



**Queensland University of Technology**  
Brisbane Australia

This may be the author's version of a work that was submitted/accepted for publication in the following source:

[Douglas, Clint](#), Wollin, Judy, & [Windsor, Carol](#)  
(2008)

Illness and demographic correlates of chronic pain among a community-based sample of people with multiple sclerosis.

*Archives of Physical Medicine and Rehabilitation*, 89(10), pp. 1923-1932.

This file was downloaded from: <https://eprints.qut.edu.au/224747/>

#### © Consult author(s) regarding copyright matters

This work is covered by copyright. Unless the document is being made available under a Creative Commons Licence, you must assume that re-use is limited to personal use and that permission from the copyright owner must be obtained for all other uses. If the document is available under a Creative Commons License (or other specified license) then refer to the Licence for details of permitted re-use. It is a condition of access that users recognise and abide by the legal requirements associated with these rights. If you believe that this work infringes copyright please provide details by email to [qut.copyright@qut.edu.au](mailto:qut.copyright@qut.edu.au)

**Notice:** *Please note that this document may not be the Version of Record (i.e. published version) of the work. Author manuscript versions (as Submitted for peer review or as Accepted for publication after peer review) can be identified by an absence of publisher branding and/or typeset appearance. If there is any doubt, please refer to the published source.*

<https://doi.org/10.1016/j.apmr.2008.03.022>



Douglas, Clint and Wollin, Judy A. and Windsor, Carol A. (2008) Illness and Demographic Correlates of Chronic Pain Among a Community-Based Sample of People with Multiple Sclerosis. *Archives of Physical Medicine and Rehabilitation*.

© Copyright 2008 Elsevier

## **Illness and Demographic Correlates of Chronic Pain Among a Community-Based Sample of People with Multiple Sclerosis**

**Objective:** To investigate the prevalence, nature, and correlates of pain among a community-based sample of people with multiple sclerosis (MS).

**Design:** Cross-sectional survey and structured pain interview.

**Setting:** Community.

**Participants:** Two hundred and nineteen people with MS recruited via systematic sampling from a randomly ordered MS society membership database.

**Intervention:** Not applicable.

**Main Outcome Measures:** Pain presence or absence, pain intensity (numerical rating scales), pain quality (McGill Pain Questionnaire), pain location(s) and extent (pain drawing), pain duration and frequency, provoking and relieving pain factors, and pain management techniques.

**Results:** Pain was found to be common with some 67.1% of the sample reporting pain during the two weeks preceding the study. Comprehensive pain assessment revealed that a substantial subset of these individuals experience chronic pain conditions characterised by moderate-to-severe pain intensity. Among those with pain, three-quarters reported pain in 3 or more locations, with participants reporting an average of 4.0 ( $SD = 1.8$ ) distinct pain sites. Women and individuals with more severe MS-related disability were significantly more likely to report both the presence of pain and greater pain intensity. In contrast, being in a married/defacto relationship and longer time since MS diagnosis were significantly associated with lower pain intensity.

**Conclusion:** Given the high prevalence and nature of pain experienced by people with MS, health care providers need to approach pain with a similar priority given to

other MS-related problems such as mobility and functional independence. Women and individuals with more severe MS-related disability appear to be at particular risk for significant pain problems and therefore these groups warrant particular attention, such that routine clinical assessment should trigger routine pain assessment.

**Key Words:** Multiple sclerosis; Pain; Prevalence.

## **Illness and Demographic Correlates of Chronic Pain Among a Community-Based Sample of People with Multiple Sclerosis**

Although an extensive literature exists on the nature of and treatments for chronic pain as a primary condition, little is known about the impact of chronic pain as a secondary problem in people who already have a disability such as multiple sclerosis (MS).<sup>1, 2</sup> Despite the paucity of literature on MS-related pain, it is evident that pain is a common problem over the course of the disease. Estimates of the prevalence of pain in MS range from as low as 29%<sup>3</sup>, to as high as 90%<sup>4</sup>, with recent studies indicating that approximately two-thirds experience pain.<sup>5-7</sup> Thus, it is clear that pain affects a considerable proportion of the MS population. Beyond this consistent finding however, the extant literature is extremely limited in size, scope and methodology.

Thus far, evidence concerning the relationship between MS-related pain and illness and demographic variables is inconclusive and contradictory. In several cross-sectional studies, the presence and intensity of pain was found to be independent of disease duration, age of disease onset, MS type and level of disability.<sup>5-10</sup> In contrast, other investigators have found significant associations between the presence of pain and greater MS-related disability.<sup>11-14</sup> Gender differences were demonstrated in three studies, with women reporting both increased frequency and intensity of pain.<sup>8, 15, 16</sup> Yet, this finding was not replicated by others.<sup>7, 9, 10, 13, 14, 17</sup> Similarly, although the prevalence of pain has been found to increase with age in several studies<sup>3, 6, 8, 15, 17</sup>, this finding is not always supported.<sup>7, 9, 10, 14</sup>

General conclusions have been limited by several factors. First, the majority of research is based on small, convenience samples presenting to MS specific clinics or hospital departments and therefore findings may not generalise to the wider MS population. Second, there is no consensus within the literature about the classification or definitions of MS-related pain. For example, researchers have adopted different time frames for classifying specific types of pain. Further, the arbitrary exclusion of various pain conditions (e.g., headaches, optic neuritis) in some studies makes comparisons difficult. Third, idiosyncratic methods of pain measurement are common and most researchers failed to use standardised pain assessment tools routinely used in the pain literature. Most authors devised specific questionnaires, the particular content or psychometric properties of which are not routinely reported. Lastly, the level of statistical analysis was most often at the univariate or bivariate level. Few researchers utilised multivariable modelling to examine complex relationships and to control for likely confounding variables.

In summary, MS-related pain is a significant problem which has historically been underinvestigated and is currently poorly understood. The vast majority of the published literature consists of prevalence studies, descriptive research and clinical reports. Where available, empirical data are often limited by methodological and analytical problems such that substantive conclusions about the scope and nature of MS-related pain remain unclear. To redress these deficiencies and provide a valid and detailed assessment of MS-related pain in the community, the following research questions were addressed in the present study:

- (1) What is the prevalence and nature of pain experienced by people with MS?

- (2) What illness and demographic variables are associated with the presence and intensity of MS-related pain?

## **METHODS**

### ***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. There is estimated to be approximately 3000 people with MS in Queensland, 2139 being registered clients of the MSSQ. Of these, approximately 1200 people met the eligibility criteria of the study. Systematic random sampling was performed such that from a randomized membership roll, every third person was selected to a total of 500. Participant eligibility criteria were (1) chronological age 18 years or older, (2) definite diagnosis of MS confirmed by their neurologist, (3) residents of Queensland within two hours drive from Brisbane City, to define a geographical area able to be covered by the researcher within the scope of the study, (4) fluency of English and therefore able to read and complete the questionnaire battery and participate in the pain interview, and (5) able to follow instructions and complete the self-report questionnaire correctly, to ensure respondents had adequate cognitive functioning. In order to maintain confidentiality, the sampling and distribution of questionnaires were undertaken by MSSQ delegates under the instructions of the researcher.

## ***Procedures***

All participants completed a piloted, self-administered questionnaire booklet containing questions about their demographic and clinical characteristics, validated measures of quality of life and MS-related disability and a question on whether or not they had experienced clinically significant pain in the previous two weeks. It took respondents approximately one hour to complete. Each questionnaire was accompanied by an introductory letter, study information sheet and a self-addressed reply-paid envelope. Request for respondents' contact details including telephone number and home address were included in the questionnaire, along with a single question determining whether they would consent to a follow-up interview. To increase the response rate, a reminder letter was sent two 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<sup>18</sup> (BPI): “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 two weeks?” Participants who answered this question affirmatively were then contacted and asked to complete an in-person, structured pain interview assessing pain characteristics (viz. intensity, quality, location, extent and duration), exacerbating and relieving factors, and pain management techniques employed. It was decided to administer the pain interviews face-to-face to enhance the accuracy of measurement as some instruments were designed to be applied by interview (e.g., the McGill Pain Questionnaire<sup>19</sup>). 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 administered at the respondents' residences, although in four cases the interview took place at another mutually agreed location. The pain interview was administered in all cases by the primary researcher (CD) in a structured interview format guided by the use of selected instruments. It focused on pain experienced in the two weeks preceding the interview in order to limit errors due to memory and cognitive impairments. Additionally and in contrast to some past investigations<sup>3, 10, 15, 17</sup>, 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-sized show cards were developed for each instrument requiring the choice of multiple answers to aid in the accuracy of responses. Average time interval from questionnaire to follow-up pain interview was two weeks (range = 1 – 3 weeks). Each interview took approximately 45 minutes in duration. The study questionnaire and protocol were approved by the Queensland University of Technology Human Research Ethics Committee.

### ***Study Measures***

The questionnaire consisted of 18 pages and was divided into three principal sections including demographic items, perceived quality of life, clinical characteristics and MS-related disability. Only the first and third sections were relevant to the purpose of this study and are discussed below.

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

**MS-related measures.** The Guy's Neurological Disability Scale<sup>20</sup> (GNDS) is a MS-specific measure of disability that evaluates functioning across 12 domains including cognition, mood, vision, speech, swallowing, upper limb function, mobility, bladder function, bowel function, fatigue, sexual function and other problems. 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), which are then summed to give an overall disability score ranging between 0 (no disability) and 60 (maximum possible disability). The GNDS has demonstrated high internal consistency and test-retest reliability<sup>20, 21</sup>, and self-report scores have been shown to correlate with clinical neurologic examination using the Expanded Disability Status Scale (EDSS).<sup>22</sup> In the current sample, the internal consistency of the GNDS was acceptable ( $\alpha = .77$ ). Two additional items assessed respondents' clinical course or type of MS, and time since their MS diagnosis.

### ***Pain Measures***

The follow-up pain interview included several standardised pain measures described below.

**Pain intensity.** 11-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, worst, least and on average over the previous two weeks. Each participant was read standardised instructions for the NRS-11 developed by Wilkie<sup>23</sup>. The reliability and validity of numerical rating scales of pain intensity is well documented.<sup>24, 25</sup>

***Pain quality.*** The McGill Pain Questionnaire<sup>26</sup> (MPQ) measures the sensory, affective and evaluative aspects of the pain experience, based on the gate-control theory. The psychometric properties of the MPQ have been well established<sup>27, 28</sup> and the MPQ is often utilised as a ‘gold standard’ against which to validate pain measures. It consists of 78 pain descriptors which are categorised into 20 groups evaluating 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-sized show cards were created for each group of words. Each of the 78 words are assigned a rank value within its group and 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.<sup>26</sup>

***Pain location and extent.*** In order to measure the sensory distribution of pain, participants also completed a pain drawing which comprised outlines of the human body, front and back, on which to shade in their pain site(s). The pain drawing was enlarged (16cm tall) to fit a single A4 page. Margolis and colleagues<sup>29, 30</sup> have developed a scoring system where 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.<sup>29, 30</sup>

***Other pain-related variables.*** Along with other components of the pain interview, data was collected from each participant about the time since onset of MS-related pain, exacerbating and relieving pain factors, and current pain management techniques employed. Data were transcribed verbatim in list format and later divided into conceptual categories for analysis.

### ***Statistical Analyses***

Data analysis was undertaken by means of the Statistical Package for the Social Sciences (SPSS, Chicago, USA). There was generally minimal missing data (<5% at the item level) across all measures, except for items concerning sexual activity in the GNDS where it reached 12%. Exploration of the pattern of missing data revealed that respondents and nonrespondents did not differ in terms of background characteristics. Since the extent of missing data was not extensive, sample mean substitution was utilized for subsequent analyses.

Descriptive statistics (means, standard deviations, ranges, frequency counts, percentages) were calculated to profile sample characteristics and to determine pain prevalence and characteristics. At the bivariate level, contingency chi-square tests, independent *t*-tests and Pearson product-moment correlations were used to evaluate the associations among illness and demographic variables and pain measures. Stepwise multiple logistic regression and multiple linear regression analyses were then undertaken to determine the most parsimonious set of variables that predicted the

presence/absence of pain and pain intensity respectively. For all analyses an alpha level of  $< .05$  (two-tailed) was considered statistically significant.

## RESULTS

### *Response Rate*

Of the 500 postal questionnaires, 30 were returned due to incorrect addresses, 7 addressees were deceased and a further 7 reported that they did not meet the eligibility criteria. Therefore, of the possible 456 questionnaires distributed, 219 were returned giving an overall response rate of 48%. Information on nonrespondents was not available since the researcher, in order to maintain participant confidentiality, did not have access to the mailing list.

### *Sample Characteristics*

The demographic characteristics of the sample are summarised in Table 1. With a mean age of 51.1 years ( $SD = 12.0$ , range = 24 – 82), 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 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). Almost half of the sample (46.6%) reported an annual household income of up to AUD\$25K per annum, which approximates the second lowest quintile of household income in Australia.<sup>31</sup>

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 score of 18.5 ( $SD = 9.4$ , range = 0 – 48). The mean number of MS-related symptoms reported on the GNDS was 7.2 ( $SD = 2.7$ , range = 0 – 12) with respondents being most affected by fatigue, bladder dysfunction, mobility and sexual problems. Speech, swallowing and visual disability, in comparison, were reported to be relatively minor. In the last subscale (i.e., '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 symptoms (i.e., numbness, paresthesias) (33%) and dizziness and vertigo (28%).

### ***What is the Prevalence and Nature of Pain Experienced by People with MS?***

Of the 219 respondents, 147 reported clinically significant pain during the two weeks preceding the study yielding a point prevalence of 67.1% (95% CI = 60.9% to 73.3%). Of those reporting pain, complete pain interview data were available for 105 respondents. Reasons for respondents not being administered the pain interview included: no or incorrect contact details given (2); respondents now lived greater than two hours drive from Brisbane Central Business District (3); respondents were unavailable or not able to be contacted (20); or they did not consent to the pain interview (as indicated on the questionnaire, 17). The following descriptive data are based on this sub-sample of 105 respondents reporting a current pain problem. When compared across background characteristics, participants who completed the pain interview were similar to those lost to follow-up except for age, with respondents slightly older (mean  $\pm SD$ , 52.3 years  $\pm 11.3$ ) compared to nonrespondents (mean, 48.1 years  $\pm 11.4$ ),  $t(139) = 2.1$ ,  $p = 0.037$ .

Participants reported a mean pain intensity ‘on average’ of 4.6 ( $SD = 2.1$ , range = 0 – 10) for the two weeks preceding the interview. Mean scores of pain ‘right now’ and ‘pain at its least’ were reported as 3.1 ( $SD = 2.5$ , range = 0 – 10) and 1.8 ( $SD = 2.0$ , range = 0 – 8), respectively. Mean pain intensity ‘at its worst’ was 7.4 ( $SD = 2.1$ , range = 2 – 10). Table 3 shows the distribution of pain intensity scores when grouped by cutpoints representing mild (1 – 4), moderate (5 – 6) and severe (7 – 10) pain, following the work of Serlin et al.<sup>32</sup>. Notably, although 41.9% of participants rated their average pain intensity as mild, the majority reported a typical background pain of moderate (37.1%) to severe (18.1%) intensity. Approximately two-thirds of the sample reported their pain intensity ‘at its worst’ to be in the severe range.

The descriptive data derived from the MPQ are shown in Table 4. MS-related pain was predominately sensory-discriminative in quality, the most frequently endorsed descriptors (chosen by > 33% of respondents) being sharp (54.3%), shooting (49.5%), cramping (45.7%), burning (43.8%), aching (42.9%), throbbing (39%) and tingling (38.1%). Affective and evaluative descriptors most frequently chosen were exhausting (59.0%), annoying (45.7%) and nagging (53.3%). In addition to these descriptors, study participants often supplemented the MPQ with analogies or metaphors to describe the quality of their pain. Common examples reported by participants included feeling as if they had ‘severe sunburn under a cold shower’, or as if their ‘legs were on fire’.

In terms of the 45 anatomical areas defined by the scoring template of the Margolis pain drawing, the median number of painful locations reported by the

sample was 10 (range = 1 – 43). The median percentage of body surface area in pain reported by the sample was 26.5% (range = 4.0 – 96.5%). Pain locations were also scored according to a broader categorization of body regions similar to classifications used by others in the MS-related pain literature<sup>5</sup> (see Table 5). Based on this classification, three-quarters of the sample reported pain in 3 or more locations, with respondents reporting an average of 4.0 ( $SD = 1.8$ ) distinct pain sites. Total number of pain sites were found to be significantly associated with overall MS-related disability score ( $r = .28, p = .006$ ). Although the median duration of pain for the sample was 6.0 years (range = 1 month – 36 years), for a substantial minority (34.3%) pain had persisted for over 10 years. The majority of participants (68.0%) reported that they experienced pain on a constant, daily basis and most of the remainder (24.5%) described their pain as intermittent.

Respondents were also able to identify a number of factors known to provoke or exacerbate their pain. Table 6 reports the percentage of respondents reporting each factor. Participants most commonly stated that prolonged activity or overexertion made their pain worse. Changes in environmental temperature, bodily posture/position, stress, fatigue and sensory stimulation were also reported to exacerbate pain. The data on pain management techniques utilised by the sample are summarised in Table 7. The mean number of pain management techniques reported by participants was 3.3 ( $SD = 1.7$ , range = 0 – 8). When compared by background characteristics, women reported more pain management techniques than men (mean,  $3.5 \pm 1.6$  vs.  $2.4 \pm 2.1$ ;  $t(103) = 2.4, p = .017$ ), as did participants in paid employment compared with those not in current paid employment (mean,  $4.1 \pm 1.8$  vs.  $2.9 \pm 1.6$ ;  $t(103) = 3.3, p = .001$ ). Number of reported techniques did not significantly differ by



other characteristics. Most participants (83.8%) took medications regularly for pain relief, although these were predominately over-the-counter, simple analgesics such as nonopioids and nonsteroidal anti-inflammatory drugs (NSAIDs). Participants employed a range of other nondrug pain management techniques including physical/exercise therapy, thermotherapy, rest/sleep, distraction, relaxation techniques, as well as a range of alternative and complementary therapies.

### ***What Illness and Demographic Variables are Associated with the Presence and Intensity of MS-related Pain?***

In order to determine whether pain prevalence differed by illness and demographic characteristics, comparisons between participants with and without MS-related pain were first conducted at the bivariate level. Location was omitted given the low cell count in suburban and rural categories. These analyses did not reveal any significant associations between the presence of pain and age, marital status, educational level, ethnicity, socioeconomic or employment status (see Table 8). In addition, although there was a notably higher proportion of women (69.3%) reporting pain compared to men (57.5%), this difference fell short of statistical significance ( $\chi^2 = 1.6, p = .21$ ). In terms of illness-related variables, no significant differences existed between the two groups with regard to disease course or time since MS diagnosis. However, the presence of pain was associated with more severe MS-related disability with a mean difference of 6.0 score units on the GNDS (95% CI = 3.5 to 8.4),  $t(217) = -4.8, p < .001$ . When pain prevalence was considered by GNDS class intervals, the report of pain became more common with increasing level of disability (see Figure 1),  $\chi^2 = 27.0, p < .001$ .

A stepwise multiple logistic regression was subsequently conducted to examine the independent associations of illness and demographic characteristics with the presence of clinically significant pain. All demographic variables were entered, along with time since diagnosis and MS type. In addition, as MS-related disability was significant at the bivariate level, all 12 GNDS scales were entered to identify important associations with specific disability scales. As shown in Table 9, the final model fit the data well (Hosmer-Lemeshow goodness-of-fit test,  $\chi^2 = 4.86$ ,  $p = .77$ ). When considered together, four of the background variables were significantly related to the likelihood of having clinically significant pain, namely gender, cognition, sexual function and ‘other problems’ (as indicated on the GNDS, e.g., spasms, vertigo, paresthesias). Being female increased participants’ likelihood of experiencing MS-related pain more than threefold relative to males (odds ratio = 3.40; Wald = 6.69,  $p = .01$ ). In addition, each unit change on the cognition (Wald = 4.25,  $p = .039$ ), sexual function (Wald = 8.61,  $p = .003$ ) and other (Wald = 20.07,  $p < .001$ ) scales of the GNDS increased participants’ likelihood of pain 1.4, 1.3 and 1.9 times, respectively.

In order to examine associations between illness and demographic characteristics and pain intensity among respondents reporting a current pain problem, a stepwise multiple linear regression analysis was employed. All illness-related and demographic variables were entered as independent variables, with pain intensity as measured by the MPQ PRI-total as the dependent variable. As shown in Table 10, the final model which accounted for 27% of the variation included disability, gender, marital status and time since diagnosis. Greater severity of MS-related disability ( $t = 4.31$ ,  $p < .001$ ) and female gender ( $t = 2.47$ ,  $p = .015$ ) were significantly associated

with higher levels of pain intensity, whereas being in a married/defacto relationship ( $t = -2.28, p = .025$ ) and longer time since MS diagnosis ( $t = -2.24, p = .028$ ) were correlated with lower pain ratings.

## DISCUSSION

In this large, community-based sample of people with MS, clinically significant pain was experienced by 67.1% of participants during the two weeks preceding the survey. This finding is consistent with a growing consensus in the literature that pain is experienced by approximately two-thirds of the MS population over the course of their illness<sup>5-8, 17</sup> and reaffirms that pain is a significant problem among people with MS. Others have found considerably lower<sup>3, 11, 13, 14</sup>, or higher<sup>4, 12, 33</sup>, prevalence rates which likely reflect differences in sampling procedures, measurement and classification systems used, or timeframes and exclusion criteria for MS-related pain.

Indeed, several inconsistencies and methodological limitations within the extant MS-related pain literature have generally precluded substantive conclusions about the prevalence and nature of pain experienced. Notably, almost all available data is based on convenience samples drawn from specialised clinics or hospital departments, thereby limiting the generalisability of findings. This study therefore sought to overcome many of these limitations by employing (1) community-based, systematic random sampling; (2) comprehensive, in-person structured pain interviews; (3) the use of standardised pain measures; and (4) the inclusion of all self-reported

pain problems within two weeks preceding the survey, so as to include clinically meaningful pain while avoiding information bias due to memory problems.

Although the current study attempted to correct a number of methodological limitations of previous prevalence studies, the findings may have been influenced by a number of factors. Despite efforts to emphasize study participation regardless of pain status, the results may reflect some degree of selection bias. That is, respondents with pain may have been more or less likely to complete the questionnaire than those without and therefore be over- or under-represented in this sample. Moreover, because the sample was restricted to members of the Queensland MS Society, the sample may have been biased toward persons with differing characteristics, such as individuals with greater access to resources. Nonetheless, the background characteristics of the sample were quite representative of the target population and other published epidemiological data.

The high prevalence of pain experienced in the MS population raises the question of why some individuals do not develop pain over the course of the disease. It could prove informative to determine what demographic, clinical and psychosocial factors protect against the development of chronic pain problems. Compatible with previous studies, the current study found the presence of MS-related pain to be unrelated to several important demographic and clinical variables including age, marital status, educational level, ethnicity, socio-economic and employment status, disease course or time since diagnosis. Pain was however, significantly correlated with level of disability, as measured by the GNDS. This suggests that pain may be

more likely amongst those with greater disease severity, although this relationship remains unclear from these cross-sectional results.

When considered independently by logistic regression, cognition, sexual function and ‘other’ scales of the GNDS were found to be significantly associated with the presence of pain. It may be that individuals with greater cognitive impairment are more likely to experience ongoing pain due to impaired cognitive coping and problem solving abilities. On the other hand, both cognitive<sup>34, 35</sup> and sexual<sup>36, 37</sup> difficulties are common among persons with chronic pain as a primary condition. MS-related pain may itself create memory and concentration difficulties and interfere with sexual interest and functioning. Further investigation is needed to determine the nature of these relationships. The only study to examine the relationship between pain and cognitive functioning in MS found no differences in performance on a task of auditory verbal learning between those with and without pain.<sup>17</sup> The finding that the ‘other’ GNDS variable was significantly associated with pain must be qualified by the fact that it commonly included potentially painful conditions such as spasms and paresthesias. Hence, this finding may simply indicate that as participants developed more MS-related symptoms that may be painful, they are more likely to develop pain.

Few consistent findings about clinical characteristics associated with pain have emerged from previous research. Several studies failed to identify any relationship between MS-related pain and indices of disease progression, such as disease course, duration or severity.<sup>5–10</sup> In contrast, Brochet et al.<sup>11</sup> prospectively assessed 108 people with MS over a 3 year period and found that pain occurred more frequently during

acute relapses and pain persisted more frequently when exacerbations were followed by residual neurological deficit. These authors reported a significant correlation between pain and increased disability, as measured by the Kurtzke Disability Status Scale (DSS). Stenager et al.<sup>12</sup> also demonstrated that over a five year period, participants with deteriorating DSS scores were significantly more likely to experience pain. Recent large, cross-sectional studies by Ehde et al.<sup>13</sup> and Solaro et al.<sup>14</sup> also found pain prevalence increased with greater disease severity, as defined by the EDSS.

Here, logistic regression also revealed that being female independently increased participants' probability of experiencing MS-related pain more than threefold (OR = 3.40, 95% CI = 1.4 to 8.6). This finding is compatible with previous studies<sup>8, 15, 16</sup> demonstrating women were significantly more likely to report MS-related pain than men. It is also consistent with increasing evidence that several chronic pain problems appear to have a specific gender distribution. Women appear to be at greater risk of a variety of recurrent and chronic pain conditions such as headache, facial pain, abdominal pain and musculoskeletal pain.<sup>38, 39</sup> Both biological and psychosocial factors have been hypothesised to account for these findings, such as gender differences in social role expectancies, cognitive appraisals, coping strategies, familial factors, anatomical structures, hormones and brain chemistry.<sup>38, 40</sup> It should be noted however, that the current sample predominately included women, yielding a female to male ratio of approximately 4:1, which does not correspond with the 2–3:1 gender ratio typical of the MS population.<sup>41</sup>

An important finding in this study was that pain in people with MS is not only common, but it is also usually chronic and often severe in nature. At the time of investigation the median duration of pain was 6 years, but for a significant minority (34.3%), pain had existed for over 10 years. Of those participants with pain, 68% reported that they experienced pain on a constant, daily basis. Most of the remainder (24.5%) also experienced pain on a daily basis, although it was described as intermittent. Thus, once MS-related pain develops, it is usually a chronic, persistent problem over the course of the illness.

Participants reported a mean pain intensity ‘on average’ of 4.6 ( $SD = 2.1$ ; on a 0–10 scale) for the two weeks preceding the interview, which is similar to that reported by other authors. Four studies found average pain intensity among people with MS to range from 4.6 to 5.8 utilising the numerical rating scale.<sup>4, 8, 9, 13</sup> Further examination of the data however, reveals that over half (55.2%) of the current sample reported a typical background pain of moderate-to-severe intensity ( $\geq 5$  on a 0 – 10 scale). In addition, approximately two-thirds (67.6%) of the sample reported their pain intensity ‘at its worst’ over the preceding fortnight to be in the severe range. These findings replicate those of Ehde et al.<sup>13</sup>, who reported average pain intensity was often moderate (35.6%) to severe (26.7%) for their community-based MS sample over the three months preceding their survey, as measured by the NRS-11.

Findings from the MPQ further demonstrate that the severity of MS-related pain is considerable. The mean total pain rating index (PRI-total) for the sample was 30.67 ( $SD = 11.43$ ), exceeding calculated normative PRI-total mean scores reported by Wilkie et al.<sup>27</sup> for chronic cancer (24.0), low back (27.9) and mixed (25.4) pain

conditions. Participants' mean scores were also appreciably higher when compared to means reported for Australian samples of chronic rheumatoid arthritis<sup>42</sup>, orofacial pain<sup>43</sup> and chronic post-surgical pain<sup>44</sup>.

The qualitative aspects of pain reported by this sample are similar to those found in the MS literature.<sup>6, 8, 45</sup> Interestingly, participants scored comparatively lower on the affective and evaluative dimensions of the MPQ. One possible explanation for this finding is that pain is less distressing or threatening to individuals in the context of other intrusive MS-related symptoms. Or, as is suggested by previous qualitative findings<sup>46</sup>, individuals may come to accept pain as a permanent consequence of disability, one that becomes an enduring part of daily life. Thus they might tend to perceive and discuss pain primarily in terms of its sensory qualities rather than its affective-evaluative dimensions.

Descriptive findings from the MPQ were also remarkably similar to those of Dudgeon et al.<sup>47</sup> who explored the qualitative features of disability-related pain among people with lower-limb amputations, spinal cord injury and cerebral palsy, using both the MPQ and open-ended pain interviews. The authors found word pattern use to be similar across groups and therefore suggested a set of 15 adjectives, derived from the most frequent descriptors, to inform disability-related pain assessment. These adjectives correspond well with the current findings and may have clinical utility in the MS population.

Like Dudgeon et al.<sup>47</sup> however, we also found that during pain interviews study participants often supplemented the MPQ with analogies or metaphors to



describe the quality of their pain. Some participants described a sensation similar to ‘severe sunburn under a cold shower’, or as if their ‘legs were on fire’, or explained their ‘whole body ached with fatigue’. Such descriptions likely represent the often frustrated attempts of individuals with central pain to convey their subjective experience<sup>48</sup> and perhaps point to a limitation of measures such as the MPQ to adequately assess the complex nature of chronic disability-related pain.<sup>47</sup>

Little is known about what factors influence pain intensity among people with MS. A correlational study by Brunet et al.<sup>49</sup> found higher income and relapsing-remitting MS predicted lower pain levels, while a family history of MS and the presence of headaches were associated with higher pain severity, as measured by the SF-36 Bodily Pain (BP) Scale. Other investigators however, have found no association between pain severity and age, disease duration, MS subtype or EDSS scores.<sup>4, 7, 9, 50</sup>

In the current study, regression analysis revealed that women and participants with greater disease severity reported significantly higher levels of pain, whereas being in a married/defacto relationship and longer time since diagnosis predicted lower pain scores on the MPQ. The finding that women reported greater pain severity is consistent with three previous studies in the MS literature<sup>8, 16, 50</sup>, as well as evidence from other pain-related conditions such as rheumatoid/osteoarthritis<sup>51, 52</sup>, HIV/AIDS<sup>53</sup> and neuromuscular disease<sup>54</sup>, suggesting that women who have chronically painful conditions are likely to report heightened pain compared to men. Overall MS-related disability score demonstrated the strongest association with pain intensity, which stands in contrast to previous findings.<sup>7, 9, 50</sup> However, since several pain variables in

this study were correlated with disease severity, the conclusion that pain is related to advanced disease seems warranted. Being in a partnered relationship was associated with significantly lower pain intensity, suggesting that social support may be an important buffer against the development of severe pain problems.<sup>55, 56</sup> Longer time since MS diagnosis also predicted lower pain intensity which may reflect increased attempts to employ self-management strategies and greater adaptation to illness over time.<sup>57</sup> Taken together, these findings suggest that in contrast to a biomedical model of disability-related pain that ties pain severity solely to disease activity and impairment, a range of factors likely interact to influence the severity of MS-related pain.

It is noteworthy that the majority of study participants reported multiple pain locations, experiencing several types of pain simultaneously. When scored across nine bodily regions, participants reported a mean of 4.0 ( $SD = 1.8$ ) different pain sites. Three-quarters of the sample reported pain in 3 or more locations. Participants most commonly described pain in the lower extremities, although pain was frequently reported in the back, neck, upper extremities and facial regions also. The number of painful regions and localization of pain as found in this study are very similar to those found by others.<sup>6, 8, 14</sup> Archibald et al.<sup>9</sup> found that 89% of subjects with MS-related pain had multiple anatomically separate pain sites, reporting a mean of 4.1 pain locations. The present data also show that number of pain locations was positively correlated with MS-related disability. Although previous studies have failed to examine this relationship, a compounded effect of multiple areas of pain on functioning seems likely. Thus, it may be important to consider more than simply the

presence or severity of pain when examining the relationship between pain and MS-related disability.

Moreover, given that individuals with MS typically experience multiple pain problems, additional studies are needed to determine the causes of these conditions and whether there are common patterns of multiple pain problems in this population. The pain variables assessed in the current study focused on the overall subjective experience of MS-related pain. However, given the diverse nature of MS-related pain, it may be useful for future research to clinically differentiate between pain conditions and perform detailed analyses by pain type, since each may have varying intensity and functional consequences.<sup>58</sup>

Participants were able to identify a number of factors that were known to provoke or exacerbate their pain. The most common triggers were prolonged activity or overexertion, changes in environmental temperatures or bodily posture/position. Others noted that stress, fatigue and sensory stimulation aggravated pain. In addition, participants reported a variety of treatments and strategies they employed to alleviate pain. Most participants (83.8%) took medications regularly for pain, although these were predominantly non-prescription, simple analgesics such as nonopioids (e.g., paracetamol and aspirin products) and NSAIDs (e.g., ibuprofen). Although anecdotally ineffectual, most study participants self-medicated with simple analgesic preparations and therefore health care providers should be aware of the extent of over-the-counter medication use when new drug therapies are initiated. Approximately less than one-fifth of participants who reported pain were being treated with opioid or adjuvant pharmacotherapy.

Several non-pharmacologic pain management strategies, including physical therapy, thermotherapy, rest/sleep, distraction, relaxation techniques and alternative therapies were also utilised by participants. It is unknown whether these strategies were initiated by study participants or whether health care professionals recommended them. However, given the number and diversity of therapies spontaneously reported, future research should examine the effectiveness and comparative effectiveness of these strategies so that clinicians can base recommendation and treatment on empirical evidence.

Study participants reported an average of 3.3 ( $SD = 1.7$ ) current pain management techniques, with greater numbers of techniques being reported by women and those in paid employment. Heckman-Stone and Stone<sup>4</sup> similarly found women with MS reported more pain management strategies than men, citing higher health care use among women and a greater willingness to try nonmedication strategies as potential explanations. Women may also be more motivated to try pain-relieving techniques since they reported greater pain intensity. Similarly, individuals may attempt to cope with MS-related pain by using a variety of self-management strategies to remain employed. Further inquiry into the effectiveness of pain management techniques used by people with MS in the community and potential barriers to self-management should be the target of future research.

## **CONCLUSIONS**

Consistent with previous research, pain was found to be common among people with MS, with approximately two-thirds (67.1%) of this community-based sample reporting pain during the two weeks preceding the study. Comprehensive pain assessment revealed that a substantial subset of these individuals experience chronic pain conditions characterised by moderate-to-severe pain intensity. Moreover, study participants reported an average of 4 concurrent pain sites. These findings underscore the need for increased clinical focus on assessment and management of MS-related pain.

In contrast to previous cross-sectional studies, greater severity of MS-related disability was found to be strongly correlated with both pain prevalence and severity. Greater disability was also associated with multiple pain locations. Taken together, these results suggest that individuals with more severe MS are at a greater risk for developing clinically significant pain. This explanation seems biologically plausible, yet one that remains confounded by the correlational research design. Longitudinal research is required that examines how MS-related disability and pain covary over time.

The findings also demonstrate significant gender differences as women were independently associated with both increased prevalence and severity of MS-related pain. Women also reported greater extent of pain compared to men and employed a greater number of self-management strategies. Thus, women with MS may be at particular risk for developing pain problems. Previous research has not examined gender differences in MS-related pain in any depth beyond prevalence studies. Future

research should seek to clarify the mechanisms that underlie these observations and consider gender differences in design and data analysis.

## References

1. Benrud-Larson LM, Wegener ST. Chronic pain in neurorehabilitation populations: Prevalence, severity and impact. *NeuroRehabil* 2000;14:127–37.
2. Ehde DM, Jensen MP, Engel JM, Turner JA, Hoffman AJ, Cardenas DD. Chronic pain secondary to disability: A review. *Clin J Pain* 2003;19:3–17.
3. Clifford DB, Trotter JL. Pain in multiple sclerosis. *Arch Neurol* 1984;41:1270–2.
4. Heckman-Stone C, Stone C. Pain management techniques used by patients with multiple sclerosis. *J Pain* 2001;2:205–8.
5. Rae-Grant AD, Eckert NJ, Bartz S, Reed JF. Sensory symptoms of multiple sclerosis: A hidden reservoir of morbidity. *Mult Scler* 1999;5:179–83.
6. Svendsen KB, Jensen TS, Overvad K, Hansen HJ, Koch-Henriksen N, Bach FW. Pain in patients with multiple sclerosis: A population-based study. *Arch Neurol* 2003;60:1089–94.
7. Beiske AG, Pedersen ED, Czujko B, Myhr KM. Pain and sensory complaints in multiple sclerosis. *Euro J Neurol* 2004;11:479–83.
8. Warnell P. The pain experience of a multiple sclerosis population: A descriptive study. *Axon* 1991;13:26–8.
9. Archibald CJ, McGrath PJ, Ritvo PG, Fisk JD, Bhan V, Maxner CE, et al. Pain prevalence, severity and impact in a clinic sample of multiple sclerosis patients. *Pain* 1994;58:89–93.
10. Indaco A, Iachetta C, Nappi C, Socci L, Carrieri PB. Chronic and acute pain syndromes in patients with multiple sclerosis. *Acta Neurol Scand* 1994;16:97–102.

11. Brochet B, Michel P, Henry P. Pain complaints in outpatients with multiple sclerosis: Description and consequences on disability. *Pain Clin* 1992;5:157–64.
12. Stenager E, Knudsen L, Jensen K. Acute and chronic pain syndromes in multiple sclerosis. A 5-year follow-up study. *Ital J Neurol Sci* 1995;16:629–32.
13. Ehde DM, Gibbons LE, Chwastiak L, Bombardier CH, Sullivan MD, Kraft GH. Chronic pain in a large community sample of persons with multiple sclerosis. *Mult Scler* 2003;9:605–11.
14. Solaro C, Bricchetto G, Amato MP, Cocco E, Colombo B, D'Aleo G, et al. The prevalence of pain in multiple sclerosis: A multicenter cross-sectional study. *Neurol* 2004;63:919–21.
15. Moulin DE, Foley KM, Ebers GC. Pain syndromes in multiple sclerosis. *Neurol* 1988;38:1830–4.
16. Buchanan RJ, Wang S, Ju H. Gender analyses of nursing home residents with multiple sclerosis. *Gend Med* 2003;6:35–46
17. Stenager E, Knudsen L, Jensen K. Acute and chronic pain syndromes in multiple sclerosis. *Acta Neurol Scand* 1991;84:197–200.
18. Cleeland CS. Measurement of pain by subjective report. In: Chapman CR, Loeser JD, editors. *Issues in pain measurement*. New York: Raven Press; 1989. p 391–403.
19. Klepac RK, Dowling J, Rokke P, Dodge L, Schafer L. Interview vs. paper-and-pencil administration of the McGill Pain Questionnaire. *Pain* 1981;11:241–6.
20. Sharrack B, Hughes RAC. The Guy's Neurological Disability Scale (GNDS): A new disability measure for multiple sclerosis. *Mult Scler* 1999;5:223–33.



21. Rossier P, Wade DT. The Guy's Neurological Disability Scale in patients with multiple sclerosis: A clinical evaluation of its reliability and validity. *Clin Rehabil* 2002;16:75–95.
22. Hoogervorst ELJ, van Winsen LML, Eikelenboom MJ, Kalkers NF, Uitdehaag BMJ, Polman CH. Comparisons of patient self-report, neurologic examination, and functional impairment in MS. *Neurol* 2001;56:934–7.
23. Wilkie DJ. Pain. In: Lewis SM, Heitkemper MM, Dirksen SR, editors. *Medical-surgical nursing: assessment and management of clinical problems*, 5th ed. St. Louis: Mosby; 2000. p 126–54.
24. Jensen MP, Turner JA, Romano JM, Fisher LD. Comparative reliability and validity of chronic pain intensity measures. *Pain* 1999;83:157–62.
25. Jensen MP, Karoly P. Self-report scales and procedures for assessing pain in adults. In: Turk DC, Melzack R, editors. *Handbook of pain assessment*, 2nd ed. New York: Guilford Press; 2001. p 15–34.
26. Melzack R. The McGill Pain Questionnaire: Major properties and scoring methods. *Pain* 1975;1:277–99.
27. Wilkie DJ, Savedra M, Holzemer WL, Tesler MD, Paul SM. Use of the McGill Pain Questionnaire to measure pain: A meta-analysis. *Nurs Res* 1990;39:36–41.
28. Melzack R, Katz J. The McGill Pain Questionnaire: Appraisal and current status. In: Turk DC, Melzack R, editors. *Handbook of pain assessment*, 2nd ed. New York: Guilford Press; 2001. p 35–52.
29. Margolis RB, Chibnall JT, Tait RC. Test-retest reliability of the Pain Drawing Instrument. *Pain* 1988;33:49–51.
30. Margolis RB, Tait RC, Krause SJ. A rating system for use with patient pain drawings. *Pain* 1986;24:57–65.

31. Australian Bureau of Statistics. Household wealth and wealth distribution, Australia 2003-04. Canberra: Commonwealth of Australia; 2006.
32. Serlin RC, Mendoza TR, Nakamura Y, Edwards KR, Cleeland CS. When is cancer pain mild, moderate or severe? Grading pain severity by its interference with function. *Pain* 1995;61:277–84.
33. Kassirer MR, Osterberg DH. Pain in chronic multiple sclerosis. *J Pain Symptom Manage* 1987;2:95–7.
34. Schnurr RF, MacDonald MR. Memory complaints in chronic pain. *Clin J Pain* 1995;11:103–11.
35. Munoz M, Esteve R. Reports of memory functioning by patients with chronic pain. *Clin J Pain* 2005;21:287–91.
36. Flor H, Turk DC, Scholz OB. Impact of chronic pain on the spouse: Marital, emotional and physical consequences. *J Psychosom Res* 1987;31:63–71.
37. Kwan KSH, Roberts LJ, Swalm DM. Sexual dysfunction and chronic pain: The role of psychological variables and impact on quality of life. *Eur J Pain* 2005;9:643–52.
38. Unruh AM. Gender variations in clinical pain experience. *Pain* 1996;65:123–67.
39. LeResche L. Gender considerations in the epidemiology of chronic pain. In: Crombie IK, editor. *Epidemiology of pain*. Seattle: IASP Press; 1999. p 43–52.
40. Fillingim RB. Sex, gender, and pain: Women and men really are different. *Curr Rev Pain* 2000;4:24–30.
41. Richards RG, Sampson FC, Beard SM, Tappenden P. A review of the natural history and epidemiology of multiple sclerosis: Implications for resource allocation and health economic models. *Health Technol Assess* 2002;6(10).

42. Roche PA, Klestov AC, Heim HM. Description of stable pain in rheumatoid arthritis: A 6 year study. *J Rheumatol* 2003;30:1733–8.
43. Vickers ER, Cousins MJ, Woodhouse A. Pain description and severity of chronic orofacial pain conditions. *Aust Dent J* 1998;43:403–9.
44. Bruce J, Poobalan AS, Smith WCS, Chambers WA. Quantitative assessment of chronic postsurgical pain using the McGill Pain Questionnaire. *Clin J Pain* 2004;20:70–5.
45. Gilmore R, Strong J. Pain and multiple sclerosis. *Br J Occ Ther* 1998;61:169–72.
46. Douglas C, Windsor C, Wollin JA. Understanding chronic pain complicating disability: Finding meaning through focus group methodology. *J Neurosci Nurs*. In press.
47. Dudgeon BJ, Ehde DM, Cardenas DD, Engel JM, Hoffman AJ, Jensen MP. Describing pain with physical disability: Narrative interviews and the McGill Pain Questionnaire. *Arch Phys Med Rehabil* 2005;86:109–15.
48. McHenry KW. Lessons from my central pain. *Pain: Clinical Updates* [serial online] 2002 Sep [cited 2007 Nov 21];X(3). Available from: <http://www.iasp-pain.org/PCU02-3.html>
49. Brunet DG, Hopman WM, Singer MA, Edgar CM, MacKenzie TA. Measurement of health-related quality of life in multiple sclerosis patients. *Can J Neurol Sci* 1996;23:99–103.
50. Kalia LV, O'Connor PW. Severity of chronic pain and its relationship to quality of life in multiple sclerosis. *Mult Scler* 2005;11:322–7.
51. Affleck G, Tennen H, Keefe FJ, Lefebvre JC, Kashikar-Zuck S, Wright K, et al. Everyday life with osteoarthritis or rheumatoid arthritis: Independent effects of disease and gender on daily pain, mood, and coping. *Pain* 1999;83:601–9.

52. Keefe FJ, Lefebvre JC, Egert JR, Affleck G, Sullivan MJ, Caldwell DS. The relationship of gender to pain, pain behavior, and disability in osteoarthritis patients: The role of catastrophizing. *Pain* 2000;87:325–34.
53. Breitbart W, McDonald MV, Rosenfeld B, Passik SD, Hewitt D, Thaler H, et al. Pain in ambulatory AIDS patients. I: Pain characteristics and medical correlates. *Pain* 1996;68:315–21.
54. Abresch RT, Carter GT, Jensen MP, Kilmer DD. Assessment of pain and health-related quality of life in slowly progressive neuromuscular disease. *Am J Hosp Palliat Care* 2002;19:39–48.
55. Feldman SI, Downey G, Schaffer-Neitz R. Pain, negative mood, and perceived support in chronic pain patients: A daily diary study of people with reflex sympathetic dystrophy syndrome. *J Consult Clin Psychol* 1999;67:776–85.
56. Jensen MP, Ehde DM, Hoffman AJ, Patterson DR, Czerniecki JM, Robinson LR. Cognitions, coping and social environment predict adjustment to phantom limb pain. *Pain* 2002;95:133–42.
57. Kerns RD. Psychological aspects of pain. *Int J MS Care* [serial online] 2000 Dec [cited 2007 Nov 21];2(4). Available from:  
<http://www.ms-care.org/cmssc/images/pdf/ijmsc-2000-dec.pdf>.
58. Jensen MP, Smith DG, Ehde DM, Robinson LR. Pain site and the effects of amputation pain: further clarification of the meaning of mild, moderate, and severe pain. *Pain* 2001;91:317–22.

## TABLES

**Table 1. Demographic characteristics of the sample ( $N = 219$ )**

<b>Characteristic</b>	<b><i>n</i></b>	<b>%</b>
<b>Gender</b>		
Female	179	81.7
Male	40	18.3
<b>Marital status</b> <sup>*</sup>		
Single	46	21.2
Married/defacto	136	62.7
Separated/widowed	35	16.1
<b>Educational level</b> <sup>†</sup>		
Less than high school graduate	22	10.1
High school graduate	108	49.5
Apprenticeship	18	8.3
University or college	53	24.3
Postgraduate	17	7.8
<b>Ethnicity</b>		
Anglo-Australian	205	93.6
European	9	4.1
Other	5	2.3
<b>Annual household income (AUD\$)</b> <sup>‡</sup>		
<\$10,000	26	13.5
\$10,000 to 24,999	64	33.1
\$25,000 to 49,999	55	28.5
>\$50,000	48	24.9
<b>Employment status</b> <sup>*</sup>		
Paid employment	73	33.6
Not in paid employment	144	66.4
<b>Location</b> <sup>§</sup>		
Urban	191	88.4
Suburban	15	6.9
Rural	10	4.6

<sup>\*</sup> 2 missing data, <sup>†</sup> 1 missing data, <sup>‡</sup> 26 missing data, <sup>§</sup> 3 missing data.

**Table 2. Clinical characteristics of the sample (*N* = 219)**

<b>Characteristic</b>		
<b>Disease course</b>	<b><i>n</i></b>	<b>%</b>
Relapsing-remitting	106	48.4
Secondary-progressive	36	16.4
Primary-progressive	46	21.0
Other	31	14.2
<b>GNDS scale</b>	<b><i>M</i></b>	<b><i>SD</i></b>
Cognition	1.3	1.1
Mood	1.3	1.3
Vision	0.8	0.7
Speech	0.5	0.9
Swallowing	0.6	1.1
Upper limb function	1.5	1.4
Lower limb function	2.2	1.7
Bladder function	2.5	1.8
Bowel function	1.3	1.5
Fatigue	2.7	1.6
Sexual function*	2.0	2.1
Other	1.8	1.7

Abbreviation: GNDS, Guy's Neurological Disability Scale.

\* 26 missing data.

**Table 3. Distribution of pain intensity scores (*n* = 105)**

	<b>Mild</b> <b>(NRS 1 – 4)</b>	<b>Moderate</b> <b>(NRS 5 – 6)</b>	<b>Severe</b> <b>(NRS 7 – 10)</b>
Present pain	46.7	21.0	10.5
Worst pain	10.5	21.9	67.6
Least pain	46.7	10.5	1.9
Average pain	41.9	37.1	18.1

NOTE. Values expressed as percentages. Percentages add up to <100 where participants could give ratings of 0.

Abbreviation: NRS, Numerical pain rating scale.

**Table 4. McGill Pain Questionnaire scores for people with MS ( $n = 105$ )**

<b>Variable</b>	<b><i>M</i></b>	<b><i>SD</i></b>	<b>Possible Range</b>	<b>Actual Range</b>
PRI–Total	30.67	11.43	0 – 78	6 – 64
PRI–Sensory	19.10	6.96	0 – 42	4 – 35
PRI–Affective	4.14	2.98	0 – 14	0 – 11
PRI–Evaluative	2.26	1.43	0 – 5	0 – 5
PRI–Miscellaneous	5.17	3.10	0 – 17	0 – 14
Number of Words Chosen	12.74	3.96	0 – 20	4 – 20

Abbreviation: PRI, Pain rating index.



**Table 5. Pain locations reported by people with MS ( $n = 105$ )**

<b>Location</b>	<b>Frequency</b>	<b>%</b>
Head	23	21.9
Back	71	67.6
Neck	40	38.1
Face	36	34.3
Arms	35	33.3
Hands	39	37.1
Trunk	26	24.8
Legs	90	85.7
Feet	57	54.3

**Table 6. Factors reported to exacerbate MS-related pain ( $n = 105$ )**

	<b>Frequency</b>	<b>%</b>
Activity/exercise	49	46.7
Environmental temperature	37	35.2
Postural (e.g., immobility, certain movements)	33	31.4
Stress	26	24.8
Fatigue	20	19.0
Sensory stimulation (e.g., light touch, friction)	9	8.6

**Table 7. Pain management techniques used for MS-related pain (*n* = 105)**

	Frequency	%
<b>Medications</b>		
Nonopioid analgesics	65	61.9
Anti-inflammatories	30	28.6
Spasmolytics	22	21.0
Antidepressants	19	18.1
Opioids	15	14.3
Anticonvulsants	11	10.5
Alternative medicines	9	8.6
Disease modifying agents	8	7.6
<b>Other treatments</b>		
Physical/exercise therapy (e.g., massage, physiotherapy)	55	52.4
Thermotherapy (e.g., hot or cold)	36	34.3
Rest/sleep	29	27.6
Distraction (e.g., work, recreation)	21	20.0
Relaxation techniques (e.g., meditation, guided imagery)	16	15.2
Alternative therapies (e.g., acupuncture, aromatherapy, hypnosis, magnetic therapy)	13	12.4

**Table 8. Comparison of participants with and without MS-related pain ( $N = 219$ )**

Variable	With Pain ( $n = 147$ )	Without Pain ( $n = 72$ )	$\chi^2 / t$	$p^*$
	$n$ (%)	$n$ (%)		
<b>Gender</b>				
Male	23 (57.5)	17 (42.5)		
Female	124 (69.3)	55 (30.7)	1.6	.21
<b>Marital Status</b>				
Single	28 (60.9)	18 (39.1)		
Married/defacto	96 (70.6)	40 (29.4)		
Separated/widowed	21 (60.0)	14 (40.0)	2.3	.31
<b>Educational Level</b>				
Less than high school graduate	14 (63.6)	8 (36.4)		
High school graduate	76 (70.4)	32 (29.6)		
Apprenticeship	12 (66.7)	6 (33.3)		
University or college	35 (66.0)	18 (34.0)		
Postgraduate	9 (52.9)	8 (47.1)	2.2	.70
<b>Ethnicity</b>				
Anglo-Australian	138 (67.3)	67 (32.7)		
Other	8 (61.5)	5 (38.5)	0.0	.90
<b>Annual Household Income</b>				
<\$10,000	16 (61.5)	10 (38.5)		
\$10,000 to 24,999	49 (76.6)	15 (23.4)		
\$25,000 to 49,999	37 (67.3)	18 (32.7)		
>\$50,000	28 (58.3)	20 (41.7)	4.6	.20
<b>Employment Status</b>				
Paid employment	46 (63.0)	27 (37.0)		
Not in paid employment	99 (68.8)	45 (31.2)	0.5	.49
<b>MS Type</b>				
Relapsing-remitting	76 (71.7)	30 (28.3)		
Secondary-progressive	31 (86.1)	5 (13.9)		
Primary-progressive	38 (82.6)	8 (17.4)	4.2	.12
<b>Age</b>				
mean ( $SD$ )	51.3 (11.5)	50.6 (13.2)	0.4	.69
<b>Time Since MS Diagnosis</b>				
mean ( $SD$ )	11.2 (9.7)	12.4 (10.3)	-0.9	.38
<b>Disability (GNDS)</b>				
mean ( $SD$ )	20.4 (8.7)	14.4 (8.5)	4.8	< .001

\*  $p$  values calculated using chi-square tests except for age, time since diagnosis and disability for which independent  $t$ -tests were used.

**Table 9. Logistic regression predicting the presence of pain from demographic and clinical characteristics in people with MS (*N* = 219)**

<b>Variable</b>	<b>Wald</b>	<b>Odds Ratio<sup>*</sup></b>	<b>95% CI</b>	<b><i>p</i></b>
Female	6.69	3.40	(1.35, 8.58)	.01
GNDS cognition scale	4.25	1.40	(1.02, 1.94)	.039
GNDS sexual function scale <sup>†</sup>	8.61	1.34	(1.10, 1.63)	.003
GNDS ‘other’ scale	20.07	1.85	(1.41, 2.42)	< .001
Constant	12.89			< .001
<b>Overall Model</b>				
–2 Log Likelihood	177.82			
Model Chi-square ( <i>df</i> = 3)	49.12			
<i>p</i>	< .001			

Abbreviation: GNDS, Guy’s Neurological Disability Scale.

<sup>\*</sup>Odds ratios mutually adjusted for all other variables, <sup>†</sup>Sample mean substitution for missing data.

**Table 10. Stepwise multiple regression predicting pain intensity from illness and demographic variables in people with MS ( $n = 105$ )**

Predictor Variables	$b$	$SE\ b$	$\beta$	$sr^2$
Disability (GNDS)	0.47	0.11	.40 <sup>†</sup>	.16
Female	6.71	2.71	.23 <sup>*</sup>	.05
Married/defacto	-5.08	2.23	-.21 <sup>*</sup>	.04
Time since diagnosis	-0.23	0.10	-.21 <sup>*</sup>	.04
Constant	20.13 <sup>†</sup>			
<b>Overall Model</b>				
$F(4, 100) = 8.0, p < .001$				
$R^2 = .27$				
* $p < .05$ , <sup>†</sup> $p < .001$				