

Guest Editorial

Employment and Community Living Issues for People with Multiple Sclerosis

For this special section of *Work: A Journal of Prevention, Assessment and Rehabilitation*, our goal was to provide a comprehensive update on community living and employment issues for people living with multiple sclerosis (MS). We have included articles that incorporate aspects of housing, transportation, assistive technology, caregiving, employment, and career development for people with MS. Consistent with the aim and scope of this journal, our primary focus in selecting articles for inclusion in this issue has been work, and specifically, the impact of MS on employment and career development, and how current research can guide and inform rehabilitation practice.

Several years ago, the Epilepsy Foundation described the employment situation for people with epilepsy as “the hardest nut” to crack [1], implying that, despite significant advances in treatment and progress in addressing the psychosocial and legal concerns of those with that intrusive illness, the employment rate among adults with epilepsy remained chronically low. As we planned for this special issue on MS, the ‘hardest nut’ metaphor came to mind. In the past decade there have been many important developments in the treatment and rehabilitation of people with MS. Significant progress has been made in modifying the disease course; treating and managing symptoms; refining effective rehabilitation and assistive technology interventions and supports; and diagnosing and treating the depression, anxiety, and other mood and cognitive changes that are common in MS [2]. Yet, as noted in the second article in this issue, these advances have not translated into improved employment outcomes for people with MS. Rather, unemployment remains an intransigent consequence of MS for far too many people, as is evident in recent estimates in the US

and internationally that suggest that 55% to 60% of working-aged people with MS are not employed [3–7].

Research conducted in the past few years on employment among people with MS continues to indicate that the physical and cognitive symptoms of MS represent a major barrier to employment. However, as the scope of this research expands, it is becoming increasingly evident that the employment barriers for people with MS are more complicated than a simple relationship between symptoms and work capacity. Employment is affected by a much broader set of factors and systems. These factors include the accessibility of, and availability of supports in the home and community; the accessibility and flexibility of health care and benefit systems; the responsiveness of national and international health and disability legislation; and the attitudes of society toward the broad inclusion of people with disabilities. Further, we are gaining new understanding of the relationship between employment and the physical and mental health and well-being among people with MS, and the negative impacts of unemployment.

In compiling the articles for this special issue, therefore, we have consciously taken a broad perspective on exploring and understanding the issues of employment and community living for people with MS. This perspective reflects a growing awareness across the professions involved in the treatment and rehabilitation of people with MS that the impact of MS on employment is multifactorial and complex. Our goals as editors, therefore, were to provide a comprehensive and multidimensional review of the current employment and community living situation for people with MS, to ensure a variety of perspectives on this situation, and to not only explore the barriers to working, but also the benefits and broad positive impacts of employment.

To this end, we begin this issue with an overview of MS, including current data on etiology and symptoms, incidence and prevalence, and current treatment strategies. We describe the impact of MS on employment and economic self-sufficiency and review recent research on effective vocational rehabilitation practice. The second article, by Rumrill, Roessler, Li, Daly, and Leslie, describes their recent national analysis of the employment concerns of Americans with MS, in which they note signs of progress and promising research directions. In the third article, Chiu, Chan, Sharp, Dutta, Hartman, and Bezyak provide an analysis of the relationship between employment, health, and quality of life, in which they offer an exciting perspective on employment as a public health intervention for people with MS. The fourth article, by Bishop, Rumrill, and Roessler, presents a replication of Rumrill, Roessler, & Fitzgerald's 2004 analysis of a three-factor model of the impact of MS on quality of life (QOL). In this article the authors evaluate the relationships between QOL, employment status, job satisfaction, job-match, and functional and psychosocial variables.

The fifth article, by Fong, Lee, Sheppard-Jones, and Bishop, presents an analysis of the Home Functioning Scale and explores its utility for the comprehensive rehabilitation assessment of residential functioning for people with MS. In the sixth article, Lee, Pieczynski, DeDios-Stern, Simonetti, and Lee report the results of their examination of gender differences in the needs, psychosocial experiences, and quality of life of spousal caregivers for people with MS, and discuss the implications of their findings for research and practice. We conclude the issue with an article by Li, Fitzgerald, Bishop, Rumrill, and Wang, which extends the current understanding of the relationship between disease-related and functional factors and employment status among adults with MS and demonstrates the importance of the nature of psychological and cognitive functioning variables in employment research among adults with MS.

Taken in aggregate, the articles in this special issue provide a comprehensive review of current employment and community living issues for people with MS, stimulate new questions and directions for research, and offer new perspectives on addressing existing barriers. We are grateful to all of the participating authors

and reviewers for their thoughtful contributions to MS research and practice. We also extend our sincere gratitude to *Work's* Editor, Dr. Karen Jacobs, for her willingness to commission this edition.

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