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RESEARCH ARTICLE

STIGMA AND DISCRIMINATION AGAINST PEOPLE LIVING WITH HIV PATIENTS IN SUDAN

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ABSTRACT

The study aimed to analyze socio economic situation of people living with HIV/AIDS (PLHIVS) and their experiences of stigma and discrimination in Sudan. Population of the study was people living with HIV/AIDS who attended hospitals for voluntary counseling and testing. The study utilized non probability sampling procedures including purposive and snow ball techniques to select 60 (30 males and 30 females) of people living with HIV/AIDS from three hospitals in Khartoum State namely: Al-Bashair Hospital in Jebalawilya locality, Bahari Hospital in Bahari locality, and Military Hospital in Omdurman locality. The study adopted a structured face-to-face interview, based on a questionnaire to collect the data. Almost half of the participants were at the productive age group (25-49). About three quarters of the respondents were sexually active. More than 90% are living with HIV and AIDS for the last ten years. 55% were illiterate, and the majority of them were females. 50% were not working. Respondents were barred from attending social activities and family gatherings and the most common reason for their exclusion was their HIV status.

The study concluded that HIV-related stigma in Sudan is exceptional in its scale, its context, and its causes. Females living with HIV should be targeted in future interventions to provide them with better educational facilities to support them to have a productive life. Even for males, since most of the PLHIVS are young. Technical education and micro credit schemes would go a long way in alleviating their sufferings.

INTRODUCTION

HIV-related stigma and discrimination have long been recognized main obstacles to the prevention, care and treatment of HIV and AIDS (Aga *et al*. 2009). People **PLHIVS** face many problems ranging from isolation to stigma. In addition they are hidden population their situation does not expose to majority of people (Assefa,Van Damme & Mariam 2010). Across Sudan there are an estimated 69 000 **PLHIVS** with 0.4% prevalence. (Sudan House Hold Survey (SHHS) conducted in 2010 estimated that the HIV/AIDS test coverage was only 1% for Sudanese population.

The spread of HIV is influenced by poverty and illiteracy, both of which are widespread in Sudan (Federal Ministry of Health, 2011). The movement of people who are pushed to migrate due harsh environmental conditions has contributed to an increase in the number of HIV/AIDS cases. War constitutes another pushing factor to people in the area and during the last few years the war in Darfur resulted in the displacement of about 2.5 million people (Sudan National AIDS program (SNAP) 2008) The Blue Nile constituted another turmoil zone whereby flux of population are pushed to migrate to different parts of the Sudan. Such high rate of mobility is documented to play a great role in the escalation of the disease in Sudan. People living with the disease are often thought to suffer social stigma community discrimination and are considered to be living in information, education, and communication isolation (WHO/UNAIDS, 2006; Badreldin *et al*. 2013; Hafsa, 2016).

All these factors contributed to that Sudan is estimated to have largest populations living with HIV in Middle-East and North Africa (Federal Ministry of Health, 2011).

HIV/AIDS is portrayed by the policy makers and the health providers in the Sudanese community as a "moral disease" as such the associated stigma of the disease is "stigmatizing" the disease carriers (AbuBaker and Farage, 2015). This implies that relevant causing factors are highly stigmatized and this explains the fact that HIV epidemic among men who have sex with men is largely hidden in the Sudan due to poor surveillance which reflects high levels of stigma and discrimination towards this group (Avert, 2011; Brener *et al*. 2013)

Data relevant to this group is often scattered and depends on individual research efforts. It is estimated that across the region, less than 1 in 10 men who had sex with men is living with HIV. Data provided by international efforts estimated that

some countries have a higher HIV prevalence than others. For example, in Egypt, Morocco, Pakistan, Sudan and Yemen, HIV prevalence among men who had sex with men is nearing 10%. (WHO UNAIDS, 2007).

External and internal stigma discourage individuals from coming for testing and seeking information relevant to the disease and measures of protection and measures not infect others (Olugbenga-Bello 2015). The study seeks to document socio-economic situation of PLHIVS and how do they live and overcome stigma and discrimination in Sudan. In particularly, the researcher is concerned with examining socio economic status of male and females living with HIV in Khartoum State and to explore their experience of stigma and discrimination from other people.

Objective to investigate the opinion of **PLHIVS** on reasons for facing the stigma and Discrimination.

MATERIAL AND METHODS

Type of the study

Hospital-based cross-sectional study conducted at three hospitals in Khartoum Sate namely: Al-Bashair Hospital in Jebalawilya locality, Bahari Hospital in Bahari locality, and Military Hospital in Omdurman locality.

Target population: male and female living with HIV/AIDS who attended hospitals of Voluntary Counseling and Testing (VCT)

Sample size

Due to stigma related to HIV/AIDS the infected population is often hidden as such it was very difficult to draw sample from them because most of them were not willing to participate in the study and to provide informed consent. The study relied on a non probability sampling technique to collect relevant data. Snow ball was used to collect relevant data from 30 males and 30 females of **PLHIVS** selected from the three conveniently identified hospitals in Khartoum Sate.

The researchers adopted a structured face-to-face interview, based on a questionnaire and data was collected by trained interviewers using structured and standardized questionnaire. The questionnaire was designed in English but subsequently translated into Arabic. The Arabic version was used to collect the required data. The questionnaire was pretested among a group of population.

Data was analyzed using the statistical package for social science [SPSS version 15] to provide, frequencies, distribution in table of data, percentage and the rates in tabular form.

Profile of PLHIVS

The above table shows that the majority of the participants of the study were females represented by 56.7% of the study population and their ages ranged between 25- 29 years old compared to the males participants represented by 6.6%. While 60% of males were 45-and above years old none of the females who shared their experience to this study were recorded to be 45 years old or above.

Table 1 Profile of **PLHIVS**

		Male	%	Female	%	Total	%
Age	20- 24	1	3.3	3	10	4	6.7
	25- 29	2	6.6	17	56.7	19	31
	30-34	6	20	5	16.7	11	18.3
	35-39	3	10	3	10	6 10	10
	40-44	0	0	2	6.6	2 3 .3	3.3
	45 and more	18	60	0	0	18 30	30
	Total	30	100	30	100	60	100
Education	Illiterate	10	33.3	23	76.7	33	55
	Primary education	13	43.3	5	16.7	18	30
	Secondary education	7	32.4	2	6.6	9	15
	University	0	0	0	0	0	0
	Total	30	100	30	100	60	100
Marital status	Single	10	33.3	3	10	13	21.7
	Married	15	50	2	6.6	17	28.3
	Divorced	5	16.7	5	16.7	10	16.7
	Widowed	0	0	20	66.7	20	33.3
	Total	30	100	30	100	60	100
Occupation	Employee	3	10	0	0	3	5
	Work in informal sector	9	30	15	50	24	40
	Not working	18	60	15	50	33	55
	Total	30	100	30	100	60	100
Place of origin	Khartoum Sate	12	40	7	32.4	19	31.7
	Migrated	18	60	23	67.6	41	68.3
	Total	30	100	30		60	100
Living with HIV/AIDs	Less than 10 years	22	73.3	25	83.3	47	78.3
	More than 10 years	8	26.7	5	18.7	13	21.7
	Total	30	100	30	100	60	100

A significant proportion 69.3% of the respondents was in the productive age group of 20-44 years of age. The result indicated low literacy of the respondents. 55% were illiterate majority of them females .30% of respondents reached up to primary education and 15% were secondary school graduate. The majority of males 50% married, compare with females 6% married, also 33,3% males single and 10% females, divorced approximately 33.3 % of the respondents were living as widower/ widow, but the proportion of widow for females rises to 66.7%. 40% of **PLHIVS** worked on informal sector 50% of them female who worked as tea sellers and domestic servants. 50% of the respondents did not work majority of them males with 50%. 68.3 of respondents were not originally from Khartoum migrated from different areas of Sudan especially conflict areas, Majority 67.6 of them were females.78.3% of those infected were living with the HIV for less than ten years.

RESULTS AND DISCUSSION

Figure (1) the experience of stigma and discrimination

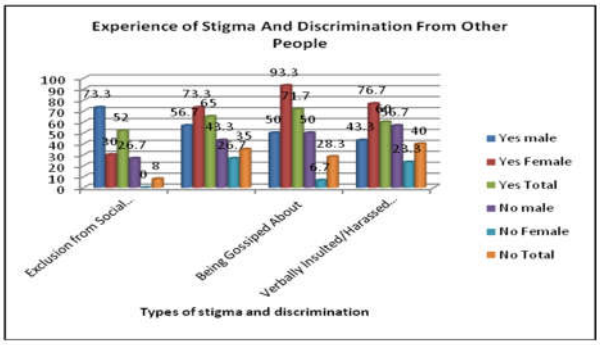

Figure 1 Experience of Stigma and Discrimination from other People

Out of all the respondents 86.6 % chose not to attend social gatherings, 100% were females. 65% isolated themselves from family and friends 73.3% of them were females, 71.8 were being gossip about 93% of them were females.60.5% of the respondents were verbally insulted 76.7% were females.

Figure (2) the experience of internal stigma

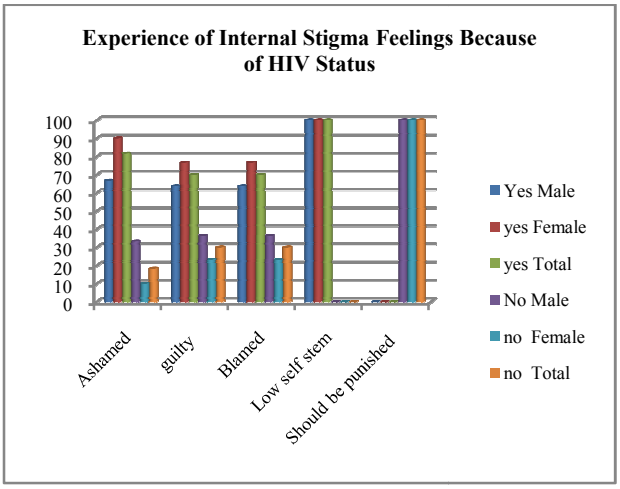

Figure 2 Experience of Internal Stigma Feelings Because of HIV Status

Internal Stigma (The Way You Feel About Yourself and Your Fears) Out of all the respondents 81.7 % felt ashamed, 70 % felt guilty, 70% blamed themselves, 100% had low self-esteem, none of them felt that they should be punished.

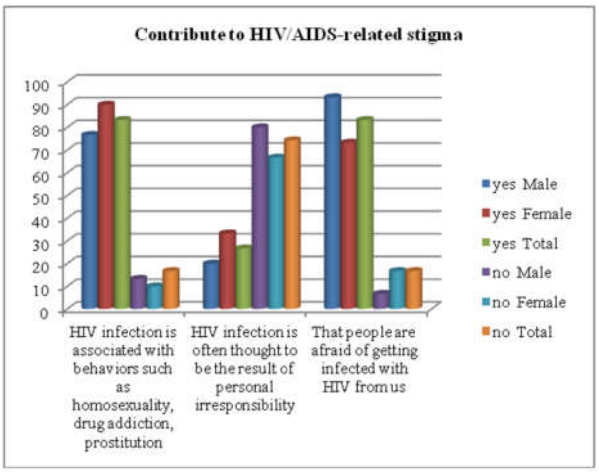

Figure 3 Reasons for facing HIV, stigma and Discrimination

Opinion of PLHIVS on Reasons for Facing HIV Stigma and Discrimination

83.3% thought that people were afraid of getting infected with HIV from them, 83.3 of respondents thought that the reason of stigma and discrimination due to HIV infection is associated with behaviors such as homosexuality, drug addiction and prostitution. 26.7% thought that HIV infection is often thought to be the result of personal irresponsibility

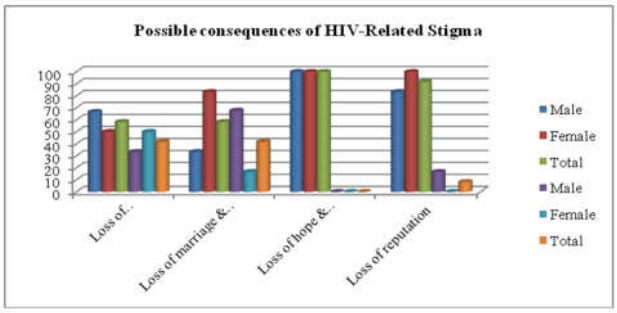

Figure 4 Possible consequences of HIV-Related Stigma

Possible consequences of HIV-Related stigma

58.3% of respondents lost their source of income of whom 66.7% were males. 8.3% lost their marriage; 83.3% of them were females. All the respondents 100% revealed that they lost hope of life and experience feelings of worthlessness. 91.7% of the respondents lost their reputation.

HIV-related stigma and discrimination exist worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals. HIV related stigma results in: Loss of income and livelihood; loss of marriage and childbearing options; poor care within the health sector; withdrawal of care-giving in the home; loss of hope and feelings of worthlessness and loss of reputation. HIV-related stigma and discrimination is a complex social process that interacts with, and reinforces, the pre-existing stigma and discrimination associated with sexuality, gender, race and poverty. Discrimination against **PLHIVS** is common in Sudan. As the disease became known in the early 1980s, the fear from the highly contagious nature of it persisted. This fear, coupled with many other reasons which was mitigated with the belief in that: HIV and AIDS are always associated with death; HIV is associated with disapproved behaviors like homosexuality, drug use, sex work or infidelity; HIV is only transmitted

through sex particularly outside the socially accepted channels like sex experiences outside the marital relations; and HIV infection is the result of personal irresponsibility or moral fault (such as infidelity) that deserves to be punished.

Results of the study indicated that young people living with HIV in the productive age, who were sexually active and are afraid of social stigma were displaying negative health seeking behavior particularly in relations to adopting, preventive measure so as not to spread the disease. According to (Steward *et al*., (2013) ramifications of HIV‐related stigma on health seeking behaviour may result in individuals fearing to get tested; and for people living **PLHIVS** with HIV/AIDS (PLWHA), negative responses include delaying or adhering to treatment and potentially not adopting preventative behaviours. Stigma is cited as a major barrier to accessing preventive and curative services. Study found that females living with HIV were vulnerable and sexually active. The study indicated that stigma and discrimination had more negative effect of female living with HIV than male counterparts they faced more gossip and verbally insulted**.** 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 (Loren Brener,2013).Women are increasingly at high risk of becoming HIV positive due to their biological vulnerabilities, low socio-economic status, dominant sexual practice of males and epidemiological factor (International Center for Research on Women ICRW, 2005).

Internal feeling of stigma had more negative impact for both males and females **PLHIVS**. Females felt shame and low self-esteem due to internal, felt or perceived stigma. Internal stigma is seen as a complex process that involves internalizing the devaluation from people around the PLWA. **PLHIVS** may also impose stigmatizing beliefs and actions themselves. This kind of self -stigma combined with a fear of a negative reaction from the community also slows the effort to address the HIV epidemic by the constant silence and embarrassment that follows the disease and the epidemic, (Olugbenga-Bello, *.et al*., (2015)

The majority of the interviewed **PLHIVS** thought that the reason of stigma and discrimination against them because HIV infection is associated with behaviors such as homosexuality, drug addiction, prostitution. Study conducted on HIV on Middle East indicated that the HIV epidemic among men who have sex with men is largely hidden due to poor surveillance which reflects high levels of stigma and discrimination towards this group. (WHO, 2006)

Majority thought that people are afraid of getting infected with HIV from us. Many studies indicated that people were still afraid that HIV can be transmitted through ordinary, daily interactions with PLHIVS and AIDS. Even though the particulars varied in each setting, people are preoccupied with unlikely modes of transmission (Brown *et al*., 2003) Study indicated PLHIVS were not ready to break the confidentiality afraid of stigma and discrimination. Study in Botswana and Zambia found that stigma against HIV-positive people and fear of mistreatment prevented people from participating in voluntary counselling and testing and programmes to prevent mother-to-child transmission.

CONCLUSION

It can be concluded that HIV-related stigma and discrimination have been acknowledged as an impediment to mitigating the HIV epidemic since its early days, yet programming and activities to reduce stigma and discrimination have been given much less attention than other aspects of the epidemic. Right from the beginning, the HIV/AIDS epidemic has been accompanied by an epidemic of fear, ignorance, and denial, leading to stigmatisation of and discrimination against people with HIV/AIDS and their family members

Moreover, it can be said that despite widespread recognition of the differential treatment of persons living with HIV/AIDS (PLHA) by society and its institutions, over the first 25 years of the epidemic, community, national, and global actors have only had limited success in alleviating the deleterious effects of HIV/AIDS stigma. It is found that the stigma prevented **PLHIVS** to participate in raising awareness of people towards the HIV/AIDS. Stigma prevented them even to contact organization provide help and support for **PLHIVS**. Different people and different institutions can provide some support, but it is important for people **PLHIVS** living with HIV and AIDS to come together and support one another. **PLHIVS** and AIDS would. Moreover it is found that Prevention of HIV among key population continued to be challenging considering the hidden nature of the population and associated stigma around sex Sudanese society led to self-stigma, causing positive people to think they are indecent, amoral and therefore deserve to be stigmatized and discriminated against. To avoid stigma and discrimination, they had to keep a low profile and isolate themselves from others. However, the feelings of guilt, modesty, frustration these feelings reflect the magnitude and intensity of stigma on positive people.

Finally it can be concluded that Overall, the study suggests that while HIV programming in Sudan has focused on HIV Prevention, Treatment Care and Support, there is still a gap with regards to HIV related stigma and discrimination. PLHIV still experience different forms of stigma and discrimination which include being gossiped about, exclusion from social, religious and family activities, verbal and physical abuse among other things. While HIV/AIDS stigma is widely invoked as a major facilitator of the epidemic, only a few studies have demonstrated an association between stigma and increased risk behavior

The recommendations

Based on the findings of this study the researchers recommend

- Immediate enacting of legal laws that offers protection against HIV related discrimination and equal enjoyment of human rights.
- Incorporation of anti-stigma strategies as integral components of the national AIDS framework
- Financial and technical assistance for capacity-building of organizations and networks of **PLHIVS** to deal with stigma and discrimination.
- Launching of social change communication that blends mass media approaches, community engagement strategies, and empowerment strategies with other forms of informational and motivational communication and advocacy in portraying the true nature of HIV and AIDS and dispel any myths and fears associated with it.

- Trainings programs for health care professionals to cater to the complex medical, physical, emotional and psychological needs of the PLHIVs.
- Education of workplace policy for all the employers to provide workplace education and non-discriminatory practices regarding HIV and AIDS.
- Involvement of religious leaders in an active role in promoting awareness about and working to reduce stigma and discrimination related to HIV and AIDS at all levels.
- Ensure meaningful and integral involvement of PLHIVs at each and every step from policy to operational level. Strengthen the capacity of **PLHIVS** to challenge and confront stigma and discrimination in their lives.
- Females living with HIV and AIDS should be targeted in future interventions to provide them with better technical educational facilities to have an independent life.

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Ethical Clearance

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