

Disclosure of HIV positive status: gender differences within the TEMPRANO trial participants, Côte d'Ivoire - ANRS I2239

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Citation recommandée • Recommended citation

Niangoran S, Fassassi R, Danel C, Badje A, N'takpe JB, Menan Kouame G, Jean K, Eholie S, Anglaret X, Desgrées du Loû A, « Disclosure of HIV positive status: gender differences within the TEMPRANO trial participants, Côte d'Ivoire - ANRS 12239 », *Working Paper du CEPED*, n°34, Ceped (UMR 196 Université Paris Descartes, IRD), Paris, March 2016.
Available at <http://www.ceped.org/wp>

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Disclosure of HIV positive status: gender differences within the TEMPRANO trial participants, Côte d'Ivoire - ANRS 12239

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Abstract

For people living with HIV, disclosure of HIV status is an important challenge: informed friends or family members can be supportive, or on the contrary can stigmatise the HIV-positive person. We aimed to compare HIV status disclosure among men and women, since gender relationships create different opportunities and difficulties for both sexes.

The study was conducted among HIV-positive adults enrolled in the TEMPRANO randomized trial in Côte d'Ivoire, which aims to compare very early antiretroviral treatment versus treatment initiation as per WHO current guidelines. All participants in this trial were asked questions on HIV status disclosure after 24 months of follow-up. Univariate and multivariate analyses were performed to compare disclosure patterns among men and women, disclosure to people living inside and/or outside the household, and in particular to the spouse or regular partner, and to identify the factors associated with disclosure.

HIV status disclosure was frequent (more than 80%) among HIV patients, with no difference between men and women ($p=0.45$). For both, the regular partner was the most frequent confidant. But patterns of disclosure were different: men more frequently disclosed to a regular partner than women (74.1% vs 64.9%, $p=0.004$), because they were more likely to live with a regular partner (58.6% of men vs 35.8% of women). Men and women living with a regular partner reported similar levels of disclosure to the spouse (82.1% for men and 82.4% for women). Women disclosed more often than men to their children, siblings and mother. For both, the confidants were more often women (sisters, mother) than men (brothers, father).

Our study shows that differences in the living conditions of men and women living with HIV and differences in gender roles induce gendered differences in HIV disclosure that should be considered in the care of the patient.

Key words

HIV disclosure; gender ; Côte d'Ivoire ; couple; early ART.

Conflict of Interest

The authors do not have any commercial or other associations that pose a conflict of interest.

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Funding Support

This trial was supported by a grant from the French Agence Nationale de Recherches sur le Sida et les hépatites virales (ANRS, Paris, France; grants ANRS 12136 and ANRS 12239). Serge Niangoran had a grant from the French Ministry of Foreign affairs and Raimi Fassassi had a visiting grant from the French Institute of Research for development (IRD) during the research program.

The sponsor of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The corresponding author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Introduction

For people living with HIV, disclosing their HIV status is an important challenge: informed friends or family members can be very supportive, or on the contrary may use this information to stigmatise the HIV-positive person (Henry *et al.*, 2014). Thus most people fear to disclose their HIV status (Bilé and Abéga, 2010). Stigma and its consequences can indeed destabilise the environment of a patient: the stability of households, the well-being of families, the social integration of PLWHA and their professional success are the main issues (De Carvalho and Coudray, 2012).

The introduction of antiretroviral therapies (ART) has now turned HIV/AIDS into a chronic disease (Desclaux *et al.*, 2012). Early treatment of HIV-infection patients is raising new hopes that were undreamt of until now: "Zero new HIV infections, zero discrimination, zero AIDS-related deaths" (UNAIDS, 2010). However, these new opportunities have not eased people's fears related to HIV disclosure, although some progress has been shown (De Carvalho and Coudray, 2012; UNAIDS, 2012).

Indeed, even if an HIV-infected person only confides in people he/she trusts, usually handpicked (Tefft, 1980), the risk of leakage of confidential information cannot be completely controlled (Rossier, 2010). To confide a secret to someone is like circulating this secret in a "space of confidentiality", the contours of which are not always under one's control. This circulation certainly encourages sympathy and moral and financial support (Lalou and Msellati, 2007) but it also carries a risk of unwanted disclosure and stigma, of the dissolution of social and family relationships or of marital relationships, of all kinds of discrimination, etc. In situations of economic insecurity, that are common on the African continent, individual dependency to social capital is particularly strong. So should one disclose his/her HIV status or keep it secret, at the risk of jeopardising the support of family and community? The choice represents a difficult alternative.

The handling of these risks may be different for men and women, who are not affected by the disease in the same way (Pannetier, 2011; Sow K., 2012). In Côte d'Ivoire, country with the highest HIV/AIDS prevalence in West Africa (UNAIDS, 2012), women are more affected by HIV than men (INS and ICF International, 2012). They are also more often tested as a consequence of the generalisation of mother-to-child transmission of HIV services and of prenatal HIV testing (Jean *et al.*, 2012). They are generally those through which HIV is disclosed within the couple and the family (Desgrées du Loû, 2011; Orne-Gliemann J. *et al.*, 2011.). Women's limited access to social and economic resources largely explains why women are often in inferior positions within gender relationships (Dédy and Tapé, 1995) and the consequences of stigma can be more serious for women than for men. In addition, in contexts of polygamy, whether formal or informal, women may experience potential competition with the other wife. We aimed to compare how men and women deal with the challenge of HIV disclosure, since gender relationships create opportunities and difficulties that may be different for both sexes.

This study was conducted among all patients in HIV care for the past 24 months as part of a clinical trial who assess the clinical individual benefits of early ART among HIV1-infected persons in West Africa (Abidjan, Côte d'Ivoire). We described whom in their entourage these patients disclosed their HIV status to, and compared disclosure patterns between men and women.

Methods

The TEMPRANO ANRS 12136 trial

The TEMPRANO ANRS 12136 clinical trial (NCT00495651) was conducted in Abidjan, the economic capital of Côte d'Ivoire, to assess the efficacy of early ARV treatment and tuberculosis prophylaxis on severe morbidity (TEMPRANO ANRS Study group *et al.*, 2015). Between March 2008 and July 2012, consenting patients attending the nine participating care centres were included in the trial whenever they met the following criteria: being adults 18 years of age or older; having HIV-1 infection; naïve of ART, having a CD4 count <800 cells/mm³, and presenting no criteria for starting ART according to the most recent WHO guideline. Patients were randomized into 4 arms, (i) immediate ART, (ii) Immediate ART and INH prophylaxis (iii) Deferred ART (iv) Deferred ART and INH prophylaxis. Each participant was followed 30 months. In the Deferred ART arm, patients started ART when the met WHO criteria. Participants went to the center every 3 months or at any time for any clinical problem.

The TEMPRANO Social Study

The TEMPRANO Social Study was a socio-behavioural study nested in the trial. Starting from January 1 2010, standardised questionnaires were used to record social and behavioural indicators among the trial participants. Questionnaires were completed during face-to-face interviews that took place at inclusion, and then during clinical visits occurring around 12 and 24 months after inclusion. Participants included before January 1st 2010, and who did not complete baseline socio-behavioural questionnaires were, however, interviewed at their inclusion anniversary visits. Questionnaires included items related to socio-demographic characteristics, type of housing and household composition, conjugal status, HIV status disclosure, ART treatment and perception of health status.

Statistical Analysis

All trial participants having completed a socio-behavioural questionnaire 24(±6) months after inclusion (in December 2014) were included in the present analysis. We first compared with Chi²-test the characteristics of male and female patients at M24 : age, educational level, type of accommodation, activity, marital status, cohabitation with the spouse, living alone or not, health status as perceived by the patient and being under ART treatment or not at M24.

Then we measured HIV status disclosure at M24. We compared between men and women the proportion of patients who had disclosed their status to at least one person in their lives, whom they disclosed to, and disclosure inside and outside the household.

Associations between HIV disclosure and age, educational level, type of housing, activity, living alone or not, conjugal status, perceived health status and being under antiretroviral treatment were analysed with bivariate and multivariate logistic regression models, for men and women separately and together. Multivariate models were adjusted for all variables mentioned above.

We compared between men and women who had a regular partner at M24 the proportion of HIV disclosure to the spouse or regular partner, according to whether the patient was on antiretroviral treatment or not, marital status, cohabitation with the spouse or partner, and HIV status of the partner. Finally we compare the feeling of being alone and union dissolution since the last visit between those who disclosed to the spouse or regular partner and those who did not. Proportions were compared with a Chi2 test.

Analyses were conducted using Stata (version 13.0, StatCorp).

Results

Patient characteristics

As of December 2012, 2056 patients had been enrolled in the Temprano trial, and 1760 had completed their 24 month follow-up visit. Among the 2056 participants who were included at the closing date (December 2014), 36 died at 24 months and 66 were lost to follow up at 24 months. Eight patients did not respond to the disclosure question and were excluded from the database. Analyses were thus conducted on 1752 patients.

Patients followed-up in the trial were mostly women (1380 women and 372 men, i.e. 78.8% women). About three in four patients (70.5%) were of Christian faith and a little less than one in two completed secondary or higher education (Table 1). Most patients were single (44.5%) and more than 3 out of 4 patients (76.3%) had initiated ART at M24. The majority of patients felt that their health was good (65.5%) or very good (25.5%). Women were younger than men, less educated, more often unemployed or working in the informal sector. They were less often in union: almost three out of five (59.6%) women were single, widowed or divorced (47.9% of single and 11.7% of widowed or divorced) versus one in three for men (36.3%). Women were less likely to live alone than men, as they more frequently lived with children. On the other hand, women were less likely to live in a couple relationship: 40.4% of women and 63.7% of men reported having a regular partner or spouse, and only 35.8% of women were co-residing with their spouse or partner, against 58.6% of men. Less than 4% of men and women reported living in polygamous union.

HIV Status Disclosure

More than 4 out of 5 participants (82.8% of men and 84.4% of women) disclosed their HIV status to at least one person and the difference according to sex was not significant ($p=0.447$, Table 2). However, if men and women reported the same overall level of disclosure, they did not inform the same people. For both sexes, the regular spouse or partner was the first confidant, and more so for men than for women (74.1% of men disclosed to their spouse or regular partner, vs. 64.9% of women, $p=0.004$). Among women, the people they disclosed most often to, just after the partner, were their sister(s) (25.6% of women informed their sister vs. 14.3% of men, $p < 0.001$) and their mother (14.3% of women disclosed to their mother vs. 8.1% of men, $p=0.002$). Women were also more likely than men to disclose to their children and other parents. Employers were rarely informed, but more so among men than women (1.6% vs. 0.2%, $p < 0.001$).

One person out of ten informed one or more friends, and gender differences were not significant. Disclosure to the father was rare, and neighbours were kept out of confidence.

When differentiating disclosure in the home and outside the home, a clear difference in behavior appeared between men and women; within the household, women were less likely to disclose their status than men (52.7% vs 57.8%, $p=0.100$) while outside the home, more women entrusted the secret of their status than men (59.9% against 49.2%, $p<0.001$).

The main factors related to the probability of HIV status disclosure to at least one person were having a spouse or regular partner (Table 3: OR=2.94 [2.05-4.22] for women and OR=3.66 [1.88-7.31] for men), the level of education (OR=3.66 [1.88-7.31] and the gender (OR=1.45 [1.02-2.08]). Among all patients, it was the three factors that remained significant after adjustment for other variables. In the analysis stratified by gender, having a spouse or regular partner was with the living in a communal courtyard rather than individual housing (OR=0.68 [0.50-0.92]) the two significant factors for women, while for men the level of education is an additional factor which were significantly associated after adjustment: the level of education (men who completed at least secondary education were more likely to disclose than less educated men (OR=2.60 [1.37-4.94])).

Disclosure to Spouse or Regular Partner

When considering only those who reported having a spouse or regular partner at M24 (n=1186), HIV disclosure rates to this regular partner were higher among men than women (Table 4: 74.1% vs. 64.9%, $p=0.004$). However when considering cohabitation with the regular partner, this difference between men and women disappeared: 82.1% of men and 82.4% women disclosed to the partner they were living with, and only 45.0% of men and 43.8% of women had informed their regular partner of their HIV status while they were not living together (Table 4).

Partner notification was also related to marital status: disclosure was less likely within polygamous households than in monogamous.

Being on antiretroviral treatment did not influence disclosure to the spouse or partner, neither among men ($p=0.976$) or women ($p=0.313$).

Disclosure to the partner was strongly associated with the partner's HIV status: when the partner's HIV status was unknown, only 31.2% of men and 31.3% of women disclosed their own status to their partner. When the partner was known HIV-negative, 80.0% of men and 87.7% of women disclosed their own status to their partner. When the partner was known HIV-positive, 94.8% of men and 96.6% of women disclosed their own status to their partner. There were no significant differences according to sex.

After Disclosure?

Not informing anyone among family or friends of his/her HIV infection was associated with a high sense of loneliness: 23.4% of men and 23.8% of women who had not disclosed to anyone reported feeling alone, with no difference across genders ($p=0.948$). Among people who had disclosed to at least one person, the feeling of loneliness decreased, but remained high among women: 18.9% of women reported feeling alone against 11.7% of men ($p=0.003$). Even among those who had a spouse or regular partner and had disclosed their HIV status to him/her, loneliness was much more common in women than in men: 14.7% of women vs. 7.0% of men ($p=0.002$).

Changes in marital status during the 24 months follow-up period were not significantly different between those who disclosed their HIV status and those who did not. We observed an overall stability of unions: for around 94.6% of the patients, marital status did not change during the two-year follow-up, whatever the sex of the patient and its disclosure status. We even observed new unions within the

patients who disclosed (5/206 among men (2.4%) and 18/589 among women (3.1%)), in proportions similar to that was observed among those who concealed their HIV status to their partner.

Discussion

The men and women followed-up in the TEMPRANO trial among which we analysed disclosure practices have a different demographic profile than the Abidjan population as a whole, which is generally younger and less educated (INS, 2005). Such a profile reflects the characteristics of the people tested for HIV in Abidjan and HIV-infected (Jean et al, 2012). The very high proportion of women followed-up in this trial can be explained partly by the fact that antenatal clinics for pregnant women are one of the main places where HIV testing is offered, in the context of PMTCT programs, for which Côte d'Ivoire was a pioneer (Desgrées du Loû, 2007), and also by the fact that the HIV epidemic in Côte d'Ivoire affects women more than men (INS and ICF International, 2012).

Among the HIV-infected patients followed-up in this trial, there was a big difference in terms of family situation between men and women: men were twice as likely to live in a couple relationship than women. This is likely to reflect the difference in the age-specific HIV prevalence in Côte d'Ivoire, with women getting infected in average at a younger age than men (INS and ICF International, 2012). The majority of women had a regular partner, but many of them did not live with their partner. The men in HIV care were more likely to live with their partner than women in HIV care. On the other hand, very few women lived completely alone, while this was the case of nearly one in ten men. In Abidjan, the living conditions we documented among people living with HIV were different according to sex, which necessarily had repercussions on their choices of HIV disclosure to family and friends.

Our study highlighted several key elements to help better understand the patterns of HIV disclosure and the environment of HIV-infected people in Côte d'Ivoire. First of all, despite a good perceived health, disclosure was frequent. Thus it was not a "disclosure under constraint" due to sickness. Second, disclosure was often limited to the "first circle": spouse, close family. This may express the fear of stigmatization.

Overall, HIV disclosure to the partner was quite low, with less than two third of the participants reporting having disclosed their HIV status to their partner. This may have implication for prevention, as HIV disclosure may be an important step toward sexual risk reduction and uptake of HIV testing by the partner.

HIV disclosure was mainly to the spouse or regular partner, for men as well as for women, especially when cohabiting with the partner. This result confirms that the couple relationship must be taken into account when providing support to people living with HIV: the spouse holds a very special and important place in the HIV disclosure network, despite fears of rejection or separation. Our results also confirmed that disclosure to the partner was not associated with a higher risk of union break-up. A previous study conducted in Abidjan among women living with HIV followed within a PMTCT program also showed that the higher union dissolution rates observed among HIV-positive women were more related to a personal choice than to a consequence of HIV disclosure to their partner (Desgrées du Loû et al, 2009). Disclosure of HIV status instead further tightened the couple relationship between partners (Tijou Traoré, 2006).

Women living in a polygamous household were less likely to inform their partner of their HIV status. This again confirms the results of previous studies (Desgrées du Loû et al., 2009) and is explained by the fact that this type of union implies competition between women.

HIV disclosure to the partner was highly dependent on the patient's knowledge of their partner's HIV status. As shown in other studies, disclosure to the partner is much more likely when he/she has been tested for HIV, even if tested HIV-negative, than when the HIV status is unknown (Rice et al., 2009). Testing of the partner may be a consequence of disclosure rather than a cause. Nevertheless, testing and mutual disclosure is an important condition for the prevention of HIV transmission in stable couples, as shown before (Desgrées du Loû, 2009; Orne-Gliemann et al., 2013).

Beyond the spouse, HIV disclosure was more common first to sisters, then to mothers and brothers, and finally to friends and children. The nuclear family thus seems to be an important crucible of solidarity for PLWHA. The women of the family in particular (sisters, mothers) are those to whom one confides, even when a man, confirming the gender roles described in the literature: women are the ones who provide care and are requested in case of illness or weakness (Gilligan, 1982). On the contrary, the father is rarely a confidant. He is a figure of authority in the household and is often the one person whose reaction is feared. Neither men nor women disclose preferably to their father.

Differences between men and women were shown in the network of disclosure beyond the spouse: women had a more diversified network of confidants. Because women were less often in a stable and cohabiting relationship than men, they less frequently confided to a spouse, but more often confided to another person. In particular, they were more likely than men to disclose to a person outside the home. These results once again highlight gender differences, and the fact that women, more than men, tend to live in relationships with others (Gilligan, 1982), which translates, when living with a disease, by a greater ability to share about illness when living with a disease (Bila, 2011).

Paradoxically, while men more often lived alone, they felt less lonely than women. Loneliness is very subjective: women are less alone physically, particularly because they often live with children, but they feel lonelier than men when facing their illness, even when they have a partner or a spouse, and even when he is informed of their HIV status. Overall, however, the feeling of loneliness is more common for people who have not informed anyone of their HIV status, confirming that entrusting one's HIV status to at least one person among family or friends is an important aspect of good quality of life with HIV.

Overall our study shows that differences in the living conditions of men and women living with HIV, and differences in the social roles that men and women experience, induce HIV disclosure strategies to a third party that differ according to gender: men and women confide in slightly different ways, and both confide more often in women. This must be taken into account in the overall management of the HIV-positive person and his entourage.

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Tables

Tableau 1. Characteristics of men and women followed-up since 2 years within the TEMPRANO trial, Abidjan, 2012 (p-values corresponds to Chi-squared test)

	Men (N= 372)		Women (N= 1380)		Total (N= 1752)		p (difference between men and women)
	%	n	%	n	%	n	
Age							
Moins de 30 ans	9.6	36	26.8	372	23.2	408	0.000
30-34 ans	16.0	60	24.6	341	22.8	401	
35-39 ans	22.2	83	20.9	290	21.2	373	
40ans et plus	52.2	195	27.7	383	32.8	578	
Education level							
No schooling	14.2	53	27.6	383	24.8	436	0.000
Primary	16.0	60	31.8	440	28.4	500	
Secondary	48.7	182	29.6	410	33.6	592	
Higher education	21.1	79	11.0	153	13.2	232	
Type of housing							
Individual housing	57.1	212	57.0	786	57.0	998	0.673
Common courtyard	42.9	159	43.0	594	43.0	753	
Activity							
Public sector	16.0	60	4.0	56	6.6	116	0.000
Private sector	41.7	156	15.2	210	20.8	366	
Informal sector	31.6	118	55.1	764	50.1	882	
Unemployed	10.7	40	25.7	356	22.5	396	
Marital status							
Single	32.3	120	47.9	660	44.5	780	0.000
Married monogamous	22.8	85	12.5	173	14.7	258	
Married polygamous	4.0	15	2.3	32	2.7	47	
Free union	36.9	137	25.6	353	28.0	490	
Divorced/Widow/Separated	4.0	15	11.7	162	10.1	177	
Lives alone	13.4	50	4.6	64	6.5	114	0.000
Has a spouse/regular partner							
Yes living together	58.6	218	35.8	495	40.7	713	0.000
Yes not living together	5.1	19	4.6	63	4.7	82	
No	36.3	135	59.6	822	54.6	957	
Perceived health status							
Excellent/very good	27.7	100	25.0	331	25.5	431	0.373
Good	64.8	234	65.7	870	65.5	1104	
Bad	7.5	27	9.3	124	9.0	151	
Under ARV treatment	74.1	277	76.9	1066	76.3	1343	0.025

Tableau 2. HIV disclosure (outside medical staff) among patients' follow-up in the Temprano trial: who is informed and where? Comparison between men and women

	Men (N=372)		Women (N=1380)		p* (difference between men and women)
	n	%	n	%	
Level of disclosure: at least one person knows the HIV status	308	82.8	1165	84.4	0.447
Who is informed?					
Spouse or regular partner	206	74.1	589	64.9	0.004
Children	17	4.6	147	10.7	0.000
Father	13	3.5	59	4.3	0.501
Mother	30	8.1	197	14.3	0.002
Brothers	36	9.7	164	11.9	0.235
Sisters	53	14.3	353	25.6	0.000
Other family members	22	5.9	130	9.4	0.033
Neighbours	3	0.8	11	0.8	0.986
Employer	6	1.6	3	0.2	0.001
Friends	35	9.4	145	10.5	0.536
Other	41	11.0	166	12.0	0.593
Where?	n/N	%	n/N	%	
Disclosure inside the household**	186/322	57.8	693/1316	52.7	0.100
Disclosure outside the household	183/372	49.2	826/1380	59.9	p <0.001

* Chi-squared test

**among people not living alone

Tableau 3. Factors associated with HIV status disclosure (outside the medical staff) among patients follow-up in the Temprano trial (Multivariate logistic regression models)

	Total (N=1685)	Women (N=1324)	Men (N=361)
	OR [95% CI]	OR [95% CI]	OR [95% CI]
Sex			
Female vs male	1.45 [1.02 ; 2.08]	-	-
Age			
30 - 34 years vs <30	1.10 [0.72 ; 1.66]	1.05 [0.67 ; 1.64]	1.23 [0.37 ; 4.09]
35 - 39 years vs <30	0.83 [0.55 ; 1.26]	0.77 [0.49 ; 1.22]	0.97 [0.31 ; 3.04]
40 years and above vs <30	0.75 [0.51 ; 1.09]	0.79 [0.53 ; 1.20]	0.65 [0.23 ; 1.87]
Education level			
Secondary or Higher vs no schooling or Primary education	1.42 [1.06 ; 1.90]	1.20 [0.87 ; 1.66]	2.60 [1.37 ; 4.94]
Type of housing			
Common courtyard vs individual housing	0.78 [0.59 ; 1.02]	0.68 [0.50 ; 0.92]	1.33 [0.71 ; 2.48]
Living alone			
Yes vs No	0.71 [0.44 ; 1.12]	0.69 [0.38 ; 1.27]	0.73 [0.32 ; 1.64]
Spouse/Regular partner at M24			
Yes vs No	2.95 [2.16 ; 4.03]	2.94 [2.05 ; 4.22]	3.66 [1.88 ; 7.13]
Perceived health status			
Good vs Excellent	0.88 [0.64 ; 1.22]	0.91 [0.63 ; 1.31]	0.80 [0.41 ; 1.54]
Bad vs Excellent	0.98 [0.58 ; 1.67]	0.82 [0.46 ; 1.45]	2.53 [0.52 ; 12.37]
Under ARV treatment			
Yes vs No	1.05 [0.77 ; 1.42]	1.13 [0.80 ; 1.60]	0.87 [0.44 ; 1.72]

Tableau 4. Proportion of patients who disclosed their HIV status to their spouse or regular partner among those in stable relationship. Comparison between men and women

	Men			Women			p-value* (difference between men and women)
	n	N	%	n	N	%	
All	206	278	74.1	589	908	64.9	0.004
According to ARV treatment							
Under ARV	157	212	74.1	464	706	65.7	0.023
Not under ARV	49	66	74.2	125	202	61.9	0.068
p-value*		0.976			0.313		
According to marital status							
Married monogamous	63	85	74.1	147	173	85.0	0.035
Married polygamous	12	15	80.0	18	32	56.3	0.114
Free union	112	137	81.8	275	353	77.9	0.348
Single	18	39	46.2	138	319	43.3	0.731
Divorced widowed separated	1	2	50.0	11	31	35.5	0.679
p-value*		<0.01			<0.01		
According to cohabitation							
Lives with spouse or regular partner	179	218	82.1	408	495	82.4	0.919
Does not live with spouse or regular partner	27	60	45.0	181	413	43.8	0.864
p-value*		<0.01			<0.01		
According to HIV status of spouse or regular partner							
Unknown	20	64	31.2	115	367	31.3	0.989
HIV-	48	60	80.0	214	244	87.7	0.121
HIV+	129	136	94.8	231	239	96.6	0.393
p-value*		<0.01			<0.01		

* Chi-squared test