

# HIV disclosure in the workplace

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**Objectives:** As HIV is currently a chronic and manageable disease, an increasing amount of people living with HIV (PLHIV) are (again) active on the labour market. Since research on this topic is scarce, this study aimed to explore experiences of PLHIV in the workplace, especially concerning disclosure and adherence to antiretroviral therapy.

**Methods:** A questionnaire was developed and validated in collaboration with Sensoa (Flemish expertise centre for sexual health) and participants were recruited using flyers and announcements on websites.

**Results:** A total of 54 PLHIV completed the questionnaire, among whom 50 (92.6%) males. Half of the participants did not disclose their HIV status in the workplace, mostly due to being afraid of social or professional consequences. Those who disclosed, reported no changes in the workplace or even reported receiving more empathy. A minority of participants have to take antiretroviral medication at work and they reported no particular problems related to medication intake.

**Conclusion:** Despite improved solidarity and information campaigns, many PLHIV still do not disclose their HIV status in the workplace, most frequently due to fear for discrimination. More actions are warranted, as well as addressing possible self-stigma. Adherence to antiretroviral therapy in the workplace posed little or no problems.

**Keywords:** HIV, Disclosure, Work

## Introduction

Current treatment strategies have turned HIV infection into a chronic disease and life expectancy for people living with HIV (PLHIV) continues to increase.<sup>1–3</sup> Moreover, treatment options are still expanding and new antiretroviral agents are less toxic and more convenient than earlier antiretroviral therapy (ART). As such, the vast majority of PLHIV can currently lead a relatively normal life. Consequently, PLHIV can make a professional career or may return to work after a period of disability.<sup>4</sup>

Previous research showed that a majority of PLHIV work. Furthermore, employment seemed to positively influence health-related quality of life.<sup>5</sup> The present study aimed to explore experiences of PLHIV in the workplace concerning disclosure and adherence to ART.

## Materials and Methods

In collaboration with Sensoa, the Flemish expertise centre for sexual health, a research project was conceived. Literature research was performed and emerging themes were discussed together with the experts of Sensoa, resulting in a scientific and practice-based approach.

### Participants

All PLHIV who were currently working or had been working in the past, were eligible for inclusion. The target audience was reached by flyers distributed in the Flemish AIDS reference centres in Antwerp, Brussels and Ghent and during HIV cafés (informal meetings among peers), by announcements on the website of Sensoa, their daughter website ‘www.livenmethiv.be’ (= ‘living with hiv’), their Facebook account and the community website ‘HivMix’.

### Questionnaire

Results from the literature research were used to outline the structure of the questionnaire.<sup>4,6–9</sup> In consultation with Sensoa, the questions were chosen and formulated, resulting in a tree-structured questionnaire examining

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two main themes: disclosure and medication-intake in the workplace. In addition, socio-demographic data (gender, age), date of HIV diagnosis and information about the work situation (work schedule, job type, etc.) were also included. It was decided to use an online questionnaire as this is an easy, low-cost and quick method to collect data.

### Statistical analyses

All results were exported from the questionnaire software ('Qualtrics') to SPSS.22 (SPSS, Inc., Chicago, IL, USA). Descriptive analyses were performed and are reported via numbers and percentages. Associations were examined via chi-square tests.

## Results

### Population

A total of 67 PLHIV participated in the study, among whom 54 fully completed the questionnaire. There were 50 men and four women, with a median age of 42 years (IQR 33–51 years). Forty-four people were currently working (12 blue-collar workers\*, 25 white-collar workers\*, five self-employed and two public servants). Ten people were unemployed and one of them did not return to work after HIV diagnosis, rendering other questions no longer applicable. Almost three quarters of the remaining participants worked full-time (39/53, 73.6%).

### Disclosure

Almost half of the respondents did not inform any of the colleagues about his/her seropositive status (23/53, 43.4%). People who disclosed, mostly told close colleagues only (22/53, 41.5%), an official trustee (13/53, 24.5%) or executives (12/53, 22.6%). When being asked what hindered disclosure, half of the people reported to have fear for professional consequences (such as discharge, loss of clients) (28/53, 52.8%) and to be afraid for social consequences (such as discrimination, nagging) (26/53, 49.1%). Twenty-one participants (42.0%) worried about people telling others and 11 respondents (22.0%) mentioned to have followed someone's advice to not disclose at the workplace.

Those who disclosed, mostly did this of their own free will (23/30, 76.7%). Justifying their changing health state (10/30, 33.3%) or the (more frequent) absences (8/30, 26.7%), but also the desire to be honest and not to live with a secret were the most cited reasons to disclose (4/30, 13.3%).

In the majority of the cases, no professional changes appeared after disclosure (18/30, 60.0%), or the change was positive (i.e. more understanding from colleagues, 8/30, 26.7%). Nonetheless, three

\* Blue collar workers perform manual labour. White collar workers perform professional, managerial or administrative labour.

participants (10%) declare that they got fired after they had disclosed.

As compared to blue-collar workers, significantly more white-collar workers had disclosed their seropositive status in the workplace (4/12, 33.3% vs 17/25, 68.0%,  $P=0.046$ ). Disclosure was not found to be associated with other factors (gender, age, time since diagnosis, disclosure to environment,  $P>0.05$ ).

### Medication intake

Forty-seven participants (88.7%) reported to take ART, among whom 38 (80.9%) once daily. Twenty-one participants took their medication in the workplace and none of them reported problems doing so, neither towards colleagues, neither towards infrastructure. Half of the 26 others took the decision not to take medication at work consciously, in consultation with their physician. Variable work time tables were most frequently reported as a hindering factor to adherence (5/21, 23.8%). On the other hand, access to food (8/21, 38.1%), drinks (7/21, 33.3%) and the proficiency to quickly take ART (7/21, 33.3%) were reported to be supporting factors.

## Discussion

Our findings confirm the general good health among PLHIV in Belgium.<sup>10</sup> For this study population, being seropositive does not necessarily hinder a professional career, since the vast majority of respondents work full-time. Strikingly, almost half of the participants did not disclose in the workplace, despite the many solidarity campaigns, etc. This number is almost double as compared to French PLHIV (29.9%),<sup>7</sup> but less than British PLHIV (61.5%).<sup>6</sup> The lower disclosure percentage seen in the French study may be partly due to the fact that this study took place in 2002–2003. Ten years ago, openness about HIV may have been less frequent. The higher disclosure percentage in the UK study is probably biased by the study population, almost completely consisting of homosexual, white men. They are more likely to disclose to employers than heterosexual men/women and homosexual men from ethnic minority groups.<sup>11</sup>

Fear for discrimination or discharge is high, and seems to be the main reason to not disclose. Previous research among French-speaking Belgian PLHIV showed that 6.5% of the people who disclosed experienced difficulties afterwards (being refused a job, blocked career, etc.)<sup>12</sup> The latter demonstrates that information and solidarity campaigns from organizations as Sensoa are highly needed. Internalized stigma, the fear and shame PLHIV experience from within, remains an increasingly recognized additional barrier.<sup>13</sup> Some PLHIV argue that disclosure will not give any added value, or they consider it a private affair.<sup>6</sup> Hence, it should be acknowledged that the decision to

disclose is a personal choice and that achieving 100% disclosure might be an unrealistic goal.

Differences in job context may influence the decision to disclose the status. We have found that white-collar workers disclose more frequently than blue-collar workers. However, this issue should be further explored in bigger study samples and confounding factors should be taken into account. Those could be: type of working environment, the reputation of the person, colleagues' knowledge about HIV, anticipated negative consequences and awareness of the sexual orientation of the person living with HIV (mainly applicable for homosexual people).<sup>6,8</sup>

Data about medication intake in the workplace, revealed that this is less an issue than expected. Many PLHIV do not take ART at work, since certain regimens need to be taken before sleep or along with the main course, which is mostly in the evening. If they do take ART at work, they do not seem to encounter difficulties. Availability of accommodations, such as flexible work hours or easy access to food and drinks, were reported to be helpful, corresponding with previous research about adherence in the workplace.<sup>9</sup>

Some limitations of this study should be acknowledged. Our relatively small sample size does not fully represent the Belgian HIV cohort, since there are more female PLHIV (37 vs 7%) and a lower percentage is on ART (75 vs 87%).<sup>10</sup> Our study methodology is also susceptible for recruitment bias towards people who are currently working. Moreover, our results should be further studied in depth by means of qualitative research (e.g. focus groups). Nevertheless, these first results already show tendencies and can inspire further actions and campaigns.

In conclusion, half of the PLHIV did not disclose their seropositive status in the workplace mainly due to fear for discrimination. The potential barriers need to be further explored.

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