

# Symptom Management Among Multiple Sclerosis Care Partners in Canada

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1. Characterize the type, number, and frequency of symptoms MS care partners manage.
2. Describe the level of symptom management difficulty in the caregiving role and types of support preferred by MS care partners.

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## ABSTRACT

**BACKGROUND:** Managing the heterogeneity and unpredictability of multiple sclerosis (MS) symptoms can be difficult for MS care partners. This study aimed to characterize the symptoms managed by MS care partners, recognize relationships between symptom management difficulty and other aspects of the caregiving role, and identify supplemental sources of caregiving support used by care partners.

**METHODS:** A Canadian cohort of MS care partners completed an online survey capturing care-partner characteristics, care-recipient symptoms, care-partner difficulty with managing symptoms, and sources of caregiving assistance. Descriptive analysis, analysis of variance, and  $\chi^2$  tests were used to compare differences in care-partner characteristics by symptom management difficulty groups, defined as low (<4 symptoms), medium (5-7 symptoms), and high difficulty (>7 symptoms).

**RESULTS:** Care partners to individuals with MS (N = 475) reported a median of 8 symptoms (IQR = 4) experienced by their care-recipients. The most frequent symptoms reported were fatigue (89.1%), weakness (87.2%), and depression (81.9%). Care partners reported a median of 6 (IQR = 5) symptoms being *somewhat* or *very difficult* to manage. Balance or mobility impairments (20.3%), depression (14.3%), and vision difficulties (13.1%) were most frequently reported as *very difficult* to manage. Assisting with activities of daily living ( $P < .001$ ) and time spent caregiving ( $P = .035$ ) varied significantly between symptom management difficulty groups. Additional help available was reported by 77.5%, 17.8%, and 41.6% of care partners reporting low, medium, and high symptom management difficulty, respectively ( $P < .001$ ).

**CONCLUSIONS:** Care partners of individuals with MS report difficulty in managing multiple, variable symptoms and often have no additional help. These findings suggest that MS care partners experience difficulty managing many diverse symptoms and may benefit from additional support.

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**M**ultiple sclerosis (MS) is a neurodegenerative disease that causes progressive physical and cognitive deficits manifesting in heterogeneous symptoms such as weakness, fatigue, mobility limitation, cognitive impairment, and changes in mood.<sup>1</sup> These symptoms have wide-reaching impacts on the independence and quality of life of individuals living with MS and can be difficult to manage, as they are often invisible, evolving, and poorly addressed with traditional approaches to care.<sup>2</sup> Strategies to manage the complex symptoms of MS such as fatigue and chronic pain tend to include multiple routes of medical and lifestyle intervention requiring active participation from the patient.<sup>3-5</sup>

Consequently, many individuals with MS need additional support for daily management of their disease and a majority of the care required is provided by care partners, such as family members or friends.<sup>6</sup> Care partners deliver a range of practical, emotional, and financial support that allows their loved ones with MS to live and fully participate within the community.<sup>7</sup> The complexity of care needs associated with having multiple co-occurring symptoms, however, can be difficult to manage for care partners.<sup>8</sup> For instance, walking limitations, executive dysfunction, aggression, anxiety, and depression have been identified as important predictors of strain in MS care partners.<sup>6,8</sup> Elevated levels of MS caregiver strain have largely been attributed to worsening care-recipient cognitive and neuropsychiatric symptoms in particular.<sup>8-10</sup>

When the demands for care exceed an individual's capacity to provide care, role-related strain supervenes.<sup>11</sup> Many MS care partners report high levels of strain, even at low levels of care-recipient disability.<sup>9</sup> The changing roles and time constraints associated with providing care may elevate reported levels of strain, which grows as MS-related disability progresses.<sup>9</sup> The multifaceted, transient, and unpredictable nature of symptom management further intensifies feelings of stress and strain.<sup>9</sup> Experiencing strain can be detrimental to the health and well-being of care partners as overwhelming demands cause feelings of grief, helplessness, and loss of self-esteem.<sup>9</sup> The psychological toll is evident and manifests as increased reporting of stress, anxiety, and depression-related symptoms among MS care partners when compared with the general public.<sup>9,12</sup> The health and well-being of caregiving populations are essential to not only the care partners themselves, but also to individuals living with MS who receive almost three-quarters of their care from informal sources.<sup>13,14</sup> This unpaid support is essential in ensuring sufficient care while alleviating the financial toll faced by already overburdened health care systems that have come to rely on informal support.<sup>15</sup>

Although the impact of MS symptoms on care partners' well-being is well reported in the literature,<sup>8-10,12</sup> current research fails to assess the practical implications of MS symptoms and their management within the caregiving role. Indeed, little is known about the types of symptoms MS care partners navigate and their ability to manage these symptoms from day to day. In order to provide comprehensive and relevant support to MS care partners, the identification of the symptoms that they manage as well as their perceived difficulty in managing them must first be understood. Therefore, the objectives of this study were to: (a) characterize the types and number of symptoms managed by MS care partners; (b) identify the relationship between symptom management

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**TABLE 1.** Care-Partner Characteristics

Variable	Total (N = 475)	Low difficulty (n = 111)	Medium difficulty (n = 219)	High difficulty (n = 145)	P value
Age, mean (SD)	39.8 (7.4)	41.4 (9.3)	38.0 (4.6)	41.6 (8.6)	< .001 <sup>a</sup>
Gender, male, n (%)	325 (68.4)	78 (70.3)	160 (73.1)	87 (60.0)	.064
Relationship to care-recipient, n (%)					< .001
Spouse/partner	312 (65.7)	45 (40.5)	184 (84.0)	83 (57.2)	
Parent	156 (32.8)	63 (56.8)	34 (15.5)	59 (40.7)	
Child	2 (0.4)	1 (0.9)	1 (0.5)	0 (0)	
Sibling	3 (0.6)	2 (1.8)	0 (0)	1 (0.7)	
Uncle/aunt	1 (0.2)	0 (0)	0 (0)	1 (0.7)	
Other	1 (0.2)	0 (0)	0 (0)	1 (0.7)	
General health status, n (%)					< .001
Excellent	31 (6.5)	23 (20.7)	2 (0.9)	6 (4.1)	
Very good	398 (83.8)	68 (61.3)	201 (91.8)	129 (89.0)	
Fair	42 (8.8)	19 (17.1)	14 (6.4)	9 (6.2)	
Poor	4 (0.8)	1 (0.9)	2 (0.9)	1 (0.7)	
Minutes of care per day, mean (SD)	60.2 (63.6)	77.6 (58.8)	53.1 (56.2)	70.5 (78.3)	.035 <sup>a</sup>
Duration of care in years, mean (SD)	5.8 (4.3)	7.7 (7.4)	5.4 (3.5)	5.9 (4.4)	.042 <sup>a</sup>
CTIMSS-ADL score, mean (SD)	14.6 (6.2)	15.6 (4.6)	11.3 (4.1)	18.9 (7.2)	< .001 <sup>a</sup>
PDDS of care-recipient, median (IQR)	3 (2)	3 (2)	2 (1)	4 (2)	< .001

CTIMSS-ADL, Caregiving Tasks in MS Scale-Activities of Daily Living Subscale; IQR, interquartile range; PDDS, Patient-Determined Disease Steps.

<sup>a</sup>Significance determined by  $\chi^2$  or analysis of variance test.

difficulty and other aspects of caregiving; and (c) identify sources of caregiving support used by care partners.

## METHODS

This manuscript reports on cross-sectional data from a longitudinal study of psychological resilience in MS care partners. Baseline data from the study has been previously reported.<sup>16</sup> The study protocol was approved by the University of Ottawa Science and Health Sciences Research Ethics Board [H-02-20-5338]. Informed consent was provided by all participants.

### Participants

From across Canada, MS care partners were recruited online through MS Canada's research portal and regional chapters, national care partner organizations, newsletters, and social media outlets. Eligibility criteria were: (1) 18 years of age or older; (2) currently providing physical, emotional, or informational assistance for an individual living with MS; (3) resident of Canada; and (4) able to complete an online survey in English. Additional details of recruitment and data collection have been previously reported.<sup>16</sup> Data collection for the current paper was completed between July 22, 2021, and August 25, 2021.

### Measurement

#### Care Partner Characteristics

The questionnaire included general items capturing age, sex, and health status.<sup>17</sup> Care-recipients' disability levels were reported by care partners using the Patient-Determined Disease Steps (PDDS) scale.<sup>18</sup> A self-report measure for MS-related disability, PDDS has 9 ordinal levels

ranging from 0 (*no disability*) to 8 (*bedridden*).<sup>18</sup> Scores on the PDDS have strongly correlated with scores on the clinically administered Expanded Disability Status Scale (EDSS).<sup>18</sup>

#### Care Partner Role

Minutes of care per day provided by care partners and their relationship to their care-recipient were collected to characterize the care-partner role. Care partner assistance with activities of daily living (ADL) was captured using the Caregiving Tasks in MS Scale ADL subscale.<sup>19</sup> This scale is a 26-item, MS-specific questionnaire evaluating the degree to which care partners assist with various instrumental, sociopractical, and psycho-emotional tasks on a 4-point scale ranging from 1 (*no help*) to 4 (*lots of help*).<sup>19</sup> The ADL subscale consists of 7 items required for basic care including feeding, toileting, and medication administration.<sup>19</sup> Care partners were also asked to report whether they had any additional help with providing MS-related care, who offered that help, and, if no additional help was available, why this was the case. A predetermined list of additional help and reasons for not receiving help were provided for care partners to choose from, as well as an *other* option that allowed respondents to specify any supplemental information via written response.<sup>17</sup>

#### Symptom Management

Care partners were provided a list of 16 common MS-related symptoms and asked to indicate whether the symptom was experienced by their care-recipient. The list of symptoms was drawn from the *Aging With Multiple Sclerosis: Unmet Needs in the Great Lakes Region* report.<sup>17</sup> If the participant indicated that their care-recipient did experience the symptom, care partners were asked to then classify how difficult

**TABLE 2.** Additional Caregiving Help Available

Variable	Total (N = 475)	Low difficulty (n = 111)	Medium difficulty (n = 219)	High difficulty (n = 145)
<b>Presence of additional help, n (%)</b>				
Yes	200 (42.1)	86 (77.5)	39 (17.8)	75 (51.7)
No	259 (54.5)	23 (20.7)	178 (81.3)	58 (40.0)
<b>If yes, relationship to individual with MS, n (%)*</b>				
Spouse	132 (23.9)	54 (28.7)	16 (7.3)	62 (42.8)
Sibling	104 (18.8)	46 (24.5)	15 (6.8)	43 (29.7)
Child	68 (12.3)	31 (16.5)	15 (6.8)	22 (15.2)
Other relative	64 (11.6)	34 (18.1)	13 (5.9)	17 (11.7)
Professional care assistant	30 (5.5)	1 (0.5)	4 (1.9)	25 (17.2)
Friend	23 (4.2)	10 (5.3)	6 (2.7)	7 (4.8)
Grandchild	3 (0.5)	0 (0)	1 (0.5)	2 (1.4)
<b>If no additional help, why, n (%)*</b>				
Will not ask for help	197 (35.7)	10 (5.3)	155 (70.8)	34 (23.5)
Have not accepted offers of help	50 (9.1)	0 (0)	34 (15.5)	16 (11.0)
No need for additional help	17 (3.1)	8 (4.3)	2 (0.9)	7 (4.8)
No one available to ask	10 (1.8)	4 (2.1)	3 (1.4)	3 (2.1)
Helpers live too far away	3 (0.5)	2 (1.1)	0 (0)	1 (0.7)

\*Participants could select multiple responses.

the symptom was for them to manage on a 3-point scale ranging from 1 (*not at all difficult*) to 3 (*very difficult*).<sup>17</sup>

### Analysis

Descriptive statistics were used to summarize care-partner characteristics and role variables. Symptoms were characterized by frequency and symptom management difficulty ratings as reported by care partners. The sample was then split into low, medium, and high symptom management difficulty groups based on the number of symptoms reported as *somewhat* or *very difficult* to manage. Participants were categorized as low (difficulty managing <4 symptoms), medium (difficulty managing 5-7 symptoms), and high (difficulty managing >8 symptoms) in order to achieve groups of approximately equal sizes. Analysis of variance with Bonferroni post hoc testing and  $\chi^2$  testing was then conducted to identify potential differences in the amount of assistance with ADLs, minutes of care per day, and the presence of additional help provided across groups based on symptom management difficulty.

## RESULTS

### Participant Characteristics and Care Partner Role

A total of 509 invitations to complete an online survey were distributed to care partners; 475 responses were received. A summary of sample characteristics is presented in **TABLE 1**. Care partners were, on average, 39.8 years of age (SD = 7.4), mostly male (68.4%), spouses (65.7%), and reported *very good* health (83.8%). The median care-partner-reported PDDS score for their care-recipient was 3 (IQR = 2), corresponding to intermittent use of a mobility aid. The mean time spent providing care per day was 60.2 minutes (SD = 63.6) and the duration of caregiving was an average of 5.8 years (SD = 4.3).

### Symptom Management

The most frequently encountered MS symptoms reported by care partners were fatigue (89.1%), weakness (87.2%), and

depression (81.9%). More than half of care partners characterized tremors (90.6%), spasticity (89.3%), and fatigue (87.2%) as *somewhat difficult* to manage. Problems with balance or mobility, depression, and vision were most often cited as *very difficult* to manage by 20.3%, 14.3%, and 13.1% of the participants, respectively. A full summary of symptom management is depicted in **FIGURE S1**.

When symptom management difficulty groups were compared, there were significant differences in ADL assistance ( $P < .001$ ) and minutes of care per day ( $P = .035$ ). Care partners experiencing high levels of symptom management difficulty assisted most with ADLs when compared with those who experienced medium ( $P < .001$ ) and low levels of difficulty ( $P < .001$ ). Post hoc comparisons among groups regarding minutes of care per day were not significant.

### Presence of Help

Of the care partners in this study, 42.1% indicated that they received additional support in their caregiving role. This additional help was most often provided by individuals in natural social support networks, such as the spouses (23.9%) or siblings (18.8%) of the care-recipient, with only 5.5% of care partners indicating the presence of formal help, such as personal support workers.

There were significant differences in the number of care partners reporting additional help according to the level of reported symptom management difficulty ( $P < .001$ ). Care partners who experienced moderate symptom management difficulty reported receiving additional assistance least often at 17.8%. Those reporting low and high levels of difficulty with symptom management reported the presence of additional help at 77.4% and 51.7%, respectively.

Of participants reporting no additional help, the most common reason was not asking for help (35.7%) or not accepting help (9.1%), despite it being available. Furthermore, 3.1% of respondents indicated that there was no need for additional



Even when dealing with low levels of disability, multiple sclerosis care partners reported difficulty managing many of their care recipients' cognitive and physical symptoms.

Less than half of care partners accessed additional assistance for their caregiving role, even if it was available.

When care partners do have additional assistance, the helpers often are also family members or friends. ■

help and 1.8% indicated no available potential help. A summary of responses is presented in **TABLE 2**.

## DISCUSSION

This study characterized the prevalence and management of MS symptoms as reported by MS care partners and investigated sources of caregiving assistance. Care partners reported a variety of symptoms experienced by their care-recipient, many of which often came with at least some degree of management difficulty. Additional caregiving help was not always present and, when it was, it predominantly consisted of individuals from natural social support networks, like other family members or friends.

The most frequently reported MS symptoms by care partners were fatigue, weakness, and depression. This is not surprising, as recent studies have indicated that fatigue and weakness are the most common self-reported manifestations of the disease in other MS samples.<sup>2,20</sup> Notably, fatigue is often described as having debilitating effects on social participation, employment, and quality of life among individuals with MS.<sup>3</sup> The successful management of fatigue is difficult, as many interventions yield mixed results and often require continuous active participation.<sup>3</sup> Therefore, the management of fatigue by MS care partners may not only be very common, but may also contribute significantly to their caregiving load.

The prevalence of depression in care-recipients reported by care partners in the current study (81.9%) is much higher than previous estimates in MS samples, which have ranged between 4.3% and 59.6%.<sup>10,21</sup> This finding may be indicative of wider methodological issues relative to identifying

and diagnosing depression in people with MS, as well as the co-occurrence of depressive symptoms with other common MS symptoms such as pain and fatigue.<sup>21</sup> Proxy-reporting of neuropsychiatric symptoms by care partners has relatively good correlation with patient-reported symptoms in other neurological conditions such as Parkinson disease and stroke; however, the prevalence and severity of symptoms may be somewhat overestimated by care partners.<sup>22,23</sup> The validation of proxy-reported symptom inventories for MS would be beneficial when creating care-partner support initiatives to ensure adequate and appropriate consideration of the complexity and variety of the symptoms they manage.

Regardless, depression was identified as one of the most challenging symptoms for care partners to manage. Neuropsychiatric symptoms, including those associated with depressive disorders, are well cited as being among the most challenging to MS care partners.<sup>2,8-10,20</sup> Our findings reinforce the need for additional systemic support to help in the management of neuropsychiatric symptoms associated with MS.<sup>8,9</sup> However, mobility and balance and decreased vision were the next most difficult symptoms to manage, emphasizing the breadth of symptoms that MS care partners face. Indeed, the physical disabilities of individuals living with MS often limits their abilities to complete ADLs, placing additional stress on and negatively impacting the quality of life of their care partners.<sup>24</sup>

Systems of support available to care partners must be sufficiently robust to acknowledge and address the complexity of MS care, including the numerous MS-related and comorbid symptoms they may be managing. Comorbid conditions in MS are common and often require supplementary care.<sup>25</sup> Additional investigation into the effect of MS comorbidity on caregiving load is warranted to better understand the scope of care being managed.

While MS care partners report difficulty managing symptoms, many do not receive additional external support. The proportion receiving additional help does not appear to increase with symptom management difficulty despite the escalating need for care partners to provide assistance with ADLs. In fact, care partners who reported moderate symptom management difficulty were *least* likely to receive additional assistance and *most* likely to not ask for help. It is possible that many care partners who do receive assistance reported low symptom management difficulty due to the additional help. Likewise, additional assistance may be essential for care partners who reported high difficulty in meeting the care-recipient's daily needs. The low frequency of additional assistance in the moderate-symptom management difficulty group may therefore be a compounding of these 2 effects. Care partners may be experiencing greater difficulty with symptom management due to the lack of assistance, while also not perceiving enough difficulty to seek out help. This dynamic could have important implications when assessing their support needs, as care partners experiencing moderate difficulty are least likely to ask for

help despite the potential for additional support to assist in symptom management. This paradigm warrants further investigation in future studies.

When additional help is present, those helpers are also most commonly informal care partners, such as friends or family members. These individuals also may have concurrent life stressors, including caring for children and managing careers<sup>9</sup> while providing supportive care. Thus, the potential for negative caregiving-related impacts may extend beyond primary care partners to affect wider social care networks.

The presence of multiple friends or family members in caregiving roles highlights the importance of informal care partners and support networks in the management of MS. Support systems that include and transcend biological ties are often required in order to meet the multifactorial needs an individual living with a disability may experience.<sup>26</sup> Investigating the composition and dynamics of extended MS caregiving support systems is a critical next step toward better understanding the caregiving role and its related stressors as a whole. Moreover, the fact that very few care partners currently receive professional assistance suggests that current professional support options may not be readily accessible or socially acceptable. Therefore, personal or informal helpers may represent the preferred resource among MS care partners and their care-recipients. This preference has been reported among other caregiving populations, including individuals caring for those with AIDS.<sup>27</sup>

Most care partners reported a persistent need for additional assistance despite acknowledging existing sources of support. This finding illustrates a possible hesitancy in initiating or accessing existing potential support. Hesitance to mobilize support networks has been noted in other caregiving populations and may be attributed to a routinization of care duties among care partners.<sup>28</sup> Recent studies have noted a preference among caregivers for passive informational support (eg, website, guides) in lieu of active participation in the form of emotional or practical support (eg, counseling, support groups).<sup>29</sup> Our findings corroborate these trends in an MS-specific caregiving population and demonstrate that support access is not sufficient. Making professional care from external agencies available and encouraging the use of informal familial support may not be sufficient to increase the amount of support ultimately received by MS care partners. Additional steps must be taken to educate and encourage care partners to mobilize support using a delivery method that is relevant and acceptable to this specific population.

With that said, future examination of the factors influencing MS care partner external support preferences is warranted, as is a renegotiation of how care partners are valued and supported in Canadian society. If care partners are relying on their natural social networks for assistance, we must ensure a balance between supporting these existing social structures and the availability and accessibility of supplemental, formal support mechanisms. Future efforts must

recognize the critical roles of both natural support structures and professional care in maintaining the well-being of individuals living with MS and their care partners.

While the current study provides a preliminary examination of symptom management and sources of informal support among MS care partners, it is important to acknowledge several limitations.

As declines in ADL participation and greater caregiving burden have been associated with increased MS-related disability,<sup>30,31</sup> the relatively low level of disability reported by our sample may underestimate the quantity and complexity of care provided by MS care partners who support individuals with higher levels of disability.

Our strategy for MS symptom reporting was broad and based on care partner reports. We did not ask care partners to specify symptom severity or how involved they were with symptom management. We also did not collect information on how effectively they were able to manage symptoms, including through medical or lifestyle interventions; we only captured the perceived difficulty of symptom management by the care-partner. These factors may have contributed to heterogeneity in care partner reporting of their lived experiences, which may limit broad generalizations of these findings. Further investigation of care-partner reported outcomes regarding MS symptoms and their management is warranted.

Cutoffs for the low, medium, and high groups were set to achieve equal group sizes as there is currently no precedent for determining symptom management difficulty for care partners. While these cutoffs maximize the power and robustness of our analyses, they may limit the practical transferability of our findings. Future research examining the effects of symptom comanagement on MS caregiving outcomes would be helpful to delineate important benchmarks in symptom management difficulty.

Data were collected in the summer of 2021, while many areas of Canada were still experiencing the effects of the COVID-19 pandemic and associated restrictions to accessing public health and social care services. Many caregivers experienced reduced external support and increased caregiving tasks as a result of lockdown measures and social distancing.<sup>32</sup> As a result, our sample population may have reported accessing less support and managing more symptoms than they may have before or after the pandemic. Additional investigation to confirm the present findings and examine the effects of pandemic-related measures on symptom management in MS care partners is warranted.

## CONCLUSIONS

This study characterized MS care-recipients' symptom management by their care partners. We note a high level of difficulty in managing symptoms and frequent absence of additional caregiving help. Our findings suggest that more needs to be done at broader community and societal levels to bolster the formal and natural social networks used by care partners. Existing and future resources not only need

to be accessible to meet the needs of care partners, but they must also be relevant and accepted by the vulnerable populations they aim to support. ■

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