Is There an Association Between Social Support and Pain Among Individuals Living With Multiple Sclerosis?

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Abstract

Context. Pain is one of the most common symptoms reported by patients living with Multiple Sclerosis (MS). Risk factors associated with pain may include individual's cognitive thinking process, emotional and behavioral response to pain and amount of social support. There is a lack of research on the influence on the amount of social support and its association to pain outcomes.

Objective. The primary objective of this study was to determine the association between amount and of social support and its association with odds of pain among individuals with MS.

Methods. The Survey on Living with Neurological Conditions in Canada (SLNCC) 2011-2012 linked to the Canadian Community Health Survey (CCHS) 2010-2011 was used to carry out a logistic regression model for this analysis (N = 78,623).

Main outcome measures. The factors that were assessed were psychological factors, problems with sleeping, self-perceived general health, self-perceived level of stress, number of years living with MS, as well as social factors. The outcome variable was pain. Results. The amount of social support was found to be significant in that individuals who had 3 or fewer types of social support were 3.02 times more likely (95% CI 1.06 to 8.59) to report being in pain as opposed to individuals who had 4 types of support. The results indicate the importance of self efficacy in overcoming symptoms of MS and the need for more home care services.

Keywords

pain, multiple sclerosis, social factors, self-efficacy, caregiver

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Introduction

Pain is a common problem in people living with Multiple Sclerosis (MS).¹ The prevalence of pain in MS patients is 50%, and 75% of patients report having pain within 1 month of their assessment.² The presence of pain among patients with MS is associated with their age, longer duration of their illness, depression, increased functional impairment and fatigue.³ From a medical perspective, pain causes changes to occur in the central nervous system (CNS) and affects the emotional processing area of the brain.⁴ When there is damage to the peripheral or CNS, neuropathic pain occurs.⁴ Although pain arises from physical problems with the body, there are also non-disease related factors associated with pain which can be explained by the cognitive behavioral model of pain processing.⁵

For people living with MS, physical pain may arise in the form of headaches, back pain, neuropathic pain and or spasms.⁶ However the non-disease factors associated with pain also exist and is linked to the individual’s cognitive thinking process along with emotional and behavioral responses.⁷ There are various models that explain the factors that play a role in pain processes such as the biopsychosocial model of pain which recognizes that psychological, social and environmental factors also contribute to how people process pain information.⁷ However the area that is very understudied is whether there is a relationship between amount of social support and pain among individuals living with MS.

Several studies have stated that the effect of chronic pain in MS patients is linked to depression and is mediated by fatigue, anxiety and sleep.²,⁸-¹⁰ Since coping with MS is difficult, not

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having the support one needs could impact the emotional well-being of MS patients and exacerbate health problems.\textsuperscript{3,11} This could then lead to a domino effect where emotional stress could impact sleep conditions and increase pain levels. Some studies that have looked at the association between social support as a predictor of mental health among MS patients found that presence of social support made a significant contribution to the mental health dimension of quality of life.\textsuperscript{12,13} This in turn may have an affect on physical symptoms such as how pain is perceived.

Social support helps in 3 areas: the first way is by providing emotional support such as love and affection, the second is instrumental support such as lending a helping hand to someone and the third is informational support such as from a physician or nurse.\textsuperscript{14} Learning to cope with the illness is also important in reducing disease burden. There are 2 types of coping strategies such as problem focused coping and emotion focused coping.\textsuperscript{15,16} Problem focused coping involves ways to change the problem that one is dealing with while emotion focused coping is related to managing the emotional distress of the situation. Each coping strategy is dependent on the person as well as the situation that they are dealing with.\textsuperscript{16}

In a study which examined the association between psychological factors and chronic pain among people living with disabilities found that the perception of social support was associated with less pain and better psychological functioning.\textsuperscript{17} Several studies have also shown that higher levels of social support are associated with higher levels of health-related quality of life and lower levels of depression.\textsuperscript{12,13,18,19} There have been few studies that have investigated the risk factors associated with pain and the emotional well-being of people living with MS. The main objective of this study is to determine the association between amount and type of social support and it’s association with odds of pain among individuals with MS. The second objective of this study is to determine if there is an interaction between psychological factors and amount of support on pain outcomes.

Methods

Data Source

The Survey on Living with Neurological Conditions in Canada (SLNCC) 2011-2012 linked to the Canadian Community Health Survey (CCHS) 2010-2011 was used for this analysis.\textsuperscript{20} The SLNCC is a cross sectional survey that collected information on Canadian’s experiences of living with chronic neurological conditions.\textsuperscript{20} There were 18 neurological conditions which were included in the 2010 and 2011 Canadian Community Health Surveys.\textsuperscript{20} The sample surveyed for the SLNCC survey were drawn from all CCHS respondents and household members who were 15 years of age and older living in the provinces being surveyed and who had one of the 18 neurological conditions.\textsuperscript{20} This research used secondary data source therefore research ethics board review was exempt.

Variables Assessed

Individuals 15 years and older were used in the analysis. The factors that were assessed were psychological factor (mood disorder such as depression, bipolar disorder, mania or dysthymia), problems with sleeping, self-perceived general health (poor or fair health, good, very good/excellent health), self-perceived level of stress (not at all or not very stressful, a bit stressful, quite a bit to extremely stressful), number of years living with MS (less than 10 years, 11 to 21 years, greater than 22 years), as well as social factors (someone to confide/talk to, someone to do something enjoyable, someone to take you to the doctor and someone to help you in an emergency).

The categorical support variables (someone to confide/talk to, someone to do something enjoyable, someone to take you to the doctor and someone to help you in an emergency) were combined and categorized as either 3 or fewer types of social support or the second category being all 4 types of support. Minimum 3 types of social support was used as a reference category since the main categories of social support are usually 3 (emotional, instrumental and informational support).\textsuperscript{21} The outcome variable was pain health status for which there were 5 categories (no pain or discomfort, pain prevents no activities, pain prevents a few activities, pain prevents some activities and pain prevent most activities). These categories were collapsed to either presence or absence of pain in order to carry out a logistic regression analysis.

Analysis

In order to take into consideration the survey design, replicate sampling weights along with bootstrapped variance estimation were used which were recommended by Statistics Canada.\textsuperscript{20} A set of \(n = 500\) replicate weights were used. These weights were used in order to account for population estimates and non-responses of people. For the SLNCC linked data set, the bootstrap replicates are the sub samples that are used in order to estimate the variance of the CCHS estimates. All analyses was conducted at the Research Data Centre using STATA IC 15. Univariate analysis using a p-value of <0.20 was used as a cut point for the entry of a variable for multivariate analysis. A logistic regression model was built using the backward method based on a p-value of <0.05. Variables that were not included in the model were tested as confounders based on whether the addition of the variable changed the other estimates in the model by more than 20\%. Receiver operating curve and the goodness of fitness test was used to determine model fit.

Results

There was a total of 78,623 respondents in the survey. Majority of respondents, 42\% were living with MS for 11 to 21 years while 35\% were living with MS for less than 10 years. There were 51\% of individuals who reported pain while 49\% reported no pain. Based on the univariate analysis, years living with MS, self-perceived general health, mood disorder, problem with sleep and amount of family support were significant in the model (Table 1). Stress was not significant in the univariate analysis and was not included in the multivariate analysis. Initially health and amount of family support were the significant variables in the final model. However after testing for confounders, all variables which were removed initially were found to change the parameter estimates of the final model by 20\% and were included back into the model.

From the results of the multivariate analysis, individuals who had poor/fair health were 5.87 times more likely (95\% CI 2.63 to 13.05) to have pain as opposed to individuals who...
had good health/excellent. The amount of social support was found to be significant in that individuals who had 3 or fewer types of social support were 3.02 times more likely (95% CI 1.06 to 8.59) to be in pain as opposed to individuals who had 4 types of support (Table 2).

Interactions were tested between mood disorder and family support and between health condition and family support. Based on the univariate analysis, both interactions were found to be significant. However when included in the multivariate analysis there were not found to be significant. Therefore both interactions were not included in the final model. Table 2 shows the results of the final model. The area under the curve gave a value of 0.75 which indicated that this model was a good model.

**Discussion**

The results of the study indicate that the 4 types of support (someone to confide/talk to, someone to do something enjoyable, someone to take to the doctor and someone to help in emergency)
enjoyable, someone to take to the doctor and someone to help in an emergency) are needed for managing pain in MS patients. Lacking in one types of social support increases the odds of pain among individual’s with MS. Caregivers, support services and self efficacy are key factors that play a role in the amount of social support a person receives. One study on coping and psychological adjustment among people with MS found that people with MS were less likely to seek out social support.23 One of the reasons for this is that they don’t want to be a burden on anyone or they might now have support from family and friends. Many people with MS who are in the later stages of MS cannot carry out activities of daily living, therefore they need support from their family or friends and because of this the burden of caregivers is increased as disability progresses. This becomes a problem because the caregivers usually tend to be the spouse of the person with MS and not everything such as bathing, dressing, moving the person from wheelchair to bed can be carried out by a spouse. Another explanation for individuals with MS living in pain is also because of the lack of services. One study on investigating the needs of people with MS found that socio-environmental support such as household adaptation, better transport and rehousing was the category that was most frequently suggested categories.24 Having better programs allows for caregivers of patients living with MS a better support system and lessens the burden. In a study done by Akku (2010) on caregivers and their level of stress in taking care of someone with MS found that the major predictors of feeling overburdened were feeling hopelessness, conflicts in decision making, not having enough time for leisure activities and social isolation.25

In addition to this, some people with MS may have loss of mobility which increases pain when carrying out even the simplest of tasks. Therefore for individuals living with MS, having a full rounded support system is key to their overall wellbeing. A study that examined the impact of walking impairment in people with MS found that among the 1011 people with MS, 41% reported having difficulty walking, with 70% stating that walking was one of the most difficult aspect of having MS and 74% stated that it disrupted their activities of daily living.26 In addition to this, 39% of people with MS stated that they never or rarely discussed the problem they have about difficulty with walking to their family doctor.26

However not all caregivers will seek the support they need. In a study done on caregivers who cared for family members with MS found that caregivers tend to reject support from other family members or friends because they did not want to face the reality that someone they love had MS.26 In other cases, rejecting help was also associated with wanting more control of the situation. Other reasons for not asking for help was the caregivers thought that no one knew the care recipient well enough to take care of them and thought it was their responsibility to do it themselves.26 Some caregivers were not satisfied with the support services in their area where many found that support services did not adequately meet the needs of the care recipient.26 It is important for caregivers to seek support when needed and talk to their doctors about getting the proper services. Having support workers, visiting nurses, home maintenance services, workplace or even vehicle modifications can improve the quality of life of both the person living with MS as well as their caregiver.27

The results of the study also indicate that having poor health is associated with increased odds of pain among individuals with MS. MS is a condition that occurs with other conditions such as migraine headaches, back pain, depression, spasms etc. Therefore, those who have MS may be in more pain because of these conditions and may have been overlooked in the diagnosis or they may not seek help for these conditions. In addition to support services, self-efficacy is equally as important in overcoming illnesses and this concept has been examined in other studies as a predictor for self-rated health.28 Self-efficacy is the ability of someone to adjust to the condition they have which would allow them to cope more effectively.28 It is linked to self-esteem and how much control a person has.28 There are 4 ways to improve self-efficacy: 1) experience of accomplishing a behavior; 2) vicarious learning or modelling the behavior; 3) through encouragement or support from others; and 4) through physiological arousal such as anxiety which is connected to the behaviour.28 Other studies have also showed that self-efficacy is a significant predictor of self-reported physical, cognitive and social functioning in MS.29 Therefore it is important for patients living with MS to seek help when they cannot cope with the illness by going to therapy, counselling or joining support groups. Through these methods, patients can gain the confidence to overcome certain aspects of the illness and improve their quality of life. We didn’t find an association between pain and conditions such as poor sleep, mood disorder or the number of years living with MS. In addition to there was no interaction between mood disorder and family support in the final model and it’s association to pain.

The strength of this study is that we were able to determine that there is a strong association between social risk factors and pain and our findings also highlight the importance of having services for patients living with MS. Some of limitations of this study was that the type of MS was not available which could have helped in determining whether pain varied based on type of MS. Since the pain category was not in a scale, it was difficult to determine the level of pain of the people who replied to the survey.

**Conclusion**

The role of caregivers is important to the well-being of people living with MS. Therefore, it is important that caregivers get the help they need in order to reduce burnout. The results of this research will inform clinicians about the importance of caregiver support and how to help their patients seek out quality services that can help them with their needs. An example of resources that clinicians can give to caregivers is caregiver educational materials. The MS society of Canada has an information and resource page on their website which provide webinars to caregivers, peer support group and caregiver guides.30 The MS society of Canada also has resources to help with
respite services which provide primary caregivers a break from their duties by providing them with a personal care worker to come in and help the patient. In addition to this self-efficacy is important when overcoming many illnesses and people with MS should seek help if they cannot cope with their illness. The results of this study will also inform health care organizations on ways to improve home care services for people with MS especially in lower income neighborhoods.

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Author Contributions
KBA was involved in conceiving and designing the study along with analyzing and interpreting the data. CD provided review, feedback, and revisions of the manuscript. Both authors approved the final version of the manuscript.

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Ethical Approval
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