

Sir Ludwig Guttmann Lecture

Trends in spinal cord injury rehabilitation outcomes from model systems in the United States: 1973–2006

MJ DeVivo^{1,*}

¹Department of Physical Medicine and Rehabilitation, National Spinal Cord Injury Statistical Center, University of Alabama at Birmingham, Spain Rehabilitation Center, Birmingham, AL, USA

Study design: Consecutive case series with 5-year follow-up.

Objective: To evaluate the spinal cord injury (SCI) model systems program in the United States by documenting improvements in treatment outcomes over time.

Setting: SCI model systems throughout the United States.

Methods: Initial data were collected on 24 332 patients injured between 1973 and 2006. Follow-up data were collected on 9225 of these patients 5 years post-injury. All data were grouped by calendar year. Descriptive statistics included means and percentages. Multiple linear or logistic regression was used to assess outcome trends after adjusting for demographics and injury severity.

Results: Acute care and rehabilitation lengths of stay declined dramatically over time ($P < 0.01$). Mean functional independence measure motor score at discharge and gain during rehabilitation decreased, whereas gain per day increased ($P < 0.01$). The probability of neurologic improvement from admission to discharge increased. Odds of medical complications decreased during in-patient treatment, but increased post-discharge ($P < 0.05$). Rehospitalizations declined over time ($P < 0.01$). Community integration improved. First year mortality rates improved, but longer term mortality rates showed no improvement since 1982.

Conclusions: Steady improvements have occurred for many treatment outcomes. Newer and more effective methods of prevention and treatment need to be developed to target those outcomes that have not improved and remain suboptimal.

Sponsorship: This research was supported by grant number H133A011201 from the National Institute on Disability and Rehabilitation Research, Office of Special Education and Rehabilitative Services, United States Department of Education, Washington, DC.

Spinal Cord (2007) 45, 713–721; doi:10.1038/sj.sc.3102026; published online 6 February 2007

Keywords: spinal cord injury; epidemiology; economics; mortality

Introduction

The outlook for most persons who sustain spinal cord injury (SCI) has improved in the last 3 decades. Previous studies that specifically evaluated trends in outcomes have demonstrated reduced in-patient lengths of stay and secondary medical complication rates during in-patient stay, continued high rates of discharge to a private residence, improved survival rates (particularly during the first post-injury year), reduced rehospitaliza-

tion rates, slightly increased post-injury employment rates, and slightly reduced divorce rates.^{1–9} More recently, however, slightly higher post-discharge medical complication rates have been reported, and progress toward improving long-term survival rates has slowed.^{2,4,10}

One element contributing to improved treatment outcomes in the United States has been the model SCI care system program of comprehensive, multidisciplinary, systematic care established in the early 1970s and sponsored by what is now known as the National Institute on Disability and Rehabilitation Research (NIDRR). This program has evolved from a single research and demonstration project into 16 model systems of care that provide an important national resource for the improved rehabilitation of persons

*Correspondence: MJ DeVivo, Department of Physical Medicine and Rehabilitation, National Spinal Cord Injury Statistical Center, University of Alabama at Birmingham, Spain Rehabilitation Center, Room 514, 1717 Sixth Avenue South, Birmingham, AL 35233-7330, USA

The Sir Ludwig Guttmann Lecture, 45th International Spinal Cord Society Annual Scientific Meeting, Boston, Massachusetts, USA, June 24–28, 2006.

with catastrophic injuries. Almost from the beginning, a national standardized data collection effort has been a part of this program so that the cost effectiveness of systematic care could be demonstrated. The present repository of this database is the National Spinal Cord Injury Statistical Center (NSCISC) located at the University of Alabama at Birmingham.^{11,12}

One way to evaluate the effectiveness of the model system program is to compare the experiences of persons treated in its early stages with those of similar persons treated more recently. Therefore, the purpose of this study was to conduct a comprehensive review of the NSCISC database to identify any long-term trends in treatment practices, costs, and outcomes that have occurred as the model system program has grown and evolved. Trends in patient demographics, causes of injury, and levels of injury severity were also evaluated for two reasons. One reason is that these patient characteristics are also related to each of the treatment outcomes being considered and therefore, trends in these characteristics could confound the analysis of outcome trends if not properly controlled. The second reason is that an accurate definition of the current target population is essential for planning and evaluating the effectiveness of primary prevention programs conducted by the model systems and other interested organizations.^{1,13-15}

Methods

Study population

The study population included 24 332 persons who were treated at any model SCI care system in the United States within 1 year of injury between 1973 and 2006 and enrolled in the NSCISC database. Additional eligibility criteria and their changes over time have been documented previously.^{11,12} Evaluations were conducted 5 years post-injury on 9225 of these persons. Reasons for not conducting a fifth annual evaluation include death or complete recovery during the first 5 years, injuries during 2001–2006 that are not yet 5 years old, injuries during the last 5 years of funding of several model systems that dropped out of the program at various times during the past 3 decades, and losses to follow-up because of inability to locate or refusal to participate. Among current model systems, the fifth annual loss to follow-up rate in 2006 is 30%.

Data collection

All data were collected prospectively by individuals located at each model system using a standard protocol. Information on the initial acute care and rehabilitation period is collected either directly from the care providers or through record review at discharge. Follow-up interviews are usually conducted by phone; however, some data collection occurs by mail, in person, or a combination of methods. Follow-up data collection occurs 1 year post-injury, 5 years post-injury, and every 5 years thereafter. All data are sent to the NSCISC at

the University of Alabama at Birmingham for maintenance, quality control, and analysis. Additional details of the data collection and quality control procedures have been reported previously.^{11,12}

Measures

Demographic information contained in the NSCISC database and used in this study includes age, gender, race/ethnicity, educational level, and employment status at time of injury and annual evaluation. Injury severity is assessed by using the most current version of the International Standards for Neurological Classification at model system admission, discharge, and annual evaluation (if the annual evaluation was performed in person).¹⁶ Measures of injury severity used in this study include the neurologic level of injury, American Spinal Injury Association (ASIA) Impairment Scale of injury completeness, and whether the person is ventilator-dependent at least part-time on a daily basis. Additional information assessed at the time of discharge from the model system includes length of stay, charges, and occurrence of certain medical complications and surgical procedures during acute care and rehabilitation.

The NSCISC database contains a variety of treatment outcome measures that have been added over time. Documentation of the place of discharge and current place of residence at annual follow-up, number of rehospitalizations during the follow-up year, number of days rehospitalized during the follow-up year, and number of days spent in a nursing home during the follow-up year has been included in the database since its inception.

Data on selected medical complications that occurred during acute care and rehabilitation were added to the database in 1996, whereas complications occurring during the follow-up year were added to the database in 1986. Before those dates, the data collection methods and complication definitions were different than they are today, making trend analysis inappropriate.

To enhance reliability of data, each complication has a specific definition to be used by all model systems for reporting purposes. Pneumonia is defined as a state of lung tissue inflammation of infectious etiology with radiographic demonstration of parenchymal disease. Pulmonary embolism is defined as a condition resulting when a pulmonary artery becomes acutely obstructed by a clot formed upstream from the pulmonary arterial vascular tree requiring definitive anticoagulation therapy, with documentation by either clinical impression or confirmation by ventilation–perfusion lung scan or pulmonary angiogram. Deep vein thrombosis (DVT) is defined as an occlusion of the venous system of a lower extremity with definitive therapy instituted and confirmed by either I-125-labeled fibrinogen uptake, impedance plethysmography, Doppler, or venography. Renal stones are defined as abnormal concretions in either the kidney or ureter that are documented by radiographic evidence. For follow-up evaluations, the complication must have occurred during the previous

year, but does not have to be present at the time of the annual evaluation.

The motor component (first 13 items) of the functional independence measure (motor FIM) assessed at rehabilitation admission and discharge was added to the database in 1988.^{17,18} Follow-up assessment of the motor FIM was added to the database in 1996.¹⁹

Five subscales of the Short Form of the Craig Handicap Assessment and Reporting Technique (CHART-SF) were added to the annual follow-up portion of the database as a measure of community integration in 1996.^{20,21} These subscales included physical independence, mobility, social integration, occupational independence, and economic self-sufficiency, with scores ranging from zero (none) to 100 (normal for the general non-spinal injured population).

The five-item measure of life satisfaction proposed by Diener *et al*²² was added to the follow-up portion of the database in 1996. Question 1 from the Medical Outcomes Survey (SF-36) that asks persons to rate their current overall health on a five-point scale from excellent (score = 1) to poor (score = 5) was also added to the follow-up portion of the database in 1996.²³

Outcome measures added to the annual evaluation questionnaire in 2000 included the nine-item Patient Health Questionnaire (PHQ-9) measure of depression, an assessment of the usual level of pain over the past 4 weeks on a 0 (no pain) to 10 (so severe you could not stand it) scale, and the CAGE questionnaire (CAGE is an acronym formed from the key words in each of the four questions: Cut down, Annoyed, Guilty, Eye-opener), as a measure of alcohol abuse on a 0–4 scale with higher scores indicating more alcohol abuse.^{24–29}

Statistical analysis

All data were grouped into six-time periods (1973–1981, 1982–1986, 1987–1991, 1992–1996, 1997–2001, 2002–2006). Outcomes were assessed at model system discharge and 5 years post-injury. Frequencies and percentages were determined for each categorical variable and compared across time periods by the χ^2 test. Means (\bar{X}) were determined for each interval level variable and compared across time periods by analysis of variance (ANOVA). Multiple logistic or linear regression was used to control for the confounding effects of secular trends in age, gender, race, injury severity, and model system where treatment occurred on the observed trends in outcomes over time. For each regression analysis, either the 1973–1981 time period or the first time period during which the outcome measure was included in the database was used as the referent category for comparison to all other individual time periods. For linear regressions, each time period coefficient (β) represents the adjusted difference in means for that outcome measure between that time period and the referent time period. For logistic regressions, adjusted odds ratios (OR) were calculated for each time period compared to the referent time period for each outcome. Analyses of in-patient medical

complications, changes in neurologic status between injury and discharge, acute care and rehabilitation lengths of stay, and charges were limited to patients admitted to the model system within 24 h of injury. All acute care and rehabilitation charges were adjusted to constant 2005 dollars by using the Medical Care component of the Consumer Price Index.

Results

Characteristics of the study population at injury appear in Table 1. Mean age increased from 28.8 years in 1973–1981 to 38.3 years in 2002–2006 ($P < 0.0001$). The percentage of male patients declined slightly from 81.6 to 77.6 ($P < 0.0001$). The percentage of African Americans peaked during 1992–1996 along with the percentage of injuries because of acts of violence ($P < 0.0001$). The percentage of injuries due to falls has increased steadily over time ($P < 0.0001$). Average education levels are higher since 2002 relative to earlier time periods ($P < 0.0001$). The percentage of high tetraplegia (C1–C4) has increased ($P < 0.0001$), whereas the percentage of neurologically complete injuries has decreased over time ($P < 0.0001$). Ventilator use increased until 1997–2001, then declined ($P < 0.0001$). These findings are all consistent with prior studies.^{13,14}

After adjusting for trends in age, sex, race, and injury severity, acute care length of stay decreased by 11.4 days and rehabilitation length of stay decreased by 62.6 days over the past 30 years (Table 2) ($P < 0.01$). However, adjusted mean acute care charges in constant 2005 dollars increased by \$127 102 ($P < 0.01$), and adjusted mean acute care charges per day increased by \$8948 ($P < 0.01$). Adjusted mean rehabilitation charges decreased by \$44 725 ($P < 0.01$), but adjusted mean rehabilitation charges per day increased by \$1018 ($P < 0.01$). Adjusted mean days rehospitalized decreased by as much as 7.8 days during 1992–1996, but has since increased slightly ($P < 0.01$). These findings are consistent with and extend the time frame of previous studies.^{5,8}

The mean number of days spent in a nursing home during post-injury year 5 was 11.1 since 2002 compared to 11.0 from 1973 to 1981. However, the study population is now almost 10 years older and more likely to have a high cervical injury level. When those trends are taken into account, the adjusted mean number of days spent in a nursing home was reduced by 4.6 days over the 30-year study period ($P = 0.04$).

FIM motor scores at in-patient rehabilitation admission and discharge decreased significantly during the past 20 years (Table 3) ($P < 0.0001$). The adjusted mean gain in FIM motor score decreased by 3.38 points ($P < 0.01$). However, the reduced gains were due entirely to reduced rehabilitation length of stay, because rehabilitation efficiency, as measured by the FIM motor score gain per day, actually increased significantly over time ($P < 0.01$).

Table 4 documents the change in ASIA Impairment Scale between injury and discharge for the latest time

Table 1 Characteristics of initial study population by calendar year ($n=24\,332$)

Characteristic	1973–1981	1982–1986	1987–1991	1992–1996	1997–2001	2002–2006
Age (\bar{X} , years)	28.8	31.5	33.3	34.7	37.0	38.3
Male (%)	81.6	83.8	80.6	81.3	78.7	77.6
<i>Race/ethnicity</i>						
White (%)	75.5	68.6	60.3	55.6	62.4	61.6
African American (%)	14.5	20.9	27.6	29.0	23.9	23.5
Hispanic (%)	7.1	7.7	9.6	12.6	10.5	12.8
Other race (%)	2.9	2.8	2.5	2.8	3.2	2.1
<i>Etiology of injury</i>						
Motor vehicle crash (%)	48.2	45.5	42.7	38.7	45.9	46.8
Violence (%)	14.2	16.8	22.4	27.8	16.6	14.0
Falls (%)	15.9	19.1	20.7	20.9	23.7	24.0
Sports (%)	14.6	12.7	8.9	6.7	7.6	9.1
Other etiology (%)	7.1	5.9	5.4	5.8	6.2	6.1
≥High school graduate (%)	58.0	61.2	58.6	60.8	69.7	77.3
<i>Injury level at discharge</i>						
C1–C4 (%)	15.3	18.9	15.9	19.6	24.4	23.1
C5–C8 (%)	38.1	35.4	34.8	29.1	29.0	32.4
T1–S5 (%)	45.6	45.1	48.9	50.7	46.0	43.9
Normal (%)	1.0	0.6	0.4	0.6	0.6	0.6
<i>ASIA impairment scale at discharge</i>						
A (%)	52.0	46.9	44.3	48.4	47.2	43.2
B (%)	9.9	11.1	11.2	10.0	11.2	11.8
C (%)	8.4	10.5	11.9	15.1	15.4	14.8
D (%)	28.7	30.9	32.2	25.9	25.6	29.6
E (%)	1.0	0.6	0.4	0.6	0.6	0.6
<i>Ventilator use</i>						
In-patient (%)	9.8	13.6	18.6	22.4	25.1	14.7
At discharge (%)	2.6	3.5	3.1	4.6	5.5	4.2

period (2002–2006). Among injuries that were initially neurologically complete, 15.1% became incomplete by discharge. Among ASIA B injuries, 45.2% improved at least one grade, whereas 54.3% of ASIA C injuries improved to at least ASIA D injuries. Trends in the likelihood of neurologic improvement over time are difficult to evaluate because of changing definitions of each ASIA Impairment Scale grade. Nonetheless, by comparison with results in Table 4, from 1973 to 1981, only 8.8% of neurologically complete injuries became incomplete. Therefore, there appear to have been some gains in the likelihood of neurologic improvement over the past 30 years.

Likelihoods of developing medical complications during initial hospitalization and during the fifth post-injury year by calendar year appear in Table 5. The risk of both pneumonia and DVT decreased significantly over time. After adjustment for confounders by logistic regression, the odds of developing pneumonia and DVT were reduced by 64 and 51%, respectively, during initial hospitalization in 2002–2006 relative to 1992–1996 ($P<0.01$). There was a statistically insignificant increase (42%) in adjusted odds of pulmonary emboli during initial hospitalization over this same time period.

The risk of DVT, skin flap surgery for pressure sores, renal stones, and depression increased significantly during the fifth post-injury year (Table 5). During 2002–2006, adjusted OR for developing DVT, renal stones, depression, and having skin flap surgery were 6.50, 1.93, 1.74, and 2.02, respectively, compared to the referent time period ($P<0.01$). Increases in the adjusted OR for pneumonia (OR=1.21) and pulmonary emboli (OR=3.07) during 2002–2006 were not statistically significant. Mean pain score also increased slightly ($P=0.07$).

Mean CHART subscale scores 5 years post-injury by calendar year appear in Table 6. The adjusted mean CHART physical independence score increased by 4.1 points ($P=0.02$). Similar gains were noted in the adjusted mean scores for occupational independence (4.3 points, $P=0.04$), social integration (4.8 points, $P<0.01$), and economic self-sufficiency (6.9 points, $P=0.01$).

Table 7 shows the adjusted odds of dying in the first post-injury year and the adjusted annual odds of dying in all subsequent post-injury years combined by calendar year. Since 2002, the odds of dying during the first post-injury year are only 44% as high as they

Table 2 Lengths of stay and charges (adjusted to \$2005) for acute care, rehabilitation, and rehospitalizations by calendar year

	1973–1981	1982–1986	1987–1991	1992–1996	1997–2001	2002–2006
<i>Acute care days</i>						
\bar{X}	28	27	22	20	19	20
β	0	-0.9	-7.6	-10.3	-13.1	-11.4
<i>Acute care \$</i>						
\bar{X}	72 507	112 614	120 424	145 671	147 504	204 441
β	0	37 386	46 809	67 649	64 706	127 102
<i>Acute care \$/day</i>						
\bar{X}	2613	3824	5282	7362	8666	11 444
β	0	1185	2712	4847	6155	8948
<i>Rehabilitation days</i>						
\bar{X}	108	89	80	59	50	45
β	0	-18.8	-25.8	-48.4	-58.7	-62.6
<i>Rehabilitation \$</i>						
\bar{X}	146 957	148 590	151 628	129 947	122 061	107 325
β	0	-2480	5012	-21 286	-34 898	-44 725
<i>Rehabilitation \$/day</i>						
\bar{X}	1380	1730	1958	2297	2400	2471
β	0	329	560	864	943	1018
<i>Rehospitalization days, year 5</i>						
\bar{X}	11.0	7.8	5.2	3.4	4.1	5.7
β	0	-2.7	-5.6	-7.8	-7.4	-5.7

Table 3 FIM motor score by calendar year

	1987–1991	1992–1996	1997–2001	2002–2006
Admission (\bar{X})	28	28	25	25
Discharge (\bar{X})	62	60	55	52
<i>Gain</i>				
\bar{X}	34	32	30	27
β	0	0.10	-1.20	-3.38
<i>Gain/day</i>				
\bar{X}	0.69	0.86	0.91	0.89
β	0	0.23	0.34	0.29

were during 1973–1981 ($P < 0.0001$). This finding is consistent with several previous studies that also showed a strong trend toward improving first post-injury year survival rates.^{1–4}

After the first post-injury year, there are no significant differences in annual odds of dying as time post-injury advances, thereby allowing those years to be combined. Beyond the first post-injury year, there was an initial drop of 20% in the annual odds of dying ($P = 0.0009$). However, no further progress has been made in long-term annual mortality rates over the past 20 years. These findings are consistent with two recent studies of this topic.^{2,4} Applying the full mortality model (data not shown) to the case of a 20-year-old white male injured in

Table 4 ASIA Impairment Scale at injury and discharge, 2002–2006

<i>Injury</i>	<i>Discharge (%)</i>					<i>Total</i>
	<i>A</i>	<i>B</i>	<i>C</i>	<i>D</i>	<i>E</i>	
A	84.9	8.2	4.6	2.1	0.2	100.0
B	6.7	48.1	25.9	19.3	0.0	100.0
C	2.7	3.3	39.6	53.8	0.5	100.0
D	0.0	1.0	1.0	93.2	4.7	100.0

a motor vehicle crash who has a C5 ASIA A injury and is not ventilator-dependent, life expectancy was 33.5 years for a new injury in 1976 and 36.9 years for a new injury in 2006. On the first anniversary of injury, life expectancy for that same person was 33.8 years in 1976 and 36.9 years in 2006.

There were no statistically significant trends in place of discharge, self-reported health, life satisfaction, CHART Mobility score, or the CAGE. During the latest time period, 88.1% of patients were discharged to a private residence. Five years post-injury, mean self-reported health score was 2.6 (a score of 2 is 'very good' and a score of 3 is 'good'), mean life satisfaction score was 20.4 (about average on a scale of 5–35), mean CHART Mobility score was 78.1, and mean CAGE score was 0.2.

Table 5 Secondary medical complications by calendar year

Complication	1982–1986	1987–1991	1992–1996	1997–2001	2002–2006
<i>Pneumonia (%)</i>					
In-patient	—	—	42.3	36.8	22.0
Year 5	4.8	2.5	3.5	3.6	4.1
<i>DVT (%)</i>					
In-patient	—	—	14.5	12.4	7.7
Year 5	0.6	0.4	0.7	1.2	2.6
<i>Pulmonary embolism (%)</i>					
In-patient	—	—	2.8	3.5	3.9
Year 5	0.0	0.2	0.0	0.4	0.7
Flap surgery, year 5 (%)	3.2	3.9	3.3	3.1	6.1
Renal stone, year 5 (%)	1.3	2.0	1.8	2.3	3.4
Pain, year 5 (\bar{X})	—	—	—	4.1	4.5
Depression, year 5 (%)	—	—	—	12.4	19.9

Table 6 CHART scores 5 years post-injury by calendar year

	1992–1996	1997–2001	2002–2006
<i>Physical independence</i>			
\bar{X}	73.4	77.6	77.0
β	0	4.1	4.1
<i>Occupational independence</i>			
\bar{X}	57.1	57.6	60.1
β	0	1.1	4.3
<i>Social integration</i>			
\bar{X}	82.9	86.7	87.3
β	0	4.0	4.8
<i>Economic self-sufficiency</i>			
\bar{X}	59.3	69.8	68.4
β	0	9.6	6.9

Table 7 Adjusted odds of dying in year 1 and subsequent post-injury years by calendar year

Year	Year 1		Later years	
	Odds ratio	P	Odds ratio	P
1973–1981	1.00	—	1.00	—
1982–1986	0.87	0.47	0.80	0.0009
1987–1991	0.61	0.02	0.80	0.0005
1992–1996	0.54	0.0006	0.81	0.0005
1997–2001	0.55	<0.0001	0.93	0.24
2002–2006	0.44	<0.0001	0.80	0.0002

Post-injury employment rates continue to be low, with only slight improvement noted. During 1973–1981, 23.6% of patients were employed 5 years after injury compared with 25.2% since 2002. One recent study of

post-injury employment rates and work life expectancies also found a slight improvement as a result of passage of the Americans with Disabilities Act.³⁰

Discussion

Most measures of short-term rehabilitation treatment outcomes have improved considerably over time since the model system program began 3 decades ago. Patients return home much faster than in the past. Mean adjusted acute care length of stay has been reduced by 11.4 days, whereas mean adjusted rehabilitation length of stay has been reduced by 62.6 days. The percentage of patients discharged home has not been adversely affected by the reduced lengths of stay. Levels of functional independence at discharge have been reduced as a result of the reduced rehabilitation days. However, in-patient rehabilitation efficiency has substantially increased. Most patients now receive additional outpatient physical and occupational therapy to help them reach the levels of functional independence formerly achieved while still an in-patient.³¹ Studies of the cost efficiency of this combined in-patient and outpatient rehabilitation approach are needed to assess its potential benefits when compared to a more traditional in-patient only approach.

Proportions of patients developing in-patient medical complications have also generally declined. It is possible that lower complication frequencies make it easier to discharge patients more quickly, but complication frequencies may be lower simply because of reduced time at risk as an in-patient. Studies that actually count episodes of each complication and determine complication rates per day hospitalized would be needed to clarify the relationship between lower percentages of patients developing complications and reduced lengths of stay found in this study. The NSCISC database does not have information on the number of times each complication occurs for each patient.

Nonetheless, reduced occurrences of medical complications have clearly had an impact on the dramatically improving short-term survival rates observed in this study. Slightly better odds of neurologic improvement may also be a factor in improving the odds of short-term survival. However, changing definitions of complete and incomplete injuries over time make assessing trends in neurologic improvement tenuous.

There have also been long-term improvements in several measures of community integration, including physical independence, social integration, occupational independence, and economic self-sufficiency. Given the small improvements in employment rates, it would appear that improvements in occupational independence are due to increasing hours of employment for those who return to work or to increasing hours of homemaker and volunteer activities that are also included in the assessment of CHART measure of occupational independence. Additional item analyses of the CHART would be needed to assess this issue definitively.

Our inability to make gains in long-term survival since 1982 is undoubtedly related to the increased annual risks of medical complications observed in this study. Pneumonia remains the leading cause of death among people with SCI,^{2,32,33} and although the trend was not quite statistically significant, the adjusted odds of pneumonia in year 5 were increased by 21%. Other leading causes of death include septicemia (often caused by pneumonia, urinary tract infections, or pressure sores), pulmonary emboli, renal failure (often secondary to renal stone formation), and suicide.^{32,33} In this study, the adjusted odds of flap surgery, renal stones, pulmonary emboli, and depression in year 5 all increased over the past decades. Pain levels also increased slightly.

These increased odds of medical complications in year 5 make the reduced rate of rehospitalization and mean days rehospitalized even more impressive. Clearly, many medical complications that were previously treated by hospitalization are now being treated on an outpatient basis, no doubt partly because of pressure from third-party payors to reduce costs of care.

Study findings related to life expectancy are particularly interesting. Given that life expectancy is now the same for a 20-year-old patient at injury as it is for a 20-year-old patient who was injured 1 year ago at age 19, it appears that the high first year mortality rate reported in previous studies has decreased so much that there is no longer a meaningful difference between year 1 and later years for most patients.^{2,33} However, there is likely still a difference in year 1 *versus* later year survival rates for some patients such as ventilator-dependent patients.³

The lack of progress toward improving long-term annual mortality rates is disturbing given that general population life expectancies for 20-year-old individuals are a few years higher today than they were in the early 1980s. However, when the increased adjusted odds of developing medical complications are considered, it would seem at least that case fatality rates for these

complications are improving. Otherwise, overall annual mortality rates would actually be increasing. Therefore, further increases in life expectancy would seem to depend more on developing better methods of prevention than better methods of treatment.

No significant improvements were noted in self-reported health or life satisfaction 5 years post-injury. Given increased odds of developing medical complications, increased mean pain levels, and increased odds of developing depression during post-injury year 5, this lack of improvement in self-reported health or life satisfaction is not surprising. These more global measures of treatment outcome will likely only get better with improved methods of prevention and treatment of medical and psychosocial complications that occur post-discharge.

Study limitations

This study has several limitations. First, the NSCISC database is not population-based, thereby precluding calculation of incidence rates and limiting possible analyses to trends in proportions. The database is also slightly biased in that African Americans, injuries caused by acts of violence, more severe injuries, men, and persons over age 60 years at injury are slightly overrepresented in the NSCISC database.^{13,34,35} This bias will affect each outcome differently depending on the relative strength of association of each of these risk factors with each individual outcome. There is no reason to believe that relationships between risk factors and outcomes are different for model system patients than patients treated elsewhere, and no reason to believe that the trend in model system outcomes is biased. However, several studies have shown that lengths of hospitalization, costs of care, mortality rates, and medical complication rates are lower, whereas functional outcomes are better for patients treated at model systems than for patients treated elsewhere.^{36–39} Therefore, given that only 10–15% of all new SCI in the United States each year are treated at model systems, overall outcomes are probably slightly overestimated by this study.¹¹ Moreover, it is possible that trends in model system treatment outcomes are not representative of trends in outcomes for patients treated elsewhere.

Losses to follow-up may also bias study results. Persons who are lost to follow-up are disproportionately less severely impaired.⁴⁰ Therefore, overall outcomes 5 years post-injury are probably slightly better than reflected in this study. However, the bias due to losses to follow-up has been relatively consistent over time, so analysis of trends should not be adversely affected.

Univariate results are confounded to varying degrees by changes in the proportion of patients submitted by each model system over time, due in part to changes in the identities of the model systems themselves.^{11,12} Model systems have different case mixes, treatment protocols, and outcomes. However, the potential confounding effects of these changes in model systems were controlled in the multivariate models.

Some overall results 5 years after injury might have been affected by differences in the method of data collection (in person, by phone, or mail). However, there are no statistically significant trends in the methods of data collection over time. Therefore, use of different follow-up data collection methods cannot confound the analysis of trends in outcomes.

Some analyses of trends, most notably in neurologic status, are confounded by changing definitions and standards of classification, thereby limiting the ability to draw meaningful inferences. Other variables were only recently added to the database, thus limiting the ability to assess trends. Other possible confounders not included in the database could affect the analyses of trends, potentially leading to false conclusions. Finally, trends in post-injury year 5 may not be representative of trends in other post-injury years. Additional analyses of other post-injury years would be needed to confirm the trends found in this study.

Conclusion

Slow and steady improvements have occurred for many medical and psychosocial measures of treatment outcome assessed at in-patient discharge and 5 years post-injury. Given the diverse nature of treatment outcomes assessed in this study, results of interest should be individually confirmed by more rigorous studies of each individual treatment outcome that would allow adjustment for all relevant potential confounders, consideration of within subject trends rather than cross-sectional trends, and inclusion of additional follow-up years. Nonetheless, these findings provide broad evidence of model system treatment effectiveness. Newer and more effective methods of prevention and treatment may need to be developed to target those outcomes that have not improved and remain suboptimal.

References

- DeVivo MJ, Rutt RD, Black KJ, Go BK, Stover SL. Trends in spinal cord injury demographics and treatment outcomes between 1973 and 1986. *Arch Phys Med Rehabil* 1992; **73**: 424–430.
- DeVivo MJ, Krause JS, Lammertse DP. Recent trends in mortality and causes of death among persons with spinal cord injury. *Arch Phys Med Rehabil* 1999; **80**: 1411–1419.
- DeVivo MJ, Ivie CS. Life expectancy of ventilator-dependent persons with spinal cord injuries. *Chest* 1995; **108**: 226–232.
- Strauss D, Paculdo D, DeVivo MJ, Shavelle R. Trends in life expectancy after spinal cord injury. *Arch Phys Med Rehabil* 2006; **87**: 1079–1085.
- Fiedler IG, Laud PW, Maiman DJ, Apple DF. Economics of managed care in spinal cord injury. *Arch Phys Med Rehabil* 1999; **80**: 1441–1449.
- Chen D, Apple DF, Hudson LM, Bode R. Medical complications during acute rehabilitation following spinal cord injury – current experience of the model systems. *Arch Phys Med Rehabil* 1999; **80**: 1397–1401.
- DeVivo MJ. Discharge disposition from model spinal cord injury care system rehabilitation programs. *Arch Phys Med Rehabil* 1999; **80**: 785–790.
- DeVivo MJ, Whiteneck GG, Charles ED. The economic impact of spinal cord injury. In: Stover SL, DeLisa JA, Whiteneck GG (eds). *Spinal Cord Injury: Clinical Outcomes from the Model Systems*. Aspen Publishers: Gaithersburg, Maryland 1995, pp 234–271.
- Ivie CS, DeVivo MJ. Predicting unplanned hospitalizations in persons with spinal cord injury. *Arch Phys Med Rehabil* 1994; **75**: 1182–1188.
- Chen Y, DeVivo MJ, Jackson AB. Pressure ulcer prevalence in people with spinal cord injury: age-period-duration effects. *Arch Phys Med Rehabil* 2005; **86**: 1208–1213.
- Stover SL, DeVivo MJ, Go BK. History, implementation, and current status of the national spinal cord injury database. *Arch Phys Med Rehabil* 1999; **80**: 1365–1371.
- DeVivo MJ, Go BK, Jackson AB. Overview of the national spinal cord injury statistical center database. *J Spinal Cord Med* 2002; **25**: 335–338.
- Nobunaga AI, Go BK, Karunas RB. Recent demographic and injury trends in people served by the model spinal cord injury care systems. *Arch Phys Med Rehabil* 1999; **80**: 1372–1382.
- Jackson AB, Dijkers M, DeVivo MJ, Poczatek RB. A demographic profile of new traumatic spinal cord injuries: change and stability over 30 years. *Arch Phys Med Rehabil* 2004; **85**: 1740–1748.
- DeVivo MJ, Vogel LC. Epidemiology of spinal cord injury in children and adolescents. *J Spinal Cord Med* 2004; **27**(Suppl): S4–S10.
- Marino RJ *et al.* International standards for neurological classification of spinal cord injury. *J Spinal Cord Med* 2003; **26**(Suppl 1): S50–S56.
- Granger CV. *Guide for the Uniform Data Set for Medical Rehabilitation (including the FIM instrument)* version 5.1. State University of New York at Buffalo: Buffalo (New York) 1997.
- Ottenbacher KJ, Hsu Y, Granger CV, Fiedler RC. The reliability of the functional independence measure: a quantitative review. *Arch Phys Med Rehabil* 1996; **77**: 1226–1232.
- Smith P, Hamilton BB, Granger CV. *Functional Independence Measure Decision Tree: the FONE FIM*. State University of New York, Center for Functional Assessment Research: Buffalo, New York 1990.
- Whiteneck G, Charlifue SW, Gerhart KA, Overholser JD, Richardson N. Quantifying handicap: a new measure of long-term rehabilitation outcomes. *Arch Phys Med Rehabil* 1992; **73**: 519–526.
- Hall KM, Dijkers M, Whiteneck G, Brooks CA, Krause JS. The Craig handicap assessment and reporting technique (CHART): metric properties and scoring. *Top Spinal Cord Inj Rehabil* 1998; **4**: 16–30.
- Diener E, Emmons RA, Larson RJ, Griffin S. The satisfaction with life scale. *J Pers Assess* 1985; **49**: 71–74.
- McHorney CA, Ware JE, Raczek AE. The MOS 36-item short form health survey (FS36): II. Psychometric and clinical tests of validity in measuring physical and mental health constructs. *Med Care* 1993; **31**: 247–263.
- Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression symptom severity measure. *J Gen Intern Med* 2001; **16**: 606–613.
- Spitzer RL, Kroenke K, Williams J. Validation and utility of a self-report version of the PRIME-MD: the PHQ

- primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA* 1999; **282**: 1737–1744.
- 26 Tate DG. The use of the CAGE questionnaire to assess alcohol abuse among spinal cord injury persons. *J Rehabil* 1994; **60**: 31–35.
- 27 Ewing JA. Detecting alcoholism: the CAGE questionnaire. *JAMA* 1984; **252**: 1905–1907.
- 28 Mayfield D, McLeod G, Hall P. The CAGE questionnaire: validation of a new alcoholism instrument. *Am J Psychiatry* 1974; **131**: 1121–1123.
- 29 Aertgeerts B, Buntinx F, Kester A. The value of the CAGE in screening for alcohol abuse and alcohol dependence in general clinical populations: a diagnostic meta-analysis. *J Clin Epidemiol* 2004; **57**: 30–39.
- 30 Pflaum C, McCollister G, Strauss DJ, Shavelle RM, DeVivo MJ. Worklife after traumatic spinal cord injury. *J Spinal Cord Med* 2006; **29**: 377–386.
- 31 Kogos SC, DeVivo MJ, Richards JS. Recent trends in spinal cord injury rehabilitation practices and outcomes. *Top Spinal Cord Inj Rehabil* 2004; **10**: 49–57.
- 32 DeVivo MJ, Black KJ, Stover SL. Causes of death during the first 12 years after spinal cord injury. *Arch Phys Med Rehabil* 1993; **74**: 248–254.
- 33 DeVivo MJ, Stover SL. Long-term survival and causes of death. In: Stover SL, DeLisa JA, Whiteneck GG (eds). *Spinal Cord Injury: Clinical Outcomes from the Model Systems*. Aspen Publishers: Gaithersburg, Maryland 1995, pp 289–316.
- 34 Go BK, DeVivo MJ, Richards JS. The epidemiology of spinal cord injury. In: Stover SL, DeLisa JA, Whiteneck GG (eds). *Spinal Cord Injury: Clinical Outcomes from the Model Systems*. Aspen Publishers: Gaithersburg, Maryland 1995, pp 21–55.
- 35 DeVivo MJ. Epidemiology of traumatic spinal cord injury. In: Kirshblum S, Campagnolo DI, DeLisa JA (eds). *Spinal Cord Medicine*. Lippincott, Williams & Wilkins: Philadelphia 2002, pp 69–81.
- 36 DeVivo MJ, Kartus PL, Stover SL, Fine PR. Benefits of early admission to an organised spinal cord injury care system. *Paraplegia* 1990; **28**: 545–555.
- 37 Yarkony GM, Bass LM, Keenan V, Meyer PR. Contractures complicating spinal cord injury: incidence and comparison between spinal cord centre and general hospital acute care. *Paraplegia* 1985; **23**: 265–271.
- 38 Heinemann AW *et al*. Functional outcome following spinal cord injury. A comparison of specialized spinal cord injury center *vs* general hospital short-term care. *Arch Neurol* 1989; **46**: 1098–1102.
- 39 Donovan WH, Carter RE, Bedbrook GM, Young JS, Griffiths ER. Incidence of medical complications in spinal cord injury: patients in specialised, compared with non-specialised centres. *Paraplegia* 1984; **22**: 282–290.
- 40 Richards JS, Go BK, Rutt RD, Lazarus PB. The national spinal cord injury collaborative database. In: Stover SL, DeLisa JA, Whiteneck GG (eds). *Spinal Cord Injury: Clinical Outcomes from the Model Systems*. Aspen Publishers: Gaithersburg, Maryland 1995, pp 10–20.