

More than half of American adults with advanced MS report mistreatment by caregivers

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Dr. Elizabeth Morrison-Banks is a health sciences clinical professor at UC Riverside. Credit: Stan Lim, UC Riverside.

Four in 10 people with advanced multiple sclerosis, or MS, are

emotionally abused by someone responsible for caring for them, reports a study led by the University of California, Riverside.

Further, the study finds one quarter are financially exploited, one in six are neglected, one in nine are battered, and one in 12 are sexually assaulted by a [caregiver](#).

"We knew we would find some level of abuse and neglect, but we were surprised by how prevalent it is," said Dr. Elizabeth Morrison-Banks, a [health sciences](#) clinical professor at the UC Riverside School of Medicine, who led the study. "The findings of this study represent a collective cry for help from so many families affected by multiple sclerosis across the United States."

MS is an autoimmune disease that affects more than 2.3 million people worldwide. This chronic, degenerative neurological condition periodically shuts communication between the brain and other parts of the body, resulting in symptoms that include numbness and tingling in the arms and legs, as well as blindness and paralysis.

"MS affects people in different ways," Morrison-Banks said. "Some people live with MS for many years but with milder symptoms, and they may remain completely self-sufficient and never require a caregiver. Others are less fortunate and develop neurological disability that can make them vulnerable to abuse and neglect if they are unable to move around independently, take care of their own finances, or get away from the situation when [family conflict](#) escalates. These problems are compounded if the person with MS and [family](#) lack financial resources."

Morrison-Banks explained that for families who are struggling economically, relying on a paid caregiver is often not an option, and family caregivers have to step in to fill the breach.

"Some family caregivers are also working full time, caring for children or other [family members](#), and sometimes dealing with health issues of their own," she said. "All of these challenges can increase risk of [mistreatment](#). I want to emphasize that the majority of family caregivers do not mistreat those they care for, even in situations that can be very challenging. Nonetheless, it is important to recognize the risk factors for mistreatment of people with disabilities, and do what we can to identify, mitigate, and prevent abuse and neglect."

Study results appear in *Multiple Sclerosis and Related Disorders*.

According to Morrison-Banks and her colleagues, the [research paper](#) is the first published survey documenting the nature and extent of caregiver mistreatment of adults with MS in the United States. The research team collaborated with the North American Research Committee on Multiple Sclerosis to conduct a telephone survey of 206 American adults with advanced MS living across the United States.

The preliminary study found nearly 55% of respondents disclosed undergoing some form of mistreatment since they started receiving care from a family member or friend.

The researchers do not fully understand all the risk factors for mistreatment. Their anonymous telephone survey did find, however, that family members who had to be the primary caregiver every day, day in and day out, were at higher risk of mistreating the person with MS. Other risk factors included the person with MS having higher levels of cognitive impairment or fatigue, the caregiver having a mental health diagnosis, alcohol use by the caregiver or by the person with MS, and lower levels of social support within the family.

As a multiple sclerosis specialist, Morrison-Banks has worked for years with many families affected by MS.

"Being a full-time family caregiver for someone with substantial neurological disability often presents significant challenges," she said. "Many families take these challenges in stride, but others end up in situations of abuse and/or neglect."

The researchers were surprised to find no published studies documenting how many people with MS have experienced mistreatment.

"We all felt it was important to study this topic in order to help families dealing with advanced MS," Morrison-Banks said, adding the first step toward addressing the problem is to recognize that people with MS are at high risk of mistreatment.

Community service organizations such as the National Multiple Sclerosis Society, the Multiple Sclerosis Association of America, and in Riverside County a local organization called Act for MS provide support and services for families in need.

"Our study is a good reminder for all that mistreatment is occurring out there for people with MS and other disabling conditions," Morrison-Banks said. "Health care professionals should maintain a high index of suspicion. We can't assume that all people with advanced MS are living in safe situations, even if they don't bring up their concerns on their own."

The study did not include paid caregivers or trained clinicians. A study of paid caregivers is an important next step for the researchers, requiring different methods for data collection. Morrison-Banks's team would study mistreatment involving paid caregivers, including those working in nursing facilities and other institutions. Another important area for future research for the team is to study the effectiveness of interventions to detect and prevent abuse and neglect of people living with advanced multiple sclerosis.

More information: Elizabeth H. Morrison et al, Abuse and neglect of people with multiple sclerosis: A survey with the North American Research Committee on Multiple Sclerosis (NARCOMS), *Multiple Sclerosis and Related Disorders* (2020). [DOI: 10.1016/j.msard.2020.102530](https://doi.org/10.1016/j.msard.2020.102530)

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