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To cite this article: Elochukwu Ernest Uzim & Po-Han Lee (2023): Lost to follow up: the (non)psychosocial barriers to HIV/AIDS care in southeast Nigeria, *AIDS Care*, DOI: [10.1080/09540121.2023.2253507](https://doi.org/10.1080/09540121.2023.2253507)

To link to this article: <https://doi.org/10.1080/09540121.2023.2253507>



Published online: 04 Sep 2023.



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Lost to follow up: the (non)psychosocial barriers to HIV/AIDS care in southeast Nigeria

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ABSTRACT

Medication withdrawal remains a problem in Nigeria's HIV care. The Enugu state of southeast Nigeria has 3,736 people living with HIV/AIDS (PLHIV), with a 1.9% HIV-positive prevalence rate among the age band of 15–49 years, higher than 1.3%, the national average for the same cohort. Despite the disease burden, many cases are “lost to follow-up” in this region. Through four focus groups of patients (20 participants in total) and in-depth interviews with four clinicians from four public hospitals, this study aimed to understand the barriers to attending healthcare appointments faced by young adults. The participants were recruited through flyers, posters, and snowballs at clinics; both data sets were first analysed separately yet used to triangulate each other. We found that clinical interruptions are mainly attributable to factors such as stigma, suicidal ideation, loss of means of livelihood due to PLHIV's “new identities”, and thus poverty and malnutrition. These barriers, complicated by the COVID-19 pandemic and armed conflicts in the region, have made medication adherence further challenging. Therefore, we recommend the Nigerian government integrate non-biomedical support for PLHIV into people-centred HIV care.

ARTICLE HISTORY

Received 21 January 2023
Accepted 25 August 2023

KEYWORDS

Antiretroviral therapy; medication adherence; Nigeria; people living with HIV/AIDS; psychosocial health; stigma

Introduction

At the 6th National Council on AIDS, held on 19 May 2022, Dr Morenike Alex-Okoh, then Nigeria's Director of Public Health at the Federal Ministry of Health, stated that Nigeria was making significant efforts towards achieving HIV epidemic control. However, substantial challenges regarding what he characterised as “the last mile push” still need to be addressed. The Nigeria HIV/AIDS Indicator and Impact Survey (NAIIS) conducted in 2018 revealed that Nigeria still faces a significant HIV burden – approximately 1.9 million people live with the virus. Among this population, young adults aged 15–49 years account for a prevalence rate of 1.3% (FoMH & NACA, 2018).

So, what should the “last-mile push” entail? Although Nigeria is considered “on track” to achieve viral load suppression for all people living with HIV/AIDS (PLHIV) in the country by 2030 (UNAIDS, 2021), psychosocial resource at all levels regarding HIV care and support is scarce; this has pushed people away from the life-saving antiretroviral therapy (ART). The treatment procedure involves pre-testing counselling for all walk-ins to ART centres, followed by linking all newly identified seropositive clients into a “Retention and Audit Determination Tool” database through which their residences, clinical appointments, drug refills, viral load statuses and so on are tracked.

Evidence from these ART service providers showed compelling arguments for cases lost to follow-up (LTFU), which usually began as a missed appointment (i.e., skipping medication refills) (PEPFAR, 2019). Hence, increasing appointment attritions is related to factors such as stigma, depression, and loss of means of livelihood due to their “new identities” (Lightfoot et al., 2005). Thus, we hypothesised that poor psychosocial health support further contributes to such risk factors that prevent young PLHIV from adhering to life-saving medication. Against this background, the study was initiated and designed to understand the reasons for the trend of such discontinuity from care by exploring the mental health and other challenges facing young adults living with HIV/AIDS.

Therefore, this study aimed to investigate the psychosocial and non-psychosocial barriers faced by young adults living with HIV/AIDS in Nigeria, focusing on clinical withdrawal, adherence and return. It gathered insights and understanding through a qualitative approach, engaging patients and clinicians to explore their experiences and perceptions concerning clinical interruptions. Our qualitative research targets the intersection between mental health and HIV seropositive status among young adults in southern Nigeria aged 20–30 years to understand how unmet mental health needs

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have become a barrier to medication and other health services. Qualitative research methods have proven helpful for studying medication and treatment adherence, especially when patients desire to have their concerns heard – including better communication from service providers and more trust in patient-provider relationships (Atanuriba et al., 2021; Kvarnström et al., 2021; Mukumbang et al., 2018).

Materials and methods

Our research was conducted in Enugu, one of the five states (besides Abia, Anambra, Ebonyi and Imo) comprising the southeast geopolitical region. With an estimated 3.2 million people within the state, out of which 197,000 are aged 15–49 years, Enugu state houses 3,736 PLHIV, accounting for 1.9% of the state's population (1.2% for men, 2.4% for women) among the similar age band of 15–49 years in the state (FMoH, 2018), which is higher than 1.3%, the national average for the same age band (see Figure 1).¹ Following from this, public health institutions in Enugu, including two high-volume tertiary hospitals such as the University of Nigeria Teaching Hospital (UNTH) and the Enugu State University Teaching Hospital (ESUTH), have been strengthened with ART provision. Such capacity aims to cater to the needs of these seropositive populations and other seropositive visitors who are referred from facilities outside the state.

To better understand the biomedical interventions in HIV care, researchers studying other societies have identified that qualitative research is a pivotal accompaniment to a richer socio-behavioural understanding of HIV patients (Syed et al., 2015; Tucker et al., 2017; Wilson et al., 2016). In ours, informed by the nature of studying the psychosocial effects of stigma and social isolation on young PLHIV, we conducted focus group interviews with young PLHIV and individual in-depth interviews with their clinicians for narrative data on lived experiences as PLHIV and perspectives on care delivery in Nigeria. Attending to the complexity of the psychosocial context of the “hard decisions” to receive/resist care (Edwards, 2006; Fields et al., 2017), we consciously avoided the influence of perceived hostility against the patients (Stutterheim & Ratcliffe, 2021), which may include condescending or judgmental reactions or not being given enough time and space to discuss their health concerns (e.g., interrupting and distracting remarks).

This study was carried out at four public health facilities, including the Udi General Hospital (UGH) and Enugu Ezike General Hospital (EEGH), in addition to UNTH and ESUTH mentioned earlier; the participants

were recruited through a poster, with the assistance of health professionals (convenience) and through word of mouth between patients (snowball). We selected these public hospitals because they share two critical features necessary for the study. First, they are classified as high-volume sites (number currently on ART (TX_CURR) > 200). Secondly, the two tertiary institutions are accessed mainly by urban dwellers, while UGH and EEGH are predominantly rural; thus, a balanced urban/rural representation. The study was pursued when the ethics approvals were granted: first, by the Enugu State Ministry of Health on 29 June 2021 (Ref. No: MH/MSD/REC21/213), the hospitals involved and later by the National Taiwan University Research Ethics Committee on 13 October 2021 (NTU-REC No: 202108HS020) where the researchers are based. Data collection started in October 2021 and lasted through to December of the same year – one facility per time across the four public hospitals.

Procedurally, the HIV-positive patients were involved in the research when they were recruited for the interviews. However, health professionals have been involved since the study protocol was developed. Fieldwork notes were taken, including observation at the facilities and the interactions between patients as well as between patients and health workers in clinical settings. All the interviews were conducted in or around the premises of the hospitals (on clinic days at the patients' convenience). With their consent to interviewing, both Igbo and English languages were used for conversations. Regarding the focus groups, we acknowledge that the recruitment procedures (flyers along with snowballing) may have led to an oversampling of women than that of men (17:3), all aged 20–30 years and have lived with HIV for varying numbers of years. Although background data on the gender breakdown of people who are in the system of HIV care and those who are lost to follow-up exist in the “Retention and Audit Determination Tool” database, access was not granted to the researchers at the time of writing.

The recruiting process stopped when both researchers identified that patterns of narratives had emerged and the point of data saturation was reached. Aside from the lunch vouchers (worth a thousand naira), no other incentive was provided to the participants. The interviews were audio recorded, and the audio data were transcribed and translated into English when necessary; they were anonymised before being shared with the second author (project supervisor). Data were not shared with the hospitals in any event, and they ensured that patients' safety and the clinicians' working status would not be compromised should disclosure occur when any participant revealed the interview

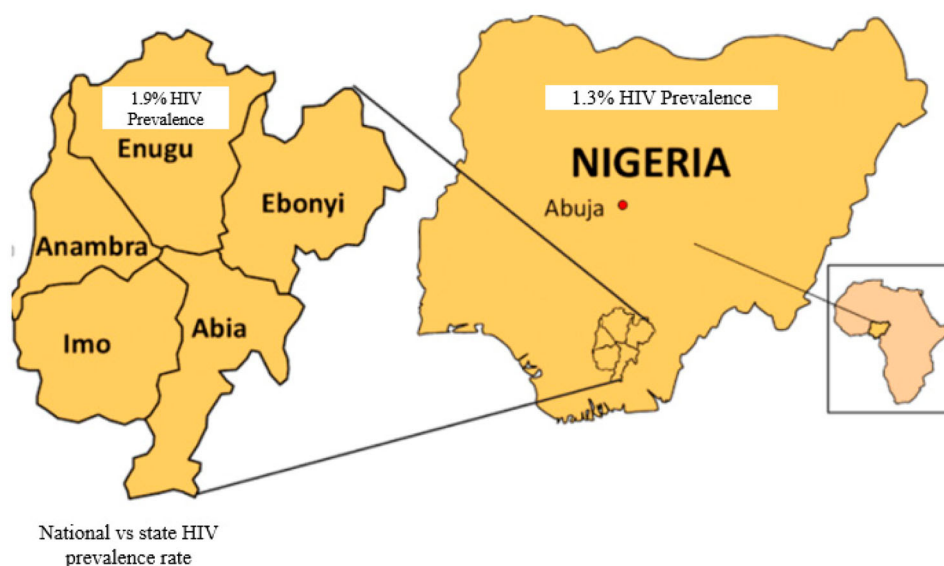


Figure 1. The map of Nigeria showing the location of the southeast region (adapted from Olive & David, 2021).

experience themselves. The research participants did not further check transcripts and findings because those who left contact information declined to do so when asked about this, whereas some refused to leave ways of personal communication.

Discussion narratives were analysed based on themes emerging from the coding processes, particularly around the topics such as stigma and prejudice, emotions (e.g., shame, guilt and loneliness) and other elements related to psychosocial health (e.g., social and material support, family and friendship) (Chime et al., 2019). The qualitative data underwent thematic analysis with software such as Microsoft Word and Excel by carefully reviewing textual data, such as interview transcripts and field notes, to identify recurring patterns, themes and concepts. Coding and grouping data segments were done to explore connections and relationships, employing a process of constant comparison and ensuring consistency between the findings and our interpretations. The first author was responsible for the coding, and the second author examined the codes, which, individually, and the relationships between them, were discussed between the two researchers. Triangulation was conducted by comparing the data between focus groups and between the group and individual interviews.

Results

We conducted four focus groups at each hospital (20 participants in total) and in-depth interviews with one clinician each from the four respective facilities (see Table 1). Key findings are discussed below under three

main themes that are further granulated into subthemes: stigmatisation facing young PLHIV, their psychosocial responses to hostilities, and the non-psychological factors of virologic failure.

Stigmas and prejudice against young PLHIV

All the study participants remarked that, due to the prejudice they anticipated or experienced, they made efforts not to disclose their serostatus to prevent anxious feelings.

Concealment as a self-protection strategy

At ESUTH, a woman aged 30 years who had been seropositive for half of her lifetime (diagnosed in 2006), stated that:

The only person who knows about that is my husband, who is equally HIV positive ... My husband and I found out about our serostatus at the same time; that helped make disclosure easier, and we both agreed to keep the news between us from our children.

(R4, ESUTH focus group)

Another woman aged 20 years who has lived with HIV since birth mentioned that:

Until today, my father and the other (seven) siblings, except my mother, do not know why I take the drugs I take. My mother tells them it is for "hormonal corrections".

(R3, EEGH focus group)

An older man at a different health facility who is 29 years old and has been HIV positive for four years (diagnosed in 2017) said:

Table 1. Biographic data of study participants.

Facility (date)	Respondents	Sex	Age	Years of HIV+	Clinical interruption in the last 24 months?	Individual interview?
UGH (28 October 2021)	1	M	29	4	Yes	Yes (IDI)
	2	F	27	3	Yes	
	3	F	28	10	Yes	
	4	F	26	1	Yes	
	5	F	28	1	Yes	
	6	F	29	10	Yes	
ESUTH (29 October 2021)	1	M	30	3	Yes	Yes (IDI)
	2	F	30	5	Yes	
	3	F	29	8	Yes	
	4	F	30	15	Yes	
EEGH (3 December 2021)	1	F	30	15	Yes	Yes (IDI)
	2	F	29	1	Yes	
	3	F	20	20	Yes	
	4	F	20	6	Yes	
	5	F	30	8	Yes	
	6	F	24	2	Yes	
UNTH (21 December 2021)	1	F	22	7	Yes	Yes (IDI)
	2	F	21	21	Yes	
	3	F	21	7	Yes	
	4	M	22	3	Yes	

My friends do not know what is happening to me. I don't want them to know. Even to date, people refuse to eat at the service of songs or burial wakes of some of our village people who are thought to have died of HIV.

(R1, UGH focus group)

PLHIV who have not disclosed and chose not to disclose their situation had long known how and to what extent others' discriminatory attitudes towards HIV could reach, which might apply to themselves before they were diagnosed. Therefore, HIV stigma-related traumas are internalised, and the fear of "being known by" or "exposed to" other people is constantly reaffirmed whenever they witness new prejudiced events; this also extends to intimate relationships. A 21-year-old woman recalled that:

A guy I met for about a few months insisted that we go run a test (because he had already started discussing marriage). I didn't want to test, so I opened up to him and told him about that [her HIV-positive status]. That was the end of the relationship.

(R3, UNTH focus group)

Young PLHIV with limited resources and means of making a living are stigmatised on multiple fronts; they have tended to conceal their seropositive status from others, even in clinical settings. For example, we chose to conduct interviews around health facilities for the participants' convenience and, equally importantly, to observe the general clinical setup of the ART units, the timeliness of care and patient-physician relationships. These factors are crucial for understanding how stigma is enacted on PLHIV by their service providers, if there is any.

Clinical hostilities against young patients

The observations at the four hospitals have helped us locate the patients' experience in the context in which clinical prejudice happened to these young PLHIV. When asked if they have ever experienced any "uneasiness" at the health facility, the four respondents from ESUTH remarked on "rudeness" of and "ill-treatment" from the nurses:

They are harsh to me when I come late for my clinic visits. They will usually give me a penalty by not collecting my card early, thus delaying me. They shout at one when one miss appointments again.

(R4, ESUTH focus group)

Relatedly, an uneasy relationship between PLHIV and people working at the hospitals presents a significant challenge to a sustainable retention drive among the young PLHIV. A clinician at UGH provided a looming insight into the nature of HIV services in Nigeria and how it reflects negatively on the mental health of young PLHIV in Enugu:

HIV interventions in Nigeria are "numbers-driven" against real change ... it is about targets and the number of people reached, with little or no emphasis on the quality of service provided for them. (UGH IDI)

PLHIV's psychosocial responses to hostilities

When these young PLHIV assume a new, unfamiliar and yet highly stigmatised identity associated with HIV, the intimacy and solidarity they hope to have with other peers would be shattered. A 26-year-old woman (who has lived with HIV for ten years) confirmed that "Yes, I feel very lonely because of my

HIV status” (R4, UGH focus group), and she is not alone.

Interpersonal and clinical stressors

All the EEGH focus group participants mentioned similar senses of aloneness and loneliness. They were all women with a median age of 26.5 years and a period of initial diagnosis ranging from 1–20 years (with one being HIV positive from birth). Yet, the participants, across different sites, have responded to such negative feelings not entirely in the same way. Some of them had delved into the emotions stemming from such social disconnection, while others might have tried to explore friendship in non-conventional forms. R6 of the EEGH focus group, who was 24 years old and had lived with HIV since 2019, felt utterly challenged by the need to adhere to ART, even if she understood that such medication is “a matter of life and death”.

There has been an urgent need for communication and discussion between adherence counsellors and their HIV patients. One ART clinician at EEGH mentioned clinicians’ failure to fully prepare their patients for the treatment process due to a differential focus on targeted testing without a consistent approach to ensuring that the treatment processes remain uninterrupted throughout the patient’s lifetime. In this light, “preparing patients with transparent information and a careful attitude is just as important as initiating ART” (EEGH IDI). Nonetheless, what was often seen at the clinics was some ART clinicians shouting at a patient for being late for their appointment and threatening to delay that patient for a more extended period as a “lesson” for them and others.

Serodiscordance, romance and HIV

The seropositive status also affects the young PLHIV’s romantic relationships. Among our study participants, serodiscordance has led to an inability to find matching partners for intimacies with others who are not HIV positive. They have faced the issue of a lack of bonding with other would-be partners.

When we are growing, we fall in love; so, thinking about having a relationship with [for example,] this guy now, how will I let him know that I am HIV positive? I feel so depressed thinking about it all. What would my life become if he goes?

(R1, UNTH focus group)

Following the researcher’s probe into what could have been done, “pairing up HIV-positive clients for marriage would be a much-welcomed idea”, she said. Her and others’ similar suggestions seemed to imply the presumed existence of mutual understanding and,

therefore, mutual support between seroconcordant partners, which may potentially avoid the risks of disclosure and rejection.

Non-psychological factors of virologic failure

While virologic failure is not the primary object of inquiry in this study, we have found that in southeast Nigeria, mental health-related challenges derived from unmet financial and nutritional stressors faced by young PLHIV, if ignored, could lead to their virologic failure.

Transitioning to this point, in-country HIV programmatic procedures become worrying when young adults, unemployed or semi-employed, are further required to withstand the worst of an additional portion of their treatment services, such as out-of-pocket expenses. How do the people directly affected by potentially losing means of livelihood react to this – particularly in addressing such challenges and making it to their appointments? At Udi, a 29-year-old man living with HIV since 2017 stated, “Money is a big challenge for me; transportation, feeding and household needs can all be solved with money ... and I don’t have that” (R1, UGH focus group).

Udi is a rural community in Enugu state. We make this point to show how, regardless of where one dwells (rural or urban), the stressors are equally felt, as the urban respondents from ESUTH demonstrated. A 30-year-old woman living with HIV since 2016 mentioned:

At my workplace, I do not usually get a permit from my employer to come for my clinic visits because they do not know my status ... I am terrified of disclosing ... as I’d automatically lose my job. I have to lie.

(R2, ESUTH focus group)

Other participants at EEGH gave similar responses. The community where this health facility is situated, known as Enugu Ezike – and the eponym of the general hospital in that locality – is a rural community of mostly subsistence farmers in which the young PLHIV share similar financial and nutritional stressors with their co-survivors in urban, tertiary health facilities. Likewise, a 22-year-old woman living with HIV since 2014 stated that:

My school activities and transportation challenges ... are big challenges that hinder meeting up with my appointments at the facility. (All the others nodding heads, agreeing with the transportation concern.)

(R1, UNTH focus group)

Resonating with the idea that non-disclosure is a cocoon to protect themselves and the people around them, R2 at ESUTH had to navigate through her clinical

appointments by telling a lie to her employer about what she comes to do at the ART clinic. At ESUTH, the clinician mentioned that before commencing treatment, index patients must pay for part of the services:

Some patients are not economically fit to pay for even a folder. Since this year (2021), they pay as high as 2,500 Naira (because of inflation) from the initial 500 Naira they paid.

(ESUTH IDI)

The amount quoted is ~ \$6 from the initial USD 1 (parallel exchange market rate as of December 2021); this is quite costly for unemployed young PLHIV. For trustworthiness purposes, after this interview, we attempted to confirm if the rates were the same across the board when we contacted other facilities such as UNTH, EEGH and UGH. They only mentioned that some charities within the state sometimes paid for newly diagnosed positive cases. How much precisely this amounted to, they did not disclose.

Discussion

This study enhances our understanding of the psychosocial and material factors contributing to medication withdrawal in Nigeria, especially among young PLHIV. We explored not only why and how they were lost but also what brought them back, an issue that has received so much less attention than it should have given that HIV/AIDS remains a highly stigmatised health condition across Africa (Mbonu et al., 2009; Rankin et al., 2005; Winskell et al., 2011; Winskell et al., 2015). In Nigeria, factors such as religion (primarily Christian and Islamic teachings) (Speakman, 2012), sociocultural beliefs (e.g., strange illness as a punishment from God for disobedience and immorality) (Muoghalu & Jegede, 2013) and the lack of scientific knowledge about the disease (Agu et al., 2020) have resulted in sustaining the HIV stigma. Our study shows that young PLHIV in southeast Nigeria, particularly in Enugu state, suffer poor psychosocial health resulting from stigmatisation, discrimination, and related clinical angsts such as depression from ART adherence. These factors ultimately led to virologic failures and even suicidal ideations.

Our group interviewees all missed one or several appointments between 2019 and 2021; fortunately, they managed to return. However, their capability to “manage to return” requires much more support beyond faith to help them overcome the social selection process built into both psychosocial (e.g., stigmatisation, marginalisation, self-isolation and loss of community and intimacy) and non-psychosocial (e.g., financial

burdens, transportation inaccessibility and malnutrition) mechanisms. The HIV stigma legitimises infections due to a person’s discreditable trait, whether known or not, and, in turn, adds another layer of reason to discredit the person (Chaudoir et al., 2013). As our findings reveal, in the context of HIV stigma, it is also important to consider the impact on those *infected* with HIV on the one hand, and on the other, those *affected* by the disease (Gilmore & Somerville, 1994). The participants’ strategy of not disclosing their seropositive status accounts for themselves and others who would be “blamed on” too. Their non-disclosure decisions were also made to protect close family members such as parents, spouses or children (Gilborn, 2002).

As we have observed, majority of our participants were going through young adulthood, a critical moment in which a person forms a strong identity through desiring and attaining shared intimacy with other young adults to develop psychological responses to the social environment, from distal to proximal, with which one interacts (Erikson, 1968; Meeus et al., 1999; Meeus et al., 2012). The narrative data suggest that the mental health of young PLHIV in southeast Nigeria has been negatively impacted by this sense of separation, emotionally and physically, from intimate relationships with themselves and others. This phenomenon, reflecting on the developmental theory’s approach to intimacy as an integral part of the full development of self-identity, suggests the possibility of a so-called “identity crisis”, a life event that makes one question what place they occupy in the world (Erikson, 1970).

Beyond the self, serodiscordance – a case in which one individual is HIV positive, and the other person (intended to be a relationship partner) is not – plays a crucial role in forming and maintaining a romantic relationship. In the African context of HIV care, low HIV status awareness has been a significant driver for the person-to-person transmission of HIV (Chihana et al., 2021). In Tanzania, for example, mutual support and “solidarity” between partners are related to treatment outcomes at the dyadic level of HIV infection, characterised as “two people’s secret” by the couples (Fonner et al., 2021). Our study has also found this among the young PLHIV in Enugu.

Informed by these young PLHIV’s lived experiences, a holistic approach to ART financing in relation to care services that attends to medication adherence for socio-cultural and economic reasons is much needed. Such an approach may further help identify the barriers and facilitators concerning stigma-related and other factors concerning these patients’ mental health. However, we are also aware that health services funding in Nigeria

is sub-optimal; nearly two million PLHIV places an additional burden on healthcare workers regarding the quality of care available (Abubakar et al., 2022). Indeed, the clinicians providing ART services, on their part, are overwhelmed with a system that does not recognise nor sufficiently reward their hard work. Problems such as understaffing and underfunding in frontline care services remain unresolved to this day.

Relatedly, the WHO has considered nutrition among PLHIV as meriting renewed focus at all programmatic levels in the country, particularly in Nigeria, where HIV is currently endemic (WHO, 2003). Like our discussion above, nutrition requires robust funding (NIN, 2019). In Nigeria, with ~40% of its several-million population living below the poverty line (137,430 Naira or \$381.75) annually (NBS, 2019), the effects of this on the young PLHIV of southeast Nigeria heighten the anxiety level of their already strained mental health. For example, most focus group participants consistently cited financial and nutritional needs as two major barriers to treatment access. Further linked to out-of-pocket expenses, the issue becomes clear as to why they might miss their clinical appointments or become an LTFU patient over time. Funding, therefore, is a contentious challenge to treatment uptake among young PLHIV in southeast Nigeria.

In summary, what we learned from all the concerns expressed by our participants is twofold. First, it is increasingly difficult to keep up with clinical appointments due to the distance between the residences of young PLHIV and the health facilities they regularly visit for uptake services. The gap exists in terms of the “differentiated service delivery” model, which focuses explicitly on meeting individual needs – as opposed to the “one-size-fits-all” approach (Adjetey et al., 2019). The model can and should be strengthened to address issues such as transportation and financial costs (e.g., home delivery of ART and community ART pickup, while considering the privacy issues), related to the mental stressors PLHIV experience. Secondly, the “truth” about one’s HIV status can sometimes be burdensome. The “lies” about leaving for medical appointments may pose a psychosocial barrier to seeing treatment positively, and the dilemma remains of how long until this untruth is discovered and what implications it may have for participants’ health outcomes.

Limitations

The limitations of this study are about its generalisability, not only because of the representation of our study participants (mostly from large hospitals, more women than men) but also due to the specificity of the context

of this research. One implication is that the themes emerging from our study represent a highly “gendered experience” due to a much larger number of women, compared to men, in the study. The disproportionate participation may not precisely represent the disease burden on women versus men (2:1) in the region, yet it provided valuable insights into the gendered experiences of women living with HIV and mental health challenges in the region. In mixed-gender focus groups, these women might not have discussed certain themes due to perceptions of social decorum with men’s (including the researcher’s) presence (Offiong et al., 2021). Under the supervisors’ guidance, the field researcher was conscious of, and paid attention to, power dynamics in the conversational exchange between participants by balancing the time and space allocated to each interlocutor.

Furthermore, data were collected mainly in 2021, a year the country was shrouded by the COVID-19 pandemic, which has overshadowed many other health concerns and contributed to PLHIV’s clinical interruptions recorded in Enugu. Meanwhile, there have been incidents of armed conflicts across southeast Nigeria between the national army and the armed groups of Indigenous People of Biafra, whose leader was arrested in June 2021, which has led to escalated civil unrest throughout the region. Such circumstances, we believe, might have made all the participants psychosocially stressed about its implications on their health since most of them are Igbo – by extension, Biafrans.

Lastly, the LTFU in HIV care is a severe problem in Nigeria; drawing on our study, the *will to survive* may not be enough for ART adherence. Integrating psychosocial and material support for these patients is necessary for holistic, people-centred HIV care. The Nigerian government at all levels should take this account more seriously if the UNAIDS goals are to be met and the last mile push is to be sustained.

List of abbreviations

AIDS: acquired immunodeficiency syndrome.
 ART: antiretroviral therapy.
 COVID-19: coronavirus disease 2019.
 EEGH: Enugu Ezike General Hospital.
 ESUTH: Enugu State University Teaching Hospital.
 FMoH: Federal Ministry of Health.
 HIV: human immunodeficiency virus.
 LTFU: lost to follow-up.
 NAIIS: Nigeria HIV/AIDS indicator and impact survey.
 NTU: National Taiwan University.
 PEPFAR: US President’s Emergency Plan for AIDS Relief.

PLHIV: people living with HIV/AIDS.
 TX_CURR: number currently on ART.
 UGH: Udi General Hospital.
 UNAIDS: Joint United Nations Programme on HIV/AIDS.
 UNTH: University of Nigeria Teaching Hospital.
 WHO: World Health Organisation.

Note

1. Notably, Nigeria has not conducted a population census since 2006. Hence, data relating to Enugu state's actual population were estimated from the country's National Population Commission (nationalpopulation.gov.ng) as used in the 2018 NAHIS study.

Acknowledgements

We thank all the research groups and study participants for their valuable information and “life stories” that they generously shared with us. We also would like to thank the anonymous reviewers, and Dr Poyao Huang and Dr Chen-I Kuan at the NTU Institute of Health Behaviours and Community Sciences and Dr Ming-Jui Yeh at the NTU Institute of Health Policy and Management, who read the previous drafts and whose critical feedback was greatly appreciated. This study was presented at the 2022 Annual Conference of the Taiwan Society for Medical Anthropology; we thank the participants for their helpful comments.

Authors' contributions

EEU conceived the idea for the project; PHL guided the study design and development of research questions. EEU conducted data collection and initial analysis; PHL supervised the organisation and presentation of results and analysis. Both authors prepared and approved this manuscript together with a consensus.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

We have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. The publication fees are supported by a research project funded by the National Science and Technology Council, R.O.C. (Taiwan) (Project No. 111-2410-H-002-092-MY2).

Data availability statement

The data supporting this study's findings are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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References

- Abubakar, I., Dalglis, S. L., Angell, B., Sanuade, O., Abimbola, S., Adamu, A. L., Adetifa, I. M. O., Colbourn, T., Ogunlesi, A. O., Onwujekwe, O., Owoaje, E. T., Okeke, I. N., Adeyemo, A., Aliyu, G., Aliyu, M. H., Aliyu, S. H., Ameh, E. A., Archibong, B., Ezech, A., ... Zanna, F. H. (2022). The Lancet Nigeria Commission: Investing in health and the future of the nation. *The Lancet*, 399(10330), 1155–1200. [https://doi.org/10.1016/S0140-6736\(21\)02488-0](https://doi.org/10.1016/S0140-6736(21)02488-0)
- Adjetey, V., Obiri-Yeboah, D., & Dornoo, B. (2019). Differentiated service delivery: A qualitative study of people living with HIV and accessing care in a tertiary facility in Ghana. *BMC Health Services Research*, 19(1), 95. <https://doi.org/10.1186/s12913-019-3878-7>
- Agu, I. C., Mbach, C. O., Okeke, C., Eze, I., Agu, C., Ezenwaka, U., Ezumah, N., & Onwujekwe, O. (2020). Misconceptions about transmission, symptoms and prevention of HIV/AIDS among adolescents in Ebonyi state, Southeast Nigeria. *BMC Research Notes*, 13(1), 244. <https://doi.org/10.1186/s13104-020-05086-2>
- Atanuriba, G. A., Apiribu, F., Boamah Mensah, A. B., Dzomeku, V. M., Afaya, R. A., Gazari, T., Kuunibe, J. K., & Amooba, P. A. (2021). Caregivers' experiences with caring for a child living with HIV/AIDS: A qualitative study in northern Ghana. *Global Pediatric Health*, 8, 2333794X211003622. <https://doi.org/10.1177/2333794X211003622>
- Chaudoir, S. R., Earnshaw, V. A., & Andel, S. (2013). “Discredited” versus “discreditable”: Understanding how shared and unique stigma mechanisms affect psychological and physical health disparities. *Basic and Applied Social Psychology*, 35(1), 75–87. <https://doi.org/10.1080/01973533.2012.746612>
- Chihana, M. L., Conan, N., Ellman, T., Poulet, E., Garone, D. B., Ortuno, R., Wanjala, S., Masiku, C., Etard, J. F., Davies, M. A., & Maman, D. (2021). The HIV cascade of care among serodiscordant couples in four high HIV prevalence settings in sub-Saharan Africa. *South African Medical Journal*, 111(8). <http://www.samj.org.za/index.php/samj/article/view/13355>
- Chime, O. H., Arinze-Onyia, S. U., & Ossai, E. N. (2019). Examining the effect of peer-support on self-stigma among persons living with HIV/AIDS. *The Pan African Medical Journal*, 34, 1–10. <https://doi.org/10.11604/pamj.2019.34.200.17652>
- Edwards, L. V. (2006). Perceived social support and HIV/AIDS medication adherence among African American women. *Qualitative Health Research*, 16(5), 679–691. <https://doi.org/10.1177/1049732305281597>
- Erikson, E. H. (1968). *Identity, youth and crisis*. Norton.
- Erikson, E. H. (1970). Autobiographic notes on the identity crisis. *Daedalus*, 99(4), 730–759. <http://www.jstor.org/stable/20023973>
- Federal Ministry of Health. (2018). *Nigeria HIV/AIDS indicator and impact survey (NAHIS): 2018 Technical report*.

- <https://ciheb.org/media/SOM/Microsites/CIHEB/documents/NAIIS-Report-2018.pdf>
- Fields, E. L., Bogart, L. M., Thurston, I. B., Hu, C. H., Skeer, M. R., Safren, S. A., & Mimiaga, M. J. (2017). Qualitative comparison of barriers to antiretroviral medication adherence among perinatally and behaviorally HIV-infected youth. *Qualitative Health Research*, 27(8), 1177–1189. <https://doi.org/10.1177/1049732317697674>
- FoMH, & NACA. (2018). *Nigeria HIV/AIDS indicator and impact survey: HIV/AIDS in Nigeria - pushing for the last mile*. National Agency for the Control of AIDS, Federal Ministry of Health. <https://www.naiis.ng/resource/NAIIS%20Key%20Messages.pdf>
- Fonner, V. A., Ntgowisangu, J., Hamidu, I., Joseph, J., Fields, J., Evans, E., Kilewo, J., Bailey, C., Goldsamt, L., Fisher, C. B., O'Reilly, K. R., Ruta, T., Mbwanbo, J., & Sweat, M. D. (2021). “We are in this together:” dyadic-level influence and decision-making among HIV serodiscordant couples in Tanzania receiving access to PrEP. *BMC Public Health*, 21(1), 720. <https://doi.org/10.1186/s12889-021-10707-x>
- Gilborn, L. Z. (2002). The effects of HIV infection and AIDS on children in Africa. *The Western Journal of Medicine*, 176(1), 12–14. <https://doi.org/10.1136/ewj.176.1.12>
- Gilmore, N., & Somerville, M. A. (1994). Stigmatization, scapegoating and discrimination in sexually transmitted diseases: Overcoming ‘them’ and ‘us’. *Social Science & Medicine*, 39(9), 1339–1358. [https://doi.org/10.1016/0277-9536\(94\)90365-4](https://doi.org/10.1016/0277-9536(94)90365-4)
- Kvarnström, K., Westerholm, A., Airaksinen, M., & Liira, H. (2021). Factors contributing to medication adherence in patients with a chronic condition: A scoping review of qualitative research. *Pharmaceutics*, 13(7), 1100. <https://www.mdpi.com/1999-4923/13/7/1100>
- Lightfoot, M., Rotheram-Borus, M. J., Milburn, N. G., & Swendeman, D. (2005). Prevention for HIV-seropositive persons: Successive approximation toward a new identity. *Behavior Modification*, 29(2), 227–255. <https://doi.org/10.1177/0145445504272599>
- Mbonu, N. C., van den Borne, B., & De Vries, N. K. (2009). Stigma of people with HIV/AIDS in Sub-Saharan Africa: A literature review. *Journal of Tropical Medicine*, 2009, 145891. <https://doi.org/10.1155/2009/145891>
- Meeus, W., Iedema, J., Helsen, M., & Vollebergh, W. (1999). Patterns of adolescent identity development: Review of literature and longitudinal analysis. *Developmental Review*, 19(4), 419–461. <https://doi.org/10.1006/drev.1999.0483>
- Meeus, W., van de Schoot, R., Keijsers, L., & Branje, S. (2012). Identity statuses as developmental trajectories: A five-wave longitudinal study in early-to-middle and middle-to-late adolescents. *Journal of Youth and Adolescence*, 41(8), 1008–1021. <https://doi.org/10.1007/s10964-011-9730-y>
- Mukumbang, F. C., Marchal, B., Van Belle, S., & van Wyk, B. (2018). “Patients are not following the [adherence] club rules anymore”: A realist case study of the antiretroviral treatment adherence club, South Africa. *Qualitative Health Research*, 28(12), 1839–1857. <https://doi.org/10.1177/1049732318784883>
- Muoghalu, C. O., & Jegede, S. A. (2013). Perception of HIV/AIDS among the Igbo of Anambra State, Nigeria. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, 10(1), 42–54. <https://doi.org/10.1080/17290376.2013.807052>
- NBS. (2019). *2019 poverty and inequality in Nigeria: Executive summary*. Nigerian National Bureau of Statistics.
- NIN. (2019). *Nigeria programs: Country brief*. Nutrition International Nigeria. <https://www.nutritionintl.org/wp-content/uploads/2019/11/Nigeria-Country-Brief.pdf>
- Offiong, E. E., Eyo, E. I., & Offiong, A. E. (2021). Patriarchy, culture and the social development of women in Nigeria. *Pinisi Journal of Art, Humanity, and Social Studies*, 1(4), 79–86. <https://ojs.unm.ac.id/PJAHSS/article/view/26708/13541>
- Olive, O. O., & David, U. K. (2021). Valuation of rice farmers’ preferences and willingness to pay for climate-smart agricultural technologies in southeast. *Nigeria. Asian Journal of Economic Modelling*, 9(1), 48–57. <https://doi.org/10.18488/journal.8.2021.91.48.57>
- PEPFAR. (2019). *Monitoring, evaluation, and reporting indicator reference guide: MER 2.0 (Version 2.4)*. US President’s Emergency Plan for AIDS Relief.
- Rankin, W. W., Brennan, S., Schell, E., Laviwa, J., & Rankin, S. H. (2005). The stigma of being HIV-positive in Africa. *PLOS Medicine*, 2(8), e247. <https://doi.org/10.1371/journal.pmed.0020247>
- Speakman, S. (2012). Comparing the impact of religious discourse on HIV/AIDS in Islam and Christianity in Africa. *Vanderbilt Undergraduate Research Journal*, 8, 1–7. <https://doi.org/10.15695/vurj.v8i0.3490>
- Stutterheim, S. E., & Ratcliffe, S. E. (2021). Understanding and addressing stigma through qualitative research: Four reasons why we need qualitative studies. *Stigma and Health*, 6(1), 8–19. <https://doi.org/10.1037/sah0000283>
- Syed, I. A., Syed, S. A., Hassali, M. A., Thiruchelvar, K., & Lee, C. K. C. (2015). A qualitative insight of HIV/AIDS patients’ perspective on disease and disclosure. *Health Expectations*, 18(6), 2841–2852. <https://doi.org/10.1111/hex.12268>
- Tucker, J. D., Tso, L. S., Hall, B., Ma, Q., Beanland, R., Best, J., Li, H., Lackey, M., Marley, G., Rich, Z. C., Sou, K. I., & Doherty, M. (2017). Enhancing public health HIV interventions: A qualitative meta-synthesis and systematic review of studies to improve linkage to care, adherence, and retention. *eBioMedicine*, 17, 163–171. <https://doi.org/10.1016/j.ebiom.2017.01.036>
- UNAIDS. (2021, 5 March 2021). *Feature story: Putting people at the centre brings good results in Nigeria* https://www.unaids.org/en/resources/presscentre/featurestories/2021/march/20210305_people-at-the-centre-nigeria
- WHO. (2003). *Nutrient requirements for people living with HIV/AIDS: Report of a technical consultation, World Health Organization, Geneva, 13–15 May 2003*. World Health Organization. <https://apps.who.int/iris/bitstream/handle/10665/42853/9241591196.pdf>
- Wilson, P. A., Valera, P., Martos, A. J., Wittlin, N. M., Muñoz-Laboy, M. A., & Parker, R. G. (2016). Contributions of qualitative research in informing HIV/AIDS interventions targeting black MSM in the United States. *The Journal of Sex Research*, 53(6), 642–654. <https://doi.org/10.1080/00224499.2015.1016139>

Winskell, K., Hill, E., & Obyerodhyambo, O. (2011). Comparing HIV-related symbolic stigma in six African countries: Social representations in young people's narratives. *Social Science & Medicine*, 73(8), 1257–1265. <https://doi.org/10.1016/j.socscimed.2011.07.007>

Winskell, K., Holmes, K., Neri, E., Berkowitz, R., Mbakwem, B., & Obyerodhyambo, O. (2015). Making sense of HIV stigma: Representations in young Africans' HIV-related narratives. *Global Public Health*, 10(8), 917–929. <https://doi.org/10.1080/17441692.2015.1045917>