

Barriers to and Facilitators of Employment among Americans with Multiple Sclerosis: Results of a Qualitative Focus Group Study

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People with multiple sclerosis (MS) are known to face a multitude of challenges in the workplace and when seeking employment. Less has been written, however, about the subjective experiences of people with MS regarding their workforce participation. This study used phone-administered focus groups to investigate work-related experiences of a national sample of individuals with MS. Using a conventional qualitative content analysis approach, the researchers derived a set of three core themes, each with subordinate sub-themes. The three core themes were: (a) facing future uncertainty, (b) feeling a sense of loss, and (c) navigating the workplace. Findings are discussed within the context of existing literature.

Multiple sclerosis (MS) is a chronic, unpredictable neurological disease characterized by cycles of relapses and remissions, although some people experience a steadily 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. Fifty percent of MS diagnoses occur before the person's 30th birthday and 75% before age 40 (Kalb, 2012). More than 2.3 million people in the world are estimated to have MS, with approximately 450,000 of these individuals living in the United States (National Multiple Sclerosis Society [NMSS], 2015). In the U.S., the national incidence rate of new MS cases has increased steadily over the past 50 years (NMSS, 2015).

MS is more common among women than it is among men, with approximately three-quarters of people with MS worldwide being women (NMSS, 2015). MS is also much more common among Caucasians of European lineage than it is among other racial and ethnic groups. 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 U.S., two-thirds of people with MS reside in the northernmost 50% of the populace (NMSS, 2015).

MS Symptoms

People with MS may experience a wide range of physiological symptoms 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). MS can also impact the person's affective responses, coping skills, and cognitive abilities. Polman, Thompson, Murray, Bowling, & Nosewor-

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thy (2006) reported that “psychiatric morbidity is increased in MS, with over 50% 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, 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 vary significantly among individuals with MS and do not appear to be strongly correlated with the degree of physical involvement (DeLuca & Nocentini, 2011).

MS and Employment

Because of the wide range of symptoms and the unpredictable nature of the disease, 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 from 2002 - 2010, 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 figure, although 98% of the sample were high school graduates and 46% were college graduates.

Not surprisingly, Americans with MS are concerned about their employment prospects following diagnosis. In a 2003 survey of 1,310 adults with MS from 10 states and Washington, DC, Roessler et al. (2003) found the majority of respondents dissatisfied with 29 out of 32 high-priority employment concerns. The majority of the individuals in the sample were satisfied with only three items: their access to service providers (51%), the treatment they received from service providers (61%), and the encouragement they received from others to take control of their lives (56%). The employment items with the highest dissatisfaction ratings clustered into three thematic categories: implementation and enforcement of the Americans with Disabilities Act (ADA), health care and health insurance coverage, and Social Security disability programs.

For many years, medical, psychological, allied health, and rehabilitation researchers have sought to understand why people with MS often make a premature exit from the labor force, usually of their own choosing, and often before they become incapable of working. Indeed, among people with MS who are unemployed, 75% left their jobs voluntarily (Roessler, Rumrill, & Hennessey, 2002), 80% believe that they retain the ability to work (Sumner, 1997), and 75% say that they would

like to re-enter the workforce (Rumrill, 2006). Two factors related to MS and unemployment might help to explain why this experienced and productive group of workers tends to leave the workforce before reaching retirement age. First, there is a significant relationship between age and MS-related functional disability and consequently between both variables and unemployment (Fraser, Kraft, Ehde, & Johnson, 2006; Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008). As the years pass and the illness progresses, the person becomes less able to meet the physical demands of employment. Second, age is positively associated with socioeconomic status. Many older people with MS have the financial means to stop working and do so voluntarily to focus on other pursuits (Rumrill, 2006).

The choice to leave the workforce is most often made by the person with MS, but it is not entirely clear to what extent discrimination in the workplace influences that choice. What is known is that perceived discrimination, especially unwillingness on the part of employers to provide reasonable accommodations, is a major obstacle to continued employment following diagnosis with MS. Sweetland, Riazzi, Cano, and Playford (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). These findings related to employer relations and workplace accommodations were echoed by Doogan and Playford (2014).

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 ADA. Specifically, relatively high numbers of respondents were dissatisfied with items related to on-the-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 of the ADA (51.7% dissatisfied); (d) understanding the benefits of disclosing disability status to employers (50.6% dissatisfied); (e) knowing what to do if they encounter discrimination at work (49.4% dissatisfied); and (f) expecting employers to respond to their accommodation needs in a timely manner (47.9% dissatisfied).

For all that is known about the factors associated with employment status and labor force participation among people with MS, limited attention has been paid in existing MS research to the subjective personal meaning that people with MS ascribe to work and career development. Moreover, there is a paucity of in-depth qualitative findings that reflect the employment concerns of people with MS in their own voices and from their own perspectives. Therefore, the purpose of this qualitative investigation was to intensively examine barriers to and facilitators of employment from the point of view of a sample of adults with MS ($N=27$) who participated in telephone focus

groups as part of a larger study of the employment issues facing Americans with physical disabilities. The research questions that guided the present investigation were as follows:

1. What are the most commonly reported barriers and facilitators to employment that are identified by people with MS?
2. What are the most commonly reported employment information and resource needs reported by people with MS?

Method

Ethical Considerations

All procedures used in this study were reviewed and approved by the Institutional Review Board at the senior authors' affiliated university. Because the focus groups included multiple people with MS, the importance of confidentiality was emphasized with the participants during the informed consent process as well as before each focus group. Identifying data such as names, addresses, and employers were removed from the data during the transcription process so that only de-identified data were used in the analysis. All participants were compensated in the form of a \$50 gift card that could be used at a retailer of their choice.

Participants

Sampling. The sample for this study was recruited as part of a larger study of the employment concerns and experiences of individuals with physical disabilities. Five stakeholder groups with physical disabilities were targeted in the larger study including individuals with MS. Five national organizations representing these groups including the National MS Society, United Spinal Cord Injury Association, World Institute on Disability, United Cerebral Palsy, and National Centers for Independent Living assisted with recruitment. An e-mail solicitation was developed by the research team that explained the purpose of the study and was disseminated by these organizations using their e-mail distribution lists and other electronic methods such as social media and organizational websites. Participation criteria were specified in the notices indicating that the researchers were looking for individuals with physical disabilities who were (a) in the age range of 18-64 years; (b) employed or unemployed but seeking employment; and (c) willing to participate in an hour-long telephone focus group regarding their employment concerns and experiences. The e-mail solicitation and other notices contained a link to an online database that provided specific information about the study, the research questions, and a mechanism for the person to consent or decline participation. This database was housed on a secure server, and only the researchers had password access to the information.

After reading the study information online, individuals clicked on a link indicating that they consented or declined to participate. If the individual consented to participate, she or he was re-directed to a screen to identify her or his disability and employment status (i.e., employed or unemployed). In addition, the person was asked to enter contact information including e-mail, telephone number, and mailing address. The database sorted the consenting participants

into groups by disability type as well as by employment status (i.e., employed or unemployed). For the present analysis, all consenting individuals who self-identified as having MS were assigned to two groups, employed and unemployed.

A total of 55 respondents to the research solicitation identified themselves as people with MS. Of these individuals, 32 were unemployed and 23 were employed. The lead researcher for this study used the database to contact the 55 individuals with MS via e-mail to schedule the telephone focus groups. Participants were asked to select from a number of possible times that would be most convenient for them to participate. Once a minimum of six individuals responded to the message selecting the same meeting time, a follow-up confirmation e-mail was sent with directions on how to call in using a toll-free number at the specific time. A total of six focus groups were conducted including three with individuals who were unemployed and three with individuals who were employed. Of the 55 individuals with MS who consented to participate, 27 called in at the appointed time and took part in the focus groups. Of the 27 focus group participants, 15 were unemployed and 12 were employed.

Participant Profile. Immediately following each focus group, an e-mail was sent to the participants thanking them for their time and asking them to provide demographic information via e-mail. Fourteen of the 15 unemployed focus group participants and 11 of the 12 employed participants provided the requested information. The lead researcher collected these data, added them to a database without individual identifiers, and then deleted participants' e-mail messages. Participants resided in all regions of the United States and ranged in age

Table 1
Demographic Characteristics of Focus Group Participants

		Employed (n=11)		Unemployed (n=14)	
		n	%	n	%
Age	20-29	2	18.1	0	0
	30-39	3	27.3	2	14.3
	40-49	3	27.3	4	28.6
	50-59	3	27.3	7	50
	60-69	0	0	1	7.1
Sex	Male	1	9.1	5	35.7
	Female	10	90.9	9	64.3
Race	Caucasian	9	81.8	9	64.3
	African American	1	9.1	5	35.7
	Multiple	1	9.1	0	0
	High School	0	0	3	21.4
Highest Education	Associate's	1	9.1	2	14.3
	Degree	2	18.2	1	7.1
	Some	6	54.5	5	35.7
	College	2	18.2	1	7.1
	4-Year	6	54.5	5	35.7
Years Since MS Onset	Degree	2	18.2	3	21.4
	0-5 years	6	54.5	3	21.4
	6-10 years	3	27.3	4	28.6
	11-15 years	0	0	2	14.3
	16-20 years	1	9.1	5	35.7
Annual Income from Work	21+ years	1	9.1	0	0
	0-\$15,000	3	27.3	-	-
	\$15,001-\$25,000	1	9.1	-	-
	\$25,001-\$50,000	3	27.3	-	-
	\$50,001-\$75,000	3	27.3	-	-
	\$75,000+	1	9.1	-	-

from 26 to 61 years. Of the 25 participants who provided demographic information, the majority ($n=18$, 72%) were Caucasian, with 24% ($n=6$) identifying themselves as male and 76% ($n=19$) as female. Table 1 provides demographic information for the 25 participants who provided this information.

Data Collection

Protocol Development. Members of the research team collaboratively developed a focus group protocol for this study. The research team brought initial ideas for questions to a group meeting, which were then combined, refined, and ordered to arrive at the initial version of the protocol. The initial questions were tested in a pilot focus group of five individuals with physical disabilities who were known to members of the research team. Feedback from the pilot group as well as analysis of the pilot results resulted in a small revision to the protocol before it was used to conduct the focus groups for this study. Revisions clarified language and provided insights into probe questions that might be used to seek deeper responses from participants on some questions.

The final focus group protocol had 13 core questions for the employed group and 12 core questions for the unemployed group. A number of follow-up questions or probes that could be used at the facilitator’s discretion were identified to elicit additional responses from participants if needed. Questions asked participants to describe their process of finding or looking for employment following their MS diagnoses, barriers and facilitators they encountered in their efforts to find work, how their career choices had been affected by their disability, workplace accommodations, and recommendations for job seekers with MS and professionals who provide vocational services. The core questions are presented in Table 2.

Focus Group Administration. In order to include a national sample of people with MS, telephone administration of the focus groups was selected. The researchers sought a national sample because the vocational services and supports available to Americans with MS may vary considerably from state to state. Although telephone-based focus groups have the drawback of limiting the contextual information that can be collected from participants (e.g., body language, seating arrangements; Novick, 2008), the telephone method has been shown to have advantages over in-person focus groups. For instance, telephonic administration of a focus group may make participants feel more comfortable sharing their thoughts and perspectives, because they are participating in the group in the comfort and privacy of their own homes (McCoyd & Kerson, 2006; Novick, 2008; Sturges & Hanrahan, 2004).

The same research team member served as the facilitator for all of the MS focus groups. At the beginning of each call, the facilitator asked participants for permission

to record the conversation. She then told the group that the recording would be transcribed and any mention of a person’s name or personal identifiers would be deleted from the transcripts. Participants were also told that they did not have to respond to all the questions and that their participation was appreciated. The facilitator then began the recording and proceeded through each of the core questions, asking related follow-up probes as needed. The facilitator confirmed with participants that they did not have any other information to add when they stopped discussing a specific question. This was done to encourage individuals who were not responding to participate. Most of the focus groups ran for approximately one hour; however, several calls extended past 60 minutes upon the agreement of participants.

Data Analysis

Contents of the audio-recorded focus groups were transcribed verbatim by a professional transcription service, and the transcripts were used as the texts for analysis. Prior to data analysis, all names and other potentially identifiable data were removed to protect the confidentiality of the participants. A five-minute section of each audio file was checked against the transcript to verify accuracy, with no discrepancies noted. The final files used for analysis contained the full content of the focus groups, absent any potentially identifying personal information.

One member of the research team who has extensive experience in conducting qualitative research analyzed all study data. Additionally, another researcher conducted analyses of sections of the data to check the first analyst’s findings, challenge the first analyst’s coding, and build shared meaning between the two analysts. The two analysts discussed their findings, negotiated discrepancies, and ultimately arrived upon shared meanings from those data, which are provided in the Findings and Discussion section of this article. Furthermore, feedback about provisional findings was obtained from other

Table 2
Core Focus Group Questions
<i>Employed Participant Version</i>
What do you do, and what is a typical day like at work?
Tell me about the steps you took to find your job.
What were the key factors in getting a job?
Give me an example of how your disability affected your finding a job.
Give me examples of how you overcame your challenges to find a job.
Tell me about any accommodations you have requested for your job.
Tell me about things that help you do your job.
What would make your job easier to do well?
How have your career choices been affected by your disability?
What do you need to find and obtain your ideal job?
What advice would you give to someone with physical disabilities who is looking for a job?
What advice would you give to a professional who is helping people with physical disabilities find jobs?
What would you like to tell me that I have not asked?
<i>Unemployed Participant Version</i>
Tell me about your ideal job. What would you like to do?
What supports and services (such as people, agencies, and information) have you used to look for a job?
Tell me an example of a service or support that has been helpful in your job search.
Tell me an example of a service or support that was not helpful.
What information do you need to find a job?
Give me an example of how your disability has affected your finding a job.
How have your career choices been affected by your disability?
What supports and services will you need to find a job and stay employed?
Where will you go to find these supports and services?
What advice would you give someone with a physical disability who is looking for a job?
What advice would you give to a professional who is helping people with physical disabilities find jobs?
What would you like to tell me that I have not asked?

members of the research team who had familiarity with the data, and their feedback was incorporated into the final interpretation of findings.

Data analysis was conducted using the software package NVivo 10, adhering to a conventional qualitative content analysis approach. The researchers chose conventional content analysis because it requires researchers to remain open to interpretation of the data, allowing the analysts to construct themes directly from the data rather than applying pre-conceived ideas regarding what themes would be of importance, as is often the case in other forms of content analysis (Hsieh & Shannon, 2005). By remaining open to interpretation of the narratives of participants with MS, the researchers hoped to accurately portray participants' experiences and perspectives regarding employment (Kondracki & Wellman, 2002).

Analysis began with a round of open coding. The lead researcher went through the entire dataset applying codes that emerged directly from the data and looking for themes that seemed to be present across participants. A second round of coding followed, during which initial themes were consolidated and organized by the lead and second researchers. Also in the second round of coding, similar themes were further consolidated, and a hierarchy of core themes was developed. These core themes were supported by subordinate sub-themes. Finally, in a third round of coding, the research analysts tested the hierarchy of themes against the whole dataset, defining, refining, and revising themes in order to arrive at the final presentation of findings.

Findings and Discussion

The findings from this research suggest a number of com-

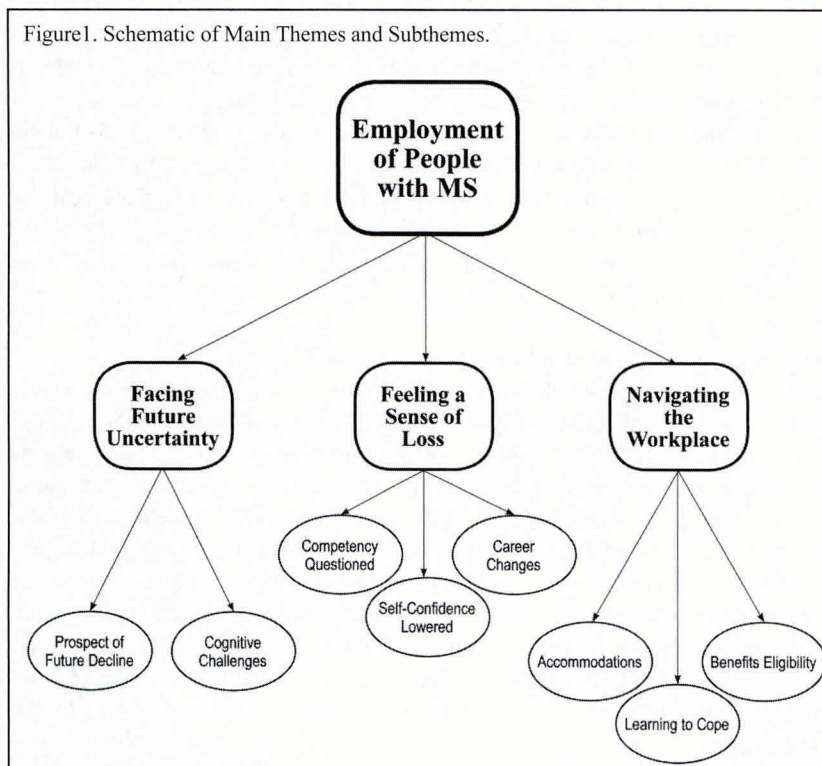
plex factors that interact to form the employment experiences of people with MS who participated in these focus groups. This blended Findings and Discussion section describes the themes that emerged from this qualitative investigation and interprets those themes within the context of existing rehabilitation literature and practice. Whereas some factors may be common to people with many types of disabilities, others may be specific to the experiences of people with MS. Three main themes emerged, each with corresponding sub-themes: (a) facing future uncertainty, (b) feeling a sense of loss, and (c) navigating the workplace. A schematic overview of main themes and sub-themes may be found in Figure 1.

Theme: Facing Future Uncertainty

One of the most salient themes to emerge from this analysis was that of uncertainty about the future progression of MS, and how this progression may affect work. The authors did not collect information on the specific course of MS that each participant was experiencing. However, the fact that the impact of MS on personal and social functioning tends to increase over time weighed heavily on the minds of these participants. The two sub-themes for facing future uncertainty included (a) prospect of future decline and (b) cognitive challenges.

Prospect of Future Decline. Participants in the focus groups discussed their concerns that MS frequently becomes a progressive disease, which may mean changes in work capacity over time as the person's age and functional limitations increase. This prospect for future decline and the unpredictable nature of MS weighed heavily on several focus group members. One participant stated, "I feel, unfortunately, like I have a career shelf life, like...I can only go so long without being able to have to be home permanently... that's always kind of in the back of my mind."

Figure 1. Schematic of Main Themes and Subthemes.



Even when participants framed the decline in their work ability less starkly, many focus group members said the MS diagnosis figured into how they sought work or career advancement. Participants had limited their job searching to match not only their current abilities, but also what they perceived to be their future abilities. In one such case, a man shared his decision to pass up promotion opportunities: There were dream jobs within my company, but they required 25% travel and being out of town for extended periods of time, and I didn't think I would be able to handle something like that. So, knowing that I had MS just prevented me from pursuing my true passion.

The combination of age and MS was also a factor in job seeking decisions for some participants. Because the onset of MS typically occurs during the prime working years and progresses to more severe symptoms over time, a number of participants, especially those who were unemployed, noted that the combination of their age and disability precluded them from

finding work. One individual shared, “I don’t want to tell them I have 38 years of working experience... the first thing they’re going to say is ‘she’s an old lady’.”

Similarly, the interaction of age, current complications of MS, and potential future decline could also prevent people from pursuing additional education. Although not many participants discussed the idea of returning to school or pursuing other advanced training, when they did, they were typically skeptical about the prospects for success. These sentiments were starkly outlined by one unemployed individual:

I have not put myself back in college... because I don’t have the confidence that I can pull it off. Not that I don’t know the information, but I can’t physically see myself spending the whole night writing a paper. I just don’t see that happening. I know there are supports in school, but I just don’t think at this age in my illness that that’s realistic and that’s killed my career, and I mean literally killed it.

This reflection is representative of the impact that MS can have on the person’s physical stamina and cognitive capabilities (Kalb, 2012), the combination of which can severely undermine one’s prospects for continued education, retraining, and other important career maintenance activities (Fraser et al., 2006; Roessler et al., 2015).

Cognitive Challenges. Fears of future decline in work abilities related to MS were particularly pronounced for the study participants who identified cognitive symptoms of MS. A number of participants suggested that they were not initially aware of their own cognitive declines, but they came to recognize their cognitive challenges through others’ reactions to them. Fraser et al. (2006) noted that cognitive impairment is one of the most under-reported symptoms of MS, and that initial signs of MS-related cognitive dysfunction are often noticed by friends and significant others rather than by people with MS themselves. One participant initially thought people were treating her differently because of their misconceptions about MS. However, she later came to realize that her cognitive state had declined, leading her to make mistakes on the job. As she stated, “... they made assumptions that, ok, the day I give myself the injection, something’s going to get messed up... like I would lose focus certain days.”

There was also a sense that cognitive declines affected work performance gradually, over the long term, but that the effects of cognitive decline on work functioning could be unpredictable from day to day. This made it difficult for participants to plan their future career activities. This finding underscores the tremendous negative impact that the unpredictability of MS has on the linear, future-oriented process of career planning that is most commonly applied in vocational rehabilitation counseling (Rubin, Roessler, & Rumrill, 2016). One unemployed participant noted her difficulty working through cognitive processing challenges that contributed to her job loss, even while sometimes having good days cognitively:

I have more issues in how I think and process at times. Not all the time. Today, I’m actually having a stellar day. But the last job I had, I would just screw up

so much stuff and people would be looking at me, so now I’m looking at me ...

Although cognitive challenges associated with MS sometimes contributed to job loss, other participants, particularly those who were employed, found ways to manage their work duties even in the context of cognitive challenges. The use of note pads and technology were cited as useful cognitive aids, especially by individuals who noted memory impairments. One such participant excitedly shared how her use of technology has allowed her to remain productively employed:

I have to tell you I have an iPad and also an iPod, which I swear both of them changed my life. Just being able to keep track of things better in notes and record myself if I need to, because I have mental issues.

Rubin and colleagues (2016) indicated that recent designers of assistive technologies have turned much attention to the needs of individuals whose limitations are primarily cognitive. Such devices as memory aids, time management devices, prompting systems, assistive technology for cognition, and stimuli control are commercially available and have the potential to increase employability and quality of life for people with MS who experience cognitive symptoms. Scherer (2012) described her cognitive support technology (CST) model for promoting independence and employment success among people with cognitive impairments resulting from traumatic brain injuries, learning disabilities, and MS. The CST approach utilizes universal-access tablet computers such as iPads coupled with cognitive enhancement applications that individuals can download to address such issues as memory, executive functioning, organizational skills, time management, and professional networking. There is some evidence that effective use of these customized assistive technology strategies leads to improved employment outcomes for people with cognitive impairments (Sauer, Parks, & Heyn, 2010).

Despite success stories of how accommodations and technology use can help to enhance career success when cognitive challenges emerge, other participants were not so fortunate. The potential for the cognitive declines that are common in MS to negatively impact one’s career was succinctly shared by one individual, who said, “Right now, I’d just like to have a job. I lost my last one partly, because I can’t comprehend things anymore.”

Theme: Feeling a Sense of Loss

For a number of study participants, the uncertainty associated with having MS while trying to maintain a competitive career brought about a sense of loss. Several participants reported work histories involving successful careers with promising professional growth that was slowed as MS came to affect their lives. Such slowed career trajectories often began with supervisors and co-workers questioning their competency, leading to reduced self-confidence and ultimately to career changes in some cases. The three sub-themes for feeling a sense of loss included (a) competency questioned, (b) self-confidence lowered, and (c) career changes.

Competency Questioned. In some instances, participants felt that their competency was questioned once they disclosed a diagnosis of MS. Although this questioning of competency was generally said to be subtle, at other times participants found it to be more blatant. One participant, who claimed that a co-worker who also had MS was spreading misinformation about MS and about the participant's abilities, noted the following:

That was just the thing. Dispelling any myths or misconceptions that people are afraid to ask questions to go over the line, but it stems from the boss on down and how the information [about MS] is disseminated.

The most severe questioning of competency was encountered by a participant who was fired from her healthcare job. In this instance, the supervisor's perception of the participant's disability seemed to directly relate to the personnel decision to terminate her employment. From the perspective of the participant, the perception of being too sick to work was unwarranted. She stated:

Let me go, because I'm not performing. I don't care about that. But, don't let me go, because you think I'm too sick. That was a decision made by two people. They never discussed it with me.

Existing research documents the profound effect that negative reactions of employers and co-workers can have on a person's prospects for continued employment following a diagnosis of MS. Large-scale national surveys by Roessler et al. (2003) and Rumrill et al. (in press) have consistently revealed that poor relationships with employers are among the most commonly cited reasons for job loss among Americans with MS. Workplace discrimination, perhaps the most overtly negative employer reaction, continues to be a major concern for people with MS (Fraser et al., 2006; Rumrill, 2006). Roessler et al. (2015) estimated that as many as half of all Americans with MS have experienced workplace discrimination on the basis of their disability status. Finally, more than one-third of all allegations of workplace discrimination filed with the United States Equal Employment Opportunity Commission since 1992 by people with MS under Title I of the ADA have accused employers of unlawful discharge (Unger, Rumrill, Roessler, & Stacklin, 2004).

For participants with MS who were not employed, frustrations about employers' perceptions of incompetence among people with MS were also present, and they were often cited as a barrier to securing employment. After expressing her observation that employers tend to favor young, healthy-looking workers, one participant summarized how she felt that employers assumed the worst of her competence during interviews:

That's been the hardest part for me, is the fact that [employers]... don't want to come out and say it, but you can feel it. You can see it when you go on interviews. You try real hard not to show that your right leg carries itself, you know.

Self-Confidence Lowered. Accompanying perceptions of incompetence for many participants was a lowering of their own self-confidence about their work abilities. For some par-

ticipants, this occurred early, as related by one individual who said, "I'm newly diagnosed, a year, so I think it's messed with my self-confidence a little bit." This comment underscores the importance of early intervention strategies to assist newly diagnosed people with MS, the vast majority of whom are still employed, in developing effective self-monitoring and self-advocacy skills that will enable them to overcome MS-related work limitations and, thereby, continue working as long as they desire (Fraser et al., 2006).

For other participants, confidence began to drop as their MS symptoms worsened. For people who were looking for work, the job search process can be particularly taxing emotionally (Rumrill, Hennessey, & Nissen, 2008). When asked what advice he would give to other people with MS who were unemployed, one individual candidly shared how the sense of lost ability could contribute to emotional strain:

I would say, don't be so hard on yourself. I mean, looking for a job is difficult enough and I think [people with MS] put so much added pressure on ourselves because of the worker we used to be... I think it's a very difficult process psychiatrically, because it can be very depressing and it can be very frustrating.

Another participant, also unemployed at the time of the study, described how difficult it is to go on interviews as a person with MS. With an understanding of the limitations that her disability presented in terms of speech, this participant described how she would question herself at interviews, and the ways in which MS limited her job-seeking confidence:

The job search process is stressful enough to begin with, and I think when you add a disability like MS on top of it, you're constantly second-guessing yourself. You're going to do that under normal circumstances, but I think with MS you're like, 'Did I just say that? Did I say that clear enough? Did I slur that word? Do I sound impaired?'

Likewise, participants who were employed often remarked on how MS-related symptoms made them less confident in carrying out their work. Among the best examples of this was a social worker who proudly shared stories about her confidence in going into dangerous settings in order to conduct her work prior to the onset of her MS. Now that her symptoms have progressed, she shared the following:

I don't have that fearlessness anymore, because I know if you come out and come at me from a certain angle, (a) I can't see you, and (b) if I go down, I can't get up if there ain't something for me to physically get up.

Career Changes. Perhaps in part due to employers' negative perceptions of the work ability of people with MS and their lowered self-confidence around work, several participants noted that they changed career paths after the onset of their MS. It is important to note that MS rarely affects a person's vocational interests, that is, he or she is usually still interested in the same type of work that was performed prior to diagnosis (Rumrill, 2006). But, many people with MS who wish to

remain in the workforce find it necessary to change jobs, or even career fields, to accommodate their MS symptoms (Fraser et al., 2006). For some participants in this study, especially those who worked in professional jobs prior to the onset of MS, declines in work-related functioning made them consider work that was far outside of their expertise. This was the case for one individual who had previously worked in healthcare management, but was unemployed at the time of the study and struggling to find work:

I can't do [healthcare management] anymore so I'm looking for more entry-level jobs, maybe like a cashier or something like that. And I can't get hired for that because of my past experience unless I lie and say I did that before.

As exemplified by the preceding quote, finding work that is concordant with one's abilities may be difficult when a person's previous experience is at a higher professional level that may be unrelated to the work they now hope to obtain. Even when participants were able to find work that they felt comfortable with, the work was sometimes not suitable to their overall lifestyle, particularly financially. Acknowledging that he could no longer perform his former work, one participant expressed the difficulty in looking for lower-level work:

The work that I'm looking for is above my ability at this point, so that the work that is available for me, it's just, I don't know... it doesn't help stress or anything because it's not enough money to live, to support my family.

Existing research supports the phenomenon observed in this study whereby people with MS reduced their work hours or took jobs below their training and experience. Roessler et al. (2015) reported that employed people with MS worked an average of only 28 hours per week, and more than 35% considered themselves to be under-employed.

Theme: Navigating the Workplace

The final overarching theme broadly includes ways in which participants navigated their own workforce participation in the context of their MS. Participants shared their struggles with deciding how and when to disclose their MS to employers, how to cope with MS in the workplace, and how to balance workforce participation with the need for support through public benefits. It should be understood that the contents of this theme were particularly contextualized by each participant's individual experience with MS, including the course of MS, the predominant symptoms, and the length of time a person had experienced MS. The three sub-themes identified under navigating the workplace included (a) accommodations, (b) learning to cope, and (c) benefits eligibility.

Accommodations. The topic of "if, when, and how" to disclose a diagnosis of MS and seek accommodations was a discussion in the focus groups. A number of participants discussed that they did not want to disclose their MS because they were concerned that others may react negatively, especially those who reportedly did not have noticeable physical symptoms. One informant, echoing the sentiments of others, noted the importance of "just telling people that there's certain things

you can't do. Being honest, I guess... but I would not do that until after I was hired."

Other participants shared their experiences of disclosing their MS and the difficulties it caused them in the workplace. There was sentiment that some employers may take an initial accommodation request as a sign that the worker could not complete essential job tasks. Participants knew their rights to accommodation under the ADA, but still worried that employers may not always act in good faith in offering accommodations if a person with MS was not ready to advocate for his or her needs. These feelings were summarized by one individual who stated the following:

I did ask for accommodations and that's when I disclosed my illness and it really proved to hurt me and not help me. I always would advocate for somebody to ask for accommodations, but it's a really sensitive topic... if you don't have that information [about the ADA], your employer can walk all over you if they're not sympathetic to your condition.

Concerns about accommodation requests, and employers' potential reactions, led some of the focus group participants to feel guilty about seeking accommodations, including one person who said, "I felt a little strange asking for something. They're going to think 'Oh, she wants special treatment'. Not everybody gets those large monitors." Other individuals declined to seek accommodations at all, even when doing so would have been consistent with the ADA. In a particular example, a participant gave up an exciting work opportunity because of an inaccessible work environment:

I was at a job once at [a luxury car dealership], and they got a new site... and I was so excited! We're going to go over there, and we did. It was all stairs and I couldn't stay. I tried. I always try, but it didn't work for that reason.

Concerns raised about disclosure of MS and the availability of on-the-job accommodations are consistent with findings reported by Rumrill et al. (in press) in their national survey of the employment concerns of Americans with MS. The majority of respondents in that study reported dissatisfaction with their knowledge regarding their rights and responsibilities related to disclosure of disability status under the ADA. In addition, major concerns were expressed regarding respondents' abilities to identify needed workplace accommodations, discuss their accommodation needs with employers without being subjected to retaliation, and evaluate the effectiveness of accommodations that are implemented to help them overcome MS-related limitations. Roessler and Rumrill (2015) developed a brochure entitled *Enhancing Productivity on Your Job: The 'Win-Win' Approach to Reasonable Accommodations*, which provides instruction for people with MS regarding disability disclosure and the accommodation request process prescribed in Title I of the ADA. The brochure advocates a collaborative, non-adversarial dialogue between the employee with MS and his or her employer as the best way to proactively solve potential on-the-job problems and avoid costly and counterproductive litigation.

Learning to Cope. Though many participants shared trepidation about asking for accommodations, others noted that accommodations were quite useful in helping them to cope with MS in the workplace. Accommodations that enabled a person to telecommute were particularly valued by many individuals, since telecommuting provided the flexibility to manage MS symptoms while remaining actively engaged in productive work. Since MS symptom acuity can be variable from day-to-day for many people, the ability to work from home, even just on days when symptoms flared, was enough to enable a person to remain employed. The importance of such flexibility was summarized by one person who shared her work arrangements:

There are days where I can't tell you if I'm going to need to work from home. So I work from home on Monday and Friday, but if there's a Thursday that my leg decides to not function properly, or if it's 100,000,000 degrees outside... it's in your best interest for me to have an unscheduled telework day.

Customizing a job that fits the ability of people within the course of their MS was also a popular route to navigating the workplace while coping with MS. Although there are numerous ways to customize job duties, participants in this study shared a couple of excellent examples that assisted them in maintaining employment as their MS progressed. One individual, a physician's assistant, was able to focus her work on paper-based files, rather than doing computer-managed medical records, since looking at the computer monitor hurt her eyes. In another example, a journalist shared how his duties shifted along with his illness, enabling him to remain in his career:

I was a journalist and so I worked in TV, and radio and newspapers, and the best was being able to get out and find the story... I just can't do that anymore. I can't really get out.....but over time I became sort of the editor, and I could sit at my desk and read the stories written by other people.

For other participants, learning to navigate the workplace with MS was less formal, not requiring elaborate accommodations but simpler modifications of their work habits. For instance, a number of people who experienced short-term memory challenges explained that they used functions on their smartphones to record notes to themselves. Others simply took a pad of paper with them at all times so that they could write notes about things they needed to do. Scherer's Cognitive Support Technology (CST) model is applicable here (Scherer, 2012). The CST approach utilizes a tablet computer and a customized array of cognitive enhancement 'apps' to help people with MS, traumatic brain injuries, and learning disabilities compensate for cognitive limitations at work. In addition, several participants credited connections with national organizations, particularly the NMSS and its local chapters, with helping them to gain insights and strategies for coping with MS at work.

Benefits Eligibility. Another important part of navigating the workplace for people with MS was balancing work with the need for public benefits. Particularly considering the unpredictable nature of MS for many individuals, Social Security Dis-

ability Insurance (SSDI) and Medicare were seen as vital benefits for many of this study's participants. Being without SSDI was seen as a dangerous proposition for some participants, including one person who efficiently summarized the sentiments of many, "Right now I can't give up my Disability [benefits]. I can't take that risk." Although SSDI was very important to many individuals, it did change how they thought about work, because exceeding income limits could result in termination of benefits. In some cases, this led people to cut back their work hours in order to maintain their benefits, including one individual who wanted to keep working but was forced to cut back:

Participant: Well, I had been working 40 a week, but I'm going to switch in January. When I go back, I will be working 20 a week.

Moderator: Are you comfortable sharing with us why you're reducing your hours at work?

Participant: I don't have a choice. In order to have Social Security Disability, I have to only make a thousand a month so I had to switch because of that.

Maintaining SSDI and Medicare was so important that some people made major lifestyle changes to protect those benefits. Deciding that the healthcare benefits afforded under Medicare outweighed the benefits of higher earnings, one focus group participant explained:

Right now I'm on Social Security Disability and it's not great. Obviously it ends up being a \$35,000 a year loss from when I was working. So with some rearranging and stuff, I get by.

These examples illustrate the major life compromises that people with MS are forced to make in order to balance their healthcare needs with other aspects of their lives (Kalb, 2012; Fraser et al., 2006). Often, participants in this study noted that their need for good health supports outweighed their career goals, requiring them to make significant sacrifices in their careers in order to secure adequate health insurance.

Conclusion

This study provides a perspective on working with MS, informed directly by individuals living with the disease, whether they were employed or unemployed. Although the study is constrained by the limitations inherent in qualitative research (most notably lack of generalizability beyond the sample), the findings give voice to the employment experiences of individuals with MS in ways that have not previously been found in the literature. In addition, the findings are consistent with previous empirical evidence on employment of individuals with MS.

Participants in this study discussed the negative impact that the unpredictability of MS has on employment. This reflection is representative of the impact that MS can have on the person's physical stamina and cognitive capabilities (Kalb, 2012), the combination of which can severely undermine one's prospects for continued education, retraining, and other important career maintenance activities (Fraser et al., 2006; Roessler et al., 2015). In addition, existing research supports the phenomenon observed in this study whereby people with MS reduced their work hours or took jobs below their training and experience.

Participants also expressed concern about navigating the workplace, including disclosing their disability and asking for accommodations. Rumrill and his colleagues (in press) reported that individuals with MS in their survey expressed major concerns regarding respondents' abilities to identify needed workplace accommodations, discuss their accommodation needs with employers without being subjected to retaliation, and evaluate the effectiveness of accommodations that are implemented to help them overcome MS-related limitations.

One of the goals of this research was to provide information on the employment experiences of individuals with MS that can be used by rehabilitation professionals. Vocational rehabilitation (VR) counselors must be aware of the issues faced by this group of consumers specifically related to the impact that MS can have on the individual's employment outcomes. Knowledge of these concerns can assist them in providing supports and services to individuals facing unique challenges in maintaining employment or returning to the workplace after a diagnosis of MS.

For instance, a job seeker with MS may need assistance in developing self-advocacy skills in order to represent his or her accommodation needs to employers including what and how to disclose to employers and coworkers. In addition, information on the types of workplace accommodations used by workers with MS may empower newly diagnosed individuals to ask for accommodations that will assist them in maintaining employment. The other sub-themes identified in this research are also areas in which people with MS need information and support services. A number of the focus group participants expressed concerns about working for fear of losing SSDI and health care benefits. Although this study did not identify what these individuals already know about benefits planning and Social Security work incentives, it does appear to indicate that information is needed in this area to address some of these concerns. Individuals in these focus groups also expressed concerns related to future uncertainty and a sense of loss related to the impact that MS had on their careers and employment opportunities. This included lower self-confidence in their abilities. Having access to information on how to manage the disease and successful case studies of people working with MS appears to be needed. Future research needs to identify additional supports and services that individuals with MS need to seek and maintain meaningful careers. This includes determining the best way of delivering this information to this group of very qualified workers.

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