

HIV-Related Discrimination in European Health Care Settings

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Abstract

This cross-sectional European study assessed self-reported HIV-related discrimination and its associated factors in health care settings. Socio-demographics, health status, support needs relating to sexual and reproductive health (SRH), and self-reported HIV-related discrimination were measured using an anonymous survey in a sample of 1549 people living with HIV from 14 countries. Thirty-two per cent of the participants had experienced HIV-related discrimination during the previous 3 years; almost half of them felt discriminated against by health care providers. For this type of discrimination, logistic regression analysis revealed significant associations with not being a migrant (OR: 2.0; IC 1.0–3.7; $p < 0.05$), having been forced into sexual activities (OR: 1.6; IC 1.2–2.2; $p < 0.001$), reporting lack of time to discuss SRH during service provision (OR: 1.7; IC 1.0–2.7; $p < 0.05$), and insufficient openness among service providers to discuss SRH (OR: 2.0; IC 1.1–3.4; $p < 0.05$). Other significant associations related to unmet support needs on safer sex practices (OR: 1.8; IC 1.0–3.2; $p < 0.05$), partner communication about sexuality (OR: 2.0; IC 1.1–3.4; $p < 0.05$), and prevention of sexually transmitted infections (OR: 1.7; IC 1.0–3.0; $p < 0.05$). Female gender had a protective effect (OR: 0.2; IC 0.0–0.9; $p < 0.05$). Being denied the opportunity to discuss SRH may translate in feelings of discrimination. Improving health care providers' communication skills, and fostering openness about SRH topics in HIV care could contribute to destigmatization of PLHIV.

Introduction

DISCRIMINATION AGAINST PEOPLE LIVING WITH HIV (PLHIV) has been documented since the beginning of the HIV epidemic, both related and unrelated to health care provision.^{1,2} Discrimination refers to a prejudicial treatment of individuals because they are part of a certain group or category. It is often linked to stigma (i.e., being disqualified from full social acceptance),³ but it is different in that it concerns the *actual behavior* towards the individuals affected, excluding or restricting them of opportunities that are available to other groups. For instance, reluctance among some health care professionals to provide adequate services has been reported.⁴ In a study from the UK, African migrants living with HIV reported about inference from healthcare workers, that immigrants from low income countries should be appreciative of any treatment they received for HIV.⁵ A body of evidence shows that stigma and discrimination in the health care setting keeps people from accessing HIV prevention, care, and treatment services and from adopting prevention behaviors.⁶

Sexual and reproductive health (SRH) aspirations and needs of PLHIV are particularly sensitive to discrimination.⁷ Discrimination in this area has been documented in many forms: violations of privacy and confidentiality, involuntary disclosure of HIV status, pressure on HIV-infected couples to take specific fertility-related decisions (e.g., abortion or forced sterilization), refusal of assistance to HIV-positive women during labor,^{4,8} or denying the right to parenthood.^{9,10} While these are important topics for PLHIV where they require unbiased information and nonjudgmental support,¹¹ it has been shown that health care providers' attitudes towards their HIV-positive patients' SRH may influence the actual services offered.¹²

Objectives

This study aims to assess the degree of self-reported HIV-related discrimination of PLHIV in Europe. We explore which factors are associated with this type of discrimination in European health care settings, with a particular focus on how health care services respond to HIV-positive people's SRH-related needs.

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Methods

Data were collected in the framework of the multi-center study 'Eurosupport 5'. This study had the overall aim to assess SRH-related needs of PLHIV including sexual risk behavior. The research was carried out in 17 HIV treatment centers and community-based HIV care facilities in 14 European countries (Austria, Belgium, Czech Republic, Greece, Germany, Hungary, Italy, Latvia, Poland, Portugal, Slovak Republic, Spain, Switzerland, and United Kingdom).

Study design and procedures

Details on the methodology of this observational and cross-sectional study were described elsewhere.¹³ All study participants ($N=1549$) provided informed written consent. Data were collected between 03–10/2007. During this period, a study nurse or a physician invited consecutive patients of both genders to participate in the study anonymously and voluntarily. Inclusion criteria were: HIV diagnosis since at least 6 months, to be able to comprehend and fill in the questions independently, and to understand the study goals and objectives.

Measures

We used an anonymous, self-administered questionnaire, which assessed the following domains: socio-demographic background; health status; sexual behavior (past 6 months); recreational drug and alcohol use; mental health (depression, anxiety, and stress); self-reported discrimination; social support and social support needs; selected SRH indicators and support needs relating to SRH and HIV service provision. Items and appropriate response categories used in the questionnaire were based on the findings of previous elicitation research.¹⁴ The measures used to assess independent and dependent variables are displayed in Table 1.

TABLE 1. MAIN VARIABLES

Measures	Frequency (n)	Percentage (%)
Whole sample: Self-reported discrimination by health care providers (HCP) ($n=1291$)	216	16.7
Sub-sample: Self-reported discrimination by HCP ($n=216$)		
Having ever been pressured into sexual activities	61	28
Perceiving HCP as not open enough for discussing SRH-topics	51	24
Having unmet support need relating to safer sex practices	68	31
Having unmet support need relating to communication (with a partner) about sexuality	56	26
Having unmet support need relating to prevention of STIs (other than HIV)	72	33

Statistical analysis

Data were analyzed using SPSS 16.0. Frequencies and proportions, means and standard deviations were calculated according to the properties of the respective variables. We first performed univariate analyses (Chi squares and Fisher's exact tests). Subsequently, all variables yielding significance at $p<0.05$ in the univariate analysis were entered into a logistic regression using a backward step-wise regression model to identify factors significantly and independently associated with the outcome variable (i.e., self-reported HIV-related discrimination by service providers during the last 3 years).

Results

Sample description

Socio-demographic characteristics. A total of 1549 PLHIV participated in this study. Participants were predominantly male (75%), and in a steady relationship. Median age was 42 years, women were significantly younger than men (39 years compared to 43 years; $p<0.001$). More than half self-identified as bi- or homosexual, and about two-thirds were living with the main partner or family. Two-thirds were employed, and more than one-third experienced financial problems. About one in five participants was a migrant (Table 2).

Self-reported health status

The majority (72%) of our sample had acquired HIV through sexual transmission. Median time since HIV

TABLE 2. MAIN CHARACTERISTICS OF STUDY PARTICIPANTS ($N=1291$)

Characteristics	Frequency (n)	Percentage ^a (%)
Gender		
Male	961	74.7
Female	326	25.3
Missing	(4)	(0.3)
Relationship		
Single	547	42.7
Steady female partner	184	14.4
Steady male partner	550	42.9
Missing	(10)	(0.8)
Origin		
Country in which study took place	1022	79.3
Other country	266	20.7
Missing	(3)	(0.2)
Sexual orientation		
Homosexual	637	51.5
Heterosexual	498	40.2
Bisexual	103	8.3
Missing	(53)	(4.1)
Being employed		
Yes	762	59.0
No	529	41.0
Missing	(0)	(0.0)
Financial difficulties		
Yes	485	38.4
No	777	61.6
Missing	(29)	(2.1.)

^aPercentages refer to valid n (missing values excluded).

diagnosis was 8 years. Most participants (80%) were taking antiretroviral medication. One in ten participants could not report the current viral load, but of those who could, two-thirds reported an undetectable viral load.

Self-reported discrimination

A total of 1482 respondents (96% of the overall sample) answered the question on perceived HIV-related discrimination during the past 3 years. Among them, 468 study participants (32%) reported having experienced any HIV-related discrimination. Study participants could further identify the source of HIV-related discrimination: 1291 people provided an answer (83% of the whole sample) to the specific question whether they felt discriminated against by medical care providers. This was the case for 216 study participants (17% of the total sample answering this specific question, equalling 46% of those who had experienced any form of discrimination; see Table 1). As shown in Table 2, PLHIV who had experienced this type of discrimination were predominantly male (75%), 51.5% were homosexual, 43% were single and originated mostly of the country in which the study took place (79%). Participants had experienced discrimination by the following categories of health care providers: non-HIV specialists (e.g., internists; 46%), dentists (39%), general practitioners (22%), gynecologists (16%), and HIV specialists (10%; data not shown in table).

Respondents stemmed from 14 different European countries. Table 3 provides an overview of the study participants' country of origin, and the respective country differences in terms of self-reported discrimination by health care provider. Countries in which study participants reported relative higher levels of discrimination by health care providers were Austria (35%), Poland (30%), and Greece (28%).

Factors associated with perceived HIV-related discrimination in health care settings

We performed univariate and multivariate analysis (Table 4) to assess associations between the outcome variable

TABLE 3. STUDY PARTICIPANTS' SELF-REPORTED DISCRIMINATION BY HEALTH CARE PROVIDERS PER PARTICIPATING COUNTRY (N=1291)

Country	Frequency (n)	Percentage ^a (%)
Austria (N=57)	20	35
Belgium (N=333)	29	8.7
Czech Republic (N=29)	3	10.3
Germany (N=218)	37	16.9
Greece (N=81)	23	28.3
Hungary (N=80)	18	22.5
Italy (N=109)	12	11
Latvia (N=29)	2	6.8
Poland (N=103)	31	30
Portugal (N=44)	7	15.9
Slovak Republic (N=26)	2	7.6
Spain (N=68)	9	13.2
Switzerland (N=33)	19	23.4
United Kingdom (N=33)	4	12.1

^aPercentages calculated based on the respective country samples.

(i.e., perceived HIV-related discrimination in health care settings) and the independent variables. They pertained to selected factors we hypothesized to influence the outcome variable.

We first present the results of the univariate analysis: in terms of the socio-demographic background, not being a migrant was significantly and positively associated with the outcome variable, while female gender was negatively associated. Other important socio-demographic background characteristics, like age, education, or country of origin, were not significantly correlated, and we thus excluded them from further analysis (data not shown). Some variables describing specific problems with sexuality were significantly and positively associated with the outcome measure (i.e., taking erection enhancing medication because of sexual problems; having been pressurized into sexual activities; see Table 4 for specific items); also selected variables measuring specific kinds of social support (i.e., material support through the family; informal support by partner) were significantly positively associated, as well as having experienced financial problems during the past 6 months. Certain aspects of how study respondents evaluated the patient-provider relationship pertaining to SRH service delivery were also significantly and positively associated with the outcome variable (i.e., not feeling understood, not having a good relationship with the provider, lack of time and openness to discuss SRH in service provision, perceiving caregivers as asking not proactively enough about SRH issues). Finally, some unmet support needs in relation to SRH were also significantly and positively associated with perceived HIV-related discrimination in HIV care settings. They pertained to areas such as child wish, safer sex practices, sexual problems, communication skills with sexual partners about sexuality, prevention of sexually transmitted infections (STIs) other than HIV, and potential side-effects of antiretroviral medication on sexuality.

In the final multivariate model, self-reported discrimination by health care providers was significantly associated with not being a migrant, having been pressured, forced, or intimidated into sexual activities, describing the health care provider-patient relationship as not open enough to discuss SRH, and reporting lack of time to discuss SRH-related issues in HIV care. Female gender was negatively associated with the outcome variable.

Also, unmet support needs in relation to safer sex practices, on communication with a sexual partner about sexuality, and on prevention of STIs other than HIV were significantly associated with self-reported discrimination by health care providers.

Discussion

Our data show that a substantial proportion of PLHIV in our sample (almost one-third) reported HIV-related discrimination, which, in almost half of these cases (46%), was linked to health care settings. Respondents perceived HIV service providers as less discriminating, compared to non-HIV specialists, for example, discrimination by gynecologists was particularly often reported by women. We also found that next to socio-demographic characteristics such as gender and origin, unmet needs in addressing SRH-related topics in European HIV-care were associated with

TABLE 4. FACTORS ASSOCIATED WITH SELF-REPORTED DISCRIMINATION BY HEALTH CARE PROVIDERS (UNIVARIATE AND MULTIVARIATE ANALYSES; N=1291)

	<i>Univariate analysis</i>			<i>Multivariate analysis</i>		
	<i>OR</i>	<i>CI (95%)</i>	<i>p Value</i>	<i>OR</i>	<i>CI (95%)</i>	<i>p Value</i>
Gender						
Male	1			1		
Female	0.2	0.4–0.8	0.003	0.2	0.7–0.9	0.032
Experiencing financial difficulties (during the last 6 months)						
No	1					
Yes	1.3	0.9–1.8	0.032	1		
Born in the country in which the questionnaire was filled in						
No	1			2.0	1.0–3.7	0.025
Yes	1.6	1.0–2.4	0.008			
Having taken erection enhancing medication during the past 6 months (because of difficulties keeping an erection)						
No	1					
Yes	0.4	0.1–1.0	0.026			
Agreeing to the statement: “A man will less likely get an HIV infection than a woman when having vaginal sex”						
No	1					
Yes	1.7	1.1–2.4	0.002			
Not having had sex during the last 6 months because participant was not “in the mood for sex”						
No	1					
Yes	2.7	1.6–4.7	0.002			
Having been pressured, forced, or intimidated into sexual activities at least once in your lifetime						
No	1			1		
Yes	2.5	1.8–3.6	0.0001	1.6	1.2–2.2	0.001
Social support: Family lends small things like effects or a little money						
No	1					
Yes	1.4	1.0–2.0	0.016			
Social support: Partner invites to party or for dinner						
No	1					
Yes	2.7	1.4–5.5	0.001			
Issues concerning SRH were discussed most of the time with a psychologist						
No	1					
Yes	1.6	1.1–2.2	0.005			
HIV physician considered as the appropriate professional to discuss issues concerning SRH						
No	1					
Yes	0.4	0.2–0.8	0.019			
General practitioner considered as the appropriate professional to discuss issues concerning SRH						
No	1					
Yes	0.5	0.3–0.8	0.002			
Psychologist considered as the appropriate professional to discuss issues concerning SRH						
No	1					
Yes	1.5	1.0–2.3	0.023			
Complaints about SRH services: Not feeling understood						
No	1					
Yes	2.2	1.0–4.8	0.034			
Complaints about SRH services: Not having a good relationship with the caregiver						
No	1					
Yes	2.3	1.3–4.0	0.002			
Complaints about SRH services: Lack of time for talking about SRH issues						
No	1			1		
Yes	1.1	1.4–2.7	0.0001	1.7	1.0–2.7	0.023
Complaints about SRH services: Lack of openness regarding SRH						
No	1			1		
Yes	2.4	1.6–3.5	0.0001	2.0	1.1–3.4	0.01
Complaints about SRH services: Caregivers do not ask actively enough						
No	1					
Yes	2.0	1.3–2.8	0.0001			

(continued)

TABLE 4. (CONTINUED)

	<i>Univariate analysis</i>			<i>Multivariate analysis</i>		
	<i>OR</i>	<i>CI (95%)</i>	<i>p Value</i>	<i>OR</i>	<i>CI (95%)</i>	<i>p Value</i>
Unmet support need relating to child wish						
No	1					
Yes	1.5	1.0–2.3	0.012			
Unmet support need relating to safer sex practices						
No	1			1		
Yes	1.8	1.3–2.5	0.0001	1.8	1.0–3.2	0.03
Unmet support need relating to sexual problems						
No	1					
Yes	1.5	1.1–2.1	0.005			
Unmet support need relating to communication with the sexual partners about sexuality						
No	1			1		
Yes	2.1	1.4–2.9	0.0001	2.0	1.1–3.4	0.01
Unmet support need relating to prevention of other STI						
No	1			1		
Yes	1.5	1.1–2.1	0.003	1.7	1.0–3.0	0.03
Unmet support need relating to side effects of antiretroviral therapy affecting sexual ability sexuality						
No	1					
Yes	1.6	1.2–2.2	0.0001			

self-reported discrimination. Social vulnerability has been shown to be a significant barrier to building a satisfying patient-provider relationship.¹⁵ In our sample, PLHIV found health care providers less open to discuss sexuality and sexual behavior than reproductive issues. Being denied the opportunity to discuss such issues may translate in feelings of discrimination, as patients may sense that their needs are being ignored. This may also be interpreted as poor quality of the patient-provider relationship. The unmet need to discuss prevention of other STIs and safer sex practices is particularly concerning with respect to positive prevention.

Our results on the perceived level of self-reported discrimination are in line with previous findings in comparable settings in Europe. Research in the UK showed that PLHIV face significant stigma and discrimination: 21% of the participants reported to have been verbally assaulted or harassed, and 17% reported being denied health services because of their HIV status at least once in the previous 12 months.¹⁶ In France, 27% of respondents reported attitudes of discrimination during interactions with health care providers.¹⁷

Our results should be interpreted against the background that PLHIV often experience double stigmatization. HIV mainly affects groups who are likely to experience stigma related other social characteristics (e.g., sexual orientation, being a migrant). Discrimination and stigma represent complex barriers for HIV service provision.¹⁸ Intersecting forms of HIV-related stigma and discrimination have recently been shown in two different studies. A Canadian study among HIV-positive black women revealed the association between HIV-related stigma, gender, racial discrimination, and depression, suggesting that these interrelated forms of stigma and discrimination present barriers to treatment care and support.¹⁹ A recent French study investigated perceived discrimination among a nationally representative sample of PLHIV.²⁰ In this study, 13% of the study participants reported HIV-related discrimination (during the last 2 years),

and 8% reported discrimination in health care settings due to different perceived reasons (i.e., gender, sexual orientation, and race). Sub-Saharan African migrant women were the group with the highest levels of self-reported discrimination. This finding is clearly different compared to our results, with women being less likely to report discrimination than men. This may be explained by the structural approach to assessing discrimination in this recent French study, which also found that HIV-related discrimination was most pronounced both in health care- and private settings.

It should be noted that migrants in our sample included also EU-citizens, who may be socio-economically less vulnerable than migrants coming from low resource settings. However, it is also possible that in our sample migrants as well as women may have underreported discrimination to preserve their self-esteem, or they may take discrimination as a day-to-day experience and subsequently resign to it. Research results on differences between women and men in terms of how they perceived discrimination are mixed: while some studies report greater adverse social reactions to men's HIV status, others have shown that women are particularly vulnerable to HIV-related stigma and discrimination.⁶ While a study in the US revealed that health care providers held more negative perceptions towards their HIV positive female than male patients, which may be rooted in their communication style,²¹ health care providers may also be more attentive to avoid stigmatization of women. They also may find it easier to discuss reproductive health issues compared to sexuality and sexual health with HIV-positive people, which is reflected by our findings on unmet support needs. The crucial role of communication in the provider-patient relationship has also been highlighted by another US-based study, which found significant communication gaps between HIV-infected women and their providers when discussing both gender-specific treatment and pregnancy-related issues.²²

The finding, that persons who were forced into sexual activities were more likely to report discrimination by service providers, is difficult to explain—based on the current results. Again, it could indicate that patients may have felt denied discussing such experiences, as health care providers rarely recognize sexual intimidation or abuse, despite its high prevalence.²³ However, this would clearly merit further exploration.

Our results cannot be generalized to the overall population of PLHIV in Europe because of the study's convenience sampling. The low number of study participants from some countries also did not allow for looking at cross-country differences in terms of discrimination. Characteristic of respondents who accepted to participate, may also be different compared to nonresponders and this could have biased the study results. Self-reported data on sexuality and SRH may be prone to social desirability, as it is the case for most studies on SRH behavior.^{24,25} Due to the cross-sectional study design, we can make no causal inferences. However, we may draw some relevant policy conclusions.

Since HIV-related discrimination seems to be persistent across Europe, clear and active anti-discrimination policies, in place in many European countries, are not enough to combat HIV-related stigma and discrimination.^{26,27} A high proportion of European countries have programs in place to reduce HIV-related stigma and discrimination, and mechanisms to document and address cases of discrimination, but few mechanisms exist to uniformly assess the extent to which individuals experience stigma and discrimination, and the actual impact this has on uptake of services.²⁸ While the reduction of stigma and discrimination should remain central components of national HIV programs to safeguard sexual and reproductive health and rights,²⁹ targeted interventions are needed at the health care level to promote both de-stigmatization and communication skills of service providers. Fostering general openness about SRH topics in a nondiscriminatory way could reduce the feeling of being discriminated against. Evidence-based guidance for health care providers is urgently needed to support them in integrating SRH issues in HIV care. Further research should determine whether perceptions of PLHIV on discrimination are associated with the actual quality of services offered.

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