
Overview of Psychosocial Health Among Youth with Spinal Cord Injury

Erin H. Kelly, PhD,^{1,2} and Lawrence C. Vogel, MD^{1,3}

¹Shriners Hospitals for Children, Chicago, Illinois; ²University of Illinois, Chicago, Illinois; ³Rush Medical College, Chicago, Illinois

Background: Psychosocial health can be conceptualized as being mentally, emotionally, and socially well. Little is known about normative psychosocial development among children and adolescents with spinal cord injury (SCI). **Objective:** To provide a comprehensive overview of psychosocial health of 410 youth with SCI from ages 2 to 18 years. To understand developmental trends, data are presented separately for ages 2-5, 6-12, 13-15, and 16-18 years. **Methods:** Youth with SCI were recruited from 1 of 3 pediatric specialty hospitals within a single hospital system. Structured surveys assessing community participation, quality of life (QOL), and mental health (including anxiety and depression) were completed by youth with SCI (for ages 6-18) or their primary caregivers (for ages 2-5). Descriptive statistics were used to assess how patients scored on all standardized measures. **Results:** Of the 410 participants, 56% were male, 64% were Caucasian, 66% had paraplegia, and 55% had complete injuries. On average, the participants were 12 years old (SD 4.87) at interview and 7.26 years old (SD 5.97) at injury. Psychosocial health outcomes were described for each of the 4 age groups: 2-5 years (n = 52), 6-12 (n = 142), 13-15 (n = 82), and 16-18 (n = 134) years. **Conclusions:** As compared to published norms, this sample of youth with SCI seemed to be experiencing decreased levels of community participation and QOL, but also decreased levels of anxiety and depression. These data provide needed information to clinicians regarding how youth with SCI may typically experience psychosocial health and where their patients fit into that typical experience. **Key words:** adolescent, child, community participation, mental health, psychosocial factors, quality of life, spinal cord injuries

Youth with spinal cord injury (SCI) have a unique development experience. In addition to dealing with the usual challenges that come with being a young person in today's society, they face the challenges involved with acquiring a new disability, which may include physical, social, and emotional issues and adaptations.^{1,2} Although acquiring a disability should not be seen as inherently detrimental to positive psychological functioning, it is important to acknowledge that facing such an experience during a vulnerable developmental stage may exacerbate stress to an individual and their family.³ Understanding outcomes among youth with SCI can help identify areas for attention and improvement.

Psychosocial health can be described as the state of being mentally, emotionally, and socially well. Three constructs key to psychosocial health include community participation, quality of life (QOL), and mental health. These outcomes are important to all people, but they may be particularly compromised among individuals dealing with a permanent disability. First, participation is a context-bound concept that has been defined as "the involvement of persons in life situations."^{4(p277)} Depending on their age, participation for youth can include play,⁵ attending and participating in school and related

activities, doing chores around the house, and working at part-time employment.¹ Past research has highlighted the importance of participation among youth with physical disabilities. Taub and Greer found that participation in physical activity provided youth with disabilities "a context for (a) legitimation of a social identity [as children] and (b) strengthening social ties."^{6(p400)} Despite the importance of this construct, research has documented limited participation among youth with physical disabilities, as they engage in fewer types of activities, particularly those social in nature, and participate in more quiet recreational activities.⁷⁻⁹ Research conducted with youth with SCI echoed these conclusions, finding that they most often participated in sedentary activities¹⁰ and participated more often in informal than formal activities.¹¹ Informal participation was found to be related to age, sex, and injury level of the child and formal participation was related to the age of the child and the education of the caregiver.¹¹

Second, QOL has been discussed in SCI research as a “key rehabilitation outcome.”¹² QOL has been defined as “an overall assessment of well-being across various broad domains,” and health-related quality of life (HRQOL) as “the subset of QOL directly related to an individual’s health.”^{13(p183)} Sawyer and colleagues further delineated HRQOL in the context of youth with chronic illness as capturing a “broad assessment of children’s health based on... [their] physical, psychological, and social functioning.”^{14(p395)} Past research has found youth with chronic conditions to experience lower HRQOL than youth without disabilities¹⁵; these results were similar to those reported in a study of youth with SCI and spina bifida.¹⁶ Other research among youth with SCI found aspects of HRQOL to be related to child age, age at injury, and injury level.¹⁷ This study also found agreement between child self-report and caregiver proxy-report of child HRQOL to be moderate at best, with youth rating their HRQOL as better than their caregivers’ ratings.¹⁷

Finally, mental health issues, including anxiety and depression, can impact psychosocial health. Depression in particular has been found to be associated with poorer subjective health, lower satisfaction with life, and more difficulty in daily role functioning.¹⁸ Although there was a time when it was thought that anxiety and depression were inevitable consequences of SCI,^{19,20} more recent studies have found rates of clinically significant levels of anxiety to be around 25% among adults with SCI and rates of clinically significant levels of depression among adults with SCI to range between 11% and 27%.^{18,20} These rates of anxiety and depression are higher than those found among controls,²⁰ indicating a particular need among individuals with SCI for mental health services. Anderson and colleagues found that 3% of their adult sample of individuals with pediatric-onset SCI displayed depressive symptoms²¹; this rate seems lower than that reported from persons who acquired their injuries as adults. Specific to youth with SCI, members of the current research team found 13% of their sample to report significant symptoms of anxiety and 6% to report significant levels of depression.²² A study of posttraumatic stress disorder (PTSD) among youth with SCI found 25% of the sample to be experiencing PTSD,

which is twice the rate found in adults veterans with SCI.²³

Examining levels of community participation, QOL, and the presence or absence of mental health problems can provide a snapshot of psychosocial health for youth with SCI. The purpose of the current study was to provide an overview of psychosocial health by mapping out levels of participation, HRQOL, and mental health problems (including anxiety and depression) among 410 youth with SCI. Further, to understand developmental trends, data were analyzed separately for youth age 2 to 5, 6 to 12, 13 to 15, and 16 to 18 years old. The intention was to begin building a database of normative psychosocial development for youth with SCI. To date, no published study has investigated the psychosocial outcomes of youths with SCI in such a comprehensive way.

Methods

Participant recruitment

Participants were recruited as part of a multisite study assessing relationships between psychosocial outcomes of youth with SCI and their primary caregivers (typically parents). Children and adolescents with SCI who were 1 to 18 years old, had been injured at least 1 year, spoke English, and were receiving services from 1 of 3 pediatric specialty hospitals within a single hospital system were recruited for participation in this larger study. Four hundred and nineteen youths were enrolled; of these, 5 youths were 1 year of age and 4 had missing data on all variables included in the current study. This article therefore focuses on the 410 youths between the ages of 2 and 18 who were enrolled and had data on at least 1 of the measures presented here.

Instruments

Several instruments were used to assess psychosocial outcomes of youth. Included in the description of each instrument is an explanation of the target age group and who completed the tool. Depending on the construct being assessed, youth began completing survey tools between the ages of 5 and 7. Whenever possible, we have presented

youth-reported data, however, for younger children we were forced to rely on caregiver-reported data.

Demographics questionnaire

A study-specific demographics questionnaire was completed by the participants' primary caregiver (usually their mother). This survey included questions on basic demographic characteristics (eg, child's race and type of community).

Medical records review

Research staff reviewed the child's medical record to gather information on the injury, including the age at injury, injury level, extent of injury (as assessed by the American Spinal Injury Association Impairment Scale [AIS]),²⁴ and injury etiology.

Participation

Assessment of Preschool Children's Participation (APCP). The APCP is a measure of participation in day-to-day activities for children ages 2 to 5 years.²⁵ The APCP is completed by parental caregivers, and the version incorporated in the current study included 45 items. The APCP assesses participation diversity (the total number of activities engaged in by the child) and intensity (the average amount of time the child spends participating in activities across the total number of possible activities) for play, active physical, social, and skill development activities. When administered to youth with cerebral palsy (CP), the APCP was found to have moderate to excellent internal consistency across the various subscales, and construct validity was established.²⁶ It should be noted that the version of the APCP evaluated in the CP validity study included 48 items, in contrast to the earlier, 45-item version incorporated in the current study. With the current sample, the 4 APCP diversity subscales demonstrated moderate internal consistency reliability, with alpha levels ranging from 0.58 to 0.67.

Children's Assessment of Participation and Enjoyment (CAPE). The CAPE is a measure of participation in activities outside of school for

youth with disabilities. It was incorporated in this study with youth ages 6 to 18.²⁷ The instrument includes 15 formal (eg, doing team sports) and 40 informal (eg, playing board games) activities, all measured on dimensions of diversity (number of activities), intensity (on a 7-point scale, from "once in the past 4 months" to "once a day or more"), with whom (on a 5-point scale, from "alone" to "with others in the community"), where (on a 6-point scale, from "home" to "beyond your community"), and enjoyment (on a 5-point scale from "not at all" to "love it"). Adequate test-retest reliability²⁷ and construct validity²⁸ have been demonstrated. The informal ($\alpha = 0.73-0.78$) and overall ($\alpha = 0.77-0.81$) diversity scales demonstrated acceptable internal consistency reliability across the age groups in the current study. In contrast, the formal diversity alpha levels were moderate at best for 6- to 12-year-olds ($\alpha = 0.61$) and 13- to 15-year-olds ($\alpha = 0.60$), but fell in an unacceptable range for 16- to 18-year-olds ($\alpha = 0.42$). As a result, formal participation data presented for 16- to 18-year-olds are presented as exploratory and should be interpreted with caution.

Quality of life

Pediatric Quality of Life Inventory (PedsQL). The quality of life study described in this article was carried out using the PedsQL, developed by Dr. James W. Varni. The Generic Core Scales were designed for use with both healthy children and children with chronic conditions.²⁹ Each age-specific module includes Emotional, Social, and School Functioning subscales that are averaged to create an overall score on the Psychosocial Health Scale; each of these scales is measured on a 100-point scale. The Physical Health Scale was not included in the present study, because of its inappropriateness with an SCI population. Both child- and parent-report versions were incorporated in the current study; here, parent-reported data will be presented for participants ages 2 to 5 and child-reported data for participants ages 6 and older. Several studies have demonstrated the reliability and validity of the PedsQL among youth with a variety of health conditions.²⁹⁻³³ Across the parent proxy-report and child self-report scales, alpha levels typically fell in the moderate to excellent range for each of the

3 subscales: Emotional ($\alpha = 0.64-0.82$), Social ($\alpha = 0.64-0.74$), and School ($\alpha = 0.56-0.80$). Overall Psychosocial Health also fell in the moderate to excellent range ($\alpha = 0.77-0.85$). Reliabilities were typically lower for the 6 to 12 age group ($\alpha = 0.56-0.77$), especially for the School subscale ($\alpha = 0.56$); this is consistent with past reports of the PedsQL.²⁹

Mental health

Behavior Assessment System for Children, Second Edition (BASC-2). The Parent Rating Scale of the BASC-2 (preschool form) was used to assess anxiety and depression among young children ages 2 to 5.³⁴ The BASC-2 includes a series of behaviors that the parent rates on a 4-point scale, from “never” to “almost always.” The BASC-2 yields a raw score and *T* score for anxiety and depression. The *T* score indicates the distance the score falls from the norm-group mean. The BASC-2 authors suggest *T* scores of 70 indicate clinically significant scores. The anxiety and depression scales have been found to demonstrate adequate reliability and validity. In the present study, moderate internal consistency was demonstrated for both (anxiety = 0.61, and depression = 0.67).

Revised Children’s Manifest Anxiety Scale (RCMAS). The RCMAS is a 37-item self-report measure of anxiety and was administered to youth ages 7 to 18.³⁵ The overall anxiety raw and *T* scores were reported in this article, with *T* scores greater than 60 demonstrating clinical concern. The authors cited several studies that have demonstrated adequate reliability and validity of the RCMAS.³⁵ In the current study, good internal consistency reliability was demonstrated across the 3 older age groups ($\alpha = 0.75-0.82$).

Children’s Depression Inventory (CDI). The CDI is a 27-item self-report symptom-oriented measure of depression that was administered to youth ages 7 to 17.³⁶ The overall depression raw and *T* scores are reported in this article, with *T* scores of 65 or higher demonstrating clinical concern. The authors of the instrument reported good reliability and validity.³⁶ In the current study, good internal consistency reliability was demonstrated across the 3 older age groups ($\alpha = 0.82-0.90$).

Procedures

After obtaining appropriate informed consent and assent, all surveys were administered during regularly scheduled inpatient or outpatient clinic visits. Project investigators secured approval from the institutional review boards at all 3 hospitals, and ethical treatment of human subjects was followed throughout the research process.

Data analyses

Descriptive statistics were used to assess how patients scored on all standardized measures. As mentioned, youth were included in the current study if they had data on at least 1 of the tools described previously, even if they were missing data on other tools. As a result, sample sizes fluctuated and are presented throughout the description of results to aid in interpretation.

Results

Participants

Of the 410 participants, 52 were 2 to 5, 142 were 6 to 12, 82 were 13 to 15, and 134 were 16 to 18 years old. Demographics for each group are summarized in **Table 1**. Overall, 56% of youth were male, and 64% were Caucasian. Their mean age was 12 years (SD 4.87), and they were injured on average at 7.26 years (SD 5.97). Sixty-six percent of participants had paraplegia and 55% had complete injuries (AIS A). In terms of primary caregivers, 76% were mothers, 16% fathers, and 8% were other family members.

Psychosocial outcomes

Young children: Ages 2 to 5

Participation. Of the 52 children ages 2 to 5, 48 parents reported on their participation. Mean and median diversity and intensity scores for play, skill development, active physical, and social activities are presented in **Table 2**. In terms of specific activities, young children were most likely to engage in playing with toys, drawing and coloring, building things, and watching television or a video

Table 1. Demographic characteristics

Characteristics	Youth overall (N=410)	Ages 2-5 years (n=52)	Ages 6-12 years (n=142)	Ages 13-15 years (n=82)	Ages 16-18 years (n=134)
Age, mean years (SD)	12.00 (4.87)	3.27 (1.05)	9.19 (2.00)	14.04 (0.81)	17.10 (0.84)
Sex, % male	56.3	57.7	54.2	48.8	62.7
Race, %					
Caucasian	63.8	60	66.2	60.8	64.8
Hispanic	20.7	16	22.1	19	22.1
African American	7.2	10	6.6	10.1	4.9
Asian	2.1	4	1.5	2.5	1.6
Native American	2.3	4	1.5	2.5	2.5
Other	3.9	6	2.2	5.1	4.1
Age at injury, mean years (SD)	7.26 (5.97)	1.10 (1.21)	3.91 (3.37)	7.79 (4.90)	12.89 (4.85)
Level of injury, % paraplegia	65.6	63.3	73.9	70.7	54.5
Extent of injury, % complete (AIS A)	55.2	52.4	51.1	50	62.8
Injury etiology, %					
Vehicular/pedestrian	46.3	26.9	50.7	50	47
Medical/surgical	32.9	61.5	40.8	29.3	15.7
Sports	8	-	0.7	8.5	18.7
Violence	7.1	5.8	3.5	7.3	11.2
Fall/flying object	4.6	3.8	3.5	3.7	6.7
Other/unknown	1	1.9	0.7	1.2	0.7
Type of community, % small town/rural area	51.1	49	49.6	57.7	49.1
Caregivers, %					
Mothers	76.1	76	73	72.2	82.7
Fathers	16	18	19	17.7	10
Others	7.9	6	8	10.1	7.2
Marital status, % married	66	64.7	74.1	61.5	60
Education, % at least some college	62.2	56.9	69.6	63.1	55
Employment, % employed in some capacity	51.5	37.3	49.3	63.6	52.3

Note: AIS = American Spinal Injury Association Injury Impairment Scale.

Table 2. Participation scores from the parent-reported Assessment of Preschool Children's Participation (APCP) for young children ages 2-5 years (n=48)

	Mean (SD)	Median	Range
Play			
Diversity	7.29 (1.71)	8	4-9
Intensity	4.63 (1.05)	4.61	2.22-6.56
Skill development			
Diversity	9.38 (1.75)	10	4-13
Intensity	3.54 (0.69)	3.53	1.67-5.13
Active physical			
Diversity	5.50 (1.96)	5.5	1-9
Intensity	2.80 (1.05)	2.8	0.2-5.20
Social			
Diversity	7.02 (2.18)	7	2-11
Intensity	2.58 (0.85)	2.68	1-4.45

and were least likely to take music lessons or do gymnastics (**Table 3**).

QOL. All 52 parents of youths ages 2 to 5 completed the PedsQL. Mean and median scores on the Emotional, Social, School, and overall Psychosocial Health QOL scales are presented in **Table 4**. Among young children overall, parents seemed to rate their emotional QOL as highest and social QOL as lowest.

Mental health. Forty-seven parents completed the BASC-2; due to missing data, only 46 youths had anxiety scores. Mean and median raw and *T* scores for anxiety and depression are presented in **Table 5**. Of the young children with BASC-2 data, 6.5% had a clinically significant anxiety score ($n = 3$) and 8.5% had a clinically significant depression score ($n = 4$).

School-aged children: Ages 6 to 12

Participation. Of the 142 children ages 6 to 12, 135 completed the CAPE. School-aged children were most likely to engage in watching TV or a rented movie, playing computer or video games, and playing board or card games and were least likely to do gymnastics or do a paid job (**Table 3**). Mean and median scores on the CAPE formal and informal subscales are presented in **Table 6**.

QOL. One hundred thirty-four youths completed the PedsQL. Mean and median scores from the Emotional, Social, School, and overall Psychosocial Health scales are presented in **Table 4**. Although subscale scores were very similar, overall the group of school-aged children seemed to rate their emotional QOL as highest and school QOL as lowest.

Mental health. Mean and median raw and *T* scores for anxiety and depression are presented in **Table 5**. One hundred twenty-one children completed the RCMAS; of these children, 7.4% fell above the clinical cutoff for anxiety ($n = 9$). One hundred nineteen children completed the CDI; of these children, 4.2% fell above the clinical cutoff for depression ($n = 5$).

Young adolescents: Ages 13 to 15

Participation. Of the 82 adolescents ages 13 to 15, 80 completed the CAPE. These younger adolescents were most likely to engage in watching television or a rented movie, listening to music, and playing computer or video games and were least likely to be learning to dance, doing gymnastics, and doing martial arts (**Table 3**). Mean and median scores on the CAPE formal and informal subscales are presented in **Table 6**.

Table 3. Most and least frequent activities engaged in by youth

Activities done by the greatest number of youth and percentage of youth who have engaged in this activity in the past 4 months			
Young children ages 2-5 years (n=48) ^a	School-aged children ages 6-12 (n=135) ^b	Young adolescents ages 13-15 (n=80) ^b	Older adolescents ages 16-18 (n=129) ^b
100% Playing with toys	99.3% Watching TV or a rented movie	95% Watching TV or a rented movie	97.7% Watching TV or a rented movie
100% Drawing and coloring	94.8% Playing computer or video games	93.8% Listening to music	96.9% Listening to music
100% Building things	91% Playing board or card games	92.5% Playing computer or video games	93.8% Talking on the phone
100% Watching TV or a video	90.2% Doing homework	90% Hanging out	91.5% Hanging out
97.9% Listening to music	87.3% Doing crafts, drawings or coloring	87.5% Talking on the phone	89.9% Playing computer or video games
95.8% Listening to a story	87.3% Playing with things or toys	86.3% Doing homework	79.1% Shopping
93.8% Doing pretend or imaginary play	85.2% Visiting	83.8% Visiting	78.3% Visiting
93.8% Picking out books, movies, dvd's, or cd's	84.2% Listening to music	82.5% Shopping	77.3% Going to the movies
93.8% Reading/looking at books	81.8% Shopping	82.5% Going to the movies	73.6% Going to a party
89.6% Creating a craft project	81.3% Talking on the phone	81.3% Playing board or card games	71.3% Playing board or card games
			71.3% Playing with pets
Activities done by the fewest number of youth and percentage of youth who have engaged in this activity in the past 4 months			
Young children ages 2-5 years (n=48) ^a	School-aged children ages 6-12 (n=135) ^b	Young adolescents ages 13-15 (n=80) ^b	Older adolescents ages 16-18 (n=129) ^b
37.5% Going to the movies	15.3% Taking art lessons	18% Racing or track and field	8.8% Gardening
35.4% Attending a play group	15.2% Learning to sing	18% Taking music lessons	8.5% Bicycling, in-line skating, or skateboarding
33.3% Gardening	14.3% Participating in school clubs	15% Playing on equipment	6.4% Doing snow sports
27.1% Doing snow activities	13.7% Doing snow sports	11.5% Gardening	6.2% Doing pretend or imaginary play
22.9% Taking swimming lessons	12.2% Doing volunteer work	11.3% Bicycling, in-line skating, or skateboarding	5.4% Playing on equipment
14.6% Learning to dance	12.1% Horseback riding	11.3% Doing pretend or imaginary play	4.8% Horseback riding
10.4% Participating in community organizations	11.4% Racing track and field	10.3% Doing snow sports	4.7% Learning to sing
4.2% Doing team sports	9.9% Doing martial arts	9% Horseback riding	3.2% Taking music lessons
2.1% Doing gymnastics	9.2% Learning to dance	5.1% Doing martial arts	2.4% Doing martial arts
2.1% Taking music lessons	6.8% Doing a paid job	5.1% Doing gymnastics	2.4% Doing gymnastics
	6.1% Doing gymnastics	1.3% Learning to dance	2.3% Learning to dance

^aData are parent proxy-report.

^bData are child self-report.

Table 4. Youth quality of life scores from the Pediatric Quality of Life Inventory (PedsQL)

	Young children ages 2-5 (n=52 unless noted) ^a	School-aged children ages 6-12 (n=134 unless noted) ^b	Young adolescents ages 13-15 (n=79) ^b	Older adolescents ages 16-18 (n=129 unless noted) ^b
	Mean (SD), median, range	Mean (SD), median, range	Mean (SD), median, range	Mean (SD), median, range
Emotional	63.34 (20.74), 67.5, 15-100	67.82 (19.65), 70, 0-100 (n=133)	72.47 (19.20), 75, 20-100	66.70 (21.47), 70, 0-100
Social	59.57 (18.81), 60, 25-100	66.77 (21.74), 70, 0-100	80.70 (15.04), 80, 35-100	74.87 (18.13), 75, 0-100
School	61.35 (17.33), 60, 33.33-100 (n=37)	66.74 (18.06), 68.33, 20-100	67.39 (20.98), 70, 5-100	64 (20.72), 65, 0-100 (n=118)
Overall Psychosocial QOL	61.06 (15.31), 59.44, 22.5-93.89	67.07 (15), 66.67, 20-96.67	73.52 (14.62), 75, 26.67-100	68.94 (15.47), 68.89, 18.33-100

^aData are parent proxy-report.

^bData are child self-report.

Table 5. Mental health scores from the Behavior Assessment System for Children: Second Edition (BASC-2), Revised Children's Manifest Anxiety Scale (RCMAS), and Children's Depression Inventory (CDI) for youth

	Young children ages 2-5 ^a	School-aged children ages 6-12 ^b	Young adolescents ages 13-15 ^b	Older adolescents ages 16-18 ^b
	Mean (SD), median, range	Mean (SD), median, range	Mean (SD), median, range	Mean (SD), median, range
Anxiety	(n=46)	(n=121)	(n=82)	(n=134)
Raw score	8.24 (5.73), 8, 0-23	8.95 (5.55), 8, 0-25	6.98 (5.34), 6, 0-25	8.57 (6), 7, 0-24
T score	52.43 (12.53), 52, 34-82	44.54 (9.93), 43, 12-73	44.29 (10.53), 44, 25-76	48.85 (11.61), 48, 27-87
Percentage of kids over the cutoff	6.5%	7.4%	7.3%	17.2%
Depression	(n=47)	(n=119)	(n=82)	(n=78)
Raw score	8.91 (4.86), 8, 1-21	6.85 (5.88), 6, 0-31	5.82 (5.84), 4, 0-30	8.32 (7.94), 6, 0-39
T score	53.38 (12.82), 52, 32-88	45.59 (8.06), 44, 35-77	43.45 (8.31), 41, 34-79	47.03 (11.20), 44, 34-86
Percentage of kids over the cutoff	8.5%	4.2%	2.4%	9%

^aData are parent proxy-report from the Behavior Assessment System for Children: Second Edition (BASC-2).

^bData are child self-report from the Revised Children's Manifest Anxiety Scale and Children's Depression Inventory.

Table 6. Participation scores from the (self-reported) Children's Assessment of Participation and Enjoyment (CAPE)^a for youth

	School-aged children ages 6-12 (n=135 unless noted)	Young adolescents ages 13-15 (n=80 unless noted)	Older adolescents ages 16-18 (n=129 unless noted)
	Mean (SD), median, range	Mean (SD), median, range	Mean (SD), median, range
Formal			
Diversity	3.25 (2.29), 3, 0-10	3.23 (2.28), 3, 0-11	2.05 (1.64), 2, 0-8 ^b
Intensity	1.09 (0.72), 0.9, 0.07-4.13 (n=122)	1.07 (0.85), 0.87, 0.07-4.53 (n=75)	0.66 (0.51), 0.53, 0.07-2.27 (n=107)
With whom	3.42 (1.02), 3.5, 1-5 (n=123)	3.77 (1.03), 4, 1-5 (n=75)	3.61 (1.13), 3.67, 1-5 (n=107)
Where	3.90 (1.22), 4, 1-6 (n=123)	4.07 (1.16), 4.17, 1-6 (n=75)	4.08 (1.35), 4.5, 1-6 (n=107)
Enjoyment	3.92 (0.92), 4, 1-5 (n=123)	3.80 (1.01), 4, 1-5 (n=75)	3.72 (0.98), 4, 1-5 (n=107)
Informal			
Diversity	22.73 (5.70), 23, 6-36	20.78 (5.03), 21.5, 9-33	17.93 (4.92), 18, 4-31
Intensity	2.70 (0.80), 2.75, 0.40-4.45	2.48 (0.68), 2.48, 1.13-4.78	2.20 (0.59), 2.2, 0.48-3.8
With whom	2.38 (0.40), 2.36, 1.58-3.76	2.56 (0.48), 2.53, 1.16-3.54	2.64 (0.59), 2.6, 1.44-4.17
Where	2.43 (0.56), 2.36, 0.94-4.39	2.67 (0.67), 2.63, 1.31-5.55	2.72 (0.81), 2.67, 0.75-5.33
Enjoyment	3.98 (0.51), 4, 2.29-5	3.80 (0.50), 3.82, 2-4.78	3.82 (0.60), 3.86, 1.62-5
Overall			
Diversity	25.98 (7.05), 26, 6-42	24 (6.44), 25, 10-44	19.98 (5.85), 20, 5-37
Intensity	2.23 (0.69), 2.27, 0.29-3.84	2.08 (0.66), 2.05, 0.89-4.71	1.75 (0.48), 1.75, 0.36-3.16
With whom	2.51 (0.43), 2.47, 1.58-3.79	2.72 (0.50), 2.67, 1.25-3.69	2.72 (0.59), 2.71, 1.42-4.24
Where	2.59 (0.56), 2.57, 1-4.34	2.83 (0.63), 2.80, 1.31-5.58	2.84 (0.80), 2.85, 0.75-4.86
Enjoyment	3.97 (0.50), 3.97, 2.58-5	3.80 (0.52), 3.87, 1.94-4.8	3.81 (0.59), 3.81, 1.64-5

^aChildren's Assessment of Participation and Enjoyment (CAPE). Copyright© 2004 NCS Pearson, Inc. Scale names reproduced with permission. All rights reserved.

^bThe Cronbach's alpha for 16-18 year olds for formal diversity fell in an unacceptable range, so results should be interpreted with caution.

QOL. Seventy-nine younger adolescents completed the PedsQL. Mean and median scores from the Emotional, Social, School, and overall Psychosocial Health scales are presented in **Table 4**. Young adolescents seemed to rate their social QOL as highest and school QOL as lowest.

Mental health. Mean and median raw and *T* scores for anxiety and depression are presented in **Table 5**. Eighty-two younger adolescents completed the RCMAS and CDI; of these, 7.3% fell above the clinical cutoff for anxiety (*n* = 6) and 2.4% above the clinical cutoff for depression (*n* = 2).

Older adolescents: Ages 16 to 18

Participation. Of the 134 adolescents ages 16 to 18, 129 completed the CAPE. Older adolescents were most likely to engage in watching television or a rented movie, listening to music, and talking on the phone and were least likely to be learning to

dance, doing gymnastics, and doing martial arts (**Table 3**). Mean and median scores on the CAPE formal and informal subscales are presented in **Table 6**.

QOL. One hundred and twenty-nine older adolescents completed the PedsQL. Mean and median scores from the Emotional, Social, School, and overall Psychosocial Health scales are presented in **Table 4**. Similar to younger adolescents, older adolescents seemed to rate their social QOL as highest and school QOL as lowest.

Mental health. Mean and median raw and *T* scores for anxiety and depression are presented in **Table 5**. One hundred thirty-four older adolescents completed the RCMAS; of these, 17.2% fell above the clinical cutoff for anxiety (*n* = 23). Seventy-eight older adolescents completed the CDI; of these, 9% fell above the clinical cutoff for depression (*n* = 7).

Discussion

The current study provides an overview of psychosocial outcomes among a large sample of youth with SCI (N = 410). This study sought to describe community participation, QOL, and rates of mental health problems (including anxiety and depression) for youth 2 to 5, 6 to 12, 13 to 15, and 16 to 18 years old. Past work by the current research team has examined relationships between outcomes including QOL and mental health^{17,22}; participation, depression, and mental health³⁷; and participation and QOL,³⁸ but the current descriptive data provide needed information to clinicians regarding how youth with SCI may be experiencing psychosocial health and where their patients fit into that typical experience.

Regarding participation, the top activities engaged in by youth within each age group seem to change along developmentally appropriate lines. Specifically, top activities shifted from play and arts and crafts activities for the youngest participants and watching television and playing video and board games for school-aged youth and adolescents to engaging more with peers for younger and older adolescents. The amount of television viewing and general "screen time" in each of the 4 age groups and the fact that the top activities tended to be more sedentary and informal are of concern. However, this may reflect a more general concern for youth in today's society,³⁹ and not necessarily a concern specific to youth with SCI. In terms of how these participation rates may compare to those of youth without disabilities, the only existing published norms for the CAPE provide information on the diversity, intensity, and enjoyment of informal (27.18, 3.79, and 3.99, respectively) and formal (4.72, 1.62, and 4.17, respectively) participation for 354 youth without disabilities who were 6 to 14 years old.⁴⁰ As compared to our sample of youth with SCI who were 6 to 12 years old, our youth seem to be participating in fewer informal and formal activities and participating less often in informal activities. Although future research is needed to better understand how youth with SCI compare to a broader age range of typically developing youth, findings suggest that youth with SCI may be in need of additional supports regarding

participation. Because participation is context-bound,⁴ intervention efforts should focus not only on the child and family, but also on the broader community. These efforts should focus on changing attitudes about the capabilities of youth with disabilities and providing appropriate opportunities for participation for youth.

Regarding QOL, the youngest participants (ages 2-5 years) seemed to have the lowest QOL, but it is important to consider that these data were parent proxy-report in contrast to the child self-report data collected from the older participants. This is consistent with past research that found parent proxy-report QOL to be lower than child self-report QOL.^{17,41,42} Future research should investigate QOL in the youngest age group to determine the factors driving this difference, if a difference truly exists. Among the older 3 age groups, school-aged children and older adolescents seemed to have slightly lower QOL than younger adolescents. It may be that these 2 age ranges are particularly stressful for youth as they experience key transition points. In terms of how these scores might compare to the HRQOL of youth without disabilities, Varni and colleagues published data collected from "healthy" youth (self-report) and their parents (proxy-report).²⁹ Even though Varni et al's data are not broken down by age group, it would appear that the present SCI sample experienced decreased HRQOL as compared to these published norms. Specifically, the HRQOL scores range from 82.64 to 91.56 for parent proxy-report and from 78.63 to 87.42 for child self-report; this compares to scores from our sample of youth with SCI, which range from 59.57 to 63.34 for parent proxy-report and 64 to 80.70 for child self-report. These findings are not too surprising in that youth with disabilities face a number of health-related challenges in the areas assessed by the PedsQL, including emotional, social, and school functioning. As a critical postinjury outcome, future research and intervention efforts should focus on improving youth's QOL.

Regarding mental health, authors of each of the 3 mental health measures incorporated in the present study (the BASC-2, RCMAS, and CDI) have suggested average *T* score ranges of 41 to 59,³⁴ 40 to 59,³⁴⁻³⁵ and 45 to 55,³⁶ respectively.

Across the age categories, our participants scored within the average range for the anxiety and depression measures, with the 1 exception being depression for youth ages 13 to 15, which actually fell slightly below the average range. It would appear that, overall, these participants with SCI are experiencing average (and even low) levels of mental health symptomatology. This finding runs somewhat contrary to expectations, so we are continuing to examine the appropriateness of our measurement tools. Although the tools incorporated are standardized and widely used, they were not developed for youth with disabilities. It is also possible that the routine care these youth receive is helping alleviate any issues they may be experiencing related to their mental health. In particular, participants see the entire SCI team twice each year, including a clinical psychologist and social worker. While some youth are still experiencing difficulty, this routine care may be preventing additional problems from occurring among the majority. Future research should continue to monitor aspects of mental health difficulties and resilience among youth with SCI.

In addition to highlighting areas for improvement, these data can be used to provide age-based norms of psychosocial health specific to youth with SCI. Although the tendency is for us to compare these participants to typically developing young people (just as we have done in this article), youth with SCI are *not* typically developing. In fact, they may experience completely different trajectories than their able-bodied peers; these trajectories may vary based on age at injury, injury duration, and current age. Future work should continue to follow these outcomes longitudinally to provide information on key transition points for youth and points in their lives when support is needed to best foster their adjustment.

Limitations

There are several limitations of the current work. First, although we attempted to look descriptively at psychosocial outcomes across childhood, data were cross-sectional. Longitudinal data are needed

to examine how outcomes change over time. Related to this, parent-report data were used for outcomes of the youngest children (ages 2-5). Past research has demonstrated that parent-report may be more a function of the parent's mental health than the child's mental health¹⁷; regardless of this, self-report data were not feasible for these youngest children. Second, some of the measurement tools incorporated in this study demonstrated internal consistencies that were moderate at best. There remains a need for valid and reliable tools to measure these complex constructs, in particular measures that span from young childhood through adolescence. Future research should strive to improve our ability to assess changes in psychosocial outcomes over time. Finally, although we compared data to published norms when available, no appropriate comparison data from youth without disabilities were collected as part of this study. The use of previously collected, published norms as a point of comparison is far from ideal, but we have referenced these data in the discussion to provide some context for interpreting results.

Conclusion

This sample of youth with SCI seemed to experience decreased levels of participation and QOL, but also decreased anxiety and depression. This work provides needed information to clinicians regarding how youth with SCI may typically be experiencing psychosocial health and where their patients fit into that typical experience. Future longitudinal research would provide information on key transition points for youth, including viable points of intervention.

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