Opportunities for research to improve employment for people with spinal cord injuries

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Objectives: This paper reviews the literature pertaining to the employment of people who experience spinal cord injury (SCI) in the United States and recommending future research.

Methods: The literature was reviewed with search terms such as SCI, employment, working from home and telework using databases in EBSCO, including Academic Search Complete and the American Psychological Association's databases.

Results: Literature and findings on key factors related to employment illustrate the multiple dimensions of work environments, and health demands, that effect employment outcomes for people with SCI.

Conclusion: Employment is important for people with SCI and valued in society. The literature reviewed indicates that researchers understand the work demands for people with SCI and may help to identify suitable supports, training and job opportunities. There remains a need for research focus on understanding future employment demands, necessary work skills, differing work environments and methods for increasing and preserving employment.

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Keywords: spinal cord injury; employment; working from home; telework; independent living

INTRODUCTION

This review article is submitted for the state of the science in spinal cord injury (SCI) Rehabilitation: informing a new research agenda. The objective of this paper is to recommend future research about employment for people who experience SCI.

METHODS

The literature was reviewed with search terms such as SCI, employment, working from home and telework using databases in EBSCO, including Academic Search Complete and the American Psychological Association's databases.

RESULTS

One of the most important goals of rehabilitation and a key to independent living after SCI is employment.¹ The need for employment in our society and the dependence that we have on it will continue in the future. The employment rate for people with SCI is low and there is little reason to believe that it will improve in the near term.² Many individuals experiencing SCI have low expectations for employment, with only 35% employed compared with 64% of working age adults without disabilities in the United States.³ Perhaps, not surprisingly, those without employment have less income and die younger.⁴

One study on adults with pediatric-onset SCI identified four factors associated with obtaining employment: education, community mobility, independence and decreased medical complications.⁵ Anderson *et al.*⁶ suggests more reasons: education, type of employment, disability severity, age, time since injury, gender, marital status and

social support, vocational counseling, medical problems related to SCI, employer's role, environment and professional interests.

People with disabilities who are working will leave jobs at faster rates after age 40 than the general population, even those with advanced degrees.⁷ In 2008, 9% of workers with disabilities left their jobs, nearly twice the rate of job exit than for workers without disabilities.⁸ Research is needed to help us understand these dynamics.

HEALTH-RELATED ISSUES

One of the biggest barriers to employment is the severity of the disability and concomitant impairment-related health issues. Studies continue to show concerns of people with SCI about the potential loss of health and income benefits,⁹ challenges finding personal assistance¹⁰ and need for additional supports at home, in the community and on the job.¹¹ Rehabilitation research can help people experiencing SCI in finding solutions for acquiring and maintaining employment, and living productive lives by gaining a better understanding of employment-related demands on stamina and challenges to psychological and physical well-being.

Employment interrupted by injury and illness leaves long breaks on resumes, lessens skills and hinders employment chances.¹² Research is needed to help understand how to best support injured employees as they communicate about their status with managers, human resources offices, insurance and other benefit programs, and physician practices. Methods for improving communications between workers with disabilities, doctors and employers need to be identified and studied.

Health-related issues may have an enormous effect on employment for individuals experiencing SCI. Psychosocial history and current emotional readiness to return to work must be considered when

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preparing for continued employment.¹³ Infections and complications of urological and other body systems must be continuously monitored and managed in the context of employment. Pressure on the skin due to sitting for long periods of time may prevent work or interrupt work, may delay task accomplishments, and may restrict travel and training. Treatment of pressure sores in the US costs more than \$1.5 billion annually.¹⁴ Even the type of bladder catheter impacts employment success.¹⁵ Research aimed at reducing and preventing secondary health conditions is vital in helping people with SCI obtain and maintain employment.

People experiencing SCI have much higher rates of depression and mood-related disorders than those in the general population.¹⁶ Workers with SCI may experience significant stress related to work adjustment, scheduling specialized transportation, finding dependable skilled personal assistance providers and organizing other needed accommodations. It is not surprising that as depression and apprehension increases, quality of life decreases.¹⁷ Some analysts suggest future research efforts should focus on the individual challenges of resilience and understanding the coping process.18 Research is needed to better understand and to help ameliorate the psychological and physical problems associated with employment.

WORKING FROM HOME

There is little research on how working from home may impact the lives of people experiencing SCI. A review on the subject by Bricout¹⁹ documented only nine published empirical studies on telework for people with disabilities. Working from home may reduce barriers to employment for individuals with SCI by reducing the need for transportation and by improving access to personal support, which may be more available in the home. Working from home would allow people with SCI to work in prone and supine positions reducing risk or preventing exacerbation of pressure sores that are of great concern to wheelchair users.²⁰ Research is needed to help document the benefits and justify the use of work-at-home strategies as accommodations.

Some employers are willing to offer part-time work-at-home opportunities when the need arises and if the employee has positive job performance. The literature suggests, new employees need to adjust to the organizational culture; at the same time, they must develop independent work skills for productive work from home.²¹ Research may identify best practices for helping employees to adjust to new work environments and for assisting them in moving between employment sites while establishing or maintaining relationships with co-workers.

Work and home environments are becoming more integrated with boundaries blurred.²² Research on work-home preferences found that to separately work from home is becoming more difficult, even for those who prefer to keep the domains apart.²³ Employees are often unpaid for extra work hours at home expected by employers.²⁴ Research is needed to better understand and to improve management of work-at-home demands, time management issues and functional business practices. Qualitative research methods may be useful and include observation, interviews and careful documentation of personal experiences.²⁵ Research findings will be important in preparing workers to deal with conflict, set boundaries, develop skills and find the right work-life balance.

AMERICANS WITH DISABILITIES ACT (ADA)

Employers continue to be resistant to work-at-home accommodation for people with disabilities. A Circuit by Circuit legal review (Yastrow and Edelson²⁶) found support for only 3 of the 71 Americans, with ADA work-at-home challenges. Employers successfully argued to the

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courts that their need for teamwork, compliance, supervision, ready access, on-site meetings and cost-effectiveness outweighed the workat-home accommodations sought by employees with disabilities. There were no people with SCI identified in the referenced case reviews, yet litigation research may provide answers for the future.

Although the ADA is not an affirmative action employment law, many observers believed the equal opportunities provisions of the law would result in increasing employment rates for people with disabilities. This has not proved to be the case.²⁷ In fact, there is little or no evidence that the employment rate for people with disabilities is improving.²⁸ Research on the impact of the ADA on employers may help to establish dialog on important employment issues. The hiring and accommodation process for people experiencing SCI is the responsibility of employers. Literature examining peer review studies on key predictors for employment success found employer goodwill and the attachment between the worker and the employer important for continued employment.²⁹ Research, however, continues to show negative attitudes of employers on hiring individuals with disabilities.³⁰

The ADA has significantly improved postsecondary campus accessibility, increasing the social presence of individuals with disabilities and educational support.³¹ On the bright side, research suggests educational attainment for individuals with SCI is higher for those who are 10 years post injury than for the general population of the United States.³² Research identifying employment trends may give educators insight into business needs and future occupational and career opportunities. There is substantial evidence that education provides a positive return on investment.33

As higher education continues to offer more educational and course opportunities online, there will be new educational and training opportunities for people with SCI. Students will need strong computer skills and access to appropriate technologies in order to benefit from these advances. The ability to work independently, achieve production and engage in online classes, while coping with distracting family and home life demands is difficult. As new distance education technology becomes available, addressing the accessibility issues for class assignments, readings and new media are a must. Research is needed to determine how best to accommodate people with disabilities in an online educational environment.³⁴

Related to the discussion of online educational strategies is the concept of social presence in the electronic classroom.³⁵ Internet users with health concerns now rank e-mail as their principal reason for using the internet.³⁶ However, usage patterns are evolving from e-mail to texting, and from simple browsing to engagement with social media. In this context, studies have indicated that web-based social presence may provide positive personal support and group discussions may produce greater emotional satisfaction among users.³⁷ Likewise, reduced isolation may increase the students' sense of community and satisfaction.³⁸

Will the ADA have the same impact on access to education in the virtual world? Information gained from research may help people with SCI realize the full potential of the internet revolution in education, employment and otherwise.

DISCUSSION

Besides the research questions stated or implied above, the following are particularly pertinent:

How can employment outcomes improve, considering individual's work history and vocational interests?

What will be the barriers and facilitators for individuals experiencing SCI in the future?

What do we still need to know about rehabilitation practices and the role of self-determination and individual choice in employment success?

What are the challenges for employers and individuals with SCI on work-at-home accommodations and employment?

How can Return to Work and Vocational Rehabilitation practitioners contribute to employment research?

What are the psychosocial dimensions of loss, coping and traumatic injury to employment?

Is there a role for participatory research in education, vocational rehabilitation and employment that includes people with SCI, their families, peers and health providers?

How will research help physicians work with their patients to keep their jobs, stay healthy and communicate needs to employers?

CONCLUSION

Employment is important for people with SCI and valued in our society. People experiencing SCI need flexible work environments. The literature reviewed indicates that researchers understand the work demands for people with SCI and may help to identify suitable supports, training and job opportunities. There remains a need for research focus on understanding future employment demands, necessary work skills, differing work environments and methods for increasing and preserving employment.

CONFLICT OF INTEREST

The authors declare no conflicts of interest.

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