

## Study on HIV and AIDS Related Stigmatization

KAMAL ELDIN HUSSEIN ELHASSAN

College of Medicine and Health Sciences  
Abdulatif Al Hammad University of Technology, Sudan

HALA ABDELRAHMAN AHMED

College of Dentistry  
Department of Preventive Dental Science  
University of Taibah, Kingdom of Saudi Arabia

SALAH ELDIN OMAR HUSSEIN<sup>1</sup>

College of Applied Medical Sciences  
Department of Medical Laboratory Technology  
University of Taibah, Kingdom of Saudi Arabia

### Abstract:

*This is a descriptive cross sectional study conducted in University of Juba in state Sudan and submitted to the Community Medicine Department at College of Medicine .*

*This report describes the research conducted on HIV/AIDS-related stigmatization among students of Juba University, Khartoum - Sudan. These issues; social responses of fear, denial, stigma and discrimination have accompanied the epidemic from the moment scientists identified HIV/AIDS. They have fuelled anxiety and prejudice against those groups most affected by HIV/AIDS. This report describes the aims, methods, and findings of the research. We highlighted particular areas of concern and made recommendations accordingly.*

**Key words:** HIV Stigmatization, AIDS Related Stigmatization

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<sup>1</sup> Corresponding author: Salah.omr@live.com

## 1. INTRODUCTION AND LITERATURE REVIEW

From the moment scientists identified HIV/AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic.

The HIV/AIDS-related stigma can be described as a 'process of devaluation' of people either living with or associated with HIV/AIDS. HIV/AIDS-related stigma builds upon, and reinforces, existing prejudices. It also plays into, and strengthens, existing social inequalities - especially those of gender, sexuality and race.

The goal of this research is to document the contents of local beliefs around HIV/AIDS to allow developing guidelines that can help in developing interventions to impact positively on HIV/AIDS stigma. It aims to (1) explore stigma experiences, prospective and variations and (2) to document promising practices which may mitigate HIV/AIDS-related stigma. The study which is cross sectional descriptive in type was conducted among students of Juba University. 380 face to face interviews were conducted. Six FGDs and three in depth interviews were held.

The discussed questions inquired about knowledge and beliefs about HIV/AIDS, feelings and attitudes towards PLWA. The collected data was analyzed using SPSS® for the questionnaires and coding for FGDs and in depth interviews. Both, overt and covert stigma forms were found out. The forms vary according to different contexts. The main factors contributing to the stigma were: low level of HIV/AIDS knowledge, fear of contracting AIDS and its association with stigmatized immoral behavior. HIV/AIDS was considered either as a crime or a horror. It is concluded that HIV/AIDS-related stigma is -manifested in Sudan- varied mainly according to the person's knowledge. Misconceptions and association with immoral behaviors reinforce this stigma. More or less stigmatization is limited in feelings and behaviors with

restriction in discriminative acts. It is recommended to increase the awareness of the students about HIV/AIDS by seminars and discussions concerning expressly transmission, to correct wrong beliefs linking HIV/AIDS with immoral behavior only, to include HIV/AIDS topics in publications, media, curriculum, etc. Also, further research in this problem will shed light upon it and supplement this work.

With 2.6 million km Sudan does occupy the largest area in Africa with a population estimated at 31 millions in 2002 and annual population growth of 2.9% Majority of the population works in agriculture which was the backbone of the economy. Since 1998 a moderate quantity of oil being produced but its effect is far from being felt, particularly at microeconomic level. Sudan is unique in its long and complex emergency situation for war, recurrent draught and famine that led to massive population movement estimated to be 2.6 million internally displaced from the war area.

Since the independence, Sudan has suffered from many internal problems that perpetuate the vulnerability factor for the spread of the communicable diseases and added a huge burden on the health sector. These include long standing civil strife that has affected one third of the country and contributed to the problem of the internal displacement of civilian with continuous movement of the warring factions both internally and with neighboring countries ranking Sudan as number one world-wide regarding the internally displaced people. Large-scale poverty that puts more than 85% of the population below the poverty line and prevailing illiteracy rate is 34% among males and 51% among females, with lower rates in rural area (1).

### **1.1 HIV/AIDS in Sudan**

HIV started to spread in Sudan in the 1980s. From available data on the epidemic, the following can be sketched with some degree of confidence. The first AIDS case was reported in 1986.

HIV/AIDS prevalence was low in the 1980s, but increased quickly in the 1990s, and rose up to an estimated 2.6% of the adult population in 2002 and overall 1.6% in the general population. Rates among women ANC at sentinel surveillance sites in Juba have exceeded 3% in 1998 and a recent study by SNAP in IDP Camps in Khartoum state estimated at 5%. In addition high rates have been reported among vulnerable groups such sex workers (5%), Tea sellers (2.5%), Refugees (4%) and street children (2.5%) as no routine surveillance exist in rural areas, the level of HIV/AIDS prevalence in these areas are difficult to estimate (1) and (2).

### **1.2 Stigma in General**

Stigma is a common and old human reaction to disease. History knew many diseases that carried stigma e.g. tuberculosis, leprosy, mental illnesses, STIs and other diseases (3). In a now classic statement, the sociologist Erving Goffman (1963) defined stigma as a “significantly discrediting” attribute possessed by a person with an “undesired difference”. Stigma is a powerful means of social control applied by marginalizing, excluding and exercising power over individuals who display certain traits. It is a common response to perceived threat when escape from, or the destruction of, this threat is impossible (4).

In general stigma is associated with disfiguring or incurable diseases especially when the disease is considered to be a result of personal behavior. The terms stigma and discrimination is often used interchangeably but their meanings do differ. Discrimination focuses on behavior; the unfair and unjustifiable difference treatment given to different individuals or groups. Stigma is defined as quality with discredits an individual in the eyes of others. So, stigma is a process.

### **1.2.1 Stigma and HIV/AIDS**

It goes without saying that HIV/AIDS is as much about social phenomena as it is about biological and medical concerns. Across the world, the global pandemic of HIV/AIDS has shown itself capable of triggering responses of compassion, solidarity and support, bringing out the best in people, their families and communities. But the disease is also associated with stigma, ostracism, repression and discrimination, as individuals affected (or believed to be affected) by HIV have been rejected by their families, their loved ones and their communities. This rejection holds as true in the rich countries of the north as it does in the poorer and developing countries of the south (5). Diseases associated with the highest degree of stigma share common attributes:

1.2.1.1 The person with the disease is seen as responsible for having the illness.

1.2.1.2 The disease is progressive and incurable.

1.2.1.3 The disease is not well understood among the public.

1.2.1.4 The symptoms cannot be concealed.

HIV and AIDS-related stigma refers to 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. HIV/AIDS-related stigma has been divided into the following categories:

Instrumental HIV/AIDS-related stigma—a reflection of the fear and apprehension that are likely to be associated with any deadly and transmissible illness

Symbolic HIV/AIDS-related stigma—the use of HIV/AIDS to express attitudes toward the social groups or “lifestyles” perceived to be associated with the disease.

Courtesy HIV/AIDS-related stigma—stigmatization of people connected to the issue of HIV/AIDS or HIV- positive

people HIV/AIDS-related stigmatization causes resources essential to preventing infection to be displaced. People are victimized and blamed, social divisions are reinforced and reproduced, and new infections continue to emerge as long as people misread the nature of the epidemic and its causes (4).

### **1.2.2 Forms of Stigma**

1.2.2.1 The four main features of any stigmatizing response are described as:

1.2.2.2 The problem that initiates the reaction

1.2.2.3 The identification of the group or individual to be targeted

1.2.2.4 The assignment of stigma to this individual or group

1.2.2.5 The development of the stigmatizing response (4)

Authors have found it helpful to distinguish between felt and enacted stigma. Felt stigma is more prevalent – feelings that individuals harbor about their condition and the likely reactions of others. Enacted stigma refers to actual experiences of stigmatization and discrimination.

Felt stigma often precedes enacted stigma and may limit the extent to which the latter is experienced. For example, some people living with HIV, aware that many people with HIV/AIDS have been treated badly by others, may conceal their serostatus. To the extent that they are successful in “passing” as non-infected, such individuals may limit the amount of enacted stigma prevalent in a society or community – at least in the short term (5). Stigma in general can be manifested as:

External stigma: this may include the experience of domination, exercise of power, blame and exclusion and may sometimes lead to violence against a person living with HIV/AIDS.

Internal stigma: shame associated with HIV/AIDS and people living with HIV/AIDS (PLWA). Internal stigma often results in refusal to disclose HIV status or the denial of HIV/AIDS and unwillingness to seek help.

There are several levels at which HIV/AIDS-related discrimination, stigmatization and denial may be experienced and felt. These include societal and community levels, in addition to the experience of individuals (6).

#### Societal and community levels

Societally, laws, rules, policies and procedures may result in the stigmatization of people living with HIV/AIDS. A significant number of countries have enacted legislation with a view to controlling the actions of HIV/AIDS-affected individuals and groups.

International experience now shows that such measures serve only to increase and reinforce the stigmatization of people living with HIV/AIDS and those at greatest risk of contracting the virus.

### **1.2.3 Individual experience**

People's experience of HIV/AIDS-related stigmatization and discrimination is affected by commonly held beliefs, forms of societal stigmatization, and factors such as the extent to which individuals are able to access supportive networks of peers, family and kin. It may also be influenced by the stage of the epidemic and whether individuals feel they can be open about their serostatus, age, gender, sexuality and social status – among a host of other variables.

Overall, the negative depiction of people living with HIV/AIDS – reinforced by the language and metaphors used to talk and think about the disease – has reconfirmed fear, avoidance and the isolation of affected individuals and, in some cases, friends and families. In a highly stigmatizing environment, people may withdraw from society as a means of self-preservation. This isolation can extend to exclusion from

social and sexual relationships and – in extreme circumstances – has led to premature death through suicide or euthanasia.

More often, however, stigmatization causes a kind of social death in which individuals no longer feel part of civil society, and are no longer able to access the services and support they need.

Who to tell, how and when, can be a potential source of fear and anxiety among many people living with HIV/AIDS and may prevent individuals from accessing treatment and care. Even where laws have been enacted to protect the rights and confidentiality of people living with HIV/AIDS, few people are prepared to litigate in case their identity will become widely known. Those who are identified as belonging to marginalized and/or minority groups may also worry about the reactions of others, regardless of their serostatus.

Fear of telling family members about their homosexuality has recently been cited by some Mexican men as equal to the fear of revealing their serostatus.

The impact of HIV/AIDS on women is particularly acute. In many developing countries, women are already economically, culturally and socially disadvantaged and lack equal access to treatment, financial support and education. Being outside the structures of power and decision-making, they may be denied the opportunity to participate equally within the community and may be subject to punitive laws, norms and practices exercising control over their bodies and sexual relations. In a number of societies, women are erroneously perceived as the main transmitters of sexually transmitted infections (STIs), which may be referred to as “women’s diseases”. Together with traditional beliefs about sex, blood and other kinds of disease transmission, these perceptions provide a fertile basis for the further stigmatization of women within the context of HIV/AIDS.



### **1.2.3 Sources of HIV/AIDS-related Stigma**

A historical and sociocultural perspective may be helpful in understanding the negative reactions triggered by HIV/AIDS. In previous epidemics, the real or supposed contagiousness of disease has resulted in the isolation and exclusion of infected people. Sexually transmitted diseases in particular are notorious for triggering such socially divisive responses and reactions (7). From early in the AIDS epidemic, a series of powerful metaphors were mobilized, which serve to reinforce and legitimate stigmatization. These include:

1.2.3.1 HIV/AIDS as death; HIV/AIDS as punishment (e.g. for immoral behavior)

1.2.3.2 HIV/AIDS as a crime (e.g. in relation to innocent and guilty victims)

1.2.3.3 HIV/AIDS as war (e.g. in relation to a virus which needs to be fought)

1.2.3.4 HIV/AIDS as horror (in which infected people are demonized and feared)

1.2.3.5 HIV/AIDS as “otherness” (in which the disease is an affliction of those set apart)

Together with the widespread belief that HIV/AIDS is shameful, these metaphors constitute a series of “ready-made” but highly inaccurate explanations that provide a powerful basis for both stigmatizing and discriminatory responses. These stereotypes also enable some people to deny that they personally are likely to be infected or affected.

People living with HIV/AIDS are seen as ignominious in many societies. Where the infection is associated with minority groups and behaviors (for example, homosexuality), HIV/AIDS may be linked to “perversion” and those infected punished. In individualistic societies, HIV/AIDS may be seen as the result of personal irresponsibility. In yet other circumstances, HIV/AIDS is seen as bringing shame upon the family and community. The manner in which people respond to HIV/AIDS therefore varies

with the ideas and resources that society makes available to them. While negative responses to HIV/AIDS are by no means inevitable, they not infrequently feed upon and reinforce dominant ideologies of good and bad with respect to sex and illness, and proper and improper behaviors (1). Five factors that contribute to HIV/AIDS stigma have been identified. HIV/AIDS as a life threatening disease. The fear of contracting HIV. The association of HIV with stigmatized behaviors (homosexuality, injection drug use, commercial sex work, etc). The fact that people living with HIV/AIDS are judged as having brought the disease themselves. Religious or moral beliefs that equate HIV/AIDS with moral fault that deserves punishment.

#### **1.2.4 Contexts of HIV/AIDS-related Stigma**

HIV-related stigmatization may appear in a variety of contexts. Central among those are the family and local community, employment and the workplace, and the health care system.

##### **1.2.4.1 The family and community**

In the majority of developing countries, families are the primary care-givers to sick members. There is clear evidence of the important role that the family can play in providing support and care for people living with HIV/AIDS. However, not all family response is positive. Infected and affected family members may still be stigmatized and discriminated against within the home. There is also mounting evidence that women and non-heterosexual family members are more likely to be badly treated than children and men.

The family's efforts to "manage" stigmatization within the wider community also have consequences for quality of care. Families may shield affected members from the wider community by keeping them within the house or by protecting them from questioning. The extent to which such strategies are successful may depend upon the wealth of the household

concerned and its capacity to provide care without calling upon other community members for support.

Fear of rejection and stigmatization within the home and local community may prevent people living with HIV/AIDS revealing their serostatus to family members. Families may reject seropositive members not only because of the stigma associated with HIV/AIDS, but also because of the connotations of homosexuality, drug use and promiscuity that HIV/AIDS carries.

#### **1.2.4.2 Employment and the workplace**

While HIV is not readily transmitted in the majority of workplace settings, the supposed risk of transmission has been used by numerous employers to terminate or refuse employment. There is also evidence that where people living with HIV/AIDS are open about their serostatus at work they are likely to experience stigmatization and ostracism by others.

#### **1.2.4.3 The health care system**

Many reports reveal the extent to which individuals are stigmatized and discriminated against by the health care system. Numerous accounts also proliferate of withheld treatment; non-attendance of hospital staff to patients left lying in their beds; HIV testing without consent, breaches of confidentiality, and denial of hospital facilities and medications.

Contributing to such responses are ignorance and lack of knowledge about HIV/AIDS transmission; fear; moralistic assumptions of guilt; and the perceived incurability of HIV/AIDS. All of these conspire to make it appear pointless to offer good-quality care.

Lack of confidentiality has been repeatedly cited as a particular problem in health care settings. Wide variations in practice exist between countries, and between health care facilities within countries. In some settings signs have been placed near people living with HIV/AIDS with words such as

“HIV-positive” and “AIDS” written on them. Elsewhere, registers of HIV-positive people have been compiled and their names released to media and police without permission.

Principles of confidentiality also vary between countries and cultures. In some places, for example, confidentiality may be less an individual issue than a community and collective concern. The term “shared confidentiality” describes a situation where family and community members feel they have the right to know the serostatus of family members, neighbors and friends.

## **2. OBJECTIVES**

### **2.1 General Objective:**

The goal of this research is to document the contents of local beliefs around HIV/AIDS to allow developing guidelines that can help in developing interventions to impact positively on HIV/SIDS stigma.

### **2.2 Specific Objectives:**

2.2.1 Exploration of stigma experiences, prospective and variations: HIV/AIDS stigma is a set of shared values, attitudes, and beliefs that can be conceptualized at both cultural and individual level.

AIDS stigma at cultural level is manifested in laws, policies, popular communication and social conditions of PLWA and those at risk of infection.

AIDS stigma at individual level takes the form of behavior and thoughts and individual. This research is concerned mainly in this level.

Primary AIDS stigma: in this case the targets of stigma are individuals with HIV and those who perceived to be HIV infected. Fear of becoming a primary target of stigma also affect those individuals whose behavior may place them at risk of infection.

Secondary AIDS stigma: the targets of this stigma include partners of PLWA, family members, and loved ones, as well as professionals who work with them or caregivers.

Documentation of promising practices which may mitigate HIV/AIDS- related stigma: Although AIDS stigma is universal, it takes different forms in different countries and even within a particular society stigma can vary across population subgroups. Accordingly interventions can be done. Inter-group differences in AIDS stigma are important for reasons that could be summarized as follows:

AIDS stigma within a particular community is likely to shape the community's response to the epidemic. (Community readiness to acknowledge its own risk of HIV in realistic manner).

Inter-group variations in stigma can create different experience for PLWA in different communities and cultures.

Cultural differences in stigma may make necessary to adopt different interventions for reducing stigma in different communities.

### **3. METHODOLOGY**

#### **3.1 Study design:**

This study is descriptive cross sectional in type.

#### **3.2 Subject**

The target was Juba university students. The University of Juba is organized in Colleges of Applied and Industrial Sciences; Arts and Humanities; Arts, Music and Drama; Computer Science and Information Technology; Education; Engineering; Law; Medicine; Natural Resources and Environmental Studies; Community Studies and Rural Development; Social and Economic Studies; the Preparatory College; and the School of Management Sciences.

Also it contains Centers for Distance Education; Human Resources Development and Continual Education; Languages and Translation; and the Centre for Peace and Development. These academic units offer a variety of academic programs leading to Diploma, Bachelor, Master and Doctoral degrees in various disciplines and specializations.

The students were selected from bachelor colleges. The study was geographically limited to the colleges in Khartoum state. The colleges involved were ten in number.

The respondents were distinctive in the diversity in religion, traditions and culture.

### **3.3 Site**

This study was carried out in the campuses of Juba University in Khartoum. These are located in (1) Elkadro, Khartoum North and (2) Elbosta, Umdurman.

### **3.4 Methods**

Three methods were used during the research; face to face interviews, focus group discussions and in depth individual interviews.

### **3.5 Face to Face Interviews:**

A total of 380 face to face close ended interviews were conducted with students from all colleges.

The calculated sample size ( $367 \approx 380$ ) was portioned proportionally to each college and further to each batch. An elucidation is provided in table (1).

**Table (1) Sample Sizes of Respondents, Face to Face Interviews**

College	Year						
Education	0	0	1	1			4
School of Management Sciences							1
Social and Economic Studies	6	4					8
Medicine						1	0
Engineering	0						4
Natural Resources & Environmental Studies	4		6				4
Community studies & Rural Development							4
Arts & Humanities	3	2		0			1
Applied & Industrial Sciences	2						7
Law							4

Random selection of students was done. The interviews were held in Arabic or English as the respondent's convenience.

The six sections of the questions inquired about: attitudes and disclosures, feeling towards persons with AIDS, coercive attitudes and blame, avoidant behavioral intentions, casual contact and risky sexual behavior and drug use. A sample of the questionnaire is attached in annex (A).

### **3.6 Focus Group Discussions:**

Six focus group discussions (FGDs) involving six to twelve people were held with students from all colleges.

By random selection the colleges were categorized into six groups. In each category students were selected conveniently and invited to the FGDs. A list is provided in table (2).

**Table (2) Sample Sizes for each Set of Respondents, Focus Group Discussions**

GD	College(s)	Participants
	Engineering	8
	School of Management Sciences Natural Resources & Environmental Studies	8
	Social and Economic Studies Applied & Industrial Sciences	12
	Law Education	10
	Community studies & Rural Development Arts & Humanities	12
	Medicine	6

The discussions were held in Arabic and English languages according to the choice of the participants. The responses were documented in writing and tape-recorded.

The questions introduced in the discussions concerned six themes: feeling toward PLWA, interactions with PLWA, symbolic contact, beliefs about transmission, attitudes toward PLWA and testing and concerns about stigma. The FGD guide is attached in annex (B).

### **3.7 In depth Interviews:**

To complement the above information, three in depth individual interviews were conducted. We spoke to:

a psychiatrist: Prof. Abdulmonem Yousif; Chief Psychiatrist, MOH

a headmistress of a school in Umdurman: Mrs. Asma Abdulraheem

a lay expert: Mr. Badawi Esma'ael

The first interview was conducted in English language and the other two were conducted in Arabic language. The interviews were further recorded in writing and with tape-recorder. Questions discussed are attached in annex (C).



## 4. Results and discussion

### 4.1 Quantitative Data:

#### 4.1.1 Face to Face interviews

### 4.2 Qualitative Data:

#### 4.2.1 Focus Group Discussions

#### 4.2.2 In Depth Interviews

### 4.1.1 Face to Face Interviews

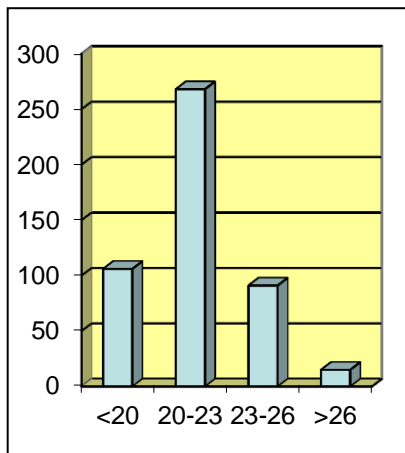
#### 4.1.1.1 Demographic Information:

The number of female respondents was slightly more than the males. Most of them were 20-23 years old. The majority of the respondents were Muslim Sudanese. Most of the respondents were not married and not working.

**Table (3) Demographic Information of the Study Respondents (Students of Juba University, 2005)**

		Frequency	Percent
Sex	Male	169	44.5
	Female	211	55.5
	Total	380	100.0
Age in years	<20	106	27.9
	20-23	168	44.2
	23-26	91	23.9
	>26	15	3.9
	Total	380	100.0
Religion	Muslim	338	88.9
	Christian	41	10.8
	Other	1	0.3
	Total	380	100.0
Nationality	Sudanese	373	98.2
	Other	7	1.8
	Total	380	100.0
Marital Status	Married	10	2.6
	Single	370	97.4
	Total	380	100.0
Working	Yes	64	16.8
	No	316	83.2
	Total	380	100.0

**Figure (I) Age in Years of the Study Respondents**



(Students of Juba University, 2005)

#### 4.1.1.2 Attitudes and Disclosure:

Majority of the respondents denied that they knew any person who was HIV positive. The most of the few who knew said that the person was not a relative or that they just “heard” about him.

**Table (4) Knowing a Person who has had a Blood Test for HIV/AIDS and is Positive in the Study Respondents (Students of Juba University, 2005)**

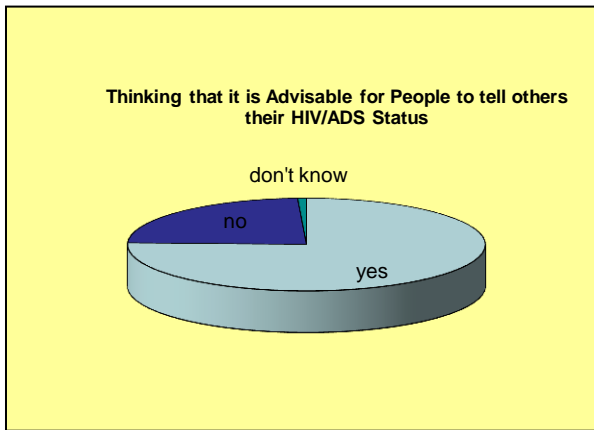
	Frequency	Percent
Yes	49	12.9
No	326	85.8
Don't know	5	1.3
Total	380	100.0

Most of the respondents thought that it is advisable for people to tell others their HIV/AIDS status. Some believed that in their view nothing should be hidden. Others agreed on the understanding that knowing the infected will enable them to avoid him!

**Table (5) Thinking that it is Advisable for People to tell others their HIV/ADS Status in the Opinion of the Study Respondents (Students of Juba University, 2005)**

	Frequency	Percent
Yes	287	75.5
No	90	23.7
Don't know	3	0.8
Total	380	100.0

**Figure (II) Thinking that it is Advisable for People to tell others their HIV/ADS Status in the Opinion of the Study Respondents**



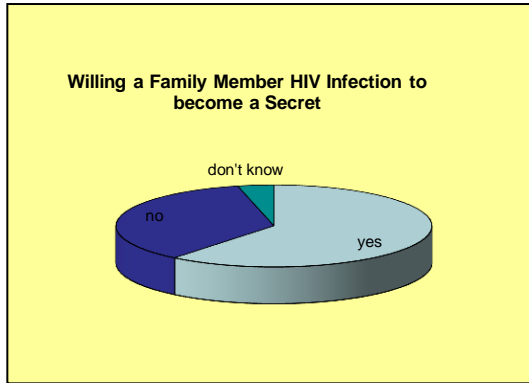
(Students of Juba University, 2005)

When asked “If a member of your family got infected with HIV/AIDS, would you want it to remain a secret?”, more people answered yes. They said that we should respect his sensibility.

**Table (6) Willing a Family Member HIV Infection to become a Secret in the Opinion of the Study Respondents (Students of Juba University, 2005)**

	Frequency	Percent
Yes	231	60.8
No	135	35.5
Don't know	14	3.7
Total	380	100.0

**Figure (III) Willing a Family Member HIV Infection to become a Secret in the Opinion of the Study Respondents (Students of Juba University, 2005)**



In the opinion of the respondents, the most appropriate person to be informed by someone's HIV status were the parents in the first place followed by wife/husband. Some respondents mentioned other people as fiancé, fiancée, brother, sister, lover, etc.

When the situation became personal, the majority also selected parent(s). The males mostly chose their friends or brothers. The females selected mainly their mothers. The most accepted way for telling the status was by showing the result "as it is inevitable".

**Table (7) Informing about HIV/AIDS Status in the Opinion of the Study Respondents (Students of Juba University, 2005)**

		Frequency	Percent
The most appropriate person to be informed by someone's HIV status	Wife/ husband	124	32.6
	Parent(s)	133	35.0
	Boyfriend / Girlfriend	28	7.4
	Colleague/ Friend	33	8.7
	Social worker	6	1.6
	Counselor	25	6.6
	Other	31	8.2
	Total	380	100.0
The first to tell if YOU were infected with HIV	Wife/ husband	34	8.9
	Parent(s)	208	54.7
	Boyfriend / Girlfriend	29	7.6

	Colleague/ Friend	44	11.6
	Social worker	5	1.3
	Counselor	11	2.9
	No one	24	6.3
	Other	25	6.6
	Total	380	100.0
Way of telling this person about YOUR HIV status	Take to him/her VCT	35	9.2
	Show him/her your result	250	65.8
	Encourage that both of you tested	66	17.4
	Don't know	24	6.3
	Other	5	1.3
	Total	380	100.0

The variation of bad treatment the PLWA face is illustrated in table (8). Some mentioned just the negative feelings without attitudes.

Predominantly, they thought that the community is responsible for this bad treatment. Other mentioned the unenlightened people.

**Table (8) Bad Treatment of People Living with HIV/AIDS in the Opinion of the Study Respondents (Students of Juba University, 2005)**

		Frequency	Percent
Kind of Bad Treatment	Isolation	149	39.2
	Verbal abuse	21	5.5
	Violence	7	1.8
	Rumors/ Gossips	39	10.3
	Rejection	76	20.0
	Ejection from home	1	0.3
	Community rejection	68	17.9
	None	9	2.4
	Other	10	2.6
	Total	380	100.0
Who Treats them Badly	Family members	40	10.5
	Neighbors	32	8.4
	Community	221	58.2
	Health workers	19	5.0
	Young people	10	2.6
	Everyone	23	6.1
	Religious group	2	0.5
	Colleagues	17	4.5

	Other	16	4.2
	Total	380	100.0

A considerable number thought that health care should be given more to PLWA than others either because he needs psychological support or because his disease is complicated.

Few respondents said that giving more care could hurt the patient by feeling that he is lower. They suggested that he deserve the same level of care as others. However, part expressed that PLWA have no right to deserve more. To a lesser extent, there was a view that as it is a fatal disease there is no need for care!

**Table (9) Giving Health Care to People Living with HIV/AIDS in Comparison to others in the Opinion of the Study Respondents (Students of Juba University, 2005)**

	Frequency	Percent
More	332	87.4
The same	30	7.9
Less	17	4.5
Don't know	1	0.3
Total	380	100.0

Families who have lost members with HIV would be treated worse than others because the disease may be transmitted to them. This was the view of the majority. On the other hand, the minority believed that treatment would not differ as the infected person is already dead!

The blame of women was obvious in the responses. Phrases like “the truth that it is a women disease” or “of course woman is always worse’ were frequent.

Orphans whose parents died of AIDS were treated with less care than others in the opinion of the respondents because the fear of being infected as well. Because the Sudanese society, by nature, is sympathetic, some thought that they may encounter the same treatment if not better.

**Table (10) Treatment of Special HIV/AIDS Infected Groups in Comparison to Others in the Opinion of the Study Respondents (Students of Juba University, 2005)**

Treatment:		Frequency	Percent
of Families who have lost members with HIV in Comparison to other Causes	Better	22	5.8
	The same	111	29.2
	Worse	235	61.8
	Don't know	12	3.2
	Total	380	100.0
of HIV Infected Woman in Comparison to Man	Better	51	13.4
	The same	111	29.2
	Worse	203	53.4
	Don't know	15	3.9
	Total	380	100.0
of Orphans whose Parents Died of HIV/AIDS in Comparison to Others	More	108	28.4
	The same	86	22.6
	Less	167	43.9
	Don't know	19	5.0
	Total	380	100.0

#### 4.1.1.3 Feeling towards Persons with AIDS:

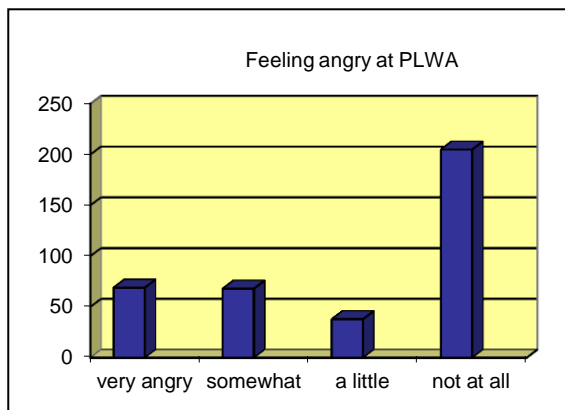
Feelings towards PLWA were very diverse. Prevalently, they were not at all angry. Being afraid or not was distributed more or less into halves. Disgusting feeling was slightly predominating. Responses of comfortable feeling in contacts with PLWA are showed in table (11).

**Table (11) Feelings towards Persons with HIV/AIDS in the Study Respondents (Students of Juba University, 2005)**

		Frequency	Percent
Angry at them	Very angry	69	18.2
	Somewhat	68	17.9
	A little	38	10.0
	Not at all angry	205	53.9
	Total	380	100.0
Afraid of them	Yes	173	45.5
	No	207	54.5
	Total	380	100.0
Disgusted by them	Yes	146	38.4
	No	234	61.6
	Total	380	100.0
Comfortable to shake hand with them	Yes	219	57.6
	No	124	32.6

	Somewhat	37	9.7
	Total	380	100.0
Comfortable to eat from the same plate with them	Yes	203	53.4
	No	139	36.6
	Somewhat	38	10.0
	Total	380	100.0
Comfortable to share work tools with them	Yes	111	29.2
	No	237	62.4
	Somewhat	32	8.4
	Total	380	100.0
Comfortable to share the same toilet with them	Yes	100	26.3
	No	247	65.7
	Somewhat	33	8.7
	Total	380	100.0
Comfortable to travel in the same vehicle with them	Yes	273	71.8
	No	71	18.7
	Somewhat	36	9.5
	Total	380	100.0

**Figure (IV) Feeling Angry at Persons with HIV/AIDS in the Study Respondents**



(Students of Juba University, 2005)

#### 4.1.1.4 Coercive Attitudes and Blame:

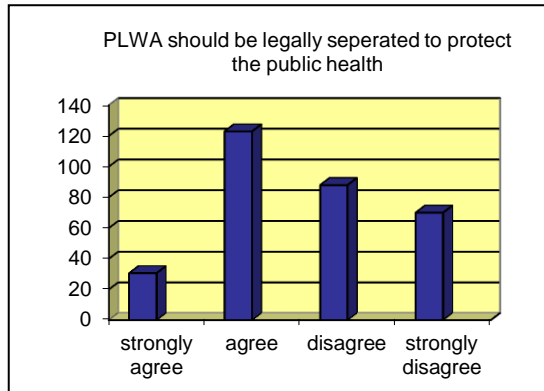
Statements were read and the respondents told their degree of agreement. The results are illustrated in table (12).



**Table (12) Coercive Attitudes and Blame towards Persons with HIV/AIDS in the Study Respondents (Students of Juba University, 2005)**

Statement		Frequency	Percent
PLWA should be legally separated to protect the public health	Strongly agree	123	32.4
	Agree	88	23.2
	Disagree	70	18.4
	Strongly disagree	99	26.1
	Total	380	100.0
PLWA names should be made public so that others can avoid them	Agree	156	41.1
	Disagree	214	56.3
	Don't know	10	2.6
	Total	380	100.0
Who got AIDS through sex/ drug use has gotten what he/she deserve	Agree	274	72.1
	Disagree	92	24.2
	Don't know	14	3.7
	Total	380	100.0
Women get HIV/AIDS more than men	Agree	160	42.1
	Disagree	146	38.4
	Don't know	74	19.5
	Total	380	100.0
Poor people get HIV/AIDS more than others	Agree	177	46.6
	Disagree	163	42.9
	Don't know	40	10.5
	Total	380	100.0
PLWA do not deserve compassion or support	Agree	36	9.5
	Disagree	338	88.9
	Don't know	6	1.6
	Total	380	100.0
HIV/AIDS is a disease of outsiders	Agree	311	81.8
	Disagree	44	11.6
	Don't know	25	6.6
	Total	380	100.0

**Figure (V) Agreement that “PLWA should be legally Separated to Protect the Public Health” in the Study Respondents (Students of Juba University, 2005)**



#### 4.1.1.5 Avoidant Behavioral Intentions:

Considerable number was willing to take care of close relative or friend who developed AIDS because “he is my relative”.

If a colleague developed AIDS they would not hurt him by avoidance but they would be cautious in their conduct.

As the relation with the food seller is not that tight, the majority would shop somewhere else if the seller develops AIDS. They thought that there is a little chance of infection. Some would continue as there is no risk for transmission or out of courtesy.

**Table (13) Avoidant Behavioral Intentions towards Persons with HIV/AIDS in the Study Respondents (Students of Juba University, 2005)**

		Frequency	Percent
Willing to take care of a close relative/friend who developed AIDS	Yes	343	90.3
	No	21	5.5
	Don't know	16	4.2
	Total	380	100.0
Behavior toward a study colleague who developed AIDS	Willing to study	120	31.6
	Transfer	8	2.1
	Avoid contact	79	20.8
	Treat as always	173	45.5
	Total	380	100.0

If the fresh food seller where you like to shop had AIDS	Shop more often	1	0.3
	Less often	52	13.7
	As usual	87	22.9
	Someplace else	240	63.2
	Total	380	100.0

#### 4.1.1.6 Causal Contact:

While part of respondents thought that it is impossible to get AIDS by kissing on the cheek, the other part answered yes since there is sexual sense in the mechanism.

All the respondents showed uncertainty when asked if sharing a drink out of the same glass with an infected person is a way of transmission. The confusion emerged as they used to share drink always but a chance could exist if there are wounds in the mouth.

The males did not accept using public toilets as a way of transmission at once. Logically, they said all Sudan people should be infected if it is truly a way. Meanwhile, the girls thought that a chance existed as toilet floors and walls may be contaminated with blood.

Most who accepted the mosquito bites as a way of transmission mentioned the malaria transmission as another example. Also, they explained the mechanism by presence of blood! Those who disagreed said that they heard this fact in the media “they said it is not a way of transmission”.

**Table (14) Knowledge about HIV Transmission of the Study Respondents (Students of Juba University, 2005)**

		Frequency	Percent
Kissing infected person on the cheek	Very likely	28	7.4
	Likely	73	19.2
	Unlikely	121	31.8
	Impossible	158	41.6
	Total	380	100.0
Sharing a drink out of the same glass with an infected person	Very likely	32	8.4
	Likely	83	21.8
	Unlikely	122	32.1
	Impossible	143	37.6
	Total	380	100.0

Using of public toilets	Very likely	48	12.6
	Likely	101	26.6
	Unlikely	124	32.6
	Impossible	107	28.2
	Total	380	100.0
Being coughed or sneezed on by someone infected	Very likely	40	10.5
	Likely	60	15.8
	Unlikely	139	36.6
	Impossible	141	37.1
	Total	380	100.0
Mosquitoes or other insects bites	Very likely	54	14.2
	Likely	89	23.4
	Unlikely	96	25.3
	Impossible	141	37.1
	Total	380	100.0

#### 4.1.1.7 Risky Sexual Behavior and Drug Use:

The largest proportion of the respondents thought that there is no chance of infection in illegitimate sexual relations as long as the partners are both healthy. However, few supposed that there may be a chance as “retribution” for the immoral behavior. This was true for hetero- and homosexual relations.

The knowledge of condom use influenced their answers: some thought that it will reduce the risk while others believed it may increase the risk as people do share the condoms and reuse it!

They did not accept possibility of infection through unshared needles in intravenous drug use because “there is no virus”. Yet, portion of them denied that it could be a way of transmission “it is only transmitted sexually”.

**Table (15) Chances of Certain Groups to become HIV Infected in Certain Situations in the Opinion of the Study Respondents (Students of Juba University, 2005)**

Situation	Infection	Frequency	Percent
Healthy man and woman neither of whom is infected with HIV& they have illegitimate sexual intercourse	Sure	16	4.2
	Strong chance	60	15.8
	Little chance	76	20.0
	No chance	228	60.0
	Total	380	100.0

Two healthy homosexual men neither of whom is infected with HIV have sexual intercourse using condoms	Sure	8	2.1
	Strong chance	37	9.7
	Little chance	89	23.4
	No chance	246	64.7
	Total	380	100.0
The same two healthy men have sexual intercourse but this time they do not use condoms	Sure	22	5.8
	Strong chance	90	23.7
	Little chance	66	17.4
	No chance	202	53.2
	Total	380	100.0
Someone who uses drugs intravenously and doesn't share needles	Sure	8	2.1
	Strong chance	30	7.9
	Little chance	47	12.4
	No chance	295	77.6
	Total	380	100.0

#### 4.1.1.8 Cross Tabulations:

**Table (16) Cross Tabulation of Attitudes and Disclosure**

		Is it Advisable for people to Tell Others their HIV/AIDS Status			Total
		Yes	No	Don't know	
Willing a Family Member HIV Infection to Become a Secret	Yes	42.6%	17.9%	0.3%	60.8%
	No	31.1%	4.2%	0.3%	35.5%
	Don't know	1.8%	1.6%	0.3%	3.7%
Total		75.5%	23.7%	0.8%	100.0%

$\chi^2=25.537$

df=40.000

**Table (17) Cross Tabulation of Feelings towards Person with AIDS**

		Disgusted by PLWA		Total
		Yes	No	
Afraid of PLWA	Yes	27.1%	18.4%	45.5%
	No	11.3%	43.2%	54.5%
Total		38.4%	61.6%	100.0%

$\chi^2=59.855$

df=10.000

**Table (18) Cross Tabulation of Coercive Attitudes and Blame**

		Names of PLWA Should be Made Public so that Others Can Avoid them			Total
		Agree	Disagree	Don't know	
PLWA should be Legally Separated to from Others to Protect the Public Health	Agree strongly	18.7%	13.2%	0.5%	32.4%
	Agree	8.7%	13.9%	0.5%	23.2%
	Disagree	6.8%	10.3%	1.3%	18.4%
	Disagree strongly	6.8%	18.9%	0.3%	26.1%
Total		41.1%	56.3%	2.6%	100.0%

$\chi^2=31.390$        $df=60.000$

**Table (19) Cross Tabulation of Coercive Attitudes and Blame & Avoidant Behavioral Intentions**

		Willing to Take Care of a Relative who Developed AIDS			Total
		Yes	No	Don't know	
People who have HIV/AIDS Do Not Deserve Compassion or Support	Yes	7.9%	0.8%	0.8%	9.5%
	No	81.3%	4.5%	3.2%	88.9%
	Don't know	1.1%	0.3%	0.3%	1.6%
Total		90.3%	5.5%	4.2%	100.0%

$\chi^2= 6.638$        $df=40.156$

## 4.2.1 Focus Group Discussions

### 4.2.1.1 Feeling towards PLWA:

Compassion and mercy were the commonest feeling exhibited by the participants. They were also: sorry for PLWA, sympathize with them, sorrowful and dolorous at them.

“I feel pity for them” a youth

To lower extent, few participants were disgusted by PLWA and afraid of them.

"It's a shameful disease, it's a disaster, crisis" young lady

"I feel disgusted by AIDS patients, but I think I must treat them better to avoid their revenge" a girl

#### **4.2.1.2 Interactions with PLWA:**

Supposing that one's brother/sister is attending a school where an HIV positive student is his/her classmate the majority of the feelings reflected fears of passing the infection with anxious. Some were passive, as they feel normal and natural.

"I will put an end to my brother/sister fears, and ignore the common bad says about his/her colleague"

Concerning their response, they predominantly encouraged the careful dealing with those patients. But some show sympathetic feelings and tendency to support.

"I will be scared to death. I will transfer my brother/sister to another school as soon as possible" a young lady

Supposing that one works in an office where a man working with them developed AIDS. The participants felt afraid and sympathetic at the same time.

Some participants were doleful with disgusting feelings.

"I feel disgusted by him/her. I would be surprised how that mature person got a disease like AIDS" a young lady

With respect to their responses most participants were still willing to work with him with caution.

Few participants would ask to be transferred someplace else.

"I will request for transferring me to another workplace without inform him/her that I request so" a young lady

Supposing that the owner of the market where one used to shop from had AIDS the participants felt sad or sorry for him. Compassion was mentioned by most of them. Some showed deep fears, disgusting and were highly anxious.

"I will exhort all the young kids from buying from him" anxious man

As regards to the responses, participants would give up shopping from there again.

"He may have a revenge desire and try to spread the disease through his goods. I'll never buy from there again" excited lady

Few participants were still willing to shop there but less frequently and restricted to cans, tin and covered food.

#### **4.2.1.3 Symbolic Contacts:**

Feelings about drinking out of glass that someone with AIDS drank out of it a few days ago were varied among the participants. However, the frequently mentioned were shock, scare, exaggerated fear, surprise, disgusting and depression.

"I'll be obsessed about AIDS whenever I feel unwell. It will come first before malaria!" an anxious man

"I will wash my mouth by phenol or any antiseptic mouth-wash immediately" a man

To a lesser extent, few respondents would feel nothing; not anxious or worry as it is not a mode for HIV transmission.

"I won't be worry; it is not a route for AIDS transmission. Or else, the disease would spread among all people in Sudan" a comment by a young man

#### **4.2.1.4 Beliefs about HIV Transmission:**

Sharing house utensils with AIDS person is a possible mode for HIV transmission was a general belief among the participants. Most of them restricted transmission when sharing personal tools as tooth brush, hair brush, soap and body shower sponge or sharing penetrating objects as knives, shaving instruments, etc.

Few participants thought it is not a mode for HIV transmission.



It could be concluded that considerable number believes that sharing shower room with AIDS person is not a mode for HIV transmission. But few participants were doubtful about this mode. They thought that it is a possible mode in special situations as presence of blood in the shower room from small wounds of PLWA.

#### **4.2.1.5 Attitudes towards PLWA:**

Most of the participants agreed that PLWA should be separated from others as they may be enviable, having revenge. Some limited this to the late stages of the disease only. Other restricted separation only in fresh food markets and in butchers.

"Although separation of PLWA may harm them psychologically, but still it is an important consideration" a young lady

Considerable number show they shouldn't separate as this may increase their suffering.

"Health education satisfies the limitation of AIDS and there is no need for separation" a young man

The majority approved that names of PLWA should not made public in aim to avoid them by others because this may discredit and devalue them and disturb their psychological status.

"This is contradictory to humanity. It is enough to deal carefully with them" a sympathized lady

Some justified that publication of names is a must.

"They must be labeled by tags or signs that they are HIV positive also!" an enthusiastic man

"No sympathy with such a disease. I agree this issue" a lady

Prevalently, participants bore PLWA the responsibility for having their illness. Depending on the way they got the disease; they were responsible if they got it by immoral sexual behavior but not if they got it by blood transfusion or by

accidents as from shaving or using infected tools. However few thought that even the later are responsible for their negligence!

Commonly they could decide that PLWA had got what they deserved or not depending on the transmission route.

#### **4.2.1.6 HIV Testing and Concerns about Stigma:**

Undergoing HIV blood test had got the approval of most participants as this made them sure and safe.

Few of them didn't accept the test as they distrusted the result reality. Some attributed the refuse to their sureness that they could never get a disease like AIDS.

"I disagree for testing as I am confident about my behavior 100% and I had never had blood transfusion" an excited lady

"I'll agree in case the test is compulsory for travelers. Otherwise it will become a sort of luxury" a young man

Participants exhibited that they would be concerned about being treated differently by others if their test proved to be positive.

"Surely people will treat me worse; I will be sad and depressed. I will never tell other about my HIV status and will continue a normal life" a girl

"I will keep my status secret and ask God to forgive me" a young man

"Although am merciless toward PLWA, in my case I want idealistic treatment for myself" one participant

### **4.2.2 In Depth Interviews**

#### **4.2.2.1 in depth interview with a psychiatrist:**

He defined stigma as the negative attitude of the society toward certain people sharing the same problem or behavior which is considered to be abnormal by the society and not confirming to the social norms.

“Stigmatization differs from one society to another. This is shown very clearly in comparison between Islamic and European communities”

Certain diseases are associated with stigma. Many people suffer from diabetes or hypertension but they are considered as usual patient and never suffer from stigmatization. Nowadays AIDS is the most stigmatized disease ranking the top.

“People consider this syndrome as punishment from God even if it is due to heterosexual practices since it is a sin”

Forms of stigma are: rejection, shame, humiliation and social isolation. PLWA are rejected as they are considered strangers. They are claimed for doing something bad. As PLWA are treated as deviant, they are given bad labels. This is exemplified in addicts and homosexuals.

“The psychological mirror for isolation of PLWA is mental retardation”

In his opinion stigma involve all people suffering from the same problem or sharing the same behavior. In contrast, discrimination when exist will harm one sector of the society. In Sudan presence of tribalism reinforces such a behavior.

He said that in the Sudanese society especially the North there is a link between stigma and gender regarding some behaviors and conducts like smoking and alcohol drinking.

“The society will never forgive an unmarried girl to have sexual relation with a man and she is going to be rejected by all people although the same man is fully accepted and lives his normal life with others”

#### **4.2.2.2 in depth interview with a headmistress:**

She defined stigma as “a mark, a sign, a shame or any disgraceful dishonorable human behavior not agreed by society, culture, religion and law”.

In her opinion AIDS “which is an imported disease in Sudan” is strongly associated with shame. So, AIDS patient

would be rejected by their society, family, friends and neighbors. Stigmatization has an economic impact when the worker is fired and “faces difficulties to find a new job”

Due to expected stigmatization, the identities of PLWA are hidden in Sudan. By this she justified that there is no further obvious discrimination toward them

She considered the situation of HIV infected woman as acute. As any Arabic society, the woman would be blamed while the man would be excused when they get infected. Even widows of men who died of AIDS; her behavior would be under suspicion.

“I wish that woman in Sudan never get AIDS because the society will never compassionate her”

#### **4.2.2.3 in-depth interview with a lay expert:**

In his view, AIDS has become a hot topic of discussion and interest. PLWA have been a subject for insult, gossip, and isolation.

Community members sometimes refuse to provide care and social support to PLWA because they fear from HIV transmission as it is lethal incurable disease. Due to the shame associated with AIDS, PLWA are rejected.

He suspected that the motive for the gossip is the nature of the disease being sexually transmitted.

“If AIDS was something transmitted like malaria, no one will bother talking about as much as happening”

He considered that laws, rules and policies in some societies can increase the discrimination of AIDS patient; such legislation may include compulsory screening and testing as limitations on international traveling and migration

In his thought women are blamed, victimized and deserted more than men in Sudan. This is true in every unacceptable behavior as cigarettes smoking, alcohol consumption, sexual relations and even psychological diseases!

So, woman with AIDS will surely be more affected particularly with incurable and sexual background of the disease.

## **5. FINDINGS**

Existence of stigma was obvious from the start. We found difficulties in inviting people to FGDs or interviews. As they knew that the topic concerns AIDS, most of them hesitated, backed down or even refused. They showed fear of discussing such an issue because its association with immoral practices. Even talking about it is shameful in their views.

There are significant indicators that stigmatizing behaviors are practiced by the respondents. They would reduce their contact with PLWA as much as possible and try to avoid them if they could. Most of the practices emerge from the sense of “fear of the incurable disease”. They are afraid of the transmission. An important point that some had misconception about HIV transmission and this exaggerate the avoidance of PLWA.

Knowledge also influenced their responses in another way. Some though that HIV/AIDS is transmitted only sexually and this is further limited to the illegitimate practices. This group would treat PLWA as cursed.

Good enough, the stigma is limited in feelings and some behaviors. Little showed tendency of discrimination. For example, they would limit their contact with an HIV positive colleague or be cautious in the relation but they will never hurt him/her by showing avoidance. Also, they did not accept separation of PLWA.

On the other hand, small proportion showed sympathy in their behaviors but not due a true feeling. The reason of their act was the “fear of revenge “!

Lamentable finding that some would avoid PLWA but when a family member gets infected they accept to take care of him. These people do know the disease well but still stigmatize

its patients. They chose the appropriate person to be informed when someone gets AIDS but refused to tell others if they themselves get infected.

Also a portion said that it is comfortable to share a vehicle, toilet, or drink with an infected person as these are common day practices. Meanwhile, they did not accept tools sharing as they are not habituated to do so.

Other influences were observed. Some participants refused to shop from an HIV-positive seller. Although that they were secure themselves, they were concerned about their little brothers and sisters who were unaware by the disease and its transmission. They were worried that they would imitate them and have contact with that seller.

A dominating idea was the link between HIV and the immoral behaviors and illegitimate sexual relations. Majority accepted that who got AIDS by sex and IDUs deserve it as “punishment for their act”.

The feelings were the same in males and females. In spite of that, males showed more courage in interactions with PLWA.

## **6. CONCLUSION AND RECOMMENDATIONS**

It is concluded that HIV/AIDS-related stigma is manifested in Sudan. Mainly misconceptions and association with immoral behaviors reinforce this stigma.

More or less stigmatization is limited in feelings and behaviors with restriction in discriminative acts.

It is observed that stigmatizing tendencies are varied according to the person’s knowledge.

It would be inappropriate to conclude this research without making reference to the question “What next?”

As many misconceptions were encountered, it would be advantageous to increase the awareness of the students about

HIV/AIDS. Seminars and discussions, concerning expressly transmission, are preferable.

The wrong belief linking HIV/AIDS with immoral behavior only should be corrected. It strengthens stigma and prevent health education in this topic. Publications in this issue would be of value.

The obnoxious manner people create about HIV/AIDS makes barriers even to discuss such an issue. These barriers would be broken if people deal with AIDS a disease not a shame. Inclusion of HIV/AIDS topics in publications, media, curriculum, etc could help.

Further research in this problem will shed light upon it and supplement this work. It is better to expand the sample **and** add groups rather than students to notice the variations. It is rational to explore more in the people's knowledge and stratify them accordingly.

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