

Quality of Life Among Aging Spinal Cord Injured Persons: Long Term Rehabilitation Outcomes

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Summary

Until recently, the sequelae of aging with a spinal cord injury (SCI) have not been examined comprehensively by the scientific community. Due to medical advances resulting in extended life expectancies for those with SCI, several investigations have been undertaken. Reviewed in the article are the results of available studies designed to evaluate the quality of life of aging SCI persons and the importance of quality of life to the evaluation of rehabilitation and the importance of quality of life to the evaluation of rehabilitation outcomes. Data indicate that the quality of life enjoyed by those with SCI, young and old, is relatively good and, in the case of older SCI veterans, is actually better than similarly aged able-bodied males.

Key words: Spinal Cord Injury; Geriatrics; Quality of Life

Scope of the problem

Prior to the mid 1940's, a paper on the topic of aging with spinal cord injury (SCI) would have constituted a brief report because typically persons with such injuries did not survive the trauma or, if they did, expired shortly afterwards. When Geisler *et al.*, (1983) examined new mortality rates among persons with SCI, an improved life expectancy was revealed when compared to 1973 study findings (Geisler *et al.*, 1977). There now exist sufficient data to recognise that SCI persons are surviving for increasingly long periods of time with some investigators (e.g. DeVivo *et al.*, 1984) contending that their life expectancy is approaching that of the able-bodied aging population.

While an extended discussion on the issue of aging with a spinal cord injury SCI is now possible, surprisingly little is known about the sequelae of aging with a SCI which is empirically based. Although Trieschmann's recent publication on aging with a disability (1987) had generated considerable interest in the SCI lay and professional communities and has helped to establish a new research agenda with aging as a priority of consideration, there are still very few large, funded initiatives

in the United States on the topic of aging with a SCI. Some of the most significant ongoing projects include a spinal cord mortality and morbidity study (Samsa *et al.*, 1990) which is designed to compare the overall survival and cause-specific mortality and morbidity of SCI veterans with non-SCI veterans; and two National Institute of Disability and Related Research (NIDRR) funded projects. One of these projects is designed to identify and evaluate secondary complications and disabilities which occur in people living many years with SCIs (Menter, 1990), and another is designed to examine the quality of life among aging SCI persons. A third project (Craig Hospital, 1990) is being conducted at the National Spinal Injuries Centre in Aylesbury, UK, and the Regional Spinal Injuries Center in Southport, UK. Funded by the Paralyzed Veterans of America (PVA) Research and Technology Foundation, its purpose is to identify and evaluate secondary complications and disabilities which occur in people living at least 20 years with a SCI. Objectives include the determination of causative factors of complications that are amenable to intervention and developing intervention methodologies to prevent or minimise the severity of these secondary disabilities.

Importance of the problem

Should the needs of older persons with SCIs be of concern to health care planners? While comprising a minute portion of the total disabled population, there are several compelling arguments which can be made warranting heightened interest in them. First, persons with SCIs in general consume enormous quantities of health care services and there is evidence that with increasing age, resource consumption increases further. For example, a recently completed study by Eisenberg and Saltz (1990) found that compared to the able-bodied aging population of veterans receiving assistance from the Department of Veterans Affairs (VA) through its nation-wide system of health care facilities, continuous supervision was being provided to two and one-half times as many SCI veterans as was being provided to other aging community-based samples, three times as many received financial assistance and nursing care, four times as many had help with meal preparation, six times as many received physical therapy, seven times as many received employment-related help and personal care services, and at least eight times as many used supportive devices or prostheses. While comparable information is not yet available for the civilian sector, there is no reason to believe that their civilian counterparts consume fewer resources.

Another reason why aging SCI persons should be of considerable concern to the health care planner is related to the shifting demographics of this group (Eisenberg and Tierney, 1985). Several decades ago, the typical SCI person was described as being young, and most likely male. While the incidence of this injury among females remains relatively low (approximately 20% of all SCI persons), it is no longer accurate to assume that if one had an SCI he or she is young. Examination of several data bases (e.g. DeVivo, 1984; Samsa, 1990) quickly confirms this trend.

A third reason why health care planners need to closely examine the projected impact persons with SCIs will have on limited health care sources is that they tend to utilise informal health support networks (Eisenberg and Saltz, 1990) and are less likely to receive services from multiple sources than the non-SCI elderly. This renders them more vulnerable than other groups should their source of care fail.

Additionally, because the SCI tend to receive primary support from their spouses, parents or other family members (Trieschmann, 1987), their support systems may be tenuous since their primary health care aids also are aging and increasingly less capable of dispensing levels of care previously provided. Also, the level of assistance required becomes greater with advancing age. Activities of daily living once performed independently often cannot be completed without some assistance. As the informal care giver support system becomes more unstable, these cord injured persons who previously were maintained in the community will be seeking long term institutional assistance.

In the past, the majority of SCI persons discharged from government (e.g. VA) medical facilities returned to their homes (Baxley, 1989). However, fewer appear to be doing so each year. For example in 1975 83% of cord injured persons discharged from VA medical facilities returned to their homes, while in 1988 only 74% were discharged home (Table). Concomitantly, the average age of these inpatients rose from 43.3 to 51.4 years during the same time period.

Here again, a trend appears to be developing which suggests greater numbers of SCI persons may be seeking long term institutional care, a development which is bound to significantly impact health care resources.

Quality of life issues

Most commonly, rehabilitation interventions are judged in terms of their functional outcomes. Has the patient's range of motion increased? Is the individual able to brush his/her teeth? Can he/she ambulate without assistance? Is his/her gait steady? Can the individual sustain himself/herself vocationally in the community? While such specific functional outcomes are important to measure and do indeed serve to justify and validate a specific rehabilitation practice or intervention, should

Table Selected data on patients discharged from VAMCs with a spinal cord injury indicator of 'PARA' or 'QUAD': fiscal years 1975-1988

Fiscal year	SCI discharges	Average age (years)	% Discharged to community
1988	11 382	51.4	74.6
1987	10 975	50.7	75.4
1986	11 161	50.1	74.9
1985	10 452	49.7	74.3
1984	9388	48.7	76.4
1983	9365	48.0	74.9
1982	9010	47.3	75.5
1981	8131	46.6	77.5
1980	7114	45.3	80.6
1979	7916	44.8	79.2
1978	7841	44.2	80.4
1977	8041	43.9	81.1
1976	10 176	43.4	83.0
1975	6888	43.3	83.2

If a veteran was discharged more than once during a given fiscal year, then the veteran is counted more than once. (Source: Spinal Cord Injury Service, VA Central Office, Washington, DC.)

such a focused evaluation be considered complete and definitive? Perhaps another set of questions also ought to be asked: Does brushing one's teeth, ambulating without assistance or increasing one's range of motion improve the patient's quality of life? For it is the totality of these factors which ultimately has meaning to the patient.

In his discussion of quality of life assessment issues, Scheer (1980) stated that it is the quality of life that makes us feel life is worth living. This matter-of-fact comment underscores the relatedness of quality of life to health care issues and outcomes. Its utility ranges from clinical decisions to limit treatment (Lo and Jonsen, 1980) to health planning and policy making (Kaplan and Bush, 1982). Its many definitions include a person's ability to perform ordinary activities of daily life (Alexander and Willems, 1981), the ability to realise life plans (Cohen, 1982), as well as objective measures of one's environment (Zautra and Goodhart, 1979). In addition to differences in definition, a wide variety of specific areas of life have been examined in quality of life studies, prescribed in part by the purpose of the particular research.

Notable interest in quality of life assessment has emerged in the field of rehabilitation (e.g. Crewe, 1980; Anderson, 1982). There has been a call for expanding traditional indices of rehabilitation impact beyond changes in functional level or readily identifiable monetary benefits related to returning persons with disabling conditions to the work force (Cardus *et al.*, 1981; Alexander and Willems, 1981). This need for expanding rehabilitation indicators stems from recognition that many non-monetary, nonobjective benefits accrue from rehabilitation, such as enhanced personal dignity and self-esteem (Kottke, 1981; Freed, 1984). Consequently, there is a need to assess the impact of rehabilitation services in a more comprehensive manner.

While several data bases are available which examine quality of life among persons with disabilities, they are exceptionally few in number and focus almost without exception on disabilities other than SCI. These investigators (e.g., Yerxa and Baum, 1968; Titley, 1969; Cameron *et al.*, 1973; Wacker *et al.*, 1983; Weinberg 1984; Fine and Asch, 1988) come to the same conclusion: That quality of life among those with even severely disabling conditions may be as high as those with no disability. They found that despite what appeared to be a poor quality of life by most accepted standards (e.g., high rates of unemployed, dependency on others, etc.), persons with severe disabilities included in their studies reported high levels of satisfaction with their living condition, social activities, and education. Further, in a recent study by Mehnert and associates (1990), it was determined that levels of life satisfaction were found to vary with age among the 675 subjects with various disabilities studied, with those between 16 and 24 years of age reporting the greatest satisfaction and those between 45 and 54 years of age reporting the least. They also found that life satisfaction was related to the age at which the disabling condition occurred; those with disabling conditions acquired before 20 years of age expressed greater life satisfaction than those whose disabilities began later. One of the most comprehensive investigations into quality of life among persons with disabilities is that conducted by the International Center for the Disabled (ICD) in co-operation with the National Council on the Handicapped (1986). This major national survey of 1000 randomly selected disabled persons examined attitudes and experiences about the impact of disability on work, social life, daily activities,

education and personal life. While results of the ICD study reported that disabled Americans expressed less satisfaction with life than their non-disabled counterparts, a majority (69%) of disabled respondents indicated that they were somewhat or very satisfied with life.

While there is a burgeoning literature on the sequelae of aging among the able-bodied and a growing literature examining ramifications of aging on persons with disabilities, there are surprisingly few data based publications available on the topic of quality of life of aging SCI persons. One such study, a recent (1988) Needs Assessment Survey conducted by the PVA of 912 of their members, was designed to identify problems related to members' health promotion, health maintenance and quality of life that might be influenced by education, training or information dissemination. Based on survey findings, a course of remediative corrective actions was recommended. Currently the PVA survey represents one of the two empirically-based inquiries into quality of life issues which employed a large SCI population which is national in scope.

The second study which used a large, nationally-drawn SCI sample was conducted by Eisenberg and Saltz (1990). This study adapted the Older Americans Research and Services Questionnaire (Duke University, 1978) for interviewing a stratified random sample of over 700 community residing SCI veterans. This study was designed to obtain descriptive data on the level of impairment in each of five areas of functioning: social resources, economic resources, mental health, physical and activities of daily living. Differences in older (55+ years) and younger (under 55 years) SCI veterans on mean impairment scores in each of the five areas as well as the impairment in combinations of the five functional areas were examined. A series of analyses were performed to identify patients whose needs were being met and those who expressed need for additional assistance. Utilisation and satisfaction in each of 24 long term care services as well as unmet need for services also were examined in relation to age, economic variables, and sources of care.

Both studies come to similar conclusions: that the quality of life enjoyed by SCI veterans, young and old, is relatively good, and in the case of the older SCI veterans, is actually better than similarly aged able-bodied males (Eisenberg and Saltz, 1990). Medical/physical disorders reported by both samples of SCI subjects as interfering with activities of daily living included chronic pain, urinary tract disorders, and skin infections (e.g. decubiti). In terms of resource utilisation and satisfaction with services, results of both the Eisenberg/Saltz and PVA studies indicate that a significant majority of respondents most often went to a VA facility for treatment. The Eisenberg/Saltz sample reported receiving a variety of services from the VA including assistance with supportive devices and prostheses, medical care, and transportation services. Additionally, respondents seemed pleased with the quality of service provided, although satisfaction was generally higher with informally provided care. In a similar vein, a majority of the PVA study group accessed the VA for care and indicated a preference for receiving this care through the VA. Financial considerations were cited as being a major reason underlying this decision.

Conclusion

Increasing attention is being addressed to the emergence of a cohort of SCI persons

living into older age, and the quality of life experienced by them as well as by others who are aging with a disability. 'Quality of life' as discussed here goes beyond measuring life satisfaction alone; utilisation, satisfaction and unmet need for services in relation to overall functioning must also be taken into account. As data on these dimensions become available, planners and policy-makers will have more definitive information on which to base decisions about the provision of services which optimize the quality of life among those in need.

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