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Review

What do we know about the situation of women living with HIV in Europe?

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At present, women represent approximately one-third of new diagnoses of HIV in Europe – most are infected by heterosexual transmission. Some specific populations of women, such as migrants, sex workers and those who are intravenous drug users, may be at increased risk of HIV infection. Women living with HIV face a range of intersecting situations and challenges distinct from those faced by men. The most familiar of these is pregnancy and motherhood; however, family and social situations will also be different for women compared with men, and can affect how individuals access care and manage their disease. The stigma of HIV can be a particular problem for women in many communities. Improved surveillance of HIV and increased study of the situations facing women living with HIV will help to identify improved strategies to support the care of this patient population.

Introduction

Globally, more than half of the people living with HIV are women [1]. In Europe specifically, the number of women living with HIV has increased over the past decade, and women now represent approximately one-third of new diagnoses – 18,180 new diagnoses in 2010, compared with 36,019 men – although there are substantial local variations in this proportion (Figure 1) [2]. More data are becoming available, but there remains a need to better understand the differences between the situations and challenges facing men and women living with HIV.

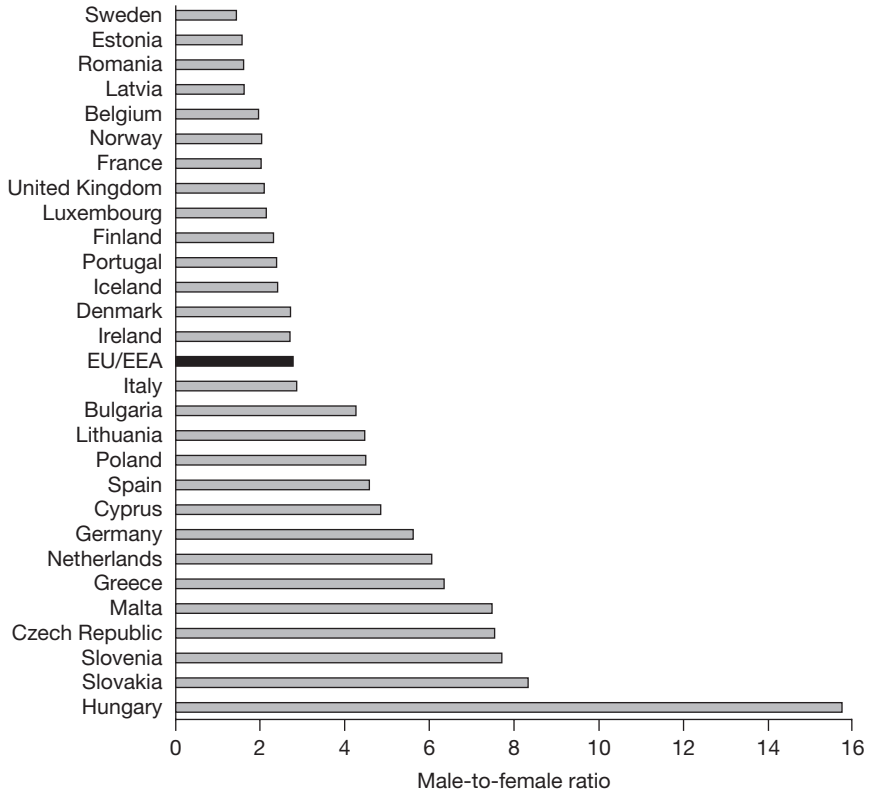
This need manifests at several levels. Data on the treatment of women living with HIV are sparse, and it is common for only a quarter or less of the patients enrolled in clinical trials to be female, as d'Arminio Monforte *et al*. [3] discuss elsewhere in this supplement. It is vital that we do not simply extrapolate data from these trials to women. The situations faced by women living with HIV differ from those facing their male counterparts in clinically relevant ways. For example, similar responses to treatment have been reported in men and women but, in comparison with men, female subjects appear to experience higher exposure to therapy, be more susceptible to adverse events and more likely to discontinue therapy [3,4]. Some of the unique challenges facing women living with HIV are associated with distinct life stages – the years of childbearing age, for instance [5], or the onset of menopause [6,7] – others with demographic factors. Many women living with HIV in Europe are migrants, while others are sex workers or intravenous drug users (IDUs). The cultural, social and psychological challenges these situations generate are complex, and not independent of each other. Issues such as body image, self-esteem, presence of support networks and negotiation of sexual activity will all affect the experience of women living with HIV. As a result, an intersectional approach is the most effective way to understand the needs of a woman living with HIV [8,9].

In this article, we survey the situations that women living with HIV in Europe often face. In many areas, more data are still needed. To address these data gaps and to design strategies to improve the care of our patients, Europe-wide initiatives and studies tailored to local needs will both be required [5].

Estimating the prevalence of HIV among women in Europe

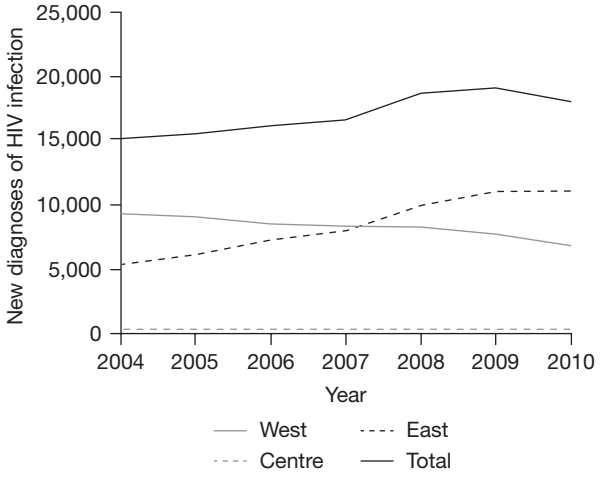
Surveys of HIV prevalence, particularly when based on numbers of newly diagnosed individuals, should be viewed with some caution. The testing and reporting of

Figure 1. Distribution of male-to-female ratio in the number of reported HIV cases by country[a]



Reproduced with permission from [2]. [a]2010.

Figure 2. New infections of women in the WHO European region, 2004–2010

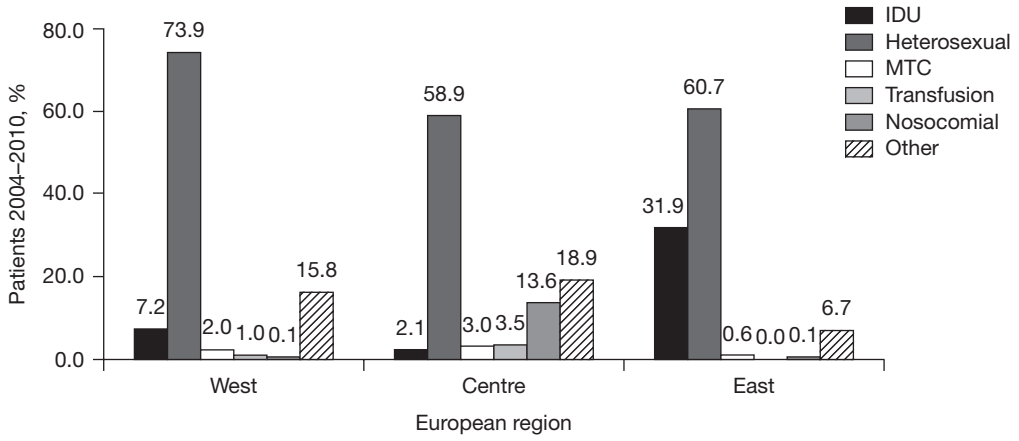


Adapted with permission from [2].

HIV infection varies between European countries and can be inconsistent, incomplete or missing, particularly for patient populations who do not fit preconceived ideas about HIV patients, as many women do not [10].

The recent increase in the number of women living with HIV in Europe, for example, is driven by an increased prevalence in Eastern Europe; over the past decade, the number of newly diagnosed HIV infections in women in Western Europe has in fact decreased slightly (Figure 2) [2]. In the Russian Federation, the proportion of women among newly registered cases of HIV recorded by the Russian Federal AIDS Centre rose from 13% in 1995 to 44% in 2006 [11]. However, within this period in Russia, there was also a drop in the total annual number of newly registered HIV cases between 2001 and 2003, which has been attributed to fewer tests being conducted in high-risk populations as a result of reduced financial support and supports the fact that HIV prevalence rates often reflect HIV testing policies [11]. It has been estimated that in the European Union as a whole, at least 30% of individuals with HIV are undiagnosed; many of these undiagnosed individuals are likely to be women [12].

Figure 3. HIV transmission route for women diagnosed with HIV in Europe, 2004–2010



Adapted with permission from [2]. IDU, injecting drug user; MTC, mother-to-child transmission.

Routes of transmission

Not surprisingly, the increase in the numbers of women living with HIV coincides with an increase in the rate of heterosexual transmission of HIV. In Europe, heterosexual transmission is by far the predominant mode of HIV transmission to women, ranging from 58.9% of cases in Central Europe to 73.9% in Western Europe (Figure 3) [2]. The prevalence of other routes of transmission varies more on a regional basis: 31.9% of women with HIV in Eastern Europe are reported as being infected as a result of injecting drug use, compared with 7.2% in Western Europe and 2.1% in Central Europe, whereas 13.6% of women with HIV in Central Europe are reported as being infected as a result of nosocomial infection, compared with 0.1% in both other regions [2]. The high rate of nosocomial HIV infections in Central Europe largely arises from the major epidemic in Romania in 1989 where thousands of institutionalized children contracted HIV through blood transfusions [13]. The majority of these cases were not diagnosed until over a decade later, such that prevalence rates were not captured until the 2004–2010 reporting period.

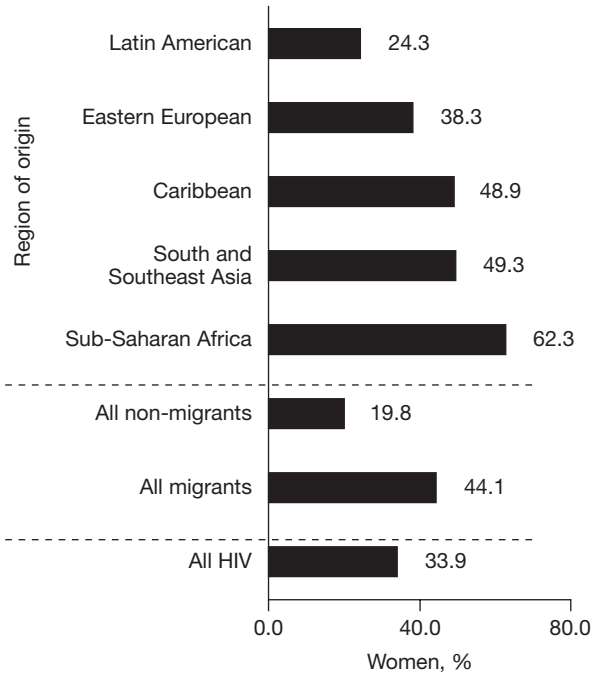
The increase in heterosexual transmission of HIV may reflect the fact that in some countries or sectors of society, women and girls do not always have the knowledge or opportunities to make sure that they are protected from transmission risk. It has been recognized for some time that migrants from sub-Saharan Africa may be at particular risk in this regard [14], as discussed in detail below. However, established power dynamics in native populations can also be problematic. In Russia, for example, there is evidence that many women feel unable to refuse unwanted or unprotected sex, and that as a result approximately 50% of the women living with HIV in Russia were infected by their permanent partner or husband [11]. Many of these women may not have realized they were at risk of infection. Such factors must be borne in mind when developing testing policies, which should be targeted to the most appropriate sites. In particular, antenatal testing presents an important opportunity for diagnosis, but could be extended to family planning and pregnancy termination clinics [15]. Simultaneous testing may be an effective strategy for couples, reducing the sense of stigma and the burden that can be created by a diagnosis.

Situations affecting women living with HIV

Migrant women

The migrant population represents a considerable and growing proportion of both HIV infections and AIDS cases in Europe. In a survey based on data collected between 1999 and 2006 in 27 European countries, the proportion of women with HIV was higher among migrants than among non-migrant populations (44.1% versus 33.9%) [16]. Among migrants newly diagnosed with HIV, the proportion of women was highest in those from sub-Saharan Africa (62.3%) and lowest in those from Latin America (24.3%; Figure 4) [17]. Historical variations in migrant destinations thus lead to heterogeneity in the numbers of migrant women with HIV at the national level, which in general are higher in Northern and Western European countries compared with Eastern and Central European countries [16]. There is

Figure 4. Proportion of migrants to Europe with new HIV infection that are women, by region of origin and in total in 2006



Adapted with permission from [17].

some evidence that such variations affect the character of the local HIV population. For example, in that survey, 41% of HIV infections reported as the result of mother-to-child transmission were in migrants from sub-Saharan Africa [16]. As noted earlier, more thorough surveillance data will improve our understanding of the HIV epidemics in different countries.

Once they arrive in Europe, migrant women may face significant barriers to accessing health-care services. They may not be fully aware of their health-care entitlements or may not trust 'the system', fearing that a diagnosis of HIV may affect their immigration status or even lead to deportation [18]. They may hold assumptions about health and medicine that lead them to be sceptical of treatment. Focus group discussions held in the UK found that migrants from Zambia, Zimbabwe and South Africa wish to use 'traditional' medicines in addition to other non-biomedical therapies, and continue to use these while in the UK, despite being made aware of their likely lack of efficacy [19]. The diagnosis of HIV itself is very likely to be associated with stigma among populations from sub-Saharan Africa [20]. Migrant women may also have their access to care supervised by men in their family and community, as an enforcement of gender roles [8]. Practical considerations related to this can affect the woman's health, such as appropriate provision of housing and food, access to transportation and personal security. It is also important to note that migrant women do not necessarily arrive in Europe already infected with HIV, but may acquire their infection while living within communities who emanate from high endemic regions [21]. Risk behaviour associated with migration status may well account for such transmission risk [22,23].

Sex workers and IDUs

Sex workers and IDUs are populations at high risk of acquiring HIV infection; however, surveillance of these populations across Europe is limited, particularly with regards to gender. The best available estimate is that approximately one-fifth of IDUs across Europe are women [2]. Sex workers, however, can be difficult to identify and reach reliably, and accurate data are often limited even in countries with effective general surveillance of women living with HIV [24]. There is an overlap of these populations in many areas, and the difficulty of tracking the women they represent, means that they are a complex and potentially explosive challenge for physicians addressing the European HIV epidemic. Eastern European countries in particular have seen alarming increases in prostitution and intravenous drug use over the past decade, correlated with rapid increases in the rates of HIV infection among women [2].

Late presentation

Patients who present late with HIV, or who have delayed access to care, are at increased risk of mortality and are more likely to experience a reduced response to treatment, compared with those who present early [25]. In Europe, reports of late presentation range between 24% and 35% in different countries [26–30]. The variation in these estimates is attributable to variation in local definitions of late presentation, as well as factors such as access to screening, and clinician awareness and willingness to test for HIV in diverse populations [31]. The lack of couple testing and low follow-up of wider family members of diagnosed individuals with HIV may account for this undiagnosed group.

In a study of 719 patients presenting with HIV between 1996 and 2002, late presenters ($CD4^+$ T-cell count <50 cells/μl) were more likely to be female (35% versus 24%), despite more regular accessing of health-care services, on average, than men [32], probably because they are often not seen as being at high risk. Migrant women are particularly likely to present late for therapy compared with their non-migrant counterparts. In a systematic screening study of migrants at an infectious disease unit in Spain, the prevalence of HIV

among asymptomatic migrants was 1.9%, with 35.5% of those diagnosed being women [33]. However, in a study of patients with HIV enrolled in a French hospital between 1997 and 2002, migrant women were less likely to have delayed access to care than men – either migrant or non-migrant – most likely due to the fact that all pregnant women in France are offered HIV screening [29]. Johnson *et al.* [10] discuss testing in more detail elsewhere in this supplement.

Complex sexual and reproductive health-care choices

Most women who are diagnosed with HIV are of childbearing age. In Europe, 76.9% of women living with HIV, with recorded ages at diagnosis, are aged 15–39 years, and 90.2% are aged 15–49 years [2]. Sexual and reproductive health-care choices are thus an important part of the experience of most women living with HIV.

These choices can be complex and psychologically challenging [34,35]. As reported in semi-structured interviews, attempting to continue a normal sexual life can be the most difficult challenge for people living with HIV, as the risk of spreading the virus can come to dominate their emotional life [35,36]. Even seemingly straightforward decisions such as the selection of a contraceptive other than condoms can become fraught; as discussed later in this supplement [5], data on the use of many common oral contraceptives with ART are limited [37].

Motherhood is increasingly an option for women living with HIV, but can still be an emotional dilemma. Women living with HIV are likely to be concerned about the risk of transmitting the virus to their child, and may also be concerned that pregnancy itself may complicate the management of their disease [38]. Physicians' discussions about motherhood should be comprehensive and emphasize that effective treatment exists that can protect both mother and child, drawing on guidelines where available [39].

Emotional and psychological support

HIV is associated with a substantial psychological burden [40]. Women living with HIV, for example, are more likely than HIV-negative individuals of similar age to report feeling that they are suffering from premature ageing [41]. Moreover, the differing situations faced by men and women make it likely that this burden will be perceived and integrated into their lives in different ways; in the same self-perception study, only 18% of men reported premature ageing [41]. Women with HIV also report high levels of anxiety, depression and suicidal ideation [40]. After adjusting for age, employment and treatment status in a study comparing heterosexual males and females, men were significantly less likely than women to suffer from high psychological and global symptom distress [42]. Relational, sexual behaviour and quality of life factors were similar for men and women. Adherence levels did not differ by gender but were suboptimal in 55.3% of female patients [42]. A cross-sectional European study found that women living with HIV experience significantly higher rates of stress, depression and anxiety than male patients, and receive less emotional support from partners and families (all $P<0.05$) [43]. Such experiences can negatively affect women's experience of HIV treatment, as well as their day-to-day quality of life [44]. Mental health problems may also affect adjustment to illness generally, and adherence to HIV medication specifically, and thereby affect the course of disease and viral suppression [45].

These results are likely the result of a mismatch between the level of support women perceive themselves as requiring and the amount they actually receive – for example, insufficient availability of child-care facilities while women visit their physicians. They may also represent the reluctance of women, particularly migrant women from sub-Saharan African communities with strong conventional gender roles, to relinquish their role as care provider and nurturer as a result of their illness [35,43]. Women are more likely than men to prioritize treatment and care for other members of their family and neglect themselves [43]. They may also be less likely to report mental health burden and symptoms and, in turn, less likely to receive support or interventions to reduce these [43].

A core issue affecting the psychological well-being of women living with HIV is disclosure (or not) of their HIV status. HIV-associated stigma is often particularly strong in communities of sub-Saharan African migrants, and a fear of this status becoming public can often complicate life for infected individuals. The practical challenges that social HIV stigma represents for HIV testing and treatment are discussed elsewhere in this supplement [10], but it also represents a substantial psychological burden that can affect women's decisions about their treatment [34,46].

Conclusions

The situations faced by women living with HIV may involve the intersection of multiple important factors; every woman's experience of HIV is different, and their care should reflect this fact. The needs of a sub-Saharan migrant living with her partner in Spain are not the same as those of a homeless Eastern European IDU, and are different again to those of a middle-aged woman with three children in Denmark. Moreover, women's experience of HIV is different to that of men. At every stage, from HIV testing, through disclosure to disease

acceptance, consideration of fertility and motherhood, and living with HIV as a long-term condition, women can face choices that are not a consideration for men, and that are often very difficult. In Europe, particularly among populations of migrant women, the effects of these choices can be profound and far-reaching.

In many cases, our understanding of the situations facing women living with HIV will be strengthened by improved surveillance of HIV and standardized analysis across Europe. It is clear, however, that care for women living with HIV is most effective when it is individualized, taking account of available social and institutional support to address the specific challenges of a given patient.

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