Introduction

Life at Work After Multiple Sclerosis

The prospect of maintaining one’s career while coping with an adult-onset chronic illness such as multiple sclerosis (MS) poses many challenges. First and most obviously, the changes that MS precipitates in the person’s central nervous system cause a wide range of physiological, sensory, and psychological symptoms, effects that can interrupt functioning in virtually every aspect of life. Second, the unpredictable disease process leaves the person uncertain about the future, which can have a negative impact on career planning and other developmental activities of adulthood. Third, coping with a serious chronic illness brings the individual into contact with service delivery and benefits systems that are based on disability status, systems that are unfamiliar to most Americans prior to the onset of disability. Fourth, legal protections available to people with disabilities under the Americans with Disabilities Act, the Family and Medical Leave Act, and the Health Insurance Portability and Accountability Act require significant self-advocacy on the part of the protected party, and people with MS often lack confidence to advocate for themselves in employment.

Cumulatively, these realities of life with MS exact a profound toll on the person’s ability to maintain productive employment. The vast majority, as many as 95 percent, of Americans with MS have employment histories, meaning that they have worked at some point in the past. Some two-thirds of people with MS nationwide were still working at the time of diagnosis, but only 25–40 percent of these individuals are able to retain employment as time and the illness progress. With funding from a Health Care Delivery and Policy Research Contract from the National Multiple Sclerosis Society, researchers at Kent State University and the University of Arkansas have undertaken a three-year initiative to better understand the employment experiences, concerns, and outcomes of people with MS. This multiple-phase project has involved a wide range of research methods, data collection procedures, sampling techniques, and analytic strategies to gain a deeper awareness of the barriers to career success that await people with MS following diagnosis.

In this issue, we feature four articles from the Multiple Sclerosis Employment Project that describe studies of such phenomena as quality of life and its relationship to employment-related variables, perceptions of employment discrimination among workers with MS, responses to employment discrimination claims filed by people with MS on the part of the United States Equal Employment Opportunity Commission, and the job accommodation needs of employed people with MS. Taken in aggregate, these studies shed light on some of the factors that contribute to the high rate of labor force attrition among people with MS, and they provide rehabilitation professionals with some concrete strategies for assisting this experienced, well-educated, yet all-too-often disenfranchised group of workers in maintaining their careers. We wish to thank our colleagues who participated in various aspects of these studies and who served as co-authors of the four articles: Dr. Shawn Fitzgerald, Dr. Darlene Unger, Ms. Courtney Vierstra, Ms. Mary Hennessey, Ms. Laura Staples, and Mr. Richard Stacklin. Special thanks go to Dr. Paul Wehman, Editor of the Journal of Vocational Rehabilitation, for providing us with the opportunity to assemble this issue.

Phillip D. Rumrill, Jr.
Kent State University
Richard T. Roessler
University of Arkansas
Guest Editors