Employment and workplace accommodation outcomes among participants in a vocational consultation service for people with multiple sclerosis

Phillip D. Rumrilla*, Robert T. Fraserb and Kurt L. Johnsonb

aSchool of Lifespan Development & Educational Sciences, Kent State University, Kent, OH, USA
bUniversity of Washington, Seattle, WA, USA

Accepted January 2013

Abstract. Unemployment is higher among people with multiple sclerosis (MS) than would be expected and vocational rehabilitation efforts to help people with MS retain or regain employment have been marginally successful. To better understand the role workplace accommodations may play in employment, 41 people with MS who had contacted the Kent State Employment Assistance Center between 10 and 15 years ago were telephoned as part of a program evaluation follow-up and asked about their experience with the accommodations and short term and long term employment outcomes. Sixty percent reported they were still working, and subjects reported that low cost, low impact accommodations were more likely to be provided. Further research was recommended.

Keywords: Multiple sclerosis, vocational rehabilitation, employment, accommodations

1. Introduction

Multiple sclerosis (MS) is a chronic, progressive disease of the central nervous system affecting over 400,000 people in the U.S (National MS Society, 2012). People living with MS often have functional limitations associated with neuro-cognitive changes, fatigue, pain, mobility changes, etc. which may result in disability (Johnson, Amtmann, Yorkston, Klasner, & Kuehn, 2004). Although approximately 90% of people with MS have a history of employment, only 30% are found to be employed in many studies (Johnson, Bamer, & Fraser, 2009).

Vocational rehabilitation clients with MS as a specific disability group have received relatively minimal attention within the field. There have, however, been a number of vocational demonstration projects chiefly funded by the Rehabilitation Services Administration (RSA) with a mixture of efforts by university-based personnel and the National Multiple Sclerosis Society (NMSS) and its affiliates. These projects include the MS Back to Work or Operation Job Match Program (1980), the Job Raising Program (1993), the Return to Work Program (1983), the Career Possibilities Project (1994), and the multi-site Project Alliance (1997).

These different demonstration projects were reviewed by Rumrill (1996), Fraser, Clemmons, and Bennett (2002), and Johnson, Amott, Yorkston, Klasner, and Kuehn (2004). The initial projects in this sequence of efforts basically involved assisting clients through job seeking skills training and providing direct job placement assistance with an MS-specific job bank or mentoring by employers. Later projects maintained the job seeking skills training emphasis,
but increased the focus on placement training and strategizing solutions for jobsite barrier removal. The later projects, specifically Project Alliance (National Multiple Sclerosis Society, 1997), were influenced by the implementation of the Americans With Disabilities Act (ADA) 1990 and the focus upon reasonable accommodation for qualified workers with disabilities. In a systematic Cochrane review, Kahn, Ng, & Turner-Stokes (2011) found only two low-quality randomized controlled trials of vocational rehabilitation interventions in the literature, although there were a variety of other kinds of designs, and concluded there was no evidence that vocational rehabilitation is effective for people with MS. The lack of effective vocational rehabilitation may also be manifest in the low rate of employment noted earlier. There has been some evidence, however, that vocational rehabilitation interventions that emphasize workplace accommodations and increasing feelings of self-confidence or self-efficacy in dealing with work related problems, do make a difference (Varekamp, Verbeek, & Van Dijk, 2006).

The Project Alliance study (National Multiple Sclerosis Society, 1997) was of particular interest because it emphasized early accommodation and collaborative problem-solving between the employee and the employer rather than the more traditional job seeking skills training and placement assistance. The focus of this project was to coach the participant with multiple sclerosis to take a proactive employment retention stance involving a non-adversarial early intervention with his or her employer. A trained rehabilitation specialist met with the employer and employee with MS to encourage open communication and to strategize job accommodations as a means of facilitating stability before resignation or termination of the worker’s job occurred.

Two thirds of potential participants did not agree to have the rehabilitation specialist on site providing assistance, but of those participants who completed the full Project Alliance intervention, including a complete job analysis performed by the rehabilitation specialist, 85% were still working at a one-year follow-up. The most frequently encountered barriers to job retention centered on fatigue and a wide range of cognitive impairments. It is likely that fears related to stigmatization, employer perceptions of the worker’s loss of capacity, and employers’ possible refusal to provide needed accommodations presented too much perceived risk for many workers with MS in order to consent to participate in the full intervention.

In the present study, an effort was made to more closely examine the actual accommodation process. This is the first investigation to consider the impact of accommodation-related employment services for employed people with MS over time. The scientific method described in the following section was guided by the following research questions:

1. What types of accommodation-related assistance did participants seek from operators of the MS Employment Assistance Service?
2. What were the short-term outcomes of the accommodation-related assistance in terms of percentage of employers who agreed to provide on-the-job accommodations and what types of accommodations were provided?
3. What factors were attributed to successful and unsuccessful outcomes of the accommodation process?
4. What were participants’ employment and accommodation experiences following their engagement in the MS Employment Assistance Service in terms of whether they maintained employment during the follow-up period, employment rate at follow-up, work satisfaction, and vocational assistance sought?
5. Were there specific health-related and demographic factors such as number and severity of symptoms and personal income that were associated with employment and job accommodation outcomes?

2. Method

Data for this study were collected during a follow-up survey of U.S. adults with multiple sclerosis (MS) who had participated in a telephone and Internet-based employment assistance service between 2001 and 2006 as part of a program evaluation. The Kent State Employment Assistance Center provided reasonable accommodation consultation under contract with a number of state affiliate chapters of the National Multiple Sclerosis Society. Forty one individuals with MS who had contacted the employment assistance service seeking information or consultation regarding workplace accommodations were contacted for the survey.

The purpose of this study was to identify the outcomes of the accommodation-related assistance that respondents had received from the service and to evaluate respondents’ current employment status and accommodation experiences.
2.1. Participants

The study sample consisted of 41 adults with MS, 26 women (63%) and 15 men (37%), who ranged in age from 31 to 62 years (M = 46.9 years, SD = 8.4). Six respondents (15%) identified themselves as African-Americans, with the remaining 85% of the sample (n = 35) being Caucasians. Like the broader population of Americans with MS, participants in this study were well-educated; all 41 respondents reported being high school graduates, and 26 of these individuals (63%) had earned four-year college degrees or graduate degrees. Almost all of the respondents were involved in skilled work activity (e.g., nurse, financial advisor, grocery manager, architect, social worker, etc.).

On average, these respondents had been coping with MS for 14.8 years (SD = 8.0). They reported experiencing a wide range of MS symptoms, with the most common symptoms being fatigue, mobility problems, numbness and tingling in the extremities, spasticity, and cognitive impairment. All 41 respondents had been employed either full or part-time when they participated in the employment assistance service, and 24 of these individuals (59%) were still working at the time of this study. Most of these employed people were working full-time, reporting an average weekly work schedule of 39 hours (SD = 9.4). Of the 17 individuals who were not working at the time of this study (41%), nine had retired early due to health reasons and were receiving long-term disability and/or Social Security Disability Insurance (SSDI) benefits.

Twenty-one respondents (51%) were either married or living with a significant other at the time of this study, and 20 (49%) were divorced, widowed, or never married. When asked about their total annual household incomes, respondents reported the following: less than $25,000 – 0 respondents, 0%; $25,000–$40,000 – 8 respondents, 19.5%; $41,000–$55,000 – 3 respondents, 7.3%; $56,000–$70,000 – 5 respondents, 12.2%; $71,000–$85,000 – 6 respondents, 14.6%; $85,000–$100,000 – 6 respondents, 14.6%; and more than $100,000 – 13 respondents, 31.7%.

2.2. Instrumentation

Data for this program evaluation were collected in telephone interviews using a 48-item protocol with fixed and open response sets. The structured interviews began by eliciting background information from respondents including the year they were diagnosed with MS, the year in which they had begun receiving services from the employment assistance program, educational and work histories, and the nature of the accommodation assistance they had sought from the employment program. Other items called for detailed information about the process by which respondents had requested reasonable accommodations from their employers, the types of accommodations requested, whether their employers had provided any on-the-job accommodations, which accommodations were provided, reasons for the success or failure of accommodation requests, whether and how respondents had disclosed their disability status to their employers, the role of accommodations in respondents’ current employment status, the reasons why unemployed respondents had left the workforce, and services and benefits that respondents were using at the time of the study. The final section of the protocol elicited demographic and health status information such as age, gender, race/ethnicity, marital status, height, weight, waist size, MS symptoms experienced, and individual and household income.

2.3. Procedures

This follow-up study involved 41 adults with MS who had participated in a telephonic and Internet-based employment assistance service over a five-year period. A total of 51 participants in the larger employment assistance service had registered with the service as being in need of assistance with on-the-job accommodations; of these, 10 individuals either could not be located at the time of the program evaluation survey (n = 8), or chose not to participate in the follow-up interviews (n = 2). The remaining 41 individuals responded to this study and comprised the above-described sample.

Data were collected via telephone interviews conducted by an experienced rehabilitation counselor and researcher. Prior to the interviews, the interviewer explained the purpose of the study and obtained informed consent. All items in the above-described protocol were administered to each of the 41 respondents in the same order. The interviews took an average of 42.6 minutes to complete (SD = 8.3 minutes). Participation in the interviews was voluntary, and participants were not compensated.

2.4. Protection of human subjects

The data collected for the program evaluation were de-identified and approval for an exemption for “off the
Table 1
Nature of Accommodation/Employment concerns

<table>
<thead>
<tr>
<th>Nature of Accommodation</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schedule modification</td>
<td>11</td>
<td>23%</td>
</tr>
<tr>
<td>Equipment/Assistive technology</td>
<td>12</td>
<td>26%</td>
</tr>
<tr>
<td>(e.g., enlarged computer screen, scooter, voice-activated software, etc.)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climate control/Air conditioning</td>
<td>6</td>
<td>13%</td>
</tr>
<tr>
<td>Reassignment/Reduction of hours</td>
<td>6</td>
<td>13%</td>
</tr>
<tr>
<td>ADA/Disclosure information</td>
<td>6</td>
<td>13%</td>
</tr>
<tr>
<td>Physical accessibility</td>
<td>3</td>
<td>6%</td>
</tr>
<tr>
<td>(e.g., restroom, parking spot)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other (viz., scribe)</td>
<td>1</td>
<td>2%</td>
</tr>
<tr>
<td>Missing data</td>
<td>2</td>
<td>4%</td>
</tr>
<tr>
<td>Total</td>
<td>47</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 2
Accommodations provided by employers

<table>
<thead>
<tr>
<th>Accommodation</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Equipment/Assistive technology (e.g., scooter, software, keyboard, etc.)</td>
<td>11</td>
<td>42%</td>
</tr>
<tr>
<td>Schedule modification</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Physical accessibility</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Sick leave/FMLA</td>
<td>2</td>
<td>8%</td>
</tr>
<tr>
<td>Driver</td>
<td>2</td>
<td>8%</td>
</tr>
<tr>
<td>Reduced hours</td>
<td>2</td>
<td>8%</td>
</tr>
<tr>
<td>Air conditioning</td>
<td>3</td>
<td>12%</td>
</tr>
<tr>
<td>Total</td>
<td>26</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 3
Reasons for job accommodation success

<table>
<thead>
<tr>
<th>Reason</th>
<th>Number</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accommodation low cost</td>
<td>8</td>
<td>33.3%</td>
</tr>
<tr>
<td>Good worker/Committed employer</td>
<td>3</td>
<td>12.5%</td>
</tr>
<tr>
<td>Made own accommodation</td>
<td>3</td>
<td>12.5%</td>
</tr>
<tr>
<td>Quality of communication</td>
<td>2</td>
<td>8.3%</td>
</tr>
<tr>
<td>Not sure</td>
<td>2</td>
<td>8.3%</td>
</tr>
<tr>
<td>Other (e.g., schedule improved, fatigue alleviated, etc.)</td>
<td>6</td>
<td>25.0%</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

2.5. Data analysis
This descriptive follow-up study utilized both qualitative and quantitative data that were elicited from participants in the structured telephone interviews. Data from the interviews were transcribed from the hard copy interview protocol forms into an Excel spreadsheet, and quantitative data were transported to an SPSS program for analysis. Qualitative data were analyzed directly from the Excel spreadsheet using open, selective, and axial coding (Bellini & Rumrill, 2009).

3. Results
The presentation of results is organized according to the five over-arching research questions. This mixed-method study blends narrative descriptions of qualitative data with tabular and graphic depictions of quantitative data for each question.
Across the sample, 47 different accommodations were requested from the 41 participants. When asked categorically to describe their accommodation needs, 11 participants (23%) described a need for a schedule change at the workstation and 12 (26%) described a need for equipment or assistive technology. Climate control/air conditioning, reassignment/reduction of hours, and ADA/disclosure-accommodation information each respectively accounted for 13% of the requests. More specific review of participants’ accommodation concerns is provided in Table 1.
In terms of actual job accommodation, 23 (56%) were provided an accommodation by their employers, 7 (17%) were not and lost the job, 3 (7%) were not and didn’t need one, 3 (7%) were not and their employer didn’t know they had MS, 3 (7%) never asked, and 2 (5%) asked and were denied. Table 2 provides a profile of the actual accommodations made.
It is of interest that equipment and assistive technology (often computer-related) constituted the most frequently provided accommodation category. A few received more than one accommodation. Scheduling modifications did occur, but not as often as desired and generally involved a work-from-home option. It was also of interest that two drivers were provided as reasonable accommodations, especially because drivers were not specifically requested or considered as a concern by any of the participants. This accommodation could have been suggested by the employers or offered by co-workers.
For those who received accommodations, questions were asked as to why an accommodation was successful or unsuccessful. Table 3 lists participants’ stated reasons why implemented accommodations were successful—in a few cases, there was more than one reason.
It is noteworthy that “low cost” was perceived as the chief reason for success of the accommodation request. Other reasons were also related to simply “good business” such as keeping a good, committed employee or that the individual, with consultation, was able to make his or her own accommodation. Of course,
participants had the most autonomy in accommodation planning when they were self-employed. The quality of the accommodation discussion, interestingly, was referenced less than 10% of the time and other reasons were quite diverse.

In terms of unsuccessful accommodation outcomes, there were fewer reasons offered by participants (12). The majority of these, 8 (67%), believed that the employer wanted to terminate the worker’s employment following disclosure of the worker’s MS, did not want to establish a precedent that would lead to accommodation requests by other workers, or considered the worker incapable of performing the job. Other reasons for unsuccessful accommodation outcomes were more diverse, but two individuals (17%), believed that they hadn’t appropriately asked for on-the-job accommodations.

A final look at this study’s participants involves profiling the group’s current employment status, accommodations, and related outcomes. At follow-up, 58.5% of these individuals were working, the mode being one job, with nearly 80 percent of those who were employed having been continuously employed since they took part in the employment assistance program. All but one of those working, a hotel receptionist, were at a skilled level of work (U.S. Department of Labor, 1991). Approximately one-third, 34.1%, preferred to work more hours but could not due to their health or to their disability benefits status. Among those not working, they were chiefly being supported on SSDI and long-term disability insurance.

There was very limited contact with state vocational rehabilitation agencies – only 26.8% across the whole sample. No participant had utilized a private pay vocational or psychology specialist for assistance in securing work.

As a group, participants on a scale of 0–10 (severe symptoms) were most troubled by weakness, mean rating = 4.1; fatigue, mean rating = 7.3; imbalance, mean rating = 3.4; and memory issues, mean rating = 3.1. Most of the other MS symptom severity ratings were well below a “3”. The group was also quite self-sufficient in performing activities of daily living, as evidenced by modal ratings of “0” for both paid help and help from family/friends.

Total household income appeared to be related to employment status; of the eight respondents whose total household income was reported as less than $40,000 per year, only two (25%) were employed at the time of the study. Conversely, 12 of the 13 (92%) respondents whose total household incomes were greater than $100,000 per year were employed at the time of the study. In terms of symptoms, respondents who reported more than four MS symptoms at a severity rating of greater than 3 were employed at a rate of 18 percent at the time of the study, whereas respondents who reported no or only one MS symptom at a severity level of 3 or higher were employed at a rate of 78 percent. Respondents’ current health status was not related to the provision of accommodations by their employers during their participation in the MS Employment Assistance Service some years earlier, most likely owing to the long time interval between their accommodation requests and the follow-up study.

4. Discussion

This is a unique study inasmuch as it examines the impact of job accommodation consultation for workers with MS at five to 10 years from the point of consultation. Contact was made with 80% of those who requested accommodation assistance. It was of interest that requests for equipment and assistive technology were provided much more readily than work schedule modifications. Similarly, it was of interest that low cost was a salient reason given for the success of accommodation provision. If the accommodation is financially easy to provide and doesn’t involve restructuring an individual’s work activities, it seems more likely to occur. When requests were unsuccessful, the accommodation seeker seemed to perceive that the employer was set on termination. Whether this involved employer discrimination or the worker couldn’t perform the essential functions of the job is unknown. It is also unknown whether any legal recourse was pursued in relation to these cases.

This MS population is unusual since 59% were working at follow-up. The salary level is also of note inasmuch as 60% were earning greater than $70,000 annually and a quarter were earning more than $100,000. It may be that these high earners, chiefly with college or graduate degrees, were invested in the accommodation process and sought out resources. It could also be the case that they are quite valuable to the company and ownership is more committed to keeping them – 12 of 13 (92%) of the group earning more than $100,000 were still working at follow-up. Conversely, among those reporting earning less than $40,000, only two of eight (25%) were working. This is of interest and could be a function of less disparity between disability pensions and salary earnings for the individual. They
also may be not as valued, providing the employer less incentive to accommodate.

Although these workers had sought out an accommodation service, it is of interest that only a quarter had actually contacted a state vocational rehabilitation agency. This could be for a number of reasons to include personal self-confidence in handling their situation, a lack of trust in a state agency, or simply a lack of knowledge of the state/federal vocational rehabilitation program(s).

There are a number of limitations to this study. The sample size is relatively small and there is not a uniform follow point from contact with the Kent State Employment Assistance Center. The information is also self-report from a population that can often have cognitive difficulties, particularly at several years from the initial consultation. Further studies might involve a larger sample, a standard follow-up point (e.g., one year from consultation), and consider, if possible, confirming the information with a significant other.

Acknowledgments

Funding for this project was provided by a grant from Department of Education, NIDRR grant number H133B080025 to the University of Washington Multiple Sclerosis Rehabilitation Research and Training Center. However, those contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.

References


