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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 18 and older) 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 one time point.

Interventions—None

Main Outcome Measure(s)—Medical Outcomes Study sleep (MOS-S) scale, Patient Reported Outcomes Information System (PROMIS) Sleep Disturbance (PROMIS-SD) and PROMIS Sleep Related Impairments (PROMIS-SRI) short forms

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 US general population ($p<.0001$ for each group). The PROMIS-SD and PROMIS-SRI scores of the MS sample were also significantly different than those reported for the calibration cohort ($p<.0001$ on each scale). However, while the SCI sample's scores were significantly different from those of the comparison cohort for the PROMIS-SRI ($p=.045$), the differences on the PROMIS-SD were not significant ($p=.069$).

Conclusions—While 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-SD and PROMIS-SRI suggest that not enough is

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currently known about how these instruments function when applied to those with chronic neurological dysfunction.

Keywords

Sleep; Spinal Cord Injuries; Multiple Sclerosis; Questionnaires; Self-Report

The critical role of sleep in maintaining health, functional ability, and quality o f life within the general population has received increasing attention in recent years but relatively little is known about the prevalence and impact of sleep disturbances in chronic neurological 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. While 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 which 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 (e.g., total sleep time, sleep onset latency) and subjective (e.g., sleep quality) characteristics of sleep. 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 either polysomnography or 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 neurological 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 neurological impairment has not yet emerged due in part to 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 neurological disorders.

One such measure, the Medical Outcomes Study Sleep scale (MOS-S) has been used in studies of sleep of the general population[7] as well as diagnostic groups including rheumatoid arthritis[8] and breast cancer.[9] The MOS-S assesses six dimensions of sleep, including sleep disturbance, snoring, shortness of breath or other respiratory issues, sleep quantity, sleep adequacy, and daytime somnolence as well as 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 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 two item banks; one which

addresses sleep disturbances, while the other focuses on impairments that are related to sleep but experienced while awake. The PROMIS sleep disturbance (v1.0 8b; PROMIS-SD) and sleep-related impairments (v1.0 8a; PROMIS-SRI) short forms were developed to measure these content areas.[1]

The objective of the current study was to examine sleep in two samples of individuals with either MS or SCI using the Medical Outcomes Study Sleep (MOS-S)[10] and the Patient Reported Outcomes Information System (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 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 either through the Northwest Regional Spinal Cord Injury 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 16 months after study commencement), which was the only point at which the MOS-S, PROMIS-SD and PROMIS-SRI short forms 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 twelve items measuring six dimensions of sleep, including 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 (0 = none of the time, 5 = all the time). One question about how long it took to fall asleep is on a scale of 1 to 5 (1=0–15 minutes, 5 = more than 60 minutes). The final item, which relates to sleep quantity, is reported as average number of hours slept each night. There is a four-week response frame for all items. 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 for subscales measuring five of the six sleep dimensions range from 0–100, with higher scores indicating more of the attribute measured. In studies of large populations, the MOS-S scale 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-SD short form includes eight items assessing the participant’s perception of aspects of sleep such as its quality and adequacy and the ease of both falling and staying asleep. The PROMIS-SRI short form, also consisting of eight items, assesses difficulties that are related to sleep but experienced while awake, such as sleepiness and difficulty

concentrating because of poor sleep. The response frame for both short forms is seven days. For each short form, individual items are scored on a scale from 1 to 5, and 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 IRT-base scores using the lookup tables provided with the PROMIS scoring guides. All PROMIS scores use a T metric, i.e., the mean is 50 and the standard deviation is 10. The sample used for calibrating the items for both PROMIS short forms (N=2,252) included two cohorts. The first N=1993) was drawn from the general population. A second cohort (N=259) was recruited from 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 Buysee's general population sample to create a subgroup that is matched to the 2000 US census data on age and gender.

Analyses

Descriptive statistics were used to summarize demographic information for each sample (MS and SCI). Demographic information on the two previously reported cohorts used for comparison with our samples are also described in Table 1. The first of these comparison groups is the general population cohort reported by Hays et al.,[7] and the second is a subgroup of the sample used by Buysse et al.[1] for calibrating PROMIS-SD and PROMIS-SRI scores. Of the 700 surveys received during this time point (MS N=461; SCI N=239), data on the MOS-S item about snoring while asleep was missing from 5.9% (N=27) of the MS sample and 2% (N=5) of the SCI sample; these were the only missing data for the MOS-S. This item was included in Sleep Index II and the sole item on the snoring subscale. In accordance with the scoring guidelines for the MOS-S, the Sleep Index II score was calculated as an average of the non-missing items for these two participants and the snoring subscale was not scored. Two participants with MS had missing data for the PROMIS-SD and the PROMIS-SRI; there were no missing data for the SCI participants on either of these measures. Participants who missed any item on one of the PROMIS short forms had a missing score for that scale.

The MS and SCI samples' scores for the summary MOS-S scale (sleep index II), each of the MOS-S subscales, the PROMIS-SD and PROMIS-SRI were examined using histograms and Quantile-Quantile (QQ) plots and tested for normality with the Shapiro-Wilk statistic.

Scores for each of the neurologically impaired samples on the MOS-S Sleep Index II (the summary measure of sleep) were compared to those of the general population cohort reported by Hays using the one-sample t-test (see Table 2). We elected to use the one-sample t-test despite the fact that the assumptions of normality were not fully met, as the median scores which would be required to perform non-parametric tests were not available for the Hays cohort.

The standardized T-scores for the PROMIS-SD and PROMIS-SRI short forms from the MS and SCI samples were compared to those of the calibration sample using the Wilcoxon signed rank test (Table3).

Pearson's product-moment correlations were calculated to examine the relationships between the MOS-S subscales and the PROMIS-SD and PROMIS-SRI (Table 4). The internal consistency of the MOS-S subscales with three or more items (Sleep Problem Index II, Sleep Disturbance, and Sleep Somnolence), the PROMIS-SD and the PROMIS-SRI was examined using Cronbach's alpha.

Results

The average age of MS sample was 52.8 years, and 91.5% of these participants were white. Among those with SCI, the average age was younger (47.4 years), and the percentage of white participants was lower (78.7%). The high percentage of women among the MS sample (82%) and of men in the SCI sample (61.5%) are both consistent with the distribution in the population. For both cohorts, the average time since diagnosis was over a decade (MS = 14.5 years; SCI = 13.4 years) (see Table 1).

The Shapiro-Wilk test indicated significant departures from normality ($p<0.05$) for all distributions tested.

In comparison with the MOS-S general population cohort, both the MS and SCI samples had significantly worse scores on the MOS-S scale's summary index (sleep index II). Further analysis of the MOS-S subscales revealed significant differences between both samples and the general population cohort for sleep disturbance, respiratory problems, sleep quantity, sleep adequacy, and daytime somnolence (Table 2). The MS sample reported significantly more sleep than the general population; the difference for the SCI sample was not significant. For both of the neurological samples, scores for snoring did not differ significantly from those of the general population cohort.

The MS sample summary T-scores for both the PROMIS-SD and PROMIS-SRI were significantly higher than those of the calibration cohort ($p<.05$). The SCI sample's T-scores for the PROMIS202 SRI were significantly different from those of the PROMIS calibration cohort, while scores for the PROMIS-SD were not (Table 3).

All correlations tested between MOS-S subscales and PROMIS-SD and PROMIS-SRI were statistically significant. The MOS-S Sleep Index II correlated very strongly (>0.74) with both the PROMIS-SD and PROMIS-SRI. The MOS-S Sleep Disturbance and Sleep Adequacy scales each correlated very strongly (>0.7) with PROMIS-SD scores.

The Cronbach's alpha coefficient for the MOS-S sleep problem index II was 0.41 for the MS sample and 0.54 for the SCI sample. The Cronbach's alpha coefficients were the same in both samples for MOS-S sleep disturbance (4 items, $\alpha=0.84$) and sleep somnolence subscales (3 items, $\alpha=.75$). The PROMIS-SD and PROMIS-SRI scales each had Cronbach's alpha coefficients above 0.9.

Discussion

In this study, we examined measures of sleep and sleep-related impairments in a sample of adults with chronic central nervous system impairment due to either MS or SCI by concurrently administering the MOS-S, PROMIS-SD, and PROMIS-SRI scales.

Scores for both the MS and SCI samples on the MOS-S summary measure, Sleep Index II, as well as on most of the subscales differed significantly from those of the general population cohort previously reported by Hays.[7] The findings from the MOS-S scale are consistent with existing literature concerning sleep in those with MS or SCI using measures other than the MOS-S.[2, 4–6] In each of these studies, neurological impairment was associated with significantly disturbed sleep, lending face validity to the MOS-S findings from this study.

Like the MOS-S, the scores on the PROMIS sleep domain short forms for the MS sample were significantly different than that of the calibration group. The responses of the SCI sample on the PROMIS-SRI also showed significantly higher amounts of impairment than the calibration cohort, but no such differences were detected on the PROMIS-SD. This finding contradicts not only previous research, but also the results of the MOS-S when administered to the same sample at the same time.

Furthermore, the magnitude of the differences between the PROMIS- SD and PROMIS-SR scores for both diagnostic samples and those of the calibration cohort, even when they reached statistical significance, are not clinically significant. When the means for these two samples are compared to those of the calibration cohort, three of the comparisons (the PROMIS-SD for both samples and the PROMIS-SRI for the SCI sample) yield an absolute difference of less than one point. Even the largest of these differences (2.55 for the MS sample's PROMIS-SRI score) is well within one half of a standard deviation, a commonly accepted standard for minimally important clinical difference.[12]

There are a number of possible reasons that the MOS-S showed significant sleep difficulties for those with SCI while the PROMIS did not. One of the notable differences between the instruments is the measurement window. While the MOS-S asks about the participants' experiences over the past four weeks, the PROMIS instruments use a seven day timeframe. While the shorter measurement window employed by the PROMIS instruments would likely increase recall accuracy, it may have resulted in under-reporting of more episodic or transitory sleep problems.

The discrepancy in findings could also be due to the characteristics of the comparison groups used for the different measures. Both of these comparison groups were drawn from the general adult population, and were comparable in terms of average age (MOS-S = 46; PROMIS=45) and gender (MOS-S=51% women; PROMIS=51.88% women). Comparison of the two cohorts in terms of race is more difficult because of the different coding schemes used. Participants in the PROMIS calibration sub-group could endorse more than one race, and Hispanic/Latino was reported as a separate item. As noted above, the calibration sample for the two PROMIS sleep domain measures included a greater proportion of individuals with sleep complaints than would be found in the general population. However, the mean

scores for the subsample we used, which was drawn from the general population rather than the clinical one, matched that of Buysee's sample as a whole.

Alternatively, although the correlations between the MOS-S and PROMIS measures are statistically significant, they do not suggest that they measure the same construct other than for sleep disturbance and sleep adequacy. This may be related to the fact that important aspects of sleep in neurologic populations are not represented in PROMIS sleep instruments. The MOS-S scale includes items related to respiratory problems, snoring, and sleep quantity, which the PROMIS scales do not address. It is also possible that the MOS-S is detecting issues related to disease characteristics that are not necessarily related to sleep. For example, fatigue, which is highly prevalent in both MS[13] and SCI[14], is both commonly associated with and may be confounded with sleepiness. This could also help account for the low Cronbach's alpha levels for the MOS-S scores of both of the neurologic samples.

Study limitations

Ideally, we would have used non-parametric tests to examine the differences between the MS and SCI samples' scores and those of the general population cohort on the MOS-S because these scores were not normally distributed. We were unable to do so because the median scores were not reported for the comparison group.

Conclusion

The findings of this study highlight the difficulties involved in measuring a complex, multidimensional construct such as sleep through self-reported outcome measures and the importance of carefully selecting comparison groups. While the MOS-S clearly identified that those with either MS or SCI had significant levels of sleep disturbance, the findings from the PROMIS measures were more ambiguous. The lack of a significant difference in PROMIS-SD scores between those with SCI and the calibration cohort was particularly surprising, given the body of literature suggesting that sleep is significantly impacted in this population. Although the differences between the MS sample for both PROMIS measures and the calibration cohort did reach statistical significance, the magnitude of these differences is unlikely to be clinically meaningful. This is also true for the SCI sample scores for the PROMIS-SRI. Based on this analysis, either the MOS-S is better able to detect difficulties with sleep in those with either MS or SCI than the PROMIS sleep domain short forms, or it includes somatic symptoms of these conditions that are not necessarily related to sleep. These findings suggest that we do not currently know enough about how the PROMIS-SD and PROMIS-SRI items should be interpreted in those with chronic neurological difficulties to use these measures with confidence, and that particular care should be used in comparing scores from individuals with chronic neurological conditions to those of the general population.

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List of Abbreviations

MS	Multiple Sclerosis
SCI	Spinal Cord Injury
MOS-S	Medical Outcomes Study Sleep Scale
PROMIS	Patient Outcomes Information System
PROMIS-SD	Patient Outcomes Information System Sleep Disturbance Short Form
PROMIS-SRI	Patient Outcomes Information System Sleep-Related Impairments Short Form

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Table 1

Demographic information

			Comparison Groups	
	MS (N=461)	**SCI (N=239)**	**MOS-S * General Population (N=1011)**	**PROMIS† Calibration Sample (N=453)**
Age (years)				
Mean (SD)	52.8 (10.9)	47.4 (14.1)	46‡	44.99 (16.77)
Sex (%)				
Male	17.4	61.5	49	48.12
Female	82.6	38.5	51	51.88
Race (%)				
White	91.5§	78.7§	81	70.9
Black/African American	1.7§	10§	8	15.2
Asian	0.7§	2.1§	1	0.9
Other/unknown/multiple	6.1	9.2	10	13
Time since diagnosis/injury (years)				
Mean (SD)	14.5 (9.9)	13.4 (9.9)		
Range	2–61	2–47		

*from Hays et al.[7]

†Subgroup of sample reported by Buysse et al.[1]

‡Standard deviation not available

§Non-Hispanic

Table 2

Comparison of MOS-S scores of individuals with MS and SCI to the general population

	MS	**SCI**	**General Population** *
	N=461	N=239	N=1011
MOS-S:	Mean (SD)	Mean (SD)	Mean
Sleep problems index II	36.24 (19.09) p < 0.0001 t = 11.75	34.74 (19.51) p < 0.0001 t = 7.09	25.79
Sleep disturbance (initiation and maintenance)	33.10 (25.21) p < 0.0001 t = 7.36	35.06 (24.90) p < 0.0001 t = 6.57	24.47
Snoring	28.43 (31.08) p = 0.95 t = 0.069	31.62 (33.12) p = 0.13 t = 1.52	28.33
Respiratory/ shortness of breath	13.71 (21.09) p < 0.0001 t = 0.39	13.81 (24.15) p < 0.0001 t = 0.35	9.45
Sleep quantity (hours/night)	6.99 (1.56) p = 0.006 t = 2.77	6.7918 (1.79) p = 0.99 t = 0.02	6.79
Sleep adequacy	48.70 (27.48) p < 0.0001 t = −9.20	54.06 (26.33) p < 0.0001 t = −3.77	60.47
Daytime somnolence	37.34 (23.65) p < 0.0001 t = 14.02	31.40 (21.81) p < 0.0001 t = 6.75	21.89

* from Hays et al.[7]

Table 3

Comparison of PROMIS sleep domain scores of individuals with MS and SCI to calibration cohort

PROMIS	MS	SCI	Calibration Sample *
	N=461	N=239	N=453
Sleep Disturbance			
Mean (SD)	50.79 (10.08)	49.48 (9.40)	50 (10)
Median	51.2 P<.001	52.2 P=.069	49.33
Sleep Related Impairments			
Mean (SD)	52.55 (9.24)	50.27 (10.05)	50 (10)
Median	52.9 P<.001	50.3 P=.045	48.36

* Subgroup of sample reported by Buysse et al[1]

Table 4

Correlations among scores for MOS-S subscales, PROMIS-SD and PROMIS-SRI

MOS-S Scale	PROMIS-SD	PROMIS-SRI
Sleep Index II	MS: .869† SCI: .854†	MS: .743† SCI: .751†
Sleep Disturbance	MS: .815† SCI: .776†	MS: .493† SCI: .536†
Snoring	MS: .157† SCI: .152*	MS: .186† SCI: .168†
Respiratory	MS: .323† SCI: .370†	MS: .307† SCI: .334†
Sleep Quantity	MS: −.493† SCI: −.421†	MS: −.287† SCI: −.211†
Sleep Adequacy	MS: −.713† SCI: −.706†	MS: −.613† SCI: −.630†
Daytime Somnolence	MS: .302† SCI: .468†	MS: .653† SCI: .699†

*Significant at 0.05 level (2-tailed)

†Significant at 0.01 level (2-tailed)