Original Research Article

‘We don’t want to be noticed collecting Drugs’: the Effects of Stigma and Discrimination on Adherence to Medication amongst People Living with HIV in Tiv Land, North Central Nigeria

Abstract

In spite the identification of stigma as a factor impeding the public utilisation of HIV counselling, testing, and treatment services in Nigeria, gaps still exist in knowledge on the impact of stigma, and discrimination on adherence to medication amongst people living with HIV (PLWH). This study examines the impact of stigma and discrimination on adherence to medication amongst PLWH in Nigeria. A sample of 1,621 respondents was collected using multi-stage and purposive sampling methods. Structured and in-depth interviews were used for data collection. SPSS (version 21) was used for quantitative data analysis. There are 46.3% men and 53.7% women. Generally, their income is low, 70.7% are earning less than N25, 000 (approximately $125 USD) per month. Some of the HIV patients are stigmatised. In reaction, they avoid public places, travel long distances away from their immediate community to collect drugs, to avoid been noticed around the centers. They sometimes miss taking drugs regularly as prescribed, suffer depression and die. Stigma and discrimination impede adherence to medication amongst PLHW in Nigeria. More efforts should be made to create awareness to reduce stigma and discrimination of HIV patients, while augmenting their income to meet up with the challenges of adherence to medication.

Keywords: Stigma; Discrimination; HIV; Adherence to Medication; Nigeria

1.0 Introduction

The view that HIV is ‘incurable and fatal, contagious, a threat to life of others, physically degenerative and disfiguring, and associated with a painful or anaesthetic death’ [1] has elicited stigmatisation and discrimination of people living with HIV in Tiv land, North central Nigeria. Stigma is defined as ‘an attribute that is deeply discrediting’; it is socially constructed through a process that involves stereotyping and labelling which culminates in distinguishing between ‘them and us’ [2]. Within the context of HIV infection and its attendant medical conditions amongst the Tiv people, there are socio- medical constructions of *nguedanzaria man nguedanzaria ga* (those living with HIV and those not living with HIV). HIV possesses all the characteristics of stigmatised medical conditions [3].

Stigma had been and will continue to be one of the factors influencing prevention and treatment of some diseases in the health sector, if adequate measures are not taken to address it. For example, diseases such as leprosy, mental illness and urinary incontinence are not free from stigma [4]. Stigma is also associated with HIV and in Sub-Saharan Africa, it has been reported that people living with HIV are stigmatised [4, 5]. In Nigeria, 3.2 million people are living with HIV and the incidence rate of HIV infection in 2014 was 227,318 [6]. As the knowledge of familiar individuals who have tested positive, and have been placed on drugs filters down to the people in the communities, it creates fear and the tendency to avoid infection and those living with the disease in the minds of those not living with the virus. The resultant effect is that those living with HIV avoid people and public places including health centers where they receive Anti-retroviral Therapy (ART). The focus of this study is on the impact of stigma on adherence to medication amongst PLWH in Tiv land, North central Nigeira. Stigma is a critical factor for the uptake of voluntary counselling services in Nigeria [7], but its impact on adherence to medication remains unclear. Information with regard to the relationship between stigma and adherence to medication would benefit the individuals, and collectively, public health with regard to HIV prevention, treatment and control.

In Sub-Saharan Africa, the negative implications of stigma and discrimination on HIV voluntary counselling and testing have been noted in South Africa [8] and in Nigeria [7]. Russell and his colleagues [1] have reported that antiretroviral therapy has not significantly changed the structural drivers of stigmatisation in Uganda. Other studies in Nigeria, have implicated social isolation, discrimination, stigmatization, and abandonment by partner as some of the reasons why HIV/AIDS seropositive individuals fear to disclose status to partners, relations and the public [9, 10, 11]. It has been observed that even health care workers isolate HIV/AIDS patients from other ones, fuse to admit them in the hospital, wear extra cloves when examining them and charge very high fees for care [10].

It has been argued that uptake of ART can reduce some stigmatising characteristics especially where progression of the disease is reversed, allowing the individual to play his or her social roles 2]. Other studies have reported that ART is capable of reducing internalised and enacted stigma, as observed in Haiti [12] and South Africa, where some of the individuals who recovered due to the utilisation of ART were no longer afraid to disclose their HIV status and also campaigned for access to treatment [13]. Available information indicate that ART is capable of reducing self-stigmatisation amongst PLWH [14, 15, 16, 17, 18].

In spite of the benefits of ART uptake, stigma still persist in sub-Saharan Africa [19, 20, 21]. In some instances where ART has not changed the underlying causes of stigma such as moral discourses that pass judgement on actions perceived to be against societal norms, individuals may continue to anticipate and experience stigma from others [22, 23, 16, 17, 18]. The social conditions in Tiv land, have produced a pattern of stigma that is rooted in the fear of HIV as excruciating terminal disease. Structural poverty and intake of mostly carbohydrate foods have made recovery and good physical appearance for most individuals on ART very slow. Hence, their presence in any gathering, public institutions, or even at home creates a picture of individuals in agony, thereby, enhancing both self and anticipatory stigma from others amongst PLWH. Stigma has impacted negatively on HIV prevention and treatment in Nigeria.

1.1 Social Capacity, Motivation, Stigma and Discrimination

Stigmatisation and discrimination of PLWH in Tiv land are based on the inequality that exist between those whose health, strength and good physical appearance have been degraded by HIV and those who are conceivably normal. The notion is that those who are normal don't want to suffer untold hardship and death, consequent upon being infected with HIV which is an incurable disease. They are motivated by the desire to remain healthy through avoiding PLWH. Further, the patients are isolated, they sit, eat and drink water in personalised seats and plates; uncomplimentary statements are made about them.

Conversely, most of the PHWL lack sound education, good income and other social support that would have developed their social capacity to be resilient. In reaction, they indulge in self and anticipatory stigma by avoiding public places, if possible, they travel long distances away from their immediate community to collect drugs, to avoid been noticed around the centers

2.0 Methods

2.1 Quantitative Methods

A sample of 1,621 (864 women; 757 men) respondents was collected from 2 clinics (Mkar; Aliade) and other 2 locations (Jyovkundan; Udei) using multi-stage and purposive sampling methods. A probability sampling without replacement (raffle draws) was used in selecting Gwer West (urban area) and Guma (rural area) from the homogeneous settlements of Ichongu block; while Gboko (urban area) and Konshisha (rural area) were selected from the Ipusu using the same method. General Hospital, Aliade was then selected from Gwer West, while NKST Hospital, Mkar was selected from Gboko to obtain samples of those living with HIV. The table of random numbers was used in selecting Udei from Guma out of several other rural settlements such as Kaseyor, Yerwata, Ukohor, Umenga, Agasha, Daudu, Uluva, Yogbo etc. Similarly, Jovkyundan was selected from Konshisha out of other rural settlements such as Tse-Agberagba, Gungul, Korinya, Agbeede, Awajir, Tsuwe, Mbaakpur, Achoho, Iber, Akputu etc.

An eight page questionnaire with closed and open ended questions was used for quantitative data collection amongst 805 HIV seropositive clinic attendees and 796 HIV seronegative individuals on background characteristics, motivations for sexual relationships, sero-discordant relationships, risky sexual behaviours, and HIV risk. The target groups were individuals including men and women aged between 18 and 65 years old, who were presumed to be sexually active, in relationship (partners), had tested for HIV prior to the study, and were either HIV positive or negative. The sample excluded those below the age of 18years; those with AIDS and opportunistic infections, pregnant women and those who were mentally ill. .

At the completion of data collection, the responses were coded and entered into Statistical Product and Service Solution (SPSS) version 21 software, which has provision for the Generalised Linear Regression with Cumulative Link, was used for the analysis of quantitative data.

2.2 Qualitative Methods

In this segment of data collection, purposive sampling was used in selecting 20 respondents who participated in in-depth interviews. Five individuals were selected in each location. The interviews were conducted in Tiv language using a guide with questions on structural factors, background characteristics, knowledge and attitude towards HIV, risky sexual behaviours poverty, stigma and discrimination. An audio recorder was used for recording the discussions during the in-depth interviews for the purpose of transcription after the data collection sessions. The data were transcribed and analysed by the researcher following the principles of concurrent transformative strategy (either nested or concurrent triangulation). It ensures that better insight would be obtained from the qualitative data to provide deeper understanding of some findings from the quantitative. The findings from qualitative data provided further insight into the intricacies of sexual behaviours, HIV, stigma and discrimination.

3.0 Results

3.1 Descriptive Statistics on Background Characteristics of Respondents and other variables

They are 46.3% men and 53.7% women. Those between 30 and 34 years are 23.4%, while those between the ages of 25 and 29 years are 21.9%. Approximately 55% are married, 17.9% are either divorced or separated, while the single and those cohabiting are 26.2% and 0.6% respectively. Generally, their income is low, 70.7% are earning less than N25, 000 (approximately $125 USD) per month, and by educational attainment, 7.6% have not obtained formal education, while 11.7% have completed only primary education. The percentage of completion of secondary education seems to be high (47.5%) because all respondents who have completed some form of secondary education (the junior secondary school) are in this category. The respondents who have completed some form of higher education (Diploma, Higher Diploma, First degree, Postgraduate) are 530 (33.1%). One thousand five hundred and four (93.9%) of the respondents know someone living with HIV. The respondents who are seropositive are on drugs at the time of the interviews. And amongst those who are seronegative, 737 (92.6%) either agreed or strongly agreed that they would feel bad if infected with HIV (see Table). Thus indicating that they would do every possible to avoid being infected with HIV. The individuals known to the respondents as living with HIV/AIDS are mostly friends 563 (35.2%), husband or wife 189 (11.8%), and sister 219 (13.7%, see Table 1).

Table 1: Selected Characteristics of Respondents, Attitude to and Knowledge of HIV Patients

Age	Frequency	Percentage
18-19yrs	163	10.2
20-24yrs	293	18.3
25-29yrs	342	21.4
30-34yrs	336	21.0
35-39yrs	120	7.5
40-44yrs	136	8.5
45-49yrs	98	6.1
50-54yrs	67	4.2
55-59yrs	35	2.2
60+	11	0.7
Total	1601	100
Relationship Status		
Married	820	51.2
Single	527	32.9
Widowed	123	7.7
Divorced	59	3.7
Separated	65	4.1
Cohabiting	7	0.4
Total	1601	100
Education		
No formal schooling	122	7.6
Primary	188	11.7
Secondary	761	47.5
Tertiary	530	33.1
Total	1601	100
whether they will feel bad if infected with HIV Response		
Strongly disagree	30	3.8
Disagree	29	3.6
Agree	307	38.6
Strongly agree	430	54.0
Total	796	100
Knowledge of someone living with HIV Knowledge		
Yes	1504	93.9
No	97	6.1
Total	1601	100
Relationship of Respondents with someone living with HIV/AIDS		

Husband/Wife	189	11.8
Brother	176	11.0
Sister	219	13.7
Friend	563	35.2
Parents	38	2.4
Children	27	1.7
Others	292	18.2
Don’t know	97	6.1
Total	1601	100

Note. The source of data is from field survey, 2014

3.2 Qualitative Findings on HIV Variables

Stigmatisation of those living with HIV is still rife, though there is general awareness about the sources of spread of the disease in the study areas. However, sexual intercourse constitutes a major source of infection, therefore HIV positive status is considered as a product of infidelity. Thus, most men who are sero-negative status find it difficult to accept women who are HIV positive. This issue is captured in the statement below:

You see HIV is contracted through sex, so for women who have HIV and their partner don’t have it; it will take the grace of God for the man not to divorce the woman, because it is seen as a product of infidelity (Female; 30 years, Married).

Relations, friends, and neighbours avoid those living with HIV in a surreptitious manner believing that they may want to deliberately infect them:

We avoid people with HIV, we don’t want to talk to them, or eat with them or wash their clothes or sleep with them because we will be infected; but we do this secretly. If they know that you are avoiding them, they will not be happy. Some people are wicked; they will want to infect others, so we are afraid because we don’t know the intention of the person (Female; 23 years; single).

There are those who don’t want to mingle with HIV positive individuals. They avoid drinking water in the same cup or sleep in the same bed with them; just on very rare occasions, they might eat with them:

I don't want to be with those infected, but I go for tests very often so that if I am infected, I will know. I will not sleep in the same bed with an infected person. I will not drink water in the same cup with the person, not even my husband, but I can eat with the person, if the person is my relation (Female; 22 years; married).

Corroborating what others have said, another respondent points out that the treatment melted on PLWH could be likened to one which slaves were subjected to during the slave era. She says

Neighbours discriminate against HIV patients, if you drink water in a cup, they will not use it; they will not eat with you. If you use a sponge for bath, they will not use it. When you are with them, they see you as a different person just like they used to see slaves in the ancient times (Female; 30 years, Married).

Due to stigmatisation, HIV positive individuals are afraid to disclose their status; they avoid public places and drug collection centres, in order not to be seen by relations, friends or neighbours collecting antiretroviral drugs. A female respondent captures the issue in the statement below:

This has made many of the HIV patients to hide their status and avoid centres where they are given drugs, so that they will not be seen collecting drugs (Female; 21 years; single).

In a similar manner, another female respondent points out that those infected with HIV suffer discrimination as if they are cursed, as a result, they refuse to disclose their status, avoid taking drugs and prefer death to life.

How can one get it through eating? I feel those people should be kind to those infected with HIV. It is like a curse. Some people have died because of this. People are afraid to disclose their status because so and so person will see them taking drugs, so they have refused to take drugs and they have died (Female; 24yeras; Separated)

Further, some people discuss those living with HIV. They point fingers at them each time they are passing and avoid the seat where any of the PLWH have sat. Apart from hiding their

HIV status PLWH avoid drug collection centers. These acts are captured in the following words:

Sometimes when they are passing, people discuss them and point fingers are them, and avoid sitting where they have sat. They refuse to eat from the plates used by them. This has made many of the HIV patients hide their status and avoid centres where they are given drugs, so that they will not be seen collecting drugs (Female; 21 years; single).

Some HIV positive individuals who don't want to be seen collecting drugs travel to far collection centers to do so.

Some years *ago, there were no drugs for HIV and so people who got the disease where highly discriminated. But now it is better. However, people are still going to distant centres to collect drugs, so that they will not be seen by their neighbours* (Male; 35 years; married).

As a result of stigmatisation, some individuals living with HIV suffer depression, they isolate themselves and die.

The people that I know who have HIV have their cups for drinking water; some people don't like eating with them, though other people shake hands with them; some of them who have HIV don't like to go to where there are people and even to attend church service. They are depressed. Many of them are dying because of that (Male; 31 years; married).

However, it is the desire of PLWH to be loved and cared for, just like those not living with the disease.

People should stop discriminating those infected with HIV. Apart from giving drugs to them, they should also help them with food; because those infected are afraid of discrimination, people move to very far places like Makurdi and Abuja to collect drugs; the government should help (Female; 24 years; separated).

4.0 Discussion

As indicated elsewhere, the full utilisation of programmes in place for prevention of HIV infection and treatment of PLWH in Nigeria are threatened by stigma and discrimination. While there is information on the negative implications of stigma and discrimination on the uptake of voluntary counselling services in Nigeria [7], the influence of stigma on adherence to medication remains unclear. This study has documented failure to adhere to Anti-retroviral treatment due to stigma and discrimination.

Some of the HIV patients are isolated, they sit, eat and drink water in personalised seats and plates; uncomplimentary statements are made about them. As a result, some of the PLWH are afraid to disclose their HIV sero-positive status and would like to be unnoticed collecting drugs. They travel to Drugs Collection Centers that are far from their place of residence and where their identity may remain hidden. Travelling to far places in search of conducive environment for drugs collection has additional burden in terms of cost. It adds to the overall HIV burden on the individual who is infected and his or her relations. In the face of low income and structural poverty, the individuals would sometimes fail to raise enough funds, to enable them travel to these centers to honour appointment and replenish their exhausted stock of drugs. Consequently, they sometimes miss taking their drugs regularly as prescribed. The inability to adhere strictly to medication would lead to treatment failure and attendant issues.

It is worthy to note that treatment failure may lead to complications and death. Thus stigma and discrimination are capable of increasing treatment failure and death amongst PLWH. This finding underscore the importance of eliminating stigma and discrimination in order to ensure adherence to medication amongst PLWH. If stigma is eradicated, PLWH would disclose their sero-positive status and also feel free to patronise Drugs Centers closer to their place of residence. Relatively, PLWH would need lesser amount of money to access treatment centes to honour appointments, thereby increasing adherence to medication through regular check-up and replenishment of exhausted stock of drugs. The overall benefits would be enhanced mechanism of HIV prevention, treatment and control in the study area.

5.0 Conclusion

Due to stigma and discrimination, some of the PLWH are isolated, they sit, eat and drink water in personalised seats and plates; uncomplimentary statements are made about them. In reaction to stigma and discriminations, some of them avoid public places, if possible, they travel long distances away from their immediate community to collect drugs, to avoid been noticed around the centers. Thus, they sometimes miss taking drugs regularly as prescribed, suffer depression and die. If stigma is eradicated, PLWH would disclose their sero-positive status and also feel free to patronise Drugs Centers closer to their place of residence. Relatively, PLWH would need lesser amount of money to access treatment centes, thereby increasing adherence to medication. The overall benefits would be enhanced mechanism of HIV prevention, treatment and control in the study area.

Competing interest

The authors declares no conflict of interest.

Consent to Publish

Both the consent to participate in the study and for the publication of the findings was obtained from the participants using ACU consent form before data collection activities.

Availability of data and material

The datasets during and /or analysed during the current study are not publicly available due to ethical issues but are from the corresponding author on reasonable

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