

Paid Personal Assistance for Individuals with Longstanding MS in the Community

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Purpose: This study aims to investigate whether the use of paid personal assistance for individuals with long-standing Multiple Sclerosis (MS) living within the community improves health promotion and functional abilities.

Methods: Data from an ongoing longitudinal study with persons with MS were used to address the research questions. This sample was originally recruited in 1996 and participants receive annual surveys about their health behaviors and factors influencing their quality of life. Questions adapted from a preexisting instrument, the Customer Assessment of Healthcare Providers and Systems (CAHPS) were added in the most recent year's survey (2021; Y25). The survey was mailed to 235 participants in March 2021. There were 144 individuals (61%) who returned the survey. Because of the small subsample who reported using assistance, a Mann U Whitney test was used to analyze differences between those using (n= 26) or not using (n=118) paid personal assistance on scores of the Health Promoting Lifestyle Profile II (HPLP II), Personal Research Questionnaire (PRQ), the Center of Epidemiology study of Depression scale (CESD-10), and Incapacity Status Scale (ISS).

Findings: The sample of participants had an average age of 69.2 years. The majority of the sample was female (85.8%) and Caucasian (95.7%). The average years of education for the sample was 15.1. The individuals reported an average of 33.5 years since their diagnosis of MS. Among these 141 individuals in

the sample who responded to the question about use of paid personal assistance, 26 claimed to have had someone who was paid come into their home in the last 3 months to help them. The two categories that the 26 individuals reported to be “Usually” or “Always” an area the paid personal assistant helped with, were household chores and errands in the community. Among the individuals who did not have a paid personal assistant 11.4% indicated they needed it and were unable to get it. The Mann U Whitney Z value for the scores on levels of social support, PRQ, CESD-10, ISS, and the HPLP II were all greater than -1.96 indicating no significant difference between people who report having paid personal assistance and those who do not.

Conclusions: The majority of individuals in this sample of persons with longstanding MS do not have a paid personal assistant and report that they do not need one. The lack of significant difference between those who have paid personal assistance and those who do not in HPLP II, CESD-10, PRQ, and ISS scores could be because family members or friends are available to help these individuals.

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