Psychosocial outcomes among youth with spinal cord injury by neurological impairment

Anne Riordan¹, Erin H. Kelly^{1,2}, Sara J. Klaas¹, Lawrence C. Vogel^{1,3}

¹Shriners Hospitals for Children, Chicago, IL, USA, ²Department of Disability and Human Development, University of Illinois, Chicago, IL, USA, ³Department of Pediatrics, Rush Medical College, Chicago, IL, USA

Objective: Examine psychosocial outcomes of youth with spinal cord injury (SCI) as a function of neurological level (paraplegia/tetraplegia) and severity (American Spinal Injury Association (ASIA) Impairment Scale (AIS)).

Design: Survey research.

Setting: Three pediatric SCI specialty centers in the USA.

Participants: Youth with SCI ages 5–18 with neurological impairment classifications of: tetraplegia AIS ABC (tetraplegia ABC), paraplegia AIS ABC (paraplegia ABC), or AIS D.

Outcome Measures: Children's Assessment of Participation and Enjoyment, Pediatric Quality of Life Inventory, Revised Children's Manifest Anxiety Scale, and Children's Depression Inventory.

Results: Three hundred and forty youth participated; 57% were male; 60% were Caucasian, 21% Hispanic, 7% African-American, 2% Native American, and 3% reported "other". Their mean age was 8.15 years (standard deviation (SD) = 5.84) at injury and 13.18 years (SD = 3.87) at interview. Ninety-six youth (28%) had tetraplegia ABC injuries, 191 (56%) paraplegia ABC injuries, and 53 (16%) AIS D injuries. Neurological impairment was significantly related to participation and quality of life (QOL). Specifically, youth with paraplegia ABC and AIS D injuries participated in more activities than youth with tetraplegia ABC ($P = 0.002$; $P = 0.018$, respectively) and youth with paraplegia ABC participated more often than youth with tetraplegia ABC ($P = 0.006$). Youth with paraplegia ABC reported higher social QOL than youth with tetraplegia ABC ($P = 0.001$) and AIS D injuries ($P = 0.002$). Groups did not differ regarding mental health.

Conclusion: Interventions should target youth with tetraplegia ABC, as they may need support in terms of participation, and both youth with tetraplegia ABC and AIS D injuries in terms of social integration.

Keywords: Outcome assessment (healthcare), Paraplegia, Pediatrics, Spinal cord injuries, Tetraplegia

Introduction

A spinal cord injury (SCI) has a profound impact on the trajectory of typical physical and psychological development of children and adolescents, requiring a process of continual adjustment that inevitably guides the roles, activities, and goals of those affected. Compared with adults, youth who have sustained SCI face a unique set of issues as they are experiencing the rapid physical and psychological growth paramount during childhood and adolescence, while simultaneously navigating the challenges related to their injury. A clear understanding of what those affected by SCI should expect in terms of outcomes is critical to providing support to youth and families who need it most.¹ However, past research describing psychosocial outcomes in relation to extent

of injury is unclear. While Anderson *et al.*² did not find mental health outcomes to differ by level or completeness of injury, other research has reported that level of injury did affect frequency of participation in informal activities.³ In terms of health-related quality of life (QOL), Garma *et al.*⁴ found that youth with paraplegia reported higher social QOL scores than youth with tetraplegia. In an attempt to address these mixed findings, the purpose of this paper was to examine psychosocial outcomes of youth with SCI according to extent of injury, with the goal of providing data-based expectations of outcomes for youth in each neurological category.

While labeled as one group, individuals with SCI can vary greatly in terms of their severity of injury. Individuals with SCI have commonly been classified by their neurological level of injury (NLI) and whether their injury is complete (as assessed by the American

Correspondence to: Anne Riordan, Shriners Hospitals for Children, Chicago, 2211 North Oak Park Avenue, Chicago, IL 60707-3392, USA.
Email: ariordan@shrinersnet.org

Spinal Injury Association Impairment Scale (AIS)).⁵ NLI is defined as the lowest level of the spinal cord that has normal motor and sensory function, ranging from the first vertebrae in the cervical region (C1) to the lowest vertebrae in the sacral region (S5). A complete injury (AIS A) is defined as the absence of sacral sparing (sensory and motor function in the lowest sacral segments, S4–5), whereas an incomplete injury (AIS B, C, or D) is defined as the presence of sacral sparing. In a sensory incomplete SCI (AIS B), sensory but not motor function is preserved below the neurological level. There are two groups of motor incomplete SCI, with the first (AIS C) defined by greater than half of key muscle functions below the level of injury having a muscle grade less than 3, and the second (AIS D) defined by at least half of key muscle functions below the level of injury having a muscle grade 3 or greater.

To best characterize the extent of injury, DeVivo *et al.*⁶ proposed a classification system combining NLI and completeness of injury. This classification system categorizes individuals into five groups of neurological impairment, including (1) C1–C4 AIS ABC, (2) C5–C8 AIS ABC, (3) T1–S5 AIS ABC, (4) AIS D at any injury level, and (5) ventilator dependent at any injury level. The authors further suggested collapsing the first two groups, if necessary, to preserve statistical power.⁶ While a version of this classification system has been used to describe long-term outcomes of adults with pediatric onset SCI,⁷ this system has yet to be used with a pediatric SCI population.

Purpose

In order to better understand the role of neurological impairment in the development of psychosocial outcomes among youth with SCI, these outcomes were studied as a function of neurological impairment using a modified version of the classification system offered by DeVivo *et al.*⁶ Specifically, two modifications were made to the original five-group classification described by DeVivo *et al.*: first, due to the relatively small number of youth in the C1–C4 AIS ABC ($n = 32$) and C5–C8 AIS ABC ($n = 64$) groups, those groups were collapsed into one, and second, there were no ventilator-dependent youth in the current sample. The use of this classification system among a pediatric SCI population allows for a more thorough understanding of the role of neurological impairment in terms of psychosocial health. These data can begin to offer realistic expectations for future achievements in many facets of life for youth with SCI, their families, and healthcare professionals. Therefore, the objective of the current study was to

compare participation, QOL, and mental health outcomes (including anxiety and depression) for youth with tetraplegia AIS ABC (tetraplegia ABC), paraplegia AIS ABC (paraplegia ABC), and AIS D injuries.

Methods

Participants

Eligible participants included youth ages 5–18 years with SCI, receiving care at one of the three pediatric specialty hospitals in the USA. All youth were enrolled between March 2007 and December 2010. Youth were recruited as part of a larger project examining psychosocial outcomes in children with SCI ages 1–18 years. Inclusion criteria required youth to have sustained their injury at least 1 year prior to participation and to speak English or Spanish. Youth were excluded if they had significant cognitive issues that prevented them from completing surveys, per clinical judgment or documentation in their medical record.

A total of 419 youth participated in the overall research study and 56 refused participation. Of the 419 participants, 368 youth met the age criteria of 5–18 for the current study; this age range was selected because 5 years was the age at which youth began self-reporting outcomes. Of these 368 participants, 21 were missing AIS data, 2 were missing level of injury data, and 3 were missing both. Of the remaining 342 youth, two were missing data on all psychosocial outcomes and so were excluded; therefore, 340 youth composed the sample for the present study. While no data are available for those who refused participation, a comparison of the 340 participants and 28 excluded youth revealed no significant differences in terms of current age, age at injury, or sex.

Procedure

Approval from the Institutional Review Boards at the participating hospitals was secured prior to the start of data collection and ethical treatment of human subjects was followed throughout the research process. Participants were recruited during inpatient or outpatient hospital visits. Potential participants were approached, assessed for eligibility, and informed of the purpose, procedure, confidentiality, risks/benefits, and voluntary nature of participation in this study. After obtaining written consent and/or assent from youth and their legal guardians, measures were completed either alone or with the help of a research assistant. Total survey administration typically took 45–75 minutes.

Measures

A study-specific questionnaire was completed by the patient's primary caregiver and was used to collect

basic demographics, such as the patient's race and educational background. Injury-related information, including date, level, and completeness of injury, was collected from the patients' medical record. Impairment was measured using neurological level and the AIS as defined by the *International Standards for the Neurological Classification of Spinal Cord Injury* and as described above.⁵

Standardized measures were also used to assess participation, QOL, and mental health. Frequency of participation was measured using the Children's Assessment of Participation and Enjoyment (CAPE), which was developed for youth ages 6–21 and includes 55 items. The two subscales that assess participation frequency were incorporated, including overall participation *diversity* (number of activities) and *intensity* (how often youth participate, on a 7-point scale, from “once in the past 4 months” to “once per day or more”).⁸ In past research, the CAPE has demonstrated acceptable test-retest reliability and content and construct validity.^{8,9}

The QOL study described in this paper was carried out using the Pediatric Quality of Life Inventory (PedsQL™), developed by Dr Varni *et al.*¹⁰ The child self-report version was developed for youth ages 5–18 and was used in the current study. Specifically, the Psychosocial Health portion of the Generic Core Scales was incorporated and includes emotional, social, and school functioning subscales; these are averaged to create the overall psychosocial health summary score (overall). This 15-item measure has been demonstrated as reliable and valid.¹⁰ Adequate internal consistency reliability was demonstrated with the current sample for the emotional ($\alpha = 0.73$), social ($\alpha = 0.72$), school ($\alpha = 0.70$), and overall ($\alpha = 0.82$) subscales.

Mental health, specifically anxiety and depression, was measured using the Revised Children's Manifest Anxiety Scale (RCMAS) and the Children's Depression Inventory (CDI), respectively. The RCMAS is a 37-item self-report measure of anxiety for youth between the ages of 7 and 18 years.¹¹ The RCMAS is composed of three subscales that measure different symptoms of anxiety, including: physiological (suggests that youth experience physiological responses to anxiety), worry/oversensitivity (suggests that youth internalize anxiety and may feel overwhelmed when attempting to relieve anxiety), and fear/concentration (suggests that youth feel unable to meet the expectations of other significant people in their lives). The CDI is a 27-item self-report symptom-oriented measure of depression for youth between the ages of 7 and 17 years.¹² The CDI is composed of five subscales that measure different components of depression,

including: anhedonia (inability or reduced ability to experience pleasure), negative self-esteem (personal belief that you are not good at anything), ineffectiveness (inability or lack of motivation to complete tasks), interpersonal problems (difficulty in developing and maintaining close relationships), and negative mood (irritability or anger). Excellent internal consistency reliability was demonstrated for the RCMAS and CDI with the current sample ($\alpha = 0.81$ and 0.85 , respectively). For the current study, two sets of scores were analyzed, including overall and subscale mean scores for the RCMAS and CDI and the percentage of youth exceeding the clinical cutoff, using clinical cutoff scores stipulated by the authors of the instruments (for the RCMAS: *T*-scores > 60 , and for the CDI: *T*-scores ≥ 65).

Statistical analysis

Participants were separated into three neurological categories: (1) tetraplegia ABC, (2) paraplegia ABC, and (3) all AIS D. As previously mentioned, there were no ventilator-dependent youth in the current sample, and due to the small number of youth with tetraplegia, the original two cervical-level AIS ABC groups presented by DeVivo *et al.*⁶ were collapsed into a tetraplegia ABC grouping. Descriptive statistics were then used to summarize demographics and psychosocial outcomes for youth in these three neurological categories.

Differences in demographic variables between the three groups were assessed using chi-square analyses (categorical variables) and analysis of variance (ANOVA; continuous variables). Differences in participation, QOL, and mental health between the three groups were assessed using multivariate ANOVA (MANOVA), as this technique allows for control over type I error.¹³ Specifically, three one-way MANOVA tests were used to assess differences in outcomes related to child level of impairment. The dependent variables for these three equations were as follows: (1) the two participation subscales: diversity and intensity; (2) the three QOL subscales: emotional, social, and school QOL; and (3) the eight mental health subscales: physiological anxiety, worry/oversensitivity, fear/concentration, anhedonia, negative self-esteem, ineffectiveness, interpersonal problems, and negative mood. For each MANOVA, the reported results include the *F*-statistic and *P* value for all effects (Pillai's trace was used because the participation and QOL MANOVA tests yielded significant Box's *M* results), and partial η^2 to assess effect size for each significant finding. ANOVA tests were conducted to follow-up on significant effects. We screened for normality and the presence of

outliers; the outcomes of data screening are presented below. All other assumptions of MANOVA were met. Three multivariate analyses of covariance were also conducted to evaluate the impact of impairment on outcomes while adjusting for child age and sex. The resulting relationships between impairment and the outcomes were not different from the MANOVA results and therefore will not be discussed. Finally, chi-square analysis was used to analyze the difference between groups in terms of youth exceeding clinical cutoff scores for anxiety and depression.

Related to sample sizes, it should be noted that the CAPE, RCMAS, and CDI were developed for (and therefore only administered to) youth ages 6–18, 7–18, and 7–17, respectively; as a result the sample sizes for these three tools are slightly lower than those for the PedsQL™, which was administered to youth ages 5–18. Youth were included in the current study if they had completed at least one of the survey tools, so there were other minor differences in sample size due to missing data. Further, if they were not in school, youth did not complete the school QOL subscale, so the sample size for that tool is lower. As a result, sample sizes are presented throughout to aid in the interpretation of results.

Results

Participants

Table 1 presents detailed demographic information on youth from each of these three neurological impairment groups. Of the 340 participants, 57% were male and their mean age was 8.15 years (standard deviation (SD) = 5.84) at injury and 13.18 years (SD = 3.87) at interview. Twenty-eight percent of participants had tetraplegia ABC injuries ($n = 96$), 56% had paraplegia ABC injuries ($n = 191$), and 16% had AIS D injuries ($n = 53$). Significant differences between the three groups with respect to key demographic characteristics included that those with tetraplegia ABC were older at interview, those with paraplegia ABC were more likely to be male, and those with AIS D were younger at injury. Differences also emerged relating to injury etiology, in that youth with tetraplegia ABC were proportionately more likely to have sports-related injuries and youth with AIS D injuries were more likely to have injuries resulting from illness or surgical procedures.

Data screening

Among the 340 participants, data screening revealed that all outcome variables, with the exception of

Table 1 Demographic characteristics

Characteristics	Youth overall ($n = 340$)	Tetra ABC ($n = 96$)	Para ABC ($n = 191$)	All D's ($n = 53$)
Age at interview, mean years* (SD)	13.18 (3.87)	14.00 (3.94) ^a	13.07 (3.71)	12.07 (4.08) ^a
Age at injury, mean years (SD)*	8.15 (5.84)	9.36 (6.25) ^b	8.01 (5.52)	6.45 (5.80) ^b
Sex, % male (n)*	57.4 (195)	67.7 (65) ^c	52.4 (100) ^c	56.6 (30)
Race, % (n)				
Caucasian	59.7 (203)	64.6 (62)	58.6 (112)	54.7 (29)
Hispanic/Latino	20.9 (71)	20.8 (20)	20.4 (39)	22.6 (12)
African American	6.5 (22)	3.1 (3)	8.4 (16)	5.7 (3)
Native American	2.4 (8)	1.0 (1)	3.1 (6)	1.9 (1)
Asian	1.8 (6)	1.0 (1)	2.1 (4)	1.9 (1)
Other, unclassified	2.9 (10)	5.2 (5)	1.6 (3)	3.8 (2)
Missing	5.9 (20)	4.2 (4)	5.8 (11)	9.4 (5)
Level of injury, % (n)				
Paraplegia	64.7 (220)	—	100.0 (191)	54.7 (29)
Tetraplegia	35.3 (120)	100.0 (96)	—	45.3 (24)
Extent of injury, % (n)				
AIS A	55.3 (188)	56.3 (54)	70.2 (134)	—
AIS B	16.2 (55)	21.9 (21)	17.8 (34)	—
AIS C	12.9 (44)	21.9 (21)	12.0 (23)	—
AIS D	15.6 (53)	—	—	100 (53)
Injury etiology, % (n)*				
Vehicular/pedestrian	49.1 (167)	42.7 (41)	58.1 (111)	28.3 (15)
Medical/surgical	28.2 (96)	19.8 (19)	25.1 (48)	54.7 (29)
Sports	9.1 (31)	24.0 (23)	4.2 (8)	—
Violence	7.6 (26)	6.3 (6)	8.9 (17)	5.7 (3)
Fall/flying object	5.0 (17)	7.3 (7)	3.1 (6)	7.5 (4)
Other/unknown	0.9 (3)	—	0.5 (1)	3.8 (2)

* $P < 0.05$.

Tetra ABC, C1–C8 neurological-level injuries with AIS A, B, and C classifications; Para ABC, T1–S5 neurological-level injuries with AIS A, B, and C classifications; All D's, all injuries with AIS D classifications; AIS, American Spinal Injury Association Injury Impairment Scale.

^{a–c}Means are significantly different from each other.

Table 2 Participation frequency outcomes by neurological category (mean (SD), median) (n = 323)

CAPE subscales	Tetra ABC (n = 90)	Para ABC (n = 183)	All D's (n = 50)
Diversity	20.92 (6.65), 21.00	24.05 (6.77), 25.00	24.32 (6.94), 24.5
Intensity	1.83 (0.58), 1.83	2.09 (0.63), 2.05	2.09 (0.74), 2.13

Tetra ABC, C1–C8 neurological-level injuries with AIS A, B, and C classifications; Para ABC, T1–S5 neurological-level injuries with AIS A, B, and C classifications; All D's, all injuries with AIS D classifications; CAPE, Children's Assessment of Participation and Enjoyment.

participation diversity, experienced significant skew, so logarithmic transformations were conducted on those variables. Further screening then revealed 19 univariate outliers across 6 variables and 18 youth. The majority of the outliers ($n = 16$) involved extremely low scores on one of the QOL subscales; the remaining outliers included an extremely high score on participation diversity, an extremely low score on participation intensity, and an extremely high score on interpersonal problems. In order to lessen the impact of these extreme scores, score substitution was used, where 16 of the original scores were changed to a value that was 10% less/greater than the next closest value. For example, the QOL scales ranged from 0 to 100, therefore deviant scores were changed to 0.10 times 100, or 10 less/greater than the next closest value. Therefore, resulting scores kept their place in the distribution, but were less extreme.¹³ The remaining three scores were not changed as they were already within 10% of the next closest value. Using Mahalanobis distance with $P < 0.001$, seven multivariate outliers were detected. In order to meet the assumptions of the multivariate analyses, these seven participants were not included in the three MANOVA tests.

Differences in psychosocial outcomes between the groups

Three one-way MANOVA tests were conducted to evaluate the relationship between neurological impairment and psychosocial outcomes. For participation ($n = 316$), the combined dependent variables were significantly related to neurological impairment ($F_{4,626} = 3.467$, $P = 0.008$, partial $\eta^2 = 0.022$). Given the significance of the overall test, the univariate main effects were examined. Significant univariate main effects for neurological impairment were obtained for diversity ($F_{2,313} = 6.543$, $P = 0.002$, partial $\eta^2 = 0.040$) and intensity ($F_{2,313} = 4.948$, $P = 0.008$, partial $\eta^2 = 0.031$). *Post hoc* analyses revealed that youth with paraplegia ABC and AIS D injuries participated in more activities than youth with tetraplegia ABC ($P = 0.002$ and $P = 0.018$, respectively), and youth with paraplegia ABC participated more often than youth with tetraplegia ABC ($P = 0.006$). There were no significant differences between the participation

frequency of youth with paraplegia ABC and youth with AIS D injuries (see Table 2 for mean participation scores by subgroup).

For QOL ($n = 307$), the combined dependent variables were significantly related to neurological impairment ($F_{6,606} = 4.085$, $P < 0.001$, partial $\eta^2 = 0.039$). Given the significance of the overall test, the univariate main effects were examined. A significant univariate main effect for neurological impairment was found for social QOL ($F_{2,304} = 9.645$, $P < 0.001$, partial $\eta^2 = 0.060$). *Post hoc* analyses revealed that youth with paraplegia ABC reported higher social QOL than youth with tetraplegia ABC ($P = 0.001$). In addition, youth with paraplegia ABC reported greater social QOL than youth with AIS D injuries ($P = 0.002$) (see Table 3 for mean QOL scores by subgroup). No significant univariate main effect for neurological impairment was found for emotional ($F_{2,304} = 1.508$, $P = 0.223$) or school ($F_{2,304} = 1.520$, $P = 0.220$) QOL.

For mental health ($n = 256$), the combined dependent variables were not significantly related to neurological impairment ($F_{16,494} = 0.837$, $P = 0.644$) (see Table 4 for mean mental health scores by subgroup). Further, there were no differences between youth in the three neurological impairment categories when examining scores exceeding the clinical cutoff for anxiety ($\chi^2(2, N = 316) = 1.054$, $P = 0.590$) or depression ($\chi^2(2, N = 262) = 0.864$, $P = 0.649$) (Table 5). However, while not statistically significant, it appears that youth with AIS D injuries tended to have higher mean overall scores for anxiety and depression, and were more likely to exceed the clinical cutoff for anxiety.

Discussion

This study examined outcomes among youth with SCI by neurological impairment, applying a previously established classification system. DeVivo *et al.*⁶ asserted that current assessment of SCI impairment is unstandardized and, therefore, insufficient; a lack of gold standard of SCI disability assessment can limit continuity in the description of outcomes among this population.¹⁴ The outcomes assessed in the current study included frequency of participation, QOL, and mental health, represented by depression and anxiety. While a number of individual,

Table 3 Quality of life outcomes by neurological category (mean (SD), median) (n = 324)*

PedsQL™ means	Tetra ABC (n = 90)	Para ABC (n = 184)	All D's (n = 50)
Emotional	65.17 (19.04), 65.00	69.62 (19.85), 75.00	67.50 (22.95), 72.50
Social	68.32 (18.45), 70.00	76.49 (19.76), 80.00	67.08 (22.15), 70.00
School	63.05 (19.56), 65.00 (n = 86)	65.10 (20.0), 65.00 (n = 178)	70.20 (18.07), 70.00 (n = 50)
Overall	65.75 (13.58), 66.67	70.55 (15.56), 71.67	68.26 (17.13), 69.17

Tetra ABC, C1–C8 neurological-level injuries with AIS A, B, and C classifications; Para ABC, T1–S5 neurological-level injuries with AIS A, B, and C classifications; All D's, all injuries with AIS D classifications; PedsQL™, Pediatric Quality of Life Inventory.

*Sample sizes varied for the school subscale as youth who were not in school did not complete these questions; therefore school sample sizes are presented separately.

Table 4 Mental health outcomes by neurological category (mean (SD), median)

	Tetra ABC	Para ABC	All D's
RCMAS (n = 316)	n = 88	n = 180	n = 48
Physiological anxiety subscale	2.84 (2.08), 3.00	2.88 (2.12), 3.00	3.10 (2.39), 3.00
Worry/oversensitivity subscale	3.31 (3.23), 2.00	3.09 (2.80), 2.00	3.85 (3.14), 4.00
Social concerns/concentration subscale	2.40 (1.79), 2.00	2.00 (1.54), 2.00	2.33 (1.77), 2.00
Overall scale	8.55 (5.98), 7.00	7.97 (5.41), 7.00	9.29 (6.33), 8.00
CDI (n = 262)	n = 68	n = 153	n = 41
Negative mood subscale	1.43 (1.93), 1.00	1.28 (1.60), 1.00	1.83 (2.22), 1.00
Interpersonal problems subscale	0.57 (1.07), 0.00	0.64 (0.96), 0.00	0.63 (0.94), 0.00
Ineffectiveness subscale	1.22 (1.36), 1.00	1.49 (1.52), 1.00	1.22 (1.51), 1.00
Anhedonia subscale	2.72 (2.22), 2.50	2.59 (2.57), 2.00	2.83 (2.52), 3.00
Negative self-esteem subscale	0.91 (1.40), 1.00	1.00 (1.43), 0.00	1.02 (1.64), 1.00
Overall scale	6.85 (6.02), 6.00	7.01 (6.44), 5.00	7.54 (6.78), 6.00

Tetra ABC, C1–C8 neurological-level injuries with AIS A, B, and C classifications; Para ABC, T1–S5 neurological-level injuries with AIS A, B, and C classifications; All D's, all injuries with AIS D classifications; RCMAS, Revised Children's Manifest Anxiety Scale; CDI, Children's Depression Inventory.

Table 5 Mental health scores above cutoff by neurological category (%)

	Tetra ABC	Para ABC	All D's
RCMAS	n = 88	n = 180	n = 48
Above cutoff score	9.1	7.8	12.5
CDI	n = 68	n = 153	n = 41
Above cutoff score	2.9	5.9	4.9

Tetra ABC, C1–C8 neurological-level injuries with AIS A, B, and C classifications; Para ABC, T1–S5 neurological-level injuries with AIS A, B, and C classifications; All D's, all injuries with AIS D classifications; RCMAS, Revised Children's Manifest Anxiety Scale; CDI, Children's Depression Inventory.

family, and community-level variables will likely impact outcomes, these data can begin to offer realistic expectations regarding areas of psychosocial health among youth with SCI with varying neurological impairments, for youth, their families, and healthcare professionals. These results also highlight those in particular need of support as they adjust to living with SCI, and can identify interventions that will improve outcomes of participation, QOL, and mental health.

Results revealed that a child's level of neurological impairment significantly impacted their frequency of participation. Specifically, youth with tetraplegia ABC participated in fewer activities than youth with paraplegia ABC and AIS D injuries, and participated less often than youth with paraplegia ABC injuries. This is consistent with past research in which youth and adults with less

severe injuries were more likely to participate in more community activities.^{3,15} More research should be done to investigate potential barriers to participation among youth with tetraplegia ABC. Research exploring levels of barriers (e.g. internal, social, community) would be most beneficial so that effective interventions can be designed and implemented among this population. No significant differences were found between participation patterns among youth with paraplegia ABC and AIS D injuries. Therefore, in this context, it seems that youth with paraplegia ABC injuries are participating at similar rates to youth with AIS D injuries.

Neurological impairment was also significantly related to QOL. In particular, youth with tetraplegia ABC reported lower social QOL than youth with paraplegia ABC. Similar findings were reported in previous research

regarding social QOL, in that youth with tetraplegia reported lower scores than youth with paraplegia.⁴ It is possible that this is related to the differences in participation patterns above, in that youth with tetraplegia ABC are participating in fewer activities and participating less often than youth with less severe injuries, so therefore may have fewer opportunities to build relationships with others. Research has also shown that societal attitudes and being treated differently may make it difficult for youth with disabilities to feel comfortable socializing with their peers.¹⁶ As a result, having less involvement and interaction with others may contribute to lower social QOL among youth with tetraplegia ABC injuries. Further research should investigate factors most closely related to QOL among youth with SCI in order to develop appropriate interventions.

A second finding related to QOL shows that youth with AIS D injuries reported lower social QOL than youth with paraplegia ABC injuries. Furthermore, mean scores show that youth with AIS D injuries (i.e. youth who theoretically have the least severe injuries) reported the lowest social QOL of all three groups. This is particularly interesting because, as described earlier, youth with paraplegia ABC and AIS D injuries seem to be functioning similarly in terms of participation. One explanation for this finding may be that youth with AIS D injuries do not feel a sense of belonging with either other youth with SCI or able-bodied youth, as they may have functional abilities that differ from individuals in both these groups. Alternatively, youth with AIS D injuries often have higher levels of functioning than other youth with SCI, and may therefore be comparing themselves with children without disabilities. This self-comparison is typical among youth¹⁷ and may contribute to youth with AIS D injuries experiencing increased negative self-perceptions and psychosocial consequences, as research among youth with other disabilities has reflected.¹⁸ Another explanation is supported by research finding that, regardless of injury level or classification, it is individuals' *perceptions* of their injury severity, not the *objective* category of their injury severity, that have been found to be significantly related to psychological well-being.¹⁹ Future research should address the social integration of this subgroup of youth with SCI and also examine the relationship between perceived levels of injury severity and psychosocial outcomes among youth with SCI.

The current study did not reveal any differences between the three groups of youth in terms of mental health. This may indicate that youth are more resilient in situations that might negatively affect mental health. While it is noteworthy to mention that one

study reported that reduced functional independence resulted in significantly higher depression scores among youth with SCI, in general, the limited published literature focusing on youth with SCI has found little to no difference in mental health among youth with SCI with different levels of injury severity.² On the contrary, previous research examining neurological impairment categories suggested that adults with AIS D injuries reported poorer perceived mental health compared with groups with more severe injuries.⁷ Furthermore, individuals with less severe injuries have reported greater levels of mental health problems,²⁰ particularly among adults who have recently acquired SCI^{21–24} and among adults who sustained their SCI as children or adolescents.²⁵ In the current study, an inspection of the mental health mean scores follows along these lines, as youth with AIS D injuries tended to have the highest levels of overall anxiety and depression. It is possible that significant findings would emerge with larger samples; mental health outcomes among youth with SCI with various levels of neurological impairment require further investigation and long-term follow-up.

Limitations

This study includes youth receiving care from a single hospital system in the USA. While the three participating sites are spread out across the country, therefore attracting a wide-ranging geographical, social, and economic pool, participants may not be representative of the general population of youth with SCI. Further, because youth with cognitive limitations were excluded from participation, the generalizability of these results may be limited; future research should look more closely at whether outcomes of youth with cognitive deficits change by neurological impairment. It should also be noted that because of the ages for which measures had been developed, mental health was not assessed among the 5- and 6-year-old youth; future research should evaluate relationships between their mental health and neurological impairment, using age-appropriate assessment strategies. Future research should also examine these findings among larger samples, allowing for an investigation of the variation between youth with C1–C4 ABC injuries and youth with C5–C8 ABC injuries. Finally, it is important to note that the effect sizes reported in the current study were relatively small. As discussed in past research, psychosocial outcomes are complex and likely related to a number of factors. While the current findings can provide some guidance to caregivers, youth, and families regarding future functioning, future research should strive for innovative methodologies that incorporate a

multitude of factors into assessment, in order to identify how best to support youth in their development.

Conclusion

This study investigated community participation, QOL, and mental health among youth with tetraplegia ABC, paraplegia ABC, and AIS D neurological classifications. Results revealed neurological impairment was related to participation and QOL outcomes. In particular, youth with paraplegia ABC and AIS D injuries reported greater frequency of participation than youth with tetraplegia ABC. In addition, youth with paraplegia ABC reported higher social and overall QOL than youth with tetraplegia ABC, but also higher social QOL than youth with AIS D injuries. Interventions should target youth with tetraplegia ABC, as they may need the most support in terms of participation, and both youth with tetraplegia ABC and AIS D injuries in terms of social integration.

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Conflicts of interest None.

Ethics approval Approval from the Institutional Review Boards at the participating hospitals was secured prior to the start of data collection and adherence to the Ethical Treatment of Human Subjects protocol was maintained throughout the course of this study.

References

- Vogel LC, Hickey KJ, Klaas SJ, Anderson CJ. Unique issues in pediatric spinal cord injury. *Orthop Nurs* 2004;23(5):300–8.
- Anderson CJ, Kelly EH, Klaas SJ, Russell H, Daharsh E, Vogel LC. Anxiety and depression in children and adolescents with spinal cord injuries. *Dev Med Child Neurol* 2009;51(10):826–32.
- Klaas SJ, Kelly EH, Gorzkowski J, Homko E, Vogel LC. Assessing patterns of participation and enjoyment in children with spinal cord injury. *Dev Med Child Neurol* 2010;52:468–74.
- Garma SI, Kelly EH, Daharsh EZ, Vogel LC. Health-related quality of life after pediatric spinal cord injury. *J Pediatr Psychol* 2011;36(2):226–36.
- Burns S, Biering-Sørensen F, Donovan W, Graves DE, Jha A, Johansen M, et al. International Standards for Neurological Classification of Spinal Cord Injury, revised 2011. *Top Spinal Cord Inj Rehabil*. 2012;18(1):88–99.
- 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.
- Vogel LC, Chlan KM, Zebracki K, Anderson CJ. Long-term outcomes of adults with pediatric onset spinal cord injuries as a function of neurological impairment. *J Spinal Cord Med* 2011;34(1):60–6.
- King GA, Law M, King S, Hurley P, Hanna S, Kertoy M, et al. Measuring children's participation in recreation and leisure activities: construct validation of the CAPE and PAC. *Child Care Health Dev* 2006;33(1):28–39.
- King GA, Law M, King S, Hurley P, Rosenbaum P, Hanna S, et al. Children's assessment of participation and enjoyment & preferences for activities of children: manual. San Antonio, TX: Harcourt Assessment, Inc.; 2004.
- Varni JW, Seid M, Kurtin P. PedsQL™ 4.0: reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Medical Care* 2001;39(8):800–12.
- Reynolds CR, Richmond BO. Revised children's manifest anxiety scale (RCMAS): manual. Los Angeles, CA: Western Psychological Services; 2000.
- Kovacs M. Children's Depression Inventory (CDI): technical manual update. North Tonawanda, NY: Multi-Health Systems Inc.; 2003.
- Tabachnick BG, Fidell LS. Using multivariate statistics. 3rd ed. New York, NY: HarperCollins College Publishers; 1996.
- Furlan JC, Noonan V, Singh A, Fehlings MG. Assessment of disability in patients with acute traumatic spinal cord injury: a systematic review of the literature. *J Neurotrauma* 2011;28(8):1413–30.
- Noreau L, Fougereyrolas P. Long-term consequences of spinal cord injury on social participation: the occurrence of handicap situations. *Disabil Rehabil* 2000;22(4):170–80.
- Hendrickson JM, Shokoohi-Yekta M, Hamre-Nietupski S, Gable RA. Middle and high school students' perceptions on being friends with peers with severe disabilities. *Exceptional Child*. 1996;63(1):19–28.
- Harter S. Processes underlying the construction, maintenance, and enhancement of the self-concept in children. In: Suls J, Greenwald AG (eds.) *Psychology perspectives on the self*. Hillsdale, NJ: Erlbaum; 1986. p. 136–82.
- Appleton PL, Ellis NC, Minchom PE, Lawson V, Boll V, Jones P. Depressive symptoms and self-concept in youth people with spina bifida. *J Pediatr Psychol* 1997;22(5):707–22.
- deRoos-Cassini TA, de St. Aubin E, Valvano A, Hastings J, Horn P. Psychological well-being after spinal cord injury: perception of loss and meaning-making. *Rehabil Psychol* 2009;54(3):306–14.
- Migliorini CE, New PW, Tonge BJ. Comparison of depression, anxiety and stress in persons with traumatic and non-traumatic post-acute spinal cord injury. *Spinal Cord* 2009;47(11):783–8.
- Arango-Lasparilla JC, Ketchum JM, Starkweather A, Nicholls E, Wilk AR. Factors predicting depression among persons with spinal cord injury 1 to 5 years post injury. *NeuroRehabilitation* 2011;29(1):9–21.
- Kishi Y, Robinson RG, Kosier JT. Suicidal ideation among patients with acute life-threatening physical illness: patients with stroke, traumatic brain injury, myocardial infarction, and spinal cord injury. *Psychosomatics* 2001;42(5):382–90.
- DeVivo MJ, Black KJ, Richard JS, Stover SL. Suicide following spinal cord injury. *Paraplegia* 1991;29(9):620–7.
- Richards JS. Psychologic adjustment to spinal cord injury during first postdischarge year. *Arch Phys Med Rehabil* 1986;67(6):362–5.
- Anderson CJ, Vogel LC, Chlan KM, Betz RR, McDonald CM. Depression in adults who sustained spinal cord injuries as children or adolescents. *J Spinal Cord Med* 2007;30(S1):88–99.