



ORIGINAL RESEARCH

Development and Psychometric Evaluation of a Fatigability Index for Full-Time Wheelchair Users With Spinal Cord Injury

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Abstract

Objective: To develop and evaluate psychometrically a self-reported instrument assessing physical fatigability (PF) and mental fatigability (MF) in adults with spinal cord injury (SCI).

Design: Cross-sectional.

Setting: Peer-support groups at rehabilitation centers, online support groups.

Participants: Adults with SCI (N=464) in the United States.

Interventions: Not applicable.

Main Outcome Measures: The dimensional structure was assessed by confirmatory factor analysis. The relationship between item responses and fatigability was measured with item response theory (graded response model). Reliability was measured with test information functions. Differential item functioning was evaluated with Wald chi-square tests and the weighted area between the curves. Construct validity was assessed using the known groups method.

Results: An 82-item pool was developed from prior qualitative research and consultations with rehabilitation experts. A non-probability sample (N=464) was used to evaluate the psychometric properties of the PF and MF scales. The item pool was reduced to 75 based on factor loadings and R². Both scales are primarily unidimensional, despite moderate multidimensionality. There is good discrimination overall: 18 PF items and 26 MF items have high or very high discrimination power (slopes > 1.35). The measurement precision in the theta range -2.0 to 2.5 is the equivalent of 0.94 reliability for PF and 0.91 for MF. For both measures, F statistics P values were significant at P<.01, and means were higher for those with paraplegia vs quadriplegia, and for those with incomplete paraplegia.

Conclusions: The Fatigability Index is the first instrument designed to assess physical and mental fatigability in adults with SCI. The index highlights causes of fatigue and areas requiring immediate intervention. Development of short-forms and further research on representative samples are necessary.

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Spinal cord injury (SCI) affects approximately 300,000 individuals in the United States.¹ A prevalent symptom associated with SCI is fatigue, “a subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual or desired activities.”^{2(para.4)} About 25% of individuals with SCI report fatigue severe enough to affect daily functioning and well-being.^{3,4} Adults with SCI may experience fatigue associated with their age, their full-time use of a wheelchair, daily

activities, comorbidities, and other consequences of SCI (eg, poor posture, pressure management).⁴⁻¹¹ Just like non-SCI adults, persons with SCI may try to avoid fatigue and exhaustion by decreasing or completely eliminating certain activities (cooking) or wheelchair maneuvers (wheelchair-to-car transfers).

Fatigability is “a characteristic describing an individual’s susceptibility to experiencing fatigue for a given quantifiable demand.”^{2(para.5)} There are 2 forms of fatigability. The first is performance-related fatigability, which is observed and could be measured by a clinician, and refers to erosion in force, power, speed or stamina related to performance of a given activity.² The second type of fatigability is perceived (self-reported) fatigability, which is the focus of this study: it refers to feelings of tiredness and wear related to duration and intensity of an activity.² Self-reported fatigability has been measured in contexts other than SCI, with instruments such as the Physical Energy Scale from the Motivation and Energy Inventory, the Dutch Exertion Fatigue Scale, the Situational Fatigue Scale, and the Pittsburgh Fatigability Scale.¹²⁻¹⁷ To date, no self-reported fatigability instrument specifically for SCI individuals has been developed and assessed psychometrically.

Development of such targeted instruments aligns with patient-centered care goals of being “respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”^{18(p.6)} In this study we aimed to develop and evaluate a SCI fatigability measure that could complement clinical processes like rehabilitation, seating, pressure/posture management, or other interventions to ameliorate the symptoms.

Methods

We developed the measures following the International Society for Quality of Life Research minimum standards and recommendations for patient-reported outcome measures (fig 1).¹⁹

Initial fatigability 82-item pool

First, we conducted a literature review to identify areas of interest relating to fatigue, that is, causes of fatigue in adults with SCI, and the relationship between fatigue and health-related quality of life in this subgroup of the population.³⁻¹⁷ We also identified existing fatigue instruments that were evaluated psychometrically among persons with SCI.³⁻¹⁷ We conducted 20 in-depth interviews with adults with SCI who are full-time wheelchair users, exploring

quality of life in the context of SCI, and preferences for different health outcome measures, with findings reported elsewhere.²⁰ The need for 2 separate scales emerged from these in-depth interviews. Physical fatigue was defined as reduced physical function due to wear or disease (tiredness and weakness are symptoms of fatigue). Physical fatigue was also described as progressive, increasing in severity over time. Interviewees defined mental fatigue as reduced mental function due to perceived high level of stress, worries about the future, perceived need for extensive logistical planning, and perceived bureaucratic burden (such as filling out forms for health or welfare benefits). Participants disclosed that, for many activities, physical and mental fatigue can compete and conspire to frustrate and reduce what a disabled person can do. With input from experts in wheelchair and seating assessment, rehabilitation, wheelchair sports coaching, survey development and psychometric evaluation, we drafted a large pool of physical fatigability (PF) and mental fatigability (MF) items (table 1). The items represent 4 areas of fatigability: (1) health problems, (2) problems in the home environment, (3) activities in the home, and (4) activities away from home (which may be more demanding, with varying degrees of logistical challenges and physical exertion). For example, going to a doctor’s appointment differs from taking an overnight trip away from home.

We asked, separately, about the level of physical and mental fatigue associated with 41 activities, using the following response scale: 0 (no fatigue), 1 (mild fatigue), 2 (moderate fatigue), and 3 (extreme fatigue) as well as a *Did not have this/Did not do this* response. In addition, we assessed the importance of each item to the respondent. About health, they were asked, *How important is it that each of the following is treated?* About activities, they were asked, *How important is it that you can perform each of these activities?* The “importance” questions were not used in the analyses reported here.

Field test data collection and sampling

Eligibility criteria for inclusion of participants in the study included an age of 18 years or older, residency in the United States, a self-reported diagnosis of SCI, at least 1-year post hospital discharge, full-time wheelchair use, and the ability to read and write in English. Exclusion criteria included the inability to provide informed consent (including cognitive impairments such as dementia or Alzheimer’s disease) and part-time wheelchair use.

This was a non-probability (convenience) sample recruited nationally through 2 methods: (1) print advertisements distributed through peer support groups in the United States and support groups for U.S. military veterans (local chapters of Paralyzed Veterans of America), and (2) online advertisements distributed through organizations such as The Dana and Christopher Reeve Foundation (Members’ Board: <http://www.spinalcordinjury-paralysis.org/>) and the United Spinal Association (<http://www.spinalcord.org/resource-center/askus/index.php>). In addition, 4 paid advertising campaigns were conducted via Facebook Ads at 2-week intervals, with target specifications that named the United States as a location, “SCI” and “wheelchairs” as user interests, and a population target of 12,000 for each campaign. Upon expressing interest in being interviewed, participants were sent an e-mail with information about the study and given the option to take the survey online or via the phone. All respondents in this study, including several with high neck injuries who were on ventilators, chose to take the survey online between January 2017 and May 2017. No remuneration was provided for survey participation. Of

List of abbreviations:

SCI	spinal cord injury
PF	physical fatigability
MF	mental fatigability
CFA	confirmatory factor analysis
IRT	item response theory
DIF	differential item functioning
wABC	weighted area between the curves
RMSEA	Root Mean Square Error of Approximation
CFI	Comparative Fit Index
TLI	Tucker-Lewis Index
PUC	percent uncontaminated correlations
ECV _{GEN}	explained common variance on the general dimension
I-ECV	individual explained common variance

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