

University of Washington

Multiple Sclerosis and Participation: Barriers and Facilitators

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National Rehabilitation Research and Training Center on MS

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Goal: To promote health and wellness, and to improve the functioning and employment status of persons with MS.

Activities in MSRRTC

- MSRRTC1: Clinical trials on MI to facilitate adherence to fitness; Clinical trial on effexor to treat depression; large cross-sectional survey; qualitative studies on employment and depression
- MSRRTC2: Clinical trials on exercise and depression, exercise and preserving function and participation, MI on preserving employment, cross sectional and longitudinal surveys on correlates of participation

MSRRTC3

- Clinical trial on self-management techniques to cope with distress and enhance health and well being
- Natural history studies of pain, depression, fatigue, anxiety, participation, employment
- Natural history studies of aging with MS
- Examination of contributors to changes in employment status

Rehabilitation Approach

From George Kraft:

~~“Doctor, my T cells are attacking my myelin”~~

“Doctor, I keep tripping.”

“Doctor, I am having difficulty at work.”

“Rehabilitation is clearly the only practical means of significantly improving function in patients with MS.” Lancet, Vol. 354.

Employment & MS: A Snapshot

- 90% have a work history
- 60% working at time of diagnosis
- 20-30% working 10-15 years from diagnosis
- 30% of employed & 70 % of unemployed have cognitive deficits
- Women < 45 y/o report responsibility for > 60% of household work

» (Johnson, Yorkston, Klasner, Kuehn, Johnson, & Amtmann, 2004)

Purpose: To gain. . .

- A better understanding of participation in the workplace
- An understanding of the ecological events surrounding changes in employment status
- An understanding of the resources people living with MS bring to bear on employment

Participants

- 37 individuals with MS
 - currently employed, or
 - recently left work
- Gender distribution
 - 34 women, 3 men
- Age range: 35-62 years
- Duration of MS
 - range 5 - 14 years
 - Mean 6.4 years

Themes in Employment

- Cost-benefit economy of working
- Fatigue and cognitive change: a troublesome cycle
- Stress and work
- Accommodations to address barriers

Economy of Work

- Value of Work
 - “My doctor recommended I go on long-term disability but I’m not ready for that...I need to work and pull in an income.” GH
 - “I can’t believe how expensive medicine is. I am so glad I am working and have benefits.” BL

Economy of Work

- Working has a cost
 - “It cost me having a life outside of work sometimes, because I am pretty much exhausted at the end of the day but I actually like my job.” EP

Economy of Work

- Working is 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 it...if I am home [recovering], I get really depressed.” VB

Economy of Work

- Working is therapeutic
 - “I think somebody always has to have a reason to get up and get going, or it’s much easier to get depressed, if you are not in some kind of an activity.”
 - “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.”

Fatigue and Cognitive Change: A Troublesome Cycle

- Explaining fatigue: the MS perspective
 - “We use the word *fatigue* to describe it, you think tired. It’s different. Your reserves are depleted and they don’t refill...you can’t refill them.” ST
 - “...fatigue means not being able to get out of bed at all. Days where physically you just can’t do anything.” DS

Fatigue and Cognitive Change: A Troublesome Cycle

- Fatigue alters thinking: thinking is hard work
 - “I function better in the morning and really, the tired starts around 1:00 and goes downhill from there...I’m just not as quick mentally” MR
 - “There are cognitive problems (in the afternoon)...I don’t think as clearly. It doesn’t mean I can’t do my job, but I think it is a struggle...most things are a struggle.” BL

Fatigue and Cognitive Change: A Troublesome Cycle

- Fatigue alters thinking: thinking is hard work
 - “I have trouble concentrating...I have to work a little harder to think about what people are saying.” EP
 - “I just have to remind myself to think before I give out an answer.” PI

Fatigue and Cognitive Change: A Troublesome Cycle

- Fatigue alters thinking: thinking is hard work
 - “I have cognitive changes...I struggle with what I want to say and I have short-term memory problems and problems concentrating. I have to read things more than once or if I’m asked about it, it’s gone.” PI
 - “I had the ability to understand concepts and understand the rational without having to touch, feel them in the past...now I can’t retain information unless I do a lot of hands-on working with it immediately.” PW

Fatigue and Cognitive Change: A Troublesome Cycle

- Fatigue alters thinking: thinking is hard work
 - “I am always concentrating – I cannot talk to someone and walk. I don’t look for something in my purse and walk...I am either walking or I am stopping...same thing with talking...it’s just not automatic...I need to think about it or I slur a lot more than I do. Natural things you should do, I have to think about in order to do.”

Fatigue and Cognitive Change: A Troublesome Cycle

- Cognitive changes are frightening
 - Using the language of fatigue as a proxy for cognitive changes: “...cognitive changes scare me to death...I say I have problems because of fatigue...I wouldn’t ever want to say anything about the mind when I work in a job where I need to be sharp and have my mind alert.” BL

Stress in the Workplace

- A feeling influenced by the environment
 - “The attorneys we work with, particularly the defense attorneys, can be pretty demanding. They lack social skills, they can be very abrupt and aggressive and sometimes rude and patronizing, condescending, so that is stressful for me to deal with.” PI

Stress in the Workplace

- Exceeding your resources
 - “There was a time that I could easily do my job to make order out of chaos. Let me at it. That is just what I enjoyed most...but now I don't have the energy to gather my wits...too hard to think...can 't juggle all of those balls anymore.” CW
 - “Sometimes when I am by myself and my caseload is very busy, that I am so overwhelmed I get stressed out and anxious, anxious to the point of paralysis fright and I can't do my work.” PI

Stress in the Workplace

- Stress makes things worse
 - “When I get stressed I can’t talk very well. I talk like I’m drunk. I can’t walk very well. It makes my MS worse immediately.” GL
 - “It’s kind of like a round robin effect...the more stress there is the more confused I get, and the more confused I get, the more that stresses me.”

Stress in the Workplace

- Stress makes things worse
 - The presumption of others: “My supervisor told me, ‘I am afraid that sometimes I hold back putting your name out there for promotion because I worry about the toll the stress would take on you.’ She totally respects my work, but she was concerned because of my MS that the stress would be too much for me. So she didn’t consider me.” GH

Accommodations to Address Barriers

- Concern about the reactions of others
 - “It’s nice to think that people don’t discriminate, but they do.” AA
 - “I think basically you get stereotyped and they see you as your ailment and they don’t see you for yourself.” BL
 - “I just don’t feel like training a new manager about my MS every six months...It’s just not worth it.” EP

Accommodations to Address Barriers

- Concern about the reactions of others
 - “I just try to hide MS from my boss. I feel like I am being penalized for my disability. My boss reneged on a promise to give me partnership a couple of years ago...I always wonder if it isn't because she doesn't want a partner who is disabled.” PI

Accommodations to Address Barriers

- Concern about the reactions of others
 - “When I was fatigued in December, I just said I had a cold. It is just so much easier than trying to explain...people know about colds...colds are real...but if I say I’m tired, people think that, well, everyone is tired.” AA

Accommodations to Address Barriers

- Providing what is needed
 - “If I really need something, I will let you know and you don’t have to make a big show of finding something for me.” GH
 - “I used to work as a teaching assistant...I’d write stuff on the board but I couldn’t see it. If someone asked me a question about ‘what does that say?’ I’d have to sort of trick them into pointing me to where on the board.” DS

Accommodations to Address Barriers

- Providing what is needed
 - “I have a routine about how and when I do things. It makes me faster and I don’t forget as much.” BL
 - “I do a morning break, but I tack my afternoon break on to lunch so I can really rest.” MR
 - “In preparation for interviews, I read and re-read material so I can remember what the pertinent issues are.” PI

Accommodations to Address Barriers

- Providing what is needed
 - “They were saying, whatever you need...you can work half a day, and sometimes you can come in and then go home, or call and say, ‘I’m not coming in at all.’ There was no formal agreement...if I get up in the morning and I’m just not doing real well, I can turn on my computer they bought me and connect to my email.” GH

Accommodations to Address Barriers

- Providing what is needed
 - “I do use a power chair at work provided by DVR...I am always far away from the restroom and it takes so much energy to walk so that helps quite a bit. It is a very nice electric chair...professional looking, and they gave me a bigger cubicle to accommodate the chair.” BL

Accommodations to Address Barriers

- Providing what is needed
 - “It’s very cool...when the OT brought the chair to me and I was trying it out, just practicing, the manager of the building saw me. I was saying, maybe I could attach it to the bicycle rack, but he thought it is such a nice chair and it would have gotten dirty so they built a little cupboard for me in the garage and put doors and a lock on it. “ BL

Accommodations to Address Barriers

- Work outside the workplace
 - “I have now said, look, I can’t do everything...the laundry, dishes, and clean house when I get home from work. After I’ve been gone for 11 hours, I am thoroughly exhausted...I need to get my rest or else I am a mess the next day.” GG

Accommodations to Address Barriers

- Working outside the workplace
 - “Around the house, my husband helps out a lot. We divvied up what I can do and what I can’t do. He’ll do the vacuuming and sweeping, hands me items to dust. Now cooking, I might start the meal, I’ll do the chopping, I’ll stand and do stuff, and then if it’s stuff that needs to be flipped or turned, I’ll sit down and he’ll finish it off and serve it up.

SOS on Psych Soc and Participaiton

- Fatigue: 75% (MFIS)¹
- Depression: up to 50% (PHQ9) (50% anxious)^{1,2}
- Impaired cognition: 30 – 70%^{1,2}
- Pain: 71% last 3 months, half report significant interference (BPI)²
- Sleep Problems: 41% (MOS)²
- Anxiety: 25% (HADS) (75% depressed)²

¹Kraft, Johnson, et al (in press). **Multiple Sclerosis**

²From MSRRTC cross-sectional survey, N = 1400

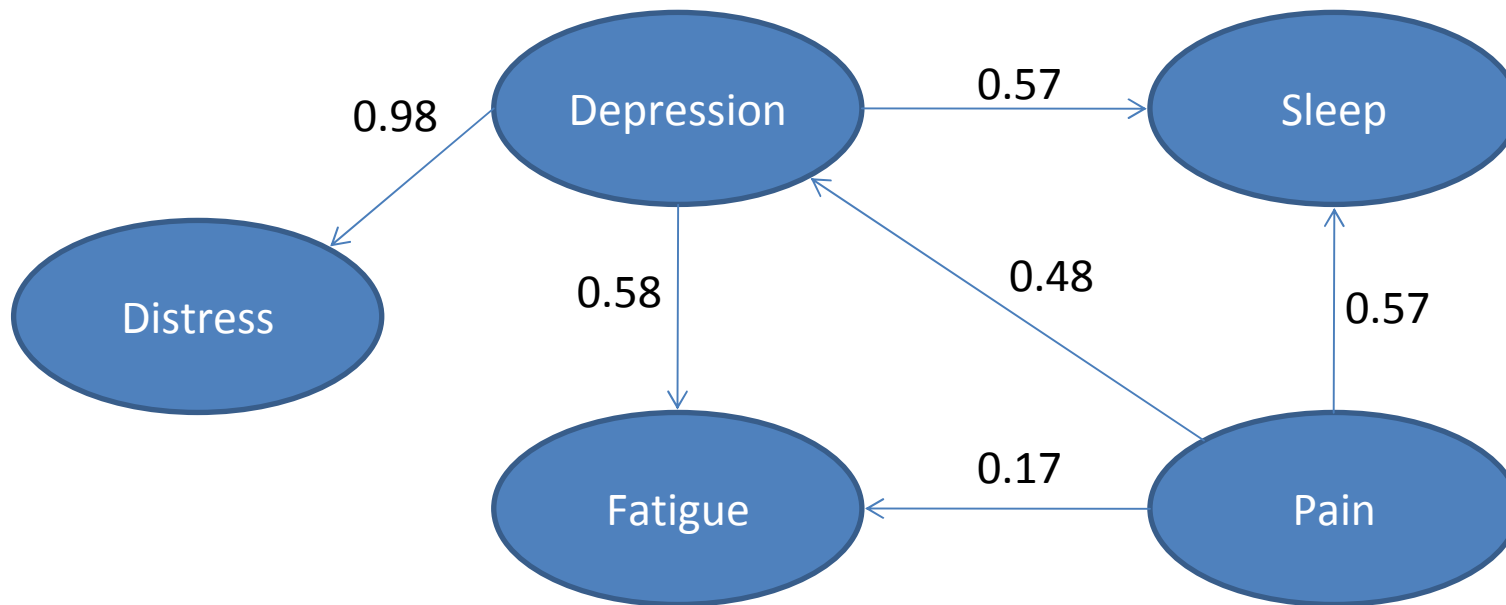
SOS Continued

- Antidepressants: about 50% taking antidepressants, 50% depressed, 50% overlap¹
- Assistive Technology²
 - Memory strategies: 72%
 - Walking aids: 51%
 - Electronic memory aids: 45%

¹Cetin, Johnson, Ehde et al (2007). **Multiple Sclerosis**

²Johnson, Bamer, Yorkston, & Amtmann (in press). **Disability and Rehabilitation**

Symptom Modeling



Conclusions

- Multiple stressors interact with multiple symptoms requiring resources from diminishing cognitive economy
- Reduced self-efficacy decreases potential to manage
- Treating individual symptoms is not likely to result in increased meaningful participation
- Collaborative strategy combining medical, psychosocial, and self-management

Recommendations for Health Care Providers

- Work is important to people with MS
- People believe exposure to stress exacerbates their MS
- They believe their healthcare providers have equated work with stress
- Subjects believe they have been encouraged to quite work by health care provider
- Many can continue to work with accommodations
- Accommodations lessen stress

Recommendations for Health Care Providers

- Inquire about cognitive issues (fatigue or stress may be proxies)
- Ask patients to elaborate on the triad of fatigue, cognition & stress
- Ask about pain, sleep, and other psychosocial issues
- Encourage self-management of symptoms

Thank you!

- Discussion
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