

Research In Focus: A Weekly Digest of New Research from the NIDILRR Community

Which Symptoms are Most Challenging for People with Multiple Sclerosis?

Multiple sclerosis (MS) is a chronic condition affecting the central nervous system. MS is related to a variety of symptoms that are often variable and unpredictable. Symptoms of MS can either come and go (relapsing-remitting MS) or get worse over time (progressive MS). Common MS symptoms include trouble walking, fatigue, weakness, pain, and problems with thinking and memory. These symptoms can increase the risk of mental health problems. They can also make it difficult to participate in life activities, such as working, socializing, and managing household tasks. One recent NIDILRR-funded study looked at eight MS symptoms to see which ones are most common, most severe, and most strongly related to mental health and participation at home and in the community.

Researchers from the [Multiple Sclerosis Rehabilitation Research and Training Center](#) analyzed data from surveys of 180 people with MS, aged between 24 and 87 years old. The surveys asked respondents to rate how severely they experienced 8 symptoms of MS on an 11-point scale from 0 (none) through 10 (very severe). The symptoms were fatigue, imbalance, weakness, numbness, pain, memory loss, vision loss, and shortness of breath. The survey also asked how much MS affected the respondents' mobility and whether their MS was relapsing-remitting (the type that comes and goes) or progressive (the type that gets worse over time). They also answered questions regarding their mental health and ability to participate in household tasks such as shopping and cooking, social activities outside the home, and work or school activities.

Most respondents reported experiencing multiple MS symptoms and at least one symptom that was severe. Different symptoms were related to different aspects of functioning. Specifically, the researchers found that:

- On average, respondents reported experiencing about five symptoms. Most respondents (64%) had at least one severe symptom.
- The most common symptoms were fatigue, weakness, imbalance, and numbness, with at least three-fourths of respondents experiencing each of these symptoms.
- Pain, memory loss, and vision loss were also very common, with over half of respondents endorsing each of these symptoms.
- The least common symptom was shortness of breath, affecting only about a quarter of respondents.

- Fatigue, weakness, and imbalance were more severe for respondents with progressive forms of MS than for people with relapsing-remitting MS.
- Generally, respondents with greater mobility limitations reported worse fatigue, weakness, numbness, and pain. However, other symptoms like vision and memory loss were not closely related to mobility status.
- Respondents who experienced greater weakness reported more difficulty in completing household tasks, working or studying, and socializing.
- Respondents who experienced vision loss or memory loss were less likely to be working or in school than those who did not have these symptoms.
- Respondents who experienced memory loss reported greater difficulties with social activities outside the home.
- Respondents who experienced fatigue reported more difficulty completing home-related tasks such as shopping and cooking.
- Pain, fatigue, and memory loss were associated with worse mental health.

The authors noted that medical categories such as the type of MS and the level of progression do not tell the whole story when it comes to how the symptoms affect the person's quality of life. The severity of MS is often graded based on mobility symptoms alone. However, different people with the same level of severity or type of MS could have very different experiences, both in terms of the types of symptoms and the impact of those symptoms on mental well-being and ability to participate at home and in the community. The authors suggested that these results highlight the importance of assessing all MS symptoms and their impact on quality of life, rather than focusing on just a few symptoms to determine the severity of MS. For instance, mobility-related symptoms may have different effects on daily life compared to other symptoms such as memory and vision loss.

As suggested by the authors, clinicians may want to develop individualized treatment plans with patients based on their unique goals and priorities related to MS symptom management. For example, for individuals wishing to stay employed, it may be most important to manage the effects of memory or vision loss. Understanding how the most common symptoms of MS impact everyday life may help people with MS and their healthcare providers address limitations, target overall wellness, and maintain active participation in the community.

The respondents in this study tended to have more severe MS than the general MS population. Findings may be different in people with milder forms of MS. In addition, future studies may be useful in examining how particular symptoms affect changes in functioning and mental health over time.

To Learn More

The MS Rehabilitation Research and Training Center completed its NIDILRR-funded research activities in 2014. Their website has great collection of resources including

- The MS Workbook: Living Fully with Multiple Sclerosis is a comprehensive guide to help you manage fatigue and weakness, cope with pain, get the most out of the health care system, combat anxiety and depression, optimize activity levels, create a career and financial plan, maintain intimacy with a partner, and gain support from family, friends, and the community:
<http://msrrtc.washington.edu/info/msworkbook>
- MS from A to Z video series: <http://msrrtc.washington.edu/info/msatoz>
- Living Well with MS factsheets: <http://msrrtc.washington.edu/info/factsheets>

The Living Well with a Disability program from the Rehabilitation Research and Training Center on Disability in Rural Communities is a ten week peer-facilitated health promotion workshop for people with disabilities. Participants in the program learn the life skills they need to set and achieve quality-of-life goals and the important role health plays in helping them reach their dreams.

<http://livingandworkingwell.ruralinstitute.umt.edu/>

The National MS Society also offers comprehensive resources for people with living with MS, clinicians and other healthcare providers, and people supporting loved ones with MS: <http://www.nationalmssociety.org>

The Chronic Disease Self-Management Program can help people with conditions like MS learn to manage symptoms that impact everyday life. Find a local provider:
<https://www.ncoa.org/healthy-aging/chronic-disease/chronic-disease-self-management-program/>

To Learn More About this Study

Kratz, A.L., Ehde, D.M., Hanley, M.A., Jensen, M.P., Osborn, T.L., and Kraft, G.H. (2016) [Cross-sectional examination of the associations between symptoms, community integration, and mental health in multiple sclerosis](#). Archives of Physical Medicine and Rehabilitation, 97, 386-394.

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