

Cultural Perceptions of HIV, Stigma and Discrimination in Plateau State, Nigeria 2012-2013

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Abstract

The study investigated the cultural perceptions of HIV, stigma and discrimination, which have been recognised as hampering HIV prevention and utilisation of health care services for people infected with the virus. The study was conducted among community members in Plateau State aged 15 years and above, purposively selected from areas of high, medium and low HIV prevalence rates. Focus group discussions and semi structured interviews were used for data collection while qualitative and quantitative data analyses based on content analysis and descriptive statistics were used in analysing the data. It was found that terminologies used in describing HIV had negative and stigmatising connotations that discouraged disclosure and lead to greater risky behaviour. Some community members were reported to have avoided HIV counselling and test (HCT) due to fear and stigma. Perceived increase in prevalence rates were variously blamed on People Living with HIV and AIDS (PLWHA); who were said to resort to risky sex when stigmatised as vendetta; but some were reported to be looking healthy due to anti-retroviral therapies (ARTs) which makes it possible for infected persons to engage in risky sex with them. While all PLWHA reportedly suffered discrimination, young girls and people with lower socio-economic status and the elderly were experienced greater stigma and discrimination. A greater decentralisation of HCT services to the local levels with budgetary provisions are recommended as the way forward. A synergy that target stigma reduction involving the Network of PLWHA, community leaders, people affected by AIDS with the LACAs was recommended to ensure a community driven stigma reduction strategy.

Key words: AIDS, Discrimination, HIV, Prevention, Stigma.

Perceptions culturelles du VIH, stigmatisation et discrimination dans l'État du Plateau, Nigéria 2012-2013

Abstrait

L'étude a examiné les perceptions culturelles du VIH, de la stigmatisation et de la discrimination, qui ont été reconnues comme entravant la prévention du VIH et l'utilisation des services de soins de santé pour les personnes infectées par le virus. L'étude a été menée auprès de membres de la communauté de 15 ans et plus dans l'État du Plateau, choisis délibérément dans des régions où la prévalence du VIH était élevée, moyenne et faible. Des discussions de groupe et des entretiens semi-structurés ont été utilisés pour la collecte de données, tandis que des analyses de données qualitatives et quantitatives basées sur l'analyse de contenu et des

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statistiques descriptives ont été utilisées pour analyser les données. Il a été constaté que les terminologies utilisées pour décrire le VIH avaient des connotations négatives et stigmatisantes qui décourageaient la divulgation et conduisaient à un plus grand comportement à risque. Certains membres de la communauté auraient évité le conseil et le test du VIH, en raison de la peur et de la stigmatisation. L'augmentation perçue des taux de prévalence a été imputée de diverses manières aux personnes vivant avec le VIH et le sida (PVVS); qui auraient eu recours à des rapports sexuels à risque lorsqu'ils étaient stigmatisés sous le nom de vendetta; mais certaines personnes semblaient en bonne santé en raison de traitements antirétroviraux (ART) qui permettent aux personnes infectées d'avoir des relations sexuelles à risque. Bien que toutes les personnes vivant avec le VIH / sida aient été victimes de discrimination, les jeunes filles et les personnes ayant un statut socio-économique inférieur et les personnes âgées ont été victimes de plus grande stigmatisation et de discrimination. Une plus grande décentralisation des services HCT au niveau local avec des provisions budgétaires est recommandée comme voie à suivre. Une synergie ciblant la réduction de la stigmatisation impliquant le réseau de personnes vivant avec le VIH / SIDA, les chefs de communautés, les personnes touchées par le SIDA et les communautés autochtones et locales vulnérables a été recommandée pour assurer une stratégie de réduction de la stigmatisation pilotée par la communauté.

Mots-clés: SIDA, Discrimination, VIH, Prévention, Stigmatisation,

Introduction

The perceived gains of the multi-sectoral responses adopted to prevent and mitigate the impact of HIV and AIDS due to the limitations of biomedical sciences alone have not been satisfactorily realised due to stigma and discrimination against people living with HIV and AIDS (PLWHA). Stigma and discrimination have been referred to as the 'third epidemic' of HIV that has reduced the effectiveness of prevention, treatment, care and support for people living with the virus (Odimegwu, Adedini & Ononokpono, 2013). HIV- related Stigma has been defined as:

The negative beliefs, feelings and attitudes towards people living with HIV, groups associated with people living with HIV (e.g. the families of people living with HIV) and other key populations at higher risk of HIV infection such people who inject drugs, sex workers, men who have sex with men and transgender people (UNAIDS, 2014b, p. 2).

The persistence of HIV-related stigma and discrimination according to a recent UNAIDS report of consultations at regional and country levels from 2010-2013, showed that stigma and discrimination affect prevention efforts (UNAIDS, 2014b). This is partly explained by the fact issues of stigma and discrimination were relegated to the background both in priority and funding of the HIV response, thus its high levels (Mahajan et al., 2008; MacQuarrie, Eckhaus & Nyblade, 2009; Stangl, Lloyd, Brady, Holland & Baral, 2013). Due to the fear of stigma and discrimination, people are unwilling to test for HIV, hide their positive sero-status from their sexual partners and refuse the use of the biomedical services that help in achieving primary and secondary prevention (Stangl et al., 2013, p 2).

About two thirds of people living with HIV in Sub-Saharan Africa are reported live in resource constrained environments that hamper access to quality medical care as well as with social challenges including stigma and discrimination (Dahlui et al, 2015; Mbonu, Borne & De Vries, 2009). Stigma and discrimination have been reported to be especially high in Sub-Saharan Africa, which has a tenth of the world's population but accounts for 70% of global infections, largely transmitted through casual/multiple-partner and heterosexual intercourse (NACA, 2014, p. 12; UNAIDS, 2014a, p. 18; UNAIDS, 2014b; Mbonu, et al., 2009). People with concerns about their health status are afraid to seek information including voluntary

counselling and testing (VCT), as PLWHA are reluctant to use available services and or imbibe safer practices to avoid suspicion and the attendant stigmatising and discriminatory reactions from others (Dahlui et al, 2015, p.4; Bharat 2011). This therefore weakens communities' capacity to protect themselves as people live in denial or are unwilling to disclose their HIV positive status to family members, sexual partners and other community members (UNAIDS, 2014b; Mbonu, et al., 2009). Stigma can be external, when PLWHA experience overt or enacted stigma through discrimination. Internal or perceived stigma, on the other hand is felt or imagined stigma, which results in feelings of guilt, shame and fear of discrimination (Rispel, Cloete, & Metcalf, 2015, Stangl et al., 2013; Mbonu, et al., 2009).

Nigeria has the second burden of HIV in Sub-Saharan Africa and all states in the federation have experienced a generalised epidemic. A study conducted in some selected states among members of the Network of people with HIV and AIDS in Nigeria (NEPHWAN) indicated that experienced and internalised stigma was quite high among its members (NEPHWAN, 2011). Mbonu, et al. (2009) similarly found that fear, misinformation, socially shared ignorance and denial lead to high levels of stigma in Nigeria, particularly among the younger males, as well as among those with low educational status and wealth. A study in Imo and Ogun States in Nigeria conducted by Odimegwu et al. (2013) similarly found some of the stigmatising beliefs about PLWHA, were due to initial media portrayals of fearful images of those at the terminal stages of illness, which evoked fear, leading to isolation and distancing of PLWHA.

Plateau state in Central Nigeria has had more than its fair share of HIV prevalence rates and was categorised for many years in the 'hot zone' of HIV infections. The state's HIV prevalence level has been higher than the National average in all HIV/syphilis sero-sentinel survey (HSS) from 1992 to 2010 except that of 2008 (FMOH 1999, 2006, 2008, 2010 & PLACA 2002, 2008). Despite the seeming decline of State prevalence from 11.0% in 1995/1996 to 7.7% in 2010, the prevalence is still high, considering that Plateau State action committee on AIDS was the first in the country to be changed to an agency i.e., Plateau State Agency on AIDS (PLACA), which had budgetary allocation for its activities including donor grants particularly the World Bank (Best, 2016, p 8). The impact of the epidemic is still felt in the lives of the people. The persistent internal crises that escalated in 2001 followed by the herdsmen attacks and displacements of many communities are all precursors for increased casual sex and risk taking, whether voluntary or involuntary in an environment experiencing high levels of anomie (Best, 2016, pp. 7, 8; Okigbo, McCarraher, Chen & Pack, 2014). Therefore, the cycle of vulnerability due to risky lifestyles will continue to hamper prevention efforts that aim to end the epidemic.

This paper is part of findings of a larger study conducted in Plateau State Nigeria in 2012/2013, which sought to understand the role of gender inequalities in the prevention, management and treatment of HIV in Plateau State, which is a linguistically and culturally diverse state with about 52 linguistic and cultural groups spread in 17 LGAs (Alubo, 2006). This paper utilises some of the data that addressed the objective of prevention of HIV, through investigating the perceptions and attitudes of people to HIV that can be precursors to stigma and discrimination in communities.

Theoretical Framework

The labelling theory shall be employed in explaining the stigma and discrimination experienced by PLWHA. According to Goffman (1963) when a person is adjudged to have attributes that are different from what is obtainable in the society, they suffer from a discredited identity due to societal reaction to their perceived difference; thus their real identity is replaced by the virtual one, a 'spoiled identity' that is different. Societal reaction to the perceived difference, which produces stigma, can lead to discriminatory attitudes towards the person with a spoiled

identity. He identified three forms of stigma: that arising from physical defects or bodily differences from what is obtainable, defects in character or behaviour that leads to stigma, as well as those differentiations against large groups: racial, ethnic, which are inherited (Goffman, 1963; Mahajan et al., 2008; Stangl et al., 2013 p. 1,2). Goffman's three categorisations apply to PLWHA and have been basis for stigma. Link and Phelehan (as cited in Stangl et al., 2013) posited that negative stereotypes are attributed to people who are labelled, differentiating and separating 'them' from 'us', results in the status loss of people so labelled. Gilmore and Somerville (as cited in Mbonu, et al., 2009, p 3) identified the four processes of stigmatisation and labelling: first, there must be a problem, which is considered a discredited attribute that distinguishes and labels people, secondly, the identification of a group to be so labelled, who have recognisable attributes; thirdly, the stigma is applied and finally, the outcome of stigma.

Mbonu, et al. (2009, p 3) apply these four processes and first identified the problem as HIV and AIDS, which has been identified as the third epidemic affecting prevention. Secondly, the group has been distinguished and the label of people living with HIV and AIDS (PLWHA) and similar acronyms such as most at risk populations (MARPs), are employed in the HIV response actually differentiates them from the general population. In awareness creation, information about routes of transmission, particularly casual, multiple partner and unprotected sexual intercourse as well as the symptoms of HIV infection, which are disseminated to encourage use of biomedical interventions and to help in prevention, have the latent effect of communities using the distinguishable attributes such as weight loss and rashes to differentiate infected people that are labelled PLWHA. The stigma is then applied and infected people can be seen as immoral and attributed negative stereotypes. Finally, infected people experience the outcome of stigma in distancing, isolation, where the stigmatised are disempowered by the stigmatisers who determine the nature of relationships with the people so labelled and stigmatised, creating inequalities in communities.

Goffman's identification of bodily defects, character defects as well as differentiation of large groups for stigma all apply to the situation of PLWHA. The changes in the physical health and appearance due to infection; the attribution of HIV to unacceptable sexual behaviours that question the moral integrity of those infected, particularly in Sub Saharan Africa, as well as the large numbers of people from across different social strata, given the label of PLWHA, who are seen as different from the 'normals' explain the stigma, which leads to denial, fear, distancing, isolation, non-adherence to treatment and positive living.

Methodology

The cross sectional methodology was employed in gathering the data for this study in 2012/2013. The research population consisted of youth and adults in Plateau state from the ages of 15 and above years old, as surveys have shown that the route of HIV infections for most people in this category in Sub Saharan Africa is heterosexual intercourse (Nasidi & Harry, 2006 p. 20). Young people have been known to be sexually active even before the age of 15, especially in cultures where girl children are considered ready for marriage upon the onset of menstruation. The study adopted the findings of a State-wide prevalence survey conducted in 2008 by the state's agency (PLACA, 2008 p. 52) that categorised the state into LGAs of high (4.60% and above), medium (2.6% - 4.50%) and low (0 – 2.50%) prevalence, in selection of the sample. The prevalence rates PLACA reported were captured based on the senatorial zones, which showed that the Southern, Northern and Central zones recorded high, medium and low prevalence respectively. Thus, Shendam, Jos South and Mangu LGAs were purposively selected to represent areas of high, medium and low HIV prevalence as well as Southern, Northern and Central Senatorial zones of the State respectively. However, Jos North was also included in the study, bringing the total sample of local government areas to four. Its selection was based on the fact that part of the State Capital is located there and due to its cosmopolitan

nature, it also has the most heterogeneous populations that needed to be included in the study. Furthermore, an urban community in each selected LGA, (the local government headquarters) and a rural community were purposively selected to reflect a representation of the diverse cultures of the state in each LGA for the study.

Jos North Local Government Area has a total population of 437,217 (220,856 males and 216,361 females). Apata in Jos North was purposively selected as the urban community. There are high, low and middle income populations in formal and informal work in the community, predominantly of the Christian faith. Kunga, a largely low income population, was selected as the rural community in Jos North. The Anaguta are the indigenous population but there are Fulanis settled in the area but declined participation in the study. A few students from the University of Jos who live off-campus are resident in the community due to its proximity to the institution.

Shendam LGA with a total population of 205,119 (101,951 males and 103, 168 females) is in the high prevalence stratum with 12.20%. Shendam town was selected to serve as the urban community. Its major indigenous population are the Goemai but also populated by other Plateau indigenous populations as well as other groups from various parts of the country. The Goemai practice the Christian (mainly Catholic) and Muslim faiths with a significant number of traditional worshippers. It has middle and low income earners engaged in public and private sectors of the economy, particularly commerce. Kalong, a largely homogeneous Goemai community, was selected to represent the rural communities in Shendam. The population are largely low income subsistence farmers.

Jos South, has a total population of 311,392 (154,067 males, 154,325 females) and a medium HIV prevalence (2.62%). Bwandang community in Bukuru, the LGA headquarters, which has a heterogeneous population, was selected as the urban area. Bukuru is a bustling commercial hub and administrative headquarters, with high, medium and low income earners in both the formal and informal sectors of the economy. Majority of the population is Christian with a significant Muslim presence in some parts. Kuru was selected as the rural community. The indigenous population are the Berom and some other ethnic groups live in the community. The people are engaged in subsistence farming but quite a number are employed in the public and private sectors, with middle and low income population.

Mangu LGA represented the stratum of low HIV prevalence with a 1.33% and a total population of 300,520 (148,590 males, 151,930 females). The Mwaghavul are the major ethnic group in the Local Government among other ethnic nationalities. Mangu town is the administrative headquarters as well as commercial hub of the LGA. Fridays are the main market days and attracts many traders from various parts of the state and country for the purchase of grains, Irish potatoes and vegetables. Gaya Layout in Mangu town was selected purposively selected as the urban site for the study. It is a predominantly Christian area, with a population of people employed in the formal and non-formal sectors (farmers and traders). Chanso, which was selected as the rural site is predominantly a Muslim area and the major ethnic group are Pyem, who communicate in both Pyem and Hausa.

Willing participants were selected for focus group discussion disaggregated by age and gender: male and female youth groups aged 15 – 30 years as well as male and female adults 30 years old and above. Qualitative data was collected through focus group discussions (FGDs) and through semi-structured interviews (SSIs). Four FGDs were conducted in each community among the groups described, making a total of 32 FGDs. Furthermore, SSIs were conducted with community opinion leaders (ward heads, youth/women leaders) and health service providers. The Statistical Package for Social Sciences (SPSS) was used to analyse some of the data quantitatively to generate descriptive statistics. Qualitative data was thematically analysed in the study.

FINDINGS

In all, 339 people participated in the FGDs. There was greater participation of females 207 (61.1%) than the males 132 (38.9%) as more females were available and more willing to participate in the discussions. The disaggregation of participants by age was not significantly different as youth aged 15 – 30 years constituted slightly less than half of the participants, while the female and male adults were slightly more in number 160 (47.2%). 27 of the participants could however not provide their ages. More than two thirds of participants were still in their reproductive and or sexually active ages (179 of 276). Information obtained on marital status showed that (64.9%) were married and more than two thirds (194 out of 268) of the respondents had at least a child with 6% indicating they had 10 or more children. There were more respondents (61.6%) with primary or secondary education thus had lower formal employment 20% and a significant number (35.9) was made up of students and the unemployed. Others were in the informal sector as subsistence farmers, traders or artisans.

Beliefs and Attitudes to HIV and AIDS

What is in a name? This seemingly every day question has consequences for those given a name as well as those who call the names. The terminologies used to describe HIV and AIDS portray people's perceptions, beliefs, attitudes towards HIV as well as those infected or affected by it. This is particularly so that HIV has been around for just three decades and the condition is not part of the traditional/local vocabulary. For the educationally limited, understanding the science about 'viruses' and the course it takes in the human system is not so easy, thus the study investigated how the descriptive terms of HIV in the communities convey the meaning and attitude towards this condition. In all the groups, people knew about HIV and acknowledged that there are people in their communities who are infected by the virus. The participants in the FGDs and SSIs were further asked terminologies that are used in describing HIV in the various communities.

The outcome indicated that different ethnic groups describe HIV as a modern or new illness and most employ the Hausa term for modern things or what is in vogue '*zamani*' along with the term for illness in their languages to describe HIV: The Anaguta call it '*ukono zamani*'/ukono kison, '*roh zamani*''/roh pas' (Berom), *mun zamani* (Mushere), *gok Nasara* (Goemai), meaning white man/foreign illness and '*ciwon zamani*' (Hausa). These names associate HIV with modernity, which was hitherto unknown and alien to the normal illnesses people were used to. Modernity, or modernisation, which has brought growth and in some cases, development, through technological inventions and innovations (depending on the society in question), is in this regard viewed as an unwanted and negative influence since what it introduces is ill health. Other illnesses and conditions, like cancers, liver cirrhosis, sickle cell anaemia etc., which were strange to traditional knowledge, have over time been known and treated by the increasing use of biomedical treatments. However, none has received common labels in communities and stigmatised such as HIV and AIDS. Therefore, when the term 'modern' (*zamani* in Hausa) is employed, no one is in doubt about the reference to HIV. Perhaps it is the scale and devastation of the scourge that explain the usage of such terminologies i.e., its globalised nature and the high number of mortalities and morbidities associated with the condition. More so, the use of the term gives the impression that what is obtainable is alien to the community or society. Thus it places blame on PLWHA for bringing the modern condition into their midst. These are issues directly related to stigma and discrimination, which fuels HIV as infected people deviated from societal norms to introduce a destructive foreign condition.

Closely associated with the modern nature of HIV is the term used to describe its impact: ‘evil’ or ‘wicked’ illness. It is described in Hausa as ‘*mugun ciwo*’, ‘*roh ves*’ – (Berom), some of the attributes of evil is the lack of pity or sympathy to a situation or person(s) and the destructive tendencies therein: This term, therefore aptly describes the devastating impact of HIV particularly when it degenerates to full blown AIDS. A participant describes the hopelessness: ‘It is a *bad disease* that can never be cured but can be cooled down. Scientist are now bringing solution for us to cool this disease but can never be cured’ (FGD, Male Youth, Apata, emphasis added). The recurring hopeless outcome of infections at the terminal stages, particularly in poverty-ridden societies such as obtainable in Plateau State, partly explains this perception. Odimegwu et al. (2013) had reported that fearful documentaries and pictures of people ravaged by HIV and AIDS were circulated in the awareness campaigns that were meant to help in prevention. Such images would have the latent effect of instilling fear, distancing and isolation, once people in the community are known to be infected.

A popular reference to HIV in all communities, particularly among the young people is the description of those infected among them as ‘*sun ci leda bag*’ (i.e. ‘they have ingested plastic bags’ in the Hausa language). Free ranging sheep and goats are known to eat ‘*leda*’ (plastic bags) used to package or convey goods purchased that are discarded indiscriminately, which leads to fatal outcomes. Using the same analogy stereotypes infected people and assumes their agency in infection, by roaming (i.e. casual sexual/social networking) and in the course of such roaming have contracted the incurable HIV.

HIV is also referred to in Hausa as an illness that causes frequent stooling/diarrhoea: ‘*ciwon zawo*’ (Hausa), ‘*gok dias*’ (Goemai). This name is derived from the frequent stooling associated with some infected persons. Frequent and loose stooling is regarded as a health challenge as it also dehydrates people. It is associated more with children particularly when they are teething and considered a normal process that stabilises with some interventions. However, when this occurs in adults, it is not considered normal and thus the frequent stooling is associated with HIV. This association can however be a faulty indicator for establishing sero-status and fuelling stigma and discrimination when people use such observed outward symptoms, which may be due to a problematic digestive system in ‘knowing’ who is infected or not.

Ciwon takwas - the illness of the number ‘eight’, which sounds like “AIDS” is sometimes used in Hausa ‘*takwas*’ to describe HIV in the absence of a more apt term. This popular term number ‘eight’ has further been mystified by the youth who employ simple arithmetic problems that arrive at the answer ‘eight’ to describe HIV such as ‘*7+1*’, ‘*18 – 10*’, ‘*4+4*’ or ‘*10 – 2*’. The use of such coded terms serve youth in their sub-culture as the most affected by the virus but can also affect willingness to disclose sero status and further denial among those infected who would want to avoid such labelling among their peers and the internalised feelings of being stigmatised.

There are other names used to describe HIV, which were mentioned by some of the participants that are not general to all communities but demonstrate divergent individual and ethnic perceptions of HIV. The terms used to describe HIV in different localities provided in table 1 reinforce stereotypes below. All convey negative and hopeless outcomes for PLWHA, except for *kanjemou*, the formal term used to refer to HIV in Hausa. People generally have a healthy fear of death and people die from various conditions. However, the label of HIV as an illness that ultimately leads to death or the grave (due to the high mortalities that have been experienced), decimates community and family populations or those that describe the fearful impact of the illness place HIV in a special category that evokes fear, distancing and discriminating attitudes.

Table 1: Terminologies used to describe HIV

S/No	Ethnic Group	Terminology for HIV	Meaning and Interpretation
i.	Berom	<i>Bogom</i>	Meaning gorilla reference to the source or intensity of HIV (gorillas are big in size, which could imply that the illness has enormous impact on people).
ii.	Berom	<i>Kipyenge</i>	'a small white substance' i.e. sputum from cough, which is sometimes associated with HIV (Berom). The use of this coded term rather than cough in the local dialect conveys the subtle stigma associated with TB as an opportunistic infection, which was largely controlled before the outbreak of HIV in the general community. It can be misconstrued among HIV negative people, who suffer from tuberculosis, as infected with HIV.
iii.	Berom	<i>loh yu</i>	Quiet house - decimation of the family's population through AIDS-related deaths.
iv.	Berom	<i>roh jema beha</i>	Illness contracted from sexual relationships with women, portrayed as vectors of HIV.
v.	English	'Red fliers'	The colour red signifies danger so those who are infected are on the danger list.
vi.	Igbo	<i>obili n'ala-ocha</i>	Sickness that will end you in the grave.
vii.	Igede	<i>Obeja</i>	'Sometin wey somebody eat remain you come carry am' (Pidgin English) i.e. eating or taking someone else's leftover.
viii.	Hausa	<i>ciwon gamagari</i>	An illness that finishes the town (i.e. wipes off the population).
ix.	Hausa	<i>ciwon kanjemou</i>	Formal term used to describe HIV.
x.	Hausa	<i>ciwon manya</i>	The illness of 'big people' – literally can mean the illness of great/influential people who perhaps contract such illnesses due to their power bases and lifestyles. However, satirically it could mean PLWHA are placed in a special category due to the notoriety of the condition.
xi.	Hausa	<i>ciwon wan da zaka dinga ramewa har kamutu</i>	The illness that continues to make one lean till you die.
xii.	Hausa	<i>duhu bisama</i>	Wicked illness, very hot when it gets in the body.
xiii.	Hausa	<i>Karara</i>	A plant that itches badly on contact with the body. Some PLWHA have irritable and itchy skin problems.
xiv.	Hausa	<i>ya taka laka</i>	Meaning the person has stepped on mud. This could signify uncleanness/dirt, or being 'stuck' as vehicles frequently do in mud, with little options. A person with HIV can be seen as someone stuck in a health condition that cannot be salvaged.
xv.	Mushere	<i>mwonton ti bwang</i>	A big/serious illness
xvi.	Mwaghavul	<i>muut dwa dyes</i>	A severe/persistent or debilitating illness
xvii.	Mwaghavul	<i>muut kishirok</i>	Illness that turns one into a skeleton.
xviii.	Mwaghavul	<i>muut shwape</i>	The illness that dries up (causes leanness).
xix.	Hausa and English	'ka hitting'	Could be hitting the target (sarcasm for deviant behaviour) or hitting a brick wall – nowhere to go to – limited options.

Source: FGDs and SSIs with Community members and Opinion Leaders 2012/2013

It is generally recognised that HIV is feminised, particularly in Sub-Saharan Africa and women and young girls' vulnerability and prevalence is higher, therefore they constitute the major subject of the adjectives referring to HIV and PLWHA. None of these terms makes

reference to women's vulnerability and the salient role of men in heterosexual relations in perpetrating their risk but the only gendered term contained in the discussions describe women as vectors of HIV in Berom.

Stigmatising Attitude towards People Infected with HIV

All communities in the study acknowledged that HIV exists in their communities but when opinions were sought on the prevalence, many expressed stigmatising opinions against PLWHA. They expressed misgivings concerning the biomedical interventions that offer palliative care/treatment to PLWHA. The provision of anti-retroviral therapies (ARTs) and drugs for opportunistic infections to PLWHA were said to blur bodily defects/poor physical appearance of PLWHA, which was differentiates infected people from the uninfected as expressed below:

We are in times where people are aware of taking care of themselves and taking medication because unless one who is infected becomes perpetually sick we can't know. Some when they become positive *quickly run and start taking medication and then look normal* (FGD, Female Adult, Bukuru, emphasis added).

A similar view was re-echoed in the same group by another participant. 'Most positive people are fatter than we the normal ones, so one can't be sure' (FGD, Female Adult, Bukuru). Thus the use of ARTs to stabilise PLWHA and improve their wellbeing is not considered a positive development as it disenables physical differentiation and the attendant stigmatisation.

Some of the stigma arising from the availability and use of ARTs is also directed against the female gender, who are blamed for their fine appearances despite their sero-status that attract married men to them: 'Some take the medicine and look finer and you see married men following them. You won't know they have AIDS' (Apata, Jos North, personal communication). A participant from another location restates the same feeling, absolving himself of personal responsibility for staying uninfected: 'Government is the one cheating us. Why would they give drugs? It makes them look more beautiful, (FGD, Male Youth, Kalong).

More stigmatising attitudes were expressed by male participants, some recommended the outright discrimination of PLWHA from receiving health care in the belief that the mortalities will serve as deterrence though others raised objection: 'This injection that is being given is increasing but if you allow them [PLWHA] to go [die], it will scare people (FGD, Adult Males, Kunga). A similar view was re-echoed from another location: 'My advice is they should stop giving ARV because it is the reason why more people are alive and spreading it, but when they stop, the spread will reduce' (FGD, Adult Males, Mangu).

The study also found out that the awareness of stigma generated fear in the general population, affecting the willingness to participate in general population screenings, which were envisaged to help people know their status. A participant recounted peoples reaction in her place of worship to free HCT services: 'There was a test conducted in the church, the people thought it was malaria, when they heard it was AIDS, then they ran away' (FGD, Female Youth Kuru).

Some people were reported to hide their sero status due to feelings of shame as there is a general notion that HIV is contracted in immoral sexual encounters. Such behaviour directly contravenes religious teachings and tenets and increases non-disclosure among PLWHA as described by this participant: 'Missionaries stayed here in the past, so the people with HIV hide themselves because it is a shameful thing' (FGD, Adult Males, Kuru).

Community opinion leaders also admitted that non-disclosure of HIV status was due to fear of stigma. In one of the interviews, it was reported that the sero-status of women in their reproductive years was only established when they do not breastfeed their children to prevent mother to child transmission: 'HIV is something that is prevalent but most people don't want to come out and say it especially when it comes to breast feeding you find out they don't breast

feed because of the HIV.’ (Personal communication, Women Community and Religious Leader, Bukuru, Jos South).

The shame and fear of stigma among some infected people led to the attribution of their infections to malevolent people refusing and denying themselves the benefits of the palliative care offered in hospitals: ‘Denial and fear of stigmatisation has led people to promote spiritual forces and say *‘anyi mashi magani’* i.e. someone poisoned him, someone killed him/her, they will refuse to go to hospital’ (FGD, Female Adults, Shendam).

On the other hand, infected people, particularly youth were reported to resort to vendetta through risky sex in reaction to overt stigma they experienced from community members: ‘Where youth have been diagnosed with the illness and go to collect drugs, some people laugh at them so they seek ways of infecting others’ (FGD, Female Youth Shendam).

The study investigated whether variables such as socio-economic status, age, gender and educational attainments of PLWHA affected their experience of stigma and discrimination in the society. Opinions were divided on whether or not some of these variables determined stigmatisation for PLWHA. There were views that PLWHA experience universal stigma and discrimination once their sero-status is known in the community: ‘It starts from stage 1 and progresses. Those who are positive will be discriminated- it doesn’t matter who it is’ (FGD, Female Youth, Apata).

Those who said that differences exist based on gender posited that women suffer more than men once infected with HIV. They report that such women are mocked in the community. Sometimes, mockery is employed to deter HIV positive women from consenting to relationships with married men who seek out. On the other hand sero-negative women were reported to consent marital relationships with sero-positive men, where the men still enjoy power in the relationship: ‘Women suffer more. Women who are positive are mocked and when men go after them, the news gets to their wives. Women love a lot so they can even marry a positive man. She is also scared of upsetting him (FGD, Female Youth, Chanso). Another participant from Chanso, a predominantly Muslim community that practices polygyny relates the greater stigma and discrimination female PLWHA experience to their lower social status: ‘Women are mostly affected. In general *women mostly suffer discrimination because they are inferior*. For example, if a man takes drugs, he goes on with life’ (FGD, Male Youth, Chanso, emphasis added).

Women were reported to experience greater internalised stigma that could further undermine their health: ‘The women feel it more than the men’; ‘The women may fall sick due to fear and HBP (FGD, Female Youth, Shendam). Another perspective to the discrimination against women, particularly those in their reproductive ages, was attributed to the fact that they undergo routine tests during ante natal clinic (ANC) visits, including screening for HIV, thus making their status known, unlike men who chose whether or not to use HCT services.

Stigma and discrimination based on age was reported to exist. While the youth were reported to have higher prevalence of HIV, they were acknowledged to be more proactive in seeking medical care/treatment and lower stigma and discrimination compared to the elderly: ‘It is the adult that will mostly be discriminated because it is a shameful thing. It is meant for the youth’ (FGD, Male Youth, Chanso). This is re-echoed among the adult group themselves: ‘The elder is most likely to be discriminated’ (FGD, Adult Males, Chanso). The moral bent accorded to positive HIV status consistently relates HIV infection to unacceptable sexual practices, precluding other modes of transmission, which explains the less charitable attitude to adults who are expected to regulate their sexual behaviour more than youth.

The socio-economic status of people living with HIV was reported to influence stigmatising and discriminatory attitudes from other community members as well as in the health outcomes they experience. While those who are poor remain in the communities and suffer stigma, the well-off are able to relocate in order to hide their status and are also better

able to take care of their health as attested to by these discussants: ‘Once they are sick, everyone will know. The rich can leave the place or get better treatment’ (FGD, Female Youth, Shendam). This view reiterated in another location ‘Poor people are mocked more. Rich people will take care of themselves and it won’t show. There are different symptoms’ (FGD, Female Youth, Chanso). Poverty was said to inhibit the capacity of PLWHA to even live healthy lives: ‘The poor must succumb to the smallest infection due to poverty and malnutrition’ (FGD, Female Youth, Shendam).

The educational attainment of people was reported to also affect their quality of care and wellbeing. Non-literates were however reported to have a lower capacity to understand and follow drug regimens. Furthermore, the lower socio-economic status of most people who have not attained any significant education constrains what they have access to eat and the quality of their lives, which affect the nature and outcome of their social interactions as presented in the discussions below:

Educated people control themselves and eat right and live right (clean, neat and hygienic) but uneducated people are very careless- they don’t bother with hygiene or drugs and may not know how to take drugs. Some illiterates don’t know the difference between drugs and may collect different drugs from the prescription (FGD, Female Youth, Chanso).

Discussion of Findings

The study found that generally, PLWHA are stigmatised through name calling and labelling through the common use of terminologies to describe HIV and or PLWHA in the communities. Rispel et al. (2015) similarly found discordant couples in South Africa and Tanzania had varied experiences of gossip, rumours and name-calling about their sero-status. This study further revealed that the labels and names have negative connotations, as descriptions were associated with the negative impact of modernity on traditional ways of living, which places blame on PLWHA for introducing HIV into the communities. This is consistent with the findings of Dahlui et al (2015) from the 2013 National Demographic and Health Survey (NDHS), that PLWHA should be ashamed of introducing HIV to their communities. The terminologies also described the seriousness of the condition and its consequences to infected people and the community. Some of the stigmatising descriptions of HIV found in the study are a result of socially shared ignorance, incorrect knowledge, beliefs and irrational fears about the virus (Dahlui et al, 2015; UNAIDS, 2014b; Mbonu, et al., 2009). Mbonu, et al. (2009) found that stigmatisation of PLWHAs is a result of the symbolic association of HIV with danger, sinful or shameful acts, producing the fears that lead to isolation. This is explained by Goffman (1963), who states that once people are identified with an attribute that is adjudged to be different and undesirable from the norm, they are adjudged to have lost their true identity, which is replaced with a virtual, spoilt identity that is discrediting. According to Link and Phelan (as cited in Mbonu, et al., 2009), discredited people are distinguished and labelled and targeted for stigmatisation. Stangl et al. (2013) identified several fears associated with HIV that are drivers of the epidemic: fear of contacting the virus through interaction, the fear of economic losses or the social breakdown of families and communities, which summarise the inherent fears in the terms used to describe HIV. These fears were found to also reduce the general population’s willingness to undergo HCT even when it is free

The wide or common usage of negative terminologies that are used in communities to describe HIV or PLWHA further produces stereotypes in the structures of communities. According to Mahajan et al., (2008), when stereotypes are employed by large groups such as families, neighbourhoods, villages and communities, relationships of power are created that devalue and discredit PLWHA, while according a superior status to the stigmatisers. The use

of such terminologies in communities is also oblivious of the harmful impact and consequences of stigma on its victims (UNAIDS, 2014b; Stangl et al., 2013; Mahajan et al., 2008). Dahlui et al (2015) similarly posit that isolation reduces the quality of the social life (familial and work-related) of PLWHA due to the consciousness of their status. Thus even in the absence of overt discrimination, there is a consciousness in PLWHA of being devalued (Mbonu, et al., 2009).

PLWHA were also found to live in shame due to the association of HIV with immoral sexual conduct, which puts the moral and religious integrity of PLWHA to question, therefore choosing to hide their sero-status due to the fear of stigma and discrimination. Community members and opinion leaders attest to low disclosure of positive status by PLWHA. Rispel et al. (2015) found in their study of sero-discordant couples in South Africa and Tanzania that disclosure of sero-status did not guarantee acceptance nor were the couples' choice respected and accepted. On the other hand, non-disclosure or denial of sero-status by PLWHA is considered as a survivalist behaviour that is adopted in order to avoid rejection, isolation from communal activities, stigma and discrimination (Mbonu, et al., 2009). The finding that PLWHA attribute their condition to witchcraft is consistent to that of Mbonu, et al. (2009) that infected people sometimes resort to self-diagnosis or attribute their condition to witchcraft, patronising traditional healers in order to reduce the shame. Furthermore, some infected people resort to risky or low quality lifestyles, including refusal to use biomedical interventions for care and treatment (Dahlui et al, 2015; UNAIDS, 2014b; Mbonu, et al., 2009) to appear 'normal' and hide the shame.

The study found that stigma and discrimination are feminised and layered (multiple). HIV positive women and girls are blamed when men seek out relationships with them and face overt discriminations but are more accepting of HIV positive men, whose marital and none marital relations are not opposed. Patriarchal societies are found to discriminate more against women infected with HIV (Rispel et al., 2015). Education, socio-economic status and age were found to affect experiences of stigma and discrimination thus positive women suffered multiple experiences of stigma as PLWHA but also as the poorer and less literate groups, with lower socio-economic status. The elderly were also identified as being stigmatised for indulging in immoral behaviour that is incongruent with their ages. Stangl et al. (2013) had found that people experienced intersecting or layered stigma due to their HIV status, gender, profession, migrancy, drug use poverty, marital status, sexual and gender orientation.

The gaps in HIV responses were found in the negative and stigmatising attitudes to PLWHA that decry their improved health with the use of ARTs as masking the physical symptoms of infection. Goffman (1963) postulated that bodily defects are means of differentiation and discrediting people with 'abnormal' bodies. The blame on the blurred distinctions made between 'normal' people and those with a discredited identity were found in group discussions, with some participants placing blame on PLWHA for 'looking fine' or even 'looking fatter than us, the normal ones'. Link and Phelehan (as cited in Stangl et al., 2013), associate negative stereotypes that separate 'us' from 'them' to status loss and discrimination, which was clearly found in the study as people discountenanced other attributes of PLWHA in the socio-economic and political structures and concentrated on HIV status as the major distinction. The study found that extreme views in the male groups recommended the withdrawal of palliative care from PLWHA to restore bodily degradation/morbidities as a means of isolation and distancing as well as to allow HIV-induced deaths to serve as deterrence and improve prevention infringe on the human rights of infected people. This finding is consistent with the study of Dahlui et al, 2015 that young males exhibited greater stigmatising and discriminatory attitudes and the study by NEPHWAN (2011) in Nigeria that their members experience both internal and overt stigma. Such recommendations constitute social judgements, prejudices and stereotypes against PLWHA (UNAID, 2014b).

Another gap in HIV response is community member's preference of a spoiled physical identity as a means of prevention rather than behaviour change and modification in the community. People already infected with the virus are held responsible for the risk-taking of other community members. Moreover, awareness created on different modes of HIV transmission is lost with the focus on casual and multiple partnered heterosexual intercourse, which casts a moral slur on PLWHA irrespective of how they got infected.

Conclusion

The persistence of stigma and discrimination, which were acknowledged to have been relegated in the HIV response need greater attention to achieve the goal of a community owned and driven initiative to in ending the HIV epidemic. This will involve greater community engagement to discourage name-calling and stigmatising terminologies. The local action committees on AIDS (LACAs) in the local government areas need to be changed to agencies, as obtainable at Federal and State levels, with the needed budgetary allocations for HIV activities at the local governments for prevention, treatment and management of HIV, prioritising stigma reduction. The Network of Persons Living with HIV and AIDS (NEPHWAN) and people affected by AIDS should form a key group of stakeholders working with the agencies and community leaders on interventions addressing stigma and discrimination from the respective community perspectives.

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