

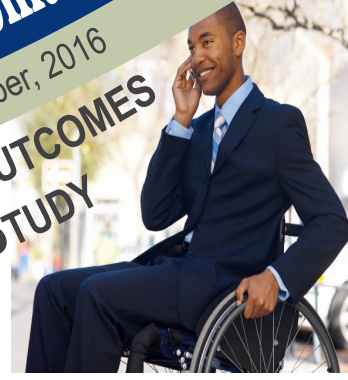
VCU-RRTC on Employment of People with Physical Disabilities

Research Study #2 -- Research Brief #5

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PERCEPTIONS OF QUALITY OF EMPLOYMENT OUTCOMES AFTER MULTIPLE SCLEROSIS: A QUALITATIVE STUDY

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Introduction

Employment is fundamental to adult life and is related to health, life satisfaction, and longevity (Lin, Rogot, Johnson, Sorlie, & Arias, 2003; Lucas, Clark, Georgellis, & Diener, 2004). However, multiple sclerosis (MS) is associated with some of the highest rates of unemployment among groups of individuals with severe and chronic disabilities (Doogan & Playford, 2014). Less than 50% of individuals with MS in the United States are currently employed, although many left their jobs voluntarily and would like to re-enter the workforce (Roessler, Rumrill, Li, & Leslie, 2015; Rumrill, 2006).

Exacerbation and progression of physical symptoms of MS are strong predictors of job loss (Falvo, 2014). Individuals who have a higher education, higher socioeconomic status, and are younger in age are more likely to be employed than those with lower education, lower socioeconomic status (SES), and who are older in age (Edgley, Sullivan, & Dehoux, 1991; Roessler, Rumrill, & Fitzgerald, 2004; Rumrill, Hennessy, & Nissen, 2008). 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 et al., 2008).

Purpose

Although the association between work and personal characteristics among people with MS is detailed in previous research, few studies have examined subjective aspects of the employment experiences of people with MS. What is missing is the perspective of those with MS regarding the employment outcomes they perceived to be of greatest importance. The findings presented in this research brief are from a study conducted by the Rehabilitation Research and Training Center (RRTC) on Employment of People with Physical Disabilities. A total of eight focus groups in three distinct regions of the United States (South Carolina, Georgia, and Ohio) were conducted consisting of four to nine participants each for a total of 74 participants. All participants were 18 years of age or older, spoke English, and had worked after their diagnosis. Participants were asked questions to elicit information about the personal, environmental, and policy related factors influencing job attainment, maintenance, and advancement following the onset of MS. Professional transcripts of focus group recordings was completed, and transcripts were uploaded into NVivo 10, a software used to analyze qualitative narratives.

Study Results

Narrative responses fell into 14 overlapping themes grouped under three broad categories. The broad categories included Compensation, Personal Well-being, and Benefitting Others. Three themes were identified for Compensation. Eight themes were identified for Personal Well-being, and three themes were identified for Benefitting Others. The tables below present these findings with quotes included to illustrate the themes.

TABLE 1 -- Compensation

Themes	Participant Quote
1. Salary	<i>"Like [other participants] 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."</i>
2. Support responsibilities and lifestyle	<i>"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."</i>
3. Pay for health needs, including medications	<i>"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."</i>

TABLE 2 -- Personal Well-Being

Themes	Participant Quote
1. Maintain health and wellness	<i>"Like [other participants] 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."</i>
2. Something to do and a reason to get up.	<i>"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."</i>
3. Socialization and interacting with other people	<i>"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."</i>
4. Sense of purpose and direction	<i>"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."</i>
5. Pride and sense of accomplishment	<i>"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."</i>

6. Identity	<i>"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."</i>
7. Enjoyment	<i>"It brings happiness, fulfillment, gives me something to do. I really feel working keeps me going."</i>
8. Stress and burden	<i>"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."</i>

TABLE 3 -- Benefitting Others

Themes	Participant Quote
1. Value added and general helping others	<i>"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."</i>
2. Providing direct help or assistance	<i>"My job keeps me going, particularly now. It's fulfilling. You're helping people."</i>
3. Inspiring others	<i>"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."</i>

Discussion

Results 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 findings from this study shed potentially important light on the meaning that people with MS ascribe to their career development. Results provide some encouraging evidence that people with MS (most in this study were still employed) view work as an important social role and as a means of staying active and retain-

ing one's identity. By understanding the considerations that impede or enhance participants' prospects for ongoing employment after diagnosis with MS, rehabilitation professionals can develop consumer-centered interventions. These interventions should 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.

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