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Stigma, discrimination, and sexual (dis)satisfaction among people living with HIV: results from the "*AIDES et toi*" survey

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The effects of HIV-related stigma and discrimination have been studied in several areas, such as access to testing, quality of care quality, and access to work. Nevertheless, the effects of stigma and discrimination on the sexual life of people living with HIV/AIDS (PLWHA) have not been studied enough. AIDES, a French community-based organization, has developed a biannual survey which assesses several socioeconomical and psychosocial dimensions of the people in contact with this organization. A focus on the results concerning sexual (dis)satisfaction and the factors associated are presented here. A convenience sample of 521 HIV-positive men having sex with men, heterosexual men and women was analyzed. A logistic regression was performed to examine which factors were significantly associated with sexual dissatisfaction. Results showed that being older, not having a full-time job, not having a steady sexual partner, lower frequency of sexual intercourse, discrimination in the sexual relationship setting, and the perception of loneliness were independently associated with sexual dissatisfaction. A quality health approach must include the aspects linked to sexual life and sexual satisfaction. Given the potentially harmful effects that HIV-related stigma and discrimination have on PLWHA's well-being, more specific actions and advocacy in this direction should be developed and implemented.

Keywords: HIV/AIDS; sexual satisfaction; stigma; discrimination; community-based organization

Introduction

Stigma was defined by Goffman (1963) as "a deeply discrediting attribute" that reduces the bearer "from a whole and usual person to a tainted, discounted one." It has been demonstrated that this circumstance impacts on people's psychological well-being and health (Beals, Peplau, & Gable, 2009; Quinn & Chaudoir, 2009). On the other hand, discrimination, defined as "any measure entailing any arbitrary distinction among persons depending on their confirmed or suspected HIV serostatus or state of health" (UNAIDS, 2000), makes reference to the enacted stigma, that is, "to the acts or omissions in which the content of stigma is applied at an individual or social level" (Brown, Macintyre, & Trujillo, 2003).

Since the beginning of the HIV/AIDS epidemic, the psycho-social well-being of the people living with HIV/AIDS (PLWHA) has certainly been mediated by the stigma and discrimination that this illness arouses (Bos, Schaalma, & Pryor, 2008; Logie & Gadalla, 2009). Even more, HIV/AIDS-related stigma has been shown as strongly linked to the negative attitudes toward certain populations where the epidemic has been especially aggressive, e.g., men having sex with men (MSM; Herek & Capitanio, 1999).

It has been demonstrated that stigma and discrimination are barriers to HIV testing (Genberg et al., 2009; Spielberg et al., 2003), adequate health care (Kinsler, Wong, Sayles, Davis, & Cunningham, 2007; Maman et al., 2009), access to work (Anderson et al., 2008; Rao, Angell, Lam, & Corrigan, 2008), and so on. Therefore, it is not surprising that there exists a relationship between the experience of stigma and discrimination and the psychosocial aspects of PLWHA's quality of life (Préau et al., 2007; Subramanian, Gupte, Dorairaj, Periannan, & Mathai, 2009). However, there is a lack of literature regarding sexual satisfaction among PLWHA (Inoue, Yamazaki, Seki, Wakabayashi, & Kihara, 2004; Lambert, Keegan, & Petrak, 2005) and, to our knowledge, its association with the HIV-related stigma and discrimination has been barely studied (Bouhnik et al., 2008).

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On the other hand, AIDES, the largest French HIV/AIDS community-based organization, created in 1984, has focused most of its actions and lobbying on the rights of PLWHA. Nevertheless, other activities concerning issues such as prevention and legal support have an important role. This organization (AIDES), which embraces the principles of community-based research (Minkler & Wallerstein, 2008), decided, as in previous community-based researches (Bohl, Raymond, Arnold, & McFarland, 2009; Henry et al., 2009; O'Donnell et al., 2009), to conduct a survey on the needs and the socioeconomic and psychosocial conditions of the people in contact with it. The information obtained is used to develop actions and lobbying responding to the detected needs.

Based on the large experience that this community-based organization has had with PLWHA as well as on previous works (Bouhnik et al., 2008; Inoue et al., 2004; Siegel, Schrimshaw, & Lekas, 2006), we hypothesized that feeling sexually (dis)satisfied could be related to the experience of stigma and discrimination in sexual settings. Consequently, the present work aims to determine if there is a link between discrimination and stigma, and sexual (dis)satisfaction among PLWHA from the data collected by a community-based survey called "*AIDES et toi*."

Methods

Data collection

In 2007, AIDES carried out the fourth edition of its biannual cross-sectional nation-wide survey conducted among a sample of users. They were recruited at the local offices and at outreach venues throughout France. During one week, 3168 people in contact with the organization were asked to fill out a self-administered questionnaire and 2434 respondents accepted. The comparison between respondents and non-respondents showed that the latter were more likely to be younger than 25 years old (9.2% vs. 13.1% of respondents; $p < 0.001$) and being solicited in the outreach venues rather than in the local offices (72.7% vs. 51.3%; $p < 0.001$). No statistical differences were found concerning gender.

The questionnaire included standardized items presented in four sections: (a) sociodemographics; (b) health status, quality of life, and discrimination; (c) sexual life; and (d) HIV stigma, disclosure, and biological markers. A fifth section concerning the use of the organization was also included, but it will not be laid out for the present work.

Sample

Of the whole sample, 1098 people declared being HIV-positive. The sample for the present study was drawn from the 521 HIV-positive participants who answered the items concerning sexual (dis)satisfaction. We decided to include the people who reported no sexual activity during the last 6 months (23%) because sexual (in)activity has been shown as a sexual satisfaction determinant (Beutel, Schumacher, Weidner, & Brähler, 2002).

Questionnaire

Individuals who agreed to participate answered a self-administered, 136-item questionnaire. However, in order to resolve any potential linguistic or cultural doubts about the questions, a trained interviewer was available during the whole process.

Variables

Sociodemographics

Sociodemographic characteristics included age, gender, nationality, family status (in couples/single), medical insurance, employment status, and housing (stable/instable).

Health status (satisfaction), quality of life, and discrimination

Participants were asked about their HIV, HBV, and HVC status (positive/negative/unaware), current substance use, and substitution treatment. The questionnaire also measured perceived satisfaction with their health status and quality of life. No previous validated scales were used to assess these two dimensions, instead single-items were applied. Finally, another question dealt with the fact of having being discriminated against during the last two years (yes/no) because of seven possible reasons: (a) being HIV-positive; (b) having hepatitis; (c) being a woman; (d) being homosexual; (e) being a migrant; (f) skin color; and (g) substance use. We also asked about the setting where this discrimination occurred (work place, health care, intimate relationship, sexual relationship, daily life, and own community).

Sexual life (satisfaction)

Concerning sexual life, several questions were addressed to know the kind (steady/casual) and number of sexual partners, HIV serology of the sexual partners, frequency of condom use, and sexual satisfaction. This last item was formulated as follows: "In general, concerning your sexual life, you would say that you are" (satisfied/dissatisfied).

Disclosure, HIV-related stigma, and biological markers

Disclosure to significant others, and the free will to disclose was evaluated. The French-language version of the HIV Stigma Scale (HSS; Berger, Ferrans, & Lashley, 2001) was used in order to measure HIV-related discrimination experienced by PLWHA. It consisted of 26 items (e.g., "I have lost sexual partners when disclosing my HIV-positive status," "I feel anxious about being judged because of my HIV status") with the answer scale for each item ranging from (1) "*strongly disagree*" to (4) "*strongly agree*." Participants were also asked to indicate if they were taking antiretroviral treatment, for how long, their last CD4 cell count, their viral load (detectable/undetectable), and if they had already used post-exposition prophylaxis during the last year.

Statistical analysis

The associations between the different variables of the questionnaire and the individual satisfaction or dissatisfaction with sexual life were examined using Pearson's Chi-squared tests. To identify the factors independently associated with sexual dissatisfaction, logistic models were used. A backward stepwise (likelihood ratio) procedure was used to select statistically significant factors in a multivariate model (entry threshold $p < 0.10$). This procedure enables to test the statistical significance of the variables one by one, deleting those that are not significant. Statistical analyses were performed using the SPSS v17.0 software program (SPSS Inc., Chicago, IL, USA).

Results

Descriptive characteristics

Sociodemographics

The main results are summarized in Table 1. From the sample of PLWHA who answered the sexual satisfaction section ($N = 521$), the mean age was 42.8 years old; men represented 63.3% of the sample and 26.5% fulfilled migration criteria. Concerning sexual orientation, MSM accounted for 61.2% of men. In the sample, 58.7% were in couples, 52.8% had children, 39.5% were employed, and 79.3% had stable housing. As to co-infection, 11% were also HBV-positive and 20.5% were HCV-positive. Finally, 84.6% were undergoing treatment, 75.5% had an undetectable viral load, and 88.3% had a >200/ml CD4 cell count.

Table 1. Characteristics of the "*AIDES et toi*" survey respondents ($n = 521$).

	Frequency or mean (%)
Gender	
Men	330 (63.3)
Women	191 (36.7)
Sexuality	
Heterosexual women	191 (36.7)
Heterosexual men	128 (24.6)
MSM	202 (38.8)
Age	42.8
>40	188 (37.2)
<40	318 (62.8)
Migrant	
Yes	137 (26.5)
No	380 (73.5)
Housing	
Stable	402 (79.3)
Instable	105 (20.7)
Full-time job	
Yes	136 (26.1)
No	385 (73.9)
Stable sexual partner (last 6 months)	
Yes	361 (77.0)
No	108 (23.0)
Frequency of sexual intercourse (steady partner)	
>three times/month	179 (46.6)
<three times/month	205 (53.4)
Frequency of sexual intercourse (occasional partner)	
>three times/month	52 (33.6)
<three times/month	103 (66.4)
Having had sex during the last month	
Yes	351 (69.5)
No	154 (30.5)
Sexual satisfaction	
Satisfied	318 (61.0)
Dissatisfied	203 (39.0)
Quality of life	
(Very)Good	229 (44.3)
(Very)Poor	92 (17.8)
Health status satisfaction	
(Very)Satisfied	242 (64.3)
(Very)Dissatisfied	134 (35.7)
HAART	
Yes	411 (84.6)
No	75 (15.4)
CD4 cell counts	
<200	49 (11.7)
>200	371 (88.3)

Table 1 (*Continued*)

	Frequency or mean (%)
Viral load	
Undetectable	346 (75.5)
Detectable	118 (24.5)
Discrimination in the sexual relationship setting	
Yes	63 (28.7)
No	185 (71.3)

Sexual satisfaction

In relation to satisfaction with sexual life, 39% of respondents reported being dissatisfied. No significant differences were observed when MSM, heterosexual men and women were compared.

Stigma and discrimination

Concerning items about stigma, we found that 87.3% declared "I am very careful about who I disclose my HIV-positive status to," 70.6% declared "I feel anxious that people will judge me when they find out that I am HIV-positive," and 69.6% reported "I feel anxious that the people who know my HIV-positive status will disclose it to others."

Among respondents, 46.7% declared having been discriminated against during the previous two years. When asked about the reasons why this discrimination occurred, discrimination because of their HIV status was the most frequently reported reason (77.4%). As for the setting, daily life and health care (48% and 41.9%, respectively) accounted for the largest percentages (for detailed results see Table 2).

Univariate analysis

The results of the cross-tabulation of sexual (dis)satisfaction with each survey item will be presented following the same order as the questionnaire's sections.

Sociodemographics

Concerning sociodemographic characteristics, the variables significantly associated to sexual dissatisfaction were: being older than 40 years ($p = 0.002$); not being in couples ($p < 0.001$); and not having a full-time job ($p = 0.025$). The variable "having free health care for people on low incomes" instead of private health insurance almost reached significance ($p = 0.05$).

Health status (satisfaction), quality of life, and discrimination

The variable significantly associated with being dissatisfied was "having been discriminated against in the sexual relationship setting" ($p < 0.001$). Current substance use and being HCV-positive almost reached significance.

Sexual life (satisfaction)

In relation to the participant's sexual life, we found that not having sex during the last month was significantly associated to being sexually dissatisfied ($p < 0.001$). The other variables showing a significant link with sexual dissatisfaction were "not having a steady sexual partner" ($p < 0.001$), and a lower frequency of sexual intercourse with both steady and casual sexual partners ($p < 0.001$ and $p < 0.002$, respectively). There was no link between HIV status of the sexual partners (steady or casual) and consistency of condom use and sexual (dis)satisfaction.

Disclosure, HIV-related stigma, and biological markers

As for biological markers and disclosure of HIV-positive status, no significant results were found. However, the choice of disclosing HIV status to friends and acquaintances almost reached significance.

Nevertheless, in relation to the stigma items, we found several statistically significant associations. Concretely, the items "I feel apart, isolated from the rest of the world" ($p < 0.001$), "I am very careful about who I disclose my HIV-positive status to" ($p = 0.032$), "Some people aware of my HIV-positive status have become distant" ($p = 0.020$), "I feel anxious that the people who know my HIV-positive status will disclose it to others" ($p = 0.045$), "Some people are afraid of being rejected because they are close to me" ($p = 0.018$), "I have lost some sexual partners when I told them I was HIV-positive" ($p = 0.024$), "Some people who know my HIV-positive status tend to ignore my personal qualities" ($p = 0.032$), "Some people seem to be afraid of me because I am HIV-positive" ($p = 0.017$) were significantly associated with sexual dissatisfaction. The item "Some sexual partners recoiled from me" almost reached significance.

Multivariate analysis

The results of the multivariate model are shown in Table 3. The variables that remained significantly associated with sexual dissatisfaction were: (1) age (>40 years old); (2) having been discriminated against in the sexual relationship setting during the last two years; (3) not having a steady sexual partner;

Table 2. Discrimination and stigma descriptive results – "*AIDES et toi*" survey ($n = 521$).

	(Strongly) Agree *N* (%)	(Strongly) Disagree *N* (%)
In several areas of my life nobody knows that I am HIV-positive	223 (49.3)	229 (50.7)
It has usually been a mistake to disclose my HIV-positive status	194 (44.2)	245 (55.8)
People avoid touching me if they know that I am HIV-positive	144 (33.3)	288 (66.7)
It is risky to tell someone that I am HIV-positive	324 (70.1)	138 (29.9)
Some people don't want me to be with their children since they know that I am HIV-positive	163 (38.3)	263 (61.7)
I stopped socializing with some people because of their reactions	226 (51.6)	212 (48.4)
I make a lot of efforts to keep my HIV-positive status secret	264 (56.8)	201 (43.2)
People I care about stopped calling me when they found out that I was HIV-positive	168 (38.7)	266 (61.3)
Some people told me that I deserved to be HIV-positive because of my life style	171 (38.8)	270 (61.2)
Some people recoiled from me	205 (46.3)	238 (53.7)
Some sexual partners recoiled from me	203 (47.4)	225 (52.6)
Some people act as if being HIV-positive was my fault	210 (48.5)	223 (51.5)
I feel apart, isolated from the rest of the world	202 (45.3)	244 (54.7)
I am very careful about who I disclose my HIV-positive status to	391 (87.3)	57 (12.7)
Some people aware of my HIV-positive status have become distant	209 (48)	226 (52)
I never feel the need to hide my HIV-positive status	164 (36.8)	282 (63.2)
I feel anxious that people will judge me when they find out that I am HIV-positive	320 (70.6)	133 (29.4)
I feel hurt by the way people react when they find out that I am HIV-positive	258 (58.9)	180 (41.1)
I feel anxious that the people who know my HIV-positive status will disclose it to others	311 (69.6)	136 (30.4)
I regret having disclosed my HIV-positive status to some people	264 (59.2)	182 (40.8)
Some people are afraid of being rejected because they are close to me	168 (38.9)	264 (61.1)
I have lost some friends when I told them I was HIV-positive	190 (44.5)	237 (55.5)
I have lost some sexual partners when I told them I was HIV-positive	201 (48.3)	215 (51.7)
I told my relatives and friends to keep my HIV-positive status secret	290 (65.5)	153 (34.5)
Some people who know my HIV-positive status tend to ignore my personal qualities	170 (40)	255 (60)
Some people seem to be afraid of me because I am HIV-positive	186 (43.5)	242 (56.5)

(4) answering yes to the item "I feel apart, isolated from the rest of the world"; (5) not having a full-time job; and (6) a lower frequency of sexual intercourse with casual sexual partners.

Discussion

These results show that stigma and discrimination toward PLWHA responding to the survey are prevalent. We also observe that the sample who answered this survey declared being sexually dissatisfied in a larger percentage than the general French population; 39% of the respondents reported being dissatisfied vs. 17% of the former (Colson, Lemaire, Pinton, Hamidi, & Klein, 2006). Bouhnik et al. (2008) found that 33% of respondents declared having sexual difficulties. In addition, another study found that as much as 60% of HIV-positive respondents declared being dissatisfied with their sexual lives (Inoue et al., 2004).

Some limitations must be highlighted before discussing our results. Firstly, we are presenting cross-sectional data instead of longitudinal data, more appropriate to understand the association between the different factors studied. Secondly, the sample size was half of those who declared being HIV-positive. We believe that the sexual life items location in the questionnaire was not the most adequate, preventing some of the respondents from answering these items. Thirdly, data proceeding from self-reported information may include a well-known desirability bias. Fourthly, no items concerning sexual dysfunction were included. Therefore, we could be missing a potential determinant of sexual dissatisfaction. Finally, our sample is not a representative random sample of PLWHA but a convenience sample. Furthermore, it is possible that our sample is especially sensitive to discrimination or came to the organization because of the experience of discrimination.

We can state that our results reflect two main dimensions related to sexual dissatisfaction: one includes age, full-time job, and sexual activity (partner and frequency); the other one is strictly associated to HIV-stigma and discrimination in the sexual setting. Concerning the first dimension, we find a potentially obvious result: not having a sexual life, and as shown elsewhere (Beutel et al., 2002; Dunn, Croft, & Hackett, 2000), is linked to a greater sexual dissatisfaction. The relevance of this result arises from the fact that a non-negligible percentage of the sample of

Table 3. Factors associated with sexual dissatisfaction –univariate and multivariate analyses – "*AIDES et toi*" survey ($n = 521$).

	Univariate analysis			Multivariate analysis		
	OR	CI (95%)	*p*-Value	OR	CI (95%)	*p*-Value
Age						
≤40	1		0.002	1		0.022
>40	1.8	1.2–2.6		1.6	1.0–2.4	
Full-time job						
Yes	1		0.025	1		0.045
No	1.6	1.0–2.4		1.5	1.0–2.4	
Stable sexual partner (last 6 months)						
Yes	1		<0.001	1		<0.001
No	3.9	2.4–6.1		1.7	1.3–2.2	
Frequency of sexual intercourse (steady partner)						
>three times/month	1		<0.001			
<three times/month	3.8	2.4–6.2				
Frequency of sexual intercourse (occasional partner)						
>three times/month	1		<0.001	1		0.010
<three times/month	3.9	1.7–8.7		3.0	1.2–7.0	
Discrimination in the sexual relationship setting						
Yes	1		<0.001	1		<0.001
No	0.3	0.1–0.6		0.3	0.1–0.5	
I feel apart, isolated from the rest of the world						
Yes	1		<0.001	1		<0.001
No	0.4	0.3–0.6		0.4	0.3–0.7	
I am very careful about who I disclose my HIV-positive status to						
Yes	1		0.032			
No	0.5	0.2–0.9				
Some people aware of my HIV-positive status have become distant						
Yes	1		0.02			
No	0.6	0.4–0.9				
I feel anxious that the people who know my HIV-positive status will disclose it to others						
Yes	1		0.045			
No	0.6	0.4–0.9				

Table 3 (*Continued*)

	Univariate analysis			Multivariate analysis		
	OR	CI (95%)	*p*-Value	OR	CI (95%)	*p*-Value
Some people are afraid of being rejected because they are close to me						
Yes	1		0.018			
No	0.6	0.4–0.9				
I have lost some sexual partners when I told them I was HIV-positive						
Yes	1		0.024			
No	0.6	0.4–0.9				
Some people who know my HIV-positive status tend to ignore my personal qualities						
Yes	1		0.032			
No	0.6	0.4–0.9				
Some people seem to be afraid of me because I am HIV-positive						
Yes	1		0.017			
No	0.6	0.4–0.9				

PLWHA surveyed does not have a sexual life and consequently is sexually dissatisfied. The lack of sexual life in PLWHA seems to be explained, at least partially, by the second dimension mentioned before, HIV-related stigma and discrimination in the sexual setting.

The results from the present work show a significant relationship between sexual dissatisfaction and several indicators of fear of stigma and enacted stigma or discrimination. When univariate analyses were performed, nine variables reflecting experiences of rejection, detachment, fear and unfair treatment because of HIV-positive status were found to predict sexual dissatisfaction. Concretely, two items made reference to the fear of stigma, mainly to the hesitation of disclosing their HIV-positive status because of the dread that it would be revealed to others. Seven other items were related to enacted stigma. Moreover, the item "I have been discriminated against in the sexual relationship setting (during the previous two years)," not pertaining to the HSS, was also statistically associated. Of all these variables, the latter and the HSS referring to the feeling of loneliness remained significantly associated to sexual dissatisfaction. Therefore, we found both, an enacted and an affective component of stigma predicting sexual dissatisfaction.

Another interesting result makes reference to the link between sexual satisfaction and having a full-time job. On the one hand, having a full-time job is a sign of a better health status, and this better health status has been shown to be associated with a more fulfilled sexual life. On the other hand, and even if the subject has not been studied in depth, one psychosocial factor linked to sexual dissatisfaction is unemployment (Abdo, Oliveira Junior, Moreira Junior, Abdo, & Fitipaldi., 2005; Meisler & Carey, 1991). Our results could support this association. It must also be noted that age was related to sexual dissatisfaction; another study (Asboe et al., 2007) has already demonstrated that this factor is also associated with sexual dysfunction in HIV-positive men.

We did not find any association between sexual dissatisfaction and biological markers or antiretroviral treatment. These results are partially supported by previous research; Bouhnik et al. (2008) did not find any relationship between "sexual difficulties" and immuno-virological outcomes, however, they did find an association between HIV-treatment experience and sexual difficulties.

Current results suggest that improving PLWHA's quality of life and care do not only imply offering quality medical care, but also ensuring a global health and well-being approach, which necessarily involves the effects of stigma and discrimination in different areas. Experiencing stigma and discrimination in the sexual setting is a good example of the harmful effects these can have on the well-being of PLWHA. Besides, given that improving sexual satisfaction in HIV-positive people has been demonstrated as a factor that encourages preventive attitudes (Troussier & Tourette-Turgis, 2006), we can state that PLWHA's sexual satisfaction has a potential public health benefit. Therefore, there is still a dramatic need to develop actions and advocacy addressed to reduce HIV-related stigma.

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