Attitudes Towards Individuals with Spinal Cord Injury

2010 Submission

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Abstract

This paper will shed light on the lives of persons with spinal cord injuries by revealing the literature on spinal cord injuries that focuses on research that can shed light on attitudes towards persons with spinal cord injuries. The background literature related to incidences, the definition of spinal cord injury, and vocational opportunities are valuable areas to review as obtaining a better quality of life can allow the individual with spinal cord injuries to be a part of the workforce. This, in essence, will allow others to view the quality of life and the importance of positive attitudes in working with this population.

Introduction

People who have had a stroke or spinal cord injury often experience their bodies as limited and have difficulties in performing daily activities (Kvigne & Kirkevold, 2003). They often find activities that were once taken for granted, such as eating breakfast or taking a shower, difficult to perform. To enable performance, it is necessary to consider changes within the person's context (Kielhonfer, 2008). Recapturing denotes a process of engaging in self-care to regain the ability to participate in self-care activities (Guidetti, Asaba, & Tham, 2009). It is likely for individuals with SCI to have less involvement in the community due to the major adjustment of the disability. The psychosocial issues that are associated with SCI are depression, anxiety, guilt, and anger. These psychosocial issues can have a powerful affect on someone who suffers from SCI. When an individual first encounters the incident the initial thought is depression. They feel helpless because of their condition, and they would have concerns on how people would perceive them.

This paper will shed light on the lives of persons with spinal cord injuries by revealing the literature on spinal cord injuries that focuses on research that can shed light on attitudes towards persons with spinal cord injuries. The background literature related to incidences, the definition of spinal cord injury, and vocational opportunities are valuable areas to review as obtaining a better quality of life can allow the individual with spinal cord injuries to be a part of the workforce. This, in essence, will allow others to view the quality of life and the importance of positive attitudes in working with this population.

The Prevalence and Incident rates

It is estimated that the annual incidence of spinal cord injury (SCI), not including those who die at the scene of the accident, is approximately 40 cases per million population in the U. S. or approximately 12,000 new cases each year. Since 2008, approximately 259,000 persons, with a range of 229,000 to 306,000 persons are alive due to a spinal cord injury **(**The University of Alabama at Birmingham, 2003). In addition, to the estimation of SCI, there are numerous factors that cause different conditions. Motor vehicle crashes account for 42.1% of reported SCI cases. The next most common cause of SCI is falls, followed by acts of violence (primarily gunshot wounds), and recreational sporting activities. The proportion of injuries that are due to sports has decreased over time while the proportion of injuries due to falls has increased. Violence caused 13.3% of spinal cord injuries prior to 1980, and peaked between 1990 and 1999 at 24.8% before declining to only 15.1% since 2005 (The University of Alabama at Birmingham, 2003).

According to Robinson (2006), "six percent of people who receive injuries to the lower spine die within a year, and 40% of people who receive the more frequent higher injuries die within a year" (p.3492). According to literature, males are affected with SCI more so than woman (The University of Alabama at Birmingham, 2003). There are different levels an individual could experience during a spinal cord injury such as C1-C4 head and neck, C3-C5 diaphragm (chest and breathing), C5-T1 shoulders, arms and hands, T2-T12 chest and abdomen (excluding internal organs), L1-L4 abdomen (excluding internal organs), buttocks, genitals, and upper legs, L4-S1 legs, and S2-S4 genitals and muscles of the perineum (Robinson, 2006).

Employment and SCI

Research has consistently reported low employment rates among people with spinal cord injury (SCI) ranging from 13% to 69% (Krause, Pickelsimer 2008). The National Spinal Cord Injury Statistical Center reported that 59% of individuals with a Spinal Cord Injury (SCI) between the ages of 16 to 59 were working at the time of their injury. However, only 29% were employed eight years later (Targett, Wehman, Mckinley & Young 2004).Three investigations identified perceived barriers to employment among participants with SCI who were unemployed and indicated that the most prominent barriers endorsed included inability to physically perform the same type of work following injury, health and stamina (Krause, Pickelsimer 2008). However, poorer outcomes were also noted for those who reported they were not physically capable of working or were in too poor of health to work (Krause, Pickelsimer 2008).Even after completing post secondary education and training programs, individuals with disabilities continue to experience rates of unemployment that far exceed those of the general population (Targett, Wehman, Mckinley & Young 2004).

Advantage of Employment and SCI

The advantage of gaining proper employment is the Supported Employment (SE) approach. This program advocates and helps individuals with spinal cord injury find a job. Supported Employment uses vocational rehabilitation professional sometimes referred to as an “Employment Specialist” or job coach to assist person with disabilities with gaining and maintaining work (Targett, Wehman, Mckinley & Young 2004). There is another program that can help assist persons with disabilities; it is known as Job

Accommodation Network (JAN). This program provides services and it also advocates for individuals with disabilities within the work force arena. A study, by the Job Accommodation Network (JAN), surveyed more than 1000 individuals with SCI who were employed. This study revealed that 75% of those individuals requested assistance with accommodations in order to maintain employment or improve their productivity at work. More than 50% of the requests were for information on new products or modifications to existing equipment (Targett, Wehman, Mckinley & Young 2004).

Disadvantage of Employment and SCI

The disadvantage of not finding employment while having spinal cord injury is not having the proper support system, or not having that drive to overcome the disability and to be active despite of the injury. Other obstacles preventing return to work include, lack of transportation, structural design problems that limit physical access to or around the work place, difficulties performing essential job functions, not being perceived as a person who could get the job done by hiring agents, or the need for a personal assistant (Targett, Wehman, Mckinley & Young 2004).

Spinal Cord Injury, Disability and Employment

Spinal cord injury (SCI) can occur suddenly and result in a number of major changes in an individual's life. SCI affects all aspects of life, including social, psychological and physical performance (Song & Nam, 2010). A key area in the lives of people with SCI is employment. Any disease which affects one's ability to carry out daily duties will in turn have an impact on whether or not he or she can work. As a result,

several studies have investigated the link between SCI and employment. One of the main issues in the lives of people with SCI and other traumatic disabling conditions is the ability to obtain employment. Employment rates after SCI are consistently lower than those of the general population despite legislation implemented to improve employment outcomes after the onset of disabling conditions (Krause & Reed, 2010).

The Harris Survey of American with Disabilities (2004) reported that 35% of persons with severe disabilities are employed, up slightly from the 31% employment rate found by the same survey in 2000, but very low compared to the employment rate of about 78% or 80% of the general population (Harris Survey, 2004, 2000; U.S. Census Bureau (SIPP, 1997). More recent research concerning post-injury vocational interests of individuals with SCI have focused on the myriad of factors affecting their ability to obtain employment.

Research by Rohe and Athelstan, (1962) indicated that occupations that persons with SCI may be interested in may not be feasible due to their reduced physical abilities. This had implications for rehabilitation counselors as they would have to be creative in assisting the affected individuals in finding vocational alternatives. Later research by the same authors in 1984 deduced that physical ability and vocational interests were relatively independent of each other, and the interest profiles of individuals changed very little after injury.

According to Andrew (2008), it is unlikely that a person with a spinal cord injury will change interests as a result of the injury. Therefore, decisions related to education, training, and employment will reflect their personal interests and desire regardless of the

physical impairments. One approach to addressing this issue is to examine the individual's transferrable job skills.

A rehabilitation counselor must help assist individual with disabilities when searching for jobs that will benefit them, and make accommodations and modifications. However, there is a high rise in unemployment of people with disabilities, for people in general because of the economic state in America. Employment programs offer solutions to address specific problems that deny persons with disabilities an equal opportunity to get the job, such as educational programs to counter negative employer or coworker stereotypes, workplace assessments to identify accessibility concerns in the physical lay-out and organization of the workplace, workplace supports to encourage employee integration with coworkers, and financial incentives and legal initiatives to counter externalities that would give employers a disincentive to hire an employee with a disability (Potts, 2005).

The major available public vocational assistance service for adults with disabilities in the United States is the federal vocational rehabilitation (VR) program, and it provides services to an estimated 1.21 million individuals with disabilities abilities each year (Beveridge & Fabian, 2007). One compelling reason for the emphasis on consumer choice in the VR process emerged from the disability community, which demanded more equal participation in the process (Capella, 2002). The ability to be employed is important for many reasons. First, working in competitive employment provides an opportunity to receive wages and benefits that may lead to greater independence and mobility in the community at large (Revella & Kregela, 2000).

Outcomes of Employment /Opportunities

The degree of the SCI can vary widely from person to person. The severity of the SCI can directly affect the employment outcomes for these individuals. A recent study by James Krause, (2010), which investigated the ability to ambulate as a factor in post injury employment, determined that those who required assistance from others in ambulation were considerably less likely to receive employment that those who could ambulate independently. An interesting implication of the study is that no matter the level of the SCI, obtaining employment would still be difficult for those with such injuries. Although individuals with less severe impairment after SCI, defined by the ability to ambulate, are more likely to find gainful employment after injury, this factor is still not enough to promote better employment outcomes for this group. The Workforce Investment Act (WIA) of 1998 established a national system to meet the needs of businesses and jobseekers through a one-stop system of employment services, job training, and education (Elinsona, Freya, Lia, Palana, & Horneb 2008).

Employment outcomes can determine a person's destiny of either being employed or unemployed. Customized employment is a flexible balance of different services and principles designed to meet the vocational goals of a job seeker and the labor needs of employers (Elinsona, Freya, Lia, Palana, & Horneb 2008). Employment outcomes in supported employment have been heavily linked to entry-level jobs in limited areas of occupations (Revella & O' Brien 2005). Increasingly, careful job matches are the basis for employment outcomes, frequently involving negotiated arrangements with employers (Revella & O' Brien 2005). Because of this, the counselor should consider the

consumer's personal and professional goals, especially in deciding to employ the individual so that the outcome can be an even bigger success.

Race-Ethnicity and Employment after Spinal Cord Injury

In 2010, Krause, Saunders and Staten explored the relationship between race-ethnicity and employment after spinal cord injury. The study involved adults who were not students or homemakers and had lingering impairment at least one year post-injury. The study indicated that employment rates have fallen well below those of the general population for individuals with SCI. The main factors in the disparity between employments rates were the severity of the injury, educational attainments (which we will examine in another study), and race-ethnicity. In general, employment rates for African Americans and Hispanics with SCI are lower than those of Caucasians with such injury. Data shows that 12.1 and 7.9% of Hispanics and African Americans respectively were gainfully employed compared with 34.6% of Caucasians after SCI (National SCI Statistical Center (NSCISC) of the US, Krause et al 2010). The differences were not only visible between ethnic groups, but among members of the same ethnic group as well; with African American women reporting more favorable outcomes than men.

The severity of the injury also affected the rate of employment for individuals with SCI. According to Krause, Saunders and Staten, 2010:

> "Data from the same study of the NSCISC (Krause et al., 1999) identified employment rates ranging from a low of 13.7% for participants with C1 through C4 SCI with ASIA grades A through C to a high of 38.7% for those with motor functional injuries (ASIA D, all injury levels)." (Krause et al., 2010, p1, para.4)

Education also played a major role in determining whether individuals were able to find employment after SCI. According to Krause et al, 2010, African Americans had the lowest employment outcomes of the ethnic groups as well as substantially lower education levels. This implies a link between level of education achieved and the likelihood of employment. The study concluded that education is the best single vehicle for better employment outcomes; however other factors which also need to be considered are racial disparities in income, labor market discrimination and residential segregation among other related factors.

Vocational Interest/Opportunities

Another study by Krause and Reed, 2009, examined the vocational interests of individuals with SCI based on education levels before and after injury. The level of education obtained had a direct effect on post injury employment (PIE). The study referred to data from a previous study by Krause in 1996, which showed that employment rates for individuals with SCI increased from 9% to 52% as the level of education increased from 'less than high school" to "more than 16 years of education. This, however, did not take into account education obtained after the injury occurred. As indicated by previous research, education is the main factor in PIE. This particular study expands on these findings by illustrating that those who were able to obtain a bachelor's or master's degree after SCI had employment rates of more than 90%.

The results of Krause and Reed's (2009) research strongly supports the theory that completion of education beyond the high school level after injury was associated with increased chances of employment than education completed before the injury

occurred. Overall, their findings suggest that “even with very high levels of pre-injury educational attainment, post-injury education and training might be needed to maximize PIE.” (p5, para.8). This indicates that even individuals with a strong educational background and extensive training at the time of the injury would benefit from post-injury education as a means of increasing the likelihood of employment.

The ability of persons with SCI to obtain employment after injury is a key area of interest for these persons and their families. The research, by Krause and Reed (2009) indicates that although their vocational interests remain the same after injury, the physical limitations imposed by their disability can decrease the probability of them obtaining employment. Whether or not they are willing to work becomes irrelevant when other outside factors are taken into account. These factors include: ethnic issues, the severity of the injury, and education which is one of the main factors. It is therefore imperative for rehabilitation counselors to find ways to address and minimize the effect of such factors to improve the employment outcomes and standard of living for persons with SCI.

Acts/ Programs that Advocate for Person with disabilities

In addition, to employment and disabilities outcomes here are a couple of acts that advocate for equal rights whether it is on the job, education, or health benefits for individual with disabilities. The first is The 1990 American with Disabilities Act was established to help individuals with disabilities the right to work on the job. The Workforce Investment Act of 1998 is to consolidate workforce preparation and employment services into a unified system of support that is responsive to the need for job seekers, employer, and communities (Parker, Szymanski& Patterson, 2005). The

Ticket to work program is a program that help persons with disabilities who are receiving federal aid from the Social Security Administration (SSA) obtain employment (Mc-Donnall-Capella, 2008).

Rehabilitation Process and Spinal Cord

According to Murphy & King, 2007, persons with SCI have a long journey to return to community participation and achieving an adequate quality of life. Adjusting to new ways to live and learning how to manage and cope with the new changes is a major task. Persons with SCI must learn new skills, behaviors, set new goals, and adapt to new coping methods. According to Carpenter (1994), adjustments occur over a period of years and this lifelong process must be better understood. There is a striking diversity in these accounts regarding perceived quality of life and length of time required for adjustments. Short-term adjustment strategies and behaviors are taught to consumers as part of the rehabilitation process.

Conclusion

Attitudes towards persons with spinal cord injuries have changed over the last years. However, there is still room to adjust attitudes towards person with spinal cord injuries. In this review, it is apparent that there are many areas to consider when providing care, counseling, and vocational opportunities. It is evident that more research can focus on race, ethnicity, and general areas of persons with spinal cord injuries. There is more than one variable to consider so that the attitudes towards this population will be helpful versus stigmatizing or labeling

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