REHABILITATION MEDICINE Adding Life to Years

Spinal Cord Injury
Rehabilitation Adds Life to Years

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The National Spinal Cord Injury Statistical Center data base contains information collected prospectively on 13,763 persons injured since 1973 and treated at model systems of care throughout the United States. These data clearly demonstrate improved neurologic status and independent function in activities of daily living following acute care and rehabilitation for most persons with spinal cord injuries. Decreased lengths of initial and subsequent hospital stays and increased survival rates are also documented. Most persons are discharged to a private residence in the community and remain there. Many complete their educations and return to gainful employment after injury. Spinal cord injury has only a short-term effect on marriage and divorce rates, which appears to dissipate within a few years after injury. Overall, these figures demonstrate the dramatic improvements in length and quality of life achieved by most persons with spinal cord injuries during the past two decades.

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In the early 1970s, the US Department of Health, Education, and Welfare began funding a national network of model regional spinal cord injury (SCI) systems of care based on the concept of an organized continuum of services beginning with primary prevention activities and including emergency medical services, acute care, multidisciplinary rehabilitation, community reintegration, and long-term follow-up. Today, 13 of these systems of care are funded by the National Institute on Disability and Rehabilitation Research within the US Department of Education. From its modest beginnings, the program has evolved to include both individual intrasystem and collaborative research activities, as well as the development of a standardized data base presently housed at the National Spinal Cord Injury Statistical Center (NSCISC).

Information from the NSCISC data base on demographics and medical, vocational, and economic outcomes for persons injured from 1973 to 1985 was published in 1986.[1(pp13-60)] This report updates some of the findings published in that book, which are now more than five years old, and supplements those findings with a review of pertinent literature.

Methods

Since 1973, information on acute care, rehabilitation, and annual follow-up has been collected prospectively on 13,763 persons treated at model systems located throughout the country. This information is submitted on standardized forms in accordance with a detailed set of instructions that is reviewed and revised periodically to enhance both validity and reliability. All data are subjected to several quality control measures, including visual inspection for face validity and computer cross-checking of variables for internal consistency with current and prior information submitted for each patient. No data are used for analysis until they pass quality control.

Current eligibility criteria for a patient to be included in the data base are as follows:

- SCI due to trauma;
- Admission to a model system of care within 60 days of injury (within 365 days of injury for persons injured before October 1986);
- Place of injury and residence within the geographic catchment area of the model system;
- Clinically discernible degree of spinal cord neurologic impairment on admission (spinal column fractures without neurologic deficit are excluded);
- Continual hospitalization from injury to model system admission, except for brief periods no longer than normally accepted as a therapeutic leave of absence;
- Discharge from the model system as either neurologically recovered, completed rehabilitation, or died; and
- Signed informed consent.

Some of the following analyses include all patients in the data base, and others use samples appropriate to the question under consideration. For example, to avoid possible selection bias and confounding by treatment practices at other facilities, some analyses are restricted to persons admitted to the model system within 24 hours of injury. Therefore, the exact number of patients used is identified for each analysis.

Results

Demographics

The mean age for all patients studied is 30.5 years (standard deviation, 14.9). The median age is 26 years; the most common age is 19 years, and 59.3% of patients are between the ages of 16 and 30 years. The effect of age on rehabilitation outcomes for persons with SCI has been documented in detail elsewhere.[2]

Overall, 82.3% of persons enrolled in the NSCISC data base are male. As with most injuries, the incidence rate of

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ABBREVIATIONS USED IN TEXT

DVR = Department of Vocational Rehabilitation
FIM = functional independence measure
NSCISC = National Spinal Cord Injury Statistical Center
SCI = spinal cord injury

SCI is higher among nonwhites.[3,4] Because there are so many more white persons in the United States, however, most persons who sustain these injuries are white, including 71.1% of persons enrolled in the NSCISC data base.

Motor vehicle crashes are the leading cause of SCI (44.8%), followed by falls (21.7%), acts of violence (16.0%), sports (13.0%), and all other causes (4.5%). Almost all spinal cord injuries due to acts of violence are the result of gunshot wounds (89.6%), and most sports-related spinal cord injuries are due to diving accidents (66.5%).

Neurologic Impairment and Recovery

The neurologic level of injury is defined as the most caudal spinal cord segment that tests normal for both sensory and motor function. Overall, 54.2% of persons enrolled in the NSCISC data base had cervical injuries, 35.3% had thoracic injuries, and 10.5% had lumbosacral injuries. More than 42% of persons enrolled in the data base had injuries at the C-4 (13.0%), C-5 (16.0%), or C-6 (12.9%) levels. The next most common level of injury was T-12 (7.5%). Persons with cervical injuries are classified as having quadriplegia, and persons with lower level lesions are classified as having paraplegia. The percentage of cervical injuries is substantially higher among persons enrolled in the NSCISC data base than has been observed in population-based studies[3,5]; thus, it appears that more severely injured persons are disproportionately sent to model systems for treatment whereas less severely injured persons are disproportionately treated at other facilities.

Another important measure of injury severity is the degree of preserved neurologic function below the lesion level. For persons enrolled in the NSCISC data base, the degree of preserved neurologic function was assessed using Frankel's classification system.[6] The five classification categories in this system are as follows:

- **A,** Neurologically complete: no preservation of any motor or sensory function below the zone of partial preservation;
- **B,** Preserved sensation only: preservation of any demonstrable, reproducible sensation excluding phantom sensation below the zone of partial preservation;
- **C,** Preserved motor (nonfunctional): preservation of voluntary motor function that is minimal and performs no useful purpose; minimal is defined as preserved voluntary motor ability below the level of injury where the majority of key muscles test less than grade 3;
- **D,** Preserved motor (functional): preservation of functionally useful voluntary motor function in which the majority of key muscles below the level of injury test at least grade 3; and
- **E,** Complete recovery: complete return of all motor and sensory function, although reflexes may still be abnormal.

For our purposes, the zone of partial preservation is defined as three or fewer neurologic segments at the point of damage to the spinal cord, where there is frequently some preservation of motor or sensory function.

TABLE 1.—*Change in Degree of Preserved Neurologic Function (Frankel Grade) Between Injury and Discharge From Rehabilitation (n = 4,934)*

Frankel Grade	Frankel Grade Changes, %				
	Percent at Injury	Improved	No Change	Declined	Percent at Discharge
Complete (A)	51.9	10.3	89.7	...	47.4
Preserved sensation (B)	13.1	45.2	50.3	4.5	9.3
Motor, nonfunctional (C)	13.1	55.9	41.5	2.6	9.0
Motor, functional (D)	21.9	7.3	90.7	2.0	32.3
Recovery (E)	...	...	...	...	2.0

To assess the degree of neurologic recovery, only persons admitted to the model system within 24 hours of injury for whom complete neurologic data were available at both admission and discharge were used (n = 4,934). Initially, 51.9% of lesions among these persons were neurologically complete, 13.1% were Frankel grade B, 13.1% were Frankel grade C, and 21.9% were Frankel grade D (Table 1). Only 10.3% of persons with complete injuries had neurologic improvement sufficient to alter the Frankel grade by the date of discharge. However, 45.2% of persons with Frankel grade B injuries and 55.9% of persons with Frankel grade C injuries had substantial neurologic improvement of at least one Frankel grade by the date of discharge. Although most persons with Frankel grade D injuries on admission continued to have a measurable degree of impairment at discharge, most showed some improvement, and 7.3% had complete neurologic recovery. Moreover, some persons continued to improve neurologically for as long as 18 months after discharge. Continued neurologic improvement beyond 18 months after injury is relatively rare.

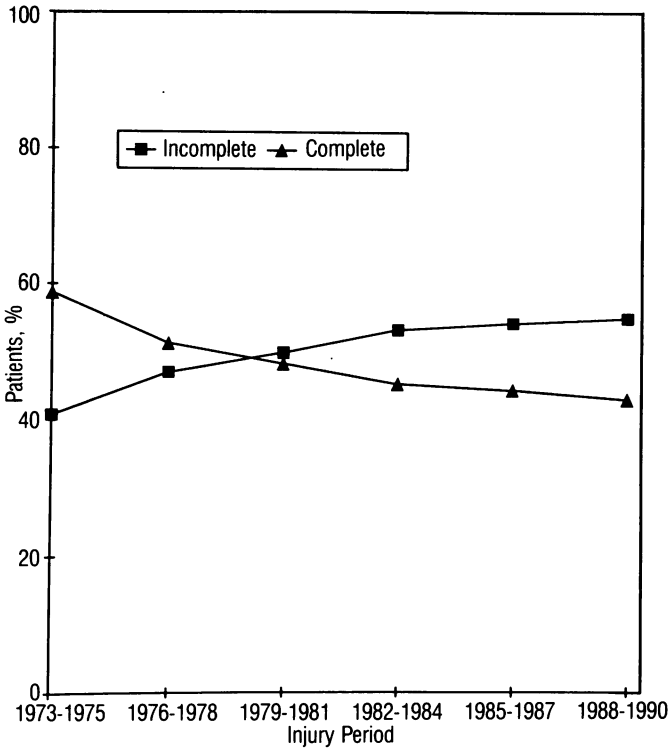

Figure 1.—Neurologic extent of injury at discharge is compared by injury period for all persons enrolled in the national spinal cord injury data base (n = 13,763).

TABLE 2.—*Mean Gain in Total Functional Independence Measure Score Between Admission to and Discharge From Rehabilitation by Neurologic Level and Degree of Injury Completeness (n = 751)*

Time	Total Functional Independence Measure Score: Incomplete Paraplegia, n = 179	Complete Paraplegia, n = 211	Incomplete Quadriplegia, n = 242	Complete Quadriplegia, n = 119
Admission to rehabilitation	73	68	59	47
Discharge from rehabilitation...	110	104	93	62
Gain during rehabilitation	37	36	34	15

The percentage of all persons enrolled in the NSCISC data base with neurologically incomplete lesions at discharge is depicted by injury year in Figure 1. The proportion of persons with neurologically incomplete lesions at discharge increased from 40.8% during 1973-1975 to 55.2% during 1988-1990. This increase in the percentage of neurologically incomplete lesions is undoubtedly the result of secondary prevention activities, such as the use of seat belts to reduce injury severity, improved emergency medical services at the scene of accidents to prevent initially incomplete injuries from becoming complete, and improved methods of medical and surgical management during acute care and rehabilitation. In fact, these figures probably underestimate the actual trend because of the bias in recent years toward disproportionate referral of severely injured persons to model system facilities.

Functional Enhancement

Since October 1988, the functional capability of persons enrolled in the NSCISC data base has been assessed by the functional independence measure (FIM) that is recorded at the time of admission to rehabilitation and at discharge from rehabilitation. The FIM was introduced in 1986 by the Task Force to Develop a Uniform Data System for Medical Rehabilitation and is currently in use at many facilities throughout the country.[7] It is an 18-item, 7-level ordinal scale, with 18 being the lowest possible score and 126 the highest, representing the most independent level of function. Items include feeding, grooming, bathing, dressing upper and lower body, toileting, bladder and bowel control, transfer to bed or chair, toilet, tub or shower, locomotion, stair climbing, communication (comprehension and expression), and social cognition (social interaction, problem solving, and memory).

So far, these data have been collected on 751 persons enrolled in the data base; the results appear in Table 2. The mean total FIM score at rehabilitation admission ranged from 73 for persons with neurologically incomplete paraplegia to 47 for those with neurologically complete quadriplegia. Mean total FIM scores at discharge ranged from 110 to 62 for the same neurologic categories. Mean total FIM score gain was essentially the same for all persons (34 to 37 units) except for those with neurologically complete quadriplegia, who had an average gain of 15 units during rehabilitation. With appropriate outpatient therapy, continued improvement may occur following discharge.

Length of Hospital Stay

The total length of hospital stay for acute care and rehabilitation for persons enrolled in the NSCISC data base appears in Figure 2. Once again, only persons admitted to the model system within 24 hours of injury were included in this analysis to avoid confounding by treatment practices at other facilities. As can be seen, the mean length of hospital stay has decreased substantially since the program began. In 1974, the mean length of hospital stay was 149.6 days for persons with quadriplegia and 122.3 days for persons with paraplegia. By 1989 (the most recent year for which complete data are available), the mean length of hospital stay had decreased to 92.4 days and 74.9 days for persons with quadriplegia and paraplegia, respectively.

Place of Residence

Among persons who completed rehabilitation (n = 13,330), 94.1% were discharged to a private residence within the community, 4.0% were discharged to a nursing home, 1.5% were discharged to another hospital, and 0.4% were discharged to another destination. Moreover, among 1,366 persons who were being followed ten years after injury, 98.0% still resided in private residences within the community.

Level of Education

Of patients enrolled in the NSCISC data base, 55.6% had at least a high school education. Of those admitted between the ages of 18 and 21 years, 67% had at least a high school education, somewhat less than the nationwide norm of 78%.[8(p150)] Approximately 11.7% of the sample had an 8th-grade education or below. These figures represent only the number of grades of school completed; they do not necessarily reflect the level of academic achievement. Overall, 51.2% of those with a 9th- to 11th-grade education successfully completed their high school education within the first five years following injury. Of those with a high school education at the time of injury, 11.6% achieved a higher academic degree within the first five years following injury. An unknown additional percentage may have been pursuing postsecondary education, but our figures do not reflect those persons. Although it would be difficult to determine the percentage of persons with these demographic and socioeconomic characteristics who would be expected to finish high

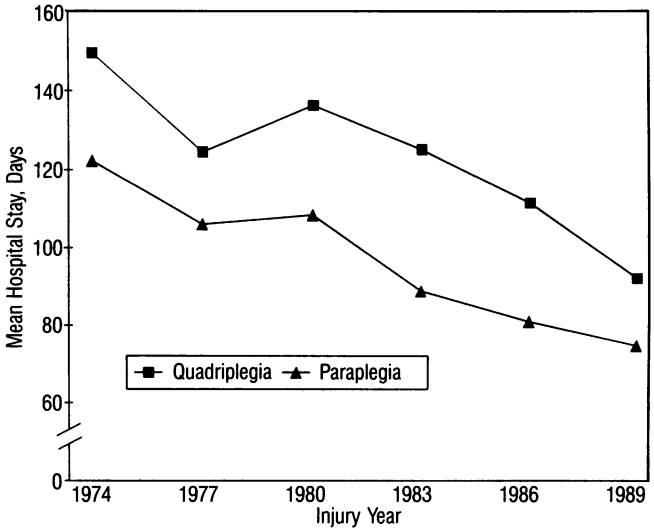

Figure 2.—Mean days of hospital stay for acute care and rehabilitation are compared by injury year and neurologic level of injury for persons admitted within 24 hours of injury to a model system facility (n = 4,889).

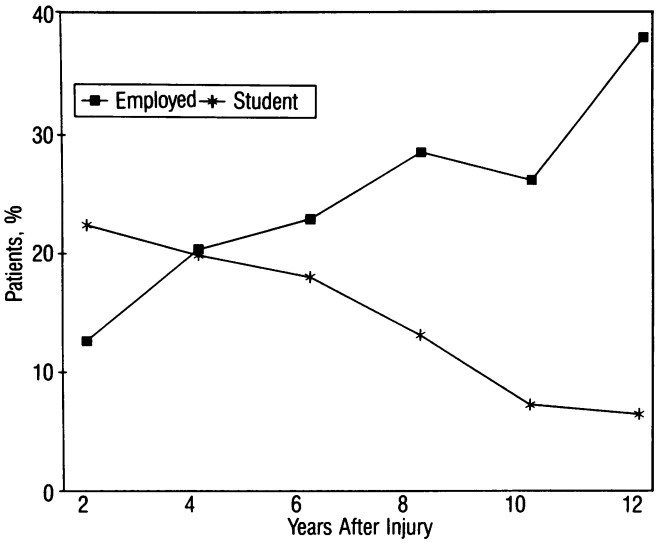

Figure 3.—The percentage of persons with spinal cord injuries between 16 and 59 years of age who are either employed in the competitive labor market or in school each year after injury is shown (n = 6,862).

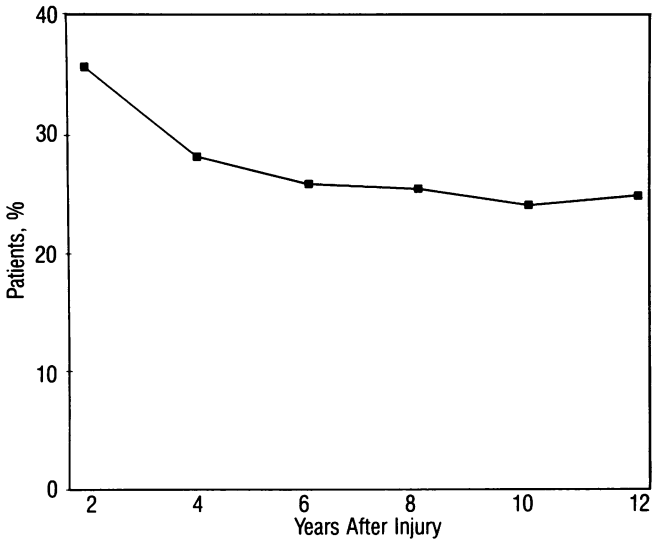

Figure 4.—The percentage of all persons enrolled in the national spinal cord injury data base who are readmitted to a hospital each year after injury is shown.

school or postsecondary degrees or both in this time span, it is clear that many persons with SCI successfully further their education after injury.

Employment

The percentage of persons with SCI who are either employed in the competitive labor market or in school are compared by postinjury year in Figure 3. Only persons between 16 and 59 years of age with known employment status were included in this analysis (n = 6,862). The percentage of employed persons increased from 12.6% 2 years after injury to 38.3% 12 years after injury. Persons who are reemployed shortly after injury virtually always return to the same job with the same employer, whereas those whose reentry into the labor market is delayed usually obtain a different type of job with a different employer, often after appropriate retraining. At the time of injury, 63.7% of these persons were employed and 14.7% were students. Significant predictors of postinjury employment include younger age, male sex, being white, having a higher educational level, being highly motivated, having higher functional ability scores, and being employed before the injury.[9]

Client Status

Only 6.5% of the NSCISC sample were Department of Vocational Rehabilitation (DVR) clients at the time of admission, but this proportion had increased to 37.9% by discharge. There was a steady decline in the percentage of persons with SCI who remained DVR clients over time. By 13 years after injury, only 8.2% were still DVR clients. These data mirror the data presented elsewhere on educational and occupational status. It appears that many persons with SCI seek further education after injury and, with the help of DVR, are able over time to return to some form of gainful employment.

Marital Status

Of persons with SCI who were enrolled in the data base, 53.4% were single at the time of injury, a fact that is not surprising given the young age at which most injuries occur. Most (88%) of those single at injury remained so five years after injury, however, whereas the expected percentage of those remaining single for an age-sex-matched uninjured control group would be 65.3%. Similarly, in the NSCISC sample, the attrition rate of intact marriages at the time of injury is slightly higher than that of an age-sex-matched uninjured control group. Of 1,001 persons with SCI married at the time of injury, 80.7% were still married five years later; the expected percentage remaining married for persons without SCI would be 88.8%. Visual examination of the data suggests that the risk for divorce assumes an inverted U-shaped function during the first five years after injury: little difference between the divorce rates of SCI and matched uninjured groups during the first year after injury, a relatively greater risk for divorce among persons with SCI during the second and third years, and close to the expected rate of divorce during the fourth and fifth years. Although further follow-up is needed, these figures imply that, after an initial period of high risk, divorce rates for persons with SCI may return to normal. Significant risk factors for divorce include young age, being female, being black, having no children, having previous marriages that ended in divorce, and being nonambulatory.[10]

Postdischarge Readmission to Hospital

The percentage of persons with SCI who are readmitted to a hospital each year after injury appears in Figure 4. About a third of all persons with SCI are readmitted to a hospital at least briefly during the rest of the first postinjury year following rehabilitation discharge. During the second year after injury, 35.7% of persons with SCI are rehospitalized. This percentage declines steadily thereafter, however, such that by the 12th postinjury year, only 25% are readmitted. Among persons who are readmitted to a hospital, many have more than one admission, and the average length of stay for all hospital stays during the year is approximately 25 days. Interestingly, there are considerably fewer readmissions and shorter lengths of stay today than there were in the early 1970s.[11] For example, the length of stay per readmission during the second postinjury year has decreased from 15.5 days before 1980 to 11.7 days in 1988.

Survival

The overall 16-year cumulative survival for persons with SCI enrolled in the NSCISC data base is 76.9%. In fact, during the first 12 years after injury, the cumulative survival has increased to slightly more than 88% of what would be expected in the absence of injury.[12] Younger persons, those with paraplegia, and those with neurologically incomplete injuries have even better relative survival rates.[12,13]

Years ago, the leading cause of death for persons with SCI was renal failure. Today, with improved methods of prevention and management, deaths due to renal failure during the first 12 years after injury are uncommon.[14,15] Instead, causes of death with the highest excess mortality are pneumonia; pulmonary embolism; and septicemia due to pressure sores or respiratory or urinary tract infections.[14,15] In fact, life expectancies would approach (but not yet equal) normal if these three causes of death were eliminated.

Discussion

Developing and maintaining a national collaborative SCI data set has allowed us to track changes over time in the basic demographic, neurologic, and medical characteristics of persons with SCI and to document changes in rehabilitation outcomes. Prospects for surviving SCI appear to be improving, and more persons who receive such injuries are left with neurologically incomplete (hence more remaining functional ability) rather than complete injuries. Improvements in postacute care have resulted in a substantial reduction in morbidity and mortality due to renal complications. Our data further suggest that the next focus for improving survival rates should be in the areas of pulmonary function and septicemia. Persons with SCI frequently return to school to further their education, and an increasing number are also able to return to competitive employment over time. The fact that some persons with SCI do not return to work is likely a reflection of a number of factors, such as functional limitations, societal and architectural barriers, and financial disincentives.

Increasingly, questions are being raised about quality of life and aging with an SCI.[16] The primary research focus in the past has been on acute care and rehabilitation, but, increasingly, researchers are studying the short- and long-term outcomes following rehabilitation for this group of persons and their families. Survival is important, but the resulting quality of life is even more important.

For the most part, the developing picture indicates that a high quality of life can be achieved. For example, earlier views that depression was inevitable and often prolonged and severe are being replaced by empiric data suggesting this is not necessarily so.[17,18] Several interventions are now available to improve the mechanics of male sexual functioning and increase the possibilities for fathering children. Access to the world outside the home has been augmented by legislation mandating the removal of architectural barriers. Persons with SCI are therefore more able to return to school and work and to become involved in the social and cultural mainstream.

Adjusting to SCI is an ongoing process, and higher-than-expected divorce rates for the first few years after injury suggest that a toll may be exacted for some persons. A return to or initiation of drug or alcohol abuse or both is also a problem for some persons.[19] Other findings suggest that persons with SCI do best when they have an effective social support system.[20] These findings together suggest that more research is needed on the effects of SCI on care givers and that follow-up contact and social support services may be needed along with medical follow-up.

Persons with SCI, along with other persons with disabilities, are becoming increasingly effective legislative advocates for themselves. The recent passage of the Americans With Disabilities Act is a case in point.[21] The focus of this legislation is on eliminating architectural and attitudinal barriers to full participation in the mainstream of society. In a sense, the message from persons with disabilities is that they are only as handicapped as we make them. If we give them the tools, they will do the rest. Facilitating the feeling of and possibility for control and self-direction is one of the next great challenges for rehabilitation.

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