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# Correlates and consequences of internalized stigma of mental illness among people living with HIV/AIDS in Nigeria, West Africa

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There is evidence that internalized stigma significantly impacts the lives of depressed people living with human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) (PLWHA). Nevertheless, there is paucity of data on the extent, domains and demographic correlates of internalized stigma among PLWHA; hence the need for this study. This was a hospital based, cross sectional, descriptive study of one hundred and seventy depressed PLWHA. The PHQ-9 was used to screen for depression. The severity of the depression was classified as minimal, mild, moderate and severe. The three keys of social determinants of depression (SDS) were assessed and the association with stigma sought. A modified version of stigma of mental illness scale (ISMI) was used as a measure of their self stigma. The prevalence of depressive disorders was 57%. The spectrum of stigmatization was as follows, 103 (60.6%), minimal, 33 (19.4%), mildly, 19 (11.2%), moderately and 15 (8.8%) severely stigmatized. There was a strong association between stigma and age group, educational level, monthly income, stressful life events as well as social cohesion. Self-stigma is a common phenomenon in depressed PLWHA. It is not possible to manage PLWHA without considering the highly stigmatizing context in which they are embedded. Moreover, due to the high burden of depressive disorders and its association with AIDS related stigma, routine screening of PLWHA for both conditions is recommended.

**Key words:** Internalized stigma, mental illness, human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS), Nigeria.

#### INTRODUCTION

Self stigma is the prejudice which people with depression turn against themselves (Corrigan, 2000). It is a product of internalization of shame, blame, hopelessness, guilt and fear associated with depression (Corrihan, 1998). In self stigma, patients may hold negative belief about self as being incompetent with character weakness.

Moreover, internal stigma is a powerful survival mechanism aimed at protecting oneself from external stigma and often results in thoughts or behavior such as the refusal or reluctance to disclose a positive human immunodeficiency virus (HIV) status, denial of human immunodeficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) and unwillingness to accept help (Greeff et al., 2008). Eandeshaw (2012) while trying to study the role of stigma in depression at Gonder University Hospital, Ethiopia found that majority of the HIV patients (78%) reported experience of stigma.

Nearly two-thirds of all people with diagnosable depression do not seek treatment (Farina et al., 1968). Stigma surrounding the receipt of mental health treatment was among the many barriers that discourage people from seeking treatment. The stigmatization of depression and the lack of information of the symptoms of depression are seen as the main barriers of seeking helps for mental health. Stigma leads to low self-esteem, isolation and hopelessness. Furthermore, low self-worth in response to stigmatization is found to be a predictor of poorer social adjustment (Farina et al., 1968). Social support is a useful resource that helps minimize psychological stress. It also plays a key role in buffering the negative effects of HIV-related stigma (Brouard, 2012). Social support is particularly important for women as they rely more on social relationships compared with men in similar situations (Hurdle, 2001). There is a welldocumented inverse relationship between social support and depression in people living with HIV/AIDS (PLWH) (McDowell, 2007).

The dual existence of AIDS related stigma and depressive disorders among PLWHA could lead to a number of adverse health outcomes. Stigma in Sub-Saharan Africa seems to be particularly common because what happens to one person concerns the whole community. The communal life in itself poses a dilemma because it brings about stigmatization when PLWHA are faced with low social cohesion (Greeff et al., 2008). Other studies show that family members of a person who died of HIV/AIDS or family members who live with PLWHA are stigmatized; therefore family members encourage PLWHA to remain silent to avoid social rejection (Wood et al., 2008). Receiving assistance from the government also enhances a perception of difference from other members of the community since it is assumed that only PLWHA are offered such support in a community where almost everybody is poor and needs support (Greeff et al., 2008).

The effectiveness of efforts designed to address mental illness stigma will rest mainly on our ability to comprehend stigma processes, the factors that produce such processes, and the mechanisms that lead from stigmatization to detrimental consequences. Critical to such an understanding is our capacity to measure the essential components of stigma processes. Little work

had been done to find out the association between AIDS related stigma and depressive disorders in Sub-Saharan Africa (Kalichman, 2003; Simbayi, 2007; Sorsdahl, 2011), despite the fact that examining the relationship between AIDS related stigma and major depressive could be useful in holistically assessing the patients.

#### **METHODOLOGY**

This study was conducted at the HIV/AIDS clinic at Kwara State Specialist Hospital, Ilorin, in North Central Nigeria. This study was a descriptive, cross-sectional study carried out from 1st of June to 31th August, 2013. The sample size was estimated using the Fisher formula (Araoye, 2003), using 21.3% from a previous study (Ndu et al., 2011), as the best estimate of depressive disorders among people living with HIV/AIDS. A minimum size of 218 was calculated using Fisher's formula but 300 was used to increase the power and reliability of the study. Every adult HIV/AIDS patients who concerted were recruited until the sample size of 300 was obtained.

The patients health questionnaire PHQ-9 (Appendix A) is a brief, 9-item, patients self-report depression assessment tool that was derived from the interview-based PRIME-MD (Krooenke et al., 2001, 2003). It was specifically developed for use in primary care general medical settings. It is the only short self-report tool that can reasonably be used both for diagnosis of DSM-4 major depression as well as for tracking of severity of major depression over time (Liang, 2001). In Nigeria, Abiodun et al. (2006) found out that the internal consistency was 0.85. The PHQ-9 had good concurrent validity. It also had good test-retest reliability. Sensitivity was 0.897. Specificity was 0.989, while the positive predictive value (PPV) was 0.875.

Based of existing research (World Health Organization (WHO), 2008, 2010; Stewart et al., 2007), we used three keys SDH: socioeconomic status, social cohesion and negative life events (Appendix B). Socioeconomic status included two indicators: years of schooling and self-reported economic status of the family, in general, in the previous year. Categories for years of schooling were as follows: above average (7 years and above), average (1 to 6 years) and below average (0 years). Economic status of the family was self-reported as good, average or poor. Social cohesion was assessed from responses to two questions: (1) in the previous vear, how often did vou ask someone for help when vou had problems? (Never = 1; Seldom = 2; Sometimes = 3; Often = 4), and when you had problems? (spouse or lover; parents, brothers, sisters or children; other relatives; people outside the family; organization or schools with whom you are affiliated; government, party or trade unions; religious or non-governmental organizations; other organizations) (no = 0; yes = 1). (2) Negative life events were gauge using a 12-item scale (serious illness in oneself, serious illness in the family, financial difficulties, conflict with spouse, conflict with other family members, conflict with people in the village, conflict between family members, infertility issues, problems at work or school, problems in an intimate relationship, abuse and other events).

Age, gender, marital status, education level, self-rated financial status, social support and social cohesion, employment status and estimated monthly income were the socio-demographic variables and potential confounders. Monthly income was assessed using the minimum wage stipulated by the Federal Government of Nigeria, which is Twenty Thousand Naira (N20, 000).

Internalized stigma of mental illness (ISMI) was the questionnaire used in the present study which included 55 items pertaining to internalized stigma, which were abridged to produce the 29-item ISMI (Stephannie, 2013). Each statement is assessed on the

following 4-point Likert scale: 1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree. Items were grouped theoretically a priori into five subscales: Alienation, stereotype endorsement, perceived discrimination, social withdrawal, and stigma resistance. In sub-Saharan African, the internalized stigma scale was internally consistent, as suggested by Cronbach's alpha of 0.73 (95% confidence interval [CI], 0.69 to 0.78) (Alexander et al., 2013).

Completed questionnaire and measurements were entered into a computer data base. The data were analyzed using the Epidemiological information (Epi-info) (2005) software package. The 2 by 2 contingency tables were used to carry out Chi-square test and to find out the level of significance and values less than 0.05 were regarded as statistically significant.

## **RESULTS**

Table 1 shows the socio-demographic characteristics of the respondents. A total of one hundred and seventy sero-positive respondents with depression were recruited to the study. The age range 36 to 40 years had the highest number of respondents 50 (29.4%). Females 139 (81.8%) outnumbered males 31 (18.2%), giving a male: female ratio of 1:4.5. Majority of them 56 (32.9%) had no formal education 55 (32.4%). Table 2 displayed the treatment variables. Sixty eight (40%) were on AZT+3TC+NVP while 5 (2.9%) were on AZT+3TC+LPV/r. Table 3 shows that 103 (60.6%) were minimally, 33 (19.4%) mildly, 19 (11.2%) moderately and 15 (8.8%) severely stigmatized. The p value was statistically significance (p < 0.001). Table 4 displayed the association between socio-demographic factors and level of stigma. Females had higher stigma scores. Stigma was very common among 36 to 40 years, as well as those with low social-economic status. Table 5 shows that higher level of internalized stigma was associated with stressful life events 13 (24.5%) and low social cohesion 13 (9.7%). Table 6 shows the evaluation of the components of the Internationalized Stigma of Mental Illness Scale (ISMI), adjusted for depressive disorders, the mean scores and the standard deviation

## **DISCUSSION**

The prevalence of depressive disorders among HIV/AIDS patients attending the highly active anti-retroviral therapy (HAART) clinic, at the Kwara State Specialist Hospital Sobi, was 57%. One hundred and nine (36.3%) had minimal depression, while 4 (13%) were severely depressed. Depressive symptomatology in the population mirrored presentation of depression in other setting (Bing, 2001; Pence, 2007). The study replicates previous findings among PLWHA patients in Nigeria in particular. It also falls within the rates seen internationally (Chikezie, 2013; Olisah, 2010; Bradley 2013).

The highest age group 36 to 40 years was similar to 30 to 39 years of Hassan et al. (2012), but different in terms

of gender, where 64% of the PLWHA were male and 35% female compared to our study, where 18.2% were male and majority 81.8% were female. Contrary to our finding, where female were more severely stigmatized, Hassan et al. (2012) found that the males were more likely to experience a higher level of internalized stigma. Zierler et al. (2000) found no gender differences in reporting stigma, nor were there ethnic or age differences.

In this study, internalized stigma was associated with stressful life events and low social cohesion. Social support is a useful resource that helps minimize psychological stress. It also plays a key role in buffering the negative effects of HIV-related stigma (Brouard, 2006). There is a well-documented inverse relationship between social support and depression in PLWHA (Catz, 2002). As regards level of stigma, the group that developed ISMI (Ritsher 2003) suggests using the midpoint of the scale (an average score equal or above 2.5 on the 1 to 4 point scale) as a possible level of high internalized stigma. Similarly, Adewuya et al. (2011) reported high selfstigma. Another way of determining the level of stigma was suggested by Lysaker et al. (2012). They proposed that a score of 2 or less should be labeled "minimal stigma", scores between 2 and less than 2.5 could be labeled as "mild stigma", scores between 2.5 and 3 could be labeled as "severe stigma".

Army et al. (2013) reported 35% of moderate to severe levels of internalized stigma. Similarly, Santos et al. (2011) reported that individual with depressive symptomatology showed significant levels of HIV stigma in comparison to non-depressed participants. In Jamaica (White 2005), there was a high level of stigma associated with being HIV-positive and therefore many HIV-infected patients do not disclosed their status. The stigma associated with being known to be HIV-infected has been found to correlate significantly with having depressive symptoms (Li Li, 2009). The HIV-infected patients tend to go to clinics outside their communities to ensure that they are not recognized by members of their local community. This level of anonymity and reduced isolation may act as a buffer for depression. Similarly, PLWHA in Thailand (2009) face tremendous challenges, including HIV-related stigma, lack of social support, and mental health issues such as depression.

Dranpalski et al. (2013) also reported moderate to severe levels of internalized stigma. Elaine et al. (2010) found out that over one fifth of the participants (21.7%) reported moderate or high levels of self-stigma, 59.7% moderate or high stigma resistance, 63% moderate or high empowerment, and 71.6% moderate or high perceived discrimination. In a reduced multivariate model, 27% of the variance in self-stigma scores, among people with a diagnosis of bipolar disorder or depression, was accounted for by levels of empowerment, perceived discrimination, and number of areas of social contact, education and employment. These observed differences

 Table 1. Socio-demographic characteristics of respondents.

Variable	N = 170	(%)	Others
Age group (years)			
< 26	19	11.2	
26 – 30	27	15.9	
31 – 35	20	11.8	
36 – 40	50	29.4	
41 – 45	11	6.5	Mean age is 39 years with
46 – 50	19	11.1	SD of ± 10.8
51 <b>–</b> 55	6	3.5	
56 – 60	11	6.5	
>60	7	4.1	
>00	,	7.1	
Gender			
Male	31	18.2	_
Female	139	81.8	
Ethnicity			
Hausa	39	22.9	
Yoruba	92	54.1	
Igbo	28	16.5	-
Others	11	6.5	
Others	'''	0.5	
Religion			
Christianity	30	17.6	
Islam	139	81.8	-
Traditional	1	0.6	
Marital Status			
Single	14	8.2	
Married	14	8.2	
Separated/divorced	116	68.3	-
Widowed/widower	26	15.3	
widowed/widowei	20	13.3	
<b>Educational level</b>			
Non-Formal	56	32.9	
Primary	55	32.4	_
Secondary	42	24.7	-
Tertiary	17	10.0	
Occupation			
Trader	91	53.5	
Civil servant	16	9.4	
Self employed	43	25.4	_
Unemployed	43 14	8.2	-
Students	6	3.5	
Gladerila	· ·	0.0	
Monthly Income			
No Income	20	11.8	
≤20000	129	75.9	
20001-30000	10	5.8	_
30001-40000	6	3.5	•
40001-50000	3	1.8	
>50000	2	1.2	

Table 2. Treatment variables of HIV patients at the Specialist hospital, Sobi, Ilorin, Nigeria.

Combination	Frequency	Percentage (%)
AZT+3TC+NVP	68	40
AZT+3TC+EFV	34	20
4DT+3TC+NVP	13	7.6
TDF+FTC+EFV	28	16.5
TDF+FTC+NVP	15	8.8
ABC+3TC+NVP	7	4.2
AZT+3TC+LPV/r	5	2.9
Total	170	100

AZT = Zidovudine, 3TC = Lamivudine, NVP = Neviripine, EFV = Efavirence, TDF = Abacavir.

**Table 3.** Association between stigma and depression among HIV/AIDS patients at Kwara State Specialist Hospital Sobi, Kwara State.

Score	Stigma level	Depressed (%)	P-value
<2	Minimal	103 (60.6)	
2.0-2.49	Mild	33 (19.4)	
2.50-2.99	Moderate	19 (11.2)	0.0001
≥ 3.0	Severe	15 (8.8)	
	Total	170 (100.0)	

Table 4. Association between ISMI, gender, age group and educational level as a measure of socio-demographic factors.

•		T . ( . 1 (0/)				
Sex	< 2	Level of st 2.00 – 2.49	2.50 - 2.99	≥3.00	Total (%)	p-value
Male	23 (74.2)	5 (16.1)	1 (3.2)	2 (6.5)	31 (100.0)	
Female	81 (58.3)	28 (20.1)	18 (13.0)	12 (8.6)	139 (100.0)	0.289
Total	104 (61.2)	33 (19.4)	19 (11.2)	14 (8.2)	170 (100.0)	
Age group						
<26	14 (73.7)	0 (0.0)	0 (0.0)	0 (0.0)	19 (100.0)	
26-30	14 (51.9)	4 (14.8)	8 (29.6)	1 (3.7)	27 (100.0)	
31-35	18 (90.0)	2 (10.0)	0 (0.0)	0 (0.0)	20 (100.0)	
36-40	29 (58.0)	15 (30.0)	3 (6.0)	3 (6.0)	50 (100.0)	
41-45	5 (45.5)	4 (36.4)	5 (26.3)	0 (0.0)	11 (100.0)	0.001
46-50	10 (52.6)	4 (21.1)	5 (26.3)	0 (0.0)	19 (100.0)	0.001
51-55	3 (50.0)	1 (16.7)	2 (33.3)	0 (0.0)	6 (100.0)	
56-60	7 (63.6)	2 (18.2)	0 (0.0)	2 (18.2)	11 (100.0)	
>60	4 (57.1)	1 (14.3)	1 (14.3)	1 (14.3)	7 (100.0)	
Total	104 (61.2)	33 (19.4)	19 (11.2)	14 (8.2)	170 (100.0)	
Educational level						
Non-formal	37 (66.1)	10 (17.9)	5 (8.9)	4 (7.1)	56 (100.0)	
Primary	35 (63.6)	10 (18.2)	8 (14.5)	2 (3.6)	55 (100.0)	
Secondary	17 (40.5)	13 (31.0)	5 (11.9)	7 (16.7)	42 (100.0)	0.035
Tertiary	15 (88.2)	0 (0.0)	1 (5.9)	1 (5.9)	17 (100.0)	
Total	104 (61.2)	33 (19.4)	19 (11.2)	14 (8.2)	170 (100.0)	

Table 4. Contd.

Monthly income						
No Income	11 (57.9)	1 (5.3)	3 (15.8)	4 (21.1)	19 (100.0)	
Less or equal to 20000	80 (61.5)	27 (20.8)	15 (11.5)	8 (6.2)	130 (100.0)	
20001-30000	5 (50.0)	5 (50.0)	0 (0.0)	0 (0.0)	10 (100.0)	
30001-40000	6 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	6 (100.0)	0.003
40001-50000	1 (33.3)	0 (0.0)	0 (0.0)	2 (66.7)	3 (100.0)	
>50000	1 (50.0)	0 (0.0)	1 (50.0)	0 (0.0)	2 (100.0)	
Total	104 (61.2)	33 (19.4)	19 (11.2)	14 (8.2)	170 (100.0)	

**Table 5.** Association between ISMI, negative life events and social cohesion as a measure of social determinants of health.

No notive life events		Level of	stigma			
Negative life events	< 2	2.00 - 2.49	2.50 - 2.99	≥3.00	Total (%)	p-value
0	22 (66.8)	8 (25.0)	2 (6.2)	0 (0.0)	32 (100.0)	
1	33 (66.0)	11 (22.0)	5 (10.0)	1 (2.0)	50 (100.0)	
2	27 (77.1)	5 (14.3)	3 (8.6)	0 (0.0)	35 (100.0)	0.000
>3	22 (41.5)	9 (17.0)	9 (17.0)	13 (24.5)	53 (100.0)	
Total	104 (61.2)	33 (19.4) 19 (11.2)		14 (8.2)	170 (100.0)	
Social cohesion						
Low	82 (6.12)	20 (14.9)	19 (14.2)	13 (9.7)	134 (100.0)	
Fair	20 (58.8)	13 (38.2)	0 (0.0)	1 (2.9)	34 (100.0)	0.018
High	2 (100.0)	0 (0.0)	0 (0.0)	0 (0.0)	2 (100.0)	0.018
Total	104 (61.2)	33 (19.4)	19 (11.2)	14 (8.2)	170 (100.0)	

Table 6. Internationalized stigma of mental illness scale (ISMI), adjusted for depressive disorders.

•		Mean	
No.	Alienation		SD
-		score	
1	I feel out of place in the world because I have depression	1.58	0.81
2	Having depression has spoiled my life	1.66	0.79
3	People without depression could not possibly understand me	1.59	0.76
4	I am embarrassed or ashamed that I have depression	1.67	0.79
5	I am disappointed in myself for having depression	1.67	0.79
6	I fell inferior to others who don't have depression	1.65	0.78
	Stereotype endorsement		
7	Stereotypes about depression affected people apply to me	1.60	0.78
8	People can tell that I have depression by the way I look	1.64	0.77
9	Because I have depression, I need others to make most decisions for me	1.83	2.66
10	People with depression cannot live a good, rewarding life	1.64	0.72
11	Depression affected people should not marry	1.82	2.66
12	I can't contribute anything to society because I have depression	1.62	0.72
	Discrimination experience		
13	People discriminate against because I have depression	1.64	0.75
14	Others think that I cant achieve much in life because I have depression	1.64	0.77
15	People ignore me or take me less seriously just because I have depressive	1.71	0.84
16	People often patronize-me, or treat me like a child, just because I have depression.	1.91	2.67
17	Nobody would be interest in getting close to me because I have depression	1.68	0.78

Table 6. Contd.

	Social withdrawal		
18	I don't talk about myself much because I don't want to burden others with my depression.	1.08	1.08
19	I don't socialize as much as I used to because my depression might make me look 'weird"	0.79	0.79
20	Negative stereotypes about depressive keep me isolated from the normal world	0.80	0.80
21	I stay away from social situations in order to protect my family or friends from embarrassment	0.77	0.77
22	Being around people who don't have depression makes me feel out of place or inadequate	0.76	0.76
23	I avoid getting close to people who don't have a mental illness to avoid rejection	0.79	0.79
	Stigma resistance		
24	I feel comfortable being seen in public with a person obviously affected by depression	1.69	0.77
25	In general, I am able to live life the way I want to	2.10	0.96
26	I can have a good fulfilling life, despite my depression	2.04	0.99
27	People with depression make important contribution to society	2.13	0.99
28	Living with depression has made me a tough survivor	2.14	0.98

could be attributed to the sample size, culture, differences in diagnostic groups and regional variations.

Similarly, the prevalence of internalized stigmas among 420 HIV-positive men and 643 HIV-positive women from having HIV infection and one in five had lost a place to stay or a job because of their HIV status. More than one in three participants indicated feeling dirty, ashamed, or guilty because of their HIV status.

The results confirmed that internalized stigma does erode morale over time-even in this group of people who had already been coping with stigma and mental illness for years. The most consistently harmful consequences were those of alienation. People who experienced alienation related to their SMI were likely to deal with more distress, as their morale worsened further. This suggests that feeling different and divided from others may be a powerful component of internalized stigma. These results indicate an urgent need for social reform to reduce AIDS stigmas and the design of interventions to assist people living with HIV/AIDS to adjust and adapt to the social conditions of AIDS in Nigeria.

#### Conclusion

The stigma of mental illness is strong in our society and causes harm to many people with severe mental illness (SMI). The most obvious form of stigma is when people reject, put down, or discriminate against those with mental illness because of negative stereotypes. Previous research has found that when people with SMI believe recruited from AIDS services in Cape Town, South Africa. The anonymous was found to be 40% of persons with HIV/AIDS who had experienced discrimination resulting that most people reject and devalue people with mental illnesses, they may suffer a number of negative outcomes, such as demoralization, lowered self-esteem,

impaired social adaptation, unemployment, income loss and reduced psychiatric medication adherence. People with SMI who do not hold these beliefs as strongly suffer fewer of these negative consequences. It is important to recognize that the harmful effects of stigma may work not only through the external effects of discrimination by others, but also through the internal perceptions, beliefs and emotions of the stigmatized person.

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## **Appendices**

#### A.

The Patient Health Questionnaire -9 (PHQ-9).

Ov	er the last 2 weeks, how often have you been bothered by any of the following problems?	Not at all	Several days	More than half the days	Nearly every day
1	Little interest or pleasure in doing things	0	1	2	3
2	Feeling down, depressed, or hopeless	0	1	2	3
3	Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4	Feeling tired or having little energy	0	1	2	3
5	Poor appetite or overeating	0	1	2	3
6	Feeling bad about yourself-or that you are a failure or have let yourself or your family down	0	1	2	3
7	Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8	Moving or speaking so slowly that other people could have noticed, or the opposite-being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9	Thoughts that you would be better off dead, or of hurting yourself in some way	0	1	2	3
		Add o	columns:		
		0	±	±	±
				= Total S	Score:

Scoring: 1-4: Minimal depression; 5-9: Mild depression; 10-14:

Moderate depression; 15-19: Moderately severe depression; 20-27: Severe depression

# В

The variables of social determinants of health.

SELF REPORTED ECONOMIC STATUS OF FAMILY

Poor
Average
Good
YEARS OF SCHOOLING
Below average (0 year)
Average 1-6 years
Above average 7 years and above
SOCIAL COHESION
Low 1-2 points
Fair 3-5 points
High 6-9 points
NEGATIVE LIFE EVENTS
> 3 2 1 0