

PERCEIVED PAIN-RELATED ILLNESS INTRUSIVENESS AMONG PERSONS WITH MULTIPLE SCLEROSIS (PWMS)

Elizabeth S. Gromisch, Ph.D.^{1,2}, Robert D. Kerns, Ph.D.^{2,3,4}, & John Beauvais, Ph.D.^{2,3}



¹ Mandell Center for Multiple Sclerosis Care and Neuroscience Research, Mount Sinai Rehabilitation Hospital, Trinity Health Of New England, Hartford, CT, USA

² Psychology Service, VA Connecticut Healthcare System, West Haven, CT, USA

³ Yale University School of Medicine, New Haven, CT, USA

⁴ Pain Research, Informatics, Multimorbidities and Education (PRIME) Center, VA Connecticut Healthcare System, West Haven, CT, USA

Contact Information: Elizabeth S. Gromisch, elizabeth.gromisch@stfranciscare.org



Background

More than half of persons with multiple sclerosis (PwMS) have pain, which has been described by 32% as one of their worst symptoms [1,2]. PwMS who report pain endorse poorer psychological functioning and level of productivity compared to those without pain [3]. In addition, as with their overall disease, PwMS have indicated that their pain interferes with several aspects of their daily functioning [4,5].

One way of examining the influence of a disease on an individual's quality of life (QoL) is through the construct of perceived illness intrusiveness, in other words, how the disease or its related treatments disrupt engagement in activities and interests, resulting in poorer psychological well-being [6]. While its association with other factors (e.g., emotional distress) has been studied in MS [7], no study has examined pain-related illness intrusiveness in relation to MS symptoms more generally.

Objective

To determine the extent to which PwMS experience pain as a particularly intrusive problem among the totality of their experience of MS-related challenges including their current level of functioning and disability.

Methods

Participants: 161 PwMS with at least mild pain; majority were women (N = 130) with relapsing remitting MS (N = 86) in middle adulthood (59.25 ± 8.31).

Procedures: Participants were recruited through the North American Research Committee on MS (NARCOMS) Registry and completed a one time online questionnaire.

Measures:

- Illness Intrusiveness Ratings Scale (IIRS):** a 13-item questionnaire using a Likert scale ranging from 1 (not very much) to 7 (very much) [6]. Participants were asked to fill the measure out twice: once with regards to their MS, and once with regards to their pain.
 - Unforced principal component analyses (PCA) with promax rotations were used to evaluate whether the two versions evaluated similar constructs and if certain items should be dropped.
- Pain item from the Performance Scales:** a valid self-report measure of pain severity in PwMS [8], ranging from 0 (normal) to 5 (total disabling pain).
- Patient Determined Disease Steps (PDDS):** a self-report measure of disability [9-12], ranging from 0 (normal) to 8 (bedridden).

Statistical Analyses: After the PCA, a multiple regression was conducted to assess the amount of variance of the MS-related IIRS that is accounted for by the pain-related IIRS, with the PDDS and pain severity as covariates.

Results

Pain Duration	16.60 ± 10.39
Pain Severity	3.42 ± 0.80
Number of Pain Locations	3.32 ± 1.54
Legs/Feet	85.71%
Lower Back	65.22%
Neck	50.31%
Arms/Hands	44.72%
Upper Back	31.68%
Head/Facial	31.68%
Other	22.98%

Table 1: Pain-related clinical characteristics

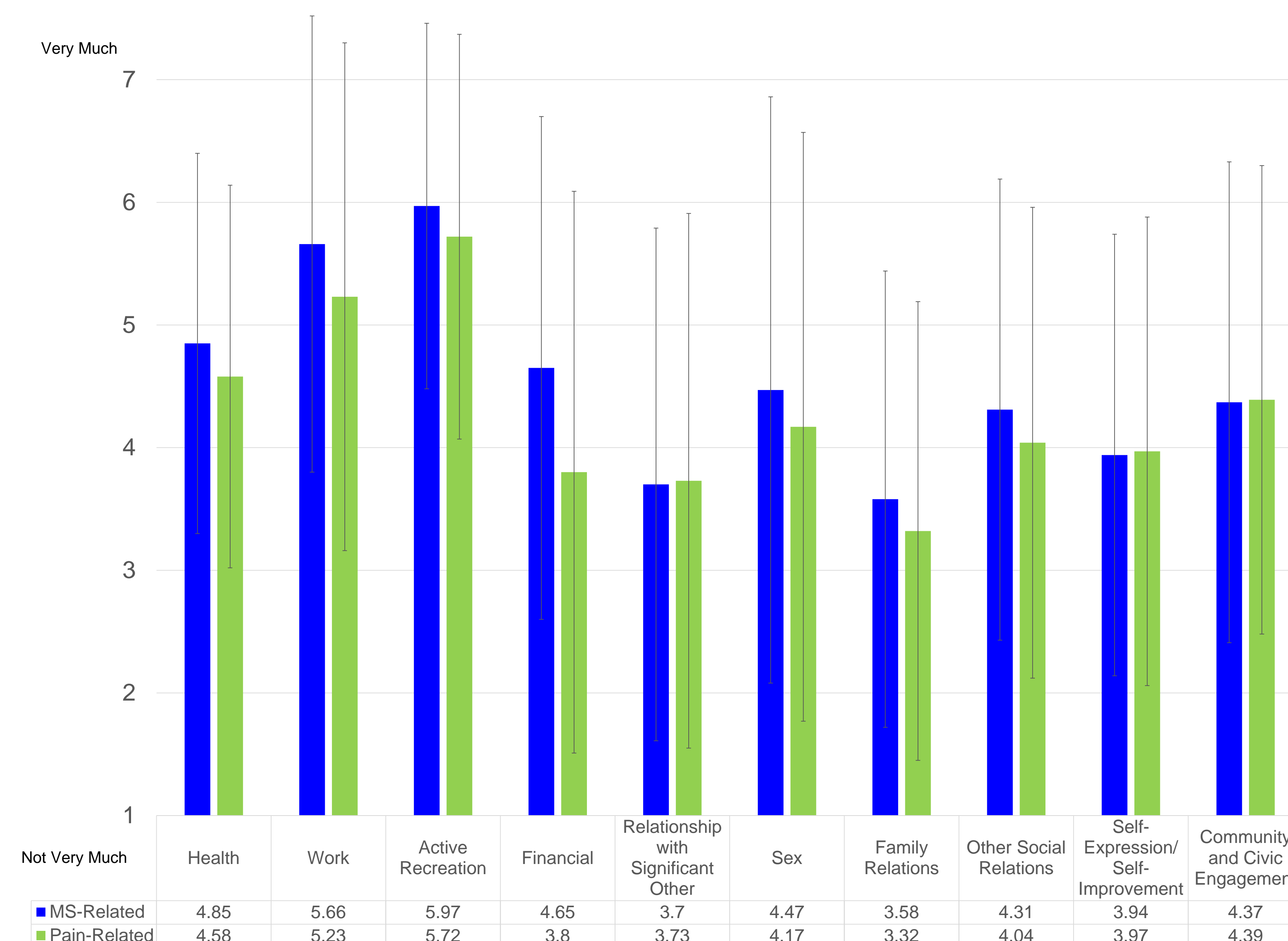


Figure 1: Item responses for the MS-related and pain-related versions of the modified IIRS.

		R ²	B(SE)	t
Step 1	Constant	0.22	21.58 (4.00)	
	PDDS		1.95 (0.53)	3.67**
	Pain Severity		4.63 (1.22)	3.81**
Step 2	Constant	0.69	11.31 (2.63)	
	PDDS		1.52 (0.34)	4.51**
	Pain Severity		-1.40 (0.87)	-1.62
	Modified Pain-Related IIRS		0.76 (0.05)	15.40**

Table 2: Multiple regression with overall MS-related IIRS as the outcome variable. ** p < .001

Results (Cont.)

Based on the factor loadings from the PCA, 10 of the original 13 items of the IIRS were retained in each version. The three items (Diet, Passive Recreation, and Religious Expression) were removed due to poor internal consistency in both versions of the IIRS. The final versions each demonstrated good internal consistency ($\alpha = 0.87$). In addition, the MS-related and pain-related IIRS were highly related to each other (ICC = 0.89).

Even after considering the level of disease severity, pain-related illness intrusiveness was a significant predictor of overall MS-related illness intrusiveness, accounting for 47% of the variance.

Conclusions

Like their overall MS, PwMS view their pain, which was on average moderate to severe, as a significant disruptive factor in their daily life. The areas they noted pain as being the most intrusive included engagement in active recreation, work, health, and community and civic engagement. Furthermore, perceived pain-related illness intrusiveness was a significant contributor to their experience of MS-related challenges, even after accounting for the level of disease severity. Future research may explore how intrusive other MS symptoms, such as fatigue, are in relation to pain among the totality of PwMS' experience.

References

- Stenager E, Knudsen L, Jensen K. Acute and chronic pain syndromes in multiple sclerosis. *Acta Neurol Scand.* 1991; 84: 197-200.
- Foley PL, et al. Prevalence and natural history of pain in adults with multiple sclerosis: systematic review and meta-analysis. *Pain.* 2013; 154: 632-642.
- Ehde DM, Osborne TL, Hanley MA, Jensen MP, Kraft GH. The scope and nature of pain in persons with multiple sclerosis. *Multiple Sclerosis.* 2006; 12: 629-638.
- Kerns RD, Kassirer M, Otis J. Pain in multiple sclerosis: a biopsychosocial perspective. *Journal of Rehabilitation Research and Development.* 2002; 225-232.
- Hadjimichael O, Kerns RD, Rizzo MA, Cutter G, Vollmer T. Persistent pain and uncomfortable sensations in persons with multiple sclerosis. *Pain.* 2007; 127: 35-41.
- Devins GM. Using the Illness Intrusiveness Ratings Scale to understand health-related quality of life in chronic disease. *Journal of Psychosomatic Research.* 2010; 68: 591-602.
- Snyder S, Foley FW, Farrell E, Beier M, Zemon V. Psychological and physical predictors of illness intrusiveness in patients with multiple sclerosis. *Journal of the Neurological Sciences.* 2013; 332: 41-44.
- Marrie RA, Cutter G, Tyry T, Hadjimichael O, Vollmer T. Validation of the NARCOMS registry: pain assessment. *Multiple Sclerosis Journal.* 2005; 11: 338-342.
- Hohol MJ, Orav EJ, Weiner HL. Disease steps in multiple sclerosis: a simple approach to evaluate disease progression. *Neurology.* 1995; 45: 251-255.
- Hohol MJ, Orav EJ, Weiner HL. Disease steps in multiple sclerosis: a longitudinal study comparing disease steps and EDSS to evaluate disease progression. *Multiple Sclerosis Journal.* 1999; 5: 349-354.
- Marrie RA, Goldman M. Validity of performance scales for disability assessment in multiple sclerosis. *Multiple Sclerosis.* 2007; 13: 1176-1182.
- Learmonth YC, Motl RW, Sandroff BM, Pula JH, Cadavid D. Validation of patient determined disease step scale scores in persons with multiple sclerosis. *BMC Neurology.* 2013; 13: 37.

Acknowledgements

The views expressed in this poster are those of the authors and do not necessarily reflect the position or policy of the Department of Veterans Affairs. This study was funded by a pilot grant from the Consortium of Multiple Sclerosis Centers (CMSC). The NARCOMS registry is supported in part by the CMSC and the Foundation of the CMSC.