

Reasons for Late Presentation to HIV care of sub-Saharan Africans in Switzerland

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Abstract

Objectives: Late presentation (LP) to HIV care disproportionately affects individuals from sub-Saharan Africa (SSA). We explored the reasons for late presentation to care among this group of patients in the Swiss HIV Cohort Study.

Methods: The prevalence of LP was compared between patients from Western Europe (WE) and those from SSA enrolled between 2009 and 2012. Patients were asked about HIV testing, including access to testing and reasons for deferring it, during face-to-face interviews.

Results: The proportion of LP was 45.8% (435/950) among patients from WE, and 64.6% (126/195) among those from SSA ($p < 0.001$). Women from WE were slightly more likely to present late than men (52.6% versus 44.5%, $p = 0.06$), whereas there was no sex difference in patients from SSA (65.6% versus 63.2%, $p = 0.73$). Compared to late presenters from WE, those from SSA were more likely to be diagnosed during pregnancy (9.1% versus 0%, $p < 0.001$), but less likely to be tested by general practitioners (25.0%, versus 44.6%, $p = 0.001$). Late presenters from SSA more frequently reported “not knowing about anonymous testing possibilities” (46.4% versus 27.3%, $p = 0.04$) and “fear about negative reaction in relatives” (39.3% versus 21.7%, $p = 0.05$) as reasons for late testing. Fear from being expelled from Switzerland was reported by 26.1% of late presenters from SSA.

Conclusions: The majority of patients from SSA were late presenters, independent of sex or education level. Difficulties in accessing testing facilities, lack of knowledge about HIV testing and fear-related issues are important drivers for LP in this population.

Introduction

Late presentation (LP) to HIV care, defined as presenting with a CD4 count below 350 cells/ μ l and/or an AIDS-defining event affects over 50% of HIV-infected individuals in Europe and has been associated with increased mortality, health-care costs and risk of HIV transmission (1,2). Recent efforts to improve access to HIV testing among men having sex with men (MSM) have resulted in

reduced LP rates, while other risk groups, including migrants from sub-Saharan Africa (SSA), remain disproportionately affected by LP (1,3,4). In Switzerland, missed opportunities to test migrants from SSA for HIV are frequent. This population is also more likely of being lost to follow-up during care and to experience virological failure (5–7).

Whereas the circumstances and drivers of late HIV testing in specific sub-populations such as older individuals and heterosexual men have been recognized (8), the reasons for LP to HIV care among patients from SSA remain ill-defined. The unique social, economic and legal circumstances experienced by many migrants in Europe have implications along the whole continuum of HIV care. The fact that LP remains a substantial problem in Western European countries, where access to care is relatively good, shows that a large spectrum of barriers need to be considered in order to understand and overcome LP(9). In order to improve our understanding of the cultural and psychosocial determinants of LP to HIV care in patients of sub-Saharan African origin, we explored the circumstances and individual reasons for late HIV testing among this population within the Swiss HIV Cohort Study (SHCS).

Methods

Study population and definitions

All adults enrolled in the SHCS between July 2009 and June 2012 were considered for participation in this study. The SHCS is a nationwide prospective cohort of HIV-infected patients with ongoing enrollment since 1988 (10). It covers the majority of the HIV infections declared to the Swiss public health authorities and relies on systematic collection of information on demographics, risk behavior, clinical events, co-infections, and treatment. Local ethical committees of all study sites approved the study and written consent was obtained from all participants.

Individuals were classified into two groups according to their region of origin: Western-Europe (WE) and sub-Saharan Africa (SSA). As the aim of our study was to compare reasons for LP between patients from SSA and a homogeneous group from high-income countries, we excluded individuals originating from countries outside of these two pre-defined regions. We defined late presenters as

patients having a first CD4 count <350 cells/ μ l or an AIDS-defining event within 3 months of presentation to HIV care. Patients with known acute HIV infection at time of presentation were classified as non-late presenters regardless of initial CD4 cell count. Education level was defined as low if no or only basic education was completed.

Questionnaire

All late presenters enrolled during the study period were asked to participate in the survey. Information on the circumstances of HIV testing, behavioral risk factors, awareness and knowledge of HIV, presence of symptoms, missed opportunities for HIV testing and individual reasons for deferring testing were obtained through face-to-face interviews between October 2012 and June 2013, using a standardized questionnaire, with the help of translators if needed (2). Reasons for late testing were grouped into i) lack of knowledge, ii) low risk perception, and iii) fear.

Statistical analyses

Differences in baseline characteristics and circumstances of LP between participants from WE and SSA were assessed using Mann-Whitney and Chi-square tests for continuous and categorical variables, respectively. Self-reported reasons for LP to care were compared between the two groups using the Chi-square test. Data from the paper-based questionnaire were managed with REDCap (Research Electronic Data Capture, www.redcap.vanderbilt.edu/) (11). All statistical analyses were performed with Stata Version 12.1 (StataCorp 2012, Stata Statistical Software, College Station, TX, USA) (12).

Results

Proportion and characteristics of late presenters according to region of origin

Of 1,366 patients newly enrolled in the SHCS during the study period, 221 (16.2%) of origin other than WE or SSA were excluded (Supplementary Figure 1). Among the remaining individuals, 195 (17.0%) were from SSA and 950 (83.0%) from WE. Participants from SSA were younger than those from WE (median age: 35 versus 42 years, $P < 0.001$), more likely to be female (61.0% versus 16.2%, $p < 0.001$) and to have a low level of education (29.2% versus 2.1%, $p < 0.001$, Table 1).

Overall, 561 (49.0%) individuals were late presenters. The proportion of LP was higher in patients from SSA (64.6%) compared to those from WE (45.8%, $p < 0.001$, [Table 1](#)). Overall, 85.3% of late presenters underwent an HIV test late during the course of disease but presented to care within 3 months of diagnosis (“late testers”). The proportion of “delayed presenters” (>3 months between HIV testing and presentation to care) was low (14.7%), and didn’t differ between patients from WE and SSA. Whereas the proportion of LP in the WE group was slightly higher in women compared to men (52.6% versus 44.5%, $p = 0.06$), there was no sex difference in patients from SSA (65.6% in women versus 63.2% in men, $p = 0.73$). Low education level did not seem to have a significant impact on LP in patients from WE (55.0% LP vs. 45.7% LP in those with higher education, $p = 0.41$) and SSA (59.7% vs. 66.7%, $p = 0.35$).

Testing circumstances of late presenters

The questionnaire completion rate did not differ significantly between patients from WE and SSA (76.1% versus 69.8%, $P = 0.12$). Late presenters from WE were more likely to have their first positive HIV test performed by a general practitioner (GP) (44.6% versus 25.0%, $p = 0.001$) or in the context of relevant symptoms (25.2% versus 14.8%, $p = 0.04$) compared to those from SSA. The proportion of late presenters with an initial diagnosis during hospitalization was similar in both groups, ranging from 20.4% in WE to 25.0% in SSA ($p = 0.34$). HIV diagnosis during pregnancy occurred in 9.1% of late presenters from SSA but in none of the women of WE origin ([Table 1](#)).

Reasons for late testing

Self-reported reasons for late HIV testing were associated with low risk perception in 88.0% of LP, lack of information/knowledge in 74.9% and fear in 60.4% of them ([Figure 1](#)). “Not feeling at risk for HIV infection” was the single most common reason for late testing in patients from WE and SSA. This was especially true for Western-European women (100%) and African men (92.2%) ([Supplementary Table 1](#)). There was no difference in the overall proportion of patients with low risk perception, missing knowledge and fear between the two groups. However, “not being aware of anonymous HIV testing possibilities” (46.4% versus 27.3%, $p = 0.04$) and “fear about negative

reaction in relatives” (39.3% versus 21.7%, $p=0.05$) were more frequently reported by late presenters from SSA compared to those from WE (Figure 1). Fear from being expelled from Switzerland was mentioned as an important reason for late HIV testing in 26.1% of late presenters from SSA. Finally, women from SSA were more likely to report fear-related testing barriers compared to women from WE (72.2% versus 38.9%) (Supplementary Table 1).

Discussion

In Switzerland, HIV-infected individuals of sub-Saharan African origin are more likely to present late for HIV care than those of European origin, independent of sex and education level. Limited knowledge of anonymous HIV testing possibilities as well as fear of being expelled from Switzerland or rejected by relatives seem to be important drivers for LP in patients from SSA. Our results underline the need for tailoring strategies to migrant populations in order to improve access to HIV testing services early during the course of disease.

The higher proportion of HIV diagnoses during pregnancy and the reduced number of infections diagnosed by GPs in patients from SSA compared to those from WE reflect the difficulties in accessing routine medical care among specific migrant communities. Structural barriers to access health care have been described as important reasons for LP in low-income countries but also for groups with poor socioeconomic status in high-income settings (13). The phenomenon is not restricted to HIV care: Tariq et al. recently reported that women from SSA living with HIV in the UK and Ireland were three times more likely to present late to antenatal care compared to women of other origins (14). Furthermore, self-initiated testing following a risk situation, due to symptoms or as part of a regular check-up is less likely in individuals from SSA than in those from WE. In addition to structural issues, it is recognized that health-seeking behavior differs across communities, with some populations being more likely to seek health care only for specific needs or symptoms (15). Although provider-initiated testing remains the most frequent circumstance of HIV diagnosis among patients from SSA, many issues related to migration, including language barriers, reticence in broaching culturally sensitive issues such as sexuality, and competing priorities due to other social problems,

are frequent reasons for missed opportunities for HIV testing (2,9,16,17).

Fear of relatives' reaction was a disproportionately frequent reason for deferring HIV testing in patients of SSA origin. Stigma and social exclusion seem to be particularly prominent in this population, as reported by several qualitative studies (15,18) and confirmed in a meta-analysis (19). Fear of losing social status and community support is an important barrier to HIV testing and often outweighs the perceived advantages of being aware of HIV status. Stigma and exclusion of HIV-infected individuals from SSA reflect cultural values and perceptions, which often do not depend on education or sex, as shown in our data. Approximately one-half of late presenters from SSA did not know about the availability of anonymous testing possibilities and were not aware of the benefits of HIV treatment. On the one hand, lack of knowledge about HIV transmission can reinforce low risk perception, the most common reason for late HIV testing in our study, and on the other hand lack of knowledge around HIV care possibilities can enhance the fear of disclosure and of the consequences of HIV infection (9,20).

Our study provides unique insight into reasons for LP to HIV care among individuals from SSA within a nationwide cohort. The combination of quantitative cohort data and information on testing circumstances and individual barriers obtained from face-to-face interviews is of particular interest for informing strategies to improve access to health services among specific populations. Although survey completion rates did not differ significantly between patients from SSA and those from WE, Africans with low education are probably under-represented in the SHCS, which limits the generalizability of our findings (6). In addition, information collected through face-to-face interviews might have been biased by perceived social desirability of the interviewees or by recall difficulties given the possibility of a delay of up to four years between the presentation to care and the interview. Finally, we were not able to perform extensive sub-group analyses (for example stratified by sex and educational level or individual countries) due to our sample size. As individual perceptions may differ across populations from different countries in SSA, a note of caution is warranted when interpreting the findings of our study which grouped all patients from SSA together.

Patients from SSA living in Switzerland are at high risk of presenting late for HIV care. Structural difficulties in accessing medical care, lack of information on HIV testing and management possibilities, as well as specific psychosocial and cultural perceptions reinforcing fear-related barriers, are among the most important reasons for LP in this population. Targeted strategies to increase knowledge about anonymous testing, treatment possibilities and the implications of an HIV diagnosis on immigration rights are necessary steps to improve access to care and reduce fear. Considering the difficulties in accessing routine medical care among individuals of African origin, minimizing missed opportunities of HIV testing seems particularly important. The use of HIV self-testing kits, which are available in Switzerland since 2018, may represent an attractive option to improve access to HIV testing of individuals from SSA. Policies should aim at simplifying the HIV testing consent process, increasing reimbursement, reducing logistical barriers and improving HIV knowledge of health-care providers. Future studies including qualitative research efforts should focus on interventions designed to improve access to HIV care for migrants from SSA.

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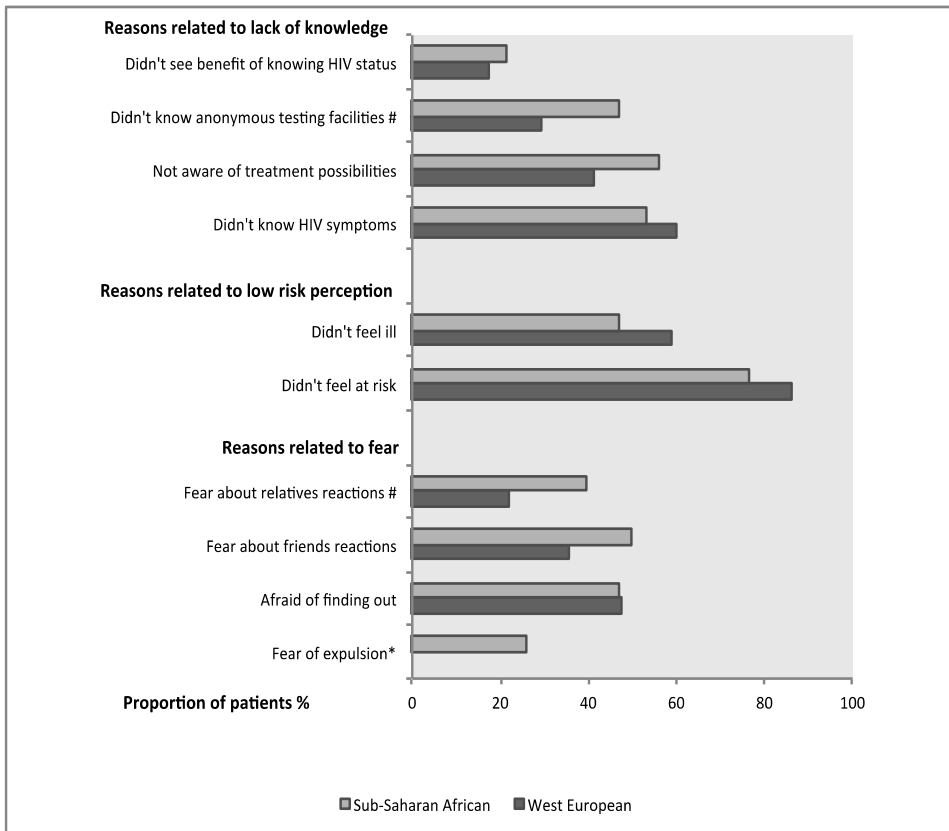
Table 1: Demographic, clinical characteristics and testing circumstances of patients living with HIV in Switzerland, according to region of origin

	Western Europe	Sub-Saharan Africa	P-value
<u>Demographic characteristics</u>	N= 950	N=195	
Age in years (IQR)	42 (33-49)	35 (30-41)	<0.001
Female sex (%)	154 (16.2)	119 (61.0)	<0.001
Transmission group (%)			<0.001
- MSM	578 (60.8)	6 (3.1)	
- Heterosexual	258 (27.2)	171 (87.7)	
- People who inject drugs	70 (7.4)	3 (1.5)	
- Other	44 (4.6)	15 (7.7)	
Low education (%)	20 (2.1)	57 (29.2)	<0.001
<u>Clinical characteristics</u>	N=950	N=195	
Median CD4 in cells/ μ l (IQR)	370 (206-558)	276 (151-429)	<0.001
CDC stage C (%)	140 (14.7)	38 (19.5)	0.10
Late presenters (%)	435 (45.8)	126 (64.6)	<0.001
<u>Testing circumstances of LPs (%)*</u>	N= 331	N=88	
Hospitalization	68 (20.4)	22 (25.0)	0.34
Pregnancy (% of women)	0 (0.0)	8 (9.1)	<0.001
General practitioner consultation	149 (44.6)	22 (25.0)	0.001
After risk situation	36 (10.8)	5 (5.7)	0.15
Doctor’s suggestion	84 (25.2)	26 (29.6)	0.40
Symptoms	84 (25.2)	13 (14.8)	0.04
Regular check-up	48 (14.4)	9 (10.2)	0.31

IQR: interquartile range, MSM: men who have sex with men

* Multiple answers possible

Figure 1: Reasons for late HIV testing, by region of origin (n=419)



*Question only applies for late presenters from sub-Saharan Africa

$p \leq 0.05$

Supplementary Table 1: Reasons for late testing of Western European and sub-Saharan African late presenters according to sex

Reasons for late testing	West European women	Sub-Saharan African women	West European men	Sub-Saharan African men
At least 1 lack of information related reason	17 (85.0)	12 (75.0)	95 (73.1)	10 (76.2)
Didn't know HIV symptoms	12 (60.0)	8 (53.3)	64 (48.5)	8 (57.1)
Didn't know treatment possibilities	7 (42.0)	9 (56.3)	57 (44.2)	7 (46.7)
Didn't know anonymous testing facilities	5 (29.4)	7 (46.7)	34 (27.0)	6 (46.2)
Didn't see benefit of knowing HIV status	3 (17.7)	3 (21.4)	29 (23.4)	5 (41.7)
At least 1 low risk perception related reason	22 (100)	15 (88.2)	118 (85.5)	13 (92.9)
Didn't feel ill	10 (58.8)	7 (46.7)	83 (63.9)	10 (76.9)
Didn't feel at risk	19 (86.4)	13 (76.5)	97 (70.3)	10 (71.4)
At least 1 fear related reason	7 (38.9)	13 (72.2)	80 (62.0)	8 (57.1)
Afraid of finding out	6 (33.4)	9 (56.3)	64 (49.6)	5 (35.7)
Fear of relatives' reaction	1 (5.6)	7 (46.7)	30 (24.0)	4 (30.8)
Fear of friends' reaction	5 (27.8)	7 (50.0)	47 (36.4)	7 (50.0)
Fear of Expulsion*		4 (36.4)	Not applicable	2 (16.7)

Supplementary figure 1: Patients included in the study

