Social Issues in Spinal Cord Injury

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The onset of a spinal cord injury (SCI) creates tremendous changes throughout many aspects of life for individuals and their families. Although rehabilitation programs include psychosocial services to begin to prepare persons with SCI for life after returning home, many of the social and environmental issues are not realized until after discharge from the rehabilitation setting. As lengths of stay have decreased in the last decade, this has become even more of a reality. There is precious little time to learn the basic skills for physical functioning, let alone time for adaptation to the myriad of very real social consequences of SCI. Despite the time constraints, it is imperative that rehabilitation professionals assist the individual and family in exploring resources and alternatives for managing the social impact of SCI.

Family Relationships

SCI creates a devastating impact on the family, as well as for the individual. In addition to the stresses and uncertainties of this life-threatening event for a loved one, the day-to-day responsibilities of caring for a family must also be managed. The disruption of roles, especially during the initial phases post-injury, may create a sense of disequilibrium within the family. When the individual receives rehabilitation services in a distant community, as opposed to the home community, the issues are further magnified. How does a spouse continue to work and manage a family, yet be available and supportive? Are children left with other family members or friends for extended periods of time? How do elderly relatives arrange travel and coordination for visits? How is the balance of support for the family and support for the person with SCI achieved? The emotional needs and the toll of SCI for family members must be acknowledged and addressed not only during the initial rehabilitation process, but throughout the continuum of care as follow-up services are provided. Peer support can assist the individual and family in learning new coping strategies from individuals who have experienced similar catastrophic situations (Treischmann 1987).

The importance of family relationships and social support as they relate to rehabilitation outcomes must also be considered. For those individuals who have burned bridges with family members long ago, there may be limited incentive and motivation to get better in rehabilitation. If the only discharge prospect is nursing home placement because of a lack of family support and the physical inability to live independently, one can understand why some of these individuals do not achieve the rehabilitation outcomes anticipated. Conversely, those individuals with good family support are more likely to adapt well to SCI. In a study of thirty-four individuals in SCI rehabilitation, in which the family was incorporated in the treatment program, Moore et al. reported better outcomes on six of seven dependent measures when compared to the control group without family involvement (Moore 1989).

Marriage and Divorce

A marital or couples relationship is subjected to the ultimate test as a result of SCI. Many times, the spouse may be in a dual role of caregiver and partner. This may lead to conflicts and a negative impact on the couple’s...
relationship (Kreuter 1994). Spouses who serve as caregivers have reported higher levels of depression, physical stress, emotional stress, fatigue, anger, and resentment than the individual with SCI and other spouses who are not caregivers (Weitzenkamp 1997). The importance of respite care and peer support must be acknowledged and appropriately addressed with individuals with SCI and caregivers in an effort to minimize the burden of caregiving. Just as importantly, spouses are in need of ongoing emotional support as a mitigating factor to cope with the stress of dealing with the relationship changes triggered by a SCI (Sheja 2005).

Some studies examining marriages after SCI have found fewer problems and higher levels of marital satisfaction. Crewe et al. (1979) found life satisfaction to be higher in post-injury marriages. Crewe and Krause (1988) conducted a questionnaire follow-up study of 300 subjects and reported that better adjustment in post-injury marriages persisted over time. Kreuter et al. found no differences in pre-injury and post-injury marriages from the perspective of emotional attachment and satisfaction with the marriage. Phelps (2001) found that for married or partnered men with SCI, relationship factors including partner satisfaction and relationship quality are significantly related to sexual satisfaction.

There is also the question of meeting new people and forming new relationships after SCI. Some people have expressed difficulties in meeting new people and attracting a partner while in a wheelchair. Crewe and Krause (1992) found that persons with SCI who get married after their SCI were more active both socially and vocationally while single, when compared to those who remain single. This suggests that those individuals who increase their activity level and do not succumb to social isolation after a SCI increase their chances of finding a partner. The importance of community reintegration during the initial rehab program cannot be emphasized enough to help individuals develop a sense of confidence and appropriate social skills for successful relationships post-injury.

Parenting
Buck and Hohmann (1981,1982) found no difference in the emotional stability of children raised by a disabled father when compared with a group raised by a family without a physical disability. There were also no differences in the child’s adjustment based on severity of SCI, specifically paraplegia versus quadriplegia. They also found that the children of disabled fathers reported more physical and verbal affection from the father than the children of nondisabled fathers reported. Alexander (2002) also found that SCI in mothers does not appear to affect their children adversely in terms of individual adjustment, attitudes toward their parents, self-esteem, gender roles, and family functioning. The onset of SCI often prompts the individual to re-examine values and priorities in life, placing greater emphasis on the importance of a satisfying family life.
Financial Issues
The cost of SCI is indeed a critical social issue that impacts many aspects of the individual’s life post-injury. We would be remiss if the importance of adequate finances to meet basic life needs were not briefly addressed. Treischmann (1987) reports, “Life with a physical disability imposes a financial penalty on the individual and the family because the cost of adaptive equipment, medical expenses, home modifications, and the purchase of services reduces the discretionary income for vacations, new clothing and furniture, recreational equipment and activities, dining out, and socializing. The standard of living for the entire family is reduced in comparison to a family without a disability with the same income.” The financial burden associated with life after SCI cannot be overemphasized. Brown and Giese (1986) report that financial security is a major factor in marriage and divorce rates. Ernst et al. (1988) conducted a survey of 253 long-term survivors of SCI, individuals who were at least 25 years post-injury and a minimum of 45 years of age. Sixty-three percent reported inadequate financial resources to meet their needs, 28 percent reported financial difficulties in obtaining medical equipment, and 19 percent reported that a lack of finances prevented them from leading more active lives. A definite financial impact exists across the spectrum of social issues for individuals with SCI. Recreation and leisure, housing, medications and medical supplies, personal assistance services, transportation, and quality of life all are negatively affected for individuals with inadequate financial resources.

It is essential that rehabilitation professionals assist the individual and family in exploring all of the resources (state, local, federal) that may be of benefit to them. There may also be alternative support opportunities in local communities, such as churches, veteran service organizations, civic clubs, and other nonprofit organizations. Every effort should be made to assist in decreasing the environmental and financial barriers that compromise quality of life. As health professionals, we should also advocate for health policies that eliminate barriers to equitable access to quality services.

Productivity
Although many rehabilitation programs look at return to school or employment as a measure of successful rehabilitation outcomes, for many individuals financial disincentives may counter a return to gainful employment. For those individuals who are injured after they have already retired from the workforce, certainly returning to work would not be a goal or personal choice. As a result, it may be more appropriate to focus on productivity and meaningful use of time rather than employment as we examine outcomes in this area. Webster (1990) defines productivity as follows: “…producing abundantly; fertile; prolific; yielding favorable or useful results; constructive; involved in the creation of goods and services to produce wealth or value.” If we look at productivity after SCI, it seems that a key ingredient is that there are some goal-directed activities for which the individual achieves a sense of accomplishment. This may be in many forms, including employment, vocational rehabilitation and return to school, volunteerism, activities in the home, and recreation and leisure pursuits. Fuhrer et al. (1993) found those individuals with less involvement in employment, school, volunteer work, or other self-improvement activities reported higher degrees of depressive symptomatology.

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Employment
The National SCI Statistics Center reports that 60.5 percent of individuals admitted to a Model SCI Care System reported being employed at the time of their injury. Return to work post-injury is higher for individuals with paraplegia as opposed to tetraplegia. By post-injury year 10, 35.3 percent of individuals with paraplegia are employed, as opposed to 24.3 percent of individuals with tetraplegia (National SCI Statistical Center 1999). Being at a younger age at time of injury (under age 30) and being able to drive independently were identified as key factors in return to employment, as were being in a higher-scale pre-injury occupation and having a higher level of education (Conroy 1998, El Ghatit 1978). The pre-injury physical intensity of the occupation is also predictive of return to employment, with persons having less physically demanding pre-injury occupations more likely to be employed post injury (Tomasson 2000). Lack of transportation and personal assistance needs
are variables that limit employment opportunities for some individuals. Financial disincentives are also very real for many individuals, because they may face the reality of receiving less income from gainful employment than their current disability benefits. As a result, in the veteran population, service-connected veterans who are not at risk of losing financial benefits are more likely to work than nonservice connected veterans.

Vocational rehabilitation services often play a vital role in return to the workforce after SCI. Timing in the provision of these services is especially important. McAweeney et al. (1996) reported that 64 percent of their study participants identified a need for a vocational assessment after SCI. How soon should the individual “adapted” to living with SCI be ready to focus energies on return to school or work? Should vocational rehabilitation be an integral component of the initial rehabilitation experience, or is it better to pursue vocational rehabilitation a year or two after onset of SCI? The key to success is the individual’s readiness, and it is important for rehabilitation professionals to assist in providing basic education about what services may be available, as well as completing a vocational assessment and assisting with referrals for services. Follow-up assessments of vocational readiness must be incorporated in rehabilitation follow-up visits. In view of the evidence that those with lower levels of pre-injury education and onset above age 30 are least likely to return to work or school after their injury, it would seem especially important for rehab professionals to target interventions in vocational rehabilitation programs to assist these individuals. The importance of long-term support in finding a job, as opposed to the traditional approaches in vocational rehabilitation, must also be addressed.

Recreation and Leisure
Participation in meaningful activities is important to all of us if we are to have any level of life satisfaction. After SCI, the individual may find that there are a number of pre-injury recreation and leisure options that either are no longer available or must be modified as a result of physical limitations. Assisting the individual in exploring leisure options after SCI is an important component of the rehabilitation process. Satisfaction with leisure activities has been positively correlated with successful adjustment for individuals with severe disabilities (Crewe1988). Elliott and Shewchuk (1995) found depressive behavior to be directly associated with less leisure activity. McAweeney et al. (1996) reported that 37.1 percent subjects in a study with 122 participants had unmet needs in the area of peer recreation. Kerstin found that physical activity in people with SCI is important for maintaining physical health and for increasing the possibility of living an independent life (Kerstin 2006). The importance of assisting individuals in finding their niche in leisure activities, whether sedentary or physical, cannot be overemphasized. Some individuals elect to become involved in competitive sports; the numbers of participants in the Paralympics and National Wheelchair Games are increasing steadily. The success stories of individuals who participate for the first time and blossom are very common on rehab units, because team activity and competition enhance self-image and a sense of physical and mental well-being. Giola reported that sports activity is associated with better psychological status in persons with SCI, irrespective of teraplegia and paraplegia, and that psychological benefits are not emphasized by demographic factor (Gioia 2006).

Socioeconomic Status and Cultural Issues
How an individual adapts to SCI is inherently correlated with socioeconomic status and cultural background. Although there is little published in the literature on this topic, there is increasing evidence that race and ethnicity, as well as socioeconomic status, affect social participation (Hall 1998). Kerr and Thomp-
son (1992) reported that those with less education and greater financial hardships had difficulties in adjusting to SCI. Education is a strong predictor of employment for African-Americans (James 1993). Individuals from Latino backgrounds reported higher overall depression scores than African-American or Caucasian participants in a recent study reported by Kemp et al. (1999). American Indians reported elevated levels of depression and diminished social well-being in five of eight areas when compared with previous studies on other populations (Krause 1999). Some express concern that the psychometric instruments used in rehabilitation may not be culturally sensitive. This is an issue that researchers must address, because the SCI minority population is expected to grow. It is also especially important for rehabilitation professionals to be sensitive to the cultural differences of patients to ensure that services are designed to address areas where we know individuals from different ethnic backgrounds have increased susceptibility to problems.

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Personal Assistance Services (PAS)

Finding and keeping reliable personal assistance services is consistently listed as one of the most difficult problems for individuals with SCI. Entire textbooks and patient education manuals (DeGraff 1988, Ulincy 1987, PVA 2000) are devoted to this topic, so we will focus briefly on some of the central issues that rehabilitation professionals should be prepared to address during the rehab process. For those individuals who are functionally dependent in some aspects of daily living, it is essential that the rehab program provide training in the management of personal assistance services. Needs can range from personal grooming, toileting, and transfers to grocery shopping, running errands, and housekeeping. Although in some cases the services are provided through home health agencies, with increasing frequency individuals are finding and hiring their own attendants, controlling and directing the services that they need. Frost et al. (1999) report that the demand for personal care assistants has made this position the fastest growing occupation monitored by the government. They also report that the Federal Bureau of Labor Statistics predicts the number of people working in this occupation will increase from 347,000 in 1992 to 827,000 in 2005.

The training programs should at a minimum cover the following topics: defining personal assistance needs; advertising and recruitment of a personal assistant; interviewing skills and strategies; training the personal assistant; managing the employee/employer relationship; and back-up plans. Role play and rehearsals are encouraged to assist in skills development. Rehabilitation professionals also must assist in exploring funding options, because they vary widely from state to state. There is also the issue of the individual's eligibility for various programs. Exchange of services, such as providing a place to stay in lieu of payment, has proven to be a viable alternative for many.

Access to reliable personal assistance services has been fraught with problems. Services are often severely limited as a result of funding sources. The low wages typically provided for these services are a matter of concern to the high turnover rate in agencies, as well as individuals hired directly. There have also been reports of patients being abused or neglected both physically and verbally by the attendant, an especially high-risk concern for individuals who are physically dependent on these individuals and often unable to physically protect themselves. It is important for training programs to strongly address patient rights and the steps to take to deal with potentially abusive situations.

Community Reintegration

Marcel Dijker defined community reintegration as "a term used in human service fields to refer to being part of the mainstream of family and community life, discharging normal roles and responsibilities, and being an active and contributing member of one's social groups and of society as a whole" (Dijker 1998). This definition aptly describes what community reintegration means for individuals following SCI. The term reintegration as opposed to integration is used, because in most cases this is a return to community living after SCI. Resuming old roles or modifying them as needed is a part of the process of adaptation following SCI.

Rehabilitation programs must provide community reentry activities to assist the individual with SCI in testing the community and society and developing the skills needed for success. How to maneuver in a wheelchair, how to open doors, and how to deal with stairs or other architectural barriers are only a few
of the essential mobility skills. How to interact with the non-disabled public and put them at ease may require the development of new skills. Dunn (1997) identified situations of social discomfort for individuals following SCI and advocated for the provision of social skills training to assist in mastering these situations. Social skills training must be a component of patient and family education programs so that there is opportunity to develop skills for the potentially uncomfortable or embarrassing situations often experienced by individuals after SCI. Anecdotally, former patients tell stories of their recall of how to manage new problematic situations when they occur, as a result of the role plays and behavioral rehearsals during their rehabilitation. Song emphasized the importance of individual coping strategies. He found that the social integration of persons with SCI was influenced most by emotion focused coping followed by family support, informational support, perceived stress, and dealing with social barriers (Song 2005).

Community reentry outings prior to discharge from the rehab setting are requisite. Trips to the mall, the grocery store, the movies, and other recreational or sports activities allow patients opportunities to practice the skills they have developed in rehab. Although the activity planned might not be of particular interest to all participants, the value of the community outing should be emphasized in preparation for resuming roles in the community.

Many real activity participation barriers persist in the environment for individuals with disabilities. Wheelchair-accessible housing is limited and long waiting lists are common for handicap-accessible apartments through federal or local programs. People who lack the financial resources to modify their homes for wheelchair accessibility may well experience a significant compromise in quality of life as a result of their living conditions and home environment. Lack of accessible, reliable, and affordable transportation severely limits the activity level of many individuals with SCI. This is especially true for those living in rural areas without access to any public transportation. Several studies report that transportation services are an unmet need for individuals with SCI (McAweeney 1996,
Means 1994, Tate 1994). Lack of transportation was reported to prevent seeking medical care (13 percent); interfere with independence (48 percent); and prevent socialization (31 percent) in a long-term care needs survey conducted by the American Association of SCI Psychologists and Social Workers (Ernst 1988). Patient-education programs also must have a component focusing on community resources and community involvement. It is important for individuals to have a knowledge of available resources, as well as good problem-solving skills to address their unmet needs in the community. Involvement in independent living center activities may afford opportunities for expanding social support networks and developing new skills. Volunteering in the community can provide a sense of satisfaction by giving to others. Participation in peer support groups may help facilitate community reintegration by learning from others who have been there. Gerhart et al. (1992) emphasizes the value of independent living services in adaptation to SCI.

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**Quality of Life**

In recent years, increased attention has been given to the concept of quality of life, as it relates to people with disabilities. A high degree of consensus concurs that quality of life is an important attribute, but defining the concept has not been an easy task. Edlund and Tancredi (1985) postulated several different meanings—fulfillment; the ability to lead a “normal life;” and the social usefulness of an individual, from a rational objective point of view, or from an individualistic, subjective point of view. Hennquist (1982) sees the degree of need satisfaction as the driving principle. Cohen (1982) defines quality of life as the capacity of the individual to realize life plans. Campbell (1976) states, “quality of life is a vague and ethereal entity, something that many people talk about but which nobody very clearly knows what to do about.” Although defining the concept is difficult, determining what contributes to a high level of life satisfaction and quality of life for individuals with SCI has found some interesting results.

Time since injury has been noted to have a positive correlation with life satisfaction in some studies (Krause 1991, Schulz 1985), reflecting that quality of life improves for individuals given time to adapt to SCI. Conversely, McColl and Rosenthal (1994) found the opposite results. Krause and Crewe (1988) reported that older persons are less likely to have an active, rewarding life after SCI than younger persons, suggesting that increased chronologic age has a negative correlation with quality of life. Krause (1998), in a 20-year longitudinal study, found that although there was improvement for participants in the areas of time engaged in employment, sitting tolerance, education, and numbers of hospitalizations, self-rated adjustment decreased. Dijkers (1999) found the highest levels of life satisfaction with individuals who were married, competitively employed, and had the highest levels of education. Lowest satisfaction was reported for individuals who were separated, residing in nursing homes or long-stay hospitals, retired or unemployed, and had the lowest levels of education. This study found a positive correlation of time since injury and satisfaction with life but age had no effect. Individuals from ethnic minorities and with lower levels of education reported less life satisfaction as a result of higher levels of handicap and lower levels of social participation. Leisure satisfaction was found to be the most significant predictor of life satisfaction in another study (Coyle 1994), although there is no correlation between physical activity and subjective well-being (Manns 1999). No correlation was found in relation to level of injury; that is, paraplegia versus tetraplegia (Fuhler 1992).

As one begins to look critically at what variables appear to have direct impact on quality of life, it becomes very obvious that many of the social issues facing individuals after SCI influence their quality of life. Clearly adequate finances, education, employment, leisure, and family support have a critical bearing on one’s satisfaction in life. Whiteneck found that persons with SCI reported, in descending order, the top five environmental barriers to their satisfaction with life as being the natural environment, transportation, need for help in the house, availability of health care, and governmental policies (Whiteneck 2004). The role of ethnicity warrants further investigation, but the impact of handicap as it relates to community reintegration is apparent.

**Aging**

Aging with a spinal cord injury is no longer uncommon. Many individuals live with a spinal cord injury 20, 30, 40, 50 years
post-injury. As a result, these individuals experience many of the same medical conditions and psychosocial issues that same age non-SCI individuals experience, e.g. hypertension, diabetes, congestive heart failure, chronic obstructive pulmonary disease, social isolation, decrease in social functioning. They also experience issues related to their SCI and often times these issues are gender specific. Women with SCI have characterized their aging experience as "accelerated" while men have characterized it as "complicated." Women reported more effects of pain, fatigue, and skin problems and more transportation problems. Men experienced more health problems, more diabetes, and more adaptive equipment changes. (McColl 2004) A 30 year longitudinal study by Krause (2006) indicated changes in life satisfaction, general health, activities, and adjustment over three decades among individuals with SCI. He found a mixed pattern of changes over the 30 years with increases noted during the first 15 year period in sitting tolerance, educational and employment outcomes, satisfaction with employment, and adjustment. Although these changes tended to remain stable during the last 15 years, subtle changes were suggested in some areas, with clear declines noted in terms of diminished sitting tolerance, an increase in the number of physician visits and decreased satisfaction with one’s social life and sex life. Charlifue found that as a person with SCI ages there was a general decline in community integration over time in terms of physical independence, mobility, occupation, social integration, and life satisfaction. (Charlifue 2004)

Conclusion

It is incumbent on rehabilitation professionals who work with individuals with SCI throughout the lifespan to systematically review and assess the status of these key social issues that are so important to quality of life. Life situations change, and we must be prepared to assist our patients with those changes. A divorce for someone with SCI can have a far more devastating impact than for someone who is able-bodied; there may be a need to look for new wheelchair-accessible housing and find a new caregiver in addition to the usual stressors associated with divorce. The death or illness of a parent, if that parent was the primary caregiver, can produce equally devastating consequences. Offering guidance and support in developing a back-up system of care and planning for the future has increased significance in working with individuals with SCI. What might be an inconvenience for an able-bodied person may constitute a genuine psychosocial emergency for someone with SCI. Failure to address and resolve these issues may lead to costly health complications as well.

A version of this article will be published by Demos publishing as a book chapter in "Spinal Cord Medicine"

References
