

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% 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

25 1.0 Introduction

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

35 Stigma had been and will continue to be one of the factors influencing prevention and
36 treatment of some diseases in the health sector, if adequate measures are not taken to address
37 it. For example, diseases such as leprosy, mental illness and urinary incontinence are not free
38 from stigma [4]. Stigma is also associated with HIV and in Sub-Saharan Africa, it has been
39 reported that people living with HIV are stigmatised [4, 5]. In Nigeria, 3.2 million people are
40 living with HIV and the incidence rate of HIV infection in 2014 was 227,518 [6]. As the
41 knowledge of familiar individuals who have tested positive, and have been placed on drugs
42 filters down to the people in the communities, it creates fear and the tendency to avoid
43 infection and those living with the disease in the minds of those not living with the virus. The
44 resultant effect is that those living with HIV avoid people and public places including health
45 centers where they receive Anti-retroviral Therapy (ART). The focus of this study is on the
46 **impact of stigma on adherence to medication amongst PLWH in Tiv land, North central**
47 **Nigeria.** Stigma is a critical factor for the uptake of voluntary counselling services in Nigeria
48 [7], but its impact on adherence to medication remains unclear. Information with regard to the

49 relationship between stigma and adherence to medication would benefit the individuals, and
50 collectively, public health with regard to HIV prevention, treatment and control.

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

60 It has been argued that uptake of ART can reduce some stigmatising characteristics
61 especially where progression of the disease is reversed, allowing the individual to play his or
62 her social roles [12]. Other studies have reported that ART is capable of reducing
63 internalised and enacted stigma, as observed in Haiti [12] and South Africa, where some of
64 the individuals who recovered due to the utilisation of ART were no longer afraid to disclose
65 their HIV status and also campaigned for access to treatment [13]. Available information
66 indicate that ART is capable of reducing self-stigmatisation amongst PLWH [14, 15, 16, 17,
67 18].

68 In spite of the benefits of ART uptake, stigma still persist in sub-Saharan Africa [19,
69 20, 21]. In some instances where ART has not changed the underlying causes of stigma such
70 as moral discourses that pass judgement on actions perceived to be against societal norms,
71 individuals may continue to anticipate and experience stigma from others [22, 23, 16, 17, 18].
72 The social conditions in Tiv land, have produced a pattern of stigma that is rooted in the fear
73 of HIV as excruciating terminal disease. Structural poverty and intake of mostly carbohydrate

74 foods have made recovery and good physical appearance for most individuals on ART very
75 slow. Hence, their presence in any gathering, public institutions, or even at home creates a
76 picture of individuals in agony, thereby, enhancing both self and anticipatory stigma from
77 others amongst PLWH. Stigma has impacted negatively on HIV prevention and treatment in
78 Nigeria.

79 **1.1 Social Capacity, Motivation, Stigma and Discrimination**

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

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

92 **2.0 Method**

93 **2.1 Quantitative Methods**

94 A sample of 1,621 (864 women; 757 men) respondents was collected from 2 clinics (Mkar;
95 Aliade) and other 2 locations (Jyovkundan; Udei) using multi-stage and purposive sampling
96 methods. A probability sampling without replacement (raffle draws) was used in selecting
97 Gwer West (urban area) and Guma (rural area) from the homogeneous settlements of Ichongu

98 block; while Gboko (urban area) and Konshisha (rural area) were selected from the Ipusu
99 using the same method. General Hospital, Aliade was then selected from Gwer West, while
100 NKST Hospital, Mkar was selected from Gboko to obtain samples of those living with HIV.
101 The table of random numbers was used in selecting Udei from Guma out of several other
102 rural settlements such as Kaseyor, Yerwata, Ukohor, Umenga, Agasha, Daudu, Uluva, Yogbo
103 etc. Similarly, Jovkyundan was selected from Konshisha out of other rural settlements such
104 as Tse-Agberagba, Gungul, Korinya, Agbeede, Awajir, Tsuwe, Mbaakpur, Achoho, Iber,
105 Akputu etc.

106 **An eight page questionnaire with closed and open ended questions** was used for quantitative
107 data collection amongst 805 HIV seropositive clinic attendees and **796 HIV seronegative**
108 **individuals on background characteristics, motivations for sexual relationships, sero-**
109 **discordant relationships, risky sexual behaviours, and HIV risk.** The target groups were
110 individuals including men and women aged between 18 and 65 years old, who were
111 presumed to be sexually active, in relationship (partners), had tested for HIV prior to the
112 study, and were either HIV positive or negative. The sample excluded those below the age of
113 18years; those with AIDS and opportunistic infections, pregnant women and those who were
114 mentally ill. .

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

119 **2.2 Qualitative Method**

120 In this segment of data collection, purposive sampling was used in selecting 20 respondents
121 who participated in in-depth interviews. Five individuals were selected in each location. The

122 interviews were conducted in Tiv language using a guide with questions on structural factors,
123 background characteristics, knowledge and attitude towards HIV, risky sexual behaviours
124 poverty, stigma and discrimination. An audio recorder was used for recording the discussions
125 during the in-depth interviews for the purpose of transcription after the data collection
126 sessions. The data were transcribed and analysed by the researcher following the principles of
127 concurrent transformative strategy (either nested or concurrent triangulation). It ensures that
128 better insight would be obtained from the qualitative data to provide deeper understanding of
129 some findings from the quantitative. The findings from qualitative data provided further
130 insight into the intricacies of sexual behaviours, HIV, stigma and discrimination.

131 3.0 Results

132 3.1 Descriptive Statistics on Background Characteristics of Respondents and other 133 variables

134 They are 46.3% men and 53.7% women. Those between 30 and 34 years are 23.4%, while
135 those between the ages of 25 and 29 years are 21.9%. Approximately 55% are married,
136 17.9% are either divorced or separated, while the single and those cohabiting are 26.2% and
137 0.6% respectively. Generally, their income is low, 70.7% are earning less than N25, 000
138 (approximately \$125 USD) per month, and by educational attainment, 7.6% have not
139 obtained formal education, while 11.7% have completed only primary education. The
140 percentage of completion of secondary education seems to be high (47.5%) because all
141 respondents who have completed some form of secondary education (the junior secondary
142 school) are in this category. The respondents who have completed some form of higher
143 education (Diploma, Higher Diploma, First degree, Postgraduate) are 530 (33.1%). One
144 thousand five hundred and four (93.9%) of the respondents know someone living with HIV.
145 The respondents who are seropositive are on drugs at the time of the interviews. And amongst
146 those who are seronegative, 737 (92.6%) either agreed or strongly agreed that they would

147 bad if infected with HIV (see Table). Thus indicating that they would do every possible to
 148 avoid being infected with HIV. The individuals known to the respondents as living with
 149 HIV/AIDS are mostly friends 563 (35.2%), husband or wife 189 (11.8%), and sister 219
 150 (13.7%, see Table 1).

151  **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
<i>whether they will feel bad if infected with HIV</i> Response		
Strongly disagree	30	3.8
Disagree	29	3.6
Agree	307	38.6
Strongly agree	435	54.0
Total	792	100
<i>Knowledge of someone living with HIV</i> Knowledge		
Yes	1504	93.9
No	97	6.1
Total	1601	100
<i>Relationship of Respondents with someone living with HIV/AIDS</i>		

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

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

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155 **3.2 Qualitative Findings on HIV variables** 

156 Stigmatisation of those living with HIV is still rife, though there is general awareness about

157 the sources of spread of the disease in the study areas. However, sexual intercourse

158 constitutes a major source of infection, therefore HIV positive status is considered as a

159 product of infidelity  Thus, most men who are sero-negative status find it difficult to accept

160 women who are HIV positive. This issue is captured in the statement below:

161 *You see HIV is contracted through sex, so for women who have HIV and their partner don't*

162 *have it; it will take the grace of God for the man not to divorce the woman, because it is seen*

163 *as a product of infidelity* (Female; 30 years, Married).

164 Relations, friends, and neighbours avoid those living with HIV in a surreptitious manner

165 believing that they may want to deliberately infect them:

166 *We avoid people with HIV, we don't want to talk to them, or eat with them or wash their*

167 *clothes or sleep with them because we will be infected; but we do this secretly. If they know*

168 *that you are avoiding them, they will not be happy. Some people are wicked; they will want to*

169 *infect others, so we are afraid because we don't know the intention of the person* (Female; 23

170 years; single).


171 There are those who don't want to mingle with HIV positive individuals. They avoid drinking

172 water in the same cup or sleep in the same bed with them; just on very rare occasions, they


173 might eat with them:

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

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

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

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

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

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

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

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

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

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

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

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

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


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


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

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

224 4.0 Discussion

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

230 treatment due to stigma and discrimination 

231 Some of the HIV patients are isolated, they sit, eat and drink water in personalised seats and
232 plates; uncomplimentary statements are made about them. As a result, some of the PLWH are
233 afraid to disclose their HIV sero-positive status and would like to be unnoticed collecting
234 drugs. They travel to Drugs Collection Centers that are far from their place of residence and
235 where their identity may remain hidden. 

Travelling to far places in search of conducive
236 environment for drugs collection has additional burden in terms of cost. It adds to the overall HIV
237 burden on the individual who is infected and his or her relations. In the face of low income and
238 structural poverty, the individuals would sometimes fail to raise enough funds, to enable them
239 travel to these centers to honour appointment and replenish their exhausted stock of drugs.
240 Consequently, they sometimes miss taking their drugs regularly as prescribed. The inability to
241 adhere strictly to medication would lead to treatment failure and attendant issues.

242 It is worthy to note that treatment failure may lead to complications and death. Thus stigma and
243 discrimination are capable of increasing treatment failure and death amongst PLWH. This finding
244 underscore the importance of eliminating stigma and discrimination in order to ensure adherence
245 to medication amongst PLWH. If stigma is eradicated, PLWH would disclose their sero-positive
246 status and also feel free to patronise Drugs Centers closer to their place of residence. Relatively,
247 PLWH would need lesser amount of money to access treatment centres to honour appointments,
248 thereby increasing adherence to medication through regular check-up and replenishment of

249 exhausted stock of drugs. The overall benefits would be enhanced mechanism of HIV prevention,
250 treatment and control in the study area.

251 **5.0 Conclusion**

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


262 **Competing interest**

263 The authors declares no conflict of interest.

264 **Consent to Publish**

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

267 **Availability of data and material**

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

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