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Perceptions of Quality of Employment Outcomes after Multiple Sclerosis: A Qualitative Study

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Objective: The purpose of this study was to identify quality outcomes of employment, as defined by those with MS who worked at some point following their diagnosis. **Research Methods:** Qualitative approach using eight focus groups at three sites (Ohio, Georgia, South Carolina) with a total of 74 participants. **Inclusion criteria:** (1) >18 years, (2) < 65 at time of diagnosis, (3) physical disability from MS, and (4) must have been employed after diagnosis. The majority of participants were identified through MS advocacy organizations and support groups in the three states. **Results:** Narrative responses fell into 14 overlapping themes grouped under the 3 broad categories of (1) Compensation, (2) Personal Well-being, and (3) Benefitting Others. Compensation included three themes: Salary; Support responsibilities and lifestyle; and Pay for health needs, including medications. Personal Well-being encompassed eight themes: Maintain health and wellness; Stress and burden; Something to do and a reason to get up; Socialization and interacting with others; Sense of purpose and direction; Pride and sense of accomplishment; Identity; and Enjoyment. Three themes were within Benefitting Others: Value added and general helping others; Providing direct help or assistance; and Inspiring others.

Conclusion: The importance of work to the lives of people with MS and other disabling conditions cannot be measured by employment rate alone. Results of this study provide some encouraging evidence that people with MS view work as an important social role and as a means of staying active and retaining one's identity.

The onset of multiple sclerosis (MS) typically occurs between ages 20-40, during the most active employment years (Kalb, 2016; Super, 1980). However, career development often slows or stops as MS symptoms advance. More than 90% of Americans with MS have employment histories (Nissen & Rumrill, 2016), with more than three-quar-

ters still working at the time of diagnosis, despite the lapse between onset and diagnosis (Falvo, 2014). As the illness progresses, employment sharply declines, with only 20-30% of people with MS employed 15 years after diagnosis (Fraser, Clemmons, & Bennett, 2002) and less than 50% in the US currently employed (Roessler, Rumrill, Li, & Leslie, 2015). The majority (75%) of unemployed people with MS leave their jobs voluntarily (Roessler et al., 2015), although most believe they are able to work (Nissen & Rumrill, 2016) and would like to re-enter the workforce (Rumrill, 2015).

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Despite the importance of employment, we only have a general understanding of factors related to premature exit from the labor force after the onset of MS. The majority of research focuses on attributable differences related to demographic or disease-related characteristics, with less research on environmental factors that may have policy implications. Women are significantly less likely to be employed than men (Roessler et al., 2015), and both sexes are more likely to leave the workforce if they have a working spouse (Rumrill, Hennessey, & Nissen, 2008). An inverse linear relationship has been found between employment and age (Rumrill et al., 2008).

Exacerbation and progression of physical symptoms of MS are strong predictors of job loss (Falvo, 2014). In addition to the type of symptoms experienced, Roessler, Rumrill, and Fitzgerald (2004) found that people who experience MS symptoms most or all of the time, especially if the persistent symptoms are greater in number and more severe, are more likely to be unemployed. Nearly a third of unemployed participants attribute their jobless status to physiological effects of MS (Fraser et al., 2002; Rumrill, 2015). Nearly half of unemployed respondents have cited ambulation difficulty as the primary reason for leaving the workforce, and 39% describe fatigue as the most important factor (Edgley et al., 1991). Cognitive impairment represents a significant barrier to employment (Kalb, 2016), with those reporting cognitive impairments being four times more likely to be unemployed (Roessler et al., 2015), and frequency of perceived cognitive problems is directly related to the rate of unemployment (DeLuca & Nocentini, 2011). Not surprisingly, education level and socioeconomic status (SES) are inversely related to the probability of employment (Roessler et al., 2015).

Discrimination has also been implicated in impacting the employment status of individuals with MS. Between 1992 and 2003, the United States Equal Employment Opportunity Commission received and resolved 3,669 allegations of employment discrimination from people with MS under Title I of the Americans with Disabilities Act (ADA; Unger, Rumrill, Roessler, & Stacklin, 2004). Unlawful termination was the most commonly cited form of workplace discrimination (29.9%), followed by complaints of the lack of reasonable accommodations (21.9%), terms and conditions of work (9.8%), and harassment (6.7%). Compared to complainants with other disabilities, people with MS were more likely to allege discrimination in the areas of reasonable accommodations, terms and conditions of employment, constructive discharge, and demotion. They were less likely to allege discrimination in the area of hiring and more likely to have their allegations resolved in their favor (Unger et al., 2004). More recently, Roessler et al. (2015) found that primary employment concerns were related to enforcement of the ADA, health care and health insurance coverage, and Social Security disability programs. Those with MS progress from active employment to short-term disability insurance, long-term disability insurance, and Social Security Disability Insurance (SSDI) at higher and faster rates than people with most other disabilities (Fraser, McMahan, & Danczyk-Hawley, 2004). This is

especially problematic given the estimate that less than 1% of Americans with MS who receive SSDI benefits will ever resume gainful employment (DeLuca & Nocentini, 2011; Fraser et al., 2002).

A few qualitative studies have examined barriers to employment faced by persons with MS (Johnson et al., 2004; O'Day, 1998), but none have been conducted in the last decade. More recent qualitative work has examined the perceptions of people with MS as to the nature of their experiences (Fallahi-Khoshknab, Ghafari, Nourozi, & Mohammadi, 2014), coping and adaptation to MS (DiLorenzo, Becker-Feigeles, Halper, & Picone, 2008; Ghafari, Fallahi-Khoshknab, Nourozi, & Mohammadi, 2015), social identity following diagnosis (Barker, das Nair, Lincoln, & Hunt, 2014), physical activity (Plow, Resnik, & Allen, 2009), self-management and activities of daily living (Johnson, Weir, Verrall, Yorkston, & Amtmann, 2012; McMullen et al., 2009; Ploughman, Austin, Murdoch, Kearney, Godwin, et al., 2012), and healthy aging (Ploughman, Austin, Murdoch, Kearney, Fisk, et al., 2012). While important, these studies are typically small in scale, with average sample sizes ranging from 12-35.

Although the association between work and personal characteristics among people with MS is detailed in extant research, the literature is devoid of studies examining subjective aspects of the employment experiences of people with MS. Therefore, the purpose of the current study was to gain the perspective of those with physical disability secondary to MS regarding the employment outcomes they perceived to be of greatest importance.

Methods

Institutional review board approval was received prior to the initiation of the study. The majority of participants were identified through MS advocacy organizations and support groups in three states (South Carolina, Ohio, and Georgia). All participants were 18 years of age or older, could speak English, and had worked after their diagnosis with MS, although they were not necessarily employed at the time of the study.

A total of 8 focus groups were conducted consisting of between 4 and 9 participants each for a total of 74 participants. Participants ranged in age from 20 to 81 years old ($M=46.79$ years; $SD=13.48$) with an average age at diagnosis of 34.63 years ($SD=9.70$) and time since diagnosis ranging from 0 to 44 years ($M=11.63$; $SD=9.18$). Women accounted for 79.7% of participants; individuals from racial and ethnic minority backgrounds accounted for 25.7% of the sample. Over half of the participants were employed (57.7%), 39.4% were not currently employed, and 2.8% were retired.

Data Collection Procedures

Informed consent was obtained prior to the start of the focus groups. Groups were conducted at the 3 sites and audio and video recorded, following a semi-structured format lasting between 2 and 3 hours. Two facilitators led each group – one led the discussion and the second took notes. The questions

were designed to elicit information about the personal, environmental, and policy related factors influencing job attainment, maintenance, and advancement following onset of MS. In particular, participants were queried about what constituted quality employment outcomes. The primary question associated with this subject was: "Over the years, what employment outcomes have meant the most to you?"

Recordings were professionally transcribed and returned to group facilitators for review. Errors were noted and corrected. Once "cleaned," transcripts were uploaded into NVivo10 qualitative software. Transcripts were reviewed multiple times before being coded by 2 of the authors to extract topics, themes, and patterns from the source documents. In addition, transcripts were coded into various nodes based on participant, region, and group type.

Results

Narrative responses fell into 14 overlapping themes grouped under the 3 broad categories of (1) Compensation, (2) Personal Well-being, and (3) Benefitting Others. The tangible benefit of Compensation was reflected in three themes: Salary (Theme 1), Support responsibilities and lifestyle (Theme 2), and Pay for health needs, including medications (Theme 3). Personal Well-being encompassed eight themes: Maintain health and wellness (Theme 4); Stress and burden (Theme 5); Something to do and a reason to get up (Theme 6); Socialization and interacting with other people (Theme 7); Sense of purpose and direction (Theme 8); Pride and sense of accomplishment (Theme 9); Identity (Theme 10); Enjoyment (Theme 11). Three themes were within Benefitting Others: Value added and general helping others (Theme 12); Providing direct help or assistance (Theme 13); and Inspiring others (Theme 14). The changing reasons for employment wove throughout the narratives. Given the volume of narrative, what follows is a distillation of perspectives highlighting the quality of employment outcomes, as perceived by study participants.

Compensation

Salary. Many participants reported that salary and monetary compensation were the primary benefits of working. Rachel stated, "Like [other participant] said, a paycheck. That's basically what it boils down to. Yes, I love my job; and I like the social aspect, and I like making people happy, but it's all about a paycheck." Rebecca shared the importance of salary in determining Social Security benefits:

I was fortunate because I did make a lot of money during my career; so when I had to go from making six figures to finally admitting that I had to go on Social Security disability, I got the max.

Perhaps Shelley said it most simply: "Money's always nice."

Support responsibilities and lifestyle. For many focus group members, work was how they obtained the money to support their responsibilities and the lifestyle they wanted. Responsibilities included keeping a roof over one's head and providing for a family. For example, Maggie shared, "It's a

necessity, something I have to do. I need to pay for my insurance and my home and support myself. So it's a necessity." Colin echoed this sentiment. "I was scared to death that I was gonna end up on the street . . . work has always been [a] central part of my life." Indicating the importance of earned income to support a family, Jan stated, "Work means paying for my twins to go back to college." The need for money to support a particular lifestyle was evident in Isaac's statement, "Work is a paycheck that allows me to go on vacation in certain areas."

Pay for health needs, including medications. Many of our participants emphasized the financial burden associated with MS. Employment was valued as a way of paying health-related expenses, including medications. Katie specifically addressed the cost of medications, "Why do I work? Partly \$4,200, \$4,400 of Avanex every month." Her thoughts were also endorsed by Desiree, " . . . you definitely want to have benefits because the medication's expensive." A few participants explained how the financial burden of health-related expenses increased after the onset of MS. Vanessa shared:

Now, yes, it's a necessity to pay my bills, do insurance and all that whereas before I had a couple years where I was working I didn't have insurance, and I didn't care because I wasn't sick. I was a pretty healthy person, and didn't go to the doctor every 6 weeks or whatever. Didn't take any medication at all.

Wendy indicated how the need for money for her health needs impacted her job advancement:

In terms of changing, in the last 10 years, I, at some point, I realized that I wasn't going to be going for that next step up. I needed to stay where I was and probably keep my job . . .

Personal Well-Being

Maintain health and wellness. One of the primary motivators for working was to maintain physical and psychological health. Participants felt that employment was particularly important for keeping their minds active. As Stella indicated:

So keeping your mind active and just being busy doing something else that's meaningful, rather than just sitting around doing nothing. It keeps you sharp, and it makes you work, makes you move, makes you do things that you may not do if you didn't have that particular thing to do. So it's big benefit.

Similarly, Gwen found it motivating to use her brain:

Using my brain. I just . . . I started in insurance claims when I was 18 years old, and [sic] that's all I ever did. And I really liked the calculating, the math, the [sic] just using my brain.

Even when energy levels were low, work was important for keeping the mind focused, as indicated by Jan:

Unfortunately, what has happened to me, or whatever, is I don't have really the energy for play or other things. So a lot of my focus goes to work, but I really like what I do, so that's good. But I just don't have

the energy for the other stuff. I know that's important, but . . .

Something to do and a reason to get up. For a number of participants, employment provided something to do and a reason to get up each day. This is increasingly important as people with MS age because symptoms tend to intensify over time, making it more difficult to prepare for and perform daily activities (Falvo, 2014). Although not all jobs may be feasible given the functional limitations that accompany MS, doing anything is better than nothing according to Paulette: *"But when I applied for the job, you know, it wasn't feasible, so that's why I just do work over the computer sometime[s]. Just anything to keep myself busy."* Having something to do is one way to prevent negative emotional responses, as stated by Shelley:

For me, it's that drive to get up and work through it because all the doctors have told me sitting around, moping around is only gonna make it worse. So, for me, it's that drive to get up and be productive.

Stella also indicated:

The benefits, like everyone said, achievement, working your mind, having something to do. Like I still work for the office. I mean, sitting around doing nothing all day watching TV, that just . . . it would drive me crazy, so I have to do something.

Socialization and interacting with other people. Work provided important social connections and support. Brandy shared:

Then the other thing is the socialization. I think just . . . being around people, too, that have similar experiences, because you have your peer group when you work. When you don't work, you lose a little bit of that because your friends are working, and they have peer groups that they have at their jobs.

Social connections at work often provide an emotional boost, as indicated by Carly:

I think when I was working, of course we had a peer-support structure. You might not have seen everybody every day for a long period of time, but they were there and the camaraderie and those types of things always boosted you.

Socialization was also important for not feeling isolated and lonely. According to Maria, *"For me, it also means social interactions. I'd be a little isolated without work. So it's important. It's a huge part of my life."* Amy also explained:

But in the big picture, I don't know what I would have done if I wouldn't have been able to go back to work. Like [other participant] said, I would have been isolated. I wouldn't have had social interaction the way I should. I probably would have become a hermit and just been miserable.

Sense of purpose and direction. The value of work in providing a sense of purpose and direction in life was clearly indicated by a number of participants. Patricia discussed how work kept her moving despite her illness:

Work keeps me going. MS is, instead of moving

slowly I'm moving straight forward. I got to keep going. I have something to accomplish . . . work means everything to me. Keeps me active. Keeps me going. I got to keep going. Got to move straight forward.

Work became John's purpose in life:

For me, initially, I had already gone into college knowing I was going to get a career. . . That was already something I had thought of; so for me at the time, work meant existence. . . Afterwards, it became purpose. It kind of cleared up a lot of stuff for me and, like I said, gave me direction, gave me . . . it went from simply keep me afloat and existing to the reason I get up.

Deriving a sense of purpose through work was often about contributing or being productive, which Marjorie described as:

For me, work was about contribution and productivity. . . so I find myself . . . channeling that into my volunteer activities. So I don't volunteer just to fill in time. In order for me to say yes, it has to have some meaning for me, that I'm contributing something or [am] productive in some way.

The positive feelings associated with moving in the right direction were expressed by Sylvia:

I think when I was workin', like you say the socialization of workin' and my accomplishment because I had made it to administration in the hospital after I got my master's. It made me feel good. I was goin' in the right direction. Upwardly mobile in [my] position.

Pride and sense of accomplishment. Many focus group participants identified the feelings of pride and accomplishment as motivators of their employment. Stella expressed, *"You feel good at the end of the day because you've done something worthwhile."* She was joined by Harry who also took pride in his work:

Mine was a sense of accomplishment. It's one thing when you're looking at a wooded lot or whatever, and then you say, "Well, you don't see much there now." But then after you build a house, I built that. Your sense of accomplishment.

Several participants placed the sense of pride and accomplishment alongside compensation as a highly important work motivator. Melinda shared, *"Of course it was necessary to pay my bills and take care of myself and my family, but also it was a place I took pride in going to."* Rebecca similarly stated, *"So I did have some financial cushion, but also it did give me a sense of accomplishment that I was able to work all of those years while having MS."*

Identity. Many participants expressed the influence of work in defining who they are and how that identity derived through work was impacted by the onset of MS. Denise explained how she had to learn new ways to validate herself after the onset of MS because she had previously defined her worth through work:

Work means everything. It's your worth. Just really quickly, I have a lot of cognitive issues. I know that

I'm completely different from the woman that I used to be. That was the only way that I used to validate myself, so now I'm learning the other parts of myself.

With identity being so closely tied to work, having to leave work due to the onset or progression of MS was a frightening proposition. Colin revealed, "And my identity. It's like ahhhhh, what in the world am I gonna do now?" Lucille also expressed fear and sadness due to loss of identity:

I think the identity was the hardest thing for me. I remember when I left teaching, I cried, I kept saying, "I've lost my whole identity." People didn't understand that. They really didn't, but I felt like I . . . I taught 30 years, and I just felt like that was everything I had trained for.

Enjoyment. Another major benefit of employment was simply the enjoyment gained by working. When asked about the meaning of work, Darla said, "Meaning of work, hum. I absolutely love what I do." Several participants expressed the happiness and fulfillment work provided them. Jeffrey shared, "The benefits of employment? Just mainly happy that I can do it, and when I used to work on cars and that, really made me happy. Just achieving things [and] getting through with something. That made me happy." Joy and Carol voiced similar opinions:

Joy: I'd say my job actually brings me happiness and fulfillment; and I believe that, religiously, that God put me there.

Carol: It brings happiness, fulfillment, gives me something to do. I really feel working keeps me going.

Stress and burden. Several participants, though, were unable to view work as a positive outcome, perceiving it instead as a cause of additional stress and burden, mainly due to factors related to MS. Kristin discussed feeling pressure to work on days when she was not feeling well:

Having a chronic illness, I didn't know how blessed I was before chronic illness. So now, if I don't feel good, I don't . . . I don't take off because I just want to take off. I take off if I really don't feel good; so, to me, my sick time means a lot to me.

Sandy was particularly affected by having to miss out on other activities because working was all she had the energy to do:

I get angry because sometimes I use my work to the point to where I'm a little too tired to do the zoo and the things like that, and I think that's wrong. I know I need to stop, and I need to let go of . . . It will be there tomorrow.

Benefitting Others

Value added and general helping others. In general, participants endorsed how work led to feeling as though they were "value added" by providing an opportunity to help others and contribute to the greater good. Brandy described her experience:

There's a word . . . The term that comes to mind as something that I guess I'm used to from accounting.

But it's "value added." I feel like when I'm working, I am value added. I am adding value. I am adding value to my family. I am adding value to myself. I'm adding value to my employer, and that makes me feel really good. It makes me feel really, really good when I feel like I can add value to something, that my involvement has made a difference a big project or a small project; but it's just . . . That is huge to me; and when I'm not working, sometimes it's very hard to find things in life where you feel like you can add value, and that's been something that I struggled with.

Stella held a similar perspective, "So I enjoy going in the office and working and helping people. You felt rewarded. You felt like you were contributing to a positive, the greater good." Lillie explained how the feeling of contributing through work made it easier to ask for help for herself:

I work . . . Yeah, there's necessity and all those other kind of things, but there's a lot things that I could do. But I push myself to do some of the things that I do because I want to contribute as much as I can for as long as I can because I don't know next year what I'll be able to contribute. And if I ever have to ask for help, I want to be able to say, "You know what?" And I look myself in the mirror. I gave everything I had for as long as I had to give it. And I'm okay now. I can be okay with saying I need help.

Providing direct help or assistance. The direct experience of helping others was another benefit of working, and many participants indicated that they found it fulfilling and enriching to help people. Kimberly enjoyed helping veterans specifically:

But right now and even at the VA hospital, I get up and I get to go out and mix and mingle with some of the veterans. And I get to help them. Or make sure they get to their appointments. You know, like being an asset. That's what really what I like."

Roger expressed that, through work, he was "...making a difference in other people's lives including my own. It enriches our lives and the people that we take care of." Katie also felt she benefited from helping others, "My job keeps me going, particularly now. It's fulfilling. You're helping people." Finally, Tammy saw work as a way to give back, "I also feel like, since I work with kids, it's a way of giving back and trying to get them on the right track. That's work for me."

Inspiring others. Part of the value in employment was how it could inspire others. Lillie explained how she wanted to inspire her children to face adversity, "I have...twins who are the greatest gift I have ever been given besides my husband, and I want them to have the example that you don't stop. You just keep going." Being an example to others with MS was also indicated by several participants, as Katie stated:

And the people diagnosed up here, and I think I have MS; so it's a real witnessing opportunity for me because it's like, "You know, girl, you just get up. You can't go on? You're going to be sad. You got to go." I'm a witness. "You have MS?" "Yes, for a long time." You just got to go.

Darla summed it up by saying:

What inspires me is to have people come to me and say I'm their inspiration because I'm doing so well with my MS. And they look up to me; and they think if I can do it, anybody can do it.

Discussion

This qualitative study examined the perceptions of people with MS as to what employment outcomes they felt were most important. Results clearly indicate that the meaning and motivation participants ascribed to work were many and multi-dimensional. Participants described employment as a means of financially supporting oneself and family, providing a sense of purpose and accomplishment, defining oneself, promoting socialization and limiting isolation, providing happiness and fulfillment, and meeting the need to help and inspire others. Focus group members felt better about themselves when they had something to do and a reason to get up, although the stress and burden of working did take its toll at times. The following paragraphs provide a discussion of key findings, organized around the three broad categories of Compensation, Personal Well-being, and Benefitting Others that subsume the themes in participants' narrative responses. Implications for service delivery and future research are also discussed.

Compensation

Certainly, many participants identified financial remuneration as a major impetus for employment. Of particular note was the finding that a considerable proportion of individuals who participated in this study felt the need to work to pay for medication and other health related costs. This reason for employment is in stark contrast to the reports of individuals with other disabling conditions, such as spinal cord injury (SCI), who often feel as if they are unable to work out of fear of losing social security payments and Medicaid, which cover many of their health related costs (Krause & Reed, 2011). Possible reasons for this contrast may include the duration of time over which MS impairments often occur (Murray, 2016), the lack of education about public assistance programs, and the relative difficulty many individuals with MS have in being declared disabled and obtaining social security benefits (Rumrill, Roessler, Li, Daly, & Leslie, 2015).

Employed participants in this study may not have been vulnerable to disability benefits disincentives for the simple fact that they were still in the workforce at the time of the study. Keeping people with MS on the job for as long as possible must be a priority in vocational rehabilitation efforts with this population. Proven job retention strategies to help people with MS continue working, maintain an income stream, and thereby avoid enrollment in SSDI until absolutely necessary include self-advocacy training regarding disclosure of disability status and how to make accommodation requests (Roessler & Rumrill, 2015), consultation with employers regarding job modifications, training for workers with MS on their legal rights, and referrals to the state-Federal Vocational Rehabilitation program (Nissen & Rumrill, 2016). Similar to the present findings, the difficulty that people with MS experi-

ence in paying for health insurance and medical treatment was a major theme in the national survey of 1,924 Americans with MS conducted by Rumrill et al. (2015). Survey respondents identified the costs of prescription medications and the lack of affordable health care coverage among their 10 most prominent employment-related concerns. They also noted inadequate transportation and the unavailability of affordable specialized housing as major threats to their economic solvency. Based on findings from the Rumrill et al. (2015) survey and the results of this qualitative study, financial planning services are needed to help people with MS project the financial costs of treating and managing their disease.

Potential future strategies to address compensation should include financial planning, specifically, an initial consultation with a benefits specialist at the time of MS diagnosis to provide the person with concrete, accurate information about the Social Security Administration programs available including SSDI, the process to become eligible for SSDI, as well as Medicare. The intent of this consultation is to prepare the person for the eventual decision process of modifying or terminating his or her employment as a result of his or her deteriorated health due to MS symptoms.

Personal Well-Being

Work as an important element of personal identity, as a vehicle for socialization, as a reason to stay physically active and mentally alert, and as a purpose in one's life recurred often in the themes under the Personal Well-Being category. Purpose in life has been linked to important outcomes after disability, although the specific source of purpose is not always defined (Thompson, Coker, Krause, & Henry, 2003). Within the current context, it is clear that employment provided purpose for many of the study participants.

These findings also indicate that the Minnesota Theory of Work Adjustment (Dawis & Lofquist, 1984) is alive and well as an explanatory framework for the meaning that people with MS derive from employment. Research indicates that the onset of MS has no significant impact on a person's work personality, vocational interests, or underlying career values (Rumrill et al., 2008). The disease does often affect the person's ability to work, but the importance that he or she attributes to work and career development is thought to be (a) formed prior to the typical age of onset of MS and (b) stable throughout adulthood regardless of changes in one's health status (Super, 1980).

This does not imply, however, that all people with MS view working in beneficial terms. Even though most participants described employment as an important element of their identities and identified numerous intrinsic reinforcers that motivated them to continue working, some did not see work as a benefit but rather as an additional stressor and burden in their lives. This finding may simply reflect the intrusive and energy-depleting nature of MS, its wide-ranging symptoms, and its unpredictable course (Falvo, 2014), which according to people with MS often leave them without the physical, cognitive, and emotional capacities to continue their careers

(Kalb, 2016; Roessler & Rumrill, 2015; Rumrill et al., 2015). Managing stress at work was one of the most important items identified in the employment concerns survey of people with MS conducted by Rumrill et al. (2015), and coping with psychological stress is a major element of most comprehensive MS symptom management programs (Kalb, 2016). Accordingly, personal adjustment counseling, psychiatric treatment, couples and family therapy, and MS support groups sponsored by the National MS Society and other MS advocacy organizations are recommended to help people with MS manage employment.

The theme of work as a burden and stressor may also be emblematic of the difficulty that people with MS report in implementing reasonable accommodations in the workplace as per the Americans with Disabilities Act Amendments Act (ADAAA; Rumrill, Fraser, & Johnson, 2013). Indeed, only approximately 20 percent of employed people with MS nationwide use workplace accommodations of any kind (Leslie, Kinyanjui, Bishop, Rumrill, & Roessler, 2015). Other employment-related stressors identified as major employment concerns in a national survey (Rumrill et al., 2015) included a lack of awareness of legal protections in the ADAAA and the Affordable Care Act, lack of understanding on the part of employers regarding MS and its effects, and difficulties managing the physical and psychological symptoms of MS while attempting to maintain one's career. Referring people with MS to informational and technical assistance resources such as the Job Accommodation Network and the National ADA Network is an important element of effective accommodation planning and career re-entry or maintenance services, and it may serve to alleviate the stress that is often associated with attempts to resume or continue employment while coping with the intrusive effects of the disease (Nissen & Rumrill, 2016; Schultz & Gatchel, 2016). It is also important to note that the theme of employment as a stressor or burden is partly attributable to the fact that most people with MS nationwide (82%; Roessler & Rumrill, 2015) were still working at the time of diagnosis, and nearly 60% of the present sample were employed at the time of the study. This means that focus group participants had considerable experience with the often competing challenges of paid employment and coping with an unpredictable chronic illness.

It is possible that, in cases, employment may actually work to exacerbate physiologic stress which could contribute to MS relapses. Although there is no direct evidence of that from the current study, this would be consistent with the construct of allostatic load and the physiologic consequences of prolonged exposure to repeated stressors (McEwen, 1998). This is an empirical question for further research.

The situation for people with MS contrasts with those with some types of other disabling conditions, such as individuals with SCI, who typically lose their employment at the time of onset and then work to regain employment (Krause, Terza, Saunders, & Dismuke, 2010). It is noteworthy that job retention or return to work models where the individual either maintains or resumes employment with the pre-disability em-

ployer, which was the case for most employed participants in the present study, is essentially a different employment paradigm than the transition to new work often seen with SCI. Vocational specialists may benefit from applying these alternative models. Specifically with MS, rather than the near exclusive focus on job retention, more innovative use of retraining and addressing the barriers to return to work after leaving the pre-MS job may ultimately promote better employment rates for those people with MS who disengage from the labor force after diagnosis (Nissen & Rumrill, 2016).

In addition, given the traumatic nature of the initial diagnosis of MS, a peer mentor can be invaluable in providing a newly diagnosed person with MS information about the importance of continuing to work, from an emotional and self-worth perspective, as well as the need to take care of one's health in order to maintain employment.

Benefitting Others

Helping others was viewed as a positive aspect of working, either through generally feeling valuable, inspiring others, or providing direct assistance. The benefit of feeling valuable due to work was described as "contributing to...the greater good" and "value added." Feeling valued helped participants advocate for themselves, which is a vital strategy for empowering people with MS to return to work and maintain employment (Rumrill, 2016).

Numerous studies have reported on how MS impacts quality of life, with the greatest negative influences being related to health and function, such as fatigue, depression, and mobility impairments (Janardhan & Bakshi, 2002; Zwibel, 2009). However, an overlooked, yet important, aspect of quality of life is how we view our impact on others (Ventegodt, Flensburg-Madsen, Andersen, & Merrick, 2008). Work provided an opportunity for many participants to directly offer support to others, as well as giving them a platform to inspire family members, co-workers, and others with MS. Previous research on peer support has revealed similar findings (Schwartz & Sendor, 1999) that helping others can result in positive changes in confidence, self-esteem, and even depression.

Accessing a peer network, such as the National MS Society, provides newly diagnosed people with emotional support and information from other people with MS who can relate to them based on their common experiences. New members can learn from the people who have dealt successfully with MS and utilize information about local resources to make informed decisions about future aspects of their life (locating doctors, finding DME providers, how to approach employers about workplace accommodations).

Future Directions

Taken in aggregate, the findings from this study shed potentially important light on the meaning that people with MS ascribe to their career development. By understanding the considerations that impede or enhance participants' prospects for ongoing employment after diagnosis with MS, rehabili-

tation professionals can develop consumer-centered interventions that facilitate work-motivating conditions in the lives of people with MS, thereby increasing the likelihood of fuller participation in the world of work for this experienced, well-trained, but all-too-often disenfranchised population.

Limitations

Limitations of the present study included the convenience nature of the sample, possible inaccuracies that may have occurred in transcribing and coding the large volume of narrative data, and the difficulties of establishing construct validity inherent to qualitative research methodology. It should also be noted that results from this investigation are not intended to be generalized to the broader population of people with MS; rather, these results are offered to provide a preliminary basis for further study of the employment motivations and outcomes of people with MS and other disabling conditions. Other studies utilizing both qualitative and quantitative research methods are needed to develop a thorough understanding of the meaning and motivations that people with MS ascribe to work in today's (and tomorrow's) competitive and dynamic global marketplace.

Table 1. Participant information

Alias	Region	Sex	Diag year	Onset Age	Current Age	Race	Education	Work status
Gage	SC	male	1985			W	College	Retired
Roger	SC	male	2001	23	36	W	Some college	Self-Employed
Adam	SC	male	2000	50	63	AA		Not working
Vicki	SC	female	2000	30	41	AA		Not working
Loise	SC	female	2005	29	38	AA		Working
Colin	SC	male	2005			W	College	Not working
Carly	SC	female	1986	30		W	Grad School	Not working
Lucille	SC	female	1995	49	69	W	College	Working
Sylvia	SC	female	1995		55	W		Working
Carrie	SC	female	2006	49	55	W	Grad School	Working
Eloise	SC	female	1999	49	65	W	College	Working
Andrea	SC	female	1972	40	81	W		Retired
Angela	SC	female	1998	27	45	W	College	Working
Darla	SC	female	1995	38	47	W	HS	Working, PT
Amy	Ohio	female	2003	37	48	W	High School	Working, FT
Tanya	Ohio	female	1998	36	52	W	Associates	Working, PT
Celia	Ohio	female	2007	42	49	W	College	Working, PT
Jody	Ohio	female	1990	48	71	W	Technical School	Disability
Philip	Ohio	male	2004	29	39	W	High School	Disability
Wayne	Ohio	male	2012	27	30	W	Some college	Unemployed, Applying for Disability
Hannah	Ohio	female	2005	34	44	AA	College	Unemployed
Maria	Ohio	female	1983	34	64	W	Grad School	Working, PT
Adrienne	Ohio	female	2013	27	28	W	College	Working, FT
Cynthia	Ohio	female	2014	20	20	W	Currently in College	Working, PT
Jan	Ohio	female	2003	45	54	W	College	Working, FT
Sandy	Ohio	female	2013	48	49	W	Some college	Working, FT
Jessica	Ohio	female	1999	15	31	W	Associates	Working, FT
Lorraine	Ohio	female		29	52	W	College	Unemployed
Diana	Ohio	female	2009	23	28	W	College	Working, FT
Kristin	Ohio	female	2008	43	49	AA	Grad School	Working, FT
Denise	Ohio	female	2012	29	30	AA	Some college	Working, PT
Thomas	Ohio	male	2003	30	42	W	Grad School	Working, FT
Johanna	Ohio	female	2004	49	59	W	Bachelors	Disability
Tammy	Ohio	female	2014	27	28	W	Grad School	Working, FT
Carol	Ohio	female	2012	32	34	W /Asian	Associates	Working, FT
Ruth	Ohio	female	2005	45	56	W	Bachelors	Disability
Joy	Ohio	female	2008	46	52	W	Associates	Working, FT
Rachel	Ohio	female	2013	28	29	W	High School	Working, FT
Courtney	Ohio	female		35	48	W	Grad School	Full-Time
Katie	Ohio	female	1991	34	57	W	Associates	Working, PT

Olivia	Ohio	female				W		
Isaac	Ohio	male	2007	42	49	W	Grad School	Working, FT
Danielle	Ohio	female		47	57	W	3 years of college	Working, Disability
Patricia	Ohio	female	2005	35	44	AA	2 years of college	Working, FT
Melinda	Ohio	female		34	49	AA	Some college	Disability
Lillie	Ohio	female	2002	30	42	W	Masters	Working, FT
Desiree	Ohio	female	2012	34	36	AA	Associates	Working, FT
Wendy	Ohio	female				W		
Amber	Ohio	female	2006	45	53	W	High School	Working, FT
Vanessa	Ohio	female	2012	55	57	W	College	Working, FT
Marjorie	Ohio	female	2002	32	44	W	Grad School	Disability
John	Ohio	male	2011	21	24	W	College	Working, FT
Maggie	Ohio	female	2005	41	50	W	1 year of college	Working, FT
Shirley	Ohio	female	2009	26	31	W	Some College	Working, FT
Sherman	GA	male	2003					Not working
Jill	GA	female	1984	32	62	W	Grad School	Disability
Charlotte	GA	female	1999	30	44	AA	Grad School	Working, PT
Audrey	GA	female	2007	27	34	AA	Grad School	Unemployed
Rebecca	GA	female	1992	22	44	AA	College	Disability
Shelley	GA	female	2013	22	23		HS	Not working
Lee	GA	male	1970	32	76	W	Grad School	Retired
April	GA	female				AA	military/LP	Unemployed
Stella	GA	female	2010					Worked home business-
Jeffrey	GA	male	1999	23	38	AA	HS/military	Disability
Dora	GA	female	2000	46	60	AA	Associates	Disability
Nicole	GA	female						Not working
Brandy	GA	female	2002	27	39	W	CPA	Occasional work
Kimberly	GA	female	2014	38	38	AA	Currently in college	Working, PT
Harry	GA	male	2000			AA	Some college	Not Working
Paulette	GA	female	2008			AA	HS	Disability
Gwen	GA	female	1994	36	55	W	Some college	Not working
Kurt	GA	male	1992	30	52	W	Grad School	Disability

Note: W = White; AA = African American; HS = High school; PT = part-time; FT = full-time

Conclusion

Results of this study provide some encouraging evidence that people with MS (most of whom in this investigation were still employed) view work as an important social role and as a means of staying active and retaining one's identity. Factors that motivated these participants to work included compensation, personal well-being, and benefitting others, although a number of comments from focus group members identified the stress associated with employment as a de-motivating factor.

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