

# The Meaning of Work for People with Multiple Sclerosis: A Qualitative Study



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# Background

- such as income and health insurance and intangible benefits related to psychological adaptation and purpose in life.
- ➤ Onset of multiple sclerosis (MS) typically occurs between ages 20-40, during the most active employment years, and presents significant challenges to maintaining or obtaining employment.
- ■ As MS progresses, there is a sharp decline in employment, with only 20-30% employed 15 years after diagnosis and less than 50% in the US currently employed.
- ➤ Of those who left the workplace, the majority left their jobs voluntarily (75%), although most believe they are able to work and would like to reenter the workforce.
- ➤ Rehabilitative support for employment varies substantially between individuals and states, and, typically, cases are closed by Vocational Rehabilitation (VR) after 90 days of employment.
- ➤ The philosophy of the current research is that employment after disability must be systematically investigated throughout the work life cycle rather than the focus on employment rate or case closures.

# Purpose

The purpose of this study was to identify quality outcomes of employment, as defined by those with MS who have worked at some point following their diagnosis.

# Methods & Participants

Qualitative approach using 3 focus groups at 3 sites (Ohio, Georgia, South Carolina) with a semi-structured interview format led by 2 group facilitators. Groups were heterogeneous., Inclusion criteria: (1) >18 years, (2) < 65 at time of diagnosis, (3) physical disability from MS, and (4) must have been employed after diagnosis.

#### Participants (N=74)

- ➤ Average current age: 46.79 years
- ➤ Average age at diagnosis: 34.63 years
- ➤ Average time post-diagnosis: 11.63 years
- × 20.3% male
- × 25.7% non-white

# Identified Categories (3) & Themes (14)

#### Pay for health needs

"...you definitely want to have benefits because the medication's expensive."

"Why do I work? Partly \$4,200, \$4,400 of Avanex every month."

#### **Support responsibilities and lifestyle**

"Work is a paycheck that allows me to go on vacation in certain areas."

"Work means paying for my twins to go back to College."

#### **Inspiring others**

"What inspires me is to have people come to me and say I'm there 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."

#### **Providing direct help or assistance**

"So I enjoy going in the office and working and helping people. You felt rewarded."

"I'd say my job actually brings me happiness and fulfillment;

and I believe that, religiously, that God put me there."

**Enjoyment** 

Salary/Money

"Yes, I love my job; and I like the social aspect,

and I like making people happy, but it's all

about a paycheck."

# Compensation

**Helping Others** 

### **General helping (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..."

# **Identity and sense of direction**

"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..."

## Pride and sense of accomplishment

"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."

#### Sense of purpose

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."

# **Social connections and social support**

"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."

# To maintain health and wellness

"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."

#### **Stress and burden**

"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 take off because I just want to take off. I take off if I really don't feel good; so, to me, my sick times means a lot to me."

#### Something to do and reason to get up

"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."

# Conclusions

We need to expand our focus from attempting to improve the portion of people that are employed after disability to a greater emphasis on the quality of employment among those who have become employed because the importance of work to the lives of people with MS and other disabling conditions can not be measured by employment rate alone. The emphasis on the employment rate obscures the importance of career development and associated benefits with participation, health, and quality-of-life.

**Personal Well-being** 

Future research should work toward maximizing employment outcomes among those with disabling conditions, rather than focusing on return to employment or transition only and enhance prediction of changes in employment outcomes, which will allow for more accurate assessment of lifetime needs, such as is done in the life care plan.



