

VCU-RRTC on Employment of People with Physical Disabilities

Research Study 2 -- Research Brief #3

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CONSIDERATIONS AND CONSEQUENCES FOR EMPLOYMENT OF DISCLOSING A DIAGNOSIS OF MULTIPLE SCLEROSIS (MS)



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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.

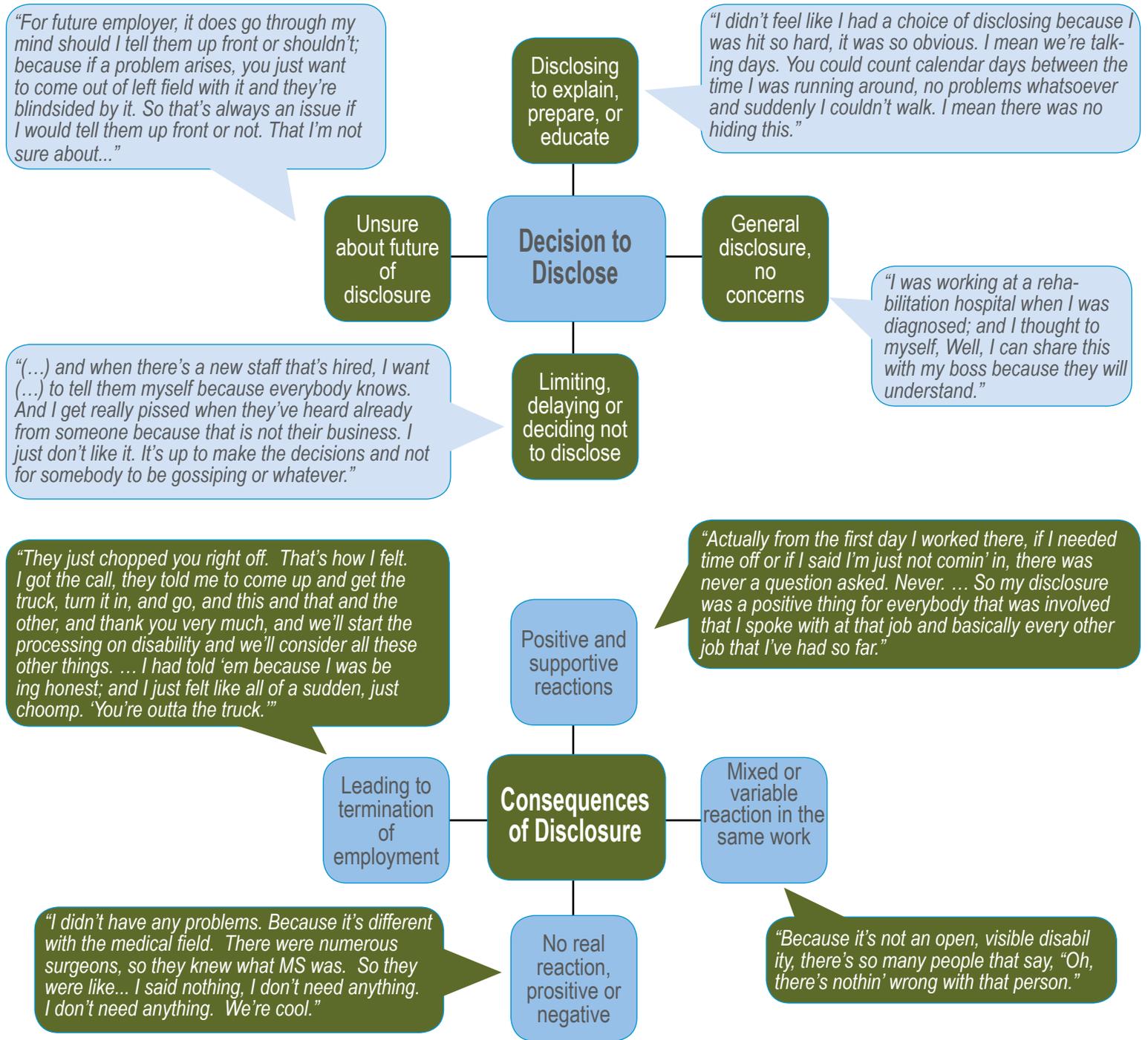
Methods ■ ■ ■ A total of eight focus groups in three distinct regions of the United States (South Carolina, Georgia, and Ohio) were conducted consisting of between four to nine participants each for a total of 74 participants. All participants were 18 years of age or older, spoke English, and had worked 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)



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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