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# To be or not to be sick and tired: Managing the visibility of HIV and HIV-related fatigue

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## Abstract

This article takes a new direction in exploring HIV-related fatigue by adopting a qualitative interactionist approach. We analyse the social meanings attributed to fatigue among people living with HIV in France, the social gains and losses of its visibility and the social frames that condition its discursive and physical expression. The two-part methodology combines grounded theory analysis of 50 transcribed unstructured interviews conducted across France and participant observations within four HIV-related associations. Results reveal that the visibility of fatigue is in part dependent on the visibility of this stigmatized illness. The expression of fatigue is therefore closely linked with disclosure and concerns about HIV stigma. The degree to which HIV and HIV-related fatigue are rendered (in)visible also depends on structural factors including gender prescriptions, as well as context effects such as the type of social or 'care' relations involved in the social frame of interaction.

## Keywords

fatigue, gender and health, HIV/AIDS, illness behaviour

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## Introduction

Chronic fatigue plays a major role in the day-to-day lives of many people living with HIV. Often defined as a feeling of exhaustion or lack of energy (Lee et al., 1994), perceived fatigue among people living with HIV varies in prevalence from 33% to 88% (Jong et al., 2010). Because increased understanding of HIV-related fatigue 'requires a multidisciplinary approach' (Jong et al., 2010), the present study takes a new direction by adopting a qualitative interactionist approach. Complementing a long line of quantitative work pursuing demographic, psychological and physiological factors of HIV-related fatigue (Barroso et al., 2003; Barroso and Voss, 2013), this study explores rather some of the social mechanisms that may underlie different modes of socially 'managing' (Goffman, 1999 [1959]) HIV-related fatigue. With this aim, we analyse here the social processes, stakes and contexts that condition the discursive and physical expression of HIV-related fatigue. Results show how these processes are entwined with (non)disclosure, HIV stigma and gender.

While physiological variables, such as the prevalence of lymphocytes T CD4+ or the viral load, have so far shown no consistent correlation with perceived fatigue, certain psychological (viz. depression) and social factors have been found to 'put HIV-infected persons at risk for greater fatigue intensity and fatigue-related impairment' (Barroso et al., 2010: 1415). These social factors include unemployment, inadequate income or a low level of social support. In some studies, women living with HIV (Breitbart et al., 1998), and in particular poorer women, more often declare fatigue than men (Harmon et al., 2008; Thomas et al., 2012; Voss, 2005). Although social determinants such as class and gender therefore emerge as predominant factors of HIV-related fatigue, the social mechanisms underlying such differences in the perception or manifestation of HIV-related fatigue have yet to be explored.

The contexts and discourse surrounding HIV-related fatigue were investigated in this study through interviews and participant observations conducted across France. Before exposing the methods and the three-part findings, which show that the expression of fatigue depends on structural and contextual social relations and is closely linked with disclosure and concerns about HIV stigma, we shall first consider the scientific literature in these domains.

## Fatigue

Fatigue is a multifaceted notion with multiple meanings and interpretations, ranging from 'a physical or mental weariness resulting from exertion; a sensation of boredom and lassitude due to absence of stimulation' or 'the decreased capacity or complete inability [...] to function normally because of excessive stimulation or prolonged exertion' (Stedman, 1995). Many authors write of chronic exhaustion or lack of energy (Lee et al., 1994) in order to differentiate from acute fatigue resulting from physical activity. While this definition informs our understanding of fatigue, we are interested here in the meanings attributed to fatigue by people living with HIV themselves, and its perceived social effects or uses.

Although the expression and experience of fatigue remain overall poorly documented (Walters and Denton, 1997), fatigue has recently emerged in sociological analyses

through studies of chronic fatigue syndrome and fibromyalgia (Asbring and Narvanen, 2002; Clarke and James, 2003). Chronic fatigue syndrome is what Conrad and Barker (2010: 70) term a ‘contested disease’ due to the social and medical view of fatigue as not constituting a ‘legitimate problem’ (Popay, 1992; Walters and Denton, 1997: 65). Not only is the feeling of fatigue difficult to measure objectively, but it is also difficult to differentiate from that experienced by the general population. Fatigue is even at times viewed as a typical symptom or ‘embodiment’ of modern times (Widerberg, 2006). When expressed as a symptom of illness, fatigue has been related to the experience of stigma. The absence of a medical diagnosis legitimizing subjective symptoms such as pain or fatigue, as in the case of chronic fatigue syndrome or fibromyalgia, has for some patients led to an assumption that the complaints be unwarranted or psychological (Asbring and Narvanen, 2002).

Existing studies on fatigue have documented not only a class but also a gender dimension. Gender prescriptions influence the reasons given for feeling fatigued or for concealing fatigue (Widerberg, 2006). This may include preserving gender roles, such as women not wanting to imply experiencing gender inequality in terms of domestic tasks in a heterosexual family context, or men not wanting to be asked to invest less at work (Widerberg, 2006: 115–117). The declaration of illness-related pain and fatigue has also been shown to be gendered. Overall, women declare more severe fatigue than men and generally more often declare illness-related symptoms (Miaskowski, 2004; Van Wijk and Kolk, 1997). The social mechanisms behind gendered patterns in terms of illness-related fatigue, and in particular in terms of HIV-related fatigue, are investigated here. This is done through an interactionist approach to fatigue. Viewed – like illness – as having a dimension that is socially constructed (Conrad and Barker, 2010) and socially performed (Charmaz, 1991; Clarke and James, 2003), we seek to analyse the place of fatigue as outwardly expressed or repressed during social experiences and (inter)actions within specific contexts. The purpose is to consider, beyond the physiological or psychological dimensions, the ‘interactional’ or social dimension of fatigue.

### *Gender, sexuality and HIV-related fatigue*

Gender and sexuality are salient systems of social categorization in the HIV/AIDS epidemic, in particular due to the fact that unprotected sexual relations remain the primary mode of transmission (79% in France). The population living with HIV in France consists of 39% men who have sex with men and of 28% and 33% predominantly heterosexual men and women, respectively (Dray-Spira et al., 2013). The present analysis of HIV-related fatigue takes into account the ways in which gender and sexual prescriptions, including heteronormativity and gender roles, affect social experiences of illness and fatigue within particular ‘frames’ of social interactions (Goffman, 1999 [1959]). Gender is viewed here as a hierarchical social system that organizes the social world both symbolically and materially on the basis of binary biological categories. As a socially constructed system of power, gender subsists through the reiterated social performance of gender norms and differences (Butler, 1990), performances that participate in making the latter appear as ‘natural’. Like other modes of social differentiation such as race or class (Hankivsky, 2012), gender has been correlated to differing health experiences and

trajectories, including the declaration of HIV-related fatigue (Harmon et al., 2008; Voss, 2005) or experiences of HIV-related stigma (Geary et al., 2014). As experiences of HIV and HIV-related symptoms and stigma have been shown to vary along lines of gender and sexuality, these structural systems of social division and hierarchy appear as central to understanding the social expression of illness.

Performance-based approaches to identity, including in terms of gender and sexual roles, therefore seem particularly compelling in the analysis of the expression or performance of illness or fatigue in various social contexts. In adopting an interactionist approach to the study of HIV-related fatigue, we are interested in the unexplored territory of how the social expression and management of HIV-related fatigue take part in social performances of social identity in terms of gender (Goffman, 1999 [1959]), sexuality (Butler, 1990) and illness (Charmaz, 1991; Clarke and James, 2003). In turn, we are interested in how social frameworks and prescriptions, in various contexts of interaction in France, partake in conditioning the expression of fatigue. In this light, the expression of fatigue – through the body or words – is considered to be socially faceted. The concept of socially constructed realities has proven to be a useful approach to the study of men's and women's experience of both fatigue (Walters and Denton, 1997) and illness (Conrad and Barker, 2010).

### *HIV stigma and disclosure*

HIV stigma and disclosure are central to our analysis because the expression of fatigue, as we shall see in the results, depends on perceived risks of stigma and disclosure status in a given context. Stigma and disclosure, alongside more structural elements such as gender and sexuality, appear as key elements of context affecting the social performance of illness and its symptoms. Stigma can be defined as a characteristic that socially 'disqualifies' the person who bears it (Goffman, 1963). This can transpire in situations of social power that enable labelling of social difference accompanied by stereotyping, status loss and discrimination (Link and Phelan, 2001). A 'fundamental dimension of stigmas concerns the degree to which they can be concealed from others' (Stutterheim et al., 2011: 382), as concealment would prevent labelling and thus the process of stigmatization according to Link and Phelan's (2001) model. Indeed, visible stigma has often been observed to be more detrimental than concealable stigma (Goffman, 1999 [1959]; Persson, 2005; Stutterheim et al., 2011), such as HIV. In this light, context-specific choices to disclose HIV or express fatigue are likely to gravitate around the gains and losses of keeping the illness 'invisible' or else accepting the risk of being discredited or stigmatized.

Stigma is tightly related to disclosure. A major factor of revealing or concealing HIV concerns HIV-related stigma (Marsicano et al., 2014; Petrak et al., 2001; Stutterheim et al., 2011), as HIV remains a particularly 'stigmatised illness' (Gussow and Tracy, 1968). Research exploring men and women's experience of HIV has highlighted the salience of stigma in living and dealing with HIV. Worry about stigma or discrimination – meaning differential, unfair treatment on the basis of socially constructed difference – affects concerns about the visibility of HIV, disclosure and the risk of social exclusion, as has been shown within sexually or racially defined communities (Flowers et al., 2000,

2006). HIV stigma stems in part from social representations of HIV, which have tended to relate this illness to other stigmatized social categories and practices, namely, homosexuality, drug use or prostitution, due to the history of the social construction, treatment and prevention of HIV (Thiaudière, 2002; Weitz, 1990; Wyatt et al., 2013). The perception of deviant behaviours contributes to negative perceptions of people living with HIV as 'responsible' for their illness (Devos-Comby and Devos, 2001). Attribution of responsibility, in particular when it comes to illness, plays a role in 'sanctioning' behaviours that violate dominant social norms (Parsons, 1951; Roth, 1972). Negative social judgment and the attribution of responsibility for HIV have also been shown to fluctuate not only along social lines of gender and sexual orientation, but also along lines of race and class (Devos-Comby and Devos, 2001; Dworkin and Wachs, 2000; Geary et al., 2014; Parker and Aggleton, 2003). This supports the understanding of stigma as a social process, of labelling the 'undesirable', which is 'used as a tool to assert dominance over individuals who are already marginalised on the basis of extant inequalities such as those related to race, class, religion or gender' (Daftary, 2012). In other words, 'stigma is linked to the workings of social inequality' (Parker and Aggleton, 2003: 16). More specifically, HIV and AIDS-related stigma 'feeds upon, strengthens and reproduces existing inequalities of class, race, gender and sexuality' (Parker and Aggleton, 2003: 13).

Depending on the context of social interaction and hierarchies, some forms of social deviance can be more stigmatizing than others, deviance in terms of gender roles being more socially sanctioned than substance abuse. It has been found, for example, that '[r] egardless of mode of HIV transmission, women were held less accountable for their illness than were men' (Borchert and Rickabaugh, 1995: 657). Paradoxically, studies covering populations in the United States, Ethiopia, Mozambique and Uganda have shown that women living with HIV interiorize higher levels of perceived HIV and AIDS-related stigma than men and have more concerns about disclosure (Fekete et al., 2016; Geary et al., 2014).

While we have now elucidated certain key elements of the nexus intertwining fatigue, gender, HIV stigma and social strategies of disclosure, we shall explore in this article their links with the expression of fatigue among people living with HIV in France.

## Methods

The field research involved two qualitative exploration methods: unstructured interviews and participant observations. The analyses from both methods focused on the uses and expressions of fatigue within specific social frames of interaction (Goffman, 1999 [1959]). While the interviews allowed us to analyse context-specific examples of the meanings or uses of fatigue and its expression as interpreted by the individual, the observations allowed us to analyse objectively any uses and expressions of fatigue *in situ*. The methods were therefore viewed as complementary by providing different subjectivities – from people living with HIV and researchers – surrounding the uses and expressions of HIV-related fatigue.

The unstructured interviews were conducted in the framework of a nationwide French project exploring the trajectories of people living with HIV before and after diagnosis, through an approach based on their experiences and trajectories in relation to exercise

and physical activity (cf. Thomas et al., 2012). Fifty autobiographical interviews (Bertaux, 1981) were conducted between 2010 and 2012 across France. Consent for the anonymised recorded interviews was obtained prior to each interview in accordance with French law on non-invasive and anonymous qualitative study, while national approvals were obtained from the National Commission for Data Protection and Liberties (CNIL) concerning the compilation of anonymous quantitative data.

In order to maximize the diversity of the interviewed population, participants were recruited via email listings, websites and interpersonal contacts obtained through participating HIV-related associations, institutions and hospital services, many of which were situated in and around cities of central, northwestern, eastern and southern France (Paris, Rennes, Strasbourg and Montpellier). This non-randomized nationwide sample of interviewed persons included 39% predominantly heterosexual women and 61% men. Of the latter, 70% considered themselves homosexual or bisexual and 30% heterosexual. The median age of interviewed participants was 42, the ages ranging from 19 to 77. The interviewed participants had been living with HIV from between 3 months and 27 years, the median year of contraction being 1997. The medical histories of the participants were thus extremely diverse in terms of types and spans of treatments. This, along with other biomedical and psychosocial characteristics, may affect fatigue levels. The use or not of combination antiretroviral therapy has, for example, been correlated to reduced fatigue (Jong et al., 2010), suggesting that those diagnosed and treated prior to the prescription of more effective treatments (Highly Active Antiretroviral Therapy (HAART)) in the late 1990s may have traversed greater medical problems including fatigue, as well as greater stress or depression related to medical and social difficulties, including a deadly image of HIV. Despite disparities in fatigue levels, the diverse selection of people living with HIV allowed us to fulfil our objectives of analysing shared and diverse meanings, uses and expressions of fatigue, and potentially linking these to social or biomedical profiles.

The interviews were conducted by several participating researchers experienced in qualitative research methods. Interviewers relied on a common starting point of announcing the general direction of the interview in relation to three principal questions pertaining to the combined views and experiences of HIV and physical activities. Particular attention was paid to the changes in views and practices after the diagnosis, viewed as a 'biographical disruption' (Bury, 1982). Interviews lasted a minimum of 1 hour, generally lasting 2 or more hours. Although the topic of study pertained more specifically to physical activity, fatigue was mentioned freely by the interviewee during the course of most interviews.

The 50 interviews, transcribed verbatim and rendered anonymous via pseudonyms, were analysed through content analysis relying on the principles of grounded theory (Charmaz, 2000; Glaser and Strauss, 1967). The software program N'Vivo<sup>®</sup> was used to facilitate the application of grounded theory by allowing the researcher to code transcribed discourse into single or multiple conceptual categories and subcategories, while retaining the relations between the coded content and the enunciator. Using this technique, all discursive uses and expressions of fatigue were identified, including metaphors and other associated terms as mentioned freely by the interviewee throughout the autobiographical interview. The coding allowed for the creation of categories and subcategories. For instance, the category 'HIV and homosexuality' was created in order to group

together the recurring metaphors and discourse linking the disclosure of HIV to that of male homosexuality. This process later emerged as linked to the discourse on fatigue as we shall see. In another instance, the category ‘fatigue as strategic’ was created in order to group together the often explicit social uses of expressing fatigue, such as soliciting recognition of illness-related difficulties. This conceptual category became a primary category of analysis, complemented by subcategories based on the effects of expressing fatigue as described in the interviews.

The second research method entailed participant observations by two researchers in four HIV-related associations located in four French cities. As each structure or local branch of a nationwide association functioned somewhat differently in terms of its objectives, modes of organization and social profiles and dynamics between workers, volunteers and members, it was assumed that the specific geographical situations of these structures were less determinant of the observed social processes than the context-specific situations. The profiles of the association members were predominantly men and women over 40 years and of diverse social origins, yet who for the most part were not employed at the time of the study. The organizations and members of each association consented that the researchers participate in various focus groups as well as the health- or leisure-oriented physical activities offered explicitly for people living with HIV and, in one case, for people living with various types of chronic illness. As the latter association was initially dedicated to HIV-infected people at the time of its creation in 2010, a majority (80%) of its current adherents were HIV-positive. The researchers each participated in the associations’ physical activities over the course of several months, being present before, during and after each activity in order to exchange freely with the other participants.

Although the researcher in each association was clearly identified as a researcher, the long-term participation allowed for the salience of this difference to be somewhat reduced. In addition, the object of ‘fatigue’ was not emphasized in the presentation of the study in order to minimize any modifications of usual social expressions of fatigue during the interactions. Rather, the more global objectives of each of the research projects concerned were emphasized: access to leisure activities or ‘quality of life’ among people living with HIV. Data and notes from the observations were kept in a field notebook (Denzin, 2009: 185–218) in order to keep track of the specific contexts (association, activity, persons present), situations and types of complaints. Within the encompassing subject of complaints and the expression of discomfort through words or gestures, including expressions of pain and fatigue, particular attention was paid to the latter.

## Findings

Before discussing what the expression of fatigue in a given social context may represent socially, it is important to underline what was meant by ‘fatigue’ when this notion emerged freely during the unstructured interviews, freely in that fatigue was never introduced or focused on specifically by the interviewer. Most often, fatigue was evoked as a lack of motivation or as a general feeling of being ‘fed-up’, and as something that is ‘in the head’ or ‘psychological’. In other words, it was generally viewed as a lack of mental energy, which in turn affects the body. Less predominantly, fatigue was also expressed as emanating from the ‘tired body’, a physical fatigue that may prevent physical activity or,



more frequently cited, social activity. Fatigue was therefore evoked during the interviews in descriptions of day-to-day life, rarely expressed as an outcome of physical activity (in which cases it was referred to as 'good fatigue'), despite this topic of exploration. The purpose of the following analysis is, however, less to identify the definitions attributed to fatigue than to analyse the contextual expressions, meanings and uses of this polysemous notion: the contexts of social interaction in which a form of fatigue was expressed, by whom and with what social effects.

### *Expressing fatigue as rendering HIV 'visible'*

The interviews revealed that, globally, expressing fatigue was explicitly viewed as rendering HIV 'visible'. Independently of gender or sexual orientation, many interviewees explained that when their fatigue became apparent to others, they felt obliged to disclose their HIV-positive status or else to provide another legitimate, plausible explanation. As one man stated, *'Today 10 people know'* about his HIV-positive status because *'it was visible'* – due to the fatigue and weight loss. Another man found an alternate excuse: *'I didn't tell anyone [about being HIV-positive]. Actually I said I had mono, which explained why I was super tired'*. In this case, the unpreventable visibility of fatigue was explained by a less stigmatizing illness.

Many excerpts underlined this association between managing the visibility of fatigue and that of HIV. Fatigue was viewed as making HIV difficult to conceal. When a friend missed a lot of work due to HIV-related fatigue, one man remarked, *'Good thing there were people who protected us, who knew we were HIV-positive'*. In other words, the fatigue handicapped his friend to the point where the disclosure of his HIV-positive status was only prevented by the help of friends to manage the visibility of both the fatigue, the signifier, and the HIV illness, the signified. Similarly, one woman explained having attempted to hide her HIV-positive status from colleagues and peers, yet the fatigue made this difficult. *'I admit sometimes it was hard; because sometimes I was feeling tired'*. In another case, a former professional soccer player explained that the fatigue led her to work out *'lighter than the others'* during practice, but specified that this did not become a problem because *'it wasn't obvious'*. The importance was placed on the visibility of the fatigue, rather than on its effects. Such visibility was directly associated with the risks of rendering the illness itself visible within a social space not related to social or medical care.

Another interviewee drew an interactionist, dramaturgical portrait of this management of the visibility of HIV, comparing it with taking on and off a mask according to the contextual 'frame' (Goffman, 1999 [1959]). She stated that going to the hospital or HIV-related associations

is the only way to take the mask off. I don't have to hide there. For example, last time [...] everyone was there and I didn't hide. I said I was tired [...]. I said, 'yeah my treatment, it's tough' [...]. I say it makes me tired. And I stop there.

Without 'the mask', not only could she reveal her HIV-positive status, but she could also express fatigue. She could play a social role that more closely corresponded to her social and physical reality. Fatigue was explicitly identified as an element that could only

be expressed freely in a context where the real-life role of living with HIV could be assumed, where one's HIV-positive status was revealed and socially acceptable. While the choice to disclose could be spurred by a number of contexts and circumstances, the interviews highlighted the role that fatigue or other perceived illness symptoms might play in this choice. They demonstrated how the tight management of knowledge about one's HIV-positive status (Ferez et al., 2014; Stutterheim et al., 2011) led to equally tight management of the expression of fatigue.

### *Men and women in their relations to HIV-related stigma and fatigue*

The link between the visibility of HIV and fatigue, conjointly managed, appeared across the board independently of gender or sexual orientation. Nonetheless, according to the interviews, the extent to which one disclosed HIV or expressed fatigue varied greatly. Some of the gendered social patterns and contextual factors contributing to the expression or concealment of HIV-related fatigue shall be discussed here.

*The case of homosexual men: managing the visibility of HIV, homosexuality and fatigue.* In the discourse of homosexual men, the recurrent use of the expression 'coming out' revealed a direct association between disclosure of homosexuality and that of HIV. One man stated, for example, '*After having done my homosexual coming out, I'd like to do my HIV-positive coming out*'. The metaphor between a homosexual and HIV 'coming out' was echoed in numerous accounts, in which is similar to results from a study among people living with HIV/AIDS in Arizona in the mid-1980s (Weitz, 1990: 35). These stigmas were perceived as closely linked: '*there's a problem with HIV and there's a problem with homosexuality, and it's coupled*'. For many, this explicitly produced the effect of only being comfortable with revealing HIV when comfortable with revealing one's sexuality: '*I was never comfortable with my sexuality, so obviously not with being HIV-positive either*'.

The visibility of fatigue, viewed as rendering HIV visible, followed these patterns, being expressed in social contexts where homosexuality and HIV could be comfortably assumed. The following excerpt illustrates the associations of these processes:

I was never able to reveal my homosexuality in a heterosexual [volleyball] club. On top of that, announcing that I was tired because I was HIV-positive ... I don't think I could have lived through it [...]. I was afraid of being rejected.

While playing in a heteronormative club, he concealed all three of these aspects – fatigue, HIV and homosexuality – in order to avoid the twofold stigma. After having changed to a lesbian, gay, bisexual, and transgender (LBGT) volleyball club, where he was open about his sexuality, he disclosed HIV and expressed fatigue. It is interesting to note that in this scenario, when finally able to express his fatigue and explain its illness-related origin, he tired faster: '*I got tired faster, I skipped every other practice [...] I played less, I was tired faster and I think it was as much a physical fatigue as a nervous one*'. Beyond demonstrating the links between disclosure and the expression of fatigue, this excerpt suggests that there may be a relation between the externalized social expression of

fatigue and the internalized perception of physical fatigue, whether due to concerns about self-image and stigma or due to increased internalization of expressed fatigue.

*The case of heterosexual men: the social risks of contingent stigma.* The stakes of revealing HIV and expressing fatigue appeared to be somewhat different for heterosexual men, although the double stigma of homosexuality and HIV also seemed to play a role in the management of the (non)disclosure of HIV and the expression of fatigue. In the words of one man, disclosing HIV makes others ‘deduct [...] or suspect several things, like your sexual orientation, or your drug use or I don’t know what’. Most people think HIV ‘only effects homosexuals and drug-users, so if you’re HIV-positive, you’re one or the other’. This deduction or suspicion acted as a mechanism identical to that concerning homosexual men in heteronormative contexts. One man, for example, asserted his right to not disclose his HIV-positive status, comparing it to that of homosexuality, its frequent metaphor. ‘It’s nobody’s business. It’s like if I were homosexual, I don’t have to say it, it’s my business!’ He therefore revealed his HIV-positive status to next to no one beyond his wife.

Likewise, heterosexual men rarely expressed fatigue according to the recounts and expressions of fatigue during the interviews and participant observations. The analysis of the interviews showed, for example, that when fatigue was mentioned by heterosexual men, it was often evoked in an indirect way and as something that was dismissed or concealed. As one man wondered rhetorically, ‘As long as I can do what’s asked of me [at practice], and follow the others running, why would I say I’m HIV positive?’ In other words, as long as any fatigue or incapacities were kept at bay or at best invisible, HIV could also remain invisible.

*Women and men faced with drug use assumptions.* It is significant that during the interviews, discourse on fatigue was *explicitly* linked to concerns about disclosure and risk of stigma namely in men’s discourse. This is not to say that women were not affected by concerns surrounding disclosure and HIV stigma, only that the latter were not explicitly associated with fatigue during the interviews. For women – sexual orientation being less salient in the life stories of women living with HIV – HIV stigma was equally attached to deviant behaviour, but emerged in the form of drug use assumptions, despite this form of contamination concerning only 11% of people living with HIV in France, of whom only 4% are women (Dray-Spira et al., 2013). One woman explained, for example, that she avoided mentioning HIV because ‘people judge you. Yes, because in France you did dirty things if you get AIDS’. Another woman recounted two situations where medical personnel assumed her to be a drug user. She then added that overall ‘people used to say they [HIV-infected people] are drug-users, homosexuals, lesbians, prostitutes ... That stayed in people’s heads. [...] You got a label: she must not lead a wholesome lifestyle.’ Unlike for homosexuality, the association between HIV and drug use was not gendered. Assumptions of drug use coming from the medical community were also reported by men. One man spoke of how a doctor who ‘had never seen an HIV-positive person in his life’ refused to treat him. The doctor told him, ‘I just see people with hepatitis and that’s all’. The interviewee concluded, ‘Oh, ok, so he makes a link between HIV and hepatitis. Which means that HIV-positive people are, for him, drug-users. Oh ok. And so he refused to treat me’. Such anecdotes illustrate how men and women alike are at risk of being

affected – socially and medically – by disqualifying social stigma, which may as in this case lead to discrimination. This context conditions – for both men and women living with HIV – the management of the visibility of HIV and, concomitantly, that of fatigue.

### *Uses and effects of expressing HIV-related fatigue*

We have seen how the management of the visibility of HIV and fatigue partly depended on the management of potential (and potentially gendered) HIV-related stigma. The interview analysis combined with the participant observations in HIV-related associations allowed us to consider the social frames associated with the expression or concealment of fatigue. We shall expose here certain social contexts in which the expression of both HIV and fatigue was enabled, encouraged or hindered, for whom, and with what strategic purposes or social effects.

*Fatigue as a means of expressing illness-related needs in spaces of HIV care.* In contexts where HIV was disclosed, and in particular where HIV was the object of care relations, the expression of fatigue constituted one means of legitimizing illness-related needs or difficulties. One woman, for example, entreated the interviewer and her HIV-related association's sports trainers for their continued interest and social support for people living with HIV: *'please don't leave us, because we don't have the force [...] Because life tires us enough – with the treatment, the outside image [...] Don't leave us'*. The appeal for recognition and support of illness-related difficulties, including stigma (*'the outside image'*), was made through specific reference to fatigue (*'we don't have the force'*; *'life tires us'*).

Another woman spoke of *'jealousy problems'* within one association concerning *'recognition'* of one's health problems. She related how different members at times engaged in *'competitions'* of illness, vying for the position of being *'more ill'* or having more legitimate health problems. Likewise, in an observed conversation between two members of the same association, one woman complimented a third person, explaining, *'She's the one who has the most problems but who complains the least'*. The right to complain about one's illness-related difficulties, including the expression of fatigue, was accorded to particular persons in particular spaces of care. This phenomenon was also documented in Widerberg's work on tiredness in modern times, where tiredness was a *'much-discussed topic of conversation'* which often led to a *'tiredness competition – who is the most tired and has the most legitimate reasons'* (Widerberg, 2006: 117). In HIV-related associations in France, illness-related difficulties were the *'legitimate reasons'* of tiredness, and which legitimized the right to complain or to underline social, physical or material needs.

Wielding fatigue to seek social recognition of illness-related difficulties was also at times consciously strategic. Two participants mentioned how they exaggerated fatigue in order to receive state benefits for adults living with a handicap:

I thought, 'Ok, I know how I'm going to play it!' [...] I limp a little when I'm tired, and so I arrived limping [...]. He [the doctor] says, 'Are you ok?' I say, 'Yes ... no, I'm a little tired [...]. I got out of the hospital yesterday'. Because, you know, you have to add a little.

And,

With the advice of [an HIV-related association] if you will, I said that I tired somewhat, which is, well ... I'm nonetheless in good shape, um ... physically. But it's true that if I'm standing a long time, etcetera ... And I admit frankly that ... if that can allow me to have welfare benefits ... I am in a bad position to have this and not have work.

Beyond demonstrating the social construction of fatigue, highlighted by the explicit use of fatigue as advised by an HIV-related association, the expression of fatigue was used here to legitimize one's illness-related needs. The tactical use of fatigue represented in other words a means of negotiating recognition – in this case official administrative recognition – of one's illness-related difficulties.

*Gendered management of fatigue in HIV-related associations.* The social stakes of expressing fatigue and legitimizing illness-related difficulties depended on the social frame and appeared to differ along gender lines. The example of one association particularly illustrated this point. The association aimed for its members to reintegrate into 'regular' social activities when possible. Those who were viewed as having become 'self-sufficient' were invited to leave the association's activities in order to make space for its more 'dependent' members. In the fitness and water aerobics courses, physical difficulties became a decisive factor of being able to continue the activities within the association.

In the fitness course, the participants were mainly heterosexual women and homosexual men, 30 to 60 years old, in relatively good shape. This activity was intended for the most self-sufficient: those who should be encouraged to leave the association. Within this activity, there was an elevated rate and consistency of expressions of fatigue although this led neither to an adaptation of the activity's intensity nor to sympathetic words from the instructor. The social expression of fatigue appeared to have the sole effect of legitimizing physical difficulties and therefore one's place as 'dependent' on the association's activities. Consistent with the interview analysis regarding gender and sexual prescriptions, the participants, predominantly women and homosexual men, seemed to express fatigue indifferently.

The water aerobics course, conducted in a pool situated within a medical structure, was followed by a diverse group of women and homosexual and heterosexual men. During this activity, only the women expressed fatigue or pain, despite the fact that the possibility to continue this activity relied on the association's recognition of each participant's 'dependence' on the association and its adapted activities. Conversely, no explanation was provided by one man leaving a session mid-activity, despite body expressions that hinted at physical discomfort such as pain or fatigue. Therefore, while the expression of fatigue enabled the women to secure their place within the activity, gender prescriptions therefore seemed to have discouraged all men from expressing fatigue, and thus from securing their place within the activity. A dominant masculine model of behavioural norms, in terms of expressing fatigue or managing HIV, may have taken precedence within this gendered activity. As we have seen, the heterosexual masculine model of managing fatigue and HIV consisted of infrequent expressions of fatigue in accordance with infrequent disclosure of HIV. In addition, the general social representation of water

aerobics as being ‘feminine’ or ‘easy’ may have consolidated adhesion to gender norms among men.

Overall fatigue appeared as particularly expressed in certain contexts of HIV-related care. Beyond the expression of an immediate physical need with the effect of obtaining sympathy or adapted expectations (Ferez et al., 2013), the expression of pain or fatigue appeared to have the effect of obtaining social recognition of illness-related hardships, depending on the gendered and context-specific social gains or losses of being recognized as ill.

## Discussion

Despite popular understanding of fatigue as a typical symptom of a modern lifestyle, for people living with HIV the expression of fatigue often signified the expression of illness and its being rendered visible. As Harris wrote on Hepatitis C stigma based on her research and personal experience, ‘My tiredness is formless and invisible. It is perceived as “everyday”, not a requisite marker of a “proper” illness. So, with my invisible illness, I can “pass”, as many with hepatitis C choose to do’ (Harris, 2009: 49). Fatigue represented in this sense a ‘symptom’ which had to be socially managed, in that any visibility or disclosure of the illness, or one of its perceived symptoms, entailed risking social ‘discredit’ (Goffman, 1999 [1959]) and stigma attached to HIV (Persson, 2005; Stutterheim et al., 2011). Viewed as a socially discrediting symptom, the visibility of fatigue – like HIV – was generally kept under control, invisible or secret. These results are coherent with the perceived risks of expressing illness-related fatigue in the cases of fibromyalgia or chronic fatigue syndrome (Asbring and Narvanen, 2002). In these cases, the expression of extensive fatigue or other physical discomfort was felt as stigmatizing if not legitimized by a medical diagnosis of physical (and not mental) illness. This combination of findings further suggests that corporeal complaints are socially regulated and kept at bay unless considered as symptomatic of an illness that is both legitimized and diagnosed by the medical community.

In the case of HIV, the control of the visibility of illness and its symptoms are all the more socially managed due to stigma resulting from negative associations between HIV and socially stigmatized social categories and deviant behaviours. The stigma leads to different forms of ‘passing’, concept that refers to the feigning of social characteristics or identity (Goffman, 1963). In the case of avoiding stigmatized identities, passing entails accepting or instigating others’ incorrect assumptions about one’s social identity, what Daniel Renfrow (2004) terms ‘reactive’ and ‘proactive’ passing, respectively. We have observed examples of ‘reactive everyday passing’ (Renfrow, 2004: 493), such as rendering fatigue and illness invisible in order to let others assume HIV negativity – strategy that has been observed in many experiences of HIV/AIDS (e.g., Weitz, 1990). We have also observed examples of ‘proactive passing’, such as wilfully attributing fatigue to a less stigmatizing illness such as mononucleosis. The study of fatigue, since frequently construed as an illness symptom, thereby illustrated how strategies of passing constituted forms of impression management that aimed to conceal HIV and its perceived symptoms and, ultimately, avoid discrediting social identity and stigma (Goffman, 1963).

While the social mechanisms underlying the tight management of the visibility of HIV and fatigue were gender-neutral, the social gains and losses of revealing HIV and fatigue were not. Women appeared as more encouraged or able to disclose their HIV-positive status or to express health difficulties and symptoms such as fatigue within care-related or HIV-related contexts and activities. This is coherent with findings in the United States that women living with HIV may be less socially stigmatized than men, male homosexuality entailing a perception of accountability for HIV (Borchert and Rickabaugh, 1995). This is also coherent with statistics in France showing that women are more likely to disclose HIV (Dray-Spira et al., 2013). However, studies have shown that women living with HIV have higher levels of internalized stigma and greater concerns about disclosure (Fekete et al., 2016; Geary et al., 2014), concerns possibly confounded by social disadvantage tied to gender. It is therefore unlikely that the observed gender differences in the expression of HIV-related discomfort relate to overall social concerns about disclosure or stigma. Rather, in such contexts where HIV is disclosed, the expression of HIV-related fatigue may be influenced by gender roles that allow women facilitated expression of physical discomfort.

Among men, a relation appeared between the management of HIV stigma related to gender and sexuality and the expression of fatigue. Whereas homosexual men spoke of disclosing HIV and expressing fatigue primarily in contexts where their sexual orientation was revealed, further complicating choices of disclosure and the management of perceived illness symptoms such as fatigue, heterosexual men rarely evoked disclosing HIV or expressing fatigue or other illness-related difficulties. The latter, likewise, were not observed to express fatigue during the observed physical activities.

These tendencies may be partly linked to gender prescriptions that posit among men minimal show of 'weakness' such as fatigue (Widerberg, 2006). It is possible that the transgression of gender roles, such as expressing fatigue, is facilitated for disclosed men whose sexuality transgresses normative gender and sexual prescriptions. In addition, social support has been positively linked with disclosure (Petрак et al., 2001; Stutterheim et al., 2011) and negatively linked with perceived stigma (Smith et al., 2008). In addition, social support networks may differ along lines of male sexuality, some studies having found greater social support among homosexual men living with HIV (Petрак et al., 2001). For heterosexual men or non-disclosed homosexual men, the desire to keep any illness 'symptoms' invisible also appeared to be linked to the 'management of double stigma' (Daftary, 2012) tied to both homosexuality and HIV.

Whether fatigue and the illness itself were to be revealed or concealed depended on the social stakes of rendering illness visible, and thus of being socially viewed or recognized as 'ill'. Beyond the management of HIV-related stigma, which encouraged keeping fatigue and HIV invisible in order to avoid negative social reactions, we have seen that there appeared to be 'illness gains' (Asbring, 2001) or 'secondary gains' (Parsons, 1951) in certain care-related social contexts. It is helpful to consider here Parsons' (1951) concept of the 'sick role': the adoption of social norms and behaviours specifically expected for the ill, entailing exemption from usual social roles or norms. In this light, a 'sick role' appeared to be adopted in particular social contexts where 'the privileges and exemptions of the sick role [...] become objects of a "secondary gain" which the patient is positively motivated, usually unconsciously, to secure or to retain' (Parsons, 1951: 437). In

such contexts, where HIV was not only expressed but was also the very object of the social or care relations, the expression of fatigue may partake in the performance of the very health problems that justify the care relations framing the social context of interaction. Such performance of the expected sick role – or ‘performance of legitimacy’ (Hillman, 2014) – has been shown here, as in other contexts related to social or health care (Clarke, 1999; Hillman, 2014), to at times enable social or even physical gains, such as adapted social or medical treatment. However, such gains were nuanced by gender and sexual prescriptions and expectations.

## Conclusion

These trends emerged from combined evidence stemming from mixed research methods. While the interview analyses provided discursive explanations behind (non)disclosure of HIV, the expression of fatigue and the management of potential HIV-related stigma, the participant observations provided insight into certain contexts of HIV care where the expression of fatigue had strategic uses or specific social effects. This interactionist approach to fatigue allowed to reveal certain frames of interaction where playing the ‘sick role’ and revealing fatigue or other perceived illness symptoms were acceptable, at times even allowing for certain ‘illness gains’ however minimal. The social uses and expressions of fatigue, and the management of its visibility, therefore appear as social ‘choices’ – however reduced – closely linked with choices surrounding the visibility and disclosure of HIV. To some extent, living with chronic illness means measuring the stakes of the ‘sick role’ before measuring to what extent ‘to be or not to be’ sick, socially, or to show tiredness or other illness signifiers.

In the case of HIV, the stakes of disclosure and the ‘sick role’ are high owing to HIV-related stigma, which include stigma surrounding not only male sexuality but also drug use. The ‘sick role’ and the management of illness and symptom visibility were likewise found to depend on structural factors such as gender and sexual prescriptions, such as showing ‘weakness’ or risking assumptions about sexual orientation. Such social prescriptions and risks were more or less determinant of interactional choices according to context effects, contexts involving illness-related support and potential ‘illness gains’, more or less enabling the adoption of the ‘sick role’ or the expression of illness symptoms such as fatigue. In this sense, the expression or concealment of fatigue, viewed by our participants as an illness ‘symptom’, constituted one aspect, however small, of the overall negotiation of positive social recognition in terms of – or in spite of – chronic illness. In this way, our findings underscored the close link between HIV stigma, HIV care relations and the expression of HIV-related discomfort. While the policy implications of this underline the dire need for increased societal awareness about HIV and AIDS in order to reduce stigma, the health implications highlight a need for recognition of perceived illness symptoms such as fatigue within medical and social care communities, and this regardless of the patient and his or her outward appearance or behaviour as ‘sick’.

The findings also underline the interest of considering the role of gender and sexual prescriptions within the social and medical experiences of people living with HIV and more generally with chronic illness. Gender and sexuality, and most likely other ‘intersecting’ social categories inscribed in social relations of power, such as race and class



(Hankivsky, 2012), may affect ‘chronic illness trajectories’ (Corbin and Strauss, 1991), affecting the ways in which illness and its symptoms are experienced, expressed and understood. Knowledge of these structural differences may facilitate increasingly adapted symptom care. In this light, further study of such social processes and health experiences could strengthen the ‘intersectional’ approach, considering the effects of multiple social relations such as race, class and age distinctions. It would also be interesting to compare the results with those in various local and national sociocultural contexts, particularly where gender norms, illness stigma, or racial, class or doctor–patient relations may differ. Likewise, it would be pertinent to investigate the degree to which modes of expressing or concealing fatigue compare with those among populations living with other forms of chronic illness. This would enable greater understanding of the degree to which specific stigma relating to HIV, including gendered sexual stigma, influence the observed strategies of socially managing perceived illness symptoms.

Finally, it would be relevant in further research to explore the relations between the social expression of fatigue, which has been shown here to depend on the immediate social contexts of interaction, and the declared feeling of fatigue, or ‘perceived fatigue’, as measured in questionnaires. Study in this direction might shed light on possible biases or mechanisms underlying HIV-related fatigue as measured in quantitative studies. Beyond formerly contradicted hypotheses that the declared perception of HIV-related fatigue may be linked to biological factors, physiological markers, specific treatments or the duration of time living with HIV, perceived HIV-related fatigue may be in some ways linked to the opportunities or constraints surrounding its social expression. Some evidence presented here pointed, for example, to increased fatigue in contexts where fatigue and HIV were expressed. This trend may be linked to increased vulnerability or concerns regarding stigma, or perhaps linked to a psychological process in which outwardly expressed symptoms are perceived more acutely. However, other evidence has suggested that fatigue may be amplified by the effort of double or triple concealment of one’s life experiences – the effort of passing (Renfrow, 2004) or the ‘*wearing of the mask*’ as described by one participant – including the concealment of one’s HIV-positive status, sexual orientation or fatigue. Recent work has shown, for instance, that disclosure of HIV and sexual orientation are positively linked to CD4 cell counts and thus to more positive health outcomes, possibly due to differences in stress levels linked to concealment or disclosure (Strachan et al., 2007). Lower levels of cortisol and psychiatric symptoms of stress have also been observed in disclosed lesbian, gay and bisexual individuals (LGB) as compared with non-disclosed LGBs (Juster et al., 2013). It would be pertinent to explore the extent to which similar correlations might be found between disclosure of HIV and both expressed and perceived fatigue. Further knowledge of these social processes and interrelations may represent a step towards understanding and reducing HIV-related fatigue.

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