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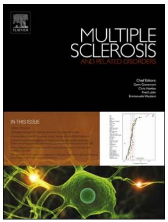

Upper limb impairment is associated with use of assistive devices and unemployment in multiple sclerosis

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ABSTRACT

Background: Individuals with multiple sclerosis (MS) frequently suffer from impaired sensory function, reduced strength and tremor in the upper limbs, which may interfere with upper limb function. However, upper limb impairment in MS is under-recognized and understudied. We aimed to evaluate the prevalence of upper limb impairment in a large sample of persons with MS; the association between upper limb function and employment status in MS; and the frequency of use of assistive devices aimed at addressing upper limb impairments.

Methods: We surveyed participants in the North American Research Committee on Multiple Sclerosis (NARCOMS) Registry regarding upper limb function using the ABILHAND questionnaire, and asked about use of assistive devices intended to improve the performance on upper limb activities. We evaluated the association between ABILHAND scores and current employment status using multivariable logistic regression analysis, and the association between ABILHAND scores and the use of an assistive device.

Results: Of 7463 eligible respondents, 5846 (78.3%) were female and mean (SD) age of 57.4 (10.2) years. The median (IQR) score on the ABILHAND was 45 (39–46). Higher levels of disability, as measured by the PDDS, correlated moderately with lower (worse) scores on the ABILHAND (r=−0.50; 95%CI: −0.48, −0.52). Over half of participants reported that they possessed an assistive device to aid upper limb function (3914, 56.0%). Older age, female sex, greater ambulatory disability, higher levels of fatigue, sensory impairment, spasticity and cognitive impairment, and visiting an occupational therapist were independently associated with increased odds of using an assistive device. After accounting for disability, perceived cognitive impairment, and fatigue, impaired upper limb function was associated with decreased odds of being employed (OR/1 point rise in ABILHAND 0.97; 95%CI: 0.96, 0.98).

Conclusions: Upper limb impairment is common in older MS patients, and adversely affects the ability to perform many common daily activities.

1. Introduction

Individuals with multiple sclerosis (MS) frequently suffer from impaired sensory function, reduced strength and tremor in the upper limbs, which may interfere with upper limb function (Bertoni et al., 2015; Rinker et al., 2015). Impaired upper limb function is associated with reduced community participation in MS (Bertoni et al., 2015). Poor performance on the nine-hole peg test is associated with increased health care costs (Koch et al., 2014). However, upper limb impairment in MS is under-recognized and understudied (Kraft et al., 2014).

To maintain independence despite upper limb impairments, daily tasks may be adapted through the use of assistive devices, which may help to maintain work roles (Stolp-Smith et al., 1997; Moyers, 1999). Among 882 Canadians with MS surveyed in 1997, nearly 50% reported the use of assistive devices, most commonly mobility aids or grab bars. Little emphasis was placed on devices aimed at addressing impaired upper limb function. Further, the

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findings may not generalize to regions which lack universal health systems.

Therefore, we evaluated (i) the prevalence of upper limb impairment in a large sample of persons with MS; (ii) the association between upper limb function and employment status in MS; and (iii) the frequency of use of assistive devices aimed at addressing upper limb impairments.

2. Materials and methods

2.1. NARCOMS registry

The North American Research Committee on Multiple Sclerosis (NARCOMS) Registry captures self-reported demographic and clinical information from individuals with MS via enrollment and semi-annual update questionnaires either online or on paper as they choose. The registry is approved by the Institutional Review Board at the University of Alabama at Birmingham. Participants agree to the use of their information for research. Diagnoses of MS were validated in a random sample of participants (Marrie et al., 2007). The questionnaires that capture clinical course, year of symptom onset, and disability status have been validated.(Marrie et al., 2007; Marrie and Goldman, 2007).

We used information from the enrollment questionnaire and the Fall 2013 Update survey. The enrollment questionnaire provided demographic information: sex, date of birth, race (white vs. non-white), level of education (< high school, high school/GED, Associate's Degree, Bachelor's Degree, Post-graduate education, and Technical degree) and clinical information: ages at symptom onset and diagnosis. The update survey provided information regarding: annual household income, current employment status (yes/no), disability status, upper limb function, and use of assistive devices. Annual household income was reported as: < $15,000 (reference group), $15,001-$30,000, $30,001-$50,000, $50,001-$100,000, > $100,000 and "I do not wish to answer". We measured disability status using Patient Determined Disease Steps (PDDS), which correlates strongly with the physician-scored Expanded Disability Status Scale (Marrie and Goldman, 2007). Values include: 0 (normal), 1 (mild disability), 2 (moderate disability), 3 (gait disability), 4 (early cane), 5 (late cane), 6 (bilateral support), 7 (wheelchair/scooter) and 8 (bedridden). We measured symptom severity using the Performance Scales, which capture eight domains (mobility, hand, vision, fatigue, cognition, bowel and bladder, sensory and spasticity), each of which are scored as 0 (normal), 1 (minimal), 2 (mild), 3 (moderate), 4 (severe), or 5 (total disability), except mobility, which is scored from 0 to 6. Performance Scales are valid and reliable (Schwartz et al., 1999).

2.2. Upper limb function

Participants reported which hand they currently considered their dominant hand (right/left/ambidextrous), and whether this had changed due to MS (yes/no). Participants reported whether their hand function limited their daily activities, and if yes, whether this was due to MS, another condition or they did not know. If the limitation was due to MS, we asked whether this was mainly due to spasticity, weakness, numbness, or tremor/incoordination.

We measured upper limb function using the ABILHAND, a 23-item instrument initially designed for patients with rheumatoid arthritis to report their manual abilities, (Massimo Penta et al., 1998) and subsequently adapted for use after stroke (Massimo Penta et al., 2001). It is valid and reliable in the MS population (Barrett et al., 2013). Smoothness of upper limb movement during daily activities correlates with ABILHAND scores (Pellegrino et al., 2015). The ABILHAND assesses the ability to manage daily activities using the upper limbs but does not capture whether assistive devices are used to complete tasks. Each item is scored as 0 (impossible), 1 (difficult) and 2 (easy). Total scores range from 0 to 46; lower scores indicate more difficulties.

Participants reported their use of assistive devices/technology including cups/glasses with lids, plates with lids, reachers, card/book holder, fingertip moistener, weighted utensils, smart pen, digital recorder, long-handled shoehorn, Velcro closure shoes, elastic shoe laces, stocking aid, button-hook, elastic thread, wrist weights, zipper pull, key holder, and dressing stick. This list was developed in consultation with an occupational therapist with experience working with persons with MS. For each item participants indicated one of the following responses: (0) have it and do use it; (1) I have it and don't use it; (2) I don't have it. I'm interested in knowing more about it; and (3) I don't have it and don't need it.

2.3. Statistical analysis

We restricted the analysis to respondents reporting physician-diagnosed MS, living in the US, and with complete information regarding sex, date of birth, age of MS symptom onset, and the ABILHAND. We summarized continuous variables using mean (standard deviation [SD]) or median (interquartile range [IQR]), and categorical variables using frequency (percent). Univariate analyses employed chi-square tests, student's *t*-tests, Kruskal-Wallis tests, or Spearman correlations as appropriate.

We evaluated the association between ABILHAND scores and current employment status (unemployed vs. employed) using multivariable logistic regression after restricting the sample to individuals of usual working age, 18–65 years. Covariates included demographic characteristics (sex, race, age), education level as a measure of socioeconomic status not itself influenced by employment status, and clinical characteristics (overall disability as measured by PDDS, cognition, fatigue) associated with employment status (Simmons et al., 2010). Sex was included as female versus male (reference group). Race was included as white versus non-white (reference group). To ensure adequate cell sizes and address linearity assumptions we collapsed education level into fewer categories, and categorized age, PDDS and fatigue. Education level was dichotomized as ≤high school/GED and > high school. Age was categorized as 23–49 (reference group), 50–55, 56–60, and 61–65 years. PDDS was categorized as mild (0–2; reference group), moderate (3–4) and severe (5–8). Fatigue was categorized as mild (0–1; reference group), moderate (2–3), and severe (4–5). Cognition was included as an ordinal variable. We did not include current income as this likely reflected employment status.

We evaluated factors associated with using an assistive device using multivariable logistic regression. We considered the same variables as in the prior model and added sensory status and spasticity status, categorized in the same way as fatigue, and seeing an occupational therapist in the prior six months. We report the associations as odds ratios (OR) and 95% confidence intervals (CI).

Statistical analyses were conducted using SAS V9.4 (SAS Institute Inc., Cary, NC).

3. Results

3.1. Participants

We distributed the survey to 12,590 NARCOMS participants, of whom 8115 (64.5%) responded. As compared to responders, non-responders were less likely to be white (78.2% vs. 91.3%, $p < 0.0001$) or male (19.8% vs. 21.7%, $p=0.0092$), and had an earlier mean (SD) age of symptom onset (30.3 [9.9] vs. 31.0 [10.1], $p=0.0002$). Responders and non-responders did not differ with respect to disability. Of the responders, 7463 (92.0%) met the inclusion criteria. Slightly more than three-quarters of the participants were women, they had a typical mean age of MS symptom onset, and 70% had completed more than a high school education (Table 1).