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Measuring fatigue in people living with HIV/AIDS: psychometric characteristics of the HIV-Related Fatigue Scale

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Abstract

In the era of life-prolonging antiretroviral therapy, chronic fatigue is one of the most prevalent and disabling symptoms of people living with HIV/AIDS, yet its measurement remains challenging. No instruments have been developed specifically to describe HIV-related fatigue. We assessed the reliability and construct validity of the HIV-Related Fatigue Scale (HRFS), a 56-item self-report instrument developed through formative qualitative research and designed to measure the intensity and consequences of fatigue as well as the circumstances surrounding fatigue in people living with HIV. The HRFS has three main scales, which measure fatigue intensity, the responsiveness of fatigue to circumstances and fatigue-related impairment of functioning. The functioning scale can be further divided into subscales measuring impairment of activities of daily living, impairment of mental functioning and impairment of social functioning. Each scale demonstrated high internal consistency (Cronbach's alpha=0.93, 0.91 and 0.97 for the intensity, responsiveness and functioning scales, respectively). The HRFS scales also demonstrated satisfactory convergent validity when compared to other fatigue measures. HIV-Related Fatigue Scales were moderately correlated with quality of nighttime sleep (rho = 0.46, 0.47 and 0.35) but showed only weak correlations with daytime sleepiness (rho = 0.20, 0.33 and 0.18). The scales were also moderately correlated with general mental and physical health as measured by the SF-36 Health Survey (rho ranged from 0.30 to 0.68 across the 8 SF-36 subscales with most >0.40). The HRFS is a promising tool to help facilitate research on the prevalence, etiology and consequences of fatigue in people living with HIV.

Keywords

fatigue; HIV; measurement; psychometric properties; validity

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Introduction

In the era of life-prolonging antiretroviral therapy, chronic fatigue is one of the most prevalent and disabling symptoms of people living with HIV/AIDS (Duran et al., 2001; Henderson, Safa, Easterbrook, & Hotopf, 2005; Jenkin, Koch, & Kralik, 2006; Voss, 2005). Nevertheless, the precise definition, prevalence and etiology of HIV-related fatigue remain poorly described.

Multiple instruments have been developed to measure fatigue, although until recently there was no instrument that adequately measured fatigue in HIV-positive individuals (Barroso, 1999). Aaronson et al. (1999) highlighted the difficulty in measuring a construct as subjective as fatigue and noted that different measures tap into different aspects of fatigue. Some instruments simply measure the presence or absence of fatigue; others measure only one aspect of fatigue (e.g. physical fatigue or decreased muscle strength) (Hoover et al., 1993; Palenicek et al., 1993; Penkower et al., 1995; Perkins et al., 1995; Piedrola et al., 1996; Singh, Squier, Sivek, Wagener, & Yu, 1997; Vlahovet al., 1994; Whalen, Antani, Carey, & Landefeld, 1994). Some researchers have borrowed tools developed to measure concepts other than fatigue (e.g. performance or vitality) (O'Dell, Meighen, & Riggs, 1996; Reillo, 1993). Many of the instruments used to measure fatigue are very brief (four questions or less) and, although most of them have acceptable psychometric properties, they do not capture the full experience of HIV-related fatigue as encountered in our clinical experience (Barroso, 1999).

To fill this measurement need, our principal investigator (JB) developed a 56-item tool designed specifically to measure fatigue in people living with HIV (Barroso & Lynn, 2002). The HIV-Related Fatigue Scale (HRFS) was developed through formative qualitative research and designed to measure the intensity and consequences of fatigue as well as the circumstances surrounding fatigue in people living with HIV. In this paper we examined the reliability of the HRFS as well as its construct validity compared to other measures of fatigue and to measures of sleep quality and general health.

Methods

Instrument

The rationale for, and development of, the HRFS have been described in detail previously (Barroso & Lynn, 2002). In brief, through qualitative research with people living with HIV, a clinical investigator with 16 years of experience in HIV treatment (JB) identified conceptual distinctions between three primary dimensions of HIV-related fatigue: the intensity of the fatigue, the circumstances surrounding the fatigue and the consequences of fatigue (Barroso, 2001). Consequences of fatigue could be further categorized into impairment of performance of activities of daily living, impairment of social activities and impairment of mental functioning. A comprehensive literature review of the multiple instruments used to measure fatigue identified no instruments designed to adequately capture all three of the dimensions identified in the qualitative research and further identified no instruments that had been specifically developed for or validated in people living with HIV (Barroso, 1999; Barroso & Lynn, 2002). We therefore developed a new tool to measure HIV-related fatigue, informed by the existing literature and the prior qualitative research.

We developed the 56-item HRFS by adopting items from five existing fatigue instruments created for non-HIV populations (with authors' permission) that matched the domains identified through the initial qualitative work and by creating additional items to address findings from the formative qualitative research that were not captured by any tool. Items were adopted from the Multidimensional Assessment of Fatigue (MAF: entirety – 16 items) (Belza, Henke, Yelin, Epstein, & Gilliss, 1993); the Fatigue Assessment Instrument (FAI: entirety – 29 items) (Schwartz, Jandorf, & Krupp, 1993); the General Fatigue Scale (2 of 7 items) (Meek

& Nail, 1997); the Fatigue Impact Scale (4 of 40 items) (Fisk, Pontefract, Ritvo, Archibald, & Murray, 1994); and the Sleep and Infection Questionnaire (3 of 17 items) (Darko, McCutchan, Kripke, Gillin, & Golshan, 1992). Items were then divided into conceptually distinct groups corresponding to the domains identified in the formative qualitative research: fatigue intensity (8 items), fatigue-related impairment of functioning (22 items) and the responsiveness of the fatigue to circumstances (15 items). Remaining items are used individually to describe the respondent's fatigue experience. The fatigue-related impairment items were further divided into three subscales: impairment of activities of daily living (12 items), impairment of socialization (6 items) and impairment of mental functioning (4 items) (Figure 1). All scales were coded to range from 1–10 with a higher value indicating more fatigue, impairment or responsiveness. Initial psychometric testing of the HRFS in 54 people living with HIV has been reported previously (Barroso & Lynn, 2002) and indicated strong content validity of the instrument and high internal consistency of each scale.

Sample

The present study reports estimates of reliability and convergent construct validity of the HRFS in 128 people living with HIV recruited for a longitudinal cohort study of the causes and consequences of fatigue in people living with HIV. Participants were recruited via flyers advertising the study at HIV/AIDS treatment centers and service organizations in a southern US state. Interested individuals were invited to participate if they met the following inclusion criteria: (1) HIV-positive, (2) ≥21 years old, (3) able to read and speak English competently and (4) mentally competent to provide reliable data. Both fatigued and non-fatigued individuals were eligible to enroll. Individuals were excluded if they had a co-morbid condition marked by fatigue such as renal disease, cancer or multiple sclerosis. Pregnant women and women less than 12 months postpartum were also excluded. In all, 128 individuals enrolled in the study and completed the baseline assessment. All study procedures were approved by the Duke University Institutional Review Board and all study participants provided written informed consent.

Data collection

Participants completed the HRFS during the inperson baseline assessment. Other instruments from the baseline assessment used in this analysis include the Pittsburgh Sleep Quality Index (PSQI) (Buysse, Reynolds, Monk, Berman, & Kupfer, 1989; Carpenter & Andrykowski, 1998), the Epworth Sleepiness Scale (ESS) (Johns, 2000, 2002) and the SF-36 Health Survey (Ware & Sherbourne, 1992; Ware et al., 1995) The PSQI yields a global scale of the respondent's nighttime sleep quality, including overall quality, duration, efficacy, disturbed sleep, sleep-related dys-function and need for sleep medications; a higher score indicates poorer quality sleep (range 0–21). The ESS measures daytime sleepiness with questions addressing the respondent's likelihood of dozing off or falling asleep during eight daytime activities such as reading, watching TV or riding in a car; a higher score indicates more daytime sleepiness (range: 0–24). The SF-36 measures eight domains of general health, including vitality, bodily pain and mental health; a higher score indicates better health (range: 0–100). The interviewer checked all instruments for completeness and clarified any skipped or missing items with the participant.

Statistical analysis

We measured reliability (the extent to which the items composing each scale are measuring a common latent construct) for each scale and subscale of the HRFS using Cronbach's alpha. Generally, a Cronbach's alpha of >0.70 is considered acceptable for a psychometric scale (Nunnally, 1978). We also calculated, for each item, the item-rest correlation (the correlation between that item and the scale formed from the remaining items) and Cronbach's alpha of the

scale formed from all items but the item in question. We computed correlation coefficients among the various HRFS scales.

We assessed convergent construct validity (the extent to which a scale correlates with other measures targeting the same latent construct) by correlating the HRFS with fatigue measures based on the MAF and the FAI (two shorter instruments embedded within the HRFS). We further examined correlation coefficients between the HRFS scales and the PSQI, the ESS and the SF-36 scales. We hypothesized that the HRFS scales would be moderately but not strongly correlated with nighttime sleep quality (PSQI) and that the HRFS would be only weakly correlated with daytime sleepiness (ESS). We further hypothesized that the HRFS would be moderately correlated with both mental and physical health as measured by the SF-36, and particularly with the SF-36 vitality scale. We refer to correlation coefficients >0.70 as strong, 0.40–0.70 as moderate and <0.40 as weak (Denton, Durning, & Hemmer, 2004) All reported *p*-values are from two-sided hypothesis tests.

Results

Sample characteristics

The sample has been described in detail elsewhere (Harmon, Barroso, Pence, Leserman, & Salahuddin, in press). The majority of the 128 participants were African American (66%) with the remainder primarily Caucasian (30%) (data not shown). Sixty-six percent of the subjects were male and most subjects were in their late thirties or forties (median age 44 years; interquartile range [IQR] 38–48). A majority of subjects were unemployed at baseline ($n = 86$; 67%). The sample predominantly comprised people who had lived with HIV infection for a long time, with a median time since diagnosis of 10 years (IQR 6–15 years). Most (82%) were on antiretroviral therapy at baseline. Many (65%) reported living with at least one other chronic illness (e.g. hypertension, depression, arthritis).

Reliability of HRFS

All scales and subscales of the HRFS demonstrated acceptable internal consistency, with values for Cronbach's alpha of 0.93 (fatigue intensity), 0.97 (fatigue-related impairment of functioning) and 0.91 (responsiveness of fatigue to circumstances) for the primary scales, and 0.95 (impairment of ADL), 0.93 (impairment of socialization) and 0.92 (impairment of mental functioning) for the subscales of the fatiguerelated impairment scale (Table 1). All items demonstrated reasonable evidence of belonging to their assigned scale as supported by item-rest correlations and reliability coefficients calculated by eliminating individual items from each scale. The three primary scales of the HRFS were strongly correlated (range 0.71–0.86) (Table 2). The three subscales of fatiguerelated impairment of functioning were also strongly correlated (range 0.80–0.89).

Convergent construct validity of HRFS

All HRFS scales were moderately to strongly correlated with the Multidimensional Assessment of Fatigue (MAF) (ρ ranged from 0.65–0.95) (Table 3). The HRFS intensity scale was strongly correlated with the Severity scale of the Fatigue Assessment Instrument (FAI) ($\rho = 0.71$) but not associated with the Situation-specific, Psychological Consequences or Responds to Rest/Sleep scales. The HRFS fatiguerelated impairment of functioning scale was moderately to strongly correlated with the FAI Severity ($\rho = 0.81$) and Psychological Consequences ($\rho = 0.59$) scales but showed little correlation with the other two FAI scales ($\rho < 0.30$). The HRFS responsiveness of fatigue to circumstances scale was strongly correlated with the FAI Situation-Specific scale ($\rho = 0.79$) and moderately correlated with the other three FAI scales (ρ ranged from 0.48–0.60). Note that the MAF and FAI scales are embedded in the HRFS and were constructed from HRFS responses, which may partially explain the observed correlations.

Specifically, the 8-item HRFS intensity scale contains 4 MAF and 2 FAI items, the 22-item HRFS fatigue-related impairment of functioning scale contains 11 MAF and 3 FAI items and the 15-item HRFS responsiveness of fatigue to circumstances scale contains 0 MAF and 9 FAI items.

Poorer quality of nighttime sleep, as measured with the PSQI, was weakly to moderately associated with greater fatigue intensity, fatigue-related impairment and responsiveness of fatigue to circumstances (ρ = 0.46, 0.47 and 0.35, respectively) (Table 4). In examining individual components of the PSQI, most HRFS scales were moderately correlated with overall self-reported quality of sleep and sleep-related dys-function, i.e. having trouble staying awake during daytime activities (ρ ranged from 0.38–0.46) but showed weak correlation with average hours of sleep per night, sleep efficacy (i.e. percent of time in bed spent sleeping) and use of sleep medications (ρ ranged from 0.13–0.25) (data not shown). Greater daytime sleepiness, as measured by the ESS, demonstrated a weak correlation with all fatigue scales (ρ = 0.20, 0.33 and 0.18 for the intensity, impairment of functioning and responsiveness to circumstances scales, respectively).

The HRFS scales were weakly to moderately correlated with all SF-36 health subscales and composite scores, with correlation coefficients ranging from 0.37–0.60 (fatigue intensity scale), 0.34–0.68 (fatigue-related impairment of functioning) and 0.36–0.54 (responsiveness of fatigue to circumstances). Of the eight SF-36 scales, the Social Functioning scale showed the highest correlation with the HRFS fatigue intensity and impairment of functioning scales, whereas the Role Physical scale showed the highest correlation with the HRFS responsiveness to circumstances scale. Of note, the SF-36 Vitality scale showed a moderate correlation with each of the three HRFS scales (ρ = 0.58, 0.60 and 0.50 for the intensity, impairment of functioning and responsiveness to circumstances scales, respectively), although several other SF-36 scales showed correlations of similar magnitude.

Discussion

In these analyses, the HRFS demonstrated satisfactory reliability as well as convergent and construct validity in describing the intensity, circumstances and consequences of fatigue in individuals living with HIV/AIDS. The three primary scales of the HRFS – fatigue intensity, fatigue-related impairment of functioning and responsiveness of fatigue to circumstances – each had acceptable reliability coefficients and each question showed evidence of belonging to its assigned scale. These results correspond well to an initial report from a smaller sample in which the reliability of the three HRFS scales were 0.84 (intensity), 0.95 (impairment of functioning) and 0.73 (responsiveness to circumstances) (Barroso & Lynn, 2002).

In assessing the instrument's convergent construct validity, HRFS scales were strongly correlated with other fatigue instruments measuring similar constructs. It should be noted that we only compared the HRFS with fatigue instruments whose questions had been incorporated into the HRFS; further studies in which participants sequentially completed the HRFS and alternative fatigue instruments would provide additional valuable insights. Further, HRFS scales were moderately correlated with most SF-36 physical and mental health scores and with quality of nighttime sleep. Of note, the HRFS scales demonstrated a weak correlation with a measure of daytime sleepiness, underscoring the conceptual distinction between 'sleepiness' and chronic fatigue.

We chose to select items for inclusion in the HRFS and to group the items into scales based on the conceptual framework and dimensions identified through the formative qualitative research rather than employing a data-driven procedure such as exploratory factor analysis. The three HRFS scales did demonstrate strong correlations, ranging from 0.71–0.86,

suggesting that the dimensions in the conceptual framework do overlap to a certain extent. Nevertheless, these separate subscales may be of use in describing the characteristics of HIV-related fatigue and in elucidating potential intervention opportunities.

This analysis was restricted to people living with HIV and did not include a sample of healthy controls. While the study was open to both fatigued and nonfatigued individuals, the large majority of participants reported being fatigued at baseline. Thus in the current analysis we were unable to assess the discriminant validity of the HRFS – the ability of the instrument to distinguish between those expected to be fatigued and non-fatigued. A future comparison of HRFS scores in this sample to scores in a sample of healthy controls would provide helpful further evidence on the utility of the HRFS.

The self-referral method of recruitment in this study may have introduced selection bias. Specifically, individuals experiencing fatigue may have been more likely to respond to study advertisements than those not fatigued; hence, this sample may have higher average fatigue scores than would be observed in a representative sample of people living with HIV. We note that the distributions of age, sex and race in this sample matched closely with the characteristics of prevalent HIV cases from the geographic area of recruitment.

The HRFS fills an important need for research seeking to describe and understand the etiology of HIV-related fatigue (Barroso, 1999; Barroso & Lynn, 2002). With potent antiretroviral therapy extending the lives of people living with HIV, HIV treatment plans must increasingly focus on the effective management of chronic symptoms and side-effects. Chronic fatigue is one of the most prevalent and debilitating symptoms of those living with HIV infection, yet the prevalence and etiology of HIVrelated fatigue have remained challenging to describe, due in part to limitations of existing measures of fatigue. Validation of tools such as the HRFS will facilitate more systematic research to describe the prevalence and characteristics of HIV-related fatigue and investigate its etiology as well as means to alleviate the fatigue of people living with HIV. Indeed, the HRFS has already been adopted by multiple domestic and international research projects. If further research indicates that the HRFS can identify changes in fatigue over time, it may further serve as a useful tool in evaluating the effectiveness of interventions seeking to ameliorate HIV-related fatigue.

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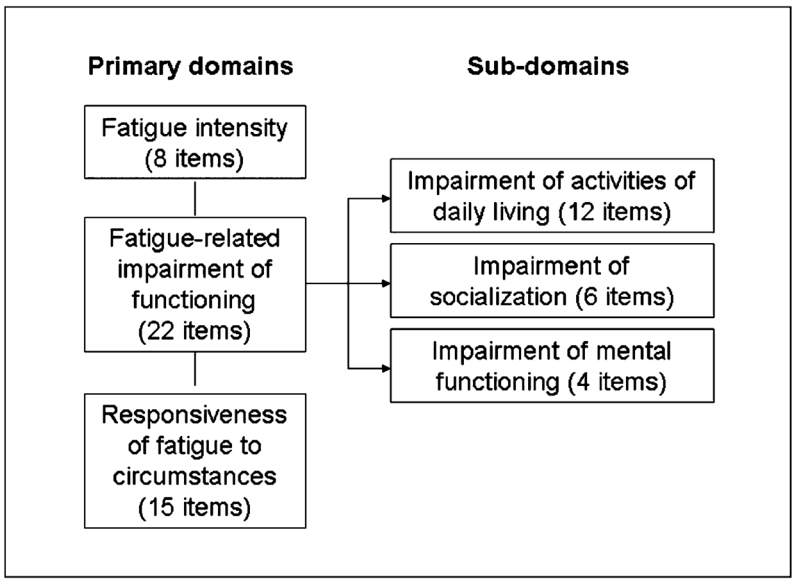

Figure 1.
The HIV-Related Fatigue Scale (HRFS): conceptual framework.

Table 1

Reliability of scales and subscales of the HIV-Related Fatigue Scale (HRFS) in 128 HIV-positive patients.

	Scale			Subscale		
	Cronbach's alpha	Iterm-rest correlation*	Cronbach's alpha without this item**	Cronbach's alpha	Iterm-rest correlation*	Cronbach's alpha without this item**
Fatigue intensity	0.93					
Level of fatigue today		0.61	0.93			
Level of fatigue most days		0.79	0.92			
To what degree has experienced fatigue		0.79	0.92			
Severity of fatigue		0.81	0.92			
Fatigue caused distress		0.81	0.92			
How often fatigued past week		0.76	0.92			
Easily fatigued		0.78	0.92			
Fatigue causes frequent problems		0.74	0.92			
Responsiveness of fatigue to circumstances						
Fatigue is brought on by …	0.91					
HIV medications		0.46	0.91			
exercise		0.62	0.91			
heat		0.69	0.90			
long periods of inactivity		0.65	0.91			
stress		0.69	0.90			
depression		0.64	0.91			
work		0.58	0.91			
performance of activities of daily living		0.64	0.91			
prolonged fatigue after exercise		0.64	0.91			
Fatigue is alleviated by …						
rest		0.65	0.91			
sleeping		0.59	0.91			
cool temperatures		0.58	0.91			
positive experiences		0.63	0.91			
Fatigue is …						
worse in the afternoon		0.64	0.91			
worse in the morning		0.45	0.91			
Fatigue-related impairment of functioning	0.97					
Subscale: Impairment of activities of daily living				0.95		
Fatigue interferes with …						
household chores		0.82	0.97		0.82	0.95
cooking		0.76	0.97		0.73	0.95
bathing/washing		0.66	0.97		0.66	0.95
dressing		0.71	0.97		0.72	0.95
working		0.75	0.97		0.72	0.95
shopping/errands		0.88	0.97		0.86	0.95
walking		0.82	0.97		0.83	0.95
exercise other than walking		0.80	0.97		0.80	0.95
planning activities		0.80	0.97		0.75	0.95
physical functioning		0.78	0.97		0.79	0.95
sustained physical functioning		0.75	0.97		0.77	0.95
carrying out duties/responsibilities		0.78	0.97		0.80	0.95
Subscale: Impairment of socialization				0.93		
Fatigue interferes with…						
visiting/socializing		0.79	0.97		0.85	0.90
sexual activity		0.73	0.97		0.77	0.91

	Scale			Subscale		
	Cronbach's alpha	Iterm-rest correlation*	Cronbach's alpha without this item**	Cronbach's alpha	Iterm-rest correlation*	Cronbach's alpha without this item**
leisure/recreation		0.83	0.97		0.85	0.90
controlling temper		0.72	0.97		0.66	0.93
interactions with others outside home		0.82	0.97		0.83	0.91
work, family, social life		0.84	0.97		0.76	0.92
Subscale: Impairment of mental functioning				0.92		
Fatigue interferes with…						
thinking clearly		0.80	0.97		0.84	0.88
thinking quickly		0.85	0.97		0.92	0.86
learning new things		0.79	0.97		0.80	0.90
concentration		0.73	0.97		0.69	0.93

* Correlation between the item and the scale formed from the remaining items.

** Cronbach's alpha of the scale formed from all items except this item.

Table 2

Correlations between scales and subscales of the HIV-Related Fatigue Scale.

				Impairment subscales		
	Fatigue intensity	**Responsiveness to circumstances**	**Impairment of functioning (overall)**	**Impairment of ADL**	**Impairment of Socialization**	**Impairment of mental functioning**
Fatigue intensity	1					
Responsiveness to circumstances	0.72	1				
Impairment of functioning (overall)	0.86	0.71	1			
Impairment of ADL	0.86	0.70	0.98	1		
Impairment of socialization	0.80	0.63	0.94	0.89	1	
Impairment of mental functioning	0.76	0.69	0.90	0.84	0.80	1

ADL: Activities of daily living.

Table 3

Convergent construct validity of HRFS: correlation with other fatigue instruments.

	HRFS Scale		
	Fatigue intensity	**Impairment of functioning**	**Responsiveness to circumstances**
MAF	0.95	0.79	0.65
FAI: Severity	0.71	0.81	0.60
FAI: Situation-specific	0.23	0.29	0.79
FAI: Psychological consequences	0.35	0.59	0.48
FAI: Responds to rest/sleep	−0.05	−0.02	0.50

MAF: Multidimensional Assessment of Fatigue. FAI: Fatigue Assessment Instrument.

Table 4

Convergent construct validity of HRFS: correlation with measures of sleep and general health.

	HRFS Scale		
	Fatigue intensity	**Impairment of functioning**	**Responsiveness to circumstances**
Pittsburgh Sleep Quality Index	0.46	0.47	0.35
Epworth Sleepiness Scale	0.20	0.33	0.18
SF-36 scales			
Physical functioning	−0.55	−0.63	−0.48
Role physical	−0.58	−0.68	−0.54
Bodily pain	−0.45	−0.55	−0.37
General health	−0.37	−0.34	−0.30
Vitality	−0.58	−0.60	−0.50
Social functioning	−0.60	−0.68	−0.46
Role emotional	−0.55	−0.63	−0.43
Mental health	−0.51	−0.57	−0.36
Physical composite score	−0.51	−0.59	−0.47
Mental composite score	−0.51	−0.56	−0.37