ORIGINAL ARTICLE

Comparison of Self-Report Sleep Measures for Individuals With Multiple Sclerosis and Spinal Cord Injury

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Abstract

Objective: To investigate self-report measures of sleep disturbances and sleep-related impairments in samples of individuals with multiple sclerosis (MS) or spinal cord injury (SCI).

Design: Cross-sectional survey.

Setting: Community based.

Participants: Adults (age ≥18y) (N=700) with either MS (n=461) or SCI (n=239) who were enrolled in a longitudinal survey of self-reported health outcomes and who completed self-report sleep measures at 1 time point.

Interventions: None.

Main Outcome Measures: Medical Outcomes Study Sleep Scale (MOS-S), Patient Reported Outcomes Measurement Information System (PROMIS) sleep disturbance short form, and PROMIS sleep-related impairments short form.

Results: Mean scores on the MOS-S sleep index II were significantly worse for both the MS and SCI samples than those of previously reported samples representative of the U.S. general population (*P*<.0001 for each group). The PROMIS sleep disturbance short form and PROMIS sleep-related impairments short form scores of the MS sample were also significantly different from those reported for the calibration cohort (*P*<.0001 on each scale). However, although the scores of the SCI sample were significantly different from those of the comparison cohort for the PROMIS sleep-related impairments short form (*P*=.045), the differences on the PROMIS sleep disturbance short form were not significant (*P*=.069).

Conclusions: Although the MOS-S scores for the MS and SCI cohorts clearly indicated significantly high levels of sleep-related problems and were consistent with existing literature, the more ambiguous findings from the PROMIS sleep disturbance short form and PROMIS sleep-related impairments short form suggest that not enough is currently known about how these instruments function when applied to those with chronic neurologic dysfunction.

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The critical role of sleep in maintaining health, functional ability, and quality of life within the general population has received increasing attention in recent years. However, relatively little is known about the prevalence and impact of sleep disturbances in chronic neurologic conditions such as multiple sclerosis (MS) and spinal cord injury (SCI). One factor that has hampered research efforts in this area has been the difficulty of accurately assessing sleep in these populations. Although many aspects of sleep can be measured using polysomnography and/or actigraphy, both of these methods require relatively expensive equipment and interpretation

of the results by specially trained personnel, factors that make it difficult to administer to large study samples.

Self-report measures represent an additional complementary approach to assessing sleep and allow for individuals to provide information about their own sleep experience. A number of self-report measures have been developed to assess various aspects of sleep, including both objective (eg, total sleep time, sleep onset latency) and subjective (eg, sleep quality) characteristics. Self-report measures are relatively inexpensive to administer, do not require specialized equipment, and do not require as much time or expertise to score as polysomnography and actigraphy.

The use of self-report measures to assess sleep is also hindered by a number of factors.[1] One of the defining hallmarks of sleep is a diminution of awareness, making self-report of sleep an inherently difficult proposition. Additionally, most individuals experience night-to-night variation in their sleep, complicating the task of describing a typical night's sleep.

Despite these limitations, much of the existing research examining sleep in the context of chronic neurologic disorders is based on such self-report measures.[2-6] All of these studies documented a high prevalence of disturbances of sleep and sleep-related function. However, a clear picture of sleep in the context of chronic neurologic impairment has not yet emerged, partly because of the diversity of self-report measures that have been used in this small number of studies. This raises the question of which instrument is best suited to assessing sleep-related disturbances in those with chronic neurologic disorders.

One such measure, the Medical Outcomes Study Sleep Scale (MOS-S), has been used in studies of sleep of the general population[7] and in diagnostic groups, including rheumatoid arthritis[8] and breast cancer.[9] The MOS-S assesses 6 dimensions of sleep—sleep disturbance, snoring, shortness of breath or other respiratory issues, sleep quantity, sleep adequacy, and daytime somnolence—and a summary measure of sleep quality. In addition, in an effort to address some of the limitations of self-report measures, the National Institutes of Health devised the Patient Reported Outcomes Measurement Information System (PROMIS) initiative with the aim of developing a set of self-report item banks for measuring multiple domains of health and well-being. The sleep domain consists of 2 item banks: one addresses sleep disturbances, whereas the other focuses on impairments that are related to sleep but are experienced while awake. The PROMIS sleep disturbance (version 1.0 8b) and sleep-related impairments (version 1.0 8a) short forms were developed to measure these content areas.[1]

The objective of the current study was to examine sleep in 2 samples of individuals with either MS or SCI using the MOS-S[10] and the PROMIS sleep domain measures[1] and to compare scores for both of these groups with published normative scores.

Methods

Data for this study represent a cross-sectional assessment collected as part of a longitudinal study of the self-reported health of people with MS or SCI. The Human Subjects Division of the

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List of abbreviations:

MOS-S	Medical Outcomes Study Sleep Scale
MS	multiple sclerosis
PROMIS	Patient Reported Outcomes Measurement Information System
SCI	spinal cord injury

University of Washington approved all study procedures for the initial data collection, which are described in detail in a previous publication.[11] Briefly, participants with MS were recruited through the Western Washington chapter of the National MS Society, and those with SCI were recruited through either the Northwest Regional SCI Model System at the University of Washington (Seattle, WA) or the Shepherd Center, Virginia Crawford Research Institute (Atlanta, GA). All participants were at least 18 years of age at enrollment and reported a definitive diagnosis of either MS or SCI. Data for this study were collected at the fifth time point in the longitudinal study (approximately 16mo after study commencement), which was the only point at which the MOS-S, PROMIS sleep disturbance short form, and PROMIS sleep-related impairments short form were all included in the survey. A total of 700 participants (MS: n=461; SCI: n=239) returned surveys during that administration.

Measures

The MOS-S consists of 12 items measuring 6 dimensions of sleep: sleep disturbance (incorporating both initiation and maintenance of sleep), snoring, shortness of breath or other respiratory issues, sleep quantity, sleep adequacy, and daytime somnolence. Ten of the items on this scale are scored on a scale from 0 to 5, with lower numbers reflecting lower frequency of the sleep-related complaint (where 0 is none of the time, and 5 is all the time). One question about how long it took to fall asleep is on a scale of 1 to 5 (where 1 is 0−15min, and 5 is >60min). The final item, which relates to sleep quantity, is reported as the average number of hours slept each night. There is a 4-week response frame for all items. The sleep problems index II is a summary measure of sleep quality derived from scores on 9 of the 12 items. Scores for the summary index and subscales measuring 5 of 6 sleep dimensions range from 0 to 100, with higher scores indicating more of the attribute measured. In studies of large populations, the MOS-S has shown good psychometric properties.[7] Comparison scores for this measure are from a study of the psychometric properties of the MOS-S reported by Hays et al.[7]

The PROMIS sleep disturbance short form includes 8 items assessing the participant's perception of aspects of sleep (eg, quality and adequacy, ease of both falling and staying asleep). The PROMIS sleep-related impairments short form, also consisting of 8 items, assesses difficulties that are related to sleep but experienced while awake (eg, sleepiness, difficulty concentrating because of poor sleep). The response frame for both short forms is 7 days. For each short form, individual items are scored on a scale from 1 to 5. Scores were summed to yield a total raw score between 8 and 40, with lower scores indicating better sleep or a lesser degree of sleep-related impairments. The summed raw scores were used to find corresponding item response theory-based scores using the lookup tables provided with the PROMIS scoring guides. All PROMIS scores use a T metric (ie, the mean is 50 and the SD is 10). The sample used for calibrating the items for both PROMIS short forms (N=2252) included 2 cohorts. The first (n=1993) was drawn from the general population. A second cohort (n=259) was recruited from a sleep clinic, creating a sample (N=2252) that included a higher proportion of individuals experiencing sleep disturbances than would be expected in the general population.[1] We randomly selected 453 individuals from the general population sample from Buysse et al[1] to create a subgroup that matched the 2000 U.S. census data on age and sex.