The Impact of Pain on the Quality of Life of People with Multiple Sclerosis: A Community Survey

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The purpose of this study was to examine the impact of pain on functioning across multiple quality of life (QOL) domains among individuals with multiple sclerosis (MS). A total of 219 people were recruited from a regional MS society membership database to serve as the community-based study sample. All participants completed a questionnaire containing items about their demographic and clinical characteristics, validated measures of QOL and MS-related disability, and a question on whether or not they had experienced clinically significant pain in the preceding 2 weeks. Respondents who reported pain then completed an in-person structured pain interview assessing pain characteristics (intensity, quality, location, extent, and duration). Comparisons between participants with and without MS-related pain demonstrated that pain prevalence and intensity were strongly correlated with QOL: physical health, psychological health, level of independence, and global QOL were more likely to be impaired among people with MS when pain was present, and the extent of impairment was associated with the intensity of pain. Moreover, these relationships remained significant even after statistically controlling for multiple demographic and clinical covariates associated with self-reported QOL. These findings suggest that for people with MS, pain is an important source of distress and disability beyond that caused by neurologic impairments. Int J MS Care. 2009;11:127–136.

Perhaps one of the most neglected yet pervasive symptoms experienced by the person with multiple sclerosis (MS) is pain. Several recent cross-sectional studies have found that between 43% and 80% of people with MS experience pain.1–12 The pain is often chronic and due to both the disease process itself and the resulting physical disability, although characteristic acute pain conditions are also noted, which may be associated with the active inflammatory process that occurs during an MS exacerbation.1,5,10 People with MS often report multiple pain conditions, and most describe several different pain sites.4,10 A notable subset of the MS population reports pain as the worst symptom of the disease.1,9 These studies show that pain is a common problem for community-dwelling people with MS, and that a substantial subset of these individuals experience chronic pain conditions of moderate-to-severe intensity. Beyond these consistent findings, however, the extant literature is limited in size, scope, and methodology.

Among the most fundamental issues is the extent to which pain is problematic in a population that is already impaired by other physical disabilities. Little is known about the specific impact of pain on the quality of life (QOL) of people with MS. The scant literature that has examined the psychosocial and functional impact of MS-related pain indicates that people with MS and chronic pain may be at risk for poorer psychological functioning, reduced working capacity, impaired social roles and relationships, and poorer overall health compared with those without pain.3,4,9 Very little empirical research has been conducted on this problem, however, and many basic questions remain unanswered concerning the role that pain plays in the overall adjustment and QOL of people with MS.

One way to examine how pain might independently contribute to functional and psychosocial difficulties is to compare people with MS who do and who do not
experience chronic pain on measures of QOL. The few comparative studies available suggest that MS-related pain is associated with reduced QOL beyond the impact of the disease itself, although there are some notable inconsistencies. Svendsen et al. found that people with MS-related pain reported lower scores across all domains of the 36-item Short Form Health Status Survey (SF-36) compared with age- and gender-matched MS and healthy controls without pain. In contrast, Kalia and O’Connor found that pain prevalence matched MS and healthy controls without pain. In contrast, a recent Australian study found that community-dwelling individuals with MS with and without chronic pain differed only in terms of psychological well-being using the Assessment of Quality of Life scale. Among those with MS-related pain, greater pain severity (as categorized by the Graded Chronic Pain Scale) was associated with poorer independent living and total QOL domain scores.

It is clear that further research is needed that systematically examines the impact of pain across multiple domains of QOL functioning in people with MS, independent of the contribution of physical disability. Information on which QOL domains are most sensitive to disruption secondary to pain would help target treatment intervention efforts by health-care providers, as well as help further characterize the relationships among pain ratings, functional ability, and handicap.

Although several QOL studies of people with MS have included pain as an element of QOL, the lack of comparisons between those with and without pain and lack of control of demographic and clinical characteristics that may influence QOL limit the extent to which reduced QOL can be specifically attributed to pain. Therefore, the present study examined the impact of pain by comparing QOL scores in people with and without MS-related pain, after controlling for demographic and clinical covariates. We thereby attempted to more specifically distinguish the influence of pain, as opposed to a variety of other factors, on QOL.

**Methods**

**Design**

The prevalence, nature, and impact of pain on QOL among a community-based sample of people with MS were investigated using an ex post facto, cross-sectional design by postal questionnaire and subsequent pain interviews. The prevalence and characteristics of pain were not the focus of this study and are reported elsewhere. Briefly, 67.1% of the sample reported clinically significant pain during the 2 weeks preceding the survey. Among those with pain, three-quarters reported pain in three or more locations, with a mean (SD) of 4.0 (1.8) distinct pain sites. On the numerical rating scale of 0 to 10, mean (SD) pain intensity “on average” was 4.6 (2.1) and mean (SD) pain “at its worst” was 7.4 (2.1), with over half (55.2%) of the sample reporting a typical background pain of moderate-to-severe intensity (≥5 on the 0–10 scale).

**Participants**

Postal questionnaires were sent to a community-based sample of people with MS (N = 500) recruited from the Multiple Sclerosis Society of Queensland (MSSQ) membership database. Participant eligibility criteria were as follows: 1) chronological age of 18 years or older; 2) definite diagnosis of MS confirmed by the individual’s neurologist; 3) resident of Queensland within a 2-hour drive of Brisbane (to define a geographic area that the researcher could cover within the scope of the study); 4) fluency in English (to ensure the ability to read and complete the questionnaire battery and participate in the pain interview); and 5) ability to follow instructions and complete the self-report questionnaire correctly (to ensure that the respondent had adequate cognitive functioning). Systematic random sampling was applied to the mailing list based on sample size calculations after removal of individuals not meeting the eligibility criteria. In order to maintain confidentiality, the sampling and distribution of questionnaires were performed by MSSQ delegates under the instructions of the researcher.

Of the 500 postal questionnaires, 30 were returned because of incorrect addresses, 7 addressees were deceased, and an additional 7 people reported that they did not have access to the mailing list in order to maintain participant confidentiality.

**Data-Collection Procedures**

All participants completed a piloted, self-administered questionnaire booklet containing items about their demographic and clinical characteristics, validated meas-
ures of QOL and MS-related disability, and a question on whether or not they had experienced clinically significant pain in the preceding 2 weeks. Each questionnaire was accompanied by an introductory letter, a study information sheet, and a self-addressed postage-paid envelope. To increase the response rate, a reminder letter was sent 2 weeks after the distribution of questionnaires.

To identify a subgroup likely to have clinically significant pain, participants responded to the following question from the Brief Pain Inventory (BPI)37: “Throughout our lives, most of us have had pain from time to time (such as minor headaches, sprains, and toothaches). Have you had pain other than these everyday types of pain in the last 2 weeks?” Of the 147 participants who answered this question affirmatively, 105 were able to be contacted and completed an in-person, structured pain interview assessing pain characteristics (intensity, quality, location, extent, and duration), exacerbating and relieving factors, and pain-management techniques used. It was decided to conduct the pain interviews face-to-face to enhance the accuracy of measurement, as some instruments were designed to be administered by interview (e.g., the McGill Pain Questionnaire).18 In addition, this method was chosen to prevent missing data and to allow for clarification of responses.

The researcher negotiated, by telephone, a suitable time for the pain interview to take place. Most interviews were conducted at the respondents’ homes, although in four cases the interview took place at another mutually agreed-upon location. In all cases, the pain interview was conducted by the primary researcher in a structured interview format guided by the use of selected instruments. It focused on pain experienced in the 2 weeks preceding the interview in order to limit errors due to memory and cognitive impairments. Additionally, and in contrast to some past investigations,3,10,19,20 all types of self-reported pain were included (e.g., headache) on the grounds that such painful experiences may be related to MS either as a direct biological consequence or as a response to the stress of adapting to the disease. A4-size display cards were developed for each instrument requiring a choice among multiple answers to aid in the accuracy of responses. The average time interval from questionnaire to follow-up pain interview was 2 weeks (range, 1–3 weeks). Each interview lasted approximately 45 minutes. The study questionnaire and protocol were approved by the Queensland University of Technology Human Research Ethics Committee.

Measures

Demographics

Demographic items elicited information about gender, age, marital status, highest educational attainment, ethnicity, total annual household income, employment status and number of hours of paid employment per week, and residential location.

MS-Related Measures

The Guy’s Neurological Disability Scale (GNDS) is an MS-specific measure of disability that evaluates functioning across 12 domains: cognition, mood, vision, speech, swallowing, upper-limb function, mobility, bladder function, bowel function, fatigue, sexual function, and other problems.21 Each subscale is graded according to its severity and impact on the individual, from 0 (normal function) to 5 (total loss of function with maximal assistance required); the subscale scores are then summed to yield an overall disability score ranging from 0 (no disability) to 60 (maximum possible disability). The GNDS has demonstrated high internal consistency and test-retest reliability,21,22 and self-report scores have been shown to correlate with clinical neurologic examination using the Expanded Disability Status Scale (EDSS).23 In the current sample, the internal consistency of the GNDS was acceptable (α = .77). Two additional items assessed each respondent’s clinical course or type of MS and time since MS diagnosis.

Quality of Life

The Australian World Health Organization Quality of Life–100 instrument (WHOQOL-100) is a 100-item self-report, multidimensional QOL scale.24 All items are scored on one of five types of 5-point Likert response scales. From the WHOQOL-100, it is possible to derive a comprehensive QOL profile including 24 individual facet scores, 6 domain scores (physical health, psychological health, level of independence, social relationships, environmental health, and spirituality), and a global QOL and general health score. There is substantial evidence that the WHOQOL-100 possesses sound psychometric properties.25,26 After negatively scored items were recoded, the overall internal consistency of the instrument was found to be excellent (α = .95) in the current sample.

Pain Intensity

Eleven-point numerical rating scales (NRS-11; 0 = no pain, 10 = pain as bad as it could be) from the BPI were
used to assess pain intensity levels at present and over the preceding 2 weeks (worst, least, and on average). Each participant was read standardized instructions for the NRS-11 developed by Wilkie.27 The reliability and validity of numerical rating scales of pain intensity are well documented.28,29

Pain Quality

The McGill Pain Questionnaire (MPQ) measures the sensory, affective, and evaluative aspects of the pain experience, based on the gate-control theory.30 The psychometric properties of the MPQ have been well established,31,32 and the MPQ is often used as a “gold standard” against which to validate pain measures. It consists of 78 pain descriptors that are categorized into 20 groups according to the major dimensions of pain quality. Participants were read each list of descriptors and could select one word from each group if applicable to their pain. In order to prevent measurement error due to MS-related memory or recall problems, A4-size display cards were created for each group of words. Each of the 78 words has been assigned a rank value within its group. From these data, it is possible to derive a pain rating index (PRI) for the sensory, affective, evaluative, and miscellaneous subscales, as well as a total PRI.30

Pain Location and Extent

In order to measure the sensory distribution of pain, participants also completed a pain drawing consisting of outlines of the human body, front and back, on which to shade in their pain site(s). The pain drawing was enlarged (16 cm tall) to fit a single A4-size page. Margolis and colleagues33,34 have developed a scoring system in which the drawing is divided into 45 areas, each with a corresponding percentage value, in order to compute the total body area percentage in pain. This technique was applied using a clear plastic template to score percentage values. The test-retest and inter-rater reliability of data from these pain drawings have been established.33,34

Pain Duration

Along with other components of the pain interview, data were collected from each participant on the time since onset of MS-related pain.

Statistical Analyses

Data analysis was performed using the SPSS software program (SPSS, Chicago, IL). Descriptive statistics were calculated to profile sample characteristics and summarize data. To examine overall group differences in QOL functioning, a multivariate analysis of covariance (MANCOVA) was employed using pain group status as the between-subjects variable and the seven QOL domain scores as the dependent variables. Illness and demographic variables that were found to be associated with QOL at the bivariate level (P < .05) were entered as covariates (specifically age, employment status, socioeconomic status, MS subtype, and disability). Follow-up univariate analyses (ANCOVAs) were then conducted to identify specific QOL domains that were associated with the presence of pain even after controlling for illness and demographic variables. Pearson product moment correlations were also used to explore the relationships among specific pain characteristics (intensity, quality, extent, and duration) and QOL domains. An α level of .01 was considered statistically significant for all analyses.

Results

Sample Characteristics

The demographic characteristics of the study sample are summarized in Table 1. With a mean (SD) age of 51.1 (12.0) years (range, 24–82 years), respondents were predominantly Anglo-Australian women who were married, well educated, and living in an urban area. Approximately two-thirds of the sample indicated that they were not engaged in paid employment at the time of the investigation. Participants who were employed reported a median of 25 hours of work per week (range, 3–55 hours). Almost half of the sample (46.6%) reported an annual household income of less than A$25K, which approximates the second-lowest quintile of household income in Australia.35

Table 2 presents the clinical characteristics of the sample. The median time since MS diagnosis was 9 years (range, 0.5–60.0 years). Approximately half of the sample described a relapsing-remitting disease course. Respondents’ GNDS scores reflected a range of severity of MS-related disability within the sample, with an overall mean (SD) score of 18.5 (9.4) (range, 0–48). The mean (SD) number of MS-related symptoms reported on the GNDS was 7.2 (2.7) (range, 0–12), with respondents being most affected by fatigue, bladder dysfunction, mobility, and sexual problems. In comparison, speech, swallowing, and visual problems were reported to be relatively minor. In the last subscale (“other problems”), 62.1% of the sample identified a problem not previously addressed by the scale. Of these, the most frequent was spasticity (39%), followed by sensory symp-
Table 1. Demographic characteristics of the sample

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>179</td>
<td>81.7</td>
</tr>
<tr>
<td>Male</td>
<td>40</td>
<td>18.3</td>
</tr>
<tr>
<td>Marital statusa</td>
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<td></td>
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<tr>
<td>Single</td>
<td>46</td>
<td>21.2</td>
</tr>
<tr>
<td>Married/de facto</td>
<td>136</td>
<td>62.7</td>
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<tr>
<td>Separated/widowed</td>
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<td>16.1</td>
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<tr>
<td>Educational levelb</td>
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<td></td>
</tr>
<tr>
<td>Less than high school graduate</td>
<td>22</td>
<td>10.1</td>
</tr>
<tr>
<td>High school graduate</td>
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<td>49.5</td>
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<tr>
<td>Apprenticeship</td>
<td>18</td>
<td>8.3</td>
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<tr>
<td>University or college</td>
<td>53</td>
<td>24.3</td>
</tr>
<tr>
<td>Postgraduate</td>
<td>17</td>
<td>7.8</td>
</tr>
<tr>
<td>Ethnicity</td>
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<td></td>
</tr>
<tr>
<td>Anglo-Australian</td>
<td>205</td>
<td>93.6</td>
</tr>
<tr>
<td>European</td>
<td>9</td>
<td>4.1</td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>2.3</td>
</tr>
<tr>
<td>Annual household income (A$)c</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;$10,000</td>
<td>26</td>
<td>13.5</td>
</tr>
<tr>
<td>$10,000 to 24,999</td>
<td>64</td>
<td>33.2</td>
</tr>
<tr>
<td>$25,000 to 49,999</td>
<td>55</td>
<td>28.5</td>
</tr>
<tr>
<td>≥$50,000</td>
<td>48</td>
<td>24.9</td>
</tr>
<tr>
<td>Employment statusa</td>
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<td></td>
</tr>
<tr>
<td>Paid employment</td>
<td>73</td>
<td>33.6</td>
</tr>
<tr>
<td>Not in paid employment</td>
<td>144</td>
<td>66.4</td>
</tr>
<tr>
<td>Locationd</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>191</td>
<td>88.4</td>
</tr>
<tr>
<td>Suburban</td>
<td>15</td>
<td>6.9</td>
</tr>
<tr>
<td>Rural</td>
<td>10</td>
<td>4.6</td>
</tr>
</tbody>
</table>

*a*Data missing for 2 participants.  
*b*Data missing for 1 participant.  
*c*Data missing for 26 participants.  
*d*Data missing for 3 participants.

Comparisons Between Persons With and Without MS-Related Pain

Table 3 presents a summary of mean QOL domain scores for participants with and without MS-related pain. A one-way MANCOVA indicated a statistically significant difference between groups on the combined dependent variables (Wilks $\Lambda = 0.77$, $F_{1,137} = 5.2$, $P < .001$). When the results for the dependent variables were considered separately, even after controlling for illness and demographic variables, the presence of pain was statistically associated with lower physical health ($F_{1,206} = 32.3$, $P < .001$), psychological health ($F_{1,199} = 7.1$, $P = .009$), level of independence ($F_{1,200} = 7.8$, $P = .006$), and global QOL ($F_{1,215} = 7.2$, $P = .008$). The effect sizes (using the average standard deviations between groups) for these significant group differences ranged from 0.42 to 1.05. Significant group differences were not, however, observed for social ($F_{1,172} = 0.5$, $P = .46$), environmental ($F_{1,180} = 2.3$, $P = .13$), or spiritual ($F_{1,210} = 0.1$, $P = .91$) QOL domains.

Correlations Among Pain Characteristics and QOL

Correlations among pain measures and QOL domain scores are presented in Table 4. The pattern of results shows generally that pain is negatively associated with broad and important areas of well-being and functioning.

Average pain intensity as measured by the NRS-11 was found to have the strongest association with QOL across multiple facets and domains. Moderate negative correlations were observed between pain intensity scores and physical ($r = -0.43$, $P < .001$), psychological ($r = -0.27$, $P = .008$), independence ($r = -0.47$, $P < .001$), environmental ($r = -0.31$, $P = .003$), and global ($r = -0.35$, $P < .001$) QOL domains. With increasing average pain intensity, participants reported poorer QOL related to pain interference ($r = -0.61$, $P < .001$), positive affect ($r = -0.25$, $P = .01$), mobility ($r = -0.33$, $P = .001$), activities of daily living ($r = -0.42$, $P < .001$), dependence on medications ($r = -0.40$, $P < .001$), work-
Table 3. Post hoc ANCOVAs of QOL domain means by pain group

<table>
<thead>
<tr>
<th>Dependent variable</th>
<th>Pain group</th>
<th>No pain group</th>
<th>Effect size (d)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health</td>
<td>11.2 (0.2)</td>
<td>14.1 (0.4)</td>
<td>1.05</td>
</tr>
<tr>
<td>Psychological health</td>
<td>13.8 (0.2)</td>
<td>15.0 (0.4)</td>
<td>0.43</td>
</tr>
<tr>
<td>Level of independence</td>
<td>11.9 (0.3)</td>
<td>13.5 (0.5)</td>
<td>0.42</td>
</tr>
<tr>
<td>Social relationships</td>
<td>13.9 (0.3)</td>
<td>14.3 (0.5)</td>
<td>0.1</td>
</tr>
<tr>
<td>Environmental health</td>
<td>14.6 (0.2)</td>
<td>15.1 (0.3)</td>
<td>0.2</td>
</tr>
<tr>
<td>Spirituality</td>
<td>13.1 (0.4)</td>
<td>13.0 (0.8)</td>
<td>0.02</td>
</tr>
<tr>
<td>Overall QOL and general health</td>
<td>12.8 (0.3)</td>
<td>14.6 (0.6)</td>
<td>0.43</td>
</tr>
</tbody>
</table>

Abbreviations: ANCOVA, analysis of covariance; QOL, quality of life; SE, standard error.
Note: Means adjusted for participants’ age, employment status, socioeconomic status, MS type, and disability.

Table 4. Pearson correlations between pain measures and QOL domain scores

<table>
<thead>
<tr>
<th>Domain</th>
<th>NRS pain intensity</th>
<th>MPQ PRI-total</th>
<th>Number of sites</th>
<th>Pain extent</th>
<th>Pain duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health</td>
<td>−0.43a</td>
<td>−0.40a</td>
<td>−0.25</td>
<td>−0.21</td>
<td>0.06</td>
</tr>
<tr>
<td>Psychological health</td>
<td>−0.27b</td>
<td>−0.17</td>
<td>−0.13</td>
<td>−0.08</td>
<td>0.04</td>
</tr>
<tr>
<td>Level of independence</td>
<td>−0.47a</td>
<td>−0.27b</td>
<td>−0.32b</td>
<td>−0.27b</td>
<td>0.04</td>
</tr>
<tr>
<td>Social relationships</td>
<td>−0.25</td>
<td>−0.21</td>
<td>−0.19</td>
<td>−0.16</td>
<td>−0.02</td>
</tr>
<tr>
<td>Environmental health</td>
<td>−0.31b</td>
<td>−0.20</td>
<td>−0.20</td>
<td>−0.08</td>
<td>0.01</td>
</tr>
<tr>
<td>Spirituality</td>
<td>−0.13</td>
<td>0.04</td>
<td>0.07</td>
<td>0.02</td>
<td>0.14</td>
</tr>
<tr>
<td>Global QOL</td>
<td>−0.35a</td>
<td>−0.25</td>
<td>−0.24</td>
<td>−0.21</td>
<td>−0.06</td>
</tr>
</tbody>
</table>

Abbreviations: MPQ, McGill Pain Questionnaire; NRS, numerical rating scale; PRI, pain rating index; QOL, quality of life.

Discussion

Consistent with previous studies, overall the results revealed pain to be of great importance in participants’ subjective assessment of QOL, and its presence or absence was found to influence the way people with MS responded to questions about many aspects of their QOL. Between-subjects analyses revealed that individuals with pain reported significantly poorer QOL pertaining to physical health, psychological health, and level of independence than those without pain. Moreover, individuals with pain had significantly lower global perceptions of general health and overall QOL than those without pain. These associations remained significant even after statistically controlling for the influence of important demographic and disease-related variables (ie, age, employment status, socioeconomic status, MS type, and GNDS score). Because numerous demographic and clinical characteristics were either specifically controlled for or not significantly different between groups, it seems reasonable to attribute differences in QOL functioning primarily to the influence of pain.

Consistent with the general pain literature, it appears that the physical domain is very important in discriminating between the QOL of participants with and without MS-related pain, with each facet of this domain showing significant differences. Importantly, the presence of pain was associated with greater fatigue and sleep disturbance, both of which are prominent problems among chronic pain populations. Only one study of MS-related pain has included a standardized fatigue scale, from which the investigators found that the presence of fatigue was associated with higher pain intensity, although others have noted a similar trend. Another study showed that greater fatigue was associated with increased pain-related interference with daily activities in a community-based MS sample.
data suggest an association between MS-related pain and fatigue that is likely reciprocal and additive in nature. Difficulties with sleeping may be particularly problematic for people with chronic pain. Studies of other chronic pain populations have found that sleep disturbance is correlated with higher pain intensity, greater levels of depression and anxiety, and reduced activity levels. Warnell found that, among a sample of MS outpatients, 44% reported difficulties getting to sleep, staying asleep, or both because of pain. Similarly, Stanton et al. found that pain and discomfort, anxiety, and nocturia were the most common causes of insomnia reported by people with MS. Taken together, these findings suggest the importance of screening for sleep disturbance among people with MS-related pain with the provision of strategies to promote restorative sleep when indicated.

The finding that the pain group reported poorer levels of independence, encompassing facets such as mobility, activities of daily living, dependence on medications, and working capacity, is consistent with previous studies showing substantial pain-related interference with daily activities, work, relationships, and social roles among people with MS. It suggests that pain may further compromise activity and participation in people with MS or, alternatively, that lower levels of independence contribute to pain and discomfort. There is some support for the former hypothesis, however, in that there was a significant association between pain and level of independence even after controlling for demographic and clinical covariates, including MS-related disability.

Consistent with previous studies, the presence of pain was also associated with lower levels of psychological functioning in people with MS. This finding is not surprising given the high prevalence of concomitant emotional distress among chronic pain populations, including anxiety, depression, and anger. Cognitive-behavioral models suggest that it is the way one thinks about pain or behaves in response to pain that causes poorer psychological health. From a behavioral perspective, the physical and functional limitations (mobility, leisure activities) reported by the pain group may further prevent activities that are intrinsically rewarding, leading to decreased positive reinforcement, reduced activities, and ultimately depressive symptomatology. Similarly, from a learned helplessness perspective, the low perceptions of control over pain observed among study participants may lead to decreased motivation to cope with pain and poorer psychological health.

In the Archibald et al. study, individuals with MS acknowledging pain reported poorer overall psychological health than those without pain, as measured by the Mental Health Inventory. Notably, mean scores of the pain group fell in the lowest quartile of scores for a normative sample. Similarly, Ehde et al. found that among people with MS, depression symptom severity was significantly higher among individuals with chronic pain than among those without chronic pain. Moreover, within the pain group, higher depression scores were associated with greater pain interference with daily activities. Together, these data suggest that pain is a significant correlate of psychological health among people with MS.

Interestingly, in the current study, the presence of pain was found to be unrelated to social, environmental, and spiritual QOL domains. The finding that the social domain was unrelated to pain status is surprising given that while over half (55.2%) of the pain group experienced moderate-to-severe pain, often on a daily basis, they report QOL similar to that of those without pain in terms of social support, personal relationships, and sexual activity. Schwartz et al. found a similar pattern of results among people with cerebral palsy, such that despite the typically moderate-to-severe pain experienced by their sample, participants rated its interference with recreational, social, and family activities as only minor. Furthermore, 65% of those acknowledging pain reported no pain-related interference with social activities in the 3 months preceding the study. The authors speculated that the relatively minimal impact of pain in this sample may reflect a floor effect resulting from the already low level of activity typical of people with cerebral palsy. Similarly, it may be that the independent impact of pain on social functioning perceived by people with MS is small in the context of already diminished social relationships, or in comparison with other MS-related problems such as fatigue or incontinence.

The finding that QOL relating to spirituality, religion, and personal beliefs is largely detached from pain also replicates previous research with the WHOQOL-100 among samples of heterogeneous pain patients. Skevington hypothesized that the disconnection observed between pain and spirituality may explain some of the comfort derived by those with spiritual, religious, or personal beliefs at times of suffering and that in this way spiritual beliefs may provide a strategy for the self-management of pain.

Beyond conclusions regarding the impact of pain on QOL functioning in terms of its global presence or
absence among the sample, further correlational analyses were undertaken to explore the relationships between specific pain characteristics (i.e., intensity, quality, extent, and duration) and QOL domains. As expected, average pain intensity was moderately and inversely associated with a number of QOL domains, the strongest of these being level of independence, physical health, and global QOL. These data suggest that as pain intensity increases, it is functional capacity that is most affected in people with MS, especially mobility, activities of daily living, working capacity, and dependence on medications and treatments. Even when level of MS-related disability is controlled for, partial correlations show significant associations between pain intensity and physical (\( r = -0.30, P = .002 \)) and independence (\( r = -0.33, P = .001 \)) domains. It is possible that transient increases in pain result in decreased activity and impaired functioning among individuals with MS. Furthermore, reduced physical health and independence related to pain, activity avoidance, and decreased tolerance of pain mutually reinforce one another, thereby creating a maladaptive cycle resulting in deconditioning and unnecessary functional limitations.\(^49\) Weaker, yet significant, negative correlations were also observed between average pain intensity and psychological and environmental domains. These findings have obvious clinical implications, underscoring the importance of effectively treating MS-related pain.

Interestingly, of the three dimensions or qualities of pain defined by the MPQ, global QOL was significantly associated with affective and evaluative but not with sensory pain ratings. Moreover, PRI-affective scores were negatively correlated with five of the six QOL domains, the exception being spirituality. These findings replicate those of Skevington,\(^25\) showing that it is the emotional component of pain that most affects QOL (or vice versa) when pain is present. Whereas pain intensity reflects the overall magnitude of the pain, pain affect can be viewed as the distress caused by pain.\(^29\) These conceptually distinct yet interrelated aspects of pain show differential relationships with QOL among people with MS. While pain intensity correlates strongly with physical and functional well-being, pain-related distress has more broad-ranging effects on QOL functioning, including psychosocial domains. These findings suggest that clinicians might gainfully assess global pain intensity in conjunction with the emotional aspects of pain in order to tap the most relevant dimensions of the pain experience.

In accordance with previous research,\(^50,51\) the extent of pain also had important implications for QOL, with both number of pain locations and percentage of body area in pain demonstrating significant negative associations with level of independence. Hoitsma et al.\(^52\) observed similar relationships between number of pain categories and WHOQOL-100 scores in a Dutch sarcoidosis population. They found that a greater number of pain types was negatively correlated with all domains except spirituality, with the strongest correlations being with level of independence and physical health. Thus, it appears that widespread pain impairs QOL more than regional pain does.

The finding that the duration of pain showed poor associations with QOL prompts some reflection. No significant associations were found between duration of pain and QOL facets and domains; the highest correlation coefficient was 0.14. This finding suggests that the deterioration in QOL observed among those reporting the presence of pain may occur quickly and is not necessarily a linear function of the length of time in pain. Thus, QOL may best be improved for persons with MS-related pain through early intervention and management.

**Limitations**

Despite efforts to correct several methodological shortcomings of previous research, the findings of this study must be interpreted in the context of a number of limitations. Foremost among these is the cross-sectional research design, which precludes the drawing of any causal or directional conclusions from these data. It is unclear from these findings to what extent QOL is driven by, versus a determinant of, the pain experience of people with MS. In addition, this relationship may be confounded by a “third” variable not controlled for in this study. Questions concerning cause-and-effect relationships between pain and QOL clearly warrant further exploration through longitudinal and experimental research designs.

A second limitation relates to the exclusive reliance on self-report measures. While the inherent subjectivity of constructs such as pain and QOL necessitates self-report data, it does raise the question of response bias. Furthermore, since both independent and outcome variables were assessed by self-report, some of the associations found between study measures may be due in part to shared method variance. Future studies are needed to
replicate these findings using more objective measures where possible.

In addition, as is the case with all mail surveys, the conditions under which the questionnaires were completed were uncontrolled, and this may have affected the study findings. It is likely that some participants did not complete the questionnaire independently but were assisted by family members or caregivers. This is a particularly salient issue for this population because impaired manual dexterity may pose difficulties in completing written questionnaires. In these cases, there may be some degree of response bias, particularly for questions concerning personal or sensitive issues such as family relationships and support or sexual activity.

Third, since a large number of statistical tests were performed, some significant associations are likely to be due to chance factors and would therefore not generalize to other samples. It is argued, however, that this kind of exploratory approach is justified at this relatively early stage in understanding the pain experience of people with MS in the community. It was of interest to explore potential interrelationships among variables, viewing the potential negative consequences of a type II error as more serious than those associated with a type I error. Thus, further research is needed to determine which of the associations found in the current study can be replicated.

Fourth, although a strength of this study is the community-based sample, the generalizability of these findings may be affected by several factors. As the sample was restricted to members of the Queensland MS Society, it may have been somewhat biased toward more positively adjusted individuals with greater access to resources. These findings were also limited to adults with no or mild cognitive impairment. Despite the methodological challenges they would present, studies including individuals with moderate-to-severe MS-related cognitive impairment are also needed. Furthermore, because women predominated in the sample, the findings may be most applicable to women. Studies involving greater numbers of men with MS are needed to replicate the gender differences found in this study.

**Conclusion**

Overall, the findings from the present study suggest that pain has a substantial adverse impact on QOL and functional ability among people with MS. Pain prevalence and intensity were found to be strongly correlated with QOL: physical health, psychological health, level of independence, and global QOL were more likely to be impaired among people with MS when pain was present, and the extent of impairment was associated with the intensity of pain. These relationships remained significant even after statistically controlling for the influence of important demographic and clinical covariates. Thus, these findings suggest that for people with MS, pain is an important source of distress and disability beyond that caused by neurologic impairments.

These data also lead to the hypothesis that recognition and effective treatment of pain would improve the QOL of people with MS, regardless of their level of neurologic disability. There is a pressing need for research to determine the effectiveness of pain treatments in people with MS and the impact of decreases in pain on measures of disability and QOL functioning. Although the current findings suggest that effective pain management would improve QOL, conclusive evidence regarding the impact of pain treatment awaits controlled intervention research. Nevertheless, the findings from this study extend our understanding of the relationships between pain and QOL among people with MS in the community and underscore the clinical significance of pain in this population.

**Practice Points**

- MS-related pain is independently associated with quality of life.
- Recognition and effective treatment of MS-related pain is likely to lead to more effective rehabilitation and improved quality of life, regardless of level of neurologic disability.
- An adequate clinical assessment must go beyond pain characteristics and physical mechanisms to determine how MS-related pain interferes with physical and psychosocial functioning.
- Successful treatment of MS-related pain must address the impact of pain on the individual’s quality of life.

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