Background: Although 98% of Americans with MS have employment histories and more than 80% were still working at the time of diagnosis, the first 10 years after diagnosis is marked by a significant decline in labor force participation. Only about 40% of people with MS nationwide are presently employed for pay, and estimates suggest that only 20% of this experienced group of workers will continue working until retirement age. The medical and psychosocial accompaniments of MS, though intrusive and sometimes severe, do not come close to fully explaining the extremely high rate of labor force attrition observed in people with MS.

Problem Statement: To improve employment outcomes, we must better understand the ramifications of disclosing the MS diagnosis in the workplace.

Learning Objectives:
1. Identify two categories related to disclosure of MS diagnosis and employment.
2. Discuss factors which may influence the decision to disclose MS diagnosis to an employer.
3. Discuss potential consequences to employment resulting from disclosure of MS diagnosis.

Methods: A total of eight focus groups in three distinct regions of the United States (South Carolina, Georgia, and Ohio) were conducted consisting of between four to nine participants each for a total of 74 participants. All participants were 18 years of age or older, spoke English, and had worked after MS diagnosis, although not all were employed at the time of the study. Participants ranged in age from 20 to 81 years old (M=46.79 years old; SD=13.48) with an average age at diagnosis of 34.63 years (SD=9.70) and time since diagnosis ranging from 0 to 44 years (M=11.63; SD=9.18). Women accounted for just under 80% of participants; individuals from racial and ethnic minority backgrounds accounted for 25.7% of the sample. Over half of the participants were currently working (57.7%), 18.3% were not working at the time of the focus group, and 2.8% were retired.

Data Analysis: Professional transcription of focus group recordings were completed and returned to group facilitators, who noted and corrected errors. Transcripts were uploaded into NVivo 10 qualitative software. After reviewing the transcripts, three authors extracted topics, themes, and patterns from the source documents.

Results: Upon qualitative analysis of focus group narratives, we found that narrative responses indicated eight themes that fell into one of two categories, decision to disclose and consequences of disclosure. In the category of Decision to Disclose, themes included (1) disclosing to explain, prepare, or education, (2) general disclosure, no concerns, (3) limiting, delaying, or deciding not to disclose, and (4) unsure about future disclosure. Within consequences of disclosure, themes include (5) positive and supportive reactions, (6) mixed or variable reaction in the same work environment, (7) no real reaction, positive or negative, and (8) leading to termination of employment.

Significance & Conclusion: The findings from this study shed important light on how the decision to disclose a diagnosis of MS, or any diagnosis or impairment, is a personal one with a range of possible consequences. Factors that motivated these participants to disclose included feeling the need to explain, prepare, or educate their employer and thinking they would receive support, although a number of participants revealed unintended consequences, such as termination.
Categories (2) & Themes (8)

**For future employer, it does go through my mind should I tell them up front or shouldn’t: because if a problem arises, you just want to come out of left field with it and they’re blindsided by it. So that’s always an issue if I would tell them up front or not. That I’m not sure about...**

**Decision to Disclose**

**Mixed or variable reaction in the same work**

**I didn’t feel like I had a choice of disclosing because I was hit so hard, it was so obvious. I mean we’re talking days. You could count calendar days between the time I was running around, no problems whatsoever and suddenly I couldn’t walk. I mean there was no hiding this.**

**General disclosure, no concerns**

**I was working at a rehabilitation hospital when I was diagnosed; and I thought to myself, Well, I can share this with my boss because they will understand.**

**Unsure about future of disclosure**

**Limiting, delaying or deciding not to disclose**

**“(...) and when there’s a new staff that’s hired, I want (...) to tell them myself because everybody knows. And I get really pissed when they’ve heard already from someone because that is not their business. I just don’t like it. It’s up to make the decisions and not for somebody to be gossiping or whatever.”**

**Consequences of Disclosure**

**Leading to termination of employment**

**“They just chopped you right off. That’s how I felt. I got the call, they told me to come up and get the truck, turn it in, and go, and this and that and the other, and thank you very much, and we’ll start the processing on disability and we’ll consider all these other things. ... I had told ‘em because I was being honest; and I just felt like all of a sudden, just choomp. ‘You’re outta the truck.’”**

**Positive and supportive reactions**

**“Actually from the first day I worked there, if I needed time off or if I said I’m just not comin’ in, there was never a question asked. Never. ... So my disclosure was a positive thing for everybody that was involved that I spoke with at that job and basically every other job that I’ve had so far.”**

**Mixed or variable reaction in the same work**

**“Because it’s not an open, visible disability, there’s so many people that say, “Oh, there’s nothin’ wrong with that person.”**

**No real reaction, positive or negative**

**I didn’t have any problems. Because it’s different with the medical field. There were numerous surgeons, so they knew what MS was. So they were like... I said nothing, I don’t need anything. I don’t need anything. We’re cool.”**

**Information for this research brief was developed for the VCU-RRTC on Employment of People with Physical Disabilities. The author is James Krause, Ph.D., Medical University of South Carolina. Questions on this brief should be directed to Dr. James Krause at krause@musc.edu.**

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