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:
1) 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.

2) Pain from the Performance Scales: a valid self-report measure of pain severity in PwMS [8], ranging from 0 (normal) to 5 (total disabling pain).

3) 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

<table>
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<th>Table 1: Pain-related clinical characteristics</th>
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<tr>
<td><strong>Very Much</strong></td>
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<td><strong>Neck</strong></td>
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<tr>
<td><strong>Arms/Hands</strong></td>
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<tr>
<td><strong>Pain Duration</strong></td>
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<td><strong>Pain Severity</strong></td>
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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 (α = .87). In addition, the MS-related and pain-related IIRS were highly related to each other (ICC = .089).

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


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