Research article

Longitudinal changes in medical complications in adults with pediatric-onset spinal cord injury

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Objectives: To determine longitudinal changes in the occurrence of medical complications in adults with pediatric-onset spinal cord injury (SCI).

Design: Longitudinal study of long-term outcomes.

Setting: Community.

Participants: Individuals who had sustained an SCI before age 19, were 23 years of age or older at initial interview, and followed annually between 1996 and 2011. They were classified into four American Spinal Injury Association (ASIA) Impairment Scale (AIS) severity groups: C1–4 AIS ABC, C5–8 AIS ABC, T1–S5 AIS ABC, AIS D.

Outcome measures: Generalized estimating equation (GEE) models were formulated to obtain the odds ratio (OR) of having a medical complication over time.

Results: A total of 1793 interviews were conducted among 226 men and 125 women (86% Caucasian; age at baseline, 26.7 ± 3.6 years; time since injury at baseline, 12.9 ± 5.2 years). Odds of complication occurrence over time varied among severity groups, with increased ORs of severe urinary tract infection (1.05, confidence interval (CI) 1.02–1.09), autonomic dysreflexia (AD) (1.09, CI 1.05–1.14), spasticity (1.06, CI 1.01–1.11), pneumonia/respiratory failure (1.09, CI 1.03–1.16), and hypertension/cardiac disease (1.07, CI 1.01–1.15) in the C1–4 ABC group; AD (1.08, CI 1.04–1.13) and pneumonia/respiratory failure (1.09, CI 1.02–1.16) in the C5–8 ABC group; and hypertension/cardiac disease (1.08, CI 1.02–1.14) in the T1–S5 ABC group. Upper extremity joint pain had increased odds of occurrence in all injury severity groups.

Conclusion: The significantly increased odds of having medical complications over time warrants awareness of risk factors and implementation of preventive measures to avoid adverse consequences of complications and to maintain independence in individuals with pediatric-onset SCI.

Keywords: Longitudinal changes, Medical complications, Pediatric, Spinal cord injury

Introduction

The presence of medical complications in individuals with spinal cord injury (SCI) has been associated with decreased quality of life and increased morbidity and mortality.^{1–5} With increasing duration of injury, the occurrence of SCI-related complications and overuse syndromes may increase, and together with the increased risk of chronic health conditions that accompany aging such as cardiovascular disease and diabetes,

these complications may further hinder one's health and functional independence.^{6–8} For those who had sustained a SCI in childhood or adolescence, the impact of medical complications may be greater than those with adult-onset SCI as these individuals have a longer life span with the SCI and are under the cumulative effects of these complications.⁹

Previous studies in adults with pediatric-onset SCI have reported the prevalence of medical complications and their impact on quality of life, independence, and social participation.^{10–12} Common complications in this population include urinary tract infections (UTI),

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bladder and bowel incontinence, autonomic dysreflexia (AD), pressure ulcers (PUs), and urinary tract stones,¹⁰ the prevalence rates of which were comparable to those for individuals with adult-onset SCI.^{13–15} A study investigating the impact of complications on adult outcomes in individuals with pediatric-onset SCI determined that PUs, severe UTIs (UTIs requiring intravenous antibiotics and/or hospitalizations), and spasticity were significantly associated with poorer outcomes in areas of employment, independent living, social participation, and life satisfaction.¹² Another study that investigated the long-term outcomes of adults with pediatric-onset SCI as a function of neurological impairment reported different prevalence rates of several different medical complications. For example, the prevalence of spasticity and severe UTIs were greater in those with tetraplegia, whereas the prevalence of wrist pain was greater in those with paraplegia.⁹ These studies were cross-sectional reports that provided understanding into the risk factors of medical complications as well as the long-term outcomes associated with the presence of certain complications. Longitudinal analyses can provide more robust findings in these areas and also provide insight into changes in complications with aging. Several studies have shown significant differences between the cross-sectional and longitudinal effects of age and duration of injury on medical outcomes, with the cross-sectional effects shown to be insufficient for representing the effects of aging in predicting risk of secondary medical conditions in SCI.^{16,17} Longitudinal analyses, on the other hand, are able to describe the effects of aging and changes over time in relation to medical and psychosocial outcomes,^{17–19} the results of which can be applied in the clinical setting to prevent untoward complications and plan alternative therapeutic strategies to enhance long-term outcomes.

The purpose of this study was to investigate in individuals with pediatric-onset SCI, the changes in the occurrence of medical complications longitudinally over time in relation to neurologic level and severity (ASIA Impairment Scale, AIS) of injury.²⁰ We hypothesized that (i) the odds of developing an SCI-related complication would increase with increasing duration of injury; and (ii) the odds of having an SCI-related complication over time would vary depending on the type of complication and the individual's neurologic level and severity of injury (e.g. those with C5 complete injury will have increased odds of having PUs over time due to impaired mobility, and those with paraplegia will be at greater risk of wrist pain due to chronic manual wheelchair propulsion).

Methods

This study was part of an ongoing longitudinal study investigating the long-term outcomes of adults with pediatric-onset SCI. The participants were individuals who had sustained an SCI at less than 19 years of age and were at least 23 years old at initial interview, did not have a significant brain injury, were able to communicate in English, and were living in the United States or Canada. All participants had previously been enrolled in one of the SCI specialty programs of Shriners Hospitals for Children® in Chicago, Philadelphia, and Northern California. Informed consent was obtained from those interested in participating in the study and telephone interviews were conducted annually for the enrolled participants. Additionally, medical and injury-related information were obtained from medical charts and the Shriners Hospitals for Children SCI database. This study was approved by the institutional review boards of the three Shriners Hospitals for Children.

A structured questionnaire was used to determine demographic information and the occurrence of medical complications during the one-year period prior to each interview. The questionnaire included items specific to each of the following conditions: UTI, severe UTI (UTI requiring hospitalizations or intravenous antibiotics), PUs, AD, bladder and bowel accidents (frequency at least once a month), urolithiasis, spasticity requiring medication, bone fracture, pneumonia/respiratory failure, hypertension/cardiac disease, upper extremity joint (shoulder, elbow, wrist) pain, and activity-limiting upper extremity joint pain. These conditions were chosen because of their common prevalence and their impact on long-term outcomes such as independence, participation, and life satisfaction in adults with pediatric-onset SCI.¹² UTI, severe UTI, PU, urolithiasis, fracture, pneumonia/respiratory failure, and hypertension/cardiac disease were reported by the participant if they had been diagnosed and treated by their physicians. AD, bladder and bowel accidents, spasticity, and upper extremity joint pain were reported to have occurred when the participant recognized the specific symptoms and signs of the complication.

Data analyses

Descriptive statistics were used to summarize demographic and injury-related data for all participants at initial interview. *T*-test and χ^2 analyses with a significance level of 0.05 were used to compare demographic and injury-related data between individuals who participated for two or more annual interviews and those who

had participated only once. Cross-sectional prevalence of medical complications between the first and last interviews was compared to determine a general pattern of change over time, but statistical analyses were not carried out as the number of interviews as well as the interval between first and last interview varied among the participants. Longitudinal analyses for yearly odds of complication occurrence over time were conducted utilizing the generalized estimating equations (GEEs) as this method accounts for repeated measurements correlated within a subject.^{21,22} GEE models were utilized to determine the odds ratio (OR) of having a medical complication over time (1-year increments) in relation to neurologic level and severity of injury, which was categorized into four AIS groups: C1-4 AIS ABC, C5-8 AIS ABC, T1-S5 AIS ABC, AIS D.²³ As the presence or absence of a medical complication is a dichotomous outcome, the GEE models were generated with a logit link function with binomial variance distribution, and autoregressive AR(1) correlation matrix was utilized to account for correlation of observations between sequential time points of data collection. Interaction between duration and AIS severity was tested within the GEE model to determine the change in odds of having a complication over time as a function of AIS severity. In order to assess changes over time, data were analyzed only on participants who had completed at least two annual interviews. IBM® SPSS® Statistics 20 (IBM Corporation, 2011; Armonk, NY, USA) was used for all analyses.

Results

A total of 431 participants were enrolled in the study, of which 351 were interviewed for at least two consecutive annual interviews. Comparison between those with two or more interviews ($n = 351$) and those who were interviewed only once ($n = 80$) revealed no significant difference in age, age at injury, duration of injury, sex, race (Caucasian vs. non-Caucasian), marital status (single vs. married), or distribution of AIS classification. There was, however, a higher proportion of individuals with paraplegia who were interviewed only once compared to those who had completed 2 or more interviews (59.5% versus 43.3%; $\chi^2 = 6.798$, $P = 0.009$).

The demographic characteristics of the 351 participants are presented in Table 1. At initial interview, mean age was 26.7 years, mean duration of injury was 12.9 years, and mean age at injury was 13.8 years (range, 0–18). Cross-sectional prevalence of medical complications at the first and last interviews is presented in Table 2. The prevalence of PU, AD, and spasticity were higher in those with more rostral neurologic level

Table 1 Demographic characteristics of participants ($N = 351$)

Characteristics	<i>N</i> (%)
Sex	
Male	226 (64.4)
Race/ethnicity	
Caucasian	300 (85.5)
African-American	23 (6.6)
Other	24 (7.1)
Etiology	
Traumatic	314 (89.4)
Medical/surgical	29 (8.3)
Unknown	8 (2.3)
Impairment group	
C1–4 ABC	52 (14.8)
C5–8 ABC	126 (35.9)
T1–S5 ABC	136 (38.7)
AIS D	34 (9.7)
Missing	3 (0.9)
Number of interviews	
2	71 (20.2)
3	53 (15.1)
4	48 (13.7)
5	37 (10.5)
6	54 (15.4)
7	27 (7.7)
8	18 (5.1)
9	10 (2.8)
10	11 (3.1)
11	10 (2.8)
12	8 (2.3)
13	3 (1.1)
Total	1793
Median	5
Median interval between interviews (years)	1.1

of injury, whereas the prevalence of most complications were lower in the AIS D group compared to the other impairment groups. At first interview, the prevalence of hypertension/cardiac disease was similar among the injury severity groups (2.0–2.9%), as was the prevalence of shoulder pain (38–50%). Over a median interval of 5.1 years between the first and last interviews in all our participants ($N = 351$), the prevalence of bladder accidents, hypertension/cardiac disease, and activity limiting upper extremity joint pain showed a tendency to increase. The prevalence of PUs, urolithiasis and bone fractures showed a pattern of decrease, while no patterns of change in prevalence was noted for UTI, AD, spasticity, pneumonia/respiratory failure, and bowel accidents between the two time points.

Longitudinal changes in medical complication occurrence were assessed with the ORs determined by the GEE models obtained from the interview data comprising a total 1793 interviews from the 351 participants collected over a course of up to 15 years follow-up. GEE models were generated to determine the ORs of medical complication occurrence over time as a function of neurologic level and severity of injury (Table 3). Severe UTIs and spasticity had significantly increased

Table 2 Prevalence of medical complications between the first and last interviews

	C1–4 ABC (n = 52)		C5–8 ABC (n = 126)		T1–S5 ABC (n = 136)		AIS D (n = 34)		Total (N = 351)	
	First	Last	First	Last	First	Last	First	Last	First	Last
Age (years)	26.9 (3.2)	34.0 (5.3)	27.2 (4.2)	33.1 (5.7)	26.2 (3.1)	31.7 (5.1)	27.0 (3.5)	33.1 (4.7)	26.7 (3.6)	32.7 (5.4)
Median interval (years)	7.0		5.2		4.6		5.4		5.1	
UTI	71.2	75.5	83.3	74.4	75.7	66.2	38.2	50.0	74.1	68.9
Severe UTI	34.3	25.6	17.0	17.2	9.0	17.8	16.7	5.9	16.1	17.8
Pressure ulcer	54.2	47.2	45.2	34.4	35.8	23.5	14.7	23.5	40.0	31.1
Urolithiasis	32.7	15.1	17.5	8.8	14.7	8.8	12.5	2.9	18.3	9.1
AD	86.3	69.8	69.8	75.2	22.2	28.7	9.7	23.5	48.3	51.3
Spasticity	80.8	69.8	57.9	58.4	38.2	28.7	32.4	29.4	51.3	45.3
Pneumonia/ respiratory failure	2.9	3.8	1.0	6.5	1.7	2.2	0.0	2.9	1.4	4.0
Bladder accidents*	33.3	26.4	27.0	39.2	36.6	46.3	12.1	27.3	30.3	39.1
Bowel accidents*	17.6	15.1	14.4	11.2	10.4	17.6	2.9	5.9	12.1	13.7
Bone fractures	14.6	1.9	17.3	6.4	12.4	2.9	11.5	2.9	14.3	4.0
Hypertension/ cardiac disease	2.0	12.1	2.4	3.4	2.3	8.0	2.9	7.7	2.3	6.8
Shoulder pain	44.2	70.6	49.2	54.2	50.0	52.3	38.2	35.3	47.9	54.2
Shoulder pain limits activity	7.7	20.8	9.5	26.4	10.3	18.4	5.9	11.8	9.1	20.8
Elbow pain	5.8	13.7	8.7	18.6	15.6	22.2	14.7	11.8	11.4	18.4
Elbow pain limits activity	1.9	5.7	6.3	8.8	2.2	6.6	2.9	8.8	3.7	7.4
Wrist pain	1.9	7.8	7.9	20.3	18.4	31.5	5.9	29.4	10.8	23.4
Wrist pain limits activity	0.0	3.8	1.6	3.6	4.4	11.8	0.0	8.8	2.8	8.5

Values are % or mean (SD) unless specified otherwise.

*Frequency of accidents $\geq$ once monthly.

ORs of occurrence over time in the C1-4 ABC group, while AD and pneumonia/respiratory failure had increased risk of occurrence over time in the C1-4 ABC and C5-8 ABC groups. Hypertension/cardiac

disease had significantly increased OR in the C1-4 ABC and T1-S5 ABC groups. Activity limiting-shoulder pain was found to have increased odds of occurrence over time in all impairment groups, while

Table 3 OR of medical complication occurrence with 1-year increase in duration of SCI as a function of AIS severity

	OR (95% CI)			
	C1–4 ABC	C5–8 ABC	T1–S5 ABC	AIS D
UTI	1.00 (0.96–1.04)	1.00 (0.97–1.04)	0.98 (0.96–1.01)	0.94 (0.90–0.98)[†]
Severe UTI	1.05 (1.02–1.09)*	1.02 (0.99–1.06)	1.00 (0.96–1.04)	0.99 (0.92–1.06)
Pressure ulcer	1.04 (1.00–1.08)	1.00 (0.97–1.03)	0.98 (0.95–1.01)	0.94 (0.90–0.99)*
Urolithiasis	0.99 (0.95–1.03)	1.00 (0.97–1.02)	0.097 (0.94–1.01)	0.93 (0.88–0.99)*
AD	1.09 (1.05–1.14)[‡]	1.08 (1.04–1.13)[‡]	0.96 (0.93–0.99)*	0.96 (0.91–1.01)
Spasticity	1.06 (1.01–1.11)*	1.02 (0.99–1.05)	0.97 (0.94–1.00)*	0.95 (0.91–1.00)*
Pneumonia/respiratory failure	1.09 (1.03–1.16)[†]	1.09 (1.02–1.16)[†]	1.04 (0.96–1.14)	1.02 (0.92–1.12)
Bladder accidents ^a	0.98 (0.94–1.01)	1.00 (0.97–1.03)	1.02 (0.99–1.04)	0.96 (0.91–1.01)
Bowel accidents ^a	1.00 (0.95–1.04)	1.00 (0.96–1.05)	1.01 (0.98–1.05)	0.93 (0.86–1.00)*
Hypertension/cardiac disease	1.07 (1.01–1.15)*	1.04 (0.98–1.11)	1.08 (1.02–1.14)[†]	1.07 (0.97–1.17)
Shoulder pain	1.06 (1.03–1.09)[‡]	1.05 (1.03–1.08)[‡]	1.06 (1.03–1.08)[‡]	1.03 (0.99–1.07)
Shoulder pain limits activity	1.06 (1.01–1.12)*	1.08 (1.05–1.12)[‡]	1.07 (1.03–1.10)[‡]	1.07 (1.02–1.12)[†]
Elbow pain	1.04 (0.99–1.09)	1.06 (1.03–1.09)[‡]	1.07 (1.05–1.10)[‡]	1.04 (1.00–1.08)
Elbow pain limits activity	1.03 (0.97–1.09)	1.08 (1.04–1.13)[‡]	1.08 (1.04–1.12)[‡]	1.08 (1.02–1.13)[†]
Wrist pain	0.98 (0.94–1.04)	1.06 (1.03–1.09)[‡]	1.08 (1.05–1.11)[‡]	1.07 (1.04–1.11)[‡]
Wrist pain limits activity	0.96 (0.89–1.03)	1.05 (1.01–1.09)*	1.05 (1.02–1.08)[†]	1.07 (1.02–1.11)[†]

^aFrequency of accidents $\geq$ once monthly.

*P < 0.05, [†]P < 0.01, [‡]P < 0.001.

Bold indicates significant OR.

activity-limiting elbow and wrist pain had increased OR of occurrence in the C5-8 ABC, T1-S5 ABC, and AIS D groups. The odds of AD and spasticity decreased with time in the T1-S5 ABC group, and ORs of UTI, PU, urolithiasis, spasticity, and bowel accident occurrences were found to decrease over time in those with AIS D injury.

Discussion

This is the first study we know of to report longitudinal changes of medical complications in adults with pediatric-onset SCI. Utilizing GEE models, we were able to determine the ORs of occurrence of specific medical complications in 1-year increments of injury duration, and predict which complications were likely to develop over time, as well as in which injury severity group to expect such complications. Our study findings suggest that the risk of developing hypertension/cardiac disease, upper extremity joint pain, and activity-limiting upper extremity joint pain significantly increases over time in this population of adults with pediatric-onset SCI. The increased odds of occurrence of these complications is intuitive when considering that hypertension and cardiac diseases are associated with the physiologic aging process^{24,25} and that long-term use of the upper extremities for wheelchair propulsion and transfers will lead to overuse injuries and joint pathologies.^{6,11}

The prevalence of hypertension/cardiac disease in our total study population showed a pattern of increase from 2.3% at first interview to 6.8% at the last interview (Table 2), and this is comparable to the 6.7–9.1% reported for the general population of the 20–34 year old age group during the period of 2007 to 2010.^{24,25} The American Heart Association reports increasing prevalence of hypertension with each 10-years increase in age,²⁴ and the prevalence rates of hypertension reported for individuals with adult-onset SCI mirror these age-related changes.^{26,27} In our study population, the odds of having hypertension/cardiac disease were found to increase 4–8% with each additional year of living with a SCI (Table 3). While this pattern of increased odds over time in our participants is similar to that of the general population, the impact of having hypertension/cardiac disease is potentially greater when considering the relative inactivity of individuals with SCI as they are less physically able to attain cardiovascular fitness through lifestyle modifications such as aerobic exercise and maintenance of lean body mass.^{28,29}

While the odds of hypertension/cardiac disease were observed to increase in all groups, ORs reached statistical significance only in the C1-4 ABC and T1-S5 ABC groups. A previous study on a British cohort of

individuals with long-term SCI reported increased risk of cardiovascular diseases (e.g. coronary heart disease, cerebrovascular disease, dysrhythmias, etc.) with increasing age, rostral level of injury, and greater severity of SCI.³⁰ This same study, however, reported a protective effect of rostral level of injury on hypertension, findings which support the physiology of lower resting blood pressures in cervical injuries due to loss of tonic sympathetic control of vasculature below the level of injury, namely the splanchnic vessels.^{27,31} As our study did not investigate the occurrences of hypertension and cardiac disease separately, we were not able to discern differences in ORs between the two conditions in relation to neurologic level of injury. The significantly increased OR of hypertension/cardiac disease in our C1-4 ABC group appears contradictory to autonomic physiology in regard to blood pressure, and our findings may be explained by the relatively small number of participants in the C1-4 group (14.8%) in which there might have been a higher proportion of hypertension relative to the general SCI population. Alternatively, the greater prevalence of AD in this severity group might have had a confounding effect in increasing the self-report of hypertension, especially because many individuals who have frequent episodes of AD take antihypertensive medications preventatively.³² It is likely, however, that the differences among the injury severity groups in ORs of hypertension/cardiac disease occurrence will subsequently change as our study population ages and the prevalence of cardiovascular disease increases,^{9,26,30} and thus consistent monitoring of cardiovascular function and appropriate management is warranted.

The increased OR of having upper extremity joint pain with increasing duration of SCI is significant as the use of the upper extremities for daily activities and mobility is essential for independence and social participation. Pain and functional limitations of the upper extremity potentially have greater impact on individuals with pediatric-onset SCI as they have been using their upper extremities for a longer duration of time and must continue to do so, not only for work activities and wheelchair propulsion but also for whole body weight-bearing during transfers. This is evidenced by the prevalence of shoulder pain at first interview in our younger population (mean age, 26.7 years; mean duration of injury, 12.9 years) in which the prevalence rate of 47.9% is comparable to the prevalence of 30–51% reported for those with adult-onset SCI with similar injury duration and older age.^{6,33–35}

The increased risk of activity-limiting shoulder pain in all AIS groups most likely reflects overuse.

Additionally, although those with C1-4 ABC injuries may not have functional use of the shoulder, immobility-related contractures of the shoulder girdle muscles and joint capsules can result in pain during activities which require shoulder joint movement.³⁵ The absence of motor control and possibly sensory impairment below the shoulder explains the non-significant changes in the ORs of elbow and wrist pain in the C1-4 ABC group. The increased ORs of activity-limiting elbow and wrist pain were expected in the C5-8 ABC and T1-S5 ABC groups as these individuals rely on upper extremity use for mobility and activities of daily living. The similarly increased ORs in the AIS D group, however, was an interesting finding and may be attributed to the use of canes and crutches, or wheelchair propulsion for long distances within the community. While this study investigated only pain as an upper extremity outcome, it is important to be aware of other pathologies associated with overuse including joint capsule tears/ruptures, inflammatory tendinitis/synovitis, and entrapment neuropathies such as carpal tunnel syndrome.^{6,36-38} Awareness of the potential for these conditions with increasing injury duration is crucial in preventing the onset of such complications, and should lead to education of proper methods of wheelchair propulsion³⁹ and transfers, as well as to the development of enhanced designs for wheelchairs and other assistive/adaptive equipment.

Several complications were found to have different ORs of occurrence in relation to the specific AIS impairment group. The C1-4 ABC group showed significantly increased ORs of severe UTI, pneumonia/respiratory failure, AD, and spasticity. Individuals in this group do not have the upper extremity function to perform intermittent catheterization and must depend on others for bladder management and/or have indwelling urethral/suprapubic catheter placement, predisposing them to UTIs. Spasticity manifests below the level of injury in suprasacral spinal lesions, thus individuals in the C1-4 ABC group are more likely to experience painful or activity-limiting spasticity in more muscle groups compared to the other AIS impairment groups. The cervical level of injury in both C1-4 ABC and C5-8 ABC groups accounts for loss of control of the respiratory muscles (diaphragm, intercostals, and abdominal muscles) and the sympathetic nervous system, leading to increased odds of having pneumonia/respiratory failure and AD, respectively. In contrast, the T1-S5 ABC group was found to have decreased odds of AD and spasticity occurrences over time, which may imply resolution of these complications in the long term or possibly reflect acclimation to symptoms. The wide

range of spinal levels which comprise this group, however, precludes making conclusive predictions regarding resolution of AD or spasticity, and further investigation in relation to specific spinal levels of injury is needed to ascertain the impact of spinal level on long-term changes of these conditions. The AIS D group showed significantly decreased odds of having UTI, PU, urolithiasis, spasticity, and bowel accidents, reflecting a negative association between activity-limiting medical conditions and independent mobility/physical function.

Study limitations

There are several limitations to this study. Firstly, data on medical complications were obtained by self-report, and thus may have resulted in inaccurate estimation of the occurrence at each follow-up interview. While it would have been ideal to collect data prospectively, the complications reported were in response to dichotomous questions on the occurrence of each specific condition which was diagnosed by the participants' physician (UTI, PU, urolithiasis, fracture, pneumonia/respiratory failure, hypertension/cardiac disease) or specific symptoms and signs (AD, incontinence, spasticity, upper extremity pain), and were considered reliable for purpose of the study. Secondly, not all interviews took place at 1-year intervals, and this data could not account for the complications which occurred in previous years in those cases where the intervals between consecutive interviews were greater than 2 years. The majority (88.3%) of the interview intervals, however, were between 1.0 and 1.9 years (median interval between interviews of 1.1 years), and by limiting the time of recall to the 1-year period prior to the interview in our relatively young study population, we believe errors pertaining to recall were minimized. In addition, utilizing the autoregressive AR(1) correlation matrix in the GEEs allowed for measuring correlations between sequential observations despite the non-uniform time intervals of data collection.^{21,22,40} Also, it would have been ideal to compare the findings of our study participants to age- and sex-matched controls in order to determine the effects of having an SCI and aging on the occurrence of medical complications; however, such data were not available. Finally, while the ORs obtained from GEE models allowed determination of increased or decreased odds of complication occurrence over time, we did not control for other factors associated with complications as it was beyond the scope of this investigation. Further work should include analysis of frequency and severity of medical complications over time, estimation of time to onset or aggravation of medical complications, and determination of causative

factors and their effects on medical and psychosocial outcomes in this population of pediatric-onset SCI.

Conclusion

Several medical conditions including hypertension and upper extremity pain were found to have increased occurrence with increasing duration of time after injury in adults with SCI sustained during childhood. It is important to identify the medical conditions, which may develop or worsen over time in these younger adults with SCI in order to maintain and enhance organ system functions and to prevent occurrences of complications which may hinder the independence of individuals with pediatric-onset SCI in the long term.

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References

- McKinley WO, Jackson AB, Cardenas DD, DeVivo MJ. Long-term medical complications after traumatic spinal cord injury: a regional model systems analysis. *Arch Phys Med Rehabil* 1999; 80(11):1402–10.
- McColl MA, Arnold R, Charlifue S, Glass C, Savic G, Frankel H. Aging, spinal cord injury, and quality of life: structural relationships. *Arch Phys Med Rehabil* 2003;84(8):1137–44.
- Krause JS, Saunders LL. Health, secondary conditions, and life expectancy after spinal cord injury. *Arch Phys Med Rehabil* 2011;92(11):1770–5.
- DeVivo MJ, Krause JS, Lammertse DP. Recent trends in mortality and causes of death among persons with spinal cord injury. *Arch Phys Med Rehabil* 1999;80(11):1411–9.
- Pershhouse KJ, Barker RN, Kendall MB, Buettner PG, Kuipers P, Schuurs SB, *et al.* Investigating changes in quality of life and function along the lifespan for people with spinal cord injury. *Arch Phys Med Rehabil* 2012;93:413–9.
- Pentland WE, Twomey LT. Upper limb function in persons with long term paraplegia and implications for independence: part I. *Paraplegia* 1994;32(4):211–8.
- Groah SL, Charlifue S, Tate D, Jensen MP, Molton IR, Forchheimer M, *et al.* Spinal cord injury and aging: challenges and recommendations for future research. *Am J Phys Med Rehabil* 2012;91(1):80–93.
- LaVela SL, Evans CT, Prohaska TR, Miskevics S, Ganesh SP, Weaver FM. Males aging with a spinal cord injury: prevalence of cardiovascular and metabolic conditions. *Arch Phys Med Rehabil* 2012;93(1):90–5.
- Vogel LC, Chlan KM, Zebracki K, Anderson CJ. Long-term outcomes of adults with pediatric-onset spinal cord injuries as a function of neurologic impairment. *J Spinal Cord Med* 2011;34(1):60–6.
- Vogel LC, Krajci KA, Anderson CJ. Adults with pediatric-onset spinal cord injury: part 1: prevalence of medical complications. *J Spinal Cord Med* 2002;25(2):106–16.
- Vogel LC, Krajci KA, Anderson CJ. Adults with pediatric-onset spinal cord injury: part 2: musculoskeletal and neurological complications. *J Spinal Cord Med* 2002;25(2):117–23.
- Vogel LC, Krajci KA, Anderson CJ. Adults with pediatric-onset spinal cord injury: part 3: impact of medical complications. *J Spinal Cord Med* 2002;25(4):297–305.
- Meyers AR, Mitra M, Walker DK, Wilber N, Allen D. Predictors of secondary conditions in a sample of independently living adults with high-level spinal cord injury. *Top Spinal Cord Inj Rehabil* 2000;6(1):1–8.
- Noreau L, Proulx P, Gagnon L, Drolet M, Laramée MT. Secondary impairments after spinal cord injury: population-based study. *Am J Phys Med Rehabil* 2000;79(6):526–35.
- Levi R, Hultling C, Nash MS, Seiger Å. The Stockholm Spinal Cord Injury Study: 1. Medical problems in a regional SCI population. *Paraplegia* 1995;33(6):308–15.
- Weitzenkamp DA, Jones RH, Whiteneck GG, Young DA. Ageing with spinal cord injury: cross-sectional and longitudinal effects. *Spinal Cord* 2001;39(6):301–9.
- Coll JR. Cross-sectional and longitudinal effects of aging for the secondary conditions of spinal cord injury. *Top Spinal Cord Inj Rehabil* 2007;12(3):15–22.
- Charlifue SW, Weitzenkamp DA, Whiteneck GG. Longitudinal outcomes in spinal cord injury: aging, secondary conditions, and well-being. *Arch Phys Med Rehabil* 1999;80(11):1429–34.
- Hitzig SL, Campbell KA, McGillivray CF, Boschen KA, Craven BC. Understanding age effects associated with changes in secondary health conditions in a Canadian spinal cord injury cohort. *Spinal Cord* 2010;48(4):330–5.
- Kirshblum SC, Burns SP, Biering-Sorensen F, Donovan W, Graves DE, Jha A, *et al.* International standards for neurological classification of spinal cord injury (revised 2011). *J Spinal Cord Med* 2011;34(6):535–46.
- Burton P, Gurrin L, Sly P. Extending the simple linear regression model to account for correlated responses: an introduction to generalized estimating equations and multi-level mixed modelling. *Statist Med* 1998;17(11):1261–91.
- Ghisletta P, Spini D. An introduction to generalized estimating equations and an application to assess selectivity effects in a longitudinal study on very old individuals. *J Educ Behav Stat* 2004; 29(4):421–37.
- DeVivo MJ, Biering-Sorensen F, New P, Chen Y. Standardization of data analysis and reporting of results from the International Spinal Cord Injury Core Data Set. *Spinal Cord* 2011;49(5):596–9.
- Yoon SS, Burt V, Louis T, Carroll MD. Hypertension among adults in the United States, 2009–2010. NCHS data brief, no 107, Hyattsville, MD: National Center for Health Statistics; 2012.
- Go AS, Mozaffarian D, Roger VL, Benjamin EJ, Berry JD, Borden WB, *et al.* Heart disease and stroke statistics–2013 update: a report from the American Heart Association. *Circulation* 2013;127(1):143–52.
- Barry W, St Andre JR, Evans CT, Sabharwal S, Miskevics S, Weaver FM, *et al.* Hypertension and antihypertensive treatment in veterans with spinal cord injury and disorders. *Spinal Cord* 2013;51(2):109–15.
- West CR, Mills P, Krassioukov AV. Influence of the neurological level of spinal cord injury on cardiovascular outcomes in humans: a meta-analysis. *Spinal Cord* 2012;50(7):484–92.
- Bauman WA, Spungen AM, Adkins RH, Kemp BJ. Metabolic and endocrine changes in persons aging with spinal cord injury. *Assist Technol* 1999;11(20):88–96.
- Kocina P. Body composition of spinal cord injured adults. *Sports Med* 1997;23(1):48–60.
- Groah SL, Weitzenkamp D, Sett P, Soni B, Savic G. The relationship between neurological level of injury and symptomatic cardiovascular disease risk in the aging spinal injured. *Spinal Cord* 2001; 39(6):310–7.
- Teasell RW, Arnold JMO, Krassioukov A, Delaney GA. Cardiovascular consequences of loss of supraspinal control of the sympathetic nervous system after spinal cord injury. *Arch Phys Med Rehabil* 2000;81(4):506–16.
- Consortium for Spinal Cord Medicine. Acute management of autonomic dysreflexia: individuals with spinal cord injury presenting to health-care facilities. *J Spinal Cord Med*. 2002; 25 Suppl 1:S67–88.

- 33 Sie IH, Waters RL, Adkins RH, Gellman H. Upper extremity pain in the postrehabilitation spinal cord injured patient. *Arch Phys Med Rehabil* 1992;73(1):44–8.
- 34 Alm M, Saraste H, Norrbrink C. Shoulder pain in persons with thoracic spinal cord injury: prevalence and characteristics. *J Rehabil Med* 2008;40(4):277–83.
- 35 Dyson-Hudson TA, Kirshblum SC. Shoulder pain in chronic spinal cord injury, part 1: epidemiology, etiology, and pathomechanics. *J Spinal Cord Med* 2004;27(1):4–17.
- 36 Ballinger DA, Rintala DH, Hart KA. The relation of shoulder pain and range of motion problems to functional limitations, disability, and perceived health of men with spinal cord injury: a multifaceted longitudinal study. *Arch Phys Med Rehabil* 2000;81(12):1575–81.
- 37 Yang J, Boninger ML, Leath JD, Fitzgerald SG, Dyson-Hudson TA, Change MW. Carpal tunnel syndrome in manual wheelchair users with spinal cord injury: a cross-sectional multicenter study. *Am J Phys Med Rehabil* 2009;88(12):1007–16.
- 38 Nemchausky BA, Ubilluz RM. Upper extremity neuropathies in patients with spinal cord injuries. *J Spinal Cord Med* 1995;18(20):95–7.
- 39 Slavens BA, Graf A, Krzak J, Vogel L, Harris GF. Upper extremity wheelchair kinematics in children with spinal cord injury. *Conf Proc IEEE Eng Med Biol Soc.* 2011;011:8158–6. doi: 10.1109/IEMBS.2011.6092012.
- 40 Hanley JA, Negassa A, Edwardes MD, Forrester JE. Statistical analysis of correlated data using generalized estimating equations: an orientation. *Am J Epidemiol* 2003;157(4):364–75.