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New estimates of the direct costs of traumatic spinal cord injuries: results of a nationwide survey

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New estimates of the direct costs of traumatic spinal cord injuries (SCI) are obtained from a comprehensive survey of the US SCI population. These direct costs, defined as the value (in 1988 dollars) of resources used specifically to treat or to adapt to the SCI condition, represent the average experience of the US SCI population. Responses to a detailed questionnaire administered to a sample of traumatic SCI persons in the United States provide the primary source of data for this study. Analysis of this survey data indicates that more recently injured SCI persons (ie those injured since 1970) spent an average of 171 days in a hospital over the first 2 years post injury. Initial hospital expenses will average $95,203. Home modification costs in excess of $8,000 can also be expected. After recovery and rehabilitation, a SCI person will pay, on average, $2,958 per year in hospital expenses and $4,908 per year for other medical services, supplies and adaptive equipment. Personal assistance costs and costs of institutional care will average $6,269 per year. These cost estimates represent the incremental costs of SCI, ie they exclude any costs that would have been incurred in the absence of SCI.

Keywords: spinal cord injury; cost; hospitalization.

Introduction

A catastrophic event such as spinal cord injury (SCI) will entail significant expenses for medical treatment, rehabilitation and readjustment after injury. Previous attempts to document the magnitude of these costs have typically used data representing only a subset of the national SCI population. Data sources in these studies are confined to a particular age group (eg Bureau of Economic Research),[1] etiology (Smart and Sanders),[2] place of treatment (eg Young *et al*),[3] or source of payment (Webb *et al*).[4] In most of these studies, no attempt is made to account for the incremental impact of SCI. Hospital charges and physician costs are estimated without acknowledging that the non SCI population also incurs the same types of expenses, but to a lesser extent.

New estimates of the direct costs of traumatic SCI based on a comprehensive survey of the US SCI population (hereafter referred to as the PSA survey) are now available. These direct costs, defined as the value (in 1988 dollars) of resources used specifically to treat or to adapt to the SCI condition, reflect the actual experience of the entire US SCI population, regardless of place of treatment or circumstances of injury.

This paper presents these estimates of direct costs of traumatic SCI. We first describe the data and methodology used to assess SCI direct costs. Results by type of cost are then presented and discussed.

We estimate that the average expenditures for initial hospitalization will total $95,203; another $8,208 will be spent on home modifications. After recovery and rehabilitation, an SCI person can expect to pay, on average, $7,866 per year for medical services, supplies and adaptive equipment.

Personal assistance costs and the costs of institutional care will amount to $6,269 per year.

These incremental costs are averaged over the entire SCI population. They will vary by severity of injury; costs for persons with complete quadriplegia will be much higher, while incomplete paraplegics will incur considerably lower expenses. Many other factors, including age, specific treatment regimen, financial resources and patient motivation, can also produce wide variations around these averages. Finally, we stress that these costs reflect the actual experience of the US SCI population. We make no attempt to determine whether SCI persons are receiving optimal or even adequate care.

Data

Our data scource is a sample of 758 SCI persons who completed an in-depth interview sometime between October 1988 and May 1989. Ninety-five of these persons were located via an area probability sample designed to estimate the SCI population in private residences, while 88 persons were selected from a probability sample of nursing homes and other long term care facilities. (For a complete description of the sample design and methodology, see Harvey *et al.*) These two probability samples were used to estimate SCI prevalence within the continental United States; the result was a prevalence estimate of 176,965 persons.[5]

To bolster the sample for analytical purposes, an additional 575 persons were located from membership lists from organizations representing the disabled population, from independent living centers, and from referrals from other interviewed SCI persons. Weights were assigned to these 758 sample points; the weights sum to the estimated 1988 SCI population of 176,965 persons and preserve the characteristics and composition of this population.[6] The result is a statistically valid representative sample of the US SCI population. Table I describes the demographics and the injury characteristics of this population.

Each SCI person in our sample completed a questionnaire designed to gather information on both the enormous initial costs of SCI and the annual treatment and maintenance costs incurred in the years following initial treatment and rehabilitation. The survey questionnaire explicitly identified the following direct expense categories associated with SCI:

- Hospitalization
  - First 2 years post injury
  - Recent hospitalization (ie 1 year prior to interview)
- Medical practitioner services
- Prescription drugs
- Non prescription drugs and supplies
- Adaptive equipment

Table I PSA survey summary: characteristics of the SCI population

Sex	
Male	71.0%
Female	29.0%
Current age	
0–24 years	5.3%
25–44 years	54.2%
45–64 years	27.8%
65+ years	12.7%
Race	
White	89.4%
Non white	10.6%
Level/severity of injury	
Complete quadriplegia	7.0%
Incomplete quadriplegia	36.7%
Complete paraplegia	9.6%
Incomplete paraplegia	45.9%
Unknown	0.9%
Age at injury	
0–15 years	7.6%
16–30 years	49.4%
31–45 years	24.3%
46–60 years	13.4%
61+ years	4.1%
Unknown	1.2%
Etiology	
Falls	16.8%
Pedestrian	2.0%
Medical/surgical complication	3.2%
Sports accident	16.3%
Vehicular accident	45.4%
Violence	5.2%
Other	8.4%
Unknown	2.7%

- Personal assistance
- Home modifications

More precise detail on the exact types of information collected for each of these cost categories is given in Figure 1.

Methodology

Pretests of the PSA survey questionnaire indicated that, although respondents could identify amounts of various medical goods and services consumed (eg the number of days of hospitalization, number of wheelchairs purchased etc), they did not always know how much they had spent on these items. This was not suprising. In many cases, the time lapse between the injury and interview dates was sufficiently long to hinder respondents' recollections of exact expenditures. Also, insurance carriers or other parties may have paid for most or all of SCI related expenditures, and the respondent may have no information on the amounts paid. Given the inability of respondents to provide accurate information on SCI related expenditures, we chose to collect information on the quantities of medical goods and services used. (We obtained information on expenditures for two

TYPE OF COST	SURVEY INFORMATION
Hospitalization	Dates and duration of hospital episodes in the year prior to interview and over the first 2 years post injury. Respondents identified, for each separate hospital episode, type of facility used (ie community hospital, rehabilitation hospital etc), length of stay, reason for hospitalization (ie surgery, rehabilitation etc), number of days in intensive care or on a respirator, sources of payment for the hospitalization and percentage of expenses paid by each source.
Practitioners	Survey listed several types of medical practitioners, both physicians and non physicians. Survey respondents identified each type of medical practitioner seen outside of the hospital over the previous year, how many times each practitioner had been consulted, reasons for seeing each practitioner, sources of payment for practitioner visits in total, and percentage of the costs paid by each source. In-hospital physician visits are not included in these data.
Personal assistance	Survey identified SCI persons who receive assistance from others to perform daily tasks, and amount of assistance (hours) received from each provider. Assistance providers identified by relationship to SCI person. Types of tasks performed by each provider, amount of payment (if any) rendered, and source of payment for each paid assistance provider are also available.
Prescription and non prescription items	Respondents reported current use of several broad classes of prescription medications. For each type of medication, information provided on form (tablet, bottle etc), quantity, and frequency of use. No information on exact dosages prescribed. Payment sources and percentage of prescription drug costs paid by each source provided.
	Similar data collected for a wide range of non prescription items, such as catheters, leg bags and non prescription pain relievers.
Adaptive equipment	Respondents reported number of various types of adaptive equipment items (ie wheelchairs, bed lifts etc) obtained since injury. Sources of payment for total purchases and percentage paid by each source were identified.
Home modifications	Respondents provided information on expenditures since injury for specific types of modifications. Source of payment and percentage of cost paid by each source also identified.

Figure 1 Summary of PSA survey information by direct cost category.

categories of direct costs, home modifications and personal assistance.) Thus, our methodology required that we first quantify the incremental demand for items and services attributable to the SCI condition (ie the number of practitioner visits, hospital days etc) and then that we price these quantities, using the market prices for these items in 1988.

The term 'incremental demand' deserves further comment. Not all expenses incurred by an SCI person should be included as a cost of SCI. Non disabled persons visit doctors or incur expenses for hospitalization and prescription drugs. Ideally, the direct costs of SCI should include only the incremental use of those goods and services that is attributable solely to the SCI condition. Wherever possible, we measured the incremental impact of SCI on medical and other expenditures by comparing the behaviour of the SCI population with that of non disabled persons. Non disabled persons are those who are not limited in the pursuit of their daily activity due to any health condition or impairment. Daily activity is age-specific (ie play or attendance at school for children aged 17 or under, and actual or potential ability to work for pay outside the household or to perform housework for those aged 18 and over). Information on the use of various medical goods and services by this population were obtained from analyses of data from the 1980 National Medical Care Utilization and Expenditure Survey.[7]

Specific details regarding the application of this methodology for each cost category are presented in Figure 2. Figure 3 summarizes the sources and limitations of the price data used to value the goods and services consumed by the SCI population.

The costs presented below represent the actual experience of the US population. We make no attempt to assess unmet needs or

TYPE OF COST	METHODOLOGY	DATA ADJUSTMENTS
Hospital 2 years post injury	Reported hospital stays are multiplied by the average daily hospital charge in 1988 for type of facility used. Costs of inpatient physician visits calculated using average number of physician visits per hospital day from 1980 National Medical Care Utilization and Expenditure Survey (NMCUES) and the hospital visit fee for a general practitioner.	Costs averaged over SCI persons with known hospital periods injured since 1970, excluding those injured for less than 2 years. If type of facility is unknown, daily rate for general hospital is used.
Hospital post rehabilitation	Averge hospital inpatient days from NMCUES for non disabled persons, by age and by sex, approximate the probable need for hospital services by PSA survey respondents if they were not SCI. Costs for predicted hospital days calculated, using average daily hospital rates for community or general hospitals. Actual hospital days reported by each PSA survey respondent priced using *per diem* hospital rates for the type of facility used. Difference between predicted and actual costs is the incremental impact of SCI on post recovery hospital costs. Costs for inpatient physician visits calculated using number of physician visits per hospital day from NMCUES; these visits priced using the hospital visit fee for a general practitioner. Physician costs calculated for both actual and predicted hospital stays; the difference is incremental cost of inpatient physician visits attributable to SCI.	Costs calculated and averaged over all SCI persons with known hospital periods injured at least 3 years. Where the type of facility is unknown, the daily rate for a general hospital is used.

Figure 2 Estimation of SCI direct costs: methodological notes.

TYPE OF COST	METHODOLOGY	DATA ADJUSTMENTS
Practitioners	NMCUES data used to assess use of practitioner services by non disabled persons. Two-stage procedure (see Heckman[8]) used to predict probability of visiting a practitioner within 1 year and the number of such visits for those who use these services. Estimated model parameters used in conjunction with PSA survey data to simulate each respondent's non SCI-related use of practitioner services. Costs for actual and predicted visits calculated and compared, using average practitioner fees.	Costs calculated and averaged over all SCI persons where the number of practitioner visits is known, excluding those persons injured within one year of interview.
Personal assistance	Costs calculated using hourly assistance wage for each hour of assistance (paid or unpaid) received; assistance costs are adjusted downward to remove costs for any time spent as a hospital inpatient. We assume that no personal assistance expenses are incurred in the absence of SCI. This is not strictly true, since some of our survey respondents may also be impaired by another disabling condition in the absence of their SCI. Estimates of personal assistance costs include assistance provided to SCI persons residing in institutions by relatives and friends for activities such as running errands, paying bills etc.	Some respondents reported excessive hours of assistance (ie up to 168 hours per week) from one person. Others reported excessive hours from several sources. For paraplegics, total amount of assistance received per week was limited to 168 hours or less; no one person could supply more than 84 hours per week. Maximum hours for quadriplegics was increased to 280 hours per week; hours provided by one person could not exceed 112 hours. Costs averaged over all SCI persons injured more than 3 years prior to interview.
Long term care costs	An average daily incremental cost of institutional care is applied to persons who resided in a long term care facility in 1988. Incremental daily expense defined as daily rate paid for facility net of average daily living expenses for food, clothing, shelter etc, incurred by all persons, regardless of residence.	We assume that all institutionalized SCI persons reside in a long term care facility for an entire year, except for hospitalization.
Prescription drugs	Average annual expenditures on prescription drugs in 1980, by sex, age, and number of outpatient physician visits, obtained from NMCUES for non disabled persons. These costs adjusted to 1988 dollars (using the prescription drug CPI) and compared to actual expenditures on prescription drugs reported by PSA survey respondents. Actual expenditures calculated using average price for each type and form of drug used by each PSA survey respondent.	Costs calculated and averaged over those medications used on a regular basis. All SCI persons injured within one year of interview are excluded.

Figure 2 Estimation of SCI direct costs: methodological notes (cont).

TYPE OF COST	METHODOLOGY	DATA ADJUSTMENTS
Non prescription items	Costs for non prescription items calculated by pricing out the actual quantities of each type of item used as reported by PSA survey respondents.	Costs calculated for all SCI persons using known quantities on a regular basis, excluding those injured within one year of interview.
Adaptive equipment	The cost of each type of equipment used by each respondent is spread over its estimated lifetime. Average annual use is calculated for each item by dividing number purchased since injury by number of years since injury. Quantity per year of each type of equipment is then priced, using average 1988 prices. We assume that all equipment purchases are prompted by SCI.	Equipment costs reflect only purchase or replacement costs; we have not included any maintenance expenses.
Home modifications	Reported home modification expenditures assumed to occur in the second year post injury. For most types of home modifications, we assume that reported expenditures are incremental to SCI. This is reasonable for all cases except for construction of additional rooms or a new home, which are reported together. To distinguish between renovations and new construction and to assess incremental effect of SCI on new construction costs, we compare this reported expense to mediam sales price of new private homes in that year by region. If reported expense is less than median house price, we assume that modification cost refers to renovation to an existing structure, and include these reported expenditures (provided that renovation costs not exceed one third of new home construction costs). If reported expenses exceed median house price, we assume a new dwelling. Incremental impact of SCI calculated as the difference between reported expenditure and new housing construction costs; these expenditures limited to one third or less of median new house construction costs. Estimated expenditures on all home modifications adjusted to 1988 dollars using the shelter component of the CPI.	To mitigate the impact of rising construction costs on our estimates, costs are estimated for those persons injured since 1980.

Figure 2 Estimation of SCI direct costs: methodological notes (cont).

to compare the actual receipt of medical care, adaptive equipment acquisition etc. with what might be considered optimal (or even adequate) by clinicians or rehabilitation consultants. Our cost estimates are also averaged over the entire SCI population, including both those who consume the particular goods or service in question and those who do not. For those items for which a significant number of SCI persons do not incur any expense, we also present costs averaged over that subgroup of persons who report such an expenditure.

Our estimates of SCI direct costs, averaged over the entire US SCI population, are summarized in Table II, in total and by

TYPE OF COST	DATA SOURCES AND LIMITATIONS
Hospital	*Per diem* hospital charges for community/general hospitals and VA hospitals obtained from American Hospital Association.[9] Rehabilitation hospital changes taken from Hosek *et al.*[10] *Per diem* rates for regional SCI centers calculated from unpublished NSCISC data. Charges include basic hospital charges, charges for operating rooms, intensive care services, laboratory and ancillary services, and drugs and supplies. They do not include physician fees. Excepting rehabilitation hospitals and regional SCI centers, these charges are not specific to the SCI condition; they represent average costs over all persons admitted to hospitals in the United States in 1988.
Practitioner	Average practitioner fees per visit obtained from many sources, including Medical Economics (Kirchner),[11] American Occupational Therapy Association,[12] Bunch,[13] Gonzalez[14,15] and US Bureau of Labor Statistics.[16]
Personal assistance	An assistance wage of $5.00 per hour was calculated from data collected in a national survey of attendant care programs in the United States (Litvak *et al*).[17] Average hourly wages received by various types of assistance providers averaged and adjusted to 1988 dollars. Wages do not include fringe benefits, agency overhead or training costs.
Long term care	Daily average living expenses are subtracted from daily institutional expenses to yield an estimate of the incremental daily cost of institutional care. Average annual expenses incurred by private patients in intermediate care facilities in 1985, as per the 1985 National Nursing Home Survey (NCHS)[18] are adjusted upward to 1988 prices using the Medical Care Services CPI. Average annual living expenses in 1988 estimated from personal consumption expenditures (US Bureau of Economic Analysis)[19] and the total resident civilian population in the US in 1988 (US Bureau of the Census).[20]
Prescription drugs	Prescription drug wholesale prices from *American Druggist Blue Book*[21] and the *Drug Topics Red Book*.[22] Wholesale unit prices for different brands and dosages averaged to develop a price for each type of drug. A retail 25% mark-up is applied to these wholesale prices.
Non prescription items	Wholesale prices for such items as pain relievers, rubbing alcohol and vitamins taken from the *American Druggist Blue Book*[21] and the *Drug Topics Red Book*.[22] Retail prices for such items as catheters, diapers and leg bags were taken from various manufacturers' catalogs and from American Medical Association.[23] Since each item is generally available in a wide variety of sizes, types etc, unit prices were averaged over the types of items most likely to be used by SCI persons in typical circumstances.
Adaptive equipment	Adaptive equipment price data obtained from catalogs of several manufacturers across the country, including local and national surgical and medical supply companies and national retail stores. Data supplemented by an on-line search of a national adaptive equipment database (ABLEDATA). A single price for each type of adaptive equipment was developed by averaging retail prices from all available sources, after deleting outlying prices. Where possible, we narrowed the available choices by determining the types of products usually used by SCI persons.

Figure 3 Sources and limitations of pricing data.

severity of injury. Below, we provide a more detailed discussion of these results, by type of expenditure. The discussion will include data on the actual use by SCI persons of various types of medical and non medical items and services that underlie our cost estimates. Where needed, we also highlight some important methodological issues spe-

Table II Summary of average SCI direct costs (1988 dollars)

	Total	Complete quad	Incomplete quad	Complete para	Incomplete para
Initial costs					
Hospitalization	$95,203	$136,029	$115,028	$101,537	$65,955
Home modifications	$8,208	$17,473	$5,969	$9,344	$8,140
Total costs	$103,411	$153,502	$120,997	$110,881	$74,095
Recurring annual expenses					
Hospitalization	$2,958	$3,484	$5,169	$1,975	$1,384
Practitioner	$2,248	$3,783	$3,300	$1,975	$1.310
Personal assistance and institutional care	$6,269	$14,243	$8,090	$3,783	$3,934
Prescription drugs	$113	$304	$61	$52	$138
Non prescription items	$1,686	$2,468	$2,043	$1,712	$1,328
Adaptive equipment	$861	$1,874	$1,292	$800	449
Total costs	$14,135	$26,156	$19,955	$10,297	$8,543

cific to the type of expenditure under discussion.

Direct costs of SCI—initial expenses

The direct costs of SCI are not distributed evenly over the entire post injury period. Very large expenses are incurred immediately for acute care and rehabilitation, initial acquisition of adaptive equipment, and enviromental modifications to accommodate the injury. In this section, we focus on reported need for hospitalization in the first 2 years post injury, and on the amount and type of home modifications made by SCI persons.

Initial hospitalization

Not surprisingly, everyone who incurs an injury to the spinal cord is hospitalized overnight at least once following the event. Most SCI persons are admitted 2 or more times to a hospital in the 2 year period following their injury, according to Table III. In many cases, this may reflect some brief initial treatment at an acute care facility, followed by a transfer to a rehabilitation facility for a prolonged period. The survey data will treat this situation as 2 separate admissions. (According to the survey data, only about 22% of the SCI population report a single episode of hospitalization in the first 2 years post injury.)

Reported total inpatient hospital days over this initial 2 year post injury period vary with the time (year) that the injury was incurred, Average length hospital stay in the 2 years following injury has declined significantly over time. This reduction in hospital stay reflects medical advance in the treatment of SCI, as well as improved management and delivery of health care services to these patients. For purposes of cost calculations, we focus on the hospitalization experiences of those SCI persons injured since 1970; this will provide some adjustment to our results for the introduction of new methods for treating SCI.

On average, an SCI individual will spend about 171 days in the hospital over the first 2 years following injury (see Table III). Length of hospitalization will vary directly with the severity of injury. However, survey results also suggest a wide variation in initial hospitalization experience that is not entirely explained by level/severity of injury. Some persons with quadriplegia may spend as little as a month or less in the hospital over this period; on the other hand, a few paraplegics spend a year or more in the hospital for initial treatment and rehabilitation. A number of factors, including age, presence of additional complication from the injury, presence of other health conditions that may complicate initial treatment,

Table III Hospital admissions 2 years post injury*

	Average number of admissions	Average inpatient days per admission
All cases	2.5	171 days
Complete quadriplegia	2.8	242 days
Incomplete quadriplegia	2.6	214 days
Complete paraplegia	2.7	166 days
Incomplete paraplegia	2.4	117 days

*For all SCI persons injured after 1970, excluding those injured within 2 years of their interview.

where the SCI individual received treatment, and the source of payment for treatment, may explain this variation.

Average hospitalization expenses over the first 2 years after injury, in 1988 dollars, will average $95,203 per SCI person. In general, a variety of factors can interact to determine hospitalization expenses for SCI persons. Unfortunately, we could not accurately estimate these costs for very small, specifically defined subgroups of the population (eg male complete paraplegics aged 25–34). Our sample sizes for these types of subgroups were too small to ensure statistically valid estimates.

Our estimated average length of hospitalization, 171 days, is similar to those reported by Smart and Sanders[2] and Webb *et al.*[4] Our estimated average hospital expense of $95,203 does not appear unreasonable, when compared to other estimates (eg Webb *et al*[4] or Smart and Sanders,[2] adjusted to 1988 dollars by means of the Medical Care Services CPI.

Home modifications

About 60% of all SCI persons have made some modification to their living quarters to accommodate their disability (see Table IV). The most frequently reported modification is the addition of access ramps. More than 20% of the SCI population reported that they widened doorways, installed grab bars, and/or built a new home or an addition to an existing residence. The 'other' category of home modifications, reported by over 11% of the SCI population, includes the purchase and installation of items such as elevators and stair lifts, garage door openers and water fountains, as well as the construction of decks and modification of closets.

As expected, the tendency to make a home modification varies directly with

Table IV Home modifications

Type of modification	Total SCI population	Complete quad	Incomplete quad	Complete para	Incomplete para
Additional rooms/ new house	23.0%	54.5%	23.7%	18.8%	17.3%
Kitchen/bathroom counters	10.6%	24.9%	9.5%	18.6%	7.7%
Electrical work	6.9%	6.3%	8.8%	20.2%	2.9%
Ramps	44.0%	70.4%	51.9%	57.4%	30.1%
Widened doors	23.7%	34.9%	27.8%	34.6%	15.3%
Grab bars	22.0%	18.2%	19.3%	23.2%	24.7%
Door handles	6.8%	18.1%	12.8%	2.8%	1.4%
Alarms	5.3%	7.8%	5.0%	19.0%	2.4%
Other	11.4%	10.1%	7.8%	5.3%	15.8%
Any modification	60.2%	82.4%	64.4%	59.0%	53.3%

severity of injury. Quadriplegics are more likely to require some type of environmental modification than are paraplegics.

Estimation of the costs of home modifications to the SCI population is hampered by a lack of detailed information on both the timing of these expenditures and the amount of modification that occurred. To mitigate, to some extent, the impact of rising construction costs on our estimates, we specifically analyzed expenditures made by SCI persons injured since 1980. While their home modification expenses will reflect some varation in construction prices over time (ie from 1980 to the interview date), we hope to confine the impact of rising construction prices to the recent decade.

For most categories of home modifications, we assume that all reported expenditures on these items are incremental to SCI, ie they would not have occurred in the absence of SCI. This is reasonable for all reported modifications except house additions or new construction. While adding a room or two to an existing structure may be reasonably classed as an incremental expense attributable to SCI, the total costs of constructing a new house modified to accommodate an SCI person are certainly not entirely incremental to the SCI condition. A certain amount of housing would be required in the absence of SCI. Unfortunately, we cannot easily deduct the portion of new house construction costs that would be incurred without SCI, in part because we have no indication from the survey response whether the reported expense was due to structural modification or to new construction. Figure 2 reports all adjustments made to our methodology to estimate costs of home modification.

Expenditures on home modifications averaged over the entire SCI population (including those who did not incur these type of expenses) come to just over $8.000 (see Table V). Expenditures by complete quadriplegics are appreciably higher than for any other impairment group. Inexplicably, however, incomplete quadriplegics pay less, on average, on this category of expenses than do paraplegics. Our method of estimating the cost of home modifications can lead to a high degree of variance between observations. For instance, housing prices vary dramatically between regions and from year to year. This was especially true for the 7-year period from 1980 to 1986. Furthermore, limiting the sample to those injured between these years increases the sample variance, particularly when we further divide the sample into subgroups. This high variance would lead us to expect some inconsistencies, such as the uncommomly high estimates for complete quadriplegics and the low estimate for incomplete quadriplegics. Given this high sample variance, complete quadriplegics are the only group that can be considered significantly different from the others.

For comparison, Table V also includes average home modification expenditures for those who actually make these modifications. Average home modification expenditures for this group are, of course, higher, at $14,545.

Table V SCI direct cost estimates of home modifications (1988 dollars)

	Average expense (all SCI persons)*	Average expense (those who made modifications)**
Total SCI population	$8,208	$14,545
Complete quadriplegia	$17,473	$20,086
Incomplete quadriplegia	$5,969	$11,550
Complete paraplegia	$9,344	$14,347
Incomplete paraplegia	$8,140	$15,115

*Averaged over all SCI persons injured between 1980 and 1986.
**Averaged over all SCI persons injured between 1980 and 1986 who reported expenditures on home modifications.

Direct costs of SCI—recurring annual expenses

After this initial period of recovery and rehabilitation, persons with SCI will still require medical services, drugs and medical supplies to maintain their functional level and to treat complications that arise from their injury. Additional adaptive equipment will be purchased periodically to replace or supplement the existing stock of equipment. Personal assistance services may be required for the SCI person to function at home. Expenses are also incurred if the SCI person requires skilled nursing services or custodial care within a long term care facility. As Table II indicates, annual expenses for these items and services may be sizable, depending on the level and severity of injury.

Annual hospitalization

After their initial period of recovery and rehabilitation, SCI persons have a higher propensity to be rehospitalized than their non disabled counterparts. According to Table VI, almost 29% of SCI persons who have been injured for at least 3 years were hospitalized at least once in the year prior to their interview. Most of these persons were hospitalized only once; however a few report multiple episodes of hospitalization in a single year. Quadriplegics are more likely to be rehospitalized than paraplegics.

The length of stay for post recovery hospitalization episodes averages out to almost 1 week. While most SCI persons are rehospitalized for a week or less, a few may spend several months in the hospital. Length of stay will vary roughly with severity of injury; however, incomplete quadriplegics will spend 2 days more in a hospital, on average, than complete quadriplegics. We speculate that this may reflect differences in the age distribution of these two groups, as well as differences in their neurological level of injury. The incomplete quadriplegic population is slightly older, on average, than complete quadriplegics. (Of incomplete quadriplegics in our weighted hospitalization sample, 17.4% were 60 years of age or older, as opposed to only 4.4% for complete quadriplegics.) We suspect that an interaction of age with disability may result in greater hospitalization time for incomplete quadriplegics. Also, a larger percentage of incomplete quadriplegics have very high lesions (ie in the C1–C3 range). Complete quadriplegics, on the other hand, tend toward lower levels of cervical injuries. (Only 12.7% of all complete quadriplegics report a neurological injury level of C1–C3. Almost 32% of all incomplete quadriplegics fall into the C1–C3 range.)

These differences in hospitalization time are reflected in the annual hospitalization costs reported in Table II. On average, individuals with SCI will spend almost 6 days more each year in a hospital compared to the non disabled population. (From Table VI we know that annual hospitalization stay for an SCI person will average between 6 and 7 days. Average annual hospital stay for a non disabled person is under 1 day.) On average, each SCI person spends $3,479 per year on hospitalization; if they were not SCI, we estimate that hospital costs would average $521 per year. The net cost (ie $2,985) represents the incremental average per annum hospital cost associated with SCI. (These incremental impacts on

Table VI Annual hospital admissions: post-rehabilitation hospitalization*

	One or more admissions	Average annual inpatient days
All cases	28.9%	6.6 days
Complete quadriplegia	41.5%	8.2 days
Incomplete quadriplegia	35.3%	10.6 days
Complete paraplegia	22.0%	4.5 days
Incomplete paraplegia	22.1%	3.6 days

*Excludes all SCI persons injured less than 3 years before interview.

hospital days and hospital costs may not seem very large. Recall, however, that they are averaged over the entire SCI population. Not all SCI persons require hospitalizaton in any given year.)

Medical practitioner visits

According to PSA survey results tabulated in Table VII, most SCI persons, 86.3%, see a physician at least once a year. A lower proportion of the SCI population, 50.6%, reported that they saw a non physician practitioner such as a nurse, physical therapist, psychologist etc in the past year. Overall, more than 90% of the SCI population saw a physician, a non physician practitioner or both over the previous year.

The SCI population averages over 18 visits per year to some type of physician, and almost 48 visits per year to some type of non physician practitioner. Average visits will vary with severity of injury; quadriplegics will require more practitioner services than paraplegics.

The incremental cost of practitioner visits averages $2,248 per year for the SCI person. This estimate excludes the annual expenditures on these services that SCI persons would incur in the absence of their SCI; the process used to develop this estimate is described in Figure 2.

Personal assistance and institutional costs

Like other disabled person, SCI persons often require some assistance from others to perform daily tasks such as getting around the house, personal hygiene, meal preparation etc. Such assistance may come from other household members, such as spouse or child, or it may come from friends, relatives or other persons from outside the home. Assistance may be provided on a volunteer basis, or the assistant may be paid, either by the SCI person, by the family or by some third party.

According to the data summary presented in Table VIII, about two thirds of the SCI population receive such assistance. Of those who do not receive at least some assistance, more than half receive 40 hours per week of assistance or less. Most SCI persons receive assistance from one or 2 persons. Most of these assistants are unpaid. We estimate that only 10.1% of all assistance providers who live within the household are paid; however, 57.4% of all non household providers are paid for their services. Overall, 72.6% of all those who provide assistance to SCI persons do so on a voluntary basis.

Overall, the SCI population receives 25.1 hours per week of assistance. The amount of assistance received by the SCI population varies, as expected, by severity of injury.

The fact that most assistance providers

Table VII Utilization of practitioner services*

	Physicians	Non physician practitioner	All practitioners*
Percent who utilize services			
All cases	86.3%	50.6%	90.5%
Complete quadriplegia	96.6%	64.9%	97.8%
Incomplete quadriplegia	80.7%	60.7%	89.6%
Complete paraplegia	88.2%	41.7%	93.7%
Incomplete paraplegia	88.5%	43.2%	89.1%
Average annual visits			
All cases	18.3	47.5	68.5
Complete quadriplegia	27.9	88.1	121.1
Incomplete quadriplegia	19.9	83.0	105.4
Complete paraplegia	20.3	34.3	55.7
Incomplete paraplegia	15.4	17.8	36.4

*Excludes all SCI person injured less than 1 year before interview. Data for all practitioners includes visits to some other types of practitioners not specifically listed in the survey.

Table VIII Utilization of personal assistance services

	Total SCI population	Complete quad	Incomplete quad	Complete para	Incomplete para
Hours per week					
None	34.5%				
Less than 10	16.4%				
11–20 hours	8.0%				
21–30 hours	6.8%				
31–40 hours	8.3%				
More than 40	20.1%				
Unknown	5.9%				
Number of providers*					
1	42.4%				
2	33.6%				
More than 2	24.0%				
Average hours per week	25.1	56.3	31.9	13.5	16.9

*For those who report at least 1 hour of assistance.

are not paid does not mean that their services are costless. However, estimating these costs is a difficult task, since we do not know how these assistants would otherwise allocate this time. We can, however, take some of these costs into account by imputing a cost to assistance that is provided voluntarily. Following the procedure described in Figure 2, we estimate that personal assistance costs for an SCI person average $6,080 per year.

A very small percentage of the traumatic SCI population in the United States resides in nursing homes and other types of long term care facilities. About 4,575 SCI persons, or 2.6% of the total SCI population, live in these types of institutions. As Table IX indicates, over 52% of these persons are incomplete quadriplegics, with complete quadriplegics accounting for another 27.4% of the institutionalized SCI population. For these persons, costs of institutional care constitute a major portion of the annual costs of their impairment.

Through our survey effort, we located and interviewed a number of institutionalized SCI persons. The survey questionnaire did not include any questions regarding the details of their institutional experience or expenses. Therefore, we must rely on data from secondary sources to estimate these costs; Figure 2 summarizes this methodology.

We estimate that the incremental costs of institutionalized care average about $25 per day. Applying these *per diem* costs to our institutionalized SCI population and netting out hospitalization periods yields an average annual expenditure of $7,959 on institutional care (see Table X). Variations in costs

Table IX Composition of institutional SCI population

	Number of SCI persons	Percent of institutional SCI population
Complete quadriplegic	1,254	27.4%
Incomplete quadriplegic	2,420	52.9%
Complete paraplegics	352	7.7%
Incomplete paraplegics	549	12.0%
Total institutionalized SCI population	4,575	100.0%

by level of impairment reflect, to a large extent, differentials in annual hospitalization time. As noted earlier, incomplete quadriplegics tend to spend more time, on average, in the hospital each year than do either complete quadriplegics or paraplegics; this explains the drop in institutional costs for this level of impairment. When averaged over the entire SCI population, institutionalization costs will fall sharply, to $189 per year. Bear in mind that this estimate reflects both the annual cost of institutionalization for SCI persons and their probability of being institutionalized. Since only 2.6% of all SCI persons receive these services, the average cost of such services over the entire SCI population will be very low.

Prescription drugs

Almost 82% of all SCI persons in the United States use at least one type of prescription medication either on a regular basis or as needed. Most SCI persons use anywhere from one to 4 different types of medications. Usage varies with the level and severity of lesion. About 91% of all persons with complete quadriplegia use some sort of prescription medicine; comparable usage data for incomplete quadriplegia, complete paraplegia and incomplete paraplegia are 84.4% 80.7% and 79.3%, respectively.

Annual prescription drug costs are summarized in Table II. These costs are averaged over all SCI persons whether or not they use one or more such medications on a regular basis. On average, an SCI person will pay $113 more per year for prescription medication than a non disabled person. Costs are highest for complete quadriplegics; they decline sharply for incomplete quadriplegics and complete paraplegics. However, incomplete paraplegics report a higher usage of prescription medication, with consequently higher expenditures, as compared to complete paraplegics. Compared to persons with incomplete quadriplegia or complete paraplegia, incomplete paraplegics spend approximately three times as much on pain medicine and approximately twice as much on anti muscle calcification medication. In fact, these 2 drugs constitute almost 50% of incomplete paraplegics' expenditures on prescription medicine.

Non prescription items

SCI persons use a wide variety of non prescription supplies and medications, including aspirin and other non prescription pain relievers, catheters, laxatives, vitamins, dressings and bandages, foam rubber, finger cots etc. Many of these items come in a wide range of types and sizes, some of which are specifically designed for a particular medical situation. For example, the type of catheter used by SCI persons will depend on each person's specific bladder management regimen. To the extent possible, we accommodated these types of item-specific attributes in our cost estimates.

Unfortunately, we have no information on the likely use of any of these items by the non disabled population; thus, we cannot make any informed adjustment to our estimates for the incremental impact of SCI. The cost estimates presented in Table II are somewhat overstated for those items that would be used in the absence of the SCI condition.

On average, an SCI person can expect to

Table X SCI direct cost estimates: institutionalization costs (1988 dollars)

	Average annual cost for SCI institutionalized population	Average annual cost for total SCI population
Total SCI population	$7,959	$189
Complete quadriplegia	$8,646	$877
Incomplete quadriplegia	$7,437	$237
Complete paraplegia	$8,113	$176
Incomplete paraplegia	$8,223	$53

pay $1,686 per year for these types of items. These costs vary directly with severity of injury. Catheters (and other items associated with bladder care) constitute the single largest expenditure item in this category; about 70% of average total expenditures on non prescription items are for bladder care products. Non prescription costs for those SCI persons who use catheters will tend to be much higher than the average costs presented in Table II. (Analysis of PSA survey respondents indicates that about 50% of the SCI population use catheters on a regular basis; another 4% use catheters periodically as needed.)

Adaptive equipment

Adaptive equipment items are durable goods that are purchased periodically and used over long periods of time. Thus, an SCI individual will incur a sizable expense for equipment purchases at the onset of the condition, with periodic replacement costs. In calculating equipment expense for the SCI population, we made no attempt to duplicate the exact pattern of equipment purchases in terms of initial and replacement expenses. Rather, we spread out the costs of each type of equipment over its estimated life span, using a procedure described in Figure 2.

Separate equipment cost calculations are performed for those injured within the past 5 years and those injured for more than 5 years. This was done to minimize any upward bias in annual costs attributable to the inclusion of large equipment purchases by recently injured persons. Separate estimates for those who are recently injured will also highlight the asymmetry in expenditure patterns, where high costs are incurred up front as the SCI person acquires an initial stock of equipment.

Average annual equipment costs are presented in Table XI for both newly injured SCI persons and those injured for 5 years or more. These costs are based on actual quantities of equipment that PSA survey respondents have used since their injury.

Equipment costs, on average, will amount to $861 per year. However, in the first years following injury, these expenditures will average as high as $2,602 per year; thereafter, annual expenditures should decline sharply.

Discussion

Costs for the initial treatment and rehabilitation of SCI are quite high, averaging $95,203 per SCI person. Home modification expenses will increase these initial expenses by $8,208. However, the financial burden of SCI does not disappear once rehabilitation is complete. SCI persons can also expect to incur annual costs in excess of $14,000 on an on-going basis throughout their post rehabilitation lives. These costs will generally vary directly with severity of injury.

These cost estimates are conservative in the following respects:

- They do not include all persons who incur an SCI over the course of a year. Only costs for persons who survive their initial treatment are included.
- We are unable to estimate costs for all

Table XI SCI direct cost estimates: annual adaptive equipment costs (1988 dollars)

	Persons injured for more than 5 years*	Persons injured within the last 5 years
Total SCI population	$861	$2,602
Complete quadriplegia	$1,874	$4,931
Incomplete quadriplegia	$1,292	$3,175
Complete paraplegia	$800	$2,480
Incomplete paraplegia	$449	$1,596

*These results include purchases made within the first 5 years following injury.

types of medical and non medical services utilized by SCI persons. Costs for items such as emergency medical services, post rehabilitation laboratory tests and procedures, and specific physician services (eg physician fees for surgery) are excluded, as well as the costs of vocational rehabilitation and transportation to medical facilities for treatment.

Wherever possible, we elected to take a conservative course in our methodologies for estimating costs. For example, our prices for hospital and practitioner services are probably lower than those actually paid by most SCI persons, since they are national averages over the entire population and thus do not specifically reflect the types of services entailed in the treatment of SCI. However, some specific categories of direct costs may be slightly overstated, since data limitations preclude an accurate assessment of the true incremental impact of SCI. This is a problem specifically for personal assistance, equipment, and some types of non prescription drugs and supplies.

Our basic intent in this study was to estimate the economic costs incurred in the United States as a result of SCI. To do this, we focused on average expenses actually incurred by SCI persons. The average cost estimates presented in this report thus mask a wide variation in costs observed over the SCI population, even after accounting for severity of injury. Treatment and rehabilitation costs can be affected by numerous factors, including age and sex of the patient, precise level and severity of the lesion, place of treatment (as characterized by available resources, SCI case management philosophy etc), financial resources available to the patient, and patient motivation. Individual circumstances must be taken into account when assessment of the probable costs of SCI for any specific case is attempted.

These average costs are based on the actual use of medical and non medical resources by the SCI population, as reported in the PSA survey. Some SCI persons are, no doubt, receiving the best care available. Others, however, do not have the financial or personal resources required for optimal (or even adequate) medical care for their injury and its attendant complications. Further investigation is required to assess the extent to which current needs of the SCI population are met.

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