you are free to refuse to take part or to withdraw at any time without affecting or jeopardizing your future medical care.

For further information, you may contact the Chair Person, Biomedical Ethics Committee of the University of Zambia, School of Medicine, PO Box 50110, Ridgeway campus, Lusaka. Telephone number 211 256 067.

#### **Consent**

I have been given a copy of this form and I have read it. The purpose of this research has been fully explained to me. I also understand that my rights and privacy will be respected. I agree to participate in this study.

Name of participant: .....

Signature or thumb print of participant .....

Name and signature of interviewer .....

#### Appendix IV – Budget Estimates (Kwacha)

Item	Qty	Unit cost	Total
Reams of paper	20	25,000	500,000
Transport for researcher (Fuel)	1	4,000,000	4,000,000
Token for Participants	260	30,000	7,800,000
Research Assistants	4	250,000	1,000,000
Large envelopes	300	500	150,000
Pens	50	3,000	150,000
Plain folders	10	1,000	10,000
File fasteners	10	500	5,000
Pencils	10	300	3,000
Rubber	10	500	5,000
Flash disk	1	150,000	150,000
Data processing	1	3,000,000	3,000,000
Total			16,770,000
Contingency (10%)			1,677,030
<b>Grand Total</b>			<b>18,447,330</b>

***Letters granting Permission to collect Data at the Four clinics***