Unemployment in multiple sclerosis (MS): The Importance of Staying Active

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Part 3. What you should know and need to do to stay “active” and assure a good quality of life if not working
“Employment serves as a proxy for issues critical to patients' perceived QOL and well-being, and MS clearly has an impact on employment. Physicians and others providing health care to people with MS should routinely ask about employment and support thoughtful decision making about employment status.”

(Johnson & Fraser, 2005, p. 581)

Unemployment in MS

- 90% to 96% of individuals with MS are employed prior to their diagnosis.
- However, it is estimated that 24% to 80% of individuals with MS are unemployed and in general, only 40% are employed.
- More striking, is that 70% to 80% are unemployed within five years of diagnosis.
- Several factors account for an individual’s decision to leave the workforce.
Factors Related to Unemployment in MS

- Older age
- Female gender
- Less education
- Progressive course
- Fatigue
- Cognitive slowing
- Greater disease severity
- Unemployment in MS

Symptoms Related to Leaving Workforce

<table>
<thead>
<tr>
<th>MS Symptom</th>
<th>1985 1</th>
<th>2003 2</th>
<th>2007 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>13.9%</td>
<td>79.1%</td>
<td>69.5%</td>
</tr>
<tr>
<td>Lower extremity physical problems</td>
<td>27.5%</td>
<td>54.9%</td>
<td>43.8%</td>
</tr>
<tr>
<td>Upper extremity physical problems</td>
<td></td>
<td>44.8%</td>
<td>39.4%</td>
</tr>
<tr>
<td>Cognitive difficulties</td>
<td>34.7%</td>
<td>36.7%</td>
<td></td>
</tr>
<tr>
<td>Balance or dizziness</td>
<td>41.5%</td>
<td>31.2%</td>
<td></td>
</tr>
<tr>
<td>Heat sensitivity</td>
<td>34.1%</td>
<td>30.0%</td>
<td></td>
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<tr>
<td>Bowel/bladder problems</td>
<td>28.3%</td>
<td>23.1%</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td>20.8%</td>
<td>23.3%</td>
<td></td>
</tr>
<tr>
<td>Poor vision</td>
<td>7.4%</td>
<td>23.5%</td>
<td>17.1%</td>
</tr>
<tr>
<td>Tremor</td>
<td>15.7%</td>
<td>14.9%</td>
<td></td>
</tr>
<tr>
<td>Non-pain sensation symptoms</td>
<td>16.1%</td>
<td>13.1%</td>
<td></td>
</tr>
<tr>
<td>Speaking difficulties</td>
<td>9.7%</td>
<td>9.7%</td>
<td></td>
</tr>
</tbody>
</table>

1. LaRocca, Kalb, Scheinberg, & Kendall, 1985
2. Simmons, Tribe, & McDonald, 2010
Reasons for Leaving Work

- In a sample of 68 women, 27 (39.7%) reported leaving work because of their MS.
- Reasons for leaving included:
  - Fatigue (44%)
  - Mobility difficulties (41%)
  - Cognitive difficulties (30%)
  - Physical weakness (28%)
  - Pain (15%), balance/dizziness/equilibrium difficulties (15%), fine motor difficulties (11%), emotional difficulties (7%), bladder/bowel problems (7%), vision problems (7%), and heat sensitivity (4%)

Current Research

- Demographics and disease variables only account for 14% to 21% of the variance in predicting unemployment in MS.
- We have verified the role of certain demographics, disease variables, fatigue, and cognition on unemployment in MS.
- However, we are presently researching the role of other, person-specific factors that may also contribute to individuals leaving the workforce.
Person-specific factors that contribute to unemployment in MS

- Coping
  - Maladaptive coping (e.g., behavioral disengagement, mental disengagement, substance use)

- Personality
  - Greater levels of neuroticism, lower levels of extraversion

- Anxiety
  - Greater trait anxiety

- Self-efficacy
  - Lower general self-efficacy

- Locus of Control
  - Lower locus of control (or external)

- Perceived self-management of MS
  - Lower sense of self-efficacy over managing or controlling one’s illness

Why is it so important to identify and understand the CAUSES of unemployment in MS?

Because of the OUTCOMES associated with being unemployed and the desire of so many to STAY employed...
PART 2. OUTCOMES ASSOCIATED WITH EMPLOYMENT STATUS

Unemployment is known to gravely impact overall quality of life.

“Silent” costs of unemployment:
- Poorer overall physical health (e.g., cardiovascular disease)
- Increased mental health problems
  - depression, anxiety, sleep disturbance
- Increased mortality
- Even a greater suicide rate

Benefits of Employment

- Engagement in the workforce among women results in increased confidence and self-esteem.\(^1,2\)
- Individuals whose work is more complex are likely to:\(^3\):
  - be more intellectually flexible
  - take more personal responsibility
  - have greater self-esteem
  - engage in intellectually demanding leisure activities
  - be receptive to innovation and change

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Benefits of Employment

- Individuals with MS view work as important to their identity, self-esteem, and social contact, with many viewing it as “therapeutic.”

“I don’t think about being tired when I’m at work, my mind is too busy to think about my legs hurting. That’s the best reason why people should work. You forget about the MS. If I am home, I get really depressed.” – BL, p.203

“If I make myself get up and go I feel better. Lying in bed and thinking about everything that’s going wrong makes me feel worse.” – GH, p.203

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Johnson, et al. (2004). *Archives of Physical Medicine and Rehabilitation*
Benefits of Employment

40% of unemployed individuals with MS report wanting to return to work, stating that it is a way of being part of society.

“I want to do a good job, and be valuable and worthwhile. No matter how hard you try, a lot of your self-esteem is based on your work…. You have to realize that you need to be a part of society.” – GH, p.20

“If you lose your interaction with people, your world is going to shrink.” - MR, p.203

PART 3. WHAT TO DO IF NOT WORKING: THE IMPORTANCE OF STAYING ACTIVE
Mental & Physical Activity in the Elderly

- Comparing individuals with Alzheimer’s disease to individuals without AD, those who did not have AD were found to have engaged in “active” past times (e.g., knitting, reading, gardening, playing a musical instrument, competitive sports) during their 20s to 60s as opposed to more “passive” activities (e.g., watching television, talking on the phone) (Friedland et al., 2001).

- In fact, those that engaged in passive activities had a 250% increased risk of developing AD.

Cognitive Reserve/Intellectual Enrichment in MS

- Adopted from the Alzheimer’s literature cognitive reserve is the idea that there are heritable/genetic and environmental factors that contribute to one’s “reserve” against disease-related cognitive decline.
  - Genetic/heritable factor – Maximal lifetime brain growth
  - Environmental – Intellectual enrichment

- Higher intellectual enrichment reduces one’s risk for dementia and moderates the effect of AD pathology on cognitive status.

- Researchers at Kessler Foundation (Sumowski et al., 2013) have in fact shown that individuals with higher intellectual enrichment have some protection from disease-related cognitive impairment.
What is intellectual enrichment?

- Measured by many variables
  - Education level
  - Vocabulary
  - Occupational attainment
  - Cognitive leisure activities

Cognitive leisure activities in early life found to be related to intact cognitive status in MS and ability to withstand more severe brain atrophy before/without suffering cognitive impairment (Sumowski et al., 2012)

Cognitive Leisure Activities

- Reading books
- Reading magazines
- Producing art (e.g., painting, poetry, sculpture, songwriting, ballet)
- Producing non-artistic writing (e.g., diary, newsletter, essay, blogs)
- Playing a musical instrument
- Playing structured card games (e.g., cards, board games, crossword puzzles)
- Participating in hobbies (e.g., gardening, model building, Web design)
Physical Activity & MS

- Aerobic fitness known to affect grey matter volume and white matter tract integrity.

- Physical activity influences resting-state functional connectivity on the hippocampus and cortex.

- Researchers at Kessler have pilot data with two participants demonstrating that aerobic exercise (30 minutes, 3X a week for 12 weeks) resulted in increased hippocampal volume, increased hippocampal resting-state functional connectivity and improved performance on verbal and nonverbal memory measures (Leavitt et al., 2013)

Physical Activity & MS

- Fatigue – inconsistent findings. But in general, does not worsen but may improve fatigue.

- Investigations have also looked at depression. But, findings have been inconsistent as well.

- With regard to cognition, there have been null findings

- Physical activity known to contribute to improved quality of life (QOL). Structure Equation Modeling showed that those who were more physically active had greater self-efficacy and better functional capacity, which led to greater QOL.
Community Participation & Well-being: Staying Social

- Perceived level of social support has been shown to be one of the greatest predictors of depression in MS
- Again, stated earlier, many individuals with MS stress the importance of social support as being one of the facets of employment that is most important
- In general, women also perceive the socialization of the workplace as being more important than the “tasks” of their job.
- Individuals with MS who engage in supportive interactions also reported having a greater sense of purpose and less depression (Miller, 1997).

- Social support found to be a factor that helps individuals cope with their diagnosis and adjustment to MS (Miller, 1997; Wurgaft, 1999).
- Also a buffer for stressful life events (Brandt & Weinert, 1981; Thoits, 1995).
- Being employed and living with a spouse have been shown to contribute to QOL (Gulick, 1997; Koch et al., 2001)
- Even when controlling for demographics and disease variables, social support is a significant determinant of QOL (Schwartz & Frohner, 2005).
- Additionally, those with perceived social support also report less fatigue, pain, and cognitive dysfunction and better general health.
Preserving Mental Health

- Depression
  - Important to stay involved and maintain a good social support network
  - Assuring sense of purpose, meaning, and self-efficacy important

- Sleep
  - Important to engage in good sleep hygiene behaviors
  - Avoid the “no work, no alarm” tendency. Try to get up at the same time every day
  - Physical exercise also helps with sleep

- Fatigue
  - Sleep problems are a significant predictor of fatigue in MS (Go back to the tips above 😊)

In Summary…

- Employment is a significant proxy for QOL in MS
  - Purpose/meaning
  - Social support
  - Self-confidence, self-efficacy
  - Overall well-being

- Unemployment is associated with many “silent” costs
  - Poorer overall health
  - Mental health issues (depression, anxiety, sleep problems)
  - Mortality and suicide rate
Summary

- Predictors of employment are both disease related and person specific
  - Disease course and duration
  - Fatigue
  - Processing speed and memory
  - Personality, coping, self-efficacy, LOC, anxiety, perceived self-management of MS

- Consideration of both are warranted when making determinations regarding employment status
  - Interventions tailored to address the individual and factors specific to them are likely to have the best result in assisting individuals in maintaining employment

Summary

- If needing to leave the workforce, it is important to maintain one’s health
  - Mental health
  - Cognitive health
  - Physical health

- Arrange for the engagement of cognitive, physical, and social leisure activities.

- Volunteer or engage in some sort of activity that provides a sense of meaning/purpose
Final Take Home Message

USE IT OR LOSE IT!!

THANK YOU