



## Influence of Perceived Stigmatization on Self-Disclosure of HIV/AIDS Status by People Living With the Disease in Jos

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### **Abstract**

*This study examined the influence of perceived stigmatization on self disclosure of HIV/AIDS status among People living with HIV/AIDS (PLWHA) in Jos metropolis. It adopted a 2x2 factorial design. Participants, whose ages ranged from 19-65 years, comprised of 167 females and 79 males came from various educational backgrounds. Purposive sampling technique was employed in the recruitment of the study participants. The reliability coefficient of the HIV stigma scale used in the study was .96 Cronbach's alpha. Perceived stigmatization significantly influenced self-disclosure of HIV/AIDS status among People Living with HIV and AIDS, [ $t(244) = -12.41, p < .05$ ]. It was therefore recommended that government and civil society groups like global fund, Ghain, Aids Prevention Initiative In Nigeria (APIN) and President's Emergency Plan for AIDS Relief (PEPFAR) should embark on intensive education programs and media campaigns to promote stigma reduction and serostatus disclosure. The identification and referral of victims for psychosocial support and counseling was recommended as this would ease disclosure and in the long run prevent transmission of the disease.*

**Keywords:** self-disclosure, stigmatization, HIV/AIDS status

### **Introduction**

Over the years HIV/AIDS has plagued the world with damaging consequences on human life and society. The most worrisome aspects of the disease are issues surrounding it. The latter include stigma and discrimination which are said to exist worldwide, although they manifest themselves differently across countries, communities, religious groups and individuals. There is a high prevalence rate of HIV/AIDS in Plateau State for instance Plateau has been listed as one of the leading States in mother to child transmission of HIV/AIDS in Nigeria (Onyebuchi 2014). Out of 5,021 subjects screened, 245 (4.88%) were seropositive. Local Government prevalence ranged from 0.68% in Bassa to 16.07% in Jos North. On average, LGAs in the Southern Senatorial Zone had higher rates. Most (over 80%) positive cases were younger than 40 years. Females had a significantly higher (6.85%)



prevalence than males (2.72%). Age-specific prevalence was higher among females aged 25 to 29 years (2.09%). Risk factors identified for acquisition of HIV infection were previous history of STDs (6, 16.28%); men having sex with men (2, 11.76%); having multiple sexual partners (97; 10.49%); intravenous drug use (10, 7.58%); sharing of sharp objects (20, 4.82%); and history of blood transfusion (21, 3.65%).(Gomwalk , Nimzing, Mawak, Ladep, Dapep, Damshak . et al 2014).From the high rate, there is the likelihood of perceived stigmatization that will affect self-disclosure.

This research work is an attempt to assess the impact of perceived stigma, social support, sex and education on self- disclosure of HIV/AIDS status by people living with the disease in Jos metropolis. One of the main concerns regarding disclosure of HIV status is stigmatization(Black & Miles, 2002; Derlega, Winstead, Greene, Serovich, and Elwood, 2002, 2004; Petrak, Doyle, Smith, Skinner and Hedge, 2001; Serovich, 2001; Health and Development Networks Moderation Team, 2004). Although stigma is an issue in all cultures, it becomes even more powerful in family oriented societies. HIV-related stigma is borne not only by the individual but also by the family and community. A study by Songwathana and Manderson(2001)in Thailand showed that if the status of a PLWHA is disclosed to the community, then the entire family fears losing face. Furthermore, social networks in Thailand often treat an entire family discriminatorily because one of its members is HIV positive. In South India, one of the main reasons cited for nondisclosure is disgrace of self and family, with concerns about the future of family members

### **Statement of Problem**

There are so many HIV/AIDS victims in Plateau state and elsewhere in the world who are directly or indirectly experiencing problems associated with HIV/AIDS which include stigma. Government on her part has put forward a number of measures aimed at curtailing the challenges associated with the scourge of the disease in order to ensure better control of the disease.Although the National Agency for the Control of AIDS (NACA) has been carrying out activities based on its mandate, it appears the aim of setting up HIV/AIDS control centres tocheck the spread of the disease has not yet been fully achieved. Stigma and discrimination have continued to rise unchecked. Social support to victims which will ameliorate the social stigma is not always there. Men and women are commonly seen today suspecting or pointing accusing fingers at one another for their woes. Marriages have suffered divorce or separation sequel to the disharmony and suspicions that have characterized marital relationships today. Some of these predicaments could be blamed on the level of awareness of the victims as majority are ignorant of the dynamics of the disease.

### **Objectives of the study**

The objective of this study is to examine the influence of perceivedstigmatization on self disclosure of HIV/AIDS status among victims in Jos metropolis.

**Research Question**

The research question to be raised at this point in time is “What is the influence of perceived stigmatization on self disclosure of HIV/AIDS status by PLWHA in Jos ?

**Research Hypothesis(H<sub>A</sub>)**

Perceived stigmatization will significantly influence self-disclosure of HIV/AIDS status among People Living with HIV and AIDS (PLWHAs).

**Null Hypothesis(H<sub>0</sub>)**

Perceived stigmatization will not significantly influence self-disclosure of HIV/AIDS status among People Living with HIV and AIDS (PLWHAs).

**Significance of the Study**

The significance of this study hinges on the expectation that it will give government and other stake-holders direction on legislation and enforcement of laws in connection with HIV/AIDS.

**Scope of the Study**

The scope of this study is the Jos metropolis in Plateau State Nigeria. The AIDS Prevention Initiative (APIN) centre in Jos was the setting where the bulk of the respondents was drawn. Care was taken to capture all gender, races, cultural and educational backgrounds.

**The concept of stigma**

Sociologist and writer [Goffman](#)(1963) defines stigma as an attribute that is deeply discrediting; a stigmatized individual is one who is not accepted and not accorded the respect and regard of his peers, who is disqualified from full social acceptance. One area negatively impacting those living with HIV in the African American community is the stigma associated with having HIV. Stigma can take two forms: perceived or enacted (Brown, Macintyre, Trujillo ,2003). According to them, perceived (or felt) stigma occurs when there is a real or imagined fear of societal attitudes regarding a particular condition and a concern that this could result in acts of discrimination directed to individuals with that condition. Enacted (or actual) stigma, in turn, refers to “experiences of discrimination directed to individuals because of specific attributes or conditions that characterize them”(Goffmann,2013).

Differences are said to exist along racial lines in terms of perception of HIV stigma. For a community disproportionately affected by HIV, African Americans also have the additional burden of dealing with the negative effects associated with the stigma of HIV. HIV-positive African American women have been found to report a fear of societal stigma related to HIV from a variety of sources, including family members, fellow church congregants, health care professionals and the broader community (Mandell et’ al, 2010). Similarly, older female African American caregivers of HIV-positive people have reported not widely disclosing the HIV diagnosis of their loved ones because of the fear of HIV-



related stigma (Sepkowitz, 2001). From the foregoing, we notice that stigma is seen to be associated with prejudices but that does not seem to be so as not everybody that is stigmatized that is prejudged and discriminated.

**Self-disclosure** is a process of communication through which one person reveals himself or herself to another. It comprises everything an individual chooses to tell the other person about himself or herself, making him or her known. The information can be descriptive or evaluative and can include thoughts, feelings, aspirations, goals, failures, successes, fears, dreams as well as one's likes, dislikes, and favorites(Ignatius, Emmi, Marja and Kokkonen,2007).Ignatius et, al (2007)also put it that self–disclosure is not simply providing information to another person but sharing information with others that they would not normally know or discover. Self –disclosure involves risk of breaking confidence on the part of the person sharing the information.

A useful way of viewing self – disclosure is the Johari window. The Johari window is a way of showing how much information you know about yourself and how much others know about you. The window contains four panes, as shown below.

Table 1-.Showing self-disclosure panes between self and others.

	<i>Known to self</i>	<i>Unknown to self</i>
Known to others	<b>Open Pane</b> Known to self and others	<b>Blind Pane</b> Blind to self, seen by others
Unknown to others	<b>Hidden Pane</b> Open to self, hidden from others	<b>Unknown Pane</b> Unknown to self and others

**Source:** Tim Bochers (1999)

As theories tend to explain or justify behaviour, influence of perceived stigmatization can be explicitly explainedTheAttribution theory was developed in the field of social psychology in the late 1950s as a tool for explaining the processes by which "people infer the causes of behavior" and as such, it serves to explain the ways people understand their own behavior as well as the behaviors of others (Heider, 1958).

Regardless of the emphasis or particular perspective taken, the main assumption guiding attribution theory is that people interpret behavior in terms of its causes and the interpretations are significant in determining reactions to the behavior (Kelley & Michela, 1980; Littlejohn, 1983). According to the theory, a major function of attributions is to create a more stable, predictable world for the individual by creating a sense of justification for specific behaviors or circumstances (Heider, 1958)

**Attribution Theory and HIV Disclosure**

Disclosure of an HIV-positive diagnosis can be easily understood in terms of attribution theory as the two factors necessary for making attributions (dispositional factors and situational factors) are likely be involved in this disclosure process. Regardless of



whether it is the HIV-positive individual him/herself or a family member with the information, in the case of disclosing one's HIV-positive status, attributions regarding the potential recipient of the information in deciding whether or not to reveal the diagnosis are likely to occur. For example, dispositional factors such as, is the person likely to be supportive of the HIV-positive individual or discloser or is the potential recipient someone who the HIV-positive individual or discloser will have to take care of emotionally, might be considered. Next, how has the person responded in the past to disclosures of distressing information? Likewise, the HIV-positive individual or family member with the information must also entertain situational constraints about the potential recipient of the information that may promote or restrict disclosure. For example, is the person physically healthy or are attributions likely to be made that the potential recipient is too ill and his/her condition may worsen if disclosure occurs?(Judy, 1996)

### **Predictors of HIV-Disclosure**

Erku , Megabiaw and Wubshet (2012) Carried out a study to assess the magnitude and factors associated of HIV seropositive status disclosure to sexual partners among peoples living with HIV/AIDS in Ethiopia. The study was carried out among systematically selected 334 HIV patients attending at Woldia hospital, Ethiopia. Data were collected through pre-tested questionnaire, using exit interview. Bivariate and multivariable logistic regression models were fitted to identify associated factors for disclosing their HIV seropositive status to sexual partner. One hundred and ninety nine (59.6%) was females, 218(65%) was from urban area, 297(85.8%) were on antiretroviral therapy. The study found a significant association between higher educational status of the respondents (AOR:0.4; 95%CI (0.17-0.92)) and sexual partners (AOR: 9.0; 95% CI(2.8-29.3)), knowing HIV status of sexual partner (AOR:8.1; 95%CI(3.4 -19.2)), being on antiretroviral therapy (AOR:7.9; 95%CI(3.42-18.5)), having follow up counseling (AOR:5.26; 95%CI(2.2-12.5)), and being tested for HIV in ante natal care clinic (AOR:0.21; 95%CI(1.14- 6.46)) with disclosure of HIV status to sexual partner.

### **Recipients of Disclosure**

To whom a person discloses is an important factor in deciding to reveal personal information (Chelune, 1979; Deriega, Metts, Petronio, and Margulis , 1993; Pennebaker&Susman, 1988; Tardy, Hosman and Bradac., 1981). Further, people are expected to disclose information about themselves to family members and friends, and these relationships are likely to suffer in the absence of disclosure (Altman & Taylor,1973). Studies which have examined the disclosure of one's HIV-positive status suggest, "Most likely, people with HIV evaluate subjectively the potential consequence of informing a particular target person before a disclosure is made" (Marks et al, 1992b, p. 300), thus the potential recipient of information is an unimportant consideration in decisions regarding disclosure. This is in direct accordance with attribution theory in which one of the primary



situational factors for making attributions is the potential recipient of those attributions (Heider, 1958; Kelley & Michela, 1980). In their examination of appropriate recipients for disclosure of HIV-information, Serovich and colleagues (1992) and Serovich and Greene (1993) suggest the couple subsystem consisting of spouses/partners or lovers were deemed the most appropriate recipients of HIV-testing information (Serovich et al., 1992; Serovich & Greene, 1993) with the nuclear family subsystem the next most appropriate subsystem for receiving HIV testing information.

**Unitary theory of Stigmatization by Haghightat (2001):** Stigmatization involves self-sheltering and self-seeking behaviour. It is a protective device for the stigmatizer and, in a good number of cases, unfair on the stigmatized, as the latter may simply be the victim of a rumour or may not be the one among the stigmatized who would cause harm. In view of the fact that different origins of stigmatization point to the individual's seeking of personal gain, can it be thought improbable that the fundamental basis of all stigmatization is the pursuit of self-interest? Can we doubt (given the fact that self-interest presents as the essence of stigmatization in all domains) that when there is no pursuit of self-interest there will be no stigmatization and as long as we pursue self-interest we have to face the consequences of our stigmatization of others? The stigmatizer, on each occasion of avoiding the stigmatized, draws primary gain from reducing his or her anxiety and is thus powerfully reinforced. The stigmatizer also draws secondary benefits from stigmatization by avoiding possible loss, danger and victimization and by increasing his or her chances of economic survival (Haghightat 2001). From the foregoing, the unitary theory sees stigmatization as an attempt to self upliftment, enhancement and or promotion of the stigmatizer. Personally, I see stigmatization an attempt to dissociate self from an unacceptable stimulus in the environment. For stigmatization to be a chance for economic survival is more unacceptable as no stigmatizer in history ever testified of any economic gains from stigmatizing others.

### **Theories of HIV Disclosure**

**Disease Progression Theory (Kalichman, 1995)** According to the disease progression theory, individuals disclose their HIV diagnosis as they become ill because when HIV progresses to AIDS they can no longer keep it a secret (Babcock, 1998; Kalichman, 1995). Disease progression often results in hospitalizations and physical deterioration, which, in some cases, mandates individuals to explain their illness (Kalichman, 1995). Holt, Court, Vedhara, Nott, Holmes & Snow (1998) further put it that not only would hospitalization require explanation, but if death is imminent or individuals fear they will need additional assistance to manage their illness, they may disclose as a means of accessing additional needed resources. Delaying disclosure may be a way to normalize their life and protect others from pain (Babcock, 1998).

### **Stigma-related Factors**



Olalekan , Akintunde and Olatunji (2014) assessed the perception and behavior of PLWHAs towards societal stigma and discrimination in Lagos, Nigeria. This was a qualitative, descriptive cross sectional study among PLWHAs from three of the three senatorial districts in Lagos State selected using simple random sampling. Six focus group discussions (FGDs), consisting of eight eligible respondents each were held using structured FGD guide. Collected data were analyzed using simple content analysis. About three quarter of all the discussants said life had become miserable following episodes of stigma and discrimination against their personality in public, family, health care settings and the work-place. Some had feelings of guilt and depression towards these actions. About three quarter had coped with the situation by living a low-keyed lifestyle, dissociating themselves from the public and avoiding seeking care in HIV care centers. Majority of respondents were not willing to come out to publicly discuss their positive HIV status for fear of discrimination. Discussants recommended continuous awareness campaigns about HIV to further educate the general public towards reduction of societal stigma and discrimination against PLWHAs.

This research must have been carried out in a particular setting(s). Not mentioning it or them, makes it difficult to comment on whether extraneous variables were well taken care of or not. The research lacks clarity in that aspect. Adejumo(2011) investigated the relationship between perceived HIV stigmatization, HIV/AIDS cognition, personality and HIV self-disclosure (HSD) . The influence of age and gender on these was also examined. PLWHA (N421) in Ibadan, Nigeria participated in the cross-sectional study. A positive relationship of extraversion ( $r=-.738$ ,  $df=421$ ,  $P<.05$ ), HIV cognition ( $r=-.621$ ,  $df=421$ ,  $P<.05$ ), neuroticism ( $r=-.212$ ,  $df=421$ ,  $P<.05$ ) and agreeableness personality traits ( $r=-.155$ ,  $df=421$ ,  $P<.05$ ) with HSD was observed. A 2x2x2x2 factorial analysis showed that old females, with low perceived stigmatisation, but with good HIV cognition ( $n=23$ ,  $X =18.2$ ,  $SD=3.8$ ) were most likely to disclose their status. Perceived stigmatisation, HIV cognition, and personality jointly predicted HSD ( $R^2=.52$ ;  $F(3,418) =7.66$   $P <.05$ ). It was concluded that Negative HIV cognition, perceived stigmatization, openness and conscientious personality traits are major barriers to HSD. Non disclosure remains an enormous barrier to the fight against HIV and AIDS. It was subsequently recommended that Policies and actions should therefore focus on these issues in HIV prevention, care and support. From the foregoing, researcher could not state what personality(ies) predicted more disclosure than the other. Secondly one would tend to query the mode used to measure cognition as the study did not mention any instrument used.

### **Methodology:**

The study employed the 2x2 factorial design to examine the influence of perceived stigmatization,(low and high), on self disclosure (low and high)of HIV/AIDS status by



PLWHAs. The Taro Yamane sample size determination formula was employed to arrive at the sample size for the study .The formula states thus:

$$n = \frac{N}{1 + Ne^2}$$

where n=sample size, N=population size, e=the error of sampling. So with a population size of 1018 a sample of 287 was recruited at an error level of .05. In order to recruit participants for the study, purposive sampling technique was employed. This was to ensure that the sample was non-probable and selection was based on the targeted characteristic of HIV/AIDS positivity of the participants. From a total population of 1,018 PLWAs at JUTH APIN Center, 287 of them were sampled for the study with a mean age of 42 years, 255 of them were Christians while 30 and 2 were Muslims and free thinkers respectively. At the end of the exercise 246 questionnaires were collected. Out of this, 79 of the participants were males while 167 of them were females within the age range of 19 to 65 years. Table 1 shows the socio-demographic characteristics of participants. The table shows that the majority 167 (67.8%) of the participants were females, while 79 (32.2%) were males. Regarding the highest education attainment of participants, the table revealed that the majority 110 (44.9%) of the participants had tertiary educational qualification; while 16 (6.6%) had informal education, 59 (23.8%) had primary education, and 61 (24.7%) had secondary education.

**Table 2: Socio-demographic Characteristics of Participants**

	Frequency	Percentage %
<b>Gender</b>		
Male	79	32.2
Female	167	67.8
<b>Total</b>	<b>246</b>	<b>100.0</b>
<b>Highest Educational Attainment</b>		
Informal	16	6.6
Primary	59	23.8
Secondary	61	24.7
Tertiary	110	44.9
<b>Total</b>	<b>246</b>	<b>100.0</b>

**Instruments**

The Berger, Ferrans and Lashley (2001) HIV Stigma Scale(HSS) was adopted for the study. This instrument(i.e HSS) was designed at the College of Nursing University of Illinois at Chicago by Berger et’al(2001). It measures perceived stigma by people living with HIV. The 40 items of the HIV stigma scale focus on experiences, feelings and opinions as to how people living with HIV feel and how they are treated. The person living with HIV responds to these items using a four point scale to indicate level of agreement or disagreement. This scale has 4 subscales.



**Validity and Reliability of HIV Stigma Scale:** Berger et al (2001) standardised this instrument via administration of 318 questionnaires to (19% women, 21% African – American 8% Hispanic) . Four factors emerged from exploratory analysis: personalized stigma, disclosure concerns, negative self-image, and concern with public attitudes towards people living with HIV. Construct validity was supported by relationships with related constructs: self - esteem, depression, social support, and social conflicts. Coefficient alphas between .90 and .93 for subscales and .96 for the 40 – item instrument provided evidence of internal consistency reliability. The HIV stigma scale was reliable and value with a large, diverse simple of people living with HIV (Berger, Carol, Ferrans, and Lashley, 2001).

**Scoring of the HIV Stigma Scale and Sub Scales:** Items are scored on a 4-point likert scale as follows:

- Strongly disagree - 1
- Disagree - 2
- Agree - 3
- Strongly agree - 4

**Procedure**

First of all ethical clearance from the ethical committee of the Hospital (Jos University Teaching Hospital) was sought. This was to facilitate the early commencement and co-operation of the targeted participants . Prior to the administration of the questionnaires consent forms were given to and signed by the respondents to indicate their willingness to participate in the research. Data were collected through administered questionnaires. The services of at least 6 research assistants were employed. Through the assistance of the latter, completed questionnaires were collected centrally. The t-test statistical technique was employed in the computation of the data collected. The t-test technique was used as there were two levels of perceived stigmatization whose means were to be compared,

**Null Hypothesis 1:** Perceived stigmatization will significantly influence self-disclosure of HIV/AIDS status among People Living with HIV and AIDS (PLWHAs).

Table 3: t-test Summary of effect of perceived stigmatization (I.V) on self-disclosure(D.V) of HIV/AIDS status among People Living with HIV and AIDS (PLWHAs).

Variables	Perceived stigmatization	N	Mean	Std	t	Df	Sig	P
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Self-Disclosure	Low	130	23.94	3.69	-12.41	244	.000	<.05
	High	116	29.09	2.81				

Table 3 shows that there was significant difference in the self-disclosure of the participants with low and high perceived stigmatization [t (244) = -12.41, p<.05]. The mean observation shows that participants with high perceived stigma showed significant higher self-disclosure ( $\bar{X} = 29.09$ ) than participants with low perceived stigma with a mean difference of 5.16. The Research hypothesis was therefore confirmed. This implies that at the height of perceived stigma, victims still disclose their status commensurately.

The Null Hypothesis sought to examine if there was significant influence of perceived stigmatization on self disclosure of HIV/AIDS status by victims. The result of this study confirmed this hypothesis meaning that there was a significant influence of perceived stigmatization on self disclosure of HIV/AIDS Status. By this finding, it translates that the higher the level of perceived stigmatization, the higher the predisposition to disclose the status and the reverse is true. It is possible that some of the respondents' attributes could have mediated and accounted for this finding. Similarly, in a study titled Relationship Between Psychodemographic Factors And Perceived Stigmatization Among People Living With Hiv/Aids In Ibadan, Nigeria, Olalekan(2012) observed that those who were females, young, poor on HIV cognition, but with high HIV disclosure recorded the highest mean on perceived stigmatization..Lyimo, Stutterheim, Hospers, Teuntje, van der Venand de Bruin(2013) put it thatperceived stigma is primarily related to involuntary disclosure.Adejumo (2011) came up with a contrary finding in a study titled "Perceived HIV stigmatization, HIV/AIDS cognition and personality as correlates of HIV self-disclosure among people living with HIV in Ibadan, Nigeria" where he discovered that Perceived stigmatization represents a major barrier to HIV/AIDS status disclosure.Adejumo (2004) puts it that stigmatization has inverse relationship with HIV disclosure. However, a plausible explanation for this current research's finding is that as awareness and understanding on stigmatization continue to increase due to aggressive HIV/AIDS education, disclosure continues to increase regardless of level of stigmatization.

**Conclusion**

Owing to the findings of this study we can expressly conclude that perceived stigmatization has a significant influence on disclosure of HIV/AIDS status.though successful, the was constrained by the fact it was conducted in only one treatment facility. Besides, instead of recruiting not less than ten(10) research assistants, the researchers could only afford to hire six who assisted in the administration and translation of the instruments used. Because of these hitches, the research lasted longer than necessary.



### Recommendations

Based on the finding of this research, certain recommendations were proffered to relevant bodies to address the challenges associated with perceived stigmatization and self disclosure of HIV/AIDS status by people living with the disease(PLWHAs).It was recommended that:

- 1 Studies in this area should be intensified by all concerned (e.g GHAIN, Global FUND, NACA, PEPFAR etc) in order to establish the rationale behind this relationship.
- 2 Intensive awareness campaigns should be conducted on the dynamics of the disease towards its total control by relevant stakeholders(hospitals,Schools,communities, Associations, groupsetc)

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