Long-term outcomes of adults with pediatric-onset spinal cord injuries as a function of neurological impairment

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Objective: To identify outcomes of participation, life satisfaction, and medical complications as a function of impairment in adults with pediatric-onset spinal cord injury (SCI).

Methods: Study participants were adults who sustained SCI at age 18 years or younger and were interviewed at age 24 years or older ($M = 26.9$, $SD = 3.5$). The telephone interview included a questionnaire and several standardized measures: FIM® instrument (FIM®), Craig Handicap Assessment and Reporting Technique (CHART), SF-12® Health Survey, and Satisfaction with Life Scale. Using the International Standards for Neurological Classification of Spinal Cord Injury and the American Spinal Injury Association (ASIA) Impairment Scale (AIS), subjects were grouped into four impairment categories: C1–C4 ABC, C5–C8 ABC, T1–L4 ABC, and AIS D.

Results: Of the 410 participants, 62% were male, 54% had tetraplegia, 70% had AIS A lesions, and average age at injury was 14 years ($SD = 4.3$). Of the 407 subjects who had complete neurological information, 59 had C1–C4 ABC, 140 had C5–C8 ABC, 168 had T1–L4 ABC, and 40 had AIS D lesions. The outcomes were delineated for education, employment, independent living and driving, marriage, participation, medical complications, health-related quality of life, and global life satisfaction, in addition to the ASIA motor score and FIM® motor scores, for each of the four impairment groups.

Conclusions: This information should help focus interventions that facilitate positive outcomes in relationship to the severity of impairment. In addition, these data can provide a level of expectation about long-term outcomes for newly injured children and their parents.

Keywords: Spinal cord injuries, Pediatrics, Child, Adolescent, Tetraplegia, Paraplegia, Quality of life, Outcomes

Introduction

Expected functional independence outcomes as a function of neurological level have been published as a clinical practice guideline.¹ This clinical practice guideline assists both consumers and professionals in establishing short- and long-term goals in order to achieve these expected functional outcomes. In addition, the guidelines can be used to judge the effectiveness of different rehabilitation interventions and to assess performance across facilities with similar populations of individuals with spinal cord injuries (SCIs). The clinical practice guideline primarily describes functional outcomes as a function of neurological impairment. Using the World Health Organization's disablement model, the ICD-9, a more comprehensive delineation of outcomes would also include outcomes such as participation.²

Delineation of the outcomes in the area of community participation, quality of life, and medical complications, based on severity of injury, could assist healthcare providers in establishing realistic long-term goals for patients based on the degree of their neurological impairment. This information would also allow healthcare providers to offer appropriate anticipatory guidance for patients and their families regarding expected future outcomes. Such knowledge would be particularly pertinent to pediatric-onset SCI since appropriate interventions during childhood, adolescence, and young adulthood may improve the important adult outcomes of participation, employment, life satisfaction, and medical complications.

Therefore, the purpose of this paper is to describe the outcomes of participation, life satisfaction, health-related quality of life, and medical complications in adults with pediatric-onset SCI as a function of category of impairment. When available, normative data are

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presented in order to provide a comparison for the outcomes observed in adults with pediatric-onset SCI.

Method

Participants

Eligible subjects were individuals who sustained an SCI at age 18 years or younger, were 24 years or older at follow-up, did not have a significant brain injury, and were living in the United States or Canada. All individuals who received care at the SCI programs of the Shriners Hospitals for Children® in Chicago, Philadelphia, or Northern California were potential subjects for this study. Patients are permanently discharged from the system when they reach the age of 21.

Procedures

This project was approved by the Institutional Review Boards at the Shriners Hospitals for Children in Chicago, Philadelphia, and Northern California, and all institutional regulations concerning the ethical use of human volunteers were followed during the course of this research. Eligible patients were identified and then located using the following methods: review of contact information from Shriners Hospitals for Children medical charts, computer search of White Pages directories (e.g. TheUltimates.com), search of the Social Security Death Index, and search by a professional search service. Each patient contacted was informed of the purposes, procedure, confidentiality, and voluntary nature of participation in the study. After providing written informed consents, the participants were enrolled in the study and the participants themselves were interviewed by telephone. In addition, medical chart reviews and the Shriners Hospitals for Children SCI database were used to obtain injury-related information.

Instruments

A structured questionnaire designed for this study was used to collect demographic information such as employment status, education level, living situation, and medical complications. Participants were classified as living independently if they were not living with their parents/guardians or residing in a residential nursing home setting. Standardized measures were also utilized, all of them commonly applied to SCI populations. Participants were asked if they had experienced any of the following medical complications within the past year: pressure ulcers, urinary tract infections (UTIs), severe UTIs (UTIs requiring a hospitalization or intravenous antibiotics), fractured bones, and hospitalizations. In addition, the presence of spasticity,

bowel or bladder accidents (at least one accident per month), and wrist, elbow, or shoulder pain incidence in the past year were noted. These medical complications were chosen because they are common complications in adults with pediatric-onset SCI and have previously been shown to significantly impact long-term outcomes in this patient population.³⁻⁵

Impairment was measured using neurological level, the American Spinal Injury Association (ASIA) Impairment Scale (AIS), and ASIA Motor score as defined by the *International Standards for the Neurological Classification of Spinal Cord Injury*.⁶ This information was obtained from the medical records and SCI database of the Shriners Hospitals for Children. Therefore, these data reflected participants' status at the time of their permanent discharge from the Shriners Hospitals for Children, prior to turning 21 years.

Functional limitations were assessed with the telephone version of the FIM® instrument (FIM®).⁷⁻⁹ (FIM is a trademark of Uniform Data System for Medical Rehabilitation ('UDSMR'), a division of UB Foundation Activities Inc., Amherst, NY, USA. The use of the FIM instrument to collect data for this research study was authorized and conducted in accordance with the terms of a special-purpose license granted to licensee by UDSMR. The patient data collected during the course of this research study have not been processed by UDSMR and no implication is intended that such data have been or will be subjected to UDSMR's standard data processing procedures or that they are otherwise comparable to data processed by UDSMR. The telephone version of the FIM instrument was used to assess independent performance in self-care, sphincter control, transfers, locomotion, communication, and social cognition. The motor domain, consisting of self-care, transfers, locomotion, and sphincter control, was used for these analyses. Items are scored on a Likert scale ranging from 1 (total assistance) to 7 (complete independence).) A seven-point scale was used to identify the level of independence with which an individual performs each activity. Higher scores indicate more functional independence.

Health-related quality of life was assessed with the *SF-12® Health Survey*, QualityMetric Inc., Lincoln, RI, USA, which includes 12 questions from which mental and physical component scores are generated.¹⁰ This standardized measure assesses an individual's perception of their health-related quality of life, with higher scores indicating greater perceived health. Each of the component scores has a mean of 50 and a range of about 10–70 in the normative population.

Participation was measured using the *Craig Handicap Assessment and Reporting Technique* (CHART).^{11–13} The CHART produces a total score as well as scores for six separate subscales: physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency. The physical independence subscale assesses the degree to which an individual independently manages or supervises physical needs, such as dressing or bathing. The cognitive independence subscale assesses the amount of assistance needed for cognitive tasks such as remembering, decision-making, and judgment. The mobility subscale assesses the ability to move about effectively in the community, including being able to go when and where the individual wishes. The occupation subscale assesses how individuals productively use their time, including school, work, household activities, volunteer activities, and hobbies, but not including activities such as watching television or sleeping. The social integration subscale assesses the ability to participate in and maintain adult social relationships. The economic self-sufficiency subscale assesses the ability to maintain customary financial independence. Each dimension is scored on a 100-point scale with higher scores indicating greater community integration.

Perceived global life satisfaction, or subjective quality of life, was assessed with the *Satisfaction with Life Scale* (SWLS).¹⁴ This scale consists of five statements which individuals rate on a seven-point scale, strongly disagree to strongly agree, with higher scores reflecting more satisfaction.

Data analysis

Participants were separated into four impairment groups: (1) C1–C4 ABC, (2) C5–C8 ABC, (3) T1–L4 ABC, and (4) AIS D. Individuals with tetraplegia and

AIS scores of A, B, or C were separated into those with little upper extremity function (C1–C4 ABC) and those with varying degrees of functional arm and hand activity (C5–C8 ABC). The third impairment group included those with paraplegia and AIS scores of A, B, or C (T1–L4 ABC), and the fourth group consisted of those with AIS scores of D (AIS D). The use of these four impairment groups is a commonly employed classification scheme used in analyzing data, including life expectancy, community reintegration, and employment of individuals with SCI from the model SCI system.^{14–16}

Descriptive statistics were used to identify demographic, injury-related, functional, and outcome data separately for each of the four impairment groups. Chi-square and *t*-test analyses with a significance level of 0.05 were utilized for statistical comparisons between participants and non-participants. Means with standard deviations were reported for variables with a normal distribution: age at injury, age at interview, duration of injury, ASIA motor score, FIM[®] motor score, SF-12[®], and SWLS. Medians with interquartile ranges (IQRs) were reported for the CHART scores in accordance with the CHART manual. Analyses were conducted using SPSS statistical package version 17.0.

Results

Of the 675 patients in the hospital system's SCI database, 410 (60.7%) patients were part of the larger longitudinal study. Compared to non-participants, participants were more likely to be female ($P = 0.001$) and Caucasian ($P < 0.001$), and have tetraplegia ($P = 0.011$); however, both groups had a similar distribution of AIS scores (Table 1). Reasons for non-participation included death ($n = 54$), lack of interest ($n = 97$), or

Table 1 Comparison of individuals interviewed versus those who were not interviewed

	Interviewed <i>n</i> = 410	Not interviewed <i>n</i> = 265	Significance
Sex			$\chi^2 = 11.734$, $P = 0.001^*$
Male	62%	75%	
Race/ethnicity			$\chi^2 = 12.470$, $P < 0.001^*$
Caucasian	86%	75%	
Age at injury (years)			$P = 0.330^\dagger$
Mean (SD)	14.0 (4.2)	13.6 (4.2)	
Level of injury			$\chi^2 = 6.420$, $P = 0.011^*$
Tetraplegia	54%	44%	
ASIA impairment scale			$\chi^2 = 2.341$, $P = 0.505^*$
A	70%	69%	
B	14%	11%	
C	6%	7%	
D	10%	13%	

Notes: $^*\chi^2$ test.

$^\dagger t$ -test.

inability to locate patients ($n = 114$). Because accurate information on the neurologic status of 3 subjects was unavailable, 407 participants were included in data analyses.

Table 2 summarizes the demographic and injury-related information and FIM[®] motor scores for each of the impairment groups. Key outcomes, including education, employment, independent living and driving, marriage, participation, medical complications, health-related quality of life, and global life satisfaction, for each of the four impairment groups are shown in Table 3.

Discussion

This manuscript delineates the adult outcomes of individuals with pediatric-onset SCI as a function of impairment groups. The outcomes studied included education, employment, independent living and driving, marriage, participation, medical complications, health-related quality of life, and global life satisfaction. These data can provide youth with SCI, their families, and health-care providers with realistic expectations for future achievements in several key spheres of adult life.

In addition to education being an important outcome for children, adolescents, and young adults with SCI, education would also be expected to be a critical factor for other outcomes such as employment. Compared to the general population where 26–29% of adults aged 25–34 years have a college degree, all four impairment groups had comparable or greater educational achievement with 28–39% having a college

degree.¹⁷ The employment rate of 93–94% for the general population aged 25–34 years is significantly greater than the employment rate for those with SCI (42–69%), especially the two tetraplegia groups (42 and 52%).¹⁸ However, the employment rate for adults with pediatric-onset SCI is much higher than employment rates (19–23%) reported among individuals who sustained their SCI as adults.¹⁹ Reasons for the lower employment rate for those with adult-onset SCI may include the fact that this population may be at an age where return to work is not reasonable or returning to their prior job is not physically possible. For adults with pediatric-onset SCI, the discrepancy between the low rate of employment and reasonably high educational achievement may result from barriers to employment such as environmental factors, particularly for those with tetraplegia, or failure of education to be more vocationally oriented.

Adults with pediatric-onset SCI were less likely to live independently, drive independently, or be married compared to the general population. Adults with pediatric-onset SCI in all four impairment groups were less likely to live independently (42–70%) compared to the general population of adults aged 25–34 years where 84–90% live independently.²⁰ Adults with pediatric-onset SCI in all four impairment groups were less likely to drive independently (42–70%) compared to the general population of middle adulthood where approximately 90% have a driver's license.²¹ Lastly,

Table 2 Neurological impairment and demographic or injury-related factors

Number of subjects	C1–C4 ABC <i>n</i> = 59	C5–C8 ABC <i>n</i> = 140	T1–L4 ABC <i>n</i> = 168	AIS D <i>n</i> = 40
Sex				
Male	85%	61%	55%	60%
Race/ethnicity				
Caucasian	86%	89%	84%	87%
Age at injury (years)				
Mean (SD)	15.3 (2.2)	14.7 (3.3)	12.6 (5.3)	13.9 (3.8)
Range	7–18	0–18	0–18	0–18
Age at interview (years)				
Mean (SD)	27.1 (3.0)	27.3 (3.9)	26.5 (3.3)	26.8 (3.2)
Range	24–34	24–37	24–39	24–35
Duration of injury (years)				
Mean (SD)	11.3 (3.6)	12.2 (4.6)	13.5 (5.9)	12.4 (4.1)
Range	5–18	5–24	5–31	6–25
Etiology				
Vehicular	32%	44%	61%	31%
Violence	5%	7%	13%	8%
Fall	9%	6%	5%	11%
Sports	49%	38%	5%	31%
Medical/surgical	3%	3%	14%	14%
Other	2%	1%	2%	6%
ASIA motor score				
Mean (SD)	11.1 (9.1)	25.0 (11.9)	51.7 (6.6)	72.1 (17.1)
FIM [®] motor items, mean (SD)	28.8 (15.0)	47.3 (19.1)	75.4 (8.0)	79.7 (12.8)

Table 3 Neurological impairment and outcomes

Number of subjects	C1–C4 ABC <i>n</i> = 59	C5–C8 ABC <i>n</i> = 140	T1–L4 ABC <i>n</i> = 168	AIS D <i>n</i> = 40
College degree or higher	39%	36%	29%	28%
Independent driving	20%	54%	86%	75%
Employed	42%	52%	69%	64%
Living independently	42%	57%	70%	65%
Married	9%	18%	20%	23%
CHART, median (IQR*)				
Physical	80 (64–88)	90 (84–96)	100 (99–100)	100 (98–100)
Cognitive	100 (96–100)	100 (94–100)	100 (94–100)	96 (94–96)
Mobility	82 (66–100)	99.0 (81–100)	100 (91–100)	100 (87–100)
Occupation	80 (24–100)	94 (51–100)	100 (77–100)	100 (88–100)
Social integration	95 (85–100)	100 (90–100)	100 (89–100)	100 (87–100)
Economic self-sufficiency	100 (25–100)	100 (50–100)	100 (50–100)	100 (25–100)
Total score	513 (423–564)	539 (478–580)	569 (513–595)	562 (499–593)
SF-12®				
Physical component				
Mean (SD)	41.9 (9.3)	41.9 (10.2)	48.6 (9.3)	47.6 (7.8)
Range	24.1–57.5	12.9–63.7	21.3–63.3	30.8–59.6
Mental component				
Mean (SD)	52.7 (8.6)	51.3 (9.0)	52.2 (8.5)	50.9 (8.6)
Range	16.2–63.6	13.7–63.9	19.1–64.9	34.3–64.4
Satisfaction with life				
Mean (SD)	22.4 (7.7)	23.1 (7.7)	25.4 (6.3)	24.5 (6.6)
Range	5–35	5–35	7–35	9–35
Pressure ulcer†	53%	41%	36%	18%
UTI†	71%	84%	74%	41%
Severe UTI†	26%	19%	7%	8%
Bowel accidents‡	14%	14%	11%	3%
Bladder accidents‡	31%	29%	38%	15%
Muscle spasms†	85%	61%	35%	30%
Bone fractures†	14%	17%	11%	9%
Hospitalizations†	32%	29%	22%	21%
Wrist pain†	2%	9%	24%	8%
Shoulder pain†	46%	51%	51%	40%
Elbow pain†	9%	12%	16%	13%

Notes: *Interquartile range.

†Prevalence last year.

‡Incontinence at least once per month.

adults with pediatric-onset SCI in all four impairment groups were less likely to be married (9–23%) compared to the general population of adults aged 25–34 years of whom 44–64% are married.²²

The subscale scores for the CHART for the general population would be a score of 100, the maximum possible score. All four impairment groups had median CHART subscale scores in the 90s, except that the C1–C4 ABC group had median scores less than 90 for the physical (80), mobility (82), and occupational (80) subscales.

The mean score of the physical or mental component of the SF-12® for the normative population is 50. All four impairment groups had mean scores for the mental component (50.9–52.7) equivalent to the normative data. The mean scores (41.9) for the physical component for the two tetraplegia (C1–C4 ABC and C5–C8 ABC) groups were both lower than the normative population, whereas the mean scores (47.6–48.6) for the

physical component for the T1–L4 ABC and the AIS D groups were equivalent to the normative population.

The mean scores for life satisfaction ranging from 22.4 to 25.4 are comparable to the normative data (means of 23–28) for the SWLS reported by Pavot and Diener.²³

Because medical complications are a major cause of morbidity and mortality for individuals with SCI, prevention of these complications is a major goal in caring for individuals with SCI of all ages. In view of the young age at injury and relatively long life span, individuals with pediatric-onset SCI are at risk of SCI-related complications for a longer duration than those with adult-onset SCI. As a consequence, individuals with pediatric-onset SCI may experience a greater number of medical complications during their lifetime in contrast to adult-onset SCI, and they may also be impacted by the cumulative effect of some complications such as upper extremity pain in relationship to transfers

and manual wheelchair mobility. The greater number of lifetime medical complications and overuse injuries, such as upper extremity pain, may significantly impact key adult outcomes such as employment, independent living, participation, and quality of life.³⁻⁵

The prevalence of pressure ulcers in all four impairment groups was significant, ranging from 53% in those in the high tetraplegia group to 18% in those with AIS D lesions. These prevalence figures generally exceed those reported for adult SCI populations.^{24,25} However, comparison of the prevalence of pressure ulcers in the current study with other published findings is confounded by the different methods of identifying their occurrence as well as staging of ulcers. Because of the high prevalence and the significant consequences of pressure ulcers, preventative measures are important and must take into account the degree of neurologic impairment and the age of the individual. For example, preventative measures for individuals with tetraplegia should include proper seating systems and wheelchair designs that facilitate pressure relief and should also be directed to caregivers who perform transfers and who are responsible for turning. In addition to appropriate seating systems, pressure ulcer prevention in those with paraplegia should be targeted to the patients themselves and include proper pressure relief and transfer techniques. Because of the developmental aspects of pediatric-onset SCI, preventative measures need to be targeted to age and cognitive level of the child and responsibility must shift from parents to the youth as they grow older.

Except for the occurrence of bowel incontinence in the AIS D group, the prevalence of UTIs and urinary and bowel incontinence was common in all four of the neurologic groups. Therefore, prevention of infections and incontinence must focus on proper technique and hygienic and timely performance of the bladder management program.

Those with paraplegia demonstrated the highest prevalence of wrist pain, presumably reflecting the impact of strenuous activity, such as transfers and manual wheelchair use in this impairment group. In contrast to wrist pain, the prevalence of shoulder and elbow pain was similar among the four impairment groups. The very high prevalence (40–51%) of shoulder pain in these adults with pediatric-onset SCI is comparable to the prevalence (30–60%) of shoulder pain in individuals with adult-onset SCI.²⁶⁻²⁸ The high prevalence of upper extremity pain in adults with pediatric-onset SCI highlights the need for measures that preserve upper extremity function and minimize pain. This includes proper wheelchair propulsion and transfer

techniques, appropriate wheelchair selection that includes changes in the size of the wheelchair and function as the individual progresses from childhood into adulthood, and the judicious use of power mobility.²⁹

It is not surprising that those with less severe neurological impairment are more likely to be employed, live independently, and experience greater community participation. This confirms findings in previous studies of adults with pediatric-onset SCI where the level of injury was related to employment and community participation.^{30,31} Therefore, rehabilitation programs for children with SCI must help patients with more severe injuries find ways to overcome the barriers that are limiting their employment, mobility, independent living, and participation.

Limitations

This study includes former patients from a single hospital system. Although the three hospitals are at various locations in the United States, have a large catchment area, and treat patients with diverse social and economic backgrounds, participants may not necessarily represent the general population of adults with pediatric-onset SCI surviving past 21 years of age. A larger study population would provide a more precise estimate of outcomes, particularly for the two impairment groups (C1–C4 ABC and AIS D) with the smallest sample sizes. A larger study population would also be helpful in assessing the outcomes in more homogenous neurological groupings, for example, assessing outcomes as a function of individual neurological levels for those with tetraplegia and individual AIS scores (A, B, C, and D). For example, outcomes may be dramatically different between an individual with a C5 AIS A lesion and one with a C8 AIS C lesion. In addition, this study is limited by being based on patient responses rather than direct patient evaluation. Future research should include reports from multiple raters using multiple methods. From the potential subjects, the sample interviewed was biased toward those who were female, those who were Caucasian, and those with tetraplegia.

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