

Contents lists available at ScienceDirect

Asian Pacific Journal of Tropical Biomedicine

journal homepage: www.elsevier.com/locate/apjtb



Management and decision-making

http://dx.doi.org/10.1016/j.apjtb.2015.05.010

Decliners of provider-initiated HIV testing and counselling: Characteristics of participants who refused HIV testing in a population survey in Zambia



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ARTICLE INFO

Article history:
Received 29 Apr 2015
Received in revised form 7 May, 2nd revised form 8 May 2015
Accepted 19 May 2015
Available online 8 July 2015

Keywords:
HIV/AIDS
Zambia
Testing
Refusals
Population survey

ABSTRACT

Objective: To assess the prevalence of HIV infection, to highlight HIV-testing refusal rates among participants in a population-based tuberculosis survey and to assess the implication for programme implementation.

Methods: This cross-sectional study on the characteristics of participants who refused HIV testing was conducted in a national survey in Zambia. All eligible participants were aged above 15 years and included in the analysis.

Results: Out of the 44 791 tuberculosis survey participants, 14 164 (31.6%) refused to participate in HIV testing. The unemployed, rural dwellers, married, and those aged 15–24 years were associated with higher refusal rates.

Conclusions: Strategies to improve HIV testing acceptance are necessary. Qualitative research is recommended to understand the reasons for testing refusals so that remedial interventions can be implemented.

1. Introduction

HIV/AIDS is one of the major public health issues in Zambia and is estimated to have accounted for 27 000 (range 23 000–32 000) deaths in 2013 [1]. An improved HIV testing rate would lead to an increased case detection rate which will in turn increase the uptake of anti-retroviral therapy (ART) and strengthen access to appropriate HIV care to those infected with the virus [2]. People living with HIV co-infected with *Mycobacterium tuberculosis* face persistent inequity in access to ART; for instance, in 2011, 58% of all eligible people living with HIV worldwide were provided ART compared to 48% of HIV/tuberculosis (TB) co-infected patients [3]. According to the 2012 UNAIDS report, the HIV prevalence in Zambia stood at an estimated 12.5 percent. Unlike other countries where poverty is

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Foundation Project: Supported by the government of the Republic of Zambia (GRZ) through Ministry of Health (budget support) and United States Government (USG) through USAID and CDC Zambia, Grant U2GPS001792.

commonly associated with HIV, in Zambia, infection rates are higher among those from affluent backgrounds and advanced education [4]. HIV transmission in adults occurs primarily through heterosexual activity and is higher among women than men [5]. In 2012, only 15 percent of Zambian adults aged 15–49 had received a test in the last 12 months and knew their HIV status [4].

With the development of the first ARTs in the mid 1990s, testing positive for HIV was no longer considered terminal but more as a chronic illness. HIV testing is most commonly associated with anxiety, psychological trauma and fear of stigma which can be overcome through supportive and effective counselling. However, on the other hand, timely HIV testing provides the benefits of reduction of the spread of the virus and continued health of infected individuals through access to HIV health care services. Several studies have shown that patients who initiate early ART are less likely to spread the virus [6–8]. Furthermore, testing pregnant women have shown to play an important role in Prevention of Mother to Child Transmission (PMTCT) [9]. HIV testing provides an opportunity for early diagnosis and access to therapy. The Zambian Government launched its national policy of providing free and universal

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access to ART in 2003 and later expanded to include all related services in 2005 [10].

HIV testing is important for the estimation of disease prevalence. However, high rates of refusal may result in underestimation of prevalence rates. This highlights a need for more acceptable test settings and improved strategies if refusal bias is to be minimised.

Despite the known benefits of HIV testing and counselling (HTC), in Zambia acceptance rates have so far been documented to vary from 69% to 98.5% [11,12]. Nonetheless, there is limited literature regarding individuals who refuse HIV testing in population-based surveys.

Studies show that there is a significant difference in the prevalence of HIV infection among acceptors and decliners of HIV testing. For example, one study found that the relative risk of undetected HIV infection was 2.74 [95% confidence interval (CI) 1.44–5.18] times greater in the group that refused testing than among those that accepted to be tested [13]. In another study, Plitt and colleagues found that the HIV seroprevalence among women that declined prenatal HIV screening was 3.3 times higher than among the acceptors [14].

Due to the importance of HIV and its co-infection with *Mycobacterium tuberculosis* in Zambia, participants in a national TB prevalence survey were also required to participate in a field level screening for HIV to assess the prevalence of HIV infection. This article highlights HIV-testing refusal rates among participants in a population-based TB survey and assesses the implication for programme implementation.

2. Materials and methods

This was a cross-sectional study within a population-based national TB prevalence survey that was conducted according to the WHO guidelines on TB prevalence surveys [15]; after completing the procedures related to TB survey, an HIV specific written informed consent was administered to each participant. The social demographic details, symptom status, health-seeking behaviour for all the survey participants were already collected during the TB screening procedures by using a separate consent process. If the participant agreed to participate, the HIV testing and counselling were conducted in accordance with national algorithm and elaborated in standard operating procedures (SOPs). Participants who consented to HIV testing had their blood collected through a finger prick and the blood was placed directly onto the screening rapid test strip (Determine TM). A unique identification number (barcode) was affixed to the filter paper card, the Dried Blood Spot (DBS) and the barcode were linked to other variables already collected through the standard questionnaire. No other identifiers were attached to the DBS samples. Those who declined to participate were allowed to exit the study.

Pre-test and post-test counselling were provided to all participants who choose to know their results. Pre-test counselling was done prior to testing. For participants, who did not wish to know their HIV test result, the post-test counselling was not performed. The HIV test results were available within 10–20 min and thereafter, post-test counselling followed. If the test was non-reactive, a negative result was communicated to the participant. However, if the test was reactive, the participant was asked to give a second blood sample from another finger

prick for a confirmatory test (Uni-Gold[™] Recombigen[®]). If the second test was reactive, the participant was informed of the positive status, appropriately counselled and referred for further management to the nearest health facility which was already identified in the vicinity of each and every survey cluster. If the second test was non-reactive, the result was considered indeterminate and the participant was advised to visit the nearest health facility for a further testing after six weeks

The data were analysed by using STATA Version 12.0. Comparison of categorical variables was done through the *Chi*-square tests. Significant testing was done at 95% *CI*. Association tests were done by using *Chi*-square tests for binary variables and logistic regression as appropriate; the design effect was accounted for in the analysis by calculating robust standard errors as implemented in the STATA "svy" commands.

The study protocol was cleared by the University of Zambia Biomedical Research Ethics Committee (UNZABREC) No: 020-08-12. Authorisation to conduct the survey was sought in line with the existing national policies and guidelines at national, provincial and district levels. Written informed consent was obtained from all individuals who agreed to participate in the survey.

3. Results

Out of the 44791 TB survey participants, 14164 (31.6%) refused to participate in HIV testing. The mean age of those who refused to test for HIV was 36.9 years, with a range of 15–110 years. Of the people who refused testing, majority were aged 15–24 years (32.3%), married (52.9%), females (58.0%) and from rural areas (57.1%). Majority of those who refused testing had at least some secondary level of education (43.1%), were from the highest wealth quintile (28.6%), and unemployed (26.71%) as outlined in Table 1.

More than 90% of the decliners did not report any of the three cardinal symptoms for TB (that is no history of fever or cough or chest pain). Of the symptomatic survey participants who refused HIV testing, 60.2% of them had not sought care from a health facility before.

By age, participants from the younger age band (15–24 years) were more likely to refuse than those of the other age groups (P=0.0002). Residents from rural areas had significantly higher refusal rates than their urban counterparts (P=0.0002). By marital status, the currently married were associated with higher refusal rates than their unmarried colleagues (P=0.0003). The unemployed (P=0.0000), highest wealth quintile (P=0.0023) and participants with at least some secondary level education (P=0.012) also reported significantly higher refusal rates.

There was no significant difference in the refusal rates by gender, status of current TB treatment and previous treatment history as shown in Table 1.

The Copperbelt and Luapula Provinces had the highest rates of testing refusals, at 41.7% and 42.0% respectively with corresponding higher HIV prevalence estimated at 8.3% and 5.2%. Northern Province, on the other hand, had the lowest rate of refusals at 12.4% with the HIV prevalence estimated at 3.0%. There was a significant difference in the HIV refusal rates by province (P = 0.0000) as shown in Table 2.

Table 1
The background characteristics of those who refused HIV testing.

Background characteristics	Background characteristics	Number	Percentage	95% Binomial CI
Age (N = 14 164)	15–24	4 573	32.3	31.5–33.1
	25–34	2871	20.3	19.6-20.9
	35–44	2 4 6 1	17.4	16.8-18.0
	45–54	1 607	11.4	10.8-11.9
	55–64	1 188	8.4	7.9-8.9
	65+	1 464	10.3	9.8-10.8
Marital status ($N = 14164$)	Never married	4 3 0 4	30.4	29.6-31.2
,	Married or living as married	7 500	52.9	52.1-53.8
	Divorced or separated	900	6.4	6.0-6.8
	Widowed	1 460	10.3	9.8-10.8
Sex $(N = 14164)$	Male	5 9 5 2	42.0	41.2-42.8
	Female	8 2 1 2	58.0	57.2-58.8
Setting	Urban	6071	42.9	42.0-43.7
Ü	Rural	8 093	57.1	56.3-58.0
Education level ($N = 14164$)	No schooling	1 490	10.5	10.00-11.00
200000000000000000000000000000000000000	Primary	5 921	41.8	41.00-42.60
	Secondary	6111	43.1	42.30-44.00
	Tertiary	625	4.4	4.10-4.80
	Unknown	17	1.1	0.07-0.20
Wealth index $(N = 12383)$	Lowest	1 884	15.21	14.6-15.9
	Second Lowest	1 746	14.10	13.5-14.7
	Middle	2 287	18.47	17.8-19.2
	Fourth	2 9 2 5	23.62	22.9-24.4
	Highest	3 541	28.60	27.8-29.4
Occupation $(N = 14 164)$	Unemployed	3 783	26.71	26.0-27.4
	Occasional/seasonal	362	2.56	2.3-2.8
	Employed by Government	379	2.68	2.4-3.0
	Employed in private s	928	6.55	6.1-7.0
	Self-employed	1 431	10.10	9.6-10.6
	Pupil/student	2 483	17.53	16.9-18.2
	Housewife/homemaker	1 025	7.24	6.8–7.7
	Working on own land	3 648	25.76	25.0-26.5
	Other	125	0.88	0.7-1.0
Symptom screening result ($N = 14164$)	Negative	12951	91.44	91.00-91.90
, 1	Positive	1 205	8.51	8.10–9.00
	Not applicable	8	0.06	0.02-0.10
Health seeking ^a $(N = 6708)$	No	4 0 3 8	60.20	59.0-61.4
6 (1 1 1 1 7)	Yes	2 340	34.88	33.7–36.0
	Not applicable	330	4.92	4.4–5.5

^a: This was in a subgroup of individuals eligible to submit sputum for TB diagnosis.

Table 2
HIV-testing refusal rates and HIV prevalence estimates by regions.

Region		HIV estimate (%)	95% CI	Refused testing (%)
Overall		6.8	5.6-7.9	30.7
By province	Central	5.2	3.6-6.8	20.8
	Copperbelt	8.3	6.6-9.9	41.7
	Eastern	3.4	1.7 - 5.1	23.0
	Luapula	5.2	2.4 - 8.0	42.0
	Lusaka	11.3	9.4-13.2	32.5
	Muchinga	1.5	1.5 - 1.6	18.8
	Northern	3.0	1.3-4.6	12.4
	North Western	5.9	3.8-8.0	37.8
	Southern	8.1	4.9-11.2	35.7
	Western	11.9	8.0-15.8	17.6

4. Discussion

This is the first study to document the HIV-testing refusal rates in the context of a national TB prevalence survey or indeed any other population-based surveys in Zambia. The overall refusal rate was found to be 31.6%, however, there seems to be no literature as yet on the acceptable rate of HIV-testing refusal

rates in national TB prevalence surveys in low-resource settings in Africa. The refusal rate that was found in this study was, however, lower than what has been reported before in some hospital-based studies in Zambia [11,12]. The findings from this study showed that the HIV-testing refusal rates varied with the background characteristics of the survey participants. There was no significant difference between the mean age of those who declined and those who accepted to test. This is similar to the findings of a study conducted in an emergency hospital department among adults aged 18–64 years in the USA [13].

There were higher refusal rates among those with at least some level of secondary education and also among married participants than those without any level of secondary and the unmarried respectively. Probably, this implies that the level of education may play a role in whether one will refuse or accept to take the HIV test in such a survey; being married equally seems to lead to an increased likelihood of refusal. In fact, these findings are similar to the study reported from Ethiopia which showed that 48.2% of the women that refused to be tested during antenatal visits had completed primary level of education (1–8 grades) and the majority were married [16]; however, this was a in a different setting and from a special group of individuals.

This article also highlights the fact that the younger age groups (15–24 years) were more likely to decline HIV testing as compared to the older age groups. This, however, is in contrast with the findings by Setse and Maxwell [17], who noted that in an emergency department setting, persons over 55 years of age were more likely to refuse testing. Nevertheless, in a population-based study in rural South Africa [18], it was found that those in the middle age groups (males aged 30-34 years; females aged 25-29) were more likely to repeatedly refuse to get tested compared to the younger and older age groups. In addition, Giordano and colleagues [18] found that males were significantly more likely than females to refuse HIV testing and those residents in urban areas within the surveillance area. Our study has further shown that the female participants were more likely to refuse testing than the male participants and that those in the rural areas were more likely to refuse HIV testing than those in the urban areas. On the other hand, increasing level of education and relative wealth tended to increase the likelihood of testing refusals. Further exploration and qualitative studies would be required to provide some explanation for these discrepancies.

The majority (90%) of those not testing for HIV were asymptomatic during TB screening; that is, they did not report any history of fever, cough or chest pain. Of the symptomatic survey participants who refused HIV testing, 58% of them had not sought care from a health facility before.

This study has highlighted the need to further explore the reasons behind the HIV-testing refusals. This is because most of the subgroups which were found to be declining an HIV test are also the groups expected to have high HIV incidence; that is the young and the married. If such groups do not participate in testing programs at national level, this may affect the accuracy of the HIV burden estimates and therefore introduce bias in estimates of incidence and prevalence.

The study was conducted as part of the national TB prevalence survey and data on reasons for HIV-testing refusal were not collected. Furthermore, the role of the test setting environment in acceptance or refusal of testing was not explored. Future studies should take into account the factors of HIV-testing refusals and explore the role of provider-initiated HIV testing and counselling (PITC) or self-testing in population-based studies.

HIV-testing refusals in Zambia vary by background characteristics of the population. Targeted information education communication may help to provide the minimum level of knowledge required by community members. Future studies should incorporate reasons for testing refusals. Given the relatively low acceptance rates of HIV screening, more needs to be done to encourage uptake so as to provide more accurate estimates of the HIV burden in the country.

Conflict of interest statement

We declare that we have no conflict of interest.

Acknowledgments

The funding for this survey was made possible with support from the government of the Republic of Zambia (GRZ) through Ministry of Health (budget support) and United States Government (USG) through USAID and CDC Zambia, Grant U2GPS001792. We would like to thank all the survey participants for their insights and much appreciation is for the

community health workers who worked with the research assistants during data collection.

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