

**THE PERCEIVED AND EXPERIENCED BARRIERS AND  
REPORTED CONSEQUENCES OF HIV POSITIVE  
STATUS DISCLOSURE BY PEOPLE LIVING WITH HIV  
TO THEIR PARTNERS AND FAMILY MEMBERS IN  
DJIBOUTI.**

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A mini-thesis submitted in partial fulfilment of the requirements for the  
degree of Masters in Public Health at the School of Public Health,

University of the Western Cape.

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## KEY WORDS

- Djibouti
- HIV
- Disclosure
- People living with HIV (PLHIV)
- Barriers
- Consequences
- Partners
- Family members
- Health workers
- Qualitative research methods



## **ABSTRACT**

**Background:** In Djibouti people living with the Human Immunodeficiency Virus (HIV) are encouraged to disclose their HIV status to their partners and/or family members after using the voluntary counselling and testing services. Nevertheless, disclosing ones HIV positive status to another person appears to be a risky endeavour. This study was therefore undertaken to understand some of the perceived barriers and reported consequences of HIV positive status disclosure within the context of Djibouti.

**Aim:** This study aimed to investigate barriers and consequences of HIV status disclosure by people living with HIV in Djibouti and to develop a set of recommendations around the issue of disclosure that will serve to inform the future development of local HIV prevention, counselling and treatment programmes in Djibouti.

**Methods:** This was a descriptive qualitative study. Eight people living with HIV, four of which had disclosed their status, were individually interviewed. Two focus group discussions (each comprising 6 participants) were also conducted with health workers. The study was based at an urban TB hospital which is currently providing a range of HIV-related services including HIV Voluntary Counselling and Testing, case management and treatment.

**Results:** The anticipated partner and family members' reactions following HIV positive status disclosure, which could include stigma and discrimination, violence and other

adverse consequences, create substantial barriers to disclosure in the context of Djibouti. Women living with HIV in Djibouti may particularly not disclose their status due to fear of violence from partners and family members. It appears however that disclosure is not confined to only negative consequences: people living with HIV in Djibouti who decide to disclose their status are also likely to experience positive outcomes characterized with love, understanding, care and support from partners and family members.

**Conclusion:** This study indicates that HIV positive status disclosure decision-making is a difficult challenge facing most people living with HIV in Djibouti, both within the context of their primary relationship and amongst their family members. Unfortunately, as a result of the fear of disclosure those living with HIV (who do not disclose their status) put their partners at risk for HIV infection, as they are unlikely to practice safer sex. It is recommended that programmes that can assist people living with HIV in making informed decisions about disclosing a positive HIV status and in developing the skills to do so be developed. A larger scale study on this subject needs also to be conducted so as to address the gaps in health worker's understanding of how people living with HIV can best be supported to disclose their status without negative consequences.

## DECLARATION

I declare that *“The perceived and experienced barriers and reported consequences of HIV positive status disclosure by people living with HIV to their partners and family members in Djibouti”* is my own work, that it has not been submitted for any degree or examination in any university, and that all sources I have used or quoted have been indicated and acknowledged by complete references. PE

Naaman N. Kajura

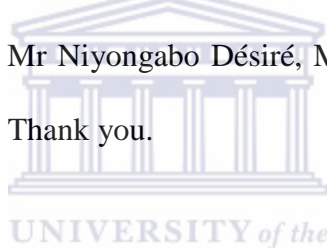
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## **ABBREVIATIONS**

AIDS	Acquired Immunodeficiency Syndrome
ARC	AIDS-related complex
ARV	Antiretroviral Therapy
CDC	(US) Centers for Diseases Control
FGD(s)	Focus Group Discussion(s)
PLHIV	People Living with HIV
PLWHA	People Living with HIV/AIDS
PMTCT	Prevention of HIV from Mother to Child Transmission
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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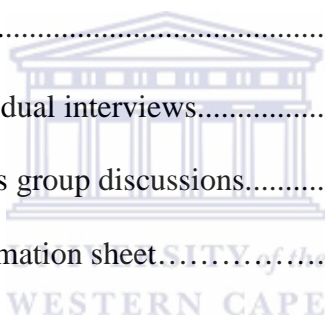
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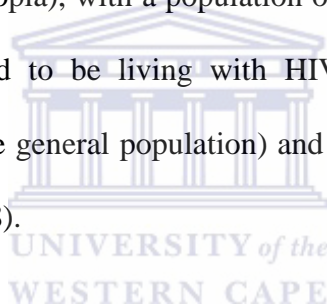
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# CHAPTER ONE: A DISCRIPTION OF THE STUDY

## 1.1. Introduction

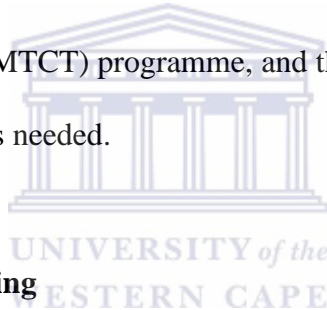
Globally, over 7000 people become infected with HIV every day, and more than 33 million are living with HIV (UNAIDS/WHO, 2007; UNAIDS/WHO, 2009). Sub-Saharan Africa is the most affected region. Nearly 70% of all People Living with HIV (PLHIV) worldwide live in this region, and the majority of these are among 15 – 49 year olds, with nearly 50% occurring among 15–24 year olds (UNAIDS/WHO, 2007; UNAIDS/WHO, 2009). Djibouti, a country on the horn of Africa (bordering the Red Sea, Eritrea, Somalia and Ethiopia), with a population of approximately 795,000, about 15,000 people were estimated to be living with HIV/AIDS, giving the country a prevalence rate of 2.9% (in the general population) and 3.1% amongst those aged 15 – 49 (Ministère de la Santé, 2008).



Although the rates in Djibouti are small compared to what is experienced in Southern Africa, HIV is still considered to be one of the country's most significant public health problems given its low literacy levels, the fact that the country acts as a major trade corridor to Ethiopia, and is accompanied by the existence of an active sex work community – factors which are known to fuel the HIV epidemic. The situation is made even more difficult by high levels of poverty and unemployment. Nevertheless, Djibouti has developed a National Strategic Plan on HIV/AIDS, which presents a holistic package of services for both PLHIV and the general population (Ministère de la Santé, 2003). These include preventive interventions such as education and information, condom promotion and voluntary counselling and testing of HIV (VCT). The package

also includes medical, nutritional, psychological and social support to PLHIV and their families.

The national response is multisectoral – involving a range of government ministries, non-governmental organizations, people living with HIV/AIDS, faith-based organizations and the private sector. All ministries also develop their yearly plans and implement them. In the health sector, all antenatal clinics, public hospitals and health centres are now offering VCT services, and all people who test positive are offered treatment free of charge. Pregnant mothers in antenatal clinics are also given medicines to reduce the risk of HIV transmission to their babies under the Prevention of Mother to Child Transmission of HIV (PMTCT) programme, and then antiretroviral drugs (ARVs) to maintain their own health, as needed.



## **1.2. HIV counselling and testing**

To benefit from available HIV/AIDS care and support services (social, psychological, health, and other services that are increasingly available to PLHIV) individuals ought to be tested for HIV. In the context of Djibouti, this is carried out in a variety of circumstances. These include:

- *Voluntary HIV counselling and testing* – HIV testing provided to individuals who seek the service out of their will without any coercion. In VCT service, clients receive pre-test counselling, HIV testing and post-test counselling during which they are given their HIV test results, and if necessary, they are later usually referred for follow up care and support.

- *Voluntary HIV counselling and testing for PMTCT* – this is provided to a target population of pregnant women for the primary purpose of enabling them to make decisions about PMTCT.
- *HIV testing for clinical purposes* – this is aimed to assist the clinicians to manage patients. The clinician usually requests the test and the results are linked to the name of the patient.
- *Testing of people seeking certain services e.g. visas* – some institutions or foreign governments have policies that require knowing the HIV status of some persons before they apply for certain privileges or services, and so testing becomes necessary. People testing positive within this way are also referred for follow up care and support if they wish.
- *HIV testing after occupational exposure* – this applies to health workers and other emergency workers who may accidentally be exposed to body fluids of a person – the potential source of infection and the potential recipient undergo voluntary HIV counselling and testing to establish their status.

Under all the above mentioned HIV testing circumstances except for “*HIV testing for clinical purposes*”, clients are offered *pre-test counselling*, and when results are ready, they are provided *post-test counselling* during which test results are given. All people who test HIV-positive are then referred to other units responsible for assessment for care and support – for the clients and clinicians to plan and schedule subsequent follow – up sessions where the decision on ART could also be made.

### 1.3. HIV testing and disclosure

Also discussed during post-test counselling, is the issue of HIV status disclosure. The counsellors or clinicians discuss with the client the advantages and disadvantages of disclosure, various options of disclosure, and the timing of disclosure. It is however up to the client to decide to disclose his/her HIV status. It is also up to the client to decide when and how to do it (Personal communication with N. Désiré, HIV counsellor, Centre Paul Faure, 20 September 2008).

Although disclosure of HIV positive status can result in negative consequences such as stigma and discrimination of PLHIV, it is widely recognized that PLHIV could still benefit from disclosure. Specifically, it is believed that individuals to whom one chooses to disclose could serve as a source of emotional and moral support (Matthews, Kuhn, Fransman, Hussey & Dikweni, 1999; Brou *et al.*, 2007). In addition, community benefits such as the reduced incidence of HIV infection and reductions in stigma and discrimination can potentially be increased by supporting and increasing the number of PLHIV who are comfortable disclosing their status. Counsellors and clinicians, therefore, encourage their clients to disclose their status to significant others.

Notwithstanding the potential benefits in terms of care and support for PLHIV, and for HIV prevention in the general public, disclosure of HIV positive status is often difficult and a potentially risky endeavour. For example, it has been established that in cultures where more traditional values associated with gender roles is emphasised, it may be difficult to tolerate a female HIV-positive member (Ichikawa & Natpratan, 2006). This might be due to the perception and/or belief that a positive HIV status can suggest to

others an adoption of negative behaviours associated with HIV infection (Katz, 1997; Kalichman & Nachimson, 1999). The discussion of one's HIV positive status within a relationship or amongst family members, for individuals from these cultural identities, is therefore unlikely to be possible or necessarily easy.

#### **1.4. HIV status disclosure in the context of Djibouti**

There are perceptions among health workers working in HIV related care and support services that the reactions of families after learning that one of its members is infected with HIV could range from acceptance to rejection, blame, stigma and discrimination (Personal communication with F. Mohamed & N. Désiré, HIV counsellors, Centre Paul Faure, 20 September 2008). It is perceived that PLHIV are likely to experience negative consequences following disclosure, in particular, due to being suspected of having been engaged in sexual practices which their families were unaware of, and are often regarded as morally wrong. For example, a woman identified as being HIV positive could be blamed by her partner and/ or family members of infidelity and prostitution and therefore be rejected by her partner and/or family members.

However, although there is a paucity of information on HIV status disclosure in the context of Djibouti, it is currently believed that men are less likely to experience negative consequences associated with HIV status disclosure – mainly, because there is less societal tolerance for women perceived to have multiple sexual partners than for men (Personal communication with F. Mohamed & N. Désiré, HIV counsellors, Centre Paul Faure, 20 September 2008).



Moreover, as notes Fatouma Youssouf Amel, a president of the “*Nouvel Espoir*” (*New Hope*) – an association of women currently providing HIV-related care and support services to over 100 women living with HIV in Djibouti, even women who acquire HIV from their husbands are none the less still stigmatized:

*‘A woman may have similar needs to a man’s, but if she gets infected, she is treated as if she is a cursed and dirty being. She is not even given the chance to explain how she got infected! Because women are rejected ...I receive them in my shelter, where they can feel welcome and be free to stay for a while... What touches me most about the women is how difficult it is for them to manage once they learn that they are HIV positive. They are disrespected, and shunned even by their own families.... Some of them die. Two women died and I could not help them because I had been denied access to them, and their families could not even let us participate in their funerals. We offer a little funding to enable those rejected women to have a decent burial (Global Fund, undated: 1)’.*

To substantiate this, Fatouma Youssouf Amel gives an example of one woman who was once sheltered by her organisation following rejection by her partner – after learning that she was HIV positive:

*‘For instance with Aisha, one of the last women I sheltered, who is married with nine children. Her husband is a taxi driver, and he infected her with HIV. Her husband had discovered his HIV+ status much earlier and had been receiving medical attention in hospital for a long time, and yet had not told her! Much later when she learned and informed him about her HIV positive status, instead of telling her the truth, he blamed and kicked her out of the house! She came to*

*our association with her four youngest children... I therefore took an elderly lady with me to see a friend of Aisha's husband. We convinced him to ask Aisha's husband to discuss the issue with us. We were lucky that the husband empathized with our views because we were also HIV +. We informed him that his wife had not been seeing other people- that it was actually he who transmitted the disease to her. We told him that we had found out he had been on ARV treatment since much earlier... Aisha's husband denied everything that we were saying, "There is no way you could tell if I infected her! I could not have done that!" he said, "Besides, she accuses me of cheating all the time, it was probably she who went looking for it! She is the one to blame.... (Global Fund, undated: 1)'.*



### **1.5. Problem statement**

In Djibouti, PLHIV are encouraged to disclose their status to partners and/or family members after they have used the VCT services (Ministère de la Santé, 2008). This is also emphasised by UNAIDS/WHO (2000) and CDC (2002 in Medley *et al.*, 2004) in their guidelines for HIV testing and counselling. However, because of the negative consequences associated with HIV, such as stigma and discrimination, disclosure can be seen by PLHIV as a difficult decision to make – and one which might mean PLHIV opt to keep their HIV positive status a secret. This (non-disclosure) may ultimately result in a lack of access to important sources of family and social support, and to the loss of opportunities for the prevention of new infections (Matthews *et al.*, 1999; Medley *et al.*, 2004).

So far, no studies have been conducted to establish the barriers and consequences of disclosing ones HIV positive status to ones partner and/or family members in the context of Djibouti. An investigation to understand some of the perceived barriers and consequences of HIV disclosure within the context of Djibouti, which was the aim of this study, was therefore considered important – both in terms of assisting health service policy and/or decision- makers, programme managers and health workers in improving the future support provided to PLHIV and to design and implement policies and programmes that assist in reducing the progression of the HIV epidemic in the country.

#### **1.6. Purpose of the study**

Studies have shown that disclosure of HIV positive status could be a pivotal factor in reducing the behaviours that continue to transmit the HI virus (Marks, Richardson & Maldonado, 1991 in Serovich, 2001). It is also acknowledged that disclosure of HIV positive status is important for the acquisition of social support (especially from family members) necessary for patients' adherence to treatment (Matthews *et al.*, 1999; Waddell & Messeri, 2006). Although disclosure of HIV positive status is important and PLHIV in Djibouti and elsewhere are often advised to disclose their status, there are always barriers and consequences associated with such disclosure. This study therefore aimed to explore and gain an understanding on the perceived and/or experienced barriers and consequences of HIV positive status disclosure to one's partner and/or family members in the context of Djibouti and make recommendations that will serve to inform the future development of local HIV prevention, counselling and treatment programmes.

## **CHAPTER TWO: LITERATURE REVIEW**

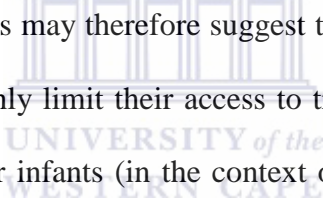
### **2.1. Introduction**

The following literature review explores some of what has been written on HIV positive status disclosure. It begins by citing the benefits of HIV positive status disclosure, followed by the identification of the factors that could motivate PLHIV to disclose their status. This is followed by a description of the perceived and reported barriers and consequences of HIV positive status disclosure. It ends with a section on interventions to help support individuals through the process of disclosure.

### **2.2. The benefits of HIV positive status disclosure**

HIV status disclosure is recognised as an important public health strategy for HIV prevention, as well as care and support. Disclosure helps PLHIV mainly in terms of supporting their physical, emotional and spiritual health – thus allowing them to continue to live productively and positively with HIV, and access HIV-related health care resources. Specifically, disclosure decreases anxiety and increases social support among PLHIV (Matthews *et al.*, 1999; Cline and Boyd, 1993 in Sowell *et al.*, 2003). In addition according to Paxton (2002), disclosure liberates PLHIV from the burden of secrecy and shame. This in turn facilitates the initiation of HIV treatment and medications (Klitzman *et al.*, 2004 in UCSF, 2007) and leads to greater acceptance and adherence to HIV treatment (Waddell & Messeri, 2006; Stirratt *et al.*, 2006 in UCSF, 2007).

From the perspective of public health, it is assumed that disclosure could reduce the spread of HIV infection, by creating awareness of risk to untested partners (Kalichman & Nachimson, 1999 in Sowell *et al.*, 2003; Simbayi *et al.*, 2007). That is, following disclosure some people may opt not to have sex with an HIV-positive partner or may agree only to engage in very low-risk sexual activities (such as using condoms after learning that their partner is HIV positive). The usefulness of HIV positive status disclosure as an HIV risk reduction strategy is also demonstrated in a recent mathematical modeling analysis by Pinkerton & Galletly (2007). It is suggested that an intervention that increases HIV positive status disclosure could result in reductions in HIV transmission risk by between 17.9 % and 40.6% (Pinkerton & Galletly, 2007).



Findings from the above studies may therefore suggest that PLHIV in Djibouti, who do not disclose their status, not only limit their access to treatment, care and support, but also place their partners and or infants (in the context of mother to child transmission (MTCT)) at risk of HIV infection. Hence, a better understanding of the perceived and experienced barriers, and the consequences of HIV-positive status disclosure by PLHIV in Djibouti will assist counsellors and other health workers in the health services in working effectively to help PLHIV in making the most appropriate decisions regarding disclosure, and thus ultimately support their well-being and the risk they might pose to others in relation to HIV transmission.

### **2.3. Factors that could motivate PLHIV to disclose their status**

There are various factors which are believed to encourage or to facilitate PLHIV to disclose their status. Social factors which include the sense of ethical responsibility for

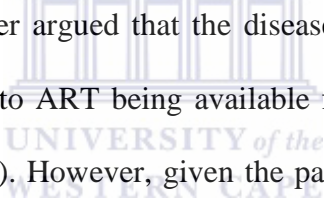
their partners' health (Bayer, 1996) and their own need for social support (Antelman *et al.*, 2001), play a major role. Antelman *et al.* (2001) also established in their study of women attending an antenatal clinic in Tanzania that as the length of time since HIV diagnosis increases, the rate of disclosure also increases (Antelman *et al.*, 2001). They specifically found that disclosure to partners increased from 22% within two months of diagnosis to 41% after nearly four years (Antelman *et al.*, 2001). Severity of illness and the balance between costs and benefits of disclosure have also been found to be predictors of disclosure. This is well explained through the two proposed theories of disclosure, namely: the "Disease progression theory" and the "Consequence theory" (Serovich, 2001; Serovich, Lim & Mason, 2008).

### **2.3.1. Disease progression theory**

It is theorized that individuals are likely to disclose their HIV status as they become symptomatic (Serovich, 2001). This is supported by arguments that as HIV progresses to AIDS individuals may feel that they will need additional assistance to manage their illness and thus decide to disclose their status – as a means of accessing necessary social and material support (Mansergh, Marks & Simoni, 1995; Holt *et al.*, 1998). Given that disease progression could result in hospitalisation and physical deterioration, it is believed that this situation may necessitate some individuals to disclose their status to others (Kalichman, 1995 in Serovich, 2001).

Disclosure appears also to be linked with variables such as CD4T-cell count – which is actually a parameter used to determine the severity of an HIV infection (O'Brien *et al.*, 2003). These researchers have shown that individuals with CD4T-cell count above 500

are less likely to disclose their status. And when these levels drop and individuals' conditions progress to AIDS diagnosis, they are dramatically more likely to disclose – from about 50% during symptomatic HIV to 75% during AIDS-related complex (ARC) and AIDS (O'Brien *et al.*, 2003). The relationship between disease progression and disclosure has been also reported by other researchers such as Hays *et al.* (1993). It was found in this cohort study of 163 asymptomatic and symptomatic men living with HIV that 98% of asymptomatic men had not disclosed to their partners, whereas all symptomatic men and women with AIDS had disclosed to their partners. These researchers concluded that an ego that is hurt and a self– confidence that is lowered due to illness necessitates disclosure (Hays *et al.*, 1993).



Some researchers have however argued that the disease progression model was more applicable to the period *prior* to ART being available for PLHIV (Yang *et al.*, 2006; Serovich, Lim & Mason, 2008). However, given the paucity of information that exists in some settings such as Djibouti about the triggers and the decision-making processes associated with the disclosure of one's HIV positive status, it is hard to back up or judge these researchers' arguments, specifically whether this model could or couldn't be suitably applied, if at all, to settings like Djibouti.

### ***2.3.2. The consequence theory***

This theory suggests that disease progression influences disclosure through individuals' perception of the consequences anticipated as a result of disclosure (Serovich, 2001; Serovich, Lim & Mason, 2008). It is perceived that as the disease progresses, the need to evaluate the consequences of disclosure becomes more pronounced. The decision to

disclose one's HIV status is thus presented, in this model, as the outcome of a calculation of the immediate benefits and risks of disclosure; and once the benefits for disclosing outweigh the associated risks, then, PLHIV are likely to disclose their status (Serovich, 2001; Serovich, Lim & Mason, 2008). Nevertheless, the decision to disclose one's HIV status remains reliant on an individual's psychological state, personal communication skills (the individual's inherent confidence in dealing with potentially confrontational situations such as disclosure), individual motivations for disclosure and some interventions to help support individuals through the process of disclosure (WHO, 2004).

#### **2.4. Perceived and reported barriers to HIV status disclosure**

Despite the potential benefits to disclosure, there are a number of commonly reported barriers that would prevent PLHIV from disclosing their HIV positive status. As a result, rates of HIV disclosure have been reported to range from 16, 7% to 86% in developing countries and 42% to 100% in developed countries (Medley *et al.*, 2004). Fear of the perceived negative consequences such as abandonment, stigma and discrimination and isolation from family members and from the community prevent many PLHIV to disclose their status (Kalichman & Simbayi, 2003). Some researchers also report that some of the PLHIV decide to hide their status in order to avoid upsetting family members, disappointing them and or protecting them from shame and obligation to help (Yoshioka & Schustack, 2001).

It would appear also that a person living with HIV's level of education is associated with HIV status disclosure. This was observed in one prospective study conducted with



79 pregnant women living with HIV who were tested as part of antenatal care in Burkina Faso (Issiaka *et al.*, 2001). It is reported in this quantitative study that educated women were more likely to disclose their status to partners than were illiterate women (Issiaka *et al.*, 2001).

Moreover, while disclosure appears to be an ongoing process (whereby PLHIV may decide to inform some of their confidants and others on a later time, rather than telling them all at once), it is reported in one study of 413 men and 641 women living with HIV in South Africa that individuals with previous HIV-related negative experiences (resulting from previous disclosures) are less likely to continue to disclose their status to others (Simbayi *et al.*, 2007). Similar findings were observed in a comparative study involving 139 PLHIV who had disclosed their status and 139 PLHIV who had not disclosed their status in Uganda (Isaac & Fred, 2009). Researchers found that PLHIV who had never witnessed mistreatment of PLHIV following their disclosure, were more likely to disclose their status compared to those who had witnessed PLHIV being mistreated (Isaac & Fred, 2009).

## **2.5. The reported consequences of HIV status disclosure**

Despite the above mentioned benefits, a number of risks for individuals who disclose their HIV positive status also exist. These include physical violence such as hitting, punching and slapping, (Finney & Njoko, 2000) and psychological violence such as stigma and discrimination (Gielen, O'Campo, Faden & Eke, 1997). PLHIV who disclose their status are also likely to experience socioeconomic discrimination including blame, abandonment or separation, loss of the custody of their children as well as loss of financial support (WHO, 2004).

It would appear, however, that the negative consequences of disclosure as reported by some recent studies, are not as devastating as one might anticipate – notwithstanding the fact that in many societies significant levels of HIV-related stigma and discrimination still exist and will be harmful for those living with HIV (whether they have disclosed their status or not). For example, it is reported in one quantitative study of 684 men living with HIV, conducted in the US, that only 10.4% of respondents experienced negative consequences from their partners following disclosure (Mansergh, Marks & Simoni, 1995). Findings from this study were consistent with findings from a larger study conducted in the same setting (Zierler *et al.*, 2000) where it was reported that among a sample of 2684 women and men living with HIV only 10% of the women and 7.7% of the men experienced negative consequences from their partners following disclosure of their status (Zierler *et al.*, 2000).

These findings concur with results from one cohort study in Cote d'Ivoire (Brou *et al.*, 2007). In this study, 980 pregnant women were tested for HIV during antenatal services. Among women living with HIV who disclosed their status, 82.1% experienced positive reactions, characterised with understanding and moral support from their partners. Only 0.4% women experienced violence after disclosure; 2.4% ended their relationship with their partners; and only 2% declared their partner did not believe their positive test results (Brou *et al.*, 2007).

## **2.6. Interventions to help support individuals through the process of disclosure**

A number of studies have explored the ways in which disclosure can be facilitated. Counselling and the role of health professionals or HIV counsellors appear to be playing a role in this regard. For example, a study conducted in the US found that the rate of

disclosure is likely to increase with the number of times health officials discuss issues of HIV disclosure during the provision of HIV services (De Rosa & Marks, 1998 in WHO, 2004). Similarly, in studies conducted in Tanzania, people who disclosed their status reported that counsellors played an important role in assisting them to disclose (Maman *et al.*, 2001; Maman *et al.*, 2003).

## **2.7. Conclusion**

This literature review sought to summarise some of the literature related to HIV positive status disclosure. It looked at the benefits of HIV positive status disclosure and the factors that could motivate PLHIV to disclose their status. It also looked at some of the perceived and reported barriers and consequences of HIV status disclosure. Some of the interventions that could be helpful in supporting PLHIV through the process of disclosure were also explored. However, although internationally there is a wide range of literature on HIV status disclosure, it has been observed that there is a lack of data on the subject in the context of Djibouti. It is therefore anticipated that this research will make a significant contribution in filling this gap.

## **CHAPTER THREE: METHODOLOGY**

### **3.1. Introduction**

The previous chapters introduced the study and summarized some of the literature related to HIV positive status disclosure. This chapter presents the methodology used to conduct the study. It sets out the aim and objectives of the study, the study design, the study setting and population. It then describes the sample size and sampling approach for the study population. Methods used to collect and analyse data, rigour and ethical considerations are also presented in this chapter.

### **3.2. Study aim and objectives**

The aim of this study was to investigate the perceived and experienced barriers and the reported consequences of HIV positive status disclosure to partners and family members by PLHIV attending a health facility in Djibouti Ville, Djibouti.

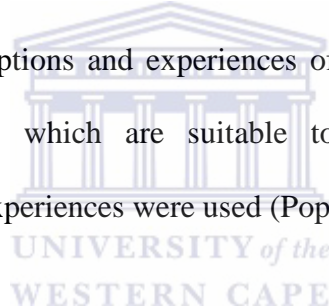
The objectives were as follows:

- 1) To explore with PLHIV the decision-making processes, the circumstances and the experiences associated with the disclosure (or non-disclosure) of their HIV positive status to their partners and/or family members.
- 2) To explore with health workers their understanding of the decision-making processes, the circumstances and the experiences associated with the disclosure (or non-disclosure) of their client's HIV positive status to their partner and/or family members.

- 3) To describe the factors PLHIV and health workers believe either prevent or facilitate PLHIV to disclose their status to partners and/or family members in Djibouti.
- 4) To develop a set of recommendations around the issue of HIV positive status disclosure that will serve to inform the future development of local HIV prevention, counselling and treatment programmes in Djibouti.

### **3.3. Study design**

This was a descriptive qualitative study utilising semi-structured interviews and focus group discussions (FGDs) as data collection methods. Since the aim of the study was to investigate participants' perceptions and experiences of the issue under investigation, qualitative research methods which are suitable to a deeper understanding of individuals' perceptions and experiences were used (Pope & Mays, 1995).



### **3.4. Study setting**

The study was based at Centre Paul Faure, a hospital located in Djibouti Ville, which is the capital city of Djibouti. Centre Paul Faure has 175 beds, and about 40 patients are attended, daily, in the outpatient clinic. It is actually the biggest TB hospital in Djibouti. In addition to the regular TB clinical services, the hospital provides a range of HIV specific services including VCT, HIV case management and treatment across the continuum of HIV infection. Patients attending TB and HIV-related services at Centre Paul Faure come from all six districts of Djibouti. The hospital was selected amongst other health facilities because of having more PLHIV attending the HIV-related services than any other health facility in Djibouti. And though the researcher had no link to the

hospital, the two health professionals who worked with the researcher as research assistants (also referred to in this report as colleagues) worked at this hospital as HIV counsellor and psychologist.

### **3.5. Study population**

Study participants were PLHIV and health workers. PLHIV participants were drawn from known PLHIV regularly attending the outpatient clinic at Centre Paul Faure. According to the research assistants, who worked at Centre Paul Faure as HIV counsellors, at least 10–15 PLHIV are often attended to daily in the outpatient clinic at Centre Paul Faure (Personal communication with F. Mohamed & N. Désiré, HIV counsellors, Centre Paul Faure, 20 September 2008). However, only those PLHIV who fulfilled the selection criteria were eligible for the study – specifically those who were diagnosed through VCT services at Centre Paul Faure and who were enrolled in the ART programme and or other HIV-related clinical and counselling programmes at this hospital. And though the hospital had more than 50 health workers by the time this study was conducted, only those dealing with PLHIV’s HIV-related care and support services were eligible and were invited to participate in the study. These included doctors, nurses and HIV counsellors.

### **3.6. Sampling procedure and sample size**

Liamputtong & Ezzy (2005:45) suggest that sampling in qualitative studies ought to aim at identifying participants who “*will provide a full and sophisticated understanding of all aspects of the phenomenon*”. Additionally, Bernard (2002:193) proposes that the study participants should to be “*...people to whom you can talk easily, who understand the information you need and who are glad to give it to you...*” For this reason, a

purposive sample (non-probability sample) of 8 PLHIV and 12 health workers who the researcher believed were able and willing to provide such an understanding of the issue that forms the focus of the research were recruited into the study. 8 PLHIV included 4 (2 men and 2 women) who had disclosed their status to partners and/or family members and 4 (2 men and 2 women) who had not told anybody that they were living with HIV were recruited.

PLHIV participants were identified directly from registers by the researcher, his colleagues and the co-ordinator of HIV/AIDS clinical and support services, at Centre Paul Faure. Given that the decision-making process for disclosure requires amongst other things an individual to adjust to the diagnosis before deciding on who should be told (Kimberly & Serovich, 1995), it was decided that only PLHIV who had received post-test counselling at this hospital four months or longer prior to the data collection be eligible to participate in the study. No evidences from other studies have shown this period ( $\geq 4$  months) as a cut-off time for inclusion of participants in the study, but based on the experiences of the researcher's colleagues who worked at this hospital as HIV counsellors, four months since diagnosis is considered a reasonable amount of time for people to begin sharing their disclosure experiences.

It was also required that PLHIV be attending the out-patient facility rather than being patients within the hospital wards. PLHIV attending the outpatient clinic were preferred by the researcher (as compared to those admitted to the hospital) because they were assumed to have had more opportunity to psychologically prepare themselves on whether to disclose or not and thus be able to make informed decisions around the issue

of disclosure. Moreover, they appeared to be physically healthy compared to the inpatients and thus better able to interact with the researcher during the course of an interview.

However, due to the sensitive nature of the topic and limited time, it was difficult to get in more PLHIV meeting above mentioned criteria for inclusion in the study. As a result, PLHIV participants were under-sampled when compared with health worker participants. The researcher believed however that this won't have negative effects in terms of the credibility of the study findings. Moreover, it has been long claimed that the credibility of the study findings depends less on sample size than on the richness of the information gathered and on the analytical abilities of the researcher (Patton, 1990).

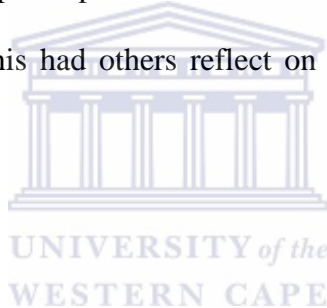
In relation to health workers, participants included 2 medical doctors who worked in CPF as general practitioners – thus treating both TB and HIV patients; 4 professional HIV counsellors who worked in the hospital's VCT services; and 6 trained nurses who worked as general nurses.

The criteria for inclusion in the study were that they should be working at Centre Paul Faure during the study period; be willing to participate voluntarily in the study; and should be reasonably "*homogeneous*" i.e. have a common characteristic, experience, or expertise (Liamputtong and Ezzy, 2005:82) – in this case it was their experience in providing clinical and psycho-social support to PLHIV; and in relation to the topic under discussion. This strategy thus excluded some workers, such as secretaries and other office clerks. It has been urged that a more homogeneous profile of participants



within each focus group enables the researcher to increase group comfort level when discussing sensitive topics such as this one related to HIV issues (Liamputtong and Ezzy, 2005).

Health worker participants were recruited into two FGDs – each comprised of 6 participants. The participants were divided into these groups based on their availability from their daily duties. Conducting FGDs with health workers who spend most of their time providing care and support services to different PLHIV enabled the researcher to gain depth of information that may have been limited by the first data collection method. This method allowed participants to recall and share some of their experiences within a group and through this had others reflect on whether their own experiences have been similar or different.



### **3.7. Data collection**

#### ***3.7.1 Interviews with PLHIV***

Semi-structured interviews were conducted with PLHIV between January and February 2009. The researcher contacted the authority at Centre Paul Faure, informed them about the study, provided them with necessary details about the study purpose and process and requested their permission to conduct the study. After obtaining the permission, the researcher contacted the co-ordinator of HIV/AIDS clinical and support activities at Centre Paul Faure in order to obtain his help in selecting suitable participants and making the initial contact with them.

Potential PLHIV participants were all provided with necessary information about the study (see Appendix III & IV) by the researcher and the co-ordinator of HIV/AIDS clinical and support activities at Centre Paul Faure a week before the data collection started. Four of the eight participants were provided with this information when they came to collect their medicines (ARVs) at the clinic. Others (4) were provided with this information when they made appointments for laboratory investigations. The HIV/AIDS co-ordinator asked participants whether they would voluntarily agree to participate in the study and thus participate in an interview with the researcher. Whoever agreed, an appointment was made with him/her to meet with the researcher. Information about the study was provided in written and verbal format in participants' local language, namely Somali. All PLHIV contacted agreed to participate in the study.

A total of 8 individual interviews were conducted with PLHIV during the study period. Each interview lasted between 30–45 minutes. Interviews were conducted in participants' preferred language (Somali or French) and took place in one of the counsellors' offices in Centre Paul Faure. The researcher made use of a semi-structured questionnaire (Appendix I) as a guide in conducting the interviews. In addition to collecting background information (age, marital status, education level and employment), the interview guide included questions related to the participant's experience with HIV counselling and testing; HIV disclosure; and a question on disclosure and sexual risk behaviour. The study guide was piloted with two men and two women living with HIV, and this resulted in modifying the interview guide - particularly in relation to refining the probing questions on the reasons for disclosure and non-disclosure. Transcripts from the 4 PLHIV interviewed in the pilot were not included in the final analysis.

One nurse, working in Centre Paul Faure and familiar with issues related to HIV, was appointed by the researcher, in advance, to help him with translation, i.e. from local languages to the language spoken by the researcher (i.e. French). This nurse was chosen not only because she had experience in issues related to HIV and counselling, but also had already established a rapport with all PLHIV interviewed. This made both male and female participants feel free to share their experience with the researcher. Three men living with HIV, however, understood French, and so translation was not needed. All interviews were tape recorded and transcribed. At the end of each interview, every participant was given 1,750 DJf (the equivalent of 10 USD) as a compensation for his/her time.



### ***3.7.2. Focus group discussions with health workers***

FGDs were conducted in mid February 2009. Participants were made aware of the study through the researcher's colleague, who also works at Centre Paul Faure as psychologist and HIV counsellor. Participants were also given the necessary information about the purpose and procedure of the study prior to the FGDs being held (Appendix III & IV) and asked if they are willing to participate. An appointment was made with those who agreed to participate.

When each group of participants gathered for the discussion, the researcher and his colleague introduced themselves, as a facilitator and note taker, respectively. The researcher, again, explained the purpose of the discussion, how the information collected will be used, and the group rules, such as speaking one at a time and avoiding interrupting or monopolizing the discussion. He also explained that the discussion is

confidential and that participants should respect each other's right to privacy by not discussing what was talked about in the group with people outside of the focus group.

Participants were reminded that their participation in the FGD was voluntary and that they were not obliged as a member of the staff at the facility to participate in the discussion. They were also reminded that they could excuse themselves from the focus group and withdraw from the discussion at any time. Of special importance, participants were informed that they would be asked general questions about issues related to HIV status disclosure in their communities and amongst their clients. FGDs were conducted in French and facilitated by the researcher. The researcher asked questions as summarized in the topic guide (Appendix II) and asked the study participants to discuss them in group. The researcher's colleague was responsible for tape recording, taking notes and observing the group process. Each FGD lasted for approximately an hour.

The interview guide for FGDs was piloted with two professional nurses prior to the FGDs being held, after which a few adjustments were made before its use in the two FGDs. These 2 health workers didn't however take part in the later FGDs. The FGDs were also held in one of the counsellors' offices in Centre Paul Faure. FGD participants were served with soft drinks and snacks obtained at a nearby restaurant.

### **3.8. Data analysis**

Data were analysed and interpreted using a thematic analysis (Green and Thorogood, 2004) and principles of qualitative data analysis as outlined by Gifford (undated (a)) were followed. The focus was on identifying emerging themes from both the semi-structured interviews and FGDs. Themes are described as units derived from patterns

such as conversation topics, vocabulary, feelings, proverbs etc (Taylor and Bogdan, 1984) and are identified by “*bringing together components or fragments of ideas or experiences which often are meaningless when viewed alone*” (Leininger, 1985: 60).

In terms of process the researcher, from the transcribed FGDs and individual interview transcripts, looked and then listed the emerging patterns related to the perceptions, opinions, feelings and experiences expressed by participants during the data collection processes. This included direct quotes and paraphrased ideas. The next step was to identify all data that related to these classified patterns. That is, all statements which fitted under the specific pattern were identified and placed with the corresponding pattern. This was followed by combining and categorising related patterns into sub-themes, which together formed a comprehensive picture of the participants’ collective experiences, perceptions and opinions.



### **3.9. Rigour**

To establish the credibility of the study findings a triangulation of methods was used (Mays, & Pope, 2000; Gifford, undated (b)). The perspectives of both those living with HIV and health workers working in the field of HIV were explored, using two different data collection methods, and their personal experiences and views considered in terms of similarity or consistency and differences. The preliminary findings from the research were also shared with some of the participants so as to be sure the representation of their experiences and opinions were accurate. Specifically, the process called “*member checking*” was used (Riley, 1996 in Goulding, 1999: 16). That is, participants were asked to assess whether the analysis made is an accurate representation of their conversations or reflections.

In terms of PLHIV, this happened during data collection. That is, at the end of each interview every participant was requested to listen to what had been noted down during the interview and assess whether their viewpoints were faithfully interpreted. The researcher then summarized some of the key points made by each interviewee. And, in relation to health workers, the researcher asked them, at the end of each FGD, whether they could be contacted to discuss the analysis made by the researcher of the discussion that have been facilitated. All FGD participants accepted and a draft version of the results and discussion section of the study were sent to some of them, namely, one medical doctor, two HIV counsellors and one trained nurse. The researcher contacted them a month later to discuss their reading of the draft document. At the meeting, the manuscript was reviewed critically and the participants approved it.

In addition, the two health professionals who assisted the researcher during the FGDs and individual interviews also worked with the researcher to summarise key points at the end of each FGD and individual interview. They were invited again two months later, to review the preliminary findings with the researcher. Their interpretation, along with that of the researcher, and most importantly, the participants' views and experiences on the perceived and experienced barriers and consequences of HIV status disclosure are collectively included in this final study report.

### **3.10. Ethical considerations**

Participation in the study was voluntary. All participants were provided with a letter explaining the research study, requesting their participation and ensuring them of confidentiality. The information regarding confidentiality, the purpose and process of

the study, including participants' right to withdraw, is summarised in the participants' information sheet and consent form below (Appendixes III & IV, respectively). Participants were, specifically, informed of their right to withdraw from the study at any time, and were assured that refusal to participate would not jeopardise their treatment and follow - up care in any way.

Participants were also told that confidentiality would be maintained at all times. Their names were not written anywhere and only pseudonyms and numbers were used, which were only known to the researcher's colleagues, namely, a nurse counsellor and a psychologist – who helped the researcher in the interviews with PLHIV and in the FGDs with health workers, respectively. A request to complete the informed consent forms among PLHIV was made by the Co-ordinator of HIV/AIDS clinical and support activities at Centre Paul Faure, following initial contact and explanation of the study. The researcher's colleague, a psychologist, who also works at Centre Paul Faure helped to facilitate this exercise with health workers. Signed informed consent was obtained from each participant before commencing data collection. All individuals contacted accepted to voluntarily participate in the study.

An approval to conduct the study at Centre Paul Faure was obtained from responsible authorities (Centre Paul Faure) and the research protocol was approved by the University of the Western Cape Ethics Committee, before the data collection started. It was however anticipated that the research could cause no harm to the research participants. However, given the two research assistants were trained as a psychologist and a nurse counsellor and were present in both the FGDs and the individual interviews

respectively, participants were informed that they both would be available to provide follow-up counselling and psycho-social support if any of the participants felt that this was necessary.

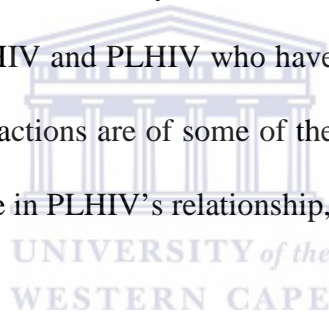




## **CHAPTER FOUR: RESULTS**

### **4.1. Introduction**

The previous chapter dealt with the research methodology. This chapter presents the findings of this study. More specifically, the chapter presents the main characteristics of the study participants and outlines and describes what PLHIV and health worker participants perceive as some of the main barriers to disclosing one's HIV positive status to one's partner and/or family members. It also describes the decision-making process, the circumstances and the experiences associated with the disclosure of one's HIV positive status to partner and/or family members – this includes the experiences of those working in the field of HIV and PLHIV who have disclosed their status – that is, how do they do it, what the reactions are of some of the people PLHIV disclose to and whether this results in a change in PLHIV's relationship, including sexual behaviour.



### **4.2. Characteristics of the study participants**

#### ***4.2.1. PLHIV study participants***

As shown in Figures 1 and 2, the analysis involved 8 PLHIV (4 men and 4 women). Their ages ranged from 29 to 46 years, and all PLHIV interviewed were married and lived with their partners, except one man whose relationship had broken up as a result of his disclosure. Educationally, 1 woman reported to have no formal education, 4 had attained primary education, 1 had attained secondary education, and 2 individuals had attained tertiary/higher education. The majority (7 of the 8 participants) had been aware of their HIV positive status for a period of 1 – 2 years. And of the 8 PLHIV 4 had disclosed their status – 3 of which had disclosed to their partner and their family

members and one to only their partner. Only 3 of the 8 PLHIV participants were employed.

**Figure 1: The main characteristics of PLHIV study participants**

Characteristic	Category	Sex		Participants (n)
		Male	Female	
Marital status	Married and have children	3	3	6
	Married but have no children	0	1	1
	Separated but have children	1	0	1
Education level	Non formal education	0	1	1
	Primary education	1	3	4
	Secondary education	1	0	1
	Higher education/ Tertiary	2	0	2
Employment status	Employed	3	0	3
	Unemployed	1	4	5
HIV knowledge before diagnosis	Knew something about HIV	4	4	8
	Didn't know	0	0	0
Length of time since diagnosis	Less than 1 year but more than 6 months	0	1	1
	More than 1 year but less than 2 years	4	3	7
Advise on HIV status disclosure	Advised to disclose	4	4	8
	Not advised to disclose	0	0	0
	Disclosed to partner only	0	1	1
	Disclosed to partner & family members	2	1	3
	Disclosed to family members only	0	0	0
	Non-disclosure	2	2	4
Hospitalisation since diagnosis	Hospitalized	1	0	1
	Never been hospitalized	3	4	7
HIV treatment	Currently on ART	4	4	8

**Figure 2: Age distribution of PLHIV study participants**

Age groups	Sex		Participants (n)
	Male	Female	
20-30	0	2	2
31-40	2	2	4
41-50	2	0	2
Total	4	4	8

#### **4.2.2. Health worker study participants**

As shown in Figure 3, twelve health workers participated in the study. They included two medical officers who worked in CPF as general practitioners (treating both TB and HIV patients), six trained nurses who also worked as general nurses, and four professional HIV counsellors who worked in the hospital's VCT services. Although their demographic information was not disclosed, through observation, their ages ranged from 30 – 45 years.

**Figure 3: Health workers (FGD Participants)**

Characteristic	Category	Sex		Participants (n)
		Male	Female	
Doctor	Medical Officer (GP)	1	1	2
Nurse	Trained nurse	2	4	6
HIV counsellor	Professional	3	1	4
Total		6	6	12

### 4.3. Participants' perceptions on the community attitudes and knowledge on HIV

When asked about whether they knew something about HIV prior to HIV testing, all PLHIV interviewed reported having prior knowledge about HIV which they had obtained from the radio, TV, news papers and discussions with other people. As one respondent noted:

*You can find HIV/AIDS information everywhere here and everyone knows this quite well. In news papers, radio, TV, etc, you'll always find something about HIV/AIDS.*

(41 – year old, male participant, not disclosed his HIV positive status)

Some of the respondents (4 of the 8) also believed that every person in Djibouti knows that HIV/AIDS exists and there are people dying due to HIV/AIDS. For example, as one of these respondents suggested:

*Who doesn't know HIV/AIDS in Djibouti? ...Everybody knows that it exists and kills many people....there're always HIV programmes on the radio and TV, and almost every person here has a radio or a TV.*

(46–year old, male participant, not disclosed his HIV positive status)

Nevertheless, even though all this information is apparently disseminated and some of the interviewees felt that everyone knows about HIV, the understanding of the public is not always correct. There are still many myths and denial surrounding HIV/AIDS in Djibouti. For example, when PLHIV participants who did not disclose their status were asked to recall when they first learned about their HIV diagnosis and inform the

researcher about specific reasons that might have influenced not disclosing about their HIV status to a partner and/or family members, two of the four participants noted that:

*You know if people hear that you have HIV, not even one would shake your hand or share anything with you ... they all think that you'll contaminate them.*

(34 – year old, female participant, not disclosed her HIV positive status)

*If people here get to know that I have it, nobody will come over my home again. Nobody could still lend out something from my home, they'll all run away thinking that they'll be contaminated.*

(41 – year old, male participant, not disclosed his HIV positive status)

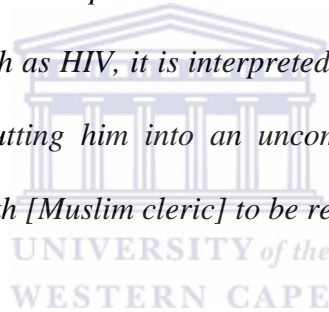
This was later confirmed in the FGDs when one health worker participant noted that, the community associates HIV infection with behaviours known to cause the infection (promiscuity or infidelity) and there are unfounded fears of HIV transmission following casual exposure to PLHIV. The quotation below illustrates this point:

*First of all ... [some people] believe that to acquire HIV/AIDS a person should have had sexual contact with an infected individual. Such people... perceive that PLHIV are either prostitutes or are clients of prostitutes and are infidel ... PLHIV are [also] seen by the community as bad people... There are some people ... who think that they could contract HIV by simply shaking hands or sharing something with an individual with HIV. Such people also tend to develop avoidant behaviours with PLHIV and would isolate themselves from them and their families.*

(Trained Nurse, FGD)

One participant in the FGDs also noted that, some people still believe that HIV is sent by ‘Allah’ (the Almighty), or that it’s a ‘jinni’ (a spirit that can take on various human and animal forms and makes mischievous use of its supernatural powers) that makes people fall sick, as a form of punishment (divine punishment) and a result of moral misconduct. Consequently, they believe that if they read the Qu’ran, ‘Allah’ will restore them to health. The following quotation illustrates this point:

*People here believe that ... there are jinns everywhere ... in big stones, large trees, in caves and in hills...that one needs to respect their customs... Parents advise their children to respect certain instructions... So when a person contracts a disease such as HIV, it is interpreted that one has come into contact with these spirits... putting him into an uncomfortable situation... They are advised to see the Sheikh [Muslim cleric] to be read the Holy Qu’ran.*



(HIV Counsellor, FGD)

It was also noted that, in a relationship, the first to be tested for HIV is generally considered to be the guilty party no matter if it was actually the other person that was first HIV positive. The quotation below illustrates:

*And you know the big problem for us women is that even if it's my husband who brought it, he can not accept that it's him! Never! He'll rather blame me so that every person points at me. And moreover I am the first to be tested- people here believe that if you're the first to be tested, fall sick or die first, then you're the one who brought the virus.*

(29 – year old, female participant, not disclosed her HIV positive status)

Given the above, PLHIV are inevitably seen by the community as “bad people”. This expression (bad people or a bad person) was frequently used by FGD participants to refer to the community’s judgement against PLHIV and was described by both PLHIV and FGD participants as meaning “prostitutes and people who drink alcohol and or go to night clubs”. As a result one participant in the FGDs noted that:

*Since everyone knows very well that this exists [community judgement against PLHIV], the majority choose not to tell anybody when they find out that they are infected [with HIV].*

(HIV Counsellor, FGD)

#### **4.4. PLHIV participants’ HIV counselling and testing experiences**

With regard to HIV testing, all PLHIV participants reported to have been tested in Centre Paul Faure as a result of having been diagnosed with TB and thus recommended by their doctors and nurses to take an HIV test. The researcher was thus made to understand that, as TB is one of the main opportunistic infections associated with HIV, all TB patients at Centre Paul Faure who have not previously been diagnosed with HIV infection are encouraged to have an HIV test. This probably reflects the WHO and UNAIDS strategy and recommendations for collaboration between TB and HIV services or activities for better practices (Nunn *et al.*, 2002; UNAIDS, 2004). On observation, all respondents appeared relatively healthy and only one reported to have been hospitalized, once, since diagnosis.

When asked whether they felt free to accept their HIV test results, all PLHIV including those who were yet to disclose their status informed the researcher that they freely accepted their HIV test results after using the VCT services. Below is what, for example, three of the eight PLHIV participants said in relation to this type of willingness to accept the HIV test results:

*I was down sick for about 6 months, with diarrhoeas, coughs, fevers, etc. When they told me that I have HIV, I felt even better than before, because I said that at least I know my killer! I wasn't worried at all.*

(37 – year old, male participant, not disclosed his HIV positive status)

*Of course, accepting to be tested meant accepting everything that would come out.*

(37 – year old, female participant, not disclosed her HIV positive status)

*I trusted my doctors and I suspected myself. So there was nothing to refuse about the results.*

(38 – year old, male participant, disclosed his HIV positive status)

They further reported that they were advised by their doctors, nurses and HIV counsellors to share their test results with someone else they trusted, particularly their partners and encourage partners to go for HIV testing. For example, when asked whether they were advised to share their test results with someone else, two of the eight PLHIV participants said that:



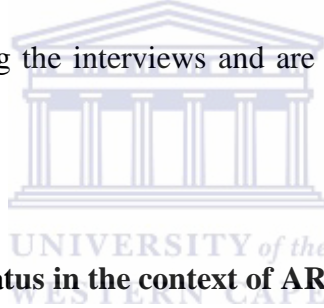
*Yes, yes, after the results... They said it was better to inform some people in the family, especially, my wife and if possible bring her so that she could also be tested.*

(46 – year old, male participant, not disclosed his HIV positive status)

*Yes, the doctors and counsellors told me... to tell my wife about the test results and bring her for an HIV test.*

(39 – year old, male participant, disclosed his HIV positive status)

Reasons for non-disclosure among people who decided to keep their status a secret and experiences of those who decided to disclose their status to partners and/or family members were explored during the interviews and are described in details in the next section.



#### **4.5. Non-disclosure of HIV status in the context of ART**

The 4 PLHIV who did not disclose their status were all on ART. And so, bearing in mind that the taking of such medication was likely to raise some suspicion or questions from family members, the researcher asked the PLHIV whether those in their social network knew they were on ART. Three of the four respondents told the researcher that they would readily respond with a lie to any inquisitive question as to why they are always on medications or if they were seen accessing TB/HIV clinics. For example, respondents noted that:

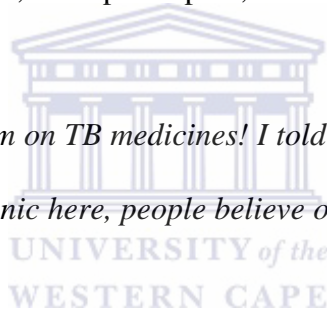
*I simply tell them that I have TB. But I first look at who is asking; because other people are also intelligent or they fear TB. Those who fear TB I just say that I have a chronic bronchitis or dig up another smart lie.*

(46 – year old, male participant, not disclosed his HIV positive status)

*I just respond with a white lie! Moreover my family knows that I had TB. So I continue to say that I'm going to Centre Paul Faure for some TB medicines! I have got some X-Ray films also I just take them with me and show those who pretend to be too much know (laughter).*

(41 – year old, male participant, not disclosed his HIV positive status)

*Everyone knows that I'm on TB medicines! I told them all that my TB is chronic! And because TB is chronic here, people believe on what I tell them and so take it easy.*



(29 – year old, female participant, not disclosed her HIV positive status)

For one woman (one of the respondents who did not disclose their status) to keep her status a secret she had to hide her medicines and dispose of all the materials related to HIV medicines (e.g. leaflets) as far as possible:

*I hide all my medicines in my kiosk and I pretend to be strict, even my husband can not enter in ... And I always make sure that I burn or throw away all the documents [instruction leaflets etc] relating to HIV medicines.*

(37 – year old, female participant, not disclosed her HIV positive status)

#### **4.6. Barriers and consequences of HIV status disclosure cited by participants**

In order to gain an insight into the perceived and experienced barriers and consequences of HIV positive status disclosure to one's partner and/or family members, PLHIV who did not disclose their status were asked about the reason why they decided to keep their status a secret. And those who had disclosed were asked to describe their decision-making processes and the circumstances and the experiences associated with the disclosure of their HIV positive status. Similarly, FGDs were also held with health workers, in order to explore their understanding of the decision-making processes, the circumstances and the experiences associated with the disclosure or non-disclosure of their clients' HIV positive status to partner and/or family members, and to describe the factors they believed either prevent or facilitate their clients to disclose their status to partners and/or family members.



##### ***4.6.1. Barriers to HIV status disclosure***

PLHIV and health worker participants cited a number of barriers to HIV positive status disclosure in the context of Djibouti, ranging from a fear of experiencing some form of HIV-related stigmatization and discrimination to losing their source of income. These are explored below:

##### **4.6.1.1. Anticipating HIV-related stigma and discrimination**

When asked to mention people they were closest to, all PLHIV reported a large social network including relatives and friends. However, in responding to the questions "Have you told them that you were tested for HIV and about your test results?" and "What is your fear about telling your partner or any member of your family that you were tested

for HIV and had positive results?”, everyone who had not disclosed their status demonstrated a high perception of stigma and discrimination.

Specifically, one male participant (46 - year old) questioned that “May be you know our people uh-huh?”... “What would you expect from them after learning that you have HIV/AIDS?” and explained that “...if people here get to know that you have it [HIV], you’ll think about committing suicide or fleeing the village”. He further stated that if people realise that someone is infected with HIV, they will be looking at him/her and say to others that “...see this man or see this woman [gesticulates] [laughter] and all start gossiping about [him/her]”. He concluded that “...if you don’t like people to point at you wherever they see you, you simply keep quiet.”

Similar views were expressed by other PLHIV participants, including one of those who had disclosed their status. She said that:

*My husband doesn't like me to tell other people, because they'll think that he's also infected and they'll start gossiping about us! He also feels that people will say he married a prostitute or that I have been unfaithful within just this short period of time! It's just two years since we got married.*

(30 – year old, female participant whose partner had tested HIV (-)  
following her disclosure)

The above comments were further confirmed in the FGDs when one member in the group, on being asked about some of the factors they believe prevent or encourage their clients (PLHIV) to disclose their status, said that:


*(T)he information that they are infected makes them always feel desperate and unsure about their lives and their future. They combine this situation with the existing atmosphere of stigmatisation and discrimination against PLWHA. This makes always the decision to disclose really difficult.*

(HIV Counsellor, FGD)

He also added that:

*They call them funny names, judge them and people even fear to talk to people with HIV/AIDS. People feel that people are infected because they are promiscuous and they see them like people who are going to die straight away.*

(HIV Counsellor, FGD)



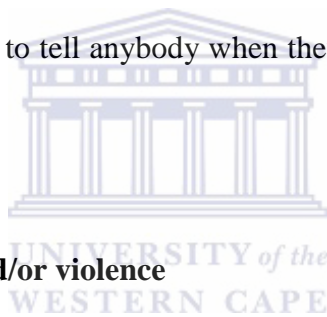
Actually, from the perspective of health workers, PLHIV are often discriminated against because their communities associate HIV infection with behaviours known to cause the infection (promiscuity or infidelity) and from an unfounded fear of HIV transmission following casual exposure to PLHIV. For this reason PLHIV decide to keep their status a secret – in order to avoid such detrimental reactions from the community. The quotation below illustrates this point further:

*First of all ... [some people] believe that to acquire HIV/AIDS a person should have had sexual contact with an infected individual. Such people therefore perceive that PLHIV are either prostitutes or are clients of prostitutes and are infidel ... PLHIV are [also] seen by the community as bad people... Secondly, there are some people here who think that they could contract HIV by simply shaking hands or sharing something with an individual with HIV. Such people*

*also tend to develop avoidant behaviours with PLHIV and would isolate themselves from them and their families. PLHIV are aware of such community belief and behaviour.*

(Trained Nurse, FGD)

PLHIV are seen by the community as “bad people”. This expression “bad people” or a “bad person” was frequently used by FGD participants to refer to the community judgement against PLHIV and was described by both PLHIV and FGD participants as meaning “prostitutes and people who drink alcohol and or go to night clubs”. And according to one participant in the FGDs “... since everyone knows very well that this exists, the majority choose not to tell anybody when they find out that they are infected (HIV Counsellor, FGD).



#### **4.6.1.2. Fear of separation and/or violence**

##### **4.6.1.2.1. Fear of separation**

Fear of abandonment or separation from partner was everyone’s major concern amongst those who did not disclose, and so their major barrier to disclosure. The expressions below made by three participants illustrate this:

*He may divorce me, and I’m sure there will be noise and even fighting.*

(37 – year old, female participant, not disclosed her HIV positive status)

*For sure, if my wife hears that I have it will runaway or immediately request divorce.*

(41 – year old, male participant, not disclosed his HIV positive status)

*Oh she'll immediately go away or kill her self if she realise that she's also infected, because I am sure she can't take it on.*

(46 – year old, male participant, not disclosed his HIV positive status)

In fact, as the quotation below illustrates, this became a reality for one participant who disclosed his status.

*[She] got angry to hear ... and started crying and shouting on me; she could not even give me time to finish what the doctor had told me. She said 'it is true you have it and you deserve it' and left.*

(38 – year old, male participant, disclosed his HIV positive status)

#### **4.6.1.2.2. Fear of violence**

Disclosure of one's HIV positive status in Djibouti may present exceptional risks. Women, in particular, avoided disclosure of their status because of fearing violence and other adverse outcomes, such as divorce and rejection by their partner and family members. Consequently, suicide was something that one female respondent contemplated if her family was to discover that she was living with HIV. Here is how, for example, she explained why she had not disclosed to her partner and family members:

*I can't dare to tell him. Oh never, I can't...I know him ...unless I need to be finished ... He may divorce me, and I'm sure there will be noise and even fighting. And if it reaches my father, then I must find my way, maybe suicide or fleeing... to another country were people don't know me and die there!*

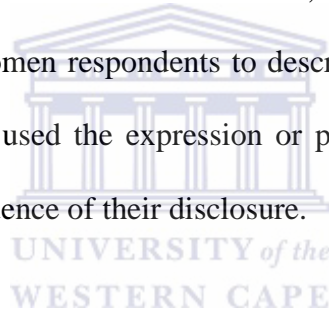
(37 – year old, female participant, not disclosed her HIV positive status)

Some fears related to potential violence were of a more serious nature: one woman, the youngest of the PLHIV interviewed said she had not disclosed her status because of the bad temper of her husband – she did not disclose her status out of a fear of being killed or beaten to death. She said that:

*How can I tell my husband for example? ...simply hearing that I tested for HIV itself will finish me, and how can I dare to say to him that I have it?*

(29 – year old, female participant, not disclosed her HIV positive status)

The expressions “will finish me” “I’ll be finished”, and “they’ll finish me”, were frequently used by PLHIV women respondents to describe killing or beating. None of the male PLHIV respondents used the expression or perceived experiencing physical violence as a potential consequence of their disclosure.



One woman, who had disclosed her status, had spent nine months considering disclosing to her partner out of similar feelings of fear. When asked to explain why she spent nine months without telling her partner that she had tested and had HIV positive results, she said:

*Every time I thought like telling him, I thought I'll be finished or I'll be told to go away and I'll be asked to tell where I got it.*

(34 – year old, female participant, disclosed her HIV positive status)



#### **4.6.1.3. Fear of being rejected by family members and experiencing their scorn**

Both female and male PLHIV participants – whether they had or had not disclosed feared that they would be rejected or detested by their family members if they realised that they were HIV positive.

*I'm sure it'll reach my father and he'll be angry with me. He may not even need to see me again in his family. My brothers too - will hate me and could even finish me ...You know, if you have HIV every person hates you, even if it's your mother. For example, my parents ... don't want other people in the village to hear that their daughter has AIDS; it's a big shame here. My brothers and everyone in the family will also feel the same. They all feel ashamed because they think people are looking at them and say that their daughter or sister is a prostitute because has AIDS.*

(37 – year old, female participant, not disclosed her HIV positive status)

*It's just two years since we got married! And if his family understands that I'm sick, they'll harass him to make sure that he divorces me. ...he is still young! He turned thirty five just last September 2008.*

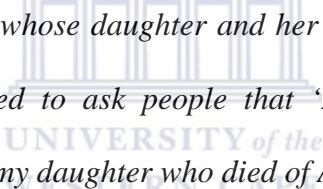
(30 – year old, female participant, disclosed her HIV positive status)

It was also reported that disclosure of one's status may lead to stigmatisation and discrimination of one's children by their grandparents. The quotations below illustrate this:

*Usually, in our community, if a man divorces his wife his children go to live with their paternal grandparents. Now it's impossible because my parents will think that our children are also contaminated, and so will hate them. Even if my mother accepts to take them they'll be humiliated. She'll be always telling people that 'these are the children of my son who's sick'. She can not treat them like other children.*

(41 – year old, male participant, not disclosed his HIV positive status)

This participant also made reference to what had happened in his village to three children whose parents had died of AIDS. He said that:



*I know one old woman whose daughter and her husband died of AIDS and left three children. She used to ask people that 'Do you know these children? They're the children of my daughter who died of AIDS.'*

(41 – year old, male participant, not disclosed his HIV positive status)

PLHIV participants believed also that disclosing one's HIV positive status could upset family members, and lead to individuals being scorned by family members. The quotations below illustrate this point:

*My mother and my sisters will be really disappointed. You see I'm only 29 year old, and I'm the last born! They all love me so much, and now if they hear that I'm sick, oh they'll be really disappointed.*

(29 – year old, female participant, not disclosed her HIV positive status)

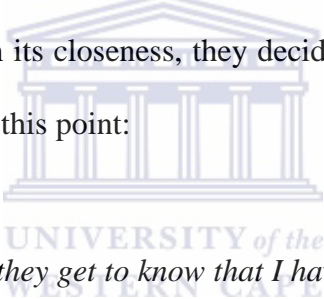
*They will be very discouraged and angry! And that's why I say right now I am not going to tell anybody! Because I know my family, especially my father and my brothers; they will be angry with me, and they would scorn me and what not. And you know this is not something that I can tell to my mother - because I know her - she may even collapse. I know my father too.*

(46 – year old, male participant, not disclosed his HIV positive status)

#### **4.6.1.4. Fear of being isolated from others**

PLHIV who did not disclose their status felt mainly that they'll be isolated from their social network if other people realise that they have HIV. And so, to remain in their community and to benefit from its closeness, they decided to keep their status a secret.

The quotation below illustrates this point:



*I know people here... If they get to know that I have it, nobody will come over my home again. Nobody could still lend out something from my home, they'll all run away ... And that means I'll be disconnected from other people.*

(41 – year old, male participant, not disclosed his HIV positive status)

This was also confirmed by participants in the FGDs, where one nurse stated that:

*Everyone takes it as a big shame ... Leave alone saying that I tested and have it; even saying that someone in my family has HIV, it embarrasses some people. And more over people found to be HIV positive know this in advance, and so few are likely to tell others that they tested or have it.*

(Trained Nurse, FGD)

#### **4.6.1.5. Fear of loss of financial support**

One man who did not earn any income other than what his wife brought in from selling fruits and vegetables (informal selling of goods in the community) said that as long as he was not working and therefore unable to support his family, he could not disclose his status. He believed that disclosing his HIV status could result in separation or being abandoned by partner who helped to get necessities for the family. This is how he put it:

*For sure, if my wife hears that I have it will runaway or immediately request divorce. And I told you I'm currently not working and she's the only one making us survive. So you can imagine if I say to her that I have it and she goes away! Where shall I get food for the children? And who will look after the children if their mother is not there? ...Mh?*

(41 – year old, male participant, not disclosed his HIV positive status)

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#### **4.6.1.6. Services related factors: inability to provide sufficient support**

Health workers in the FGDs revealed that in Djibouti, people who are counselled to disclose their status are often encouraged to disclose their status but not necessarily given sufficient practical advice about how they could go about doing it. In addition, they suggested that no follow up strategies are available to establish whether people that are counselled to disclose, do it or not – and how the barriers that they're experiencing in relation to disclosure could be addressed. This was therefore seen by health workers as another contributing factor for non-disclosure.

*In Djibouti, when people are counselled, they are simply suggested to disclose, but people are not often engaged in practical strategies of how to do it. And once people are counselled, no further follow ups [strategies] are made to know whether they disclose or not - except if they come back ... for some other clinical or counselling services, where they could be asked if they did it or not. This may therefore be another factor for non- disclosure.*

(Medical Officer, FGD)

*Well...our job is just to suggest the individual to disclose... The problem here is that when a lack of understanding between for example, couples, arises, you end up frustrated, especially because for some people it may end up with divorce and even rejection by family members. And they'll be always coming to you, and yet we can't help them... I mean you feel like you did not give adequate care to your clients.*

(HIV Counsellor, FGD)

Given the above, two health workers suggested that:

*It may possibly be useful if counselling sessions could include activities demonstrating strategies of disclosure and people are followed up to ensure that what prevents them to disclose are known and addressed.*

(Medical Officer, FGD)

*I think programs need to be developed that can assist PLHIV in making informed decisions about disclosing a positive status and in developing the skills to do so. We also need to promote community based programs to reduce stigma and discrimination against PLWHA and to enable community to initiate dialogue about HIV risk and violence within couples' relationships.*

(Trained Nurse, FGD)

#### **4.6.2. Some of the reported consequences of disclosure**

As shown in Figure 1, four PLHIV had disclosed their status. Of these, 3 (2 men and 1 woman) had disclosed to their partners and family members and one woman had disclosed only to partner. All of these individuals, except one man whose home had broken up in the process of disclosure, knew their partners' HIV status. And of these four PLHIV, 2 (1 woman and 1 man) were living with partners who were HIV-negative – and the other one was living with a partner who was also HIV positive. Participants were asked to recall when they first learned about their HIV diagnosis, to tell reasons that might have influenced disclosing about their HIV status, and about the circumstances following disclosure.

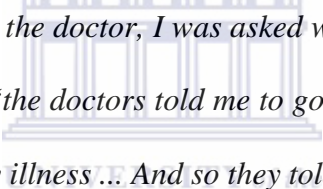
##### **4.6.2.1. Reasons cited by respondents for their disclosure**

When asked on what had influenced their decision to disclose their status, all four PLHIV who had disclosed their status noted that the need to start HIV treatment and the information and encouragement they had received from health workers appeared to have had some influence on their decision to disclose. Obviously the extent to which such dialogue with the health workers actually increased the rate of disclosure within

this group was not ascertained in this study, but the following quotations do highlight the important role played by health workers in facilitating the respondents' disclosure of their HIV positive status:

*They told me that I have HIV and advised me that it would be better if I discuss it with my husband, so that I could easily use medicines and other services ... I didn't hesitate, I called him in the office of the counsellors where they explained everything to him.*

(30 – year old, female participant, disclosed her HIV positive status)



*Every time I went to see the doctor, I was asked whether I had told him ... and so one day I told him that 'the doctors told me to go with you so that they could tell you something about my illness ... And so they told him everything.*

(34 – year old, female participant, disclosed her HIV positive status)

*The counsellors made me understand that even though I was infected my wife could be negative. I therefore took the decision to inform her – so that she could also be checked and so have a chance of using medicines, in case she was also infected.*

(39 – year old, male participant, disclosed his HIV positive status)

In addition to the desire to use HIV medicines and views of health workers, one of the participants quoted above noticed that keeping an HIV positive status a secret while on medications was something stressful and worrying. She kept on questioning herself

whether her partner wasn't aware of her status and whether he didn't know that she was on HIV treatment – a situation that made her decide to disclose. She said that:

*When I started using medicines I got worried! He kept on questioning me about my medicines, and some of his questions made me fear. Finally, I said this can't continue.*

(34 – year old, female participant, disclosed her HIV positive status)

In the FGDs, health worker participants were asked to relate incidents that they themselves observed in their daily duties, and those that they experienced in the community and in families, in relation to HIV status disclosure. It was suggested that people who look ailing at the time of testing are more likely to disclose their status. Amongst the reasons for disclosure in such cases, as said by one HIV counsellor is that “... it reaches a point where their family starts enquiring about their sickness, and so people decide to inform them”. Indeed, this concurs with experiences shared by one man living with HIV. He said that:

*First I was very sick and I needed someone's help. Secondly, I was requested by the counsellors to look for someone who will help me if I start (ARV) treatment...And you know I said people cannot help me if I hide ...my problem.*

(38 – year old, male participant, disclosed his HIV positive status)

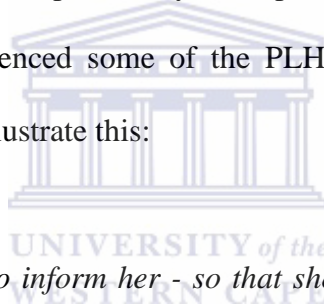
It appeared also that people who are accompanied by their family members and/ or partners for blood tests are likely to disclose their status to them. The quotation below illustrates this point:



*We were together here when they took my blood, although they didn't tell him that it was for HIV test ... Three days later I told him that we'll have to go [back to Centre Paul Faure] for the blood test results! So we came together again ... They told me that I have HIV and advised me that it would be better if I discuss it with my husband, so that I could easily use medicines and other services ... I didn't hesitate, I called him in the office of the counsellors where they explained everything to him.*

(30 – year old, female participant, disclosed her HIV positive status)

Honesty and a sense of ethical responsibility for a partner's health by PLHIV and the future of one's children influenced some of the PLHIV's decision to disclose their status. The quotations below illustrate this:



*I ... took the decision to inform her - so that she could also be checked and so have a chance of using medicines, in case she was also infected. I however prayed that Oh God Almighty let her become negative so that she could take care of our children if I die! And thank God Almighty she became negative.*

(39 – year old, male participant, disclosed his HIV positive status)

*I felt all the time that it's better to tell him so that he could be tested and if he is negative will look after our four children if I die or start medicines if he is also sick. These feelings made me always think about telling him.*

(34 – year old, female participant, disclosed her HIV positive status)

#### 4.6.2.2. Circumstances following the disclosure

Participants were asked about the circumstances following the disclosure of their HIV positive status – specifically in terms of whether they had been treated differently by their partners and or family members because of their known HIV positive status. A number of both negative and positive consequences were reported such as separation (for example, the break-up of the marriage); a greater understanding and strengthening of the relationship between family members and increased care and support from both partner and family members. For example, in describing the reactions of their partners and family members to the disclosure of their HIV status, two respondents said that:

*(T)hey have been very kind and supportive. And they're ever so friendly. And you know ... My sisters used to quarrel with my wife and have stopped after this problem! Probably, because of her understanding of my problem and her supportive nature [and joked that] or because they know she's negative and their brother is a bad man (laughter).*

(39 – year old, male participant, disclosed his HIV positive status)

And regarding the reaction of his parents, this participant said:

*My mother prepares some special food and invites me to share with them! She also asked one doctor who's a friend of mine about the types of food she can cook for me, so this showed me her position.*

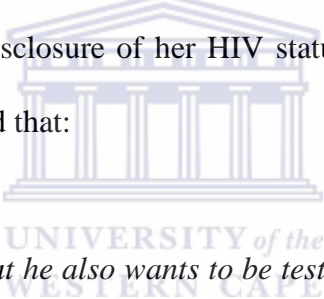
(39 – year old, male participant, disclosed his HIV positive status)

Another respondent, a woman whose husband was also living with HIV, said that:

*They're all so close to us and they regularly come to see us ...two of my sisters in law come with us here [at Centre Paul Faure] each time we come to collect our medications.*

(34 – year old, female participant, disclosed her HIV positive status)

Disclosure also led to partner taking an HIV test, i.e. of the four PLHIV who had disclosed their status three reported that their partners requested an HIV test after realising that the other partner is infected. For example, when asked to describe the circumstances following the disclosure of her HIV status to partner, one of the above quoted PLHIV respondents said that:



*He immediately said that he also wants to be tested. They took his blood and his results came positive! We were then counselled together and we made the pledge that there will be no time to blame each other but to plan the future of our four children. That's all!*

(34 – year old, female participant, disclosed her HIV positive status)

Other respondents experienced mixed reactions. For one man, though reported to have been understood and obtained supportive response from family members, the diagnosis led to his marriage break-up – and this seemed to justify the fear of those who did not disclose their status. In describing his plight this man said:

*I didn't tell them directly that I tested or I have it. I just said that I discussed with the doctor and he needs to check my blood for HIV...I thought that my wife would think about it and probably suggest something, but she got angry to hear that I was going to be tested, and started crying and shouting on me; she could not even give me time to finish what the doctor had told me. She said 'it is true you have it and you deserve it' and left.*

(38 – year old, male participant, disclosed his HIV positive status)

And when asked about the reaction of his family members after realizing that he had HIV, he responded that:

*They didn't say anything and no one is blaming me. They seem to be understanding that this is a mistake that anybody can make, and my sisters and brothers are all very close to me and spend much of their time with me! And we are now together with one of my sisters. We were also here last week with my brother and his wife.*

(38 – year old, male participant, disclosed his HIV positive status)

Although one woman experienced support and understanding from her partner after disclosure, disclosure did not work as anticipated in the context of HIV prevention. That is, although her husband requested an HIV test immediately after learning that she was infected, and despite the fact that he was HIV negative and were counselled to use condoms, they continued to have unprotected sexual intercourse. She said that:

*He loves me and life continues normally ... The only problem is that we haven't children and his family is asking him all the time if I am pregnant! This makes him think we should have a child, even though the doctors said that we must use condoms.*

(30 – year old, female participant, disclosed her HIV positive status)

As elsewhere, PLHIV in Djibouti appear to be socially stigmatized because of their health condition – i.e. they are blamed for causing the condition through their risky behaviours. However, it appears that those who disclose are likely to lower their perception of negative attitudes regarding HIV status. Three PLHIV participants who had disclosed their status to both partner and family members informed the researcher that they generally pay no attention to what people might say about them. And while all were married and had children they all believed that they'll rather concentrate on the future of their children, than thinking about people's opinions. The three respondents said:

*If you want to know how many people know that you have HIV, you'll also need to find out what they say! We have passed the level of finding out what people say or would say. The only little time we have is to think about the future of our children.*

(34 –year old, female participant, disclosed her HIV positive status)

*To find out what people talk and think about will be a waste of time and a creation of problems on my side. Moreover, people will talk about you only if they believe that you pay attention to what they say. It's just not in my character to behave like that.*

(39 – year old, male participant, disclosed his HIV positive status)

*Of course this doesn't mean that people are not talking about me! Some people are pointing at me when they see me ... but I always act as if they don't exist and concentrate on my life and the future of my children.*

(38 – year old, male participant, disclosed his HIV positive status)

#### **4.7. HIV status disclosure and sexual behaviour**

##### **4.7.1. Unsafe sex practices amongst non-disclosures**

PLHIV who participated in this study were all married and all, except one man, lived with their partners. A question on their sexual behaviour was therefore put to all of them –specifically whether they have been having sexual intercourse with their partners; if they knew their partners' HIV status; and whether they used condoms. Although all 8 PLHIV participants were well informed about condom use and all respondents indicated that they understood that having sex with a condom could prevent HIV transmission, the majority (3 of the 4) PLHIV who had not disclosed their status, 2 of which were women, admitted that they had sex with their partners and did not use condoms ever since they were diagnosed with HIV. Moreover, none of these individuals knew their partner's HIV status.

The reason given by these participants was that they did not want their partners to discover or suspect their status i.e. they feared that proposing use of condoms could raise partner's suspicions, and lead to discovering their status – which could ultimately lead to separation and/or other adverse outcomes. The quotations below illustrate this point:

*She'll ask me 'What's this?' and what can I say?*

(46 – year old, male participant, not disclosed his HIV positive status)

*But even if I am to save him from catching it how can I tell him that I have it.*

(29 – year old, female participant, not disclosed her HIV positive status)

*But how can I tell her that I need to use a condom? Can she really accept? She'll ask why? What can I say? Everybody in Djibouti knows that you use condoms when you are going to sleep with a prostitute not your wife! So she'll ask me 'am I a prostitute?' And she'll try to find out why I proposed this and may be go for an HIV test thinking that I sleep with prostitutes. And of course if she finds that we are sick that will be the end.*

(41 – year old, male participant, not disclosed his HIV positive status)

#### **4.7.2. Total or temporary abstinence**

One respondent who disclosed his status and whose partner tested HIV negative informed the researcher that he abstained from sex following his wife's blood test results. Here is what he said, when asked "From the time when you were tested, have you been sleeping (having sex) with your partner?"

*Oh! No... I told you, 'the Almighty made his miracles', how could I think again about that? She's just like my sister now! In fact I forgot about those things.*

(39 – year old, male participant, disclosed his HIV positive status)

And one respondent, though had not disclosed his status to partner, believed that apart from being infected, his partner could be HIV negative, and so decided to abstain from sex. He said that:

*First, I feel to some extent depressed and sick and no sexual desire at all. Second, I have children and I love them. I know that if my wife is negative will keep them if I die. I am therefore still thinking about testing her. And so we can't sleep together.*

(46 –year old, male participant, not disclosed his HIV positive status)

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#### **4.8. Conclusion**

This chapter has presented the main findings of the study. The following chapter discusses and analyses these results in relation to the study objectives.



## CHAPTER FIVE: DISCUSSION

### 5.1. Introduction

This study sought to identify and describe the perceived and experienced barriers and the reported consequences of HIV positive status disclosure by PLHIV to their partners and or family members in Djibouti. Among the objectives of the study was to describe the factors PLHIV and health workers believe either prevent or facilitate PLHIV in Djibouti to disclose their status to partners and/or family members.

### 5.2. Factors associated with non-disclosure of HIV positive status in Djibouti

The study has found that the fear of experiencing HIV-related stigma and discrimination, of separation, of violence, of rejection and of being detested by family members act as barriers for PLHIV in Djibouti to disclose their status. The fear of upsetting family members and experiencing their scorn, the fear of being isolated from the community, and of the loss of financial support, are other factors associated with non-disclosure in the context of Djibouti.

In essence, these barriers are directly related to the stigma and discrimination that is attached to HIV/AIDS in Djibouti society in general. The prevalence of stigma and discrimination is clearly observed from statements made by participants such as *“everyone takes it as a big shame”*, *“you tell one person they tell others until everybody knows that you have it”*, *“If they get to know that I have it, nobody will come over my home again...they’ll all run away”* and thinking that *“they could contract HIV by simply shaking hands or sharing something with an individual with HIV”*. Nonetheless,

research has shown that stigmatising beliefs come from the community's misinformation about HIV/AIDS (Kalichman & Simbayi, 2003). Consequently, the HIV/AIDS epidemic has been described by researchers as an epidemic of ignorance, fear and denial (Kalichman & Simbayi, 2003). This therefore highlights the need for more interventions at community level to address root causes of stigmatisation and discrimination, including amongst other things HIV/AIDS-related misconceptions, ignorance and prejudices.

The study indicates specifically that women living with HIV in Djibouti may not disclose their status due to fear of experiencing rejection and violence from their partners and family members – as a result suicide was something that one woman contemplated if her partner and or family members discover that she has HIV. Indeed, an association between HIV status disclosure and violence against women has been reported by many researchers in various settings. For example, in Baltimore (USA), Rothenberg and Paskey (1995) found that among a sample of 136 health care providers serving women living with HIV, 24% (of providers) had at least one female patient who experienced physical abuse following disclosure to a partner. Similarly, in Nairobi, Temmerman *et al.* (1995) reported in their study that among 66 women who disclosed to partners, 11 were chased out of their homes or replaced by another wife, 7 were beaten, and 1 committed suicide.

These findings are in line with findings from other studies cited in the literature (Serovich, 2001; Serovich, Lim & Mason, 2008) and suggest that women's decisions related to disclosure are likely to be influenced by their evaluation of the consequences

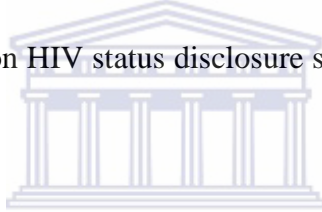
of disclosure – i.e. are likely to disclose once benefits of disclosure outweigh associated costs. There is therefore a need for greater support for women undergoing VCT and other forms of HIV counselling and testing in Djibouti – for instance, through screening for the risk of violence in relation to disclosure, and referring for social and legal support. Associations like “*Nouvel Espoir*” (*New Hope*) mentioned in chapter one could also be helpful in encouraging individuals to disclose their HIV status and in reducing the stigma associated with HIV. In addition, those associations may help women to discuss their HIV positive results with partners and or family members.

The study has also revealed that PLHIV who are financially depending on others (i.e. not working/unemployed and unable to support themselves and their family), are less likely to disclose their status – they believe that disclosure could result in being abandoned - and so lose their source of financial support. This is in accordance with findings from other studies cited in the literature (WHO, 2004) and suggests a greater need for health workers to focus on issues related to their client’s financial and material resources and needs in addition to recognizing where expert psychological and/or counselling support is needed in such circumstances.

The study indicates further that in Djibouti PLHIV are often encouraged to disclose their status but not necessarily given sufficient practical advice about how they could go about doing it. Moreover, no follow up strategies are available to establish whether people that are counselled to disclose, do it or not – and how the barriers that they are experiencing in relation to disclosure could be addressed. The literature suggests that HIV positive status disclosure should be viewed as a process, rather than being a single

event (WHO, 2004). That is, the decision to disclose one's HIV positive status cannot be made just on the basis of a single counselling session, but through continuous counselling and closer follow up of clients. Basically, disclosure needs to be discussed not only during post-test counselling, but over some time (and follow up counselling sessions) to give the client the opportunity to come to terms with the diagnosis and develop an understanding of the condition.

This finding therefore highlights the need to develop or refine existing strategies intended to assist PLHIV in making informed decisions about disclosing a positive status and in developing the skills to do so. There is also a need to improve the knowledge of the counsellors on HIV status disclosure so that they can correctly inform their clients on how to do it.



### **5.3. Factors associated with disclosure of HIV positive status in Djibouti**

Several factors were found to be associated with disclosure: the need to use HIV drugs, a sense of ethical responsibility for a partner's health, and advice given by health facilities or services (such as the discussion about disclosure and the encouragement received from health workers during post-test counselling) are some of the factors appearing to be influencing disclosure – both to partners and family members. It was also found that, people who are accompanied by partners or family members for blood tests are likely to share their test results with them.

Although other studies suggest that disclosure is correlated with symptoms (Hays *et al.*, 1993; Serovich, 2001) and the length of time since diagnosis (Antelman *et al.*, 2001), neither of these associations was observed regarding disclosure to partner and/or family

members in this study. The majority (3 of the 4 PLHIV respondents who had disclosed their status) had disclosed their status immediately after receiving their HIV test results – with only one woman having disclosed to her partner nine months after learning about her status. And though all PLHIV interviewed reported to have been diagnosed with TB prior to HIV testing, none of the disclosures reported to have disclosed their status as a result of being symptomatic for the HIV. This suggests therefore that specific factors may differentially influence the decision to disclose or when individuals are willing to disclose their status.

Findings from this study may however be linked with the consequence theory of disclosure – suggesting that the decision to disclose one’s HIV status might be influenced by an internal cost-benefit analysis of one’s potential disclosure (Serovich, 2001; Serovich, Lim & Mason, 2008). Statements made by participants such as *I [decided] to inform her so that she could also be checked and so have a chance of using medicines, in case she was also infected... [and if] negative...take care of our children if I die* (39 – year old, male participant, disclosed his HIV positive status) and “... *it's better to tell him so that he could be tested and if he is negative... look after our four children if I die or start medicines if he is also sick* (34 – year old, female participant, disclosed her HIV positive status), illustrate this point.

However, these findings may not necessarily contend the relationship between the disease progression theory and disclosure (Serovich, 2001). For example, as has been the experience of the researcher, with the onset of (even minor) symptoms and visible signs of illness, someone living with HIV (and even if on ART) would still have to visit

a clinic or a doctor or be hospitalized. This could potentially create a “question mark” in their partner’s or family members’ mind about their health. And so in societies such as the Djiboutian society, where cultural norms place a greater emphasis on collectivism, rather than individualism, family members may put pressure on an individual, that they suspect might be HIV positive, to get tested, or request that, when they are hospitalized, that the health workers test them for HIV. Thus someone’s HIV status sometimes gets disclosed (involuntarily) to other family members, including their partner.

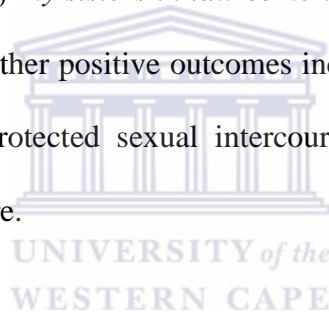
#### **5.4. Outcomes of HIV positive status disclosure in Djibouti**

Among the objectives of the study was also to explore with PLHIV the circumstances and the experiences associated with the disclosure of their HIV positive status to their partners and/or family members. PLHIV participants who had disclosed their HIV positive status were specifically probed on the reactions of some of the people they disclosed to.

Both negative and positive outcomes of disclosure were reported by the 4 PLHIVs that were interviewed and had disclosed their HIV positive status to their partner and/or members of their family. Negative outcomes included marriage break-up and perceptions and experiences of HIV-related stigma and discrimination. Negative consequences were however less cited by PLHIV who had disclosed their status than was originally anticipated by the researcher – with only one man reporting a marriage break-up and stigmatization following his disclosure. Interestingly, 2 of the 4 PLHIV participants who had disclosed their status (including 1 woman) reported that they lived with partners who were HIV negative – and none of them experienced adverse

consequences of disclosure such as violence, discrimination and scorn as perceived by PLHIV who had not disclosed their status.

Positive outcomes on the other hand included a greater understanding and strengthening of the relationship between family members, and increased care and support from both partner and family members. This is obvious from experiences shared by participants who had disclosed their status – and is reflected in their statements such as: *“Nothing happened though he seemed to be shocked”*, *“My mother prepares some special food and invites me to share with them ...”*, *“They’re all so close to us and they regularly come to see us”*, and *“... two of my sisters in law come with us here each time we come to collect our medications”*. Other positive outcomes included risk reduction behaviour - including abstinence and protected sexual intercourse, partner seeking VCT, and motivation to plan for the future.



Specifically, of the four PLHIV who disclosed their status, three confirmed that their partners took an HIV test following their disclosure, one respondent reported using condoms to avoid further pregnancies after realising that the couple was infected and pledged not to blame each other but to plan for their future. These findings suggest that PLHIV who decide to disclose their status to partners and/or family members might very well experience positive outcomes associated with their disclosure. This also highlights the importance of continuing to encourage and support PLHIV, where appropriate, to disclose their status.

Underlying the incentive to encourage PLHIV to disclose their status to their partners is the assumption that disclosure can allow both PLHIV and partners, particularly uninfected partners, to make informed choices about their sexual behaviour – e.g. by facilitating the discussion of safer sex with an informed partner (Simbayi *et al.*, 2007). However, in this study, one woman living with HIV noted that although her partner sought VCT following her disclosure, and despite the fact that he tested HIV negative, they continued to have unprotected sexual intercourse. This finding confirms that of an early, community-based study of patients with symptomatic HIV in Lusaka, Zambia (Hira, 1990). It was found in Lusaka that of the 52 discordantly HIV infected couples followed for 1 year, after using VCT services, 46 continued to have unprotected sexual intercourse with their partners and 21% of these seroconverted to HIV (Hira, 1990).

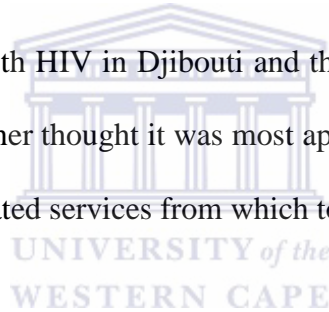
Nevertheless, as previous researchers have suggested, disclosure of an HIV status does not necessarily mean that individuals will use the information to protect themselves and or others, rather some may knowingly place themselves and others at risk for HIV infection (Serovich and Mosach, 2003 in Simon and Pantalone, 2004). Marks and Crepaz (2001) termed this situation, where some people turn their back on protection (refuse to take preventive measures) and get engaged in risk behaviours, as “informed disposure” – this was following an observation that of 206 men living with HIV who participated in their study, 12% informed their partners about their status and engaged in unsafe sexual behaviour. They therefore recommended that interventions are needed to address the social and psychological processes that give rise to risk behaviour patterns in PLHIV (Marks & Crepaz, 2001).



In essence, findings in the current study appear to suggest that PLHIV's decisions related to disclosure of their HIV positive status and the outcomes associated with disclosure will largely depend on how their society members perceive HIV, its mode of transmission and prevention. These findings can therefore inform the development of interventions to improve the future support provided to PLHIV particularly in relation to HIV counselling, testing and disclosure.

### **5.5. Limitations of the study**

Participants for this study were drawn only from those PLHIV accessing HIV care and support services at Centre Paul Faure in the urban area of Djibouti Ville. However, given the stigma associated with HIV in Djibouti and the lack of public discussion and “voice” of PLHIV, the researcher thought it was most appropriate to use the main site in Djibouti which offers HIV-related services from which to recruit study participants.



Therefore, the researcher did not include or did he attempt to get in PLHIV that were, for various reasons, not accessing these or other HIV services and who are likely to be more marginalized and might very well have not disclosed their HIV positive status to others. It must be acknowledged that the findings of this study are thus drawn from a small, purposeful sample and thus might be limited in their applicability. As such, it cannot be assumed that they represent the *range* of experiences and opinions of PLHIV living in Djibouti (for example, those living in more rural areas or PLHIV from more marginalized population groups, such as sex workers) - and for that matter, PLHIV in other settings.

## **CHAPTER SIX: CONCLUSION**

This chapter presents a conclusion of the study and a description of some of the realistic recommendations on disclosure in the context of Djibouti.

Based on the research findings, it is obvious that HIV positive status disclosure is still a difficult decision to make among people living with HIV in Djibouti. The potential for rejection, abandonment, physical and emotional abuse and other adverse consequences that have been cited in the literature and explanations from research participants create such a difficult situation – that is, they serve as substantial barriers to disclosing ones HIV positive status to partner and/or family members in Djibouti. The literature (Mansergh, Marks & Simoni, 1995; Zierler *et al.*, 2000; Brou *et al.*, 2007) however suggests that the benefits of disclosure could outweigh the potential risks. And though there are insufficient support systems for clients (such as use of role plays and support groups) and providers (guidelines) to facilitate disclosure in Djibouti, the important thing now – specifically within the health facilities - is to build the capacity of health service providers so that they have the necessary skills to provide increased support and greater opportunities for their HIV positive clients to engage more thoroughly with the issue of disclosure and, through this, develop the confidence to be able to disclose their HIV status to their partners and, where appropriate, to their family.

### **6.1. Recommendations**

The following are 6 recommendations based on the study findings and the associated literature review:

- 1) This study reveals the great need for HIV interventions in Djibouti to focus on strategies to eradicate stigma and discrimination related to HIV/AIDS. It is therefore imperative to promote or design intervention and education programmes to convey information for individuals at varied levels (i.e. both at an individual and community level) to reduce the stigma and discrimination that is currently attached to HIV/AIDS in Djibouti.
- 2) The most common barriers to disclosure mentioned by women participants (PLHIV) included fear of abandonment, rejection, accusation of infidelity and violence. This finding has highlighted the need to also address gender inequality in the efforts to reduce HIV-related stigma and discrimination.
- 3) Health workers view with great importance the need to develop better approaches within the VCT programmes to assist PLHIV in disclosing their HIV status. In particular, programmes need to be developed that can assist PLHIV in making informed decisions about disclosing a positive status and in developing the skills to do so. PLHIV who are counselled to disclose their status may also need special attention and ongoing counselling interventions such as being encouraged to join a follow-up PLHIV support group.
- 4) The literature review and findings suggest that HIV positive status disclosure helps prevent HIV transmission and increases social support for PLHIV. There is therefore a great need for Djibouti to develop such programmes to encourage disclosure. Programmes may include discussions of the benefits of disclosure, when to disclose and to whom. Programmes should also include practicing skills to discuss HIV status negotiation and engagement. And given that PLHIV who do not disclose are less likely to practice safer sex; other disclosure approaches

should aim at encouraging both PLHIV and HIV negative persons to disclose their status and practice safer sex. There is therefore a need to improve the knowledge of the counsellors on this subject of HIV status disclosure to partners and/or family members so that they can correctly inform their clients on how to best do it.

- 5) There is a need to normalize and facilitate comfortable discussions about HIV amongst families, so that disclosure of HIV positive status isn't such a difficult thing to do. The more HIV is talked about, and the more people come out about being HIV positive, the fewer stigmatisations there will be. This could also be achieved through encouraging/promoting VCT, partner counselling and testing, and implementing HIV-related public information and media campaigns that promote tolerance and compassion.
- 6) A larger-scale study on the subject of PLHIV disclosure is also recommended, involving more marginalized communities of PLHIV, so as to address the gaps in health worker's understanding of how PLHIV can best be supported to disclose their status without negative consequences.

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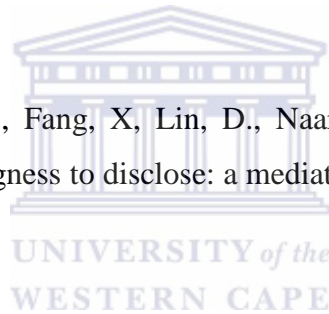
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## 8. APPENDICES

### APPENDIX I: TOPIC GUIDE INDIVIDUAL INTERVIEWS

#### 1) Background information

1. Could you please tell me about your self? Your age? Your education level, etc?
2. Where do you live now? Where is your home town?
3. Who lives with you now?
4. Are you married?
5. Are you currently working? What kind of work do you do?

#### 2) Questions on HIV counselling and testing:

1. In what year were you tested for HIV?
2. Did you know anything about HIV before getting an HIV test? How did you know this?
3. Was the test voluntary?
4. What most influenced your choice to be tested?
5. Did you feel free to accept the HIV test results? Why or Why not?
6. Were you advised to share your test results with anybody, for example, your partner or any member of your family? If yes: who advised you?

#### 3) Questions regarding disclosure:

1. Who are the people you are closest to?
2. Have you told them that you were tested for HIV and your test results?

#### Probing questions: PLHIV who have not disclosed their status

- 7) What is your fear about telling your partner or any member of your family that you were tested for HIV and had positive results?
- 8) What does the community say about people who are living with HIV?
- 9) Are you currently taking ART?
  - *If Yes:* Does any body (not including health workers) know that you are on these treatments? *If yes*, how did they know that? *If No*, Why?
  - *If No:* Why?

4. Have you been hospitalised at least once for an HIV- related problem?

*If Yes:*

1. Who went with you to the hospital?
2. Did they know or suspect you were hospitalised because of HIV?

**Probing questions: PLHIV who have disclosed their status**

1. To whom did you tell your status?
2. When did you tell them?
3. How did you tell him/her that you were tested and about the results?
4. What happened next?
5. What influenced/helped you to disclose your test results and why?

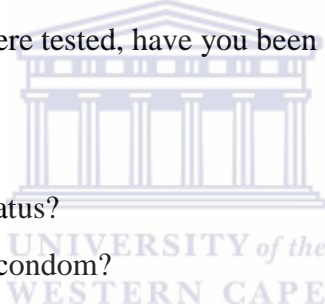
**4) Question on disclosure and sexual behaviour:**

1. From the time when you were tested, have you been having sex with your partner?

*If No: Why?*

*If Yes:*

- Do you know his/her status?
- Have you been using a condom?



Thank you for your time and co-operation. We hope the information you have provided will assist in future HIV prevention, care and support programs. Thank you.

## APPENDIX II: TOPIC GUIDE FOCUS GROUP DISCUSSIONS

### Questions:

1. HIV status disclosure is a very important part of your work; do you however think that people should disclose their status? Why or why not?
2. Have you ever advised any person to disclose his/her HIV status to partner and/ or family members?
3. What was their reaction?
4. *Counsellors*: Is it easy for you to ask your participants to disclose their status? How?
5. *Counsellors*: How do your participants respond if you ask them to disclose their status to others?
6. *All*: Have you had PLHIV who have disclosed and came back to share their experience?
7. What experiences do they share?
8. What factors do you think prevent or encourage PLHIV to disclose their status?
9. What does the community think about people living with HIV?
10. Before we finish I would like to know, what you think should be done to get more PLHIV disclosing their status?

Thank you for your time and co-operation. We hope the information you have provided will assist in future HIV prevention, care and support programs. Thank you.

### **APPENDIX III: PARTICIPANT INFORMATION SHEET**

Dear Participant

I am **Naaman Kajura** - I work at Djibouti Medical Centre. I am also a student at the SOPH, University of the Western Cape, South Africa. In order to fulfill the requirements for my Masters Degree in Public Health, I am conducting a research project. The title of my research is: “The perceived and experienced barriers and reported consequences of HIV positive status disclosure by people living with HIV to their partners and family members in Djibouti.”

I would like to ask you if you are willing to participate in this research project. In order for you to be able to make this decision it is important that you first understand what my study is about and have some time to think about whether you would like to participate in it or not. It is entirely up to you whether you want to participate in the study or not – and there will not be any negative consequences if you decide you would prefer not to participate in the study. If you decide to participate in the study I will need to get your written consent

Should you have any questions about this research study, please feel free to ask me. You can contact me as follows:

Naaman Kajura

Student N°: 2522604

Telephone: (253) 70 52 95 or 35 04 62

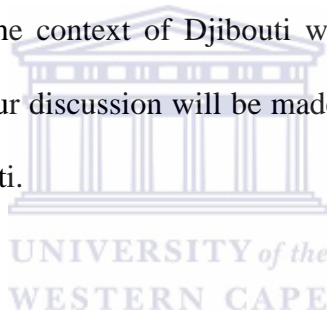
Fax: (253) 35 70 00

E-mail: 2522604@uwc.ac.za

I am accountable to **Ms Nikki Schaay, SOPH, UWC** who is contactable at 021-959-2809 / 021-788-4186 / 084-211-5544 or E-mail: [schaay@mweb.co.za](mailto:schaay@mweb.co.za).

## **PURPOSE OF THE STUDY**

This research is being conducted to fulfill the requirements for my Masters Degree in Public Health at the SOPH, University of the Western Cape. In addition to fulfilling these requirements, the research also aims to generate information that could be used in improving care and support services provided to PLHIV in Djibouti. It is believed that with your participation, a better understanding of barriers and consequences of HIV-positive status disclosure in the context of Djibouti will be gained and that a set of recommendations based on your discussion will be made for future decisions in the ongoing HIV programs in Djibouti.



## **DESCRIPTION OF THE STUDY**

In this study, I will ask you some questions about your perceptions and experience regarding the various barriers and consequences of HIV-positive status disclosure by people living with HIV to their partners and family members here in Djibouti. I would like you to discuss them with me (in an individual interview – *for PLHIV participants* OR in a group with other health workers (*for FGDs participants*)). This will take about an hour of your time. I also would like to request you to allow me to tape-record the interview/discussion.

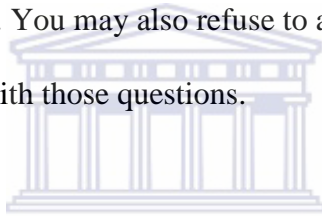


## **ANONYMITY OF CONTRIBUTORS**

At all times, I will keep the source of the information confidential and refer to you or your words by a pseudonym or invented name which I would like you to choose. I shall keep any other records of your participation locked away at all times, and destroy them at the completion of the research project.

## **RIGHT OF REFUSAL TO PARTICIPATE AND WITHDRAWAL**

You are free to choose to participate in this study. You may also refuse to participate without any negative effects either. You may also withdraw any time from the discussion if you wish to do so. You may also refuse to answer some or all the questions if you don't feel comfortable with those questions.



## **POSSIBLE RISKS OR BENEFITS**

There is no risk involved in this study except your valuable time. There is no direct benefit to you also. However, the results of the study may help us to formulate guidelines for improving care and support services for PLHIV.

## **INFORMED CONSENT**

As said earlier, you are required to give your consent to me before I conduct interviews/discussions with you. I have included the consent form with this information sheet so that you will be able to review it and decide whether to participate in this study or not.

## APPENDIX IV: INFORMED CONSENT

**Interviewee's name (pseudonym):**

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**Place at which the interview was conducted:**

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**Research title:**

The perceived and experienced barriers and reported consequences of HIV positive status disclosure by people living with HIV to their partners and family members in Djibouti.

**Participation in this research study:**

As I mentioned in the *Participants Information Sheet*: You may **choose or refuse to participate** in this study. Should you choose to participate, there will be no direct benefits to you. There will be no negative consequences resulting from your refusal to participate in the study too.

*If you choose to participate:* you may withdraw at any time if you wish to do so; and you may refuse to answer some or all the questions if you don't feel comfortable with those questions. Your signed consent is however required before I start conducting interviews or discussions with you.

**Things that may affect your willingness to participate:**

The interview/discussion may touch on issues which you may feel uncomfortable to hear. If there is anything that you would prefer not to discuss, please feel free to say so.

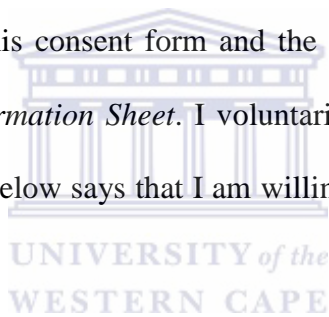
I will appreciate your guidance should I ask anything which you see as intrusive

**Confidentiality:**

Your name and identity will not be identified. The information provided by you will remain confidential. Nobody except me will have an access to it. However the data may be seen by my supervisor and may be published in journal and elsewhere without disclosing your identity. I would like also to assure you that the rules of confidentiality extend to everyone participating in this research.

**Interviewee's agreement:**

I have read and understood this consent form and the information about the study as given in the *Participants Information Sheet*. I voluntarily choose to participate in this research study. My signature below says that I am willing to participate in this research study.



Participant Name : \_\_\_\_\_

Participant Signature: \_\_\_\_\_ Consent Date: \_\_\_\_\_

Researcher: \_\_\_\_\_

Researcher's Signature: \_\_\_\_\_ Date: \_\_\_\_\_