

Profiling Symptom Management in Multiple Sclerosis Care-Partners: A Canadian Cross-Sectional Study

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Background

- Disability in multiple sclerosis (MS) can manifest in a variety of physical and cognitive symptoms¹.
- To manage progressive disability, many people with MS rely on informal, unpaid care-partners, such as friends or family members².
- The variety and variability in symptom management can lead to burden and distress among MS care-partners³.

Objectives

- To characterize the types and number of symptoms managed by MS care-partners in their caregiving roles; and
- To examine trends in characteristics related to the caregiving role according to symptom burden.

Methods

- MS care-partners were recruited via online materials distributed by the MS Society of Canada's Research Portal, newsletters and social media outlets.
- Cross-sectional, online survey of MS care-partners from across Canada (n=475).
- Self-reported demographics, symptom management, caregiving tasks (Caregiving Task Inventory for MS), and sources of support.
- Descriptive analyses, ANOVA and chi square testing with post-hoc analyses were performed to identify and assess associations.

Results

- A median of 8 symptoms (IQR=4) were reported by care-partners with them reporting some degree of difficulty in managing a median of 6 symptoms (IQR=5).
- The three most common MS symptoms care-partners reported within their care recipients were fatigue (89.1%), weakness (87.2%), and depression (81.9%).
- The MS symptoms reported as most difficult to manage by care-partners were problems with balance or mobility (20.3%), depression (14.3%), and problems seeing (13.1%).
- Only 42.1% of care-partners reported having additional helpers with their caregiving role.
- Care-partners reporting a high symptom burden (difficulty in managing >8 symptoms) assisted with the most activities of daily life (p<0.001) and most often had additional assistance (p<0.001) at 56.4% indicating the presence of helpers.

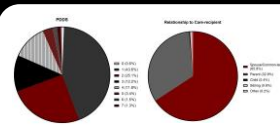


Figure 2. Distribution of PDDS and relationship to care-recipients among respondents.

MS Symptoms Reported by Care-partners

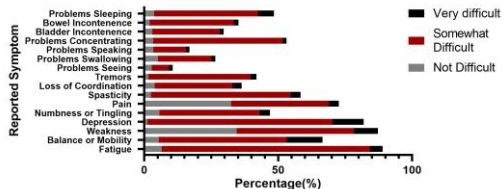


Fig 1. MS symptoms experienced by care-recipients as reported by care-partners. Symptoms are further categorized by how difficult care-partners perceive they are to manage

Conclusions

- Many MS care-partners do not receive additional assistance in their caregiving role despite reporting to struggle with managing many symptoms.
- Care-partners managing multiple symptoms may benefit from additional support in their caregiving role, particularly those managing mobility limitations and/or depressive symptoms in their care recipients.

References

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Key Findings

- Care-partners report difficulty in managing numerous symptoms of MS in their care recipients.
- Depressive symptoms are one of the most common symptoms of MS reported by care-partners and one of the most difficult to manage.
- Care-partners often have no additional sources of help with their caregiving role, regardless of symptom burden.

