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To be or not to be sick and tired.

Managing the visibility of HIV and HIV-related fatigue

Laura Schuft, Estelle Duval-Marin, Julie Thomas, Sylvain Ferez

Abstract

This paper 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 the discursive and physical expression of fatigue. The two-part methodology combines content analysis of fifty transcribed unstructured interviews conducted across France and participant observations within four HIV-related associations. Results reveal that the visibility of fatigue is associated with the visibility of this stigmatised 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, but also context effects such as the type of social or “care” relations involved in a given social frame of interaction.

Key words: HIV; fatigue; stigma; disclosure; gender

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Introduction

Chronic fatigue plays a major role in the day-to-day lives of people living with the human immunodeficiency virus (HIV). Often defined as a feeling of exhaustion or lack of energy (Lee et al., 1994), the prevalence of perceived fatigue varies from 33 to 88% among people living with HIV (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 and Voss, 2013), this study explores rather some of the social mechanisms that may underlie different modes of “displaying” or “managing” (Goffman, 1999) 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 during social interaction. Results show how these processes are entwined with (non)disclosure, HIV stigma and gender.

Recent studies have sought to combine analyses of biological factors, types of treatments, and psychological antecedents in comprehensive studies of the factors of fatigue (Barroso et al., 2010; Leserman et al., 2008), many taking into account socio-demographic factors (Bensing et al., 1999; Jong et al., 2010; Voss, 2005). While physiological variables, such as the prevalence of lymphocytes T CD4+ or the viral load, have so far shown no correlation with perceived fatigue, certain psychological (namely 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). The social factors include unemployment, inadequate income or a low level of social support. In addition, some studies have shown that poorer women living with HIV more often declare fatigue (Thomas et al., 2012; Harmon et al., 2008; 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 the expression of HIV-related fatigue were investigated through semi-structured interviews and participant observations conducted across France. Before exposing the methods and the three-part findings, showing that the expression of fatigue is gendered and closely linked with disclosure and concerns about HIV stigma, we shall first consider the scientific literature in these domains.

Fatigue

Fatigue is a multi-faceted 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” (American Heritage Stedman's Medical Dictionary, 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 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 (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 fatigue experienced by the general population. Fatigue is even at times viewed as a typical symptom or “embodiment” of modern times (Widerberg, 2006).

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 within the heterosexual family, or men not wanting to be asked to invest less at work (Widerberg, 2006: 115-7). 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 (Van Wijk and Kolk, 1997; Miaskowski, 2004). The social mechanisms behind gendered patterns in terms of illness-related fatigue, and in particular in terms of HIV-related fatigue, shall be investigated here.

Gender and HIV-related fatigue

The present analysis of HIV-related fatigue takes into account the ways in which gender prescriptions, including heteronormativity and gender roles, affect social experiences and “performances” (of fatigue) within particular “frames” of social interactions (Goffman, 1999).

Gender is viewed here as a hierarchical social system which organises the social world both symbolically and physically. As a socially constructed system of power, gender subsists through the reiterated social performance of gender norms and differences (Butler, 1990). Like other modes of social differentiation such as race or class (Hankivsky, 2012), gender is correlated to differing health experiences and trajectories , including the declaration of HIV-related fatigue (Harmon et al., 2008; Voss, 2005).

In adopting a gendered interactionist approach to the study of HIV-related fatigue, we are interested here in the unexplored territory of how the social expression and management of HIV-related fatigue takes part in social performances of the gendered social self (Goffman, 1999) or the chronically ill self (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 words or the body – is considered to be socially faceted. The concept of socially constructed realities has proven to be a compelling approach to the study of men and women’s experience of both fatigue (Walters and Denton, 1997) and illness (Conrad and Barker, 2010).

HIV stigma and disclosure

Stigma can be defined as a characteristic that socially “disqualifies” the person who bears it (Goffman, 1963). As a “fundamental dimension of stigmas concerns the degree to which they can be concealed from others” (Stutterheim et al., 2011: 382), visible stigma has been observed to be more detrimental than concealable stigma (Goffman, 1999; 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 stigmatised.

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). Social representations of HIV tend to relate this illness to other stigmatised 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). These “deviant” social behaviours and categories are mobilised in 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). 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). Some forms of social deviance are more stigmatising than others, deviance in terms of gender roles being more socially sanctioned than substance abuse. It has been found for example that, “Regardless of mode of HIV transmission, women were held less accountable for their illness than were men” (Borchert and Rickabaugh, 1995: 657).

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 paper 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 stemming from a nationwide study and participant observations in four HIV-related structures. 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 maximise the diversity of the interviewed population, participants were recruited via e-mail listings, web-sites 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-randomised 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 persons 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.

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 one hour, generally lasting two or more hours. Although the topic of study pertained more specifically to physical activity, fatigue was mentioned during the course of most interviews.

The fifty 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 © 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 sub-categories. 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 uses of expressing fatigue, for example seeking recognition of one’s HIV-related difficulties. This conceptual category became a primary category of analysis, and was complemented by sub-categories 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 towns. As each association or local branch of a nationwide association functions somewhat differently in terms of its objectives, modes of organisation and social profiles and dynamics involving 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 forty and of diverse social origins, yet who for the most part were not employed at the time of the study. The organisations 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 are 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 emphasised in the presentation of the study in order

to minimise any modifications of usual social expressions of fatigue during the interactions. Rather, the more global objectives of each of the research projects concerned were emphasised: 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 during the interviews. 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 which 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 being the 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 is expressed, by whom and with what social effects.

Expressing fatigue as rendering HIV “visible”

The discourse analysis revealed that, globally, expressing fatigue is explicitly viewed as rendering HIV “visible”. Independently of gender or sexual orientation, many interviewees explain 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 stigmatising 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 physical effects. Such visibility is directly associated with the risks of rendering the illness itself visible within a non-medical, non-care-related social space.

Another interviewee drew an interactionist, dramaturgical portrait of this management of the visibility of HIV and fatigue, comparing it to taking on and off a mask according to the contextual “frame” (Goffman, 1999). 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 her 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. Overall, these interview excerpts 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 discourse analysis, the extent to which one disclosed HIV or expressed fatigue varies 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, a direct link appeared between the expression of fatigue and disclosure in terms of both HIV and homosexuality. Disclosing HIV and expressing fatigue appeared as associated with the level of comfort in revealing a homosexual identity in specific contexts of interaction. Firstly, the recurrent use of the expression “coming out” revealed a direct association between disclosed of homosexuality and 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, these stigmas being perceived as closely linked: *“there’s a problem with HIV and there’s a problem with homosexuality, and it’s coupled”*. For some, this explicitly produced the effect of only being comfortable with revealing HIV when comfortable with revealing homosexuality: *“I was never comfortable with my sexuality, so obviously not with being HIV-positive either”*.

Fatigue represented another link on this chain. In many of the interviews with homosexual men, having been able to reveal one’s homosexuality emerged as paving the way for being able to reveal HIV and, in turn, being able to express fatigue. The following excerpt illustrated 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 LBGT volleyball club, where he was open about his sexual orientation, he soon disclosed his illness and expressed his fatigue. It is interesting to note that in this scenario, when he was 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 openness about homosexuality, disclosure of HIV and expression of fatigue, this excerpt suggested that there may be a relation between the externalised social expression of fatigue and the internalised perception of physical fatigue, whether due to concerns about self image and stigma or due to increased internalisation 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 they gravitated around similar factors. Indeed, 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 adds stigma to stigma, acting as a mechanism identical to that concerning homosexual men in heteronormative contexts where their sexual orientation is not disclosed. One heterosexual man sternly claimed 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 kept this information to himself, having revealed his HIV-positive status to next to no one beyond his wife.

Likewise, heterosexual men appeared to express fatigue less, according to the complaints, recounts and expressions of fatigue during the interviews and participant observations. The discourse 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, there was no need to consider disclosing HIV in this context.

Women and men faced with drug-use assumptions. As for heterosexual or homosexual women – sexual orientation being less salient in the life stories of women living with HIV, HIV stigma was equally attached to deviant behaviour, in particular drug use. 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 how on two different occasions medical personnel assumed her to be a former or current drug-user. She recounted how “*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 speaks 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 concludes: “*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 all at risk of being affected – socially and medically – by disqualifying social stigma due to social representations that associate deviant behaviour with HIV. 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, according to the experiences of men and women living with HIV, the management of the visibility of HIV and fatigue partly depended on the management of potential (and potentially gendered) HIV-related stigma. The content 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. With an eye to the role of gender prescriptions, we shall explore 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 has been disclosed, and in particular where HIV is the object of care relations, fatigue is at times wielded as a means to plea for social support or recognition of illness-related difficulties. One woman for example entreats 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 entreaty for recognition and support of illness-related difficulties – including stigma (*"the outside image"*) – is made through specific reference to fatigue (*"we don't have the force"; "life tires us"*).

The expression of fatigue constituted one means of legitimising one's illness-related needs or difficulties within the specific context of HIV-related associations. One 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,

ving 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, appeared as 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, fatigue was often mobilised to illustrate illness-related difficulties (the “legitimate reasons” of tiredness), which in turn legitimised the right to complain or to underline social, physical or material needs.

The wielding of fatigue to seek social recognition of illness-related difficulties could also be consciously strategic. Two participants mentioned how they exaggerated fatigue in order to receive Handicapped Adult Benefits:

“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”.

Or:

“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 legitimise 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 legitimising 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 to reintegrate its members 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 women and homosexual men, thirty to sixty 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 legitimising physical difficulties and therefore one's place as “dependent” on the association's activities. Consistent with the content analysis, 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, when a heterosexual man left a session mid-activity, no reason was provided, 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, a gender barrier seemed to discourage both homosexual and heterosexual men from expressing fatigue within this activity, and thus from securing their place within the activity. In this particular context, the gender barrier may have been linked to the general social representation of this activity as being "feminine" and "easy". 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 consists of infrequent expressions of fatigue in accordance with infrequent disclosure of HIV.

Overall fatigue appeared as particularly expressed in certain contexts of HIV-related care. Beyond the expression of an immediate physical need or experience 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 recognised 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” that must be socially managed, in that any visibility or disclosure of the illness, or one of its perceived symptoms, may entail enduring some of the social “discredit” (Goffman, 1999) and stigma attached to HIV (Stutterheim et al., 2011; Persson, 2005). Viewed as a socially discrediting symptom, fatigue – like HIV– is generally kept under control or even kept invisible or secret.

Stigma resulting from negative associations between HIV and socially stigmatised social categories and deviant behaviours underlied much of the tight management of the visibility of fatigue, regardless of gender. However, we might underline that 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 that women living with HIV may be less socially stigmatised than men, male homosexuality entailing greater accountability for HIV (Borchert and Rickabaugh, 1995). Among men, a relation appeared between the management of gendered HIV stigma and the expression of fatigue. Whereas homosexual men spoke of disclosing HIV and expressing fatigue primarily in contexts where their sexual orientation was revealed,

heterosexual men rarely evoked disclosing HIV or expressing fatigue or other illness-related difficulties. They likewise rarely expressed fatigue during the observed physical activities.

These tendencies may be partly linked to gender prescriptions which 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 prescriptions. In addition, social support has been strongly tied to disclosure (Petрак et al., 2001; Stutterheim, 2011), and social support networks may differ between heterosexual and homosexual men, the latter living with HIV more often finding support among peers (Petрак et al., 2001). For heterosexual men or non-disclosed homosexual men, the desire to keep any illness “symptom” 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 recognised 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’s (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” may be adopted by people living with HIV 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.

Conclusion

These trends emerged from combined evidence stemming from mixed research methods. While the content analysis provided the discursive explanations behind (non)disclosure of HIV or 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. The findings underscored the close link between HIV stigma, HIV care relations and the expression of HIV-related discomfort. The study of fatigue, as expressed by people living with HIV in France, has proved to constitute an approach for the study of how the visibility of HIV is managed in different social contexts, in light of avoiding HIV stigma or weighing in a “secondary gain” of illness or disclosure. In this sense, the expression or concealment of fatigue, viewed by our participants as an illness “symptom”, constitutes one aspect, however small, of the overall negotiation of positive social recognition in terms of – or in spite of – chronic illness.

The findings underline the interest of considering the role of gender prescriptions within the social and medical experiences of people living with HIV and more generally with chronic illness. Gender, and most likely other “intersecting” social categories such as race and class (Hankivsky, 2012), may affect “chronic illness trajectories” (Corbin and Strauss, 1991), impacting the ways in which illness is labelled and in which symptoms are expressed and

understood. 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 these modes of expressing or concealing fatigue compare with those among other populations living with chronic illness.

Lastly, it would be relevant in further research to explore the relations between, on the one hand, the social expression of fatigue, which has been shown here to depend on the immediate social contexts of interaction, and, on the other hand, 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 indeed be linked to the opportunities or constraints surrounding its social expression. Some evidence presented here points 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 felt more acutely. However, other evidence suggests that fatigue may be amplified by the effort of double or triple concealment of one’s life experiences – 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 expressed and perceived fatigue. Further knowledge of these social processes and interrelations may represent a step toward understanding and reducing HIV-related fatigue.

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