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Stigma Perceived by Persons With Human Immunodeficiency Virus Attending the Infectious Diseases Clinic of Centre Hospitalier Universitaire de Fann in Dakar, Senegal

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STIGMA PERCEIVED BY PERSONS WITH HUMAN IMMUNODEFICIENCY VIRUS ATTENDING THE INFECTIOUS DISEASES CLINIC OF CENTRE HOSPITALIER UNIVERSITAIRE DE FANN IN DAKAR, SENEGAL

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Yale University School of Medicine and School of Epidemiology and Public Health
In Partial Fulfillment of the Requirements for the
Degree of Doctor of Medicine and Master of Public Health

By
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2007

STIGMA PERCEIVED BY PERSONS WITH HUMAN IMMUNODEFICIENCY VIRUS ATTENDING THE INFECTIOUS DISEASES CLINIC OF CENTRE HOSPITALIER UNIVERSITAIRE DE FANN IN DAKAR, SENEGAL

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Human Immunodeficiency Virus (HIV)-associated stigma is pervasive throughout the world. This stigma affects the ability of HIV-positive individuals to cope with their illness and it also affects behaviors around sexual practices, disclosure to others and the use of healthcare. The purpose of the research project was to examine the experience of internalized stigma among HIV-positive persons and their perceptions of stigmatizing attitudes in the community. The study also examined disclosure of HIV serostatus and identified factors contributing to disclosure and stigma in Senegal, a low prevalence Muslim country in West Africa. A cross-sectional study was conducted at Centre Hospitalier Universitaire de Fann in the form of a structured interview using a newly developed stigma instrument. The interviews were carried out in French and/or Wolof and the participants were interviewed during a routine visit to Fann Hospital. 15 men and 28 women aged between 19 and 55 years participated in the study. The mean period of time since diagnosis was 3.6 years (+/- 2.5 years). The stigma instrument showed a mean internalized stigma score of 5.4 +/- 3.5 (maximum score: 15) and an even higher level of perceived stigmatizing attitudes in the community of 7.9 +/- 4.8. Males had greater stigma scores than females. Almost 80 percent of the people interviewed had received some counseling, yet less than two-thirds of the study participants had disclosed their HIV status to others. People who had disclosed their HIV status used counseling less. The majority of subjects reported positive experiences with healthcare personnel in the Infectious Diseases Clinic of Fann Hospital. The level of internalized stigma and the perception of stigmatizing attitudes in the community are high with males experiencing more guilt. About three-fifths of the participants in the study had not disclosed their HIV status to even one other person; men disclosed their serostatus more frequently than women. Women were more likely to use counseling services compared to their male counterparts, and individuals who had disclosed their serostatus attended counseling less. Finally, despite the level of stigma perceived, the majority of people interviewed reported positive experiences with healthcare workers.

ACKNOWLEDGEMENTS

Those whose palm-kernels were cracked for them by a benevolent spirit should not forget to be humble – Ashanti Proverb

Me de aseda ma Nyame.

It is said by the elders that one finger alone cannot extract thorns from a foot. During my journey, there are several individuals who have encouraged and supported me. I would like to thank my mother, Akosua Akyaa Asafu-Agyei, whose love and guidance have been a consistent source of support. She taught me , through her example, how to achieve all that I set my mind to. Many thanks go to my siblings – Gerald Yaw Asafu-Agyei, William Kwaku Asafu-Agyei, Afua Anyamesem Rida and Hayet Kyiraa Rida – you made me smile and because of you, I was kept sane. Kobina Sam, *ma kuma mu tofe*, thank you.

To the Ghanaian Community at Yale (Filla-List), I thank you for the opportunity to spend many fulfilling years as *Ebusuapanyin*. I will certainly miss the 'meet-me-there' gatherings and discussions.

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I wish to thank Dr. Brian Forsyth, Dr. Papa Salif Sow and Prof. Kari Hartwig for serving as advisers for this thesis project. Thank you to the Yale University Department of Pediatrics for reviewing the thesis and supporting my application to residency.

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This thesis is dedicated to my father, Mr. Emmanuel Asafu-Agyei, whom I was never fortunate to meet.

TABLE OF CONTENTS

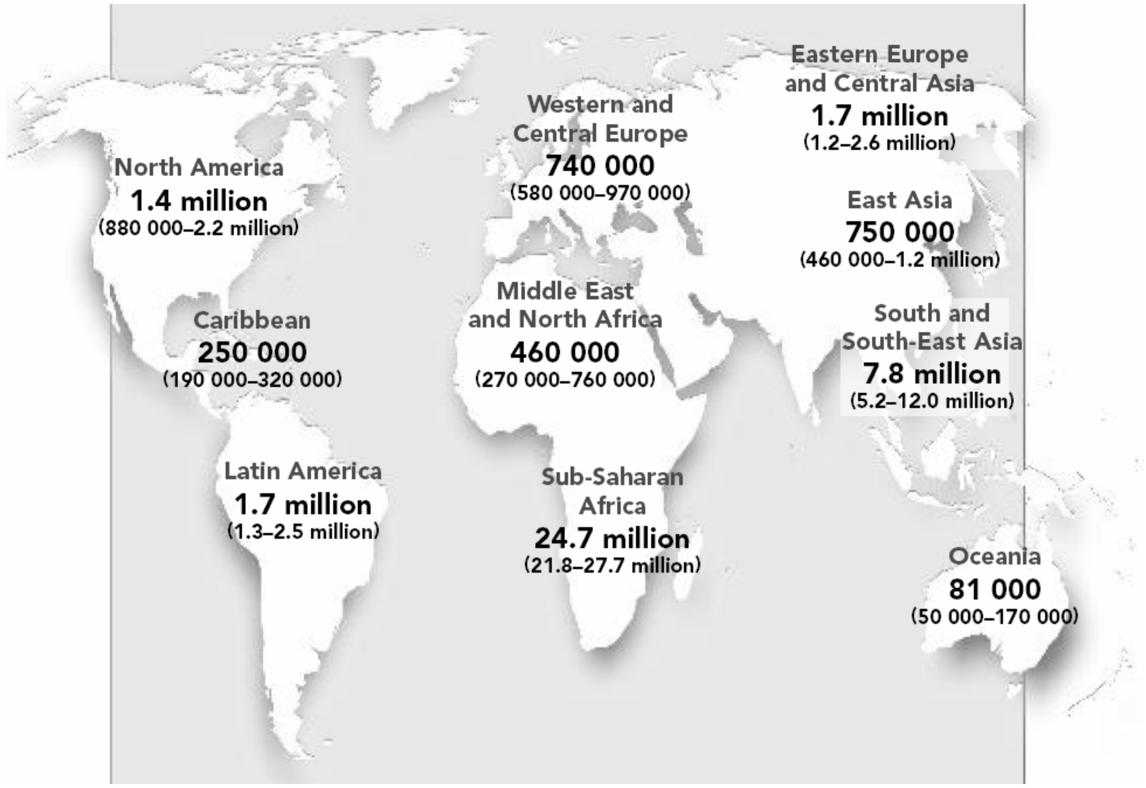
LIST OF TABLES

Stigma, silence, discrimination and denial, as well as lack of confidentiality, undermine prevention, care and treatment efforts and increase the impact of the epidemic on individuals, families, communities and nations - United Nations Declaration of Commitment on HIV/AIDS [1]

INTRODUCTION

According to the Joint United Nations Program on HIV/AIDS (UNAIDS) and the World Health Organization (WHO), at the end of 2006, there were 39.5 million people living with Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) worldwide. Of that number, 2.3 million were children under the age of 15 years. Despite the current knowledge about the means through which the virus is transmitted and the methods of prevention, 4.3 million people were newly infected with HIV in 2006 [2].

Figure 1 Adults and Children Estimated to be Living with HIV in 2006 [2]



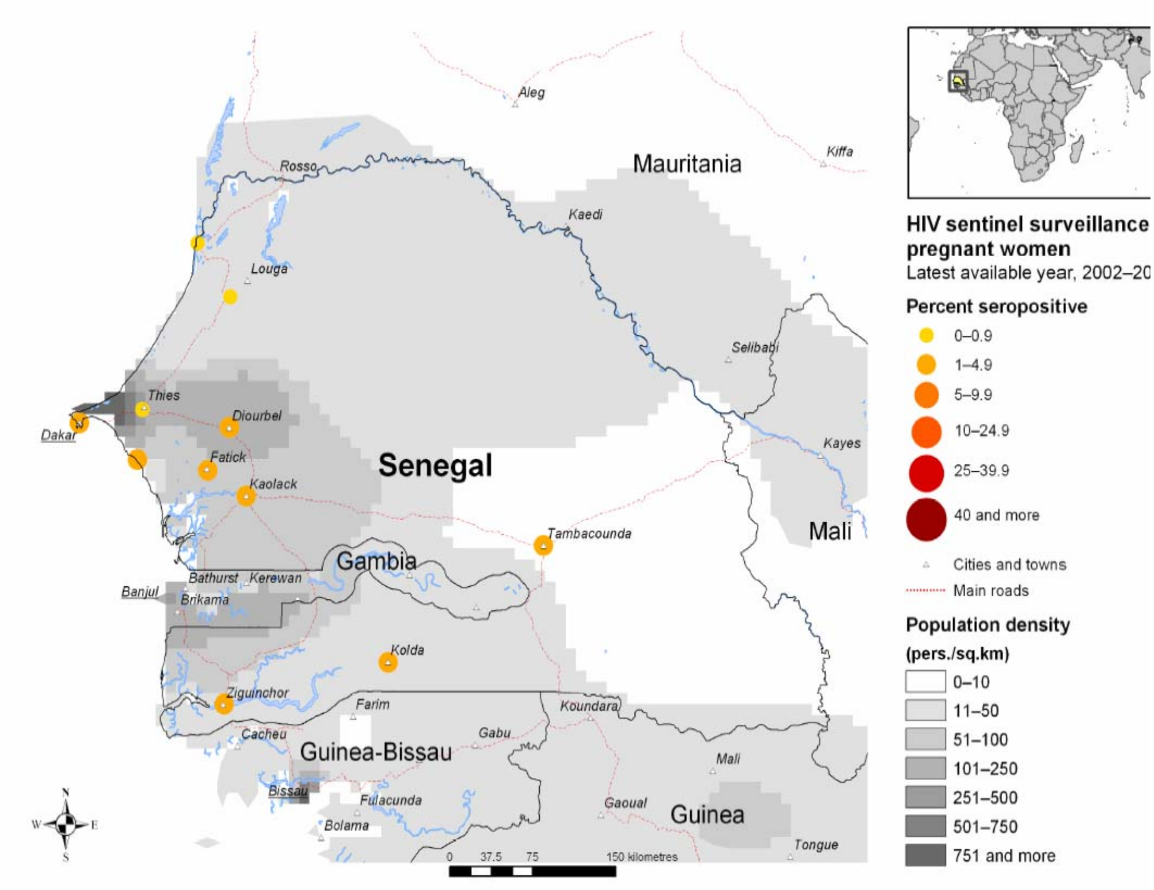
The greater part of the epidemic is concentrated in sub-Saharan Africa. Almost two-thirds of those living with the disease live in this region – particularly in southern Africa where about one-third of HIV-positive individuals worldwide live. Of the 2.9 million deaths from AIDS in 2006, 2.1 million of them were in Africa [2]. This is in spite of improving access to antiretroviral medications (ARVs). Unlike in Latin America and Asia, the African epidemic disproportionately affects females; 59 percent of individuals older than 15 years who are infected with HIV in sub-Saharan Africa are female. The predominant means of HIV transmission in the region is heterosexual sex and from mother-to-child although recently, there has been an increase in the use of injection drugs in Kenya, Tanzania, Nigeria and South Africa.

The Senegalese Situation

Almost a third of the adult population in a number of southern African nations are infected with HIV. In contrast, in West Africa prevalence rates are generally below 4 percent with the exception of la Cote d'Ivoire. While the number of people infected with HIV continues to increase in most of southern Africa, rates in West Africa are relatively stable or declining.

The HIV/AIDS situation in Senegal is unique even within West Africa. Senegal gained independence from France in 1960 and is governed by a democratically elected president and parliament. It has a population of approximately 11.9 million of which about 40 percent are below 14 years of age. Ninety-four percent of the population is Muslim. The national HIV prevalence in 2006 was 0.9 percent after having peaked in the early 2000s [3]. About 61,000 people were known to be HIV-positive at the end of 2005, and the total deaths due to AIDS numbered 5200 that same year. Among 15-24 year-olds, women had three times the prevalence of men.

Figure 2 Map of Senegal Showing Population Density and HIV Prevalence Among Women Attending Antenatal Clinics [3]



There are several reasons why Senegal has maintained a low prevalence rate. The first case of AIDS was reported in 1986 and that same year, the government created the *Programme National de Lutte Contre le SIDA* (National Program for the Fight against AIDS) which is now called the *Conseil National de Lutte Contre le SIDA* (National Council for the Fight against AIDS). The National Council was quick to set up a number of measures to reduce the spread of the virus. In addition to the swift response, the commitment of the government ensured that the support has been consistent through the years. The Senegalese government reinstituted a national blood supply and began screening all donated blood samples for HIV. By the end of 1987, every blood unit for transfusion in all the ten regions of the country was screened for HIV antibodies [4].

Commercial sex work was legalized in Senegal in 1969. Since then, sex workers have been required to register and attend regular health clinics where they are screened and treated for sexually transmitted infections. With the advent of AIDS, education about the virus and promotion of condom use was incorporated into programs for commercial sex workers. Condom use was also encouraged through social marketing campaigns in the community and free condoms were provided to high-risk populations [5]. As a result, condom use increased from being practically non-existent in the early 1990s to about 67 percent among men having casual sex by 1997 [6].

Since the mid-1980s, surveillance data from antenatal clinics has been collected and the information used to guide sex education and disease prevention [7]. Most importantly, religious leaders, both Muslim and Christian, were recruited to educate their followers about HIV. In particular Muslim leaders, worked to reinforce traditional sexual practices. They incorporated HIV education into religious teachings and they educated their congregation about AIDS and its effects at Friday prayers [8].

Figure 3 Examples of HIV/AIDS Education Materials

Senegal took advantage of low cost antiretroviral medications (ARVs) offered to African nations early, and she increased the budget allocated for purchasing ARVs in the late 1980s and early 1990s [9]. There are currently about 32 centers providing ARVs in Senegal. Through a program known as *d'Initiative Senegalaise* (the Senegalese Initiative), ARVs are provided on a sliding scale or free-of-charge to all who meet specified treatment criteria. A prospective study performed by Laurent et al to investigate the government's highly active antiretroviral therapy (HAART) program showed that the HAART program was effective and adherence and response rates were comparable to those in Western nations [10].

The measures instituted by the government had a profound effect on prevention and have contributed to the low prevalence of HIV/AIDS in Senegal. Educational campaigns aimed at improving knowledge were key. In a repeat cross-sectional study conducted in 1997 and 1998, more than 95 percent of children in secondary school and 99 percent of sex workers knew about AIDS and were able to correctly identify two methods of prevention. Between 70 and 80 percent knew that the virus could be transmitted by someone who looked healthy [11]. The result is that, HIV infection in Senegal is concentrated within specific populations in particular regions of the country. The southern regions of Zigiunchor and Kolda have prevalence rates of 2.2 and 2 percent respectively [12]. In Zigiunchor, however, about 30 percent of female sex workers are HIV-positive and sex workers remain a source of transmission to the general population [13].

In Senegal, Wade et al investigated the potential contribution of men who have sex with men (MSM) to the HIV situation. Until recently, the role of MSM was disregarded especially since homosexuality is illegal in Senegal. In this study, 94 percent of MSM also had sex with women. Wade et al found that 22 per cent of MSM in five urban cities (Dakar, Kaolack, Mbour, Saint-Louis and Thies) were infected with HIV and less than half of MSM reported using condoms during sexual interactions in the last month [14].

The Psychological Perspective

Treating the biological disease is only one aspect of the care of an individual infected with HIV. Strengthening coping mechanisms, alleviating suffering and improving quality of life are also important components of treatment. A number of studies by Susan Folkman et al have evaluated how HIV-positive individuals and their caregivers manage. Their findings indicate that focusing on the psychological well being of a patient and how they cope is essential as a complement to traditional medicine [15,16]. Other studies looking at psychosocial care have also shown that when psychosocial factors are ignored, it could lead to social problems such as alienation and even a deterioration of medical conditions [17]. In Kenya, Vollmer and Valadez concluded that HIV infected men and women raised at least eight psychological issues during a counseling session with paraprofessional counselors and it was important to address those issues [18]. Most of the psychological concerns relate to the infected person feeling stigmatized because of his or her disease.

Stigma

HIV stigma is defined as “all unfavorable attitudes, beliefs, and policies directed toward people perceived to have HIV/AIDS as well as toward their significant others and loved ones, close associates, social groups, and communities [19].” This can result in discrimination and violence particularly towards groups that have historically been marginalized such as women and MSM. The stigma in turn affects an individual’s ability to cope, their actions and whether they choose to disclose their serostatus. It exists in all parts of the world and has been described as the “greatest barrier to preventing further

[HIV] infections [20].”

In the early 1980s, individuals who where found to be HIV-positive in the United States and abroad were discriminated against and sometimes they lost their jobs, friends and family. By the late 1990s, despite the fact that there was a better understanding of the disease and effective treatment had become available, negative attitudes towards HIV and AIDS still persisted. A national telephone survey carried out in the United States in 1997 revealed that more than a quarter of people were uncomfortable associating with a person who had AIDS [21].

Gregory Herek has been instrumental in defining HIV stigma. He notes that four characteristics are usually found in diseases that are stigmatized. First, stigma is often associated with diseases for which the person with the illness is thought to be responsible and with HIV/AIDS, there is the association with homosexuality, unsafe sex and injection drug use. Secondly, incurable diseases evoke high levels of stigma and presently, despite the fact that the disease can be controlled by ARVs, there is no cure. Thirdly, stigmatized diseases are often those which are not well understood especially where there is the belief that it is easily transmissible to the general population. Finally, stigma is associated with diseases for which the symptoms cannot be concealed and are obvious to others, and in the late stages of AIDS, the physical effects of the disease are impossible to hide [22].

The causes of stigma may range from the lack of understanding about the disease to myths about HIV- myths that are fueled by mistaken beliefs about how the disease is transmitted, prejudice, irresponsible media reporting, social fears about sexuality and fears relating to illness and death [23]. Senegal is not immune from this stigma. Despite the high level of knowledge about HIV and how it is transmitted, misconceptions still exist. About one-third of those involved in a cross-sectional study thought that HIV could be transmitted by the mosquito or from sharing the same toilet [24]. These misconceptions breed ignorance which results in the stigmatization of those with HIV/AIDS.

The effect of stigma is profound. The fear of being ostracized because of one's sero-positive status may deter some from testing and affect the choices that they make [25]. Being thus unaware of their status, they may spread the virus. Stigma may lead to the internalization of the notions of others and the adoption of self-loathing, self-blaming and self-destructive behavior [26].

Interventions aimed at reducing stigma in the United States are often divided into those that affect policy/legal interventions and those that affect programs and services. The majority of research has been in the area of legal and policy interventions. These were developed in response to the public health fear that stigma and discrimination would drive the epidemic underground. The public health policies were an attempt to give those with HIV protection under the law.

In contrast, there is limited research examining the effects of programs and services even though sometimes the interventions required are simple. For example, Herek and

Capitanio investigated the relationship between AIDS stigma and direct or vicarious contact with people with AIDS in the United States. The study showed that those who had had contact with someone with HIV were likely to attribute less shame and disgrace to having HIV [27]. A simple programmatic intervention could provide forums for interacting with people with HIV/AIDS. Programs and services likely have an important role in changing attitudes and behaviors and modifying the environment that leads to discrimination against HIV-infected persons.

Few studies have evaluated the level of stigma perceived by HIV-infected persons in Africa and examined what factors affect an individual's experience of stigma. Senegal presents a unique challenge. In most of Africa, it is the general lack of information about HIV/AIDS and the resulting ignorance that fuels the epidemic of stigma. In Senegal, there is considerable awareness about HIV yet stigma still exists. This research project serves to characterize HIV/AIDS-stigma in Senegal.

STUDY PURPOSE

The purpose of the study was to examine the level of stigma and the degree of disclosure of a sample of HIV infected people attending the Infectious Disease Clinic of Centre Hospitalier Universitaire de Fann. The project also aimed to identify factors that may contribute to disclosure and stigma.

The research study examined internalized stigma which is the degree to which a person feels stigmatized by his/her disease. The project also examined the individual's perception of the stigmatizing attitudes of others within the community.

The research was conducted so that the results could contribute to providing a greater understanding about the HIV/AIDS experience in Senegal while addressing issues of disclosure and stigma.

HYPOTHESIS

- Levels of stigma will be high.
- The level of disclosure will be low.
- The greater the amount of stigma the less likely an individual is to disclose their serostatus.

SPECIFIC AIMS

- To describe the demographics of HIV patients seen at the infectious disease clinic of Centre Hospitalier Universitaire de Fann.
- To determine the level of stigma perceived by HIV-infected individuals attending the infectious diseases clinic.
- To establish what factors affect how stigmatized an individual feels and the nature of the relationship between those factors and internalized/personal stigma and stigma perceived in the community.
- To ascertain what factors contribute to an individual’s decision to disclose their HIV serostatus.
- To characterize the nature of the relationship between HIV-positive patients and healthcare providers at Fann Hospital.

METHODS

Setting

The research project was carried out in Dakar, the capital city of Senegal. Dakar occupies the westernmost point of Africa and is located on the Cape Verde Peninsula. It is a coastal city with a population of approximately 2.4 million of which 1 million live in Dakar proper [28]. Dakar is ethnically diverse with the Wolof being the dominant ethnic group. French is the official language but Wolof is also widely spoken.

Figure 4 Map of Senegal

The study was performed at the Infectious Diseases Clinic of Centre Hospitalier Universitaire de Fann which is affiliated with Cheikh Anta Diop University. The department contains 80 beds and takes care of patients with HIV/AIDS, malaria, meningitis, typhoid fever and tuberculosis among others. There are 10 physicians and 35 nurses. Approximately 3000 patients are hospitalized each year and about 15,000 are seen in the outpatient clinic. The HIV/AIDS center has the capability of measuring CD4 counts and viral loads. Patients have access to individual and group counseling, prophylaxis and treatment for opportunistic infections and antiretroviral therapy. ARVs are offered on a sliding scale from approximately $8 per month for persons who are employed to free-of-charge for the unemployed through the Senegalese Initiative program that was set up in 1998 [29].

Figure 5 Image Showing the Front Entrance of Fann Hospital

Study Sample

Persons older than 16 years attending the outpatient HIV Clinic at Fann Hospital were invited to participate in the study which took place from June 16, 2003 to August 15, 2003. Participation was voluntary. Individuals were excluded from participating if they were first time attendees to the clinic or inpatients at Fann Hospital. A total of 43 subjects participated in the study – 15 males and 28 females. Only 5 persons who were invited refused to participate. The most frequently cited reason was time constraint.

Interview

All interviews were carried out in French or Wolof by the author alone or in conjunction with Bintou Diaw (social worker), Mariam N'diaye (social worker) and/or Seydou Ba (HIV/AIDS patient coordinator). The author was present for all the interviews. The purpose of the study and the study procedures were explained to each participant and informed consent was obtained prior to the administration of the questionnaire. The interviews were carried out in a private room within the Infectious Diseases outpatient clinic to protect confidentiality. Each interview lasted about 30 minutes. At the end, participants were compensated 1500 FCFA (approximately $3) to be used towards transportation expenses.

Questionnaire

The questionnaire was designed with input from Dr. Brian Forsyth and Dr. Papa Salif Sow adapting a version of a stigma instrument developed in South Africa. The study protocol and questionnaire were approved by the Human Investigations Committee of Yale University School of Medicine (HIC # 25223) and the Internal Review Board of Cheikh Anta Diop University/Fann Hospital.

The original English version of the questionnaire was translated into French, back-translated, and reviewed for cultural appropriateness. HIV is not mentioned frequently in the questionnaire but referred to as “your illness” with the understanding that it meant HIV/AIDS. Each questionnaire was identified by a unique questionnaire number. No names were collected and the completed questionnaires were stored in a locked cabinet.

The questionnaire was comprised of six parts. The first section obtained socio-demographic information such as gender, age, educational background, ethnicity, length of time living in Dakar, marital status, number of children, type of living situation and employment status. Section II was designed to collect information about an individual's personal experience with HIV and included questions such as "When was your HIV test first positive?" "Why did you take the test?" "Do you know how you may have contracted HIV?" and "Are you taking antiretroviral medications?" Disclosure was measured in Section III through the questions "Have you told anyone that you are sick?" "If yes, list three people you told and their reaction" and "If no, why have you chosen not to tell others?" Section IV analyzed experience with health professionals. Study participants were required to respond to statements such as "All my experiences with the physicians and nurses have been positive" and "The physicians and nurses treat me differently because I am sick [with HIV]." Section V and VI assessed internalized stigma and perceptions of stigma in the community respectively. The statements were divided into three groups – View of Self, Fear of Experience and Fear of Transmission. For each statement that evaluated internalized stigma, there was a corresponding statement with altered wording to assess the perception of stigmatizing attitudes in the community. For example, a statement in Section V is "Because I have HIV, I should not hold a baby" and the corresponding statement in Section VI is "Most people believe that individuals with HIV should not hold babies."

Originally, the response options for Section IV, V and VI were “Strongly Agree”, “Agree”, “Disagree” and “Strongly Disagree” but it was found that in responding, participants found it difficult to determine by how much they agreed or disagreed and typically responded that they agreed or disagreed. The questionnaire was thus modified accordingly and only two response options were used – “Agree” or “Disagree”. A copy of the questionnaire has been included in the appendix.

Analysis

All 43 questionnaires that were completed were included in the analysis. Information obtained from the questionnaires was entered into a Microsoft Excel spreadsheet and statistical analysis was performed using SAS. Primary analysis included the use of descriptive statistics to describe the study population demographically. Chi-square (X^2) and t-tests were used to examine for associations between categorical data and continuous variables respectively.

RESULTS

43 questionnaires were used in the analysis.

Demographic Characteristics

Table 1 represents the demographic characteristics of the study population. Of the 43 study participants, 28 (65.1%) were female and only 15 (34.9%) were male. The mean age was 37 years (standard deviation (SD) = 7.8) years but ranged from 19 to 55 years with males having a slightly higher mean age of 38 (SD = 7.6) as compared to 36.5 (SD = 8.0) for females. The most common ethnic groups represented were the Wolof (37.2%), Toucouleur (11.6%) and the Serer (11.6%). Other groups present included the Pular, Peul, Joula, Leebu, Mande and Sarakhle. There were two participants (4.7%) who were foreign nationals. Three-quarters of the group had spent more than ten years living in Dakar. Four participants (9.3%) had spent less than a year in Dakar or commuted to the city for their clinic appointments. About two-thirds (65.1%) were employed at the time the study was carried out. Recurrent illness and lack of energy were the most frequently reported reason for not working.

A large proportion of women (42.9%) were married while only 26.7% of the men were married. In contrast, 46.7% of the men were single/never married compared to only one woman (3.6%) who had never been married. More women than men were widowed. The mean number of children was 2.3 though it ranged from zero to seven. Ten study participants (23.3%) did not have children. Most people (69.8%) lived in communal homes that they shared with their extended family or other families.

Table 1 Demographic Characteristics of the Study Population

	Demographic Characteristics			
		Female	**Male**	**Total**
Variable		Number (%)	Number (%)	Number (%)
Gender				
		28 (65.1%)	15 (34.9%)	43
Age				
	Mean	36.5	38	37
	Standard Deviation	8.0	7.6	7.8
Education				
	None	7 (25%)	3 (21.4%)	10 (23.8%)
	Primary	11 (39.3%)	1 (7.1%)	12 (28.6%)
	Secondary	10 (35.7%)	8 (57.1%)	18 (42.9%)
	Tertiary	0	2 (14.3%)	2 (4.8%)
Ethnicity				
	Wolof	9 (32.1%)	7 (46.7%)	16 (37.2%)
	Toucouleur	4 (14.3%)	1 (6.7%)	5 (11.6%)
	Serer	3 (10.7%)	2 (13.3%)	5 (11.6%)
	Pular	1 (3.57%)	3 (20.0%)	4 (9.3%)
	Other	9 (32.1%)	2 (13.3%)	11 (25.6%)
	Foreign	2 (7.1%)	0	2 (4.7%)
Years Spent in Dakar				
	<1 year	2 (7.1%)	2 (13.3%)	4 (9.3%)
	1-5 years	3 (10.7%)	2 (13.3%)	5 (11.6%)
	5-10 years	1 (3.6%)	1 (6.7%)	2 (4.7%)
	>10 years	22 (78.6%)	10 (66.7%)	32 (74.4%)
Marital Status				
	Single	1 (3.6%)	7 (46.7%)	8 (18.6%)
	Married	12 (42.9%)	4 (26.7%)	16 (37.2%)
	Separated	2 (7.14)	0	2 (4.7%)
	Divorced	5 (17.9%)	3 (20.0%)	8 (18.6%)
	Widowed	8 (28.6%)	1 (6.7%)	9 (20.9%)
Children				
	Yes	24 (85.7%)	9 (60.0%)	33 (76.7%)
	No	4 (14.3%)	6 (40.0%)	10 (23.3%)
	Mean # of children	2.5	1.9	2.3
	Standard Deviation	1.8	2.2	2
Living Situation				
	Share Home	19 (67.9%)	11 (73.3%)	30 (69.8%)
	Do Not Share Home	9 (32.1%)	4 (26.7%)	13 (30.2%)
Employment Status				
	Yes	17 (60.7%)	11 (73.3%)	28 (65.1%)
	No	11 (39.3%)	4 (26.7%)	15 (34.9%)

HIV Experience

The mean amount of time since an individual was diagnosed with HIV was 3.6 years (SD = 2.5) which was comparable to the mean number of years that study participants had been receiving care at Fann Hospital (3.4 years). The majority of men (71.4%) and women (60.7%) were aware of how they contracted HIV. Most people were tested for HIV when they were ill usually with opportunistic infections such as shingles or tuberculosis. One woman tested positive for HIV after her newborn became ill and was found to have HIV. One person reported injection-drug use and another reported a blood transfusion as the source of their HIV infection. All others were thought to have acquired HIV through heterosexual sex. Many who were aware of how they had contracted HIV, believed that they got it from a spouse. In Senegal, antiretroviral medications are provided to all persons who present with an opportunistic infection or have a CD4 count less than 350. About two-thirds (65.1%) of the participants in the study met this criteria. While only 53.3 percent of males reported having access to counseling or a forum in which they were able to talk about their experience with HIV, almost all (92.9%) of women reported having had counseling.

Table 2 HIV Experience

		HIV Experience		
		Female	**Male**	**Total**
Variable		Number (%)	Number (%)	Number (%)
Years since diagnosis				
	Mean	3.8	3.2	3.6
	Std. Deviation	2.5	2.3	2.5
Duration of care provided by Fann Hospital				
	Mean	3.6	3.1	3.4
	Std. Deviation	2.6	2.4	2.6
Knowledge of how personally infected with HIV				
	Yes	11 (39.3%)	4 (28.6%)	15 (35.7%)
	No	17 (60.7%)	10 (71.4%)	27 (64.3%)
Antiretroviral Treatment				
	Yes	19 (67.9%)	9 (60.0%)	28 (65.1%)
	No	9 (32.1%)	6 (40.0%)	15 (34.9%)
Access to Counseling				
	Yes	26 (92.9)	8 (53.3%)	34 (79.1%)
	No	2 (7.1)	7 (46.7%)	9 (20.9%)

Disclosure

Twenty-six individuals (60.5%) had disclosed their HIV positive status to another person. Men were more likely to have disclosed their HIV status (80%) whereas only half of the women had. Married individuals also had less disclosure (50%) compared to those who were not married (66.6%). Other trends that were related with more disclosure were sharing a home, having no children, knowing how one was infected with HIV and taking antiretroviral medication. Education did not appear to have an effect on disclosure as the rates were comparable between those who had no education and those who had some education – 60.0% versus 59.4%.

The only significant association ($p < 0.05$) was between disclosure and previous counseling experience. Those with no previous counseling experience were more likely to have disclosed their HIV status (88.9%) while only 52.9 percent of those who had had access to counseling had disclosed their status.

Much fear and anxiety surrounds disclosure. Most respondents agreed that they worried that someone they told would tell others (74.4%) and that they were careful whom they told they have HIV (88.4%). None of these associations were statistically significant between gender groups.

Table 3 Factors Affecting Disclosure of Serostatus

			Disclosure	
			No	**Yes**
Variable		n	Number (%)	Number (%)
Gender				
	Female	28	14 (50.0%)	14 (50.0%)
	Male	15	3 (20.0%)	12 (80.0%)
Marital Status				
	Married	16	8 (50.0%)	8 (50.0%)
	Not Married	27	9 (33.3%)	18 (66.6%)
Education				
	Some Education	32	13 (40.6%)	19 (59.4%)
	No Education	10	4 (40.0%)	6 (60.0%)
Living Situation				
	Share Home	30	11 (36.7%)	19 (63.3%)
	Do Not Share Home	13	6 (46.2%)	7 (53.9%)
Children				
	Yes	33	14 (42.4%)	19 (57.6%)
	No	10	3 (30.0%)	7 (70.0%)
Knowledge of how infected with HIV				
	Yes	15	5 (33.3%)	10 (66.7%)
	No	27	12 (44.4%)	15 (55.6%)
Antiretroviral Treatment				
	Yes	28	10 (35.7%)	18 (64.3%)
	No	15	7 (46.7%)	8 (53.3%)
Access to Counseling[A]				
	Yes	34	16 (47.1%)	18 (52.9%)
	No	9	1 (11.1%)	8 (88.9%)

[A] Statistically significant, $p<0.05$

Table 4 Participant Responses to Statements Concerning Disclosure

Statement	n	**Disagree** Number (%)	**Agree** Number (%)
I worry that those who know I have HIV will tell others	43	11 (25.6%)	32 (74.4%)
I am careful whom I tell that I have HIV	43	5 (11.6%)	38 (88.4%)

Internalized Stigma

The mean internalized stigma score was 5.4 (SD = 3.5) with a range from 0 to 14. There were no significant differences between internalized stigma and the variables examined in Table 5 (gender, education, marital status, time spent in Dakar, employment, living situation, disclosure and antiretroviral treatment status). Despite the fact that none of the associations were significant, the mean stigma score for those with no formal education (7.0, SD = 4.3) was higher than that for those with some education (4.9, SD = 3.2). This same relationship was observed for those living in Dakar for less than 10 years who had mean stigma scores of 7.0 (SD = 3.5) as compared with 4.9 (SD = 3.4) for those who have lived in Dakar for more than 10 years.

Men and women also responded similarly to most of the statements aimed at eliciting the amount of internalized stigma. There were significant differences with regards to gender for only two of statements – I feel guilty about having HIV (p-value < 0.05) and I must have done something wrong to deserve getting HIV (p-value < 0.05). For both of these statements, men experienced more stigma then women. Consistently for statements concerning View of Self, a higher proportion of men relative to women responded in a manner that showed they felt stigmatized. On the other hand, with regards to Fear of Experience, the responses were such that a larger percentage of women agreed with the stigma statements. For Fear of Transmission, a slightly larger proportion of females agreed with the statements.

Table 5 Association Between Various Factors and Internalized Stigma

Variable	Factors Associated with Internalized Stigma	Mean Stigma Score	Standard Deviation
Gender			
	Female	5.1	3.4
	Male	5.9	3.9
Education			
	Some education	4.9	3.2
	No education	7	4.3
Marital Status			
	Married	5.3	3
	Not married	5.5	3.9
Time spent in Dakar			
	< 10 years	7	3.5
	> 10 years	4.9	3.4
Employment			
	Yes	4.9	3.1
	No	6.5	4.1
Living Situation			
	Share Home	4.9	3.4
	Do Not Share Home	6.5	3.8
Disclosure			
	Yes	4.7	3.4
	No	6.5	3.8
Antiretroviral Treatment			
	Yes	5.9	4
	No	4.5	2.3
Access to Counseling			
	Yes	5.6	3.5
	No	4.8	3.7

Table 6 Responses to Statements Concerning Internalized Stigma by Gender

		Response		
		Disagree	**Agree**	**P-value**
Internalized Stigma Statement		Number (%)	Number (%)	
View of Self				
**Although I am sick, I deserve as much respect as others who are not sick				
	Female	4 (14.3%)	24 (85.7%)	NS[A]
	Male	2 (13.3%)	13 (86.7%)	
**Although I am sick, I believe that I am no different from others				
	Female	8 (28.6%)	20 (71.4%)	NS
	Male	4 (26.7%)	11 (73.3%)	
I am ashamed that I have HIV				
	Female	9 (33.3%)	18 (66.7%)	NS
	Male	4 (26.7%)	11 (73.3%)	
I think that I am a bad person				
	Female	23 (82.1%)	5 (17.9%)	NS
	Male	11 (73.3%)	4 (26.7%)	
I feel guilty about having HIV				
	Female	22 (78.6%)	6 (21.4%)	**0.033**[B]
	Male	7 (46.7%)	8 (55.3%)	
Since learning I have HIV, I feel more isolated				
	Female	18 (64.3%)	10 (35.7%)	NS
	Male	8 (53.3%)	7 (46.7%)	
I think that having HIV is punishment for bad behavior				
	Female	19 (67.9%)	9 (32.1%)	NS
	Male	8 (53.3%)	7 (46.7%)	
I understand why people do not want to be friends with me				
	Female	19 (67.9%)	9 (32.1%)	NS
	Male	10 (66.7%)	5 (33.3%)	
I must have done something wrong to deserve getting HIV				
	Female	24 (92.3%)	2 (7.7%)	**0.036**[B]
	Male	10 (66.7%)	5 (33.3%)	
**I think that I am a person of good moral character				
	Female	0	28 (100%)	NS
	Male	1 (6.7%)	14 (93.3%)	
Fear of Experience				
Some people who know that I have HIV have grown more distant				
	Female	15 (55.6%)	12 (44.4%)	NS
	Male	11 (73.3%)	4 (26.7%)	
People are afraid of me because I have HIV				
	Female	14 (50.0%)	14 (50.0%)	NS
	Male	9 (60.0%)	6 (40.0%)	
Fear of Transmission				
Because of my HIV, I should not hold babies				
	Female	16 (61.5%)	10 (38.5%)	NS
	Male	11 (73.3%)	4 (26.7%)	
Because of my HIV, no one will hire me				
	Female	18 (64.3%)	10 (35.7%)	NS
	Male	10 (66.7%)	5 (33.3%)	
If I drink from a water fountain and someone knows that I am HIV positive, they will not drink from the same water fountain				
	Female	13 (46.4%)	15 53.6%)	NS
	Male	7 (46.7%)	8 (53.3%)	
If people know that I am HIV positive, they will not sit next to me in a bus				
	Female	16 (57.1%)	12 (42.9%)	NS
	Male	7 (46.7%)	8 (53.3%)	

[A] NS – not statistically significant

[B] Statistically significant, $p<0.05$

** Items reverse scored

Perception of Stigmatizing Attitudes in the Community

The mean stigma score was 7.9 (SD = 4.8). Males perceived that people in the community were more stigmatizing (8.5, SD = 4.7) than did women (7.6, SD = 4.9) – the difference was not significant. There was, however, a significant association between the perception of stigmatizing attitudes in the community and living situation (p-value < 0.01), and between perceived stigma and whether or not a person was on antiretroviral medication (p-value < 0.05). Persons who did not share their home had higher stigma scores (10.6, SD = 3.5) than those who did (6.7, SD = 4.8). Those who were taking antiretroviral medication also perceived others to be more stigmatizing (9.0, SD = 5.3) than those who were not (5.9, SD = 2.9). Education, gender, martial status, time spent in Dakar, employment, disclosure and access to counseling did not show an association with the perception of stigmatizing attitudes in the community.

Comparing gender differences in the response to statements concerning perceived stigma in the community only one statement - Most people believe that persons with HIV are of good moral character (reverse-scored item) - was significant with a p-value < 0.01. Almost half of all men interviewed agreed with the statement while only 11.1% of women agreed with the statement.

Table 7 Association Between Various Factors and Perception of Stigmatizing Attitudes in the Community

Factors Associated with the Perception of Stigmatizing Attitudes in the Community

Variable		Mean Stigma Score	Standard Deviation	P-value
Gender				
	Female	7.6	4.9	NS[A]
	Male	8.5	4.7	
Education				
	Some education	7.7	4.9	NS
	No education	8.7	4.7	
Marital Status				
	Married	7.9	3.7	NS

	Not Married	7.9	5.4	
Time spent in Dakar				
	< 10 years	9	4.4	NS
	> 10 years	7.6	4.9	
Employment				
	Yes	7.7	4.8	NS
	No	8.4	4.9	
Living Situation				
	Share Home	6.7	4.8	**0.006**[B]
	Do Not Share Home	10.6	3.5	
Disclosure				
	Yes	7.7	5.1	NS
	No	8.3	4.3	
Antiretroviral Treatment				
	Yes	9	5.3	**0.019**[B]
	No	5.9	2.9	
Access to Counseling				
	Yes	8.1	4.9	NS
	No	7.2	4.6	

[A] NS – not statistically significant
[B] Statistically significant, $p<0.05$

Comparison Between Responses to Corresponding Internalized Stigma and Perception of Stigmatizing Attitudes in the Community

The mean perception of stigmatizing attitudes in the community (7.9, SD = 4.8) was greater than the mean level of internalized stigma (5.4, SD = 3.5). Out of a total of 15 corresponding statements, six showed significant differences in the way that individuals responded. Consistently for all significant results, more individuals agreed with the statement that elicited the level of perceived stigma in the community and more participants disagreed with the same statement worded to show internalized stigma. For example, 93.3 percent agreed with the statement "Most people think that persons with HIV should not touch babies" while only 44 percent agreed with "Because of my illness, I should not touch babies."

Table 8 Statements Showing Significant Association in the Comparison Between Responses to Corresponding Internalized Stigma and the Perception of Stigmatizing Attitudes

Comparison Between Responses to Corresponding Internalized Stigma and Perception of Stigmatizing Attitudes Statements

Internalized Stigma	**Perception of Stigmatizing Attitudes**	**P-value**
Some people who know that I have HIV have grown more distant	Most people who will reject those with HIV	0.0018
I am ashamed that I have HIV	Most people feel that having HIV is something to be ashamed about	0.014
Because of my HIV, I should not hold someone's baby	Most people think that persons with HIV should not hold babies	0.0064
Because of my HIV, no one will hire me	Most employers will not hire someone with HIV	0.0035
If I drink from a fountain and someone knows that I am HIV positive, they will not drink from the same fountain	Most people will not drink from the same fountain as someone who has HIV	<0.0001
I understand why people do not want to be friends with me	Most people are afraid of those with HIV	0.0012

Experience with Medical Professionals

Study participants reported positive interactions with health professionals. The mean value for negative experiences with health professionals was 1.6 (SD = 1.0) out of 6 and varied from 0 to 4. There were non-significant differences in the mean response for the variables shown in Table 9. Though none of the relationships were statistically significant, three-quarters of those having positive experiences had some education and almost three-quarters had lived in Dakar for more that ten years. Most people with good health care experiences did not live alone (73.2%) and 65 percent were taking ARVs.

There was a significant difference in the way that males and females responded to "All my experiences with doctors and nurses have been positive" (reverse-scored item). One hundred percent of women agreed with the statement as opposed to only 69.2 percent of men ($p<0.01$). There was no significant difference in the responses to other statements.

Table 9 Association Between Various Factors and Experience with Medical Professionals

Factors Associated with Experiences with Health Professionals		
Variable		**Number (%)**
Gender		
	Female	28 (68.3%)
	Male	13 (31.7%)
Education		
	Some education	31 (75.6%)
	No education	10 (24.4%)
Marital Status		
	Married	15 (36.6%)
	Not Married	26 (63.4%)
Time spent in Dakar		
	< 10 years	11 (26.8%)
	> 10 years	30 (73.2%)
Employment		
	Yes	27 (65.9%)
	No	14 (34.1%)
Living Situation		
	Share Home	30 (73.2%)
	Do Not Share Home	11 (26.8%)
Disclosure		
	Yes	24 (58.5%)
	No	17 (41.5%)
Antiretroviral Medication		
	Yes	27 (65.9%)
	No	14 (34.1%)
Access to Counseling		
	Yes	33 (80.5%)
	No	8 (19.5%)

DISCUSSION

The study sample was made up of almost two-thirds women. Though an attempt was made to enroll an equal number of males and females, the final number represents the fact that more women attended the clinic. For three women who denied prior blood transfusion, injection drug use or sexual intercourse with anyone but their husbands, they reported that their spouses refused to be tested. The representation of ethnic groups was similar to that which exists in Dakar.

Three-quarters of the study participants had lived in Dakar for more than ten years. This is not unexpected given that the clinic is located in Dakar and other clinics offer HIV treatment and care in different parts of the country.

HIV Experience

Related to HIV experience, 71.4 percent of men knew how they contracted HIV and a lesser number of women (60.7%) were aware of how they got the disease. Individuals may have failed to report how they contracted HIV because they were embarrassed e.g. if they contracted the disease from a sex worker, intravenous drug use or homosexual sex. They may also have been afraid that the information may influence how they are treated at the clinic.

All persons seen at the Infectious Disease Clinic have access to counseling both one-on-one and in a group. Bok Jef (Acting Together) is a network of people living with HIVAIDS in Dakar and meets monthly at the Clinic. The sessions were free yet only

53.3 percent of men reported having attended a counseling or group session while almost all women reported they had (92.9%). The men may feel more of the need to present a strong front and may not permit themselves to attend such sessions because it may appear as a sign of weakness. They may also be more afraid of being recognized by others at a group meeting. Men may also feel more guilt about being HIV infected because of the methods by which they acquired the disease.

Disclosure

Close to two-thirds (60.5%) of participants in the study had disclosed their HIV status to others. Disclosure occurred more frequently among men (80%) than women (50%). Those who had not disclosed their serostatus most often reported fear of a negative reaction as the reason for their decision. Disclosure rates were higher for men possibly because women are more vulnerable to the effects of discrimination. They could potentially lose their home, children and livelihood if it is known that they have HIV, while men, who are often the breadwinners, have less to lose.

While there were many non-significant associations between disclosure and independent variables, there was a significant association between disclosure and prior counseling experience. Those without prior access to counseling were more likely to have disclosed their HIV status to another person (p-value < 0.05). Individuals who have disclosed their status to others may have less of a need to go to counseling. This is because they may have the social support of those they have informed, whereas individuals who have not disclosed their status will have the counseling sessions as the only times in which they can talk about their experience with HIV. Other trends that were related to more disclosure were living with others, knowing how one contracted HIV and not having any children though none of these relationships were statistically significant.

Response to the statements in Table 4 indicate that there is a lot of concern around telling others that one is HIV positive because of previous negative experiences and the worry that telling one person can easily lead to everyone knowing. For each item, at least thirty individuals responded that they agreed with the stigmatizing statement. Response patterns were similar between males and females though more women had been hurt by the way people reacted and they worried more frequently that people they had told would tell others. Men on the other hand, were more concerned about whom they told that they had HIV.

Stigma

The stigma scores for men and women were similar. The mean internalized stigma score for men was 5.9 (SD = 3.9) and that for women was 5.1 (SD = 3.4). For the perception of stigmatizing attitudes in the community, the mean score for men was 8.5 (SD = 4.7) compared with 7.6 (SD = 4.9) for women. There are many reasons why men could possibly have had the slightly higher, though not statistically significant, mean stigma scores than women. Males may feel more remorse about having HIV because of the means through which they acquired the disease. This can be seen in the fact that more men reported feeling guilty about having HIV (p-value = 0.033) and that more men also felt that they must have done something wrong to deserve getting HIV (p-value = 0.036).

Having experienced counseling, the women may be less inclined to feel this way. On the other hand, when it came to the perception of stigmatizing attitudes in the community, fewer women (11.1%) compared with 46.7 percent of men agreed with the item – Most people believe that persons with HIV are of good moral character ($p\text{-value} < 0.01$). Women were more likely to be affected or worry about what those in the community thought.

The mean scores for an individual's perception of stigmatizing attitudes within the community were at least two points higher than the mean internalized stigma scores. This trend could indicate that people with HIV believe that there is incomplete knowledge or misconceptions about HIV in the community.

Stigma can be associated with ignorance. The lack of understanding about the disease and misconceptions may make individuals embarrassed about their condition. This may then cause them to feel more stigma in their environment. Hence, less stigma was experienced among individuals with some formal education.

Being on antiretroviral medications and living alone were significantly associated ($p < 0.05$) with a greater perception of the stigmatizing attitudes of others within the community. To be started on antiretroviral medication in Senegal an individual must have a CD4 count less than 350 or an opportunistic infection. These persons are, therefore, more sick and may have obvious signs of wasting that is typically associated with

HIV/AIDS in Africa. They may, as a result, be stigmatized by others in the community based on assumptions made based on their physical appearance.

Experience with Medical Professionals

The majority of study participants reported positive experiences with health professionals. The mean satisfaction scores were similar irrespective of gender, education, marital status, the amount of time spent living in Dakar, employment, living situation, disclosure status, antiretroviral treatment status or access to counseling. A gender difference was seen only in response to the statement “All my experiences with doctors and nurses have been positive” ($p < 0.01$). Almost 90 percent of women agreed with the statement compared to only 53.3 percent of men. The men may experience more guilt regarding how they contracted HIV and hence may be more reserved when dealing with health professionals by limiting their interactions and experiences.

Limitation

In interpreting the results, there are several factors that affect its generalizability. The study took place over a period of nine weeks. It was cross-sectional and not longitudinal, hence changes over time in the psychological frame of mind of the study participants could not be assessed. The study was, therefore, exploratory and descriptive in nature. The final sample size of forty-three was small and may not have been a truly representative sample of the HIV population in Senegal and their experience with stigma. The sample also represented an urban population. Though studies looking at the level of HIV/AIDS knowledge in both urban and rural populations in Senegal show that there are no differences, there might be differences in the way that people deal with the disease (e.g. the family structure tends to be stronger in rural than urban environments). Though an attempt was made to try and recruit an equal number of males and females, the final sample represented approximately two-thirds women. This may have skewed the results such that they may predominantly represent the opinions of women.

CONCLUSION

- Disclosure was fairly low among study participants and women disclosed less than men. Factors that appeared to be positively related to more disclosure were not being married, sharing one’s home, not having children, knowledge about how HIV was contracted and taking antiretroviral medications.
- Individuals who had disclosed their HIV status did not need to go to counseling.
- Women used counseling services more frequently than men.
- A considerable level of stigma was perceived among participants in the study.
- Men felt more guilt than women with regards to having HIV, and they felt more often that they must have done something wrong to contract HIV.
- Study participants had positive experiences with the healthcare workers at the clinic.

The findings of this research indicate the need for more interventions to decrease the psychological burden that HIV-positive individuals bear and it reinforces the need to design interventions to reduce feelings of internalized stigma and perceptions of stigmatizing attitudes in the community.

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Appendix

STIGMATIZATION QUESTIONNAIRE

Section I: Demographic Information

Date: ☐☐/☐☐/☐☐ (MM/DD/YY)

1. Research ID #:☐ ☐ ☐ ☐

2. Gender: ☐ 0 - Female
☐ 1 - Male

3. Age: ☐☐

4. Educational level: ☐None ☐Primary ☐Secondary
☐Tertiary

5. Ethnicity:

6. Marital status: ☐Single ☐Married ☐Separated ☐Divorced
☐Widowed

7. Do you have any children? ☐ Yes ☐No
↘
If yes, how many? ☐ ☐

8. Do you share your home? ☐ Yes ☐No

If yes, ↘ with whom do you live?

9. What is your source of income?

Section II: Personal Experience with HIV

1. When was the first time your HIV test was positive?

2. Why did you take the test?

3. Do you know how you may have contracted the disease? If yes, please describe.

4. Do you understand your illness?

5. How long have you been coming to Fann Hospital?

6. Have you had any counseling? ☐ Yes ☐No
If yes, please describe.

7. Do you take antiretroviral medications? ☐ Yes ☐No

Section III: Disclosure

1. Have you told anyone that you are sick? ☐ Yes ☐ No

2. If yes, list the first three people that you told and indicate their initial reaction.

Relationship	Reaction (positive or negative)

3. If no, why have you chosen not to tell others?

Section IV: Medical Experience

	Agree	Do Not Agree
1. All my experiences with doctors and nurses have been positive		
2. I think that I can talk to the doctors and nurses		
3. I am embarrassed to come to the hospital		
4. The doctors and nurses treat me differently because of my illness		
5. The doctors and nurses need more training on how to talk to people with my illness		
6. I feel that at the hospital my emotional needs are catered to		

Section V: Internalized Stigma

A number of questions assume that you have shared information about your status with others. If you have not disclosed this information, respond to the questions how you think that you would feel if you had disclosed the information.

	Agree	Do Not Agree
1. Although I am sick, I deserve as much respect as others who are not sick.		
2. I have been hurt by how people reacted when I told them that I am HIV positive		
3. I worry that people who know that I am sick will tell others		
4. Although I am sick, I believe that I am no different from others		
5. Some people who know that I have HIV have grown more distant		
6. I am ashamed that I have HIV		
7. Because of my HIV, I should not hold babies		
8. Because of my HIV, no one will hire me		
9. If I drink from a fountain and someone knows that I am HIV positive, they will not drink from the same fountain		
10. I think that I am a bad person		
11. I feel guilty about having HIV		
12. If people know that I am HIV positive, they will not sit next to me in a bus		
13. Since learning that I have HIV, I feel more isolated		
14. I am careful whom I tell that I have HIV		
15. I think that having HIV is punishment for previous bad behavior		
16. I think that I have been bewitched		
17. People are afraid of me because I have HIV		
18. I understand why people do not want to be friends with me		
19. I must have done something wrong to deserve getting HIV		
20. I think that I am a person of good moral character		

Section VI: Perceived Stigma in the Community

	Agree	Do Not Agree
1. Most people think that persons with HIV deserve as much respect as persons without HIV		
2. Most people think that someone with HIV is no different from others		
3. Most people think that persons with HIV are bad people		
4. Most people maltreat persons who have HIV		
5. Most people feel that having HIV is something to be ashamed about		
6. Most people think that persons with HIV should not touch babies		
7. Most employers will not hire someone with HIV		
8. Most people will not drink from the same fountain as someone who has HIV		
9. Most people will reject those with HIV		
10. Most people feel that a person with HIV should feel guilty about their status		
11. Most people will not sit next to a person with HIV in a bus		
12. Most people agree that when a person finds out that they are HIV positive he/she is abandoned by others		
13. Most people prefer to not know when someone is HIV positive		
14. Most people think that having HIV is punishment for bad behavior		
15. Most people believe that those with HIV have been bewitched		
16. Most people are afraid of those with HIV		
17. Most people would rather not be friends with someone who has HIV		
18. Most people believe that persons with HIV have done something bad		
19. Most people believe that persons with HIV are of good moral character		