Aging After Spinal Cord Injury: A 30-Year Longitudinal Study

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Abstract

Background/Objective: This longitudinal study investigated changes in life satisfaction, general health, activities, and adjustment over 3 decades among individuals with spinal cord injury (SCI).

Participants: The cohort of participants was identified from outpatient records of a large Midwestern United States university hospital. In 1973, 256 individuals completed an initial survey. There were 5 subsequent follow-up surveys, with the most recent being in 2002. Seventy-eight participants completed materials on all 6 occasions.

Methods: The Life Situation Questionnaire was used to identify changes over the 30-year period in 6 areas of life satisfaction, self-rated adjustment (current and predicted), employment status, activities, and medical treatments.

Analyses: These analyses used data from 3 points in time, separated by approximately 15-year intervals. One-way analysis of variance with repeated measures was used to identify changes in outcomes between 1973, 1988, and 2002 for all continuous variables.

Results: We found a mixed pattern of changes over the 30 years, with increases noted during the first 15-year period in sitting tolerance, educational and employment outcomes, satisfaction with employment, and adjustment. Although these changes tended to remain stable during the last 15 years, subtle declines were suggested in some areas, with clear declines noted in terms of diminished sitting tolerance, an increase in the number of physician visits, and decreased satisfaction with social life and sex life.

Conclusions: The results suggest that many positive changes occur within the first 2 decades after SCI, followed by a period of stability in some life areas, but decline with aging in some participation and health-related aspects of life.

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Key Words: Spinal cord injuries; Rehabilitation; Aging; Quality of life; Life satisfaction

INTRODUCTION

Adapting to advancing age presents a challenge for individuals who have the longevity to experience aging-related changes. These challenges intensify among individuals with disabling conditions, including spinal cord injury (SCI), because they occur earlier in life and may be more highly related to the number of years lived with a disabling condition rather than age *per se*. With SCI, age-related changes have been found to occur as early as 15 years after injury and around 45 years of age

(1–2). Identification of the natural course of SCI with advancing age is an important area of research with important implications for clinical practice.

Whereas cross-sectional studies may identify the association of aging components, including chronologic age and years lived since disability onset with outcomes, only longitudinal data can identify actual changes over time. However, when using longitudinal designs, one cannot assume that changes in outcomes are caused by aging alone. Environmental factors also change over time, which may be particularly critical to the lives of individuals with disabling conditions, because individuals with SCI not only face physical limitations associated with a disabling condition, but also social and economic changes that result from injury. A substantial number of

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individuals with SCI have highly limited income that enhances their sensitivity, both positive and negative, to changes in public policy, government benefits, and other legislation.

Several cross-sectional studies examined the association of aging parameters with various outcomes after SCI. Individuals who are older at injury onset have reported poorer health outcomes. For instance, DeVivo et al (3) found that individuals who were at least 61 years old at time of injury were more likely to develop pneumonia, gastrointestinal hemorrhage, pulmonary emboli, or renal stones before their initial hospital discharge. They were more likely to be rehospitalized during the second year after injury, to require ventilator support, and to be discharged to a nursing home than individuals 16 to 30 years of age at time of injury. A greater number of medical complications were associated with older age and duration of injury (4). Investigators who examined functional changes over time in individuals 20 or more years after injury noted a greater need for physical assistance and a greater need for additional help with activities of daily living as they aged (5). Other studies found urinary tract changes, functional declines (especially caused by pain and weakness), and lessened ability to perform activities of daily living associated with aging (6–8).

While cross-sectional studies provide valuable insight into aging with SCI, longitudinal studies have the ability to examine changes over time in the same individuals, allowing researchers to determine when and how changes can take place. Longitudinal studies have found changes in shoulder pain and decreased range of motion, an increased number of health problems, increased fatigue, and disability-related problems (9,10). Another study found that physical independence, mobility, occupation, and economic self-sufficiency scores on the Craig Hospital Assessment and Reporting Technique declined with age, whereas social integration scores improved; however, morale declined, whereas depressive symptomatology increased (11).

Results from a cohort followed longitudinally over a 25-year interval suggest complex and dynamic relationships between aging and changes in outcomes over 11- (12), 15- (13), 20- (14), and 25-year periods (15). Rather than observing a simple pattern of change, there has been a mixed pattern of favorable and unfavorable changes. Subtle differences were observed over time, with general improvements in employment outcomes, overall adjustment, and satisfaction with employment and finances. In contrast, there was a tendency for increases in need for medical care (hospitalizations), diminished social participation, and satisfaction with health, social life, and sex life. It is important to determine whether the pattern of changes will persist over longer intervals, or whether there will be a trend toward more rapid decline as participants reach more extremes in aging.

Purpose

The purpose of this study was to identify the natural course of aging over nearly 3 decades for a cohort of participants with SCI. We selected 3 times of measurement over the 30-year period: the initial measure, 15-year follow-up, and the most recent follow-up approximately 30 years after the initial data collection. Use of 3 times of measurement over nearly equal 15-year follow-up intervals represents a substantial enhancement over previous research in that it allows for patterns of change to be observed over substantial intervals where short-term changes are not anticipated.

Hypotheses

Our hypotheses were as follows: Participants who did not respond to the 30-year follow-up survey will be more likely to report poorer outcomes at initial survey than those who respond to all surveys (ie, attrition will be selective). Participants will report significant declines in activity level and health status between the initial and the 30-year follow-up survey. Participants will report significant declines in satisfaction with activity and health status between the initial and the 30-year follow-up survey. Participants will report significant increases in adjustment, satisfaction with career, and employment outcomes between the initial and the 30-year follow-up survey.

METHODS

Participants

All patients with SCI who received renal function services at a large Midwestern University hospital clinic before 1973 comprised the initial participant pool. Because these services were routine follow-up and considered standard care at the time, participant selection from this source was largely representative of the population served in this geographic region. There were 3 screening criteria: (a) traumatic SCI, (b) at least 18 years of age, and (c) a minimum of 2 years after injury. There were 256 respondents in 1973, with an 85% response rate. Seventy-eight participants responded to all 3 follow-up surveys conducted over nearly 3 decades. The majority of nonrespondents were deceased ($n = 92$), and another 47 could not be located. The overall response rate was 30.4% when considering all causes of attrition. However, the adjusted response rate was 69% when excluding those who were either deceased or not located.

The 78 respondents averaged 55.7 ± 7.6 (SD) years of age at the time of the 30-year follow-up and averaged 35.8 ± 4.7 years since injury. At baseline, the full cohort averaged 9.7 ± 6.9 years after injury, with an average age of 35.1 ± 13.9 years. Eighty-six percent were men. Sixty-eight percent reported cervical injuries, with 31% reporting no sensation or movement below the level of injury and 36% reporting sensation only, 23% reported nonfunctional motor recovery, and 10% were at least

partially ambulatory. Fifty-five percent were working in 2002. They averaged 15.1 years of education.

Procedures

To initiate data collection for each period of measurement, cover letters describing the study and encouraging their participation were mailed to all eligible participants. The instrument was sent 4 to 6 weeks later, with additional mailings sent and phone calls made to nonrespondents.

Instruments

The Life Situation Questionnaire (LSQ) was developed in 1973 to measure objective aspects of an individual's life after SCI (12). Few outcome studies were available to guide instrumentation. Although the LSQ has been expanded on several occasions, for this study, analyses were restricted to items that were used in 1973, 1988, and 2002. These 5 sets of items included education and employment, activities/ participation, recent treatments, self-rated adjustment, and life satisfaction.

Education was defined as number of years of formal education. Employment was defined as "working for pay" and assessed by the number of hours per week an individual spent working and the number of years working at their current job. There were 6 life satisfaction items, each required participants to rate their satisfaction with particular areas of life on a 5-point scale, with 1 being very dissatisfied and 5 being very satisfied (In the original data collection, item scales were in the opposite direction, with 1 = very satisfied and 5 = very dissatisfied, but they have all been converted to higher scores indicating greater satisfaction). These items included living arrangements, employment, finances, social life, sex life, and general health. Self-rated adjustment included two 10-point adjustment scales. The first asked participants to rate their current adjustment, whereas the second scale required them to predict what their adjustment would be in 5 years (1 = worst possible adjustment; 10 = best possible adjustment).

Activity patterns included the number of weekly visitors, frequency of weekly outings, and sitting tolerance. They were presented as multiple choice, grouped frequencies (ie, rarely; 1 to 3 times per month; 1 to 2 times per week; 3 or more times per week). Recent medical history within the past 2 years included number of nonroutine doctor visits, number of hospitalizations, and days hospitalized. As with participation items, these items were presented as grouped frequencies. The number of physician visits and hospitalizations were categorized as 0, 1 to 3, 4 to 10, and more than 10. Days hospitalized were categorized as none, less than a week, 1 to 4 weeks, and more than 4 weeks.

Activity patterns and medical history variables were treated as continuous for data analytic purposes, with midpoints of each category used as the values. Use of midpoints represents a substantial improvement over

previous analyses of these data (15) but still does not reflect true ratio measurement.

Mean replacement was used for missing responses on satisfaction and adjustment items, because there were a total of 42 missing values across the 8 items and 3 times a measurement (2.2% of the total items). We did not estimate missing values for objective outcomes, which would have required more stringent assumptions given the categorical nature of the data.

Analyses

We evaluated selective attrition by comparing biographic and injury characteristics and outcomes of participants who remained in the study since 1973 ($n = 78$) with those who dropped out by the 30-year follow-up ($n = 178$). t tests and χ^2 statistics were used to test the significance of differences.

In the primary set of analyses, each outcome variable was compared across 3 times of measurement: 1973, 1988, and 2002. Repeated-measures one-way analysis of variance with follow-up trend analyses were conducted on each of the continuous variables. There was no correction for multiple significance tests because it was important to identify even the most modest trends in changes between the 2 occasions in outcomes. We considered breaking the sample into cohorts based on years lived after injury or chronologic age, but there were not sufficient cases to do so. For employment status, we restricted the analyses to participants who had not reached the traditional retirement age of 65 years by the 2002 follow-up. The McNemar test was used to identify changes in the employment rate between each pair of times a measurement (ie, 1973 to 1987, 1988 to 2002, and 1973 to 2002).

RESULTS

Attrition

Attrition analyses between respondents and nonrespondents identified several significant differences. Respondents were younger both at time of the 1973 data collection ($t[252] = -6.05$, $P \leq 0.001$) and at injury onset ($t[252] = -4.52$, $P \leq 0.001$), had lived fewer years after injury at that time ($t[254] = -3.31$, $P \leq 0.001$), and were more likely to have cervical injuries ($\chi^2 = 4.43$, $P \leq 0.05$). Respondents also reported more years of education ($t[185] = 3.26$, $P \leq 0.001$), greater satisfaction with health ($t[249] = -2.61$, $P \leq 0.01$), greater sitting tolerance ($t[248] = 2.53$, $P \leq 0.05$), and more frequent social outings ($t[251] = 3.48$, $P \leq 0.001$).

Changes in Outcomes

Table 1 summarizes the results between the 3 times of measurement. Years of education significantly increased from 13.8 to 15.6 years over the 30-year period, as significant linear ($F_{1,55} = 30.0$, $P < 0.001$) and quadratic trends ($F_{1,55} = 15.1$, $P < 0.001$) were observed. The majority of change occurred during the first 15 years.

Table 1. Longitudinal Comparisons of Outcomes Across 3 Times of Measurement

	Time 1		Time 2		Time 3		F	Linear Effect	Quadratic Effect
	Mean	SD	Mean	SD	Mean	SD			
Satisfaction with									
Living arrangements	4.36	0.88	4.44	0.96	4.18	1.13	2.11	1.37	2.16
Employment	3.10	1.29	3.61	1.30	3.37	1.36	3.59*	2.02	5.28*
Finances	3.30	1.35	3.60	1.18	3.32	1.29	2.36	0.02	4.75*
Social life	3.97	1.09	4.11	0.99	3.61	1.18	7.30‡	5.54*	8.57†
Sex life	3.24	1.39	3.32	1.45	2.54	1.19	16.32‡	16.33‡	7.59†
Health	3.96	1.20	3.91	0.93	3.64	0.95	2.94	3.93*	0.87
Present adjustment	7.76	2.17	8.34	1.74	8.36	1.51	2.99	4.85*	2.82
5-year adjustment	8.53	1.94	8.48	1.88	8.30	1.99	0.52	0.78	0.12
Visits with others	7.17	4.43	5.90	4.10	6.23	4.61	2.26	2.45	2.39
Outings	8.21	4.48	8.18	4.13	8.13	4.40	0.01	0.02	0.00
Sitting tolerance	13.79	5.50	15.39	4.26	14.16	5.06	4.44*	0.29	8.96†
Treatments	3.48	4.21	3.61	3.82	4.81	3.98	3.51*	5.61*	1.03
Hospitalizations	1.55	2.46	0.87	1.21	1.12	1.39	2.53	2.29	5.01*
Days hospitalized	9.38	13.24	5.06	8.95	6.47	10.15	2.74	2.38	4.57*
Years of education	13.84	2.01	15.52	3.23	15.59	3.26	15.72‡	29.99‡	15.14‡
No. hours worked	10.32	15.57	21.77	22.76	18.56	21.97	7.72‡	6.88*	7.54†

* $P < 0.05$, † $P < 0.01$, ‡ $P < 0.001$.

When considering only participants who were younger than 65 years of age in 2002, the employment rate changed significantly from 1973 to 1988, as the rate increased from 44% to 63% ($P < 0.05$), and the rate change from 1973 to 2002 was 61% ($P < 0.05$). As a secondary analysis, we compared hours spent working per week across the 3 times a measurement, coding 0 hours for those who were unemployed. Significant differences were observed ($F_{2,60} = 7.72$, $P < 0.001$), which were accounted for by both linear times and quadratic effects. Hours worked per week increased between 1973 (10.3) and 1988 (22.8) but changed little thereafter (22.0).

Of the 3 activity indicators, a significant difference was observed for sitting tolerance ($F_{1,71} = 4.44$, $P < 0.05$). A significant quadratic effect ($F_{1,72} = 9.0$, $P < 0.002$) was observed as sitting tolerance increased between 1973 and 1988 (13.8 and 15.4, respectively), but decreased by 2002 (14.2). Neither the frequency of weekly visitors or weekly outings changed significantly over time. With regards to medical treatments, the number of nonroutine physician visits increased in a linear fashion ($F_{1,73} = 3.5$, $P < 0.01$). The overall F-ratio for both the number of hospitalizations and days hospitalized just missed significance ($P = 0.09$ and $P = 0.07$, respectively), although significant quadratic trends were observed on both variables, indicating a decrease in hospitalization parameters from 1973 through 1988, with a subsequent increase by 2002.

Three of the 6 life satisfaction variables significantly changed over the 30-year period (employment, social life,

sex life), and a fourth (finances) just missed significance. A significant quadratic effect was observed for satisfaction with employment ($F_{1,77} = 5.3$, $P < 0.05$), as it improved between 1973 and 1988 (3.1 to 3.6), but subsequently decreased somewhat by 2002 (3.4). Significant changes were observed in satisfaction with social life ($F_{2,76} = 7.3$, $P < 0.001$) and satisfaction with sex life ($F_{2,76} = 16.3$, $P < 0.001$). Both linear and quadratic effects were observed for each of these 2 satisfaction variables, as both declined significantly over the 30-year period, with the decline occurring during the latter 15 years. None of the other 3 satisfaction variables or either of the two adjustment variables significantly changed, although trends toward significance were observed for both satisfaction and health ($P = 0.059$) which declined over time, and self-rated adjustment ($P = 0.056$), which increased over time.

DISCUSSION

This study was designed to identify the natural course of aging over a 30-year period among a cohort of participants with SCI from the Midwestern United States. Unlike some previous reports from this 30-year longitudinal study, we analyzed data from 3 points in time over relatively equal intervals of 15 years. This allowed us not only to determine overall changes in outcomes over the nearly 30-year period, but to identify the relative amount of change observed during each 15-year period. It is reasonable to anticipate that the change would be greater during the latter 15 years because of the cumulative impact of aging. The results of these analyses help to define the long-term course of aging after SCI by

identifying both favorable and unfavorable areas of change. The results also differ from recent analyses that only looked at 2 times of measurement over a 25-year period (15).

Summary of Major Findings

The major study hypotheses were generally confirmed, in that there was a mixed pattern of changes over the 30-year period. Overall, participants reported more years of education, and the percentage of participants returning to work increased during the first 15 years. Satisfaction with employment also increased, although it diminished somewhat by the end of the 30-year period. Self-rated adjustment showed a marginally significant increase over the 30-year period. Sitting tolerance did not decline throughout the study period as expected, but rather increased substantially during the first 15 years before declining somewhat in the latter 15 years. Taken together, the trend analyses suggest that favorable changes generally occurred earlier in the 30-year cycle, suggesting a period of growth followed by stability in the areas of education, employment, and adaptation. This is a somewhat different conclusion than would be reached by simply looking at the beginning and endpoints of the data collection.

In contrast with these favorable changes, there were prominent declines in satisfaction with social life and sex life. As already stated, there was already a decrease in sitting tolerance, which reflects diminished activities over the last 15 years, and there was an increased need for medical services as reflected by the number of non-routine physician visits. These findings suggest aging does impact outcomes after a substantial period of time and has its primary effects in social and health areas, rather than vocational.

With regard to attrition, as would be expected, participants who remained in the study were younger and had been injured for fewer years at the time the study was initiated. Participants who dropped out were less active and reported lower satisfaction with their health. Previous research on survival (16) had clearly established a link between life adjustment and life expectancy among individuals with SCI, so these findings likely represent a survivor effect (the tendency for the healthiest and best adjusted to survive and continue to participate).

Implications for Rehabilitation Professionals

The study findings have direct implications for rehabilitation professionals. First, because individuals frequently do not return to the site of their initial rehabilitation, particularly those without significant health complications, rehabilitation professionals have a much greater understanding of the short-term rather than the long-term natural course of SCI. These analyses suggest that declines in sitting tolerance and diminished satisfaction with social and interpersonal relationships are

indicators of change. It also seems likely that the increase in physician visits corresponds with advancing age; this may also be taken as an indication of declines related to aging. Unfortunately, by the time these changes occur, the individual is already experiencing decline, and preventative measures may be less successful because they are, by definition, secondary prevention at that point. Proactive measures should be taken, such as routine screening for health problems related to advancing age. Although proactive measures may be costly, they are more likely to be as cost-effective as preventative health screenings used in the general population.

It is also important to acknowledge that vocational outcomes do not seem to substantially decline over time. It may be that greater energy is committed to maintaining vocational status than social activities and that the demands of maintaining employment may directly lead to diminished outcomes in other areas. These data do not speak to this potential causal link, yet it clearly is a topic that demands further study. It is important to assess how function relates to employment and whether job accommodations may be made that serve the dual purpose of helping individuals maintain employment, while at the same time limiting the extent to which energy expended on employment restricts participation in other aspects of life.

There are also clear implications for specialty counseling, particularly in the areas of interpersonal relations and sexual function. After individuals leave the rehabilitation hospital, they may no longer have access to or knowledge of resources that may help them maintain social or sexual functioning. Because they may also lack direct access to rehabilitation professionals or otherwise may not seek traditional treatments, it is incumbent on rehabilitation centers and independent living centers to disseminate as much information as possible through multiple outreach efforts. Clearly, individuals with the most limited resources are ones that will be less likely to have access to information disseminated through Internet or other electronic sources. We must therefore accept the challenge of finding unique ways to meet these needs.

Limitations

There were several limitations to this study, some of which have been presented throughout the study. First, the instrumentation used during the first phase of the study would not meet the more rigorous standards for measures commonly used today. This is an inherent limitation in using longitudinal designs, because methodologies are constantly being improved. As a result, the LSQ was limited in the breadth of content coverage. For instance, because no standardized measures of participation were available at the beginning, only very general activity indicators were used (eg, sitting tolerance, outings). With regard to item formats, measures of recent medical history and activity patterns were limited

by the grouped frequencies that decreased the power of our analyses. Use of midpoints was a reasonable solution to this limitation and improved the analyses over those used in previous reports. Second, attrition from all causes was relatively high over the 30-year period, mostly because of mortality. This is also an inherent limitation of longitudinal designs, particularly those that focus on conditions with diminished life expectancy such as SCI. However, because we only compared changes in outcomes among participants from all times of measurement (ie, only 78 respondents, rather than all 256 from 1973 with the 78 from 2002), this limitation does not likely contribute substantially to the observed pattern of longitudinal changes. Third, no racial-ethnic minorities participated because of the geographic location in which the cohort was identified. Fourth, although statistically significant, some changes were not large, and this limits clinical significance. Nevertheless, even relatively small mean differences are magnified at the extremes of the distributions and changes in multiple outcomes certainly would have a clinical impact on individuals. Last, although we attribute the patterns of change over time to aging, this is not a study of aging. Other factors, particularly environmental factors, no doubt contributed to the observed results. Some outcomes are clearly influenced by public policy, such as disincentives to employment, vocational rehabilitation programs to enhance employment outcomes, and reimbursement policies that influence hospitalizations and other types of service use.

Future Research

It is important to continue research on aging and SCI, because participant cohorts are just now reaching aging milestones such as 30 or 40 years after injury. It is tempting to conclude that we have learned all that we can from following the same participant cohorts over time. However, this would be a dangerous conclusion, because studies of the natural course of aging are our only means of fully understanding the outcomes of those who have lived longest with SCI. We also cannot dismiss the possibility that changes observed in this study and other natural course studies that have been conducted over a shorter duration of time measure both the natural aging process and unique characteristics of the participants or the environments around the times of their injuries. Rehabilitation programs have changed dramatically in the past 30 years. As sample sizes permit, use of sequential designs that account for variations in years lived after injury and chronologic age may help us to better understand how aging influences outcomes after SCI. Public policy and other changes have also occurred, not all of which are favorable. We must continue to assess the trends in aging as life expectancy continues to increase and the portion of individuals with SCI in the oldest age groups, based on both chronologic age and

years lived since injury onset, continues to grow. There is also a need to identify explanatory factors that account for changes in outcomes over time. We need to learn more from those who successfully adapt to SCI and who have aged without experiencing substantial declines in social activity or health to identify keys to successful outcomes. This would require a change of focus from what goes wrong to a focus of what goes right.

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