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Quality employment outcomes after multiple sclerosis: A comparison of participants from a specialty hospital and the National MS Society

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Abstract.
BACKGROUND: Employment is of great importance to adult life and the onset of a disabling condition presents significant challenges to maintaining employment or obtaining new employment. Diagnosis of multiple sclerosis (MS) typically occurs during the most active years of employment.
OBJECTIVE: To identify employment status, earnings, and job satisfaction of participants with MS and to compare these findings with that from a study of the National MS Society (NMSS).
METHODS: Data were collected via mailed and web self-report assessment.
RESULTS: We found an overall employment rate of 44.6%. This was higher than the rate observed in the NMSS study (39.3%). Among those who were employed, the majority of participants were in the two lowest earning categories (less than $25,000 = 23.1%; $25,000–49,999 = 24.3%). Education was highly related to employment. For race/ethnicity, the highest employment rate was observed for non-Hispanic white participants (48.19%), followed by Hispanic (44.68%) and non-Hispanic blacks (35.9%).
CONCLUSIONS: MS is related to diminishing employment outcomes that may affect participation and quality of life.

Keywords: Multiple sclerosis, employment, job satisfaction

1. Introduction

Multiple sclerosis (MS) is one of the most common neurological diseases in the world, affecting approximately 450,000 people in the United States and 2.3 million people in the world (National Multiple Sclerosis Society [NMSS], 2015). MS is a chronic and unpredictable disorder typified by cycles of relapses and remissions, although some people experience a steadily progressive course (Falvo, 2014). MS usually begins to manifest itself in early to middle adulthood; 75% of MS diagnoses are conferred before age 40 (Kalb, 2012). MS incidence rates have been on the rise worldwide for the past 50 years (NMSS, 2015).

MS is three times more common among women than it is among men, and it is more common among Caucasians of European lineage than it is among other racial and ethnic groups (NMSS, 2015). The highest prevalence rates for MS are observed in temperate

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regions of the globe, with much lower prevalence rates reported in warmer and tropical regions. In the United States, two-thirds of people with MS live in the northernmost 50% of the population (NMSS, 2015).

Frequent physiological symptoms of MS include fatigue, mobility problems, spasticity, numbness and tingling in the extremities, tremor, diminished strength and coordination, chronic pain, hypersensitivity to heat, visual impairments, bowel and bladder dysfunction, and sexual dysfunction (Antao et al., 2013). MS can also impact a person's affective responses, coping skills, and cognitive abilities. Polman, Thompson, Murray, Bowling, and Noseworthy (2006) reported that "psychiatric morbidity is increased in MS, with over 50% of patients being symptomatic at some stage" (p. 85). Between 43% and 70% of people with MS report cognitive impairments as part of their symptomology (Chiaravalloti & DeLuca, 2008; Polman et al., 2006). Cognitive functions most often affected by MS include speed of information processing, executive functions, memory, high-level language functions, and visual perceptual skills (Amato, Zipoli, & Portaccio, 2006; Chiaravalloti & DeLuca, 2008).

Given the wide range of symptoms that can accompany MS and its unpredictable nature, it is not surprising that MS has a significant impact on employment status. Although 98% of people with MS have employment histories and 82% were still working at the time of diagnosis (Roessler, Rumrill, Li, & Leslie, 2015), the vast majority of workers with MS disengage from the workforce before retirement age. In a review of international literature on MS and employment spanning a ten-year period following the turn of the 21st Century, Schiavolin et al. (2013) found that 59% of adults with MS worldwide were unemployed. In a study of people with MS in the United States, Roessler et al. (2015) reported an identical jobless rate, although 98% of the sample were high school graduates and 46% were college graduates. Roessler et al. (2015) reported that women, people who experience cognitive impairments, individuals with lower levels of education, and those whose customary occupations require a high degree of physical exertion are most vulnerable to early disengagement from the workforce.

1.1. Purpose

Our purpose was to describe a large-scale study of employment outcomes among persons with MS who were identified from a specialty hospital. This *study of quality employment throughout the work lifecycle after MS* is a key component of the Rehabilitation Research and Training Center on Employment of People with Physical Disabilities.

This is a mixed methods study using a combination of qualitative and quantitative components. The quantitative self-report assessment was completed by mail. Although the qualitative data have been summarized previously (Meade, Reed, Rumrill, Aust, & Krause, 2016), this is the first manuscript in which we report analysis of the quantitative data. The data are jointly analyzed with raw data from the national study of nine chapters of the NMSS.

2. Methods

2.1. Participants

Institutional review board approval was obtained at both the lead center, an academic medical university in the southeastern United States, and the specialty hospital from which the participants were identified. Individuals who met the following criteria were invited to participate: (1) diagnosis of MS, (2) adult, and (3) under the age of 65 at diagnosis. For the current analysis, there was the additional criterion of less than 65 years of age at the time of assessment. There was an initial pool of 3231 eligible individuals who were sent cover letters, 345 of which were returned undeliverable, leaving 2886 potential participants. Of these, 1324 completed study materials and 341 were probable lost (could not be contacted by phone).

2.2. Data collection procedures

Introductory letters were sent from the specialty hospital notifying participants materials would be forthcoming. The instrument package was mailed 2–4 weeks later directly from the lead site, the academic medical center. We sent follow-up packets to non-respondents 4–6 weeks later, followed by a phone call. The self-report assessment was made available online using REDcap. Both collaborating centers assisted in contacting the non-respondents. A third and final mailing was initiated to maximize response. Participants were offered $50 for their participation. Incoming data was processed at the lead site.

2.3. Labor force participation model and instrument development

This study of quality employment is part of a program of research on quality employment throughout the work lifecycle. We measure predictors of diverse employment outcomes related to successful employment. We developed the Labor Force Participation Model (LFPM, Fig. 1) to guide our selection of predictor variables and outcome measures. This model was adapted from the Theoretical Risk and Prevention Model developed to identify risk and protective factors for secondary health conditions and mortality after traumatic onset disability (Krause, 1996; Krause, Saunders, DiPiro, & Reed, 2013). Within the LFPM, we break the predictor variables into two primary categories, control variables and policy variables, consistent with our preliminary work with spinal cord injury (Krause, Terza, & Dismuke, 2008). While each condition has its own specific set of parameters to measure that condition, the overall blueprint is one that applies to multiple populations and includes core variables on disability.

Control variables include two subsets of variables: (1) demographic characteristics and (2) impairment and disability related characteristics. The demographic characteristics include age, sex, and race/ethnicity. MS is typically categorized by its course, such as relapsing remitting, primary progressive, secondary progressive, and progressive relapsing. Disability characteristics, at least conceptually, are stable and would not be the focus of interventions per se to improve employment so we define these effects as *attributable differences*.

Although these characteristics may not be the focus of change directly, they may be used to target particular groups for interventions. For instance, our findings indicate lower employment rates for non-Hispanic black participants. So, interventions may be targeted to this group or in combination with other types of factors that can be used as agents of change, such as vocational rehabilitation services.

The second set of variables, referred to as *policy* factors, conceptually may become the focus of change. Policy factors lend themselves much more to interventions focused on change as a means of promoting employment outcomes. The list of potential factors reported in Fig. 1 is far from comprehensive. Psychological factors include vocational interests, personality, and work needs. They help us to understand the types of occupations to which someone is drawn (interests), the characteristics that may affect how the individual does within that environment (personality), and what the person hopes to get from working (needs). Although conceptually an opportunity for change, psychological characteristics, such as vocational interests, are often more appropriate for guiding interventions to produce the best fit between the individual and the occupation. This may be particularly true of vocational interests and personality, which are known to be stable over time (Swanson & Hansen, 1988).

Socio-environmental factors are a broad category that encompasses many of the fundamental factors that may facilitate or impede successful employment outcomes. Examples include basic training and education, vocational rehabilitation services, and policies regarding disincentives. It also includes very specific environmental factors related to a particular job, such as job accommodations.

Two additional categories relate to behaviors and health factors. Key behaviors include preparing for employment, identifying job opportunities, and obtaining employment. These activities are as simple as preparing a resume or as directly related to employment as participating in a job interview. Consideration of such activities is essential to understanding employment outcomes, as they give an indication of what individuals have done to prepare themselves for potential employment, even if unemployed, and how actively they have sought employment. Health factors also clearly relate to employment and should be under consideration, although they are not necessarily the focus of interventions to promote employment.

We focus on two types of vocational outcomes, *participation* and *quality* outcomes. Participation outcomes are quantified indicators of labor force participation, such as hours per week spent working, number of years worked since disability onset, portion of time working from onset until retirement, and age at retirement. They reflect the extent to which individuals have participated in the labor force, but they do not identify quality per se.

Quality outcomes fundamentally relate to those aspects of employment that lead to tangible and intangible benefits and career development. Earnings are perhaps the most fundamental of all indicators of quality outcomes. Job benefits are also important, as are promotions and other types of job recognition. The actual level of job satisfaction or type of occupation is important to consider in assessing quality of employment. At least one aspect of

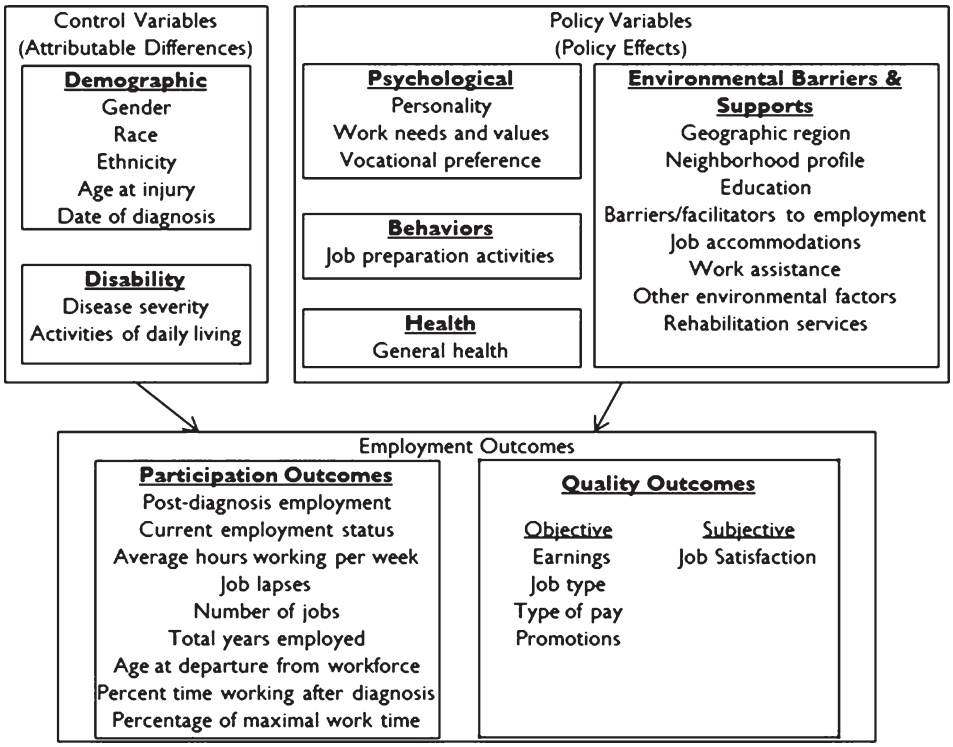

Fig. 1. Labor force participation model.

quality employment, job satisfaction, by definition, is subjective in nature.

The assessment package was derived directly from the LFPM. We used a combination of existing measures, emphasizing those with direct comparability to parameters measured in national studies, and newly developed items where there was a lack of sufficient content. We measured variables intended to assess attributable differences, related to both demographic and disability characteristics. We also measured at least one policy related variable within each of the major categories (psychological, socio-environmental, behavioral, and health).

2.4. *Overview of NMSS study 2 participants and methods*

The methodology for the NMSS study has been detailed in several places elsewhere (Roessler et al., 2015; Rumrill, Roessler, Li, Daly, & Leslie, 2015), so we will only provide a brief overview. The study identified 8,000 eligible participants through the NMSS. The total sample consisted of 1,924 members of nine NMSS chapters representing 21 states and Washington, DC. Our current analyses uses a subset of individuals who were under the age of 65 at the time of assessment. Participants responded via mailed, phone, and web self-report assessment.

2.5. *Common items between the quality employment and NMSS studies*

We identified common items, matching categories if items had multiple choices or ranges. Some of the variables that were included in the quality employment study were taken directly from the NMSS study at the time of selection of items. We utilized four demographic variables: age, sex, race/ethnicity, marital/relationship status. Categories for marital/relationship status included married, divorced, widowed, separated, never married, or member of unmarried couple. We measured educational status using the following categories: (1) high school degree or less, (2) 2 year/trade school degree, (3) 4 year/bachelor's degree, and (4) post-grad degree.

MS variables included diagnosis/course, severity of symptoms, and cognitive impairment. The course of MS (or diagnosis) was broken down into four types that included (1) relapsing-remitting, (2) primary progressive, (3) secondary progressive, and (4) progressive relapsing (a fifth category was for "unknown"). Severity of current symptoms was

Table 1
Characteristics of participants in the quality employment, NMSS, and combined studies

	Quality employment	NMSS	Combined	Significance
Race				**<0.001**
White	66.3	75.6	71.9	
African-American	27.2	11.2	17.7	
Hispanic	3.6	10.8	7.9	
Other	2.9	2.4	2.6	
Age	**49.5**	**53.9**	**52.2**	**<0.001**
Age at diagnosis	**36.8**	**37.4**	**37.2**	**0.003**
Marital status				**<0.001**
Married/Member of unmarried couple	64.7	64.7	64.7	
Divorced, Widowed, or Separated	20.0	22.2	21.3	
Never married	15.3	13.2	14.1	
Education				**0.012**
High school graduate or less	26.5	25.4	25.8	
2 year/Trade school	23.6	29.1	26.8	
4 year college graduate	28.8	24.9	26.5	
Master/PhD	21.1	20.7	20.9	
MS Course				**<0.001**
Relapsing-remitting	72.6	65.0	67.9	
Primary progressive, secondary progressive, progressive relapsing	17.3	24.0	21.3	
I do not know	10.1	11.3	10.8	
Severity				**0.005**
No current symptoms	33.1	32.0	32.4	
Some symptoms that affect functioning	39.7	44.95	42.8	
Multiple, severe symptoms that limit functioning	27.2	23.1	24.7	
Cognitive symptoms				0.06
Normal cognition	20.2	20.1	20.1	
Minimal – mild disability	54.4	50.8	52.3	
Moderate – total disability	25.4	29.1	27.6	

measured on a 5-point scale from (1) no current symptoms to (5) multiple severe symptoms that affect functioning. Cognitive difficulties was broken down into six response categories: (1) normal cognition, (2) minimal cognitive disability, (3) mild cognitive disability, (4) moderate cognitive disability, (5) severe cognitive disability, and (6) total cognitive disability.

The primary focus of this manuscript is current employment status, although we also report on earnings and job satisfaction. These outcomes were the focus of state of the science conference presentation and are the focus of the current manuscript.

2.6. Data analysis

The Chi-squared statistic and *t*-tests were used to compare the characteristics of the participants between the two studies.

3. Results

3.1. Descriptive

The majority of participants in the current study were non-Hispanic white (66.3%), with 27.2% being non-Hispanic black, 3.6% Hispanic, and 2.9% other (Table 1). The portion of non-Hispanic blacks was smaller in the NMSS study (11.2%), although the percentage of Hispanics was higher (10.8%). Just over 60% of the participants were married. The participants were somewhat highly educated with slightly less than 50% having a 4-year college degree or above (Quality employment = 49.96%; NMSS = 47.39%).

Relapsing remitting was by far the most common course of MS (72.6%; 64.7%). The severity of current symptoms was distributed fairly evenly among response categories, ranging from 27.2% with multiple severe symptoms to 39.7% with some symptoms. Over half of the participants reported minimal to mild cognitive disability (54.4%), with 25.4% reporting moderate to severe cognitive deficits, and only 20.2% reporting normal cognition (the differences with the NMSS study were not significant).

3.2. Employment outcomes

The overall employment rate was 44.6%, which was significantly higher than that from the NMSS

Table 2
Employment rate, earnings, and job satisfaction

	Quality employment	NMSS	Combined	Significance
Employed now				**0.003**
Yes	44.6	39.3	41.4	
No	55.4	60.7	58.6	
Earnings				0.085
<$25,000 k	23.1	21.0	22.0	
$25,000–49,999	24.3	27.6	26.0	
$50,000–74,999	22.0	22.7	22.4	
$75,000–99,999	14.2	13.0	13.6	
$100,000–124,999	6.8	9.2	8.0	
>$125,000	9.6	6.6	8.0	
Satisfaction among those employed				**0.01**
Very dissatisfied	3.5	4.5	4.1	
Dissatisfied	8.8	8.8	8.8	
Neutral/undecided	15.4	12.6	13.8	
Satisfied	50.0	44.0	46.6	
Very satisfied	22.4	30.1	26.7	

Note: Significance calculations are for the Quality employment study.

study (39.3%) (Table 2). Among those who were employed, the majority of participants were in the two lowest earning categories (less than $25,000 = 23.1%; $25,000–$49,999 = 24.3%). The median earnings were in the $50,000–$74,999 range (22.0%). Earnings did not significantly differ between the two studies. Most of the participants were either satisfied (50%) or very satisfied (22.2%) with their jobs. Only 8.5% were dissatisfied and 3.6% very dissatisfied. There was a significant difference between the two studies accounted for by the greater percentage of those in the very satisfied category (30.1%) in the NMSS study.

In terms of race/ethnicity, the highest employment rate was observed for non-Hispanic white participants (48.19%), followed by Hispanic (44.68%) and non-Hispanic blacks (35.9%) (Table 3). The most sizable difference between the two studies was for non-Hispanic whites. The employment rate was higher for men (49.5% compared with 42.6% for women), which is the opposite of the trend in the NMSS study. Those who were married or in a non-married couple had the highest employment rate (48.7%), whereas those who were separated, widowed, or divorced had the lowest rate (32.3%). Those who were employed were younger than those unemployed (47.7 years; 55.4 years), and they had fewer years since diagnosis (11.7 years; 17.3 years) (Table 4). For education, there was a clear trend with improving employment rates for each additional advance in education (see Fig. 2).

3.3. MS characteristics and employment

Each of the three MS characteristics was highly related to employment status. As is apparent in Figs. 3–5 the employment rate was highest for those with relapsing-remitting, no current symptoms, and normal cognition. The employment rate for those who did not know their diagnosis was actually second to those with relapsing remitting (Fig. 3). Employment rates diminished with increasing number of symptoms (Fig. 4) and increasing cognitive impairment (Fig. 5). Those with no symptoms or very mild symptoms had employment rates just below 80% (77.3% and 76.3% respectively), whereas those with the most severe symptoms were rarely employed (6.7%). These findings are all relatively consistent with that of the NMSS study. When looking at symptoms, the primary differences between the two studies were the higher employment rates observed in the current study for those with the least severe MS as defined by symptoms (only 63.5% and 65.8% for those with no or mild symptoms in the NMSS study). Also, the ceiling of employment for those with no cognitive impairment was higher in the current study (62.2% compared with 47.8%).

4. Discussion

MS is related to diminishing employment outcomes that may affect participation and quality of life, with poorer outcomes dependent on the diagnosis,

Table 3
Employment rates as a function of demographic, injury, and MS characteristics

	Quality employment	NMSS	Combined	Significance
Overall	44.56	39.29	41.40	
Sex				**0.037**
Male	49.48	35.37	41.23	
Female	42.60	40.54	41.37	
Race				**0.031**
White	48.19	39.99	43.03	
African-American	35.90	32.56	34.63	
Hispanic	44.68	43.20	43.48	
Other	35.14	34.78	34.94	
Marital status				**<0.001**
Married/Member of unmarried couple	48.74	43.35	45.05	
Divorced/Widowed/Separated	30.23	29.56	31.95	
Never married	41.92	39.92	40.80	
Education				**<0.001**
High school graduate or less	27.78	10.64	19.21	
2 year/trade school	34.06	32.19	33.13	
4 year college graduate	51.44	45.38	48.07	
Master/PhD	60.57	53.40	56.63	
MS Course				**<0.001**
Relapsing-remitting	51.93	49.84	50.74	
Primary progressive, secondary progressive, progressive relapsing	17.57	42.53	42.95	
I do not know	40.77	32.56	35.65	
Severity/symptoms				**<0.001**
No current symptoms	77.25	63.48	69.27	
2	76.25	65.87	70.11	
Some symptoms that affect functioning	39.77	35.32	36.99	
4	19.35	18.18	18.73	
Multiple, severe symptoms that limit functioning	6.67	6.96	6.84	
Cognitive symptoms				**<0.001**
Normal cognition	62.16	47.77	53.59	
Minimal – mild disability	49.57	45.69	92.54	
Moderate – total disability	22.70	23.23	50.42	

Table 4
Comparison of employed and unemployed participants on aging variables

	Employed	Unemployed	Significance
Age	55.4 (12.0)	47.7 (10.7)	**<0.001**
Age at diagnosis	38.0 (10.8)	36.0 (9.6)	**0.003**
Time since diagnosis	17.3 (10.5)	11.7 (8.5)	**<0.001**

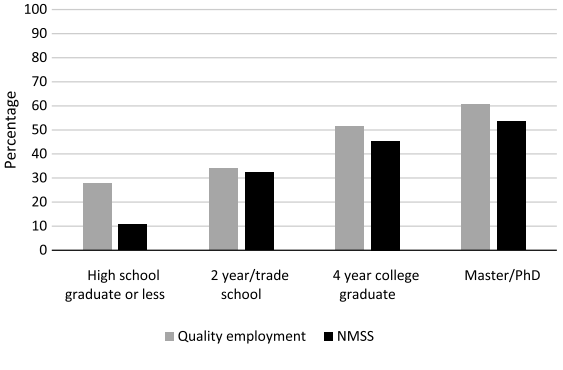

Fig. 2. Employed now by highest education achieved.

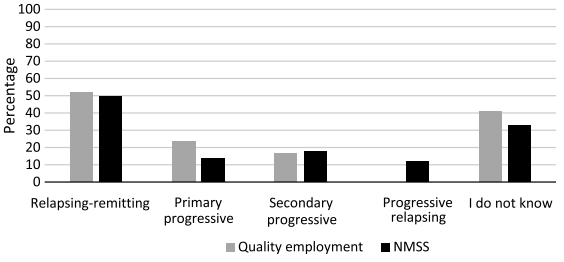

Fig. 3. Employed now by course of MS.

symptoms, and cognition. This study extends findings from the NMSS, reporting an employment rate of 41%, similar to that reported in the literature (Schiavolin et al., 2013). The study findings allow us to better identify the employment rate both between and across studies, so the findings are more precise. Although the employment rate was somewhat higher than the NMSS study, it is well below that of the general population (Bureau of Labor Statistics, 2017).

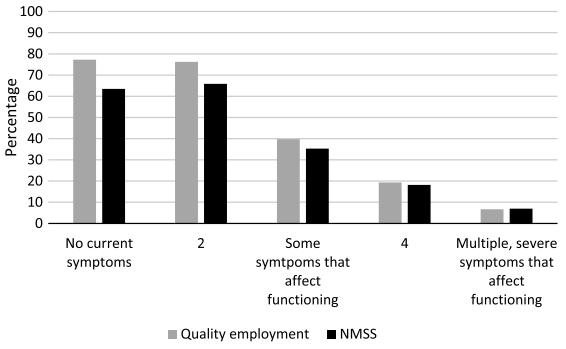

Fig. 4. Employed now by severity of symptoms.

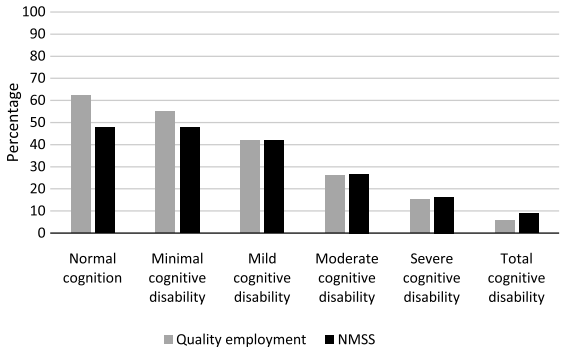

Fig. 5. Employed now by cognitive difficulties.

4.1. Implications

Our findings have several implications within the larger LFPM. First, the findings reinforce the importance of MS management to employment. Successful management of MS symptoms will likely be associated with more favorable employment outcomes. The relationship between MS course and employment, although not directing us to interventions per se, highlights the need to provide key information to people with MS that helps them understand the potential consequences of different courses of MS. Second, the findings related to cognition emphasize the importance of evaluating both physical functioning and cognition in relation to employment. Subtle cognitive changes may present a significant barrier to employment. Third, there was a relatively clear gradation of higher employment rate with each successive level of education, and these findings underscore the importance of training. Most people with MS obtained their training prior to disease onset, but the findings also emphasize the potential for post-MS training as a means of promoting job retention and raising employment rates. Fourth, among those who were employed, the findings were encouraging. Although the two highest percentages of employed participants were in the two lowest earnings groups, over half of the employed participants made $50,000 or more with a substantial portion having significantly higher earnings. Most individuals were satisfied with their jobs, although we did find a lower percentage of those very satisfied when compared to the NMSS study.

4.2. Methodologic considerations

There are several strengths and weaknesses in the current research. In terms of strengths, this study reported outcomes on a large number of people with MS and included variables allowing us to differentiate employment outcomes related to key characteristics, such as MS course, symptoms, and cognitive impairment. Therefore, rather than simply projecting an overall employment rate among people with MS, we were able to differentiate outcomes relative to MS characteristics. Second, by combining data with that of the previously conducted NMSS study, we were able to compare outcomes directly using the two studies. This allowed us to identify common patterns in outcomes between studies. This clearly is a much stronger approach than simply analyzing the new data alone and then comparing it with the reported findings from the literature. Furthermore, that two participant cohorts were identified from very different sources, one clinical and one from membership of a voluntary organization, which helps to enhance the generalizability of the study findings. One may have thought that those identified through the NMSS would have had better employment outcomes, but this was not the case.

The use of a self-report assessment is a limitation in both the quality employment and NMSS studies. Self-report methods are always vulnerable to errors in retrospective recall and reporting. Second, although having two distinct study cohorts is a strength in that it allows us to enhance generalizability, it also introduces the possibility of systematic differences between cohorts that may not be easily determined with the research project itself. Third, non-response is always an issue. Nonresponse may particularly affect overall estimates of employment rates or earnings but is much less likely to affect the relationship between predictive factors, including MS characteristics and employment outcomes.

4.3. Future research

The current findings clearly only scratch the surface of the relationship of MS or physical disability with employment outcomes and represent only the first in a number of future analyses, each of which will focus upon a particular outcome in greater detail using the full LFPM. Econometric models will be used to identify attributable differences and policy effects related to multiple quality employment outcomes. Additional research will also include other populations, such as SCI, for which the data has been collected.

Research on quality employment outcomes through longitudinal studies of employment among those with physical disability is needed to evaluate job retention, changes in job quality, and use of additional services to compensate for aging and functional changes. We also need to apply the principles of quality employment throughout the lifecycle to additional populations, such as amputation, cerebral palsy, and stroke, using a similar template to ensure comparability between studies.

Lastly, more research is needed that develops and tests interventions, including policy-based changes, on a broad range of quality employment outcomes throughout the lifetime. It is only through continued research and its integration into policy and practice that we will improve the quality of employment outcomes for people with physical and other disabling conditions.

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Conflict of interest

None to report.

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