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Full Length Research Paper

Experience of HIV-related stigma by people living with HIV/AIDS (PLWHA), based on gender: A case of PLWHA attending clinic in the Federal Medical Center, Owerri, Imo states, Nigeria

Nworuh Okwuchi Blessed[1] and Anthony Ikechukwu Ogbalu[2]

[1]Department of Public Health Technology, Federal University of Technology, Owerri, Nigeria.
[2]Department of Human Kinetics and Health Education, Nnamdi Azikiwe University, Awka, Nigeria.

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Stigma is a discrediting social label that changes the way an individual looks at himself and disqualifies him from full social acceptance. Related researches show that HIV-related stigma is universal, but the stigma experiences vary from person to person. This paper indentified four forms of stigma experience (internalized stigma, disclosure stigma, public attitude stigma and negative self image stigma); and measured them among people living with HIV/AIDS (PLWHA) based on gender. With a purposive sample of 1,552 HIV-positive persons comprising of PLWHA that attended clinic on the four clinic days and willingly completed and returned the questionnaire within the one month of collecting data. 626 of them, representing 40.3% were males while 926 representing 59.7% were females. A 40 item standard Berger-Stigma survey questionnaire was used. Data collected were scored and analyzed using t-test to get the mean score of stigma experience for each form of stigma at 5% level of significance. The male and female PLWHA experience the four forms of stigma (107.32 stigma mean score for females and 101.46 stigma mean score for males); but the females have higher mean scores of stigma experience than males in internalized stigma, disclosure and negative self image. Hence, there is a significant difference in stigma experience of PLWHA based on gender. Recommendations include gender sensitive anti-stigma programme, formation of female HIV-support groups, government policy to protect the rights of HIV positive women.

Key words: Stigma, forms, experience, gender.

INTRODUCTION

A dictionary definition of stigma is a disgrace or a reproach attached to something. Stigma is often described as the negative labels or stereotypes used when talking about something or somebody. According to Lichtenstein (2003), stigma is a discrediting social label that changes the way an individual looks at himself/herself and disqualifies them from full social acceptance.

The first three components of stigma was proposed by Link and Phelan (2006) with items related to labeling, devaluing and isolation of people living with HIV/AIDS (PLWHA), but also encompasses items on the shame of PLWHA, blame for the responsibility for HIV infection on the HIV-positive individual and positive and negative feelings about PLWHA. This also incorporates attitudes regarding the isolation of individuals with HIV/AIDS and

*Corresponding author. E-mail: pray4women@ymail.com

their families within the community and by employers. These three components by Link and Phelan (2006) are internalized stigma, disclosure stigma and negative image stigma. In another study, Berger (2001) quoted in UNAIDS (2008), conducted a psychometric assessment of a HIV stigma scale and four factors or forms of stigma emerged: personalized or internalized stigma, disclosure concerns, negative self-image and concerns with public attitudes, towards people living with HIV infection.

Berger's stigma scale questionnaire based on the four forms of stigma is reported to have good construct validity and internally consistent reliabilities with coefficient alphas between 90 and 93 for each of the forms (also called subscales) and 96 for the 40 item measures (USAID, 2008). Lichtenstein (2003) and Bunn et al., (2007) identified the same four forms of stigma, but described them as four domains of stigma experiences.

Personalized/Internalized HIV-related stigma experience is the stigma effects on the PLWHA; as it is internalized into their self-perception and sense of identity, impacting on the person's perceptions and how they interact in the world. Research has found that people with HIV feel isolated, guilty, dirty and full of shame. This is often incorporated into identity (NACA, 2004).

Disclosure stigma experience is related to the concern to control information, keeping one's HIV status secret, or worrying that those who know about the HIV status will tell others. Disclosure concern form of stigma is described by UNAIDS (2006) as a form of stigma that drives HIV out of the public sight, so reducing the pressure for behaviors change. This form of stigma also introduces a desire not to know one's own status, thus delaying testing and access to treatment.

According to Spiegel (2004) disclosure related stigma experiences counter acts trust. This often leaves those infected alone and distanced from the rest of their communities, colleagues and even family. Disclosure stigma experience has been described by Shapiro (2003) to be capable of increasing the risk of infection for the sexual partner of HIV-positive person.

Public attitude stigma experience is a form of stigma experience that refers to what most people think about a person with HIV or what 'most people' with HIV can expect when others learn they have HIV infection (Berger, 2007). Denying the rights of people with HIV/AIDS limits their ability to care for themselves and their families and makes them more vulnerable to infection and susceptible to stigma. Paxton (2005) talking about people's attitudes, described stigmatization as cruel social processes that offer some feeling of protection to the powerful, while increasing the load on the individual or group who is victimized in the process. Religious groups may intentionally or inadvertently contribute to stigmatizing PLWHA by making explicit or implicit judgements against those who are infected with HIV. Leclerc-Madlala (2002) opined that the attachment of gender discrimination to HIV stigma has led to women being blamed for spreading the epidemic. Thus women are contradictorily expected to provide sexual services to men generally, be chaste and pure and take on the responsibility of preventing disease. Talking about the experiences of stigma related to peoples attitude, Parker and Aggleton (2002) stated that there are many examples at a national level of stigmatization and also discrimination that is introduced by socially conservative governments, including policies of restriction of admission, deportation of foreigners, mandatory testing for those seeking work permits or tourist visas.

Negative self-image refers to feeling unclean, not as good as others or bad as a person, because of being HIV-infected (Lichtenstein, 2003). HIV stigma comes from the powerful combination of shame and fear. Shame because sex being a source of transmission, is surrounded by taboo and moral judgment; fear because AIDS is relatively fearful and deadly. The only way of making progress against the epidemic is to replace shame with solidarity and fear with hope (Bunn et al., 2007).

According to Ajuwon (2011), aside from the news or media reporting, the experiences of stigma faced by HIV and AIDS persons in Nigeria have not really been properly investigated through scientific researches. The HIV and AIDS related (published) studies done in Nigeria mainly focused on knowledge, prevalence and reviews on discriminations. It is pertinent therefore to identify and measure the experience of stigma by male and female persons living with HIV and AIDS, this will help for articulated and properly directed intervention.

Purpose of the study

This study specifically assessed the experience of HIV-related stigma on PLWHA based on their gender.

Research questions

How is the stigma experience of PLWHA based on their gender? Is the experience of HIV-related stigma same for both male and female plwha in all forms of stigma?

Hypothesis

There is no significant difference in the stigma experience of people living with HIV and AIDS based on their gender.

METHODOLOGY

This is a descriptive survey that identified and measured the stigma experience of male and female PLWHA that were attending clinic at the federal medical center, Owerri. Purposive sampling technique

Table 1. t-Test analysis result for difference in mean score for various forms of stigma experienced by male and female PLWHA.

Stigma domain	Gender	N	Mean	Standard deviation	Standard error	t-Test value	P-value
Experiences of personalized stigma	Male	626	32.90	7.395	0.296	143.030	0.000
	Female	926	37.05	6.217	0.204		
	Total	1552	35.38	7.018	0.178		
Disclosure stigma experience	Male	626	23.25	5.915	0.236	6.708	0.010
	Female	926	24.03	5.748	0.189		
	Total	1552	23.71	5.827	0.148		
Public attitude stigma experience	Male	626	25.73	7.405	0.296	0.555	0.456
	Female	926	25.46	6.694	0.220		
	Total	1552	25.57	6.988	0.177		
Negative self image stigma experience	Male	626	19.59	5.886	0.235	16.727	0.000
	Female	926	20.78	5.432	0.179		
	Total	1552	20.30	5.648	0.143		
Total stigma combined	Male	626	101.46	18.260	0.730	48.746	0.000
	Female	926	107.32	14.663	0.482		
	Total	1552	104.96	16.457	0.418		

was used considering the peculiar characteristics of PLWHA. Subjects comprised of PLWHA that attended clinic on any of the four clinic days and were willing to fill out the questionnaire within one month of data collection for this research (a clinic day is one day in a week for free testing, counseling and distribution of anti retroviral drugs). Data was collected using Berger's stigma survey questionnaire (2001), containing 40 question items for the four forms of stigma experience. The questionnaire was distributed to the subjects and collected same day in each of the four clinic days, with the assistance of the counselor working in the HIV unit of the hospital. Subjects indicated their opinion on a scale of: 1 [strongly disagree] to 4 [strongly agree]. The least score in all the scales would be 40 (1 multiply by 40 items); while the highest score would be 160 (4 multiply by 40 items). Each subscale, that is, the scale used to measure one form of stigma experience was calculated by simply adding the values of the items belonging to that subscale. The higher scores on any of the forms/subscale were indicative of increase in the experience of stigma.

Data analysis

Gender related experience of stigma was tested with t-test statistic to find out if there was a statistically significant difference in the HIV-related stigma experience of male and female persons living with HIV and AIDS. The mean scores of each of the four forms of stigma experience were also determined based on the gender of the subjects. Finally, the statistical significance of the subjects' stigma experience in relation to their gender was determined at 5% level of significance Table 1.

RESULTS

For experience of personalized stigma

There is a difference in the mean score of stigma experienced by male and female PLWHA. Females experience more personalized stigma (mean score=37.05) when compared with male subjects (mean score=32.09) at 5% level of significance.

For disclosure stigma experience

There is a difference in the mean score of stigma experienced by male and female PLWHA. Females experience more disclosure concern stigma (mean score=24.03) when compared with male patients (mean score=23.25) at 5% level of significance.

For public attitude stigma experience

There is no difference in the mean score of stigma experienced by male and female patients. Males experience relatively same public attitude concern stigma (mean score=25.73) when compared with female patients (mean score=25.46) at 5% level of significance.

For negative self image stigma experience

There is a difference in the mean score of stigma experienced by male and female. Females experience more negative self image (mean score=20.78) when compared with male patients (mean score=19.59) at 5% level of significance.

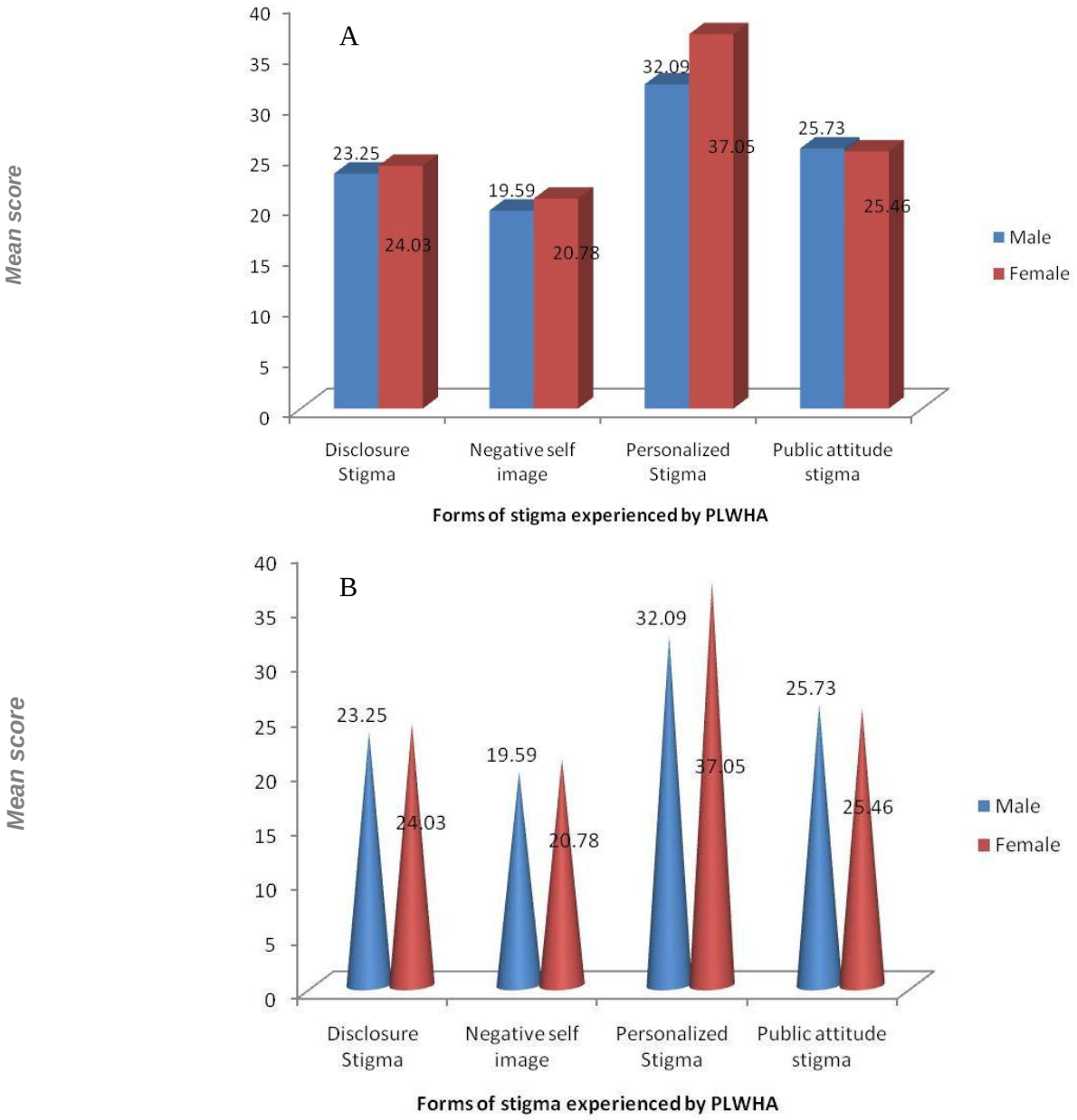

Figure 1. Mean score of forms of stigma experienced by PLWHA

For total stigma experienced

There is a difference in the mean score of overall stigma experienced by male and female PLWHA. Females experience more stigma (mean score=107.32) when compared with male patients (mean score=101.46) at 5% level of significance Figure 1.

DISCUSSION

The sample for this study comprised of 1,552 HIV-positive persons; females 926 (59.7%), and males 626 (40.35%). The female PLWHA had a consistent higher mean score of stigma experience in three forms of stigma than the males. This could be because HIV and AIDS-related stigma often build upon and reinforces other existing prejudices, such as those related to gender (Paxton, 2005). Also, women may suffer more stigmas, because women with HIV and AIDS are viewed as having been promiscuous, despite evidence to suggest that in the majority of cases, they acquired the infection from their husbands or male partners.

The media images of HIV and AIDS as a woman's disease, reinforces the stigma on women and plays into existing social inequality that make women inferior to

men. According to Paxton (2005) within the family and the community, women are significantly more likely to experience personalized stigma than men, including ridicule and harassment, physical assault and being forced out of their homes. Women are often more conscious of their self identity and desire social acceptance more than men; on this note, most women with HIV may think that their identity and self worth have been damaged. Russell (2005) stated that blame is often assigned to black people and women, thereby exposing women to more stigma experience than men. Men also blame women for infecting them and also spreading the virus.

Conclusively, male and female PLWHA experience the four forms of stigma which include personalized [internal] stigma [stigma related to ones identity and self worth because of HIV], disclosure concern [this is stigma related to disclosure of HIV status], public attitude concern [stigma related to attitude of people towards a HIV positive person], and negative self image [stigma related to ones feeling of guilt-and ashamed because of his/her HIV status].

The implication of the aforementioned finding and results is that both male and female PLWHA are heavily burdened with different forms of stigma experience due to HIV. This will demand an articulate selection of enlightenment, inspirational and empowerment programme that will be embracing enough to cut across gender.

Since gender is statistically significant to stigma experience, measures that will be adopted will take into consideration the make-up and psychology of the female gender. This could also mean that the complications associated with HIV will be obvious on the females, especially pre-natal and post-natal females.

RECOMMENDATIONS

Ensuring legal and policy protections for female HIV-positive persons is essential to reduce the HIV-related stigma experienced by females. A careful development of gender centered and sensitive anti HIV stigma programme will certainly help. In such, gender selective programme relationship is enhanced, experiences are shared and females will be supported by other females. Communities should actively participate in anti-stigma programmes specially supported by the community leaders.

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