Life Expectancy of Ventilator-Dependent Persons With Spinal Cord Injuries*

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Objective: The purpose of this study is to estimate agespecific life expectancies for ventilator-dependent persons with spinal cord injury (SCI).

Design: Nonconcurrent prospective study.

Setting: Federally designated model SCI care systems. Patients: The study included all 435 persons admitted to a model SCI care system between 1973 and 1992 who survived at least 24 h postinjury and who were either ventilator dependent at rehabilitation discharge or who died prior to discharge while still ventilator dependent. Intervention: None.

Outcome measures: Standardized mortality ratio (SMR), life expectancy, and causes of death.

Results: The overall 1-year survival rate was 25.4%, while the 15-year survival rate was 16.8%. Among those who survived the first year, cumulative survival over the next 14 years was 61.4%. The mortality rate for persons injured since 1980 was reduced by 60% compared with persons injured between 1973 and 1979. Among year 1 survivors, the subsequent mortality rate was reduced by

39% for persons injured between 1980 and 1985, and 91% for persons injured since 1986, relative to persons injured between 1973 and 1979. The leading cause of death was respiratory complications, particularly pneumonia.

Conclusions: With the development of improved methods of prevention and management of respiratory complications in this population, life expectancies should continue to improve. As a result, additional attention should be focused on enhancing the quality of life for these individuals. (CHEST 1995; 108:226-32)

ICD-9-CM=International Classification of Diseases, 9th revision, clinical modification; SCI=spinal cord injury; SMR=standardized mortality ratio

Key words: mortality; spinal cord injury; ventilator dependency

There have been numerous studies of long-term survival and causes of death after spinal cord injury (SCI) published during the past two decades. 1-23 However, survival of the subgroup of ventilator-dependent persons with SCI was assessed in only four studies, each of which was limited by both very small sample sizes and use of statistical methods that precluded estimation of either survival rates or life expectancies from the time of injury. 24-27

The issue of long-term survival among ventilator-dependent persons with SCI has become increasingly important to insurance companies, case managers, attorneys, clinicians, health policy analysts, and individuals who sustain these injuries because of the trend toward increasing numbers of ventilator-dependent persons who survive the initial injury and the enormously high costs associated with both initial and long-term treatment of these individuals. ^{24,28,29} Therefore, the purpose of this study was to estimate

the age-specific life expectancies of a relatively large population of ventilator-dependent persons with SCI, to determine the extent that long-term survival of this population has improved over the past two decades, and to determine the most frequent causes of death in this population.

METHODS

Study Population

This study was conducted on 435 persons who sustained a traumatic SCI between 1978 and 1992 that resulted in ventilator dependency, who survived at least 24h after injury, and who were admitted within 1 year of injury to a federally designated model regional SCI care system located throughout the United States (the identity of each facility appears in the acknowledgment). All persons either remained ventilator dependent at the time of discharge from rehabilitation or died prior to discharge while still ventilator dependent. For purposes of this study, ventilator dependency was defined as requiring either partial or total respiratory support on a daily basis. Persons with electrophrenic pacers implanted prior to discharge from rehabilitation were excluded due to insufficient sample size and possible differences in survival rates when compared with ventilator-dependent persons.

Data Collection

Information on date of injury, age at injury, sex, race, number of days from injury to SCI care system admission, neurologic level of lesion, degree of injury completeness, and date of death (or date last known to be alive) was abstracted from each person's medical record. When applicable, cause of death was determined

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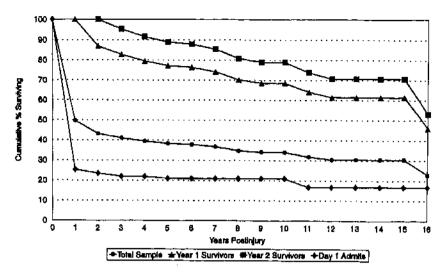


FIGURE 1. Cumulative 16-year survival for each group of ventilator-dependent persons with spinal cord injury.

from all available information, including the hospital discharge summary, death certificate, and/or autopsy report. Autopsies were performed for 49% of deaths, a figure that is somewhat higher than for the SCI population in general.¹

The support of the Social Security Administration was enlisted to assist in identifying the survival status of persons who were otherwise unavailable for follow-up by searching its Muster Beneficiary Record and Summary Earnings Record files for information on persons for whom benefit claims were submitted or for whom benefits were terminated because of death, Social Security Administration data were found to be 92.4% sensitive and 99.5% specific with respect to mortality of a large national sample of persons with SCI.³

Statistical Analysis

For analytic purposes, follow-up of study subjects ended December 31, 1993. Only deaths occurring before this date were considered; persons dying after this date were considered "withdrawn alive."

Cumulative survival over time was analyzed using the Cutler-Ederer life-table technique. OP Proportional-hazards regression analysis was used to assess the trend in survival rates since 1973 while controlling for trends in age at injury, sex, race, neurologic level of injury, and completeness of injury.

Expected numbers of deaths in the absence of SCI were calculated using life tables specific for age, sex, and race published by the federal government for the year 1982 (the approximate midyear of the study follow-up period). A separate standardized mortulity ratio (SMR) was then calculated as the ratio of observed to expected deaths for each of three age groups (1 to 30, 31 to 60, and 61+ years). These SMRs were then applied to 1988 general population mortality rates (the most recent available) to determine life expectancies using the method described by Smart and Sanders. A

Simple linear regression of age against the square root of life expectancy was used to smooth out the decline in life expectancy projections with advancing age that was caused by having only three SMR estimates rather than a distinct SMR for each individual age. The square root transformation was used because it provided the best fit (highest proportion of explained variance) when compared with other potential models.

Each analysis was performed separately for the entire sample, the subsample of persons admitted to the model SCI care system within 24 h of injury, the subsample of persons who survived the first postinjury year, and the subsample of persons who also survived the second postinjury year. This approach allowed an assessment of both the potential bias caused by slightly delayed admissions and the improved prognosis for persons who survive the initial 2 years postinjury when risk of death is highest.

RESULTS

The mean and SD age at injury of the entire study population was 39.6 ± 22.6 years. Median age at injury was 33 years. The comparable mean and median ages at injury for the overall spinal cord injury population are 30.5 ± 14.9 years and 26 years, respectively. Therefore, persons who sustain SCI resulting in ventilator dependency are on average, slightly older than those who do not require ventilators. Typical of SCI in general, 81.4% of the study population were men, 75.4% were white, 18.2% were African-American, 5.3% were Hispanic, and 1.1% were from other racial/ethnic groups. 29.35

Neurologic levels of injury were as follows: C1, 15.6%; C2, 19.8%; C3, 18.2%; C4, 18.2%; C5, 9.4%; C6, 7.3%; C7, 2.4%; C8, 0.5%; and T1 and below, 8.6%. Not surprisingly, this distribution of neurologic levels of injury is quite different from that of the general SCI population among whom the most common injury levels are the following: C5, 16.0%; C4, 13.0%; C6, 12.9%; and T12, 7.5%. Overall, approximately 54% of all new SCIs occur in the cervical region. Most persons had neurologically complete injuries (71.1%), while 11.5% had sensory sparing

Table 1—SMRs for Ventilator-Dependent Persons With SCI Who Survive at Least 24 h Postinjury by Age and Elapsed Time Since Injury

Age Group, yr	Total Sample	Day 1 Admits	Year 1 Survivors	Year 2 Survivors
1-30	85.40	211.60	34.85	20.86
31-60	44.51	51.91	13.99	8.87
61+	30.17	43.62	4.42	2.38

Table 2—Life Expectancy for Venillator Dependent Persons With SCI Who Survive at Least 24 h Postinjury by Age and Elapsed Time Since Injury

Age,	Normal	Total Sample	Day 1 Admits	Year 1 Survivors	Year 2 Survivors
yr	Normai				
5	70.8	16.7	8.0	26.8	\$5.8
10	65.9	14.6	7.8	24.4	33.2
15	61.0	12.7	6.6	22.1	30.6
20	56.3	10.9	6.0	19.9	28.2
25	51.6	9.2	5.4	17.9	25.8
80	46,9	7.7	4.8	15.9	23.6
35	42.2	6.3	4.3	14.1	21.4
40	37.6	5.0	3.8	12.4	19.4
45	33.0	3.9	3.3	10.8	17.5
50	28.6	3.0	2.9	9.3	15.6
55	24.4	2.1	2.5	7.9	13.9
60	20.5	1.4	2.1	6.6	12.2
65	9.81	0.9	1.7	5.4	10.7
70	13.6	0.5	1.4	4.4	9.3
75	10.7	0.2	1.1	3.4	7.9
80	8.1	0.1	0.9	2.6	6.7

below the injury level, 8.5% had nonfunctional motor capability, and 8.9% had functional motor capability. Conversely, only 47.4% of all persons are discharged from the model SCI care system with a neurologically complete injury.³⁵

Figure 1 depicts cumulative survival over time for the entire study population and each subsample. One-year survival for the entire population was 49.7%. However, when only persons admitted within 24 h were considered, 1-year survival decreased to only 25.4%. This upward bias in survival for the entire population is caused by the inclusion of delayed admissions to the model SCI care system while those who died prior to admission are of necessity excluded. The mean and SD number of days from injury to model SCI care system admission for the entire sample was 34±58. Fifteen-year cumulative survival was 30.5% ± 3.1% for the entire study population and 16.8% ±4.5% for persons admitted within 24 h of injury. Survival estimates shown in Figure 1 for year 16 are somewhat unstable due to small sample size.

Persons who survive the initial period of high risk have a considerably better prognosis. Among those who survived the first postinjury year, cumulative survival for the next 14 years was 61.4% $\pm 5.5\%$, while those persons who survived the first 2 postinjury years had a cumulative survival for the next 13 years of 70.7% $\pm 6.0\%$. Again, survival estimates shown in Figure 1 for the final year of follow-up are somewhat unstable due to small sample size and probably underestimate the true survival rate for that year.

The SMRs for each study subsample by age group appear in Table 1. In general, the SMR decreases with advancing age for each subsample. Among persons admitted within 24 h of injury who were in the

youngest age group, there were 211.6 times more deaths than expected given the age, sex, race, and length of follow-up of those individuals. However, most of these excess deaths occur during the first 2 postinjury years. Among those in the youngest age group who survived this high-risk period, there were only 20.86 times more deaths than expected over the remaining years.

Based on the SMRs appearing in Table 1, life expectancies were calculated by age for each study subsample (Table 2). In this analysis, rather than using constant SMRs over time, reduced SMRs from Table 1 were used as time postinjury increased thereby causing younger persons to advance into older age groups. For a 20-year-old person at injury, life expectancy is reduced from 56.3 to only 6.0 years (an 89.3% reduction). However, for those 20-year-old persons who survive the initial 2 postinjury years, life expectancy increases to approximately 27.2 years despite the fact that they are now 2 years older (age 22 years). This represents a reduction of only 50% compared with the normal life expectancy of 54.4 years at age 22 years.

Beyond age 50 years, use of the regression model resulted in a statistical artifact of slightly lower life expectancy estimates for the entire sample than for the subsample of persons admitted within 24 h of injury. Therefore, the life expectancy estimates for persons admitted within 24 h of injury over age 50 years should probably be replaced by the estimates for the entire study population because of the larger sample size and greater stability of the latter estimates.

Based on the linear regression models using the square root transformation of life expectancy, the proportion of variance in life expectancy explained by age was 95.3% for the total study population, 47.0% for the 24-h admission subsample, 95.8% for the 1-year survivors, and 98.2% for the 2-year survivors. Because of the substantial differences in SMR by age for the 24-h admission subsample (Table 1), its life expectancy estimates were affected the most by failure to use a more continuous function of SMRs by age, and as a result, the regression model did not fit that subsample as well as the others.

Results of the proportional hazards regression analysis appear in Table 3. Interestingly, while results of other studies of survival after SCI that were not limited to ventilator-dependent persons revealed a relative risk of approximately 1.2 for male subjects and 1.3 for nonwhites, 3 sex was not a significant risk factor for any subsample of ventilator-dependent persons (p>0.05). Nonwhites were at significantly higher risk in both the overall sample and the 24-h admission subsample than their white counterparts (p<0.05). However, race was not a significant pre-

Table 3—Relative Risks and 95% Confidence Limits of Mortality for Ventilator-Dependent Persons With SCI for Each Prognostic Factor Based on Proportional-Hazards Regression Analysis

	Prognostic Factors							
	Injury Year				· · · · · · · · · · · · · · · · · · ·		C1 C2	Complete
	1973-1979	1980-1985	1986-1992	Men	Nonwhite	Age*	C1-C3 Injury	Injury
Total sample (n=	435)							
Relative risk	1.00	0.51	0.41	0.86	1.78	1.03	0.54	1,17
95% limits		0.38-0.69	0.28-0.59	0.63-1.18	1.35-2.36	1,02-1.04	0.41 - 0.71	1.08-1.26
Day 1 admit (n=	203)							
Relative risk	1.00	0.40	0.39	0.85	1.47	1.02	0.76	1.09
95% limits		0.26-0.61	0.25 - 0.62	0.56-1.29	1.04-2.06	1.01-1.03	0,51-1.11	0.99-1.19
Year 1 survivors (n=201)							
Relative risk	1.00	0.61	0.09	0.65	0.71	1.04	2.41	3.90
95% limits		0.33-1.13	0,02-0,31	0.35 - 1.23	0.28-1.84	1.02-1.06	0.99-5,85	1.83-11.44
Year 2 survivors (п⇔155)							
Relative risk	1,00	0.60	0.11	0.91	0.73	1.03	3.14	1.78
95% limits		0.25 - 1.46	0.02-0.58	0.33 - 2.50	0.21-2.55	1.00-1.07	0.73-13.56	0.49 - 6.49

^{*}Based on a 1-year increase in age at injury.

dictor of mortality among the year 1 and year 2 survivor subsamples (p>0.05). The relationship between age at injury and mortality was consistent across all subsamples with each year of increased age resulting in approximately 2 to 4% increased mortality rates.

In a previous study of all persons admitted since 1973 to a model SCI care system within 24 h of injury that was not limited to ventilator-dependent persons, it was shown that persons with injury levels between C1 and C3 had a relative risk of mortality of 11.1 compared with persons with thoracic or lumbosacral injuries, and 3.8 compared with persons with C4 or C5 injury levels. However, among ventilator-dependent persons, those with injury levels below C3 apparently have higher mortality rates during the first year than persons with injury levels at C3 or above (Table 3). It is not surprising that persons with low-level tetraplegia or paraplegia who are ventilator dependent have a relatively poor prognosis initially because those individuals would ordinarily not be ventilator dependent based solely on their injury level. Therefore, concomitant injuries and preexisting conditions may be negatively affecting their short-term chance of survival. However, after the first year, as expected, those who have higher injury levels have a poorer prognosis. Also as expected, persons with neurologically complete injuries have a poorer prognosis than persons with incomplete injuries, particularly after the first year

After controlling for time trends for age at injury, sex, race, neurologic level of injury, and neurologic completeness of injury, a significant decrease in mortality was observed since 1973 for each subsample. Among persons admitted within 24 h of injury, the mortality rate for persons injured between 1980

and 1985 was only 0.40 times the mortality rate for persons injured between 1973 and 1979 (a reduction of 60%). However, no significant further improvement in survival rates for this subgroup has occurred since then. Among year 1 survivors, the trend is even more striking, with mortality rates for persons injured between 1980 and 1985 that were only 0.61 times those for persons injured before 1980 (a 39% reduction). Moreover, for persons injured since 1986, mortality rates for year 1 survivors were only 0.09 times the mortality rates for persons injured before 1980 (a 91% reduction). These trends are even greater than those found in nonventilator-dependent persons with SCI.²⁸

The most frequent underlying cause of death was pneumonia, accounting for 27.3% of all deaths of known cause (Table 4). Symptoms and ill-defined conditions caused an additional 12.3% of deaths. These were always respiratory in nature, usually

Table 4—Underlying Cause of Death for Ventilator-Dependent Persons With SCI Who Survive at Least 24 h After Injury (n=265)*

Causes of Death	N (%)		
Pneumonia (480-486)	62 (27.3)		
Heart disease (410-414, 420-429, 458)	55 (24.6)		
Symptoms and ill-defined conditions (780-799)	28 (12.3)		
Infectious and parasitic diseases (88, 40.8)	19 (8.4)		
Other respiratory diseases (492.8, 510-519)	14 (6.2)		
Cerebrovascular disease (430-438)	11 (4.8)		
Pulmonary embolism (415.1)	9 (4.0)		
Diseases of the digestive system (520-579)	8 (3.1)		
Renal disease (586, 593.9)	7 (3.1)		
External causes (E800-E999)	4 (1.8)		
All others (189, 250, 269.9, 308.9, 337.9, 348)	10 (4.4)		
Unknown	38		

^{*}ICD-9-CM codes are in parentheses.

cardiorespiratory failure. If pulmonary emboli and other respiratory diseases are also included, then respiratory conditions are the underlying cause of 49.8% of deaths among ventilator-dependent persons with SCI.

Heart disease was the underlying cause for 24.6% of deaths. However, 50.9% of heart disease deaths were coded as cardiac arrests not otherwise specified (International Classification of Diseases, 9th revision, clinical modification [ICD-9-CM] code 427.5), a category that is sometimes used when the cause of death is uncertain. Most of these deaths occurred among young persons with no history of heart disease, and autopsies were usually not performed. These sudden deaths may be secondary to vagal arrest rather than intrinsic cardiac disease. 26 Therefore, the percentage of deaths due to heart disease may be slightly overestimated. Of the remaining deaths due to heart disease, there were 15 cases of symptomatic nonischemic heart disease (ICD-9-CM codes 420-429), 9 cases of ischemic heart disease. 2 deaths due to diseases of the arteries, and 2 cases of orthostatic hypotension.

All but two deaths in the infectious and parasitic disease category were due to septicemia that was secondary to respiratory infections, urinary tract infections, or pressure sores. Given the relatively young age of most persons in this population, it is not surprising that there were only 11 deaths due to cerebrovascular disease and only one death due to cancer. External causes of death included three unintentional injuries and one suicide.

DISCUSSION

This study provides the most up-to-date, complete, and accurate information currently available about long-term survival and causes of death for a relatively large sample of ventilator-dependent persons followed up prospectively for several years by the model SCI care systems. Perhaps the most striking and by far the most encouraging finding is the substantial improvement in survival rates that has occurred since the inception of the model SCI care system program, particularly among persons who survive the first year. The improved survival experience documented in Table 3 is confirmed by superficial comparison of these results with previously published reports. Although previous investigators used different analytic methods that preclude calculation of the exact amount of improvement in survival rates through comparative techniques, it is clear that the survival rates observed in this study are substantially increased from those reported previously.24,27 Nevertheless, while there has been improvement in first year survival rates as well, three fourths of ventilator-dependent

persons admitted to a model SCI care system within 1 day of injury still die within the first year.

The incidence of respiratory complications is exceptionally high during the first few weeks following cervical SCI. Jackson and Groomes³⁶ recently reported that 63% of persons with C1 to C4 quadriplegia developed pneumonia, and 40% developed atelectasis prior to rehabilitation discharge, with many persons developing more than one episode of each. They reported average time from injury to onset of first episode of pneumonia was 30 days, and the average duration of each episode was 19 days. Moreover, all nine reported deaths during initial care and rehabilitation were due to respiratory complications, with five of the nine due to pneumonia.³⁶

Similarly, Fishburn et al³⁷ reported that 74% of persons with high-level quadriplegia developed either atelectasis or pneumonia, with a mean time from injury to onset of 8 days. They also reported that 96% of patients had lower lobe involvement, with a 4:1 ratio of left to right lung involvement. Recognition of this pattern may lead to earlier diagnosis and more effective intervention. Aggressive prophylactic pulmonary hygiene programs and weaning protocols for this population have been described in detail elsewhere. ^{24,27,37,38}

Given the extraordinarily high incidence rates of pneumonia and the difficulty in managing episodes of pneumonia once they develop, it is not surprising that pneumonia remains the leading cause of death in this population. As a result, pneumococcal vaccination seems warranted at the earliest effective time. Darquiche et al³⁹ recently reported that only 1 of 25 persons with SCI who were considered to be at high risk for developing pneumococcal disease had been immunized against pneumococcal infection. Adequate antibody response to pneumococcal vaccination can be obtained when administered more than 1 year after injury; however, immune function is usually diminished during the first few weeks after SCI, so it is unclear how soon after injury that the vaccine administration will be effective. 39 A doubleblind, randomized trial is presently underway at our institution to address this question. It is recognized, however, that pneumonia is often caused by microorganisms other than pneumococcus. Therefore, even under the best of circumstances, pneumococcal vaccination will be only partially successful in reducing the risk of pneumonia.

Postdischarge information on ventilator status was not available. Therefore, it is possible some persons in the study population were successfully weaned after discharge. Although many factors affect weanability, the fact that several persons in this study population had injury levels below C3 suggests that at least some were candidates for additional weaning attempts. ^{24,27}

By the time of rehabilitation discharge, Wicks and Menter²⁷ reported successfully weaning 28% of persons with C2 injury levels, 51% of persons with C3 injury levels, and 78% of persons with cervical injury levels at C4 and below who were initially ventilator dependent. They also reported that of 47 persons who were still ventilator dependent at discharge, six (13%) were subsequently weaned.²⁷ Life expectancies are considerably improved for those individuals who are successfully weaned.³

Interestingly, despite the one suicide that occurred in this study population and the 1987 case report of a person who chose to end his life as a ventilator-dependent quadriplegic, for those who survive, self-reported quality of life is no different for ventilator-dependent and ventilator-independent persons with SCI, and only slightly below that of healthy controls. And only slightly below that of healthy controls. In fact, quality of life appears to be much better than anticipated by health-care professionals. Most ventilator-dependent persons (79%) return to a private residence, with only 12% residing in nursing homes, and only 9% remaining in hospitals. Return to work has been reported in 29% of survivors.

These increasing survival rates have considerable economic implications for escalating the consumption of limited health-care resources. Adjusting data reported by Whiteneck²⁹ to 1994 dollars, average charges for initial care and rehabilitation for a ventilator-dependent person with SCI are approximately \$580,000, while average annual charges thereafter for the remainder of the person's life will be almost \$200,000. Similarly, recent predictive models developed at the National Spinal Cord Injury Statistical Center suggest that average health-care charges incurred during the entire first postinjury year will be approximately \$650,000 in 1994 dollars, and annual charges incurred by a ventilator-dependent person with SCI for the remainder of the person's life will average approximately \$250,000.43 Assuming that 5% of all new cases of SCI occurring each year in the United States result in ventilator dependency (approximately 500 new cases per year), 28 then the aggregate cost of initial care for these persons will be approximately \$325 million. Moreover, because of increased mortality rates for ventilator-dependent persons compared with other persons with SCI, if one assumes that only 1% of the approximately 200,000 persons living with SCI in the United States are ventilator dependent.44 then aggregate annual charges for persons with preexisting SCI would be \$500 million, bringing the total cost of ventilator-dependent SCI to \$825 million annually.

In conclusion, the high costs associated with both initial and long-term management of these persons are well justified based on both future life expectancy

and the relatively good quality of life that can be achieved. With the development of improved methods of prevention and management of pneumonia, pulmonary emboli, and septicemia, life expectancies should continue to improve. Given the increased prevalence of ventilator-dependent persons with SCI, and the improved life expectancies already achieved, additional attention should be focused on further enhancing the community integration and quality of life of these individuals.

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