

**FACTORS THAT INFLUENCE DISCLOSURE OR
NON-DISCLOSURE OF ONE'S HIV-POSITIVE
STATUS TO FRIENDS, FAMILY AND REGULAR
SEXUAL PARTNERS IN LINGUERE, SENEGAL**

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KEY WORDS

- HIV/AIDS
- Disclosure to family, friends and regular sexual partners
- Types of disclosure
- Motivators and barriers
- Consequence theory
- Support groups
- Role of service providers
- Qualitative research
- Senegal
- Rural setting



ABSTRACT

Background:

Disclosure in the context of HIV is the sharing of information about one's HIV-positive status with someone else. In the case of people living with HIV (PLHIV), many factors influence their decision to disclose. As with other illnesses there is a concern about possible discrimination or stigma. On the other hand, disclosure can lead to higher levels of support and better management of HIV infection. Types of disclosure can also vary depending on the need of the PLHIV, being partial or full, in order to gain the most benefit. Self-disclosure or mediated disclosure with the assistance of someone else is controlled by the PLHIV, whereas involuntary or forced disclosure might not be under the PLHIV's control and thus more likely to have negative consequences. No studies have been done in the rural area of Linguère, Senegal or in the rest of the country to identify the factors that influence the decisions of PLHIV around disclosure. Senegal has a concentrated HIV epidemic with national HIV prevalence stable at 0.7% in 2005 and 2010 Demographic and Health Surveys. Linguère District's HIV prevalence was at 0.8% in 2003. By knowing more about what motivates PLHIV to disclose or not disclose their status, service providers and others can better support PLHIV to practise beneficial disclosure.

Aim:

The aim of this study was to explore factors that influence the decision to disclose or not disclose one's HIV-positive status to regular sexual partners, friends and family in Linguère District, Senegal.

Methods:

A qualitative method with in-depth interviews was used to explore the factors that influenced decisions concerning disclosure. Fifteen PLHIV were identified through purposive sampling based on criteria such as marital status, gender and prior disclosure decisions. In addition, four service providers from the AIDS service organization, Projet SSP, and the district health and social workers served as key informants. The interviews were recorded, transcribed and translated from the local languages into French. Record reviews of the HIV/AIDS service organization complemented the interviews. The fieldwork was conducted in the study setting for two weeks in January 2012. The data was analysed through thematic analysis.

Findings:

The main themes that emerged as reasons for disclosure were maintaining psychosocial well-being, existence of trusting relationships, need for support with health care, reciprocal obligations and

concern for others, whereas reasons for non-disclosure included stigma and discrimination and negative impact on family. However, the factors varied from one participant to another and could not consistently be attributed to one group or another, whether man or woman, married or divorced, etc. Influencing factors were related to gaining support for the participant or avoiding problems. Concerns about stigma were great and included reference to wanting others to have *soutoura*—privacy, dignity, respect. There were also factors which took into consideration the consequence for the person to whom they might disclose, such as desire to avoid upset or desire to seek testing and possible care for a spouse. Of the participants who had disclosed, there were no cases of severe negative consequences. Not one participant expressed regret for having disclosed, rather they acknowledged that there were positive benefits for themselves and sometimes also the other person to whom disclosure was made. The roles of the service providers and the support group were also influential in decision-making around disclosure, with a good number of cases of mediated disclosure.

Conclusion:

In line with consequence theory, PLHIV weighed up their benefits and costs when decisions around disclosure were contemplated. The benefits were that PLHIV who chose to disclose gained from increased social support and better management of their HIV infection. At the same time further transmission of infection was potentially reduced and others were oriented for testing and for access to care if needed. In general, HIV continues to be a particularly stigmatising condition and thus the majority of PLHIV in this study judged that it is not worth the risk of possible abandonment, rejection or slander to disclose their status, regardless of the fact that few have actually experienced severe negative consequences as a result of actual disclosure. Because of support provided through service providers and the support group, however, those participants who had chosen to disclose to someone outside of the support group were reaping benefits and also likely avoiding the need to turn to risky activities, such as transactional sex or formal sex work.

Recommendations:

Recommendations drawn from this study include the need to support programmes or initiatives which seek to reduce HIV-related stigma. There is also the need for leaders in the community to show support for PLHIV which can reduce stigma. Health care and service providers should be aware of the needs of PLHIV and the changes that may arise over time which could lead to a decision to practise beneficial disclosure. They should also learn from the experiences shared by other PLHIV which can in turn be shared. They should receive further training in order to better understand the complexity of disclosure and to assist with mediated disclosure.

DECLARATION

I declare that **Factors that Influence Disclosure or Non-Disclosure of One's HIV-Positive Status to Friends, Family and Regular Sexual Partners in Linguère, Senegal** is my own work. It has not been submitted for any degree or examination in any university. All the sources that I have used or quoted have been indicated and acknowledged by complete references

Anne Ruedisili Langdji

Signed:

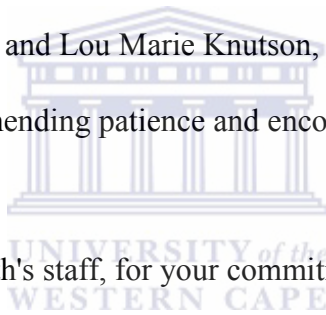


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ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ARV	Antiretroviral
ART	Antiretroviral Therapy
CNLS	Conseil National de Lutte contre le SIDA
DHS	Demographic and Health Survey
EELS	Eglise Evangélique Luthérienne du Sénégal or Evangelical Lutheran Church of Senegal
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus
ISAARV	Initiative Sénégalaise d'Accès aux Antiretroviraux or Senegalese Initiative for Access to Antiretrovirals
MSPM	Ministère de la Santé et de la Prévention Médicale
NGO	Non-Governmental Organization
PLHIV	People/Person Living with HIV
SAHARA	Social Aspects of HIV and AIDS Research in Africa
SLDS	Services Luthériens de Développement au Sénégal
SSP	Soins de Santé Primaire or Primary Health Care
UNAIDS	Joint United Nations Programme on HIV/AIDS
VCT	Voluntary Counselling and Testing
WHO	World Health Organization

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CHAPTER 1: INTRODUCTION

1.1. Background to study

A recent slogan shared by the executive director of UNAIDS is: “zero new Human Immunodeficiency Virus (HIV) infections, zero discrimination, zero Acquired Immune Deficiency Syndrome (AIDS)-related deaths” (UNAIDS, 2012a: 9). These are huge goals, but serve to motivate those around the world who are engaged in the response to HIV/AIDS. As reports of a slow-down or stabilisation in the pandemic come from different countries, scientists and activists alike are seeking to improve on gains and ultimately work to attain the ambitious UNAIDS goal (Coates, Richter & Caceres, 2008; Conseil National de Lutte contre le SIDA (CNLS), 2011; Foley & Nguer, 2010)

Sub-Saharan Africa continues to account for the vast majority of the world's HIV infections, almost 23.5 million of 34 million worldwide (UNAIDS, 2012a: 10). The countries that are most affected are resource poor and are thus responding to the pandemic with assistance from foreign governments and non-governmental agencies. Services are provided to those persons living with HIV (PLHIV) who know their status and have sought care, while other efforts, such as education campaigns and promotion of testing, are made to prevent further transmission of HIV in communities (Coates *et al.*, 2008; CNLS, 2011; UNAIDS, 2012a).

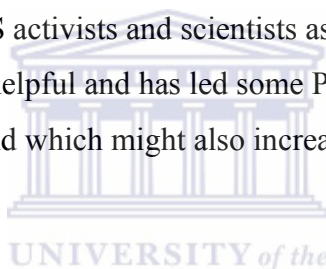
The West African nation of Senegal has a concentrated HIV epidemic. According to the last two Demographic and Health Surveys of 2005 and 2010, HIV prevalence has remained at 0.7%, with prevalence for men at 0.4% and for women at 0.8% reported in 2010 (Agence Nationale de la Statistique et de la Démographie (ANSD) [Sénégal] & ICF International, 2012; Ndiaye & Ayad, 2006). The Senegalese government was one of the first in Africa to start a programme for access to care and antiretroviral therapy (ART) at no cost to the patient. It is called the Senegalese Initiative for Access to Antiretrovirals (ISAARV) (Conseil National de Lutte contre le SIDA (CNLS), 2007; Foley & Nguer, 2010). ISAARV provides ART and check-ups, however it does not cover any other care or prescriptions for opportunistic infections. In order to complement the ISAARV programme, the Projet Soins de Santé Primaire (Projet SSP) or Primary Health Care Project of the Eglise Evangélique Luthérienne du Sénégal/Services Luthériens de Développement au Sénégal (EELS/SLDS) collaborates with the health authorities to provide support to PLHIV in the Linguère Department which includes two health districts: Linguère and Dahra. The EELS/SLDS is a

religious association with non-governmental organisation (NGO) status. Additionally the EELS/SLDS has recently started a programme called Embrace AIDS, which is working with community and religious leaders in a few of the rural communities to fight attitudes of stigma and discrimination around HIV/AIDS. Another NGO collaborating with the health districts is Awa, a Dakar-based organisation specifically addressing the situation of sex workers. Occasionally other organisations seek to carry out HIV-related activities in Linguère and Dahra Districts, such as for assistance to orphans and vulnerable children. In most cases they work through the Health Districts or Projet SSP.

In 2009, 105 adults and three children benefited from Projet SSP activities such as treatment literacy, financial assistance for transportation to check-ups and for other medical care and prescriptions, nutritional support, support groups, as well as other activities (EELS, 2009). In 2011 the number had increased to 147 (EELS, 2011). The activities carried out by Projet SSP are encouraged by health authorities and in line with practices that are promoted in the country. Those PLHIV who received support from Projet SSP were referred by a doctor or social worker after they tested positive for HIV and had agreed to disclose their status to the two staff members of Projet SSP. The majority of PLHIV were women and were diagnosed at an advanced stage of infection. In almost all cases, PLHIV started ART within weeks of diagnosis due to the advanced stage of infection. As Projet SSP has worked in the districts for more than twenty years, principally supporting health huts, the organisation has a good reputation and is trusted in the district, both by communities and the health authorities. The diversity of its activities outside of HIV/AIDS support might also decrease the risk of stigmatisation for PLHIV who visit its offices and have contact with its staff. Only some of the state ISAARV centres have social workers and there are few activities beyond clinical care in those structures unless supported by other NGOs.

The support group which grew out of Projet SSP's conversations with PLHIV and encouragement from national HIV-related associations has been greatly appreciated by most of those who have joined. PLHIV are informed about the existence of the support group by the health care providers and also by Projet SSP staff, but their membership is completely voluntary. About half of the PLHIV served by Projet SSP have joined the support group which meets monthly for a meal, organises educational sessions, identifies participants for national training sessions or seminars and benefits from additional support activities, such as funds for school-going children of the members. The members promise to not disclose anyone's status outside of the group.

Disclosure of HIV-positive status is generally considered important to reduce rates of transmission (UNAIDS, 2000; Coates *et al.*, 2008; Bairan, Taylor, Blake, Akers, Sowell & Mendiola, 2007). However, unlike some other health conditions, HIV has carried with it great stigma and thus public disclosure is very rare and even limited disclosure is not practised by all (Almeleh, 2006; Greeff, Phetlhu, Makoae, Dlamini, Holzemer, Naidoo, Kohi, Uys & Chirwa, 2008; Paxton, 2002). An interesting finding when measuring the correlation between quality of life and HIV-related stigma was that it was worst in cases of self-stigma, where, according to Lorentzen and Morris (2003, as cited by Ndiaye, 2008), the individual puts stigma on themselves by internalising their sense of shame or blame related to HIV infection. The still widespread fear of HIV-related discrimination and stigma is understandable in many contexts due to PLHIV experiencing enacted discrimination and stigma. This can discourage PLHIV from seeking care and assistance to manage HIV from service providers, let alone from other individuals to whom they would then have to disclose their status (Simoni, Demas, Mason, Drossman & Davis, 2000). In some countries, laws have been passed to criminalise non-disclosure of HIV-positive status. However this practice is being discouraged by UNAIDS, HIV/AIDS activists and scientists as most research shows that such a strong stance is harmful rather than helpful and has led some PLHIV to choose behaviours which put them and others at greater risk and which might also increase rates of transmission (UNAIDS, 2012a: 68, UNAIDS, 2012b).



Out of the 105 adult PLHIV served by Projet SSP in 2009 in both districts, 39% had disclosed their HIV status to their regular sexual partners and 30% had disclosed to other family members or friends (EELS, 2009). Only seven individuals had disclosed to both a regular sexual partner and a friend or family member. Of the 65 PLHIV claiming to be married, 39 individuals had shared their HIV status with their spouse, either through self-disclosure or allowing the project or a health provider to propose HIV testing to the partner (EELS, 2009). More PLHIV had disclosed to spouses (60%) than to friends or family. These figures show us that disclosure is not widely practised in this context. The health district does not require disclosure, but does encourage it, especially in order to have sexual partners and children tested.

Projet SSP educates about the benefits and consequences of disclosure and has used alternative means, with the PLHIV's permission, to encourage sexual partners to be tested when the individual has chosen not to self-disclose. Projet SSP acknowledges the serious concerns that some PLHIV have about possible negative consequences resulting from disclosure. The importance of disclosure is addressed repeatedly, but in a manner that avoids threatening the trust that has developed between

Projet SSP and the PLHIV as it is essential to retain people in the continuum of care.

The present coordinator of Projet SSP, Mariame Hanne, has worked with the project for more than twenty years and has lived in the community even longer. Due to her intimate knowledge of the context, mastery of the languages and long experience, she served, in this study, as an ideal translator and assistant.

1.2. Research problem

Studies about disclosure of serious illnesses, including of HIV, have been undertaken in different contexts, but few have been in Africa, as noted by Norman, Chopra and Kadiyala (2007).

Additionally, studies about factors that influence the decision to disclose one's HIV-positive status have been done in other parts of the world, but none in rural Senegal (Yang, Li, Stanton, Fang, Lin & Naar-King, 2006; Emler, 2006; Gillett & Parr, 2010). Regionally, a conference of SAHARA (Social Aspects of HIV/AIDS Research in Africa) held in Kenya in 2007 concluded that policy frameworks needed to take issues of disclosure into consideration (Setswe, Peltzer, Banyini, Skinner, Seager, Maile, Sedumedi, Gomis & van der Linde, 2007). In order to do this, they suggested further research about disclosure be undertaken on the continent.

In its Strategic Plan for the Fight Against AIDS 2007-2011, as well as the one for 2011-2015, the National Committee for the Fight Against AIDS in Senegal identified the need for research into the particular situation of vulnerable groups, which includes PLHIV (CNLS, 2007; CNLS, 2011). They are also attempting to focus more attention on rural populations who have been neglected in the past. As the issue of disclosure is so closely tied to that of stigma, a specific objective in these strategic plans has been to fight stigma and discrimination of PLHIV and other vulnerable groups. Seeking to improve knowledge about determinants of HIV disclosure therefore falls in line with this objective (UNAIDS, 2012a; Hardon, Davey, Gerrits, Hodgkin, Irunde, Kgatlwane, Kinsman, Nakiyemba & Laing, 2006; Kidd & Clay, 2003, Emler, 2006). Therefore, during a workshop which brought together a group of PLHIV and health personnel in Linguère to address issues of stigma and discrimination they were facing, it was agreed that learning more about reasons for disclosure or non-disclosure would be useful. Local health personnel felt that studying this question could lead to improvements in ways of encouraging beneficial disclosure by PLHIV (Personal communication during Africa Consultants International workshop, Linguère Health District, May 30, 2009).

1.3. Purpose

Understanding the reasons why PLHIV in rural Senegal choose to disclose or not disclose their HIV status might assist PLHIV and health personnel to know when and how or if disclosure is in the best interest of the PLHIV and those around them. Identifying these factors can also have implications for national and regional policies, such as those concerning access to treatment or criminalisation of HIV transmission (Norman *et al.*, 2007). Coates *et al.* (2008) also argued that more research looking at locally developed programmes and behavioural observational studies were important for knowing the best strategies for reducing HIV transmission and this includes how the issue of disclosure is approached with PLHIV. This study therefore set out to explore the factors influencing PLHIV's decision to disclose or not disclose their HIV-positive status to friends, family and regular sexual partners in Linguère, Senegal.

1.4. Study setting

This study was carried out in Linguère District in north central Senegal. It is a health district in the administrative department of Linguère, which consists of two health districts and is found in the administrative region of Louga.

Linguère Department, which is characterised by a dry, harsh, Sahelian climate, is where all of Projet SSP's clients reside. The health district is sparsely populated with approximately 90,000 inhabitants spread over 15,375 km² (Comité Régional de Lutte Contre le SIDA, 2006). The major ethnic groups are the Wolof, who are predominantly farmers, and the Fulani, who are pastoralists. Many Fulani, who have a social caste system, still live semi-nomadic lifestyles and thus the area is accustomed to constant population movement. Poverty levels are high and men in particular often migrate in search of work, either seasonally or more permanently to other African countries, Europe or the United States (US). Literacy in any language is estimated at 25% in the rural areas of Senegal (CNLS, 2007).

Polygamy is commonly practised and close to 100% of the population is Muslim. There are high rates of divorce which might partly be due to arranged marriages at a very young age, particularly among the Fulani, because when the wife matures she is unsatisfied with the husband who was selected for her. The choice of an appropriate spouse is also based on caste. Both the Fulani and Wolof often arrange or encourage marriages within the family, between cousins. Couples make their homes in the family compound or, because of the common migration to find work or for cattle-herding, the wife will live with the mother-in-law. In the case of death, widow inheritance is often

practised. The woman will marry her deceased husband's brother or the man will marry a deceased wife's sister.

The Linguère Health District infrastructure is made up of one newly constructed District Health Centre, seven health posts and more than forty health huts, the majority of which are not functional. Health workers include two medical doctors, a dental surgeon, ten nurses (seven of whom are health post heads), and five nurse mid-wives. Apart from the medical staff, other associated health staff who are key to service provision include community health workers and traditional birth attendants working out of health huts. In 1999 in Senegal, there was an average of one health post per 11,000 inhabitants and that is still the present ratio in Linguère District (Ministère de la Santé et de la Prévention Médicale, 2007). However the geographic access is difficult, as over 25% of inhabitants live five to fifteen km from a health post and more than 27% live even further than fifteen km (District Sanitaire de Linguère, 2004). The only paved road connects Linguère with other towns to the west, including Louga, the location of the regional referral hospital, 130 km away. Within the district most people use donkey or horse carts to travel on sandy paths. This makes medical evacuations and general travel extremely difficult. The health system does not have an information system which keeps individual's records either, so PLHIV, and all other patients, have envelopes of paperwork and prescriptions for which they are responsible.

Antenatal surveillance in Louga Region, in which Linguère District is found, showed HIV prevalence at 0.8% in 2003 (CNLS, 2003). In 2010 the Demographic and Health Survey included testing for HIV and found 0.1% HIV prevalence among a sample of men from 15-59 years old (n=244) and women from 15-49 years old (n=381) in Louga District (ANSD & ICF International, 2012). In Linguère District, voluntary counselling and testing (VCT) is only available at the district health centre or during occasional campaigns in surrounding villages.

1.5. Researcher's relationship

From 2000 to 2009, I, the researcher, served as the Coordinator of Projet SSP and Mariame Hanne served as a health educator. In my capacity as coordinator, I identified the opportunity to expand the Primary Health Care work to HIV/AIDS support as the government started its Senegalese Initiative for Access to ARVs and improved care. As a result of this work and due to the relatively long period of time during which I lived and worked in Linguère, I was privileged to be a part of the lives of many of the PLHIV who were served by Projet SSP. I heard the joys and pains, many of which related to finding or not finding support. Often ignorant, negative messages in the

community or in the press regarding HIV and those living with HIV led many PLHIV to feel the need to hide their status. The fact that some had found a way to live positively despite those messages was an encouragement and I saw the need to better understand why it was possible for them and also what might be done to improve the situation of all of the PLHIV in the district. One practice that seemed to improve the situation of some PLHIV was having someone besides me and Projet SSP to confide in.

These experiences took place in our offices, in the homes of PLHIV on home visits and in my home when they visited me. My relationships with these individuals were so important to me and to them that even when my son received his Christian baptism, a group of over twenty women living with HIV and a few others prepared the feast and dressed up in matching dresses they had sewn and danced for the celebration. In the spirit of *teranga* or hospitality, an important Senegalese value, I, as a foreigner (an American who now resides in Cameroon)—whom they renamed Aissata Hanne when I arrived to be more local—also benefited from the care and support of Projet SSP clients.

1.6. Outline of this report

This study includes six chapters covering the following:

- An introduction
- A review of the literature related to the subject
- A presentation of the research design and methodology used, with the aims and objectives, as well as procedures followed, ethical considerations and limitations.
- A presentation of the findings.
- A discussion based on the findings.
- A conclusion based on the key findings and presentation of recommendations based on these key findings.



CHAPTER 2: LITERATURE REVIEW

2.1. Introduction

In order to better understand already existing information and knowledge about HIV disclosure and the context of this study, a review of the literature was carried out. This review included summaries and information from programme documents developed by organisations that focus on the response to HIV/AIDS, as well as from scientific articles that present studies carried out in different parts of the world, although focusing mainly on African countries.

The literature review first looked at the concept of HIV disclosure, from a social, clinical and legal perspective. Statistics that show the varying rates of disclosure by PLHIV are presented. Then the specific factors that affect the decision to disclose or to not disclose as found in different studies are discussed. They include studies that sought to look at the impact of a specific, pre-determined factor, such as HIV-related stigma and discrimination, as well as studies that sought to identify together the different factors that affect disclosure of HIV status. Literature specific to HIV in Senegal showed a lack of research about the effects of different factors on disclosure. Finally, studies were also reviewed that present particular theories for understanding HIV disclosure. Some of the reviewed studies presented further information about disclosure, such as timing and outcomes of disclosure as practised by participants. Although also interesting information, this is not presented here due to the scope of the present study.

2.2. The concept of HIV disclosure

The term disclosure, as defined by UNAIDS (2000: 12) and used by many organizations such as the International HIV/AIDS Alliance (2003), refers to “the act of informing any individual or organisation (e.g. health authority, employer, school) of the serostatus of a person with HIV”. This can be done by the individual or by a third party and can be with or without the individual's consent. For this reason, the term self-disclosure is sometimes used to specify disclosure by the individual him- or herself. Others use the term managed disclosure which is also by the PLHIV and can be from selective to full, with the PLHIV either choosing to share partial information without specifically stating he or she is HIV-positive or being completely forthcoming (Greeff *et al.*, 2008). The same authors and others note that voluntary disclosure as practised by PLHIV can be a desirable, good thing or it can be done out of necessity (Greeff *et al.*, 2008; Chandra, Deepthivarma

& Manjula, 2003). Public disclosure is when PLHIV speak about their status openly and is the most uncommon. This practice which makes it possible for PLHIV to live openly is done most often in order to educate and increase awareness about HIV by sharing the first-hand experiences of PLHIV (Paxton, 2002). Mediated disclosure describes when PLHIV have decided to disclose, but request assistance from a third party, such as a service provider, in order to support them in the process (Bairan *et al.*, 2007). In some cases the third party will disclose the status of the PLHIV in their presence, but sometimes in their absence.

It is important to recognise that disclosure can be beneficial or harmful. At the same time, it is generally accepted that there is an ethical obligation for PLHIV who are aware of their status to seek to protect any individuals from infection who might be at risk such as sexual partners and injecting drug users (Gable, Gamharter, Gostin, Hodge & van Puymbroeck, 2007; Gillett & Parr, 2010). By this thinking, disclosure seems essential for HIV prevention. However, there is not always an association between disclosure and safer sex. In some cases a PLHIV may disclose to a sexual partner who then says that they expect they will be infected in any case and refuses to practise protected sex, which is termed informed exposure (Simoni & Pantalone, 2005).

Alternatively, some PLHIV who refrain from disclosing to their sexual partners find other arguments to practise protected sex and therefore reduce the risk of transmission (Miller & Rubin, 2007). This practice is sometimes called uninformed protection and often may be associated with partial disclosure (Simoni & Pantalone, 2005).

UNAIDS (2000) regards harmful disclosure as that being done without the consent of the PLHIV and possibly resulting in stigmatisation, violence or similar negative consequences, such as discouraging HIV testing. It would include most cases of mandatory disclosure. UNAIDS and the United Nations Office of the High Commissioner for Human Rights (OHCHR) have made a statement referring to the seriousness of harmful disclosure, calling it a violation of human rights (UNAIDS & OHCHR, 2008; UNAIDS, 2012b). Not only can there be negative consequences for the individual or their family, but it threatens prevention efforts as it has been found to discourage HIV testing and counselling due to people's fear of stigma and discrimination (UNAIDS, 2000; International HIV/AIDS Alliance, 2003; Gable *et al.*, 2007). Voluntary disclosure which is based on the PLHIV feeling they have no other choice can also be harmful if they suffer negative consequences as a result (Greef *et al.*, 2008; Gillett & Parr, 2010; Chandra *et al.*, 2003).

However, voluntary disclosure can be beneficial. UNAIDS (2000) regards beneficial disclosure as

that which:

“respects the autonomy and dignity of the affected individuals; maintains confidentiality as appropriate; leads to beneficial results for those individuals, and for their families and sexual and drug-injecting partners; leads to greater openness in the community about HIV/AIDS; and meets the ethical imperatives of the situation where there is a need to prevent onward transmission of HIV.” (UNAIDS (2000:12)

It is widely found that beneficial disclosure has both public health and personal benefits (O'Brien, Richardson-Alston, Ayoub, Magnus, Peterman & Kissinger, 2003; UNAIDS, 2000). For example, increased social support for the individual can result from disclosure to significant others which is a personal benefit (Bairan *et al.*, 2007; Chandra *et al.*, 2003; Miller & Rubin, 2007).

Disclosure is itself a factor that affects other aspects of HIV/AIDS. As noted above, it can improve the possibilities for social support, whether that be from family or community. It has been found that disclosure also affects the management of HIV infection, being a necessity for access to treatment programmes, but most importantly as a key to adherence to treatment regimens (Norman *et al.*, 2007: 1775; Hardon *et al.*, 2006; Klitzman, Kirshenbaum, Dodge, Remien, Ehrhardt, Johnson, Kittel, Daya, Morin, Kelly, Lightfoot & Rotherham-Borus, 2004).

This previous research regarding disclosure underlines its importance as a factor in both the prevention and management of HIV. At the same time, the work is not exhaustive and as the HIV epidemic evolves and more work is being done in different settings, the knowledge base about disclosure will hopefully grow.

2.3. Rates of HIV disclosure in Africa

Studies which looked at aspects of disclosure as practised by PLHIV found differing rates of disclosure. For example, in two culturally similar, but geographically different communities in South Africa (one urban, one rural), rates were very different: 70% and 30% respectively (Norman *et al.*, 2007). In another setting in Botswana, 94% of PLHIV did not disclose their status to the community and a further 69% had not disclosed to their families (Wolfe, Weiser, Bangsberg, Thior, Makhema, Dickinson, Mompoti & Marlink, 2006). In that study of 56 men and 56 women, 12% had not disclosed to anyone.

Among studies that focused on women's disclosure of their HIV-positive status to sexual partners, rates of disclosure varied by country and site (see Table 1). These might also have been reported at

different times since learning of their HIV infection, so are difficult to compare, but the percentages of those who had disclosed are as follows.

Table 1. Women's disclosure rates to sexual partners

Country	Percentage Disclosure to Sexual Partners	Number of Women
Côte d'Ivoire (Brou <i>et al.</i> , 2007)	46,2%	546
Tanzania	22% at 2 months, 40% at 4 months	815
Kenya	31%	290
Burkina Faso	18%	306
Tanzania	17%	288
Côte d'Ivoire (Desgrées du Loû, 2005)	40%	149

(Brou, Djohan, Becquet, Allou, Ekouevi, Viho, Leroy & Desgrées du Loû, 2007; Desgrées du Loû, 2005)

Under 50% of women in these countries had disclosed their HIV-positive status to their spouses or sexual partners, which shows that the practice is not common, especially in Burkina Faso and Tanzania.

Despite there being no studies which focus specifically on disclosure in a Senegalese context, a few studies have sought that information from participants while investigating other questions. Sow, Toure, Coume, Dia and Traore (2012) in their study about adherence found that of a sample of thirty men and thirty women, 92% of the participants interviewed had disclosed to their spouse. Ndiaye (2008) reported that of 201 participants interviewed in Dakar, Senegal, one hundred, or close to 50%, claimed to have disclosed their status to at least one person.

Obermeyer and Osborn (2007) summarised evidence about HIV testing and its social and behavioural dimensions finding disclosure rates as low as 17% and as high as 86% in five African countries. Comparatively they found that black Africans in London disclosed to their partners at a rate of 85% and adolescents and adults in the United States (US) at rates ranging from 47 to 60% (Obermeyer & Osborn, 2007).

We see from the research presented here that rates of disclosure vary widely, thus it seems that in no setting or group has disclosure become a common practice.

2.4. Factors affecting disclosure

2.4.1. Motivators

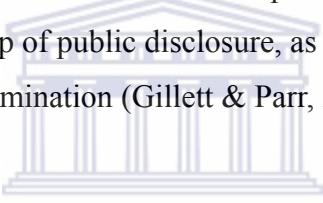
Studies undertaken around the world to better understand HIV disclosure or non-disclosure have often focused on factors that affect PLHIV's decisions concerning disclosure. Some of those studies identified motivators that led PLHIV to disclose their status at least to specific people or groups. Generally, it has been found that there is a desire to prevent further transmission of HIV and this is a reason for disclosure (Bairan *et al.*, 2007; Calin, Green, Hetherington & Brook, 2007). However, there are also other reasons. For example, in a study in South India, 65% of the 68 participants (35 men and 33 women) who had disclosed their status reported self-disclosure, mainly to family, a few to friends and some only to health professionals (Chandra *et al.*, 2003). The remaining 35% reported that disclosure had occurred without their consent. Reasons given by those who self-disclosed were to share emotions or information, sometimes out of a felt necessity, however only half gave complete, truthful information, practising full disclosure, while the other half disguised the truth as an illness that carried less stigma, which can be regarded as partial disclosure (Chandra *et al.*, 2003). In the study by Calin *et al.* (2007) among HIV-positive black Africans in London, only 4% had not disclosed to anyone outside the health system, although only 56% had disclosed to partners. Primary reasons given for disclosure to sexual partners were that partners were at risk and that relationships were close and trusting, which was also a cited reason for disclosing to family and friends (Calin *et al.*, 2007). A United States (US) study which looked at patterns of disclosure and sexual behaviour of 1090 sexually active women found that they were more likely to disclose to partners with whom they'd been in a relationship for some time than to those in which the partnership was recently initiated (Wilson, Feldman, Vega, Gandhi, Richardson, Cohen, McKaig, Ostrow, Robison & Gange, 2007). The quality and nature of the relationship with the person to whom they were disclosing was found to be important as well.

Other motivators identified in the study of HIV-positive black Africans in London included declining health, belief in imminent death or to get emotional support, as well as knowing a confidant who was also HIV-positive, relief in confiding and needing to get more information about HIV services (Calin *et al.*, 2007). Having a confidant was also a motivator in a study in the US, as well as needing to be part of the HIV service network (Emlet, 2006). Most of these factors were

specifically self-focused, with a perceived benefit coming directly to the PLHIV as a result of disclosure (Chandra *et al.*, 2003).

Some of these motivators seem to be practical, whereas others are emotional and some parallels can be drawn between different countries and groups of people. For instance, in both the US and London studies having a confidant was a reason for disclosing. In both the London and India studies PLHIV were motivated by the need for emotional support.

In a study in rural Kenya looking at the role of support groups in relation to disclosure, the majority of participants had disclosed to at least one person. The authors categorised the reasons into three sub-themes: “a duty to others”, “responsibility to the wider community” and “treatment adherence” (Gillett & Parr, 2010:340). In considering their duty to others, women had felt the need to prepare for care for their children in case of their death. They had also decided to disclose to their partners in order for them to be tested and to prevent transmission. Many women agreed that public disclosure was an effective way to teach others in order to prevent further transmission and to get tested. They noted that taking the step of public disclosure, as done by the support group leader, assisted in reducing stigma and discrimination (Gillett & Parr, 2010). And finally, as the support group leader also shared:



“And with the adherence, you have to disclose, because you have to be very strict with the time of taking drugs...if I have not disclosed to you [husband], what will I do? Am I going under the bed? Or going out for the loo so I can take my drug?” (Gillett & Parr, 2010:340)

In order to adhere to treatment, the concern was the need to not hide the medicines from people close to the PLHIV. Being able to take the treatment openly also meant that when someone was ill they would receive support (Gillett & Parr, 2010). The study did not identify the same kind of self-focused motivators as other studies, such as need for emotional support, except with regard to treatment adherence which is self-focused. However, they did not discuss why their findings were different.

In another study looking at treatment for PLHIV in four US cities, the inter-relationship between HIV disclosure and ART was studied (Klitzman *et al.*, 2004). The study specifically investigated how disclosure affects adherence, but results also showed that being on ART and then subsequently looking well was sometimes a factor for disclosure. Some PLHIV identified diverse motivators for disclosure and yet in these cases disclosure was still limited to a small number of individuals,

except for the rare examples of public disclosure illustrated by support group leaders (Klitzman *et al.*, 2004).

Finally, PLHIV who knew their status had most often been in contact with health care providers and attended pre-test and post-test counselling or other sessions. In some cases the PLHIV were counselled to disclose their status because of the benefits it could bring the individual and the community (Simoni *et al.*, 2000; UNAIDS, 2000). However, De Rosa and Marks (1998, as cited by Simoni & Pantalone, 2005) found that only emphasizing the benefits of disclosure at the time of the post-test is insufficient to encourage the practice and that repetition of the discussion about disclosure is important.

In summary, considering the complexity of the decision to disclose because of the above factors and the characteristics of both the PLHIV and the individuals to whom they would disclose, it seems important for those providing care and support to be in regular discussion with the PLHIV about their thoughts concerning disclosure. This may be applicable in every setting as PLHIV who accept their status would always be in contact with service providers.

2.4.2. Barriers

The literature related to disclosure of HIV status has identified more barriers to disclosure than motivators. Some of these are related to the individual, some to relationships and some to community. A good number of these studies have attempted to understand the association of disclosure with the experience or fear of stigmatisation. For example, a study in the US which looked at the association of disclosure with stigma found that younger adults with HIV were more likely to disclose compared to older adults with HIV, except to their children, because older adults were more likely to make moral judgements (Emlet, 2006).

In a study in China, 4111 rural to urban migrants, both male and female, responded to a question about whether they would be willing to disclose their status to someone if they were HIV-positive. 70.6% said they would be willing to disclose their status, with only a slightly higher percentage of men than women (Yang *et al.*, 2006). It was found that HIV-related stigma and misconceptions about HIV were both negatively associated with willingness to disclose in that context. In several east African studies of stigma, this factor again arose as influencing the decision, particularly of women, to disclose or not. Women specifically cited fear of blame and rejection or more generally fear of their partner's reaction and the concern that disclosure would make their situation worse due

to stigma (Kidd & Clay, 2003; Obermeyer & Osborn, 2007). A study among HIV-positive men and women in Cape Town, South Africa showed that stigma and discrimination were associated with non-disclosure of HIV status to sexual partners (Simbayi, Kalichman, Strebel, Cloete, Henda & Mqeketo, 2007). Non-disclosure was also associated with HIV transmission risk behaviours in that study.

From the aforementioned studies it can be seen that the importance of stigma as experienced or perceived by PLHIV and those around them cannot be over-emphasized and is repeatedly noted as influencing the decision to disclose or not. There is not a context or a group of people who have avoided being affected by HIV-related stigma according to the literature on disclosure. Thus it is essential to understand and address this aspect as it relates to prevention and management of HIV and specifically the way it affects decisions concerning disclosure.

Several studies reported reasons for disclosure related to relationships, particularly sexual relationships. For example, in Botswana, where the number of sexual partners was identified as an influencing factor, of 247 adults with only one steady sexual partner, 7% had not disclosed to anyone, compared to 26% of the 62 adults who reported multiple partners (Kalichman, Ntseane, Nthomang, Segwabe, Phorano & Simbayi, 2007). However, they did not give any explanations for this difference. Another study from the US of 1090 sexually active HIV-positive women sought to determine patterns of disclosure and sexual behaviour (Wilson *et al.*, 2007). The results showed that women were more likely to refrain from disclosing their HIV status to partners with whom they'd recently initiated sexual relationships. In the study of PLHIV of both genders in Cape Town, those who had not disclosed to sexual partners were more likely to have experienced HIV-related discrimination, possibly including having lost a job or housing (Simbayi *et al.*, 2007). Another factor that emerged was an individual's experience of negative outcomes as a result of previous disclosures which discouraged further disclosure (Simbayi *et al.*, 2007). It can be concluded that although disclosing to sexual partners is recommended by service providers in order to adopt behaviour to avoid further HIV infection, both men and women living with HIV have concerns about sharing their status in certain relationships (UNAIDS, 2000; Bairan *et al.*, 2007). Some of this is due to stigma, some to discrimination and likely due to other factors as well. One can also conclude that in different contexts the length and quality of relationship affects the PLHIV's decision to disclose or not.

PLHIV not only fear discrimination from sexual partners, but also from other people to whom PLHIV might disclose their status. For example, Gillett and Parr (2010) noted that fear of abandonment or slander discouraged disclosure. The women who were a part of that study in Kenya referred to HIV's association with witchcraft and promiscuity. One woman shared that were she to disclose to her mother-in-law she would go around “ruining me—divulging her daughter-in-law's status or slandering her (Gillett & Parr, 2010:340).

The different reactions of those to whom the PLHIV might disclose are cause for concern to PLHIV. The women in rural Kenya also expressed fear of disclosing to a partner which might result in potential loss of financial support (Gillett & Parr, 2010). Fear of abandonment was closely related to the fear of losing economic support from a partner in settings where access to financial resources is difficult (Medley, Garcia-Moreno, McGill & Maman, 2004). In only one instance in the Kenya study was there mention of violence, however this is a more important barrier to disclosure in other contexts (Gillett & Parr, 2010; Miller & Rubin, 2007; Greeff *et al.*, 2008; Bell, Mthembu, O'Sullivan & Moody, 2007). In cases where domestic violence is already a reality for women, sometimes the situation continues or is exacerbated when a woman discloses to her spouse (Ramodike, 2009). This violence can be physical, verbal, sexual or financial, as experienced by women interviewed in South Africa (Ramodike, 2009).

PLHIV also showed concern about how their status would affect others and not just themselves. These reasons for non-disclosure did not assume negative reactions towards the PLHIV. For instance the case noted above by Medley *et al.* (2004) found the desire to avoid upsetting family as a factor. In the study of HIV-positive black Africans in London, although reasons identified for non-disclosure included not trusting those with whom they were in relationships, they also included wanting to keep family from becoming distressed due to the prevailing opinion that being HIV-positive equated with a death sentence (Calin *et al.*, 2007). Similarly, in a study in South India which used both quantitative and qualitative analyses to identify factors affecting disclosure decisions, reasons cited for not disclosing included keeping the family from worrying or becoming distressed, but also the concern of causing disgrace to the family (Chandra *et al.*, 2003). In these cases PLHIV believed that the best decision for their families was to keep their status secret from them, despite the fact that the family might be the best source of emotional support.

One study looked at a specific factor to see if it was linked to decisions regarding disclosure. The authors tried to determine the level of fatalism among Malians and their beliefs about HIV and

AIDS. The participants responded that if they knew their HIV status, around 58% would disclose, whereas 41% would not (Hess & McKinney, 2007). However, an association between fatalistic beliefs and intention to disclose or not disclose one's HIV-positive status was not significant, but might be in another setting and might help understand how PLHIV make decisions regarding the management of HIV infection, including disclosure (Hess & McKinney, 2007).

As demonstrated with the above studies, barriers to disclosure vary from individual to individual, context to context. They can be affected by many variables, including life changes of PLHIV such as their marital status and their community's evolving awareness of HIV, particularly stigma, and discrimination, different relationships, and the reactions within them and the concern about the effects on others.

Although the range of contexts of these studies varied greatly, the experience of PLHIV also varies within a context. Having a broad picture of the situation of PLHIV can assist in understanding PLHIV's experience in Senegal. The contexts most similar to Senegal among these studies include the rural Kenya and east African, as well as the other African settings.

2.5. Investigations of HIV disclosure in Senegal

Most of the previous studies on disclosure are from outside of West Africa. To date no studies specifically investigating HIV disclosure rates, influencing factors or consequences in Senegal have been found and those in the West African region are rare. Certain studies that investigated other HIV-related topics do provide insight into possible factors that affect disclosure and investigate other aspects that concern disclosure in Senegal. For instance, the Demographic and Health Surveys (DHS) in both 2005 and five years later in 2010 investigated attitudes held by people who had heard of HIV/AIDS (Ndiaye & Ayad, 2006; ANSD & ICF International, 2012). These reflected high levels of discrimination and stigma, as well as misconceptions about transmission in communities. The DHS used indicators to measure attitudes of tolerance and acceptance of PLHIV and how they might be treated in families and in the community. In interviews with women for the 2010 survey, close to 80% stated that they would be prepared to care for an HIV-positive family member at their home and 18% thought that it was not necessary to keep secret the status of an HIV-positive family member, thus accepting living openly with HIV as normal (ANSD & ICF International, 2012). However, this likely means that the majority believed it was necessary to keep their HIV-positive status a secret. Around 48% of women would buy fresh vegetables from an HIV-positive salesperson and close to 60% thought that a female teacher living with HIV should be

allowed to continue to teach (ANSD & ICF International, 2012). These indicators show a moderate level of acceptance of PLHIV in normal community activities, yet a large number still show they would not treat PLHIV with the same respect as other individuals.

The percentages were not too different with male interviewees. When the four indicators measuring stigma are taken together—caring for an HIV-positive family member at home, keeping secret the situation of an HIV-positive family member, buying vegetables from an HIV-positive salesperson, and allowing a female teacher living with HIV to keep teaching—only 4% of women and 5% of men in Senegal showed a higher level of tolerance giving the preferred answer to all four of the questions (ANSD & ICF International, 2012). Such societal attitudes may influence a PLHIV's decision to disclose as they sense a continually high level of stigma in the community and in families. Though in some regions and groups (rural vs. urban, educated vs. non, etc.) there have been improvements, the general picture has not changed greatly from 2005. In fact in 2005 the men's positive responses to the four indicators measuring tolerance were actually higher at 9%, as compared to only 5% in 2010, thus a slide backward (Ndiaye & Ayad, 2006; ANSD & ICF International, 2012).

It is not surprising then that in a book by Bronsard, Boissy and Sylla (2002) which analysed and evaluated the first three years of ISAARV (Senegalese Initiative for Access to ARVs), a PLHIV explained his reticence in disclosing his status:

“They tell me I must talk about it with my family so I feel better...I can't...they will know that it's my fault...and even if I tell them I have medicines they will think that I'm lost...It's only when I come to the hospital that I can talk about it” (Bronsard, Boissy & Sylla, 2002: 8).

Even published studies about adherence to ART in Senegal seem not to address the impact of disclosure (Lanièce, Ciss, Desclaux, Diop, Mbodj, Ndiaye, Sylla, Delaporte & Ndoye, 2003). A recent study in Dakar of adherence rates did determine the percentage of PLHIV who had disclosed to their spouse, but it did not investigate whether disclosure was a factor for adherence or vice versa (Sow *et al.*, 2012). However, as we have seen from the studies presented earlier, disclosure as a factor for adherence, as well as factors that influence the decision to disclose, are aspects of HIV management that are increasingly important to understand in different contexts, including in Senegal.

One study which specifically assessed HIV prevention in Senegal and the challenges of HIV reduction documented experiences of disclosure in Senegal when they interviewed sex workers, a group whose rate of HIV infection was much higher than the general population (Foley & Nguer, 2010). What they determined was that Senegal had made appropriate attempts at controlling the HIV epidemic with public health measures, but it had not adequately addressed the social determinants or the protection of human rights of the most marginalised. In interviews and focus groups with sex workers, stories of disclosure were also shared. Though AIDS service organisations and support groups existed to provide assistance, most participants said they would not seek other assistance because of stigma. The authors reported one participant as saying: “If I had HIV, I would hide it and get treatment” (Foley & Nguer, 2010:333). The possibility of disclosing to family, when suggested to participants, was quickly dismissed and included one response of: “I would expect nothing from my family” (Foley & Nguer, 2010:333). However, a few individuals noted that a family member might be supportive, particularly a mother.

“In my family I can count on my mother. Our mothers can forgive us and help us during difficult times, such as being infected. They won't abandon us. Brothers, sisters, other family members could do or say anything. But our mothers will always be our mothers” (Foley & Nguer, 2010:333).

According to Foley and Nguer (2010), programmes have targeted vulnerable groups, yet nothing has successfully addressed the need for public acceptance of and support for PLHIV. They cited the dilemma of disclosure to intimate partners and family as one of the issues that has been overlooked in the response to HIV and AIDS in Senegal. As in other countries, there is not a sense that disclosure can always safely be made to a specific individual (e.g. a spouse), but rather there continues to be a concern that PLHIV risk being stigmatised from different sources.

The concept of *soutoura* (privacy, dignity, respect) is a common value of the majority Wolof ethnic group in Senegal and is a term used even by non-Wolof (Ndiaye, 2008; Diaw, 2007). Research by Ndiaye (2008) which made use of both quantitative and qualitative methods sought to investigate the concept of *soutoura* as it concerns stigma related to HIV and AIDS in Senegal. Through interviews with PLHIV in the capital, Dakar, she learnt of particular experiences, some of which concerned disclosure as related to stigma. The author referred to cases of AIDS being kept as a family secret and that the decision to disclose or not included the possibility that the PLHIV might want to withhold information in an attempt to avoid more questions about his/her situation (Ndiaye, 2008). She stated that her study found similarities with other studies elsewhere as concerns stigma

and its connection to disclosure. In her survey, Ndiaye (2008) found that only half of the participants, or one hundred people, stated that they had disclosed to at least one person). The relationship of the person to whom disclosure was made was, by order of importance: a sibling, another PLHIV, a spouse (20%), another relative (cousin, aunt or uncle living with them), parent (10%), whole family, friend, boyfriend/girlfriend (5%), sexual partner, work/school colleague, community, spiritual/religious leader, nurse/doctor (Ndiaye, 2008).

Ndiaye (2008) stressed the importance of respecting the PLHIV's right to decide about disclosure. One example of a problem related to stigma addressed by support groups was their attempt to end home care visits by health workers in white coats which ultimately forced disclosure. She noted that the effectiveness of the Senegalese government's access to ARVs programme (ISAARV) meant that many PLHIV stayed healthy and did not show evidence of illness. She stated that this led to reduction in stigma and thus more control over disclosure because signs of poor physical health might otherwise have obliged the PLHIV to disclose (Ndiaye, 2008). She also noted that:

“Lack of disclosure to some family members may not be automatically a sign of fear of stigma but rather in line with the emic manner of handling medical ailments. This researcher's personal experience is that in Senegal, for example, family members may not enter into details about illnesses, choosing to simply say that a family member is ill (regardless of which disease is involved)” (Ndiaye, 2008:26).

However, one of the PLHIV shared in a focus group that dignity, *soutoura*, could be recovered through successful disclosure, showing that in Senegal there were some who have benefited from disclosure (Ndiaye, 2008).

These studies from Senegal help to inform further research into disclosure and point to individual, family and cultural aspects of HIV-related questions.

2.6. HIV disclosure theories

Different theories and models have been used or developed to help explain disclosure or non-disclosure of HIV status since the early 1990s (Yang *et al.*, 2006). They were often based on earlier work in the area of self-disclosure which itself was limited in its ability to address particularities of HIV (Simoni & Pantalone, 2005). For instance, disclosure theory, pioneered by Jourard (1971, as cited by Simoni & Pantalone, 2005), did not adequately take into account context; content such as HIV which is highly stigmatising; consequences, which in the case of HIV can be negative, such as

losing social support; or cultural values that can influence whether an individual is likely to disclose personal information. These situational and contextual factors often contribute to a tendency not to disclose (Zea *et al.*, 2004, as cited by Simoni & Pantalone, 2005).

More recent theories were therefore developed to attempt to understand disclosure specific to HIV. Serovich (2001, as cited by Simoni & Pantalone, 2005) did some of the first conceptual work on two theories: disease progression theory and consequence theory of HIV disclosure. The first, disease progression theory, proposes that due to the worsening health of people living with HIV to a stage that cannot be hidden, PLHIV will disclose to those close to them (Serovich, Lim & Mason, 2008). Kalichman (1995, as cited by Yang *et al.*, 2007) found that this was often the case prior to the increased availability of ART, that as HIV infection progressed to AIDS individuals would feel the need to disclose, for instance when hospitalised and needing to explain the cause of their illness. Yang *et al.* (2007) report mixed results from those who have tested this theory. It was sometimes judged to be over simplistic as it did not account for the PLHIV's own volition to disclose, but rather was based solely on the evolution of illness (Almeleh, 2006).

The second theory which emerged was consequence theory, which proposes that as the perceived benefits of disclosure start to outweigh the costs, PLHIV will disclose their status (Yang *et al.*, 2001; Simoni & Pantalone, 2005; Serovich *et al.*, 2008; Fennie, Chen, Williams, Wang, Xianhong & Khoshnood, 2012, Almeleh, 2006). Serovich (2001, as cited by Simoni & Pantalone, 2005), had noted that rewards or benefits might be the ability to keep others safe, the possibility to be understood by others, and an obligation to disclose whereas the costs were fears of fighting, moral judgements and blame. Yang *et al.* (2006) found that this theory also allows for the recognition of cultural influences on disclosure. However, Norman *et al.* (2007) found that little empirical evidence for the application of this theory came from African contexts.

Fennie *et al.* (2012) recently looked at the existing theories that have been used to understand HIV disclosure and modified the consequence theory in an attempt to apply their use in a Chinese cultural context where perception of stigma and duty to family, as well as other factors, might be understood differently. They noted, however, that in some areas ART is not yet easily accessible, so the disease progression theory may still contribute some important elements which then become a part of the adjusted consequence theory. The context of Senegal would be different again so the applicability of these theories could be useful for the Senegalese context too.

In conclusion, the literature related to disclosure describes the practice in different settings and has used both quantitative and qualitative methods in its investigation. Rates of disclosure vary greatly and the influencing factors for disclosure or non-disclosure also varied. Few studies have specifically looked at the practice of disclosure in Africa and none has sought to describe the factors that influence disclosure in Senegal.



CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

In this chapter, the methodology used in the study is presented. Included are the aim and objectives, the study design, study population, sample size, sampling procedures, data collection tool and method, data analysis, rigour, as well as a discussion of limitations and ethical considerations.

3.1. Aim and objectives of study

The aim of this study was to explore factors that influence the decision to disclose one's HIV-positive status to regular sexual partners, friends and family in Linguère District, Senegal.

The **objectives** of this study were:

- To explore with PLHIV their perceived or experienced barriers or motivators to HIV disclosure.
- To explore with HIV/AIDS service providers what they perceive as factors affecting the decision of PLHIV to disclose their HIV status.



3.2. Study design

In order to better understand the point of view of PLHIV in Linguère District, a qualitative study design was used. Qualitative methods allow for a deeper understanding of the lived experience of PLHIV, through PLHIV themselves and also the observations of service providers. The aim of this study fit the characteristics of a qualitative approach. For example, allowing people living with HIV to speak in-depth about their situations is naturalistic and is possible because of already existing relationships of trust and well-established rapport between PLHIV and Projet SSP and also Projet SSP's relationship with other service providers. I approached PLHIV with respect for their point of view and with respect for their social situation. As an example, although questions were open-ended and allowed for sharing about different sexual partners, I did not probe to get information about sexual partners who were not spouses as I was concerned probing about less socially acceptable relationships would lead to less openness in sharing of other information. Being well versed in the local culture and able to speak some Wolof and Pulaar, the language of the Fulani, allowed me to better understand their experiences of their decision-making behaviour regarding disclosure. As early data were collected and analysed, the approach was able to change

according to the context of the particular participant in order to achieve a rich description and understanding. As information emerged, specific issues could be studied in depth and detail (Durrheim, 2006). This approach allowed for different world views which arose as participants' points of view were clarified. It also provided for countering widely held assumptions, such as the idea that disclosure is necessary to prevent further infections.

From the literature review it was found that there are few studies of barriers and motivators to disclosure of HIV in Africa and even fewer using qualitative methods. The studies which most resemble the current study are those of Chandra *et al.* (2003) in India, Norman *et al.* (2007) in South Africa, Calin *et al.* (2007) in London and Gillett and Parr in rural Kenya (2010), as well as portions of Ndiaye (2008) in Dakar, Senegal. All five studies used qualitative methods, although the London, India and Dakar studies also included quantitative methods. Additionally, a study was carried out in Kenya to understand “why, how and to whom people living with HIV/AIDS disclose their diagnosis” (Miller & Rubin, 2007:586). It also used qualitative methodology to reveal patterns of disclosure and the results were an in-depth understanding of the factors and patterns for disclosure or non-disclosure, similar to the aim of this current study (Miller & Rubin, 2007). The current study also drew on the Gillett and Parr (2010) study which, like this study, had a rural setting with significant involvement of support groups.

In conclusion, in some contexts thorough studies have already been done to identify and better understand factors that influence the decision to disclose or not disclose one's HIV-positive status and thus inform policy and programming. However, little research around these factors has been undertaken in Africa. Many of the studies reviewed recommended that to improve care and support programmes for PLHIV, further research needs to be done in this area. Some specifically suggest the use of qualitative methods for deeper understanding.

3.3. Study population and sampling

3.3.1. Study population

Two main groups of people were interviewed. The first group were PLHIV who were enrolled in ISAARV and who accessed services from Projet SSP. In order to obtain maximum variation PLHIV with different characteristics were selected. The second group of people who were interviewed were service providers from Projet SSP and the Health District who had provided services while I was still working in Senegal.

3.3.2. Sample size

Twelve PLHIV were initially identified through purposive sampling on the basis of the criteria described in Table 2. Three additional PLHIV were interviewed, bringing the total to fifteen, in order to respond to the inclusion criteria as earlier participants were found to be supplementary in some groups. Two of the three also were PLHIV who would otherwise wonder why we were not interested in interviewing them. This could have had a detrimental effect and weakened their relationship with Projet SSP, the service provider. The only criteria not found was one divorced/widowed/unmarried man living with HIV who had not disclosed to another person. Four service providers served as key informants.

Table 2. Sample size

PLHIV Criteria	Desired Number	Actual Number
Married woman who has disclosed to partner	2	3
Married woman who has not disclosed to partner	2	2
Married man who has disclosed to partner	2	3
Married man who has not disclosed to partner	2	2
Divorced/widowed/unmarried woman who has disclosed to another person	1	2
Divorced/widowed/unmarried woman who has not disclosed to another person	1	1
Divorced/widowed/unmarried man who has disclosed to another person	1	0
Divorced/widowed/unmarried man who has not disclosed to another person	1	2
Total PLHIV	12	15
Key informants	Desired Number	Actual Number
Health education/counselor of EELS Projet SSP	1	1
Linguere Health District Social Worker	1	1
Doctors/nurse-midwives providing services to PLHIV	2	2
Total key informants	4	4
Total number of interviewees:	16	19

3.3.3. Sampling criteria and procedure

Due to the heterogeneity of the PLHIV and their experiences with disclosure, a sampling strategy seeking maximum variation was followed (Rice & Ezzy, 1999). This strategy was purposive and sought to find information-rich people among the PLHIV. The criteria that were taken into account when trying to make an even-handed selection were: gender, marital status (married, divorced, widowed or unmarried) and experience of disclosure to regular sexual partners, friends or family members and gender. Prior to my arrival to embark on the study, Projet SSP informed PLHIV about the need for participants for the study. Mariame (Projet SSP and translator for this study) had copies of the information sheet which allowed her to clearly describe the study to PLHIV. It was also e-mailed to the Linguère District Medical Director.

Upon my arrival in Linguère, I visited the District Medical Director to verify his authorisation of the study and also to request a time to interview him. Importantly, he identified which of the health personnel in the maternal and reproductive health service he felt should be an informant and he agreed that the third provider from the health district should be the social worker in charge of continuum of care for PLHIV and ARV distribution. These workers had had more contact with PLHIV and had often referred them to Projet SSP and vice versa and I had previously collaborated with them. They were therefore purposively selected as key informants.

In order to identify potential PLHIV participants, Mariame and I consulted an older list of PLHIV who were clients of Projet SSP (from the time of my residence there) to see who fitted the criteria and resided in Linguère District (not the neighbouring district which is also served by Projet SSP). After identifying individuals, they were contacted by cell phone, via someone else, or we just expected them or someone they knew would come to the office and might be asked to inform them. When they were contacted, they were again informed about the study and asked if they were willing to participate, while stating clearly that their refusal would not affect the services they received. All those approached agreed to participate and interview dates, times and locations were arranged.

3.4. Data collection tools and methods

For this study the data collection methods used were in-depth interviews with PLHIV, key informant interviews and record review. Interviews allowed for one-on-one conversations which protected the participant's privacy. Considering the sensitivity of the topic and ethical concerns regarding confidentiality, focus groups, another method which can provide rich information, would not have been appropriate. Data collection was carried out from January 9 to 20, 2012 in Linguère.

Apart from one interview held in a village health hut in one PLHIV's village (her choice), the other interviews with PLHIV were held on the property which serves as Projet SSP offices, but which also houses Mariame. This is familiar territory for the PLHIV and the choice of room was made based on which space was most private at the time. The interviews were audio-recorded from the point of asking the first question from the interview guide and ended when discussion of the last question had concluded. The audio-recorded interviews generally lasted around half an hour, although our time together was longer due to casual conversation prior to or following the formal recorded portion of the interview, as well as going over the participant information sheet and gaining consent. The interviews with the three Linguère District service providers were at their places of work and only in the case of the midwife was I accompanied by Mariame. The longest interview was with the district social worker, but was still under one hour. The interview of Mariame, as service provider, was in her room. All of the interviews with key informants were in French.

Qualitative interviews allowed for exploration of the questions with the participants in a broad way, using a semi-structured interview guide (see Appendix 1) which I personally had translated into French. The semi-structured format of the interview guide allowed the PLHIV to speak freely without providing rote answers to closed questions but still keeping the focus of the topic. Probes were used to encourage reflections to go deeper or for clarification (Robson, 1993; Liamputtong & Ezzy, 2005). Interviews with service providers were also carried out with a semi-structured guide in French (Appendix 2).

3.4.1. Individual interviews

I carried out the interviews with PLHIV with a translator (Mariame, Projet SSP) to clarify any language misunderstandings as the interviews were conducted in one of three languages which were not my first language. I speak one fluently, understand the second quite well, but struggle to understand complex ideas in the third. During the interview, body language and other non-verbal language were noted and I also noted important points or things to come back to. All participants were asked permission to be recorded for transcription and translation.

When participants arrived for their interview, there were often others in the compound and they would engage in friendly conversation. If there were other support group members present, they maybe would have surmised the purpose of the visit, however it was not stated and could not be assumed due to the regularity with which PLHIV visit the Projet SSP office. Others present would

have had no way to know the purpose of the participant's visit. Depending on our activities, we unobtrusively moved with the participant to the office or Mariame's room for more privacy. In the office we sat on chairs and in Mariame's room we sat on the floor on mats. The casual conversation continued for some minutes as we greeted one another and asked about family, etc. With some participants the friendly banter could be considered quite crude, in particular between certain women and Mariame. From my own experience, this is a characteristic of Senegalese women. Not all women engage in it or might only do so with particular relatives or acquaintances, however even in the mixed support group as at other gatherings this can be witnessed and attests to the closeness of relationships. I have purposely taken part in such conversations as it recognises common practice in the culture. The apparent casualness and acceptance of cultural practices by Projet SSP is an intentional approach. Being a part of the community and accepting these practices helps develop the trust needed for the project to be accepted and approachable.

After going through the participant information sheet and gaining consent, I again explained the use of audio recording and how it would be used. Only upon confirmation of acceptance did I start recording. The first questions were related to demographics, information which was completed and confirmed through record review. However, questions about marital status and partners led more naturally into discussion of disclosure. Depending on the participant and their preference, we decided in which language to carry out most of the interview. Knowing them well, we encouraged the use of their first language, except in cases where we felt they could adequately express themselves in a language that I better understood. Almost every interview ended up using a mixture of languages, as is common in regular conversation (Pulaar with some Wolof, Wolof with some French, etc.). I asked a question in French, in which I am fluent, to which the PLHIV often responded or Mariame would translate if she sensed they needed to hear the question in Wolof or Pulaar. Everyone understood at a least a little of the other languages. As the participants responded I affirmed that I understood directly, either verbally or with a nod. I sometimes repeated the response in French or Pulaar if I wanted to verify my understanding. Sometimes the participant would affirm or sometimes the participant or Mariame corrected my understanding. If I did not understand the response directly I asked Mariame to translate. If that happened once or twice in an interview she automatically translated the bulk of the interview. As we knew each other very well, working together for nine years, she knew my level of Pulaar and Wolof. However having been out of the country for two years meant I had lost some comprehension skill.

Throughout all the interviews we often rephrased or even repeated the question later. For example in a couple of cases I went back to an earlier question to ask someone to respond again based on a more recent statement. The initial conversation was very individual-specific and at a later point we asked them to respond reflecting on what were the experiences of their peers from the support group with regard to disclosure, particularly people they knew in the support group. All of the PLHIV interviewed were members of the support group, so had evidently disclosed within that group. Mariame served as an oral file in a few instances and recalled something particular about a participant's experience, such as if Projet SSP was involved in mediating disclosure or what the circumstances were of a particular disclosure. This method did not bring the same level of detail, but was used as a prompt for discussing a participant's situation (Kelly, 2006a; Robson, 1993). For instance, Mariame's knowledge of one participant's former marriages allowed for further probing and thus richer information was shared during the interview. We chose not to probe about less socially acceptable partnerships in order to avoid discomfort which might have inhibited sharing about acceptable relationships.

There was a great willingness to participate. Some PLHIV travelled long distances on difficult modes of transportation (horse or donkey carts, foot, rickety trucks with boards across the back) with long waiting times for transport, to respond to our invitation. Generally, this willingness showed an openness and trust. However, in certain cases it more strongly reflected the cultural value or practice of showing gratefulness to one who helps provide for you. In almost every case the participant found time to give thanks and recognition to Projet SSP, to me and in particular to Mariame for her support. With the very first interview, after the recorder was turned off and Mariame had gone out of the room to attend to someone, the participant thanked Projet SSP for being there when he was first ill and said that he would not have been alive without us.

Although none of the spaces where we held the interviews was completely quiet or removed from activity, in only a couple circumstances did the PLHIV seem concerned about being overheard and when they did we made adjustments, such as asking someone to leave or shutting a door. One case was in the village health hut. The village health worker was busy in the other room with a group of visitors from the US and yet the PLHIV was a bit uneasy. She had always been very resistant to disclosure, even to the health worker who was highly trusted in the community. We took every measure to make her more comfortable and had a good interview.

3.4.2. Key informant interviews

The key informant interviews were collegial. My rapport with both the doctor and social worker was strong, with the midwife more reserved. In fact, Projet SSP had had issues with her behaviour towards a pregnant PLHIV early in her time in Linguère. However, that was some years ago and the relationship was now stronger. Mariame only attended the interview with the midwife which was helpful as she reminded the midwife of other PLHIV when she seemed not to recall some cases where she knew about disclosure status or motivators. The office was very quiet due to a sit-in by health workers and there was only one interruption when someone asked her if she was not doing the sit-in. Fortunately we are well known by all of the health workers and they understood that she agreed to “work” with us for a few minutes. In the case of the doctor and social worker, I saw them both at the District Health Centre on my last evening in Linguère. All of these interviews were in French and thus the presence of Mariame was not necessary for assistance with translation.

3.4.3. Record review

Interviews were complemented by record review. The files that are kept on each PLHIV who receives services from Projet SSP assisted in the selection of participants who met the criteria. These files were up to date at the time that I looked at them (January 2012). Further review of the participants' files was carried out following the completion of the interviews. As Projet SSP has recorded information at every office contact with the PLHIV, this source allowed me to triangulate the information with the data collected from the interviews and for any other relevant information that was not in the interviews that could add to a better understanding of the participants' situation.

3.5. Data management

After each day of interviews, the audio files were downloaded and given to the transcriber who lives in Linguère. Transcriptions in the different languages were produced with French translations. I cleaned the data by correcting typing mistakes, double-checking with the recordings and replacing any proper names that had been used. Back up copies of the transcriptions and audio files were made as suggested by Willms and Johnson (1993).

3.6. Data analysis

As the design of this study was qualitative, data analysis coincided with data collection. Although I did not receive the transcripts immediately, I made notes after the interviews and reflected on them, also listening to the audio recordings. At the end of every interview I summarized and verified

main points with the participant. Mariame and I would discuss any particular issues about approach or content after the participant left.

The type of analysis used was thematic analysis. As transcripts were completed, I formatted them with each line numbered and did manual coding. I read and re-read the transcripts. I initially identified codes in eight of the interviews (seven PLHIV and one service provider), then organized those codes into categories, using both what came out of the data and what was found in the literature review (Gifford, 1998; Green & Thorogood, 2004). Those categories were then used in the identification of data from the remaining interviews. Through constant comparison of categories all items were taken into account (Pope, Ziebland & Mays, 2000). Additional categories were added when needed during the analysis. Relationships were then sought between the themes that emerged from the comparison of data in the different categories (Green & Thorogood, 2004). Table 3 is an example of how the themes were developed. Throughout the analysis reflection led to adjustments. Further literature was sought to assist in the understanding of the data.

Table 3. Thematic analysis example

Themes	Categories	Codes
Stigma:	Lack of information:	Aware of HIV, but ignorant
		Others fear of HIV
	<i>Soutoura:</i>	Spouse's refusal of further disclosure
		Keeping secret
	Abandonment:	Fear of abandonment
		Family problems
Emotional needs:	Relief:	Inability to keep from person
		Shared management of situation
		Loneliness
	Support:	Stress leads to ill health
		Mental health
		Solidarity

3.7. Rigour

In carrying out this study I used techniques to ensure rigour for the reliability and validity of the study (Green & Thorogood, 2004). The specific techniques included recording my theoretical approach, preconceptions and ideas about the questions; stating my own viewpoint, position, relationship to the individuals interviewed and the context. I kept a journal of my own ideas and perceptions, as well as a research record, which serves as an audit trail. These techniques relate to reflexivity in the research which allows readers to know my position as the researcher and they lend credibility as research activities and decisions can be identified. The context is described in full, including the interview situation and the participants so that verisimilitude is created in order for readers to feel almost present in the setting (Creswell & Miller, 2000). This also allows readers to determine the transferability of the findings to other settings.

I personally conducted the interviews in order to verify that procedures were consistent and systematic. At the end of each interview and consistently throughout, I verified with participants if I had understood them correctly. After preliminary analysis of data (done while still collecting data), deviant cases and outliers were identified in order to maximise reliability and allow for comparisons. For example, Khadim was a unique case due to the fact that he had disclosed to no one and showed absolutely no interest in disclosing. He expressed complete satisfaction with his decision to keep his status private apart from Projet SSP and the support group.

Another form of rigour used was triangulation. In order to view the data from different angles, efforts must be made to verify if information received from one source can be confirmed or negated through another source and to eventually identify common themes or categories (Creswell & Miller, 2000). One technique used to check what was learned from PLHIV was the review of records of Projet SSP. In the review of records, there were only a few instances of additional information, which confirmed that the interviews provided rich, complete information. Triangulation was also sought by talking with other sources such as service providers in the continuum of care. In the case of Mariame, in particular, she knew what was in the records and recalled many details pertaining to each PLHIV, not just overarching ideas. Another technique included the discussion of identified themes with my supervisor and reporting the most common themes back to participants for validation, explaining that it was an overall picture and did not necessarily reflect any specific individual (Green & Thorogood, 2004; Kelly, 2006b; Sandelowski, 1986). I was fortunate to have the opportunity to see the support group on the day of my departure. All of the PLHIV who were interviewed were members of that group, although they were not all present that day. The support group had been informed about this study when it was being proposed. In reporting back, I thanked

them for their participation and shared emerging themes. No objections or remarks were made concerning the themes, only appreciation for Projet SSP.

3.8. Limitations

As the sample was taken only from those PLHIV who have contact with Projet SSP as an HIV/AIDS service provider, I did not hear from those who might either be the most hesitant about disclosing their status or those who are able to access all the support they need through other means, thus we might have missed extreme or negative cases. This study can only represent the experiences and views of the Projet SSP client base.

The fact that all of the participants were members of the support group meant that they acknowledged the value of disclosure at a certain level, even if the support group and the project are the only people to whom they have disclosed. It seems that having limited the participants to support group members might have excluded PLHIV from certain demographic groups and thus there is a strong bias toward those who are both receiving support from Projet SSP and members of the support group. This study did not include any participants identifying themselves as single, having never been married, nor was anyone very young and therefore this can be regarded as limitation. This group might also be slightly more in need of support for care and thus showed willingness to approach Projet SSP.

Due to the fact that participants reported decisions that they had made in the past, some of their reasons could very well have been influenced by the actual results of their disclosure or non-disclosure, or by the effect of knowing other's experiences through the support group or even the suggested reasons by service providers. Considering that none of the participants had fully disclosed publicly, they most likely were continuing to weigh up the costs and benefits of further disclosure, thus the factors they shared were still pertinent.

The study did not specifically attempt to collect data about casual sexual partners, only regular sexual partners, specifically spouses. However, questions were open-ended and that information would have been included if shared. It would be valuable to know more about disclosure to casual sexual partners due to the aspect of prevention of sexual transmission, as well as the importance of testing and access to care of those who have been at risk. I mentioned this when I reported back to the support group after the completion of all of the interviews and people were coy about it, but did not offer any thoughts due to the sensitivity of the question and the communal setting of the support group. Very little was shared about former

sexual partners, although participants were asked whether they had disclosed to former spouses, if they were still alive at the time of their diagnosis.

The need to use four different languages was a challenge and may have compromised some of the data. However, having Mariame present at the interviews and serving as a translator minimised this due to her fluency in all of the languages. The use of multiple languages also meant that questions were posed repeatedly in different ways in order to get the best sense of what the participant was saying.

In interviewing Mariame, I regretted not having started with her. Due to her being present in all the prior interviews it felt like she was reflecting on the experiences of those we had heard most recently and not her longer term experience with PLHIV which would have added to the richness of the data.

Finally, Mariame and I both have worked closely with the participants who were interviewed. They knew us and we knew them quite well. The roles we played certainly affected our relationships with the participants and how we engage with others. In the case of Mariame, besides being the Projet SSP coordinator, she is a Fulani woman and a noble in the caste system. Though this is disregarded for some activities, particularly professional work, it is still a part of the culture and may affect how people relate to her, even if it is not at all obvious and would only be known by insiders. This aspect might influence both the motivation of some PLHIV to participate in the study, as well as their responses. Mariame also provides them support, so there might be a sense of deference to her.

As for me, as the former coordinator and the one who represents the funder of Projet SSP, there might be some of that same deference. However, due to the approach of openness and acceptance and compassion used by Projet SSP and the genuine relationships that exist, I feel confident that the information shared with us was truthful and that the data was not compromised. Some information was very intimate adding to the richness of the data and I could not have expected to learn such information from people I did not know personally. In some instances it was surprising to hear someone say something that we thought they might not say since they knew it would not please us. And in other cases they might have said something that they knew would satisfy us, but because we knew them so well that risk was less because we would question them on it. One illustration of the close relationships between Mariame, myself and the participants is where Ramata told us that she

“would have come to interview naked if we'd asked her”. Some of the relationships dated back to more than twenty years for Mariame and fifteen for me. Although the closeness of relationship that Mariame and I had with the participants could have led to bias, I believe that it rather has led to a deep sense of trust which in turn resulted in open sharing. As stated by one participant, if we were going to break *soutoura* we would have done it long before and therefore I am confident that the information provided is truthful.

Another limitation is that due to financial and time constraints saturation was not reached as is expected in qualitative research. However, I feel that the data collected provided sufficient information for me to gain a full picture of the participants' experiences.

3.9. Ethical considerations

This study was undertaken after a determination that no harm would come to any group as a result. All participants were informed about the purpose of the study via a participant information sheet they could read or which was explained to them in their chosen language. Their informed consent was noted by me after their verbal consent (as most were illiterate) or signatures received on the consent sheet prior to interviews and audio recording. Confidentiality was assured and participation was voluntary, with the participants being told that they could withdraw at any point. Participants were asked to provide pseudonyms in order to guarantee anonymity and protect their privacy. Any documents with identifying characteristics will be destroyed and data, both written and audio, will only be accessed by myself and stored in a locked place, using passwords for electronic materials. At the completion of the transcriptions the transcriber was requested to destroy the copies of the audio files he had, both on hard drives and the backups on CDs, as well as any documents. He confirmed that this was done. I will keep my copies until the thesis has been examined.

Only one PLHIV chose to keep a copy of the Participant Information letter (Appendix 3). I did not encourage giving them to others as it might inadvertently disclose their status. Almost all of the PLHIV interviewed were illiterate. Typically when someone has a formal document, they keep it folded up in a suitcase or in a piece of furniture. They might not be able to distinguish which paper is which, so if they need one, they have to present them all to someone who is literate to find the correct document. In this case, if the information letter were with other documents that the PLHIV was responsible for, presenting it to someone might inadvertently have disclosed their HIV-positive status to that person.

Participants were given a small sum of money to cover their transportation costs and as a gesture of thanks. Those who were present at a meal time ate with us. (Meals in Senegal are very communal around one huge platter of rice and sauce, generally.) Those who arrived early after travelling during breakfast time were given breakfast prior to our interview.

In a couple of instances there was an issue raised in the interview that we (researcher and Mariame) identified as needing follow-up. An example was a man who had disclosed to his wife some years earlier, but she had still not come for testing. He shared that she had not been well for some time and so it was determined that Mariame would find a way to reach her to ask that she come to Linguère for follow up. Mariame took note of these cases and Projet SSP would follow up.

This study was undertaken only after receiving approval from the Research and Ethics Committees of the University of Western Cape and the Linguère District Medical authorities. Upon completion and examination of this thesis, feedback will be provided to all of the participants in the study by presenting the results and recommendations to the support group, as well as to the key informants.



CHAPTER 4: FINDINGS

This chapter presents the findings from in-depth interviews with PLHIV and key informant interviews with service providers which were carried out for this study. The main themes that emerged as reasons for disclosure or for non-disclosure were maintaining psychosocial well-being, trusting relationships, need for support with health care, reciprocal obligations and concern for others, stigma and discrimination and negative impact on family.

When using the term participants in this thesis, I am referring to the PLHIV that were interviewed for this study. It does not include the key informants whom I refer to by their professional roles performed, e.g. doctor or social worker.

4.1. Sociodemographic characteristics of participants

All the participants who were interviewed lived in Linguère District, with some living in the surrounding rural communities and others in town. All the participants received services from Projet SSP which meant that they had at least accepted to disclose their status to the service providers after referral by a health care provider. They had also all joined the support group which was established with the assistance of Projet SSP although this was not a requirement. It was just coincidental that all of the participants in the interviews were support group members. All of the participants were diagnosed at a late stage which meant that they had started ART shortly after diagnosis. None had refused ART. One woman had known her status for over fifteen years, most for around five to ten years and a few more recently. The participants consisted of eight women and seven men, ranging in age from 33 to 66 years old (see Table 4). All were or had been married, with most of them having been in polygamous relationships at some point. At the time of interview, four women were in polygamous relationships. Only two of the men and one woman stated being in their first marriage and the cases of multiple divorces or widowhood were common.

Many participants lived with extended families, with the spouse's family often being part of the household or living close by. Most of the participants were farmers, cattle herders (not necessarily owners), market salespeople (vegetables and foodstuff), or had low paying employment such as a guard or houseworker. The participants' education levels ranged from none at all for three of them to a few years at university for one man. One man and one woman were literate in Pulaar and several participants had received some Quranic education which concentrated on the Islamic

teachings and principles only and not the formal education. Generally the education level was low and reflected the norm in rural Senegal.

Table 4. Sociodemographic characteristics of participants

Pseudo-nyms	Gender	Age	Marital Status	Presently polygamous ?	Age at First Marriage	Educational Level	Disclosed to (apart from Projet SSP)
Boury	F	42	M (2nd)	No	19	Secondary (4 of 7 years)	Spouse
Haby	F	35	M (2nd)	No	15	None	Spouse Spouse (W)
Ramata	F	38	M (4th, 2D, 1W)	Yes, 2 co-wives	9	Quranic	Parents Siblings
Penda	F	44	M (4th)	Yes	13	Pulaar	None
Fatou	F	45	Remarried (2 nd) Widowed	Yes, 1 co-wife	8	None	Friend Brother Sister (F)
Djibo	M	33	M	No	15	None	Spouse Cousin Aunt/Uncle (F)
Ndiaye	M	47	M	No	25	Arabic	Spouse
Salif	M	59	M (2 nd time)	No	32	University (3 years)	Spouse
Khadim	M	66	M (3: 2 at once, now 1)	No	26	Quranic	None
Demba	M	50	M (3, 1D, 1W)	No	19	None	Spouse
Binta	F	45	D (3 times)	-	18	None	Daughter
Aida	F	37	W	No	20	None	Mother Friend (TBA)
Aissata	F	35	M (poly)	Yes, 1 co-wife	20	Primary	Brother (F)
Abdou	M	57	D (2 times)	No	25	None	None
Sow	M	41	D (W first)	No	25	Pulaar, Quranic	None

M: Married; D: Divorced; W: Widowed; TBA: Traditional Birth Attendant; F: from project files, not from interview

The key informants were two women, a health centre midwife and the Projet SSP coordinator, and two men, the district social worker and the district medical director who was a medical doctor involved in the care of PLHIV. All of them, except the midwife, knew all of the PLHIV who were interviewed.

4.2. Disclosure practise

Disclosure was practised in different ways, whether self-disclosure, mediated disclosure or disclosure without consent. There were no cases of public disclosure. Table 5 gives an idea of the frequency of each type and each participant might have used different types with different individuals. The table only includes full disclosure, not partial disclosure.

Each participant also had a different pattern of disclosure. Some of the fifteen had disclosed to several people, while one woman and three men had disclosed to no one except the service providers and support group (see Table 4.). Three women and three men had only disclosed to their spouse and no one else, although for one woman it was to a previous spouse who had died and not her present spouse. One additional man had been disclosed to by his spouse and had chosen to disclose to her in turn, as well as to a relative, and four women had disclosed to a family member or friend or combination thereof. Only two of those included disclosure to a friend, both women to female friends. It is interesting that so few had chosen to disclose their status to a family member considering the geographic and emotional proximity of family.

Table 5. Type of disclosure

Type of disclosure	Male	Female
Self-disclosure	6	3
Mediated disclosure	3	1
Without consent/involuntary	1	1
None (apart from the Projet SSP)	1	3

Note: The totals add to more than the 15 participant PLHIV due to multiple responses.

4.3. Reasons for disclosure

Many factors influenced the participants' decision to disclose their HIV-positive status to others. Some of the reasons given by participants related to a benefit that the individual hoped to gain or

negative consequences he or she sought to avoid. Among the motivators for disclosure were also reasons that focused on someone else. These were factors where protection or well-being was sought for someone other than the PLHIV. These factors related to safeguarding or improving relationships between the PLHIV and other individuals, groups or the community.

4.3.1. Maintaining psychosocial well-being

A few participants shared that they had been motivated to disclose to either a spouse or family member or friend because they felt a need for emotional support. In one case, the widowed Aida who had disclosed to her mother depended completely on her mother who in turn needed support to help her with Aida. The person that supported them both was Aida's aunt who was not only the village birth attendant, but a friend. Aida trusted her to assist with access to care and thus she disclosed to her voluntarily, albeit out of necessity. She acknowledged that it was because of the support and encouragement of these two women that she had the courage to be amongst people again which she would not have been able to do had she not disclosed to them. Djibo spoke about how after he and his wife had both learnt that they were HIV positive, they were counselled by the wife's uncle who had served as an interpreter during their testing as the health workers did not speak Pulaar. The uncle reassured and told them to accept the results, that the infection could be managed and that they could get care. Even though this was involuntary disclosure, the support from the uncle was still beneficial to them. In addition, the couple also supported each other. Djibo went on to say how through it all, including losing one child to HIV-related illnesses and having another HIV-negative child, the mutual support between him and his wife as a result of knowing each other's status was very important to him.

Several participants described their decision to disclose as being motivated by their desire for relief. They perceived that disclosing their status to someone else would ease the burden they carried because the stress that they had felt from non-disclosure could be harmful. In addition, some participants acknowledged that part of their sense of relief came from the desire to feel less lonely and thus in some cases resulted in disclosure to a spouse. One participant who mentioned this factor was Binta, a rather sombre woman who was three times divorced and who made a meagre living working as a laundress from her home. Several years after knowing her status she decided to disclose to her teenage daughter whom she considered her closest friend. She said that this step to disclose to someone whom she trusted helped her to lessen her feelings of loneliness. She went so far as to say she thought disclosure meant that there would not be the feeling of isolation which was

important for longevity.

“You can have sorrow in your heart and the [negative] thoughts which could shorten your life. So, removing those things which weigh down your spirit can help to lengthen your life. The consequences of not disclosing can reinforce the solitude, sorrow. That can stress you to the point of falling ill...[it can] shorten your life span.” [Binta]

Some women also stated that the reason for disclosure to someone close was to help them deal with the sadness they experienced living with HIV.

Five of the women interviewed acknowledged another factor that was important to them in determining to disclose: the desire to live positively. For some this might be a reason in retrospect, however for others they had felt that need even prior to disclosure. In fact, four of the five had disclosed and were pleased to have done so, whereas the last one desired to, but did not trust anyone close to her. The term *living positively* itself was one used by Projet SSP and also in the support group and these women had appropriated it. These five participants described it as making it possible to live more openly, to go to someone to share their concerns, to be able to make decisions to live better and more safely, such as using condoms with their HIV-negative husbands to protect them from infection.

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Mariame, as the Projet SSP coordinator, described the case of one woman who was not a participant in this study, but was a member of the support group. She said that as a result of the woman disclosing voluntarily to her new husband, in fact prior to their marriage, he gave her more freedom to live positively than many women might otherwise have been able to have in that context.

“Her husband allows her to go to seminars, to [PLHIV] community meals, to go to the support group and if she had not disclosed, he would say “No! You travel too much! You can't do that!””

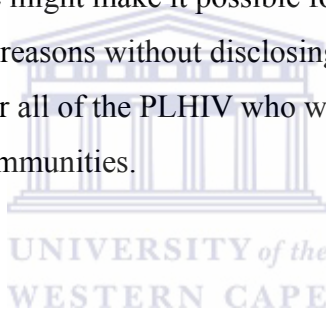
In the case of this woman, Mariame believed she would not have married this man had he not shown her that he intended to make it possible for her to live positively.

Three participants stated quite strongly that it was not possible to keep their status a secret and thus disclosed to someone close to them. All three shared the experience of being married to someone who was either living with HIV or not in good physical health, although not diagnosed as living

with HIV. Although they all had limited the disclosure to just one or two people, they felt that it was essential to disclose, as the response of one woman shows:

“Because it is an illness that can't be treated [cured]...and I know it is a long illness...I can't live without explaining it to him.” [Boury]

Similarly, one married man, Salif, said that if he had not disclosed to his wife and she had learnt about it by some other means, then what might have happened to him? He had not disclosed immediately, so it seems that it took him some time to come to that decision. Although Salif, who had more formal education than the other participants, had only disclosed to his wife, he went on to say that those who were not married should tell their family, such as mother or father, even if the reaction was one of “disgust”. He said he would have disclosed to his mother, but she was no longer alive. Salif’s opinion was that in order to participate in the support group and access care and treatment the PLHIV would have to travel and the multiple trips could be suspicious. Disclosure might make it possible for the person to whom disclosure happened to assist in giving credible reasons without disclosing further. This need to travel or be absent from home was a reality for all of the PLHIV who would also be asked questions by those close to them in these small communities.



4.3.2. Trusting relationships

An overarching concern for all participants was that of trust. In the cases where participants had chosen to self-disclose it was often because they had at least one trusting relationship. The benefit for some in having this trusting relationship was the belief that the other person would not disclose the participant's status to others without his/her permission.

In the case of Aissata, who carried both the knowledge of her HIV-positive status as well as that of her young son, she at first said that she had not disclosed to anyone. Project records showed that she had disclosed to a brother who worked in the health department in another city, but this was noted after the interview. We also had to explain the concept of disclosure to her in more detail than with the others which might explain the lack of clarity in her initial response to the question about the people to whom she had disclosed. In the interview, Aissata subsequently shared with us that she thought she could disclose to her brother whom she trusted now because he had not yet said anything to her mother about her illness meaning that he would keep it confidential. So either she had practised partial or involuntary disclosure with him when she was seeking care with his support.

Other examples of trust showed the particularity of each participant and varying opinions about the strength of different kinds of relationships. In some instances, trust in a spouse was regarded as an important factor to consider for disclosure. Abdou, who was twice divorced and had not disclosed to anyone, was of the opinion that if someone had a good, trustworthy wife, that person could disclose to her. Another man, Ndiaye, who disclosed to his spouse because of his trust in her said that her trust was confirmed when she expressed her appreciation for his disclosure to her. Similarly, some women said the same of their husbands as illustrated with this quote:

“Talking with one's husband is more important and there is more confidentiality. You live together. He will be obliged to keep “soutoura” [secret]. Some family would make your secret public.... From the side of the husband, if he is infected, he should disclose to his wife and from the other side, vice versa. I am for disclosure. Disclosure is best. One has seen people who have suffered because of non-disclosure, many have suffered.” [Haby]

When asked whether that was physical or emotional suffering, the response was both. As is expected in qualitative research, not all participants had the same opinions. For some participants, the spouse was not the trusted one, but rather a friend or a family member.

“A friend can keep the secret, whereas the husband, he can have another reaction, [going] as far as divorce.” [Fatou]

Another married man, Djibo, who had disclosed to his wife did not feel the same level of trust toward his family. However, when a cousin was seriously ill, he suspected it was HIV and disclosed to the cousin in solidarity and to give the cousin hope. However, as only two women reported disclosing to a friend, it is clear that participants were more likely to trust a family member or spouse than a friend which was the opinion of the doctor too.

In all cases, the aspect of trust in the other person was seen to be highly important when a participant was determining if disclosure would be of benefit to him/herself.

4.3.3. Need for support with health care

Among those who shared factors for deciding to disclose to family, friends or spouses, many agreed that needing health care support was one of the reasons that they thought was important and therefore disclosed. This meant recognising the need for having someone at their bedside when

they were hospitalised or even at home, as well as paying for care that might not be available through the government programme or Projet SSP.

“I could arrive at a point where I couldn't even stretch out my hand to get my medicines, even if it is close to me. So it is in trust that I spoke. And she knows how I must take them.” [Binta]

Ramata had been diagnosed at a very advanced stage of HIV and when she was discharged she brought her whole family together to disclose her status. Part of her motivation was knowing she would need care and wanted the family to be prepared for that. Similarly, Demba planned to disclose to a brother because he expected the need for family support if he became ill.

Aida's concern about having support when she was ill was unique due to the fact that at the time of her acceptance of her diagnosis and need for care she had become almost blind.

“If I had hidden [my status], I would already be dead, because I couldn't do anything.”

Again, despite many participants affirming that disclosure was done to gain more support for health care, only six had disclosed to someone in their families, with five of the eight women having done so. Several women shared that by disclosing their status to a family member or spouse they had also improved their treatment adherence. According to Mariame, the person to whom they had disclosed would remind them to take their medicines and also sometimes check with the project to make sure the PLHIV was coming for adherence visits. This did not seem like a major motivating factor, but had likely been one aspect in the decision, as it was suggested as a benefit by service providers in particular. For example Binta, who disclosed to her daughter, described how the daughter checked up on her:

“Ever since she learned about the medicines, even if she has been gone, if she hears I am not doing well she will take me aside to tell me not to neglect my medicines and ask me if I am following the recommended dosage. “Do not miss because your life and your health depend on it.””

Similarly, Fatou had only partially disclosed to her husband, telling him she was sick and therefore needed to have protected sex and needed to take medication. She said she knew she would have to

tell him at some point, but for now he regularly reminded her to take her medicine. In another case, Ramata, the only participant to have disclosed to her mother and father, shared that her father's commitment to her was seen in his reluctance in having her marry someone who would take her away. He felt that she would then run the risk of not taking her ARVs because she would not have her parents close by to check on her and support her. In all of these cases the participants understood that their disclosing was assisting them in adhering to treatment.

Several other participants acknowledged that in their case it was due to the services provided by Projet SSP that they were still alive. This illustrates another source of support for health care which was made available to them by disclosing to the project.

4.3.4. Reciprocal obligations and concern for others

As in the cases where participants cited trust as a reason that they felt prepared to disclose for their own benefit, there were also many participants who felt that they had a responsibility to disclose to friends or family or spouses, in the other person's interest. In these cases, obligation towards others was a key factor because the participant showed concern for the effect of his/her situation on the other person.

For Aida, who was a widow, seeing her mother suffer and tire while caring for her when she was ill made her realise she should fully disclose to her. She therefore felt a sense of responsibility, though she had other self-focused reasons for disclosing as well. Another married man, Salif, recalled clearly stating to the doctor his decision to self-disclose to his wife out of a sense of obligation to her. Many participants, both men and women, shared that the importance of having spouses tested and accessing treatment, if necessary, and the need for practising protected sex were important reasons to disclose to their spouses. However, it is interesting to note that only six out of the eleven who claimed to be married had actually fully disclosed to their current spouses. An additional woman, Fatou, had partially disclosed to her spouse and she intended on fully disclosing to him at some point.

The common practice of polygamy meant that in some cases there was concern about the status of and prevention of transmission to a spouse, as well as any co-wives. The doctor gave an example where a husband who found that his second wife was HIV-positive, but that his first wife was HIV-negative, asked the first wife if she wanted a divorce so she could be safe. She refused, saying that since she was still of childbearing age someone would likely want to marry her and if she did not

know that man's status she would be at even greater risk of HIV infection.

In another case of disclosure to a spouse, one older man, Demba, said he did not want to see his wife suffer and he regretted having delayed in telling her as he saw that she might have benefited from knowing her status and could have started on ART sooner. Salif, who had disclosed soon after learning his status, was more forceful in his opinion, saying that in his opinion no one should hide their status from a spouse because spreading it to others would be a sin before God. Some other participants acknowledged the need for disclosure to a spouse, but it was not very emphatic, possibly due to the fact that not all the participants had been quick to disclose to their spouses.

In one instance, a woman whose husband was HIV negative said that had she not disclosed to him there might have been negative circumstances for the family, although she might not have thought that prior to her disclosure to him.

“...that could have been worse, that the husband would have been ill like me, that could be something very dangerous, for the whole family, had we not talked.”

[Haby]

The social worker presented a case of a woman who had been diagnosed with HIV and who had informed her husband in order for him to be tested. The woman assumed that her husband was also living with HIV and she wanted to avoid re-infection. However he tested HIV-negative and as a result they were able to practise protected sex in order to avoid transmission.

In the case of a couple where they were both infected, they decided together that they would not have sexual relations with anyone else in order to avoid further transmission. Djibo acknowledged that they did not always practise protected sex as they wanted a child. They had had a child just after their diagnoses who unfortunately did not survive due to HIV-related illnesses and that caused them pain. The woman subsequently gave birth to a baby who was HIV-negative, this time giving them great joy. Djibo spoke with understanding from his personal experience about what it meant to gain access to care which fortunately enabled the couple to have a healthy child and he stated that he thought that was also a reason why other PLHIV disclosed their status to spouses.

Ramata shared how she was not prepared to self-disclose to her husband, but rather she discussed with the social worker about him proposing testing to her husband without disclosing

her status, which was mediated partial disclosure. Unfortunately the husband refused, although he said he would go and get tested on his own. She had hoped that by this mediated partial disclosure to the present husband, had he learnt that he was HIV-positive, they could have managed their situation together. Ramata had been married three times prior and the husband to whom she was married at the time when she learnt of her status was tested HIV-positive, but refused care. She ended up asking for a divorce due to his refusal to accept his status and consequently get treatment. This was the only clear example of negative consequences to disclosure heard from the participants.

The social worker spoke about another woman who was living with HIV and whose family was encouraging her to remarry after being widowed, seeing that she had two children to raise and needed support. The situation was putting pressure on her to disclose when she was otherwise not prepared to do so, in order to have her family understand her refusal to remarry. The woman also referred to possible legal repercussions and was aware of the risk of marrying without disclosing.

Only one woman spoke about the importance of prevention of transmission within a family setting. Ramata had disclosed to her parents and siblings due to the fact that they lived together and she was concerned they might be exposed if she had an accident or cut. She specifically described how if she were to have a child, her mother would be washing her soiled linens. It is not unusual for women to continue to live with or to spend substantial time living within their family compound rather than moving to join a husband, as was the case for Ramata, and therefore disclosure to family was important to her.

Another factor identified in this study was wanting to prepare for the future: for oneself, one's spouse, one's children and one's family. Again in the case of Ramata, who had disclosed to her immediate family, one of the reasons for disclosure included her hope that her siblings might learn from her experience.

“So it is better to disclose, that way you will put them on their guard if you have HIV. Avoid behaviours that can give them HIV.”

Another participant who was a divorced woman had confided only in one of her daughters and said she told her:

“In order that nothing surprises you, I want you to watch yourself. You should 'tie your loincloth tightly' [refuse sexual relations] so that what happened to me doesn't fall on you, which would destroy your youth and your life.” [Binta]

These two women were the only ones who spoke of using disclosure as an opportunity to advise others to take precautions for prevention.

Ramata also hoped to have children at some point and therefore she felt it was important that those who might eventually care for her children, in the case of her death, be aware that the children might be HIV positive. She visualised a scenario where her sisters did not know her or her children's status.

“They could treat the child poorly or if the child was sick they would not know what he was suffering from....avoid taking the future children to the marabout [traditional healer] while knowing that it is HIV.”

Another married woman, Haby, who had not disclosed to anyone apart from her husband, thought it might be good for others to inform their mothers in case after their death the mothers might be caring for children who also have HIV. However she and her husband who was HIV-negative had decided she would not disclose to anyone else.

In another case, Aissata, who had not disclosed to her spouse nor parents, spoke of wanting to prepare for her children's future were she not there and therefore considered fully disclosing to her brother. As she had a child who was also living with HIV, she was considering accepting the offer of her brother (to whom she had only partially disclosed her status, but not that of the child) to raise the child which is a common practice. She was, however, adamant that her children not learn of her infection because she wanted to protect her reputation with them even after she died.

Only one man spoke about preparing for the future. He intended to disclose to his brother because he hoped to remarry another woman living with HIV. He was concerned that were he to die first, his family would practise widow inheritance.

“And my brothers will want to do it, if I don't tell them, that would continue the chain...” [Sow].

4.3.5. Additional reasons for disclosure

Two married women remembered how they were encouraged to disclose by the service providers who did post-test counselling with them. They shared that they did not feel pressured, but rather that the arguments given by the service providers convinced them that it was best to disclose to their spouses and they did so immediately. One man, Demba, also recalled being encouraged by service providers to disclose to his spouse, but he delayed for at least a year while she was ill. Finally her illness and the continued encouragement from service providers convinced him to disclose to her.

The doctor felt that more needed to be done in this area, suggesting that health care providers should play an even greater role. His argument was that if people received better pre- and post-test counselling then more people would be willing to disclose, despite the cultural and social barriers.

“Seeing all the other aspects, all the commentary around this illness, they are people who will hide their serological status to the end of their lives.”

He regarded the role that the support group played as positive development, because in that setting the spirit of hiding one's status could be banished. As he visualised fellow members seeing one another on the street and making nothing of it, he hoped that that attitude would lead to better health and confidence in living more openly, including greater self-disclosure. Boury also noted that involvement in the support group was an encouragement to disclose as people shared their own positive and practical experiences.

The social worker also noted that the sharing of experiences encouraged others to disclose. He gave the example of serodiscordant couples or couples where both were living with HIV who obviously had disclosed their status to each other and where the marriage was still strong. He felt this was a model to other PLHIV who were maybe reluctant about disclosing.

4.4. Reasons for non-disclosure

There were also factors associated with non-disclosure which are presented in this section, including stigma and discrimination and negative impact on family. Despite the diverse reasons motivating for disclosure, many participants still gave reasons for not disclosing, either to no one at all (apart from the project) or to particular individuals.

4.4.1. Stigma and discrimination

Every participant spoke about stigma and discrimination in some form or another impacting on their decision to disclose. For example, a male participant had the following to say:

“[To]avoid stigmatisation...It's not like other illnesses, it's an illness that everyone says is a bad illness. That's what causes people to fear disclosing. The fact that it's a bad illness, a serious illness.” [Demba]

Many of the participants repeatedly emphasised their desire to keep their status secret. They felt that they risked involuntary disclosure by the one who was confided in, which could lead to the stigmatisation of participants and their families. In some cases the stigma and discrimination was with regard to family members, in others friends and in others spouses. Some expected it from all the people they knew. Here I describe some of the specific reasons that were cited. It is interesting that some felt so strongly about this and therefore did not disclose and others, whilst acknowledging the problem of stigma and discrimination, had at least found someone they felt they could trust to disclose to.

Although only explicitly mentioned by two married men, the multiple references to stigma and to the publicly expressed attitude of people about HIV showed this as an important factor.

“With people I hear it a lot. When they suspect that someone is ill, “Stay away from him. He's got it. He's got it.” It never ends.” [Salif]

One man mentioned that the general awareness of HIV had created the negative environment.

“It's spoken about on the radio, on the TV. Everywhere if you disclose, there's a fear of being stigmatised or discriminated against.” [Ndiaye]

So rather than information creating a less stigmatising environment, the impression was that the greater awareness meant that there would be more stigma and discrimination, resulting in greater negative consequences for disclosure.

The social worker was of the opinion that the reluctance of the PLHIV to disclose was also in part due to the lack of positive messages coming from religious leaders. He thought that if they had provided more psychosocial support there would have been a less stigmatising environment

in the community and thus more willingness to accept PLHIV.

Another factor raised by the midwife was of situations where she knew PLHIV were concerned that health care workers would not respect confidentiality. For instance if she was not present, the PLHIV would leave and return another day rather than present themselves to another health care worker for fear of needing to disclose their HIV status.

In a context of such serious concern about stigma, it is not surprising that a lack of trust in an individual to whom disclosure might be considered was a determinant.

“The thing that keeps me from disclosing my [status], I know there are some who hold their tongues and some who do not.” [Haby]

The Wolof word *soutoura* was used by both Wolof and Fulani participants to describe the value of keeping something confidential. In some cases the women did not think their spouses would keep *soutoura*, and in other cases men did not think their wives would. Ramata, for example, said that because her present husband was not related to her, she did not trust that he would keep her status a secret. Another woman did not seem prepared to disclose to her spouse for fear of his divulging her status. On the other hand, Abdou’s opinion was that a wife who was also living with HIV would keep it confidential, but if she was HIV-negative and there were marital problems she might disclose her husband’s status to others.

Some participants said they trusted their spouses to keep *soutoura*, but they did not trust others. It is interesting that the differences in who could be trusted also informed the decisions of those who chose to disclose. Aissata had at least partially disclosed to her brother, but she was concerned that he might tell his wife who might not keep it a secret. Binta, who had told her youngest daughter, had decided not to tell her parents, sisters or her other adult children because she did not trust them. Mariame recalled some of Binta's family members showing stigmatising behaviour which could be based on suspicions they had about her status. Similarly, the doctor also acknowledged the concern that PLHIV had of disclosing to someone because they could not guarantee that that person would keep it secret.

Mariame, who is Fulani, said that the Fulani had more *soutoura* than the Wolof and thus the Wolof were more reluctant to disclose to their families because of this general reputation. This, however, contradicted the opinion of some Fulani who claimed that they were known for not keeping

soutoura. A married Fulani woman, Penda, whose husband lived in a distant town, stated her reasons for not disclosing to anyone:

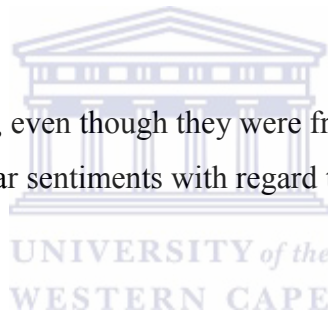
“Firstly, I'm not very loved. Secondly, the Fulani don't have secrets. Thirdly, I could have a fight with someone and that person could remind me of my status.”

Penda was still living in her parents' compound despite being married. She was quite dependent on her siblings' financial support and yet tried to find ways to support herself. Her reluctance to tell anyone was due to her fear of being rejected. Her self-protective attitude made her quite miserable and in turn kept her from realising that she might benefit from disclosure.

One divorced Wolof man, Abdou, who had disclosed to no one, stated:

“The Wolof have the art of divulging other people's secrets...I am afraid that if I have a quarrel with my sisters, my sisters could take advantage of me and remind me of my status.”

These two people, Penda and Abdou, even though they were from different ethnic groups and of different genders, expressed similar sentiments with regard to reluctance to disclose to family.



In addition, the participants expressed uncertainties about disclosure for fear of other negative reactions because of stigma and discrimination. These reactions could be considered quite serious, as they included rejection, abandonment, divorce, accusations, slander and threat of public disclosure.

In the case of rejection or abandonment, this could be by friends, family or spouses. Ndiaye, who had disclosed to his spouse, said that he had hidden his status from his friends because he was afraid that they would reject him and not want to spend time with him nor share a meal with him. Similarly, Khadim had disclosed to no one except the project, the support group and to God. He explained:

“If you disclose, all those close to you, your wife, your children, all of them will leave you.”

Khadim also claimed that in the support group he had heard the others talk about their shared

fear of divorce due to stigma and discrimination. He claimed that he was satisfied with his decision not to disclose, unlike the other two participants who had up to this point disclosed to no one, and thus he was unique among the participants.

“As a believer, I know that in the Quran God doesn't want people to divulge things. And I think that since I've kept my status a secret, that I've only told you [Mariame], I've only had good experiences... If I'd disclosed my status, I was afraid of being abandoned. And even though I've kept my status secret it hasn't kept me from living positively. I read my Qurans and do what I want.”

It can be understood from this that he was unlikely to decide to disclose to anyone while in his present state of mind.

The participants who had chosen non-disclosure to their spouses expressed fear of accusations and divorce. The doctor gave his opinion of the situation:

“So people often think that HIV is the result of a behaviour which is not appropriate. So for some men the fact of disclosing their status is going to expose them, that in fact they are the kind of people who are dishonest with their wives in a way, so that is why they can't disclose.”

Although not necessarily surprising the participants did not raise the sensitive issue of dishonesty or infidelity except for the most recently diagnosed woman whose child is also living with HIV. The midwife gave an example of a woman who feared the accusation of infidelity not only from her husband, but also from co-wives and therefore she had not disclosed. In another case reported by the midwife, a woman, also fearing accusations, did not disclose. However, because that woman's co-wife was pregnant, the midwife attempted to have the co-wife tested through the PMTCT programme, but she still refused. This approach could be considered mediated partial disclosure considering that the woman living with HIV had sought the midwife's assistance for the well-being of her co-wife. Two married women, Fatou and Aissata, who had disclosed to family and friends argued that they had not disclosed to their husbands because they feared divorce and then public disclosure. Fatou had considered disclosing to her husband, but generally she felt that she could trust her friends more because they could not really be divorced. Aissata, whose child was also living with HIV, had not disclosed to anyone besides her brother. She was considering the situation of her child and did

not want to be rejected with her child.

An additional factor here was that when a spouse was informed, some of the participants reported that the spouse often did not want the information to be disclosed further. For one woman whose husband was HIV-negative, she agreed with that decision. In the case of Ndiaye, whose wife was later found to be living with HIV as well, she had agreed that they would not disclose to others. In their case, the family not knowing their status had created a different dynamic. When the wife was ill for a long time, the family admired the husband for not abandoning her and others were helpful. Ndiaye believed that if they knew what the real cause of her illness was they would not have shown support, but rather would have abandoned them.

On the other hand, the doctor gave the example that families did not reject members of their own families with extreme mental illnesses, that they continued to care for them, even if they had been rejected by society. It is common in Senegal for families to care for their mentally ill and he used this to illustrate that it was therefore unlikely for a family to reject a PLHIV. He did, however, suggest that it was only close family, maybe of the same father or one degree of distance in relationship, to whom the PLHIV should disclose. In a way he was qualifying his argument about possible rejection.

The fear of stigma which can lead to possible rejection by a spouse or family in particular could mean the PLHIV ran the risk of not obtaining support when needed. For Aissata, this meant for herself, but it was linked to her need for assistance for her child. Although other women did not specifically cite the fear of not receiving economic support, it was evident that for them, as well as some men in that setting, financial support from others helped them survive. Thus rejection would be difficult from a financial standpoint too. Djibo was the only participant to express the fear of losing work as a result of public disclosure. He depended on people hiring him for labour and believed he ran the risk of not being asked to work if people learnt of his status.

It is obvious from the above findings that issues related to stigma and discrimination are multiple and complex, but are obviously the most common factors influencing decisions regarding disclosure as they were mentioned by all of the participants in some form or another.

4.4.2. Negative impact on family

Besides issues of stigma and discrimination, some, but not all, participants also stated that they had

concerns about causing pain or unease to family members to whom they might disclose. Due to the strong interdependence of individuals in families, the protection of the family was very important to the participants. Therefore another sensitivity participants had about their families which affected their decision not to disclose was how the stigma or discrimination that they might experience if their status became more public would affect the whole family. Ramata, who had disclosed to her whole family, said she took into consideration her family's reputation when she decided not to disclose to her current spouse. She feared that he would divorce her and make her status known publicly, which would have repercussions for her whole family. She claimed that for her earlier marriages there was no need to disclose, as one marriage was not consummated (she was between eight and fourteen years at the time) and the husband in the other marriage was not ill at all and he otherwise should have been if he was living with HIV, in her opinion.

A married man, Demba, who had disclosed to his spouse wanted to also disclose to his brother who was closest to him, but he was concerned that it would make his brother too sad. He therefore delayed, but felt that he would need to disclose to that brother whom he trusted at some point despite the pain it might cause the brother. The social worker also said he knew there were cases where PLHIV were concerned about hurting their families and they often felt guilty about their situation and the hardship it would create.

In two cases married women had sons who were very close to them, but to whom they had not disclosed. In the case of Boury, she insisted that her teenage son was too sensitive, that already when he was at her bedside when she was ill he became too upset. The other woman, Fatou, thought that with time she would tell her son, but he needed to be a bit older first. None of the others mentioned disclosure to their children and all but one had children.

This chapter presented the findings of the study with the use of quotations from the participants and key informants to illustrate some key issues. Participants have limited their disclosure to a small number of people for multiple reasons. Some of these reasons focused on the benefits to the PLHIV, such as emotional support or assistance with health-related issues, but also on the perceived negative consequences, such as stigma or negative impact on the family. These reasons are not unique to PLHIV who share the same characteristics, but are different for each individual. In the following chapter the findings will be discussed in relation to findings from the literature and my experiences working with these PLHIV.

CHAPTER 5: DISCUSSION

This study was the first to explore and describe factors influencing decisions around disclosure of one's HIV status in a rural context in Senegal and thus adds to the knowledge base concerning disclosure. This chapter discusses the findings by drawing on the literature and using the theoretical frameworks of disease progression and self-disclosure consequence theory.

5.1. Self-focused motivators and barriers to disclosure

Most of the recent studies about disclosure confirm that the consequence theory most accurately describes the motivators of PLHIV's decisions around disclosure (Emlet, 2008; Almeleh, 2006; Serovich *et al.*, 2008). It was found that PLHIV evaluate the consequences of disclosure and determine whether there is greater benefit or cost related to disclosing to particular individuals or groups (Emlet, 2008; Serovich *et al.*, 2008, Almeleh, 2006; Bairan *et al.*, 2007; Mfecane, 2012). In the current study, the information shared by participants and key informants showed that PLHIV evaluated the perceived consequences of their disclosure or non-disclosure before making their decision. Participants talked about their needs, their fears and the timing of their disclosure, as well as the choice of individual to whom they would or would not disclose. One aspect in determining the consequences related to disclosure is the progression of disease, particularly as concerns the timing of disclosure, but it is not the sole determinant as argued in disease progression theory (Serovich *et al.*, 2008). For some participants, their general fears dominated the interview and gave the impression that they had self-stigmatised and could not imagine disclosure as benefiting them. For others, it was more nuanced as they had already taken the risk of disclosing to someone which subsequently informed their decisions about further disclosure or non-disclosure. In all of the cases, there is a sense of the participants' desires and needs as influencing their decision, something which is not accounted for in disease progression theory (Almeleh, 2006, Serovich *et al.*, 2008).

Since the major barrier to disclosure was the concern about the stigma that they might experience, it is important to note that was not borne out in any of the cases where the participants had actually disclosed. Studies have found that perceived stigma or internalised stigma seem to be a better description of the influencing factor rather than actual enacted stigma where the participants are real victims of poor treatment or marginalisation based on their status. This internalised stigma is considered a component of HIV-related stigma and thus

it is not surprising that this result was found in the current study as well (Talley & Bettencourt, 2010).

According to disease progression theory, people will disclose when they cannot hide their disease any longer, yet more recent work has shown it to have serious limitations (Serovich *et al.*, 2008; Emler, 2008; Yang *et al.*, 2006). In this study, there were only two women who shared their experiences of disclosing their status when they were very ill, which was consistent with the disease progression theory's premise that disclosure would happen at that stage. In Aida's case, a widow, though not bedridden, had lost almost all of her vision and was completely dependent on her mother. She explained that at that point, in order to continue to receive assistance from her mother, she felt an obligation to disclose her status to her mother. In the second case, Ramata was hospitalized, near death, and chose to disclose to her mother who was caring for her, and shortly thereafter Ramata disclosed to her father and her siblings. In both of these cases, I did not hear the women saying they felt forced, even if they felt a sense of responsibility verging on obligation. Disease progression theory states that at the point when it is almost impossible to hide the cause of one's illness then disclosure will happen. However, this theory does not allow for other personal desires and needs, as cited by Almeleh (2006), thus it does not fully describe the situation of these two women who also took into consideration other factors, such as the desire to be open with those close to them, beyond their declining health when they decided to disclose.

Almost all of the participants in this study were diagnosed at a very late stage of illness. Testing had taken place during an illness in almost all cases or after a woman's HIV test during pregnancy. All of the participants were already receiving ART and thus the study was limited to the decisions around disclosure that were taken at the point of already needing to adhere to medication and to attend regular check-ups. These aspects required resources, but also time and movement, which would easily be noticed by those close to the participants. Again, according to the disease progression theory, the majority of the participants were at the stage where they might feel obliged to disclose their status in order to continue to receive support from friends, partners or family, but this was not the case in the current study because most of them who had disclosed had other reasons for disclosing. Thus the theory of disease progression does not adequately take into consideration the situation of the participants who were weighing multiple factors apart from the stage of the disease prior to disclosure.

In the past, diagnosis with HIV often meant that death was near. Today, with better management

which changes the progression of HIV, PLHIV quite quickly realise that they can continue to live healthy, productive lives and this may also influence decision-making related to disclosure (Serovich *et al.*, 2008). It is interesting that only a few women participants referred to treatment adherence as a reason for disclosure as studies have shown that disclosure can assist in treatment adherence (Gillett & Parr, 2010; Hardon *et al.*, 2006). It was mentioned most often in association with the need for support when ill, but also in reference to children, wanting family to seek medical treatment if the child was HIV-positive rather than turning to *marabouts*. The fact that almost all of the participants started ART almost immediately after being tested means that their entire experience of living with HIV included the necessity of adhering to complex treatment regimens. Some acknowledged that they adhered better with assistance or at least when it does not need to be hidden, as also highlighted in Ndiaye's (2008) study.

Decisions concerning disclosure also seemed to be influenced by the attitude of the participants and the roles they played in their family or community. Penda's conviction that she was not loved or respected by her family continued to keep her from envisioning the real possibility of disclosure, despite her awareness that disclosure could bring her some benefit. The potential cost, that is stigma due to disrespect for confidentiality or not keeping *soutoura*, was too high for her. This situation seemed like a case of internalised stigma, which in the literature is more common with those who have not disclosed to anyone and also more frequent among women (Talley & Bettencourt, 2010). Penda met both these characteristics.

Another attitude that became apparent was that of acceptance and fatalism. In a way, Khadim's decision to only disclose to Projet SSP, the support group and God showed a certain level of fatalism. He referred repeatedly to religion, citing that people should respect others, but his decisions did not show any trust in those closest to him, rather just reconciling himself to his status and living with it privately. My observations while working with Projet SSP and living in the community are that a common response is that diagnosis with HIV was the will of God. This understanding may help PLHIV or those close to them to accept this new situation and appears to be a mechanism for coping. As PLHIV weigh the costs and benefits of disclosure, this sense of acceptance of God's will could either make them more willing to risk disclosure or more prepared to live with their secret. The only available study discussing fatalistic beliefs in relation to HIV in West Africa did not find an association with deciding to disclose, yet it seems like this should be studied further in order to determine if it plays a role (Hess & McKinney, 2007).

Consequence theory allows for the possibility that individuals have very particular reasons for choosing to whom they will disclose. This study found that no one particular group disclosed to a particular person consistently, but rather that it varied. There were some similarities, but also contradictions. Other studies have shown, for instance, that women are more likely to disclose to other women, whether that be a sister or mother or female friend (Almeleh, 2006; Simoni *et al.*, 2000). However, in this study, it was noted that several women had only chosen to disclose to their husbands and not necessarily any women who were close to them. Calin *et al.* (2007) had found that among black African women and men in London, disclosure decisions were made based on the nature and quality of relationships and I believe that could be said of the participants of this study as well due to the decision by women to disclose to their spouses and not other women. The reasons for disclosure among the participants in the current study seemed to be embedded in their interpersonal relationships, with the reasons differing depending on the person to whom disclosure was made (Calin *et al.*, 2007). An example would be Djibo's motivation to disclose to his wife in order that they might manage their status together and stay healthy.

In line with other studies that found women were more likely to disclose to other women, there were two cases of women who had disclosed to their mothers in order to have their support and there were several others, including men, who said they would have disclosed to their mothers, were they not deceased (Almeleh, 2006; Simoni *et al.*, 2000). Similarly, Foley and Nguer (2010) heard from sex workers in Dakar that mothers were the most likely choice when considering to which family member to disclose. In that study, a sex worker stated that mothers were forgiving and tried to help in difficult times (Foley & Nguer, 2010) which is a common belief in Senegal and could be a likely reason in the current study too.

It is interesting to note that in the current study, there was only one case of disclosure to a father and no other mention of fathers, thus making it seem likely that that relationship was more distant. Only just over half of the participants had in fact disclosed to family members and this corresponded with the findings in Dakar which noted that receiving support from family was not a given and thus the determination not to disclose to family was not unusual (Foley & Nguer, 2010). Ndiaye (2008) also found that of family members, parents were not amongst the first to be disclosed to. In the current study there was one case of disclosure to an uncle, who might culturally be considered a “father”. However, it was a case of involuntary disclosure due to lack of language skills at the testing site. As was the case with the studies carried out by Chandra *et al.* (2003) in India and Greef *et al.* (2008) in southern African countries, the PLHIV in the current study did

however disclose to a family member before a friend. The doctor in this study argued that blood is thicker than water and thus PLHIV would disclose to someone in their family before they would disclose to someone outside their family. Some cited that they would be less likely to get necessary support if they were not forthcoming about their situation to those who were in a position to assist them which was usually family first because of their closeness.

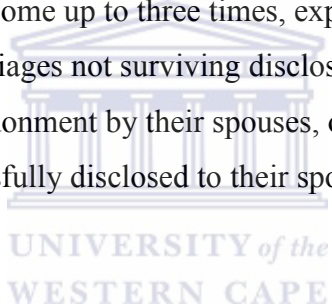
Many of the participants had chosen not to disclose to anyone in their families because the costs seemed to outweigh the benefits. In some cases it was in the perceived best interest of the participant, in others it was the perceived best interest of the family member. As participants reiterated their concern about protecting their confidentiality, they also stated in many cases that they could not trust family members to keep their status secret, to keep *soutoura*. Foley and Nguer (2010) noted the same concern with PLHIV in Dakar. Due to the stigmatising nature of HIV and considering the results of the Demographic and Health Survey which showed consistently high levels of stigmatising attitudes regarding HIV, it is not surprising that participants had this concern (ANSD & ICF International, 2012). Ndiaye had shared that during his wife's long illness, others praised him for not abandoning her and as a result offered them support and help. He felt strongly that had they known the cause of her illness the two of them would have been abandoned. Stigma was therefore a major cost in this study.

It is also important to consider that, as Ndiaye (2008) states, health-related issues are kept private in Senegal. From my own experience I found that in Senegal people generally do not fully disclose what is ailing them despite the fact that when someone is ill it is expected that others are made aware of the illness in order that they might visit and console the individual. Even close family might not know the details around the illness and this could be illustrated by the fact that despite having suffered from advanced illness often requiring hospitalisation, some participants had not fully disclosed their status to their family members. It may be that they had partially disclosed to them in order to garner support and by doing so this would satisfy the family not to ask further questions.

The general awareness about HIV in the community which in turn led to a stigmatising environment was definitely of concern to the participants and sometimes informed their decision not to disclose. As seen in the indicators of the Demographic and Health Survey which measured levels of stigma in regards to HIV in Senegal, there was still a majority who held stigmatising attitudes about PLHIV. These were more pronounced in rural areas such as

Linguère. For Aissata, who had just recently learnt of both her and her son's HIV infections, it likely meant that the cost of disclosing to her husband, which was her concern that he would divulge her status, leading to stigma, still seemed too high. Yang *et al.* (2006) found that with additional knowledge about HIV gained over time, stigma regarding HIV reduces. As Aissata learns more about HIV through her contact with service providers and the support group, her attitude regarding stigma might change. In general, as the appreciation of the consequences changes and each participant's situation changes, whether due to family situation, increased knowledge, source of support or health concerns, the cost-benefit balance concerning disclosure might change. Additionally, this cost-benefit balance should change as the public becomes more accepting of HIV (Serovich *et al.*, 2008).

The decision to disclose to spouses had brought good results for the participants, which was not always the case in other studies (Ramodike, 2009; Chandra *et al.*, 2003; Simbayi *et al.*, 2007; Desgrées du Loû, 2005; Simoni *et al.*, 2000). The fact that eleven of the fifteen participants had been divorced at least once and some up to three times, explains that it is not unusual that some felt concerned about their marriages not surviving disclosure. Despite the fact that some participants feared rejection or abandonment by their spouses, other participants who were in similar marital situations had successfully disclosed to their spouses and the results had been positive.



Those participants who did disclose to their spouses seemed to give two main benefits for doing so. The one reason was that they wanted to make it possible for the spouse to get tested and access care and treatment if necessary. The other reason was that they trusted the spouse and felt that they would receive emotional support from them. These are also key reasons cited by Calin *et al.* (2007). The issue of trust was primary in the current study. In the cases where participants had only partially disclosed, the concern seemed to be that either the marriage would end or that it would both end and the ex-spouse would not respect *soutoura* by divulging the participant's status to others. This strong lack of trust was raised by almost all of the participants, but the person not to be trusted varied by participant and was not limited to a spouse. For example, there was not a specific group that consistently stated they felt more trust in a spouse than parent or friend. As noted earlier, a divorced Wolof man and a married Fulani woman were both concerned about their siblings not keeping *soutoura*. They felt that their siblings could use the information against them, to attack them. On the other hand, Aissata, whose brother likely knew her status due to his assistance when she was tested, thought she could not trust anyone. This corresponds with findings

in other studies from Dakar and elsewhere in which the person who is trusted by PLHIV varies due to individual relationships and situations (Foley & Nguer, 2010; Ndiaye, 2008; Miller & Rubin, 2007).

Although most of the participants mentioned that disclosure allowed for prevention of further infections and also access to care for any spouses who might be infected, the predominating concern seemed to be for self and not for the other. The doctor clearly stated that those close to the PLHIV were still likely to make judgements about why that individual was HIV-positive and that that discouraged the PLHIV from disclosing. However, none of the participants spoke directly about wanting to avoid personal shame, except Aissata who specifically stated her desire that her children never know her status in order to have a good reputation in their eyes. The literature covers the issue of shame and blame and it is likely a factor for some of these participants (Foley & Nguer, 2010; Ndiaye, 2008; Miller & Rubin, 2007; Emler, 2008). However, the current study might not have probed deeply enough or that aspect might be one they did not want to address with me.

There was relatively little mention by the participants or key informants of disclosure being motivated by the need for financial support, as compared with other studies, such as that of Miller and Rubin (2007) in Kenya. Again, it might be because of the actual support provided to this particular group of people by Projet SSP, such as prescriptions and transport costs for attending support group meetings or check-ups, nutritional support, and assistance with school fees, that it was less of a concern for them. It might also be due to wanting to be discreet as they were being interviewed by those involved in providing them with that support.

5.2. Duty to others

In weighing the costs and benefits of disclosure of HIV-positive status, PLHIV also sometimes take into consideration the effect of their status on others and not just those related directly to their personal well-being. These often included a feeling of responsibility to disclose (Yang *et al.*, 2006).

In some cases, such as that of Boury, she decided to disclose to her husband immediately on the advice of the doctor. However, that does not mean that she did not first weigh up the consequences because she went on to explain her reasons for not disclosing to others around her, including extended family and her children. Others took more time to weigh up their decision, such as the case of Demba who delayed disclosing to his spouse, but whom, a year after learning of his status, disclosed to his wife due to his concern that her deteriorating health might also be due to HIV. After

initial evaluation, his decision was to not disclose, but after time and due to an evolving situation the negative consequences of non-disclosure to his wife became more serious than the benefit of not disclosing. Although their contexts were not dissimilar, the two participants had personal reasons for determining to whom and when to disclose and as they considered their situation over time and their sense of responsibility to their spouse, they came to the decision to disclose.

Another example of a duty to others was Djibo's decision to disclose to a cousin who was in an advanced stage of illness that Djibo suspected was AIDS. His motivation in telling his ill cousin was to encourage him and to assure him that contrary to popular opinion, an HIV-positive test did not automatically lead to death. Other studies have shown that individuals have decided to disclose in order to educate or assist others, both PLHIV and the general community, which was the motivation for Djibo (Bairan *et al.*, 2007; Emler, 2008).

Medley *et al.* (2004), Calin *et al.* (2007) and Chandra *et al.* (2003) were among the many who found that PLHIV chose not to disclose their status to family members because of their concern about upsetting family members. In the current study this was expressed by both men and women with regard to their family members. For example, Demba judged that his brother would be saddened by knowing his status and thus no disclosure was made in order to avoid that negative consequence, although he seemed to be considering the potential benefit of disclosure to him. For Boury, she was not prepared to disclose to her oldest son whom she felt would be too emotionally distraught as a result. She did not yet see any benefits in disclosing to him. Another reason for not disclosing to family was found to be the sense of disgrace it might bring (Chandra *et al.*, 2003). Ramata said that because she was concerned about her family being stigmatised, she was not willing to disclose to her husband in case he did not keep *soutoura*. She felt that by disclosing this might lead to future involuntary disclosure by him which in turn could bring stigma on her or her family. Again this is a demonstration of how the participants weighed up the benefits and costs in their decision to disclose.

I got the sense that in some cases the sense of responsibility and loyalty to family was stronger than the compassion or love they felt. Interestingly, when Sow talked about his desire that his family not practise widow inheritance in the case of his death, he spoke solely about preventing transmission to his family, in this case the brother who would likely marry his widow. He made no mention of his potential widow's personal situation or his children, despite the fact that widow inheritance is practised in part to provide for the well-being of the widow and orphans. His motivation could be

interpreted as seeking the survival of his siblings first over the well-being of his wife and children. I believe he was very sensitive to the need to reduce further infections since he also said he would only remarry a woman who was already living with HIV.

5.3. Influence of support group and service providers on practise of disclosure

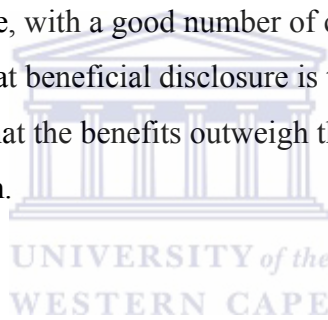
Bairan *et al.* (2007) recommend that health workers should respect the rights of PLHIV to choose to whom they will disclose. The fact that none of the participants in the current study felt particularly pressured in a negative way by health workers to disclose their status shows that either their rights were respected or there was neglect to discuss the issue of disclosure in a health care setting. The social worker and the doctor also felt that it was important for health care providers to engage the question of disclosure more actively with PLHIV and that the health care providers also should be better trained in order to encourage beneficial disclosure. They envisioned the outcomes for PLHIV being greater support, relief, solidarity, better mental and physical health and protection for others, as they had seen that those who had disclosed had only benefited from the decision.

Gillett and Parr (2010) found that in Kenya women's participation in a support group strengthened their confidence and made it more possible for them to disclose. UNAIDS (2000) encourages PLHIV membership in support groups for this reason. The doctor and social worker decried the lack of structures similar to Projet SSP that could provide further opportunities for PLHIV to meet one another as they saw it as essential in encouraging beneficial disclosure. It is possible that the success of the support group and the positive role it plays in giving PLHIV a safe community within which to disclose might be influencing people's decisions about disclosure, either encouraging them to disclose or satisfying them with their disclosure to the other members of the support group. Because of the benefits seen by PLHIV who had disclosed, the doctor and social worker were keen in having more PLHIV share their experiences of disclosure in order to convince others that the advantages outweighed the risks. It is also likely due to the safe environment of both Projet SSP and the support group that the participants were relatively positive about their situations, despite the prevailing negative environment in the community. Bell *et al.* (2007) argue that there is less stigma in communities where there are strong support groups and in turn the support groups assist members to deal with their decisions about disclosure.

When looking at the cases of the three participants who had not disclosed to anyone apart from Projet SSP and the support group, one has to wonder if having had the opportunity to disclose at that level is really sufficient. Khadim said it was, whereas Penda said she desired to share her status

with someone other than the support group, but was still very concerned about confidentiality. The decision to disclose to Projet SSP raises some questions. For example, was it Khadim's deteriorating health as he aged and his need for support, yet reluctance to disclose to anybody else, which forced him to disclose to Projet SSP? What are the reasons that PLHIV give for disclosing to a service provider? That is a question that was not covered by this study due to its focus on disclosure to friends, family and regular sexual partners only, but should be a topic for further study.

Most of the influencing factors, both motivators and barriers, were self-focused in this study and that has also been reported in other studies (Chandra *et al.*, 2003). Factors were related to gaining support for the participant, both physical and emotional, and avoiding ostracism, whether from partners, family, friends or the community. Of the participants who had disclosed, there were no cases of severe negative consequences. Not one participant expressed regret for having disclosed, rather there were positive benefits for the participant and sometimes also the other person to whom disclosure was made. The roles of the service providers and the support group were also influential in decision-making around disclosure, with a good number of cases of mediated disclosure. This discussion leads to the conclusion that beneficial disclosure is to be encouraged in Linguère District and that in most cases PLHIV find that the benefits outweigh the costs in choosing to disclose to at least one person who is close to them.



Chapter 6: CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

In this study I sought to explore factors that influenced PLHIV's decision to disclose or not disclose their HIV-positive status to friends, families and regular sexual partners in Linguère, Senegal.

In general, HIV continues to be a particularly stigmatising condition and thus the majority of PLHIV in this study have judged that it is not worth the risk of possible abandonment, rejection or slander to disclose their status, regardless of the fact that few have actually experienced severe negative consequences as a result of actual disclosure. Some individuals are just limiting their risk, whereas others seem to be consumed with unreasonable fear in this regard. Those who had practised disclosure in some form or another have benefited from receiving more support and encouragement, as well as a general sense of relief and ability to live more openly. They were also pleased that it had led to testing of spouses and access to care for those who needed it.

The role of the project with which I formerly worked and still have contact, Projet SSP, ended up being important as concerns disclosure for the participants in the study. Due to the quality of the support received from the project and from other PLHIV in the support group, participants have sometimes felt more empowered to disclose or alternately more empowered not to disclose. What this means is that in some instances, the support is sufficient and seems to discourage taking the risk of disclosing to anyone else because of the perceived cost of the disclosure. And in other instances the confidence found in disclosing to Projet SSP and the support group have likely made it easier to disclose to others because of the perceived benefits and the assurance of not losing all support even if disclosure to others leads to rejection or abandonment. This was not an expected result, but is nevertheless interesting. As the social worker noted, there is a hope that as more and more PLHIV join the support group and see and hear about the experiences of others, disclosure will start to be more acceptable and be considered as less of a risk. As a result, the expectation is that PLHIV will be both emotionally and physically healthier and will in turn reduce further risk of transmission.

My own opinion when starting this study was that despite the prevailing evidence in the

literature and practise of HIV/AIDS service and advocacy organisations to encourage disclosure, there were cases where disclosure would have led to negative consequences and thus PLHIV sometimes made the best choice not to disclose. For instance, a woman with no source of support and no possibility for work is dependent on her husband or her family. If she were to be abandoned, she might also have her children taken away. In that case, as is mentioned in the study by Foley and Nguer (2010) of sex workers in Dakar, there is a good likelihood that she might have to turn to transactional sex or formal sex work to feed and care for herself. Not only will her physical and mental health likely deteriorate, but she might also be increasing the risk of transmission to others, thus contradicting the two main arguments of beneficial disclosure. I still see these as possible consequences for some in Linguère District and this study does not disprove it.

However, after having completed this study, I see that although the preceding scenario may very well present itself, it seems that the risk of complete rejection is very low. The participants, in particular those who had joined the support group and also disclosed to someone outside the support group, were reaping the benefits and because of support provided by Projet SSP and others, the need to turn to risky activities was lessened. This was also confirmed by key informants who witnessed the improved situation of those who had disclosed to at least one other person. Thus I would now state that more should be done by all those who are in contact with PLHIV, such as Projet SSP, the health care providers and support group members, to encourage beneficial disclosure in order that they live healthier, happy lives and also in order to reduce further HIV infections. I believe these findings have applicability to many other regions and groups in Senegal. As PLHIV manage their situations, they will undoubtedly be weighing the potential benefits of disclosure against the possible costs in order to achieve the best result for themselves and those around them. I hope that from the findings of this study service providers will become more aware of these factors in order that they might work with PLHIV and together find a way to encourage beneficial disclosure.

6.2. Recommendations

As more and more is learnt about disclosure of HIV-positive status, those providing support to PLHIV can adjust and improve that support. In light of the findings of this research, I would make the following recommendations:

- It is important for service providers and the support group to be aware of changes in the community, in particular as concerns attitudes of stigma and discrimination, but also the continuing evolution of the laws concerning criminalisation of HIV transmission. Any opportunity to support or develop programmes to increase the community's understanding of HIV, in particular to fight stigma, should be taken advantage of.
- Service providers also should be aware of what the needs of particular PLHIV are at different stages of the disease. As with all aspects of providing support, the needs and interests and openness change as PLHIV's experiences change, from first learning about their diagnosis to their willingness to share with a service provider, to their willingness to contemplate sharing with others in the support group.
- PLHIV should be encouraged to share their practical experience of disclosure with others, including service providers who may become more sensitive to the needs of PLHIV and who might in turn share with those PLHIV who have not joined a support group. One of the support group members stated that: “We do not dare speak, but with your assistance...”.
- Opportunities to discuss the advantages of beneficial disclosure should be created, while always acknowledging the concerns or fears about disclosure. The subject needs to be addressed repeatedly, as noted by Simoni and Pantalone (2005).
- Service providers and Projet SSP should strengthen counselling with PLHIV in order to increase the number of PLHIV who disclose their status to their regular sexual partners considering its importance for reducing further HIV transmission.
- Health care providers and other service providers should receive further training to understand the issues surrounding disclosure especially the perceived costs and benefits so that they may be sensitive and try to address particular concerns with PLHIV. They should also be prepared and trained to assist in mediating disclosure if that is the PLHIV's preferred process of disclosure because they cannot find a manageable way to self-disclose (Miller & Rubin, 2007, Bairan *et al.*, 2007).
- Health, community and religious leaders should show more support for PLHIV and promote respect for the rights of PLHIV (Gillett & Parr, 2010, Bairan *et al.*, 2007). For instance, as no PLHIV in Linguère have disclosed publicly, the doctor could share their stories and

concerns on local radio programmes which reach a good portion of the population.

- Further studies, both quantitative and qualitative, should be undertaken to better understand disclosure in order to provide other entry points for intervention with PLHIV. For instance: what role does disclosure play in prevention; what are the results of disclosure; what other systemic factors affect decisions concerning disclosure, such as gender roles and power differentials; who are people selected to be disclosed to; and what strategies are used (Coates *et al.*, 2008; Bell *et al.*, 2007, Miller & Rubin, 2007; Serovich *et al.*, 2008, Bairan *et al.*, 2007). It would also be useful to do longitudinal studies on disclosure to see how PLHIV's decisions change over time as their circumstances change.



REFERENCES

- Agence Nationale de la Statistique et de la Démographie (ANSD) [Sénégal] & ICF International. (2012). *Enquête Démographique et de Santé à Indicateurs Multiples au Sénégal (EDS-MICS) 2010-2011*. Calverton, Maryland, USA: ANSD & ICF International. [Online], Available: <http://measuredhs.com/pubs/pdf/FR258/FR258.pdf> [Downloaded: 2/9/12 22:46]
- Almeleh, C. (2006). *Why Do People Disclose Their HIV Status? Qualitative Evidence from a Group of Activist Women in Khayelitsha*. Center for Social Science Research: AIDS and Society Research Unit Working Paper No. 163.
- Bairan, A., Taylor, G.A.J., Blake, B.J., Akers, T., Sowell, R. & Mendiola, R. (2007). A Model of HIV Disclosure: Disclosure and Types of Social Relationships. *Journal of the American Academy of Nurse Practitioners*, 19: 242-250.
- Bell, E., Mthembu, P., O'Sullivan, S. & Moody, K. (2007). Sexual and Reproductive Health Services and HIV Testing: Perspectives and Experiences of Women and Men Living with HIV and AIDS. *Reproductive Health Matters*, 15(29 supplement): 113-135.
- Bronsard, G., Boissy, L. & Sylla, O. (2002). Ch III.4-Accompagnement et Soins Psychologiques pour les Patients sous Traitement Antirétroviral au Sénégal. In A. Desclaux, I. Lanièce, Ndoye, I. & B. Taverne. (eds). *L'Initiative Sénégalaise d'Accès aux Médicaments Antirétroviraux: Analyses Economiques, Sociales, Comportementales et Médicales*. Paris: Agence Nationale de Recherches sur le SIDA: 179-191.
- Brou, H., Djohan, G., Becquet, R., Allou, G., Ekouevi, D.K., Viho, I., Leroy, V. & Desgrées-du-Loû, A. (2007). When Do HIV-Infected Women Disclose Their HIV Status to Their Male Partner and Why? A Study in a PMTCT Programme, Abidjan. *Plos Medicine*, 4(12): e342-e342.
- Calin, T., Green, J., Hetherington, J. & Brook, G. (2007). Disclosure of HIV Among Black African Men and Women Attending a London HIV clinic. *AIDS Care*, 19(3): 385-391.
- Chandra, P.S., Deepthivarma, S. & Manjula, V. (2003). Disclosure of HIV in South India: Patterns, Reasons and Reactions. *AIDS Care*, 15(2): 207.

CNLS (Conseil National de Lutte Contre le SIDA). (2003). *Bulletin Séro-Epidémiologique No. 10 de Surveillance du VIH*. Dakar, Senegal: Conseil National de Lutte Contre le SIDA.

CNLS (Conseil National de Lutte Contre le SIDA). (2007). *Plan Stratégique de Lutte Contre le VIH/SIDA 2007-2011*. Dakar, Senegal: Conseil National de Lutte Contre le SIDA.

CNLS (Conseil National de Lutte Contre le SIDA). (2011). *Plan Stratégique de Lutte Contre le VIH/SIDA 2011-2015*. Dakar, Senegal: Conseil National de Lutte Contre le SIDA. [Online], Available : http://www.ilo.org/wcmsp5/groups/public/---ed_protect/---protrav/---ilo_aids/documents/legaldocument/wcms_170729.pdf [Downloaded : 4/9/12 22:56]

Coates, T.J., Richter, L. & Caceres, C. (2008). Behavioural Strategies to Reduce HIV Transmission: How to Make Them Work Better. *The Lancet*, 372: 669-684.

Comité Régional de Lutte Contre le SIDA (CRLS). (2006). *Gestion Intégrée de la Réponse au VIH/SIDA: Région de Louga*. Louga, Senegal: Comité Régional de Lutte Contre le SIDA.

Creswell, J.W. & Miller, D.L. (2000). Determining Validity in Qualitative Inquiry. *Theory Into Practice*, 39(3): 125-130.

Desgrées du Loû, A. (2005). The Couple and HIV/AIDS in Sub-Saharan Africa: Telling the Partner, Sexual Activity and Childbearing. *Population*, 60(3): 179-198.

Diaw, A. (2007). Sewing Machines and Computers: Seeing Gender in Institutional and Intellectual Cultures at the Cheikh Anta Diop University of Dakar, Senegal. *Feminist Africa*, 9: 5-21.

District Sanitaire de Linguère. (2004). *Données Démographiques de Base pour le District de Linguère en 2004*.

Durrheim, K. (2006). Ch 3-Research Design. In M. Terre Blanche, K. Durrheim & D. Painter. (eds). *Research in Practice: Applied Methods for the Social Sciences*. Cape Town, South Africa: University of Cape Town Press: 33-59.

EELS (Eglise Evangélique Luthérienne du Sénégal). (2009). *Registre des PVVIH dans le Département de Linguère*. Linguère, Senegal: EELS.

EELS (Eglise Evangélique Luthérienne du Sénégal). (2011). *2012 SSP-EELS Global Mission Grant Packet*. Linguère, Senegal: EELS.

Emlet, C.A. (2006). A Comparison of HIV Stigma and Disclosure Patterns Between Older and Younger Adults Living with HIV/AIDS. *AIDS Patient Care & STDs*, 20(5): 350-358.

Emlet, C.A. (2008). Truth and Consequences: A qualitative Exploration of HIV Disclosure in Older Adults. *AIDS Care*: 20(6): 710-717.

Fennie, K., Chen, X., Williams, A., Wang, H., Xianhong, L. & Khoshnood, K. (2012). 19th International AIDS Conference: Abstract no. MOPE362 [Online], Available: <http://www.iasociety.org/Abstract.aspx?abstractId=200745227> [Downloaded: 20/10/12 10:30]

Foley, E. & Nguer, R. (2010). Courting Success in HIV/AIDS Prevention: The Challenges of Addressing a Concentrated Epidemic in Senegal. *African Journal of AIDS Research*, 9(4): 325-336.

Gable, L., Gamharter, K., Gostin, L.O., Hodge, Jr., J.G. & van Puymbroeck, R.V. (2007). *Legal Aspects of HIV/AIDS: A Guide for Policy and Law Reform*. Washington, DC: The World Bank.

Gifford, S. (1998). Analysis of Non-numerical Research. In C. Kerr, R. Taylor and G. Heard. (eds). *Handbook of Public Health Methods*. Sydney: McGraw Hill.

Gillett, H.J. & Parr, J. (2010). Disclosure Among HIV-Positive Women: The Role of HIV/AIDS Support Groups in Rural Kenya. *African Journal of AIDS Research*, 9(4): 337-344.

Greeff, M., Phetlhu, R., Makoae, L.N., Dlamini, P.S., Holzemer, W.L., Naidoo, J.R., Kohi, T.W., Uys, L.R. & Chirwa, M.L. (2008). Disclosure of HIV Status: Experiences and Perceptions of Persons Living with HIV/AIDS and Nurses Involved in Their Care in Africa. *Qualitative Health Research*, 18(3): 311-324.

Green, J. & Thorogood, N. (2004). *Qualitative Methods for Health Research*. London: Sage Publications.

Hardon, A., Davey, S., Gerrits, T., Hodgkin, C., Irunde, H., Kgatlwane, J., Kinsman, J., Nakiyemba, A. & Laing, R. (2006). *From Access to Adherence: The Challenges of Antiretroviral Treatment: Studies from Botswana, Tanzania and Uganda*. Geneva: World Health Organization.

Hess, R.F. & McKinney, D. (2007). Fatalism and HIV/AIDS Beliefs in Rural Mali, West Africa. *Journal of Nursing Scholarship*, 39(2): 113-118.

International HIV/AIDS Alliance. (2003). *Positive Prevention: Prevention Strategies for People with HIV/AIDS: Draft Background Paper*.

Kalichman, S.C., Ntseane, D., Nthomang, K., Segwabe, M., Phorano, O. & Simbayi, L.C. (2007). Recent Multiple Sexual Partners and HIV Transmission Risks among People Living with HIV/AIDS in Botswana. *Sexually Transmitted Infections*, 83: 371-375.

Kelly, K. (2006a). Ch 13 – From Encounter to Text: Collecting Data in Qualitative Research. In M. Terre Blanche, K. Durrheim & D. Painter. (eds). *Research in Practice: Applied Methods for the Social Sciences*. Cape Town, South Africa: University of Cape Town Press: 286-319.

Kelly, K. (2006b). Ch 16 – Calling it a Day: Reaching Conclusions in Qualitative Research. In M. Terre Blanche, K. Durrheim & D. Painter. (eds). *Research in Practice: Applied Methods for the Social Sciences*. Cape Town, South Africa: University of Cape Town Press: 370-387.

Kidd, R. & Clay, S. (2003). *Understanding and Challenging HIV Stigma: Toolkit for Action*. Washington, DC: Academy for Educational Development.

Klitzman, R.L., Kirshenbaum, S.B., Dodge, B., Remien, R.H., Ehrhardt, A.A., Johnson, M.O., Kittel, L.E., Daya, S., Morin, S.F., Kelly, J., Lightfoot, M. & Rotheram-Borus, M.J. (2004). Intricacies and Inter-relationships Between HIV Disclosure and HAART: A Qualitative Study. *AIDS Care*, 16(5): 628-640.

Lanièce, I., Ciss, M., Desclaux, A., Diop, K., Mbodj, F., Ndiaye, B., Sylla, O., Delaporte, E. & Ndoye, I. (2003). Adherence to HAART and its Principal Determinants in a Cohort of Senegalese Adults. *AIDS*, 17(suppl 3): S103-S108.

Liamputtong, P.R. & Ezzy, D. (2005). *Qualitative Research Methods*. Sydney: Oxford University Press.

Medley, A., Garcia-Moreno, C., McGill, S. & Maman, S. (2004). Rates, Barriers and Outcomes of HIV Serostatus Disclosure among Women in Developing Countries: Implication for Prevention of Mother-to-Child Transmission Programmes. *Bulletin of the World Health Organization*, 82(4): 299-

Mfecane, S. (2012). Narratives of HIV Disclosure and Masculinity in a South African Village. *Culture, Health & Sexuality*, DOI:10.1080/13691058.2011.647081 [Online], Available: <http://dx.doi.org/10.1080/13691058.2011.647081> [Downloaded: 14/11/12, 21:00]

Miller, A.N. & Rubin, D.L. (2007). Factors Leading to Self-Disclosure of a Positive HIV Diagnosis in Nairobi, Kenya: People Living with HIV/AIDS in the Sub-Sahara. *Qualitative Health Research*, 17(5): 586-598.

MSPM (Ministère de la Santé et de la Prévention Médicale). (2007). *Politique de Santé*. Dakar: Ministère de la Santé. [Online], Available: <http://www.sante.gouv.sn/politiquesanitaire.php> [Downloaded: 05/29/2007 15:00]

Ndiaye, Khadidiatou. (2008). *When Soutoura (Dignity, Respect, and Privacy) Matters Most*. [Online], Available :<https://etda.libraries.psu.edu/paper/8810/> Dissertation, The Pennsylvania State University. [Downloaded: 14/10/12 21:40]

Ndiaye, S. & Ayad, M. (2006). *Enquête Démographique et de Santé au Sénégal 2005*. Calverton, MD, USA: Centre de Recherche pour le Développement Humain et ORC Macro.

Norman, A., Chopra, M. & Kadiyala, S. (2007). Factors Related to HIV Disclosure in 2 South African Communities. *American Journal of Public Health*, 97(10): 1775-1781.

Obermeyer, C.M. & Osborn, M. (2007). The Utilization of Testing and Counseling for HIV: A Review of the Social and Behavioral Evidence. *American Journal of Public Health*, 97(10): 1762-1774.

O'Brien, M.E., Richardson-Alston, G., Ayoub, M., Magnus, M., Peterman, T.A. & Kissinger, P. (2003). Prevalence and Correlates of HIV Serostatus Disclosure. *Sexually Transmitted Diseases*, 30(9): 731-735.

Paxton, S. (2002). The Paradox of Public HIV Disclosure. *AIDS Care*, 14(4): 559-567.

Pope, C., Ziebland, S. & Mays, N. (2000). Analysing Qualitative Data. *British Medical Journal*: 320:114.

Ramodike, J.M. (2009). *The Subjective Experience of Violence After Disclosure of HIV Status Among Women*. [Online], Available: <http://upetd.up.ac.za/thesis/available/etd-09022010-182933/> [Downloaded 4/9/12 22:11]

Rice, P.R. & Ezzy, D. (1999). Sampling Strategies for Qualitative Research. In *Qualitative Research Methods – A Health Focus*. Sydney: Oxford University Press: 40-50.

Robson, C. (1993). Ch 9 – Interviews and Questionnaires. In Robson, C. *Real World Research*. Blackwell: 227-243.

Sandelowski, M. (1986). The Problem of Rigour in Qualitative Research. *Advances in Nursing Science*, 8(3): 27-37.

Serovich, J. M., Lim, J. & Mason T.L. (2008). A Retest of Two HIV Disclosure Theories: The Women's Story. *Health & Social Work*, 33(1): 23-31.

Setswe, G., Peltzer, K., Banyini, M., Skinner, D., Seager, J., Maile, S., Sedumedi, S., Gomis, D. & van der Linde, I. (2007). Report and Policy Brief from the 4th Africa Conference on Social Aspects of HIV/AIDS Research: Innovations in Access to Prevention, Treatment and Care in HIV/AIDS, Kisumu, Kenya, 29 April-3 May, 2007. *Journal of Social Aspects of HIV/AIDS*, 4(2): 640-651.

Simbayi, L.C., Kalichman, S.C., Strebel, A., Cloete, A., Henda, N. & Mqeketo, A. (2007). Disclosure of HIV Status to Sex Partners and Sexual Risk Behaviours among HIV-Positive Men and Women, Cape Town, South Africa. *Sexually Transmitted Infections*, 83: 29-34.

Simoni, J.M., Demas, P., Mason, H.R.C., Drossman, J.A. & Davis, M.L. (2000). HIV Disclosure Among Women of African Descent: Associations with Coping Social Support, and Psychological Adaptation. *AIDS and Behavior*, 4(2): 147-158.

Simoni, J.M. & Pantalone, D.W. (2005). Ch 3 – HIV Disclosure and Safer Sex In S.C. Kalichman. (ed). *Positive Prevention: Reducing HIV Transmission among People Living with HIV/AIDS*. New York: Springer: 65-98.

Sow, G., Toure, K., Coume, M., Dia, A.T. & Traore, I. (2012). Predictors of ART Adherence Among HIV Infected Individuals in Dakar, Senegal. *Journal of Medicine and Medical Science*, 3(4): 212-216.

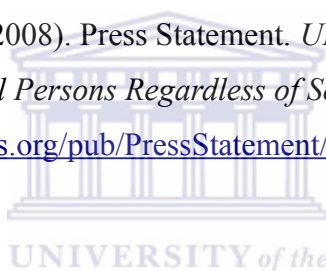
Talley, A.E. & Bettencourt, B.A. (2010). A Relationship-Oriented Model of HIV-Related Stigma Derived from a Review of the HIV-Affected Couples Literature. *AIDS Behaviour*, 14: 72-86.

UNAIDS. (2000). *Opening Up the HIV/AIDS Epidemic: Guidance on Encouraging Beneficial Disclosure, Ethical Partner Counselling and Appropriate Use of HIV Case-Reporting*. Geneva: UNAIDS.

UNAIDS. (2012a). *Together We Will End AIDS*. Geneva: UNAIDS. [Online], Available: http://www.unaids.org/en/media/unaids/contentassets/documents/epidemiology/2012/20120718_togetherwewillendaids_en.pdf [Downloaded: 2/10/12 11:45]

UNAIDS. (2012b). *Oslo Declaration on HIV Criminalization Alerts about Adverse Effect of Criminalizing HIV Non-disclosure*. Geneva: UNAIDS. [Online], Available: <http://www.unaids.org/ua/news/1435> [Downloaded: 17/11/12 20:00]

UNAIDS & OHCHR. (26 February 2008). Press Statement. *UNAIDS and OHCHR Call for Greater Protection of the Human Rights of all Persons Regardless of Sexual Orientation or HIV Status*. [Online], Available: http://data.unaids.org/pub/PressStatement/2008/080226_humanrights_en.pdf [Downloaded: 30/03/08 13:23]



Willms, D. & Johnson, N. (1993). Analysis and Interpretation. In *Essentials in Qualitative Research: A Notebook for the Field*. Newbury Park, CA: McMaster University: 69-82.

Wilson, T.E., Feldman, J., Vega, M.Y., Gandhi, M., Richardson, J., Cohen, M.H., McKaig, R., Ostrow, D., Robison, E. & Gange, S.J. (2007). Acquisition of New Sexual Partners among Women with HIV Infection: Patterns of Disclosure and Sexual Behavior within New Partnerships. *AIDS Education & Prevention*, 19(2): 151-159.

Wolfe, W.R., Weiser, S.D., Bangsberg, D.R., Thior, I., Makhema, J.M., Dickinson, D.B., Mompati, K.F. & Marlink, R.G. (2006). Effects of HIV-Related Stigma among an Early Sample of Patients Receiving Antiretroviral Therapy in Botswana. *AIDS Care*, 18(8): 931-933.

Yang, H., Li, X., Stanton, B., Fang, X., Lin, D. & Naar-King, S. (2006). HIV-Related Knowledge, Stigma, and Willingness to Disclose: A Mediation Analysis. *AIDS Care*, 18(7): 717-724.

APPENDICES

Appendix 1: Interview Guide for in-depth interviews with PLHIV

- Present marital and family situation and other demographic information
- Present level of disclosure
- Experience of disclosure (self or assisted)
- Description of factors that determined why to disclose or not
- Understanding of consequences or benefits of disclosure
- Description of the differences between disclosure to partners and disclosure to friends or family members



Appendix 2: Interview Guide for key informant interviews with service providers

- Your experience of disclosure of PLHIV
- Your understanding of factors affecting PLHIV's decision to disclose or not disclose
- Your experience of assisting PLHIV to disclose
- Your understanding of the consequences or benefits of disclosure
- Your understanding of the difference between disclosure to partners or friends and family members
- Your experience of the results of disclosure by PLHIV





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November 2011

Dear Participant,

Thank you for your willingness to be involved with this research. I would like to explain the research project and the expectations around your participation. I am undertaking this research as a requirement for obtaining the degree of Masters in Public Health at the University of the Western Cape in South Africa. If at any time something is unclear, please ask me. I have also included my contact information, as well as that of my supervisor, at the end of this letter.

Title of Research

Factors that influence disclosure or non-disclosure of one's HIV-positive status to friends, family and regular sexual partners in Linguère, Senegal

Purpose of Study

The research will try to better understand why people choose to share or not share their HIV-positive status with friends, family or partners. Through studying this question we hope that people living with HIV (PLHIV) and the people who provide care and support to them will know better how to help people decide about whether to share their status and the possible consequences, good or bad. We also hope that having more information about this will help develop policies in Senegal and in the region that are helpful to PLHIV and take into consideration their concerns around this

issue.

Description of the Study and Your Involvement

The study will consist of in-depth individual interviews, separately held with several PLHIV and service providers, such as the doctors or social worker or Projet SSP staff. Some questions that I will ask (with the help of a translator if needed) will help participants share your thoughts and ideas about the question of sharing one's HIV-positive status with others. The conversation will be recorded, but not by video.

Confidentiality

Throughout the interview and recording I will not use your name. I will ask you to choose a different name for the records. All of the recordings and documents will be kept locked away and later destroyed when the study is done. I will also ask you to sign a form if you agree to participate.

Voluntary Participation and Withdrawal

You do not have to participate in this research if you choose not to, it is voluntary. If you decide to participate and then change your mind, you can stop, even if the study has already started. Also, you can refuse to respond to some questions or discuss some issues if you prefer not to. Your participation or decision to stop participating will not affect the services you receive from Projet SSP or the health services.

Benefits, Costs and Harm

You will not gain or lose anything directly from participating in this study. However, the results of the study may lead to better understanding of the situation of PLHIV and thus may improve support services that are provided to PLHIV. There is no cost for you, only the time and energy that you offer to participate in the interview.

Informed Consent

In order to participate in this study, you must give your signed consent. With this information sheet I have included the Letter of Informed Consent so that you may read it and decide if you would like

to participate or not.

If you have questions or would like to know more, please contact me at the following address.

Please note that there are two, one for when I am in Senegal and one for when I am in Cameroon.

Anne Ruedisili Langdji

ELCA Global Mission West Africa Regional Representative

In Cameroon:

B.P. 2209 Messa Yaounde CAMEROON

Tel: +237 99 50 38 80

In Senegal:

B.P. 41 Linguère, SENEGAL

Tel: +221 77 732 1533 or 33 968 1077

E-mail address: awlangdji@hotmail.com

I am accountable to my supervisor:

Ms. Suraya Mohamed

Lecturer, School of Public Health, University of the Western Cape

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Novembre 2011

Cher Participant,

Merci pour votre volonté de participer dans ces recherches. J'aimerais expliquer le projet de recherche et les attentes pour votre participation. J'entreprends cette recherche dans le but d'obtenir le Masters en Santé Publique de l'Université de Western Cape en Afrique du Sud. Si à tout moment quelque chose n'est pas clair, veuillez bien me demander. J'ai aussi donné mes coordonnées et contacts et ceux de mon superviseur à la fin de cette lettre.

Titre de Recherche

Les facteurs qui influencent le partage ou non-partage de son statut VIH-positif aux amis, famille et partenaires sexuels à Linguère, Sénégal.

But de l'Étude

Cette recherche cherchera à mieux comprendre pourquoi les gens décident de partager ou non leur statut de VIH-positif avec leurs amis, leur famille ou leurs partenaires. À travers cette recherche nous espérons que les personnes vivant avec le VIH (PVVIH) et les prestataires des soins et les gens qui les appuient sauront mieux les aider dans cette décision à propos du partage du statut, y compris les avantages et désavantages. Nous espérons aussi que ces informations supplémentaires aideront au développement des politiques au Sénégal et dans la région qui seront utiles aux PVVIH et qui prendront en compte leurs soucis autour de cette question.

Description de l'Étude et de Votre Participation

Cette étude consistera des entretiens approfondis; tenus séparément avec des PVVIH et des prestataires de soins, comme les médecins, l'assistant social et le personnel du Projet SSP. Certaines questions vous seront posées par moi (avec un traducteur, si nécessaire) aideront au participant de partager ses idées et ses pensées par rapport à la question de partage du statut de VIH-positif. Cette conversation sera enregistrée, mais pas par vidéo.

Confidentialité

Pendant tout l'entretien et l'enregistrement je ne me servira pas de votre nom. Je vous demandera de choisir un pseudonyme pour les documents. Toutes les enregistrements et tous les documents seront gardés sous clef et ensuite détruits à la fin des recherches. Je vous demanderai aussi à signer une formulaire si vous donner votre accord à y participer.

Participation Volontaire et le Retrait

Vous n'êtes pas obligé de participer à ces recherches si vous ne le voudrez pas, il est volontaire. Si vous décidez de participer et ensuite vous changez d'avis, vous pouvez vous retirez, même si la recherche a déjà commencé. Aussi, vous pouvez refuser à répondre à certaines questions ou discuter certains points. Votre participation ou décision de vous retirer n'aura aucune influence sur les services que vous continuerez de recevoir du Projet SSP ou des services de santé.

Bénéfices, Coûts ou Mal

Vous ne gagnerez ni perdrez rien directement de votre participation dans ces recherches. Cependant, les résultats de cette étude pourrait mener à une meilleure compréhension de la situation des PVVIH et pourrait ensuite améliorer les services octroyées aux PVVIH. Il n'y aura aucun coût pour vous, seulement votre temps et votre force que vous offrez pour participer dans l'entretien individuel.

Le Consentement Eclairé

Pour pouvoir participer dans cette étude, vous devriez donner votre consentement écrite. Avec cette fiche d'information j'ai inclus aussi une Lettre de Consentement Eclairé pour que vous le lisiez et décidiez si vous aimeriez y participer ou non.

Si vous avez des questions ou si vous aimeriez savoir plus, veuillez me contacter aux adresses suivants. Notez bien qu'il y en a deux, une pour le Cameroun et une pour le Sénégal.

Anne Ruedisili Langdji

Représentant Régional pour l'Afrique de l'Ouest de ELCA Global Mission

Au Cameroun:

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Au Sénégal:

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Adresse e-mail: awlangdji@hotmail.com

Je suis responsable devant:

Mme. Suraya Mohamed

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INFORMED CONSENT TO CONDUCT AN INTERVIEW

Date:

Interviewer: Anne Ruedisili Langdji

UWC Student no:2706483

Tel: _237 99 50 38 80 (Cameroon) or +221 77 732 1533 or 33 968 1077 (Senegal)

E-mail: awlangdji@hotmail.com

Institution: School of Public Health, University of the Western Cape

Interviewee's pseudonym:

Place at which the interview was conducted:



Thank you for agreeing to allow me to interview you. What follows is an explanation of the purpose and process of this interview.

You are asked to give your consent to me on tape when we meet to conduct the interview.

1. Information about the interviewer

I am Anne Ruedisili Langdji, a student at the School of Public Health, University of the Western Cape, South Africa. As part of my Masters in Public Health, I am required to undertake a research project. I will be focusing on sharing one's HIV-positive status with friends, family or partners. I am accountable to Ms. Suraya Mohamed who is contactable at +27 21 959 2628 or c/o SOPH Fax: +27 21 959 2872 or by e-mail at sumohamed@uwc.ac.za

2. Purpose and contents of interview

Here is some information to explain the purpose and usage of my interview. The research will try to

better understand why people choose to share or not share their HIV-positive status with friends, family or partners. Through studying this question we hope that people living with HIV (PLHIV) and the people who provide care and support to them will know better how to help people decide about whether to share their status and the possible consequences, good or bad. We also hope that having more information about this will help develop policies in Senegal and in the region that are helpful to PLHIV and take into consideration their concerns around this issue.

3. The interview process

The study will consist of in-depth individual interviews, separately held with several PLHIV and service providers, such as the doctors or social worker or Projet SSP staff. Some questions that I will ask (with the help of a translator if needed) will help participants share your thoughts and ideas about the question of sharing one's HIV-positive status with others. The conversation will be recorded, but not by video.

4. Anonymity of participants

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 after the data has been collected.

5. Things that may affect your willingness to participate

The interview may touch on issues which make you uncomfortable. If there is anything that you would prefer not to discuss, please feel free to say so. I will not be offended and there will be no negative consequences if you would prefer not to answer a question. I would appreciate your guidance should I ask anything which you see as intrusive.

6. Agreement

6.1 Interviewee's agreement

The interviewee will be asked to give his/her consent below.

6.2 Interviewer's agreement

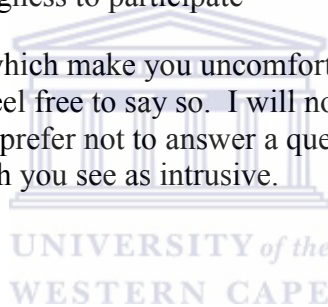
I shall keep the contents of the above research interview confidential in the sense that the pseudonym noted above will be used in all documents which refer to the interview. The contents will be used for the purposes referred to above, but may be used for published or unpublished research at a later stage without further consent. Any change from this agreement will be renegotiated with you.

Signed by interviewer:

Signed by participant:

Date:

Place:





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LETTRE DE CONSENTEMENT ECLAIRE POUR ENTRETIEN INDIVIDUEL

Date:

Chercheuse: Anne Ruedisili Langdji

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Institution: School of Public Health, University of the Western Cape

Pseudonyme du participant:

Lieu auquel l'entretien s'est tenu:

Merci de m'avoir accorder la possibilité de tenir cet entretien. Ce qui suit expliquera le but et le processus de l'entretien.

Je vous demande de me donner votre consentement au moment que nous nous rencontrons pour tenir l'entretien.

1. Information sur la chercheuse

Je m'appelle Anne Ruedisili Langdji, étudiante à l'Ecole de Santé Publique de l'Université de Western Cape, Afrique du Sud. Pour achever mon Masters en Santé Publique je dois entreprendre un projet de recherche. Je vais regarder la question du partage du statut VIH-positif avec ses amis, fa-

mille et partenaires. Je suis responsable devant Mme. Suraya Mohamed qui peut être contactée au numéro +27 21 959 2628 or c/o SOPH Fax: +27 21 959 2872 ou par courrier électronique à sumo-hamed@uwc.ac.za

2. But et contenu de l'entretien

Voici de l'information pour expliquer le but et utilisation de l'entretien. Cette recherche cherchera a mieux comprendre pourquoi les gens décident de partager ou non leur statut de VIH-positif avec leurs amis, leur famille ou leurs partenaires. A travers cette recherche nous espérons que les personnes vivants avec le VIH (PVVIH) et les prestataires des soins et les gens qui les appuient sauront mieux les aider dans cette décision à propos du partage du statut, y compris les avantages et désavantages. Nous espérons aussi que ces informations supplémentaires aideront au développement des politiques au Sénégal et dans la région qui seront utiles aux PVVIH et qui prendront en compte leurs soucis autour de cette question.

3. Le processus de l'entretien

Cette étude consistera des entretiens approfondis; tenus séparément avec des PVVIH et des prestataires de soins, comme les médecins, l'assistant social et le personnel du Projet SSP. Certaines questions vous seront posées par moi (avec un traducteur, si nécessaire) aideront au participant de partager ses idées et ses pensées par rapport à la question de partage du statut de VIH-positif. Cette conversation sera enregistrée, mais pas par vidéo.

4. Anonymat des participants

Pendant tout le processus je garderai la source des informations confidentielle et je réfèrerai à vous ou vos paroles avec un pseudonyme ou un nom que vous pourriez choisir. Je garderai toujours les documents et enregistrements sous clef et je les détruirai à la fin des recherches.

5. Quelque chose qui pourrait influencer votre volonté à participer à cette recherche

L'entretien pourrait toucher des points sensibles dont vous n'êtes pas à l'aise. S'il y a quelque chose dont vous n'aimeriez pas discuter, n'hésitez pas à le dire. Je ne serai pas déçue et il n'y aura aucune conséquence négative pour vous si vous ne répondez pas à une question. J'aimerai votre avis si je pose quelque chose d'inappropriée.

6. Consentement

6.1 Consentement du participant

Le participant est demandé de donner son consentement ci-dessous.

6.2 Consentement du chercheur

Je garderai confidentiel le contenu de l'entretien-ci en faisant que le pseudonyme noté ci-haut sera utilisé dans tous les documents qui se réfèrent à cet entretien. Le contenu sera utilisé pour le but cité

ci-haut, mais sera aussi utilisé pour la recherche publiée ou non-publiée sans consentement supplémentaire. Tout changement de cet accord sera renégocié avec vous.

Signé par la chercheuse:

Signé par le participant:

Date:

Lieu:



Appendix 7: Sample of Personal Research Record

January 13, 2012

The **first** participant today returned from the neighbouring town where she had taken her nine year-old son who was recently tested HIV positive for his first CD4. They were in good spirits and had some lunch and joked around with the folks gathered on the veranda who had eaten and who were taking their post-lunch break. Lots of people come by the SSP office/Mariame's house for social reasons, which is one of the factors that encourage PLHIV to come regularly as well.

We tried to shoo a few people away and chose to hold the interview in Mariame's room because there were others in the office who were not in the circle of confidence. It took a bit of time, in fact we paused after just a minute of recording to ask some others to leave the next room.

She was comfortable and didn't show any concern about the noise or presence of people nearby. She shared about her disclosure only to the association, having not told her husband, even now when one of her four children had tested positive. She was concerned that if she shared with someone they wouldn't keep it secret. She did, after ending the recording, say she had a brother who is a doctor in Dakar and had thought about telling him. She thinks he suspects her status and he had also offered to take charge of her son and his education, which is quite common here. He doesn't know the boy's HIV status.

She also said she's not prepared to disclose to her husband, that she knows he was tested negative and no longer has a desire to have any sexual relations. He has another wife in the north and does not live here permanently.

My **second** interview of the day was with Mariame. We talked in her room. We were only disturbed twice, fortunately, though one interruption was for about ten minutes. Since I was taking rough notes I didn't feel like we lost the thread. She shared openly, but I think since the other interviews are fresh in our minds many of her responses reflected those. After I had gone through the whole guide I went back and explored a little about areas where I had added notes in the margins of my notes to see whether she agreed with some of my analysis or other examples I remembered. There were a couple things that obviously would be identified by the project rather than the PLHIV.

I said that maybe we would record some more the next week, so if she thought of some other ideas she could share them then. But of course we're constantly in conversation, so other thoughts might be shared randomly. I think I need to go back through my lit review section as well to see if we might have been disregarding some aspects that I could at least check-in with Mariame about.

