Prevalence and Impact of Pain in Adults Aging With a Physical Disability

Comparison to a US General Population Sample

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Objectives: To describe rates of pain and pain interference in a large sample of adults aging with long-standing physical disabilities, relative to a normative US population sample.

Methods: Self-report survey data was collected for a sample of 1877 individuals with spinal cord injury, neuromuscular disease, postpolio syndrome, or multiple sclerosis. Rates of pain severity and pain interference in these samples were then compared with those taken from a large normative sample (> 20,000) collected through the NIH Patient Reported Outcomes Measurement Information System (PROMIS).

Results: Individuals with long-standing physical disabilities reported higher levels of pain and pain interference across the lifespan as compared with individuals in the normative sample. In general, individuals with disability did not experience an age-related decrease in pain and pain impact in contrast to those in the normative sample. For 3 disability groups (neuromuscular disease, postpolio syndrome, and multiple sclerosis), pain interference remained elevated and significantly higher than national norms in the "postretirement" period (ie, age 65 to 74).

Discussion: Results from this study provide a large scale data on prevalence rates of pain and pain interference in this population. Findings underscore the prevalence and impact of pain in persons with disabilities and suggest that individuals with disability may not experience the same degree of decrease in pain interference in later life that is typical of the US population. Those aging with disability may be especially at risk for pain-related impairment in later life.

Key Words: aging, pain, disability, PROMIS

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Recent improvements in the medical care and rehabilitation of people with acquired disabilities have led to a substantial increase in life expectancy. Although there are exceptions to this trend,[1] evidence suggests that increasing numbers of people with physical disabilities are living well into middle age and older adulthood.

Unfortunately, advancing age is inevitably associated with decline in health and functioning, and almost nowhere is this more true than in persons with disabilities. For these individuals, increased longevity is often accompanied by a number of challenging comorbid health problems (sometimes called secondary health conditions) that develop over time.[2–5] These secondary health conditions include spasticity, fatigue, weakness, and imbalance. Especially for older adults with disability, these symptoms can exert a profound negative effect on quality of life, community participation, and employment.

Perhaps, the most common secondary health condition in adults with disability is chronic pain. Chronic pain during disability can be musculoskeletal,[6,7] neuropathic (including paresthesias[8,9]), or as a result from associated problems such as chronic headache[10] or painful tonic spasms.[11] The majority of patients with disabilities report chronic painful sensations, and of these, 25% to 33% rate the intensity of their pain as severe.[12]

As individuals with disability age, whatever disability-related pain problems they already have may begin to interact with new pain problems associated with aging. About 70% of independently living older adults report chronic pain,[13] with even higher rates for those in assisted living facilities.[14] Even able-bodied older adults experience a number of "age-related" pain problems like diabetic neuropathy, osteoarthritis-related joint pain and, in some cases, cardiopulmonary pain (eg, angina or bronchospasm). In those aging with disability, these kinds of pain problems may begin to compound with pain that is disability-related (eg, paresthesias).

Given the higher prevalence of pain in persons with long-standing disabilities and evidence that pain can interfere with the functioning,[15] one would expect to see higher levels of pain-related interference in persons with disabilities as compared with their able-bodied but aging peers. However, this hypothesis has never been directly tested. Moreover, the possibility that pain's effect on functioning might vary as a function of age in persons with disabilities has not been adequately examined.

More knowledge regarding the extent of pain interference in persons with disabilities and how it might relate to age is important for at least 2 reasons. First, such knowledge would allow clinicians to advise patients with disabilities and chronic pain regarding what they might expect as they get older. In a series of focus groups on aging and disability conducted by our group,[16] middle aged and older participants expressed the need for more knowledge

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about how their symptoms might progress. Second, information about pain interference in individuals aging with disabilities helps scientists and clinical researchers better anticipate the impact of disability over the life course. This information can support the development and testing of interventions that might reduce the effects of pain on the lives of individuals with disabilities.

The purpose of the current study was to contribute to the knowledge base on this topic by comparing self-reported levels of pain interference collected for multiple disability populations with a large general population sample taken from the NIH-funded Patient Reported Outcomes Measurement Information System (PROMIS) project (described in detail later). Our goal was to understand the magnitude of pain interference across and between individuals with disabilities and to describe ways in which pain interferes with activities across the lifespan better. Using a community-based survey approach, we assessed pain severity and pain interference in a sample of individuals with spinal cord injury (SCI), postpolio syndrome (PPS), multiple sclerosis (MS), or neuromuscular disease (NMD), hypothesizing that pain interference would be higher in each of these 4 clinical conditions as compared with a large US sample (which was matched to the general population in terms of age, sex, and race/ethnicity). To evaluate the relationship between age and pain interference, we then compared levels of pain interference to the PROMIS normative sample means for specific age ranges (ie, 18 to 34, 35 to 44, 45 to 54, 55 to 64, 65 to 74, and 75 and older).

MATERIALS AND METHODS

Participants

Participants were recruited for an ongoing longitudinal study examining the frequency and impact of secondary health conditions in persons aging with a disability. To be eligible, participants were required to be 18 years of age or older; to be able to read, write, and understand English; and to have a self-reported diagnosis of MS, SCI, NMD or PPS or a history of polio and polio sequelae. The Institutional Review Board at the University of Washington in Seattle reviewed and approved all the study procedures.

Measures

National Comparison Data

The national comparison data for the present study came from data collected by the PROMIS, an initiative funded by the National Institutes of Health. The primary goal of PROMIS was to develop measures of key symptoms and outcomes applicable to a range of chronic conditions.[17,18] Psychometric testing for the PROMIS measures was completed using a very large sample (> 20,000).[19] A subsample (N = 3036) matched the age, demographics, and age and ethnicity of the US population (2000 census).[20] This sample was used to estimate the mean population scores for each PROMIS measure.

A unique characteristic of the scores of all PROMIS measures, including the pain interference measure used in this study, is that PROMIS scores are reported on a T-score metric. This metric is anchored to the mean of a large subsample of individuals whose distribution by age, sex, and race/ethnicity approximates to that of the 2000 US census.[19] We refer to this sample as the "PROMIS normative sample" because of its normative representation on key demographic variables. It is important to note, however, that the PROMIS sample is not normative with respect to other variables such as education, marital status, or socioeconomic status. Age cohort norms were not created for the PROMIS normative sample. For comparison with the data collected in our sample, we approximated such norms by calculating mean pain scores by age range. We refer to these as the "PROMIS age cohort means."

The PROMIS T-score metric has a mean of 50 and an SD of 10. The use of this metric improves the interpretability of scores. For example, if a person scores a 70 on a particular measure, this is a score that is 2.0 SDs [(70 − 50)/10] above the mean of the PROMIS normative sample.

Demographic and Disability-related Descriptive Variables

All participants provided basic demographic information (eg, age, race/ethnicity, sex, marital status, income, and questions about work history) and information regarding their disability (including formal diagnosis, level and completeness [for SCI], year of diagnosis, disease course, and history of medical treatment).

PROMIS Measures

To ensure comparability to PROMIS norms, we included the same measures of pain and pain interference used in the PROMIS item bank development studies (described below).

Pain Severity

Average pain severity (over the past week) was assessed using a standard 11-point numeric rating scale ranging from 0 (no pain) to 10 (pain as bad as could be). This approach is widely used in the pain literature[20] and has been shown to correlate with other measures of pain intensity.[21]

Pain Interference

Pain interference was measured using the PROMIS Pain Interference Short Form.[23] This is a 6 item measure that assesses pain impact in key areas of functioning including day-to-day activities, ability to concentrate, and social activity. The candidate item pool for the measure included 644 items collected from interviews with patients, consultation with pain experts, and a review of published instruments. The item pool was reduced to 56 items and responses to all or subsets of these items were obtained from community and clinical samples (N = 14,848). Item responses were calibrated to an item response theory model and evaluated for model fit, differential item function, precision, and validity. Forty-one items were retained from the 56 item pool. The pain interference short form was then generated by selecting a subset of 6 items with good psychometric properties (eg, high discrimination) that also, cumulatively, represented the content of the full bank. Therefore, for example, there are items that ask about pain interference on both cognition and physical function and on daily activities and social relationships. Respondents are asked to reference the past 7 days in responding. Items include "How much did pain interfere with your enjoyment of recreational activities?" and "How often did pain keep you from socializing with others?" The 5 response categories range from "not at all" to "very much."

Items had good fit to the item response theory model, were strongly unidimensional, and differential item function had negligible impact on scores. Scores provided substantial

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information across levels of pain and exhibited excellent construct and known group validity.

Other Measures

In addition to pain measures, participants completed measures of other secondary symptoms (eg, fatigue, physical function, mobility, depression, and sleep and wake function) and health conditions (eg, recent relapse, skin problems, urinary tract infection) that are not the focus of this paper.

Procedures

We recruited participants using several strategies. Invitations (n = 1692) were sent to potential individuals who participated in previous University of Washington Studies through the University of Washington Disability Registry (n = 398), the University of Washington Center on Outcomes Research in Rehabilitation (n = 473), and through disability-specific registries (Northwest Regional Spinal Cord Model Systems and the University of Rochester Neuromuscular Disease (NMD) Research Registry, n = 375). Some participants responded to web and print advertisements (n = 795) posted in clinics and with disability support organizations (National MS Society, Post-Polio Health International, Muscular Dystrophy Foundation). Other participants were referred to the study by friends or family members.

We mailed surveys to all eligible and interested participants (n = 2041) along with a postage paid return envelope. Reminder letters were sent 3 to 6 weeks after the survey was mailed to those who had not yet returned their survey. Research assistants reviewed returned surveys (n = 1877) for missing data and made up to 3 follow-up calls to retrieve the data. All participants were sent a check for $25 after their survey was returned. All procedures were approved by the University of Washington Institutional Review Board and informed consent was obtained from all participants.

Of the 1877 surveys that were returned (91% response rate), 15 were excluded because of lack of signed consent, lack of valid diagnosis of disability, return of survey after the dataset was finalized, or participant request to withdraw from the study. The remaining 1862 surveys were included in the final dataset (MD = 340, PPS = 446, MS = 584, SCI = 492). Of the 1862, 1128 (60.5%) were recruited from the disability registries, with the remaining 734 (39.5%) recruited from web and print advertisements.

Of the total potential sample of 1862 individuals, 1857 completed ratings of pain severity and were included in the present study. The PROMIS pain interference short form items were then administered to 910 randomly selected participants from this pool (MD = 171, PPS = 218, MS = 282, SCI = 239).

Data Analysis

Descriptive Analyses

For descriptive purposes, we computed means and SDs of the demographic and disability-related variables, including pain severity. These are presented in Tables 1 and 2.

Hypothesis Tests

To test the hypothesis that mean pain interference scores reported in each clinical population would exceed the mean of the PROMIS normative sample, we used one-sample *t* tests to compare the scores in our samples to the overall national PROMIS mean. Specifically, we compared mean pain interference scores for each clinical sample against a test value of 50, the US population mean was not adjusted for age. To account for the 4 comparisons (one for each disability group), we used a Bonferroni correction, yielding a corrected α value of 0.125 (0.05/4).

To test our hypothesis that reported pain interference levels in different age ranges would be higher in our clinical samples, we calculated PROMIS age cohort means based on the PROMIS norming sample.[22] PROMIS general population means have been published elsewhere. However, subnorms for different age cohorts were not calculated as a part of the PROMIS effort. Descriptive statistics for different subgroups were published but these were not adjusted based on the 2000 US census. Therefore, we calculated PROMIS age cohort means using the PROMIS norming sample.[20] This allowed us to test our hypothesis that reported pain interference levels in different age ranges would be higher in our clinical samples. This was accomplished by calculating the pain interference mean and SF of the overall norming sample (N = 3036) and linearly transforming these scores to a T-score metric (mean = 50; SD = 10). The sample was then subdivided into age-based cohorts (18 to 34, 35 to 44, 45 to 54, 55 to 64, 65 to 74, and 75 and up).

We compared our data to the PROMIS age-based means. As an example, the PROMIS 18- to 34-year-old age cohort had a mean pain interference level of 47.8. Therefore, we used this value as a comparison point for all 18- to 34-year-old individuals in the present study using a one-sample *t* test. For all comparisons, we used a conservative α value for significance of $P < 0.01$. For the PPS sample, insufficient data were available for persons who were < 45 years of age (N = 1). Therefore, only 4 *t* tests were conducted in the PPS sample. To describe the relationship between chronological age and pain interference in our clinical populations, we used linear regression to estimate both the linear and curvilinear relationships between these variables.

RESULTS

Participants

Demographic information. Disease status and demographic information is presented by the disability group in Table 1. Most participants in the present study were whites (97.7%) and middle aged (*M* age = 53.3). The mean time of living with a disability was 15.2 years.

Pain Severity

Table 2 reports the mean levels of pain reported by each disability group, as compared with the PROMIS national sample mean of 2.4. Consistent with the data from earlier studies,[12] all disability groups reported a higher mean pain than did the normative sample. These data are displayed in Figure 1.

Pain Interference

Table 3 reports the means and SDs of pain interference levels by the disability group as compared with PROMIS age cohort means. These data are displayed graphically in Figure 2.

Overall, individuals with disability reported more pain-related interference than did individuals in the general US population. However, the magnitude of the difference varied somewhat by the disability group, with individuals with PPS reporting the greatest mean difference, followed

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TABLE 1. Selected Demographic Characteristics

Characteristics	n (%)*			
	Muscular Dystrophy (N = 171)	Multiple Sclerosis (N = 282)	Postpolio (N = 218)	Spinal Cord Injury (N = 239)
Gender				
Male	76 (44.4)	49 (17.4)	55 (25.2)	163 (68.2)
Female	95 (55.6)	233 (82.6)	163 (74.8)	76 (31.8)
Ethnicity*				
African American	1 (0.6)	5 (1.8)	2 (0.9)	18 (7.6)
Asian	0 (0)	0 (0)	3 (1.4)	4 (1.7)
White	167 (97.7)	272 (96.5)	209 (95.9)	212 (89.1)
Hispanic/Chicano	1 (0.6)	4 (1.4)	3 (1.4)	3 (1.3)
Native American	3 (1.8)	2 (0.7)	4 (1.8)	5 (2.1)
Pacific Islander	0 (0)	0 (0)	0 (0)	2 (0.8)
Other	3 (1.8)	1 (0.4)	2 (0.9)	2 (0.8)
Years since diagnosis M (SD)	15.2 (11.5)	14.7 (9.8)	15.9 (10.5)	16.0 (10.9)
Age mean (Min–Max)	53.3 (20-85)	53.6 (21-83)	66.8 (41-91)	49.8 (21-88)
Level of injury†				
C1–C8				113 (47.3)
(SCI only)				
T1–T12				122 (51.1)
L1–L5				32 (13.4)
S1–S3				3 (1.3)
MS type*				
Relapsing/remitting		152 (54.7)		
Primary progressive		37 (13.3)		
Secondary progressive		64 (23.0)		
Progressive relapsing		25 (9.0)		
NMD type†				
Limb-girdle	4 (2.3)			
Myotonic dystrophy	93 (54.4)			
Facioscapulohumeral dystrophy	75 (43.9)			
Spinal muscular atrophy	2 (1.2)			
Other	6 (3.5)			

*Numbers may not add to total because of missing data.
†Numbers may add up to larger than total because of the option for selecting multiple answers.
NMD indicates neuromuscular disease.

by individuals with SCI. On average, individuals with disability were 0.58 SDs higher in pain interference than the national sample.

Age Comparisons

Regression

To describe the relationship between pain interference and chronological age in our clinical populations, we performed regression analyses to estimate both the linear and curvilinear (quadratic) relationships between chronological age and pain interference scores. Overall, the effect of age on pain interference, both linear and quadratic, was very modest (all rs < 0.10). Although some results suggested that further study was warranted (eg, there was a trend towards a curvilinear relationship between age and pain interference in individuals with SCI), no β's were significant after performing a Bonferroni adjustment to control for multiple comparisons (eg, 0.05/8 or $P < 0.00625$).

Age Cohort Analyses

Table 3 presents the results of the one-sample t tests comparing age cohort means within each clinical sample to the PROMIS age-specific norms for pain interference. For descriptive purposes, the same data are presented for pain severity in Table 2.

The pattern in the normative data (from PROMIS) suggests a pattern of pain interference that is highest in midlife and drops off in what we would normally think of as the "postretirement" and older age periods (65 to 74 and 75 +). This is consistent with a larger literature that describes decrease in pain interference in the young and middle aged.[23,24]

A similar pattern was evident in our sample of individuals with disabilities, with the notable exception that for 3 disability groups (NMD, PPS, and MS), pain interference remained quite high and significantly higher than national norms in what we would ordinarily refer to as the "postretirement" period (ie, age 65 to 74; Fig. 2). Further, each disability group demonstrated a unique pattern of pain interference across the age cohorts.

In SCI, self-reported levels of pain interference were higher than the national mean from young adulthood through middle age. Younger individuals with SCI reported similar levels of pain interference during younger and middle adulthood (35 to 44, 45 to 54, and 55 to 64). Individuals from older cohorts reported levels of pain that were slightly lower than their middle aged counterparts, at

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TABLE 2. Results of *t* Tests Comparing Mean Pain Severity Scores to PROMIS US Population Norms, by Age Cohort and Disability Group

Age Range	US Population Mean	Disability Group	Sample Mean (SD)	n	*t*	Probability (1 − Tailed)	95% Confidence Interval of the Difference	
							Lower	Upper
All ages	2.4	MD	3.3 (2.6)	338	6.6	< 0.001	0.66	1.2
		MS	3.1 (2.5)	583	6.5	< 0.001	0.48	0.89
		PPS	4.3 (2.5)	445	16.1	< 0.001	1.6	2.1
		SCI	4.3 (2.5)	491	17.0	< 0.001	1.7	2.2
18-34	1.9	MD	3.3 (2.9)	33	2.7	$P < 0.05$	0.36	2.4
		MS	2.2 (2.2)	26	0.7	NS	−0.61	1.2
		PPS*	—	—	—	—	—	—
		SCI	3.9 (2.5)	79	7.2	$P < 0.001$	1.5	2.6
35-44	2.4	MD	2.7 (2.7)	43	0.7	NS	−0.6	1.1
		MS	2.9 (2.6)	77	1.7	NS	−0.1	1.1
		PPS*	—	—	—	—	—	—
		SCI	4.3 (2.6)	90	7.1	$P < 0.001$	1.4	2.5
45-54	2.9	MD	3.8 (2.4)	102	3.5	$P < 0.001$	0.37	1.3
		MS	3.4 (2.6)	177	2.7	$P < 0.01$	0.14	0.91
		PPS	6.0 (2.1)	13	5.3	$P < 0.001$	1.8	4.3
		SCI	4.8 (2.5)	126	8.6	$P < 0.001$	1.4	2.3
55-64	2.8	MD	3.3 (2.5)	95	1.8	NS	−0.0	1.0
		MS	3.0 (2.4)	204	1.1	NS	−0.15	0.52
		PPS	4.7 (2.4)	171	10.1	$P < 0.001$	1.5	2.2
		SCI	4.4 (2.5)	125	7.0	$P < 0.001$	1.1	2.0
65-74	2.4	MD	3.4 (2.6)	53	3.0	$P < 0.01$	0.3	1.8
		MS	3.1 (2.5)	84	2.7	$P < 0.01$	0.2	1.3
		PPS	3.8 (2.5)	171	7.3	$P < 0.001$	1.0	1.8
		SCI	4.2 (2.7)	53	5.1	$P < 0.001$	1.1	2.6
75 and up	2.2	MD	2.3 (2.9)	12	0.05	NS	−1.8	1.9
		MS	2.6 (2.5)	15	0.6	NS	−1.0	1.8
		PPS	4.2 (2.4)	89	8.2	$P < 0.001$	1.5	2.5
		SCI	3.4 (2.9)	16	1.7	NS	−0.3	2.8

*n < 2.
MD indicates muscular disease; MS, multiple sclerosis; PPS, postpolio syndrome; SCI, spinal cord injury.

around 0.6 SD greater than the PROMIS norm. Differences from national PROMIS data were not significant over the age of 65, but the small sample size of individuals with SCI in these age bands makes results more difficult to interpret.

In NMD, mean pain interference levels were 0.43 SD higher than the national mean (Table 3). However, the pattern of pain interference was quite variable. Individuals with NMD from ages 35 to 44 reported levels of pain interference that were essentially the same as the PROMIS age cohort mean. In contrast, larger differences were obtained for those in young adulthood (18 to 34) and the youngest band of older adulthood (65 to 74), during which individuals with MD were approximately 0.4 SDs higher than the PROMIS age cohort mean.

Similar to what was seen in NMD, middle aged individuals with MS reported high levels of pain interference. However, the report of pain interference did not decline for those in the 65- to 74-year-old cohort, where it was nearly 0.7 SD higher than the national mean.

Finally, those with PPS demonstrated a slightly different pattern of pain interference than did any other group. For these individuals, pain interference was significantly higher than the US mean from ages of 46 to 64 (at around 0.8 SD greater than the PROMIS age cohort mean) and remained high in young-old (65 to 74) and middle-old (75 +) cohorts. In fact, for these older PPS age cohorts, reported mean pain levels were the highest observed in any disability group (0.88 SD above the PROMIS age cohort mean).

By way of clinical interpretation, the minimum clinically important difference (MCID) for PROMIS interference measures have been reported as ranging from 4 to 6 points in persons with serious medical conditions.[25] In our sample, the overall (across age) differences between the pain interference score in persons with disabilities versus the PROMIS normative sample would meet this MCID criterion for all disability groups. Looking more specifically at the age bands within disability groups, we see that wherever a statistically significant difference occurred, it met the criteria for MCID (with differences ranging from 4.0 to 8.3 points). There was only one exception—for people with MS, the differences from PROMIS means from 45 to 54 and 55 to 64 ranged from 2.5 to 3.1; these would be considered statistically significant but not clinically important by this criterion.

DISCUSSION

Chronic pain can create considerable interference for adults aging with disabilities. From the general aging literature, we know that chronic pain in older adults is associated with sleep disturbance,[26] decreased social functioning,[27] increased health care utilization and cost,[28] disability/functional dependence,[29,30] and increased negative affect.[31,32] Although pain and pain interference have been described in various disability groups,[12] to our knowledge, this is the first major survey study to use a standardized measure to compare rates of pain interference reported by people with a disability to a large sample from the general population.

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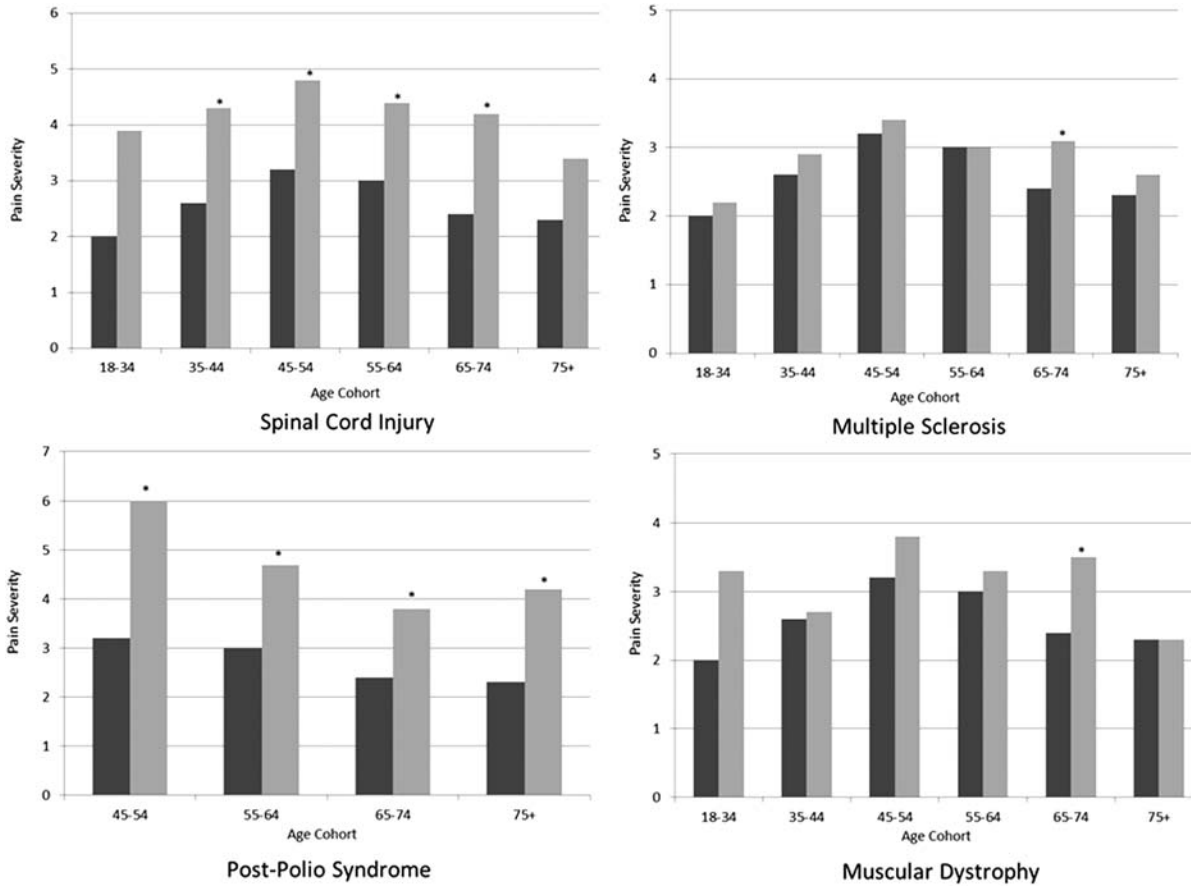

FIGURE 1. Pain severity scores by sample, age cohort, and disability group. *Significant difference between disability and comparison group ($\alpha < 0.01$). = clinical sample; = PROMIS normative sample

Although the literature on pain and aging is nuanced and complex and involves many medical and social factors (for excellent reviews, see Gibson and colleagues[33,34]), our findings regarding pain severity are generally consistent with the larger literature on chronic pain in nondisabled people.[35] Speaking broadly, it appears that while the prevalence of pain tends to increase with age (perhaps reaching a plateau around age 70), the degree to which pain interferes with mood and activities varies considerably across the lifespan based on life context and environmental demands. Pain interference may spike during midlife, in conjunction with myriad daily hassles and demands of that period. Accordingly, pain interference (and quality of life in general) in persons with chronic pain tends to improve during the postretirement period,[23,24,36,37] perhaps because of decreases in life hassles and time demands after retirement,[38] changes in attitudes about pain in one's life context,[39,40] and adaptation to pain over time with increasing age and experience.[41]

Findings from the present study are consistent with these observations about the general nondisabled population in that chronic disability pain seems to have its greatest impact during middle adulthood, from an age of approximately 45 to 65 years. However, in contrast to what is reported in nondisabled older adults, our results suggest that the "postretirement bonus" in pain interference may not be present for some individuals with disability. Rather, it seems that for at least 3 disability groups (NMD, PPS, and MS), pain may continue to create significant interference in daily activities from age 65 to 74, and in the case of PPS, these high levels of pain interference continue well into old age.

Interestingly, the effect observed in pain interference does not seem to depend on an increase in pain severity. In all but the PPS sample, older age cohorts reported lower levels of pain severity. It appears that whatever pain does exist (even if decreasing slightly over time) exerts a stable or increasing demand on individuals with disabilities as they age. Again, this is in contrast to the normative population where aging appears to provide some relief in terms of both pain intensity and pain interference.

Although we can only speculate as to why pain interference remains higher than compared with PROMIS age cohort means, in the "postretirement" periods for people with disabilities, it may be that the pain-related interference described by the general US population refers more to problems in employment and socializing, both of which usually change after leaving the workforce. For individuals with disabilities, "interference" also may impact more basic tasks such as movement and toileting, and these would not change in response to the retirement or other normative experiences of older adulthood. It is also reasonable to assume that the increase in quality of life seen after retirement age are associated with a planned change in lifestyle during that age period, which might include things like a

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TABLE 3. Results of *t* Tests Comparing Mean Pain Interference Scores to PROMIS US Population Norms, by Age Cohort and Disability Group

Age Range	US Population Mean	Disability Group	Sample Mean (SD)	n	*t*	Probability (1 − Tailed)	95% Confidence Interval of the Difference	
							Lower	Upper
All ages	50.0	NMD	54.3 (8.8)	171	6.4	< 0.0001	3.0	5.6
		MS	54.1 (9.1)	281	7.6	< 0.0001	3.1	5.2
		PPS	58.0 (7.9)	218	15.0	< 0.0001	7.0	9.1
		SCI	56.8 (8.3)	238	2.7	< 0.0001	5.7	7.9
18-34	47.8	NMD	53.1 (7.9)	17	2.8	$P < 0.05$	1.2	9.4
		MS	48.7 (8.9)	12	0.33	NS	−4.8	6.5
		PPS*	—	—	—	—	—	—
		SCI	54.5 (7.9)	35	5.1	$P < 0.001$	4.1	9.5
		Combined	53.1 (8.2)	64	5.1	$P < 0.001$	3.2	7.3
35-44	50.1	NMD	49.1 (9.1)	19	−0.5	NS	−5.4	3.4
		MS	52.4 (9.7)	43	1.55	NS	−0.7	5.3
		PPS*	—	—	—	—	—	—
		SCI	57.6 (7.7)	47	6.7	$P < 0.001$	5.3	9.8
		Combined	54.2 (9.3)	110	4.6	$P < 0.05$	2.3	5.9
45-54	51.9	NMD	57.5 (7.6)	48	5.2	$P < 0.001$	3.5	7.8
		MS	55.0 (8.9)	92	3.4	$P < 0.001$	1.3	5.0
		PPS	59.9 (10.9)	7	1.9	$P = 0.10$	−2.1	18.1
		SCI	57.4 (7.1)	60	6.0	$P < 0.001$	3.7	7.3
		Combined	56.5 (8.2)	208	8.0	$P < 0.001$	3.4	5.7
55-64	51.6	NMD	53.2 (9.8)	51	1.2	NS	−1.1	4.4
		MS	54.1 (9.0)	94	2.65	$P < 0.01$	0.6	4.3
		PPS	59.9 (7.0)	86	11.0	$P < 0.001$	6.8	9.8
		SCI	57.5 (9.3)	71	5.3	$P < 0.001$	3.7	8.1
		Combined	56.4 (9.1)	302	9.2	$P < 0.001$	3.8	5.8
65-74	49.9	NMD	54.8 (8.0)	30	4.9	$P < 0.01$	1.9	7.9
		MS	56.5 (8.0)	34	4.8	$P < 0.001$	3.8	9.4
		PPS	55.7 (8.2)	87	6.6	$P < 0.001$	4.1	7.5
		SCI	55.2 (9.3)	21	2.6	$P < 0.05$	1.0	9.6
		Combined	55.6 (8.2)	172	9.2	$P < 0.001$	4.5	7.0
75 and up	49.7	NMD	54.9 (7.8)	5	1.5	NS	−4.5	14.9
		MS	51.8 (11.6)	7	0.47	NS	−8.7	12.8
		PPS	58.5 (7.3)	37	7.3	$P < 0.001$	6.3	11.2
		SCI	54.6 (9.4)	5	1.2	NS	−6.8	16.6
		Combined	56.9 (8.3)	54	6.4	$P < 0.001$	4.9	9.4

*n $\leq$5.
NMD indicates neuromuscular disease; MS, multiple sclerosis; PPS, postpolio syndrome; SCI, spinal cord injury.

voluntary exit from the workforce, a reduction in demands associated with parenting, more control over ones time, etc. In contrast, for people living with long-standing disabilities, retirement is rarely truly voluntary, and many face additional financial strains associated with increasing health care costs, greater need for caregiver support, and an uncertain health outlook. For these individuals, there is very little decrease in the intensity of environmental demands in older age, and therefore more room for pain to interfere with necessary activities.

The findings from this study have important implications for measurement and treatment of chronic pain problems in older, disabled individuals. First, our findings suggest that it is important to measure both pain severity and pain interference in adults aging with a disability because the 2 constructs appear to provide somewhat different information. Second, the findings highlight the complex relationship between pain intensity and pain interference. This makes targeting pain severity in the elderly particularly challenging. The most common pain treatments used include opioid analgesics, many of which produce undesirable side-effects in the elderly (including constipation, impaired cognition, and unsteady gait). Although treatment of pain with analgesics may be helpful for some individuals, the current findings suggest that interventions designed to minimize pain interference may also be useful. These might include exercise, environmental modification, and psychosocial interventions such as cognitive-behavior therapy or self-hypnosis training.[42–45] Although the efficacy of these interventions on pain and pain-related interference has been established in the general population[46] and some research suggests that they may also benefit individuals with disabilities,[42–44,47] further work is needed to adapt and test these interventions in the disabled elderly.

Study Limitations

This study has a number of limitations. Most importantly, the data are cross-sectional. Although we have offered some speculations regarding the "course" or "trajectory" of pain and pain interference across the lifespan in persons with disability, these observations must be seen as preliminary, as they cannot be supported by repeated measurement over time. Longitudinal studies of pain and disability across the lifespan are indicated. In addition, individuals in our study were drawn from a convenience sample including a registry maintained at the University of Washington of individuals with disabilities

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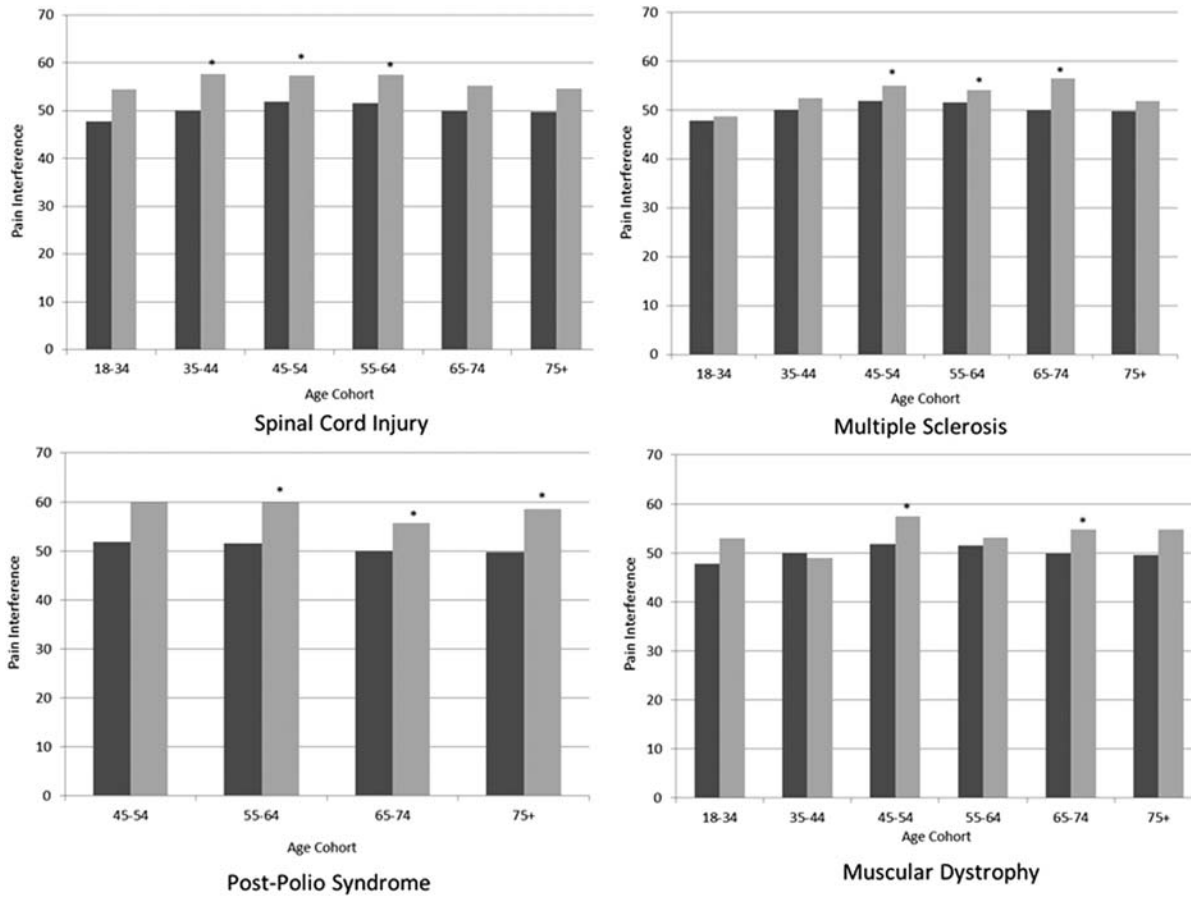

FIGURE 2. Pain interference scores, by sample, age cohort, and disability group. *Significant difference between disability and comparison group ($\alpha < 0.01$). = clinical sample; = PROMIS normative sample

and other registries and national disability-specific organizations. These individuals may not be representative of the populations of persons with MS, SCI, MD, or PPS. The same may be said of race and ethnic group; the sample included in the present study were >97% whites versus 74% whites in the PROMIS normative sample. Given that race and ethnicity have been associated with the report of pain,[48] this presents a potential confound in the interpretation of our results. Replication of this survey in additional samples of persons with disabilities, and especially in individuals from minority racial and ethnic backgrounds, would establish whether our results are generalizable. Sample size was sometimes an issue in the age by disability cells, with 4 cells having n's < 20. Although only one of these (people over age 75, with SCI) contained a difference large enough to suggest the possibility of type II error, such small sample sizes are inherently unstable and interpretation of these 4 cells must be made with caution. Finally, we were unable to determine whether the pain individuals experienced was primarily linked to disability (eg, neuropathic pain from SCI) or to other painful processes that are more prevalent in later adulthood (eg, osteoarthritis). This limited our ability to draw conclusions about "disability pain" versus pain from other sources.

CONCLUSIONS

Despite the study's limitations, the findings indicate that individuals with disability experience higher levels of pain interference than individuals who do not have a disability, a finding likely related to the fact that pain is more common and more severe in individuals with disabilities. The findings also indicate that the effects of pain on activities vary as a function of age, with different age-related effects across each disability group.

The average age of individuals with disability is increasing. With this shift in the demographics of disability, we can anticipate greater prevalence and impact of secondary health conditions such as chronic pain. Addressing this problem will require interventions supported by a multidisciplinary research effort and must include a better understanding of the ways in which older, disabled adults experience and manage secondary health conditions in later life.

REFERENCES

1. DeVivo MJ, Chen Y. Trends in new injuries, prevalent cases, and aging with spinal cord injury. *Arch Phys Med Rehabil*. 2011;92:332–338.
2. McColl MA. A house of cards: women, aging and spinal cord injury. *Spinal Cord*. 2002;40:371–373.
3. Charlifue SW, Weitzenkamp DA, Whiteneck GG. Longitudinal outcomes in spinal cord injury: aging, secondary conditions, and well-being. *Arch Phys Med Rehabil*. 1999;80:1429–1434.
4. Finlayson M. Health and social profile of older adults with MS: findings from three studies. *Int J MS Care*. 2002;4:139–151.

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5. Kalpakjian CZ, Toussaint LL, Klipp DA, et al. Development and factor analysis of an index of post-polio sequelae. *Disabil Rehabil*. 2005;27:1225–1233.
6. Abresch RT, Carter GT, Jensen MP, et al. Assessment of pain and health-related quality of life in slowly progressive neuromuscular disease. *Am J Hosp Palliat Care*. 2002;19:39–48.
7. Haisma JA, van der Woude LH, Stam HJ, et al. Complications following spinal cord injury: occurrence and risk factors in a longitudinal study during and after inpatient rehabilitation. *J Rehabil Med*. 2007;39:393–398.
8. Jensen MP, Abresch RT, Carter GT, et al. Chronic pain in persons with neuromuscular disease. *Arch Phys Med Rehabil*. 2005;86:1155–1163.
9. Kassirer M. Multiple sclerosis and pain. *Int J MS Care*. 2000;2:30–38.
10. Archibald CJ, McGrath PJ, Ritvo PG, et al. Pain prevalence, severity and impact in a clinic sample of multiple sclerosis patients. *Pain*. 1994;58:89–93.
11. Perkins FM, Moxley RT, Papciak AS. Pain in multiple sclerosis and the musuclar dystrophies. In: Block AR, Kremer F, Fernandez E, eds. *Handbook of Pain Syndromes: Biopsychosocial Perspectives*. Mahwah, NJ: Erlbaum; 1999:349–370.
12. Ehde DM, Jensen MP, Engel JM, et al. Chronic pain secondary to disability: a review. *Clin J Pain*. 2003;19:3–17.
13. Roy R, Thomas M. Pain, depression and illness behavior in a community sample of active elderly persons: elderly persons with and without pain, part 2. *Clin J Pain*. 1988;3:207–211.
14. Parmelee PA, Smith B, Katz IR. Pain complaints and cognitive status among elderly institution residents. *J Am Geriatr Soc*. 1993;41:517–522.
15. Widerstrom-Noga E, Finlayson ML. Aging with a disability: physical impairment, pain, and fatigue. In: Jensen MP, Molton IR, eds. *Physical Medicine and Rehabilitation Clinics of North America: Aging with a Physical Disability*. Philadelphia, PA: W.B. Saunders Company; 2010:321–337.
16. Yorkston KM, McMullan KA, Molton I, et al. Pathways of change experienced by people aging with disability: a focus group study. *Disabil Rehabil*. 2010;32:1697–1704.
17. Cella D, Riley W, Stone A, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. *J Clin Epidemiol*. 2010;63:1179–1194.
18. Cella D, Yount S, Rothrock N, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. *Med Care*. 2007;45(suppl 1):S3–S11.
19. Liu H, Cella D, Gershon R, et al. Representativeness of the Patient-Reported Outcomes Measurement Information System Internet panel. *J Clin Epidemiol*. 2010;63:1169–1178.
20. Jensen MP, Karoly P. Self-report scales and procedures of assessing pain in adults. In: Turk DC, Melzack R, eds. *Handbook of Pain Assessment*. New York: Guilford Press; 2000:135–151.
21. Jensen MP, Karoly P, O'Riordan EF, et al. The subjective experience of acute pain. An assessment of the utility of 10 indices. *Clin J Pain*. 1989;5:153–159.
22. National Institutes of Health. Organization, Group Validity and Interpretation Tables. 2011. Available at: http://www.nihpromis.org/science/validitystudies.aspx. Accessed April 25, 2011.
23. Riley J, Wade J, Robinson M, et al. The stages of pain processing across the adult lifespan. *J Pain*. 2000;1:162–170.
24. Rustoen T, Wahl A, Banestad B, et al. Age and the experience of chronic pain: differences in health and quality of life among younger, middle-aged, and older adults. *Clin J Pain*. 2005;21:513–523.
25. Yost KJ, Eton DT, Garcia SF, et al. Minimally important differences were estimated for six Patient-Reported Outcomes Measurement Information System-Cancer scales in advanced-stage cancer patients. *J Clin Epidemiol*. 2011;64:507–516.
26. Ferrell BA, Ferrell BR, Osterweil D. Pain in the nursing home. *J Am Geriatr Soc*. 1990;38:409–414.
27. Bookwala J, Harralson TL, Parmelee PA. Effects of pain on functioning and well-being in older adults with osteoarthritis of the knee. *Psychol Aging*. 2003;18:844–850.
28. Gallagher RM, Verma S, Mossey J. Chronic pain. Sources of late-life pain and risk factors for disability. *Geriatrics*. 2000;55:40–44, 7.
29. Dorantes-Mendoza G, Avila-Funes JA, Mejia-Arango S, et al. [Factors associated with functional dependence in older adults: a secondary analysis of the National Study on Health and Aging, Mexico, 2001]. *Rev Panam Salud Publica*. 2007;22:1–11.
30. Edwards RR. Age differences in the correlates of physical functioning in patients with chronic pain. *J Aging Health*. 2006;18:56–69.
31. Davidson H, Feldman PH, Crawford S. Measuring depressive symptoms in the frail elderly. *J Gerontol*. 1994;49:P159–P164.
32. Thomas E, Peat G, Harris L, et al. The prevalence of pain and pain interference in a general population of older adults: cross-sectional findings from the North Staffordshire Osteoarthritis Project (NorStOP). *Pain*. 2004;110:361–368.
33. Gibson SJ, Lussier D. Prevalence and relevance of pain in older persons. *Pain Med*. 2012;13(suppl 2):S23–S26.
34. Gagliese L. Pain and aging: the emergence of a new subfield of pain research. *J Pain*. 2009;10:343–353.
35. Langley PC. The prevalence, correlates and treatment of pain in the European Union. *Curr Med Res Opin*. 2011;27:463–480.
36. Mein G, Martikainen P, Hemingway H, et al. Is retirement good or bad for mental and physical health functioning? Whitehall II longitudinal study of civil servants. *J Epidemiol Community Health*. 2003;57:46–49.
37. Calasanti TM. Gender and life satisfaction in retirement: an assessment of the male model. *J Gerontol B Psychol Sci Soc Sci*. 1996;51:S18–S29.
38. Bosse R, Aldwin CM, Levenson MR, et al. How stressful is retirement? Findings from the Normative Aging Study. *J Gerontol*. 1991;46:P9–14.
39. LaChapelle D, Hadjistavropoulos HD. Age-related differences among adults coping with pain: evaluation of a developmental life-context model. *Can J Behav Sci*. 2005;37:123–137.
40. Parmelee PA. Pain and psychological function in late life. In: Mostofsky DI, Lomranz J, eds. *Handbook of Pain and Aging*. New York: Plenum Press; 1997:207–226.
41. Williamson G. The central role of restricted normal activities in adjustment to illness and disability: a model of depressed affect. *Rehabil Psychol*. 1998;43:327–347.
42. Ehde DM, Jensen MP. Feasibility of a cognitive restructuring intervention for treatment of chronic pain in persons with disabilties. *Rehabil Psychol*. 2004;49:254–258.
43. Jensen MP, Barber J, Romano JM, et al. A comparison of self-hypnosis versus progressive muscle relaxation in patients with multiple sclerosis and chronic pain. *Int J Clin Exp Hypn*. 2009;57:198–221.
44. Jensen MP, Barber J, Romano JM, et al. Effects of self-hypnosis training and EMG biofeedback relaxation training on chronic pain in persons with spinal-cord injury. *Int J Clin Exp Hypn*. 2009;57:239–268.
45. Perry KN, Nicholas MK, Middleton JW. Comparison of a pain management program with usual care in a pain management center for people with spinal cord injury-related chronic pain. *Clin J Pain*. 2010;26:206–216.
46. Molton IR, Graham C, Stoelb BL, et al. Current psychological approaches to the management of chronic pain. *Curr Opin Anaesthesiol*. 2007;20:485–489.
47. Jensen MP, Ehde DM, Gertz KJ, et al. Effects of self-hypnosis training and cognitive restructuring on daily pain intensity and catastrophizing in individuals with multiple sclerosis and chronic pain. *Int J Clin Exp Hypn*. 2011;59:45–63.
48. Hardt J, Jacobsen C, Goldberg J, et al. Prevalence of chronic pain in a representative sample in the United States. *Pain Med*. 2008;9:803–812.

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