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Mirror, mirror on the wall: the face of HIV+ women in Europe today

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Sexual and reproductive health (SRH) and rights are important components of quality of life. This cross-sectional study describes HIV-positive women's SRH aspirations and needs and the predictive value of selected SRH factors on condom use with steady sexual partners. Data were collected in a European multi-centre study in 17 HIV centres in 14 European countries by a standardised anonymous self-administered questionnaire. Descriptive statistics and hierarchical regression analysis were carried out and qualitative data from related formative research illustrated the findings.

Among 387 HIV-positive women, 57% had children and 35% had become pregnant since their HIV-diagnosis. Contraceptive needs were largely unmet: 14% had undergone a pregnancy termination. About 83% changed their sexual behaviour after HIV-diagnosis in some ways. Sixty-two percent had at least one sexual encounter with a steady partner during the past six months and 51% used condoms consistently. Significant correlations with condom use were identified for childbearing since HIV-diagnosis ($r = -0.21$, $p < 0.01$), miscarriage since HIV-diagnosis ($r = -0.24$, $p < 0.01$), the use of contraception ($r = 0.47$, $p < 0.001$) and changes in sexual behaviour after HIV-diagnosis ($r = 0.20$, $p < 0.01$). Hierarchical regression analysis controlled for education, migration background, age, undetectable viral load and partners' serostatus. The following significant predictors for condom use were established: the use of contraceptives ($\beta = 0.33$, $p < 0.001$); miscarriage since HIV-diagnosis ($\beta = -0.16$, $p < 0.01$); childbearing since HIV-diagnosis ($\beta = -0.12$, $p < 0.05$); and having an HIV-positive partner ($\beta = -0.13$, $p < 0.05$). For study population, consistent condom use performed a challenge. Selected SRH-issues predicted condom use. Sexual risk reduction and positive prevention should be discussed in the context of family planning and integrate SRH perspectives in routine HIV care.

Keywords: HIV; women; sexual and reproductive health; prevention; condom use

Introduction

When AIDS reached public awareness in the early 1980s, it was viewed as a disease of homosexual men and as a sentence of imminent death. An early study by the US Centres for Disease Control and Prevention (Center for Disease Control [CDC], 1982) quoted a one-year mortality rate of 60%. For those with access to highly-active antiretroviral treatment (HAART) and care, HIV has now become a chronic illness. More recently, the five-year risk of death from HIV was noted to be less than 5% (Antiretroviral Therapy (ART) Cohort Collaboration, 2007). In 2007, the epidemic was estimated to have spread to some 33 million people (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2008), with about 50% of cases affecting women in their reproductive ages, a proportion which continues to rise. In the WHO European region, a third (33%) of new HIV cases in 2007 was reported among women (European Centre for Disease Prevention and Control [ECDC]/WHO Regional Office for Europe, 2008).

With these shifts in the HIV epidemic, the focus of care has evolved towards improving the quality of life. Regardless of HIV, sexual expression and experience of parenthood are central issues for the quality of life of both women and men, but people living with HIV (PLHIV) have specific needs in this respect (Bharat & Mahendra, 2007; Boonstra, 2006). Many HIV-positive women of reproductive age today have only been cognizant of their serostatus in the era of HAART, where mother-to-child transmission rates of HIV are less than 2% (Volmink, Siegfried, van der Merwe, &

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Brocklehurst, 2007). Access to HAART is seen as a chance to obtain what they once thought was lost: the opportunity to have meaningful sexual relationships and bear healthy children. While SRH presents a basic human right (Gruskin, Ferguson, & O'Malley, 2007; London, Orner, & Myer, 2008; Segurado & Pavia, 2007), fulfilling SRH-related needs may pose number of challenges: PLHIV and service providers (SPs) perceive it as difficult to address sexuality in routine service provision (Nöstlinger et al., 2008). Enabling comprehensive HIV services to better meet the sexual and reproductive health (SRH)-related needs of their clients will not only contribute to increasing quality of life, but also to onwards HIV prevention.

Objectives

This European cross-sectional multi-centre study aimed at assessing SRH-related aspirations and needs of PLHIV. In this paper, we present specific results pertaining to HIV-positive women. We assessed three areas of SRH in more detail (sexual health, motherhood and contraception) and investigated the contributing role of SRH-related issues to sexual protection behaviour, i.e., condom use in steady relationships.

Methods

Procedures

The research was carried out in the framework of a European Public Health Project and research network (Eurosupport 5) consisting of 17 HIV-treatment sites, community-based and research organisations in 14 European countries (see Figure 1).

We adopted a two-phase multi-method research design combining qualitative and quantitative methods. In the first formative research phase, SRH-related aspirations and needs were investigated in detail using focus group discussions (FGDs) with PLHIV. FGDs were conducted according to the state-of-the-art (Morgan & Krueger, 1998), details on the procedures reported elsewhere (Nöstlinger et al., 2008). We used purposive sampling to recruit FGD participants until saturation of data was achieved. These results informed the cross-sectional quantitative study, by adding HIV-specific factors such as partners' HIV status, knowledge and attitudes relating to positive prevention, HIV-disclosure, etc. to the theoretical model that guided our research, i.e., the information–motivation–behavioural skills model (IMB; Fisher & Fisher, 1993). Data on the modified IMB constructs were obtained through an anonymous self-administered questionnaire (SAQU) focusing on demographics, health- and SRH-related variables and condom use (prior six months). The SAQU was piloted for feasibility with a small sample of PLHIV. Eligibility criteria were: being able to read; comprehend and answer to the survey independently; understand the study goals and objectives; and being diagnosed HIV-positive for at least six months.

Informed consent procedures were carried out at all study sites and ethical approval was obtained at the coordinating site (Institute of Tropical Medicine/University

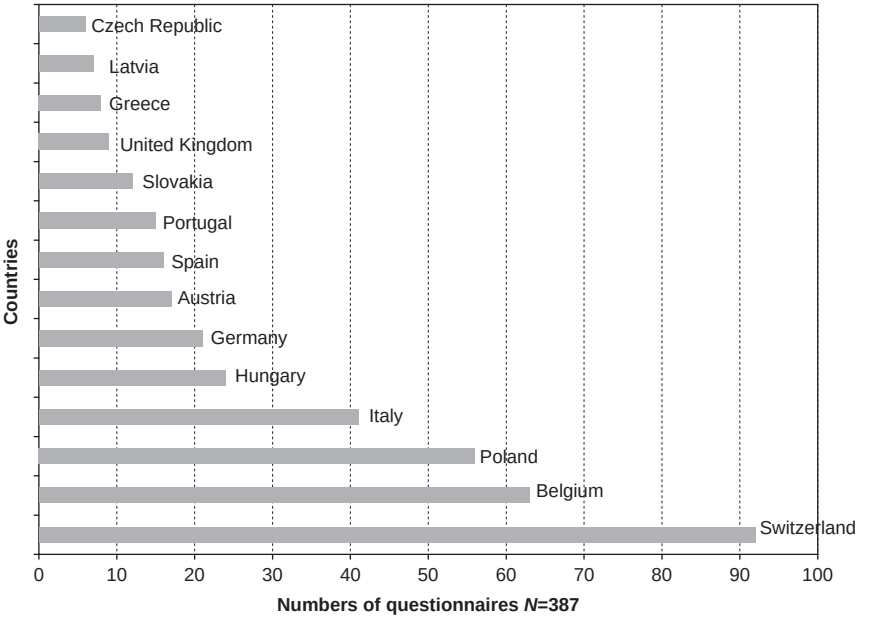

Figure 1. Participating countries (valid self-administered questionnaires).

Table 1. Reproductive and sexual health variables ($N = 387$).

Variable	*n* (%)
Having children	221 (57)
Pregnancy since HIV-diagnosis	135 (35)
Childbearing since HIV-diagnosis	97 (25)
Pregnancy termination since HIV-diagnosis	53 (14)
Having miscarriages since their HIV-diagnosis	40 (10)
Desire to have (more) children	157 (41)
Use of contraceptives %	214 (55)
Treated for STI	41 (11)
Kind of changes in sexual behaviour after HIV-diagnosis[a]	
Not having sex	73 (19)
Having fewer partners	39 (10)
Sticking to one partner	129 (33)
Using a condom more stringent	147 (38)
Avoiding risky practices	80 (21)
Other	25 (6)
Changes in sexual behaviour (0–5), Mean (SD)	1.42 (1.20)
Satisfaction with sexuality (0–10), Mean (SD)	6.70 (2.50)

[a]Multiple answers.

of Antwerp). Qualitative data were collected between December 2005 and June 2006, and quantitative data between March 2007 and April 2008.

Measures

We assessed satisfaction with sexuality through an 11-item scale ranging from "0" (="not at all satisfied") to "10" (="completely satisfied"). Changes in sexual behaviour were measured by a multiple answer question regarding different kind of changes (see Table 1). The variable "number of changes in sexual behaviour" was established by summing up these answers. This yielded an interval scaled variable ranging from "0" (="no changes") to "5" (="many changes"). Other SRH-related variables were measured directly as dichotomous variables ("yes"/"no"). The dependent variable condom use was expressed as the proportion of condom use at all sexual encounters with steady partner (0–100%).

Data analysis

Systematic contextual data analysis was used to process qualitative data. Descriptive statistical analyses using the statistical package for social science (SPSS) 16.0 were carried out employing frequency analysis. Results were described by central tendency, dispersion (mean, SD) and absolute and relative distribution, where appropriate. Bi-variate correlations and a hierarchical regression analysis were performed (Backhaus, Erichson, Plinke, & Weiber, 2003) to test the associations, respectively, the effect of SRH-related variables. We controlled for the effect of education, migration background, age, undetectable viral load and having a seroconcordant steady partner. Due to low numbers of women with casual sexual partners, only women with a steady sexual partner in the prior six months were included in the bi- and multi-variate analysis.

Results

Sociodemographics

In the qualitative study, 43 heterosexual women from nine FGDs were included in the analysis, in the quantitative study the number of participating women was 387.

Female FGD participants were on average 39 years old, had lived longer with HIV than six years. Thirty-six women (85%) were taking HAART. Nine women were migrants (21%), and more than half lived in a steady relationship.

In the quantitative study, the women's median age was also 39 years (ranging from 17 to 69 years), with the majority in their childbearing years (317/82%), defined as ages 15–45. About a quarter had a migrant background (87/22.5%). The vast majority self-identified as heterosexual (326/91%). Two-thirds reported living in a family setting (253/65%), 102 (26%) lived alone. Women were highly educated, 282 (73%) had completed secondary or higher education, and 192 (50%) were employed.

Health status and HIV-related characteristics

In the quantitative study, the median duration of HIV infection was 8 years. Women became aware of HIV infection at the median age of 29 years; 12 (3%) young women were infected through mother-to-child transmission. The most common way of infection was heterosexual transmission (208/54%), followed by the categories "unknown" (65/17%), intravenous drug use (IVDU; 44/14.5%) and IVDU plus sexual transmission (28/7%). About one-fourth (103/27%) reported to suffer from HIV-related health symptoms. While 310 (80%) were on ART, 236 (76%) had an undetectable viral load. The mean reported CD4 count was 500 cells/μl.

Sexual health and condom use

The FGD showed that the fear to transmit HIV to their partners was a commonly shared experience among many women. Some women reported being sexually abstinent either due to not having a partner or due to the fear of transmitting HIV. However, almost all

sexually active women felt that adhering to safer sex standards on a day-to-day basis was a major challenge.

> It's really challenging, you know, like you know that you should be using condoms for the rest of your life, all the time ... me: I'd just wish I could forget about it, at least sometimes ... so once in a while, we take chances and we decide to make love without... (female FGD participant with a seronegative partner, Belgium)

While some women spoke about their limited ability to negotiate safer sex issues with their male partners, others perceived unprotected sex as an expression of intimacy in the sexual relationship. Many reported their own risk–benefit analyses depending on the partner's serostatus and sexual practices, thus not always adhering to SPs' strict safer sex messages, which often were perceived as not differentiating between partners' serostatus.

> I think that he wants me to be as close to him as possible, to overcome all boundaries between us and somehow condoms symbolise this. He acts as if he wouldn't mind to become infected ... that would finally allow us to feel the same thing... (female FGD participant with a seronegative partner, Poland)

Table 1 shows that the majority of all women participating in the quantitative study were sexually active: 240 (62%) women reported at least one sexual encounter (vaginal/anal intercourse) with their steady partner. One hundred and sixteen (51%) always used condoms on these occasions. Forty-one (11%) were treated for an STI in the prior six months, and 25 (6%) had tested positive for syphilis.

HIV-diagnosis meant a change in sexual behaviour for many women: 321 (83%) reported to have changed their sexual behaviour in one or more ways, e.g., by using condoms more stringently, choosing monogamy or avoiding "risky" sexual practices. Nevertheless, the satisfaction with sexuality was quite high ($M = 6.7$, SD = 2.50).

Motherhood and HIV

Qualitative results showed that for many women pleasure and happiness were tied to parenting. Some women had decided not to have children because of SPs' advice or fear to infect the child. In the light of available treatment options, some women still struggled with that decision. Others had opted for children, but questions on the potential impact of the pregnancy on HIV remained. For most women, the crucial question focused on how to conceive safely.

Table 2. Sexual behaviour and condom use past 6 months ($N = 387$).

Variable	*n* (%)
Sexual practices[a]	
Vaginal sex	267 (69)
Passive anal sex	32 (8)
Active oral sex	148 (38)
Passive oral sex	95 (25)
None of the above	83 (21)
Sexual encounter with steady partner	240 (62)
Sexual encounter with casual partner(s)	52 (13)
Consistent condom use with steady partner	123 (51)
Consistent condom use with casual partner(s)	27 (52)

[a]Multiple answers

> Some people around me say it's quite selfish to desire another child. I do have one healthy child already out of my previous marriage, so why take chances?

> But I'd wish to become pregnant again and have a second baby ... my partner is also HIV positive and we are both undetectable. I wonder what the chances really are to harm the baby ... (FGD participant, Belgium)

Quantitative results (see Table 2) show that the majority (221/57%) had children, and 135 (35%) had become pregnant since their HIV-diagnosis. In addition, many (157/41%) wished to have more children. A further 10% (40 women) had suffered from a miscarriage. Fifty-three women (14%) had terminated a pregnancy since their HIV-diagnosis.

Contraception

In the FGDs women expressed a high need for safe contraception: while many women used condoms as primary method, many were concerned about their contraceptive efficacy. A uniform result across all FGDs was that women missed routine delivery of family planning information and advice. Women often felt left alone in the decision-making on the most suitable contraceptive method. In addition, misconceptions were highly persistent in some subgroups, such as African migrant women.

> I am afraid of using the pill, it affects a woman's health so that she never will be able to have babies again, she'll become infertile or have a miscarriage... (FGD participant, sub-Saharan African migrant, UK)

The questionnaire data showed that 214 (55%) used some form of contraception (156/40% used only a condom, 45/12% condoms in combination with other methods).

Table 3. Intercorrelations between SRH-variables and condom use with steady partner.

Variables	1	2	3	4	5	6	7	8	9
1 Condom use with steady partner	–								
2 Use of contraceptives	0.47**	–							
3 Childbearing since HIV-diagnosis	−0.21**	−0.03	–						
4 Miscarriage since HIV-diagnosis	−0.24**	−0.07	0.25**	–					
5 Abortion since HIV-diagnosis	0.02	0.11	0.16**	0.19**	–				
6 Having children/motherhood	−0.05	−0.03*	0.54**	0.05	0.06	–			
7 Child wish	0.09	−0.08	0.00	−0.03	−0.02	0.27**	–		
8 Satisfaction with sexuality	0.03	−0.10	−0.01	−.06	0.07	−0.16*	0.01	–	
9 Changes in sexual behaviour	0.20**	0.19**	0.04	0.02	0.01	0.03	0.06	0.12	–

*$p < 0.05$; **$p < 0.01$.
Note: $N = 240$.

SRH-related variables as predictors of condom use with steady partner

Table 3 shows the correlation matrix for the SRH-related variables and condom use for the 240 women who had sex with a steady partner during the past six months prior to the study. Significant associations were identified between condom use and the use of contraceptives, childbearing since HIV-diagnosis, miscarriage since HIV-diagnosis and the changes made in sexual behaviour after HIV-diagnosis. The hierarchical regression analysis established that the use of contraceptives increased condom use with steady partner, whereas having given birth to a child and having suffered from a miscarriage since HIV-diagnosis decreased the condom use. In addition, being in a steady relationship with an HIV-positive partner reduced condom use (see Table 4). The proportion of explained variance of these variables was 23%.

Discussion

Our data show that consistent condom use with steady partners presented a major challenge to sexually active many women living with HIV. Selected SRH-issues and seroconcordance predicted condom use in this group.

We should note some limitations of this cross-sectional study conducted among a convenience sample of HIV-positive women. Respondents had volunteered to participate on an anonymous basis. Therefore selection and social desirability bias apply, as to many other studies using self-reported data. These factors may limit the application of our findings to HIV-positive women in general. Notwithstanding these methodological limitations, and given the additional explanatory insights from the qualitative assessment, our study reveals some significant findings relating to the SRH needs of HIV-positive women.

Table 4. Summary of hierarchical regression analysis for SRH-variables predicting condom use with steady partner in HIV-positive women.

	Variable	B	SE B	Beta
Step 1	Age	0.23	0.27	0.05
	Undetectable viral load	6.30	6.01	0.07
	Education	1.62	1.78	0.06
	Migrational background	3.11	4.93	0.04
	Steady partner HIV-positive	−20.02	5.01	−0.26***
Step 2	Age	0.12	0.25	0.03
	Undetectable viral load	1.99	5.53	0.02
	Education	1.24	1.63	0.04
	Migration background	4.81	4.51	0.06
	Steady partner HIV-positive	−10.19	4.89	−0.13*
	Use of contraceptives	27.54	5.00	0.33***
	Childbearing since HIV-diagnosis	−9.61	4.65	−0.12*
	Miscarriage since HIV-diagnosis	−16.94	6.23	−0.16**
	Changes in sexual behaviour	2.70	1.69	0.10

*$p < 0.05$; **$p < 0.01$; ***$p < 0.001$.
Note: $N = 240$, $R^2 = 0.07$ for Step 1; $\triangle R^2 = 0.16$ for Step 2 ($p < 0.001$).

The majority of women were sexually active, but had completed their childbearing. Women reported the conspicuous absence of integrated contraceptive counselling, and the rate of pregnancy termination (almost half of all pregnancies after HIV-diagnosis) underscored this failure of service provision. While all the available reversible contraceptive methods can generally be used by HIV-infected women (Heikinheimo & Lähteenmäki, 2009; World Health Organization [WHO], 2004), women clearly need more information and support on family planning.

In addition, a substantial proportion of women (10%) experienced pregnancy loss. A recent study has highlighted that women living with HIV may be at a higher risk of experiencing pregnancy loss than the estimated 2% of the general population (Anderson et al., 2008). Cumulative immune suppression and vaginal infections may play a role in this; therefore, careful sexual health screening should be performed as early as possible in pregnancy, as recommended by current guidelines: e.g., British HIV Association and Children's HIV Association [BHIVA] guidance (de Ruiter et al., 2008) to avoid such potentially avoidable losses.

Using condoms consistently was a major challenge for the majority of women included in this study. Although partner-related aspects (i.e., partners' HIV status) were a predictor of condom use, selected SRH-related issues predicted condom use stronger. The experience of a previous miscarriage was significantly negatively related to condom use: this may suggest that women who miscarried continued to realise their child desire. Women using other forms of contraception were also more likely to use condoms with their steady partners. For them, condoms represent both a contraceptive and sexual health protection. Having an HIV-positive partner made one less likely to use condoms. From the qualitative results one may conclude that couples living with HIV established their own risk–benefit analysis of sexual risk taking. In such analyses reproductive desires may outweigh potential risks of super-infection.

Our study results are in line with current research on similar topics. However, most of the research addressed single target behaviours such as sexual risk taking or fertility-related desires, and not how comprehensive SRH-related aspirations may be inter-twined with protection behaviour.

In general, studies on reproductive choices among HIV-positive women showed that their reproductive patterns were similar to HIV-negative women (Stanwood, Cohn, Heiser, & Pugliese, 2007), and this includes both planning for having children and preventing unwanted pregnancies. A European study suggested that being HIV-infected neither influenced the desire for children, nor the decision to become pregnant (Fiore et al., 2008), which has been corroborated by our qualitative findings. It has been shown that a variety of biomedical, individual and sociocultural factors influence pregnancy decision-making for HIV-positive women (Kirshenbaum et al., 2004), availability of treatment certainly plays an important role (Cooper et al., 2009). Data from the Swiss HIV Cohort Study (Panozzo, Battegay, Friedl, Vernazza, & the Swiss HIV Cohort Study, 2003) showed that 45% of female patients expressed a desire for children. In a representative French sample of women and men living with HIV, 33% of the women and 20% of the men expected to have children in the future (Heard, Sitta, Lert, & the VESPA Study Group, 2007). Already having children may influence child desire to some extent: in a previous study carried out by the Eurosupport network among mothers living with HIV, we found that 16% of the women wished to have another child, and 17% were still undecided (Nöstlinger et al., 2006).

The evidence on extent and type of contraceptives used by HIV-positive women is still limited (Delvaux & Nöstlinger, 2007), while according to WHO's Medical Eligibility Criteria for contraceptive use (WHO, 2004), most contraceptives are considered safe and effective for HIV-positive women, though current supplies of contraceptives including females condoms to women is highly inadequate (Foss, Watts, Vickerman, & Kumaranayake, 2003). In spite of the currently available treatment options, an HIV-positive diagnosis may have a tremendous impact on a woman's decision to carry a pregnancy to term. Several studies assessed the rate of induced abortion among HIV-positive women in industrialised countries. Before the introduction of HAART these rates were around 63% (Bongain et al., 2002). The availability of treatment may have altered this picture reducing the number of pregnancy termination while at the same time the number of births increased (van Benthem et al., 2000). With regards to sexual risk taking, we found a higher rate of sexual risk taking than similar studies: the French VESPA study reported that 34% of the women surveyed had unprotected sex with their steady partners in the prior 12 months (Bouhnik et al., 2007). In another French study, 24% of the heterosexual women reported occasions of unsafe sex (Peretti-Watel et al., 2006). In this study, being unaware of partners' serostatus was a reason for sexual risk taking, next to a history of drug use and a difficult financial situation.

Conclusions

As with all studies addressing sexuality, we address a behaviour that is highly sensitive, partly unconscious and irrational. HIV adds the notion of stigma, rendering service delivery and counselling even more challenging. As a consequence, women living with HIV in our study had numerous unmet SRH needs: inadequate contraception and family planning; and challenges regarding consistent condom use. Therefore, HIV-providers must be willing and trained to discuss SRH topics in a gender-specific and culturally sensitive way despite time and language constraints. Condoms should not only be discussed as an HIV-prevention method, but also in the context of available contraception and family planning for positive women. While our study highlights SRH aspirations and behaviours as well as their potentially influencing factors, there is a need to translate these findings into programme planning and implementation, such as evidence-based guidelines for positive prevention counselling, effective strategies to address condom use for couples of both same and different HIV status. An overall integration of SRH and HIV issues should be offered in standard service provision.

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