Patterns in workplace accommodations for people with multiple sclerosis to overcome cognitive and other disease-related limitations

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Abstract

BACKGROUND: Cognitive symptoms and other functional limitations associated with multiple sclerosis (MS) have a significant negative impact on employment status. Work accommodations positively impact the ability of a person with MS to obtain and retain employment, however, current understanding of the role of accommodations in the careers of adults with MS is limited.

OBJECTIVE: To analyze the percentage of American workers with MS who utilize workplace accommodations as per Title I of the ADA, the types of accommodations most frequently required, and differences in disease variables, job-related factors, and quality of life between workers using and not using work accommodations.

METHODS: Data from 746 employed adult members of the National MS Society surveyed about career concerns were analyzed. Descriptive and inferential statistics were used as appropriate to address the research questions.

RESULTS: Approximately 25% reported having requested accommodations, and 87.7% reported receiving the requested accommodation. Participants with progressive MS, cognitive impairment, higher number of MS symptoms and greater symptom severity were more likely to use work accommodations. Participants with accommodations reported poorer job match and career optimism than those using no accommodations.

CONCLUSION: This large-scale analysis addresses several outstanding questions concerning work accommodations among workers with MS. Cognitive symptoms and disease severity are strongly associated with need for accommodations; however accommodations do not appear to promote job satisfaction or longevity. The accommodation request process and the impact of accommodations on employment retention remain important research foci.

Keywords: Multiple sclerosis, employment accommodations, cognitive symptoms, job retention

1. Introduction

Multiple sclerosis (MS) is a chronic, unpredictable neurological disorder that attacks the myelin sheath surrounding white matter tracts in the brain and spinal cord. The demyelinating attacks are caused when the immune system erroneously identifies the myelin as a foreign body. The resulting plaques, or lesions, are noticeable on Magnetic Resonance Imaging (MRI) scans, and they may bring about a wide range of symptoms depending upon their size and location in the central nervous system (DeLuca & Nocentini, 2011). The precise cause for this atypical immune response remains unknown, and there is no cure for the disease.

MS is most often characterized by unpredictable cycles of relapses and remissions, although some
people experience a steady progressive course marked by a gradual decline in general health and functioning over time (Falvo, 2014). The pattern of relapses, remissions, and progression of symptoms varies widely among and even within individuals, making MS an exceedingly difficult condition to cope with for those diagnosed and their significant others. Compounding the adjustment process is the fact that MS usually begins to manifest itself during early to middle adulthood; 50 percent of MS diagnoses are conferred before the person’s 30th birthday and 75 percent are conferred before age 40 (Kalb, 2012).

It is estimated that more than 2.3 million people in the world have MS (National Multiple Sclerosis Society [NMSS], 2015), with approximately 450,000 of these individuals living in the US. Although physicians are not legally required to report diagnoses of MS to the American Federal government, it is estimated that 10,000 new cases are identified each year in the US; this national incidence rate has increased steadily over the past 50 years (NMSS, 2015).

As with many autoimmune disorders, MS is more common among women than it is among men; approximately three-quarters of people with MS worldwide are women. MS is also much more common among Caucasians of European extraction than it is among other racial and ethnic groups. Perhaps relatedly, the highest prevalence rates for MS are observed in temperate regions of the globe, with much lower prevalence rates reported in warmer and tropical regions. In the US, two-thirds of people with MS reside in the northernmost 50 percent of the American populace (NMSS, 2015).

The constellation of physiological symptoms of MS extends over a wide range, including 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, all of which contribute to the problems that adults with MS have in acquiring and maintaining employment (Antao et al., 2013). In addition to the many physical symptoms, MS also typically impacts affective responses, coping skills, and cognitive abilities. Polman et al. (2006) reported that “psychiatric morbidity is increased in MS, with over 50 percent of patients being symptomatic at some stage” (p. 85).

The impact of MS on cognition is more significant and more prevalent than was historically believed. Current estimates of the prevalence of cognitive impairment in MS range from 43% to 70% (Chiaravalloti & DeLuca, 2008; Polman et al., 2006). Cognitive functions most affected in people with MS include speed of information processing, attention, executive functions, memory, high-level language functions, and visual perceptual skills (Amato, Zipoli, & Portaccio, 2006; Chiaravalloti & DeLuca, 2008). Areas of cognitive functioning typically unaffected by MS include simple attention and verbal skills (DeLuca & Nocentini, 2011), recognition memory, implicit learning, and speech comprehension (Lincoln et al., 2002). The severity and type of cognitive impairment (CI) vary significantly among individuals with MS and do not appear to be strongly correlated with the degree of physical involvement (DeLuca & Nocentini, 2011). Approximately, 20% to 30% of people with MS have already experienced cognitive changes before they have their first exacerbation. Those who present with CI early in the course of their MS appear to be at greater risk for decline over time (DeLuca & Nocentini, 2011).

MS-related CI is associated with reduced functional status (Abraham, Scheinberg, Smith, & LaRocca, 1997) and a negative impact on the person’s personal, occupational and social functioning. People with MS with CI are less likely to be employed, are engaged in fewer social and vocational activities, have greater difficulties carrying out routine household tasks, are more vulnerable to psychiatric illnesses, require greater personal assistance, and are less likely to engage in social activities than are people with MS who do not have CI (Finlayson, Shevil & Cho, 2009; Rao et al., 1991). People reporting MS-related CI are approximately four times less likely to be employed than their counterparts without CI (Roessler & Rumrill, 1995), and Edgley et al. (1991) found that the frequency of perceived cognitive problems was directly related to the rate of unemployment. For people with MS who are employed, Rumrill, Fraser, and Johnson (2013) found accommodations related to cognitive functioning the most difficult workplace modifications to implement. Because of the wide range of symptoms and the unpredictable nature of the disease, MS has a significant negative impact on employment status. Although 98 percent of people with MS have employment histories and 82 percent 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 (2002 – 2011), Schiafolini et al. (2013) found that 59% of adults with MS worldwide were unemployed. In a more recent study of people with MS in the United States, Roessler et al. (2015) reported an
discrimination filed with the EEOC by people with MS. Rumrill, Roessler, McMahon, and Fitzgerald (2007) surveyed people with MS who were employed or attending educational institutions and found that discrimination and how to manage it were among their most important concerns. Primarily, respondents were concerned that employers lacked awareness of and sensitivity to the needs of people with MS, especially regarding the implementation of workplace accommodations (Sweetland et al., 2007). Similar findings were reported by Doogan and Playford (2014). Rumrill and Hennessey (2001) cited workplace discrimination as the single most important explanation for the high rate of workforce attrition for Americans with MS, noting that as many as 80 percent of Americans with MS feel that they have been treated unfairly in the workplace at some point in their experience with the disease. Indeed, a national survey of 1,924 Americans with MS conducted by Rumrill et al. (in press) revealed that people with MS are often dissatisfied with the employment protections set forth for them in Title I of the Americans with Disabilities Act (ADA). Specifically, relatively high numbers of respondents were dissatisfied with items related to on-job accommodations and other ADA provisions such as: (a) knowing how to discuss their job accommodation needs with employers (53.4% dissatisfied); (b) requesting a review of their accommodation needs without fear of retaliation (52.7% dissatisfied); (c) understanding the employment protections of Title I in the Americans with Disabilities Act as Amended (ADA; 51.7% dissatisfied); (d) understanding the benefits of disclosing disability status to employers (50.6% dissatisfied); knowing what to do if they encounter discrimination at work (49.4% dissatisfied); and expecting employers to respond to their accommodation needs in a timely manner (47.9% dissatisfied).

Data from the United States Equal Employment Opportunity Commission (EEOC) shed further light on the workplace discrimination experiences of Americans with MS. Rumrill, Roessler, McMahon, and Fitzgerald (2005) examined the types of allegations of workplace discrimination filed with the EEOC by people with MS under Title I of the ADA from 1992 to 2003. Of the 3,669 allegations filed by people with MS during that period, the most commonly alleged forms of workplace discrimination were unlawful termination (29.9%), failure to provide reasonable accommodations (21.9%), unfair terms and conditions of employment (9.8%), harassment (6.7%), unlawful hiring practices (3.8%), arbitrary or unfair discipline (3.4%), constructive discharge (i.e., creating a work environment that makes it impossible for the person to continue working; 3.0%), unlawful layoff (2.8%), and inequitable promotion policies (2.5%). People with MS filing ADA Title I allegations were mostly female (66.5%), predominantly Caucasian (76.1%), and of mid-career age on average ($M_{age} = 42.47$ years, $SD = 8.54$). Allegations were most often filed against employers in the South United States Census Region (35.7%), and employers in the service, financial, insurance, and real estate industries were most often the subjects of ADA Title I complaints (Rumrill et al., 2005).

Another investigation of the EEOC database by Unger, Rumrill, Roessler, and Stacklin (2004) compared the discrimination complaints of Americans with MS to those filed by individuals with other types of disabilities. Findings from that study demonstrated that people with MS were more likely than those with other disabilities to file allegations related to benefits, health insurance, demotion, reasonable accommodations, and terms of employment (Unger et al., 2004). Sweetland et al. (2007) found that a focus group of people with MS attributed workplace discrimination primarily to a lack of understanding of MS. These findings give weight to the notion that people with MS perceive workplace discrimination differently than do people with other disabilities.

The problem of workplace discrimination was further underscored in several focus groups of people with MS conducted by Roessler et al. (2003). Focus group members identified discrimination and unfair treatment at work as one of the top agenda items for improving the rate of labor force participation among people with MS. Similarly, 38 percent of callers into Kent State University’s MS Employment Assistance Service hotline since 1999 have sought assistance with interpreting their legal rights and/or redressing employer discrimination (Rumrill, Hennessey, & Nissen, 2008).

One theme that recurs in the research regarding workplace discrimination against people with MS is the lack of willingness on the part of employers to provide on-the-job accommodations, despite the fact that research has consistently suggested that workplace
accommodations are effective in helping people with disabilities obtain and retain employment at a relatively low cost to the employer (Rubin, Roessler, & Rumrill, 2015; Schartz, Hendricks, & Blanck, 2006). For example, the Job Accommodation Network at West Virginia University (2014) stated that 57 percent of on-the-job accommodations for workers with disabilities cost nothing to provide. The U.S. Department of Labor (2014) reported that when employers paid out of pocket for accommodation expenses, the average cost was $550. Specific to workers with MS, Rumrill, Fraser, and Johnson (2013) reported that more than one-third of workplace accommodations for employees with MS involved schedule modifications that rarely resulted in any cost to their employers. The costs of workplace accommodations for people with disabilities, including people with MS, are particularly reasonable when viewed in light of the average of $300 to $400 per year that employers report investing in direct costs for the needs of qualified workers without disabilities (Schartz, Hendricks, & Blanck, 2006). Furthermore, providing accommodations to workers with disabilities can result in substantial financial benefits to employers due to the lower costs associated with training and turnover, lower health and workers compensation insurance premiums, and increased worker productivity and job satisfaction (Rubin et al., 2015). Despite these compelling data, access to reasonable accommodations in the workplace remains a critical concern for people with MS who seek to obtain or maintain employment after diagnosis.

Vocational rehabilitation interventions that emphasize workplace accommodations and increase the worker’s feelings of self-efficacy in solving on-the-job problems have proven effective in improving employment outcomes (Varekamp, Verbeek, & Van Dijk, 2006). Sweetland, Howse, and Playford (2012) suggested that workplace accommodations for employees with MS are most likely to occur when a rehabilitation professional works collaboratively with both the employer and the person with MS, providing education and recommendations on accommodations. The Project Alliance study through the National Multiple Sclerosis Society (1997) identified an employee’s unwillingness to have a rehabilitation specialist on site as a potential barrier to the provision of accommodations for workers with MS. One explanation for this refusal is the risk associated with consenting to the intervention stemming from fears related to stigmatization, employer perceptions of the worker’s loss of capacity, and employers’ possible refusal to provide needed accommodations (Rumrill et al., 2013).

The intense and unpredictable nature of MS symptoms can also pose barriers to the implementation of on-the-job accommodations. For example, unexpected absences from work can be particularly challenging for employers to accommodate (Rubin et al., 2015). However, rapid advances in technology make it much easier than ever before for workers with (and without) MS to work from home or from other remote locations (Sweetland et al., 2012). Cognitive support technology such as memory enhancement applications for tablet computers and smart phones have also proven effective to combat cognitive deficits associated with MS and other neurological disorders (Scherer, 2012).

In an exploration of workplace accommodation outcomes for 41 people with MS who had received consultation from an employment assistance service, Rumrill and colleagues (2013) found that 47 different accommodations had been requested by participants. The most commonly requested accommodations were equipment or assistive technology, schedule modifications, climate control/air-conditioning, reassignment/reduction of hours, and ADA/disclosure information. Employers were more apt to meet requests for equipment and assistive technology than they were to agree to schedule modifications, and the cost of equipment and assistive technology was a major factor in considering requests for accommodations of those types.

It is clear that receiving accommodations positively impacts the ability of a person with MS to obtain and retain employment. Existing research on this subject has provided many important insights to the accommodation process, but many unanswered questions remain. A potentially important contribution of the Rumrill et al. (2013) study was the information regarding types of accommodations requested by people with MS, but a much larger and more diverse sample is required to draw broader conclusions regarding the types of accommodations requested and subsequently implemented. Also, it is unknown how frequently people with MS actually receive and use accommodations in the workplace, and whether workers with MS who use accommodations are meaningfully different from workers with MS who do not. These data are necessary to inform vocational rehabilitation practice in terms of (a) the effects of workplace accommodations and (b) efforts to reduce barriers for people with MS to receive these accommodations.

The present study analyzed data from a large national survey of the employment concerns of Americans with MS, focusing this analysis on issues related to the
workplace accommodation process. The study was guided by five research questions:

1. What percentage of American workers with MS utilize workplace accommodations as per Title I of the ADA?
2. What types of workplace accommodations do American workers with MS use?
3. How do employed people with MS who use accommodations differ from employed people with MS who do not use accommodations in terms of demographic characteristics such as gender, age, race/ethnicity, financial status, and level of education?
4. How do employed people with MS who use accommodations differ from employed people with MS who do not in terms of disease-related variables such as number of MS symptoms, severity of MS symptoms, incidence and severity of cognitive impairment, and perceived quality of life?
5. How do employed people with MS who use accommodations differ from employed people with MS who do not in terms of perceived job-person match, job satisfaction, and career optimism?

2. Methods

The data analyzed in this study were gathered in a survey of the employment concerns of 1,839 adults with MS from nine National Multiple Sclerosis Society (NMSS) chapters in the US, representing 21 states and Washington, DC. The survey instrument contained questions regarding the demographic, disease-related, and support system variables pertinent to employment interventions that might benefit adults with MS. For the present analysis, only the responses of participants who were employed either full-time or part-time were evaluated.

2.1. Procedure

With the assistance of the NMSS, the authors identified nine chapters that provided a strong representation of geographic areas, rural/urban/suburban settings, and diverse racial/ethnic groups. The original sampling frame for this investigation included 8,000 people with MS representing the nine chapters. As a means of ensuring adequate representation of Hispanic/Latino and African-American respondents, the researchers oversampled members of those two groups within NMSS chapters that had relatively high proportions of Hispanics/Latinos and African-Americans on their client registries. Eight of the participating NMSS chapters were asked to identify stratified random sub-samples of 800 clients (stratified by racial/ethnic backgrounds depending upon the representation of Hispanics/Latinos and African Americans in their client registries), and one chapter was asked to draw a stratified random sub-sample of 1,600 clients, including 100 African Americans, 800 Hispanics/Latinos, and 700 clients from other racial and ethnic backgrounds. The goal of this sampling procedure was to ensure that at least five percent of the overall respondent sample were Hispanic/Latino individuals with MS and that at least five percent were African American; these proportions are consistent with commonly held estimates of population parameters for people with MS (Buchanan, Chakravorty, Tyry, Hatcher, & Vollmer, 2009; Marrie et al., 2008).

To improve survey return rates, the research team implemented several strategies, including a pre-notice letter to those selected for the national stratified sample (N=8,000), sent before the survey mailing, and “reminder/thank you” postcards mailed four weeks after the survey had been mailed. The survey was mailed with an explanatory cover letter from a member of the research team six to eight weeks after the chapters mailed the pre-notice letter. Each potential participant received a paper version of the survey, in either English or Spanish depending on his or her identified ethnicity. Also enclosed in that mailing, potential participants received information pertaining to accessing the survey in an on-line and telephone format, again offered in both English and Spanish. In a final effort to improve survey return rates, each chapter’s service director sent an e-mail message to each NMSS member with an available e-mail address six weeks after the “reminder/thank you” postcards asking the individual to complete and return the survey. Six hundred thirty-one surveys were returned to participating chapters as undeliverable, reducing the available target sample to 7,369 people with MS. Of the target sample, 1,927 members returned questionnaires, of which 1,839 included complete data relevant to the present analysis, resulting in a response rate of 24.96%.

2.2. Participants

Participants for the present study consisted of the 746 employed respondents. The sample included 142
males (19.1%) and 603 females (80.9%; 1 participant did not report his or her gender). The participants’ average age was 48.9 (SD = 10.84). Most of the respondents were White (76.8%), with other ethnicities reported as follows: African American (9.0%), Hispanic/Latino (12.0%), Asian or Pacific Islanders (0.8%), Native American or Alaskan Natives (0.4%) and the remainder reporting “other” or not reporting. Participants described their communities as being located in either urban (23.9%), suburban (56.6%), or rural areas (19.5%). The group was well educated, with over 99% reporting having graduated high school and 57% having completed college or post-graduate coursework. With respect to employment, 536 (71.8%) of participants were employed full-time, and 210 (28.2%) were employed part-time. The participants’ financial status was reported as follows: 69.5% reported that they were able to meet expenses, 23.3% reported having some difficulty meeting expenses, and 7.1% described themselves as being in need of financial assistance.

The mean age at MS diagnosis was 36.1 years (SD = 9.5). The majority of the sample reported the course of their MS as relapsing-remitting (81.4%), followed by secondary progressive (5.4%), primary progressive (2.7%), and progressive relapsing (1.1%) with the remaining 9.3% reporting “don’t know”.

2.3. Instrument

The survey questionnaire for this study contained 98 items and included fixed and open response sets. The items addressed demographic, health-related, support system, and employment-related information and were developed based on an iterative process including a comprehensive literature review, input from expert consultants, and review by a working group of adults with MS. Items related to workplace accommodations elicited information such as the types of accommodations respondents had requested, whether those accommodations had been implemented by their employers, and what types of on-the-job accommodations they were currently using. Perceived job match was evaluated with a single item, asking participants to rate how closely their current job matches personal skills and preferences, with responses based on a 5-point Likert-type anchored scale ranging from “does not match at all” to “perfect match”. Perceived job satisfaction was also measured with a single item, asking participants to rate their level of satisfaction with their current job based on a 5-point Likert-type, fully-anchored scale ranging from “very satisfied” to “very dissatisfied”. Career optimism score was based on participants’ response to the following question: “Looking to the future (2–5 years from now), how likely are you to give up work entirely due to MS?” with responses based on a 5-point Likert-type, fully-anchored scale ranging from “very likely” to “very unlikely”.

Number of MS symptoms was operationalized as the number of symptoms checked from a list of 18 frequently reported symptoms of MS. A five-point, partially anchored scale was used to assess self-reported symptom severity. The scale anchors included: 1 = “No current symptoms”, 3 = “Some symptoms that affect daily functioning” and 5 = “Multiple, severe symptoms, significantly limiting daily functioning”. Cognitive symptoms were measured using the NARCOMS Performance Scale for Cognitive Symptoms (Marrie & Goldman, 2007; Schwartz, Vollmer, & Lee, 1999). Perceived QOL was measured using the Quality of Life Scale. The scale was developed for use in behavioral medicine with people who have chronic health conditions. The seven-item scale requires respondents to rate on a scale of 1 (totally unsatisfying) to 7 (completely satisfying) their levels of satisfaction with their functioning in seven major life areas (i.e., social life, family life, hobbies and recreational experiences, educational and intellectual development, activities of daily living, romantic experiences, expectations and hopes for the future). The possible range for the total QOL scale is 7–49, with higher scores indicating higher levels of perceived QOL.

2.4. Statistical analysis

Descriptive statistics (e.g., means, standard deviations, frequencies, and percentages) and inferential statistics (e.g., t-tests, chi-square tests of proportions) were generated as appropriate to the research questions. Statistical analyses were completed using the Statistical Package for the Social Sciences (SPSS) software, Version 22.

3. Results

3.1. Percentage of workers with MS utilizing workplace accommodations

Among the 746 employed participants, 179 (25.7%) reported having requested accommodations from their employers. Of these, 157 (87.7%) reported receiving the requested accommodation, with only 12.3%...
reporting that they did not. Interestingly, 313 respondents (42%) reported using workplace accommodations in their present jobs, which apparently means that a sizable proportion of the accommodations that were in use among participants in this study were not preceded by accommodation requests.

3.2. Types of workplace accommodations used

Participants were asked to select the nature of the work accommodations used from a list of 12 options. As indicated in Table 1, the most frequently identified accommodation was a change in the work schedule, followed by working at home part-time, change in job duties, and modification in the work station or physical facilities. The installation of new assistive equipment represented a relatively small percentage of work accommodations, at 2.3%.

3.3. Demographic differences based on accommodation use

With respect to gender, the rate of accommodation use was very similar between males (41.5%) and females (42%), and the difference was not significant ($\chi^2(1) = 0.008, p = 0.929$). There were significant differences in accommodation use based on ethnicity ($\chi^2(5) = 15.99, p = 0.007$), with White (39.2%) and Hispanic/Latino participants (43.8%) less likely to report using accommodations than those who were African American (52.2%). Significant differences also were observed based on financial status, with those reporting being in need of financial assistance indicating a higher rate of accommodation use (58.5%) than those reporting some difficulty meeting expenses (46.8%) and those reporting that they were able to meet expenses (38.6%; $\chi^2(2) = 10.07, p = 0.007$). There was not a significant difference between groups based on education level ($\chi^2(6) = 9.086, p = 0.169$). There was, however, a significant difference in the rate of accommodation use between those who were married or living with a partner (38.6%) and those who were not married (49.8%; $\chi^2(1) = 7.98, p = 0.006$). Finally, the two groups did not differ significantly based on age ($t(734) = 1.27, p = 0.203$), with the average age of those using workplace accommodations (49.5) only approximately 1 year higher than for those who were not (48.4).

3.4. MS-related differences based on accommodation use

Participants with progressive forms of MS were significantly more likely to report using accommodations than those reporting relapsing-remitting MS ($\chi^2(4) = 15.29, p = 0.004$). Participants self-reporting any level of cognitive impairment were also significantly more likely to report using accommodations (43.8%) compared to those reporting no cognitive impairment (35.6%; $\chi^2(1) = 3.81, p = 0.05$). Those participants reporting using accommodations also reported a significantly higher number of MS symptoms (Mean = 7.04, SD = 3.44) compared to those not using accommodations (Mean = 5.01, SD = 3.12; $t(709) = 8.19, p < 0.000$), and reported a significantly higher rate of symptom severity ($t(736) = 6.50, p < 0.000$). Finally, those reporting using accommodations rated their QOL as significantly lower (Mean = 32.7, SD = 9.14) than those not using accommodations (Mean = 35.6, SD = 9.3; $t(742) = 4.22, p < 0.000$).

3.5. Job factor differences based on accommodation use

Participants who used accommodations rated their job-person match (Mean = 3.92, SD = 1.052) as slightly but significantly lower than those not using accommodations (Mean = 4.12, SD = 0.96; $t(711) = 2.703, p = 0.007$). The difference between the two groups in job satisfaction, however, was not significant ($t(713) = 0.959, p = 0.338$). Finally, those using work accommodations were less optimistic about their career future, reporting a higher likelihood of giving up work

Table 1

<table>
<thead>
<tr>
<th>Reported Accommodation</th>
<th>Number (%) reporting that they use this accommodation at work</th>
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<tbody>
<tr>
<td>Changes in work schedule</td>
<td>167 (22.39)</td>
</tr>
<tr>
<td>Work at home part of the time</td>
<td>88 (11.80)</td>
</tr>
<tr>
<td>Change in job duties/procedures</td>
<td>83 (11.13)</td>
</tr>
<tr>
<td>Modifications of work station</td>
<td>74 (9.92)</td>
</tr>
<tr>
<td>or company physical facilities</td>
<td></td>
</tr>
<tr>
<td>Work at home all of the time</td>
<td>47 (6.30)</td>
</tr>
<tr>
<td>Modification of equipment</td>
<td>32 (4.29)</td>
</tr>
<tr>
<td>Reassignment to another position</td>
<td>29 (3.89)</td>
</tr>
<tr>
<td>Installation of new</td>
<td></td>
</tr>
<tr>
<td>assistive equipment</td>
<td>17 (2.28)</td>
</tr>
<tr>
<td>Personal care assistant</td>
<td>14 (1.88)</td>
</tr>
<tr>
<td>Driver</td>
<td>13 (1.74)</td>
</tr>
<tr>
<td>Reader</td>
<td>5 (0.67)</td>
</tr>
<tr>
<td>Scribe</td>
<td>2 (0.27)</td>
</tr>
</tbody>
</table>

Note: Percentage based on N = 746 reporting either part-time or full-time employment.
entirely in the next two to five years (Mean = 4.17, SD = 1.05) than those using no accommodations (Mean = 3.63, SD = 1.22; t(563) = 6.01, p < .000).

4. Discussion

Findings from this investigation require discussion within the context of existing literature and best practices in the field of vocational rehabilitation. This section is organized around the five research questions that guided the analyses.

4.1. Frequencies of accommodations requested, approved, and utilized in the workplace

Accommodations have long been considered an integral part of workplace success for people with MS (Varekamp, Verbeek, & Van Dijk, 2006). It is therefore encouraging that 87.7% of those who had requested accommodations in the current study had those accommodations approved. In light of these promising rates of approval, it is of potential concern that only 25.7% of participants had requested an on-the-job accommodation. Given the reported rates of number and severity of MS symptoms in the current study, it would be expected that more than one-fourth of the participants in the study could have benefited from some type of workplace accommodation. Moreover, it is difficult to understand the finding that a sizable proportion of the accommodations that were being used by participants in this study were not preceded by requests for those accommodations by respondents. Given the past emphasis on the accommodation request process, more research is needed into explanations for this phenomenon to reexamine the importance of this process among workers with MS.

4.2. Types of accommodations used in the workplace

Given the unpredictable course of MS and the prevalence of the relapsing-remitting type of MS, it is unsurprising that the two most frequently used workplace accommodations for participants were changes in work schedules and working from home part of the time, accounting for more than one-third of the accommodations reported in this study. This underscores the importance of schedule flexibility and reinforces the continued emphasis on increasing opportunities for persons with MS to work from home when needed. The third most frequently used accommodation was changes in job duties/procedures which, along with changes in scheduling and ability to work from home, highlights the importance of workers with MS remaining in their current positions rather than being reassigned to a new position. Rumrill et al. (2013) reported similar findings in their follow-up accommodation study with a smaller sample of people with MS. The frequencies of use for modifications of work station or company physical facilities (9.9%) and modifications to equipment (4.3%) underscore the need for considerations related to the physical and sensory effects of MS. Sumner (1997) reported that employers of people with MS are more receptive to accommodation requests related to physical mobility and vision than they are to accommodation requests related to cognitive functioning and health.

4.3. Demographic differences in accommodation use

Despite gender differences in the prevalence and severity of MS, with more females being affected but with males having generally poorer prognoses (Tintore & Tur, 2014), the rate of workplace accommodations between the sexes was almost identical. Similarly, the utilization of accommodations was relatively uniform across educational levels, suggesting no significant differences in accommodation use based on job type (which is strongly related to education). Significant differences were noted, however, with respect to ethnicity, with more than a half of African Americans in the study reporting that they use accommodations to perform their job duties, compared to 39% of Caucasians and 43% of Hispanic/Latino people with MS in this survey. The relatively small percentages of participants from minority backgrounds make it difficult to identify the underlying cause, or causes, for this difference. In-depth investigations of the accommodation needs and experiences of African Americans with MS would shed important light on why these individuals report a significantly higher rate of accommodation use than do other groups of people with MS. Cultural differences among people with MS in access to health care, symptom management, self-advocacy, and career development should also be explored for their potential impact on workplace accommodation use and effectiveness.

There were no significant age differences between participants who used and did not use accommodations. Marital status, on the other hand, was strongly related
to accommodation use, with married people reporting lower rates of accommodation use. As several studies have shown (e.g., Harrison, Stuifbergen, Adachi, & Becker, 2004; Kiecolt-Glaser, & Newton, 2001), people with MS who are married or living with a partner report higher quality of life, including better physical and psychological functioning (McPheters & Sandberg, 2010), than those who are unmarried or living alone. Decreased stress and better physical and psychological functioning likely translate to a greater ability to function in employment without the need for accommodations for married people with MS. Moreover, people with MS living alone are more likely to have difficulties with transportation to work or support with their activities of daily living, which may result in their seeking accommodations in the form of modified work schedules. Future research that places workplace accommodations in broader community living and socialization frames than was possible in the present study would help to further elucidate the relationship between marital status and accommodation use.

4.4. Disease-related differences in accommodation use

Disease course, symptom severity, number of symptoms, and type of symptoms all played a significant role in differences in accommodation usage for workers with MS, all suggesting that accommodation use was positively associated with increased MS severity and functional limitation. Participants who experienced a progressive course, as opposed to a relapsing-remitting course, were more likely to use accommodations, as were those reporting frequent and more severe symptoms. Cognitive symptoms were associated with significantly increased usage of accommodations. This underscores the systemic impact of cognitive impairments and the wide-ranging effects they can have on an individual’s ability to carry out essential job functions.

Rehabilitation professionals, assistive technology specialists, health care providers, and employers must work together to help workers with MS develop effective symptom management strategies that enable them to maintain their health while continuing their career pursuits. Elements of the Project Alliance intervention (Sumner, 1997), now 20 years old, still hold promise for helping workers manage MS with consultation from employers and rehabilitation professionals. Cooperative dialogue between the worker with MS and the employer regarding matters of symptom management, job performance, and reasonable accommodations resulted in an 85 percent job retention rate for workers with MS at a 12-month follow-up. Helping people with MS understand how their symptoms impact their job performance and necessitate workplace accommodations has been identified as the most important job retention intervention for people coping with this intrusive and unpredictable disease (Rumrill et al., 2013; Sumner, 1997).

4.5. Job factor differences in accommodation use

A common reason for the premature disengagement from the workforce that often accompanies MS and other disabling conditions is the perception by the employee or the employer that the skills or vocational interests of the worker do not match the demands of the job (Rubin et al., 2015). Another common reason is the employee’s dissatisfaction with the job. In the current study, people with MS who used workplace accommodations and those who did not reported about the same level of job satisfaction. However, participants who used accommodations perceived a slightly but significantly weaker match between themselves and their jobs than those who did not use accommodations. This difference points to the frequently reported poor support for people with MS who return to work (Phillips & Stuifbergen, 2006; Sweetland, Rizzi, Cano, & Playford, 2007), including a lack of appropriate assessment services and the unavailability of support from “employment specialists who have expertise in managing the interaction between the impairments caused by MS, the physical environment, and the demands imposed by the work” (Sweetland et al., 2007, p. 2035). It also supports research that has found that a lack of education on the part of the employer regarding MS can lead to a lack of or poor accommodations for the worker with MS (Roessler, Rumrill, & Fitzgerald, 2004), or to a poor job match. These issues have clear implications for career expectations and job retention. A significantly larger number of participants in this study who were using accommodations indicated a high likelihood that they would permanently stop working in the next two to five years compared to participants not using accommodations. Additional research is needed to determine the possible impact of effective on-the-job accommodations on perceptions of job-person match and career optimism for people with MS, given that those two constructs are important determinants of longevity or tenure on the job (Roessler & Rumrill, 1995).
4.6. Limitations

Limitations of the present study included the low response rate (25%) for the original survey from which data for this analysis were drawn, the fact that all data utilized in the study were based on respondents’ self-reports, and the absence of information regarding the specific accommodations that participants used in the workplace (accommodations were listed in 12 general categories in the survey instrument). It should also be noted that the present findings drawn from an American sample of workers with MS may not generalize to samples of people with MS outside the U.S. It is likely that intercultural and international differences in the incidence and treatment of MS, employer attitudes toward people with disabilities, norms regarding self-advocacy and asking for assistance in the workplace, availability of assistive technology, and laws governing the implementation of workplace accommodations and other anti-discrimination requirements would yield different patterns in accommodation usage among people with MS in other countries.

5. Conclusion

The results of this study provide insight into the usage of workplace accommodations for workers with MS. Perhaps the most intriguing finding showed that a significant number of workplace accommodations being used by participants with MS were apparently not preceded by a request to the employer. Further research is needed to determine if this relationship is seen consistently across the population of workers with MS, in which case there would be significant implications for rehabilitation professionals in the approach to working with persons with MS. Traditionally, a rehabilitation plan includes extensive education and training on the accommodation request process, yet these results indicate that process may not be as important as previously believed. In fact, the approval rate for requested accommodations in this study was found to be quite high (87.7%), indicating that either employers may be willing to provide needed accommodations or the emphasis on training in the accommodation request process has been generally successful in helping workers with MS receive on-the-job accommodations.

The types of accommodations reported in the study underscore the importance of scheduling flexibility as well as ability to work from home for workers with MS. It is likely that, particularly when experiencing a symptom relapse, employees with MS need flexibility in these areas to carry out necessary job requirements. Modification of work areas and equipment are also relatively salient needs for persons with MS in the workplace, as expected with the degree of gait/mobility impairment consistent with MS symptomology. A progressive MS course, higher number of symptoms, and higher severity of symptoms all significantly contribute to an increasing need for accommodations in the workplace for individuals with MS. Each worker with MS has a unique set of disease and individual characteristics that are significantly related to the need for different types of workplace accommodations. Rehabilitation professionals must understand how each of these client characteristics can influence the need for workplace accommodations and collaboratively create an individualized rehabilitation plan for workplace accommodations accordingly.

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References


Falvo, D. R. (2014). Medical and psychosocial aspects of chronic illness and disability (5th ed.). Burlington, MA: Jones and Bartlett Publishers, LLC.


