Accuracy of self-reported HIV testing history and awareness of HIV-positive status among people living with HIV in four Sub-Saharan African countries

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Abstract

Background: In many countries in Sub-Saharan Africa, self-reported HIV testing history and awareness of HIV-positive status from household surveys are used to estimate the percentage of people living with HIV (PLHIV) who know their HIV status. Despite widespread use, there is limited empirical information on the sensitivity of those self-reports, which can be affected by non-disclosure.

Methods: Bayesian latent class models were used to estimate the sensitivity of self-reported HIV testing history and awareness of HIV-positive status in four *Population-based HIV Impact Assessment* surveys in Eswatini, Malawi, Tanzania, and Zambia. Antiretroviral (ARV) metabolites biomarkers were used to identify persons on treatment who did not accurately report their status. For those without ARV biomarkers, the pooled estimate of non-disclosure among untreated persons was 1.48 higher than those on treatment.

Results: Among PLHIV, the model-estimated sensitivity of self-reported HIV testing history ranged from 96% to 99% across surveys. The model-estimated sensitivity of self-reported awareness of HIV status varied from 91% to 97%. Non-disclosure was generally higher among men and those aged 15-24 years. Adjustments for imperfect sensitivity did not substantially influence estimates of PLHIV ever tested (difference <4%) but the proportion of PLHIV aware of their HIV-positive status was higher than the unadjusted proportion (difference <8%).

Conclusions: Self-reported HIV testing histories in four Eastern and Southern African countries are generally robust although adjustment for non-disclosure increases

estimated awareness of status. These findings can contribute to further refinements in methods for monitoring progress along the HIV testing and treatment cascade.

Keywords: Sensitivity; Bayesian latent class; Self-report; Testing behaviors; HIV disclosure; HIV/AIDS

Introduction

Monitoring the HIV treatment and care cascade is central to the *Joint United Nations Programme on HIV/AIDS'* (UNAIDS) objective of ending the AIDS epidemic as a public health risk by 2030[1]. Routine tracking of population-level progress towards the UNAIDS' 2030 95-95-95 diagnostic, treatment, and viral load suppression targets can guide public health initiatives and improve programmatic efficiencies[2]. However, estimating progress towards the first pillar of the targets –the percentage of people living with HIV (PLHIV) who know their HIV status– is challenging. In sub-Saharan Africa (SSA), where 67% of the 38 million PLHIV were estimated to reside in 2019[3], measures of awareness are typically constructed from data about self-reported HIV testing history (i.e., ever tested for HIV) synthesized using models[4, 5] or reported directly from nationally representative household surveys (i.e., reporting a positive HIV test)[6-9].

Consideration of the potential for measurement bias is needed when interpreting self-reported survey data. Studies have shown that self-reports that concern sensitive information, e.g. an individual's HIV testing history or status, could be affected by non-disclosure[8, 10, 11]. For example, inconsistencies have been documented in Kenya and Malawi between self-reported data and biomarkers for metabolites of antiretrovirals (ARVs) and viral load suppression[7, 11]. While previous studies have sought to validate the accuracy of self-reported HIV status[11-13], analyzing recent data on both non-disclosure of self-reported HIV testing history and HIV status among PLHIV is key to improving the validity of these estimates.

Surveys that collect both self-reported information and ARV biomarkers can be used to assess the accuracy of self-reported HIV testing histories and HIV awareness status. Bayesian latent class models are used to estimate the sensitivity of self-reported HIV testing history and awareness of HIV status among PLHIV based on the presence of detectable ARVs[14].

Methods

Study population

The *Population-based HIV Impact Assessment* (PHIA) surveys are nationally representative multistage household-based surveys designed to provide population-level information on the burden of HIV disease and to document the progress of HIV programs[15-18]. All four PHIA surveys with available microdata on PLHIV aged 15+ years were included in our analysis: *Swaziland (Eswatini) HIV Incidence Measurement Survey 2* (2015-2016), *Malawi PHIA* (2015-2016), *Tanzania HIV Impact Survey* (2016-2017), and *Zambia PHIA* (2016).

Self-reports and antiretroviral (ARV) status

Participants who reported having received the results of any HIV test were classified as *ever tested and received results* (hereafter referred to as *"ever tested"*; *see Table S1)*. Participants who reported having ever received a positive test result after any HIV test, were classified as *aware of HIV-positive status*. A detailed description of the PHIA and ARV laboratory algorithms can be found *Text S2.*

Bayesian latent class models

Bayesian latent class models are a useful when there are no gold standard[16] and can efficiently account for parameter uncertainty[19]. We used this type of model to quantify the sensitivity of two self-reported outcomes among PLHIV: 1) HIV testing history and 2) HIV status awareness. Cross-tabulations of self-reports with ARV biomarkers provide empirical information on their sensitivity among those with detectable ARVs (Figure 1).

For participants with detectable ARVs, it assumed that: (1) they had been tested for HIV, received their results, and were aware of their status (since they are receiving care); and (2) there were no false positives in the detection of ARV metabolites. In the four PHIA surveys, an overall 99.9% of HIV-negative participants report having never received a positive HIV result, which aligns with the findings in another literature[12], we assumed no false positive of self-reported HIV testing history, or awareness of HIV status.

As ARV metabolites data only provide information about the sensitivity of self-reports among participants receiving treatment, the ratio of non-disclosure for PLHIV without versus with detectable ARVs was given a log-normal prior distribution with a mean of *log(1.48)* (standard error: 4) to estimate the sensitivity among people without detectable ARVs. This prior was elicited by reviewing available studies. The pooling of two studies conducted in rural Mozambique and Malawi[20, 21] suggests that people not receiving ARVs are 1.48 more likely to not disclose their diagnosis. Additional analyses were conducted to investigate the influence of this prior on our results. Equations and prior distributions are presented in *Table S2 and Text S1*.

Given known biases in self-reported estimates of HIV status awareness, analysts often reclassify individuals not aware of their status but with detectable ARVs as being aware of their HIV-positive status; as in published PHIA reports. To examine the impact of this partial adjustment, we compared the unadjusted, ARV-reclassified (as in PHIA reports), and Bayesian-adjusted (ARV status and non-disclosure) estimates of PLHIV aware of their status.

Models were calibrated separately for each country and for subgroup analyses (i.e. age, sex, urban/rural and socio-economic status). Bayesian hierarchical models using Markov Chain Monte Carlo, implemented through the JAGS software[22] and the *rjags* packages, were used to approximate the posterior densities[23, 24].

Ethics

Ethics approval for secondary data analyses was obtained from McGill University's Faculty of Medicine's Institutional Review Board (A10-E72-17B).

Results

Overall, 3,003 PLHIV from Eswatini, 2,227 from Malawi, 1,831 from Tanzania, and 2,467 from Zambia were included in the analyses, with 76.0%, 68.1%, 61.5% and 53.9% of with detectable ARVs. In all countries, a high fraction of PLHIV reported having ever been tested and the proportion of PLHIV reporting being aware of their status ranged from 68.0% in Tanzania to 86.5% in Eswatini (*Table S3)*.

Sensitivity of self-reports

Self-reported testing history

Among participants with detectable ARVs, the estimated sensitivity was highest in Eswatini (99.5%; 95% credible interval [95%CrI]: 99.2-99.8%), followed by Malawi (98.2%; 97.5-98.8%), Zambia (97.4%; 96.5-98.1%), and Tanzania (96.6%; 95.3-97.6%) (Figure 2). For people without detectable ARVs, the estimated sensitivity was 2.4% points (0.1-11.4%) lower than those with detectable ARVs in Tanzania. The differences were smaller elsewhere (*Table S4)*.

Self-reported awareness of HIV status

The sensitivity of self-reported awareness of HIV-positive status among participants with ARV metabolites was 97.4% (96.7-98.0%) in Eswatini, 94.2% (93.0-95.4%) in Malawi, 92.3% (90.5-93.8%) in Tanzania, and 91.6% (90.1-92.9%) in Zambia (Figure 2A). The estimated differences in sensitivity between PLHIV with and without detectable ARVs ranged from 1.8% points (0.1-8.5%) in Eswatini to 6.2% points (0.3-29.0%) in Zambia.

Differences by gender, age, rural/urban, and socioeconomic status

Among participants with detectable ARVs, women had 0.9-2.4% points higher sensitivities of self-reported HIV testing history and HIV status awareness than men (Figure 2B). The estimated sensitivities were the lowest at age 15-24 years (94.7-97.2% for HIV testing history and 83.9-91.9% for HIV status awareness) in all countries (Figure 2C). Participants residing in urban and rural areas had similar sensitivities and variations by socio-economic status were also small (*Figure S1*). Similar results for PLHIV without detectable ARVs were observed (*Figure S2*).

Adjusted proportion of PLHIV ever tested and PLHIV aware of their status

Adjusting for ARV status and non-disclosure influenced the estimates of the proportion ever tested for HIV less (largest difference between the adjusted and the self-reports was 3.9% points in Tanzania) than the estimated proportions of PLHIV aware of their status (largest difference was 7.2% points in Zambia) (Figure 2D). Results were less affected by the assumed non-disclosure ratio for PLHIV without detectable ARVs when antiretroviral therapy (ART) coverage is high (*Figure S3*).

Discussion

Self-reported information on HIV testing and diagnosis are primary data sources used to monitor trends in the HIV treatment and care continuum[2, 10]. Such data have also been proposed to estimate cross-sectional HIV incidence[25]. In this study, we leveraged ARV biomarkers from household representative surveys in Eswatini, Malawi, Tanzania and Zambia to estimate the sensitivity of self-reported HIV testing history and awareness of HIV-positive status among PLHIV. We found that among PLHIV with detectable ARVs, self-reports of HIV testing history have a high sensitivity (>96%) and self-reported awareness of HIV status had a marginally lower sensitivity (>91%) across these settings. These findings support the use of self-reported testing history to estimate testing trends and to model diagnosis coverage[5].

Social desirability bias may partly explain the nonnegligible lower sensitivities among male PLHIV and those aged 15-24 years [26]. However, differences in survey instruments could also result in higher sensitivities for specific groups. For example, in the PHIA survey, women were asked about HIV testing up to 4 times (before

pregnancy, during pregnancy, during labor, and at their last HIV test), while men were asked only once. The classification of women based on the positive response to any of the 4 questions increased the probability of women disclosing their true status.

The availability of ARV biomarkers enables the reclassification of PLHIV who do not disclose their status but for which ARV metabolites are detected as “aware”. We have found that this partial adjustment may be insufficient, especially if ART coverage is low in the surveyed population and the ratio of non-disclosure among those not on ART is high[27-30]. To accurately estimate awareness of status, results must also be adjusted for non-disclosure among PLHIV with undetectable ARVs.

Our results need to be interpreted considering certain limitations. First, none of the PHIA surveys with publicly available micro-data, are located in the West and Central African regions, where non-disclosure could be higher[31]. Indeed, a recent meta-analysis suggest that, globally, one in five PLHIV may not report their status[32]. The PHIA included here had some of the lowest levels of non-disclosure of the reviewed studies, suggesting that other settings could have lower sensitivities. Second, our study design limited our assessment of the sensitivity of testing history to PLHIV, and findings should not be extrapolated to people not living with HIV. Finally, it is not possible to empirically validate the sensitivity of self-reports among PLHIV without ARV metabolites. As such, we used information from two previous studies that used medical records to inform the non-disclosure ratio. Results could be sensitive to this non-disclosure ratio but the high ART coverage in the four countries mitigates this influence (*Figure S3*).

Strengths of this study include the use of standardized survey and laboratory data (i.e. detection of ARV metabolites). Second, the Bayesian latent class models propagate uncertainty to our results by assuming prior distributions and generating posterior credible intervals. Finally, we examined differences in the sensitivity of self-reports within different subgroups.

In conclusion, self-reported HIV testing histories have high sensitivities in the countries examined but self-reported awareness of HIV status are lower. Whenever available, ARV biomarkers data can be used to adjust self-reports but such adjustments may still underestimate diagnosis coverage, especially if ART coverage is low in that population. Our results can be used to produce more accurate estimates of the UNAIDS targets. Future research should extend this work to other regions and populations.

Authors' Statement

YX, AG, RMM, and MMG were responsible for study design. YX was responsible for literature search, drafting the article and statistical analysis. RMM, AG, MCB, LFJ, KM, JWE and MMG were responsible for reviewing and editing the article.

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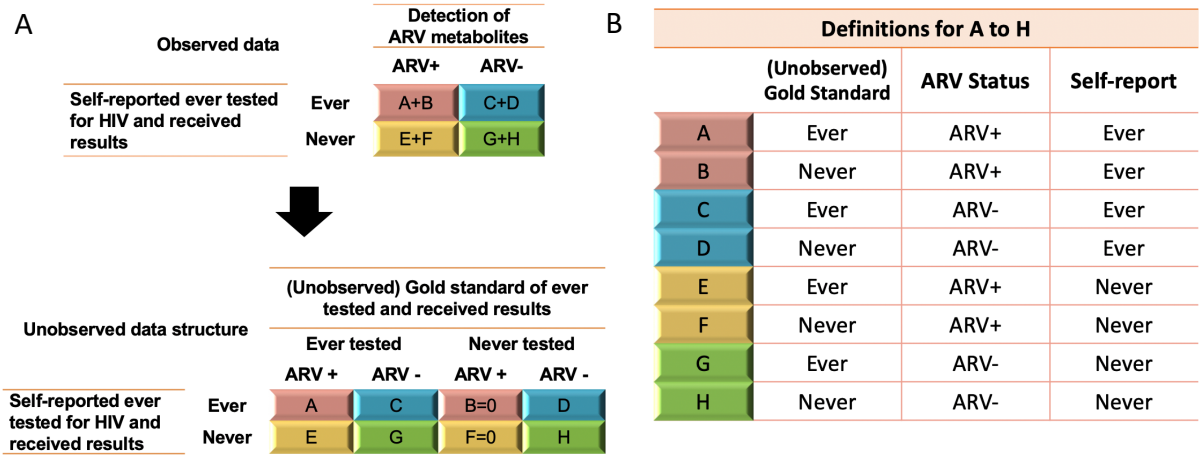

Figure 1. Observed and unobserved data structure of self-reported *ever tested and received results*, and antiretroviral (ARV) metabolites status. Definitions for cells A to H are listed in the table. As it was assumed that participants with detectable ARV must have been tested, cells B and F are *de facto* equal to zero. The same technique was applied to the self-reported awareness of HIV status and was applied to all four Sub-Saharan African countries.

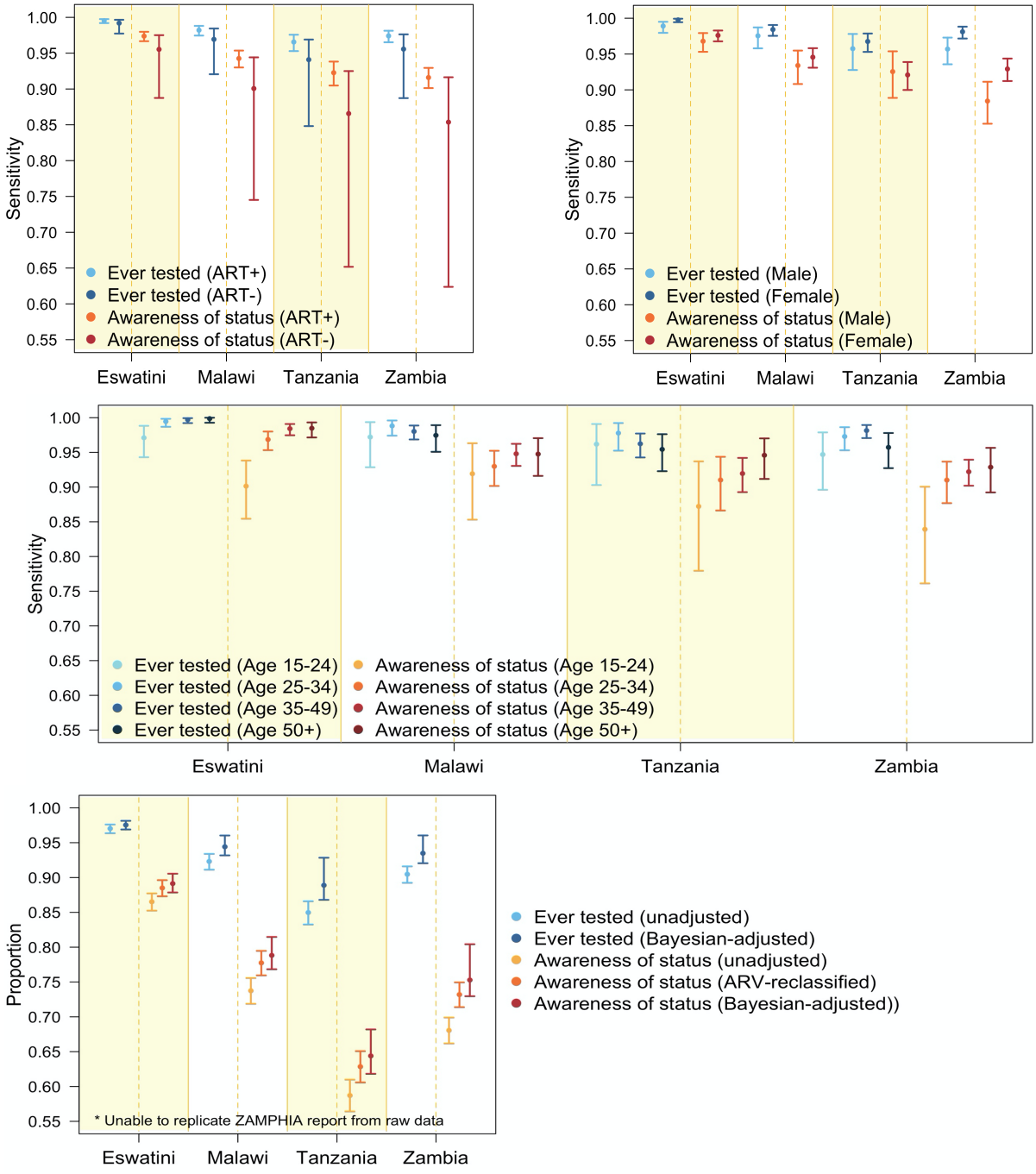

Figure 2. Posterior medians and 95% credible intervals for selected outcomes. Sensitivity (% of positives correctly identified) of self-reported ever tested and received results, and awareness of HIV-positive status among people living with HIV (PLHIV) by: (A) antiretroviral (ARV) metabolites status, (B) gender (ARV+), and (C) age groups (ARV+). Panel D portrays the overall proportion of PLHIV ever tested who received results and the awareness of HIV-positive status [self-reported vs. ARV-reclassified (as in PHIA reports) vs. Bayesian-adjusted (adjusting for ARV status and non-disclosure among PLHIV without detectable ARVs)].