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ORIGINAL RESEARCH ARTICLE

Mobility, Continence, and Life Expectancy in Persons with ASIA Impairment Scale Grade D Spinal Cord Injuries

ABSTRACT

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Objective: Previous research on the life expectancy of persons with American Spinal Injury Association (ASIA) Impairment Scale Grade D spinal cord injury has considered them as a large homogenous group, making no functional or medical distinctions. This study sought to (1) determine how survival in this group depends on ambulatory function and the extent of bowel or bladder dysfunction, (2) compute life expectancies for various subgroups, and (3) examine whether survival has improved over time.

Design: Data were from 8,206 adults with ASIA Impairment Scale Grade D spinal cord injury in the Spinal Cord Injury Model Systems database who were not ventilator dependent and who survived more than 1 yr after injury. There were a total of 114,739 person-years of follow-up and 1,730 deaths during the 1970–2011 study period. Empirical age- and sex-specific mortality rates were computed. Regression analysis of survival data with time-dependent covariates was used to determine the effect of risk factors, to test for a time trend, and to estimate mortality rates for subgroups. Life expectancies were obtained from life tables constructed for each subgroup.

Results: The ability to walk, whether independently or with an assistive device, was associated with longer survival than wheelchair dependence. The need for an indwelling catheter, and to a lesser extent intermittent catheterization, was associated with increased mortality risk. Persons who walked unaided and who did not require catheterization had life expectancies roughly 90% of normal. Those who required a wheelchair for locomotion had life expectancies comparable with that in paraplegia, less than 75% of normal. No time trend in survival was found.

Conclusions: Life expectancy of persons with ASIA Impairment Scale D spinal cord injury depends strongly on the ability to walk and the need for catheterization.

Key Words: Mortality, Life Expectancy, Urinary Bladder, Neurogenic, Walking

Persons with high-level complete tetraplegia due to spinal cord injury (SCI) generally require assistance with activities of daily living and cannot propel their own manual wheelchairs. Those with lower-level complete tetraplegia most often can propel a manual wheelchair but may need some assistance doing so depending on the environment, whereas those with complete paraplegia usually can propel a manual wheelchair and care for themselves. Persons in all of these groups often have a neurogenic bowel and bladder. Conversely, functional recovery after ASIA Impairment Scale (AIS) D SCI can vary considerably. In a comprehensive review, Kirshblum and O'Connor¹ summarized recovery of ambulation after motor or sensory incomplete SCI and for the incomplete syndromes (whether AIS B, C, or D). They documented that not all patients recover the ability to walk. In addition, Waters et al.² found that 76% of patients with incomplete paraplegia could walk 1 yr after injury (although only a fourth of these could do so without any assistive devices), whereas the remaining 24% could not. In neither study were results reported separately for the patients classified as AIS D at the time of discharge from inpatient rehabilitation. The focus here is not on the prognosis for recovery of function. Rather, it is on long-term mortality and life expectancy in AIS D SCI after the patient has stabilized.

An AIS D injury is an “incomplete injury,” wherein “partial preservation of sensory and/or motor function is found below the neurologic level and includes the lowest sacral segment.”³ In addition, AIS D is such that “motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade of 3 or more.”³ AIS definitions have been clarified several times over the years, including recently in 2011. Roughly 25% of persons with SCI in the large international registries have AIS D injuries.⁴⁻⁷

Distinctions in life expectancy have been made within the tetraplegia and paraplegia groups, where the level and grade of injury, for example, are known to be highly correlated with functional ability. But this has not been done for the AIS D group.⁴⁻⁷ Although some types of AIS D, such as Central Cord Syndrome and Brown-Sequard Syndrome, describe the type of disability, they do not in themselves indicate the extent of disability. Because the severity of disability is a key factor related to survival in other neurologic conditions (e.g., cerebral palsy,⁸ traumatic brain injury,⁹ and stroke¹⁰), it

was hypothesized that it would be a factor in this group also. In particular, it was expected that ambulatory ability (or other means of locomotion) and bowel/bladder dysfunction would be significantly associated with survival.

Motor function is intimately related to the level and grade of SCI. The ability to walk, which is well known to be associated with survival,^{11,12} depends on the strength of key muscles innervated by nerves in the lumbar and sacral regions of the spine. SCI can thus impair this ability. As is well known, neurogenic bowel and bladder are common after SCI.^{13,14} Injuries at a higher level, or of a more severe AIS grade, are more likely (although of course not certain) to lead to bowel and bladder dysfunction.¹⁵ Bowel dysfunction can cause numerous complications, including ileus, ulcers, reflux, autonomic dysreflexia, pain, distention, diverticulosis, and impaction, all of which can increase morbidity and mortality.¹³ The resultant long-term morbidity may include chronic urinary tract infections, bladder cancer, renal calculus, renal failure, and hydronephrosis.¹⁶ Clogged catheters or impacted bowels can also result in episodes of autonomic dysreflexia. Each of the above bowel or bladder complications is known to be associated with excess mortality risk.^{13,16} More significant bowel or bladder dysfunction after SCI would therefore portend worse survival.

The first objective of the present study was to determine how survival in AIS D SCI depends on locomotion ability (and whether ambulatory or by using wheelchair) and the extent of bowel or bladder dysfunction. The second was to use these findings to compute life expectancies for any relevant subgroups. The third was to determine whether survival has improved over time.

METHODS

Study Population

Data were collected through the SCI Model Systems program and submitted to the National Spinal Cord Injury Statistical Center (NSCISC). As many as 31 SCI centers located around the United States have contributed to this database at various times. Detailed descriptions of the history, eligibility criteria, data collection protocol, data quality control procedures, and current status of the SCI Model Systems database have been published previously.^{6,17} This is the largest and most comprehensive source of data on SCI available. Briefly, to be included in the database individuals must have (1) had a clinically discernible degree of neurologic

(spinal cord) impairment after a traumatic event, (2) been treated at a model system within 1 yr of injury, (3) resided in the model system geographic catchment area at the time of injury, and (4) given informed consent (beginning in 1981). The study period for the present investigation was 1970–2011. Overall, the database included 47,223 people who survived at least 24 hrs after injury. Age at injury ranged from 0 to 99 yrs (mean, 33 yrs). There were 11,770 deaths over the follow-up period.

The AIS was used to classify each person's injury.³ The present study focuses on those with AIS D SCI. The Model Systems began using the AIS in August 1993, replacing the modified Frankel scale. The latter did not require sacral sparing to be classified as Grade D. As one of the objectives was to examine whether there was a time trend, the authors opted not to discard data before 1993 and thus to combine Frankel Grade D with AIS Grade D. The authors are not aware of any evidence to show that patients diagnosed as Frankel D were systematically more or less impaired than those diagnosed as AIS D. In fact, it was found that the percentage of Grade D patients who can ambulate was rather similar between Frankel (58.6%) and AIS (59.2%) in the 4 yrs before and after, respectively, the change in criteria. On the other hand, if Frankel D patients were more severe than AIS D patients, their inclusion in this study would, if anything, lead to better survival in later years. Changes in the AIS standards for Grade D SCI since 1993 have been modest and are thus unlikely to affect the results presented here. In preliminary analyses, persons with AIS E ("neurologically normal") SCI were also examined. It was found that mortality in this group was very similar to that in the United States general population, with standardized mortality ratios (SMRs) of 0.8 and 1.0 for men and women, respectively. These points will be considered further in the discussion.

The analysis was restricted to data on persons with Grade D SCI who:

- Were older than 19 yrs at time of injury
- Were not ventilator dependent at discharge
- Survived at least 1 yr after injury

The first restriction was imposed because the effects of injury in childhood, when physiologic development is incomplete, are known to be different from those in adulthood. Long-term survival in young children with SCI has been the subject of a separate study.¹⁸ The second was imposed because the effect of ventilator dependence has been

previously studied¹⁹ and, in any event, is uncommon among persons with AIS D. Regarding the third, preliminary analysis indicated slightly higher mortality during the first postinjury year for some subgroups of AIS D SCI. To simplify matters, attention was therefore restricted to persons who survived 1 yr after injury. The study sample contained a total of 8,206 persons, 1,730 of whom died during the 41-yr study period, who contributed 114,739 person-years of follow-up.

As noted, the first aim of the present study was to investigate the effects of locomotion ability and bowel/bladder dysfunction on survival. Such information was available only for the persons who received annual follow-up by the Model Systems (roughly 60%). For these persons, method of bladder management has been part of the initial and follow-up data collection protocol since the inception of the NSCISC database. However, measures of bowel and bladder independence as well as locomotion were added to the database at inpatient rehabilitation discharge only in 1988 and annual follow-up in 1995. Therefore, many patients had missing data on these items before data collection began. Overall, 59% of patients had missing information on locomotion, 20% on bladder, and 59% on bowel. These persons were not excluded from the analyses. Rather, all of these data were retained to improve the precision of the estimates for the other risk factors (principally age and sex) and also to be able to examine the trend in survival over a longer period. Restriction of the analyses to persons with complete follow-up information on ambulation and bowel/bladder dysfunction did not materially change any of the results. For example, there were no systematic changes (higher or lower by 10%) in the effects of the risk factors in the survival models. "Last observation carried forward" was used to impute missing values. This was a conservative choice, as the potential misclassification bias in this approach would tend to mute the true differences between the groups and thus to reduce the power of the study to find statistically significant findings. For example, the observed relative risk of mortality for people who require catheterization, compared with those who do not, will be less than the true relative risk if any persons in the former group were misclassified into the latter, or vice versa.

Variables Considered in the Analyses

- Age was modeled using a single linear term. This was more parsimonious than inclusion of separate terms for each 5- or 10-yr age group. With this approach, the log odds of dying within a 1-yr

interval increases by the same amount for each extra year of age, which approximates the usual exponential increase in mortality.

- Sex was coded using an indicator variable for men compared with women.
- Race included white, African American, American Indian, and others. Indicator variables were used for each.
- Marital status at discharge was coded using an indicator variable for married *vs.* all others.
- Education level at discharge was coded using an indicator variable for college or greater *vs.* all others.
- Etiology of injury. Previous studies have shown that personal violence (as opposed, for example, to a motor vehicle accident or fall) was associated with increased mortality. Therefore, an indicator variable for personal violence *vs.* all other causes was used.
- Neurologic level of injury refers to the most caudal segment of the spinal cord with normal sensory and antigravity motor function on both sides of the body, provided that there is normal (intact) sensory and motor function rostrally. An indicator variable for cervical *vs.* lower levels was used.
- Time since injury was examined to determine whether mortality is higher in the early post-injury period (1.0–3.0 yrs after injury) than in later years. An indicator variable for this early period was used.
- Calendar year (the calendar year of the person-year of exposure time, not necessarily the year of injury or death) was included to investigate secular (time) trends in survival. Both linear and indicator terms (e.g., “years 1990 or later”) were used.
- ASIA total motor score at discharge was added to the database in 1986. It is an integer scale from 0 (no function) to 100 (highest function). A linear term was used to investigate whether better motor function was associated with longer survival.
- Locomotion was measured using two variables:
 - (1) Functional Independence Measure locomotion mode, which had four values: walking, wheelchair, both modes, and unknown; and
 - (2) Functional Independence Measure locomotion ability, which had seven levels ranging from total assistance to complete independence. The small percentage (4%) who used “both modes” were categorized as walkers. Both variables were used to create the following five groups:
 - Wheelchair is used as primary means of locomotion; with assistance or supervision (levels 1–4 for those who use a wheelchair)
 - Wheelchair is used as primary means of locomotion; operates independently; no supervision (levels 5–6 for those who use a wheelchair [there is no level 7 for wheelchair])
 - Missing or unknown
 - Walks with assistive device (e.g., cane, crutch) (levels 1–6 for those who walk as their primary form of locomotion)
 - Walks independently at least 150 feet without any assistive device (level 7 for those who walk as their primary form of locomotion)
- Bladder dysfunction was indicated in three variables: (1) bladder management method, (2) toileting assistance, and (3) number of bladder accidents per week. Preliminary analyses indicated that bladder management was the best predictor of survival, and the following groups were used:
 - Indwelling catheter or other bladder drainage techniques (except intermittent catheterization)
 - All others (includes persons with normal micturition, diapers, intermittent catheterization program, unknown, and missing values)
- Bowel dysfunction, a variable introduced to the database in 1981, was measured using the number of bowel accidents per week.

In the analyses, updated (time-varying) values of the locomotion and bladder variables were used. In the presence of the above bladder variable, the bowel variable did not add significantly to the prediction and was thus dropped from further consideration. Variables that reflect current health status, such as residence in a nursing home or hospital, were not included. Preliminary analyses showed that these were highly correlated with functional status. In addition, they are time-varying. To assume that a person with SCI will permanently have either poor or good health would be inappropriate. Depression was also not included, as again this factor may vary significantly over an individual's lifespan.

Mortality Data

The Model Systems data collectors reported date of death to the NSCISC database whenever, in the course of their routine follow-up data collection activities, they determined an individual to be deceased. In addition, during 2011, the staff of the NSCISC checked on the survival status of persons in the database by searching the Social Security Death Index online at www.ancestry.com. Persons not reported as deceased by the Model Systems and not

found in the Index were assumed alive on June 15, 2011. The Social Security Death Index has previously been found to be 92.4% sensitive and 99.5% specific for persons in the NSCISC database.²⁰ That these values are not each 100% implies that, on balance, the mortality rates calculated here may be slight underestimates and the life expectancies are slight overestimates.

Statistical Methods

The empirical mortality rates for men and women were computed. These are simply the number of deaths divided by the exposure time in each age- and sex-specific group. With the use of standard methods, the same methods used to construct the national life tables, life tables were then constructed for each sex from these rates.^{21,22} Briefly, a life table summarizes the mortality experience of a group and is completely determined by the given mortality rates at all ages. Life expectancies (average survival time) were obtained from the life tables.

The expected number of deaths for each age and sex combination was also computed, based on the 2008 United States general population mortality rates, the most recent final year available.²¹ For presentation, the results were aggregated into decennial age groups (20–29, 30–39, ..., 90–99). The mortality ratio (MR) was computed as the observed number of deaths divided by the expected number for the age- and sex-matched general population. Because no secular trend in survival was found, the most recent calendar year was chosen for comparison with the general population.

The effects of the variables were estimated using regression analysis of the survival data. In particular, a logistic regression²³ model applied to person-year data was used.²⁴ Here, the dependent variable was a binary indicator of whether the person died during the 1-yr interval. The independent variables were those listed above, including time-dependent values of age, functional disability, time since injury, and calendar year. This approach has been widely used in related work on the same SCI data.^{25–27} It is equivalent to the use of the Cox proportional hazards regression model with time-varying covariates but does not require the assumption of proportional hazards.²² This method was preferable here because the authors sought to estimate mortality rates over the lifespan, while controlling or adjusting for many factors including sex, time since injury, functional ability, and calendar year (secular trend).

First, a logistic regression survival model with terms only for age and sex was constructed. This “simple model” was used to compute mortality rates for each age and sex combination. These modeled rates and the resulting life expectancies were then compared with the empirical values. This was to ensure that this simple model was faithful to the observed data before the additional risk factors listed above were introduced. Whether this simple model was a good fit to the data was also formally tested.

Model selection for the survival models that included the other variables (such as locomotion and bladder management) was carried out using Wald and deviance statistics for nested models, and the Akaike information criterion otherwise.^{28(p79)} The latter is formally similar to the usual deviance statistic for comparing two models, but it applies when one model is not “nested” within the other.

The final survival model was used to compute mortality rates for each age, sex, and functional group. As above, these rates were used to construct life tables,^{21,22} from which the life expectancies were obtained.

RESULTS

Demographics for this study’s group of non-ventilator-dependent AIS D SCI adults who survived 1 yr after injury are given in Table 1. The average age at injury was 39 yrs, and 79% were men. Most were white (69%), lived in a private home after discharge (75%), and had a cervical injury (61%). The percentage of missing values decreased during the follow-up period, as more detailed follow-up data were collected by the Model Systems. Persons with sports injuries tended to have higher level injuries but also better ambulatory ability, whereas those with “other” etiology tended to have lower functioning overall; bladder management method was not significantly associated with the level of injury (results not shown).

Table 2 shows the empirical mortality rates and resulting empirical life expectancies by age and sex. The corresponding general population life expectancies are shown for comparison. As can be seen, and as is common in many diseases and conditions, (1) mortality rates generally rise with age and are higher in men than women and (2) the MR (also known as the relative risk of mortality) generally decreases with age and is higher in women than men.

The life expectancies computed from the simple model (the survival model with terms only for age

TABLE 1 Demographics and characteristics 1 yr or later postinjury

Factor	Values	%
Sex	Male	79
	Female	21
Race	White	69
	Black	21
	Other	10
Decade of injury	1970–1979	15
	1980–1989	36
	1990–1999	27
	2000–2010	22
Marital status	Single	34
	Married	31
	Divorced	10
	Separated	4
	Widowed	3
	Other	19
Education	8th grade or less	7
	9th through 11th grade	16
	High school diploma or equivalent	45
	Associate degree	2
	Bachelor's degree	7
	Master's degree	2
	Doctorate	1
	Other	21
Etiology	Falls	29
	Vehicular	42
	Violence	12
	Sports	8
	Other	9
Neurologic level	Cervical	61
	Thoracic	19
	Lumbar	19
	Sacral	1
	Unknown	0
	ASIA total motor score	
	0–19	0.4
	20–39	1
	40–59	5
	60–79	23
	80–99	58
	100	12
Residence at discharge from rehabilitation	Private	75
	Hospital	1
	Nursing home	4
	Group living home	1
	Unknown	19
Locomotion mode	Walking	21
	Wheelchair	17
	Both walking and wheelchair equally	4
	Unknown	59
Locomotion ability for those with mode = walking	1. Walks independently 150 ft or more	19
	2. Walks 150 ft but with brace, special shoes, cane, or crutches	49
	3. Walks 50 ft in the house, with or without assistive device	21
	4. Minimal contact assistance to walk 150 ft	8

(Continued on next page)

TABLE 1 (Continued)		
Factor	Values	%
Locomotion ability for those with mode = wheelchair	5. Moderate assistance to go 150 ft	1
	6. Maximal assistance to go 50 ft	2
	7. Total assistance to walk less than 50 ft	1
	1. Operates wheelchair independently for 150 ft	67
	2. Operates wheelchair independently only 50 ft	15
	3. Minimal contact assistance to go 150 ft	5
	4. Moderate assistance to go 150 ft	3
Bladder management	5. Maximal assistance to go 50 ft	3
	6. Total assistance to go less than 50 ft	7
	1. None—voids satisfactorily without using voiding techniques	38
	2. Voids satisfactorily using any method of reflex stimulation or any form of extrinsic pressure	5
	3. Neurogenic bladder but does not follow any established bladder management program; includes use of diapers, pampers, etc	4
	4. Intermittent Catheterization Program with or without external collector or diversion (catheter through a stoma that is not suprapubic)	20
	5. Condom catheter (men only), with or without sphincterotomy	8
	6. Indwelling catheter—urethral, suprapubic, or other, with or without augmentation or continent diversion	6
Bladder accidents/week	7. Other bladder drainage techniques such as ureterocutaneostomy (pyelostomy), electrostimulation, electromagnetic ball valve, detrusor stimulation, sacral implants, conus implants, vesicostomy, ureteral catheterization, etc	1
	8. Unknown	20
	0	16
	0, with device	12
	1–3	6
	4–5	7
	Unknown	59
	Bowel accidents/week	0
0, with device		15
1–3		6
4–5		7
Unknown		59

Figures are percentages of the total study population of 8206.

and sex) are very similar to those computed from the empirical mortality rates. This indicates that, in practical terms, the model was a good fit to the data. Formally, the model was statistically significant ($P < 0.0001$) and goodness-of-fit could not be rejected (Hosmer and Lemeshow test, $P = 0.08$). As can be seen, life expectancy is reduced in AIS D SCI compared with the general population. The average reduction across all levels of functional disability is approximately 8 yrs at the younger ages and decreases to less than a year by age 90 yrs.

No secular (time) trend in survival was found (odds ratio [OR], 1.00 [95% confidence interval 0.99, 1.01]; $P = 0.95$). That is, persons with AIS D SCI do not seem to be living longer now than they did 10 or 20 yrs ago. Nor was there any effect of time since injury after the first year (OR, 1.012; $P = 0.88$). Mortality in cervical, thoracic, and lumbar level injuries was slightly higher than in sacral ones

(a combined OR of 1.4 in univariate analyses; not shown), but the difference was not statistically significant ($P = 0.24$), and in any event, this factor was highly correlated with both ambulation and bladder function. The ASIA motor score was not a significant predictor after the locomotion and bladder terms (see below) were included in the model. The OR was, in fact, in the wrong direction (OR, 1.003; $P = 0.40$). Marital status, education, cause of injury, and race were not statistically or practically significant. For example, the OR for personal violence as etiology was 1.02 ($P = 0.80$) and for white race was 1.002 ($P = 0.96$).

The final logistic regression survival model for the ten possible functional groups (five levels for locomotion and two for bladder) is shown in Table 3. As can be seen, this is a main effects model, with terms for age, sex, locomotion, and bladder management. No meaningful interaction effects among

TABLE 2 Empirical mortality data and results

Age	Exposure	Deaths	Mortality Rate	Expected Deaths ^a	MR ^b	Empirical LE ^c	Simple Model LE ^d	GP LE ^e
Men								
20	13,439	35	0.0026	19	1.8	47	48	57
30	23,153	107	0.0046	39	2.7	39	39	47
40	24,152	197	0.0082	82	2.4	30	30	38
50	16,495	297	0.0180	124	2.4	22	22	29
60	9,044	326	0.0360	142	2.3	16	16	21
70	4,212	294	0.0698	153	1.9	10	10	14
80	1,131	146	0.1291	108	1.4	7	6	8
90	115	33	0.2776	26	1.3	4	4	4
All	91,747	1,435	0.0156	750	1.9			
Women								
20	2,932	9	0.0031	2	5.8	52	53	61
30	5,121	14	0.0027	5	3.1	44	43	52
40	5,773	39	0.0068	12	3.2	35	34	42
50	4,258	44	0.0103	19	2.3	27	26	33
60	2,694	60	0.0223	28	2.2	19	19	24
70	1,555	76	0.0489	40	1.9	13	13	16
80	662	77	0.1164	47	1.6	8	8	9
90	111	19	0.1706	21	0.9	6	5	5
All	23,184	338	0.0146	189	1.8			

^aExpected deaths are based on the 2008 United States general population age- and sex-specific mortality rates applied to the given exposure time. For example, if there were 1000 person-years of exposure time, with an expected mortality rate of 0.005 per year, the expected number of deaths would be $1000 \times 0.005 = 5$. Because there was no secular trend, a recent calendar year for the expected mortality rates was used. Had an earlier calendar year (e.g., 1988) been used, the expected deaths would have been larger and the MRs smaller, but the other figures in the table would have been the same.

^bMR = observed deaths divided by expected deaths. This term is also referred to as the relative risk of mortality. The overall figures (1.9 and 1.8) might also be referred to as SMRs.

^cLEs computed using the empirical (i.e., actual) mortality rates in this table.

^dLEs computed based on the mortality rates from the simple logistic regression survival model with terms for only age (a linear term) and sex.

^eUnited States GP life expectancy for 2008.

MR indicates mortality ratio; LE, life expectancy; GP, general population.

these or other factors were identified. For example, the effect of sex was roughly the same at each age and for each functional group. There was no interaction between the two disability measures (locomotion and bladder management, $P > 0.10$ in all cases). That is, the simple main effects model was not practically

or statistically different from models either with interaction terms or indicator variables for each of the 10 functional groups. Note that the model effects are relative to the reference groups. For example, persons who are wheelchair dependent and require assistance after AIS D SCI have 2.13 times the

TABLE 3 Final logistic regression survival model

Variable	Parameter Estimate	OR ^a	95% CI	P
Intercept	-14.3802	-	-	-
Age (for each 1-yr increase)	0.0694	1.07	1.069-1.075	<0.0001
Male	0.3635	1.44	1.28-1.62	<0.0001
Female ^b	-	1.00	-	-
Ambulatory level				
Wheelchair user; requires assistance	0.7567	2.13	1.41-3.23	0.0002
Wheelchair user; independent	0.3345	1.40	1.24-1.58	0.012
Missing or unknown	0.3151	1.37	1.04-1.81	0.006
Walks with assistive device or assistance	0.2306	1.26	0.98-1.63	0.097
Walks independently ^b	-	1.00	-	-
Bladder management				
Indwelling catheter or other drainage techniques	0.4201	1.52	1.28-1.81	<0.0001
All others (including normal micturition) ^b	-	1.00	-	-

^aOR for mortality in the given group compared with that of the reference group, which has OR = 1.00 by definition. Computed as "e" raised to the parameter estimate.

^bReference group.

OR indicates odds ratio; CI, confidence interval.

mortality risk of those who can walk independently (who, in turn, have a higher mortality risk than the general population).

The mortality risk in the group who had an intermittent catheterization program was intermediate to that of those with normal micturition and those with an indwelling catheter, with a relative risk of 1.2 compared with the former group; the difference, however, was not statistically significant ($P = 0.17$), and the authors thus opted not to present separate results for this group, but rather to include these persons in the group labeled as “all others” (see detailed description of all groups in Table 1).

Table 4 provides life expectancies for six of the ten functional groups. The other four groups are discussed below. Values for persons with paraplegia and for the general population are shown for comparison. Life expectancies of those who can walk unassisted and who do not require an indwelling catheter for bladder management are reduced by less than 10% at the youngest ages and are nearly normal at older ages. Persons who use an assistive

device to walk but who have normal micturition have a roughly 10% reduction in life expectancy from the general population at the younger ages and 15% at the older ages. The life expectancies in the “walks with assistive device, no catheter” group are quite similar to those of the entire group (“all AIS D”), suggesting that they properly represent the “average” person with AIS D SCI.

Life expectancies for persons who require assistance with their wheelchair and who have an indwelling catheter for bladder management (not shown) are even lower than for persons with paraplegia. This follows by application of the OR of 1.52 shown in Table 3. Upon further investigation, it was found that such persons were much more likely than others to (1) decline in their neurologic level or AIS grade, (2) become lost to follow-up, or (3) die within 5 yrs. In addition, the sample size for this group was very small ($n = 30$), raising the possibility of random error in the results. Thus, this group was not considered further. Also not shown in Table 4 is the unusual and relatively small group of fully ambulatory adults who required an indwelling

TABLE 4 Life expectancies for AIS Grade D SCI, stratified by age, sex, and functional group^a

Age	Paraplegia, AIS A, B, C ^b	All AIS D ^c	Wheelchair—Dependent ^d		Wheelchair—Independent ^e		Walks with Assistive Device ^f		Walks Independently ^g	
			No Catheter	Indwelling Catheter	No Catheter	Indwelling Catheter	No Catheter	No Catheter	No Catheter	GP ^h
Men										
20	42	48	42	42	47	43	49	52	57	
30	34	39	33	33	38	34	40	43	47	
40	26	30	25	25	30	26	31	34	38	
50	19	22	18	18	22	19	23	26	29	
60	14	16	12	12	16	13	17	19	21	
70	9	10	8	8	10	8	11	13	14	
80	5	6	5	5	6	5	7	8	8	
Women										
20	46	53	47	47	52	48	54	57	61	
30	37	43	38	38	43	39	44	47	52	
40	29	34	29	29	34	30	35	38	42	
50	22	26	22	22	26	23	27	30	33	
60	16	19	15	15	19	16	20	22	24	
70	10	13	10	10	13	11	14	16	16	
80	6	8	6	6	8	7	9	10	9	

^aAll of the results given here are based on the assumption of no improvement or decline in function, even in older age. That is, the life expectancies apply to someone who is assumed to remain in the stated group for the remainder of his/her life. This assumption may be overly optimistic for the higher functioning groups and lead to some overestimation of life expectancy.

^bThese values were derived using the model given in Table 3 of Strauss et al.²⁵ and are provided for comparison.

^cThe combined group of all persons with AIS D, as shown in Table 2 (“Simple Model LE”), based on mortality rates from the logistic regression survival model with terms only for age (a linear term) and sex.

^dUses wheelchair as primary means of locomotion; cannot operate independently; requires assistance or supervision.

^eUses wheelchair as primary means of locomotion; operates independently; no supervision required.

^fWalks without the assistance or supervision of another but requires brace, special shoes, cane, or crutch.

^gWalks independently at least 150 ft without any assistive device.

^hUnited States general population life expectancy for 2008.

SCI indicates spinal cord injury; GP, general population.

catheter. Their life expectancies are marginally lower than that of the best group shown in the table, again reflecting application of the OR of 1.52 shown in Table 3. The final two groups not shown in Table 4 are those based on “missing/unknown” locomotion.

DISCUSSION

As expected, it was found that life expectancy is greater in persons who can walk independently than in those who use support, which in turn is greater than in those who are wheelchair bound. Survival in the “walks with assistive device, no catheter” group was found to be close to the average among all persons with AIS D SCI. It was also found that persons with AIS D SCI who are functionally similar (i.e., use a wheelchair) to those with paraplegia (i.e., level T1 or below, AIS A, B, or C) due to SCI also have similar life expectancies. That is, survival after AIS D SCI seems to be more related to the severity of functional disability than to the nominal level or grade of injury.

Life expectancies of persons with AIS D SCI who can use a wheelchair only with assistance or supervision but who do not require a catheter are very similar to those of persons with paraplegia. Unlike the former group, most persons with paraplegia require bladder management via a catheter, whether external, indwelling, or intermittent, which would tend to make their life expectancies lower. On the other hand, they can also generally propel their own manual wheelchair independently. These two factors seem to roughly balance each other, resulting in the similar survival figures.

The life expectancies given here are, if anything, too high for the higher functioning groups, as they assume no decline in function with age. Conversely, they may be slightly too low for the lower functioning groups, as they assume no improvement. The authors examined this last issue, however, and found that improvement in ambulatory ability after 1 yr after injury was unlikely. Similarly, any improvement in bladder function was minimal (e.g., change from indwelling to intermittent catheterization program) and was more likely in younger patients.

Motor score was not a significant predictor of survival after the locomotion and bladder variables were taken into consideration. This finding echoes that of Dvorak et al.,²⁹ who found that “motor score alone does not adequately describe function and quality of life at long-term evaluation.” There was no increased mortality risk in the period 1.0 to 3.0

yrs after injury. That is, unlike a previous finding for persons with AIS A, B, or C SCI who have paraplegia or tetraplegia,²⁵ the second and third years after injury do not seem to be a higher risk period.

There was no secular trend in survival during the 1970–2011 period. Previous research has found that survival improved from the 1970s to 1980s for persons with paraplegia and tetraplegia but also remained relatively constant from 1980 to 2006.²⁵ The underlying general population life expectancy has steadily improved over the 1970–2011 period.²¹ That the AIS D group did not keep pace may suggest that (1) the severity of injury has increased over the period and is not fully captured by the ambulation and bladder variables considered here, (2) other comorbid factors, such as smoking or obesity, are involved, or (3) care for patients with AIS D in the 1970s was relatively advanced compared with the AIS A, B, and C groups. At present, however, there is no evidence to support any of these possibilities. Further research on these issues may be warranted but is outside the scope of the present study. This study’s finding that the need for catheterization in SCI is associated with increased mortality risk is not surprising. Complications in persons with neurogenic bladders are expected even under “good urologic management,”¹⁶ and such complications are well known to be associated with increased morbidity and mortality. Feifer and Corcos³⁰ found that morbidity in patients with suprapubic catheters is comparable with those using clean intermittent catheterization. They did not address mortality. In the present study, indwelling catheter use was associated with modestly higher mortality than intermittent catheterization (OR 1.5 compared with 1.2), although the difference was not statistically significant. This may be a result of the increased risk of infection with indwelling catheter or because persons who can self catheterize are generally less severely disabled overall (with better fine motor control and ability to care for themselves). Interestingly, a 2007 Cochrane analysis concluded that no single type, technique, or strategy of intermittent catheterization is better than another.³¹ The authors did not have sufficient data to examine this assertion.

Mortality due to urinary tract disease in SCI has fallen dramatically over the past 50 yrs (e.g., Frankel et al.⁴), but it remains higher than in the general population.⁶ Persons with repeated urinary tract infections are known to be at higher risk of death. For example, Krause et al.²⁶ found that a history of symptomatic urinary tract infections increased mortality risk by 7% per incident. The effect of

chronic bladder dysfunction, per se, on long-term survival in SCI has not previously been described in the medical literature. It has been documented in studies of other conditions, such as cerebrovascular accident.³² Many of those studies did not, however, control for other factors, such as the severity of the stroke. An exception is Han et al.,³³ who showed that although urinary incontinence was a significant univariate predictor of survival, it was no longer significant in a multivariate model. Here, however, urinary dysfunction was a significant risk factor even after physical disability was taken into account.

Previous studies have suggested that the Model Systems catchment areas may not be representative of the United States population as a whole.²⁵ This was listed as a limitation of those studies. As noted earlier, SMRs for the AIS E (“neurologically normal”) group were 0.8 and 1.0 for men and women, respectively, compared with the United States general population. This suggests that the Model Systems population is comparable with (women) or perhaps slightly healthier than (men) the overall United States general population from which it is drawn. This conclusion is not affected by the fact that patients treated by the Model Systems are, on average, more severely disabled than other such patients in the United States, many of whom may not obtain inpatient rehabilitation.

A limitation of the present study is that the type of wheelchair (i.e., manual or electric) used as the primary form of locomotion was not distinguished. Certainly, those who can propel a manual wheelchair are less severely disabled than those who use a power wheelchair. The authors surmise that most of the wheelchairs used here are of the manual type, suggesting that the overall figures are typical for this group. The prognosis for those who can only operate a power wheelchair might reasonably be expected to be worse than reported here, but the authors are not aware of any evidence on this issue.

Another limitation concerns the large amount of missing data. As indicated, AIS motor score was not available before 1986, whereas functional information was not available before 1985. The problem was compounded because complete follow-up evaluations were not performed every year. The “last observation carried forward” was used here to increase the power of the calculations. As noted, however, this also would tend to reduce the magnitude of the effects of the various factors. In this sense, the true effect sizes for locomotion and catheterization are thus, if anything, larger than those reported here. A further limitation is that the criteria for Grade D SCI have changed over the

40-yr study period. Originally, the Model Systems used the Modified Frankel scale, but since 1993, it has used the AIS, which itself has been revised several times. The authors note, however, that although clarifications have occurred since 1993, the basic criteria for Grade D have remained rather constant.

There were no sufficient data to determine whether the prognosis differs in persons with Central Cord Syndrome or Brown-Sequard Syndrome. In addition, in this study, there was no information on comorbid factors, such as smoking, obesity, and alcohol abuse. To the extent that impaired locomotion or neurogenic bowel/bladder is correlated with these factors, the results given here are confounded by their effects. Finally, it would be worthwhile to examine the causes of death in this AIS D population, to examine whether they differ materially from those of the SCI population in general. This, however, is outside the scope of the present study.

In this study’s population of persons with AIS D SCI, it was shown that the extent of locomotion disability after injury is a key predictor of survival. The reductions in life expectancy for independently ambulatory persons are similar to the known effects of nonneurologic occupational or lower limb injury.^{11,12} The reductions for the lowest functioning groups compare with those for paraplegia. The overall findings are consistent with most other published figures on the life expectancy of persons with AIS D SCI.^{4–7}

This study also documented that excess mortality exists for persons with need for indwelling catheterization, even after controlling for age, sex, and locomotion ability. It is possible that this effect is confounded with other factors (such as the level and type of injury). That is, bladder dysfunction may serve as a proxy for other, yet unmeasured, factors. But any such factors were not identified. Future research might usefully identify these, or examine whether this study’s findings hold true among more severe spinal cord injuries (e.g., AIS A, B, or C) or in other neurologic conditions.

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