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ABSTRACT

Despite the availability of free and anonymous HIV testing almost 60% of Swedish patients are diagnosed late. Identifying predictors of different types of barriers could inform policy makers and health care of interventions to increase testing where needed. This cross-sectional study aimed to describe and analyze barriers to HIV testing as reported by Swedish patients newly diagnosed with HIV infection. $N = 285$ patients completed the 18-item Barriers to HIV Testing Scale – Karolinska Version. Descriptive analysis and logistic regressions were performed to assess the prevalence of barriers and to identify predictors for the different investigated barriers. Barriers to testing were reported by 60%. Approximately 67% of patients originating from Sweden, 50% from Sub-Saharan Africa and 75% from Eastern European/East Asian countries reported barriers. Patients who were younger and patients who self-initiated HIV testing, had greater odds of reporting a barrier than older individuals and those who were offered a test through screening or by a healthcare professional. To counteract barriers that still exist on an individual level, healthcare-initiated HIV testing could be offered more broadly and information about risks for transmission and effectiveness of HIV treatment still needs to be disseminated among both people born in Sweden and different migrant groups.

Introduction

HIV remains a public health problem in Europe. In Sweden, around 8.000 people living with diagnosed HIV (PLWH) are followed at 29 clinics. Of these, 98% are on antiviral therapy, out of which 95% have undetectable viral loads (HIV RNA<50 copies/mL), i.e., effective virus therapy (Giardina et al., 2019; QRC Stockholm, 2020). Sweden has world-class HIV care and was the first country to report meeting the UNAIDS 90-90-90 diagnosis and treatment targets (Gisslén et al., 2017). It estimated that the incidence of undiagnosed HIV-1-infections among persons residing in Sweden decreased by almost two-thirds from 2010 to approximately 10% 2015 (Public Health Agency of Sweden, 2015; Giardina et al., 2019). However, late presentation still remains a significant problem; Swedish patients are diagnosed at a late stage of HIV infection at a rate of 58% in comparison to their counterparts in the EU/EEA at 51% (ECDC, 2017).

International and European guidelines call for increasing the number of people diagnosed at an early stage of infection (WHO, ECDC, 2017). In settings such as Sweden, with low prevalence and with an epidemic concentrated in populations at increased risk, the WHO recommends provider-initiated testing as well as indicator-condition guided testing to all individuals who present with symptoms that are clinically associated with HIV (WHO, 2015). Research in Sweden has recently described predictors which contribute to late HIV testing in Sweden (Brännström, 2016). The study demonstrated that missed opportunities at the health systems level strongly contribute to late diagnoses. Migrants, persons infected through heterosexual transmission and persons aged over 40 all had higher probability of late diagnosis. It is estimated that 19% of migrants acquired HIV infection *after* arrival to Sweden (Brännström et al., 2017), which highlights that the current strategy of offering HIV screening to all refugees

upon arrival at health examinations is not enough to identify HIV infection that occurs post-migration. Persons diagnosed late who are not from key populations, such as migrants and men who have sex with men, are more likely to have a history of missed presentation at a health care visit, to neglect symptoms of HIV, and are less likely to self-initiate HIV testing (Brännström, Johansson, et al., 2016; Brännström, Svedhem, et al., 2016), indicating a low risk perception. The Swedish national HIV strategy emphasizes the need to improve overall HIV knowledge throughout all levels of the Swedish healthcare system with the goal of increasing provider-initiated testing (Public Health Agency of Sweden, 2017).

Despite excellent HIV care outcomes in Sweden, increasing HIV testing and reducing the number of late diagnoses persist as challenges in the Swedish HIV epidemic, leading us to the importance of examining barriers from the test-takers' perspective. Understanding what individual barriers are associated with HIV-testing is essential to improve and expand current HIV testing practices. The aim of the study was, therefore, to investigate barriers to HIV testing in a group of newly diagnosed persons living with HIV in Sweden.

Specific research questions were:

(1) Do persons recently diagnosed with HIV report any barrier to HIV testing?
(2) What risk indicators are associated with each of the four categories of barriers: personal barriers, structural barriers, socio-economic barriers and barriers related to confidentiality?

Materials and methods

Research design

This was a cross-sectional and descriptive quantitative study.

Procedures

Eligible patients were informed about the study by their health care provider during a routine clinic visit. After giving written consent, participants completed a Swedish or English version of a questionnaire (see below) at the clinic. Interpreters were available by phone or in person as needed. The study was approved by the Regional ethics committee in Stockholm, Sweden (record number 2009/1029-31/1-4 and 2014/928-31) and by the Regional ethics committee in Gothenburg (record number 532-11 amended 18/11/2011).

Measures

Barriers to HIV testing were assessed with the 18-item Barriers to HIV Testing Scale – Karolinska version (Table 1; Wiklander et al., 2015). Individuals could choose one of three responses to 18 statements in the barrier scale with respective scores: very important (2), somewhat important (1) or not important (0). The instrument covers four dimensions of barriers to HIV testing: *personal consequences (*related to individual fear such as fear of losing a partner and/or family and friends, and fear of the result of an HIV test); *structural barriers* (such as not having transportation to a testing site, not knowing where to test, poor rapport with the staff at the testing site); *social and economic security* (fears of losing work, not being able to obtain insurance) and; *confidentiality (*concerns about privacy, being recognized at the testing site). Seven statements were related to personal consequences, six statements were related to structural barriers, three statements were related to social and economic barriers and two statements were related to confidentiality. Detailed socio-demographic data was collected from the Swedish national HIV registry InfCareHIV and through an additional questionnaire In addition to the ordinal and categorical data collected, the participants were asked to answer one open ended question: *What is the main reason you did not test for HIV earlier?*

Statistical analysis

Data was summarized using descriptive statistics in SPSS version 25 (SPSS Inc, Chicago, U.S.A.). Socio-demographic data were dichotomized or re-categorized before further analysis, (Table 1). Cross-tabulations with Chi-square were used to test for unadjusted relationship between the outcome barrier and all participant characteristics to determine which variables were associated with reporting a barrier to testing. All socio-demographic variables yielding a $p < 0.20$ from Chi-square testing were included in the multivariate logistic model using enter method.

Bivariate logistic regressions were performed to assess the impact of several factors on the likelihood that respondents would report any barrier and for the respective barrier sub-categories. The model contained 10 independent variables: age, country of origin, accommodation, residence in a metropolitan area, religion (respondents who reported that religion influenced daily life), initiator of test, civil status, time since immigration, previous thoughts about HIV and drug use. The variable country of origin was described by four regions: Sub-Saharan Africa, Sweden, East, Other. Sweden was

Table 1. Descriptive and bivariate analysis of explanatory variables.

Characteristics	Total N (%)	Barrier Yes (%)	P-value	Personal consequences Yes (%)	Structural barriers Yes (%)	Social and economical Yes (%)	Confidentiality Yes (%)
Total cohort	285	178 (62.5)		146 (51.2)	119 (41.8)	89 (31.2)	110 (38.6)
HIV stage							
Non-LP	103 (36.1)	72 (66.0)	0.350	61 (59.2)	41 (39.8)	37 (35.9)	48 (46.6)
LP	182 (63.9)	110 (60.4)		85 (46.7)	78 (42.9)	52 (28.6)	62 (34.1)
Gender							
Female	111 (39.0)	65 (58.6)	0.278	58 (52.3)	47 (42.3)	37 (33.3)	45 (40.5)
Male	174 (61.0)	113 (64.5)		88 (50.6)	72 (41.4)	52 (29.9)	65 (37.4)
Age (years)							
<30	60 (21.1)	41 (68.3)	0.297	35 (58.3)	28 (46.7)	21 (35.0)	27 (45.0)
31–40	102 (35.8)	67 (65.7)		52 (51.0)	45 (44.1)	27 (26.5)	40 (39.2)
41–50	68 (23.9)	41 (60.3)		35 (51.5)	29 (42.7)	24 (35.3)	26 (38.2)
>50	55 (19.3)	29 (52.7)		24 (43.6)	17 (30.9)	17 (30.9)	17 (30.9)
Mean (SD)	40.5 (11.5)	39.7 (11.2)	0.090*	39.7 (11.3)	39.6 (11.4)	41.0 (11.7)	39.4 (11.6)
Route of transmission							
Heterosexual	180 (63.2)	108 (60.0)	0.663	91 (50.6)	77 (42.8)	54 (30.0)	75 (41.7)
MSM	58 (20.4)	40 (69.0)		34 (58.6)	22 (37.9)	21 (36.2)	20 (34.5)
PWID	15 (5.3)	11 (73.3)		10 (66.7)	8 (53.3)	5 (33.3)	5 (33.3)
Unknown/other	32 (11.2)	19 (59.4)		11 (34.4)	12 (37.5)	9 (28.1)	10 (31.3)
Country of origin							
Sweden	95 (33.3)	63 (66.3)	0.031*	53 (55.8) *	36 (37.9) *	26 (27.4) *	31 (32.6) *
SSA	122 (42.8)	64 (52.5)		50 (41.0)	45 (36.9)	30 (24.6)	41 (33.6)
East	36 (12.6)	28 (77.8)		26 (72.2)	22 (61.1)	18 (50.0)	22 (61.1)
Other	32 (11.2)	23 (71.9)		17 (53.1)	16 (50.0)	15 (46.9)	16 (50.0)
Country of transmission							
Sweden	84 (29.5)	56 (66.7)	0.178*	51 (60.7) *	33 (39.3)	23 (27.4)	32 (38.1)
SSA	102 (35.8)	54 (52.9)		41 (40.2)	40 (39.2)	26 (25.5)	35 (34.3)
East	54 (19.0)	37 (68.5)		32 (59.3)	30 (55.6)	23 (42.6)	28 (51.9)
Other	45 (15.8)	31 (68.9)		22 (48.9)	16 (35.6)	17 (37.8)	15 (33.3)
Immigration time							
Swedish	95 (33.3)	63 (66.3)	0.196*	53 (55.8)	36 (37.9)	26 (27.4)	31 (32.6)
< 2 months	40 (14.0)	20 (50.0)		12 (30.0)	17 (42.5)	8 (20.0)	13 (32.5)
2 months to <1 year	56 (19.7)	30 (53.6)		24 (42.9)	24 (42.9)	19 (33.9)	18 (32.1)
1–5 years	45 (15.8)	30 (66.7)		26 (58.8)	20 (44.4)	18 (40.0)	25 (55.6)
>5 years	47 (16.5)	34 (72.3)		31 (66.0)	22 (46.8)	17 (36.2)	22 (46.8)
Unknown	2 (0.7)	1 (50.0)		0 (0.00)	0 (0.00)	1 (50.0)	1 (50.0)
Education level							
None	26 (9.1)	17 (65.4)	0.941	13 (50.0)	11 (42.3)	10 (38.5)	9 (34.6)
Pre-secondary school	75 (26.3)	44 (58.7)		34 (45.3)	36 (48.0)	25 (33.3)	24 (32.0)
Secondary school	93 (32.6)	58 (62.4)		52 (55.9)	33 (35.5)	27 (29.0)	38 (40.9)
Post-secondary school	88 (30.9)	57 (64.8)		45 (51.4)	37 (42.1)	26 (29.6)	38 (43.2)
Unknown	3 (1.1)	2 (66.7)		2 (66.7)	2 (66.7)	1 (33.3)	1 (33.3)
Source of income							
Own salary	122 (42.8)	82 (67.2)	0.357	68 (55.7)	45 (36.9)	37 (30.3)	49 (40.2)
Other	158 (55.4)	93 (58.9)		76 (48.1)	71 (44.9)	50 (31.6)	59 (37.3)
Unknown	5 (1.8)	3 (60.0)		2 (40.0)	3 (60.0)	2 (40.0)	2 (40.0)
Accommodation							
Own	178 (62.5)	116 (65.2)	0.026*	95 (53.4)	70 (39.3)	61 (34.3)	66 (37.1)
2nd hand/family	60 (21.1)	35 (58.3)		29 (48.3)	29 (48.3)	15 (25.0)	27 (45.0)
By authorities	23 (8.1)	15 (65.2)		13 (56.5)	11 (47.8)	5 (21.7)	9 (39.1)
Refugee camp	19 (6.7)	7 (36.8)		5 (26.3)	5 (26.3)	5 (26.3)	5 (26.3)
Homeless/jail	5 (1.8)	5 (100.0)		4 (80.0)	4 (80.0)	3 (60.0)	3 (60.0)
Civil status							
Single/divorced/widow	111 (39.0)	70 (63.1)	0.004*	56 (50.4)	41 (36.9)	28 (25.2)	38 (34.2)
Cohabiter/live-apart	75 (26.3)	57 (76.0)		52 (69.3)	40 (53.3)	32 (42.7)	41 (54.7)
Married/reg. partner	99 (34.7)	51 (51.5)		38 (38.4)	38 (38.4)	29 (29.3)	31 (31.3)
Children							
No	105 (36.8)	66 (62.9)	0.454	55 (52.4)	45 (42.9)	27 (25.7)	43 (41.0)
Yes	160 (56.1)	97 (60.6)		79 (49.4)	66 (41.3)	55 (34.4)	58 (36.2)
Unknown	20 (7.0)	15 (75.0)		12 (60.0)	8 (40.0)	7 (35.0)	9 (45.0)
Metropolitan area							
No	83 (29.1)	45 (54.2)	0.066*	31 (37.4)	34 (41.0)	23 (27.7)	27 (32.5)
Yes	202 (70.9)	133 (65.8)		115 (56.9)	85 (42.1)	66 (32.7)	83 (41.1)
Migration status							
Non migrant	95 (33.3)	63 (66.3)	0.011*	53 (55.8)	36 (37.9)	26 (27.4)	31 (32.6)
Refugee	85 (29.8)	42 (49.4)		30 (35.3)	34 (40.0)	19 (22.4)	30 (35.3)
Other	105 (36.8)	73 (69.5)		63 (60.0)	49 (46.7)	44 (41.9)	49 (46.7)
Religion affecting daily life							
No	179 (62.8)	118 (65.9)	0.075*	101 (56.4)	77 (43.0)	63 (35.2)	74 (41.3)
Yes	90 (31.6)	48 (53.3)		34 (37.8)	34 (37.8)	20 (22.2)	30 (33.3)
Unknown	16 (5.6)	12 (75.0)		11 (68.8)	8 (50.0)	6 (37.5)	6 (37.5)

Table 1. Continued.

Characteristics	Total N (%)	Barrier Yes (%)	P-value	Personal consequences Yes (%)	Structural barriers Yes (%)	Social and economical Yes (%)	Confidentiality Yes (%)
Psychiatric illness							
No	253 (88.8)	157 (62.1)	0.694	128 (50.6)	108 (42.7)	79 (31.2)	101 (39.9)
Yes	32 (11.2)	21 (65.6)		18 (56.2)	11 (34.4)	10 (31.3)	9 (28.1)
Drug use							
No	231 (81.0)	140 (60.6)	0.182*	112 (48.5)	97 (42.0)	71 (30.7)	90 (39.0)
Yes	54 (19.0)	38 (70.4)		34 (63.0)	22 (40.7)	18 (33.3)	20 (37.0)
Previous thoughts of HIV							
No	209 (73.3)	123 (58.8)	0.112*	97 (46.4)	87 (41.6)	58 (27.8)	79 (37.8)
Yes	66 (23.2)	48 (72.7)		43 (65.2)	27 (40.9)	27 (40.9)	27 (40.9)
Unknown	10 (3.5)	7 (70.0)		6 (60.0)	5 (50.0)	4 (40.0)	4 (40.0)
Neglect of symptoms							
No	247 (86.7)	151 (61.1)	0.240	124 (50.2)	105 (42.5)	77 (31.2)	98 (39.7)
Yes	38 (13.3)	27 (71.0)		22 (57.9)	14 (36.8)	12 (31.6)	12 (31.6)
Previous negative test							
No	176 (61.8)	107 (60.8)	0.755	88 (50.0)	70 (39.8)	51 (29.0)	67 (38.1)
Yes	91 (31.9)	59 (64.8)		48 (52.8)	42 (46.2)	33 (36.3)	34 (37.4)
Unknown	18 (6.3)	12 (66.7)		10 (55.6)	7 (38.9)	5 (27.8)	9 (50.0)
Initiator of testing							
Patient	46 (16.1)	38 (82.6)	0.002*	32 (69.6)	27 (58.7)	24 (52.2)	22 (47.8)
Physician: symptom	97 (34.0)	57 (58.8)		49 (50.5)	37 (38.1)	29 (29.9)	33 (34.0)
Screening high prev gr	80 (28.1)	43 (53.8)		32 (40.0)	29 (36.3)	20 (25.0)	29 (36.3)
Screening other	60 (21.1)	39 (65.0)		32 (53.3)	25 (41.7)	15 (25.0)	25 (41.7)
Unknown	2 (0.7)	1 (50.0)		1 (50.0)	1 (50.0)	1 (50.0)	1 (50.0)

Note. *A *p*-value of <0.20 was considered significant for inclusion in the regression models.

used as the reference. The variables "migration status" and "country of transmission" were removed since correlation testing demonstrated a strong multicollinearity with other variables. Adjusted odd ratios with 95% confidence intervals were presented in the final model. Confidentiality was maintained throughout data collection and analysis.

Qualitative analysis

In order to enrich and deepen the results obtained by the quantitative data the participants' answers on the open-ended question were analyzed by descriptive content analysis (Vaismoradi et al., 2013).

Results

Sample characteristics

Participants were consecutively recruited from eleven HIV clinics throughout Sweden from 1 October 2009 to 31 January 2012. All patients, aged 18 or above, diagnosed with HIV-1 within the last six months were eligible to participate in the study ($n = 445$). The questionnaire was completed by 292 adults recently diagnosed with HIV infection and 285 had complete data and were included in the analyses, representing 64% of eligible patients at the eleven study clinics (see Table 1). The mean age of the study population was 40.5 (SD 11.5) and the majority of the participants (61%) were men. Over 75% of the participants reported a country of origin other than Sweden, with origin from

Sub-Saharan Africa dominating the sample (42.8%). HIV acquired through heterosexual contact was the most common mode of transmission, reported by 63% of participants. Late presentation was common at 64% and as many as 40% with advanced HIV infection (defined as CD4 count $<200 \times 10^6$/ml or diagnosis of AIDS-defining condition). Only 16% of testing was patient-initiated while the majority of testing was initiated by a health care provider based on screening guidelines or due to symptoms (Table 1).

Study participants ($n = 285$) did not differ from the total number of participants who were eligible to participate in the present study, ($n = 445$) regarding sex, age or route of transmission, but participants were less likely to be born outside of Sweden (OR 0.51, CI 95%, 0.32–0.80, $p = 0.0004$). Furthermore, the study participants were representative of the total population of individuals newly diagnosed with HIV in Sweden during the study period ($n = 827$), regarding sex and origin, but were slightly older (mean age 40.5 vs. 38.9, t [2.84], $p = 0.020$), and had a lower representation of individuals with men who have sex with men (MSM) as route of transmission (OR 0.68, CI 95% 0.49–.94, $p = 0.018$).

Descriptive statistics of barriers to HIV testing

Two-thirds of the participants reported some/any type of barrier to HIV testing; personal barriers (51%), structural barriers (42%), socio-economic barriers (31%) and barriers related to confidentiality (39%, see Table 1). Amongst the specific items, fears around becoming ill,

Table 2. Descriptive statistics of items in the Barriers to HIV Testing Scale – Karolinska version, possible range 0–2, higher levels indicating stronger agreement.

Barriers to HIV-testing[a]	N	Mean	SD[b]	Total N (%) with barrier
16. I was afraid of becoming sick	284	0.70	0.890	116 (40.8)
18. I was worried about feeling like a failure	282	0.51	0.810	86 (30.5)
6. I was worried about confidentiality	280	0.50	0.790	87 (31.1)
15. I was afraid that my sex life would be negatively affected	282	0.48	0.765	89 (31.6)
14. I was afraid of losing my friends and other social contacts	283	0.47	0.773	83 (29.3)
7. People might recognize me at testing site	281	0.45	0.741	85 (30.2)
9. I did not want to know the results	284	0.42	0.736	78 (27.5)
13. I was afraid of losing my family	282	0.42	0.765	70 (24.8)
12. I was afraid of losing my partner	283	0.40	0.724	73 (25.8)
2. I did not know where to go for testing	285	0.34	0.676	63 (22.1)
17. I was worried about the legal consequences	277	0.32	0.670	56 (20.2)
11. I was afraid of losing my job	281	0.30	0.661	51 (18.1)
8. There was no cure so why get tested	283	0.29	0.653	51 (18.0)
1. I did not have transportation to a testing site	285	0.28	0.634	53 (18.6)
3. I did not have enough time	284	0.23	0.583	42 (14.8)
10. I was worried about my insurance/insurances	281	0.20	0.550	36 (12.8)
4. The testing site was too far away	281	0.15	0.443	31 (11.0)
5. I did not like the people at testing site	280	0.15	0.478	28 (10.0)

[a]Item number in the HIV-testing scale – Karolinska Version.
[b]Range 0–2; SD = standard deviation.

feeling like a failure, confidentiality and effects on sex life were the most commonly reported barriers to testing (see Table 2).

Approximately two-thirds of Swedish patients reported a barrier compared to half of patients originating from Sub-Saharan Africa, while as many as three-fourths from Eastern European/East Asian countries reported one or more barriers to HIV testing (Table 2). Patients who were offered an HIV test by a healthcare provider were less likely to report any barrier to testing ($p = 0.022$). For migrants, there appeared to be a trend, although not statistically significant, towards more barriers the longer time has passed from arrival to Sweden. Half of migrants who tested within one year of arrival reported barriers compared to two thirds among those having resided >1 year in Sweden. The latter was equivalent to barriers reported among Swedish born patients. In line with this the proportion with barriers was lower among patients with refugee status, living in refugee camps (who are routinely offered HIV testing through national screening programs).

Predictors for barriers to HIV testing

Lower odds of reporting any barrier were shown with increasing age (OR 0.972, 95% CI 0.948–0.997, $p = 0.030$) and among those who were offered a HIV test by a healthcare provider (OR 0.370, 95% CI, 0.153–0.894, $p = 0.027$). Lower odds for reporting a structural barrier were also seen when testing was initiated by a healthcare provider compared to self-initiated HIV testing (OR 0.365, 95% CI 0.172–0.776, $p = 0.009$), see Table 3.

Predictors for individual barriers according to origin and religion

Predictors for personal barriers are presented in Table 3. Predictors for reporting a personal barrier were origin from Sub-Saharan Africa (OR 2.880, 95% CI 1.023–8.107, $p = 0.045$). Living in a non-metropolitan area also increased the odds of reporting a personal barrier (OR 2.121, CI 95% 1.043–4.311, $p = 0.038$). Lower odds for reporting a personal barrier were seen in those who reported that religion affected daily life (OR 0.503, CI 95% 0.265–0.954, $p = 0.035$). Predictors in the barrier sub-category confidentiality were origin in Sub-Saharan Africa (OR 3.175, CI 95% 1.037–9.720, $p = 0.043$).

Persons who reported that religion affected daily life (OR 0.429, CI 95% 0.210–0.875, $p = 0.020$,) or for whom HIV test was initiated by a healthcare provider (OR 0.433, CI 95% 0.207–0.905, $p = 0.026$) had lower odds for reporting a socioeconomic barrier to testing. Non-Swedish born patients ("Other" in the tables), originating mainly from countries with low HIV prevalence (as opposed to Sub Saharan Africa and East) had higher odds of reporting barriers related to socioeconomic consequences than those born in Sweden.

Reasons for not testing for HIV

A total of 197 (67%) of the study participants answered the open-ended question about the reason for not testing for HIV earlier. The qualitative content analysis of the open-ended answers resulted in seven categories, which together with examples of significant comments are shown in Table 4. The results show that

Table 3. Logistic regression of determinants to barriers to HIV testing (n=285).

Variable	Any barrier Adjusted OR (95% CI)	P-value	Structural Adjusted OR (95% CI)	P-value	Personal Adjusted OR (95% CI)	P-value	Confidentiality Adjusted OR (95% CI)	P-value	Socioeconomic Adjusted OR (95% CI)	P-value
Age	0.972 (0.948–0.997)	0.030*	0.989 (0.964–1.013)	0.364	0.975 (0.949–1.001)	0.057	0.994 (0.968–1.020)	0.646	1.018 (0.990–1.047)	0.213
Country of origin										
Sweden	Ref		Ref		Ref		Ref		Ref	
Sub-Saharan Africa	0.513 (0.186–1.416)	0.197	1.879 (0.661–5.344)	0.740	3.620 (1.061–12.354)	0.040*	3.175 (1.037–9.720)	0.043*	1.476 (0.526–4141)	0.460
East	0.903 (0.261–3.127)	0.872	1.879 (0.661–5.344)	0.237	1.054 (0.398–2.794)	0.915	0.672 (0.260–1.738)	0.412	2.792 (1.006–7.700)	0.049*
Other	0.871 (0.251–4.124)	0.772	2.201 (0.832–5.821)	0.112	1.883 (0.587–6.134)	0.294	1.348 (0.453–4.016)	0.592	2.690 (0.961–7.534)	0.060
Religion affecting daily life										
No/unknown	Ref		Ref		Ref		Ref		Ref	
Yes		0.367	0.939 (0.494–1.786)	0.849	0.509 (0.260–0.994)	0.048*	0.732 (0.379–1.413)	0.352	0.410 (0.191–0.840)	0.015*
Immigration time										
Swedish	Ref		Ref		Ref		Ref		Ref	
2 months-1 year	1.219 (0.382–3.889)	0.738	0.351 (0.099–1.240)	0.104	0.374 (0.146–0.959)	0.041*	1.346 (0.452–4.003)	0.594	1.434 (0.363–5.669)	0.607
>1year-5 years	1.877 (0.540–6.522)	0.322	0.391 (0.111–1.382)	0.145	1.334 (0.405–4.319)	0.636	3.325 (1.050–10.526)	0.041*	2.596 (0.658–10.240)	0.173
>5 years	2.353 (0.798–6.935)	0.121		0.157	1.975 (0.715–5.453)	0.189	2.239 (0.848–5.910)	0.104	0.930 (0.249–3.476)	0.915
Accommodation										
Own	Ref		Ref		Ref		Ref		Ref	
2nd hand or family	2.182 (0.796–5.997)	0.129	0.921 (0.256–3.305)	0.899	2.815 (1.031–7.786)	0.043*	2.509 (0.973–6.469)	0.057	1.038 (0.373–2.888)	0.943
By authorities, homeless or jail	0.742 (0.353–1.559)	0.430	1.834 (0.844–3.806)	0.103	0.856 (0.408–1.797)	0.681	1.576 (0.748–3.232)	0.232	0.649 (0.284–1.484)	0.306
Refugee housing	0.692 (0.205–2.338)	0.554	2.599 (1.035–6.525)	0.042*	2.933 (1.057–8.137)	0.039*	1.699 (0.458–6.301)	0.428	1.351 (0.327–5.578)	0.677
Civil status										
Single	Ref		Ref		Ref		Ref		Ref	
Civil partnership	1.504 (0.717–3.115)	0.208	1.823 (0.916–3.628)	0.087	2.390 (1.151–4.959)	0.019*	2.174 (1.080–4.377)	0.030*	1.641 (0.786–3.428)	0.187
Married	0.868 (0.420–1.793)	0.703	1.317 (0.642–2.704)	0.452	0.957 (0.463–1.977)	0.905	1.074 (0.515–2.237)	0.850	1.478 (0.666–3.280)	0.337
Metropolitan area										
Yes	Ref		Ref		Ref		Ref		Ref	
No	1.217 (0.603–2.456)	0.584	0.908 (0.461–1.786)	0.849	0.424 (0.210–0.856)	0.017*	1.542 (0.751–3.165)	0.238	1.415 (0.654–3.063)	0.378

(Continued)

Table 3. Continued.

Variable	Any barrier Adjusted OR (95% CI)	P-value	Structural Adjusted OR (95% CI)	P-value	Personal Adjusted OR (95% CI)	P-value	Confidentiality Adjusted OR (95% CI)	P-value	Socioeconomic Adjusted OR (95% CI)	P-value
Initiator of test										
Patient	Ref		Ref		Ref		Ref		Ref	
Healthcare system	0.357 (0.150–0.849)	0.045*	0.358 (0.167–0.767)	0.008*	0.616 (0.285–1.330)	0.217	0.654 (0.351–1.361)	0.256	0.368 (0.173–0.786)	0.010*
Drugs										
No	Ref		Ref		Ref		Ref		Ref	
Yes	1.287 (0.603–2.749)	0.514	0.739 (0.354–1.547)	0.423	1.529 (0.726–3.217)	0.264	0.778 (0.365–1.658)	0.516	1.430 (0.659–3.100)	0.365
Previous thoughts of HIV										
No/unknown	Ref		Ref		Ref		Ref		Ref	
Yes	1.083 (0.531–2.207)	0.827			1.425 (0.717–2.834)	0.312	1.002 (0.551–1.968)	0.994	1.675 (0.833–3.369)	0.148

Note. OR, odds ratio; CI, confidence interval; Ref, Reference; *Significances $p < 0.05$.

approximately 25% of the patients had never considered an HIV diagnosis and 25% had previously tested negative and, therefore did not believe there was a risk for acquiring HIV infection (Table 4).

Discussion

All types of barriers found amongst all groups

In this study of recently diagnosed patients with HIV, over 60% reported at least one barrier to testing, despite the availability of free and anonymous testing in Sweden. This confirms findings from other studies in high-income countries where people continue to test late even when HIV testing is free and anonymous (Gardner et al., 2016; Schwarcz et al., 2011). Although persons from Sub-Saharan Africa, refugees and certain other migrant groups are often included in national HIV testing programs, these groups continued to report barriers. This can inform and improve current HIV testing strategies at the public health level. In this study, persons who considered religion affecting daily life, reported fewer socio-economic and personal barriers to testing. Previous research has shown that religion and spirituality can function both as barriers and facilitators to treatment for HIV (Kendrick, 2017). Personal barriers yielded two predictors to testing, with persons residing outside of metropolitan areas and persons from Sub-Saharan Africa reporting greater barriers of this kind. Limited options to test in rural areas may lead to delays in testing, an area that needs to be further investigated in the Swedish context and whether implementation of indicator-guided testing in Sweden could lead to earlier HIV diagnosis.

Benefits of early HIV diagnosis – increasing overall public knowledge

This study also confirmed that fears related to becoming sick continue to contribute to delaying or avoiding HIV testing. This response emerged clearly in the qualitative analysis, which revealed that 25% of respondents delayed testing due to fear. Fear and fatalistic attitudes towards a variety of health conditions are cited in previous literature as reasons given for delaying contact with a health care provider (Kannan & Veazie, 2014). Campaigns and messaging by public health agencies and other organizations should especially emphasize that early diagnosis of HIV dramatically improves prognosis and include information about where testing is available (Schwarcz et al., 2011). HIV is now considered a chronic and manageable condition and most people living with HIV in settings with general access to high

Table 4. Reasons for not testing for HIV by individuals newly diagnosed with HIV infection.

Reasons	N = 197	%	Example of open answers
Did not believe they had a reason to test	52	26	"Never had a thought of being infected"; "I did not think that I could be infected"; "Didn't think I was in a risk group".
Earlier negative test	48	24	"Tested myself a couple of times"; "Two years ago, I was tested in my country – negative"
No symptoms – felt healthy	39	20	"Everything felt fine with the body. Worked and was healthy"; "Never been ill, healthy and have never had any contacts with the healthcare. Feeling well"; "I had no problems. No disease"
Only one or few partners, or had protected sex	24	12	"Have only been with one man, trusted him"; "Never thought she could be infected"; " Practiced safe sex, always used a condom"
Fear of a positive test result	17	9	"Stigma. Fear of what having HIV brings"; "Didn't want to believe it. Postpone the decision"; "Fear of finding out the truth"
Other reasons, i.e., lack of knowledge	9	5	"Didn't think I could get HIV as I was convinced that only homosexual could get it"; "Thought that a test was taken when admitted to hospital at the reproductive health clinic for surgical treatment of a gynecological condition"
No opportunity to take an HIV-test	8	4	"Not common routine in my country"; "Didn't know where to go for testing in Sweden, waited until I got back to Thailand for holiday".

quality care and treatment, like Sweden, live without symptoms of HIV infection but are also unfortunately diagnosed late (Brännström, 2016). It is therefore of essence that this information is widely spread in order to minimize this barrier to testing. In addition, HIV-related stigma is a barrier to testing that emerged in the content analysis. Despite fear of HIV these individuals have consented to HIV testing which shows that provider-initiated testing could be one measure to address this barrier to testing. Expanding provider-initiated testing using clinical indications for testing is recommended by the European Centers for Disease Control (ECDC, 2017) as a concrete way to circumvent fear and stigma by normalizing HIV testing in primary care settings.

Opt-out testing is HIV testing, automatically included in routine care, for example in emergency care settings and patients must actively decline a test. It has been an effective way to increase uptake of HIV testing in the US, although many countries in Europe still prefer targeted testing, also known as indicator-guided testing. Indicator-guided testing entails broadly testing for HIV when patients present in healthcare settings with conditions that are associated with undiagnosed HIV infection such as having a sexual transmitted infection, oral thrush and other symptoms of a compromised immune system (Eurotest, 2014; Montoy et al., 2016). HIV testing outside of traditional settings such as sexual health clinics can also improve testing uptake since neutral settings can be less stigmatizing (Croxford et al., 2017).

Poor knowledge about what constitutes a risk for HIV was revealed in the open-ended question and many respondents did not correlate their own behavior with risk for HIV, leading to delays or avoidance of HIV testing. This also confirms previous research, which has identified low perceived risk as a major barrier to HIV testing at the individual level (Schwarcz et al., 2011). A study from Tanzania show that partners had low

knowledge about their partner's HIV-status and 96% had not disclosed their own HIV-status due to fear of divorce (Hallberg et al., 2019). This confirms the results of the present study: increasing overall public knowledge about HIV remains an ongoing priority and dismantling stereotypes about what defines HIV risk is needed to encourage testing.

Concluding remarks

The findings of this study contribute to previous research that significant barriers to HIV testing remain at the patient level. Since this was a cross-sectional study, associations between different variables can be found but these should not be interpreted as causal effects. One limitation with this study is that it examined barriers amongst individuals who were already diagnosed with HIV infection and may not be generalizable to persons who have not acquired HIV or persons who have not yet tested. Since barriers were reported after diagnosis it may be a challenge for people to retrospectively recall specific barriers to testing. A significant strength of the study is that it includes the persons we aim to reach with HIV testing since they were found to be HIV positive. These individuals are the ones we want to learn more about; specifically, about the barriers they have experienced and have shared through this study. This research therefore adds a piece to the complex puzzle of understanding barriers to HIV testing.

Recommendations for future research

These results can likely inform other high-income settings where HIV testing is free: barriers remain amongst all groups and most importantly, in groups that are both included and not included in target screening programs. Future research might include studies that administer a questionnaire or interview at the time of testing and in

different settings to identify both motivators and barriers to HIV testing.

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