

## Contextual access challenges to the antiretroviral therapy for HIV-infected persons in southeast Nigeria

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### Abstract

Despite national and international supports to increase access to the antiretroviral therapy (ART) for HIV-infected persons, contextual access challenges are evident and have the potential to limit access to ART. The purpose of this study was to investigate the contextual access challenges to ART among HIV-infected persons in southeast Nigeria. Pre-tested interviewer-administered exit questionnaires were carried out with 514 HIV-infected adults receiving treatment in four randomly selected clinics in a state capital in southeast Nigeria. Focus group discussions (FGDs) were conducted in the selected facilities. Data were analyzed using Epi- Info, SPSS, and NVivo 8 software. Most of the clients from the rural area belonged to the poorest socioeconomic quartile and experienced profound geographical and economic barriers. Those in paid employment particularly the civil servants faced a greater access challenges due to long queue at health facility ( $p < 0.01$ ) at 95% Confidence Interval. The local name given to the disease was an obstacle to early treatment uptake. Stigmatization was also a major access challenge at the community level. Besides, the cost of transportation constituted a greater access barrier to those from the rural area. Understanding the different

contextual access challenges to ART may help for a robust planning and delivery of ART with potential increase in early uptake.

**Keywords:** HIV/AIDS; access; contextual challenges; ART, Nigeria

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## **Introduction**

In Nigeria, despite national and international supports to enhance access to ART for HIV-infected persons, contextual access challenges are evident and have continued to limit access to ART. Contextual access challenges are defined as challenges resulting from the immediate physical and social settings in which HIV-infected persons live, work and access healthcare services. These factors are interconnected and may be linked to the political, economic, cultural and social life of an HIV-infected person within the community. For instance, some studies [1-3] have reported the influence of socio-cultural factors on the understanding of illness including local meaning of disease causation, transmission, and treatment. In some contexts, local names given to HIV/AIDS have contributed to heightening the level of stigma suffered by the infected persons [4-5]. Some of those local names connote hopelessness, promiscuity, pity and death, which suggests in the minds of those infected that the disease has no solution [4, 6]. The local names for HIV/AIDS depending on their meanings could affect access to ART uptake.

The length of time spent by HIV clients to access treatments is an important indicator of patient satisfaction [7]. Long waiting times discourage HIV clients from seeking treatment promptly [8-9]. It has the potential to constrain patients' subsequent visits to their providers. If patients are satisfied with shorter waiting times, they may be encouraged to return to the facility, and even recommend it to other clients. Those clients who are in paid employment may face greater challenges in managing working hours with the long waiting times in treatment centres. Studies have shown that workplace stigma and discrimination are common, and these may be potentially difficult for infected persons to disclose their status in their workplaces [1, 10]. Therefore, the feeling of insecurity may limit the liberty to take permission from their employers to access ART.

Transportation is also one of the barriers to access to medication [11-12]. A Lack of transportation could delay access to obtain routine medication, and such a delay may worsen health outcomes [13]. In Nigeria, for instance, distance to HIV clinics to access treatment could be far for some rural communities. Transportation barrier could worst hit this category of clients. The distance to health facilities and cost of transportation have been found to impact on healthcare utilization [14-16]. According to this report, people who had to travel more than ten miles to visit their doctors did so less frequently than those who had to travel shorter distances. As a consequence, a lack of access to affordable transportation could create health disparities and limit access [17].

Importantly, understanding the socio- economic status of individuals accessing health care services is imperative to knowing who benefits from a publicly-funded health care intervention [18]. Poverty has been noted as a factor that can obstruct access to health care for

low-income groups [19]. In the world over, the health status of people in the rural area is worse than those in the urban area [20]. For instance, infant mortality rate in the rural area is found to be 1.6 times higher than in the urban area, and 56% of rural dwellers live more than 5 kilometres away from health facilities [20]. Evidence also shows that there is inequity in HIV treatment services between rural and urban areas [21]. The implication of such rural-urban divide in health status indicates that the rural poor have less access to healthcare compounded by distance and transportation costs. Given the concentration of poverty and poor health status in the rural area, there is the need for a strong support to improve the health of the rural poor [20], by decentralising treatment centres to the rural area.

This study explored contextual factors in the region that pose access challenges to ART. The understanding of these factors may help to identify local obstacles to treatment for HIV-infected persons. Therefore, the study aims to generate context –based evidence on access challenges to ART uptake. The objective of the study was to investigate key contextual access challenges to ART in southeast Nigeria, and the implications for those who need the drug.

## **Methodology**

### **Study setting**

The study took place in Enugu state, southeast Nigeria. The state has an estimated population of 3.2 million [22]. The study was carried out in two public (government owned) and two mission (faith –based) hospitals in the metropolis. The HIV prevalence rate in Enugu Urban was 5.3% based on the 2010 National Sero –prevalence report [23]. The facility records at the selected ART centres showed that facility A had a total of 3,078 registered HIV clients with only 1,541 receiving ART. In facility B, out of the 1,759 registered HIV clients, only 83 were

on ART while in facility C, 885 clients registered with 395 receiving ART. In facility D, 4420 HIV clients were also registered, but only 3000 were placed on ART.

### **Study design and data collection**

This study used both quantitative and qualitative methods. Pre-tested interviewer-administered exit questionnaires were carried out with 514 diagnosed adult HIV-infected persons receiving treatment in four randomly selected ART clinics. The sample size was calculated using a power of 80% and 95% confidence level. This calculation was done using Epi Info version 6.4. Principal components analysis (PCA) was used to generate the socio-economic status (SES) index of the respondents [24-25].

The socio-economic status index examined whether there were logical differences in access to ART by different socio-economic groups. The variables included in the SES index were ownership of key assets such as car, motorcycle, radio, refrigerator, television set, bicycle, and household weekly food expenditures. This method has been used in different studies in Nigeria to generate socio-economic status groups of the study populations [26, 27]. Focus Group Discussions (FGDs) were conducted (one per facility) with HIV-infected persons who were receiving treatment at the selected health facilities. The participants in the FGDs were recruited purposively, and included only the age category of 18 years and above who had been on treatment for at least three months prior to the study. The quantitative data were analysed using the Statistical Package for Social Sciences (SPSS) version 15 and STATA software.

**Data analysis**

All the data from the four study areas were pooled, and variables of interest were cross-tabulated to determine how they posed barriers to access to ART. Where appropriate, Chi-square test was used for tests of significance to determine the level of relationship between cross-tabulated variables. All tests of significance were done based on a p-level of 0.05. The socio-economic status (SES) of the respondents was determined using an asset-based index computed by the Principal Components Analysis in STATA software, and with the help of the information obtained from the household's asset holding such as functional car, radio, television set, refrigerator, and so on including the household weekly food expenditures. Income was not used to create the SES because it was difficult for Nigerians to provide information about their income [27]. The SES index was used to divide the sample into quartiles (Q1 – Q4). The division of the sample into quartile helped to determine whether the differences in the SES have relationships to geographical locations and barriers in accessing ART.

The responses from the FGDs were transcribed verbatim from the local language to English. The transcription was done immediately after the interview to avoid losing the context of the information collected. The axial coding structure was used while the emerging theme/categories were developed by reading the transcripts many times to establish the relationship between the codes/labels and the emerging themes. Two important themes eventually developed. NVivo software (Version 8) was used to analyse the data.

**Ethical Issues**

The principle of informed consent was strictly adhered to, and respondents' identities were kept confidential. The University of Nigeria Teaching Hospital Committee on Medical and Scientific Research Ethics approved the study.

**Results****Table 1: Socio-demographic characteristics of respondents**

<b>Total</b>	<b>514(100)</b>
<b>Sex</b>	<b>N (%)</b>
Male	154 (30)
Female	360 (70)
<b>Total</b>	<b>514 (100)</b>
<b>Age</b>	
28-37	215 (42)
38-47	115 (22)
48-57	82 (16)
58-67	21 (4)
68+	3 (1)
<b>Total</b>	<b>514 (100)</b>
Mean age=37.5	
SD=10.33	
CI=27.13 – 47.79	
<b>Marital Status</b>	
Married	259(54)
Single	122 (24)
Divorced	25(5)
Widowed	81( 16)
Separated	7(1)

**Education**

Primary	128 (25)
Junior Secondary School	44 (9)
Senior Secondary School	191 (37)
College of Education	27 (5)
Uni/Poly	74 (14)
Others	50 (10)
<b>Total</b>	<b>514 (100)</b>

**Occupation**

Civil servant	75 (15)
Private sector	66 (13)
Self Employed	3 (8)
Big Business	17 (3)
Petty-trading	114 (22)
Farming	18 (4)
Unemployed	124 (24)
Others	57 (11)
<b>Total</b>	<b>514 (100)</b>

**Location**

Rural	179 (35)
Urban	335 (65)
<b>Total</b>	<b>514 (100)</b>



Male respondents totalled 154 (30%) while the female respondents constituted 360 (70%) (Table1). Most of the respondents were in the age group 28-37 years (42%) while the age group 68 and above 3 (1%) was the least. The mean age for this study, however, was 37.5 years (SD 10.33). The majority of the respondents 259 (54%) were married while 122 (24%) were single. The divorced were 25 (5%) while the widowed totalled 81 (16%). Most of the respondents were unemployed 124 (24%) followed by petty traders 114 (22%), and Civil servants comprised 75 (15%) of the respondents. Those in big business constituted only 17 (3%) of our respondents. In terms of the geographical location of the respondents, 179 (35%) were from the rural area while 335 (65%) came from the urban area.

**Table 2: Cost of transport and geographical location of respondents**

Location of respondents	N=300	N=214
	Not a barrier (%)	A barrier (%)
Rural	84 (46.9)	95 (53.0)
Urban	216 (64.5)	119 (35.5)

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$X^2$  (p-value) 14.79 (0.000)

Respondents from the rural area who did not perceive transport cost as a barrier numbered 84 (46.9%). On the other hand, those respondents who considered transportation cost as a barrier were 95 (53%). Those respondents from the urban area who did not find transport cost as a barrier totalled 216 (64.5%) whereas those who regarded transportation cost as a barrier numbered 119 (35.5%).

**Table3: Occupational groups and long queue at ART treatment center**

Occupational groups	Not a barrier N (%)	A barrier N (%)
	<b>N= 367</b>	<b>N= 147</b>
Civil servants	45 (60.0)	30 (40)
Other occupational groups	322 (73)	117 (27)

$X^2$  (p -value) 5.9(0.01)

In Table 3, 45 (60%) of the civil servants were of the view that the long queue was not a barrier. Conversely, 30 (40%) of them were of the opinion that it was a barrier. Other occupational groups 322 (73%) felt that the long queue was not a barrier while 117 (27%) of them said that it was a barrier.

**Table 4: Socio-economic status differences (SES) and geographical location of respondents**

SES	Rural	Urban	*P value (0.000)
	<b>N=179</b>	<b>N=335</b>	
Q1 (poorest)	74 (56.9)	56 (43.1)	
Q2 (very poor)	43 (33.6)	85 (66.4)	
Q3 (poor)	36 (27.3)	96 (72.2)	
Q4 (least poor)	26 ( 21.0)	98 (79.0)	

\*P values represent the tests of significance for the difference in proportions between SES and geographical location of respondents. Differences are statistically significant  $p < 0.05$ .

The poorest SES from the rural area totalled 74 (56.9%) and 56 (43.1%) from the urban area respectively. The 'very poor' from the rural area numbered 43 (33.6%) while 85 (66.4%) came from the urban area respectively. The least poor from the rural area constituted 26 (21.0%) while 98 (79.0%) came from the urban area.

### **Qualitative data**

This section presents a summary of the information obtained from the FGDs in the four selected health facilities. We included the FGD as an essential complement to the mixed method used for this study. The inclusion of the FGD was to obtain an in-depth understanding of the contextual challenges to access to ART in the area of study. Our findings show that local name given to HIV/AIDS was a challenge in accessing ART. Besides, discrimination and stigmatization was found to pose a challenge for the infected persons at the community level. The identified themes are described below.

#### **The local name given to HIV/AIDS**

The results show that the name given to HIV/AIDS was one of the leading causes of discrimination and stigmatization. The majority of the respondents held the view that there was a general belief that an HIV- infected person had no hope, but could only wait for the day of his or her death. Helplessly, the infected person would be left to die because the name given to the disease suggests that there was neither a cure nor remedy. The following excerpts expressed the situation.

'It is the local name that brings about discrimination. If a person has the virus in the community, the next thing is when they [the family members] will arrange for the person's burial' (FG.4.4).

'It took me a long time before I started accessing ART because I thought the next thing awaiting me was death. So, I was afraid and concluded that there was no need coming for the drug when I remembered the name. That the only thing was to wait for the day I would die' (FG.3.6).

'The problem is that when the disease was first discovered, it was known as a killer disease. It was called "*Obilin'aja ocha*", which means a disease without cure except the grave. Moreover, once someone heard that it is an HIV, the person will run away. People then felt that it is riskier than any other disease' (FG.4.5).

'Secondly the name given to this disease shows that there is no hope for its victims and that the end of it is in the grave. So nobody will like to associate with somebody whose life would soon end in the grave (cry of a baby). The public may not be blamed because that was the first impression people had of the disease' (FG.2.3).

### **Discrimination and stigmatization at community level are high and constitute access barrier**

It was found that discrimination and stigmatization were still high at the community level, but low at the household level. The majority of the respondents were afraid to let their status known in the community. The rights and privileges of those HIV clients whose status were known in their neighbourhoods were denied them. According to the groups, the infected persons were objects of caricature. However, at the household level, the intensity of discrimination has reduced. They suggested that most families could not avoid their blood relatives because of the disease as illustrated below.

'Discrimination from the community could be a barrier to someone from accessing this drug if the community knows that the person has the virus' (FG.2.4).

'You might be afraid to go for your drugs because the person that lives next to you on the street might see you. So because of the fear of stigmatization in the community if exposed, the person may start missing the drugs to avoid being exposed' (FG.3.1).

'If your community members are aware of your status, you may not have respect again because your respect would be lost in the community' (FG. 3.6).

'Our problem is the community because the family will always hide you. There is no way a brother of the same parents would be telling people about his brother's HIV status' (FG3.7).

## **Discussion**

This study investigated the contextual factors that restrict access to ART in southeast Nigeria. It shows that HIV-infected poorest SES group resided in the rural area and had more difficulties accessing ART due to high transportation cost. Discrimination and stigmatization still constituted access barriers at the community level. Besides, the local name given to HIV/AIDS was viewed as a death sentence that made the infected person to overlook or delay early initiation on ART. The Civil servants had difficulties in accessing ART due to the long queues at treatment centres.

The cost of transportation has been shown to be a notable access barrier for many HIV-infected persons who need ART. The cost of transportation was found statistically significant with a Chi-square test  $p < 0.000$ . Those living in the urban area did not have much problem with transportation cost as those from the rural area [14, 13]. Despite the fact that the cost of treatment was free, many HIV-infected persons who would want to go for treatment were not able to do that due to a lack of transport money [15-16]. It is noteworthy, that free ART programme does not guarantee access to the drugs, and consideration needs to be given to

obstacles to access. Besides, transportation barriers may lead to worse clinical outcomes that could result in emergencies. The use of a subsidy to alleviate the impact of transport cost is important, and could form part of ART programmes. Since effective clinical management requires one hundred percent adherence to the treatment, a compromise due to the cost of transportation could worsen their health conditions.

It was found that long waiting time at the facility was a barrier to some occupational groups particularly the civil servants from accessing ART. Our quantitative data shows a statistical significant Chi-square test  $P < 0.01$  showing a significant relationship between long waiting time and occupational groups. Long waiting time in treatment centres may discourage those in paid employment to be consistent with ART treatment as shown in some studies [8-9]. The HIV-infected worker may be confronted with a choice of absenting himself or herself from the workplace or spend the long working hours at the ART clinic on the day of the hospital appointment. The infected person might not seek permission to access ART during work hour to avoid workplace stigma and discrimination [1, 10]. Instead, he or she may go for the drug secretly. However, the fear of the long waiting time in the ART clinic could be a constraining factor, especially during work hour. This fear may be evident in all workplaces including government institutions. There is the need for a stronger commitment to the implementation of the anti-discriminatory laws at workplaces in Nigeria. The management of the treatment centres also need to make efforts to reduce long waiting time to increase ART uptake by those in different occupational groups. This strategy may increase access for those in paid employment who use work hour to access treatment.

The poorest SES group came from the rural area whereas more of the least poor were resident in the urban area. It is interesting to know that the SES of HIV-infected persons were

positively related to their geographical locations. As the SES groups move from Q1 (poorest) – Q4 (least poor), the number of the least poor SES group was increasing in the urban area while the number of the poor was decreasing. The fact that most of the comprehensive ART facilities are located in the cities gave the least poor HIV clients an advantage over the rural poor. These rural poor may face greater obstacles to access to ART [19]. The inequity in access to ART evident in the geographical locations of the respondents shows that the disparity between the rural and urban dwellers in access to ART remains a concern [21]. There is a need for decentralization of ART clinics in rural settings. The decentralization will assist the poor SES groups to have better access to the drug.

Moreover, the local name given to HIV/AIDS was a major factor for the delays in accessing ART. Our findings indicate that the name *obili n'aja ocha* was initially given to AIDS because it was known to have no cure. The name means that the grave is the end point for HIV/AIDS sufferers. The name exudes grimness and suggests in the mind of the victim, caricature, immorality, promiscuity and damnation. Hence, the sufferers were often seen as hopeless people [4]. Elsewhere in Zimbabwe this disease was given different local names such as *Chiwere* and *chepfambi* connoting a disease of the prostitute [5]. Similarly, in Namibia, local names such as *zeguru*, and *omudimba*, which connote death, are used to describe HIV/AIDS [6]. In Nigeria, the local name for HIV/AIDS was publicized by the media using a human skeleton to depict an HIV/AIDS victim as a warning to people. Those who contracted the disease became afraid and ashamed to present themselves for treatment even when it became apparent that there was a known treatment available. Despite the availability of ART, the same perception seems to trail the public as the local name suggests that the situation is hopeless for the infected person. So, with the availability of free ART, some HIV-infected persons saw it as a deception to ameliorate their psychological trauma.

As a result, many infected persons who were not informed about the efficacy of ART delayed treatment because they thought there was no hope. Therefore, the media has an onerous task to reverse the misinformation about HIV/AIDS and present the disease with a hope - given local name that will be publicized on radio jingles and television adverts. Linguistic experts too may come up with a local translation that conveys hope and recognises the humanity of the infected persons. This approach may increase ART uptake and make early access to the drug possible.

In addition to the local name, discrimination and stigmatization were found to be high at the community level [8-9, 5]. The impact, however, is the loss of Brotherhood and familial social nexus at the community level. Of course, the clients may feel more protected at the family level than at the community level because of blood affinity. The client, therefore, might be afraid to make his or her status known to remain relevant in terms of participation in community programmes and activities. The social relationship between the infected person and the community may be affected, thus, posing a challenge for those who are infected to open up and seek treatment early. HIV/AIDS awareness programmes could be carried out in communities with the involvement of the stakeholders and significant others.

Therefore, future studies could explore other access challenges to ART to generate the evidence needed for an action. This study has a limitation. It was not easy to identify directly those HIV-infected persons who may have stopped accessing ART due to contextual challenges. However, we relied on the information gathered from clients who came to obtain their routine treatment.



## Conclusion

Access to ART drugs is determined by many factors that are inherent in the social environment where the HIV-infected persons live and work. Those local access challenges have the potential to limit access to the drugs, and also restrict the possibility of achieving the Millennium Development Goal 6. Understanding the context-specific challenges may help for a robust HIV/AIDS management and planning, and could increase ART uptake. Access to ART by all that require it may remain a figment of the imagination if the contextual access challenges are not investigated and tackled.

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