



HHS Public Access

Author manuscript

AIDS. Author manuscript; available in PMC 2024 June 04.

Published in final edited form as:

AIDS. 2023 January 01; 37(1): 191–196. doi:10.1097/QAD.0000000000003404.

Individual and Household Factors Associated with Non-disclosure of Positive HIV Status in a Population-Based HIV Serosurvey

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Abstract

Objectives: Non-disclosure of positive HIV status in population-based surveys causes underestimation of national HIV diagnosis and biases inferences about engagement in the care continuum. This study investigated individual and household factors associated with HIV non-disclosure to survey interviewers in Nigeria.

Design: Secondary analysis of a cross sectional population-based household HIV survey.

Methods: We analyzed data from adults aged 15–64 years who tested positive for HIV and had antiretroviral drugs (ARVs) in their blood from a nationally representative HIV serosurvey conducted in Nigeria in 2018. We considered ARV use as a proxy for knowledge of HIV diagnosis; thus, respondents who self-reported to be unaware of their HIV status were

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Author Contributions:

J.L., M.C.L., K.S., and M.C. conceived and planned the analyses presented. J.L. performed the analyses and constructed the preliminary and revised drafts of the manuscript. M.C.L., M.C., and K.S. contributed technical and theoretical guidance on the analysis. G.A., J.I., I.D., A.B., M.S., M.B., C.A., M.C.L., K.S., and M.C. oversaw the design and implementation of the survey and provided guidance on the manuscript. All authors reviewed and approved the final manuscript.

Disclaimer: The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the funding agencies.

classified as non-disclosers. We estimated the associations between non-disclosure and various sociodemographic, clinical, and household characteristics using weighted logistic regression.

Results: Among 1,266 respondents living with HIV who were taking ARVs, 503 (40%) did not disclose their HIV status to interviewers. In multivariable statistical analyses, the adjusted odds of non-disclosure were highest among respondents aged 15–24 years, those with less than a primary school education, and those who were the only person living with HIV in their household.

Conclusions: Non-disclosure of positive HIV status to survey personnel is common among adults who are receiving treatment in Nigeria. These findings highlight the importance of validating self-reported HIV status in surveys using biomarkers of ARV use. Meanwhile, it is crucial to improve disclosure by strengthening interview procedures and tailoring strategies towards groups that are disproportionately likely to underreport HIV diagnoses.

Keywords

HIV status; HIV disclosure; self-report; antiretroviral therapy; population-based; Nigeria

Introduction

Diagnosis is the cornerstone of the HIV care continuum, enabling people living with HIV to initiate antiretroviral therapy (ART) and achieve viral load suppression [1]. The United Nations Program on HIV and AIDS (UNAIDS) established the 95–95–95 targets with the goal of 95% of people living with HIV to know their infection status, 95% of those with knowledge of infection to initiate ART, and 95% of those on ART to achieve viral suppression by 2030 [2]. Nationally representative household surveys that incorporate HIV testing and biomarker measurements enable countries to monitor progress towards these targets, information that is critical to understand the reach and effectiveness of HIV treatment and prevention strategies.

Non-disclosure of HIV status to interviewers in population-based household surveys is a threat to the accuracy of HIV indicator surveillance. In addition to underestimating known HIV diagnoses, non-disclosure prevents the collection of data measuring engagement with the later stages of the HIV continuum of care, biasing inferences from population-based HIV surveys [3–5]. As such, non-disclosure has important consequences for governments' strategic planning regarding HIV services.

The extent of non-disclosure within a survey setting can be estimated by measuring biomarkers of antiretroviral (ARV) drug use. The presence of ARV analytes in the blood of people living with HIV indicates recent use and suggests that they are aware of their serostatus. Therefore, ARV biomarkers are powerful tools for validating self-reported HIV status and adjusting population-based estimates of HIV diagnosis [3,6]. Several studies have identified concerning levels of non-disclosure in household surveys throughout sub-Saharan Africa, the region with the majority of the global HIV burden [4,7–12].

Nigeria has one of the world's largest HIV epidemics [13]. Nigeria implemented a *Treat All* strategy in 2017, but it has seen limited success, especially regarding early retention in ART [14]. As Nigeria works to control its HIV epidemic, ensuring disclosure of

positive HIV status in survey settings is crucial for obtaining accurate estimates of care continuum engagement and ensuring sound programmatic decision-making. The availability of ARV biomarker data from the 2018 Nigeria HIV/AIDS Indicator and Impact Survey (NAIIS) provides a unique opportunity to examine this issue at the national level for the first time. The aim of this study is to quantify non-disclosure of HIV seropositivity to NAIIS interviewers among respondents on ART and to identify individual and household characteristics associated with this behavior.

Methods

Study Population:

We used cross-sectional data from NAIIS, a population-based HIV impact assessment conducted in Nigeria in 2018. The primary objective of NAIIS was to obtain nationally representative estimates of HIV prevalence, incidence, and viral load suppression [5]. The methodology of NAIIS has been described in detail elsewhere [5,15]. For this analysis, we selected adults (aged 15–64 years) who tested positive for HIV in NAIIS and had ARV analytes in their blood at the time of sampling.

Interview Procedures:

Households were visited by survey personnel, who administered a face-to-face questionnaire to the head of household. Then, consenting adults who slept in the household the previous night were interviewed individually. Respondents who reported being HIV-positive also completed modules regarding their history of HIV diagnosis and treatment.

Testing Procedures:

Survey staff administered a field-based rapid HIV testing algorithm, as previously described [5]. CD4 cell count was measured for respondents who tested HIV-positive, as well as a random subset of 2% of those who tested HIV-negative. Point of care results were returned the same day and HIV-positive respondents were referred to local treatment facilities. Blood specimens were collected from respondents who tested HIV-positive for further laboratory evaluation, including confirmation of HIV status, viral load determination, and ARV biomarker detection [5,16]. The ARV assay was designed to detect efavirenz, lopinavir, atazanavir, and nevirapine, as these drugs were representative of first and second-line HIV treatment options in Nigeria during NAIIS.

HIV disclosure status:

We considered the presence of any ARV analyte to indicate knowledge of HIV seropositivity. Thus, we determined HIV disclosure status by comparing self-reported knowledge of HIV status to ARV biomarker status. We defined “disclosers” as HIV-positive, ARV-positive respondents who self-reported to be aware of their HIV status. We defined “non-disclosers” as HIV-positive, ARV-positive respondents who self-reported to be unaware of their HIV status.

Statistical Analysis:

We assessed univariate frequency distributions for each covariate and stratified distributions by HIV disclosure status. Observations with missing data were excluded from further analysis. We used weighted bivariate logistic regression models to assess the crude association between HIV disclosure status and each covariate. We then estimated the adjusted association between select variables and the odds of non-disclosure using weighted multivariable logistic regression. To construct the adjusted model, we first considered variables that were independently associated with non-disclosure at a significance level of $p < 0.2$. We then conducted backwards elimination, removing covariates one-by-one until all remaining terms met the retention threshold of $p < 0.05$. Age and sex were included in the final model *a priori* based on literature review. Survey weights were included in descriptive statistics of the sample and regression analyses to account for complex sampling strategy. All statistical procedures were performed using SAS software (Version 9.4, SAS Institute Inc.).

Ethical Considerations

Informed consent was obtained from all participants. Human subject review and permission for use of the NAIIS data was obtained from the study Principal Investigators, the Nigerian National Health Research Ethics Committee, the University of Maryland, Baltimore Institutional Review Board and the Centers for Disease Control and Prevention Institutional Review Board.

Results

HIV Status Disclosure and Sample Characteristics

Among 2,739 adults who tested positive for HIV in NAIIS, 47% (1,287/2,739) had ARV analytes detected at the time of sampling, whereas 31% (849/2,739) self-reported knowing their seropositive status. Combining self-report and ARV biomarkers, the corrected estimate of people living with HIV who were aware of their status was 50% (1,372/2,739). We included 1,266 (98.4%) individuals with detectable ARV analytes and complete data for further analysis of non-disclosure (Supplemental Figure 1).

Of respondents taking ARVs, 40% (503/1,266) reported to be previously unaware of their positive HIV status. Our sample was predominantly women (68.2%) and individuals between the ages of 25 and 49 years (69.5%). Nearly 75% of respondents had CD4 counts above 350 cells/mm³ and over 80% were virally suppressed. Complete demographic characteristics of the sample are described in Table 1.

Crude and Adjusted Regression Analyses

HIV disclosure status was significantly associated with age ($p=0.02$), education level ($p < 0.01$), wealth index ($p < 0.01$), and household HIV positivity ($p < 0.01$) in bivariate logistic regression analyses (Table 2). There were no statistically significant independent associations between HIV disclosure status and sex, religion, marital status, CD4 count, viral load suppression, community setting, or household role (Table 2).

After multivariable adjustment, the associations between non-disclosure and age, education level, and household HIV positivity remained robust. The adjusted odds of non-disclosure were significantly higher among respondents aged 15–24 years compared to those aged 50–64 years (OR: 2.17 [95% CI: 1.13 – 4.16]) (Table 2). Compared to respondents with a primary school education, the odds of non-disclosure were significantly higher among those with less than a primary school education (OR: 2.39 [95% CI: 1.52 – 3.75]), while lower among those with a tertiary education (OR: 0.57 [95% CI: 0.41 – 0.83]) (Table 2). Having additional HIV-positive members in the household was also associated with lower odds of non-disclosure compared to being the only person living with HIV in the household (OR: 0.59 [95% CI: 0.41 – 0.83]) (Table 2).

Discussion

Non-disclosure of HIV positivity in population-based surveys is a crucial barrier to accurate monitoring of progress towards epidemic control. Awareness of HIV seropositivity was underreported by 19% in NAIIS. This finding validates the importance of including ARV biomarkers in population-based HIV sero-surveys to correct estimates of HIV treatment and care engagement. Non-disclosure was associated with specific sociodemographic characteristics, yielding important implications for improving reporting accuracy in future household HIV surveys.

Young people living with HIV were significantly more likely to misreport their HIV diagnosis to survey interviewers than older adults, findings similar to other population-based surveys across sub-Saharan Africa [4,10,17]. Young adults living with HIV may be reluctant to disclose their positive status in household surveys due to fear of sensitive information being released, since HIV stigma and discrimination are key obstacles for youth [18–20]. We also observed that respondents who were the only person living with HIV in their household were significantly more likely to misreport their HIV status than those who lived with at least one additional HIV-positive individual. This also points to privacy concerns from respondents, perhaps driven by fear that other household members would overhear their responses.

Together, these findings seem to suggest that fear of stigma and discrimination underlie some instances of non-disclosure. Although perceived stigma was not measured among adults in NAIIS, previous reports show that HIV stigma is common throughout Nigeria and may be a barrier to disclosure of HIV diagnoses [21–23]. Therefore, it is critical to maximize confidentiality measures during individual interviews to assuage fear of privacy breaches and obtain accurate information about known HIV diagnoses. However, it is unlikely that deeply rooted structural factors such as HIV stigma will be overcome by improving training and questionnaires alone. In Malawi, HIV disclosure was shown to be lower in community settings compared to clinical settings, suggesting a mistrust of fieldworkers [10]. We surmise that strengthening community engagement and mobilization in population-based HIV surveys may be a more holistic route to improving trust, participation, and accuracy from respondents.

Non-disclosure was also associated with lower educational attainment. Less education may be linked to low health literacy, which could cause people living with HIV to misunderstand questions pertaining to HIV diagnosis and treatment. Indeed, there is evidence to suggest that some instances of non-disclosure can be explained by misunderstandings regarding HIV-related terminology, HIV test results, or prescribed treatments [9,24]. This finding may indicate a distinct variety of non-disclosure that can be reduced by ensuring the clarity of questionnaires, adding confirmatory questions, or training interviewers to provide educational services and facilitate proper understanding of HIV-related topics.

We acknowledge certain limitations in our approach. This study was restricted to people living with HIV who were on ART at the time of sample collection, since we could estimate the true proportion of non-disclosers in this subset. Although excluding respondents without detectable ARVs underestimates accurate disclosers, the effect was minimal, since 96% of HIV-positive NAIS respondents that knew their status were engaged in ART [5]. We also emphasize that survey non-disclosure may not equate with non-disclosure in other contexts, such as to sexual partners, families, or healthcare providers, and that different levels of disclosure may have unique patterns and implications. Finally, we acknowledge the limitations inherent in cross-sectional studies and recommend caution in the causal interpretation of the results presented.

In conclusion, our study contributes key information regarding survey non-disclosure in Nigeria that will inform strategies to maximize accurate estimation of population HIV indicators.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements:

The NAIS Group includes Principal Investigators: Isaac Adewole (Federal Ministry of Health), Sani Aliyu (National Agency for the Control of AIDS), Mahesh Swaminathan (CDC Nigeria), Megan Bronson (CDC Atlanta), Manhattan Charurat (University of Maryland, Baltimore); Co-Investigators: Evelyn Ngige, Sunday Aboje, Charles Nzelu, Emanuel Meribole, Chike Ihekweazu, Chukuma Anyaike, Kayode Ogungbemi, Mukhtar Muhammad, Gregory Ashefor, Ibrahim Dalhatu, Ibrahim Jahun, Victor Sebastian, Ahmed Mukhtar, Tapdiyel Jelpe, Orji Bassey, McPaul Okoye, Aminu Yakubu, Bharat Parekh, Hetal Patel, Andrew Voetsch, Daniel B. Williams, Kristin Brown, Stephen McCracken, Anne McIntyre, Nibretie Workneh, Bryan Morris, Rex Gadama Mpazanje, Wondimagegnehu Alemu, Erasmus Morah, Gatien Ekanmian, Gambo Aliyu, Alash'le Abimiku, Bola Gobir, Mercy Niyang, Isiramen Olajide, Baffa Ibrahim, Stephen Ohakanu, Chinedu Agbakwuru, Ryan Leo, Geoffrey Greenwell, Adedayo Adeyemi, Bamgboye Afolabi, Ekanem, Mustapha Jamda, Annie Chen, Otse Ogorry, Aminu Suleiman, Kolapo Usman, Ojor R. Ayemoba, Adebobola Bashorun; Collaborating Institutions: Federal Ministry of Health (FMOH), National Agency for the Control of AIDS (NACA), National Population Commission (NPopC), National Bureau of Statistics (NBS), the U.S. Centers for Disease Control and Prevention (CDC) Nigeria, CDC Atlanta, The Global Funds to Fight AIDS, Tuberculosis, and Malaria, University of Maryland Baltimore (UMB), ICF International, African Field Epidemiology Network, University of Washington, the Joint United Nations Programme on HIV and AIDS (UNAIDS), the World Health Organization (WHO), and the United Nations Children's Fund (UNICEF).

Funding acknowledgement:

This project is supported by the President's Emergency Plan for AIDS Relief (PEPFAR) through the Centers for Disease Control and Prevention (CDC) under the cooperative agreement #U2GGH002108 to the University of Maryland, Baltimore and by the Global Funds to Fight AIDS, Tuberculosis, and Malaria through the National Agency for the Control of AIDS, Nigeria, under the contract #NGA-H-NACA to the University of Maryland, Baltimore.

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Table 1.

Sociodemographic, household, and clinical characteristics of HIV-positive respondents aged 15 to 64 years with detectable ARVs.

Variable	Total N=1,266 n (weighted %)	Non-disclosers N=503 n (weighted %)	Disclosers N=763 n (weighted %)
Sex			
Male	358 (31.8)	124 (28.5)	234 (33.9)
Female	908 (68.2)	379 (71.5)	529 (66.1)
Age group (years)			
15–24	85 (7.7)	45 (10.8)	40 (5.7)
25–49	878 (69.5)	340 (66.0)	538 (71.8)
50–64	303 (22.8)	118 (23.2)	185 (22.6)
Religion			
Muslim	267 (20.8)	116 (23.3)	151 (19.2)
Christian	993 (78.7)	383 (75.8)	610 (80.5)
Other	6 (0.5)	4 (0.8)	2 (0.3)
Education level			
None	237 (16.7)	131 (25.1)	106 (11.3)
Primary	312 (23.7)	120 (23.5)	192 (23.8)
Secondary	475 (40.5)	182 (38.6)	293 (41.7)
Tertiary/other	242 (19.1)	70 (12.8)	172 (23.1)
Marital status			
Never married	141 (12.7)	68 (15.5)	73 (10.8)
Ever married	1,125 (87.3)	435 (84.5)	690 (89.2)
Wealth index			
Lowest	149 (10.4)	86 (15.0)	63 (7.4)
Middle	878 (68.1)	333 (65.6)	545 (69.7)
Highest	239 (21.5)	84 (19.3)	155 (22.9)
CD4 category (cells/mm ³)			
< 100	65 (5.7)	28 (6.0)	37 (5.4)
100–349	250 (20.0)	104 (21.2)	146 (19.2)
350	951 (74.3)	371 (72.7)	580 (75.4)
Viral load suppression (<1000 copies/mL)			
Not suppressed	232 (18.2)	102 (21.0)	130 (16.5)
Suppressed	1033 (81.8)	401 (79.0)	633 (83.5)
Community setting			
Urban	542 (48.3)	191 (44.7)	351 (50.6)
Rural	724 (51.7)	312 (55.3)	412 (49.4)
Household role			
Member	657 (49.7)	286 (53.2)	371 (47.4)
Head	609 (50.3)	217 (46.7)	392 (52.6)
Household HIV positivity			
Participant Only	896 (71.6)	381 (77.3)	515 (67.9)

Variable	Total N=1,266 n (weighted %)	Non-disclosers N=503 n (weighted %)	Disclosers N=763 n (weighted %)
Other members	370 (28.4)	122 (22.7)	248 (32.1)

Frequency distributions and weighted column percentages for each independent variable are displayed for the total sample and stratified by HIV disclosure status.

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Table 2:

Crude and adjusted associations between HIV non-disclosure and covariates.

Variable	Unadjusted Odds Ratio (95% CI)	p-value	Adjusted Odds Ratio (95% CI)	p-value
Sex		0.11		0.89
Male	1.0 (ref)		1.0 (ref)	
Female	1.29 (0.95 – 1.77)		0.98 (0.70 – 1.36)	
Age group (years)		0.04		0.02
15–24	1.86 (0.99 – 3.47)		2.17 (1.13 – 4.16)	
25–49	0.89 (0.65 – 1.22)		0.97 (0.69 – 1.36)	
50–64	1.0 (ref)		1.0 (ref)	
Religion		0.25		
Muslim	1.0 (ref)		--	
Christian	0.77 (0.52 – 1.14)		--	
Other	2.18 (0.33 – 14.5)		--	
Education level		< 0.01		< 0.01
None	2.26 (1.45 – 3.52)		2.39 (1.52 – 3.75)	
Primary	1.0 (ref)		1.0 (ref)	
Secondary	0.94 (0.66 – 1.34)		0.90 (0.63 – 1.29)	
Tertiary/other	0.56 (0.36 – 0.89)		0.57 (0.41 – 0.83)	
Marital status		0.11		
Never married	1.0 (ref)		--	
Ever married	0.66 (0.40 – 1.09)		--	
Wealth index		< 0.01		
Lowest	1.0 (ref)		--	
Middle	0.47 (0.29 – 0.74)		--	
Highest	0.42 (0.24 – 0.73)		--	
CD4 category (cells/mm ³)		0.70		
< 100	1.0 (ref)		--	
100–349	1.00 (0.53 – 1.89)		--	
350	0.87 (0.50 – 1.53)		--	
Viral load suppression (<1000 copies/mL)		0.11		
Not suppressed	1.0 (ref)		--	
Suppressed	0.74 (0.52 – 1.07)		--	
Community setting		0.11		
Urban	1.0 (ref)		--	
Rural	1.27 (0.95 – 1.70)		--	
Household role		0.08		
Member	1.0 (ref)		--	
Head	0.79 (0.60 – 1.03)		--	
Household HIV positivity		< 0.01		< 0.01
Participant Only	1.0 (ref)		1.0 (ref)	
Other members	0.62 (0.44 – 0.87)		0.59 (0.41 – 0.83)	

Unadjusted and adjusted odds ratios for non-disclosure are shown alongside Wald 95% confidence intervals. The adjusted model was constructed by considering all variables below a bivariate significance threshold of $p < 0.2$ and removing terms one-by-one until all remaining variables met a retention threshold of $p < 0.05$. Age group and sex were included into the adjusted model *a priori*. Survey weights were included in all statistical models.

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