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# Living with HIV/AIDS in France

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Antiretroviral treatments have turned AIDS into a chronic illness. In western industrialized countries where these therapies have been available since 1996, people living with HIV/AIDS no longer face the permanent threat of imminent death. But do they live the same lives as non-HIV-infected persons? The VESPA survey has cast light on who is living with HIV/AIDS today in metropolitan France, how they live and in what major ways the infection has changed their lives.

The AIDS epidemic is continuing to spread worldwide. It seems to have levelled off in industrialized countries, where prevention programmes and, above all, highly effective therapies have changed the overall picture. Treatments introduced since 1996 have significantly slowed down the course of the illness and lowered HIV-infection mortality (people carrying the virus, whether ill or not). While antiretroviral treatments now entail fewer constraints, they nevertheless have many side effects, and require strict adherence to be effective, while their long-term outcomes remain shrouded in uncertainty. Significantly improved survival rates notwithstanding, they do not provide a cure, and mortality among HIV-infected people is still higher than among the same-age population generally. Living with HIV in France today still involves making life adjustments in terms of employment, resources, emotional and sexual life, and parenthood decisions. A survey conducted in 2003 (the VESPA survey, see box 1) has shed more light on this population group and the adjustments they must make in the various spheres of life.

** INSERM (National Institute for Health and Medical Research)*

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(1) Nearly one in two HIV-infected men (46%) self-reports as being homosexual, one in ten as bisexual (10%) and just under two in ten (17%) have injected drugs at some time in their life. The others are heterosexuals born in France (18%) or immigrants (9%). Note that patients questioned for the VESPA survey were grouped by sexual orientation and means of HIV transmission (see box 2).

(2) 90% of foreigners living with HIV have a residence permit, 42% of them valid for one year or less.

## Seven in ten HIV-infected people are men, and one in two lives in the Ile-de-France or Provence-Alpes-Côte d'Azur region

An estimated 100,000 people are living with HIV/AIDS in metropolitan France, unequally distributed across the country. The Ile-de-France region holds only 19% of the country's population, but 43% of the HIV-infected total, and the Provence-Alpes-Côte d'Azur region is also over-represented (table 1).

Most (more than 7 in 10) are men, many infected from male-to-male sexual transmission or injecting drug use, where males greatly predominate (1). Women are still a minority, but their share has grown over time. Foreign nationals (2), both male and female, are heavily over-represented, making up 6% of the general population, but 18% of the population infected with HIV. This is especially so for women: almost one in three HIV-infected women (31%) is foreign, compared to just one

Box 1

### The VESPA survey (1)

The VESPA survey was conducted in metropolitan France in 2003 among a sample of 2,932 people followed up in hospital for HIV-infection. A list of hospitals treating HIV was first drawn up and the hospitals were divided into three strata by number of patients followed up for HIV infection; a sample of hospitals was then randomly selected. A number of patients for inclusion was fixed for each hospital to obtain a representative sample for each stratum and region. In each randomly-selected hospital, a sample of individuals was also randomly selected among HIV-infected outpatients aged over 18 diagnosed as HIV-positive more than 6 months previously. For foreign nationals, only those who had been living in France for more than 6 months were included. The randomly-selected individuals were then asked to reply to a forty-minute questionnaire administered by a trained interviewer, and to fill in a short self-administered questionnaire. Medical information was provided by the referring physician. 5,103 individuals were randomly selected from among 7,904 eligible patients, of whom 2,957 were interviewed (57%). Apart from refusals (1,765), some patients were not asked to take part because of language difficulties (117) or health problems which precluded interview (264). To allow for sex-, age-, nationality-, occupation- and certain disease-specific differences in participation, the data were adjusted by the distribution of these characteristics among eligible patients. The data were then weighted to give estimates for the whole follow-up population. Factors included between-individual variability of hospital attendance so that frequent attenders were not over-represented and infrequent attenders under-represented.

Some groups of people with HIV/AIDS are not represented in the survey, in particular undiagnosed infected individuals, whose numbers are difficult to estimate, and the proportionally few diagnosed individuals not followed up in hospital or elsewhere. Finally, hospitals with a small HIV caseload (under 60) were not included in the survey for logistical reasons, and so their patients (10% of the total followed up) are also not represented.

(1) VESPA: "VIH – Enquête Sur les Personnes Atteintes" (survey of HIV-infected persons). This survey was funded entirely by the ANRS (French agency for AIDS research).

*Table 1 Composition (%) of the population living with HIV in metropolitan France in 2003 (1)*

| | Adults aged 18 and over living with HIV in 2003 (1) | Total adult population aged 20 and over at the 1999 census |
|---|---|---|
| Male | 71.2 | 47.8 |
| Female | 28.8 | 52.2 |
| *Nationality and birthplace* | | |
| Native-born French or born in France | 78.4 | 89.4 |
| Naturalized French citizens | 3.2 | 4.6 |
| Foreign nationals (2) | 18.4 | 6.0 |
| *Region* | | |
| Île-de-France | 43.5 | 18.6 |
| PACA and Corsica | 14.6 | 8.3 |
| Rhône-Alpes | 7.4 | 9.5 |
| Midi-Pyrénées | 5.4 | 4.5 |
| Aquitaine | 5.1 | 5.1 |
| Languedoc-Roussillon | 3.9 | 4.0 |
| Other region | 20.1 | 49.9 |

1) HIV-infected people followed up in hospital, whether ill or not (see box 1).

(2) Immigrants (foreign nationals born abroad, some of whom are still foreign nationals while others have become naturalized French citizens) account for 21.6% of people living with HIV/AIDS; specifically, those born in Europe (in a country other than France) account for 4.2%, those born in the Maghreb, 2.3% and those born in sub-Saharan Africa, 11.8%.

*Sources: ANRS-VESPA survey and INSEE.*

Box 2

### Lifestyle groups

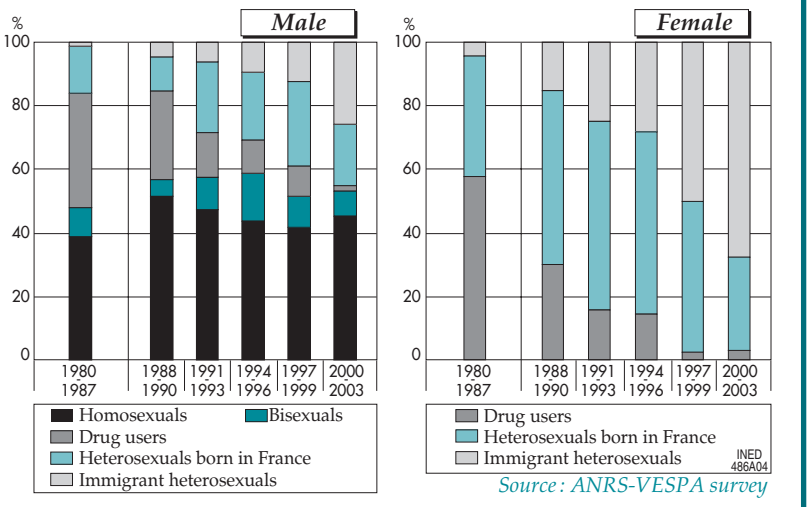
Unlike many epidemiologic studies, the results are given here by lifestyle group rather than by means of transmission. This is because the available information is more plentiful than usual, so that demographic characteristics and lifestyles can be used as categorization factors. More specifically, to allow for the very high risk of male-to-male transmission, a "homosexual" male group was defined to include those who defined themselves as such and those who refused to do so but who reported having had sex exclusively with men in 2003. Likewise, the "bisexual" male group includes men defining themselves as such and those who refused to do so but reported having had intercourse with partners of both sexes in 2003. "Drug users" comprises, for each sex, people who have injected drugs at some time, excluding men who are also homosexual or bisexual, who are classified as "homosexuals" or "bisexuals". The heterosexual group distinguishes between native-born French and immigrants born outside France. The former include French citizens by birth born abroad (e.g., children of expatriates born abroad). "Immigrants" comprises foreign nationals born abroad, some of whom are still foreign nationals while others have become naturalized French citizens.

in seven HIV-infected men (13%). Unlike foreign nationals, immigrants who have acquired French nationality are slightly under-represented: making up 4.6% of the general population, they account for only 3.2% of HIV-infected people.

Over half of HIV-infected immigrants (55%) were born in sub-Saharan Africa, compared with under one in ten (9%) of all immigrants, naturalized French citizens and foreigners combined. While sub-Saharan Africa is over-represented, the Maghreb is under-represented: one in ten immigrants living with HIV (11%) was born in the Maghreb, versus three in ten of all immigrants (30%).

The sex distribution differs widely between native-born and naturalized French, and by origin for the latter: women make up 23% of native-born French HIV-infected people, but 60% of those born in sub-Saharan Africa, 51% of those from the Maghreb and 22% of those from other European countries.

*Figure 1 - Composition of the population living with HIV/AIDS, by year of diagnosis*




*Source : ANRS-VESPA survey*

## A decreasing proportion of drug users, but more immigrants from sub-Saharan Africa

The population living with HIV in France consists of cohorts infected at different dates since the onset of the epidemic (Figure 1). More than half (excluding minors), were diagnosed as HIV-positive in 1993 or earlier, compared with just over one in three (37%) after 1996 (3). The oldest cohorts, diagnosed in the 1980s, experienced high mortality until 1996. Those members still living are survivors who benefited from combination therapies after 1996. The composition of the successive cohorts of HIV-infected people also reflects the period-specific frequencies of new cases in high-risk groups (homosexual men, injecting drug users, immigrants from sub-Saharan Africa), which in turn reflect the variable impact of prevention among the different groups. Migration streams from generalized epidemic areas have also shaped the rise in the share of immigrants in the HIV-infected population over time, especially those originating from sub-Saharan Africa.

Male homosexuals make up the biggest group in each male patient cohort, reflecting the persistent frequency of transmission in this sub-group. A comparable trend is found among bisexuals. By contrast, public health programmes to widen access to clean needles (since 1987), followed by substitution therapy (from the mid-90s), have reduced HIV transmission through needle sharing; from an originally high infection rate, the share of new diagnoses among male and female drug users has fallen over the years to very low levels. Both male and female cases in the heterosexual population born in France have stabilized, indicating a low spread of the infection in the general population.

The share of immigrants, females especially, has increased rapidly over time. The time between arrival in France and diagnosis is shortening between immigrant patient cohorts: of immigrants diagnosed since 2000, 35% of men and 59% of women had been in France for less than a year when found to be HIV-infected.

## Only half of HIV-infected individuals are in employment, and the proportion on disability benefit remains high

Even with more effective treatments, a significant share of HIV-infected people leave the labour force: among the under-60s, 40% of men and 55% of women are economically inactive. Just over a quarter of patients (27% of men and 29% of women) have a recognized disability. The proportion rises with time since diagnosis, from 8% for people diagnosed post-2000 to 46% for those diagnosed pre-1987.

Homosexual men have a high overall level of education (43% have been in higher education). While their post-diagnosis employment rates have fallen (by 15 points), a high proportion (69%) were still working at the survey date, half in senior or middle-level managerial or technical occupations. Only one in five was on disability benefit.

(3) Allowing for the time between infection and occurrence of symptoms and presentation for testing, which varies with the population, the breakdown by date of diagnosis only partially reflects the dynamics of HIV transmission.

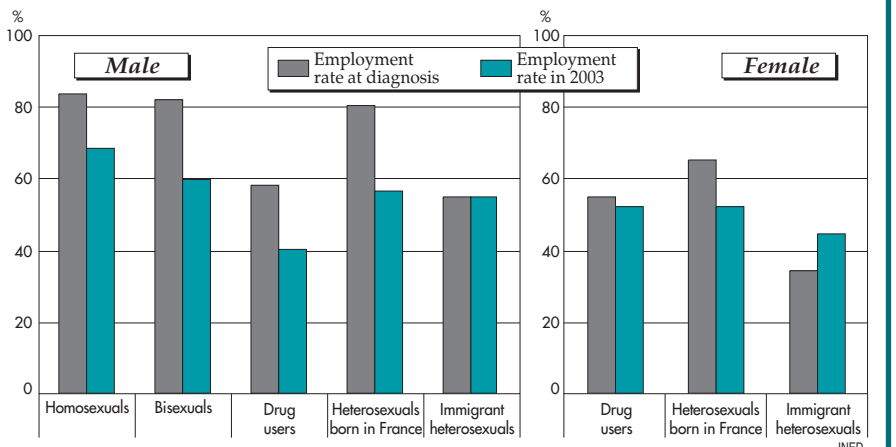
Drug users are characterized by a low educational level, low employment rate (only 38% economically active in 2003, a post-diagnosis fall of 19 points), and low occupational skills. In direct relation to their low employment rate is a very high (53%) recognized disability rate, a consequence of the cumulative effects of HIV and hepatitis C infection (4), and opiate dependency.

The employment rate for all patients, male and female, native-born French or born in France, is 55% at the survey date (73% at time of diagnosis). Two in three women in employment are non-manual or manual workers, compared to just under one in two men.

Immigrants are sharply differentiated from the other groups. More have received no schooling (9% of men and 6% of women) or have only primary school education (6% and 14%), attributable to the low levels of school enrolment in their countries of origin. Also unlike the other groups, their employment rate increases after diagnosis (from 43% to 49%). Many had no job or income at diagnosis (28% of men and 48% of women), having in many cases only recently arrived in France. Their recognized disability rate (16%) is lower than the other groups because of the more recent diagnosis and perhaps also due to their greater difficulty in claiming social security benefits, such as the adult disability allowance, for which they qualify.

Immigrants living with HIV are also characterized by housing insecurity: 15% of men and 23% of women live with friends, in a hostel or are homeless. This is an improvement from the time of diagnosis, however, when 29% of men and 37% of women did not have a permanent address.

*Figure 2 - Employment rates at time of diagnosis and in 2003*




*Source: ANRS-VESPA survey*

## One in two HIV-infected men, compared to one in four women, lives alone

Approximately six in ten people have had a cohabiting or non-cohabiting partner for at least 6 months (58% of men and 61% of women). Few differences are found between homosexual men and other male groups. A slightly lower proportion of bisexual men are in a couple (50%) than other men, and twice as many of those in a stable relationship have a female partner (35%) as a male one (15%).

Nearly one in two men (45%) lives alone, compared with just one in four women (27%). Among women, 22% are lone parents, a similar proportion live in a couple with children, and 18% live in a couple without children.

Here, too, both male and female immigrants differ markedly from the other groups: fewer live in a couple but more frequently with children, and a higher proportion of immigrant women are lone mothers. Two in three male, and three in four female immigrants had children when diagnosed as HIV-positive, compared to just under one in two male or female non-immigrant heterosexuals, one in three bisexuals (35%) and fewer than one in ten homosexuals (8%).

Immigrants are more likely to be living in a household with children under 16 (35% of men and 44% of women) but also to have children from whom they are separated (34% and 28%, respectively), most of whom (73%) are still in the country of origin.

* * *

Although belonging to very different social status groups, HIV/AIDS-infected people all share a common experience: learning that they are HIV-positive, being bound to medical follow-up and treatment regimens which, while they may alleviate the health impacts of HIV-infection, still throw future personal, social and family plans into disarray. These populations of very different origins all, to differing degrees, suffer a deterioration in their living conditions, in particular a sharp drop in their employment rate and a high disability rate.

**The researchers thank all the persons living with HIV/AIDS, the NGOs, physicians and hospital staff who took part in the survey for their valuable contribution.**

(4) Eight in ten HIV-positive injecting drug users are also infected by the hepatitis C virus.

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