Qualitative exploration of manifestations of HIV-related stigma in Kano State, Nigeria

Muktar A. Gadanya[1], Rayyan M. Garba[2]

Abstract

Background: HIV-related stigma is an important barrier to the containment of the epidemic and adversely affects the wellbeing of patients. This study explored the manifestation and consequences of HIV-related stigma in Kano State, Nigeria.

Methods: The study was descriptive and cross-sectional, that used qualitative methods involving Focus Group Discussions, in-depth interviews, and passive observations. Thematic analysis for the qualitative data was done with the aid of NVivo10.

Results: HIV-related stigma was identified by stakeholders and patients to be perverse in Kano, and often manifest in manner distinct from what is known in places where HIV stigma has been well researched. These include facial covering with *"Burqah"* to shield identity at the clinics, "proxy patients", travelling long distance away from home to access care, and use of false names to hide identity. A spot observation on four consecutive days at a HIV clinic and an ante-natal clinic yielded an interesting finding: In the antenatal clinic only 2 patients out of the 435 patients who attended the clinic on the four days (0.46%) were wearing *Burqah*. Conversely, in the HIV Clinic, 18 of the 216 female (8.33%) patients who attended the clinic in the four days period were wearing *Burqah* ($p = 0.0034$).

Conclusion: These findings lend credence to the fact that HIV-related stigma is a big reality in Kano State, and has some context specific manifestations, consequences and coping mechanisms. Follow-up quantitative and intervention studies are recommended.

Keywords: HIV, stigma, manifestations, consequences, Nigeria

Highland Med Res J 2016;16(2):51-55

Introduction

Stigma, synonyms for which are blemish and tarnish, has an origin of being *"...a mark made by a branding iron on the skin of a criminal or slave...."*[2], and in modern context refers to *"a mark of disgrace or infamy; a stain or reproach, on one's reputation"*[2, 3.] Kano State is not alien to stigma in both its modern and archaic meanings.[4-6] Researchers exploring stigma have extensively used or modified the definition of stigma fist put forward by Goffman[7] in 1963 as *"…an attribute that is deeply discrediting within a particular social interaction that reduces the bearer from a whole and usual person to a tainted, discounted one".*[7,8] HIV-related stigma can exist in various dimensions[9], and stigma is considered to be so important to the containment of HIV/AIDS epidemic that on two consecutive years (2001 and 2002) the theme of the annual World AIDS day was chosen to be stigma.[10] Kano State is the most populous and second most industrialized state in Nigeria, and is largely cosmopolitan. This cosmopolitan nature and large level of migrants added to the existence of various kinds of sexual activities.[11-14] HIV infection in any location worldwide has been accompanied by stigma and discrimination[15] with varied manifestations (how it presents).

In a study in five African countries, namely Lesotho, Malawi, South Africa, Swaziland, and Tanzania HIV positive respondents reported been verbally or physically abused as a result of their HIV status.[16,17] In the Netherlands, manifestations of HIV related stigma includes evading, rebuffing, neglect, segregation, gossiping, blaming of patients.[18,19] In a study in Osun State, Southern Nigeria, employers indicated unwillingness to employ or keep in employment a HIV positive person.[20] Dakas[21] highlighted a case of a dramatic display of stigma and discrimination in Nigeria which also gives an evidence of prejudice at all levels- when a defense counsel asked that a lady suing for wrongful termination of her employment on the basis of her HIV status should leave the court, as she constituted a health hazard. The need to withdraw from people as a result of fear of HIV stigmatization was found to afflict a staggering 60% of patients in two communities in Zimbabwe.[22,23] The use of strategies to cope or avoid stigma that entails avoidance or withdrawal has been proven to lead to psychological distress.[24-25]

In a study in USA, patients with high fear of perceived stigma are 3.3 times less likely to adhere to their medications.[26] This has religious significance to HIV patients as Habib and colleagues[27] seeking to

[1]Department of Community Medicine, Bayero University/ Aminu Kano Teaching Hospital, Kano, Nigeria. [2]Department of Community Medicine, Aminu Kano Teaching Hospital, Kano, Nigeria.

All correspondences to:
Dr. Muktar A. Gadanya
E-mail: gadanya@gmail.com

explore problem of adherence for Kano Muslim patients going for Hajj (pilgrimage to Mecca) found that having to take drugs in camps during Hajj creates fear of stigma. This account for substantial failure of adherence when compared to those who have not gone on Hajj (RR= 2.79; CI: 1.18-6.60).

Stigma and discrimination can potentially increase infection rates in a society by patients reacting against society-induced suffering and indignity with sexually careless behaviours.[28,29] In a 2008 survey in Rwanda, 89.1% of the respondent who are health care workers reported knowing attitudes by other health care workers that are stigmatizing or discriminatory to HIV patients.[30] In a survey of health workers comprising respondents from Abia, Oyo, Gombe and Kano states, 41% of healthcare workers believed that other healthcare workers with HIV should not be allowed contact with patients under any circumstance.[19] Monjok and collegues in 2009 after review of the limited literature available on HIV-related stigma in Nigeria, averred that *"…research and knowledge on HIV-related stigma and discrimination in many ethnic and cultural settings that constitute Nigeria, are important tool in understanding this "hidden factors" that are impediments to effective prevention and treatment.."* The aim of the study was to determine the manifestations of HIV-related stigma and discrimination in Kano State, Nigeria.

Material and Methods

Study Design:

The study was descriptive cross-sectional study that employed formative qualitative research using Focus Group Discussions (FGDs), in-depth interviews and observation, and was conducted in October-November 2014.

Study Population:

The study population was HIV patients attending HIV treatment clinics in randomly selected primary, secondary and tertiary healthcare centers in Kano State. There were also FGDs with HIV health care workers until saturation was reached. There was also participant observation in HIV clinics. This formative qualitative study described the phenomena under investigation, and will inform design of the quantitative aspect of the study (the questionnaires survey), as done successfully by some other studies evaluating stigma in context.[31]

In-depth Interviews with HIV patients allowed respondents to give detailed response and gave the interviewer the chance to explore issues comprehensively and with confidentiality. The guides for the interviews were pilot tested with two respondents and necessary modifications were made to the guide.

Participants' selection

In each of the three selected clinics, from each of the categories of patients and healthcare providers, purposive sample of about 20 respondents was initially selected. This, based on theory, will provide enough breadth and depth of perspectives about the issues being discussed.[32] However, if after interview of 20 respondents per category saturation level has not been reached, and more information in emerging from respondents in that category, the number of respondents may be extended depending on time and cost. However, in all categories of interviewees saturation was reached before the 20th respondent (18 respondents for HIV clients, and 12 respondents for the healthcare providers).

Conduct of interviews

Interviews were undertaken over three month's period with recruited and trained researchers, under supervision and guidance of the principal investigator. The interviews took place in quiet rooms in secondary schools near the study sites. No other person was allowed into the room or within its vicinity while interview was been conducted, and the respondents had the confidentiality and anonymity plans of the study explained to them. They were enlightened on the usefulness of correct information to the study findings and subsequent policies and interventions. These, together with observational component of the study, encouraged honest and reliable answers, and reduced biases that may arise from in-accurate or gauged responses.[33-35]

Qualitative Data analysis

The recorded interviews and FGDs were transcribed verbatim and analysed by the investigator and one external assistant who has not been involved with design of the study or collection of data. The involvement of the principal investigator (who was familiar with data collection) and an external assistant (who was not) provided a broader review and analysis of the qualitative data. Data analysis was conducted as the interviews and FGDs were taking place, this also helped to adapt the interviews and FGDs to explore unexpected themes or modify inquiries. The qualitative data was analysed by thematic analysis,[36] which involved: *Familiarisation:* this involved carefully studying as many times as required the collected data, summarizing findings and highlighting recurring issues; *Thematic framework indexing:* in this step a system was developed for coding this data; *Indexing:* list of categories to be used in the analysis were developed here. This was done by two researchers, and when there was inconsistency in coding, they were asked to review the materials and recode; *Charting:* this

involved re-arrangement of data into appropriate thematic references in charts, and entailed cutting and pasting the data to in to appropriate areas. *Mapping and interpretation:* involved scanning the charts and notes made during the development of the thematic framework and identifying and noting patterns.

Results

Used of facial coverings by female patients was found to be prevalent: For example a senior health policy maker in the state said *"… I have noticed women using Burqah at the HIV clinics; the usage is more than what it is in other units of the hospitals. Fear of stigma seems to affect many patients and they can use it for identity hiding." That may also be associated with using different names, obviously to complete the disguise!".* An in depth interview respondent said "… *I know a patient who uses a facial covering Burqah to hide damage to her eyes and face by herpes zoster which is associated with HIV. She said she uses it both in the clinic and while away, and confess that the use is not to conceal identity, but to conceal the damage caused by herpes zoster to her face and eyes". A health care worker in one of the clinics stated "in the height of heat, I asked do they need the Burqah in my office?, and they just laughed in knowing manner, as if to say, and indeed a few even said, "but you know why this is here!!, and when you come to our home, you know we don't use it*".

A HIV social worker in the State said *" I have seen four kinds of Burqah usage in the past 3 years: some start, and if you are able to identify that and ask why, they will say that the last time they came they couldn't stay as there were people from their locality. Some stopped after starting, but I only know a few of these, and most of those who use it, I believe are constant with it. I know a patient who only removes her Burqah covering when she is in this office, but remained covered in all other units of the clinic"*

Sourcing of drugs from distant and private sources was also prevalent: a patient said *" I have known a patient, who may actually have been infected by contaminated blood transfusion, but who opted to buy and take expensive antiretroviral at home without monitoring, rather than use the free clinic services and treatment".* A senior health care manager in Kano stated *"..Since the inception of large scale HIV services in our hospital, there has been an observed upsurge in patient giving addresses that are from distant states that also have their own several HIV clinics. Mostly, attempts to get these patients referred to their most proximal treatment facilities have failed, as they insist on remaining at our facilities, often giving no reason, or been explicit about the perceived lower chance of been unidentified far from home"*

Use of false names was also found to be relatively prevalent, A HIV physician stated *"..patient who has taken long to respond to the call of his "name" or with unlikely names in Nigeria, like the one I always cite -Pamela Anderson!- sometimes confess about their true names. Sometimes patients who develop conditions substantially beyond what the national HIV treatment service provides for free, ask for change to what is actually their real name because they need medical report in their true names to seek for assistance from their workplace or Local Government Councils."* While aliases are strongly discouraged at the HIV clinics in Kano, it is important to note that this is an allowed option for anonymity in Sexual Health Clinics in the United Kingdom.[37]

Proxy patients are also commons, a healthcare worker said *" I just never accept any health worker intending to collect drugs for anybody on any ground, though such demands are common occurrences".* A nurse officer said *"... a chauffeur coming on Monday to say that his Oga (boss) cannot come even though he has a bad cough and some diarrhea is clearly not what we can accept. When asked why isn't his boss here, he will eventually confess that the Oga doesn't like coming to the clinic on a busy day like Monday when people have hoarded weekend ailments and will likely be exposed to larger number of people"*

A HIV Clinician said, *"What nurses told you sometimes can possibly even be worse because the one coming may not say he is representing somebody; but may just act as if he is the patient. And in the event that there is no picture to verify identity, you only come to suspect when he stammers, hesitates and contradict himself on further questioning about the symptoms. This may explain the discrepancy we sometimes encounter sometimes between patient's symptoms and signs"*

A passive observation at the clinic while conducting these interviews yielded some quantitative measurement. A spot observation on four consecutive days at a HIV clinic and an Ante-natal clinic yielded an interesting finding:

In the Antenatal clinic only two patients of the estimated 435 patients who attended the clinic on the four days (0.46%) were wearing Burqah. Conversely, in the HIV Clinic 18 out of the estimated 216 female patients who attended the clinic in the four days period where wearing Burqah, representing 8.33%. This difference is statically significant ($p= 0.0034$). It cannot be said with certainty that this is wholly due to fear of stigma, because it is possible that patients with life threatening illness in a highly religious society like Kano, may have heightened religiosity.

Discussion

It is known that HIV stigma can manifest in distinct ways, which is context and content and specific. This study in Kano found several novel ways HIV related stigma manifests in among patients attending treatment clinics and for which, to our best of knowledge, there are no earlier reports.

The use of facial covering is a prevalent manifestation of stigma among HIV patients in Kano State. The covering can be either to hide identity or covering disfiguring facial rashes like those that can occur from herpes zoster associated with HIV. The use of the facial covering seem to be a manifestation of *anticipated stigma*[9] were patients fear that revealing their identity may lead to stigmatization among those who know them. The use however seem to fluctuate with some patients starting and stopping as they develop more self-confidence, and some other patients influenced to start by their peers at the clinic, or when they know of the existence in the clinic of healthcare workers or other patients who know them from home or work.

Travelling long distances to access care, or use of expensive private care services has huge physical and/or financial strain on many HIV patients who may not be affluent or who may have worsened economic circumstances due to their ill-health. This is even more worrisome as attempts to get these patients referred to their nearest treatment facilities have failed, as they insist on remaining at our facilities, often giving no reason, or been explicit about the perceived lower chance of been unidentified far from home.

Use of false name to cover identity may seem innocuous; however this is also likely going to associate with use of false address that can hamper home care which is part of the package of HIV care in most facilities. Problems arise too when patients request for medical reports in their real names to their employers, which are then hard to provide in names other than those on their hospital records.

A proxy patient who comes in to act in place of stigma shy patient, or a messenger sent by a patient to connive with healthcare workers to collect his drugs has great negative implication on the quality of care the actual patient will receive. This would relate to quality of history of symptoms and misleading clinical signs when clinicians do physical examination.

The lower prevalence of facial covering at the antenatal clinic (0.46%) compared to the 8.33% prevalence among female clients in the antenatal clinic over four consecutive days of passive observation is equally instructive. It cannot be said with certainty that this is wholly due to fear of stigma, because it is possible that patients with life threatening illness in a highly religious society like Kano, may have heightened religiosity.

Conclusions

These findings from the above interviews and the passive observation, lend credence to the fact that HIV-related stigma is a big reality in Kano state, and has some context specific novel manifestations and coping mechanisms.

Follow-up quantitative and intervention studies are recommended. Follow-up comparative studies are required between private and public clinics to assess the mechanisms by which some private clinics are able to offer services that cater for confidentiality needs of customers' clients.

Conflict of Interest: None

Funding: None

References

1. Joint United Nations Program on HIV/AIDS (UNAIDS). The impact of Voluntary Counseling and Testing: A global review of the benefits and challenges. Geneva 2001. Available at http://data.unaids.org/Publications/IRC-pub02/jc580-vct_en.pdf. [accessed 17th November, 2015]
2. Online Dictionary. Definition of "stigma" Available at http://dictionary.reference.com/browse/stigma, [Accessed April 2, 2010].
3. Gilmore N,Somerville MA. "Stigmatization, scapegoating and discrimination in sexually transmitted diseases: overcoming „them? and „us?,". Soc Sci Med 1994; 39:1339–1358.
4. Shillington, K (Editor). Encyclopaedia of African History. Volume 1, 1st ed. Routledge; 2004, p. 737.
5. Lovejoy, P. Transformations in Slavery: A History of Slavery in Africa. Cambridge UK, Cambridge University Press; p.195.
6. Federal Ministry of Health. 2007 National HIV/AIDS and Reproductive Health Survey (NARHS plus 2007). Abuja, 2008.
7. Goffman E. Stigma: Notes on the Management of Spoiled Identity. New York, Simon & Shuster Inc; 1963. p. 3
8. Parker R, Aggleton P. HIV and AIDS related stigma and discrimination: a conceptual Framework and implications for action. Social Sci Med 2003; 57: 13-24.
9. Why should we care about HIV stigma and discrimination in the gay community? Available at http://www.hivstigma.com/hivstigma.php [Accessed April 5, 2013]
10. Minnessota Health Department. AIDS. Available at http://www.health.state.mn.us/divs/idepc/diseases/hiv/worldaidsday/index.html [accessed August 5, 2012]
11. Kano state Ministry of Health. Report on Kano state HIV/AIDS Epidemiology, Response and Policy Synthesis, December 2009. Kano.
12. Family Health International (FHI). Kano State, Nigeria Report of Rapid Assessment In Selected LGAs, December 2000. Abuja
13. Kano state: Background Information. Available at www.kanoonline.com [accessed 23 May, 2015].
14. Montana LS, Mishra V, Hong R. Comparison of HIV prevalence estimates from antenatal care surveillance and population-based surveys in sub-Saharan Africa. Sex Transm Infect 2008;84: pp. 78-84
15. Mbonu NC, Van den Borne B, De Vries NK. Stigma of People with HIV/AIDS in Sub-Saharan Africa: A Literature Review, Journal of Tropical Medicine 2009; doi:10.1155/2009/145891. Pp.1-14
16. Dlamini PS, Kohi TW, Uys LR, et al. Verbal and physical abuse and neglect as manifestations of HIV/AIDS stigma

in five African countries. Public Health Nurs. 2007;24(5):389-99.

17. Simbayi LC, Kalichman S, Strebel A, Cloete A, Henda N, Mqeketo A. Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. Soc Sci Med 2007; 64; 1823–1831.
18. Stutterheim SE, Bos AER, Schaalma P.HIV-Related Stigma in the Netherlands. 2008, ISBN: 978-90-808752-5-8, PrintPartners Ips, Enschede,Netherlands
19. Bos AER, Kok, G, Dijker AJ. Public reactions to people with HIV/AIDS in the Netherlands. AIDS Educ Prev, 2001; 13: 219-228.
20. Adeyemo DA, Oyinloye AA. Predispositional 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: 279-292.
21. Dakas CJD. HIV/AIDS and workplace discrimination in Nigeria: Prejudice, Stigmatization and legal Shenanigans. Available at http://www.ialsnet.org/meetings/labour/papers/Dakas-Nigeria.pdf [Accessed 5th August 2010].
22. Tarwireyi F. Stigma and discrimination: coping behaviours of people living with HIV and AIDS in an urban community of Mabvuku and Tafara, Harare, Zimbabwe. Cent Afr J Med. 2005;51:71-6.
23. Moneyham L, Hennessy M, Sowell R, Demi A, Seals B, Mizuno Y. The effectiveness of coping strategies used by HIV-seropositive women. Res Nurs Health. 1998;21: 351-62.
24. Strebela A, Cloetea A, Hendaa N, Mqeketoa A. Stigma and discrimination experiences of HIV-positive men who have sex with men in Cape Town, South Africa. Soc Sci Med 2007; 64: 1823-1831
25. Wingood GM, Diclemente RJ, Mikhail I, et al. HIV discrimination and the health of women living with HIV. Women Health. 2007;46: 99-112.
26. Chirwa ML, Greeff M, Kohi TW, et al. HIV Stigma and Nurse Job Satisfaction in Five African Countries. J Assoc Nurses AIDS Care 2009; 20: 14-21.
27. Habib AG, Abdulmumini M, Dalhat MM, Hamza M, Iliyasu G. Anti-retroviral therapy among HIV infected travelers to Hajj pilgrimage. J Travel Med. 2010 ;17: 176-81.
28. Carlisle, C. “HIV and AIDS” in: Mason, T; Carlisle, C; Watkins, C. (eds) Stigma and social exclusion in healthcare, London, Routledge 2001:pp. 117-126.
29. Federal Ministry of Health (Nigeria), (2003) National HIV/AIDS and Reproductive Health Survey (NARHS), 2003, Abuja, Nigeria, FMOH).
30. Jean-Baptiste R. HIV/AIDS-related stigma, fear, and discriminatory practices among healthcare providers in Rwanda. USAID Quality Assurance Project, 2008.
31. Mahendra VS, Gilborn L, Bharat S, et al. Understanding and measuring AIDS-related stigma in health care settings: A developing country perspective, Journal of Social Aspects of HIV/AIDS 2007; 4(2). Pp-2-4
32. Bernard, H. Research Methodology in Anthropology: Qualitative and Quantitative Approaches, 2nd Edition. 1995, Walnut Creek: Altamira Press. Pp-40-46
33. Johnson M, Webb C. Rediscovering unpopular patients: the concept of social judgement. J Adv Nurs 1995; 21 (3): 466-475
34. Family Health International (FHI). Qualitative Research Methods: A Data Collector's Field Guide Module 2: Participant Observation. https://www.fhi360.org/sites/default/files/media/documents/Qualitative%20Research%20Methods%20-%20A%20Data%20Collector's%20Field%20Guide.pdf [Accessed 2nd May, 2010]
35. Campbell JP, Maxey VA, Watson WA. Hawthorne Effect: Implications for Pre-hospital Research. Ann Emerg Med 1995; 26 (5); 590-594.
36. Green J, Thorogood N. Qualitative methods for health research., London: SAGE publishers 2005. Pp 102-105
37. NHS. Sexual health clinics information: what happens? http://www.cks.nhs.uk/patient_information_leaflet/sexual_health_clinics#-464763 [Accessed August 10, 2013]