La fatigue physique chez les Personnes Vivant avec le VIH (PVVIH).

*Etude pluridisciplinaire de ses facteurs et de ses relations avec l’activité physique.*

Responsables scientifiques : F. d’Arripe-Longueville, L. Schuft et S. Colson

Mai 2019

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- le Département de Santé Publique et le département de virologie du CHU de Nice ;
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PRESENTATION GENERALE DU PROJET
1 / PRESENTATION GENERALE DU PROJET DE RECHERCHE

FICHE DE PRESENTATION

I - Laboratoire ou service du responsable du projet de recherche (LABORATOIRE A)

NOM, Prénom du responsable scientifique : D'ARRIPE-LONGUEVILLE, Fabienne ...................... Mme □ M □ Dr □ Pr ■
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Département : Faculté des Sciences du Sport .................................................................
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Centre, Institut, Hôpital, Université, Autre : .................................
Bât : ......................... N° : .......... Rue, av., bd : ........................................................................
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Organisme gestionnaire (les associations loi 1901 ne seront pas acceptées en qualité de gestionnaire)

☐ INSERM   ☐ CNRS (précisez la délégation régionale)  ........................................................................... ☐ INSTITUT PASTEUR .................................................

☐ HOPITAUX (hors AP-HP)  ............................................................................................... ☐ AP-HP ........................................................................

☐ AUTRE* (précisez) ....................................................................................................................

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Code postal, Ville : 06100 Nice .................... Tél. : 04 92 07 60 60 ..................... Fax : 04 92 29 65 49..........

* se reporter impérativement au règlement du 1er appel d’offre 2014

Titre du projet (250 signes, lettres, chiffres et espaces compris, soit une vingtaine de mots)

La fatigue physique chez les Personnes Vivant avec le VIH (PVVIH).
Étude pluridisciplinaire de ses facteurs et de ses relations avec l’activité physique

Subvention demandée à l’ANRS pour l’ensemble du projet de recherche (en euros)

<table>
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<tr>
<th>Durée prévue du programme</th>
<th>Total (euros)</th>
<th>Equipement (E) total page 29</th>
<th>Fonctionnement (F) total page 29</th>
<th>Personnel (P) total page 29</th>
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Montant total demandé toutes charges et frais inclus

- Une demande d’allocation de recherche est-elle associée à ce projet dans le cadre de cet appel d’offres?
  - oui □ non ☑
  (Si oui, se reporter au règlement de l’appel d’offres et au formulaire spécifique de demande d’allocation de recherche à renseigner)

- Dans le cas d’une demande d’allocation de recherche nominative, NOM et prénom du candidat : .................................
II - Laboratoire partenaire de la recherche, le cas échéant (LABORATOIRE B)

NOM, Prénom du responsable scientifique : FEREZ, Sylvain .................................................... Mme □ M □ Dr □ Pr □
Laboratoire, Unité, Service, Équipe (institut exact) : Santé Education Situation de Handicap (SantESiH) ..................................................
                                                                                         Précisez (Ex : Inserm U 340) : JE 2516 .................................................................
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Centre, Institut, Hôpital, Université, Autre : ............................................................................................
Bât : ........................................ N° : ...... Rue, av., bd : .................................................................
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Organisme gestionnaire (les associations loi 1901 ne seront pas acceptées en qualité de gestionnaire)

À remplir uniquement si financement demandé pour le laboratoire partenaire

INSERM □ CNRS (précisez la délégation régionale) ........................................................................ INSTITUT PASTEUR ..................................................
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AP-HP ......................................................................................................................................................... UNIVERSITÉ Montpellier 1
AUTRE* (précisez) ..............................................................................................................................
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Code postal, Ville : 34967 Montpellier ........................................ Tél. : 04 67 41 74 00 ........... Fax : .................................................

III - Laboratoire partenaire de la recherche, le cas échéant (LABORATOIRE C)

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Laboratoire, Unité, Service, Équipe (institut exact) : .................................................................
                                                                                         Précisez (Ex : Inserm U 340) : .................................................................
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NOM, Prénom du directeur : ................................................................. Mme □ M □ Dr □ Pr □
Laboratoire, Unité... (si différent) : ........................................................................................................
Centre, Institut, Hôpital, Université, Autre : ..........................................................................................
Bât : ........................................ N° : ...... Rue, av., bd : ..........................................................................
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Organisme gestionnaire (les associations loi 1901 ne seront pas acceptées en qualité de gestionnaire)

À remplir uniquement si financement demandé pour le laboratoire partenaire

INSERM □ CNRS (précisez la délégation régionale) ........................................................................ INSTITUT PASTEUR ..................................................
HOPITAUX (hors AP-HP) ..............................................................................................................................
AP-HP ......................................................................................................................................................... UNIVERSITÉS ..........................................................
AUTRE* (précisez) ..............................................................................................................................
Adresse : .....................................................................................................................................................
Code postal, Ville : ................................................................. Tél. : ................................................. Fax : .................................................

* se reporter au règlement du 1er appel d’offres 2014

Photocopier cette page autant de fois que nécessaire,
en poursuivant pour chaque laboratoire l’indexation alphabétique
Présentation générale du projet de recherche

RECAPITULATIF DES LABORATOIRES ET SERVICES DE RECHERCHE PARTICIPANT AU PROJET

En cas de partenariat, identifier selon l’ordre retenu en pages 2 et suivantes éventuellement

<table>
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<th>Responsable du projet pour chaque laboratoire</th>
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<td>A D’ARRIPE-LONGUEVILLE, Fabienne</td>
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<td>Maître de conférences, Université de Montpellier</td>
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AUTRES INFORMATIONS

- S’agit-il d’une re-soumission ? oui ☐ non ■
- Une demande d’allocation de recherche est-elle associée à ce projet dans le cadre d’un précédent appel d’offres ? oui ☐ non ☐
  Nom et prénom du candidat, année d’A0, CSS :

  ..........................................................

- Ce projet de recherche est-il mené en partenariat avec un ou plusieurs autres laboratoires ? oui ■ non ☐
- Ce projet relève-t-il de la réglementation française applicable à la recherche sur la personne (recherche biomédicale, recherche soin courant, recherche sur des échantillons biologiques, ou sur les données) ? oui ■ non ☐
  (si oui, renseigner la partie 5 du dossier)

  Pour déterminer la réglementation applicable à votre projet, référer-vous aux fiches « Typologie de la recherche sur la personne »

- Ce projet a-t-il également été déposé auprès d’un autre ou d’autres organisme(s) ?
  oui ☐ non ■
  Si oui, lequel ou lesquels ?

  ……………………………………………………………………………………………………………………………

  - en totalité ☐ en partie ☐

  - Quel est le montant total du financement ou du co-financement demandé à ces organismes ?

  ..........................................................

  - Avez-vous demandé un soutien en personnel(s) auprès d’un autre ou d’autres organisme(s) ?
  oui ☐ non ■
  Si oui, lequel ou lesquels ?

  Allocation de recherche ☐ .......................................................... Montant ........................................
  CDD ………………………………………………… Montant ................................................
  Autre ……………………………………………….. Montant ................................................

- S’agit-il d’une recherche utilisant des animaux ? oui ☐ non ■
  Si oui, numéro d’habilitation : ……………………………………………………………………………………………….
Principales publications du ou des laboratoire(s) : (restreinte aux chercheurs impliqués dans le projet)


**Mots-clés** (5 au maximum) : Fatigue, Activité physique, Santé, VIH, pluridisciplinarité
Présentation générale du projet de recherche

Nom et prénom du responsable scientifique : Pr d’ARRIPE-LONGUEVILLE, Fabienne

Titre du projet : Physical fatigue of People Living with HIV (PLHIV). A multidisciplinary study of its factors and its relations with physical activity

RESUME EN ANGLAIS

Précisez les objectifs, la situation du sujet, la problématique, les méthodes, l'échéancier des travaux et les résultats attendus. Utiliser la police Times corps 11, sans dépasser le cadre ci-dessous.

SITUATION. Although it is now scientifically established that physical activity (PA) is beneficial for the health of PLHIV (Hand et al., 2009; Malita et al., 2005; Mutimura et al., 2008), a large proportion of PLHIV are not sufficiently active according to the WHO recommendations (Thomas et al., 2012). A major reason for this is the feeling of fatigue, a predominant characteristic of PLHIV (Dulioust & Gasnault, 2009). However, the nature of this fatigue, whether in sociological, psychological or neuromuscular terms, as well as the practices and beliefs toward PA, has yet to be explored.

OBJECTIVES. This research project aims to characterize comprehensively and explicatively the physical fatigue of PLHIV. Three parts aim to study the (1) sociological, (2) psychological and (3) neuromuscular characteristics of the physical fatigue of PLHIV, and the relations between this fatigue and the representations, beliefs and practices concerning PA.

METHODS. The main question is broached through the approaches and methods from three disciplines.

- The sociological characteristics of fatigue for PLHIV and their relations with PA shall be studied through a multicentre qualitative study, composed of semi-structured interviews with PLHIV (n=40).
- The psychological characteristics of fatigue for PLHIV and their relations with PA shall be examined through a multicentre quantitative study. The latter consists of examining how practices and beliefs toward PA influence fatigue and physical self-perceptions through a national survey by psychometric questionnaires (n=500).
- The neuromuscular characteristics of physical fatigue of PLHIV and their relations to PA and perceived physical fatigue shall be examined through an interventional study based on a sample of participants from study 2 (n=75).

SCHEDULE. 1st year: Conduct of interviews and distribution of questionnaires; recruitment of participants for the neuromuscular study. 2nd year: Analysis of qualitative and quantitative human and social science data; completion and analysis of the neuromuscular study and its data. Publication of results.

EXPECTED RESULTS. We expect to observe causal relations between the social construction of fatigue, the social characteristics of PLHIV (e.g., age, gender, social class), and the representations/ beliefs and behaviors toward PA. In addition, we expect the neuromuscular fatigue of PLHIV to be positively correlated to their perceived fatigue and level of practice of PA. Globally, we expect that the results will open doors to communicational and interventional strategies aiming to reduce physical fatigue of PLHIV and to increase healthy behaviors.

Key words : Fatigue, Physical Activity, Health, HIV, multidisciplinarity
Bien que plusieurs études se soient intéressées aux corrélats entre la fatigue perçue et certains marqueurs biologiques, les diversifiés (Chaudhuri & Behan, 2004). La prise en charge des patients, tant son origine et les mécanismes responsables de son apparition sont particulièrement problématiques (Krupp et al., 1988; Lee et al., 1994), elle demeure un concept complexe et multidimensionnel dans la vie des PVVIH (Dulioust & Gasnault, 2009). En effet, chez les PVVIH, la fatigue est le symptôme le plus fréquemment rapporté avec des taux de prévalence variant de 37 à 69% (Lee et al., 2001; Sullivan & Dworkin, 2003; Phillips et al., 2004; Henderson et al., 2005). Nous nous intéressons à la « mauvaise fatigue » chez des PVVIH, à savoir un état subjectif d’épuisement qui ne peut être surmonté par le repos (Loriol, 2003). Dans la pratique clinique, la fatigue est généralement évaluée subjectivement et, est souvent décrite comme une plainte émanant du corps (e.g., fatigue perçue). Même si la fatigue peut également être définie comme un sentiment d’épuisement ou un manque d’énergie (Krupp et al., 1988; Lee et al., 1994), elle demeure un concept complexe et multidimensionnel dans la prise en charge des patients, tant son origine et les mécanismes responsables de son apparition sont particulièrement diversifiés (Chaudhuri & Behan, 2004).

Les personnes vivant avec le VIH (PVVIH) souffrent d’un vieillissement accéléré se traduisant notamment par un déconditionnement et une fatigue engendrant une limitation de motricité (Miller et al., 1995). La fatigue chronique (désignant un état de fatigue répété et récurrent ne disparaisant pas avec le repos) semble jouer un rôle de premier ordre dans la vie des PVVIH (Dulioust & Gasnault, 2009). En effet, chez les PVVIH, la fatigue est le symptôme le plus fréquemment rapporté avec des taux de prévalence variant de 37 à 69% (Lee et al., 2001; Sullivan & Dworkin, 2003; Phillips et al., 2004; Henderson et al., 2005). Nous nous intéressons à la « mauvaise fatigue » chez des PVVIH, à savoir un état subjectif d’épuisement qui ne peut être surmonté par le repos (Loriol, 2003). Dans la pratique clinique, la fatigue est généralement évaluée subjectivement et, est souvent décrite comme une plainte émanant du corps (e.g., fatigue perçue). Même si la fatigue peut également être définie comme un sentiment d’épuisement ou un manque d’énergie (Krupp et al., 1988; Lee et al., 1994), elle demeure un concept complexe et multidimensionnel problématique dans la prise en charge des patients, tant son origine et les mécanismes responsables de son apparition sont particulièrement diversifiés (Chaudhuri & Behan, 2004).

Bien que plusieurs études se soient intéressées aux corrélats entre la fatigue perçue et certains marqueurs biologiques, les résultats obtenus restent, à ce jour, extrêmement contradictoires. Par exemple, il a été rapporté que le niveau de fatigue perçue pouvait être lié à un faible taux de lymphocytes T CD4+ (Darko et al., 1992; Walker et al., 1997) alors que d’autres résultats obtenus restent, à ce jour, extrêmement contradictoires. Par exemple, il a été rapporté que le niveau de fatigue perçue pouvait être lié à un faible taux de lymphocytes T CD4+ (Darko et al., 1992; Walker et al., 1997) alors que d’autres résultats obtenus restent, à ce jour, extrêmement contradictoires.

2°) Situation actuelle du sujet dans le contexte international et références bibliographiques.

Les personnes vivant avec le VIH (PVVIH) souffrent d’un vieillissement accéléré se traduisant notamment par un déconditionnement et une fatigue engendrant une limitation de motricité (Miller et al., 1995). La fatigue chronique (désignant un état de fatigue répété et récurrent ne disparaisant pas avec le repos) semble jouer un rôle de premier ordre dans la vie des PVVIH (Dulioust & Gasnault, 2009). En effet, chez les PVVIH, la fatigue est le symptôme le plus fréquemment rapporté avec des taux de prévalence variant de 37 à 69% (Lee et al., 2001; Sullivan & Dworkin, 2003; Phillips et al., 2004; Henderson et al., 2005). Nous nous intéressons à la « mauvaise fatigue » chez des PVVIH, à savoir un état subjectif d’épuisement qui ne peut être surmonté par le repos (Loriol, 2003). Dans la pratique clinique, la fatigue est généralement évaluée subjectivement et, est souvent décrite comme une plainte émanant du corps (e.g., fatigue perçue). Même si la fatigue peut également être définie comme un sentiment d’épuisement ou un manque d’énergie (Krupp et al., 1988; Lee et al., 1994), elle demeure un concept complexe et multidimensionnel problématique dans la prise en charge des patients, tant son origine et les mécanismes responsables de son apparition sont particulièrement diversifiés (Chaudhuri & Behan, 2004).

En outre, plusieurs études se sont intéressées aux effets de la fatigue sur le plan physique (Voss et al., 2006) ou sur le plan social (Pierret, 2006). D’autres travaux ont examiné les manifestations de la fatigue selon les caractéristiques sociodémographiques des PVVIH (Bensing, 1999 ; Voss, 2005). Les études les plus récentes invitent à considérer conjointement les facteurs biologiques de la maladie, les effets secondaires des traitements, ainsi que les antécédents ou les conséquences psychosociales, dans une connaissance explicative intégrative de la fatigue (Barroso et al., 2010 ; LeSerman, 2008 ; Pence et al., 2008). Toutefois, l’exploration de ces pistes n’a pas encore permis de caractériser ou comprendre la fatigue chez les PVVIH. Une approche pluridisciplinaire – notamment en incluant les approches sociologique et neuromusculaire, à ce jour très peu développées autour de cet objet, apparaissent comme particulièrement pertinentes pour comprendre la fatigue chez les PVVIH. Par ailleurs, les relations entre la fatigue physique et l’activité physique chez les PVVIH restent également, à ce jour, inconnues.

En premier lieu, à notre connaissance aucun travail n’a traité les usages et représentations sociales de la fatigue chez les PVVIH. Or, ces interactions et dynamiques sociales ont probablement un poids important dans les facteurs de penser la fatigue, considérée comme étant en partie l’interaction physique qui structure la manière dont les interlocuteurs parlent de leur fatigue (Loriol, 2003). Les résultats d’une étude qualitative préliminaire portant sur le sport et le VIH suggèrent de plus que la fatigue soit associée à l’énergie, à la douleur, à la respiration ou encore aux traitements antirétroviraux (Ferez & Thomas, 2012). Il serait donc pertinent d’identifier les mécanismes et enjeux de la construction sociale de ces registres de la fatigue (e.g., les contextes et enjeux selon lesquels on souligne sa faiblesse ou sa fatigue, ou au contraire son énergie...
et ses capacités physiques; les effets de ces constructions de fatigue sur l’engagement dans des activités physiques) par différents groupes de PVVIH et dans des milieux de socialisation des PVVIH notamment associatifs.

En deuxième lieu, s’il est désormais bien établi dans la littérature scientifique qu’une AP régulière est globalement bénéfique pour les PVVIH, une forte proportion de ces personnes demeurent inactives physiquement (Thomas et al., 2012) et la fatigue apparaît comme un facteur explicatif important de ce manque d’activité. De nombreuses études ont montré les apports bénéfiques de l’activité physique (l’AP) dans l’amélioration de la qualité de vie des PVVIH, notamment de par ses conséquences favorables sur la santé physique, psychologique et sociale (Ciccolo et al., 2004; Dudgeon et al., 2004; Hand et al., 2009; Malita et al., 2005; Mutimura et al., 2008; O’Brien et al. 2004). Certains résultats de la littérature s’accordent sur le fait qu’une AP modérée améliore l’état de santé des PVVIH, fait tangible même au niveau des indicateurs physiologiques utilisés pour surveiller la progression du virus, comme le taux de lymphocytes T CD4+ (Ciccolo et al., 2004; Yarashekski et al., 2001). Ainsi, depuis la seconde moitié des années quatre-vingt-dix, on assiste à la diffusion d’une littérature qui encourage les PVVIH à une AP régulière et modérée (Ferez et al., 2010). Le but de ces prescriptions est de limiter les lourds effets secondaires de ces nouveaux traitements qui ont, entre autres, l’inconvénient d’accélérer le vieillissement de l’organisme.

La question qui se pose concerne les difficultés, voire les résistances des PVVIH à adopter un style de vie physiquement actif parfois encouragé par le corps médical. Différentes raisons semblent pouvoir expliquer cette non observance dans la PVVIH dans les activités physiques (Ferez & Thomas, 2012). D’autres raisons touchent la sphère des habitudes de vie, les contraintes sociales et économiques, mais aussi des barrières physiques ou psychologiques liées à des croyances négatives sur l’AP ou sur ses compétences physiques (« ne pas se sentir capable »; « penser que l’AP est incompatible avec les traitements ou présente des risques »). Les effets limitants de ces croyances pour adopter un style de vie actif ont été rapportés dans d’autres populations vulnérables telles que les seniors (Chalabaev et al., 2013) ou les patients atteints de cancer (Falzon et al., 2012) suggérant un véritable cercle vicieux du déconditionnement physique : « plus je pense que l’AP n’est pas pour moi, plus je me sens fatigué(e), moins je me sens capable d’en faire, et moins j’en fais et j’ai l’intention d’en faire ». Toutefois, les relations entre ces croyances, la fatigue physique et le niveau d’AP n’ont pas été étudiées à ce jour de manière intégrative et systémique. Une meilleure identification des facteurs psychosociaux de la fatigue perçue permettrait de mieux contrôler le cercle vicieux du déconditionnement physique chez les PVVIH.

Enfin, à notre connaissance, aucune étude ne s’est spécifiquement intéressée à la fatigue neuromusculaire chez les PVVIH. Dans les champs de la neurophysiologie et de la physiologie, la fatigue est souvent définie comme « la perte de force maximale suite à un exercice », et fait donc plutôt référence au modèle de la fatigue neuromusculaire (Bigland-Ritchie & Woods, 1984). Le modèle de la fatigue neuromusculaire a permis de caractériser la fatigue dans diverses pathologies (Schillings et al., 2007; Zwarts et al., 2008), mais jamais chez les PVVIH. Pourtant cette quantification et l’examen de ses relations avec la fatigue physique perçue et le niveau d’AP, revêtent un intérêt clinique important afin d’établir la gravité des effets physiques du symptôme, mais également d’être en mesure d’évaluer les effets des traitements proposés (Pawlikowska et al., 1994) avec l’objectif d’améliorer la qualité de vie des PVVIH.

3°) Activités antérieures de l’équipe en lien direct avec le projet et résultats préliminaires éventuels.

L’année 2012-2013 a été consacrée au renforcement de la faisabilité du projet, d’une part à travers l’établissement de collaborations autour de ce projet. D’autre part, la faisabilité a été éprouvée par des études-pilote.

Collaborations avec le milieu hospitalier

Le Laboratoire Motricité Humaine Education Sport Santé (LAMHESS, EA 6309) dispose d’une convention cadre avec le CHU de Nice et a établi des collaborations scientifiques avec certains services du CHU l’Archet. Parmi les membres du LAMHESS, figurent deux PU-PH (Pr C Pradier et Pr E Rosenthal) et un PH (Dr J Durant), qui travaillent respectivement dans les services de santé publique et de virologie-infectiologie du CHU l’Archet de Nice. Leur double appartenance garantit l’accessibilité aux patients, la possibilité de planifier le protocole et les prises de rendez-vous, et de bénéficier à l’hôpital l’Archet d’un espace dédié à la réalisation du programme de recherche. Le service virologie-infectiologie suit actuellement plus de 2645 PVVIH par an (2643 patients suivis en 2012, 13312 consultations, 3065 journées d’hospitalisation complète, 465 journées d’hospitalisation de jour), ce qui rend le protocole faisable en deux ans.

L’expertise de Pr. Christian Pradier, de Pr. Eric Rosenthal et de Dr Jacques Durant sera précieuse dans la faisabilité du projet à travers la facilitation du contact avec les patients du service virologique du CHU de Nice. De plus, ces médecins et chercheurs ont mené de nombreuses études chez les PVVIH. En outre, la demande d’approbation éthique auprès du Comité de Protection des Personnes nécessaire à la conduite de l’étude en volet 3 sera écrite et demandée sous la responsabilité du Pr Christian Pradier qui, en tant que responsable du département de santé publique du CHU de Nice, dispose de tous les atouts nécessaires pour assurer ces missions.

Ce projet de recherche a également obtenu le soutien de l’hôpital Bicêtre à Paris (service de médecine interne, dirigé par Pr. Goujard et en collaboration avec le Dr M. Duracinsky) ainsi que le soutien du CHU de Nîmes (Service des Maladies
Collaborations avec les associations
La prise de contact avec les PVVIH pour questionnaires et entretiens passe également par les associations spécialisées en l’accueil de PVVIH. Les associations participantes (cf. les lettres d’engagement, Annexe 4) constituent des associations petites et majeures, accueillant des personnes de profils divers selon l’association et ses activités (hommes et femmes d’orientation sexuelle et de classes sociales différentes) se situant autour de Montpellier, Nice et Paris :
- **Actif Santé** – association nationale de PVVIH avec des antennes d’activités à Montpellier et Paris, qui organise des randonnées pédestres.
- **AIDES** – association nationale qui mène des actions de prévention du VIH, et qui organise à Nice pour les PVVIH des journées portes ouvertes, des groupes de paroles hebdomadaires thématiques, et des activités physiques douces.
- **Fight AIDS Monaco** – association sous la présidence de la Princesse Stéphanie qui organise pour les PVVIH des journées portes ouvertes, des activités physiques douces et des weekends et séjours bien-être. La majorité des adhérents habitent à Nice.
- **D’Un Monde à l’Autre** - association montpelliéraine qui met en place des ateliers « mieux-être » pour des personnes atteintes de maladies chroniques, dont 70% sont des PVVIH.

Activités antérieures du responsable de projet
Le Pr. Fabienne d’Arripé-Longueville est professeure à l’Université de Nice et directrice adjointe du laboratoire LAMHESS. Ayant obtenu de nombreux financements (e.g., Ligue contre le Cancer, Agence Mondiale Antidopage, Ministère de la Santé et des Sports), Pr. d’Arripé-Longueville a une grande expertise dans la gestion de projets impliquant un budget et nombre de chercheurs importants. En termes de compétences scientifiques, Pr. d’Arripé-Longueville est une spécialiste reconnue de la psychologie de la santé notamment dans le domaine des comportements d’activité physique. Elle a réalisé de nombreuses études qualitatives à partir d’entretiens semi-directifs (e.g., d’Arripé-Longueville et al., 1998, 2001), ainsi que de nombreuses validations de questionnaires psychométriques (e.g., Scoffier et al., 2009, 2010, 2013).

Volet 1 – Études pilote (responsable Laura SCHUFT)


b) **Focus groups.** Des focus group ont été conduits dans la région de Nice, par trois chercheurs (dont A. Bergamaschi et L. Schuft), pendant des après-midis portes ouvertes de l’association Aides et de Fight Aids Monaco. A Fight Aids (21-2-2013), les thèmes de la fatigue et de l’AP ont été abordés en discussion de groupe. A Aides, la fatigue (28-2-2013) a été discutée par le biais de l’activité du blason où chaque participant mets trois idées sur la fatigue dans chacune des quatre catégories : « Ca provient de » ; « C’est diminué par » ; « Ca m’arrive quand » ; « Ca fait que ». Les idées sont discutées ultérieurement en groupe, qui crée un seul blason. Le thème de l’AP (27-3-2013) a été discuté par le biais d’un métaplan, où chacun écrit ses idées sur des Post-It en réponse à la question générale. L’animateur place les Post-It par thème sur le tableau à l’aide du groupe, provoquant la discussion. Les résultats de ces focus group suggèrent que la précarité et le manque de motivation sont considérés comme des sources privilégiées à la fois de la fatigue et des barrières à l’AP. Les relations entre précarité, attitudes ou croyances vis-à-vis de l’AP (relatives à la « motivation »), fatigue et pratique d’AP se profilent ainsi comme des éléments de nos hypothèses à poursuivre davantage.

c) **Le guide d’entretien.** Le guide d’entretien sociologique (Annexe 2) a été testé sur cinq PVVIH. Cette phase exploratoire a permis de mieux circonscrire la problématique et de raccourcir le guide de manière pertinente. Les résultats préliminaires suggèrent que l’expression de la fatigue est reliée aux rapports de genre (orientation sexuelle, sexe), par le biais de la volonté de rendre la séropositivité plus ou moins visible ou dissimulée selon les contextes et les enjeux sociaux (sur la gestion de la visibilité du VIH, voir Ferez & Thomas, 2012). Ces résultats confortent les résultats des observations ainsi que les hypothèses du projet.

d) **Analyse secondaire – projet Sidaction.** Une analyse secondaire des entretiens retranscrits issus de l’étude Sidaction 2010-2012 sur « Sport et VIH », porté par SANTESIH sous la responsabilité de Sylvain Ferez, a été conduite utilisant le logiciel N’Vivo 4 (ancienne version). Il s’agit d’analyser les manières par lesquelles la fatigue est...
Volet 1 – Etude pilote (responsable Fabienne d’ARRIPE-LONGUEVILLE) Questionnaires. Une étude-pilote a été conduite auprès de la population cible afin de tester les questionnaires psychométriques retenus dans le cadre de recherche. Cette étude a été réalisée sur 108 PVVIH (82 hommes et 26 femmes ; M= 50,51 ; ET= 11,47) de l’hôpital l’Archet de Nice. Les participants à l’étude étaient traités par la trithérapie et ont contracté la maladie dans les années 80’. Cette enquête a été évaluée à environ 30 minutes et a reçu un avis favorable du CCTIRS et une autorisation de la CNIL. Cette étude a permis de tester une version adaptée du Ageing Stereotypes Exercise Scale (ASES) de Chalabaev et al. (2013) aux PVVIH. Les qualités psychométriques de l’échelle se sont avérées satisfaisantes du point de vue de la structure factorielle et de la consistance interne des sous-échelles. De plus, cette enquête a montré que le niveau d’activité physique était relié négativement à la fatigue perçue, et que les croyances négatives sur l’activité physique étaient des prédicteurs négatifs de la qualité de vie, par le biais de la fatigue. Ces résultats préliminaires nous encouragent donc à tester les relations entre ces variables sur un effectif plus important.

Volet 2 – Etude pilote (responsable Serge S. COLSON) Le Pr. Colson est co-responsable de l’axe 1 du laboratoire LAMHESS dans lequel l’identification des mécanismes explicatifs de la fatigue neuromusculaire est un thème majeur. Le Pr. Colson a développé une expertise dans l’investigation de la fonction neuromusculaire et, a depuis plusieurs années des relations privilégiées avec le service de médecine physique et de réadaptation du CHU l’Archet dirigé par le Pr Desnuelle. Dans ce cadre, il a coordonné, réalisé et participé à différents projets permettant de caractériser la fatigue neuromusculaire chez des patients atteints de pathologies spécifiques.

H1. Une première hypothèse avance que les positionnements sociaux structurels des PVVIH, et les catégories sociales qui s’y créent – dont le genre, la classe sociale, l’ethnicité, le statut socioéconomique ou l’orientation sexuelle – sont des déterminants du rapport au corps, de la perception de fatigue et de l’engagement dans des activités physiques (Ferez & Thomas, 2012 ; Ministère des sports, 2003). Il a été observé par exemple que les femmes en situation de précarité se déconditionnent de la fatigue perçue et que (b) la fatigue perçue est reliée à la fatigue neuromusculaire.

H2. Une deuxième hypothèse avance que le niveau d’AP et les croyances négatives sur l’activité physique influencent la fatigue perçue qui elle-même influence les perceptions de compétence physique et l’intention de s’engager dans une activité régulière (Chalabaev et al., 2013 ; Falzon et al., 2012 ; Schwarzer et al., 2011).

H3. Enfin, les caractéristiques neuromusculaires chez les PVVIH n’ayant jamais fait l’objet d’étude, la réalité physiologique de la fatigue perçue demeure totalement inconnue, ainsi que ses relations avec le niveau d’activité physique. Nous avançons l’hypothèse que (a) la fatigue neuromusculaire des PVVIH est reliée à leur niveau d’activité physique, et que (b) la fatigue perçue est reliée à la fatigue neuromusculaire.

Volet 3. Activités antérieurs de l’équipe en lien direct avec le projet (Responsable Serge S. COLSON) Le Pr. Colson est co-responsable de l’axe 1 du laboratoire LAMHESS dans lequel l’identification des mécanismes explicatifs de la fatigue neuromusculaire est un thème majeur. Le Pr. Colson a développé une expertise dans l’investigation de la fonction neuromusculaire et, a depuis plusieurs années des relations privilégiées avec le service de médecine physique et de réadaptation du CHU l’Archet dirigé par le Pr Desnuelle. Dans ce cadre, il a coordonné, réalisé et participé à différents projets permettant de caractériser la fatigue neuromusculaire chez des patients atteints de pathologies spécifiques.

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5° Exposé détaillé du programme de recherche et des méthodologies utilisées.

RATIONNEL. S’il est désormais bien établi dans la littérature scientifique qu’une activité physique (AP) est globalement bénéfique à la santé des PVVIH (Hand et al., 2009 ; Malita et al., 2005 ; Mutimura et al., 2008), une forte proportion de ces personnes sont insuffisamment actives physiquement selon les recommandations de l’OMS (Thomas et al., 2012). Une raison importante de ce manque de participation aux activités physiques chez les PVVIH est la sensation de fatigue, caractéristique prédominante chez cette population (Dulioust & Gasnault, 2009). Toutefois, il reste à explorer les
caractéristiques de cette fatigue aux niveaux sociologique, psychologique et neuromusculaire, ainsi que le rôle des pratiques et des croyances des PVVIH à l’égard de l’AP.

**OBJECTIFS.** Ce projet vise à expliquer le cercle vicieux du déconditionnement physique chez les PVVIH en examinant la fatigue physique chez les PVVIH de manière compréhensive et explicative, et en étudiant ses relations avec l’activité physique (i.e., croyances, niveau et forme de pratique). Trois volets d’étude étudieront les caractéristiques (1) sociologiques, (2) psychologiques et (3) neuromusculaires de la fatigue physique chez les PVVIH, et les relations entre cette fatigue et l’AP.

1. **Le 1er volet de recherche vise à étudier qualitativement la construction sociale de la fatigue et ses relations avec l’AP selon les caractéristiques sociales des PVVIH (e.g. sexe, âge, classe sociale). Il vise à explorer dans quelle mesure la fatigue physique perçue des PVVIH se construit socialement en relation avec : (a) le niveau d’AP dans les modes de vie, (b) les représentations sur son corps et ses capacités à pratiquer une AP (Perera et al., 2012), (c) d’autres registres discursifs de la maladie (e.g., énergie, douleur, respiration ; Ferez & Thomas, 2012), et (d) les conditions socioéconomiques et les caractéristiques sociales revendiquées ou attribuées (e.g., sexe, âge, statuts socioéconomiques, orientation sexuelle, ethnicité ; Thomas et al., 2012).

2. **Le 2e volet a pour objet de tester un modèle hypothétique basé sur les résultats du volet 1 d’une part et de la littérature d’autre part (e.g., Schwarzer et al., 2011). Il s’agira d’examiner les relations entre le niveau hebdomadaire d’AP, les croyances de l’AP et le niveau de fatigue physique. Il s’agira par exemple de vérifier si la fatigue perçue et les perceptions du soi physique sont des médiateurs de la relation entre les croyances de l’AP.

3. **Le 3e volet a pour objet d’étudier les caractéristiques neuromusculaires de la fatigue chez les PVVIH selon le niveau d’AP, et leurs relations avec la fatigue physique perçue.

**METHODES.** Ce projet adopte des approches méthodologiques issues de la sociologie, la psychologie et la physiologie.

**METHODOLOGIE - VOLET 1 : Construction sociale de la fatigue chez les PVVIH, et relations avec L’AP**

**Type d’étude**
Cette étude qualitative et multicentrique repose sur des entretiens semi-directifs.

**Lieux de l’étude**
Les personnes à interviewer seront recrutées au sein des Centres Hospitaliers Universitaires et associations participant au projet. Ceux-ci se situent dans trois régions de la France et ainsi prennent en charge une diversité de PVVIH en termes de sexe, d’orientation sexuelle, d’origine et de classe sociale.

**Les centres hospitaliers participants :**
- CHU Nîmes. Service des Maladies Infectieuses et Tropicales (SMIT), dirigé par le Pr. Albert Sotto.
- L’Hôpital Bicêtre, Paris. Service de médecine interne, dirigé par le Pr. Goujard et en collaboration avec le Dr Duracinsky.

**Les associations participantes :**
- AIDES – Nice, Paris. Association nationale qui mène des actions de prévention du VIH, et qui organise à Nice pour les PVVIH des journées portes ouvertes, des groupes de paroles hebdomadaires autour d’un thème, et des activités physiques douces.
- Fight AIDS Monaco. Structure sous la présidence de la Princesse Stéphanie qui organise pour les PVVIH des journées portes ouvertes, des activités physiques douces et des weekends et séjours bien-être. La majorité des adhérents habitent à Nice.
- D’un Monde à l’Autre. Association montpelliéraine qui met en place des ateliers « mieux-être » pour des personnes atteintes de maladies chroniques, dont 70% sont des PVVIH.

Les entretiens seront conduits dans un espace calme et privé, e.g., dans une salle privée des structures de recrutement ou chez l’interviewé. Il s’agit de respecter la nature anonyme et personnelle des propos, et de prendre en compte les possibilités des structures d’accueil, des chercheurs et des PVVIH volontaires.

**Sélection des sujets pour entretien et durée de la participation**
Les PVVIH (n=40) seront sollicitées sur la base du volontariat à travers : la présence des chercheurs dans les associations ; les listings e-mail des associations ; la présence des chercheurs dans les services virologie des CHU pour la distribution des questionnaires ; et la notice d’information fournie (Annexe 1) par les médecins participants au sein des services de virologie des hôpitaux. En effet, une notice d’information sera fournie systématiquement aux PVVIH par les médecins participants, afin de présenter brièvement le projet et demander, en cas de consentement éclairé, les coordonnées de contact. Il s’agit d’interviewer la plus grande diversité de PVVIH en termes d’âge, de sexe, de catégorie socioprofessionnelle, d’orientation sexuelle et d’origine ethnique.
Les entretiens dureront chacun plus d’une heure, afin de dépasser le stade de discours visant à répondre aux attentes du chercheur et à libérer la parole dans une atmosphère de confiance, ainsi obtenant des résultats significatifs (Beaud & Weber, 1998). La durée des entretiens sera cependant modulée en fonction de la forme physique et des souhaits des PVVIH, l’entretien pouvant être conduit dans plusieurs sessions (cf. la notice d’information, Annexe 1).

**La récolte et l’analyse des données**

Une approche majoritairement inductive des entretiens semi-directifs permettra d’analyser les véritables enjeux de la fatigue et de l’AP, qui peuvent dépasser ceux formulés par les hypothèses. Les questions d’entretien sont conçues en fonction : (a) de nos hypothèses, elles-mêmes formulées sur la base de la littérature existante, (b) des activités de recherche renforçant la faisabilité du projet et orientant les hypothèses (cf. études-pilotes plus loin), et (c) d’un traitement secondaire des données issues des entretiens conduits dans le cadre du projet Sidaction (2009-2012) sur l’accès des PVVIH aux activités physiques et sportives (Ferez & Thomas, 2012). Ce projet a en effet permis de réaliser 50 entretiens autobiographiques sur l’évolution des trajectoires d’activités physiques et sportives suite au diagnostic. La question de la fatigue y a largement émergé.

Le guide d’entretien (Annexe 2) issu de ce travail au préalable aborde la fatigue par trois entrées : (a) la place de la fatigue, identifiée librement, dans la vie quotidienne des PVVIH ; (b) les relations potentielles entre fatigue et activité physique ; (c) les perceptions de la fatigue, ses sources et ses conséquences.


**Calendrier et implication de chaque personne dans la recherche**

**2014.** La première année de recherche sera consacrée au recrutement des participants (n=40) pour entretiens dans les hôpitaux et associations, et la conduite des entretiens. Ceci sera accompli par les sociologues dans 3 régions de France : (a) par Laura Schuft et l’Ingénieur de Recherche (IR) dans les régions de Nice et de Paris (coordination des entretiens à Paris sur 4 semaines ponctuelles de déplacement, cf. Budget) ; et (b) Sylvain Ferez et Estelle Duval, avec l’appui de l’étudiant stagiaire niveau M2 dans la région autour de Montpellier et Nîmes.

A la fin de cette année et débouchant sur la première moitié de 2015, tous les enregistrements d’entretien seront envoyés par le LAMHESS à un service spécialisé pour retranscription.

**2015.** La deuxième année de recherche sera consacrée à l’analyse des données d’entretien avec le logiciel *N’Vivo 10* par cette même équipe sociologique.

**METHODOLOGIE - VOLET 2 : Relations entre les croyances et les comportements à l’égard de l’AP chez les PVVIH : rôle médiateur de la fatigue perçue**

**Type d’étude**

Étude quantitative menée au moyen d’une enquête nationale par questionnaires psychométriques valides, faisant l’objet d’une analyse par modélisation d’équations structurelles. Investigation multicentrique sans bénéfices directs pour les sujets.

**Lieux de l’étude**

Le recueil des données aura lieu d’une part par questionnaires en version papier au sein des hôpitaux et associations listés ci-dessus à Nice, Montpellier/ Nîmes et Paris ; d’autre part par questionnaires en version électronique en ligne grâce aux listings e-mail du réseau associatif au travers d’un serveur sécurisé.

** Sélection des sujets (échantillonnage)**

En suivant les effectifs recommandés dans la littérature sur l’emploi des équations structurelles au regard du nombre de variables mesurées (El Akremi, Roussel, 1998 ; MacKinnon *et al.*, 2002), un minimum de 500 sujets volontaires seront sélectionnés pour participer à l’enquête. Ils seront recrutés au sein des services hospitaliers et associations précités, avec la possibilité de remplir un questionnaire en papier (lorsque le chercheur est présent) ou en ligne (notamment lorsque les PVVIH sont contactées par listing e-mail). Il s’agira de tirer au sort les sujets participants parmi le nombre total de volontaires, « afin de constituer un échantillon qui fournisse le reflét le plus fidèle possible de la population séropositive suivie à l’hôpital et sur le territoire » (ANRS, 2004 : 2). Le questionnaire (Annexe 3) comprendra des items permettant de retenir au moins 500 PVVIH répondant aux critères d’inclusion et d’exclusion retenus dans le volet 3 :
Critères d’inclusion : Seront incluses 500 PVVIH, âgées de 18 à 60 ans, diagnostiquées et traitées par antiviraux après 1996, indépendamment de la valeur de la charge virale et du niveau des lymphocytes CD4 au dernier bilan.

Critères d’exclusion : Seront exclues les personnes ayant interrompu leur traitement antirétroviral et /ou leur suivi médical récemment et qui présentent une reprise évolutive de leur infection, et les personnes touchées par d’autres conditions sanitaires marquées par la fatigue. Compte tenu d’une fatigue plus fréquente constatée chez les personnes co-infectées VHC ou VHB, ces dernières seront exclues de l’étude. En outre, en suivant les conseils de Harmon et al. (2008) dans leurs travaux sur la fatigue chez les PVVIH, seront également exclues les personnes ayant une comorbidité associée marquée par la fatigue (maladie rénale, cancer, sclérose en plaque) et les femmes enceintes ou ayant accouché dans les douze mois précédents.

La recolte des donnees
La passation de l’enquête par questionnaires psychométriques en langue française (cf. Annexe 3) demandera environ 30 minutes. Après avoir présenté aux participants l’objet de l’étude et obtenu leur formulaire de consentement, ils seront invités à compléter une enquête mesurant respectivement :

- la fatigue perçue : sous-échelle Fatigue physique de la Fatigue Impact Scale (FIS) (Fisk et al., 1994) traduite en langue française par Marcellin et al. (2007, 2010) ;
- les croyances sur l’AP : échelle adaptée à la population VIH du Ageing Stereotypes Exercise Scale (ASES) de Chalabaev et al. (2013) ; cette échelle comporte 3 sous échelles mesurant respectivement (a) les bénéfices perçus de l’AP ; (b) les risques perçus de l’AP ; (c) les croyances sur les effets secondaires des traitements sur l’AP ;
- les perceptions d’efficacité personnelle : échelle d’auto-efficacité vis-à-vis de l’exercice physique (adaptée de Schwarzer 2008 ; Schwarzer et al., 2011) et de la motivation pour la pratique (adaptée de Lippke et al., 2010) ;
- le niveau rapporté d’activité physique : échelle du Score d’Activité Physique (SAP) de Robert et al. (2004) ;
- le stade de changement de comportement vis-à-vis de l’AP : échelle adaptée de Prochaska et al. (1992) ;
- des variables sociodémographiques et médicales : âge, sexe, catégories socioprofessionnelles, appartenances géographiques.

Calendrier et implication de chaque personne dans la recherche
2015. La deuxième année sera consacrée à l’analyse et au traitement des données quantitatives, dont la modélisation par équations structurelles, par cette même équipe.

METHODOLOGIE - VOLET 3. Caractéristiques neuromusculaires de la fatigue physique chez les PVVIH, et relations avec le niveau d’AP et la fatigue perçue

Type d’étude
Etude interventionnelle, prospective sans bénéfices individuels pour le patient.

Lieux de l’étude
L’étude sera conduite dans l’unité de Virologie Clinique dirigée par le Dr Jacques Durant dans le service d’Infectiologie, en relation avec le Département de Santé Publique (DSP) du Centre Hospitalier Universitaire l’Archet 1 de Nice, dirigé par le Pr. Christian Pradier, et avec le service de médecine physique et de réadaptation dirigé par le Pr Desnuelle, du fait de la localisation de certains matériels d’évaluation.

Sélection des sujets et durée de participation
La sélection des sujets se fera par tirage au sort parmi les PVVIH volontaires, qui seront informées du projet notamment par les médecins praticiens du CHU en consultation (cf. lettre type en Annexe 1). Chaque participant sera mobilisé sur :
(a) une première session d’information et de recueil de données psychométriques de 30 min ; (b) une deuxième session expérimentale de 60 min correspondant à l’investigation neuromusculaire.

Critères d’inclusion : En suivant les effectifs recommandés dans la littérature pour les analyses en régression multiple, pour trois prédicteurs et une taille d’effet égale à .20 (p < .05), un minimum de 75 sujets seront nécessaires. Seront incluses 100 PVVIH volontaires, âgées de 18 à 60 ans, diagnostiquées et traitées par antiviraux après 1996, indépendamment de la valeur de la charge virale et du niveau des lymphocytes CD4 au dernier bilan.

Critères d’exclusion : Seront exclues les personnes ayant interrompu leur traitement antirétroviral et /ou leur suivi médical récemment et qui présentent une reprise évolutive de leur infection, et les personnes touchées par d’autres conditions sanitaires marquées par la fatigue. Compte tenu d’une fatigue plus fréquente constatée chez les personnes co-infectées VHC ou VHB, ces dernières seront exclues de l’étude. En outre, en suivant les conseils de Harmon et al. (2008) dans
leurs travaux sur la fatigue chez les PVVIH, seront également exclues les personnes ayant une comorbidité associée marquée par la fatigue (maladie rénale, cancer, sclérose en plaque) et les femmes enceintes ou ayant accouché dans les douze mois précédents.

Recueil et traitement des données générales

Les données seront informatisées sur une base de données spécialement dédiée pour cette étude, réalisée avec le logiciel Excel®. Cette base de données sera réalisée par un ARC en concertation avec l’investigateur principal. La base sera sous la responsabilité de l’investigateur principal. Un contrôle de qualité des données sera organisé sur les cahiers d’observation et sur la base de données informatique. Le traitement des données sera réalisé par le DSP et le Laboratoire Motricité Humaine, Education, Sport, Santé (LAMHESS) en liaison avec l’investigateur principal. Une convention cadre a été signée entre le CHU de Nice et ce laboratoire de recherche.


Un contrôle de qualité des données sera organisé sur les cahiers d’observation et réalisé par le DRCI du CHU de Nice.

Rationnel méthodologique. L’électromyographie de surface (EMGs) permet de caractériser la fonction musculaire et plus particulièrement les stratégies d’activation neuromusculaire sans donner la possibilité de quantifier le niveau d’activation musculaire (i.e. la proportion d’unités motrices activées). Afin d’estimer ce niveau d’activation, la technique de « twitch interpolation » est classiquement utilisée dans la littérature. L’originalité de la technique de « twitch interpolation » réside dans le fait que le niveau d’activation est estimé à partir de la valeur du moment musculaire. Cette technique, repose sur l’application au niveau du nerf moteur d’une stimulation électrique interpolée au cours d’une contraction volontaire (Merton, 1954). Si l’ensemble des fibres musculaires est recruté de façon maximale, la stimulation exogène n’entraîne pas de réponse mécanique additionnelle. Ainsi, l’absence de réponse mécanique serait le synonyme d’un niveau d’activation maximal de l’ensemble des UMs du groupe musculaire testé. A l’inverse, un éventuel incrément du moment serait la preuve d’un recrutement incomplet des UMs et/ou d’une fréquence de décharge de ces unités motrices sous-maximale. Cette technique a donc été très souvent utilisée pour estimer le niveau d’activation lors de contractions maximales et sous-maximales volontaires de différents groupes musculaires chez des sujets sains et pourrait être un outil très intéressant pour caractériser la fonction neuromusculaire en milieu clinique (Millet et al., 2011). Dans ce contexte, certaines études ont pu caractériser la fatigue neuromusculaire dans les maladies neuromusculaires et mettre en relation cette fatigue physiologique avec la fatigue perçue (Schillings et al., 2007). Ce type de modèle sera donc utilisé dans le présent projet afin d’identifier et caractériser la fatigue neuromusculaire les PVVIH.

Mesures neuromusculaires. Avant chaque séquence de tests neuromusculaires, les sujets seront préparés de la façon suivante : 1) préparation du sujet au recueil des signaux électromyographiques de surface (EMGs) ; 2) pose des électrodes EMGs sur les muscles rectus femoris, vastii medialis et lateralis de la cuisse droite ; 3) détermination des réponses électrophysiologiques maximales Mmax des différents muscles ainsi que de la réponse mécanique associée d’extension du genou à partir de neurostimulation électrique percutanée délivrée au repos.

Séquence de tests neuromusculaires

- Un échauffement standardisé sur ergocycle (Monark, 818E, Varberg, Suède) : 5 min de pédalage à 2 watts.kg⁻¹ avec une fréquence de pédalage de 70 rpm.
- Mesures de moment musculaire volontaire et évoqué par neurostimulation:
  - Trois stimulations doubles d’intensité maximale délivrées au repos toutes les 5s.
  - Deux contractions maximales volontaires isométriques (MVC) d’une durée de 5s séparées par 90s de repos. Pendant la réalisation de cet effort maximal, l’articulation du genou est fixée à un angle de 60° (0° correspondant à l’extension de la jambe). Afin de mesurer le niveau d’activation maximal et la potentialisation post-contraction, une stimulation double est délivrée avant, pendant et après la contraction maximale volontaire.
  - Après 10 min de repos, un test de fatigabilité selon le modèle utilisé par Schillings et al. (2007). Lors de ce test, les sujets doivent maintenir une MVC pendant 2 min au cours de laquelle seront délivrées des stimulations doubles toutes les 15 s.
  - Immédiatement après le test de fatigabilité, sans relâcher la contraction, les participants devront réaliser une MVC d’une durée de 5s avec une stimulation double délivrée pendant et après la contraction.
  - Enfin, trois stimulations doubles d’intensité maximale délivrées au repos toutes les 5s.

Recueil de la force musculaire. Afin de déterminer la capacité de production de force musculaire volontaire maximale, les sujets effectueront des actions isométriques d’extension du genou du membre inférieur droit sur un ergomètre.
Receuil des signaux EMGs. Lors de la production de force musculaire volontaire maximale d'extension du genou, un enregistrement concomitant de l’activité électrique des muscles rectus femoris (RF), vastus medialis (VM) et vastus lateralis (VL) sera réalisé. La détection est obtenue par dérivation bipolaire à l’aide d’électrodes de surface auto-adhésives d’un diamètre de 10 mm (Contrôle Graphique Médical®, Brie-Comte-Robert, France). La distance entre les électrodes (centre à centre) est de 2 cm. Ces électrodes contiennent une solution électrolytique en chlorure d’argent (Ag-AgCl) et sont fixées sur la peau qui a été préalablement préparée par un rasage des poils éventuels, un gommage grâce à du papier abrasif et un dégraissage à l’aide d’un mélange alcool-éther afin de diminuer la résistance inter-électrodes (Z<5 KΩ). La localisation de la position des électrodes s’effectue dans l’axe longitudinal du muscle à équidistance de la surface du point moteur (ventre musculaire) et de la partie distale du muscle, en accord avec les recommandations de la SENIAM (Surface Electromyography for the Non-invasive Assessment of Muscles). Une électrode de référence est placée sur la patella du membre homolatéral. Des câbles blindés assurent la liaison entre les électrodes et le système d’amplification et d’acquisition des signaux EMG (MP 100 Biopac® Systems, Inc., Holliston, MA, USA). Les signaux EMG obtenus peuvent être amplifiés et filtrés avec une bande de fréquence de 1Hz à 5kHz (CMRR=110db, Z entrée= 1000 MΩ, gain=1000) et à une fréquence d’échantillonnage de 2000 Hz. Les enregistrements des signaux EMGs seront stockés sur disque dur via un PC portable et traités ultérieurement. Enfin, un câble reliant l’ergomètre avec la chaîne électrophysiologique (EMG), permet de synchroniser les signaux électrophysiologiques et mécaniques.

6° Échéancier de la recherche, résultats et retombées attendus.

Calendrier des travaux

| Janvier 2014 – Janvier 2015 : | - Achat du matériel ; Recrutement des étudiants stagiaires M2 et IR  
- Déplacements de 2 chercheurs entre Montpellier et Nice pour une réunion de démarrage du projet abordant notamment la mise en place du volet qualitatif.  
- **Volet 1.** Recrutement des participants pour entretien dans les hôpitaux et associations ; réalisation des entretiens (n=40) dans les trois régions (Nice, Montpellier/ Nîmes, Paris)  
- **Volet 2.** Passation des 500 questionnaires psychométriques auprès des PVVIH (Nice, Nîmes, Paris – via les réseaux associatifs et hôpitaux et les listings e-mail)  
- **Volet 3.** Recrutement des PVVIH dans le CHU de Nice ; début du recueil des données neuromusculaires  
- Rapport d’étape ANRS (fin d’année) |

|  | Recueil des données  
(volets 1, 2) ;  
Recrutement des sujets  
(volet 3)  
-Janvier 2015–  
Janvier 2016  |

| Analyse des données ;  
Diffusion des résultats  
Janvier 2015-  
Janvier 2016 | - **Volet 1.** Retranscription intégrale des entretiens. Analyse des données qualitatives  
- **Volet 2.** Analyse et traitement des données quantitatives.  
- **Volet 3.** Fin de du recueil des données neuromusculaires et analyse des données  
- Rédaction du rapport d’activité final à l’ANRS (fin 2015)  
- Valorisation des résultats auprès des partenaires hospitaliers, associatifs et universitaires à travers un colloque de fin de programme de recherche (fin 2015)  
- Diffusion scientifique des résultats (congrès, articles) (fin 2015 - 2017) |

Résultats et retombées attendus

Volet 1. Nous basant sur des résultats préliminaires des études au préalable (cf. études-pilote), nous nous attendons à observer des liens entre : l’expression de la fatigue, les représentations et comportements à l’égard de l’activité physique, les perceptions de soi en tant que PVVIH/ « malade », et les caractéristiques sociales des PVVIH.

Volet 2. Nous nous attendons que le niveau d’AP et les croyances négatives sur l’activité physique influencent la fatigue perçue qui elle-même influence les perceptions de compétence physique et l’intention de s’engager dans une activité régulière (Chalabaev et al., 2013; Falzon et al., 2012 ; Schwarzer et al., 2011).

Volet 3. Nous nous attendons à ce que la fatigue physique neuromusculaire chez les PVVIH soit reliée positivement à la fatigue perçue et au niveau d’activité physique des PVVIH.

Globalement, en permettant de mieux connaître les facteurs et caractéristiques tant sociologiques que psychologiques et neuromusculaires de la fatigue perçue souvent mesurée par questionnaire (Barroso et al. 2003, 2010, etc.), les résultats devraient ouvrir des pistes interventionnelles auprès des PVVIH visant à diminuer la fatigue et à améliorer les comportements de santé.
ANRS (Agence nationale de recherches sur le sida et les hépatites virales) (2004). Enquête ANRS-VESPA, Premiers résultats, 1-12,


Présentation détaillée du projet de recherche (suite)

LISTE DES PUBLICATIONS* ET DES BREVETS DE CHAQUE EQUIPE PARTICIPANTE – LAMHESS*

* Participants au projet en gras


**LISTE DES PUBLICATIONS* ET DES BREVETS ANTERIEURS DE CHAQUE EQUIPE PARTICIPANTE – SANTESIH**

* Participants au projet en gras

1. **Publications les plus significatives des quatre dernières années (10 maximum) : Différenciations et appartenance sociales**


2. **Publications consacrées au sujet (10 maximum) : VIH**

# 3/ Description de l’équipe de recherche

## Liste des personnes participant à la recherche


<table>
<thead>
<tr>
<th>Nom et prénom (lister les noms et prénoms des personnes pour chaque laboratoire)</th>
<th>Qualification (DR, CR, IE…) et organisme</th>
<th>Signature</th>
<th>Temps consacré au projet en %</th>
<th>Évaluation du coût du personnel en Euros toutes charges de personnel incluses* sur 1 an en fonction du temps consacré au projet</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>LABORATOIRE A : LAMHESS</strong> Personnels impliqués dans le projet, hors financement ANRS</td>
<td>- Professeure (PU), Université de Nice Sophia Antipolis (UNS)</td>
<td>25%</td>
<td>23 334</td>
<td></td>
</tr>
<tr>
<td>- ARRIPÉ-LONGUEVILLE (d’) Fabienne</td>
<td>- Dr, Maître de conférences (MCF) contractuel, UNS</td>
<td>10%</td>
<td>7 411</td>
<td></td>
</tr>
<tr>
<td>- BERGAMASCHI Alessandro</td>
<td>- MCF, Habilité à Diriger des Recherches (HDR), UNS</td>
<td>10%</td>
<td>7 411</td>
<td></td>
</tr>
<tr>
<td>- BLAIN Grégory</td>
<td>- MCF, UNS</td>
<td>5%</td>
<td>3 706</td>
<td></td>
</tr>
<tr>
<td>- CLEMENT-GUILLOTIN Corentin</td>
<td>- PU, UNS</td>
<td>20%</td>
<td>18 668</td>
<td></td>
</tr>
<tr>
<td>- COLSON Serge</td>
<td>- Praticien Hospitalier (PH), CHU Nice</td>
<td>10%</td>
<td>8 894</td>
<td></td>
</tr>
<tr>
<td>- DURANT Jacques</td>
<td>- PH, PU, CHU Nice</td>
<td>10%</td>
<td>11 108</td>
<td></td>
</tr>
<tr>
<td>- PRADIER Christian</td>
<td>- PH, PU, CHU Nice</td>
<td>10%</td>
<td>11 108</td>
<td></td>
</tr>
<tr>
<td>- ROSENTHAL Eric</td>
<td>- MCF, UNS</td>
<td>20%</td>
<td>14 822</td>
<td></td>
</tr>
<tr>
<td>- SCHUFT Laura</td>
<td>- MCF, UNS</td>
<td>20%</td>
<td>14 822</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>9 chercheurs</strong></td>
<td></td>
<td></td>
<td><strong>102 756</strong></td>
</tr>
</tbody>
</table>

Personnels sur financement ANRS (en cours ou demandé dans le cadre du projet)
- **vacations** (qualification et durée) : 0
- **1 Ingénieur de Recherche SHS**
- **2 étudiants stagiaires M2 (5 mois)**

*Contactez vos organismes gestionnaires afin de connaître les salaires et charges en vigueur.*

*Les vacations sont strictement réservées à la rémunération de personnes effectuant un travail temporaire ou partiel dans la limite de 900 h.*
### Total vacations ANRS
- Allocation(s) de recherche ANRS associée(s)\(^2\):
  (MEC, MEB, pré-doc, post-doc,...)

<table>
<thead>
<tr>
<th>Total vacations ANRS</th>
<th>3 personnes</th>
<th>77 005</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>LABORATOIRE B : SANTESIH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Personnels impliqués dans le projet, hors financement ANRS</td>
</tr>
<tr>
<td>DUVAL Estelle</td>
</tr>
<tr>
<td>Doctorante, IE, Univ. Montpellier 1</td>
</tr>
<tr>
<td>FEREZ Sylvain</td>
</tr>
<tr>
<td>MCF, Univ. Montpellier 1</td>
</tr>
</tbody>
</table>

**Total** 2 chercheurs 16 949

Personnels sur financement ANRS (en cours ou demandé dans le cadre du projet)
- vacations\(^1\) (qualification et durée) : 0
- 2 étudiants stagiaires M2 (5 mois)

<table>
<thead>
<tr>
<th>Total vacations ANRS</th>
<th>2 personnes</th>
<th>4 360</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0</td>
<td>0</td>
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</tbody>
</table>

Les montants doivent être indiqués charges patronales et salariales incluses. Les allocations de recherche et les postes de MEC (moniteur d’études cliniques), de MEB (moniteur d’études biologiques) et de MESS (moniteur d’études en sciences sociales) doivent faire l’objet d’une demande séparée et sont inscrits ici pour évaluation du coût global du projet.
## RECAPITULATIF DES PROJETS ANRS EN COURS ET NOUVELLES DEMANDES

<table>
<thead>
<tr>
<th>Nom et prénom</th>
<th>Titre du projet</th>
<th>En cours de financement oui/non</th>
<th>Déposé dans le cadre du présent appel d’offres oui/non</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Laboratoire A : LAMHESS</strong></td>
<td>La fatigue physique chez les Personnes Vivant avec le VIH (PVVIIH). Etude pluridisciplinaire de ses facteurs et de ses relations avec l’activité physique</td>
<td>NON</td>
<td>OUI</td>
</tr>
<tr>
<td>Fabienne</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>BLAIN Grégory</td>
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<td>CLEMENT-GUILLOTIN Corentin</td>
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<tr>
<td>COLSON Serge</td>
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<tr>
<td>PRADIER Christian</td>
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<td>ROSENTHAL Eric</td>
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<tr>
<td>SCHUFT Laura</td>
<td></td>
<td></td>
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<tr>
<td><strong>Laboratoire B : SANTESIH</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>DUVAL Estele</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>FEREZ Sylvain</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

_A photocopier si nécessaire, en poursuivant pour chaque laboratoire l’indexation alphabétique_
4/ BUDGET PREVISIONNEL

Remplir impérativement une fiche par laboratoire

LABORATOIRE A : LAMHESS

Nom du responsable : D'ARRIPE-LONGUEVILLE Fabienne .... Organisme gestionnaire : Université de Nice Sophia Antipolis

<table>
<thead>
<tr>
<th>Postes de dépenses</th>
<th>Coût total du projet (en euros)</th>
<th>Subvention demandée à l’ANRS (en euros)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERSONNELS²</td>
<td>Année 1</td>
<td>Année 2</td>
</tr>
<tr>
<td>Personnels impliqués dans le projet, hors financement ANRS</td>
<td>102 756</td>
<td>102 756</td>
</tr>
<tr>
<td>Allocations de recherche ANRS associées² (MEC, MEB, pré-doc, post-doc,...)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Personnels temporaires ANRS (« vacations »)⁴</td>
<td>2 180</td>
<td>2 180</td>
</tr>
</tbody>
</table>
| - 2 Etudiants stagiaires niveau Master2 Réathlétisation 5 mois = 436 € x 5 mois x 2 étudiants  
- 1 CDD Ingénieur de recherche SHS sur l’année scolaire (09/2014-08/2015) = 72 645 € brut / année | 18 161 | 54 484 | 72 645 | 18 161 | 54 484 | 72 645 |
| Total Personnel (P) | 123 097 | 159 420 | 282 517 | 20 341 | 56 664 | 77 005 |

<table>
<thead>
<tr>
<th>EQUIPEMENT</th>
<th>Année 1</th>
<th>Année 2</th>
<th>Total</th>
<th>Année 1</th>
<th>Année 2</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Détail des équipements⁵</td>
<td></td>
<td></td>
<td>3612</td>
<td>0</td>
<td>3612</td>
<td>3612</td>
</tr>
</tbody>
</table>
| équipements d’un coût unitaire supérieur à 1.600 € HT et inférieur ou égal à 16.000 €  
- Neurostimulateur percutané* = 3612 € HT  
- Système de recueil de signaux électromyographiques 3 voies* = 9212 € HT  
* Devis en Annexe 5 | | | 9212 | 0 | 9212 | 9212 |
| Total Équipement (E) | 12 824 | 0 | 12 824 | 12 824 | 12 824 |

¹ L’aide demandée doit correspondre au montant hors taxes (HT) pour les EPST (Inserm, CNRS, IRD,...) et augmentée le cas échéant de la TVA non récupérable pour les autres organismes.
² Reportez les chiffres des pages 9 et 10 et n’indiquer pour chaque item que le coût total en euros.
³ Renseignez le formulaire spécifique pour les demandes d’allocations de recherche ANRS.
⁴ Les vacations sont strictement réservées à la rémunération de personnes effectuant un travail temporaire ou partiel dans la limite de 900 heures annuelles ou 6 mois non renouvelables. Les montants doivent être indiqués charges patronales et salariales incluses.
⁵ Joindre un devis pour tout équipement dont le prix unitaire est supérieur à 1 600 € HT. NB : les demandes d’équipements d’une valeur unitaire supérieure à 16 K€ HT ne sont pas prises en compte dans le cadre des appels d’offres. Elles doivent faire l’objet d’une demande séparée sur papier libre. Les montants accordés pour l’équipement ne le sont qu’au titre de la 1ère année.
<table>
<thead>
<tr>
<th>Postes de dépenses</th>
<th>Coût total du projet (en euros)</th>
<th>Subvention demandée à l’ANRS 1 (en euros)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FONCTIONNEMENT</strong></td>
<td>Année 1</td>
<td>Année 2</td>
</tr>
<tr>
<td>Achats et prestations à caractère scientifique et médical</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Petit matériel</td>
<td>301</td>
<td>0</td>
</tr>
<tr>
<td>- Electrodes EMG de surface et d’électrostimulation = 126€ + 175€</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- 2 Ordinateurs portables</td>
<td>1 260</td>
<td>0</td>
</tr>
<tr>
<td>- Passation des questionnaires ; traitement des données = 630 € x2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Traitement des échantillons cliniques et des données</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Retranscription des entretiens (40 entretiens à ~ 2.5h/l’entretien à 95 € /l’heure d’enregistrement) = 9500€</td>
<td>4 750</td>
<td>4 750</td>
</tr>
<tr>
<td>- Logiciel d’organisation des données qualitatives (N’Vivo 10) = 1410 €</td>
<td>1 410</td>
<td>0</td>
</tr>
<tr>
<td>- Logiciel de traitement statistique de données quantitatives (SPSS) = 438 € HT</td>
<td>438</td>
<td>0</td>
</tr>
<tr>
<td>- Logiciel Capture System (protection des données médicales)</td>
<td>2 000</td>
<td>0</td>
</tr>
<tr>
<td>Achats et prestations à caractère administratif</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- Assurances: Responsabilité civile = 1100 €</td>
<td>1 100</td>
<td>0</td>
</tr>
<tr>
<td>- Reprographie des questionnaires =60€</td>
<td>60</td>
<td>0</td>
</tr>
<tr>
<td>Frais de déplacements et de missions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>- 2 Déplacements de 2 chercheurs pour réunions de projet (Forfait de 310 € train/ hôtel Montpellier-Nice et Nice-Paris) = 1240€</td>
<td>1 240</td>
<td>0</td>
</tr>
<tr>
<td>- 4 Missions pour entretiens et distribution des questionnaires, Nice-Paris sur 5 jours (Forfait de 600€ la semaine) = 2400€</td>
<td>1 200</td>
<td>1 200</td>
</tr>
<tr>
<td>- 5 Missions de congrès (Forfait de 800 € congrés/ transport/ hébergement pour missions internationales pour valoriser la recherche)</td>
<td>0</td>
<td>4 000</td>
</tr>
<tr>
<td>- Colloque de fin de projet à Nice avec partenaires hospitaliers, associatifs et scientifiques (Forfait de 350€ max. pour 6 partenaires de Montpellier/Paris ; pauses café/ pots / repas 1200€ ; affiches et programmes 500€) = 3800€</td>
<td>0</td>
<td>3 800</td>
</tr>
<tr>
<td><strong>Autres dépenses (surcoûts hospitaliers, prestations)</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1 L’aide demandée doit correspondre au montant hors taxes (HT) pour les EPST (Inserm, CNRS, IRD,...) et augmentée le cas échéant de la TVA non récupérable pour les autres organismes.
1er appel d'offres 2014

<table>
<thead>
<tr>
<th>PROJETS ANRS SUR 12/24 MOIS</th>
</tr>
</thead>
</table>

---

<table>
<thead>
<tr>
<th>d'enquêtes...</th>
<th>500</th>
<th>2 000</th>
<th>2 500</th>
<th>500</th>
<th>2 000</th>
<th>2 500</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Consultation Médicale (25€/visite, 100 patients) = 2500 €</td>
<td>600</td>
<td>600</td>
<td>1200</td>
<td>600</td>
<td>600</td>
<td>1200</td>
</tr>
<tr>
<td>- Transport patients (Forfait de 30€ de frais de déplacement, pour 40 patients) = 1200 €</td>
<td>5 420</td>
<td>5 420</td>
<td>10 840</td>
<td>5 420</td>
<td>5 420</td>
<td>10 840</td>
</tr>
<tr>
<td>- ARC du CHU de Nice (10% de son temps) (data management et liaison entre médecins, sujets recrutés, chercheurs) = 5420 € / an</td>
<td>20 279 * 4% = 811 €</td>
<td>21 770 * 4% = 871 €</td>
<td>16 521 * 4% = 661 €</td>
<td>20 970 * 4% = 839 €</td>
<td>1 500 €</td>
<td></td>
</tr>
</tbody>
</table>

---

| Frais de gestion (le cas échéant) | 21 090 | 22 641 | 43 731 | 17 181 | 21 809 | 38 990 |

---

| TOTAL PROJET POUR LE LABORATOIRE A (P+E+F) | 157 011 | 182 061 | 326 248 | 50 346 | 78 473 | 128 819 |

---

1 Dans l'hypothèse où l'organisme gestionnaire applique un pourcentage de frais de gestion, merci de renseigner sur les pointillés.
**LABORATOIRE B : SANTESIH**

**Nom du responsable :** FEREZ Sylvain  
**Organisme gestionnaire :** Université Montpellier 1

<table>
<thead>
<tr>
<th>Postes de dépenses</th>
<th>Coût total du projet (en euros)</th>
<th>Subvention demandée à l’ANRS (en euros)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PERSONNELS²</td>
<td>Année 1</td>
<td>Année 2</td>
</tr>
<tr>
<td>Personnels impliqués dans le projet, hors financement ANRS</td>
<td>16 949</td>
<td>16 949</td>
</tr>
<tr>
<td>Allocations de recherche ANRS associées³</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>(MEC, MEB, pré-doc, post-doc,...)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personnels temporaires ANRS (« vacations »)⁴</td>
<td>2 180</td>
<td>2 180</td>
</tr>
<tr>
<td>- 2 Étudiants stagiaires niveau Master2 Réaîthêtisation 5 mois) = 436 € x 5 mois x 2 étudiants</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Personnel (P)</td>
<td>19 129</td>
<td>19 129</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EQUIPEMENT</th>
<th>Année 1</th>
<th>Année 2</th>
<th>Total</th>
<th>Année 1</th>
<th>Année 2</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Détail des équipements⁵</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>Ne pas remplir</td>
</tr>
<tr>
<td>équipements d’un coût unitaire supérieur à 1.600 € HT et inférieur ou égal à 16.000 €</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total Équipement (E)</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

¹ L’aide demandée doit correspondre au montant hors taxes (HT) pour les EPST (Inserm, CNRS, IRD,...) et augmentée le cas échéant de la TVA non récupérable pour les autres organismes.
² Reportez les chiffres des pages 9 et 10 et n’indiquer que le coût total en euros.
³ Renseigner le formulaire spécifique pour les demandes d’allocations de recherche ANRS.
⁴ Les vacations sont strictement réservées à la rémunération de personnes effectuant un travail temporaire ou partiel dans la limite de 900 heures annuelles ou 6 mois non renouvelables. Les montants doivent être indiqués charges patronales et salariales incluses.
⁵ Joindre un devis pour tout équipement dont le prix unitaire est supérieur à 1 600 € HT. NB : les demandes d’équipements d’une valeur unitaire supérieure à 16 K€ HT ne sont pas prises en compte dans le cadre des appels d’offres. Elles doivent faire l’objet d’une demande séparée sur papier libre. Les montants accordés pour l’équipement ne le sont qu’au titre de la 1e année.
<table>
<thead>
<tr>
<th>Postes de dépenses</th>
<th>Coût total du projet (en euros)</th>
<th>Subvention demandée à l’ANRS (en euros)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Année 1</td>
<td>Année 2</td>
</tr>
<tr>
<td><strong>FONCTIONNEMENT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Achats et prestations à caractère scientifique et médical</td>
<td>1 410</td>
<td>0</td>
</tr>
<tr>
<td>- Logiciel d’organisation des données qualitatives (N’Vivo 10)</td>
<td>1 410</td>
<td></td>
</tr>
<tr>
<td>Achats et prestations à caractère administratif</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frais de déplacements et de missions</td>
<td>1 600</td>
<td>1 600</td>
</tr>
<tr>
<td>- 2 Missions de Congrès (Forfait de 800 € congrès/ transport/ hébergement pour missions internationales pour valoriser la recherche)</td>
<td>1 600</td>
<td>1 600</td>
</tr>
<tr>
<td>Autres dépenses (surcoûts hospitaliers, prestations d’enquêtes…)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frais de gestion (le cas échéant)²......4%…</td>
<td>3 010 * 4%</td>
<td>1 600 * 4%</td>
</tr>
<tr>
<td>= 120 €</td>
<td>= 64 €</td>
<td>= 184 €</td>
</tr>
<tr>
<td>Total Fonctionnement (F)</td>
<td>3 130</td>
<td>1 664</td>
</tr>
</tbody>
</table>

| TOTAL PROJET POUR LE LABORATOIRE B (P+E+F)            |                                  |         |       |         |         |       |
|                                                      | 22 259                          | 20 793  | 43 052 | 5 310   | 3 844   | 9 154 |

*A photocopier si nécessaire, en poursuivant pour chaque laboratoire l’indexation alphabétique*

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1 L’aide demandée doit correspondre au montant hors taxes (HT) pour les EPST (Inserm, CNRS, IRD,...) et augmentée le cas échéant de la TVA non récupérable pour les autres organismes.

2 Dans l’hypothèse où l’organisme gestionnaire applique un pourcentage de frais de gestion, merci de renseigner sur les pointillés.
Coût total du projet et subvention totale demandée à l’ANRS
tous laboratoires confondus

(Somme des montants de l’ensemble des laboratoires du projet)

<table>
<thead>
<tr>
<th>Postes de dépenses</th>
<th>Coût total du projet¹ (en euros)</th>
<th>Subvention demandée à l’ANRS pour l’ensemble du projet (en euros)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Année 1</td>
<td>Année 2</td>
</tr>
<tr>
<td>Personnels² hors financement ANRS</td>
<td>119 705</td>
<td>119 705</td>
</tr>
<tr>
<td>Personnels sur financement ANRS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Allocations de recherche</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Vacations</td>
<td>22 521</td>
<td>58 844</td>
</tr>
<tr>
<td>Sous total Personnel (P)</td>
<td>142 226</td>
<td>178 549</td>
</tr>
<tr>
<td>Sous total Équipement (E)</td>
<td>12 824</td>
<td>0</td>
</tr>
<tr>
<td>Sous total Fonctionnement (F)</td>
<td>24 220</td>
<td>24 305</td>
</tr>
</tbody>
</table>

| | Coût total du projet¹ (en euros) | Subvention demandée à l’ANRS pour l’ensemble du projet (en euros) |
| | Année 1 | Année 2 | Total | Année 1 | Année 2 | Total³ |
| TOTAL GENERAL (P+E+F) | 179 270 | 202 854 | 369 300 | 55 656 | 82 317 | 137 973 |

¹ Le coût total du projet doit intégrer l’ensemble des coûts inhérents au projet (dépenses de personnels, charges directes et indirectes, dépenses sur ressources propres, sur financements ANRS et autres financements).
² Rappel : le montant des allocations de recherche ANRS ne figure que dans l’estimation du « Coût total du projet » mais n’est pas inclus dans les colonnes « Subvention demandée à l’ANRS pour l’ensemble du projet ».
³ Montant à reporter en page 1 (Total général demandé à l’ANRS).
5/ Cas particuliers des projets relevant de la réglementation française applicable à la recherche sur la personne

DEMARCHES ETHIQUES

Pour déterminer la réglementation applicable à votre projet, référez-vous aux fiches « Typologie de la recherche sur la personne » présentes sur le site Internet de l’ANRS

Merci de renseigner ci-dessous dans quelle typologie de recherche votre projet s’inscrit :

■ Recherche interventionnelle (biomédicale ou soin courant)
❑ Recherche non interventionnelle utilisant des échantillons biologiques humains
❑ Recherche non interventionnelle observationnelle

Pour les projets de recherches biomédicales telles que prévues dans le Code de la santé publique (articles L. 1121-1 et suivantes et R. 1121-1 et suivants):

- Promoteur du projet envisagé :
  Inserm-ANRS ❑
  Autre ❑ Précisez :
  Organisme ou nom : CHU Nice ..........................................................................................................
  Adresse : ........................................................................................................................................

- Demande d’avis auprès d’un Comité de protection des personnes et du comité d’éthique dont relève le site de recherche :
  - Demande prévue : oui ❑ non ❑
  - Demande effectuée : oui ❑ non ❑
  - Date et lieu de dépôt de dossier : CHU Nice N° CPP : CPP Sud-Est ; Clinical Study Number : NCT 03124914 ........

- Demande d’autorisation de réalisation de la recherche biomédicale auprès de l’ANSM :
  - Demande prévue : oui ❑ non ❑
  - Demande effectuée : oui ❑ non ❑
  - Date et lieu de dépôt de dossier : ........................................................................................................

- Joindre au dossier la note d’information et la feuille de consentement proposées pour cette recherche.

Pour les autres types de projets de recherche :

- Demande d’avis auprès d’un Comité de protection des personnes ou d’un comité d’éthique dont relève le site de recherche :
  - Demande prévue : oui ❑ non ❑
  - Demande effectuée : oui ❑ non ❑
  - Date et lieu de dépôt de dossier : ........................................................................................................

- Joindre au dossier la note d’information et la feuille de consentement proposées pour cette recherche.

1 Si et seulement si la part de l’ANRS est inférieure à 50% du coût total du projet.
RESULTATS
Le volet sociologique du projet visait à analyser les pratiques et sens sociaux associés à la fatigue chronique perçue chez les PVVIH, ainsi que les liens avec l’AP. Ces objectifs ont mené à trois études avec des sous-objectifs et méthodes distincts permettant d’élucider différentes dimensions de ce questionnement.

Dans un premier temps, une étude qualitative a été conduite auprès de 50 PPVIH afin d’identifier les processus sociaux en lien avec la perception et l’expression de la fatigue liée au VIH.

Dans un deuxième temps, nous avons examiné les principaux types d’attitudes à l’égard de l’AP à travers une autre étude qualitative menée auprès de 35 PVVIH afin de mieux comprendre les sens sociaux et comportementaux de la fatigue et de l’AP, et les relations entre elles, chez les PVVIH.

Dans un troisième temps, une étude quantitative s’appuyant sur 560 PVVIH a permis d’étudier les corrélats sociaux et culturels de la fatigue physique perçue chez les PVVIH.

Etude 1. La gestion de la visibilité du VIH et de la fatigue liée au VIH

Une première étude visait à comprendre les sens sociaux attribués à la fatigue et les enjeux de la mise en visibilité par l’expression orale ou corporelle. Il s’agissait de mieux connaître certains processus sociaux derrière la perception et l’expression de la fatigue liée au VIH. La méthode consistait en deux volets qualitatifs – par entretien et par observation.


Le deuxième volet méthodologique consistait en des observations participantes par deux chercheures dans quatre associations VIH dans quatre villes. Les chercheures ont participé
séparément aux séances d’activité physique (yoga, natation, aquagym, gym douce) au cours de plusieurs mois, étant présente dans l’association avant, pendant et après la séance pour échanger avec les participants.

Les résultats ont montré que la visibilité de la fatigue était étroitement gérée, étant perçue comme révélatrice du statut sérologique. L’expression corporelle ou orale de la fatigue était ainsi fortement reliée à la divulgation de son statut sérologique et aux inquiétudes concernant la stigmatisation associée au VIH. La mise en visibilité de la fatigue dépendait également des normes de genre (les modèles dominants de masculinité proscrivant des signes de faiblesse) et des types de relations de soin relatifs à chaque contexte d’interaction.

Cette première étude a fait l’objet de la publication suivante :
To be or not to be sick and tired: Managing the visibility of HIV and HIV-related fatigue

Laura Schuft
Université Côte d’Azur, LAMHESS, France

Estelle Duval
Univ. Montpellier, SANTESIH, France

Julie Thomas
Univ. Lyon, UJM-Saint-Etienne, Centre Max Weber, France

Sylvain Ferez
Univ. Montpellier, SANTESIH, France

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

Corresponding author:
Laura Schuft, Faculty of Sports Sciences, Université Nice Sophia Antipolis, 261 Boulevard du Mercantour, 06205 Nice, France.
Email: schuft@unice.fr
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,
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© 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 express-
ing fatigue and legitimizing illness-related difficulties depended on the social frame and
appeared to differ along gender lines. The example of one association particularly illus-
trated this point. The association aimed for its members to reintegrate into ‘regular’
social activities when possible. Those who were viewed as having become ‘self-suffi-
cient’ 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 homo-
sexual 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 legiti-
mizing physical difficulties and therefore one’s place as ‘dependent’ on the association’s
activities. Consistent with the interview analysis regarding gender and sexual prescrip-
tions, 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 partici-
plant’s ‘dependence’ on the association and its adapted activities. Conversely, no explana-
tion 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 prescrip-
tions 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 (Petruk 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 (Petruk 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).
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 interac-
tion. 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 pre-
scriptions 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 under-
line 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 symp-
toms 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 ‘inter-
secting’ 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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Etude 2. Attitudes vis-à-vis de la fatigue liée au VIH et de l’AP

La deuxième étude visait à comprendre les sens sociaux et comportements vis-à-vis de la fatigue et de l'AP, et les relations entre elles, chez les PVVIH. Grâce à des recrutements de volontaires dans trois hôpitaux (Nîmes, Paris, Nice) et trois associations, nous avons mené 35 entretiens semi-directifs auprès de PVVIH sur la vie quotidienne (pour voir dans quelle mesure la fatigue ou l’AP ressortaient), l’AP (pour voir le rapport à l’AP et la place de la fatigue) et la fatigue. L’analyse a été menée grâce à une analyse de contenu basique suivie d’une analyse de discours inductive (Denzin and Lincoln 2018). Ces analyses ont permis d’identifier quatre principaux types d’attitudes situés le long de continuums de fatigue et d’AP, menant à la réorganisation des données selon ces profils idéaux-typiques (Swedberg 2017) : (a) l’AP pour gérer la fatigue ; (b) en « bonne » santé grâce à l’AP ; (c) pas d’AP à cause de la fatigue ; (d) pas de fatigue, pas de sport, pas de problème.

Cette typologie nous a permis non seulement d’illustrer les relations entre les perceptions de la fatigue liée au VIH et les attitudes à l’égard de l’AP, mais également d’illustrer différents modes de percevoir et gérer la santé, la maladie chronique et ses symptômes. Les usages de certaines notions transversales, telle que la volonté de « préserver le corps » ou de « vivre sainement » - notamment à travers l’AP modérée, reflétaient des formes d’internalisation du statut de malade et des attentes en termes de comportements de santé. Tous sauf le profil « pas de fatigue, pas de sport, pas de problème » ont fait émergé ces concepts transversaux – dans les discours comme dans les pratiques. Ce dernier profil idéal-typique pourrait donc donner certaines clés concernant comment réduire la présence du VIH et le sentiment d’être « malade » dans l’identité sociale et la vie quotidienne des PVVIH.

Cette étude a permis la réalisation d’un article under review dans Qualitative Health Research : Attitudes toward HIV-related fatigue and physical activity. A reflection of illness experiences and narratives.
## Attitudes toward HIV-related fatigue and physical activity. A reflection of illness experiences and narratives

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Attitudes toward HIV-related fatigue and PA

Attitudes toward HIV-related fatigue and physical activity.
A reflection of illness experiences and narratives

**Abstract:** Fatigue is a major symptom associated with HIV. Although the causes are unclear, recent research has shown that physical activity (PA) can reduce acute fatigue among people living with HIV. Yet little is known about the social meanings and behaviors surrounding either chronic fatigue or PA among people living with HIV. This article analyzes the attitudes toward this illness symptom and health behavior, and how they relate to overall illness experiences and narratives. Discourse analysis of 35 semi-structured interviews with people living with HIV across France enabled the identification of four ideal type attitudes. We considered these as situated along intersecting continuums of fatigue and PA levels. This typology not only illustrated the relations between meanings and behaviors toward HIV-related fatigue and PA. It also allowed us to consider how these attitudes reflected illness experiences in terms of expected health behaviors and illness narratives.

**Keywords:** HIV; HIV-related fatigue; physical activity; chronic illness; illness narrative; France
Attitudes toward HIV-related fatigue and PA

Although fatigue is a major symptom associated with the Human Immunodeficiency Virus (HIV) and has been widely studied (Barroso & Voss, 2013; Jong et al., 2010), few studies have explored the social meanings, experiences or behaviors surrounding chronic HIV-related fatigue (Perazzo, Webel, Voss, & Prince-Paul, 2017; Schuft, Duval, Thomas, & Ferez, 2018). Social significations of fatigue have only recently become the object of qualitative analysis, in particular in relation to chronic fatigue syndrome (Asbring & Närvän, 2002; Clarke & James, 2003; Olson, Zimka, & Stein, 2015), but also in relation to other chronic illnesses (Olsson, Stafström, & Söderberg, 2013; Porr, Olson, & Hegadoren, 2010), or as compared to non-ill populations such as runners (Olson, Zimka, Pasiorowski, Iregbu, & Boulé, 2018) or society at large (Widerberg, 2006). In parallel, PA has become a focus of increasing paramedical attention in France in terms of its uses for preventing or alleviating chronic illness or illness symptoms, including for HIV (Duval, Féréz, Thomas, & Schuft, 2016; Ferez & Luauté, 2008). Like in the general population, PA has been associated with lower anxiety and depression and higher quality of life among people living with HIV (Dudgeon, Phillips, Bopp, & Hand, 2004; Quiles, Ciccolo, & Garber, 2017). Some studies have also shown that PA programs reduce “acute physical fatigue”, otherwise known as “physical endurance” or “performance fatigability” (Kluger, Krupp, & Enoka, 2013), namely as measured by time on a treadmill (Ciccolo, Jowers, & Bartholomew, 2004; Dudgeon et al., 2004; Smith et al., 2001). Yet despite increasing knowledge about the potential benefits of PA, little is known about the relations between PA and chronic HIV-related fatigue (Blinded 1 ; Webel et al., 2016), defined as feelings of “chronic exhaustion” associated with HIV (Jenkin, Koch, & Kralik, 2006).

The present study considered how people living with HIV experienced and managed chronic fatigue, how this related to their attitudes toward physical activity (PA), and in what ways these attitudes reflected part of their overall illness experiences and narratives. The analysis of 35
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semi-structured interviews with people living with HIV in France enabled us to identify four
ideal type attitudes and discourse. In illustrating the relations between meanings and behaviors
surrounding chronic HIV-related fatigue and PA, the ideal type typology allowed us to consider
how attitudes toward this illness symptom and health behavior reflected modes of internalizing
health behavior expectations and constructing illness identity narratives (Bury, 2001).

Conceptual framework

In analyzing the socially constructed dimensions of illness and illness experiences (Conrad &
Barker, 2010), we focused on the social meanings attributed to illness symptoms (i.e., fatigue)
and their management (e.g., via PA), and how those meanings related to perceptions of self as
chronically ill (Baumgartner & David, 2009; Charmaz, 1995, 2002; Clarke & James, 2003).
We considered that social meanings of chronic illness transform social constructions of the self,
resulting in transformed identity narratives – or “illness narratives” (Bury, 2001). Illness
narratives in terms of HIV are bound to be impacted by social interactions within medical and
HIV-related spaces and networks, across chronic illness trajectories (Corbin, 1998),
contributing to collective social processes which participate in “constructing” modes of viewing
or managing illness. In this study we were also confronted with what Bury (2001: 276) defined
as “moral narratives”, in which people living with chronic illness “seek to account for and
perhaps justify themselves in the altered relations of body, self and society brought about by
illness”.

We hypothesized that illness narratives and modes of managing HIV and HIV-related fatigue
would be influenced by the contemporary context of increased health messages aimed at self-
care among chronic illness patients, in particular through PA (Newman, Persson, Miller, &
Brown, 2016). Public health messages have increasingly encouraged PA and other healthy
lifestyle behaviors among the general public, all while particularly targeting people living with
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chronic illness (Collinet & Delalandre, 2015) such as HIV (Duval et al., 2016; Ferez & Luauté, 2008). In this light, Janine Pierret (2006) referred to an increase in what authors have termed “medicalization” (Crawford, 1980) of the everyday lives of French people living with HIV. Attitudes toward PA and fatigue may in this way reflect different means of interiorizing, resisting or giving sense to social and medical expectations regarding health behaviors, and these attitudes and social meanings are likely to be intertwined with illness narratives.

Methodology

We recruited volunteers in three regions surrounding three major French hospital services specializing in HIV care that were partners in this national project. The hospitals were located in the center, the southeast and the south of France, with the aim of diversifying population profiles and density of infection which vary by region. Volunteers were recruited with the help of staff in the three participating hospitals as well as in three associations offering services for people living with HIV.

In the hospitals, participating practitioners recruited volunteers by proposing participation in the study to every consecutive patient during consultations over a set period of the month. In the associations, researchers and the organization’s staff recruited volunteers after scheduled presentations about the study as well as focus groups on fatigue and PA, focus groups which also constituted exploratory study on the topic. After being informed about the study, volunteers were invited to leave their first name and phone number to be contacted by a researcher at a later date for an interview. The aim of this recruitment process was to reach the broadest possible diversity in terms of social and medical profiles of people living with HIV in France. Participating volunteers signed a consent form prior to their interview. The form informed participants of the project objectives, as well as their liberty to participate or not without consequences. The form also informed participants that data storage and analysis would be
Attitudes toward HIV-related fatigue and PA confidential and anonymous, that all contact information and audio records would be deleted within three months. On these ethical bases we obtained ethical approval for the study with regard to the French National Commission for Data Protection and Liberties (CNIL) (n° CIL/UNS/2015/00017).

Researchers experienced in qualitative methodology conducted the interviews in spaces provided by the hospital services and the associations, as well as in participants’ personal homes, depending on the preference and availability of the participants. Interviews generally lasted an average of two hours. Interviews (n=35) were conducted between September 2014 and March 2015, at which point researchers had reached “saturation” (Glaser & Strauss, 1967), or the point at which no new conceptual categories relating to PA or fatigue seemed to emerge from the interviews.

The project was re-introduced at the onset of the interview with an accent on an initial encompassing study objective of exploring quality of life, in order to reduce bias due to over-focus on PA or fatigue. The topic guide followed three main dimensions that were introduced in a specific order. The first dimension considered daily life: the place of HIV, one’s daily activities and routines and the continuities or discontinuities following HIV diagnosis. The aim was to consider how PA or fatigue emerged in these recounts without prompting. The second dimension concerned views and practices concerning PA, with an aim of identifying any spontaneous associations with fatigue. The third dimension of the interview focused on fatigue - representations on fatigue, its meanings, causes, consequences and modes of management - whether or not it had already been mentioned during the interview. The interview concluded with sociodemographic data including age, occupation, country of birth and year of diagnosis.

The interviews were transcribed verbatim and rendered anonymous. A table was created to keep track of pseudonyms in relation to interview details such as interviewer and interview date and place, and interviewee details such as sociodemographic data as well as brief summaries of their
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PA and fatigue as described by the interviewees. The first stage of analysis involved content analysis in which the discourse was coded according to the conceptual categories set by the researchers. We will consider here the analyses within the umbrella conceptual category “fatigue and PA”, concerning all discourse combining concepts related to both fatigue or energy and sport or PA. This large category of analysis was then subject to inductive discourse analysis, in which recurring concepts became categories of analysis (Denzin & Lincoln, 2018).

Following the triangulation of analyses by multiple researchers (Denzin & Lincoln, 2018), data was re-organized to test the emerging trend that attitudes and discourse toward PA varied along differing reported levels of chronic fatigue. Discourse was re-organized into four categories according to binary oppositions: between interviewees declaring to be engaged in PA as opposed to those declaring to be little or not engaged in PA; and between interviewees experiencing HIV-related fatigue as opposed to those experiencing little to no HIV-related fatigue. This re-organization gave way to an analytical framework in which individuals’ coded discourse was considered in relation to reported levels of physical activity and fatigue, creating four “ideal type” discourse and attitudes. “Ideal types” in the sense of Max Weber are exaggerated archetypal forms of classification that enable the researchers to categorize otherwise elusive concepts or phenomena, for the purpose of analysis (Swedberg, 2017).

Results: Ideal type attitudes in terms of fatigue and PA

As the characterization of levels of PA or fatigue is not, in reality, binary or clear-cut, the ideal type attitudes were theorized as situated at the far ends of a graph in which the axes represent intersecting continuums of fatigue and PA levels (Fig.1). Individual attitudes could be situated closer to or farther from an ideal type attitude, largely in relation to perceived levels of fatigue and PA at the time of the interview. Some work has suggested that “fatigue is not a continuum but rather a state along a continuum” of adaptation, located between tiredness and exhaustion
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(Olson, 2007). But because lay understandings of chronic fatigue have been shown to be
dissociated from clinical understandings and associated with diverse synonyms and symptoms
tied to the illness experience (Schuft et al., 2018), we argue that chronic fatigue can itself be
represented as a continuum. A continuum model of ideal types, previously proposed in the
domain of health and PA for example by Christiansen et al. (2017), allowed us to situate,
theoretically, not only the typified attitudes in this context, but also related transversal concepts,
such as “healthy living” or “preserving the body” (see Fig.1). To typify these attitudes and best
illustrate the theoretical model, we present here each of the four ideal type attitudes. The ideal
type attitudes not only between typified perceptions and behaviors regarding PA and fatigue,
but also between sociodemographic characteristics and narratives concerning one’s state of
illness or health. Table 1 summarizes sociodemographic characteristics of the interviewed
people by ideal type profiles.

Figure 1. Ideal type attitudes situated among intersecting continuums of PA and fatigue
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Table 1. Social profiles of interviewees by ideal type attitude

<table>
<thead>
<tr>
<th></th>
<th>Sporty to manage fatigue</th>
<th>Healthy because sporty</th>
<th>No sport because of fatigue</th>
<th>No sport, no fatigue, no problem</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>41 to 60, median age 43</td>
<td>35 to 76, median age 50</td>
<td>34 to 69, median age 50</td>
<td>84 or early 50s</td>
</tr>
<tr>
<td><strong>Gender and sexual orientation</strong></td>
<td>3 homosexual men 6 women</td>
<td>3 homosexual men 5 heterosexual men 1 woman</td>
<td>5 homosexual men 8 women</td>
<td>1 homosexual men 2 heterosexual men 1 woman</td>
</tr>
<tr>
<td><strong>Socioeconomic situation</strong></td>
<td>3 working 5 on welfare (handicap, unemployment)</td>
<td>7 working 1 retired 1 homemaker</td>
<td>2 working 3 retired 1 homemaker 7 on welfare (handicap, unemployment)</td>
<td>3 working 1 retired</td>
</tr>
</tbody>
</table>

1. Sporty to manage fatigue

Among the interviewed people living with HIV who engaged in some form of PA but who felt regularly fatigued, PA was seen as a part of healthy living, viewed as essential for managing illness and illness-related symptoms such as fatigue. Healthy living was also at times construed as particularly important for people who are “sick”, whether for managing illness or for actively combating illness or its symptoms.

*PA as a part of healthy living and used to manage illness or its symptoms*

PA was often discussed in light of its benefits in terms of illness or symptom management. For example, one interviewee whom we will call Paulette explained that PA helped her to manage fatigue, which she tied to both HIV and work:
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“My job is very demanding too, I'm a teacher, so... it's very interesting, but very exhausting too (laugh) (...). Physical activity, on the contrary, helps me!”

(Paulette, 42, teacher, diagnosed in 1996).

PA was in this way brought up by Paulette in terms of its utility for managing the mental and physical fatigue of both her illness and career.

This means of representing PA was similar for Corentin, for example, who specifically became a yoga teacher after his diagnosis. He saw this activity as a means of managing life with HIV and treatment symptoms. He has since promoted the benefits of this type of PA which provided “a boost of energy; playing sports makes you less tired”. He specifically presented PA as a tool for managing illness side-effects, such as reduced physical “endurance” for accomplishing everyday activities.

Beyond PA as a means of managing illness and illness symptoms, PA was often seen as a dimension of healthy living, viewed as a set of behaviors that could both prevent and improve illness:

“Because sport or a healthy lifestyle will prevent disease from happening if you are not sick, and if the disease is there, it will improve things a lot” (Corentin, 43, on handicap benefits, diagnosed in 1998).

Some interview excerpts illustrate how this discourse on healthy living was relayed by medical and associative organizations:

“We're sure of that, too, because... they were telling us about other people who had lives a little out of control, or things like that who didn't respond as well to treatment as we did” (Pauline, 40, sales assistant, diagnosed in 1999).

In this way, the surrounding HIV and medical community seemed to encourage particular social and health behaviors, linking PA and “healthy living” to health outcomes.
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PA as a means of actively combating illness

Beyond figuring as a means of managing illness and symptoms such as fatigue, PA was also, for some, construed as a means of actively combating the latter:

"I refuse to let fatigue take over, because otherwise I go to bed and it's a disaster! And the mornings when I wake up and I feel really tired or something, I go to the association and I force myself to stay, to help, to... to do something, to not think about this fatigue, to not feel all the negative effects. [...] I really force myself to... I have to get busy, I have to! (...) I have to not think about it [fatigue]. Because if I listen to myself (...) then I don't do anything! (...) Sometimes it's hard, but I always try to do something. (...) I mustn't listen to myself!" (Joelle, 42, on handicap benefits, diagnosed in 1996).

In this way, “forcing” herself to stay active, to ignore the fatigue or to not listen to her body represented a strategy for accomplishing things. Others spoke similarly of forcing herself “to move”:

“Whenever I was tired or coming out of major illnesses (...) even if it didn't last long, I had to go (to my physiotherapy session), I had to move!” (Isabelle, 51, on handicap benefits, diagnosed in 1990).

In these excerpts, the benefits of PA were underlined as means of managing illness or symptoms, particularly by “fighting” fatigue, in spite of fatigue. The individuals emerged, in these illness narratives, as in control of their “fight” against illness symptoms through the adoption of normative health behaviors such as PA.

2. Healthy because sporty

Like all those who engaged in PA, the interviewees who were engaged in some form of PA but who were, however, not fatigued considered PA as an essential part of healthy living. Yet,
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beyond the view that PA and healthy living were key to illness and symptom management, PA
was seen as keeping illness and fatigue at bay. The type and intensity of PA seen as enabling
health and well-being were also often specified as necessarily “moderate” activities, of limited
intensity or duration.

Illness and fatigue kept at bay “thanks to” PA and healthy living

The experience of fatigue, when described by people in particular within this profile of fatigue
and PA, was clearly opposed to a “negative” or illness-related fatigue. “Good fatigue” was
linked to regular, “normal” or chosen activities such as work or PA. This fatigue was described
as one “where we recover quickly”, and distinguished from an imposed “fatigue due to HIV”
where “there’s nothing we can do about it” (Michel). In the various descriptions opposing
“good” versus illness fatigues, descriptions might oppose for example an “energy fatigue”
versus “a real physical fatigue”, the two types being “not the same fatigue”.

For some, PA represented an antidote to illness fatigue, such as for Philippe, for whom sport
“chases away the fatigue (...) You feel good and it takes away fatigue, I find” (Philippe, 35,
massage therapist, diagnosed in 2008).

More dramatically, for George, PA “saved” and “changed” his life, and improved his “quality
of life”. Through PA, George “fought” off illness and refused to “let things beat [him]”:

“it gives me energy, it motivates me […] It’s also social. […] It saved my life! It’s
what… psychologically, physically, I think it’s the most important things that I’ve
done, to stay very active… For example, bodybuilding, for me, it’s like a rebooting,
rebooting a computer. You see, at the end of the day […] I can be psychologically
fatigued after work or whatever, I go to my sport, and when… when I get home,
everything’s fine! (laughter)” (George, 50, consultant, diagnosed in 1995).

Similarly, Giorgio depicted PA as an illness management tool, as part of his “cure for AIDS”
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(used here in lieu of HIV):

“I rediscovered the desire to live and I discovered the true medicine for AIDS, treatments applied as a rule, 100% adherence to the perfect treatment: [...] healthy living! Waking up, rules or living, life discipline, that’s the true cure for AIDS in my view. Life discipline, sport, going out, being active, never lazy, making oneself be active! AIDS, we can combat it. That’s my prescription, we combat it with optimism and being active. You mustn’t stay at home, in front of the television day and night (...) It’s a sickness which requires being active; because with the treatment” (Giorgio, 54, capital manager, diagnosed in 2002).

In these last excerpts, being energetic or active was not only associated with “good fatigue” and health, but also with a positive frame of mind and the moral value of “effort”, whereas lacking energy or activity was associated with illness but also a negative frame of mind and laziness.

Moderate PA as the appropriate form of health management

Not just any PA, or any amount of it, was touted as beneficial. The importance of moderation was abundantly underlined, and also reinforced by (para)medical personnel. Some underlined an importance of carefully dosing the amount of PA in order to harvest energy rather than fatigue:

“Sport, it’s a domain which (…) which is useful for relaxing, but not (…) I don’t see the point of going every day, that’s not relaxing, that’s fatigue” (Charles, 41, associate director, diagnosed in 1998).

Many interviewees such as Giorgio also believed that a person “sick with HIV should not exaggerate with sport”, that one “must not come home destroyed with fatigue”. Indeed, beliefs about what people living with HIV should or should not do were widely cited, mostly around the idea of moderated, healthy living:
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“A lot of people with HIV, at the beginning, they slack. They should not! A healthy lifestyle (...) PA is part of that healthy lifestyle, part of that regulated life. Not a crazy lifestyle” (Giorgio).

For many in this ideal type profile, “healthy living” and “moderate PA” were explicitly viewed as important means of preserving health for “people who have an illness”, due to the precarious health status associated with HIV:

“I had a very balanced life, which is very important in this sickness. (...) A balanced life, um, a moderate physical activity, well, that’s ideal. I think that’s the ideal for all illnesses! [...] it’s more important for [...] for people who have an illness” (Michel, 52, administrator, diagnosed in 1991).

This idea of moderate PA was associated with protecting vulnerable health and body:

“One must not be overcharged. Because if we do a little, it’s good, it boosts us, it’s good for the… the body, in terms of HIV, and if we do too much, it can also, um…, lower our immunity, I mean, well, because your body is already fighting the illness (...) We mustn’t get exhausted” (Philippe).

Similarly, Raphael spoke of avoiding “excessive” amounts of PA or “violent sports”. Throughout the interview he often stressed moderate PA: “a little”, “not too much”, “not excessively”, “not too fast”, not too “violent”. This was qualified as a means of “protecting” himself and “preserving” his body. In this way, a perceived vulnerability was associated with a desire to carefully manage health and to prevent escalation of illness or symptoms such as fatigue, namely through “healthy living” and “moderate” PA.

The (para)medical and social entourage tended to relay this view of vulnerable body and health, encouraging the protection or preservation of the latter. As stated Giorgio, “This was explained to me: (...) one must not exaggerate”. For the “healthy because sporty” profile type, such
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recommendations came in the form of appeals to curtail PA. As a veteran sprinter on the French national athletics team recounted:

“Many around me say to me ‘Maybe you should take it easy, since you’re taking a treatment, it’s poison for the body and […] the treatment on its own is exhausting’.

[…] Sometimes, the recommendations [from the general practitioner] are like ‘Ok, maybe you should stop sports’; ‘you should stop the competition’ (Gregory, 38, steward, diagnosed in 2007).

In the case of Philippe, to whom some doctors had said “to not get exhausted”, he questioned the link between HIV and PA, assuming that the link must be due to treatments, “seeing as I have an undetectable viral load”. The application of this logic underlines the contradiction between, on the one hand, the biological reality for many of those who were not fatigued or felt no symptoms connected with their serological status or treatments and, on the other hand, illness narratives - reinforced by the HIV and medical community - in which the body emerged as vulnerable and in need of protection through health behaviors such as moderate PA.

3. No sport because of fatigue

Those who were not engaged in some form of PA and who experienced chronic fatigue made up the largest of the four ideal type profiles. For many of this profile of people living with HIV, PA was considered as ill-adapted to their state of health. More specifically, while fatigue was often cited as an illness symptom preventing PA, PA was also viewed as too fatiguing for one’s state of health and energy. This attitude was consistent with a view of oneself as ill, and of the body as vulnerable.
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**Fatigue as barrier to PA**

Overall the topic of PA was met with reactions evoking fatigue as a major barrier, such as “I’m already too fatigued” or “I don’t have the energy” (Marie). In relation to the physical demands of her children, one woman recounted for example:

“playing ball, whatever, it’s ok 5 minutes, but after, I just can’t. Because I feel, after, tired and prefer to sit down on a bench […] I’m too weak” (Marion, 34, homemaker, diagnosed in 2008).

Many in this profile type spoke of chronic physical fatigue or exhaustion as a major obstacle to engaging in PA.

Yet the discourse surrounding such statements revealed other processes relating to illness and symptom experiences. In the example of Janine, fatigue and lack of energy or “muscle tone” were part of her description of living with HIV:

“Even just going to the pool, it’s… [heavy sigh]. You say you’re tired before even leaving for the pool. It requires an effort which… you know you won’t be able to make that effort” (Janine, 44, unemployed, diagnosed in 1986).

When asked if she sometimes did PA, she replied in the negative, mentioning also cost:

“No, because… (heavy sigh) there’s already fatigue… and then, there’s the lack of money, because it’s expensive!”

However, Janine later returned to the cost factor and termed it an “excuse” for multiple reasons:

“It’s expensive. And you look for the excuse, saying: ‘Well, it’s expensive’. […] So, it makes you feel less guilt. (Interviewer: “Why guilt?”). Because the doctors, the association, they push you to do things, to not stay isolated, and get out… but um… we know we’re tired (laugh), that we won’t be able to do it, so we try to feel better, by saying ‘Oh, I’m not going because it’s expensive’. In order to not say, ‘I’m not going because I’m tired and because I know I won’t be able to do it’. So,
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we feel more comfortable saying… It’s easier to say, ‘I’m not going because it’s expensive’. Rather than say, ‘because you know your body won’t be able to do it’”.

(Interviewer: “And why do you not want to say that to yourself?”) Well because it’s hard! Psychologically, it brings you back to the illness, to say, ‘If I didn’t have this illness, all the things I would do. I would do so many things! If I wasn’t all the time exhausted’”.

This excerpt shows certain links between many feelings related to illness experiences: feelings related to illness symptoms (“fatigue”); related to illness experience within medical institutions (“guilt” and “excuses” for not living up to PA recommendations); and related to illness experience and identity (seeking to deny or diminish the preponderance of illness or its symptoms). In this way, despite viewing fatigue as an obstacle to PA, Janine nonetheless felt guilty for not engaging in PA. As with other interviewees, her frustration was amplified by the medical recommendation to engage more in PA. Denying fatigue or finding alternative explanations for non-engagement in PA therefore appeared as a means of protecting one’s social identity in terms of health and illness, and the moral narrative one tells – or wants to be able to tell – about oneself. Denial has been shown to be, as in this case, one adaptive response to living with chronic illness (Telford, Kralik, & Koch, 2006). Using fatigue or other reasons to explain non-engagement in PA also appeared as a means of handling feelings of guilt due to unmet medical expectations regarding PA and health behaviors.

PA fatigues: PA as a threat to preserving well-being

Interviewees in this profile type also viewed PA as a possible source of fatigue, and thus “too tiring” to undertake. PA was in this way considered a risk to one’s fragile state of health and energy level:
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“I don’t do the whole session (of yoga at the HIV association), because it’s too much for me! And I’m not ashamed to say it there” (Marie, 48, on handicap benefits, diagnosed in 1986).

“Regarding outside activities, […] we fatigue too fast to follow the others. It’s not possible! Even yoga […] I think that, overall, it’s too bad that there aren’t any gentle fitness courses, just for us” (Carla, 56, on handicap benefits, diagnosed in 1983).

It is noteworthy that many of these interviewees used the collective “we”, referring to people living with HIV, rather than speaking of individual experiences. This seemed to anchor such difficulties in shared illness experience, through a collective illness-related identity. Unsurprisingly, viewing physical difficulties as shared among people living with HIV, some people in this profile type, like Carla, requested HIV-specific solutions such as specifically adapted PA.

Intertwined with this view of PA as “too tiring” was the view of one’s body as vulnerable. Some interviewees explicitly viewed HIV as “a sword of Damocles hanging over my head” (Marie, André, Christian), or in other words as a permanent threat to their well-being if not their lives. For many, this threat was linked to the idea of wanting to “preserve” the body not just from over-exertion but also from most forms of PA in general:

“I don’t smoke, alcohol: I drink sentimentally, not abusively, and I preserve myself a lot. I preserve myself a lot, so… if I really need some time for rest, I rest, voilà… in the sense that, outside of work… I come home, I stay at home, a small walk with the family and that’s it” (Bernard, 50, skilled worker, diagnosed in 1997).

Therefore, avoiding smoking, alcohol but also PA were cited as healthy living measures aimed at protecting or preserving the body. Paradoxically, while other ideal types viewed PA as a part of healthy living that could prevent or manage illness and its symptoms, the “no sport because
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of fatigue” profile tended to construct illness narratives in which the HIV-infected body could not or should not engage in PA, viewed as potentially harmful or risky for health.

4. No fatigue, no sport, no problem

Only four of the interviewed people living with HIV corresponded to the last profile of attitudes, which included little mention of fatigue and little to no engagement in PA. Among these interviewees, PA was globally viewed as foreign to one’s personality or lifestyle. This attitude went alongside a view of one’s body, health – and more largely one’s life – as “normal”. The attitude toward PA was one of indifference, as the lack of exercise was viewed as consistent with one’s identity and lifestyle, and as independent from HIV or its diagnosis.

PA as foreign to one’s personality or lifestyle

Among the discourse pertaining to PA as foreign to one’s personality or lifestyle, interviewees made statements such as: “It isn’t one of my usual habits”; “I’m not much of an athlete”; or “I’m lazy” (Fatima). When asked about any engagement in PA, Fatima elaborated further on this statement, laughing that if she ever did her shopping and chores by foot, “in the evening when I’d come home, I wouldn’t even make dinner, I’d go to bed, because I wouldn’t be in the habit” (Fatima, 52, nursing auxiliary, diagnosed in 1992).

Remy also made light of his physical efforts. When asked if he experienced fatigue, he laughed that:

“I’m tired by nature (laugh), because I don’t go out […] I don’t make too much effort to do sport or things like that… So, it’s true that… No, no, I don’t feel tired”

(Remy, 55, employee, diagnosed in 1987).
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As shown in the examples of Fatima and Remy, interviewees in this profile spoke of no particular fatigue but also of a lack of interest in physical efforts or activity due to personality or habit.

Health and life as “normal”

Similarly, just as these interviewees associated their level of PA with personality or habit, they also spoke of their health, fatigue level and overall lives as “normal”, “like everyone”. For Fatima, although she had wondered whether punctual fatigue was due to HIV or treatments, she did not view fatigue as a result of HIV or treatments:

“I don’t know if I’m tired because I work, because I’m taking care of the kids, I’m running here, running there, or if I’m tired because of the medicine or my immunodepression. I don’t know! [...] I wonder, but I don’t go beyond wondering (...) And then I forget, and it passes”.

Overall, for her and her husband, also HIV positive, Fatima referred to their levels of fatigue and energy as “normal”:

“Compared to people around us and who are the same age as us, they don’t seem to be more fit than us. (...) Maybe, if some at our age can do a sprint at 200 (km) per hour… We’re not athletic so, of course we couldn’t follow. But we walk, we work all the time; when there’s something to be done, we do it. We don’t feel out of breath… Know what I mean?”.

This excerpt illustrated the overall sense of normality associated with their lives, in terms of fatigue and energy. Viewing themselves overall as “normal”, “not athletic” individuals achieving their regular activities and everyday lives without a problem, the interviewees in this ideal type profile did not seem to integrate the experience or condition of living with HIV into their identity narratives.
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Discussion

*Attitudes toward fatigue and PA: comparison of sociodemographic characteristics*

The present study was one of few qualitative works on HIV-related fatigue (Perazzo et al., 2017; Schuft et al., 2018). Yet quantitative studies on HIV-related fatigue have shown various correlations with sociodemographic characteristics, providing some evidence of the socially constructed nature of illness (Conrad & Barker, 2010), and the impact of social phenomena on illness experiences and narratives. In the present study, all of the interviewed people with the most precarious economic situations, such as receiving handicap or unemployment benefits or not working due to medical leave, all evoked chronic fatigue (see Tables 1 and 2). All in all, of the 20 people who spoke of regular fatigue, only 6 were active in terms of work.

As for age, despite quantitative data showing correlations within larger sample groups (Blinded 1; Vancampfort et al., 2018), age surprisingly did not seem related to the interviewed people’s attitudes toward chronic HIV-related fatigue or PA. In terms of engagement in PA, those engaged in PA, although not younger, tended to have more recent HIV diagnoses (median years 1995 and 1996) as opposed to the more sedentary people living with HIV (median years between 1987 and 1989). This might at first glance appear as related to deteriorating health following diagnosis, leading to decreased PA over time. However, the year of diagnosis was not associated with chronic fatigue profiles in our interview sample. There therefore appeared to be more complex dynamics behind illness symptom experiences (i.e., fatigue) or health behaviors (i.e., PA), beyond sociodemographic correlates.

Gender also influenced attitudes toward illness symptoms such as fatigue. It is noteworthy that most of the interviewed women in the present study – 14 out of 16 – evoked chronic fatigue (see Table 1). The relations observed between fatigue, gender and socioeconomic conditions are consistent with the literature having shown that women, and in particular poorer women,
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have appeared to be disproportionately affected by HIV-related fatigue (Corbin, 1998; Jong et al., 2010). In addition, previous literature has suggested that women - but also homosexual men - more readily express illness symptoms such as fatigue, whereas heterosexual men seem more prone to “hegemonic” masculine gender prescriptions, which entail not showing fatigue or weakness (Courtenay, 2000; Schuft et al., 2018; Widerberg, 2006).

Gender prescriptions also seemed to impact ideal type attitudes toward fatigue and PA. Women were likely to engage in no or moderate PA (see Table 1). This lesser engagement in PA and in particular intense PA among women is consistent with gender socialization and PA trends in France (Mennesson, 2011). Heterosexual men were more likely to be situated within ideal type attitudes evoking health or “normalcy”: the “Healthy because sporty” or the “No PA, no fatigue, no problem” types. Homosexual men were more evenly distributed among ideal type profiles within our limited sample, although more present in the “No sport because of fatigue” type as opposed to the “No sport, no fatigue, no problem” type. These tendencies are consistent with literature suggesting that gender prescriptions affect men’s attitudes toward PA and HIV-related fatigue, homosexual men living with HIV demonstrating greater latitude in terms of illness narratives and the expression of illness symptoms (Schuft et al., 2018). This may once again reflect varying degrees of social pressure among men to embody “hegemonic” masculine ideals such as strength and robustness (Courtenay, 2000; Widerberg, 2006).

Illness narratives and internalized medical expectations

Beyond illustrating modes of experiencing, representing and acting upon both PA and HIV-related fatigue, the ideal type attitudes illustrated differing narratives surrounding modes of viewing and managing health, chronic illness and symptoms – such as “preserving the body” through more or less moderate PA. These narratives reflected varying degrees of internalizing illness status and expectations regarding “healthy living” behaviors. All but the “No fatigue, no
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sport, no problem” type – who spoke of little to no PA or fatigue – discussed pressure or importance surrounding healthy living, including moderate PA. While discourse on healthy living was most predominant among the “Sporty to manage fatigue” type, the importance of healthy living was largely discussed by nearly all of those who engaged in PA. In addition, some of those who did not engage in PA due to fatigue also mentioned pressure to live healthily, but in terms of guilt for not meeting medical expectations regarding PA.

Accordingly, the interviews illustrated how the medical, paramedical and social entourage influenced illness narratives by relaying health expectations messages regarding PA and other behaviors, their discourse ranging from encouraging moderate PA to discouraging intensive PA. Paradoxically, while chronic illness patients receive particular normative pressure to engage in PA, the lack of capacity for PA remains an illness stereotype that hinders engagement in PA, as has been shown with cancer patients (Falzon et al., 2012), older adults (Emile, Chalabaev, Stephan, Corrion, & D’Arripe-Longueville, 2014) and more recently people living with HIV (Gray et al., 2018). In this way, the “No sport because of fatigue” type seemed susceptible to conflicting social forces: between illness stereotypes that hinder PA, on the one hand, and pressure to engage in PA because chronically ill, on the other.

It is noteworthy that although PA was most often referred to as a means of staying healthy through “healthy living”, PA was also often viewed as a means of “battling” illness. This was the case in particular for the “Sporty to manage fatigue” type, but also, to a lesser degree, for the “Healthy because sporty” type. PA therefore at times constituted a mode of managing HIV by “battling” it, through action and positive energy as was observed in the work of Janine Pierret (2006). A similar stance toward managing HIV and cultivating a strong combative identity narrative was also observed in a case study on bodybuilding and living with HIV in France (Férez & Perera, 2018). In this case, the strength and performance gained from PA was conceived as evidence of winning over illness but also over illness stereotypes such as frailty.
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The transversal representation of the body as vulnerable or “ill”, as needing protection or preservation from over-exertion, was also present in all of the profile types excepting the “No fatigue, no sport, no problem” type. This concept however took on various forms or frequencies depending on attitudes towards fatigue and AP. The “Healthy because sporty” type were the most numerous to mention this vulnerability, and to insist on moderate intensity or duration of PA in order to continue using PA as means of preserving energy and preventing illness or symptoms. However, discourse on vulnerability was present among all those who engaged in PA, most of whom often presented PA as an instrument of illness and symptom management.

The same representation of the vulnerable body also emerged among the “No sport because of fatigue” type, although in this case PA emerged as a high-risk activity in terms of preserving energy and preventing fatigue or health decline. For this latter ideal type, representations on PA were ambivalent and contradictory, revealing tensions between the view of PA as a health risk and, on the contrary, the view of PA as a means of improving health. This ambivalence may be symptomatic of an ambivalent identity narrative in terms of health and HIV, between recognizing health limits and denying their degree of impact, as has been suggested in previous work on HIV and PA in France (Ferez, Marin-Duval, Thomas, Héas, & Fougeyrollas, 2014).

Finding alternative reasons – beyond illness – to explain lack of engagement in recommended health activities such as PA appeared as a “self-handicapping strategy”, enabling one to legitimize lack of PA without focusing on illness or symptoms such as fatigue, thereby elaborating an identity narrative less centered on illness.

Lastly, on the other end of these spectrums in terms of PA or fatigue, the “No sport, no fatigue, no problem” type wove identity narratives that were not only resistant to the representation of the body as ill or vulnerable, but also to the internalization of expected health behaviors. Interviewees in this ideal type profile did not mention guilt, health status or medical expectations regarding their disinterest in PA. Due in part to their biological health and to
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reduced interactions within HIV-related social and medical networks, this ideal type profile adopted “normalization” strategies (Bury, 2001; Ferez et al., 2014) aimed at limiting illness narratives and continuing social, professional and physical activities from before diagnosis. Such strategies of identity preservation have previously been noted among people living with HIV in France (Férez & Perera, 2018; Pierret, 2006). It is probably for this very reason that we encountered only four individuals reflecting this ideal type profile, as these individuals would be less likely to participate in illness-related studies or activities.

Conclusion

Diverse representations of fatigue emerged from these profile types and along these continuums. Fatigue was alternately viewed as “normal”, as an illness symptom representing a barrier to social or physical activities, or as a means of “combatting” illness. The distinction between types of fatigue reflected differences between what researchers refer to as acute fatigue, stemming from physical exertion, and chronic fatigue, viewed as illness-related (Kluger et al., 2013). While chronic fatigue is less understood medically, it was shown here to be typically understood, socially, as an illness-related symptom, opposed to “normal” fatigue occurring due to positive or “chosen” circumstances such as PA or work. Views on PA illustrated various degrees of interiorized medical expectations regarding health behavior expectations for the chronically ill, ranging from preserving the body from PA to preventing over-exertion through moderate PA. The ideal type attitudes enabled us to depict the diversity of discourse and attitudes regarding fatigue and PA, and the relations between them.

More largely, the lens of ideal type attitudes toward fatigue and PA allowed us to consider how attitudes toward certain illness symptoms (i.e., fatigue) or health behaviors (i.e., PA) were integrated into narratives regarding the elaboration of identity and lifestyle choices as a person living with HIV. Future research might explore further the role of socialization processes within or outside of HIV and medical networks in the elaboration of these choices, narratives and
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identity processes, recent literature having shown for example that accepting HIV and illness identity may be composed of comparable phases throughout the illness experience (Baumgartner & David, 2009). While most narratives in the present study reflected various degrees of interiorized public health messages related to healthy living and PA, these messages appeared to strengthen the omnipresence of HIV and the “medicalization” (Crawford, 1980) of the daily lives of people living with HIV (Pierret, 2006). This may suggest a need for adapting health messages and actions to reduce identities of “illness” and to facilitate feelings of “normalcy”. The “No sport, no problem” ideal type profile may provide some keys to reducing the presence of illness in identity narratives, thereby reducing the predominance of HIV in everyday life.

Despite providing an analytical framework to depict a diversity of discourse and attitudes, the ideal type typology also presented drawbacks, namely by limiting the frames of analysis. The theoretical continuum sought to compensate for this limit. Further research might seek to situate more diverse illness symptoms or health behaviors along more clearly defined continuums or among a larger number of people living with HIV. This could lead to a diversified typology and a refined understanding of illness experiences and narratives. It might also be interesting to draw clearer links between attitudes toward fatigue and PA, on the one hand, and clinical data and symptoms as understood by the medical community, on the other. Such research perspectives would continue to advance understanding of illness experiences and trajectories, and how to accompany them towards improving not only the medical dimension of health, but also its social and psychological dimensions.

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Etude 3. Corrélats sociaux et culturels de la fatigue physique perçue chez les PVVIH

La troisième étude visait à comprendre les corrélats sociaux et culturels de la fatigue physique perçue chez les PVVIH, en explorant par questionnaire : l’intensité de la fatigue, les caractéristiques sociodémographiques et le niveau d’AP. Au total, 560 PVVIH en France ont complété une mesure de la fatigue physique perçue en utilisant l'échelle d'intensité de la fatigue. Les prédicteurs visaient les caractéristiques sociodémographiques et deux mesures du niveau d’AP déclaré par les individus. Les données ont été analysées au moyen d'un modèle de régression multiple par étapes.

Les résultats ont montré notamment qu’un plus jeune âge et un plus haut niveau d’AP ou catégorie socioéconomique (CSP) étaient associés à une fatigue physique perçue moins élevée chez les PPVIH.

Ainsi, l’ensemble des résultats - obtenus grâce aux études menées dans le premier volet - suggèrent que, si des facteurs sociaux et culturels (tels que l’âge, la catégorie socioprofessionnelle ou la pratique d’AP) sont associés à la fatigue perçue, la mise en visibilité de cette fatigue – le fait de l’exprimer par son corps ou par ses discours – répond à des logiques sociales et identitaires (e.g., des effets de genre, de contexte de prise en charge, de rapport à la maladie).

Cette étude a fait l’objet de la publication suivante :
Perceived HIV-related physical fatigue, sociodemographic characteristics and physical activity: A cross-sectional study

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Abstract

Aims and objectives: To get a deeper understanding of correlates of perceived HIV-related fatigue by exploring its associations with sociodemographic characteristics and physical activity level of HIV-infected people.

Background: Previous studies on HIV-related fatigue have mainly focused on physiological and psychological characteristics, but few have considered its associations with sociodemographic variables. In addition, while physical activity has been found to reduce acute fatigue among HIV-infected people, its links with chronic HIV-related fatigue remain to be explored.

Design: The study employed an observational and cross-sectional survey design. The manuscript was organised according to STROBE guidelines.

Method: A total of 560 people living with HIV in France completed a measure of perceived physical fatigue using the Fatigue Intensity Scale. The predictors targeted sociodemographic characteristics and two measures of individuals’ reported level of physical activity. Data were analysed by a stepwise multiple regression model.

Results: The results showed that lower age, higher physical activity level and socioeconomic status were significantly associated with reduced perceived physical fatigue, explaining 25% of the variance.

Conclusions: The results highlighted the importance of considering sociodemographic and lifestyle characteristics to better characterise HIV-related fatigue, in particular in an era where HIV as a chronic illness challenges questions of quality of life throughout increasingly longer lifespans.

Relevance to clinical practice: The results of this study have implications for HIV care professionals in terms of improving strategies for managing chronic fatigue or promoting physical activity according to more specific profiles of HIV-infected people.

Keywords
active lifestyle, chronic illness, fatigue, HIV, physical activity, sociodemographic characteristics
The aim of this study was to better understand the correlates of perceived HIV-related fatigue by exploring its associations with sociodemographic characteristics and level of physical activity among people living with HIV-infected people. Fatigue is one of the most distinctive symptoms of the human immunodeficiency virus (HIV). Between 55%–65% of HIV-infected people attributed a primary role to fatigue in their daily lives (Barroso & Voss, 2013; Breitbart, McDonald, Rosenfeld, Monkman, & Passik, 1998; Fontaine, Larue, & Lassauinière, 1999). In a meta-analysis including 42 studies, Jong et al. (2010) reached a wider range, with fatigue affecting between 33%–88% of HIV-infected people. A comparative survey on quality of life among HIV-infected people in eight countries also found that fatigue was frequently reported (Duracinsky, Herrmann et al., 2012).

Fatigue is a polysemous concept that refers to a state resulting from the interaction of physical and mental sensations, from which one does not recover with simple rest and which can be present for several years (American Heritage Stedman's Medical Dictionary, 1995). The subjective feeling of fatigue, or perceived fatigue, refers to “subjective sensations of weariness, increasing sense of effort, mismatch between effort expended and actual performance, or exhaustion” (Kluger, Krupp, & Enoka, 2013). Study of fatigue has attempted to distinguish between types of fatigue, mainly chronic exhaustion and lack of energy (Krupp, LaRocca, Muir-Nash, & Steinberg, 1989; Lee, Lentz, Taylor, Mitchell, & Woods, 1994), on the one hand, and acute fatigue or fatigability resulting from physical exertion, on the other hand. The present study focused on the correlates of the former: chronic physical fatigue among HIV-infected people, referred to here as perceived physical fatigue, which can significantly impact quality of life (Barroso & Lynn, 2002).

2 | BACKGROUND

To date, the literature has focused on two main groups of variables to explain the origins or the correlates of HIV-related fatigue. On the one hand, there is a debate about the role played by physiological factors. Among these studies, some authors argued that the severity of viral load and a low CD4+ T-cell count was associated with a greater feeling of fatigue (Currier et al., 2008; Lee, Portillo, & Miramontes, 1999), while other studies found no significant correlations (Barroso, Leserman, Harmon, Hammill, & Pence, 2015; Henderson, Safa, Easterbrook, & Hotopf, 2005). Similarly, some studies put forth that fatigue may be a side effect of antiretroviral therapy (ART) (daCosta DiBonaventura, Gupta, Cho, & Mrus, 2012), but contradicting results led several authors to point out that that HIV treatments could not be a principal cause of fatigue (Barroso et al., 2010; Barroso & Voss, 2013). On the other hand, many studies have considered the role of psychological variables. Depression appears as the most significant correlate of fatigue (Barroso, 2001; Barroso & Lynn, 2002; Breitbart et al., 1998; Millkin, Rourke, Halman, & Power, 2003). Moreover, given that HIV represents a potentially anxiety-provoking pathology, studies also found correlations between anxiety and fatigue (Barroso, Carlson, & Meynell, 2003). However, although previous studies have shown that both psychological and psychological factors play an indisputable role in understanding some manifestations of fatigue, the discrepancies suggest that other factors play a role, such as social, economic or lifestyle contexts.

Some studies have indeed shown significant links between fatigue and sociodemographic characteristics among people living with HIV. For example, some authors found a correlation with socioeconomic status, likely due to the effects of job insecurity on quality of life and mental health. For instance, perceived fatigue among people living with HIV has been shown to be more prevalent among the unemployed and those with lower income levels (Barroso et al., 2010). In addition, the perception of HIV-related fatigue seems to vary according to gender, women more often perceiving HIV-related fatigue than men (Duracinsky, Lalanne et al., 2012), especially poorer women (Harmon, Barroso, Pence, Leserman, & SalahuDin, 2008; Voss, 2005). In terms of age, older people have been shown to perceive greater fatigue than younger people, especially when suffering from a chronic disease (Watt et al., 2000). These factors are therefore important variables to consider, age in particular, in view of the increasing lifespans of people living with the HIV virus (Blavan, Kampalath, & Overton, 2008; Douab et al., 2014). Other studies have underlined that fatigue within the general population is greater among minority groups such as immigrants (Castañeda et al., 2015; Fleischman, Willen, Davidovitch, & Mor, 2015) and, when comparing among people living with HIV, among gay men (Barroso et al., 2010; Sewell et al., 2000). This may be due to political or social barriers that limit social and economic opportunities and affect well-being. Furthermore, links have been found between social support and fatigue due to the negative effects of loneliness or limited social ties on mental well-being (Barroso et al., 2010; Honn & Bornstein, 2002; Murphy, Moscicki, Vermund, & Muenz, 2000).

With respect to lifestyle characteristics, the effects of an active lifestyle among HIV-positive people have long been documented in scientific literature (Nosrat, Whitworth, & Ciccolo, 2017; Quiles, Ciccolo, & Garber, 2017; Vancampfort et al., 2017). Regular and moderate physical activity has been shown to positively affect the quality of life of HIV-positive people, for example, reducing acute fatigue, muscular weakness or pain caused by antiretroviral therapy.
The aim of this study was therefore to simultaneously consider sociodemographic characteristics and physical activity level, in the larger aim of furthering the understanding of correlates of HIV-related fatigue.

However, to our knowledge, the association between physical activity and perceived fatigue has rarely been considered on a large scale beyond experimental protocols and has rarely been considered within the framework of individuals’ social and economic contexts and lifestyles. In addition, the type of fatigue tested in relation to physical activity has mainly concerned acute fatigability tied to physical exertion as tested, for example, by time spent on a treadmill (Ciccolo et al., 2004; Dudgeon, Phillips, Bopp, & Hand, 2004), whereas we were interested here in chronic fatigue (Kluger et al., 2013). In line with existing literature, this study questioned whether the sociodemographic characteristics of HIV-infected people (e.g., age; gender; and socio-economic status) and their active lifestyle (i.e., level of physical activity) were significant correlates of their perceived chronic physical fatigue. Indeed, although sociodemographic and lifestyle characteristics—namely physical activity—have been studied independently in relation to HIV-related fatigue, their respective contribution to chronic fatigue remains to be established. The aim of this study was therefore to simultaneously consider sociodemographic characteristics and physical activity level, in the larger aim of furthering the understanding of correlates of HIV-related fatigue.

3 | METHOD

3.1 | Design

A survey design was used to collect data. The present observational and cross-sectional study was part of a larger study carried out in France between 2014–2015, which was developed to evaluate and alleviate HIV-related fatigue. The structure of the manuscript agreed with STROBE requirements (See Supporting Information File S1).

3.2 | Questionnaire

In order to study the associations between perceived physical fatigue, physical activity level and particular sociodemographic characteristics, we developed a questionnaire containing several validated measures and selected sociodemographic variables.

3.2.1 | Perceived physical fatigue

Perceived physical fatigue was measured thanks to the subscale of Fisk et al. (1994)—Fatigue Intensity Scale (FIS)—which focuses on physical fatigue and has been previously used and validated in French by Marcellin, Préau, Dellamonica et al. (2007), Marcellin, Préau, Ravaux et al. (2007). An example item is: I have trouble maintaining physical effort for long periods, with 6-point Likert scales from 1 (not agree at all)—6 (strongly agree). This subscale was selected because it is specifically related to physical fatigue characteristics as opposed to other scales (e.g., Barroso & Lynn, 2002) in which the characteristics of fatigue are confounded with their triggers, circumstances and consequences. In the present study, this scale demonstrated a good internal consistency (Cronbach’s alpha = 0.87).

3.2.2 | Physical activity level

Physical activity level was measured by two scales. The first was the French version of the Stages of Change of Exercise Behavior Scale (SCEB) (Marcus & Owen, 1992). This scale enabled measuring five stages of readiness to exercise, ranging from “maintenance” of regular physical activity—namely 2:30 hr per week—(5) to “pre-contemplation” of practice, meaning the lack of feeling concerned by regular practice (1). The second measure was the Dijon Physical Activity Score (DPAS) (Robert et al., 2004) which allows to calculate physical activity level based on a nine-item scale. The scale includes: (a) an overall appraisal of one’s physical activity (e.g., “Do you consider yourself to be physically: (a) very active and athletic, to (d) completely sedentary?”); (b) two items on everyday activities (e.g., “On a weekly basis, your everyday activities take you: (a) more than 10 hr, to (e) no time spent”); (c) five items on sport and leisure activities (e.g., “For how many months of the year do you engage in these activities (sport or leisure)?”); and (d) one item on rest (e.g., “On a daily basis, you rest (sleep, nap or wakeful rest): (a) < 12 hr, to (d) more than 20 hr”). The scores for the items are added and the total score corresponds to a level of physical activity with the maximal score being 30 points. In the present study, the scale showed a good reliability (Cronbach’s alpha = 0.75). This measure has been shown to be reproducible and to be a valid measure of physical activity both in older people (Robert et al., 2004) and in chronic diseases such as coronary artery disease (Grompeux et al., 2008; Guiraud, Granger, Bousquet, & Grompeux, 2012). The use of both of these measures allowed for grasping the global engagement in physical activity. While the SCEB more narrowly focuses on physical activity in the form of designated leisure time (e.g., footing, swimming and bicycle), the DPAS includes everyday activities included in one’s active or sedentary lifestyle (e.g., walking to work, active transportation, shopping, gardening and housework).

3.2.3 | Sociodemographic variables

The following six sociodemographic independent variables were evaluated: (a) gender, (b) year of birth—as a proxy of the age, (c) marital status, (d) number of children, (e) sexual orientation, (f) country of birth, (g) socio-economic status (derived from the classification...
provided by the French National Institute of Statistic and Economic Studies, 2003) and (h) level of education.

3.3 | Data collection

We collected the data in the departments of infectious diseases within three French hospitals participating in the encompassing nationwide study supported by the French National Agency for Research on AIDS and viral hepatitis (ANRS). To collect data, we carried out a systematic sampling approach. As underlined by Coolican (2017), this strategy allows for selecting participants from a list of population members after identifying the sample size and it is more simply than a random sampling technique (Coolican, 2017). With this aim, the participating hospital departments were chosen to represent different regions in France, one from the capital and two from major cities in two other geographical poles of the country. In terms of patient recruitment, as fatigue has been shown to be more common among people co-infected with hepatitis C (HCV) (Harmon et al., 2008), HCV co-infected people were excluded. For similar reasons, people with cancer and renal dysfunction were also excluded, as were pregnant women. A total of 560 HIV-infected adults were selected by the method of proposing the survey to every consecutive patient over a set period of a month, between October and December 2014. This sample size was calculated according to Tabachnick and Fidell (2007) guidelines. The participants could read and understand the questionnaires written in French. Each participant completed the survey in a confidential space in the hospital after giving written consent. Ethical approval was obtained from the French National Commission for Data Protection and Liberties (CNIL) (no. CIL/UNS/2015/00017). Completion of the survey took between 15–25 min.

3.4 | Data analysis

Data analysis was conducted in several stages using SPSS 22. Preliminary data analysis included descriptive and bivariate analysis techniques. Multiple imputation procedure was used to handle missing data (Li, Stuart, & Allison, 2015). To identify differences in perceived physical fatigue according to sociodemographic characteristics (e.g., gender; sexual orientation; marital status; and socio-economic status), a t test for independent groups or analysis of variance (ANOVA) was employed. To identify the relationship between continuous variables (perceived physical fatigue, physical activity and age), the Pearson's correlation coefficient was used. Then, in order to determine the unique contribution of sociodemographic variables and physical activity to perceived physical fatigue, we computed a stepwise multiple regression analysis with the significant factors (p < 0.05) (Tabachnick & Fidell, 2007). The categorical variables were recorded as dummy variables. As independent variables were either dichotomic, ordinal, categorical or continuous, we followed the recommendations of Cohen (1968) for their coding with mean centring (see also Tabachnick & Fidell, 2007). The dichotomous variables were coded: -1/1.

4 | RESULTS

4.1 | Descriptive statistics

The means and standard deviations of perceived physical fatigue according to the sociodemographic characteristics are reported in Table 1. Perceived physical fatigue was significantly related to several of the sociodemographic characteristics variables tested in this study. Women reported higher scores of fatigue than men (p < 0.001), as well as people with at least one child as compared to people without children (p < 0.001) and people born in a foreign country as compared to people born in France (p < 0.001). Furthermore, unemployed people showed greater fatigue than active people (F(2, 560) = 10.01, p < 0.001; Table 1). Single people as compared to nonsingle people (p = 0.315) and heterosexual people as compared to people with other sexual orientations (p = 0.252) did not show significant differences in fatigue.

Pearson correlations between continuous variables are reported in Table 2. The Stages of Change of Exercise Behavior Scale (SCEB) (p < 0.001, r = -0.26) and the Dijon Physical Activity Score (DPAS) (p < 0.001, r = -0.41) showed significant negative correlations. In other words, the practice of physical activity was inversely correlated with the perception of physical fatigue. Lastly, although the Pearson coefficient was weak (p < 0.001, r = -0.16), the perception of physical fatigue was significantly and negatively related to the year of birth, suggesting the older the person living with HIV, the higher their perceived physical fatigue.

Stepwise multiple regression analysis was carried with the above-mentioned significant variables and displayed the following results. The first model was statistically significant (p < 0.001; R² = -0.17) (Table 3). The main predictor was the DPAS: physical activity level was negatively related to perceived physical fatigue (β = -0.413, p < 0.001). The second model was significant (p < 0.001; R² = 0.20), as was the R² change (p < 0.001). In this case, the second main predictor was the year of birth, which was inversely linked with the feeling of physical fatigue (β = -0.201, p < 0.001). Finally, the third model was significant (p < 0.001; R² = 0.20) as was the R² change (p < 0.001). The third predictor was socio-economic status: unemployed people felt greater fatigue than active people (β = 0.173, p = 0.003). The effects of the other variables were nonsignificant: gender (p = 0.124), number of children (p = 0.228), country of birth (p = 0.389) and active versus retired people (p = 0.951). The SCEB scores did not show significant contribution (p = 0.756), probably due to the role played by the DPAS. Table 3 reports more details.

5 | DISCUSSION

This study focused on under-investigated associations between HIV-related fatigue, sociodemographic characteristics and level of physical activity, the latter being considered as a lifestyle characteristic. Our main result was that physical activity level, age and socio-economic status were significantly associated
with perceived physical fatigue, explaining 23% of the variance. Regarding physical activity, the degree of physically active lifestyles was negatively associated with perceived physical fatigue among HIV-infected people. In other words, the greater the amount of physical activity, the lower the perceived physical fatigue. This result complements recent findings showing that the number of minutes of home-based physical activity was significantly associated with reduced self-reported fatigue in people living HIV (Webel et al., 2016). In the same vein, Quiles et al. (2017) found that regular physical activity, whether aerobic or muscle-strengthening, was associated with “better physical and mental health” including weakened association with depression.

### TABLE 1

<table>
<thead>
<tr>
<th>Sociodemographic characteristics and overall means scores (M) and standard deviations (SD) for perceived physical fatigue (n = 560)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>Sex</td>
</tr>
<tr>
<td>Male</td>
</tr>
<tr>
<td>Female</td>
</tr>
<tr>
<td>Children</td>
</tr>
<tr>
<td>None</td>
</tr>
<tr>
<td>1 or more</td>
</tr>
<tr>
<td>Socio-economic status (SES)</td>
</tr>
<tr>
<td>Active people</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Unemployed</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Retired</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td>Civil status</td>
</tr>
<tr>
<td>Single</td>
</tr>
<tr>
<td>In couple</td>
</tr>
<tr>
<td>Sexual orientation</td>
</tr>
<tr>
<td>Heterosexual</td>
</tr>
<tr>
<td>Other</td>
</tr>
<tr>
<td>Country of birth</td>
</tr>
<tr>
<td>Born in France</td>
</tr>
<tr>
<td>Born in foreign country</td>
</tr>
</tbody>
</table>

*a* test for independent groups. *b* Analysis of variance (ANOVA) with Bonferroni post hoc test.

### TABLE 2

Table 2: Means (M), standard deviations (SD) and the matrix of correlations for continuous variables (n = 560)

<table>
<thead>
<tr>
<th></th>
<th>M</th>
<th>SD</th>
<th>ESC</th>
<th>DPAS</th>
<th>Year of birth</th>
<th>PPF</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise stage of change</td>
<td>1.61</td>
<td>0.48</td>
<td>-0.58</td>
<td>-0.07</td>
<td>-0.26</td>
<td></td>
</tr>
<tr>
<td>p</td>
<td>&lt;0.001</td>
<td>0.071</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td></td>
<td>20.18%</td>
<td>5.54%</td>
<td>8.39%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dijon Physical Activity Score</td>
<td>20.92</td>
<td>4.41</td>
<td>1</td>
<td>-0.05</td>
<td>-0.41</td>
<td></td>
</tr>
<tr>
<td>p</td>
<td></td>
<td>0.249</td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td></td>
<td>18.93%</td>
<td>21.25%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year of birth</td>
<td></td>
<td>1962</td>
<td>10.23</td>
<td>1</td>
<td>-0.16</td>
<td></td>
</tr>
<tr>
<td>p</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing data</td>
<td></td>
<td></td>
<td>7.14%</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Perceived physical fatigue</td>
<td>3.19</td>
<td>1.56</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. ESC: exercise stage of change; DPAS: Dijon Physical Activity Score; PPF: perceived physical fatigue.
Cumulatively, these results suggest that regular physical activity and active lifestyles are associated with reduced fatigue and depression. Although the relationship between physical activity and perceived fatigue or depression can be bidirectional, these results suggest that physical activity and active lifestyles probably have attenuating and preventive effects on chronic fatigue and depression, as would also suggest the extensive literature on the benefits of physical activity among the general population as well as among people living with other chronic illnesses (Ciccolo et al., 2004).

Results also pointed to perceived physical fatigue increasing with age, measured by the year of birth. The younger the participants, the lower the perceived physical fatigue. Although this result corresponds to certain literature relative to chronic fatigue (van Mens-Verhulst & Bensing, 1998), it has rarely been evidenced in relation to HIV-related fatigue. This result therefore appears as significant, in particular in light of the evolution of HIV towards a chronic disease and the growing number of increasingly older people living with HIV. The interest of this result relates to both health policies and care. As underlined by the French survey VESPA2 (Wilson et al., 2014), it raises the question of whether older people living with HIV have specific needs in relation to HIV-negative peers, and if so how to provide adapted care. Indeed, older HIV-infected people are also more frequently concerned by side effects of ART and handicaps (Wise, 2015).

As regarding socio-economic status, unemployed people perceived greater physical fatigue than active people. This result is consistent with the literature showing an association between socio-economic conditions and both health and fatigue among people living with HIV (Barroso et al., 2010; Harmon et al., 2008; Voss, 2005). Several studies on the social and psychosocial consequences of unemployment have underlined that economic instability may have physical and mental health consequences, including the feeling of fatigue (Adler & Ostrove, 1999; McKee-Ryan, Song, Wanberg, & Kinicki, 2005). This result underlines the interest of according specific attention not only to older but also to poorer and unemployed HIV-infected people, in terms of promoting physical activity or fatigue management programmes. The question of employment also underscores the importance of increasing work opportunities for HIV-infected people, in particular by seeking to reduce HIV stigma in French society, as HIV stigma has been correlated to unemployment among HIV-related people (Liu, Canada, Shi, & Corrigan, 2012).

Despite its findings, our study should be considered in light of its limitations. First, although our study was multi-centred, our sample was not representative from an epidemiological point of view. Our correlational study allowed us to explore relationships between variables but prevented us from demonstrating causality, thereby limiting the generalisability of the results. In this sense, our results focused mainly on the internal validity of the data. Second, regarding the measure of fatigue, we voluntarily focused on a specific subscale related to perceived physical fatigue (Fisk et al., 1994). As fatigue can be defined and measured in a variety of ways, it would be interesting in future research to consider other dimensions of fatigue. An example would be the HIV-Related Fatigue Scale (HRFS) by Barroso and Lynn (2002) which aims at also grasping other aspects of fatigue such as the impact on mental functioning and the triggers/relievers of fatigue. At the same time, as fatigue is a multidimensional subjective state, a single measurement technique (e.g., questionnaire) is not sufficient to fully grasp its complexity. In this light, it would be interesting to consider physical activity and age in light of other types and measures of HIV-related fatigue, such as its social significations (Schuft, Duval, Thomas, & Perez, 2017) or through neuromuscular measures of fatigue (Twomey et al., 2017). Third, the statistical analysis we carried out showed that although the
predictors we progressively included in the models yielded significant effects, the increase in the total variance of perceived physical fatigue was relatively low. This probably means that to achieve a thorough understanding of perceived physical fatigue among HIV-positive people, additional predictors should be taken into account. In addition, during data collection for this study, we chose not to take into consideration the CD4+ T-cell level or the viral load because their correlation with fatigue is unclear according to the literature. The role of treatments was also not taken into consideration due to the immense diversity in medical profiles and treatments over diverse time spans, as well as the inconclusive results in previous studies linking fatigue to treatments (Barroso & Voss, 2013). Moreover, our data did not include depression, although correlations have recently been shown between depression and both perceived fatigue and lack of physical activity (Quiles et al., 2017). For these reasons, we preferred to focus on a reduced panel of understudied correlates of fatigue. Nonetheless, it is possible that in models containing additional sociological, psychological, physiological and clinical variables, the framework could be more complex.

Future studies should consider examining important related questions to the results of this study. It would, for example, be useful to further elucidate the nature of the relationship between physical activity and perceived physical fatigue. Do HIV-infected people participate more in physical activity when perceived fatigue is low? Alternatively, is lower perceived fatigue due to higher physical activity? It is not possible to draw causal relationships from the available data, as our design was correlational, but it would be worthy of further investigation using qualitative or experimental longitudinal approaches. In addition, the underlying mechanisms of the relationship between physical activity and fatigue require further investigation. What are the mechanisms, whether physiological, social or psychological, that explain our findings regarding the negative relation between physical activity and fatigue? The literature suggests several hypotheses that could be explored in future research. For instance, studies have reported numerous psychological and physiological benefits to specific programmes of physical activity by reducing certain side effects of antiretroviral treatments such as lipodystrophy, insomnia and depression (Dolan et al., 2006; Florindo, de Oliveira Latorre, Jaime, & Segurado, 2007; Jaggers et al., 2014), strengthening the immune system (Mimura et al., 2008) or reducing the viral load (O’Brien, Nixon, Tynan, & Glazier, 2004). It is therefore quite possible that all of these benefits increase physical tonus and mental health, subsequently reducing perceived physical fatigue. Moreover, recent studies indicate that physical activity may have a positive effect on compliance (Corbinaut & Carvalho, 2014; Penedo & Dahn, 2005), which could in turn hasten HIV disease progression (Cook, Sousa, Matthews, Meek, & Kwong, 2011; Foster et al., 2012). It would be interesting to verify the role of fatigue in this relation. It is, for example, possible that by mitigating the side effects of treatments, physical activity increases the probability of continuing treatments, which may positively affect both health and fatigue levels.

6 | CONCLUSION

Despite its limitations, this correlational study allowed to examine under-investigated associations between HIV-related fatigue, sociodemographic characteristics and level of physical activity. Results showed that physical activity level, age and socio-economic status were significantly associated with perceived physical fatigue, among HIV-infected people. This study suggests that insufficiently active lifestyle, older age and unemployment might be risk factors for perceived physical fatigue in this population.

7 | RELEVANCE TO CLINICAL PRACTICE

The results of this study suggest the importance of continuing research in order to better understand the range of correlates characterising HIV-related fatigue and its association with physical activity. The results have implications for HIV care professionals seeking to better meet the needs of specific categories of HIV-infected people who are at greater risk of suffering from fatigue. Sociodemographic and lifestyle correlates of HIV-related fatigue offer the possibility to adapt strategies of managing chronic fatigue management or promoting physical activity to more specific profiles of HIV-infected people. Our results suggest, for example, that older or poorer and unemployed people living with HIV, as well as single mothers or socially isolated HIV-infected people, more vulnerable to fatigue, could be better accompanied or oriented in terms of programs or aid for managing fatigue. This could also come in the form of a medical prescription for physical activity, owing to new French public health legislation encouraging physical activity as a form of medical care for chronic illness (article de loi 1172-1 of March 27, 2015). This might also improve patient–doctor relations by increasing medical consideration for this symptom, often felt as disregarded by medical personnel according to HIV-infected people in France (Schuft et al., 2017).

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CONFLICT OF INTEREST

The authors declare that they have no conflict of interest.

ETHICAL APPROVAL

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional
and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

INFORMED CONSENT

Informed consent was obtained from all individual participants included in the study.

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REFERENCES


**SUPPORTING INFORMATION**

Additional supporting information may be found online in the Supporting Information section at the end of the article.
L’objectif de ce deuxième volet était de mieux comprendre les relations entre les stéréotypes liés à l’AP, la fatigue physique perçue et le niveau d’AP des PVVIH. Ce volet a intégré trois étapes complémentaires. Dans un premier temps, une étude qualitative a été conduite auprès de 15 PVVIH afin d’identifier la place des stéréotypes parmi les barrières à l’AP et de caractériser le contenu de ces stéréotypes. Dans un deuxième temps, nous avons développé une échelle psychométrique permettant de mesurer ces stéréotypes. Dans un troisième temps, nous avons examiné les relations entre ces stéréotypes et le niveau d’AP des PVVIH, et le rôle joué par la fatigue physique perçue et l’auto-efficacité dans cette relation.

Etude 1: Barrières et facilitateurs perçus de l’activité physique chez les PVVIH: une étude qualitative chez un échantillon français.

Les bénéfices de l’activité physique (AP) chez les PVVIH sont nombreux et largement démontrés dans la littérature. Comprendre pourquoi les PVVIH s’engagent ou non dans l’AP apparaît comme une clé pour améliorer la qualité de vie de cette population. A travers une approche qualitative, notre étude a tenté d’identifier les barrières et les facilitateurs liés à la participation à une AP chez les PVVIH.

Un total de 15 entretiens semi-directifs effectués dans le Centre et dans le Sud de la France ont été analysés en suivant les principes de l’analyse thématique. Les résultats ont permis d’identifier des barrières et des facilitateurs liés à l’AP relevant de différentes dimensions (physique, psychologique et environnementale), venant enrichir la littérature existante.

Cette étude a débouché sur un article accepté par *Chronic Illness*: Perceived barriers to and facilitators of physical activity in people living with HIV: A qualitative study in a French sample.
Perceived barriers to and facilitators of physical activity in people living with HIV: A qualitative study in a French sample

Laura Gray1, Laura Schuft2, Alessandro Bergamaschi2, Valentine Filleul1, Serge S Colson1 and Fabienne d’Arripe-Longueville1

Abstract

Objectives: The benefits of physical activity in people living with HIV (PLHIV) are numerous and are largely reported in the literature. Understanding why PLHIV engage or not in physical activity is key to better accompanying health behaviors. Through a qualitative approach, our study sought to identify barriers to and facilitators of physical activity participation in PLHIV.

Methods: PLHIV were recruited by purposive sampling. Semi-structured interviews were carried-out in Center and Southern France. The data were analyzed following the principals of thematic analysis. Physical activity level was assessed through questions related to physical activity recommendations and a physical activity questionnaire.

Results: Fifteen semi-structured interviews (seven men and eight women; \(M_{\text{age}} = 46.6; \text{SD} = 10.3\)) were analyzed. Only a third of our sample was considered physically active with almost half being considered inactive according to recommendations. A multidimensional perspective of physical activity barriers and facilitators emerged. Barriers to and facilitators of physical activity were related to the physical, psychological and socio-environmental domains.

Discussion: Our research sought to better understand the beliefs and attitudes of PLHIV towards physical activity. Physical activity was overall viewed as beneficial by both active and less active PLHIV; however, PLHIV remain insufficiently active. This is discussed through our multidimensional approach of the barriers to and facilitators of physical activity.

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Physical activity, attitudes, fatigue, self-efficacy, social support

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Introduction
For people living with HIV (PLHIV) who have access to antiretroviral therapies, HIV is increasingly considered a chronic disease. PLHIV are living longer and are faced with health-related consequences of HIV and associated multi-morbidity. With the increasing life expectancy, quality of life and the prevention of possible co-morbidities are of increased importance. Physical activity (PA), defined as any body movement produced by skeletal muscles resulting in energy expenditure, has been widely praised as a means of improving quality of life but also of improving and sustaining the health of PLHIV. There is now an extensive volume of literature revealing benefits of regular PA for PLHIV, such as increased fitness, cardiorespiratory outcomes, improved body composition, immunological and virological outcomes, self-efficacy and life satisfaction.

Despite the multiple benefits of PA, however, a majority of PLHIV are not active enough according to the World Health Organization (WHO) recommendations consisting of at least 150 min of moderate-intensity aerobic PA per week and muscle-strengthening activities should be done on two or more days a week. Moreover, PLHIV have the highest levels of sedentary behavior reported in the literature among others, with sedentary behavior levels averaging at 9 h a day. According to one study, 53% of PLHIV walked between 10 and 30 min up to five times a week and only 28% reported meeting moderate intensity exercise recommendations. Walking was the preferred form of exercise but did not provide all the health benefits related to moderate and vigorous exercise. To encourage participation in PA, it is important to understand why PLHIV engage or not in PA.

The identification of barriers to and facilitators of PA in PLHIV is an emerging topic in scientific literature. A series of studies have used quantitative methods as evidenced in a recent review by Vancampfort et al. This review revealed that dropout from PA programs for PLHIV was higher among men, among those with a higher body mass index and among those with lower cardiorespiratory fitness and higher in aerobic training programs as compared to resistance training programs. Furthermore, Vancampfort et al. highlighted the correlates of participation in PA among PLHIV. Older age, a lower educational level, a lower number of CD4+ T cells/mm3, exposure to antiviral therapy, body pain and depression were the main barriers to PA. In contrast, higher cardiorespiratory fitness, higher self-efficacy, more perceived benefits and better health motivation were the dominant facilitators of PA.

Another series of studies adopted qualitative approaches to better understand the reasons for participating or not in PA programs. A study by Roos et al. in South Africa seeking to address PA adherence challenges in a home-based walking program highlighted physical, psychological and environmental barriers to PA among
PLHIV. Physical barriers included respiratory complaints and low-energy levels, while poor motivation and stress were considered as psychological barriers. Family responsibilities, sedentary jobs, weather and the social environment were identified among the environmental barriers to PA. With regard to facilitators of PA, fewer items were identified, but these included the involvement of family and friends (walking with a partner or children) or the community environment (i.e. access to parks or sports fields). Furthermore, Li et al.\textsuperscript{20} identified factors to consider when developing and implementing exercise programs for PLHIV, based on the evaluation of a PA program. Participants reported perceiving exercise benefits related to the physical, mental, cognitive and social domains. Moreover, they identified facilitators of accessing and participating in PA, such as structured exercise routines, low costs and group-based exercise, as well as barriers to engaging in and adhering to PA including lack of knowledge about how to exercise safely, periods of physical or mental illness such as fatigue or depression, other responsibilities resulting in lack of time (i.e. parenting and employment) and costs of gym membership. Beyond the factors to consider when developing and implementing exercise programs, a qualitative study by Montgomery et al.\textsuperscript{21} sought to describe experiences before, during and after engaging in a community-based exercise program from the perspective of PLHIV. Results highlighted how perceived benefits of exercise programs along with improvements in physical, mental and social health positively influenced adherence to exercise.

Very recently, a series of qualitative investigations in relation to theoretical frameworks such as the Transtheoretical model of change\textsuperscript{22} or the Theoretical Domains Framework (TDF)\textsuperscript{23} showed that social support, perceptions and beliefs, experience with exercise and accessibility influenced readiness to exercise among PLHIV. Vader et al.\textsuperscript{24} enriched these findings by looking at the perceptions of PLHIV towards PA and exercise. They identified beliefs related to exercise benefits (including improved physical and mental functioning, preventing isolation) and exercise risks (including risks of physical injury and fear of overdoing it). Furthermore, Quigley et al.\textsuperscript{25} revealed that barriers to and facilitators of participating in yoga among older PLHIV fitted into all 14 domains of the TDF, including social influences, reinforcement, environmental context and resources, intentions to exercise, social/professional role/identity, knowledge about PA and exercise, beliefs and capabilities to exercise and beliefs about the consequences of PA and exercise. Importantly, beliefs about the physical consequences of PA and exercise were either considered as barriers, for example, fatigue and pain, or as facilitators, in that PA and exercise improve physical condition.

The aforementioned studies investigated PA barriers and facilitators among PLHIV in relation to structured PA within home-based or community-based exercise programs. In addition, most previous studies were conducted among Canadian populations, while no study to date has been conducted in France. Consequently, our in-depth study of the perceptions and beliefs of PA in the everyday lives of French PLHIV seeks to add to the existing literature and emphasize potential areas for focus in terms of protocols for intervention and promotion of PA. The aim of our study was thus to better understand the perceived barriers to and facilitators of PA among French PLHIV through a qualitative approach. Specifically, our study considered structured (i.e. exercise) and unstructured (i.e. gardening) PA in the everyday lives of a diverse group of PLHIV in order to describe their perceptions and beliefs of
PA and to identify the facilitating and hindering factors for an active lifestyle.

**Methods**

We conducted a descriptive qualitative study using face-to-face semi-structured interviews. We specifically focused on elucidating perceptions and beliefs of PA and exercise in everyday life, focusing on both the factors that hinder participation, namely, barriers to PA, and the factors that facilitate participation in PA among PLHIV. Our approach placed primary emphasis on saturation (i.e. obtaining a comprehensive understanding by continuing to sample until no new substantive information is acquired).

**Participants**

We used purposive sampling to recruit men and women living with HIV of various professional categories who were able to speak French, who were between the ages of 40 and 65, who were following antiretroviral therapy and were followed by doctors in one of the participating hospitals. Participating hospitals were located in the center and south of France. Participants needed to be available and willing to participate and able to communicate their experiences and opinions. All potential participants were contacted by telephone or e-mail and were informed of the study purpose and the topics that would be discussed during the interview.

**Procedure**

This study received ethical approval along national standards by the University of Nice Sophia Antipolis (n°CNIL/UNS/2015/0007). For data collection, individual semi-structured interviews were conducted in French at a location deemed appropriate by the participant between September 2014 and March 2015. This was either the participant’s home or at one of the recruiting hospitals. Prior to the interviews, interviewees signed voluntary informed consent forms guaranteeing the confidentiality of all data. Interviews were guided by a structured protocol of interview topics with follow-up probes drafted in collaboration between several members of the research team on the basis of the literature and previous research conducted on the role of PA in the daily life of PLHIV. The interviewer started the interview with a brief overview of the study purpose, then discussed confidentiality, reiterated that participation was voluntary and formally requested that the interview be recorded. Participants were asked to describe any current physical activities. They were then asked if they felt that their participation in PA was influenced by their HIV diagnosis with the objective of observing the ways in which their health behaviors were modified as a consequence of diagnosis. Hereafter, they were asked about the importance of PA in their lifestyle and what helps them to engage in PA or what causes any physical inactivity (‘Could you describe a typical day. (...) What helps you to be physically active?’). We prompted participants with more specific questions as to identify the different subthemes of barriers and facilitators. The median duration of interviews was 95 min.

After interview completion, participants were asked to fill out a demographic survey indicating gender, age, PA level, sexual orientation, country of birth, marital status, highest educational status, employment status and date of diagnosis. PA level was evaluated using a PA questionnaire, the validated Dijon PA Score, comprised of nine items allowing us to assess participants’ PA level including everyday activities, sport and leisure activities and rest. This tool has been used among other populations including older adults and patients with coronary artery disease.

**Data analysis**

**Interview transcripts.** The audio recordings and notes were transcribed verbatim in
French by the two researchers who conducted the interviews. The transcripts were numbered to ensure interviewee confidentiality. We analyzed the interview transcripts using thematic analysis based on the following steps suggested by Braun and Clarke: becoming familiar with the data, generating initial codes, searching for themes, reviewing and refining themes, identifying coherent patterns, defining and naming themes and producing the report. Transcripts were examined line by line to create codes that were interpreted as main concepts related to PA barriers and facilitators. Two researchers independently coded five transcripts to identify the main themes and meet to collectively review codes and reach an agreement to establish an initial coding scheme that was then used to analyze the remaining transcripts. All data and coding were managed using Word and Excel files.

Once coded, the research team reviewed the coding interpretations together and created an analysis layout. The codes were then separated into subthemes and grouped into broader themes verifying that they were representative of either barriers to or facilitators of PA and exercise. Member checking and inter-coder agreement were respected to develop rigor. During the analysis process, the themes and subthemes were revised several times. The initial analysis and classification were discussed, critiqued and repeatedly modified to obtain a satisfactory version for all the authors. Data were analyzed until data saturation was reached. Data were coded and analyzed in French then translated into English and translated back into French to ensure linguistic equivalence of the excerpts.

**PA level.** Self-reported PA was measured based on the Dijon PA Score. The nine questions assessed: (a) overall appraisal of one’s PA (“Do you consider yourself to be physically: from (1) very active and athletic to (4) completely sedentary?”), (b) everyday activities based on two items (“On a weekly basis, your everyday activities take you: from (1) more than 10 h to (5) no time spent”), (c) sport and leisure activities based on five items (e.g. “For how many months of the year do you engage in these activities (sport or leisure?)”) and (d) rest (“On a daily basis, you rest (sleep, nap or wakeful rest): from (1) less than 12 hours, to (4) more than 20 hours”). The scores for each item were added, with the total score out of 30 points indicating a participant’s PA level. PLHIV scoring 18 of 30 or less was considered as insufficiently active according to recommendations. PLHIV with scores ranging from 19 to 22 were considered as seasonal or part-time exercisers and scores above 22 were indicators of active PLHIV. Participants were categorized as less active/inactive, seasonal exercisers or active not only based on their PA score but also taking into account verbal information given during the interview and calculated using the PA questionnaire.

**Results**

Data saturation was reached after the completion of interviews with 15 participants (seven men and eight women; mean age 46.6 ±10.3 years). All socio-demographic information for study participants can be found in Table 1. Nine of 15 participants were heterosexual (eight women and one man). Five of 15 participants were considered to be physically active, 7 of 15 participants were physically inactive and 3 of 15 were seasonal exercisers (meaning they only exercise in the summer months) based on the WHO recommendations and their reported PA discussed during the interview and calculated using the PA questionnaire. Most participants were French
and possessed higher education degrees (9 of 15). Six of the 15 participants were diagnosed before 1996 and six others between 1996 and 2005.

Line by line content analysis led to the identification of 394 coded units related to the study purpose including the characteristics of perceived barriers and the characteristics of perceived facilitators. Participants expressed a number of different perceptions and beliefs related to regular PA and exercise, as illustrated by both barriers to and facilitators of regular PA. Three main themes emerged from the data: (a) physical, (b) psychological and (c) socio-environmental aspects of PA.

### Table 1. Socio-demographic details of study participants.

<table>
<thead>
<tr>
<th>Socio-demographic details</th>
<th>Total sample (n = 15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender, n (%)</td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>7 (46.7%)</td>
</tr>
<tr>
<td>Women</td>
<td>8 (53.3%)</td>
</tr>
<tr>
<td>PA level n (%)</td>
<td></td>
</tr>
<tr>
<td>Active</td>
<td>5 (33.3%)</td>
</tr>
<tr>
<td>Inactive</td>
<td>7 (46.7)</td>
</tr>
<tr>
<td>Seasonal exercisers</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Sexual orientation n (%)</td>
<td></td>
</tr>
<tr>
<td>Heterosexual</td>
<td>9 (60%)</td>
</tr>
<tr>
<td>Homosexual</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>Age (years), mean ± SD (range)</td>
<td>46.6 ± 10.3</td>
</tr>
<tr>
<td>Country of birth</td>
<td></td>
</tr>
<tr>
<td>France</td>
<td>13 (86.7%)</td>
</tr>
<tr>
<td>Guinea</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Canada</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>Marital status n (%)</td>
<td></td>
</tr>
<tr>
<td>Single/never married</td>
<td>3 (20%)</td>
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<tr>
<td>Married/living with partner</td>
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<tr>
<td>Separated from partner</td>
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<tr>
<td>Divorced</td>
<td>2 (13.3%)</td>
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<tr>
<td>Widow</td>
<td>1 (6.7%)</td>
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<tr>
<td>Highest educational status n (%)</td>
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</tr>
<tr>
<td>Degree or higher degree</td>
<td>9 (60%)</td>
</tr>
<tr>
<td>Higher education below degree</td>
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</tr>
<tr>
<td>Secondary school qualifications</td>
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<tr>
<td>No formal qualifications</td>
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</tr>
<tr>
<td>Employment status n (%)</td>
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<tr>
<td>Employed full-time</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>Employed part-time</td>
<td>2 (13.3%)</td>
</tr>
<tr>
<td>Retired</td>
<td>3 (20%)</td>
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<tr>
<td>Disabled or unemployed</td>
<td>4 (26.7%)</td>
</tr>
<tr>
<td>Date of seropositive diagnosis n (%)</td>
<td></td>
</tr>
<tr>
<td>5 years ago</td>
<td>1 (6.7%)</td>
</tr>
<tr>
<td>5–10 years ago</td>
<td>2 (13.3%)</td>
</tr>
<tr>
<td>11–20 years ago</td>
<td>6 (40%)</td>
</tr>
<tr>
<td>20 years ago</td>
<td>6 (40%)</td>
</tr>
</tbody>
</table>

Note: Percentages were calculated based on the total number of participants. n: number; PA: physical activity; SD: standard deviation.
barriers and facilitators. All the identified themes and subthemes are presented in Table 2.

**Perceived barriers to PA**

PLHIV are faced with a number of physical, psychological and socio-environmental consequences of the disease and treatment side effects.

**Table 2.** Themes and subthemes of PA barriers and facilitators in physically active and less/non active PLHIV.

<table>
<thead>
<tr>
<th>Barriers to PA</th>
<th>N citations</th>
<th>N participants</th>
<th>Facilitators of PA</th>
<th>N citations</th>
<th>N participants</th>
</tr>
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<tbody>
<tr>
<td><strong>Physical</strong></td>
<td></td>
<td></td>
<td><strong>Benefits of PA</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td>35</td>
<td>13</td>
<td></td>
<td>13</td>
<td>11</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>14</td>
<td>7</td>
<td>Improved physical condition</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Gastric disturbances</td>
<td>6</td>
<td>4</td>
<td>Good fatigue</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Muscular and articular pain</td>
<td>8</td>
<td>3</td>
<td>Reduced pain</td>
<td>7</td>
<td>5</td>
</tr>
<tr>
<td>Emaciation</td>
<td>5</td>
<td>2</td>
<td>Resisting ageing</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td><strong>Psychological</strong></td>
<td></td>
<td></td>
<td><strong>Improved physical self-perceptions</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Negative physical self-perceptions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of perceived physical capacity</td>
<td>11</td>
<td>9</td>
<td>Improved self-efficacy</td>
<td>9</td>
<td>5</td>
</tr>
<tr>
<td>Lack of perceived physical appearance</td>
<td>9</td>
<td>5</td>
<td>To feel admired</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td><strong>Perceived risks of PA</strong></td>
<td></td>
<td></td>
<td><strong>Perceived benefits for health</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Risk of injury</td>
<td>13</td>
<td>8</td>
<td>Well-being</td>
<td>8</td>
<td>7</td>
</tr>
<tr>
<td>Contamination</td>
<td>7</td>
<td>4</td>
<td>PA as therapy</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>Fear of germs</td>
<td>5</td>
<td>2</td>
<td>PA as a way to normalization</td>
<td>5</td>
<td>2</td>
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<tr>
<td>Lack of motivation for PA</td>
<td></td>
<td></td>
<td><strong>Motivation for PA</strong></td>
<td></td>
<td></td>
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<tr>
<td>Lack of enthusiasm</td>
<td>11</td>
<td>5</td>
<td>Pleasure related to PA</td>
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<td>4</td>
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<tr>
<td>PA not a priority</td>
<td>8</td>
<td>4</td>
<td>PA as achievement</td>
<td>7</td>
<td>4</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Means of overcoming the illness</td>
<td>11</td>
<td>4</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>PA as a distraction</td>
<td>7</td>
<td>3</td>
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<tr>
<td><strong>Socio-environmental</strong></td>
<td></td>
<td></td>
<td><strong>Social facilitators</strong></td>
<td></td>
<td></td>
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<tr>
<td>Lack of social support</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No one to exercise with</td>
<td>10</td>
<td>8</td>
<td>Social ties/ affiliations</td>
<td>15</td>
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<td>Overprotective medical staff/ relatives</td>
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<td>Encouraging medical staff/ relatives</td>
<td>13</td>
<td>6</td>
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<td><strong>Social/family responsibilities/ activities</strong></td>
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<td></td>
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<tr>
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<td>6</td>
<td>Involvement in an organization</td>
<td>9</td>
<td>4</td>
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<tr>
<td>Other activities</td>
<td>13</td>
<td>5</td>
<td>Children/ Grandchildren</td>
<td>8</td>
<td>4</td>
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<tr>
<td>Studies</td>
<td>11</td>
<td>4</td>
<td>Pet to walk</td>
<td>7</td>
<td>3</td>
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<tr>
<td>Financial constraints</td>
<td>16</td>
<td>7</td>
<td>Financial support for PA</td>
<td>7</td>
<td>4</td>
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<tr>
<td>Climate constraints</td>
<td>9</td>
<td>5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of adapted PA offers</td>
<td>8</td>
<td>5</td>
<td>Adapted PA offers</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>PA adapted to fatigue</td>
<td>7</td>
<td>5</td>
</tr>
</tbody>
</table>

PA: Physical activity; N: number; PLHIV: people living with HIV.
expressed by almost all participants whether they were active or less active. One less active woman said:

But maybe, if I didn’t have this... this illness, I would have more energy, I don’t know, but... it’s difficult to do more than what I currently do. (Inactive woman)

Another frequently reported barrier among less active PLHIV was breathlessness:

It is exhausting, just going up a few stairs and I’m already out of breath. (Inactive woman)

Gastric disturbances and muscular and articular pain were also notable among less active PLHIV. At times, exercise-related pain was perceived as a barrier specifically in that it could aggravate existing pain. For example, this man spoke about pain:

Yes, I ache all over, I always have pain everywhere, in my joints and everywhere; so this does not encourage me to do physical exercise, you see what I mean. (Inactive man)

Emaciation or thinness was also one of the physical health barriers to PA identified by less active PLHIV, as weight loss was a consequential health issue. For example, this inactive woman said:

I was losing weight visibly, each time I started a physical activity, so... I gave up.

Overall, participants reported physical health barriers to PA despite their level of PA. This highlighted the importance of taking physical complaints into account when creating and implementing regular PA programs by regulating, for example, intensity, duration and recovery time.

Psychological barriers to PA. When describing their perceptions and beliefs about PA, three psychological subthemes emerged from our data: (a) negative self-perceptions, (b) perceived risks of PA and (c) lack of PA motivation. Among the psychological barriers to PA, negative physical self-perceptions related to lack of perceived physical capacity concerned six of seven less active participants but also three of five active PLHIV. The feeling of lacking physical capacity is illustrated by the following quote:

I can’t run like I did before, you see... I don’t feel capable of running... of running around the track like I did before, I just don’t... really. (Inactive woman)

Perceived risks of PA related to risk of injury was a barrier for less active and some seasonal exercisers and active PLHIV. As one person said:

Because you see... when I play... I can get injured. (Inactive woman)

Contamination was also a perceived barrier with the fear of contaminating a training partner due to an injury. For example, this seasonal exercising woman said:

It’s that if I get hurt, bleed or something, if I’m with other people, I’m really careful huh. (Seasonal exercising woman)

Finally, fear of germs appeared as a barrier to exercise in a few less active PLHIV. For example, at the swimming pool, as one inactive woman stated:

I can’t go to the hammam (steam room) anymore as I can’t sit on my mat where everyone has sat... I’ll catch all the germs there... (Inactive woman)
Furthermore, psychological barriers to PA included lack of motivation for PA, illustrated by lack of enthusiasm, which was relevant among seasonal and less active PLHIV:

Well you see I’m quite lazy, and even though I think of going for a walk, I just don’t feel like it… (Inactive man)

Participants acknowledged that they at times did not want to engage in PA due to their low perceived capacity for PA. Capacities were also often compared to the time before their diagnosis. Furthermore, some mentioned the risk of injury and contamination when considering PA participation. Lack of motivation also hindered PA participation.

Socio-environmental barriers to PA. Beyond the physical and psychological barriers identified at the individual level, more distal barriers also emerged in relation to the social environment and the accessibility of PA infrastructures. Specifically, the following subthemes were identified: (a) lack of social support, (b) time constraints, (c) financial constraints, (d) climate constraints, and (e) lack of adapted PA offers.

Lack of social support included not having someone with whom to exercise. This was mentioned by a large proportion of less active PLHIV but also by some active participants, as clearly illustrated in this less active woman’s words:

Alone, it’s hard for me to exercise. That’s the thing, alone, it’s hard for me. (Inactive woman)

Overprotective medical staff/relatives were relevant to the less active and seasonal exercisers:

My parents if they could put me in a jar… (laughter) to protect me huh… mostly, not moving, so that I can last the longest possible, perfuse me with food, so that I fatten-up, mother me huh… yes. (Inactive woman)

Time constraints related to profession or studies were also perceived barriers brought forth by active and less active PLHIV, as illustrated in the following quote:

Well, at the moment, I’m working on my classes, because I have exams in February (…) so, I don’t go to do sport, because… I’m not in the mindset to go to do sport. (Inactive woman)

Furthermore, other activities and climate constraints were also important socio-environmental barriers observed among seasonal exercisers but also one or two active and less active participants. This excerpt is an example of climate constraints:

Then in winter… at 6 o’clock it’s dark (laughter), like that, you have less desire to go (laughter). Whereas in summer… when you finish work at 3 o’clock, you go… you go do your sport, and afterwards, you go to the beach. It’s different. (Seasonal exercising man)

Finally, lack of adapted PA offers and financial constraints were also part of the socio-environmental barriers in particular among the active, less active and seasonal exercisers, although a greater proportion of less active participants referred to these barriers:

There are plenty of people who would like to do something, and I don’t mean weight lifting, maybe it’s swimming, it’s… cycling, maybe it was something, yoga or… but… they can’t afford it, it’s difficult to devote 50€ per month to… to subscribe to sports gyms or to go to the pool. (Active man)
Participants emphasized the importance of social support in engaging in PA, while the lack of someone with whom to exercise or overprotective medical staff and relatives were perceived as barriers. Time, financial and climate constraints consisted of socio-environmental barriers to PA. This suggests that home-based exercise programs may solve the environmental aspects of PA barriers. However, they may reinforce the barriers related to social support encouraging the implementation of group activities as well.

Overall the full French panel of active, inactive and seasonal exercising PLHIV reported barriers to PA. The barriers to PA appeared to be multidimensional, including physical, psychological and socio-environmental characteristics. These same multidimensional characteristics were also related to facilitators of participation in PA.

**Facilitators of PA**

The perceived facilitators of PA identified also referred to the physical, psychological and socio-environmental dimensions.

**Physical facilitators of PA.** Perceptions and beliefs that PA can promote health and provide physical benefits emerged at an individual level. Four subthemes of facilitators related to physical benefits of PA were identified: (a) improved physical condition, (b) ‘good’ fatigue, (c) reduced pain and (d) resisting ageing.

Improved physical condition was seen as a benefit of PA by both active and less active PLHIV. This less active woman said:

> I know, I know it would be good for my physical conditioning. I... I just don’t go out and do it... exercise. (Inactive woman)

‘Good’ fatigue was perceived as being generated by PA, which also emphasized the positive aspect of physical fatigue caused by voluntary exercise. For example, an active man said:

> It’s a good fatigue and I like it! I prefer this fatigue... to the one that hangs around for nothing huh, as I don’t know why I’m tired... (Active man)

Another active man explained how PA is a means to combat the disease and aging: “and combat age, as well huh, ... I don’t want... to be old...” (Active man).

Although many were not engaging in regular PA or exercise, most participants viewed PA and exercise as positive health-promoting behaviors. PA and exercise were seen as ways to maintain physical condition, generate ‘good’ fatigue, reduce pain, and reduce the effects of aging.

**Psychological facilitators of PA.** Positive beliefs and perceptions of PA were also identified at the individual level, with three main subthemes describing: (a) improved physical self-perceptions, (b) positive attitudes towards PA and (c) motivation for PA.

Improved physical self-perceptions included increased exercise self-efficacy. As this active man said:

> And there’s this motivation, to show myself that I’m still capable of doing everything (... it gives me confidence. (Active man)

Social recognition was also reported, as another active man explained:

> I attract admiration from youngsters as well because of... my sports career, huh, who don’t know my status, of course, my viral status. (Active man)

Perceived benefits for health were considered by seasonal exercisers and active
PLHIV as a means of increasing well-being or feeling normal:

“Doing sport, I feel good, (…) sport has always increased my well-being. It helps me to relax” (Active man) and even as therapy: “and physically as well… It’s an extraordinary… therapy!” (Active woman)

Motivation for PA was identified through: pleasure related to PA, PA as an achievement, PA as a distraction and PA as a means of overcoming illness. Mainly active and seasonal exercisers related to these motivations as facilitators. One active man said:

I wanted to prove to myself that… it [HIV] isn’t beating me! (…) Phew! More than that! It [PA] has saved my life! It’s what… psychologically, physically, I think it’s the most important things I’ve ever done, to… to stay very active (…) I won’t let it beat me! (Active man)

PA was perceived as a strategy to improve physical self-perceptions through increased self-efficacy and well-being. Motivation presented itself as another psychological facilitator with some participants finding pleasure in PA, viewing PA as an achievement and a means of overcoming the illness or even a distraction.

Socio-environmental facilitators to PA. At a more contextual level, four socio-environmental facilitators emerged from the analysis: (a) social facilitators, (b) social/family responsibilities and activities, (c) adapted PA offers and (d) financial access to PA. Social facilitators included encouragement from medical staff/relatives illustrated by this active woman’s quote:

I told him, my physiotherapist, that I wanted to age the least bad possible, that I needed to exercise. He answered that he wanted to make me an athlete again. (Active woman)

Social ties/affiliations were also social facilitators mentioned mainly by active PLHIV but also a few less active PLHIV. This active woman said:

Yes. Well, it’s yoga, that’s all huh; I’ve always felt really welcome, seeing the others… it’s a bond huh! (Active woman)

Social/family responsibilities and activities also acted as socio-environmental facilitators, such as involvement in an organization, taking care of children and/or grandchildren and walking a pet. These facilitators encouraged participation in PA, as illustrated by this active woman’s statement regarding her involvement in an organization:

We have a good time together that really do us good, I want to… It makes me want to dance you know!

Taking care of children/grandchildren was mentioned by both active and seasonal exercising PLHIV as a facilitator. For example, this seasonal exercising man said:

And then children, grandchildren, they make you run and move huh. (Seasonal exercising man)

Walking a pet was related by active PLHIV such as this woman:

Because my dogs need it! (laughter) Yeah. Yeah, at one point… as I got big dogs, well actually, I got big dogs and… well, a big dog, you can’t just take it out for a wee and go back inside huh; they need exercise and everything. So I started, I got big dogs, and afterwards, I started… walking, walking, and it does me good, I am happy; when I’m outdoors, when I walk with my dogs, I’m happy. (Active woman)
Moreover, adapting PA to fatigue emerged as a socio-environmental facilitator in active and even less active and seasonal exercisers, as illustrated in the following excerpt:

It’s a... it’s a fight to manage everyday, so the... uh... the jetlag... the fatigue, and then, the training. I adapt myself and I have an understanding trainer who also adapts, who adapts, adapts my training sessions. (Active man)

In addition, financial support from relatives or organizations encouraged participation in PA, as stated by active but also less active PLHIV. This revealed that although they may perceive this support as a facilitator, they may still remain insufficiently active. As one inactive woman said:

It’s my family who gave me my Nordic walking poles. (Inactive woman)

Social ties and activities were expressed as means to engage in PA with the environment within organizations considered contributing to regular PA participation through its social aspects of meeting other people but also the welcoming environment. Further environmental facilitators included the adaptive nature of PA and its implementation as well as financial support.

Perceptions of PA and exercise referred to both barriers to and facilitators of regular PA and exercise, as illustrated by physical, psychological and socio-environmental aspects of PA participation. Indeed, the perception of physical health benefits, improved physical self-perceptions, positive attitudes toward PA, PA motivation and social and environmental facilitators encouraged regular PA. Facilitators of PA were perceived not only by active PLHIV but also by less active PLHIV, even though their level of PA did not reflect their beliefs.

Discussion

The aim of our study was to enhance understanding of perceptions and beliefs about barriers to and facilitators of PA among active and less active French PLHIV through a qualitative approach. In our study, PA was overall viewed as beneficial on many levels by both active and less active PLHIV. Yet, regardless, only one third (5/15) of our participants were regularly active with almost half (7/15) considered as insufficiently active according to the WHO recommendations and less than a third (3/15) considered as seasonal exercisers as they were active only during the warmer months of the year. This distribution was in line with data provided in the recent literature review by Vancampfort et al.34 Main results revealed that both barriers to and facilitators of PA were multidimensional, with physical, psychological and socio-environmental dimensions, which supports the interplay of factors highlighted by Simonik et al.35 With regard to the barriers to PA, physical barriers were characterized by fatigue, breathlessness, gastric disturbances, muscular and articular pain and emaciation, while facilitators were related to improved physical condition, ‘good’ fatigue, reduced pain and resisting ageing. The psychological barriers were related to negative self-perceptions, perceived risks of PA and lack of motivation for PA, while the psychological facilitators were related to improved physical self-perceptions, positive attitudes toward PA and motivation for PA. As for the socio-environmental dimensions, barriers to PA included lack of social support, time, financial and climate constraints as well as a lack of adapted PA offers, while socio-environmental facilitators included social facilitators, social/family responsibilities and activities, adapted PA offers and financial support for PA.

In regard to the physical dimension, we noted that several concepts emerged both in
the perceived barriers and in the facilitators, with different meanings. Fatigue, for example, was considered a main barrier to PA, whereas ‘good’, PA-related fatigue was seen as a facilitator and a perceived benefit among physically active PLHIV. The prevalent status of fatigue highlighted in our study is in line with previous research where fatigue was reported as the most frequent symptom among PLHIV.36,37 Similarly, physical barriers such as breathlessness, muscular and articular pain and emaciation were also among the facilitators, when PA was a way of alleviating pain or improving physical condition. These physical barriers and facilitators previously identified in the literature, with muscular pain as part of body pain being reported,24,38 and higher cardiovascular fitness, as an index of improved physical condition, being associated with higher PA participation.15 Beyond the specificities of PLHIV, comparable physical barriers to and facilitators of PA have been reported among the elderly or in other populations with chronic diseases. For example, fatigue was an important barrier to participation in PA among older people39 and in cancer patients.40,41 With regard to the psychological dimension, lack of motivation for PA was an important factor acting as a barrier, reinforcing existing literature relative to PLHIV19,20,42 as well as other populations such as older adults39 and more widely in the general population.43 However, motivation was seen as a main psychological facilitator of PA, when PA was associated with pleasure, distraction, achievement or the will to overcome illness. Motivation to be active has consistently emerged as a facilitator of PA in the literature, whatever the population studied, whether children with disabilities44 or more generally adults.45

Beyond motivation, our study pointed to further psychological factors related to perceived benefits, risks and physical self-perceptions related to PA. As part of perceived benefits of PA for health, PA being used as therapy, was concomitant with the past research,42 the results of which revealed a self-care aspect of PA for many PLHIV. Perceived risks such as fear of injury, fear of contamination and fear of germs appeared to be other barriers to PA specific to PLHIV. Fear of sustaining an exercise-related injury was identified as a perceived risk and barrier to PA among PLHIV, confirming earlier findings24,42 and calling for knowledge about exercise to be considered when implementing exercise and PA programs. Fear of contamination appeared as an original barrier in our study not identified in recent literature. Although scientific literature has revealed a near zero probability of contamination in sports, fear seems to dominate these debates with the same questions reappearing.46 This fear could be reflective of HIV stigma47 and more specifically of mandatory HIV testing implemented in team sports years ago.48–50

In their negative form, physical self-perceptions concerning lack of perceived capacity to be physically active and negative perceived physical appearance consisted of barriers to PA. This lack of perceived capacity for exercise was already identified as a main psychological barrier to participation in PA among PLHIV in previous research.25 These findings are also in line with findings among cancer patients40,51 and older adults.52 Physical self-perceptions that facilitated PA among PLHIV included increased self-efficacy and body image and were in line with Fillipas et al.,53 who also showed that increased body fitness improved body image and participation in PA. Beyond the effects of self-efficacy among PLHIV, perceived exercise self-efficacy plays an important role in PA promotion in people with other chronic illness (multiple sclerosis54) and more widely in the general population.55

Finally, the socio-environmental dimension was largely characterized by social
support in our research. When related to as a barrier, lack of social support was illustrated by the idea of not having anyone to exercise with or having overprotective medical staff and/or relatives. This is largely consistent with other research revealing that lack of social support negatively impacts participation in PA among PLHIV.\(^{53,56}\) In its positive form, social support from friends, family and medical staff was an essential facilitator of PA in our research. Here again, social support has been positively related to increased PA participation among PLHIV.\(^{16,53}\) Support or lack of support from family, friends and medical staff was a persistent facilitator or barrier to PA in age- or illness-specific populations such as multiple sclerosis patients,\(^{57}\) asthma patients,\(^{58}\) or older people\(^{59}\) but also in the general population.\(^{59}\) Financial, time and climate constraints interfered with PA participation in the present study. Financial concerns and other activities were reported in previous research as prominent deterrents to PA among PLHIV.\(^{42}\) On the contrary, a stable income or financial support from relatives or organizations have encouraged PA among PLHIV.\(^{16}\) Other activities or social/family responsibilities including walking a pet or walking children to school increased PA among PLHIV and is consistent with the literature.\(^{19,42}\) Financial accessibility was also found to improve PA participation among older adults, for example.\(^{60}\) Beyond PLHIV, lack of time and weather conditions appear as generalizable dominant socio-environmental barriers to PA among the general population\(^{59}\) as well as among specific populations such as the elderly\(^{60}\) or asthma patients.\(^{58}\)

Additionally, considering the form of exercise or PA, recent research\(^{24}\) suggested that engaging in less formalized types of PA or exercise would be more realistic for long-term adherence, with further research advancing that less formalized PA may present comparable health benefits to more structured PA and exercise among PLHIV.\(^{61}\) Our findings, based on daily PA that can be considered as less structured PA, highlighted the importance of continuing to take into consideration barriers to and facilitators of both structured and unstructured PA when designing and implementing PA programs.

Despite the contributions of our study, it is important to note some limitations. This study was conducted in different regions of France with the objective of including diverse populations of PLHIV. However, participants were recruited in the virology departments of city hospitals and it is unclear if the perceptions and beliefs about PA are transferable to PLHIV in rural areas. Furthermore, these results could also be enhanced by qualitative research elucidating the perceptions and beliefs about PA for PLHIV among health providers and the general population. Additionally, participants’ PA level was self-reported and was thus susceptible to social desirability bias,\(^{62}\) warranting future research using objective measures of PA level such as accelerometer data.\(^{63}\) Finally, our study was based on qualitative data, which limited the generalizability of our findings. A more quantitative approach to the perceptions and beliefs of PLHIV toward PA by developing a specific scale to measure PA barriers and facilitators among this population would be of value.

**Conclusion and implications**

This qualitative study provided a multidimensional understanding of the perceptions and beliefs surrounding PA among French PLHIV, enriching the existing literature\(^{15,24}\) in other countries. Overall, our findings highlighted the interplay of physical (e.g. fatigue), psychological (e.g. negative self-perceptions) and socio-environmental (e.g. lack of adapted offers for PA) barriers.
Similarly, facilitators related to physical (e.g. reduced pain), psychological (e.g. positive attitudes toward PA) and socio-environmental (e.g. social support) dimensions were identified. Our results also suggest that specific psychological barriers or facilitators such as perceived risks (e.g. fear of contamination), lack of physical capacities for PA and perceived benefits might be shared beliefs among PLHIV and be considered as exercise stereotypes related to chronic illness.

In line with recent studies, our research suggests taking into account the barriers to and facilitators of PA in the conception and implementation of PA programs by acting at multiple levels. Specifically, at an individual level, addressing the fears of PLHIV related to injury and contamination through PA and knowledge about exercise should be considered. Healthcare providers should continue to promote PA as a self-management strategy encouraging self-efficacy in line with previous literature. Also, from a more contextual perspective, healthcare providers should also be aware of these barriers and facilitators to take them into consideration when implementing PA programs. Beyond the individual and contextual levels, our study points towards shared beliefs that could be considered as exercise and PA stereotypes. Thus, acting on a global level to encourage an evolution of the social representations about exercise and PA in this population seems like an important avenue for future research.

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LG contributed to the analyses, interpreted the results and wrote the manuscript; LS contributed to the data collection, interpretation of the results, writing of the manuscript and collaborated on the general project to obtain funding; AB collected data, contributed to the interpretation of results and collaborated on the general project to obtain funding; VF contributed to the analyses and data interpretation; SSC contributed to the final version of the manuscript and collaborated on the general project to obtain funding; FdAL was responsible for the scientific project and oversaw funding obtainment, oversaw the collection of data, contributed to the interpretation of results and helped write the manuscript.

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Étude 2. Développement du questionnaire psychométrique HIVESS

L’objectif principal de cette étude était de développer et de valider en français une échelle mesurant les stéréotypes liés à l’activité physique chez les PVVIH. Une série de quatre études complémentaires a été conduite auprès d’un échantillon total de 524 participants dans le but de : (a) développer une version préliminaire de l’échelle *HIV Exercise Stereotype Scale* (HIVESS) (étape 1), (b) confirmer la structure factorielle de l’instrument (étape 2), (c) évaluer la stabilité temporelle de l’instrument (étape 3) et (d) examiner la validité de construit et la validité divergente de l’échelle (étape 4).

Les résultats ont débouché sur une échelle de 14 items répartis en trois sous-échelles : (a) les stéréotypes relatifs aux bénéfices de l’exercice, (b) les stéréotypes relatifs aux risques de l’exercice et (c) les stéréotypes relatifs au manque de capacités physiques pour l’exercice présentant des alphas de Cronbach satisfaits. Ces sous échelles sont apparues comme étant significativement reliées à l’auto-efficacité, au niveau d’AP et à la qualité de vie.

L’HIVESS présente des propriétés psychométriques satisfaits, et constitue un instrument fiable et valide pour mesurer les stéréotypes liés à l’exercice chez les PVVIH. Il pourra être utilisé pour de futures recherches et pratiques cliniques.

Cette étude a fait l’objet de la publication de l’article suivant :

Exercise stereotypes and health-related outcomes in French people living with HIV: development and validation of an HIV Exercise Stereotypes Scale (HIVESS)

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Abstract

Background: The main objective of the current study was to develop and validate a French exercise stereotype scale for people living with HIV (PLHIV) in order to gain visibility to the possible barriers and facilitators for exercise in PLHIV and thus enhance their quality of life.

Methods: A series of four complementary studies was carried out with a total sample of 524 participants to: (a) develop a preliminary version of the HIV Exercise Stereotype Scale (HIVESS) (Stage 1), (b) confirm the factorial structure of the instrument (Stage 2), (c) evaluate the stability of the instrument (Stage 3), and (d) examine the construct and divergent validity of the scale (Stage 4).

Results: Results provided support for a 14-item scale with three sub-scales reporting stereotypes related to exercise benefits, exercise risks and lack of capacity for exercise with Cronbach’s alphas of .77, .69 and .76 respectively. Results showed good factorial structure, strong reliability and indicators of convergent validity relating to self-efficacy, exercise and quality of life.

Conclusion: The HIVESS presented satisfactory psychometric properties, constitutes a reliable and valid instrument to measure exercise stereotypes among PLHIV and has applications for future research and clinical practice.

Keywords: HIV/AIDS, Stereotypes, Exercise, Scale development

Background

The positive effects of exercise for people living with HIV (PLHIV) are now thoroughly reported in scientific literature. A recent meta-analysis [1], indicated that moderate exercise presents beneficial physical and psychological effects for this population (e.g., improvement of fitness, body composition and quality of life). Further physical effects noted are the moderation of the side effects of antiretroviral therapy (e.g., reducing and/or preventing uneven distribution of body fat) [2], and of cardiopulmonary fitness [3]. These physical effects coexist with notable psychological benefits such as reduced depression [4, 5] or improved self-perceptions and self-esteem [6]. Greater quality of social relationships [7] and life satisfaction has also been reported comparably to non-exercising PLHIV [8]. Lastly, some studies evidenced the ability of exercise to better antiretroviral therapy adherence [9] and to hinder anti-inflammatory consequences [10].

Regardless of the extensive literature related to the benefits of exercise in PLHIV, a large proportion of this population is not sufficiently active according to current recommendations [11, 12], for adults between 18 and 64 years of age, requiring at least, 150 min of moderate exercise and two sessions of muscle strengthening workout per week [13]. These findings are of concern and encourage further identifying barriers to exercise participation. Research related to exercise barriers in PLHIV is sparse.
In a study conducted in Rwandan PLHIV receiving high active antiretroviral therapy [14], the main perceived barriers were lack of motivation (30.5 %), lack of time (25.3 %) and fear of worsening the disease (24.3 %). Through a qualitative study conducted on South African PLHIV, a wide range of obstacles to participation, related to both the psychological sphere (e.g., low-energy levels, psychological complaints and stress levels) and the environmental and social spheres (e.g., physical environment, social environment, domestic abuse and crime) were isolated [15]. More recently, it has been reported that prominent exercise barriers include HIV symptoms (i.e., neuropathy, lipoatrophy), antiretroviral therapy effects (lipodystrophy) and fatigue, but also decreased motivation, depression, negative self-perceptions, and apprehension concerning the risks of exercise such as sustaining an injury [15].

These last results suggest that insufficiently physically active PLHIV might have negative beliefs about exercise effects (e.g., perceived risks), which might limit their participation in exercise. Furthermore, these negative beliefs might reflect the internalization of stereotypes related to physical weakness and decline due to HIV disease. Stereotypes refer to shared beliefs concerning personal characteristics, generally personality traits, and the behaviors of a group of persons [16]. According to the stereotype embodiment theory [17], stereotypes are embodied when their assimilation from the surrounding culture leads to self-definitions that, in turn, influence functioning and health. In the case of HIV, internalized stigma has shown a relation to lower mental health and social support, and greater HIV symptoms [18].

An emerging body of literature has focused on the specific influence of exercise stereotypes on different populations such as the elderly or individuals with chronic diseases. Particular measures have been generated to investigate exercise stereotypes in these populations. For example, the “Aging Stereotypes and Exercise Scale” was developed and validated to assess different aspects of aging stereotypes in the exercise sphere such as (a) stereotypes regarding exercise benefits, (b) stereotypes about exercise risks, and (c) stereotypes related to self-efficacy [19]. This line of research indicates that endorsement of negative aging exercise stereotypes is related to lower levels of exercise among the elderly [20, 21].

HIV/AIDS-related stigma is continuously brought to mind, in any discussion about effective responses to the epidemic, as a problem of detrimental and tenacious nature [23], several internalized AIDS-stigma scales have hereby been developed [24, 25]. However, no valid tool is currently available to measure stereotypes related to exercise in PLHIV. Taking into consideration the theoretical and conceptual link between exercise stereotypes and behaviors, there is a need to measure stereotypes that act as barriers or facilitators to exercise in PLHIV. This study’s main objective was thus to develop and validate the HIV Exercise Stereotypes Scale (HIVESS). The HIVESS could be used (1) in research to better explain the psychosocial factors related to exercise in PLHIV, and (2) in practice to enable health and exercise professionals to conceive effective intervention strategies that take into account exercise barriers and how to modify them favorably.

**Methods**

The HIVESS was developed and validated following Vallerand’s procedure [26], including: (i) developing an initial version and assessing the clarity of the items, (ii) analyzing and confirming the factorial structure of the instrument, (iii) analyzing the stability of the tool over time, and (iv) evidencing proof of construct validity by testing the convergent validity and discriminant validity of the scale.

To perform the successive stages in developing and validating the scale, a total of 420 voluntary French-speaking PLHIV (M_{age} = 52.51; SD = 11.44), 154 voluntary French-speaking healthy individuals (M_{age} = 28.04; SD = 10.45), including 50 French-speaking faculty students (M_{age} = 23.08; SD = 2.25) were recruited. Participants were informed of the study during routine consultations or various announcements on social media and in a local newspaper. PLHIV were recruited from three French hospitals by hospital staff and researchers following certain inclusion criteria (i.e., at least 10 years of therapy; no co-infection or other diseases). Healthy individuals and students were recruited in the local area by researchers. Ethical approval as well as participants’ informed written consent was obtained for these studies.

**Stage 1: exploratory version and content clarity**

In the first stage of this study the aim was to compile an initial version of the HIVESS. Three researchers specialized in the field of health psychology and four PLHIV formed an ad hoc committee and stipulated a series of items based on (i) content analyses of previous semi-structured interviews focused on exercise beliefs in PLHIV and (ii) two validated scales measuring different dimensions of exercise stereotypes in older adults and cancer patients [19, 22]. Items were thus theoretically...
prompted and formulated using conventional recommendations for understanding and wording literacy [27]. The concepts of qualitative saturation decided the number of initial items. Saturation was deemed attained when no new relevant item emerged [28]. During this process and in anticipation of items being deleted during the refinement process, items were added to each stereotype category [29]. The Delphi method was then used to select items [30]. The list of items was presented repeatedly until at least 80 % of the raters came to a consensus [31]. A first panel of PLHIV was asked to complete an assessment of the investigative version of the instrument after an initial expert panel review. Participants were invited to assess the clarity of each item on a six-point Likert scale ranging from 1 = “not at all clear” to 6 = “completely clear”. Each participant was interviewed as this qualitative procedure allowed discussing each item as to its pertinence, endorsement and highlighting possible needs for alterations. As suggested by Morey (2003) [29] participants were explicitly encouraged to provide feedback on items rated as being low in quality. The evaluated items, to which mean scores of “4 and/or less” were attributed, were considered as ambiguous or misunderstood. These items where then modified or reformulated according to participant comments and suggestions made by the researchers [26]. A second panel of PLHIV in a method comparable to the first evaluation protocol then assessed the revised version of the instrument.

Stage 2: factorial structure analysis
This stage aimed at examining the factorial structure of the HIVESS. As item generation was theory driven and based on existing exercise stereotypes scales (e.g., ASES [19]; CESS [22]), the number of factors was predefined. Therefore, maximum likelihood estimation confirmatory factorial analysis (CFA) was conducted in AMOS v7.0 to test the validity of the factor model [32]. Factor analysis is considered possible with a minimal sample of questionnaire items amounting to five times the number of items [33]. Each item was identified as an indicator of a single underlying stereotype sub-scale, and no items were specified to cross-load. The following indicators: chi square (χ²; significant values p ≤ .05), the Comparative Fit Index (CFI; values above 0.90), the Tucker-Lewis Index (TLI; values above 0.90), the Root Mean Square Error of Approximation (RMSEA; values below 0.08), and the 90 % Confidence Interval of the RMSEA (RMSEA 90 % CI; values ranging from 0 to 0.08) were used to assess competence of the model fit [34–36]. Sources of poor fit were examined through modification indices [37]. Cronbach’s alphas [38] were also determined to test the internal consistency of each subscale, with convention recommending values greater than 0.70.

Stage 3: temporal stability
Temporal stability, or “test-retest”, is an important measure of reliability for a psychometric instrument [39]. The purpose of this stage was to assess the temporal accuracy of the HIVESS. An instrument is considered relevant when a reasonable level of temporal stability can be associated to the determined construct measures. For assessment of test-retest reliability at least 50 participants is required for the sample [40].

An interval of 4 weeks was considered to be an acceptable compromise between an attempt to reduce recall bias and test reliability independent of significant clinical change [41]. The 17-item questionnaire was hereby administered to participants twice over a 4-week period. Intraclass correlation coefficients (ICCs) and the 95 % confidence interval of the ICCs (ICC 95 % CI), as well as paired/dependent sample t-tests were conducted as data analyses to examine significant differences in subscale scores from time 1 to time 2. Cronbach’s alphas were calculated at both time points to examine internal consistency of the scale.

Stage 4: convergent validity and discriminant validity
Stage 4 was intended to test the construct validity of the HIVESS. Here we considered the extent to which inferences can be made permissibly in the process of rigorously defining variables into measurable factors. For construct validity the theoretical constructs on which the process was based need to be empirically and qualitatively measured. Construct validity is said to be satisfied when both convergent and discriminant validities are satisfied [42]. A significant correlation of 0.3 is desired between the scale and other theoretically appropriate measures to test validity [43]. Using an alpha of 0.05 and a 1-beta equal to 0.2, 85 participants were needed to obtain a significant correlation of 0.3 or more.

Based on research on exercise stereotypes in vulnerable populations [21, 44], convergent validity of the scale was tested by examining the relationships between the three subscales of the HIVESS and a physical activity score [45], exercise self-efficacy [46] and patient-reported health-related quality of life [47]. Pearson correlation coefficients were used to measure the association between variables. Cronbach’s alphas were examined as internal consistency coefficients.

As past research has reported differences between exercise stereotypes in healthy individuals and people with chronic diseases [22] or older adults [19], we examined discriminant validity by evaluating mean differences on the HIVESS for PLHIV and healthy individuals. Specifically, significant differences were tested using univariate analyses of covariance (ANCOVAs) while controlling for level of exercise, age and gender. Based on the ANCOVA result, the two groups were expected to differ in terms of
HIV exercise stereotypes. To assess level of exercise, all participants completed the "Physical Activity Score" [45]. The internal consistency of the items scores was examined using Cronbach’s alpha coefficients.

Results

Stage 1: preliminary version and content clarity

Based on previous literature and content analysis of semi-structured interviews with PLHIV, to begin with the ad hoc committee created a pool of 30 items, ten items for each of the three following categories of stereotypes: (i) stereotypes related to exercise benefits, (ii) stereotypes related to risks of exercise, and (iii) stereotypes related to lack of capacity for exercise. The committee followed the Delphi method and retained 5 items for the benefits of exercise subscale and 6 items for the subscales related to the risks of exercise and to lack of capacity for exercise. The examination of the 17 items from the first panel of PLHIV (N = 15; M age = 50.25; SD = 9.96) reported some low scores for clarity across four items (3.62 < M < 3.93). The evaluation interviews brought to light comments enabling modifications to be made to two items related to risks of exercise and two items related to lack of capacity for exercise. Higher mean clarity scores across all items (M = 5.01; SD = .85) were produced following evaluation of item clarity with the second sample of PLHIV (N = 15; M age =50.83; SD =10.21) and discussions instigated no further modifications to the items (see Table 1). Stage 1 provided the initial 17-item HIVESS that required psychometric testing. Items were rated on a 6-point Likert scale in order to emphasize the discrimination and reliability and to reduce the risks of deviation linked to personal decision-making [48].

Stage 2: factorial structure analysis

A total of 96 PLHIV (M age = 49.95; SD = 10.61) completed the scale. A second sample of 133 PLHIV (M age = 50.46; SD = 10.88) was recruited to complete a modified version of the scale.

The first CFA results did not display a good fit [i.e., χ² (116, N = 96) = 267.83; CFI = .74; TLI = .78; RMSEA = .12 (90 % CI = .10, .14)]. Retained items should saturate with a weight greater than .55 as stated by Guttman [49]. Hereby, 3 of the 17 initial items were removed (i.e., two items on the subscale related to exercise risks and one item on the subscale related to lack of capacity for exercise). Using data from the same sample, a second CFA was conducted with the 14-item scale and showed a better fit [i.e., χ² (74, N = 96) = 98.99; CFI = .94; TLI = .93; RMSEA = .06 (90 % CI = .02, .09) (see Table 1). The model was then tested with a second sample of 133 PLHIV and also showed a satisfactory fit [i.e., χ² (74, N = 133) = 126.51; CFI = .92; TLI = .91; RMSEA = .07 (90 % CI = .05, .09)]. Cronbach’s alphas were .81 for exercise benefits, .71 for exercise risks and .85 for lack of capacity for exercise. Stage 2 rendered and supported the factorial structure of a 14-item, three-factor model of the HIVESS instrument representing HIV exercise stereotype categories related to (i) exercise benefits, (ii) exercise risks, and (iii) lack of capacity for exercise.

Stage 3: temporal stability

In this stage, 50 faculty students (M age = 23.08; SD = 2.25) were recruited to test the temporal stability of the tool. This population was selected as the questionnaire is not only destined to PLHIV as a targeted group, but also to healthy individuals as the targeters. The t-tests results are presented in Table 2. No significant differences were found between time 1 and time 2 in the scores within subscales. Cronbach’s alpha coefficients for all three factors at time 1 were .71, .78, .76 for exercise benefits, exercise risks and lack of capacity for exercise respectively. At time 2, Cronbach’s alpha coefficients were .80 for exercise benefits, .82 for exercise risks and .75 for lack of capacity for exercise. Based on these findings, the HIVESS was stable over a 4-week period and internal reliability was persistently demonstrated.

Stage 4: convergent validity and discriminant validity

In this stage, 107 (81 men and 26 women) PLHIV (M age = 52.51; SD = 11.42) were recruited to test convergent validity. The discriminant validity of the scale was assessed using the same sample of PLHIV and a sample of 104 (62 men and 45 women) healthy adults (M age = 28.04; SD = 10.45).

Convergent validity

Correlational analyses indicated that stereotypes related to lack of capacity for exercise and exercise risks among PLHIV were negatively related to exercise self-efficacy and level of physical activity. Exercise risks and lack of capacity for exercise were negatively related to patient-reported health-related quality of life. The exercise benefits stereotypes subscale was positively related to self-efficacy and level of physical activity (see Table 3). Quality of life did not reveal a significant relation to the exercise benefits subscale. Cronbach’s alphas were .77, .69 and .76 for exercise benefits, risks and lack of capacity for exercise respectively.

Discriminant validity

ANCOVA analyses including control for level of exercise (see Table 4) revealed significant differences between PLHIV and healthy individuals for subscales related to the HIVESS. Cronbach’s alphas were all satisfactory (.77 for
exercise benefits; .69 for exercise risks; and .77 for lack of capacity for exercise) in PLVIH and in healthy individuals (.71 for exercise benefits; .80 for exercise risks; and .80 for lack of capacity for exercise).

Assessments for convergent and discriminant validity, founded on the construct validity, displayed the HIVESS as being significantly related to exercise, exercise self-efficacy and quality of life in the anticipated directions.
specific to PLHIV but is noted in the general population [51]. Some studies link the coexistence of positive views of exercise and the lack of exercise among PLHIV to: lack of motivation or lack of time [14, 15], but also to population-specific barriers such as fear of worsening the illness [12], which seems to reflect exercise risks stereotypes.

The items describing stereotypes related to the risks of exercise for PLHIV conveys the idea that exercise increases the risk of injury (e.g., “Practicing a physical activity should be avoided by HIV-infected patients because it causes injuries”) and the risk of contamination (e.g., “HIV-infected patients do not practice physical activities because they could contaminate someone during the activity”). PLHIV showed the least agreement to this subscale, whereas healthy individuals revealed higher scores for exercise risk stereotypes for PLHIV. Furthermore, exercise risks were negatively related to exercise self-efficacy, self-reported level of physical activity and patient-reported health-related quality of life. This suggests that, although PLHIV present barriers to exercise linked to exercise risk such as fear of sustaining an injury during exercise [15], there is a certain resistance to exercise risk stereotype embodiment [17] by PLHIV as already evidenced in older adults [19].

Items describing stereotypes related to lack of capacity for exercise included items pertaining to exercise self-efficacy in PLHIV, treatment side effects, as well as perceptions of physical fatigue (e.g., “HIV-infected patients do not have enough physical resources to practice a physical activity”). This type of stereotype is consistent with existing exercise barriers previously reported in the literature in terms of low levels of exercise capacity and energy [14, 15]. Stereotypes linked to lack of capacity for exercise were negatively related to exercise self-efficacy, self-reported level of physical activity and health-related quality of life. Here again, we note that healthy individuals had a slightly higher level of endorsement than PLHIV. The moderate-level agreement of this type of stereotype is consistent with findings among cancer patients [22] and older adults [19], whereby a stereotype pertaining to loss of physical capabilities was also reported. These findings provide support to the assumption that individuals are more likely to develop negative stereotypes when the latter have no strong self-referential implications [52].

The scale indicated good internal consistency and stable test-retest reliability. The correlations and regression analyses confirm convergent validity of the HIVESS with a measure of exercise self-efficacy, the level of physical activity and patient-reported health-related quality of life. The negative HIV exercise stereotypes related to the risks of exercise and to the lack of capacity for exercise were inversely related to exercise self-efficacy, level of physical activity and health-related quality of life. No significant
results were observed for positive HIV exercise stereotypes evaluating the benefits of exercise warranting further investigation. Divergent validity was supported by significant differences noted between healthy individuals and PLHIV for subscales related to lack of capacity for exercise and exercise risks with healthy individuals scoring higher for both these subscales.

Conclusion

The HIVESS is a reliable and valid tool to measure HIV exercise stereotypes in PLHIV. However, it is important to point out some limitations of the scale. The procedure reported in this paper is limited by the sociodemographic characteristics of the samples. For example, our data includes a majority of men and it would be interesting to have a more balanced gender distribution. Moreover, test-retest reliability was run in a sample of faculty students and not PLHIV. This could possibly lead to some limits in the generalizability of the scale. In addition, the HIVESS, which was first developed in French, would need to be translated in other languages in order to be used internationally.

The HIVESS allows for further investigation on psychological barriers to exercise in PLHIV. A line of further research could try to identify the relationship between HIV exercise stereotypes and level of exercise. A second line of research could examine the moderators of HIV exercise stereotypes endorsement (such as being physically active vs. inactive and being healthy vs. HIV-positive). A third line of research could focus on the consequences of exercise stereotypes embodiment on levels of exercise and the potential role of fatigue which has been identified as prevalent complaint among PLHIV [50, 53] affecting quality of life. The French-language HIVESS is a concise multi-item scale facilitating completion and enabling extensive use both in clinical and research environments.

Table 4 Mean (SD) Differences Between PLHIV and Healthy Individuals

<table>
<thead>
<tr>
<th></th>
<th>PLHIV (N = 108)</th>
<th>Healthy individuals (N = 104)</th>
<th>Between-Group Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>LCE 2.91 (1.14)</td>
<td>3.20 (30)</td>
<td></td>
<td>F(1, 209) = 8.45, $\eta^2$ = .04, $p &lt; .001$</td>
</tr>
<tr>
<td>RE 2.00 (1.10)</td>
<td>2.52 (1.05)</td>
<td></td>
<td>F(1, 209) = 15.62, $\eta^2$ = .07, $p &lt; .001$</td>
</tr>
<tr>
<td>BE 4.51 (1.20)</td>
<td>4.50 (.80)</td>
<td></td>
<td>F(1, 209) = 2.40, $\eta^2$ = .01, $p &gt; .05$</td>
</tr>
</tbody>
</table>

Notes: LCE Stereotypes related to lack of capacity for exercise, RE Stereotypes related to risks of exercise, BE Stereotypes related to benefits of exercise, SD Standard deviation, $\eta^2$ Partial eta-squared

Acknowledgments

The authors sincerely thank Julie Bertany, Mari-Angie Serini and Line Hallot for their valuable assistance in the research project as well as the participants in the present study.

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Availability of data and materials

The dataset supporting the conclusions of this article is included within the article and its additional file.

Authors’ contributions

LG oversaw collection of the experimental data, performed the statistical analysis, contributed to the interpretation of the results, and drafted the manuscript; CF contributed to the development of the scale, performed the statistical analysis, interpreted the results, and drafted the manuscript; AB contributed to the development of the scale, contributed to the interpretation of the results, drafted the manuscript, and collaborated on the general project to obtain funding; LS contributed to the development of the scale, contributed to the interpretation of the results, and collaborated on the general project to obtain funding; JD contributed to the collection of the data, provided knowledge related to HIV/AIDS, and collaborated on the general project to obtain funding; ER contributed to the collection of the data, provided knowledge related to HIV/AIDS, and collaborated on the general project to obtain funding; CP, MD and IR contributed to the collection of data, provided specific knowledge related to HIV/AIDS, and collaborated on the general project to obtain funding; SSC contributed to the development of the scale, and collaborated on the general project to obtain funding; FdAL was responsible for the scientific project and oversaw funding obtaining, oversaw the collection of data and the development of the scale, contributed to the interpretation of the results, and helped writing the manuscript. All authors have read and approved the final version of the manuscript and agree with the order of presentation of the authors.

Competing interests

On behalf of all authors, the corresponding author states that there are no competing interests.

Consent for publication

Participants were informed that all data collected would remain anonymous. That data would be treated statistically only and remain confidential.

Ethics approval and consent to participate

Ethical Approval: All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent was obtained from all individual participants included in the study.

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Étude 3. Relations entre stéréotypes liés à l’AP, fatigue physique perçue et AP chez les PVVIH

Les recherches récentes suggèrent que les stéréotypes liés à l’exercice peuvent influencer l’AP par le biais de mécanismes liés à l’internalisation et à un épuisement de l’ego. L’objectif de cette étude était de mieux comprendre le rôle de l’auto-efficacité liée à l’exercice et de la fatigue physique perçue dans la relation entre les stéréotypes liés à l’exercice et l’AP.

Un total de 305 PVVIH ont été recrutés et ont répondu à des questionnaires psychométriques mesurant les stéréotypes liés à l’exercice, l’auto-efficacité liée à l’exercice, la fatigue physique perçue et leur niveau d’AP.

Les résultats ont montré que parmi les modèles présentant de bons ajustements aux données, le modèle de médiation modérée dans lequel les associations indirectes entre les stéréotypes négatifs liés à l’exercice et l’AP via la fatigue physique perçue sont modérées par l’auto-efficacité pour l’exercice) expliquait le mieux la variance dans l’AP ($R^2 = .27$).

Ce modèle suggère que les stéréotypes négatifs vis-à-vis de l’exercice pourraient influencer l’AP à travers des mécanismes d’épuisement de l’ego (opérationnalisés par la fatigue perçue) et pourraient être temporisés par le sentiment d’auto-efficacité.

Cette étude a permis la publication de l’article suivant :

Exercise stereotypes and fatigue in people living with HIV: does self-efficacy play a mediating or a moderating role?

Laura Gray 1*, Aïna Chalabaev 2, Jacques Durant 1,3, Eric Rosenthal 1,3, Christian Pradier 1,4, Martin Duracinsky 5, Isabelle Rouanet 6, Laura Schuft 1, Serge S. Colson 1 and Fabienne d’Arripe-Longueville 1

**Abstract**

**Background:** Recent research suggests that exercise stereotypes may influence physical activity through ego depletion and internalization mechanisms. The objective of this study was to better understand exercise stereotypes mechanisms among people living with HIV (PLHIV) by further examining the role of exercise self-efficacy and perceived physical fatigue in the relationship between exercise stereotypes and physical activity.

**Methods:** Three hundred five people living with HIV were recruited to provide data on their stereotypes related to exercise, exercise self-efficacy, perceived physical fatigue as well as their level of physical activity (PA).

**Results:** From the different models tested, the serial mediation model with exercise self-efficacy and perceived physical fatigue as mediators of the relationship between exercise stereotypes and PA, as well as the moderated mediation model with exercise selfefficacy as a moderator of exercise stereotypes and perceived physical fatigue a mediator, provided good fits to the data. However, the moderated mediation model (with indirect associations between negative exercise stereotypes and PA via perceived physical fatigue being moderated by exercise self-efficacy) explained the most variance in PA (R² = .27).

**Conclusion:** The moderated mediation model suggests that exercise stereotypes might influence PA through ego depletion mechanisms and be tempered by exercise self-efficacy.

**Background**

Stereotypes are defined as shared beliefs concerning personal characteristics and behaviors of a group of persons [1]. Researchers have identified numerous pathways through which stereotypes impact health behaviors, primarily through internalization into the self, stereotype threat, downward social comparison/resilience, stereotype boost and upward social comparison/role models [2]. For example, according to the Stereotype Embodiment Theory (SET) [3], in older adults the relationships between aging stereotypes and health outcomes can be explained by the stereotype internalization hypothesis. This suggests that age stereotypes are internalized into self-perceptions of aging, and aging experiences are interpreted via this process [4]. Older adults who have negative perceptions of their aging consider that health problems are inevitable consequences of aging. This, in turn, could lead older adults to view health behaviors as futile [5] and hinder self-efficacy [6]. Indeed, self-efficacy was a potential mediator in the relationship between aging stereotypes and task performance [6]. In contrast positive views of aging may enhance adoption of preventive health behaviors in older adults entailing that the higher positive self-perceptions of aging the more older adults engage in healthy practices as opposed to those with more negative aging self-perceptions [5].

Physical activity (PA) is one of the most important health behaviors associated with prevention and management of chronic diseases, and stereotypes appear as an important factor of this behavior. For example, Wurm, Tomasik, and Tesch-Romer [7] showed that positive views of aging contributed to a higher level of PA. Besides age stereotypes, exercise stereotypes have been identified in

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recent literature, as playing a major role in the relation to PA [8, 9]. These exercise stereotypes, which different populations endorse, or adhere to, to varying degrees, can be both positive and negative and have been the source of specific exercise stereotype scales being developed for the elderly [10], cancer patients [8], and more recently for people affected by HIV/AIDS [9]. These scales allowed to identify two categories of stereotypes. The positive stereotypes category included shared beliefs about exercise benefits (e.g., “Exercise improves the morale of HIV-infected patients”). The negative exercise stereotypes category was composed of shared beliefs about lack of capacity for exercise (e.g., “HIV-infected patients do not have enough physical resources to exercise”), exercise risks (e.g., “Exercise should be avoided by HIV-infected patients because it causes injuries”), and treatment side effects (e.g., “Because of treatments, HIV-infected patients do not have enough energy to exercise”).

In order to develop effective interventions, it is crucial to identify the mechanisms through which exercise stereotypes influence PA among people viewed as vulnerable such as the elderly or people living with chronic disease. A first mechanism, through which exercise stereotypes would influence PA, is stereotype internalization. In their cross-sectional study, Emile et al. [11] reported that exercise stereotypes were related to older adults’ engagement in PA through physical self-worth, suggesting such an internalization process. In a further longitudinal study, Emile et al. [12] emphasized the importance of distinguishing between general self-perceptions and more domain-specific perceptions indexed by physical self-worth and the role of this physical self-worth in health behaviors. While the stereotype internalization mechanism was supported in their study, the results revealed a direct relationship between exercise stereotype endorsement and adoption of an active lifestyle, independently of how people perceived their own aging. Thus, these results suggested that self-perceptions of aging, the active construct in internalization, may not be the only pathway through which stereotype endorsement may affect older adults’ health-related behaviors.

Another pathway through which exercise stereotypes could affect PA and health-related outcomes is ego depletion. Ego depletion corresponds to the idea that engaging in acts of self-control (i.e., overriding initial impulses or responses such as resting on a couch to watch TV to engage in regular exercise) draws from a limited “reservoir” which, when depleted, results in reduced capacity for further self-regulation [13]. Negative stereotypes have been shown to reduce self-control and affect one’s ability to self-regulate [14] because coping with such stereotypes requires mental energy, reducing in turn subjective vitality (i.e., the energy one can harness or regulate for purposive actions) or increasing perceived fatigue (i.e., fatigue that is consciously felt). Likewise, Emile et al. [12] reported that the endorsement of negative exercise stereotypes in older adults negatively predicted subjective vitality, suggesting that ego depletion could be a pathway through which exercise stereotypes affect older adults’ health, complementing the internalization pathway. In the same way, a meta-analysis by Hagger, Wood, Stiff & Chatzisarantis [15] showed a significant effect with medium to large magnitudes of exerting self-control on acute subjective or perceived fatigue.

In sum, the recent literature suggests that exercise stereotypes could influence health behaviors including PA through different pathways or mechanisms: (a) stereotype internalization and (b) ego depletion. Yet, it is necessary to further elucidate the relationships and/or role played by each mechanism. Our study takes a closer look at internalization and ego depletion mechanisms in people living with HIV (PLHIV). This population was selected as fatigue is one of the most reported recurrent symptoms with a prevalence rate varying from 33% to 88% [16, 17]. In addition PLHIV do not engage enough in regular PA according to World Health Organization standards [18, 19]. Although some possible reasons are shared by the general population (e.g., lack of interest; lack of time), other reasons might be more specifically related to chronic illness, such as the endorsement of negative exercise stereotypes acting as psychological barriers. In line with previous studies having considered self-perceptions as an index of stereotypes internalization in vulnerable populations [5, 11, 12, 20], we looked at exercise self-efficacy, defined as an individual’s belief in his or her ability to succeed in a specific situation to accomplish a task [21], as a situational indicator of the internalization mechanism. In addition, based on Hagger et al. [15], we considered perceived physical fatigue as an index of the ego depletion mechanism. Based on existing literature, this study argues that exercise self-efficacy and perceived physical fatigue would mediate relationships between exercise stereotypes and PA variables in PLHIV, and aims at determining the nature of this mediation. For this purpose, several competing mediation models were tested.

Methods
Study design
A quantitative cross-sectional study design was employed from 1st of September 2016 to 30th of June 2017 in hospitals in three populated regions of France including the capitol.

Participants
A sample of 344 men (n = 245) and women (n = 99) living with HIV participated in this study. The staff of the
three French hospitals’ departments of infectious diseases screened and assessed patients for eligibility. Participants were included in the study if they were between 40 and 65 years old, were under treatment for at least 10 years and were followed by doctors of one of the three hospitals. As fatigue seems to be more common among co-infected individuals [22], we did not include PLHIV affected by other diseases such as hepatitis C, cancer, renal dysfunction and sclerosis; for the same reason pregnant women were excluded. The participants could read and understand the questionnaires of the survey written in French, and they were not affected by cognitive impairment. The response rate was 54% ± 9%. After data cleaning, a complete analytic sample of n = 305 (men, n = 228; women, n = 77; M = 53.5; SD = 9.58) was retained for statistical analysis. All participants were informed that the survey was voluntary and that all responses would remain anonymous and confidential. The study complied with national ethical standards (n°CNIL/UNS/2015/0007).

Procedure
The survey was distributed by staff from the virology services of the three participating hospitals. The staff member presented the study objectives and project partners and assured the anonymity of participants. A room was made available by the hospital for completing the questionnaires. The staff member remained in the room to respond to any requests for clarification. The average time of completion was 20 min.

Measures
HIV exercise stereotypes
We used the HIV Exercise Stereotype Scale (HIVES) developed and validated by Gray et al. [9] to assess endorsement of exercise stereotypes in PLHIV. The HIVES consists of 14 items divided into three sub-scales: (a) five items measured stereotypes related to exercise benefits for PLHIV (e.g., “Physical activity improves the morale of HIV-infected patients”), (b) four items measured stereotypes related to exercise risks linked to injury (e.g., “Practicing a physical activity should be avoided by HIV-infected patients because it causes injuries”) and linked to contamination (e.g., “HIV-infected patients do not practice physical activities because they could contaminate someone during the activity”) and (c) five items measured stereotypes related to a lack of capacity of PLHIV for exercise (e.g., “HIV-infected patients do not have enough physical resources to practice a physical activity”). Participants answered on a 6-point Likert scale ranging from 1 (“do not agree at all”) to 6 (“totally agree”).

Perceived physical fatigue
We used the physical fatigue sub-scale of the Fatigue Intensity Scale (FIS) [23], a valid scale previously used in French individuals [24, 25]. An example item was: “I have trouble maintaining physical effort for long periods”. Participants responded on a 6-point Likert scale ranging from 1 (“do not agree at all”) to 6 (“totally agree”). This sub-scale was selected because it is specifically related to physical fatigue characteristics as opposed to other used scales such as the HIV-Related Fatigue Scale [26] in which the characteristics are confounded with their consequences, circumstances and triggers.

Exercise self-efficacy
Exercise self-efficacy was measured using six items adapted from Bandura et al. [21, 27] guidelines (e.g., “I can be physically active regularly”). Participants answered on a 6-point Likert scale ranging from 1 (“do not agree at all”) to 6 (“totally agree”).

Physical activity
We used the Dijon Physical Activity Score [28], developed and validated to measure PA level. This scale contains 9 items and assesses participants’ level of PA via: (a) an overall appraisal of one’s PA (“Do you consider yourself to be physically: from (1) very active and athletic, to (4) completely sedentary?”); (b) two items on everyday activities (“On a weekly basis, your everyday activities take you: from (1) more than 10 hours, to (5) no time spent”); (c) five items on sport and leisure activities (e.g., “For how many months of the year do you engage in these activities (sport or leisure)?”); and (d) one item on rest (“On a daily basis, you rest (sleep, nap or wakeful rest): from (1) less than 12 hours, to (4) more than 20 hours”). The scores on each item are totaled, with the total score out of 30 points indicating a participant’s level of PA (individuals who score below 18 being considered as inactive). This measure, which has been shown to be a reproducible and valid measure of PA both among older adults and among patients with coronary artery disease [29], was deemed relevant to our population with chronic illness.

Covariates
Age and previous level of physical activity were the covariates assessed in this study. These variables were chosen based on validated previous research suggesting that they are related to PA participation. Studies on older adults have revealed age differences in health related behaviors [20] and recently in PA participation [30]. Furthermore, evidence reveals an association between participation in PA in later years and earlier PA
behaviors, previous participation in PA positively predicting future engagement [31, 32].

**Age**

Age was recorded in a standard manner with the following item: “Thank you for stating your date of birth (dd/mm/yyyy).”

**Previous level of physical activity**

Previous level of physical activity (PPA) was assessed with a question asking to consider one’s level of physical activity, including daily PA such as leisure or competitive sports and active commuting (i.e., walking or cycling to work), before being diagnosed as HIV-positive [31]. This question was stated as follows: This question is related to your physical activity before the condition. “You consider yourself as having been...”. Participants were then asked to rate their answer on a Likert scale from 1 “very sportive/physically active” to 6 “not physically active at all”.

**Data analyses**

Data analyses were performed using SPSS 22 and AMOS 20.0. The analysis allowed for missing values to be replaced by using multiple imputation [33]. Statistical analyses included several methods. Descriptive analyses (i.e., mean, standard deviation) were run and the reliability of the questionnaires was assessed with Cronbach’s alpha indicating internal consistency. The significance of the relationships between all variables was calculated using Pearson bivariate correlations. To determine the variables significantly contributing to PA variance a stepwise regression analysis was computed. Then three competing mediation models were tested with SEM using AMOS 20.0. Three indexes were selected to express model fit: chi-square ($\chi^2$), the Root-Mean Square Error of Approximation (RMSEA), the Bentler Comparative Fit Index (CFI), Tucker Lewis Index (TLI) and the Normed Fit index (NFI). RMSEA values $\leq$0.08 at 90% Confidence Interval (RMSEA CI 90%) in combination with values for CFI, TLI and NFI $\geq$0.90 suggest an acceptable model fit. The hypothesized mediation effects of perceived physical fatigue and exercise self-efficacy were tested by mediation analyses following the bootstrap procedure recommendations proposed by MacKinnon and colleagues [34]. The bootstrap procedure resampled the data 5000 times and calculated the indirect effect for each sample in this study. The bias corrected 95% confidence intervals (CI) indicated significant or non-significant indirect effects when they did not contain zero.

The first model tested was a parallel mediation model in which the independent variables (IV) were the three dimensions of exercise stereotypes (i.e., exercise benefits; exercise risks; lack of capacity for exercise), exercise self-efficacy and perceived physical fatigue were the mediators, and level of PA was the dependent variable (DV) (see Fig. 1).

The second model tested was a sequential mediation model in which constructs function as a causal chain. Exercise stereotypes (IV) would hereby predict perceived self-efficacy (first mediator), which would in turn predict perceived physical fatigue (second mediator) with an overall effect on level of PA (DV) (see Fig. 2).

The third model tested examined whether the mediation of the exercise stereotypes – PA relationship by perceived physical fatigue was moderated by self-efficacy. Here the IV remained exercise stereotypes, with perceived physical fatigue as a mediator and exercise self-efficacy as a moderator and level of PA the DV (see Fig. 3).

Moderated mediation was run following recommendations from Muller et al. [35], suggesting the assessment of the overall treatment effect of the independent variable (i.e., exercise stereotypes) on the outcome variable (i.e., physical activity level). This was followed by the assessment of the moderation of the treatment effect of the independent variable on the mediator (i.e., perceived physical fatigue). Lastly, the moderation effect of the mediator on the outcome variable, as well as the moderation of the residual treatment effect (i.e., the direct effect of the independent variable controlling for the mediator) of the independent variable on the outcome variable, were assessed.

**Results**

Results are presented in three parts. First, we present descriptive analyses. Second, we describe the results from the stepwise regression analysis. Third, we present the structural equation modeling analyses by looking at the results of the three hypothesized models.

**Descriptive analyses**

Descriptive statistics, means and standard deviations; alpha values, and bivariate correlations for all study variables are presented in Table 1.

**Regression analysis**

A four-step hierarchical regression analysis identified the predictors of PA level as the dependent variable. In the first step, previous PA level (PPA) and age (AGE) ($\beta = .33, p < .001$; $\beta = -.03, p = \text{NS}$) significantly predicted PA level, $R^2 = .11$. In the second step, when exercise stereotypes dimensions were added, exercise benefits (BEN, $\beta = .15, p < .01$), exercise risks ($\beta = -.08, p = \text{NS}$) and lack of capacity for exercise ($\beta = -.19, p < .001$) significantly predicted PA level, $R^2 = .18$ ($\Delta R^2 = .07$). Perceived physical fatigue was entered in the third step and significantly predicted PA level, $R^2 = .20$ ($\Delta R^2 = .02$). In the
Fig. 1 Descriptive parallel mediation model with indirect and direct pathways of exercise stereotypes dimensions on physical activity with perceived physical fatigue and exercise self-efficacy as mediators. Notes: N = 305; Benefits: exercise benefits stereotypes (IV); Capacities: lack of capacity for exercise stereotypes (IV); Risks: exercise risks stereotypes (IV); Exercise self-efficacy (mediator); Perceived fatigue (mediator); Physical activity (DV); a path: relationship between the independent variables and each mediator; b path: relationship between each mediator and the dependent variable; c path: relationship between the independent variables and the dependent variable (direct pathway); c’ path: relationship between the independent variables and the dependent variable controlling for the mediators (indirect pathway).

Fig. 2 Descriptive serial mediation model with indirect and direct pathways of exercise stereotypes dimensions on physical activity with exercise self-efficacy and perceived physical fatigue as mediators. Notes: N = 305; Benefits: exercise benefits stereotypes (IV); Capacities: lack of capacity for exercise stereotypes (IV); Risks: exercise risks stereotypes (IV); Exercise self-efficacy (mediator); Perceived fatigue (mediator); Physical activity (DV); a path: relationship between the independent variables and each mediator; b path: relationship between each mediator and the dependent variable; c path: relationship between the independent variables and the dependent variable (direct pathway); c’ path: relationship between the independent variables and the dependent variable controlling for the mediators (indirect pathway); d path: influence of mediator 1 on mediator 2.
last step, exercise self-efficacy was added and significantly increased variance by 45% revealing the strongest prediction of PA level ($\Delta R^2 = .09$), $F_{\text{change}} (7, 305) = 35.77$, $p < 0.001$. The four steps of the hierarchical regression determining the predictors of PA level are illustrated in Table 2.

Main analyses: model fit
Three hypothetical models were assessed in order to examine the role of exercise self-efficacy and perceived physical fatigue in the relationship between exercise stereotypes and PA.

Parallel mediation model
The parallel model placing perceived physical fatigue and exercise self-efficacy on the same level (Fig. 1) and controlling for PA level before HIV infection as well as age did not provide a good model fit: $\chi^2(8) = 36.076$, $p < .001$, $CFI = .918$, $TLI = .712$, $NFI = .902$, RMSEA = .108 (90% confidence interval [CI] [.073, .144]).

Serial mediation model
The serial mediation model in which the first mediator was exercise self-efficacy and the second was perceived physical fatigue.

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Table 1 Means, Standard Deviations, Coefficient Alphas and Bivariate Correlations between exercise stereotypes dimensions, self-efficacy, perceived physical fatigue and physical activity in people living with HIV, France, 2017

<table>
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<td></td>
<td>.51</td>
</tr>
</tbody>
</table>

Notes: $N = 305$, FAT Perceived physical fatigue, BEN Exercise benefits stereotypes, RIS Exercise risks stereotypes, LCE Lack of capacity for exercise stereotypes, SE Self-efficacy, PA level of physical activity, M Mean, SD Standard deviation, $\alpha$ Cronbach’s alphas

*p < .05, **p < .01, ***p < .001
physical fatigue, controlling for PA level before HIV infection and age, provided a good fit to the data: \( \chi^2(7) = 8.59, \ p = \ .283, \ \text{CFI} = .995, \ \text{TLI} = .981, \ \text{NFI} = .977, \ \text{RMSEA} = .027 \) (90% confidence interval [CI] [.000, .079]) (see Fig. 4).

After controlling for covariates (age, previous level of PA), mediation analyses for the serial model revealed that the indirect effects of exercise stereotypes on PA were significant. No significant direct effects of exercise stereotypes on PA were observed (see Table 3). Specifically, exercise self-efficacy and perceived physical fatigue fully mediated the relationship between the different stereotypes (exercise benefits, exercise risks and lack of capacity for exercise) and PA accounting for 19% of variance in PA level.

**Moderated mediation model**

The third model examined whether the mediation of the exercise stereotypes – PA relationship by perceived physical fatigue was moderated by self-efficacy. A good fit was revealed, with the moderator: \( \chi^2(3) = 3.265, \ p = .353, \ \text{CFI} = .999, \ \text{TLI} = .988, \ \text{NFI} = .993, \ \text{RMSEA} = .017 \) (90% confidence interval [CI] [.000, .100]) (see Fig. 5).

We then followed the steps outlined by Muller et al. [35] to test for mediated moderation effect. To this purpose, parameters for three regression equations were estimated to assess: (a) the overall treatment effect of exercise stereotypes on PA level as moderated by exercise self-efficacy, (b) the treatment effect of exercise stereotypes on perceived physical fatigue as the mediator moderated by exercise self-efficacy and (c) the mediator’s (partial) effect on the outcome variable PA and the residual effect of the treatment (exercise stereotypes) on PA, controlling for the mediator (perceived physical fatigue) moderated by exercise self-efficacy (see Table 4). The first equation (a) revealed significant direct effects of exercise benefits on PA and of exercise self-efficacy on PA. The second equation (b) revealed a significant effect of lack of capacity for exercise stereotype on perceived physical fatigue that was moderated by exercise self-efficacy (b = -.06, \( p < .01 \)). The third equation (c) showed that the partial effect of perceived physical fatigue on PA was not significant but a significant interaction effect between self-efficacy and lack of capacity stereotype on PA was observed (b = .02, \( p < .05 \)). This model predicted 27% of variance in PA (see Fig. 2).

Simple slope analyses were then run following suggestions from Dawson [36] that plotting the effects allows to observe their size and precise nature making interpretation easier. With the simple slopes we can know the direction of the relationship for high and low levels of the moderating variable. In our analysis, we looked at the specific relationship between exercise stereotypes and level of PA at different levels of exercise self-efficacy. We wanted to know if, for example, for PLHIV with high exercise self-efficacy there is evidence that their exercise beliefs (stereotypes) would be beneficial for their level of PA by running simple slope tests as suggested by Cohen et al. [38]. Of course, we took into consideration that we have positive and negative exercise stereotypes and that high levels of exercise self-efficacy will interact differently with these stereotypes in the sense that high exercise self-efficacy would reduce the impact of negative exercise stereotypes whilst enhancing that of positive exercise stereotypes.

Simple slope tests were run on the significant interaction effect of exercise stereotypes related to lack of capacity for exercise (\( p = .022 \)) on PA level as the outcome, showing that lack of capacity for exercise varies as a function of exercise self-efficacy as the moderator (see Fig. 6). At low levels of self-efficacy (slope = -.804, \( t = -2.54, p < .01 \)) lack of capacity for exercise stereotypes

---

**Table 2 Stepwise regression analyses: Psychosocial predictors of physical activity in people living with HIV, France 2017**

<table>
<thead>
<tr>
<th>Steps</th>
<th>Predictors</th>
<th>β</th>
<th>t</th>
<th>( R^2 )</th>
<th>( \Delta R^2 )</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>PPA</td>
<td>.33***</td>
<td>5.98</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>AGE</td>
<td>-.03</td>
<td>-.46</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>PPA</td>
<td>.32***</td>
<td>5.89</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>AGE</td>
<td>.002</td>
<td>.04</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>BEN</td>
<td>.15**</td>
<td>2.89</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>RIS</td>
<td>-.08</td>
<td>-.144</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>LCE</td>
<td>-.19***</td>
<td>-.353</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>PAA</td>
<td>.30***</td>
<td>5.71</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>AGE</td>
<td>.01</td>
<td>.17</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>BEN</td>
<td>.13*</td>
<td>2.46</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>RIS</td>
<td>-.06</td>
<td>-.123</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>LCE</td>
<td>-.12</td>
<td>-.182</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>FAT</td>
<td>-.16*</td>
<td>-.251</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>PPA</td>
<td>.28***</td>
<td>5.50</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>AGE</td>
<td>-.01</td>
<td>-.90</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>BEN</td>
<td>.02</td>
<td>.36</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>RIS</td>
<td>-.03</td>
<td>-.63</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>LCE</td>
<td>-.08</td>
<td>-.141</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>FAT</td>
<td>-.05</td>
<td>-.80</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>SE</td>
<td>.35***</td>
<td>5.98</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Notes. \( N = 305, \ \text{BEN} \) exercise benefits stereotypes, \( \text{RIS} \) exercise risks stereotypes, \( \text{LCE} \) lack of capacity for exercise stereotypes, \( \text{SE} \) exercise self-efficacy, \( \text{FAT} \) perceived physical fatigue. Fisher-Snedecor distribution, \( \Delta R^2 \) delta R-squared or the change in \( R^2 \)-squared between two equations, \( \beta \) beta weight values, \( t \) t-statistic values \( * p < .05, ** p < .01, *** p < .001 \).
was significantly negatively related to PA level. This suggests that the more participants endorsed stereotypes related to the lack of capacity for exercise, the less they were physically active. For high levels of self-efficacy (slope = .222, \( t = 1.56, p < .05 \)), lack of capacity for exercise stereotypes was significantly positively related to PA level. Here, participants showed that lower levels of endorsement of stereotypes related to a lack of capacity for exercise corresponded to higher levels of PA.

**Discussion**

This study examined the relationship between positive and negative exercise stereotypes and PA as a health behavior, focusing on the underlying psychological mechanisms among PLHIV. Different competing models were tested in order to examine the role of exercise self-efficacy and perceived physical fatigue in the relationship between exercise stereotypes and PA. As a brief overview, the serial mediation model (with exercise self-efficacy and perceived physical fatigue as mediators), and the moderated mediation model (with exercise self-efficacy as a moderator of exercise stereotypes and perceived physical fatigue a mediator) showed good fits. The moderated mediation model explained the most variance in PA (\( R^2 = .27 \)) with indirect links for exercise benefits and risks remaining significant. Lack of capacity for exercise was moderated by exercise self-efficacy for both high and low levels with significant effects on PA.

The serial mediation was run to observe the plausible causal chain in which the constructs function. This model was contingent to Levy and Bavishi’s [39] research, which showed that the C-reactive protein, a marker of increasing stress-related inflammation, played a mediating role in the relationship between self-perceptions and longevity. This suggests additional mediators between self-perceptions and observed health outcomes. Inflammation is a stress marker and inducing stereotypes causes stress (see [40]), which can be related to fatigue and be an indicator of the ego depletion mechanism [15]. The different exercise stereotypes (exercise benefits, exercise risks and lack of capacity for exercise) were indirectly

**Table 3** Total, direct and indirect effects of exercise stereotypes dimensions as independent variables and exercise self-efficacy and perceived physical fatigue as mediators on physical activity in people living with HIV, France 2017

<table>
<thead>
<tr>
<th>Mediators</th>
<th>IV → mediator(s)</th>
<th>Mediator(s) → DV</th>
<th>Total effect</th>
<th>Direct effect</th>
<th>Indirect effect</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>BEN → PA</td>
<td>SE-FAT .38***/−.05</td>
<td>.001**/−.16</td>
<td>.16**</td>
<td>.13</td>
<td>.02**</td>
<td>[.006 to .061]</td>
</tr>
<tr>
<td>RIS → PA</td>
<td>SE-FAT −.11/−.08</td>
<td>.001**/−.16</td>
<td>−.08</td>
<td>−.06</td>
<td>−.02*</td>
<td>[−.051 to −.002]</td>
</tr>
<tr>
<td>LCE → PA</td>
<td>SE-FAT −.23/44</td>
<td>.001**/−.16</td>
<td>−.19**</td>
<td>−.12*</td>
<td>−.08*</td>
<td>[−.154 to −.018]</td>
</tr>
</tbody>
</table>

*Notes. N = 305, IV independent variable, DV dependent variable, BEN exercise benefits stereotypes, RIS exercise risks stereotypes, LCE lack of capacity for exercise stereotypes, SE exercise self-efficacy, FAT perceived physical fatigue, 95% CI lower and upper bound of bias-corrected 95% confidence interval with 5000 bootstrap samples *\( p < .05 \), **\( p < .01 \), ***\( p < .001 \)
associated to PA through exercise self-efficacy and perceived physical fatigue. Specifically, the higher the positive exercise stereotypes, the higher the exercise self-efficacy, the lower the perceived physical fatigue and the higher the level of PA, with the contrary being observed for negative exercise stereotypes. The overall model explained 19% of variance in PA level. This serial mediation of exercise self-efficacy and perceived physical fatigue confirmed the role of multiple mediators in the relationship between stereotypes and health outcomes such as PA. Our findings would extend the existing literature by showing that, beyond stress-related inflammation, perceived physical fatigue could be another valuable candidate in the relationship between self-perceptions and health outcomes.

The moderated mediation model placed self-efficacy as a moderator of exercise stereotypes in the causal chain: exercise stereotypes > perceived physical fatigue > PA level. This model was tested as previous studies have shown that people with higher self-perceptions in the physical domain have not internalized the stereotypes or have distanced themselves from their group and are thereby less sensitive to the stereotypes [30, 41, 42].

Results showed that indirect association between negative exercise stereotypes in terms of lack of capacity for exercise and PA via fatigue was fully moderated by exercise self-efficacy, explaining 27% of variance in PA level. For PLHIV with low levels of exercise self-efficacy, high negative exercise stereotypes are risk factors that increase their perceived physical fatigue, which in turn decreases their level of PA. In contrast, this negative chain is reduced in PLHIV with high levels of exercise self-efficacy. The moderated mediation model results are in

Table 4 Total, direct and indirect effects of exercise stereotypes dimensions as independent variables, perceived physical fatigue as mediator and exercise self-efficacy as a moderator on physical activity in people living with HIV, France 2017

<table>
<thead>
<tr>
<th>Mediators</th>
<th>IV → mediator(s)</th>
<th>Mediator(s) → DV</th>
<th>Total effect</th>
<th>Direct effect</th>
<th>Indirect effect</th>
<th>95% CI</th>
</tr>
</thead>
<tbody>
<tr>
<td>BEN → PA</td>
<td>FAT</td>
<td>−.12</td>
<td>.07</td>
<td>.02*</td>
<td></td>
<td>[.002 to .040]</td>
</tr>
<tr>
<td>BENxSE→PA</td>
<td>FAT</td>
<td>−.16</td>
<td>−.16**</td>
<td>−.16**</td>
<td>−.03</td>
<td>[−.017 to .004]</td>
</tr>
<tr>
<td>RIS → PA</td>
<td>FAT</td>
<td>−.09</td>
<td>−.07</td>
<td>−.01*</td>
<td></td>
<td>[−.036 to −.001]</td>
</tr>
<tr>
<td>RISxSE→PA</td>
<td>FAT</td>
<td>−.06</td>
<td>−.06</td>
<td>−.06</td>
<td>.001</td>
<td>[−.009 to .018]</td>
</tr>
<tr>
<td>LCE → PA</td>
<td>FAT</td>
<td>−.12</td>
<td>−.17**</td>
<td>−.11</td>
<td>−.06</td>
<td>[−.116 to −.007]</td>
</tr>
<tr>
<td>LCExSE→PA</td>
<td>FAT</td>
<td>−.12</td>
<td>.14*</td>
<td>.12</td>
<td>.02*</td>
<td>[.002 to .037]</td>
</tr>
</tbody>
</table>

Notes. N = 305, IV independent variable, DV dependent variable, BEN exercise benefits stereotypes, RIS exercise risks stereotypes, LCE lack of capacity for exercise stereotypes, SE exercise self-efficacy, FAT perceived physical fatigue, 95% CI lower and upper bound of bias-corrected 95% confidence interval with 5000 bootstrap samples

*p < .05, **p < .01, ***p < .001
line with previous studies that have evidenced that stereotypes can influence health outcomes through an ego depletion mechanism as operationalized through perceived fatigue in self-control task performance [15] and subjective vitality in the physical activity domain [12]. Furthermore, our results enrich this literature by showing that exercise self-efficacy could act as a moderator in this mechanism.

The parallel model that was tested revealed a near but non reliable fit, suggesting that a dual pathway, considering internalization [3] and ego depletion [12] side by side, does not best describe the mediating role of self-efficacy and perceived physical fatigue in the relationship between exercise stereotypes and PA level. However, the near fit for this model encourages the importance of each of these mechanisms and calls for further investigation as to how these mechanisms interact.

The two viable models provide support for multiple pathways of influence of positive and negative exercise stereotypes in PLHIV (i.e., internalization and ego depletion), while suggesting their differential effects on PA level. The parallel and serial mediation models are contingent with recent research (see [12]) providing support for the role of both internalization and ego depletion mechanisms in the relationship between exercise stereotypes and health outcomes such as PA. Moreover, results suggest that exercise self-efficacy would play a complex role in the relationship between exercise stereotypes and physical activity, playing either a mediating role or a moderating role. However, the higher explained variance of the moderated model ($R^2 = .27$) suggests retaining the role of self-efficacy as moderator.

Limitations and future directions for research and intervention
This study points out some limitations. The data being of correlational nature, inferences cannot be made about causal relationships between exercise stereotypes, mediators (perceived physical fatigue and self-efficacy), moderators (self-efficacy) and patients self-reported level of PA. Also, temporal causality cannot be inferred as the relationship between perceived physical fatigue and self-efficacy as regards to PA level could be recursive with a lower level of PA causing higher perceived physical fatigue or less self-efficacy which, in turn, discourages PA participation. Furthermore, the sample in this study presents specific sociodemographic characteristics in terms of gender, socioeconomic status and types and frequency of PA, thus limiting the generalization of the results. Moreover, although the moderated mediation model explains a higher variance in PA, further research is still needed to clearly establish the role of exercise self-efficacy as a mediator or as a moderator.

Despite these limitations, this study allows for several important implications in public health. First, as HIV is increasingly considered a chronic illness for people who have access to combined antiretroviral therapy, PLHIV are living longer and are faced with the health-related consequences of HIV [43–45]. Exercise presents itself as a self-management strategy that can limit disability, including mental, cognitive, physical and emotional symptoms, and enhance quality of life [46]. Hereby, the better understanding of the role of psychological barriers related to exercise stereotypes provided by the present findings, is of great interest to promoting a physically active lifestyle among PLHIV. Second, and more specifically, the fact that
positive exercise stereotypes are positively related to PA via exercise self-efficacy and perceived physical fatigue encourages the promotion of the benefits of PA among people living with HIV and health professionals through different communication strategies. Furthermore, exercise self-efficacy as a moderator of stereotypes related to lack of capacity for exercise points to the interest of positive individual PA experiences that nurture self-efficacy, through for example adapted physical activity offers and interventions [27]. Such perspectives however call for additional research based on the experimental manipulation of exercise self-efficacy and its effects on stereotype endorsement and health outcomes, and also call for longitudinal research to observe the effects of manipulated self-efficacy over time.

Conclusion
The moderated mediation model emphasizes that exercise stereotypes in people living with HIV might influence their PA through the ego depletion mechanisms as indexed by perceived physical fatigue, and be tempered by exercise self-efficacy. However, the relatively low explained variance for PA calls for further research, namely in order to investigate other variables in the relationship between exercise stereotypes and PA. Furthermore, it is of interest to consider the double status of exercise self-efficacy (moderator and mediator) in the relationship between exercise stereotypes and PA, as these roles enrich existing literature in the mechanisms at play [12] and encourage complementary experimental investigations.

Abbreviations
BEN: Exercise benefits; CFI: Comparative fit index; CI: Confidence interval; FAT: Perceived physical fatigue; HIV: Human immunodeficiency virus; LCE: Lack of capacity for exercise; NFI: Normed fit index; PA: Physical activity; PLHIV: People living with HIV; PPA: Previous physical activity; RIS: Exercise risks; RMSEA: Root mean square error of approximation; SE: Exercise self-efficacy; TLI: Tucker-Lewis index

Acknowledgments
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Ethics approval
All procedures performed in this study involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Informed consent: Signed informed consent was obtained from all individual participants included in the study.

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Availability of data and materials
The dataset supporting the conclusions of this article is included within the article and its additional file.

Authors’ contributions
LG oversaw collection of the experimental data, performed the statistical analysis, interpreted the results, and wrote the manuscript; AC contributed to the statistical analysis, interpretation of the results, and writing of the manuscript. JD provided knowledge related to HIV/AIDS, and collaborated on the general project to obtain funding; ER, CP, MD and IR contributed to the collection of data, provided specific knowledge related to HIV/AIDS, and collaborated on the general project to obtain funding; LS contributed to the data collection, interpretation of the results, and collaborated on the general project to obtain funding; SSC contributed to the development of the scale, and collaborated on the general project to obtain funding; FdAL was responsible for the scientific project and oversaw funding obtained, oversaw the collection of data, contributed to the interpretation of the results, and helped write the manuscript. All authors have read and approved the final version of the manuscript and agree with the order of presentation of the authors.

Consent for publication
Participants were informed that all data collected would remain anonymous. That data would be treated statistically only and remain confidential.

Competing interests
On behalf of all authors, the corresponding author states that there are no competing interests.

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La fatigue est de loin le symptôme principal chez les PVVIH, avec des taux de prévalence atteignant 88% (e.g., Henderson et al., 2005; Jong et al., 2010; Philips et al., 2004; Webel et al., 2016a).

L’objectif principal de cette étude était de caractériser la prévalence de la fatigue chez les PVVIH à travers une approche intégrative, prenant en compte à la fois la fatigue perçue et la fatigabilité à la performance (Kluger et al., 2013), tout en considérant le niveau d’AP des PVVIH (Webel et al., 2016a).

Dans un premier temps, nous avons fait passer des questionnaires évaluant le niveau d’AP des PVVIH afin de proposer la participation au protocole expérimental aux personnes peu actives et aux personnes très actives. Ensuite, les caractéristiques neuromusculaires des PVVIH, et leurs relations avec le niveau d’AP, la fatigabilité et la fatigue perçue ont été examinées sur un échantillon de 14 PVVIH. La fatigabilité a été induite au niveau musculaire par un exercice physique progressif composé de contractions sous-maximales volontaires. La fatigue physique perçue et le niveau d’AP ont été évalués par des questionnaires psychométriques.

Les principaux résultats ont révélé que certaines caractéristiques neuromusculaires différaient entre les PVVIH très actifs et les moins actifs. Les PVVIH ayant un niveau d’AP bas rapportent une fatigue perçue accrue et sembleraient être plus fatigables sur le plan musculaire. Ces résultats enrichissent d’une part les récents travaux de Webel et al. (2016) portant sur les relations entre AP et fatigue perçue, et d’autre part, les modèles explicatifs de la fatigue dans les maladies chroniques en général (e.g., Gruel et al., 2018; Kluger et al., 2013) et le VIH en particulier (Barroso & Voss, 2013).

Ces travaux ont permis la soumission du suivant article :
Characterizing perceived fatigue and performance fatigability in active and less active people living with HIV.
Characterizing perceived fatigue and performance fatigability in active and less active people living with HIV

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¹Université Côte d’Azur, LAMHESS, Nice, France; ²Departement of Infectious Diseases, Archet 1, Nice, France; ³Departement of Public Health, Archet 1, Nice, France
Introduction

In France, there are 6000 new HIV infections on average per year with 150000 people living with HIV (PLHIV). Though treatment can prolong the life expectancy and quality of life of those infected (Johnson et al., 2013; Lima et al., 2007), these treatments are costly. In addition, treatments can cause side effects and accentuate some of the HIV symptoms including fatigue. Studies focusing on the symptoms of HIV describe fatigue as one of the most prevalent symptoms with prevalence rates ranging from 37% to 88% (Phillips et al., 2004). Fatigue contributes greatly to physical limitations and disability making it essential to evaluate and treat (Ferrando et al., 1998). One of the biggest challenges faced by HIV/AIDS health-care professional is to characterize fatigue (Adinolfi, 2001) in order to lessen its impact on patients' quality of life.

In light of the literature, PLHIVs’ fatigue essentially reflects a multidimensional subjective complaint defined as a feeling of exhaustion or a lack of energy (Krupp, Alvarez, LaRocca, & Scheinberg, 1988; Lee, Lentz, Taylor, Mitchell, & Woods, 1994). To date, no biological factor appears to be a recurrent determining factor of fatigue in HIV infection (Barroso & Voss, 2013). Co-infection, like hepatitis C, could also participate to the fatigue symptom in PLHIV (Braitstein et al., 2010). Antiretroviral-based HIV treatments are also considered as factors that may influence perceived fatigue (Carr, Miller, Law, & Cooper, 2000; Gérard et al., 2000; Lars Hagberg Gunilla Lidin Janson, 2009). Psychological factors have been investigated and a strong correlation between depressed mood in PLHIV and fatigue was established (Barroso et al., 2003; Barroso & Lynn, 2002; Breitbart, McDonald, Rosenfeld, Monkman, & Passik, 1998; Henderson et al., 2005; Millikin, Rourke, Halman, & Power, 2003; Phillips et al., 2004; Voss, 2005). In advanced stages of the disease, fatigue is a symptom that is associated with depression but is not only a symptom of it (Ferrando et al., 1998). A study by Rabkin, Wagner, and Rabkin (1999) showed that even if depressed mood is
reduced, fatigue remains. Based on these studies, it is clearly recognized that multiple factors influence fatigue of PLHIV (Voss, Dodd, Portillo, & Holzemer, 2006). In this multidimensional approach, fatigue has only been evaluated using self-reported measures (i.e., questionnaires) that quantify perceived fatigue: Barroso & Voss, 2013; Voss et al., 2006) and reflect the so-called chronic fatigue. Surprisingly, other approaches using maximal muscular force loss, to quantify performance fatigability after a task or physical exercise has, to our knowledge, never been investigated in PLHIV.

In the scientific literature, fatigue induced by a task or physical exercise is defined as "a decrease in the ability of the muscle to develop strength or power induced by exercise, and reversible with recovery" (Bachasson, Guinot, et al., 2013a). Many studies have used this approach to characterize fatigue of different populations of individuals and under multiple experimental conditions. However, fatigue encompass both the perceived fatigue and performance fatigability (Kluger, Krupp, & Enoka, 2013). It is well accepted that the origin of performance fatigability may depend on peripheral factors and / or central factors. In patients with chronic diseases, these peripheral and central factors may be influenced by the pathophysiology of the disease. For example, in patients with multiple sclerosis, a lack of voluntary activation influences performance fatigability and contributes to perceived fatigue symptoms (Sheean, 1997). In another pathological context, central fatigue plays a major role in endurance loss and cancer-related fatigue (Yavuzsen et al., 2009). Also, in fibromyalgia syndrome, muscle contractility deficit is an important factor for patients’ functional limitations (Bachasson, Guinot, et al., 2013a). Therefore, the characterization of fatigue (i.e., both perceived fatigue and performance fatigability) is a crucial step in identifying the factors to be taken into account in the interpretation of fatigue in PLHIV.

Another important unresolved issue is the potential influence of performance fatigability on perceived fatigue. For example, Lou, Benice, Kearns, Sexton, and Nutt (2003)
observed that a decrease in motor performance (i.e., performance fatigability) was not significantly correlated with perceived fatigue. Nevertheless, several foundations suggest a possible link between performance fatigability and perceived fatigue (Twomey et al., 2017). Decreased fatigue resistance during acute exercise may result in greater functional impairment, fatigue accumulation and require greater recovery time. This accumulation of fatigue would act indirectly on the perceived fatigue modifying the homeostatic conditions of functional regulation. Thus, only an integrated approach would make it possible to understand all the dimensions of fatigue and to identify the different factors that explain perceived fatigue and performance fatigability.

For better quality of life and expected life expectancy increases, different interventional studies aimed at reducing the perceived fatigue of PLHIV by using, for example, supplementation of thyroid hormones (Derry, 1996), or therapy with androgens such as testosterone (Rabkin, Ferrando, Wagner, & Rabkin, 2000), or the practice of a regular PA. For example, Webel, Perazzo, Decker, Horvat-Davey, Sattar, et al., (2016a) showed that for every 150 minutes of moderate PA practiced, perceived fatigue decreased by 17%. Unfortunately, perceived fatigue is also one of the major reasons for the non-involvement of PLHIV in PA practice (Ferez & Thomas, 2012). This observation is not specific to PLHIV and has been reported in multiple sclerosis (Iriarte, Katsamakis, & De Castro, 2016), Parkinson's disease (Garber & Friedman, 2003) and some neuromuscular diseases (Kalkman, Schillings, Zwarts, van Engelen, & Bleijenberg, 2007). However, a recent study conducted in healthy young people, indicated that training status (i.e., trained vs. untrained) and by extrapolation, the amount of PA practiced, significantly influenced performance fatigability (Bachasson, Decorte, Wuyam, Millet, and Verges, 2016). Hence, one can postulate that physically active PLHIV may experience less perceived fatigue and less performance fatigability than less physically active PLHIV.
In this study, we seek to characterize perceived fatigue and performance fatigability in PLHIV based on their PA level. The main objective of our research is to study fatigue in a clinical research context (Kluger et al., 2013) based on two domains: perceived fatigue and performance fatigability induced by a fatiguing task. A second objective is to identify the role of PA on fatigue. Indeed, regular PA could reduce PLHIVs’ perceived fatigue (Webel, Perazzo, Decker, Horvat-Davey, Sattar, et al., 2016a), but no research has examined the characteristics of perceived fatigue and performance fatigability in relation to the PA level of PLHIV.

Method

Participants

Seven PLHIV (6 men and 1 woman; Age = 55 ± 6 years, Height = 1.71 ± 0.07 cm, Body mass = 65.3 ± 10.5 kg, BMI = 22.3 ± 2.7 kg/m²) were recruited from the Archet 1 hospital of Nice and took part in this controlled, comparative monocentric study with no individual benefit for the patient. Participants read and signed written informed consent. In addition, to be included, PLHIV had to have a Physical Activity Score (SAP of Dijon; Robert et al., 2004) greater than or equal to 22 or less than or equal to 15. This questionnaire is composed of 9 items and has a maximum of 30 points. Based on the score, PLHIV were divided into two distinct groups: a group consisting of physically active individuals (i.e., SAP ≥ 22; APLHIV), and a group of individuals with low physical activity level (i.e., SAP ≤ 18; LPLHIV). This questionnaire was chosen as it has previously been used in PLHIV (Gray et al., 2018; 2016) and other populations with various pathologies (Falzon, Radel, Cantor, & d'Arripe-Longueville, 2015; Gremeaux et al., 2008). The main criteria for non-inclusion were PLHIV with a motor disability, with a contraindication to PA, suffering from co-morbidities, with a co-infection (hepatitis B or C), a contraindication to magnetic stimulation (hearing
apparatus or metal carriers), patients who have stopped ART treatment and / or medical follow-up recently and who have a progressive recovery of their infection. Participants were informed about the procedure, signed written informed consent and were free to leave the experiment at any time. The study was conducted in accordance with the Helsinki Declaration with the approval of the local Committee on Human Research (CPP Sud-Est; Clinical Study Number: NCT03124914).

**Procedure**

All included participants took part in one evaluation session. Upon arrival, participants were briefed and prepared for the neuromuscular fatigue protocol. Anthropometric and body measurements were taken and the participants filled-out the perceived fatigue questionnaire. After a period of familiarization, they completed the fatigue protocol with the neuromuscular assessments.

**Anthropometric measures**

Each participant was measured and weighed (i.e., Tanita BF 555 impedance balance) to determine body fat and lean mass. In addition, by measuring the circumference and the anterior skin fold of the right thigh, the quadriceps cross-sectional area (qCSA) was estimated by the following formula (Housh et al., 1995):

\[
qCSA = (2,52 \times Cc) - (1,25 \times ACF) - 45,13
\]

with qCSA = cross sectional area of the quadriceps (cm\(^2\)), Cc = circumference of the middle of the thigh (cm) and ACF = anterior skin fold of the thigh (mm).
Perceived fatigue measures

The participants filled-out the EMIF-SEP questionnaire to assess their level of perceived fatigue. This questionnaire is the French version initially validated in patients with multiple sclerosis (Debouverie, Pittion-Vouyovitch, Louis, & Guillemin, 2007) of the Fatigue Impact Scale (FIS) developed and validated by Fisk et al. (1994) and widely used in PLHIV (Marcellin et al., 2007). This questionnaire includes 40 items to assess perceived fatigue and its impact on the cognitive (10 items), physical (10 items) and social (20 items) dimensions of the participants’ daily life. Participants answered the different questions on a 5-point Likert scale, ranging from 1 (strongly disagree) to 5 (strongly agree).

Knee extensor muscles’ evaluation

The measurements were performed on the right lower limb under isometric conditions as previously described (Bachasson JEK 2013). The participant was placed on an isokinetic ergometer (Biodex® System 3, BIODEX Corporation, Shirley NY, USA). The positioning of the participants on the ergometer was standardized with a trunk / thigh angle of 130 ° and a knee / leg angle of 90 °. Belts positioned around the abdomen and the thorax secured the participants to minimize body movement. Participants crossed their arms on their chest with hands on their shoulders to avoid any interfering movement. The motor of the ergometer’s axis was aligned with the knee joint’s rotation axis. The lever-arm, attached to the motor’s axis and parallel to the studied segment, was positioned two fingers above the external malleolus of the tested limb. Surface EMG signals (sEMG) of the right vastus lateralis (VL) were recorded according to SENIAM recommendations. Pairs of bipolar silver-chloride electrodes (10-mm diameter, Contrôle Graphique Medical, Brie-Comte-Robert, France) were positioned over the muscle belly of the muscle with a 25-mm interelectrode distance and the reference electrode was attached on the patella. Low impedance (< 5 kΩ) was obtained by
means of shaving and abrading the skin with emery paper and cleaning the skin with alcohol. sEMG signals were amplified (MP150 Biopac® Systems Inc., Holliston, MA, USA; CMRR = 110 db, Z input = 1000 MΩ, gain = 1000, A/D resolution = 16 bits), filtered with a bandwidth frequency ranging from 10 Hz to 500 Hz, and online digitized with a sampling frequency of 1000 Hz. Torque and sEMG were synchronized and stored on a portable computer for further off-line analysis.

*Magnetic stimulation of the femoral nerve*

Two magnetic stimulators (Magstim 200, Magstim Company Ltd, Whitland UK) connected by a dual stimulation module (BiStim Module, Magstim) were used to stimulate the femoral nerve using an eight-shaped coil (diameter 45mm, peak value of the magnetic field 2.5 T). The coil was positioned on the upper part of the femoral triangle laterally to the femoral artery. The optimal stimulation site was determined from a maximal unpotentiated twitch and a maximum electrophysiological response (M wave) of the VL muscle. The location of the coil was then marked on the skin to always stimulate the same area and was manually controlled by the same experienced investigator throughout the protocol. Single (1 Hz) and doublets (10 and 100 Hz) magnetic stimuli of 1-ms duration were delivered at maximum stimulator intensity (Bachasson, Millet, et al., 2013b; Gruet et al., 2016; Verges et al., 2009). The supramaximality of the stimulation was evaluated by stimulating the femoral nerve with an intensity ranging from 100% to 80% of the maximum intensity of the generator in 5% steps. Supramaximality was confirmed by the absence of reduction in the unpotentiated twitch and maximal M wave between the different stimulations, as previously observed (Verges et al., 2009; Gruet et al., 2016).
Knee extensor muscles fatigue protocol

Once the participant was familiarized, the neuromuscular test sequence and the fatigue protocol were performed according to the procedures reported earlier (Bachasson et al., 2016; Bachasson, Millet, et al., 2013b; Gruet et al., 2016; Verges et al., 2009) (see Figure 1). The participants started with a standardized warm-up on the ergometer. This included progressive submaximal isometric contractions of the knee extensor muscles performed intermittently for 4 minutes. This warm-up also allowed the subjects to become familiar to generate a specific torque with visual feedback. At the end of the warm-up, participants performed three maximal voluntary contractions (MVC) with 30 seconds of rest between each contraction (Gruet et al., 2016). Following these MVC allowing for muscular potentiation (Kufel, Pineda, & Mador, 2002), participants performed a sequence of neuromuscular tests including:

- A 5-s MVC during which a 1 ms double stimulation at 100 Hz followed by two double stimulations at 100 Hz and then 10 Hz (respectively Db\textsubscript{100} and Db\textsubscript{10}) delivered at rest after the MVC. These last two stimulations were 4-s apart respectively.

- 30-s after the first MVC, a second 5-s MVC was performed during which a single stimulation of 1Hz (Tw\textsubscript{s}) was delivered followed by the same stimulation delivered at rest (Tw\textsubscript{p}) after the MVC.

Once this sequence of neuromuscular tests was performed, the participant had to perform the fatigue protocol consisting of a progressive incremental test comprising several series of 10, 5 seconds on-5 seconds off intermittent voluntary contractions (Bachasson, Millet, et al., 2013b). The first set of 10 voluntary contractions was set at 10% of the previously determined MVC. The following series were performed with a 10% increase of the MVC for each series until the task failure determined by the inability to reach the target torque for two consecutive contractions. The participant could see the target torque exerted via a visual feedback on the screen of the computer throughout the experimental protocol. The
contraction and rest periods were punctuated by a rhythmic sound signal. At the end of each series of 10 contractions, at the time of exhaustion and after 10 minutes of recovery, the neuromuscular tests were performed identically to the pre-experimental measurements.

**Figure 2.** Neuromuscular fatigue test protocol.

*Notes.* MVC: maximal voluntary contraction; % pre: percentage of pre-test MVC; 100Hz: superimposed doublet and potentiated doublet; 10Hz: potentiated doublet; 1Hz superimposed and potentiated doublet; (5-s ON/5-s OFF) x 10: series of 10 sub-maximal contractions (5-s contraction/ 5-s rest); post 10’: neuromuscular assessment after 10-minutes rest. Based on Bachason et al., (2013)

**Data analysis**

The peripheral responses to single magnetic stimulation were analyzed: amplitude and duration of Tw, amplitude and area of M_max. The following peripheral responses for doublets were analyzed: Db_100, Db_0, and the Db_10: 100 ratio. These parameters were also standardized with the previously estimated qCSA. The maximum voluntary activation level (VA) determined using interpolation twitch technique (Merton, 1954) was quantified according to Allen et al.’s (1995) formula:
VA (%) = \[1 - \left(\text{Amplitude Db}_{100s} / \text{Amplitude Db}_{100}\right)\] x 100

When the stimulations were delivered before or after the maximum momentum plateau of the maximal voluntary contraction, a correction of the activation level calculation formula was applied (Strojnik & Komi, 1998):

AV (%) = \[1 - \left(\text{superimposed doublet} \times \left(\frac{M_{\text{stim}}}{M_{\text{VCC}}}\right)\right) / \text{potentiated doublet}\] x 100

with $M_{\text{stim}}$ = voluntary momentum when the stimulation is applied.

The number of submaximal contractions was taken as the index of relative endurance while the total force-time output was taken as the index of absolute endurance. The changes in muscular responses obtained during spontaneous and evoked contractions between the initial evaluation (i.e., before the fatigue protocol) and at exhaustion were used as an index of fatigability. The changes in voluntary and evoked responses between exhaustion and recovery (i.e., post 10) were used as an index of recovery.

**Statistical analysis**

Statistical analysis was performed using Statistica® software for Microsoft Windows (StatSoft, version 8.0, Tulsa, OK, USA). The significance threshold was set at 5% ($p < 0.05$). The data was presented as the mean ± standard deviation (SD). Before each analysis, the conditions of application of the various statistical tests were verified. A Mann-Whitney U test was performed to examine the differences between two groups (group factor) in pre-test, exhaustion and post 10. A non-parametric Friedman ANOVA was used to see the differences between several dependent variables during the fatigue protocol (time factor). A non-
parametric Wilcoxon test was performed on variables with a significant difference (time factor).

Results

The characteristics of active and less active PLHIV.

The PA scores of the inactive group of PLHIV was, as expected, significantly lower that the scores of the active PLHIV (see Table 1). No significant differences in the anthropometric measures (i.e., age, height, weight, IMC, qCSA) were observed between the two groups. Also, no significant differences were observed between the two groups as regards to their global perceived fatigue scores (global EMIF-SEP), the different sub-scales of the EMIF-SEP, and their pain and fatigue VAS (Table 1).

Table 1. Initial assessment based on reported PA level

<table>
<thead>
<tr>
<th></th>
<th>Less active</th>
<th>Active</th>
<th>( P )</th>
</tr>
</thead>
<tbody>
<tr>
<td>SAP</td>
<td>12 ± 2</td>
<td>24 ± 2</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>\textit{EMIF-SEP}</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cognitive</td>
<td>2.70 ± 0.10</td>
<td>2.69 ± 1.49</td>
<td>0.51</td>
</tr>
<tr>
<td>Physical</td>
<td>3.43 ± 0.76</td>
<td>2.70 ± 1.48</td>
<td>0.51</td>
</tr>
<tr>
<td>Psycho-social</td>
<td>3.19 ± 0.67</td>
<td>2.64 ± 1.21</td>
<td>0.27</td>
</tr>
<tr>
<td>Global</td>
<td>3.11 ± 0.44</td>
<td>2.68 ± 1.39</td>
<td>0.82</td>
</tr>
<tr>
<td>\textit{VAS}</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial fatigue</td>
<td>3.17 ± 3.81</td>
<td>1.60 ± 2.43</td>
<td>0.66</td>
</tr>
<tr>
<td>Initial pain</td>
<td>0.10 ± 0.17</td>
<td>0.15 ± 0.13</td>
<td>0.82</td>
</tr>
</tbody>
</table>

Notes. SAP: physical activity score; EMIF-SEP: perceived fatigue questionnaire; VAS: visual analogue scale
The neuromuscular function characteristics of the knee extensor muscles are shown in Table 2.

**Table 2. Pre-test neuromuscular function in active and inactive PLHIV**

<table>
<thead>
<tr>
<th></th>
<th>Inactive</th>
<th>Active</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>MVC (Nm)</td>
<td>104 ± 58</td>
<td>147 ± 26</td>
<td>0.27</td>
</tr>
<tr>
<td>qCSA (cm²)</td>
<td>51.5 ± 10.1</td>
<td>65.2 ± 9.8</td>
<td>0.13</td>
</tr>
<tr>
<td>MVC/qCSA (Nm/cm²)</td>
<td>1.6 ± 1.4</td>
<td>2.3 ± 0.4</td>
<td>0.82</td>
</tr>
</tbody>
</table>

_Evoked responses_

Simple potentiated stimulation

<table>
<thead>
<tr>
<th></th>
<th>Inactive</th>
<th>Active</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>$T_{wp}$ (Nm)</td>
<td>18.7 ± 9.3</td>
<td>30.5 ± 12.2</td>
<td>0.28</td>
</tr>
<tr>
<td>$T_{wp}$/qCSA (Nm/cm²)</td>
<td>0.36 ± 0.13</td>
<td>0.46 ± 0.12</td>
<td>0.51</td>
</tr>
<tr>
<td>Contraction time (ms)</td>
<td>62.3 ± 9.1</td>
<td>74.3 ± 28.3</td>
<td>0.83</td>
</tr>
<tr>
<td>Half relaxation time (ms)</td>
<td>97.0 ± 21.2</td>
<td>89.7 ± 13.3</td>
<td>0.56</td>
</tr>
<tr>
<td>M-wave amplitude (V)</td>
<td>1.34 ± 0.70</td>
<td>2.80 ± 0.44</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>Peak to peak M-wave duration (ms)</td>
<td>8.3 ± 0.3</td>
<td>9.0 ± 0.5</td>
<td>0.10</td>
</tr>
<tr>
<td>M-wave area (V.s)</td>
<td>0.011 ± 0.005</td>
<td>0.017 ± 0.004</td>
<td>0.28</td>
</tr>
</tbody>
</table>

Potentiated doublets

<table>
<thead>
<tr>
<th></th>
<th>Inactive</th>
<th>Active</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>$D_{100}$ (Nm)</td>
<td>11.3 ± 4.5</td>
<td>33.7 ± 13.6</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>$D_{100}$/qCSA (Nm/cm²)</td>
<td>0.22 ± 0.06</td>
<td>0.51 ± 0.17</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>$D_{10}$ (Nm)</td>
<td>7.4 ± 2.0</td>
<td>22.9 ± 15.1</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>$D_{10}$/qCSA (Nm/cm²)</td>
<td>0.15 ± 0.03</td>
<td>0.34 ± 0.18</td>
<td>&lt; 0.05</td>
</tr>
<tr>
<td>$D_{10:100}$</td>
<td>1.05 ± 0.56</td>
<td>0.73 ± 0.39</td>
<td>0.82</td>
</tr>
</tbody>
</table>

Central parameters

<table>
<thead>
<tr>
<th></th>
<th>Inactive</th>
<th>Active</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>VA (%)</td>
<td>72.7 ± 12.2</td>
<td>90.4 ± 4.6</td>
<td>&lt; 0.05</td>
</tr>
</tbody>
</table>

*Notes. MVC = maximal voluntary contraction; qCSA = quadriceps cross sectional area; $T_{wp}$ = single twitch at 1Hz; $D_{100}$ = doublet at 100Hz; $D_{10}$ = doublet at 10Hz; VA = Voluntary Activation*

No significant difference ($p > 0.05$) between the 2 groups was observed for MVC (absolute values or values normalized by qCSA) and mechanical response induced by simple stimulations ($T_{wp}$). On the other hand, the mechanical responses induced by double
stimulations (Db_{100} and Db_{10}) for both absolute values and values normalized by qCSA, were significantly higher in active compared to less active PLHIV (p <0.05). Similarly, active PLHIV had a higher voluntary activation than less active PLHIV (p <0.05). The M-wave amplitude of the VL muscle was significantly greater for the active group than for the inactive group (p <0.05), whereas no difference was observed regarding the M-wave duration and area. Finally, although the root mean squared (RMS) values of the VL muscle were not different between the groups, the RMS / M ratio was significantly lower for the active PLHIV (p <0.05).

**Influence of the fatigue protocol**

*Endurance.* The total number of submaximal contractions reached by active PLHIV (67 ± 9, p <0.05) was significantly higher than the inactive PLHIV (46 ± 7). The total force-time production of the active group (19993 ± 8130 Nm.s, p <0.05) was significantly higher than the inactive group (7669 ± 5329 Nm.s) at exhaustion. After 40 contractions (i.e., level reached by all participants), total force-time production was not significantly different between groups (p >0.05).

*MVCs and evoked responses.* For all participants, a significant effect of time on MVC was observed (χ² (6) = 16.34, p <0.01). A significant difference was noted between the pre-test MVC values and the 30%, 40% and exhaustion levels (p <0.05). The magnitude of the mechanical response Twp was also affected by time (χ² (5) = 11.09, p <0.05). Indeed, the pre-test values of 24.61 ± 11.63 Nm were significantly different from that at 40% (17.69 ± 14.71 Nm) and at exhaustion (15.92 ± 15.05 Nm). No significant differences were observed for the other variables.
Rate of perceived effort (RPE) and visual analogue scales. The subjective assessment of task difficulty (RPE) increased significantly between the 10% (1.08 ± 1.20), 20% (2.08 ± 2.09) and 30% (3.00 ± 2.74) increments for the 2 groups (p <0.05 between each of the three levels). Similarly, the fatigue and pain VAS significantly increased between the beginning of the protocol and exhaustion (p <0.05).

Post-test characteristics of active and inactive PLHIV and at 40% MVC.

When exhausted (post-tests), the mechanical responses Twp and Db100 of the active group were significantly higher than those of the inactive (24.87 ± 18.05 Nm vs 6.97 ± 0.40 Nm and 23.48 ± 19.45 Nm vs 19.45 ± 4.15 Nm, respectively, p <0.05). The M-wave amplitude and the RMS / M ratio of the VL muscle were significantly different between the groups (p <0.05).

At the 40% MVC level, attained by all participants, similar results were observed for the same variables. Interestingly, the relative decrease percentage of Twp in the active group was 16.8 ± 22.5%, compared to 48.9 ± 13.5%, with an effect size of 1.32 in the inactive group. Although no significant differences were observed for MVC values at 40% between the 2 groups, the relative MVC decrease percentage of active PLHIV was 12.2 ± 5.6% while that of inactive PLHIV was 22.5 ± 12.2%. The effect size calculated on these differences was greater than 1, suggesting a large effect.

Recovery period

After 10 minutes of recovery, the MVC values were significantly different from the exhaustion values (105.26 ± 46.76 Nm vs. 93.65 Nm ± 39.29, p <0.05), even if the latter remained below the pre-test MVC values (p <0.05). The Twp values did not increase significantly compared to exhaustion and remained significantly lower than the pre-test values.
Discussion

With fatigue being the most prevalent symptom in PLHIV, the main aim of this study was to characterize the performance fatigability of active and less active PLHIV. The main findings show that: i) some neuromuscular factors of knee extensor muscles differ between both groups; ii) although the MVC decrease was not different at exhaustion between the two groups, a trend towards a lower MVC reduction was observed in the active PLHIV at the 40% level for similar absolute endurance among the groups; and iii) performance fatigability appears to be predominantly peripheral for both groups with inactive PLHIV revealing greater peripheral fatigue compared to active PLHIV.

Pre-test characteristics of active and inactive PLHIV

Although PLHIV included in each group had different PA scores, the perceived fatigue measures (i.e., EMIF-SEP, fatigue VAS) did not discriminate between the two groups of participants. This observation is also valid for the MVCs produced during the pre-tests where it was legitimate to expect a difference between the groups. Indeed, a significant difference in MVCs have been reported in the literature for healthy young participants with different training status (Bachasson et al., 2016). However, when effect sizes were calculated for the MVC values produced during the pre-test a moderate effect (ES = 0.91) was found between the two groups. This trend was confirmed by the differences observed between the groups on the absolute and relative mechanical response values induced by double stimulations (Db100, Db10, Db100 / qCSA and Db10 / qCSA), the voluntary activation and the M-wave amplitude of the VL muscle. These observations give support to the possibility of favorable neuromuscular adaptations (e.g., greater muscle mass, motor unit recruitment and motoneuron excitability) induced by regular PA in active PLHIV and reinforce the importance of encouraging PLHIV to have physically active lifestyle.
The fatigue protocol chosen for this study has been widely used in the literature (Bachasson et al., 2016; Bachasson, Millet, et al., 2013b; Gruet et al., 2016) in healthy individuals and in patients with different conditions. The observed MVC decrease percentages and the number of contractions reached before exhaustion are in agreement with the data from these studies. In addition, the increase in RPE and fatigue and pain VAS values confirm that intermittent submaximal isometric contractions increased perceived effort and perceived fatigue at the end of the protocol, despite no differences between the groups being observed. However, although the MVC decrease was not significantly different at exhaustion between groups, active PLHIV had a lower tendency to decrease than inactive PLHIV at the end of the 40% MVC level for equivalent absolute endurance between the groups (12.2 ± 5.6% vs. 22.5 ± 12.2%, ES = 1.02). Therefore, we could suggest that inactive PLHIVs’ performance fatigability was greater than that of active PLHIV.

The decrease in MVC values at exhaustion could mainly be attributed to mechanisms of peripheral origin as the $T_{w_p}$ values were significantly reduced while the voluntary activation levels and the RMS / M values were not significantly modified. This reduction of the $T_{w_p}$ suggests an alteration of the excitation-contraction coupling. This alteration could in part be related to a decrease in membrane excitability since a decrease in the amplitude of the resting V wave of the VL muscle was also observed. These results were not found in healthy individuals (Bachasson et al., 2016; Bachasson, Millet, et al., 2013b) or patients with cystic fibrosis (Gruet et al., 2016). The decrease in membrane excitability observed in this study indicated that this alteration would mainly be related to physical inactivity. Indeed, an effect size calculation performed between the groups concerning the relative decrease of the M-wave at exhaustion and at 40% of the MVC value had a moderate effect on these values (ES = 0.81 and 0.79, respectively) indicating that the decrease was greater for inactive PLHIV.
Inactive people would therefore tend to develop more peripheral fatigue than active people (Bachasson et al., 2016).

No difference in the level of voluntary activation was observed between pre-test and exhaustion values or between groups of PLHIV. Along with the absence of RMS / M ratio modifications of the VL muscle, it would seem that no central nervous mechanisms could explain the decrease of MVC value, either at exhaustion or at 40% of MVC. Indeed, this protocol of intermittent sub-maximal isometric contractions is recognized to induce little fatigue of central origin (-5% at exhaustion; Bachasson, Millet, et al., 2013b).

*Performance fatigability and perceived fatigue*

The absence of a significant difference in the perceived fatigue subscales EMIF-SEP) between the groups does not corroborate the results found by Webel et al. (2016a) showing that regular PA resulted in less perceived fatigue. This result could be partly explained by the small sample size, which does not make it possible to distinguish differences statistically. However, a significant positive correlation ($r = 0.64$) between the EMIF-SEP physical fatigue subscale scores and the pre-test VAS fatigue scores was observed for all patients. PLHIV with the highest EMIF-SEP scores (measuring relatively general characteristics) were also those who reported high VAS fatigue scores (measuring situational psychological states).

During the fatigue protocol, one could expect to observe differences in the RPE values according to previous research showing that people with good physical fitness had lower perceived effort scores for a given task, compared to people in poorer physical condition (Travlos & Marisi, 2016). Again, the small number of patients in each group limits our interpretation even though the calculated effect size between the RPE values of the two groups between the 10% and 40% levels indicated a large effect on these values ($ES = 1.11$).
Limitations and perspectives

The major limitation of this study lies in its low number of patients included due to the recruitment difficulties encountered. Thus, the possibilities of interpretation and discussion are limited. The use of magnetic stimulation, although better endured by patients than electrical stimulation, remains a limited tool. Indeed, not being able to exceed 100% of the maximum power of the generator, certain stimulations are not always delivered under supramaximal conditions throughout the fatigue protocol due to the loss of excitability of the motoneurons. The use of accelerometer data to objectify the level of PA is also a way to overcome the subjectivity of the PA score using the SAP. It has been recommended as a tool to quantify the PA of patients with cystic fibrosis (Savi et al., 2013). Equipping patients with accelerometers as recommended by Migueles et al. (2017) would attest patients actual PA level.

Conclusion

In conclusion, despite its limitations, this study offers promising perspectives in understanding the mechanisms underlying perceived fatigue and fatigability in PLHIV based on their PA level in line with the integrative approach by Kluger et al. (2013). These results also encourage experimental and interventional studies that would examine the effect of PA on the pluridimensions of fatigue.
References


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L’objectif clinique était de mieux comprendre et caractériser ce symptôme fréquent et multidimensionnel du VIH dans l’optique, d’une part, de pouvoir mieux le prendre en compte et en charge, pour améliorer la qualité de vie des PVVIH. D’autre part, il s’agissait de mieux saisir comment lever la fatigue en tant que barrière à l’AP régulière, cette dernière étant bien établie dans la littérature scientifique comme ayant des effets bénéfiques sur la santé des PVVIH (e.g., O’Brien et al., 2017).

Les résultats des trois volets d’études nous ont permis, dans ce sens, de révéler plusieurs dimensions de la fatigue et de ses liens avec l’AP.

Volet 1. Approche sociologique des attitudes des PVVIH à l’égard de la fatigue et de l’AP (responsable : Laura Schuft).

L’ensemble des résultats qualitatifs sur les sens sociaux et la gestion de la fatigue ont permis d’illustrer, dans un premier temps, la dimension sociale de la fatigue liée au VIHH. Peu comprise médicalement, la fatigue chronique chez les PVVIH est socialement comprise comme un symptôme de maladie, s'opposant à la "bonne" fatigue ou à la fatigue "normale" - associée à l'AP ou à la vie de tous les jours (Schuft et al., soumis; Schuft et al., 2018).

Ce "symptôme" a également une dimension performative, étant plus ou moins mise en avant ou en (in)visibilité selon les normes sociales associées au contexte et à l'identité de l'individu (normes de genre, normes des non-dits en contexte professionnel versus associatif, etc.), et ce dans un contexte de stigmatisation du VIH et de forts enjeux autour de la mise en visibilité de ce statut sérologique (Schuft et al., 2018). Ceci n'enlève en rien, bien évidemment, de la dimension physique de la fatigue ressentie (objet du volet 3), mais montre que sa divulgation ou sa mise en (in)visibilité suivent des logiques sociales et d'identité sociale, logiques qui composent avec les trajectoires sociales et médicales de vécu avec le VIH, et avec les contextes d'interaction (Schuft et al., 2018).
Ces phénomènes et expériences sont ainsi également reliés aux caractéristiques sociales des individus, celles-ci exprimant souvent des profils différents en termes de vécus du VIH. En effet, les normes de genre semblent agir comme proscripteurs de mise en visibilité de la fatigue ou du VIH chez les hommes hétérosexuels plus particulièrement (Schuft et al. 2018), mais dont les effets sur l'identité sociale et sur le bien-être doivent encore être étudiés. De manière similaire, un plus jeune âge ou une catégorie socioprofessionnelle plus avantagée agissent comme protecteurs du ressenti de la fatigue (Bergamaschi et al., 2019), dont les mécanismes sociaux, psychologiques et physiques restent à explorer.

Dans un deuxième temps, ce volet a montré certaines dimensions sociales des relations entre la fatigue liée au VIH et l'AP. L'étude quantitative a permis de démontrer que la pratique régulière d'AP est bien reliée à une fatigue physique ressentie moindre (Bergamaschi et al., 2019), bien que les mécanismes psychologiques, sociaux et physiques derrière cette corrélation restent à explorer. Les idéaux-types des attitudes vis-à-vis de la fatigue et de l'AP, dans l'étude qualitative, ont permis de caractériser ces relations dans leurs dimensions sociales à travers quatre principaux types d’attitudes, conçus comme situés le long de continus de fatigue et d’AP (Schuft et al., soumis). Il s’agit de : (a) la pratique d’AP pour gérer la fatigue ; (b) le sentiment d’être en « bonne » santé et pas fatigué grâce à l’AP ; (c) la non pratique d’AP à cause de la fatigue ; (d) l’absence de fatigue, de pratique d’AP et de problème. Ainsi, les sens de la fatigue et de l'AP étaient reliés : la fatigue était généralement perçue comme devant être gérées (par l'AP et une "bonne hygiène de vie") ou comme une barrière aux pratiques quotidiennes (d'où l'AP). Chez ceux décrivant une certaine absence de fatigue, celle-ci était généralement perçue comme l'expression de son hygiène de vie (d'où l'AP) ou de sa vie "normale" ("comme tout le monde"). L'AP comme nouvelle attente sanitaire avait bien été internalisée par la plupart des personnes participant à cette étude, créant des sentiments de "devoir" parce que "malade" (même chez ceux ayant un taux indétectable) ou alors de culpabilité, sauf chez ceux se percevant "comme tous les autres" dans le dernier idéal-type. Cette typologie a reflété divers modes d'intériorisation du statut de malade et des attentes sociales et biomédicales en matière de comportements sociaux et sanitaires. Ces résultats ont également pointé la prépondérance du VIH dans le récit de vie et dans l’interprétation ou l’explication de son état physique et de ses activités physiques et quotidiennes.
Ces résultats suggèrent l'intérêt de futures études sur l'impact de la place du VIH dans la vie des PVVIH sur le bien-être physique, psychologique et social, et autour de comment faciliter le sentiment de "normalité" décrit par peu des PVVIH interviewées. Cette réflexion doit forcément prendre en compte les dimensions sociodémographiques des PVVIH, dont le sexe, l'orientation sexuelle, l'âge ou la CSP, variables corrélées à la fatigue liée au VIH (Bergamaschi et al., 2019) mais également à la santé et à la pratique d'AP.

Volet 2. Relations entre stéréotypes liés à l'AP, fatigue physique perçue et AP chez les PVVIH (responsable : F d’Arripe-Longueville)

Les stéréotypes liés à l’AP constituent une des barrières psychologiques à l’exercice importantes chez les populations vulnérables. Dans un premier temps, une étude qualitative auprès de 15 PVVIH (Gray et al., in press) nous a permis de caractériser le contenu de ces stéréotypes et de développer une échelle psychométrique permettant de mesurer les bénéfices perçus de l’AP chez les PVVIH, les risques perçus, et le manque de capacités physiques perçues (Gray et al., 2016). Dans un second temps, nous avons examiné les relations entre ces stéréotypes et le niveau d’AP des PVVIH, et le rôle joué par la fatigue physique perçue et l’auto-efficacité dans cette relation. Une étude corrélationnelle multicentrique impliquant 305 PVVIH a mis en évidence un modèle de médiation modérée dans lequel les relations entre les stéréotypes et l’AP sont médiées par la fatigue perçue, et modérées par l’auto-efficacité (Gray et al., 2018). Cette étude suggère que les effets négatifs des stéréotypes sur la fatigue physique perçue et l’AP pourraient être atténués par le développement du sentiment de compétence des PVVIH.

Volet 3. Relations entre fatigue neuromusculaire, fatigue physique perçue et niveau d’AP chez les PVVIH (responsable : S Colson)

Les caractéristiques neuromusculaires de la fatigue chez les PVVIH, et leurs relations avec le niveau d’AP et la fatigue perçue, ont été examinées sur un échantillon de 14 PVVIH. La fatigue musculaire a été induite par un exercice physique incrémentiel composé de contractions sous-maximales volontaires. La fatigue physique perçue et le niveau d’AP ont été évalués par des questionnaires psychométriques.

Les résultats indiquent que les PVVIH ayant un niveau d’AP bas rapportent une fatigue physique perçue accrue et sembleraient être plus fatigables sur le plan musculaire. Ces résultats enrichissent d’une part les récents travaux de Webel et al. (2016) portant sur les
relations entre AP et fatigue perçue, et d’autre part, les modèles explicatifs de la fatigue dans les maladies chroniques en général (e.g., Gruet al., 2018 ; Kluger et al., 2013) et le VIH en particulier (Barroso & Voss, 2013).

En conclusion, ce programme de recherche a permis de développer de nouvelles connaissances scientifiques relatives au rôle des stéréotypes liés à l’AP chez les PVVIH, tout en soulevant de nouvelles questions importantes pour le développement des modèles actuels de la fatigue dans des pathologies chroniques. Les résultats encouragent à prendre en compte les divers facteurs sociaux, psychologiques et musculaires pouvant impacter la fatigue des PVVIH et à développer des études interventionnelles évaluant les effets de programmes d’AP sur les différentes dimensions de cette fatigue des PVVIH et plus généralement sur leur santé.
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