



IMPORTANT EMPLOYMENT OUTCOMES REPORTED BY INDIVIDUALS WITH MULTIPLE SCLEROSIS

Introduction

Multiple sclerosis (MS) affects approximately 2.3 million people worldwide, with most individuals being diagnosed between the ages of 20 and 40 during what are usually the most active employment years.ⁱ Employment is of great importance to adult life and produces tangible (income, fringe benefits) and intangible (intrinsic benefits, purpose in life) benefits. However, MS can present significant barriers to maintaining employment. Research has found that, as the illness progresses, there is a sharp decline in employment. One study found that only 20-30% of people with MS were employed 15 years after diagnosis,ⁱⁱ and less than 50% in the US are currently employed.ⁱⁱⁱ

The majority of research on employment of people with disabilities focuses on employment rate, health, and employment, or employer perceptions. Although obtaining and maintaining work is an important employment outcome, other quality indicators of employment must be considered. Current literature is devoid of studies examining subjective aspects of the employment experiences and quality employment outcomes throughout the work life cycle of people with MS. This RRTC study sought to identify important predictors and outcomes of employment of greatest importance as defined by individuals with MS. Our objectives included the following:

1. Identify at least two sets of factors/predictors related to quality employment.
2. Identify three common themes of quality employment throughout the work life cycle after MS diagnosis.
3. Describe how qualitative and quantitative studies may work together to clarify employment outcomes.

What is the source of information?

To allow for new insights on quality outcomes of employment, a qualitative approach was used. We conducted three focus groups in three different geographic locations (Ohio, Georgia, South Carolina), in an effort to get a cross sectional representation and to assess if regional differences were linked to quality outcomes of employment. We recruited participants from a variety of different sources, including community support groups and clinics. Participants included 74 individuals who had a physical disability from MS, were over 18 years old, were less than 65 years old at the time of diagnosis, and had been employed at some point after their diagnosis. Groups were heterogeneous. A semi-structured interview format queried participants about factors impacting employment.

What are the general themes individuals with MS found to be important outcomes of employment?

Participants identified three important themes within employment outcomes, which included compensation, helping others, and personal well-being. Compensation includes things such as income and benefits, or tangible aspects of employment. In contrast, helping others and promoting personal well-being are more intangible benefits of employment.

ⁱThe National Multiple Sclerosis (MS) Society, accessed August 11, 2015, <http://www.nationalmssociety.org/What-is-MS/Who-Gets-MS>.

ⁱⁱFraser, R., Clemmons, D., & Bennett, F. (2002). Multiple sclerosis: psychosocial and vocational interventions. New York: Demos.

ⁱⁱⁱRumrill, P.D., Hennessy, M., & Nissen, S. (2008). Employment issues and multiple sclerosis (2 ed.). New York, NY: Demos Medical Publishing, Inc.



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What types of compensation do people feel are important?

Salary, pay for health needs, and compensation to support responsibilities and lifestyle were all deemed important. Many participants expressed money to pay bills and to pay for health care needs, including medications, is a primary benefit of working. As stated by one and I like making people happy, but it's all about a paycheck." For others, the benefit of working was more related to the lifestyle compensation from work participant, "Yes, I love my job, and I like the social aspect, could provide. The following quote reflects an example of how salary from employment allowed one participant to support his lifestyle: "Work is a paycheck that allows me to go on vacation in certain areas."

How does helping others impact employment?

Participants identified helping others through their jobs, such as inspiring others, providing direct help or assistance, and general helping, provided a sense of value and importance to them. One of our participants stressed how inspiring others brought fulfillment at work: "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." For others, the direct help they provide in their job, such as working with veterans or helping with a certain project, makes them feel valued for their work.

How is personal well-being related to employment?

For some participants, the main benefit to employment was increasing their personal well-being, which provides individuals with a sense of purpose and accomplishment, social connections and support, maintaining health and wellness, enjoyment, and identity. Many participants referenced how employment brings them happiness and fulfillment. As one participant stated, "Of course [employment] was necessary to pay my bills and take care of myself and my family, but also it was a place that I took pride in going to." For others, employment was a tool to stay achieve and maintain well-being: "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 a big benefit." Several participants acknowledged how employment shaped their identity, with one participant expressing the feeling of lost identity upon leaving a teaching job.

Based on the findings, what survey items did we develop?

Based on the qualitative responses by participants with multiple sclerosis (MS), the researchers developed a 10-item set of considerations or needs people have when they make vocational decisions. Each item is measured on a five point Likert scale, with options ranging from not important to extremely important. The items include:

1. Compensation (salary, wages)
2. Health insurance and other fringe benefits (retirement, leave)
3. Opportunities for advancement
4. Recognition of performance
5. Social connections (interaction, support from co-workers)
6. Enjoyment from working
7. Opportunities for helping others
8. Feeling better about self from working
9. Staying busy
10. Others share the workload

CONCLUSION

The importance of work to the lives of people with MS cannot be measured by employment rate alone. The emphasis needs to be expanded from focusing almost exclusively on the portion of people who are employed after disability to a greater emphasis on the quality of employment among those who have become employed. The emphasis on the employment rate obscures the importance of career development and associated benefits with participation, health, and quality-of-life. Quality employment will promote health, community integration, quality of life, and a sense of well-being.

Future applications should work toward maximizing employment outcomes among those with MS and other disabilities, rather than focusing on return to employment or transition only. Enhancing prediction of changes in employment outcomes, which will allow for more accurate assessment of lifetime needs (such as is in the life care plan), should be done, as well as developing equations which use weighted models for various outcomes that determine better the cost effectiveness of interventions to promote overall employment success.

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Information for this research brief was developed for the VCU-RRTC on Employment of People with Physical Disabilities. Questions on this brief should be directed to Dr. James Krause at krause@musc.edu.

For more information on the VCU-RRTC or if accommodations are needed, you may contact Dr. Katherine Inge, Project Director at kinge@vcu.edu or (804)-828-5956.