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Perception of Societal Stigma and Discrimination Towards People Living with HIV/AIDS in Lagos, Nigeria: a Qualitative Study

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ABSTRACT

Introduction: The perception of People Living with HIV/AIDS (PLWHAs) on how the public feels about them could influence their willingness to seek medical care, interaction with the society and their coping strategies. **Material and methods:** This study 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. **Results:** 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. **Conclusion:** Discussants recommended continuous awareness campaigns about HIV to further educate the general public towards reduction of societal stigma and discrimination against PLWHAs.

Key words: Stigma, discrimination, perception, awareness, PLWHAs.

1. INTRODUCTION

In most countries of the world, stigma and discrimination related to HIV/AIDS has been a prevalent problem. People Living with HIV/AIDS (PLWHA) experienced many faces of stigma and discrimination in a variety of ways in households, communities, work place, and health care settings, even in media and government places (1, 2, 3). Compared with other parts of the world, stigma seems to be particularly more common in Sub-Saharan Africa (4, 5).

Stigma and discrimination create a culture of secrecy, silence, ignorance, blame, shame and victimization leading to societal rejection, job loss, school expulsion, ostracism, and violence, lack of care and support, and loss of property (1, 3). This constitutes barriers to implementation of strategies for effective management of PLWHAs, voluntary counseling and testing, accessing integrated HIV care including effective use of Antiretroviral (ARV) drugs; and also the behavior and perception of the health care they receive (6).

In a recent study in Tanzania, 56% of respondents living with HIV had recently experienced stigma (7). These patients

do not suffer only from the physical disease process; they also experienced emotional agony because of public frenzy that ends in blaming them, and ultimately leads to their social rejection (7). Unfortunately, the health sector is one of the settings where HIV-positive individuals and those perceived to be infected with HIV experience stigma and discrimination (8, 9).

"Perceived stigma" reflects respondents' beliefs or perceptions about the magnitude of stigma in a geographically defined area. A perception of what PLWHA feel that the society believes or think about them could directly relate to the various forms of stigma they encounter from the public with which they have contacts.

This study serves as baseline evidence for taking action and would assist policies and programmes targeted towards reduction of stigma and discrimination against PLWHA in our society. The objective of this study was to assess PLWHAs perception of societal stigma and discrimination in Lagos, Southwestern Nigeria.

2. MATERIAL AND METHODS

This was a qualitative, descriptive cross sectional study among PLWHAs. Lagos state is the leading commercial nerve center of Nigeria, and has an HIV prevalence rate of about 5.1% which is a bit higher than the Nigerian national average prevalence rate (10). PLWHA recruited into this study were HIV positive adults 18 to 49 years, and who had been receiving HIV care in a health facility for at least six months.

Six focus group discussions of eight eligible respondents each were performed making a total of forty eight discussants. These discussants were homogenous in terms of age, as majority was in the reproductive age group. They were selected using multi-stage sampling method. In stage I, two out of the three senatorial districts were selected using simple random sampling employing simple balloting. In the second stage, a list of health facilities providing HIV care per district was obtained, and three facilities were chosen by simple random sampling employing simple balloting, generating a total of six health facilities. In stage three, respondents selected by simple random sampling (simple balloting) on the clinic register, who have been attended to by the clinician in a facility on a clinic day, and who verbally consented to participating in the discussion after explaining its objectives and rationale to them were recruited to participate in the discussion. In the first district containing 3 FGD groups, one group of discussants were all females while the other 2 groups were mixed. In the second district, one group were all male discussants while the other 2 groups were mixed.

A specifically designed and pre tested focus group discussion guide was used in the discussions which were conducted in both English and vernacular (Yoruba language) to ensure good understanding of questions. The use of an independent observer was employed to further guide each focus group discussion. Variables examined include a brief description of respondents' sociodemographic characteristics, how they felt when first diagnosed as HIV positive, attitude to life now as persons living with HIV, their perception of how the society feels about their HIV status, the faces of societal stigma and discrimination against them if any, lifestyle changes, coping strategies and their recommendations towards reduction of stigma and discrimination in our society. The moderator encouraged response from all discussants at any point in time that a question was asked.

Ethical approval to conduct this study was obtained from Osun State University Health Research Ethics Committee. Permission to conduct the study was obtained from selected sites project coordinators. Each participant later gave a written informed consent following the verbal consent, and after explaining the rationale for the research and plans for confidentiality and privacy of data collected.

The average length of each interview or discussion was one and half hour. Notes were taken, responses were recorded on a radio tape and both were transcribed before final reporting and recording of responses. Qualitative responses were analyzed using simple content analysis (i.e. in terms of nature and responses to questions as well as cogency and frequency of points raised in the various questions). For the sake of convenience, responses to questions were graded as 'most' for 90% and above, 'majority' for 80% to 90%, three quarter for 75%, about two thirds for 60%, half for 50%, two-fifth for 40%, 15 to less than 40% for 'some', and less than 15% for 'few'. An excel sheet was used to enter sociodemographic data of the discussants and resulting

analyzed data was presented in form of a simple frequency table.

3. FOCUS GROUP DISCUSSIONS RESULTS

Table 1 showed the personal data of discussants. About half (50.0%) were in the age range of 31 to 40 years, 28 (58.3%) were females, 30 (62.5%) had up to secondary school education while 28 (58.5%) had been diagnosed HIV positive within the last 5 years

When asked how life has been since the diagnosis of HIV, about three quarter of respondents said that life became miserable, crumbled, and more difficult to manage. About a quarter however responded that life has been the same. For about half, social life has reduced in terms of reduced frequency of visits to social gatherings, feeling of guilt, reduced interaction with people because they don't want other people to know their status, stigmatizing self, a feeling as if people already know their positive HIV status, feelings as if everybody is looking and talking about them and reduced sexual activity. A little less than two-fifths of discussants said they took to alcohol and cigarette/tobacco smoking at the initial periods following their HIV diagnosis. One of the respondents said:

It has not been easy at all. People discriminate against us every day for an offence we did not commit. My snail had no choice but to withdraw into my shell.

When asked about their perception of what the general public feels about them being HIV positive, most respondents described it as "bad". Many said that the society believed that one must have been sexually immoral, and promiscuous. Many also have fears of cross infection and because of this, those infected with the HIV virus are maltreated as if they are not part of the general population. One of the discussants responded as follows:

The society believed that we are promiscuous and unnecessarily sexually active. They said that we cannot hold our body for long, and that we are suffering for a sin that people believe that we have committed against God.

When asked about how these attitudes has affected their daily living, about majority of women and some of the men said it affected their homes as they have been having broken homes and marriages. Husbands had sent their wives out of their matrimonial homes most especially among HIV discordant couples. Some discussants however said that their work and businesses had been badly affected. Few respondents said they have been sacked from work while about half said that they don't have the strength to continue in their businesses. While majority of discussants decried neglect and injustice or partial mal-treatment they received from health care workers who they claimed were supposed to know better about HIV, about half of respondents said that their daily living has not been affected in any way mainly because they were ready for the worst to happen. A respondent said:

My husband divorced me sometimes after he learnt that I was HIV positive, though he had refused to be tested. I have lost my husband, who is my pillar of financial support. His family suddenly came to take away the children from me, and my business has crumbled to a level that I now depend on some good Samaritans.

Another respondent said:

Life has suffered me a lot. I have lost many of what I have labored for over the years. Everyday my energy have decreased, and I have lost the courage and zeal to continue

Variables	Frequency	Percentage
Age in years		
18-30	16	33.3
31-40	24	50.0
41-50	8	16.7
Sex		
Female	28	58.3
Male	20	41.7
Religion		
Christianity	22	45.8
Islam	25	52.1
Traditional	1	2.1
Others	0	0.0
Highest level of education attained		
Primary	8	16.7
Secondary	22	45.8
Tertiary	13	27.1
Post graduate	1	2.1
Others	4	8.3
Marital status		
Married	11	22.9
Single	11	22.9
Separated	12	25.0
Widowed/divorced	14	29.2
Others	0	0.0
No of years diagnosed with HIV		
<5 years	28	58.3
5-10years	16	33.3
>10years	4	8.4

Table 1. Socio-demographic characteristics of focus group discussants (n=48)

in my business

When asked how they have coped with this repulsive societal attitudes, about half of discussants said they never tell their experiences to others including their spouse, about half said they registered for HIV care in health facilities that are far away from where they live, about one third disguised while coming to hospital, about one tenth intentionally skipped their routine hospital appointments, about half disguised with ARVs by removing the drug label and replacing the drug container with that of multivitamins drugs thereby hiding identity of ARVs, about another one tenth do multiple clinics registration so that they could not be traced or tracked to any particular clinic, while many of male discussants said that their HIV positive wives registered and collected drugs on their behalf. According to one of the discussants;

HIV is not a story that you tell people anyhow. I registered in 2 places and they are both far away from where I live. At times, I asked my husband to collect drugs for me. Then I will take my turn in the next 3 months. I just must find a way round it, getting my drugs has always been my priority because I do not want to die.

While about one third said they hide ART clinic appointment cards from other people including their spouse, about one third said they intentionally attach spiritual dimension to their illness so as to divert and draw positive attention from family and friends. However about two-fifth said they got relief by joining HIV support groups. When asked about their personal feelings towards the disease, about one quarter felt a sense of guilt, and depression while about one third said they felt aggres-

sive and violent, even entertained suicidal thoughts. As regards public disclosure, four-fifth were not ready to come out in public to claim being HIV positive, while all respondents felt they wished they could come forward to appear in public to lend their words against stigmatization of HIV infected people in public.

My husband will kill me if I come out to come out and say such rubbish in the public. Shame will not let me leave. Many people have died from loneliness and other consequences of this stigmatization, and the public needs to be enlightened

When asked about how they felt societal stigma and discrimination could be reduced, over four-fifth of respondents felt that there is a need to improve awareness on modes and non modes of transmission of HIV to the general public using traditional and community means of communication, the media and health campaign sessions. One third said that government should enforce the existing legislation and policy on anti-stigma and anti-discrimination laws. About half of respondents believed that the bad attitude of health care workers need to change so that they can access care without being maltreated, and that HIV positive clients should come out in public to speak against discrimination and to tell the public that they could live positively. About one third however believe that discriminators and stigmatizers in the public should be confronted and reported promptly to concerned regulatory body at the governmental and community levels.

4. DISCUSSION

The feeling of misery concerning life among HIV positive discussants under study and decline in relating with people supports other studies in which HIV status was found to isolate people from the community, thus affecting the overall quality of life of HIV clients (4, 11, 12). In an environment like Nigeria, the fear of contracting HIV has increased including misconceptions about non modes of transmission including casual contact. Thus there is tendency for HIV positive clients to reduce interacting with people in a bid to prevent the public from knowing about their HIV positive status. This could worsen the stress PLWHA lives with, as they are forced to be silent about their status, which on its own is burdensome (4, 13, 14). This is especially so for people who need to keep their source(s) of livelihood by keeping their jobs. It may affect access to social support networks even among PLWHA or support group members that will help their psychology and sharing of experiences. Stigma could enhance secrecy and denial, which are also catalysts for HIV transmission.

The perception of unfair or bad feelings from the public towards HIV infected people agreed with findings from other studies (12, 15). HIV/AIDS is stigmatizing because it carries many symbolic associations with danger. Attribution of contagion, incurability, immorality and punishment for sinful acts is common in many societies (16). In a developing country like Nigeria where sharing of sharp objects and transfusion of HIV infected blood and blood products is of a high possibility, the usual association of HIV infection with sexual immorality may be regarded as an unfair dealings with people living with HIV/AIDs.

The claim by HIV positive clients that they faced employment challenges could be supported by other studies. A prospective study in France examined employment discrimination specifically and found that about one third of people living with

HIV experienced employment loss over the duration of the study (17). Studies among employers in both China and Nigeria found strong reluctance to hire or retain employees with HIV (18, 19), suggesting that the workplace is a setting for potential discrimination regardless of region. Loss of jobs by HIV positive clients would further worsen their financial status, and invariably their nutritional status which is very important to the recovery of an already depleted immune status. Since health care workers are at risk of contracting HIV like and even more than the general population, the faces of stigma may have extended beyond the general population to the health sector. A study in Tanzania documented a wide range of discriminatory and stigmatizing practices, and categorized them broadly into neglect, differential treatment, denial of care, testing and disclosing HIV status without consent, and verbal abuse and gossips (20).

Other studies done in Ethiopia and South Africa found that health workers struggle with self-stigma regarding a potential HIV diagnosis, as well as fear of stigmatizing attitudes and behavior from their colleagues, which contribute to a lack of uptake of HIV testing and early treatment if needed (9, 21). Thus stigma could contribute to keeping people including health workers from accessing HIV prevention, care and treatment services and adopting key preventive behaviors. HIV-related stigma and discrimination could also serve as barriers both to the delivery of quality services by health providers and to their utilization by community members and health providers themselves.

The discriminatory behaviors of health care workers who are expected to be more knowledgeable about epidemiology and control of HIV including its social aspects are not helping matters. They often take extreme precaution against HIV positive clients for fear of transmission, and at times may refuse HIV positive clients some aspects of care. This is supported by another study in which health staff was said to be worried about occupational exposure, with high levels of anxiety and fear when dealing with HIV-positive persons (22, 23). Some physicians discriminate against persons living with HIV/AIDS, including refusal to have them in their practice. Among private medical practitioners, situation is even worse as the presence of a known HIV client could discourage other clients from patronizing their medical practice. Having patients with HIV/AIDS can stigmatize a practice and lead to a reduced patient load and a loss in income (24).

5. CONCLUSION

PLWHA in Nigeria face discrimination from the public including the health systems. A coordinated and continuous health education campaign to the general public could go a long way to stem down the unfortunate menace of stigma and discrimination. This responsibility lies with coordinated and collective efforts of all stake holders including governments, Non governmental organizations, health care workers, the private sector, the media and communities.

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CONFLICT OF INTEREST: NONE DECLARED.

REFERENCES

- Emlet CA. Measuring Stigma in Older and Younger Adults with HIV/AIDS: An Analysis of an HIV Stigma Scale and Initial Exploration of Subscales. *Research on Social Work Practice*. 2005; 15(4): 291-300.
- Lau JTF, Tsui HY. Comparing the magnitude of discriminatory attitudes toward people living with HIV/AIDS and toward people with mental illness in the Hong Kong general population. *Health education research*. 2007; 22(1): 139-152.
- Ndinda C, Chimbwete C, McGrath N, Pool R. Community attitudes towards individuals living with HIV in rural KwaZulu-Natal, South Africa. *AIDS Care*. 2007; 19: 92-101.
- Greeff M, Phetlu R, Makoae LN. Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qualitative Health Research*. 2008; 18(3): 311-324.
- Miller AN, Rubin DL. Factors leading to self-disclosure of a positive HIV diagnosis in Nairobi, Kenya: people living with HIV/AIDS in the Sub-Saharan. *Qualitative Health Research*. 2007; 17(5): 586-598.
- Genberg BL, Kawichai S, Chingono A, Sendah M, Chariyalertsak S, Konda KA, Celentano DD. *AIDS Behav*. 2008; 12(5): 772-780.
- Rokach A. Correlates of loneliness as perceived by the terminally ill. *Behavioral Science Current Psychology*. 2003; 19(3): 237-248.
- UNAIDS. India: HIV and AIDS-related discrimination, stigmatization and denial. In *Best Practice Collection*. UNAIDS: Geneva, 2001.
- Nyblade L, Pande R, Mathur S, MacQuarrie K, Kidd R, Banteyerga H, Kidanu A, Kilonzo G, Mbwapo J, Bond V. Disentangling HIV and AIDS stigma in Ethiopia, Tanzania and Zambia. ICRW: Washington, DC, 2003.
- Federal Ministry of Health (FMOH). National HIV/AIDS Sero-prevalence Survey. FMOH Abuja Nigeria, 2010.
- Rankin WW, Brennan S, Schell E, Laviwa J, Rankin SH. The stigma of being HIV-positive in Africa. *PLoS Medicine*. 2005; 2(8): e247.
- Campbell C, Nair Y, Maimane S, Nicholson J. Dying twice: a multi-level model of the roots of AIDS stigma in two South African communities. *Journal of Health Psychology*. 2007; 12(3): 403-416.
- Orner P, Cooper D, Myer L, Zweigenthal V, Bekker LG, Moodley J. Clients' perspectives on HIV/AIDS care and treatment and reproductive health services in South Africa. *AIDS Care*. 2008; 20(10):1217-1223.
- Iwelunmor J, Airhihenbuwa CO, Okoror TA, Brown DC, Belue R. Family systems and HIV/AIDS in South Africa. *International Quarterly of Community Health Education*. 2006; 27(4): 321-335.
- Gilmore N, Somerville MA. Stigmatization, scapegoating and discrimination in sexually transmitted diseases: overcoming 'them' and 'us,' *Social Science and Medicine*. 1994; 39(9): 1339-1358.
- Hardon A, Boonmongkon P, Streefland P. *Applied Health Research Manual Anthropology of Health and Health Care*, The Hague: CIP-Data, Koninklijke Bibliotheek, The Netherlands, 1995.
- Dray-Spira, R, Gueguen A and Lert F. "Disease severity, self-reported experience of workplace discrimination and employment loss during the course of chronic HIV disease: differences according to gender and education." *Occupational and environmental medicine*, 2008; 65(2): 112-119.
- Adeyemo, D.A. and Oyinloye A.A. "Predisposition Factors in Stigmatization and Discrimination against HIV/AIDS Seropositive Persons in the Workplace: A Case Study of Osun State, Nigeria." *Journal of Social Sciences*, 2007; 15(3): 279-292.
- Rao D, Kekwaletswe TC, Hosek S, Martinez J, Rodriguez F. Stigma and social barriers to medication adherence with urban youth living with HIV. *AIDS Care*. 2007; 19: 28-33.
- No author. Tanzania stigma-indicators field test group: Measuring HIV stigma: results of a field test in Tanzania. Washington, DC: Synergy, 2005.
- Uebel KE, Nash J, Avalos A. Caring for the caregivers: models of HIV/AIDS care and treatment provision for health care workers in southern Africa. *The Journal of Infectious Diseases*. 2007; 196: S500-S504.
- Mulvey G, Temple-Smith M. Managing people with HIV/AIDS - the involvement of Victorian general practitioners. *Aust Fam Physician*. 1997; 26(2): S6670.
- Ros CC, Keressens JJ, Foets M, Peters L. Trends in HIV-related consultation in Dutch general practice. *Int J STD AIDS*. 1999; 10(5): 2949.
- Bredfeldt RC, Dardeau FM, Wesley RM, Vaughan-Wrobr BC, Markland L. AIDS: family physicians' attitudes and experiences. *J Fam Pract*. 1991; 32(1):715.