

Multiple sclerosis

# Caregiver burden in multiple sclerosis

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## Impact of physical disability, fatigue, cognitive dysfunction and formal ratings of dementia on caregiver burden

In the paper by Figved and colleagues<sup>1</sup> in this issue of *J Neurol Neurosurg Psychiatry*, the impact of neuropsychiatric symptoms on caregiver burden is examined (see page 1097). These investigators compared 76 multiple sclerosis (MS) and 58 Parkinson's disease (PD) patient-caregiver couples on a measure of caregiver distress (the Relative Stress Scale (RSS)) and a general quality of life measure. The RSS consists of subscales measuring personal distress relating to caregiving, life upset relating to life changes associated with caregiving and negative feelings towards the patient. The authors found that quality of life was impacted comparably in both groups. The scores of both caregiver groups was high on the RSS but the scores for the PD caregivers was significantly higher, primarily because of their reports of greater life upset.

These investigators further examined the relationship between neuropsychiatric symptoms, physical disability, fatigue and cognitive functioning with caregiver variables in the MS-caregiver dyads. Dementia and higher levels of neuropsychiatric symptoms in the patients were associated with poorer quality of life in caregivers. Additionally, higher levels of life stress were significantly associated with greater neuropsychiatric symptoms, physical disability, dementia and cognitive dysfunction. Furthermore,

higher levels of personal distress and negative feelings in caregivers were significantly associated with higher levels of neuropsychiatric symptoms, physical disability and dementia in the MS patients. The authors also reported that caregivers' highest neuropsychiatric symptoms were depression, irritability, apathy and fatigue. Finally, caregiver distress was greatest when the patients displayed symptoms of delusions, followed by disinhibition, agitation and anxiety.

This study extends previous limited research in this area by broadening the scope of neuropsychiatric symptoms considered beyond just depression and, importantly, highlights neuropsychiatric symptoms in patients that are the most distressing to caregivers. It also provides a broader context for the influence of MS symptoms on caregiver burden in MS by considering the impact of physical disability, fatigue, cognitive dysfunction and formal ratings of dementia on caregiver burden. There were some limitations to the study. Firstly, the quality of life measure used is somewhat limited in scope. It consists of only 12 items and does not allow for an analysis of different components of quality of life. Secondly, measures of depression and fatigue used for the study were one dimensional. Using measures that allow for the parsing of different aspects of depression<sup>2</sup> and fatigue<sup>3</sup> in future work would help to

expand on the current study. Thirdly, the cognitive measures used were limited to the measurement of attention/working memory, memory and speeded processing. Executive function is a cognitive domain commonly affected in MS and likely to be highly relevant to caregiver burden. Fourthly, the inclusion of a self-report measure of daily cognitive problems encountered by patients, such as the MS Neuropsychological Questionnaire,<sup>4</sup> might have been illuminating. Fifthly, although the sample included some non-spouse caregivers, the numbers were too few to allow for meaningful comparisons.

Caregiver burden is an extremely important applied issue in MS because patients are most commonly diagnosed in their 20s or 30s, thus many years of caregiving are often involved. To date, this issue has received little research attention. Future work could expand upon these authors' work by addressing some of the limitations outlined above.

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