Successful Employment and Quality Work Life After MS: A Qualitative Study

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Purpose

- The literature is devoid of studies examining subjective aspects of the employment experiences of people with MS.
- The purpose of this study was to identify important predictors and outcomes of employment, from the perspective of persons with MS.
- A qualitative approach was used to allow for new insights into the processes and to provide researchers, program developers, & policy makers with a myriad of potentially new factors which may impact the work life of persons with MS.

Learning Objectives

- Identify at least two sets of factors/predictors related to quality employment.
- Identify three common themes of quality employment throughout the work life cycle after diagnosis of multiple sclerosis.
- Describe how qualitative and quantitative studies may work together to clarify employment outcomes.
Employment and Disability

- Employment is of great importance to adult life, including that of people with disabling conditions.
- Tangible benefits include income and benefits such as health insurance.
- Intangible benefits relate to psychological adaptation and purpose in life.
- The onset of a disabling condition presents significant challenges to maintaining employment or to obtaining new employment.

Employment and Multiple Sclerosis

- Onset of MS typically occurs between ages 20-40, during the most active employment years.¹
- As illness progresses, there is a sharp decline in employment, with only 20-30% employed 15 years after diagnosis² and less than 50% in the US currently employed.³
- Of those who left the workplace, most left their jobs voluntarily (75%),⁴ although most believe they are able to work⁵ and would like to re-enter the workforce.⁶
Rehabilitative Issues in Employment

- The Federal government and state governments have taken leadership roles in promoting employment outcomes after the onset of a disabling condition or among youth with disabilities who are transitioning to adulthood.
- The nature of the support may include retraining and varying levels of education. Education is the single most important factor to multiple employment outcomes.
- Support varies substantially between individuals and between states.
- Typically, cases are closed by Vocational Rehabilitation (VR) after the individual has been employed for 90 days (although some support services may remain). These closures are deemed successful.

Philosophy of the Research

- The philosophy of the current research is that employment after disability must be systematically investigated throughout the work life cycle, with attention to quality outcomes, rather than the focus on current employment status or case closures.
- The challenges for those with disabilities begin after the first 90 days when services are typically terminated, and return or transition to employment represent only the first step to successful quality employment.
- Until research and practice focus on a wider array of outcomes, people with disabling conditions, even when employed, will lag behind the general population in (1) quality of employment, (2) quality of life, and (3) longevity.
- Our mission is to use a systematic approach to investigating employment outcomes throughout the work life cycle as a prelude to intervention.
Key Aspects of the Research

- Use of the Labor Participation Model (LPM)
  - The LPM identifies key variables and allows for the determination of attributable differences, related to non-changeable control characteristics, and policy effects related to variables that may become the focus of policy change.
- Diverse stakeholder involvement in advisory panels and qualitative research
- Use of econometric modeling

![Labor Participation Model Diagram]
Participants

- N=74
- Average current age: 46.79 years
- Average age at diagnosis: 34.63 years
- Average of 11.63 years post-diagnosis
- 20.3% male
- 25.7% non-white
- All had been employed at some point since diagnosis
- Groups were heterogeneous.

Methods

- Qualitative approach using 3 focus groups at 3 sites (Ohio, Georgia, South Carolina)
- Semi-structured interview format with two group facilitators.
- Focus groups were recorded and transcribed.
- Transcripts entered into NVivo, a program designed to facilitate the processing and analysis of text-based documents.
Methods

- A constant comparative method was used, a form of latent content analysis which involves:
  - Noting similarities/dissimilarities in the data
  - Searching for themes and patterns
  - Drawing inferences about patterns
  - Confirming and disconfirming findings

- The detailed transcription process and data analytic methods were all designed to limit threats to validity, as was the use of two group facilitators.

Results: Quality Outcomes

<table>
<thead>
<tr>
<th>Compensation</th>
<th>Personal Well-being</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary/Money</td>
<td>Enjoyment</td>
</tr>
<tr>
<td>Pay for health needs</td>
<td>Identity and sense of direction</td>
</tr>
<tr>
<td>Support responsibilities and lifestyle</td>
<td>Pride and sense of accomplishment</td>
</tr>
<tr>
<td>Helping Others</td>
<td>Sense of purpose</td>
</tr>
<tr>
<td>Inspiring others</td>
<td>Social connections and social support</td>
</tr>
<tr>
<td>Providing direct help or assistance</td>
<td>Something to do and reason to get up</td>
</tr>
<tr>
<td>General helping others (value added)</td>
<td>Stress and burden</td>
</tr>
<tr>
<td></td>
<td>To maintain health and wellness</td>
</tr>
</tbody>
</table>
Compensation

- Salary/money is a primary benefit of working
  
  - 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.

  - Money’s always nice.

  - 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.

Compensation

- Pay for health needs, including medications (4)
  
  - Why do I work? Partly $4,200, $4,400 of [Avanex] every month.

  - …you definitely want to have benefits because the medication’s expensive.

  - 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.

  - 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 because I didn’t want to lose some disability before that [unintelligible] law passed. So I settled down.
Compensation

- Working provides money to support responsibilities and lifestyle you want
  - 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.
  - 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 was scared to death that I was gonna end up on the street... work has always been [a] central part of my life.

Benefiting Others

- Inspiring others
  - I have 8½-year-old twins who are the greatest gift I have ever been given besides my husband, & I want them to have the ex. that you don’t stop. You just keep going.
  - 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.

  - (participant): 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.
  - (facilitator): The impact on others and the influence you have.
  - (participant): Yes sir.
Benefiting Others

- Providing direct help or assistance
  - 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.

  - 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.

  - My job keeps me going, particularly now. It’s fulfilling. You’re helping people.

  - …it’s making a difference in other people’s lives including my own. It enriches our lives and the people that we take care of.

  - 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.

Benefiting Others

- General helping others (value added)
  - 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.
Benefiting Others

- General helping others (value added)
  - 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.

Personal Well-being

- Enjoyment
  - Meaning of work, hum. I absolutely love what I do.

  - 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.

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

  - It brings happiness, fulfillment, gives me something to do. I really feel working keeps me going.
Personal Well-being

Identity and sense of direction

- Yeah, I had to figure out what direction I was going in, which was why I joined the Coast Guard in the first place. I had no direction. So then I left, I'm sick, and I don't have any direction; so, as far as it comes to work, yeah.

- I think when I was working, like you say the socialization of working 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 going in the right direction. Upwardly mobile in [my] position.

- 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 [or 3?] years, and I just felt like that was everything I had trained for.

- And my identity. It's like ahhhhhh, what in the world am I gonna do now?

- 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.
Personal Well-being

- **Pride and sense of accomplishment**
  - You feel good at the end of the day because you've done something worthwhile.
  - 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.
  - 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.
  - 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 yrs while having MS.

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Personal Well-being

- **Sense of purpose**
  - 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.
  - 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.
  - 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.
Personal Well-being

• Social connections and social support
  • 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.
  • 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.
  • 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.
  • 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.

Personal Well-being

• Something to do and reason to get up
  • 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.
  • 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.
  • It’s because it keeps your mind - being, you know, we suffer from cognitive, here and there - but it keeps your mind busy. It makes you feel alive like you doin’ something for yourself, not for somebody else.
  • 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.
Personal Well-being

- 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 . . . 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.
  - 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.
  - My gait is effected quite a bit; and even in doing health and safety, I can’t bend down and look at different pieces of equipment in that. But that’s what it is, so that’s why I decided to move on to something different. So I just have to make decisions. Compensate.

Personal Well-being

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

- 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.
- Quality employment will promote health, community integration, quality of life, and the sense of well-being.
- 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.

Future Applications

- Work toward maximizing employment outcomes among those with disabling conditions, rather than focusing on return to employment or transition only.
- 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.
- Develop equations which use weighted models for various outcomes that better determine the cost effectiveness of interventions to promote overall employment success.
- Development of the new metrics, such as earnings based contributions to taxes.
References


