

Experiences of discrimination among youth with HIV/AIDS in Ibadan, Nigeria

Adesola O. Sangowawa, Eme T. Owoaje
Department of Community Medicine,
College of Medicine, University of
Ibadan/ University College Hospital
(UCH), Ibadan, Nigeria

Abstract

Nigerian youth currently bear a disproportionate burden of the HIV epidemic. This paper presents findings on the occurrence of HIV-related discrimination among youth with HIV accessing care in Ibadan, Nigeria. A cross-sectional study was conducted and information on history of discrimination experienced by 170 youth with HIV was obtained. About 80% of respondents had disclosed their HIV status. The majority had informed their spouses (66.3%), mothers (47.1%), fathers (39.1%) and siblings (37.7%). Sixteen (11.5%) respondents [15 (93.8%) females and one (6.2%) male] had suffered discrimination since disclosure of their status. Of these, 25.0% respondents were sent out of their matrimonial homes by their husbands, 25.0% were abandoned by their spouses and 12.5% indicated their fiancé broke up their relationship. A higher proportion of females (12.9%) than males (4.3%) had suffered discrimination. In addition, a significant proportion of respondents who were separated/divorced (73.3%) had been victims of discrimination compared with those who were widowed (10.5%) or single (5.9%) ($P < 0.05$). The study confirmed that young people living with HIV/AIDS, especially women experience extreme forms of discrimination. More efforts aimed at addressing HIV/AIDS-related discrimination are required especially as it is a known barrier to HIV prevention and treatment efforts.

Introduction

The prevalence of HIV/AIDS has remained high in sub-Saharan Africa. In Nigeria, the national HIV sentinel survey conducted in 2008 showed that the national HIV prevalence for women attending antenatal clinics was 4.6% and those in the 25-29 year age group recorded the highest prevalence.¹

Stigma and discrimination are major consequences of HIV/AIDS in spite of the fact that effective drugs, which improve the health of People Living with HIV/AIDS (PLWHA), now

exist. In 2002, the Joint United Nations Programme on HIV/AIDS (UNAIDS) published a report declaring that the stigma associated with HIV was one of the *greatest barriers* to preventing new infections and alleviating the impact of the disease.² Generally, stigma refers to the branding or labeling of a person or group of persons as being unworthy of inclusion in human community, resulting in discrimination and ostracization.³ This branding is usually related to some perceived physical, psychological or moral condition believed to render the individual or group unworthy of full inclusion in the community. HIV-related stigma consists of negative attitudes directed at those infected or suspected of being infected with HIV as well as those affected by AIDS by association (such as orphans or the children or families of PLWHA). Discrimination as defined by the UNAIDS protocol for identification of discrimination against PLWHA refers to any form of arbitrary distinction, exclusion or restriction affecting people because of their confirmed or suspected HIV-positive status.

HIV/AIDS stigma has dire consequences for PLWHA and those taking care of them.⁴⁻⁶ Generally, PLWHA are wary about disclosing their status because of the fear of stigma and discrimination associated with the disease. Many individuals and affected families thus refuse to share the diagnosis with others because of a sense of guilt and shame associated with the disease and also the fear of community disapproval of the sickness. This is because disapproval often leads to stigmatization, isolation and termination of association with the infected individual and his family.⁷ HIV-related stigma and discrimination also affects whether people go for voluntary counseling and testing VCT,⁸⁻¹¹ as well as their willingness to share their fears with family, friends or colleagues. Stigma also affects adherence to Anti-Retroviral Therapy by PLWHA thus affecting their quality of life and increasing complications.^{4,8,12-15} It also leads to public denial of HIV/AIDS and this neither helps to reduce the HIV/AIDS infection nor help in fighting stigma.^{4,16,17} Stigma and discrimination are issues which PLWHA and those caring for them have to deal with on a daily basis and working in synergy, they place a burden on human development by denying many people of the chance of reaching their full potential.³

A study carried out in France reported that more than one third of a sample of 889 PLWHA had experienced HIV-related discrimination in different aspects of their social life in the five year preceding the survey.¹⁸ A study carried out among physicians, nurses and midwives in four Nigerian states and documented by UNAIDS reported that 10% of respondents admitted to having refused care to a patient

Correspondence: Adesola O. Sangowawa, Institute of Child Health, College of Medicine, University of Ibadan, PMB 5116, Ibadan, Oyo State, Nigeria, 200001.
Tel. +2348033265796 - Fax: +234-2-2411768.
E-mail: daisyolu@yahoo.co.uk

Key words: discrimination, stigma, people living with HIV/AIDS, youth.

Acknowledgements: the authors would like to thank the research assistants, coordinators of the support groups and all the respondents.

Contributions: the authors contributed equally.

Conflict of interest: the authors report no conflicts of interest.

Received for publication: 22 February 2011.

Revision received: 22 February 2011.

Accepted for publication: 9 January 2012.

This work is licensed under a Creative Commons Attribution NonCommercial 3.0 License (CC BY-NC 3.0).

©Copyright A.O. Sangowawa and E.T. Owoaje, 2011
Licensee PAGEPress, Italy
Journal of Public Health in Africa 2012; 3:e10
doi:10.4081/jphia.2012.e10

with HIV or AIDS.¹⁹ In India, 70% of the people with HIV studied said they had faced discrimination, most commonly in families or within health-care settings.²⁰ PLWHA are sometimes victims of extreme forms of discrimination, for example Septimus reported that some people with HIV were thrown out of their family homes, some lost their jobs and a woman with HIV was mobbed in Ghana.²¹

Nigerian youth (aged 18-35 years) comprise a broad and dynamic group. They represent the most active, volatile, and vulnerable segment of the nation's population.²² Currently, they are the worst hit by the HIV epidemic.¹ This places an additional burden on their development especially in the face of the existing socio-economic milieu of the country. This paper reports experiences of discrimination among youth with HIV following disclosure of their HIV status. Findings are part of a larger study on the social and economic problems of PLWHA in Ibadan.

Materials and Methods

A cross-sectional study was conducted in Ibadan, the capital of Oyo state. Oyo state is one of the 36 states in Nigeria. It was created in 1976 out of the old Western region and has an estimated population of over 5 million.²³ Ibadan has an estimated population of over 1

million. Respondents were recruited from two HIV/AIDS support groups as well as from the Anti-Retroviral treatment Clinic via the General Out-patients clinic, University College Hospital, Ibadan, Oyo State, Nigeria. The definition of youth used here conforms to that given by the National Youth Policy and strategic Plan of Action of the Federal Republic of Nigeria which states that, youth comprise of all males and females aged 18 to 35, who are citizens of the Federal Republic of Nigeria.²²

A list of the registered non-governmental organizations (NGOs) providing care and support for PLWHAs in Ibadan was obtained and two of the three NGOs which were registered at the time of the survey were selected using simple random sampling technique. All consenting individuals in each site were subsequently interviewed. A total sample of PLWHA referred to the antivirals (ARVs) clinic, University College Hospital (UCH), from the general outpatient department, during the study period was carried out.

Ethical approval for the study was obtained from the U.I/UCH Ethical Review Board and informed consent was obtained from respondents. The questionnaire was translated into Yoruba, the local language and back translated to English to ensure the original meaning was retained. The questionnaire was pre-tested on a group of PLWHA obtaining care in the Federal Medical Centre, Abeokuta. The data obtained was analysed using the Statistical Package for Social Sciences (SPSS Inc., Chicago, IL, USA - version 15).

Results

Socio-demographic characteristics

There were 170 young people aged 18-35 years, 140 (82.4%) were female and 30 (17.6%) male, 77 (44.7%) were in the 25-30 year age group. The majority of respondents (97.8%) were diagnosed HIV positive in the 5-year period preceding the study. Sixty-seven (39.4%) were currently married, 55 (82.1%) of who were in monogamous marriages; 115 (67.6%) were Christians and the highest level of education for 89 (52.4%) of the respondents was secondary education. One hundred and eight (63.5%) respondents were currently employed, 57 (52.8%) of who were traders (Table 1).

Experiences of discrimination

One hundred and thirty-eight (81.1%) of respondents had disclosed their HIV status. Fifty-five (66.3%) of the 83 respondents who were currently married and separated/divorced had informed their spouses of their status. Two currently widowed respondents had also disclosed their status to their spouses before

their demise. Other people respondents had disclosed their status to included mothers (47.1%), fathers (39.1%) and siblings (37.7%), (Table 2). Among those who had disclosed their status, 16 (11.5%) [15 (93.8%) females and one (6.2%) male] had suffered discrimination. Discriminatory acts took various forms: four (25.0%) respondents were sent out of their matrimonial home by their husbands and four (25.0%) were abandoned by their

spouses. Two (12.5%) indicated their fiancé broke up their relationship with them when they learnt that they were positive, two (12.5%) of the respondents reported that their husbands became hostile towards them and one (6.2%) each had experienced hostile behaviour from their mother, another relation and a health worker. The only male respondent who had experienced discrimination reported that his mother was the perpetrator and that

Table 1. Socio-demographic characteristics of respondents.

Socio-demographic characteristics	N.	%
Age group (years)		
≤24	17	10.0
25-30	77	45.3
31-35	76	44.7
Sex		
Male	30	17.6
Female	140	82.4
Highest level of education		
No formal education	5	2.9
Primary	27	15.9
Secondary	89	52.4
Tertiary	49	28.8
Religion		
Christianity	115	67.6
Islam	55	32.4
Marital status		
Single	67	39.4
Married	67	39.4
Widowed	20	11.8
Separated/divorced	16	9.4
Family type (n=67)		
Monogamous	55	82.1
Polygamous	12	17.9
Currently employed		
Yes	108	63.5
No	62	36.5
Occupation (n=108)		
Trading	57	52.8
Artisans	19	17.6
Civil servant	10	9.2
Business people	5	4.6
Driving	4	3.7
Professionals	4	3.7
Teaching	2	1.9
Others	7	6.5

Table 2. Respondents and disclosures list.

	N.	%
Disclosures		
Yes	138	81.2
No	32	18.8
To whom* n=138		
Spouse (n = 83) ^o	55	66.3
Mother	65	47.1
Father	54	39.1
Sibling	52	37.7
Friend	16	11.6
Other relative	12	8.7
In-law	5	3.6
Partner	3	2.2
Others [#]	7	5.1

*Multiple response; ^ocomprised all those who were currently married and separated/divorced; [#]others included children=2, religious leader = 2, colleagues = 2 and fiancé = 1.

although she was initially hostile towards him, she had since become caring and supportive (Table 3).

Factors associated with experience of discrimination

More females (12.9%) than males (4.3%) had been discriminated against and discrimination was highest among those with primary education. A significant proportion of respondents who were separated/divorced (73.3%) had been victims of discrimination compared with those who were widowed (10.5%) or single (5.9%). None of the currently married youth had experienced discrimination. More of those who were unemployed (14.5%) versus those employed (9.5%) had been discriminated against and 16.7% of those who did not know their spouse' HIV status had been discriminated against compared with those who knew their spouse' HIV status (Table 4).

Discussion

Over 80% of the respondents had disclosed their status; mostly to their spouse/partner, their parents, siblings and friends. Findings from a pilot study carried out in Kenya showed that about 89.5% of PLWHA had disclosed their status. Participants in the Kenyan study also reported a preference for disclosing to a spouse, as did the respondents in Ibadan.²⁴ About ninety-three per cent of PLWHA studied in India had disclosed their HIV status and majority revealed it to their spouse (76.9%) followed by parents (10.2%) and friends (5.1%). Other confidants were their siblings, co-workers, neighbours or any close relative.²⁰ The lower figure obtained in our study could be attributed to the fact that HIV-related stigma is still a problem in Nigeria. In addition, at the time of the study, ARVs were not yet universally available to PLWHA in the study area as pre-requisite investigations still had to be paid for by patients. About a tenth of respondents who had disclosed their status had been victims of discriminatory behaviour.

This is lower than the figure obtained in a study carried out in France, which reported that more than one third of the study participants had experienced HIV-related discrimination in different aspects of their social life.¹⁸ Among the PLWHA studied in India, as many as 70 per cent of the respondents had reportedly faced discrimination which mainly occurred at the family level (33.3%), in hospitals (32.5%) and from neighbours (18.3%), within the community (9.17%), educational institutes, relatives and workplace.²⁰ This difference might have been due to the fact that a lower proportion of respondents in Ibadan had disclosed their status and those who disclosed informed close family

members; the majority of who had been quite supportive. Our study showed that females were about three times as likely to have experienced discrimination since they were diagnosed HIV positive compared with the males. In addition, discrimination reportedly occurred mainly from their spouses. Studies have documented that in addition to being at greater risk of contracting HIV than men, women are also more likely to suffer from stigma and discrimination. They are often treated more negatively by family and household members than men.^{24,25} Similar extreme acts of discrimination have been documented by other studies.^{8,21} The women in our

study experienced a variety of negative reactions following disclosure of their status. These ranged from hostile behaviour from their spouses to abandonment. Other studies among PLWHA have also reported that women who share HIV test results with their partners experienced negative reactions such as accusations, discrimination, physical violence and abandonment.^{6,8,21,26-31} Our study revealed that discrimination occurred more among those who were separated/divorced and this is not surprising since their current marital state of being separated/divorced was an aftermath of discriminatory behaviour.

Table 3. Proportion of respondents who have experienced discrimination and sources of discrimination.

	N.	%
History of discrimination		
Yes	16	11.5
No	123	88.5
Sources of discriminatory behaviour (n = 16)		
Spouse	11	68.9
Fiancé	2	12.5
Parent	1	6.2
Other relatives	1	6.2
Health worker	1	6.2
Types of discriminatory behaviour (n=16)		
Sent out of matrimonial home	4	25.0
Abandoned by spouse	4	25.0
Fiancé broke relationship	2	12.5
Hostile spouse	2	12.5
Hostile mother/ relative/ health worker	3	18.8
Spouse divorced respondent	1	6.2

Table 4. Factors associated with experience of discrimination.

Socio-demographic characteristics	Discrimination		Fisher's exact P
	Yes (%)	No (%)	
Sex (n=139)			
Male	1 (4.3)	22 (95.7)	0.472
Female	15 (12.9)	101 (87.1)	
Age group			
24 and below	1 (7.1)	13 (92.9)	0.928
25-30	7 (10.8)	58 (89.2)	
31-35	8 (13.3)	52 (86.7)	
Level of education (n=139)			
No formal education	0	5 (100.0)	0.352
Primary	4 (17.4)	19 (82.6)	
Secondary	10 (14.1)	61 (85.9)	
Tertiary	2 (5.0)	38 (95.0)	
Marital status (n=279)			
Single	3 (5.9)	48 (94.1)	<0.001
Married	0	54 (100.0)	
Separated/ divorced	11 (73.3)	4 (26.7)	
Widowed	2 (10.5)	17 (89.5)	
Currently employed			
Yes	8 (9.5)	76 (90.5)	0.420
No	8 (14.5)	47 (85.5)	
HIV status of spouse/regular sexual partner (n=120)			
Positive	2 (6.1)	31 (93.9)	0.241
Negative	1 (4.8)	20 (95.2)	
Not known	11 (16.7)	55 (83.3)	

Conclusions

The study confirmed that young PLWHA especially the females had experienced extreme forms of discrimination. More efforts by government aimed at addressing HIV/AIDS-related stigma and discrimination are thus required. The general populace including relatives of PLWHA also needs to be educated on the negative effect stigma and discrimination has on PLWHA. This would ultimately lead to improvements in the quality of life of those infected and affected by the virus.

References

1. Federal Ministry of Health (2010). Technical Report on the 2008 National HIV/Syphilis Sero-prevalence Sentinel Survey among Pregnant women attending Antenatal Clinics in Nigeria. Department of Public Health, National AIDS/STI Control Programme. Abuja: Nigeria.
2. Aggleton P, Parker R (2002). World AIDS campaign 2002–2003. A conceptual framework and basis for action: HIV/AIDS stigma and discrimination. Joint United Nations Programme on HIV/AIDS. Available from: http://data.unaids.org/publications/IRC-pub02/jc891-wac_framework_en.pdf Accessed: 19 September 2006.
3. UNAIDS (2005). A report of a theological workshop focusing on HIV – and AIDS-related stigma. 8th – 11th December 2003, Windhoek, Namibia/ supported by UNAIDS. <http://www.unaids.org> Accessed: 29 November 2006.
4. 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. *J Health Psychol* 2007;12: 403-16.
5. Ulasi CI, Preko PO, Baidoo JA, et al. HIV/AIDS-related stigma in Kumasi, Ghana. *Health Place* 2009;5:255-62.
6. Okoror TA, Airhihenbuwa CO, Zungu M, et al. "My mother told me I must not cook anymore" - food, culture, and the context of HIV- and AIDS - related stigma in three communities in South Africa. *Int Q Community Health Educ* 2007-2008;28: 201-13.
7. Osei-Hwedie K. AIDS, the individual, family and community: Psychosocial Issues. *J Soc Dev Afr* 1994;9:31-43.
8. Greeff M, Phetlhu, Makoae RLN, et al. Disclosure of HIV status: experiences and perceptions of persons living with HIV/AIDS and nurses involved in their care in Africa. *Qual Health Res* 2008;18: 311-24.
9. Duffy L. Suffering, shame, and silence: the stigma of HIV/AIDS. *J Assoc Nurses AIDS Care* 2005;16:13-20.
10. Weiser SD, Heisler M, Leiter K, et al. Routine HIV testing in Botswana: a population-based study on attitudes, practices, and human rights concerns. *PLoS Med* 2006;3:e261.
11. Ndinya-Achola J, Ambani J, Temmerman M, Piot P. The right not to know HIV-test results. *Lancet* 1995;345:969-70.
12. Nachega JB, Lehman DA, Hlatshwayo D, et al. HIV/AIDS and antiretroviral treatment knowledge, attitudes, beliefs, and practices in HIV-infected adults in Soweto, South Africa. *J Acquir Immune Defic Syndr* 2005;38:196-201.
13. Sanjoko N, Frich JC, Fretheim A. Barriers and facilitators to patients' adherence to antiretroviral treatment in Zambia: a qualitative study. *SAHARA J* 2008;5:136-43.
14. Ncama BP, McInerney PA, Bhengu BR, et al. Social support and medication adherence in HIV disease in KwaZulu- Natal, South Africa. *Int J Nurs Stud* 2008;45:1757-63.
15. Weiser SD, Heisler M, Leiter K, et al. Routine HIV testing in Botswana: a population-based study on attitudes, practices, and human rights concerns. *PLoS Med* 2006;3:e261.
16. Wood K, Lambert H. Coded talk, scripted omissions: the micropolitics of AIDS talk in South Africa. *Med Anthropol Q* 2008; 22:213-33.
17. Campbell C, Foulis CA, Maimane S, Sibiyi Z. I have an evil child at my house: stigma and HIV/AIDS management in a South African community. *Am J Public Health* 2005;95:808-15.
18. Lert, F, Obaiya Y, Dray-Spira R, et al. (2001). Study of the Social Situation of Persons living with HIV/AIDS and the responsiveness of the health care system and social services (in French). Paris, France: INSERM U88-ORS PACA/INSERM U379.
19. UNAIDS (2003). AIDS Epidemic Update, UNAIDS and World Health Organization. Available from: http://data.unaids.org/publications/irc-pub06/jc943-epiupdate2003_en.pdf
20. ILO Decent Work Team for South Asia and ILO Country Office for India (DWT/CO-New Delhi) (2003). Socio-Economic impact of HIV/AIDS on people living with HIV/AIDS and their families. Accessed at <http://www.ilo.org/public/english/region/asro/newdelhi/aids/download/socioec.pdf> Accessed: 10 January, 2007.
21. Septimus A. Caring for HIV- infected children and their families: Psychosocial Ramifications. In: GR Anderson (ed). *Courage to Care: Responding to the Crisis of Children with AIDS*. Washington, DC: Child Welfare League of America Inc.; 1990.
22. Federal Ministry of Youth Development. National Youth Policy 2009. Available from: <http://nigeria.unfpa.org/pdf/snyp2009.pdf>
23. National Population Commission, 2006. Available from: <http://www.population.gov.ng/>
24. Kaai S, Sarna A, Hawken M, et al. PLHA preference for disclosure: building family support to promote adherence to HAART. International Conference on AIDS (15th: 2004: Bangkok, Thailand). *Int Conf AIDS* 2004;15: abstract no. ThPeD7811.
25. Ngozi CM, van den Borne B, De Vries NK. Stigma of People with HIV/AIDS in Sub-Saharan Africa: Literature Review. *J Trop Med* 2009;2009:145891.
26. 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-Sahara. *Qual Health Res* 2007;17:586-98.
27. Iwelunmor J, Airhihenbuwa CO, Okoror TA, et al. Family systems and HIV/AIDS in South Africa. *Int Q Community Health Educ* 2006;27:321-35.
29. Amuyunzu-Nyamongo M, Okeng'o L, Wagura A, Mwenzwa E. Putting on a brave face: the experiences of women living with HIV and AIDS in informal settlements of Nairobi, Kenya. *AIDS Care* 2007;S1:S25-S34.
30. Maman S, Mbwapo J, Hogan NM, et al. Women's barriers to HIV-1 testing and disclosure: challenges for HIV-1 voluntary counselling and testing. *AIDS Care* 2001; 13:595-603.
31. Ndinya-Achola J, Ambani J, Temmerman M, Piot P. The right not to know HIV-test results. *Lancet* 1995;345:969-70.