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ORIGINAL CONTRIBUTION

Stability of Transition to Adulthood Among Individuals With Pediatric-onset Spinal Cord Injuries

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Abstract

Background/Objective: Cross-sectional studies have provided information about the outcomes of adults with pediatric-onset spinal cord injuries (SCIs), but there has been no information about the stability of those outcomes over time. The purpose of this study was to assess the stability of independent living, employment, and life satisfaction and to determine factors associated with stable, successful outcomes.

Methods: Structured interviews of individuals who had sustained an SCI at age 18 years or younger and were 24 years or older at first interview. The primary standardized measures used include the Functional Independence Measure, Craig Handicap Assessment and Recording Technique (CHART), Short-Form 12 measure of perceived health, and the Satisfaction with Life Scale.

Results: One hundred sixty-six individuals had 3 consecutive annual interviews. Mean age at interview was 29 years (range, 24–36 years). Of this group, 64% lived independently at the first interview, and 90% of those continued to live independently; 64% were employed at first interview, of which 83% continued to be employed; and 48% reported life satisfaction at the first interview, and 84% of these continued to be satisfied. Factors most closely associated with stable independent living were CHART subscales of physical independence, mobility, and occupation. Factors associated with stable employment were sex, race, independent living, CHART mobility, and cognitive independence. Factors associated with stable life satisfaction were CHART occupation subscale and fewer pressure ulcers.

Conclusions: Many individuals with pediatric-onset SCI achieve successful, stable adult outcomes. The factors associated with that success can help us improve rehabilitation for future patients.

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INTRODUCTION

When children or adolescents sustain spinal cord injuries (SCIs), there is a significant disruption in their lives and the lives of their families. The SCI continues to impact these individuals as they grow and develop and transition to adulthood. Cross-sectional data show that adults with pediatric-onset SCI have educational achievement levels comparable with their peers but are less likely to be employed, are less likely to live independently, and are less likely to be satisfied with their lives than their peers are (1–4). For adults with pediatric-onset SCI, the longitudinal trends of outcomes over decades during adulthood have not yet been identified. Because stable employment is one of the hallmarks of adult life, the ideal goal would be that those who were employed at first follow-up would remain employed and those unemployed at first follow-up would become employed, with similar trends for all the major outcomes. However, there are concerns that adults with pediatric-onset SCI may have less stable successful outcomes than expected. SCI is a risk factor for a number of medical complications, whether the injury is sustained in childhood or adulthood (5–8). In cross-sectional studies, medical complications have been found to have an impact on many outcomes, including employment, independent living, and life satisfaction in adults with pediatric-onset SCI (9). One would expect that the constant risk of these complica-

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tions might negatively impact an individual's ability to be consistently employed, independent, or satisfied. In addition, most young adults may experience job and income instability as they begin their careers, and those with SCI may have even more difficulty maintaining employment. For this reason, annual follow-up interviews have the potential to provide a clearer understanding of the adult lives of individuals with pediatric-onset SCI compared with a single, cross-sectional interview that provides just a "snapshot" of outcomes.

The ultimate purpose of our study was to obtain long-term longitudinal data over decades. The purpose of this paper is to report the initial data on 3 consecutive annual interviews with adults who have pediatric-onset SCI to determine the stability of outcomes over the short term. This report will focus on 3 key outcomes and the factors that are associated with successful, stable adult outcomes.

Two of the outcomes selected for study are employment and independent living. Recent survey data done in the United States showed that employment and independent living are 2 of the milestones that are believed to define successful transition to adulthood in this country (10). The third outcome that will be studied is self-reported satisfaction with life. The importance of including a subjective measure of overall quality of life or life satisfaction has been emphasized in much of the recent SCI literature (11–14). The rationale is that, regardless of the objective milestones that clinicians or researchers deem to be important outcomes, the individuals' own perspectives of their quality of life are arguably the most important outcome (15).

METHODS

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 significant brain injury, and were living in the United States or Canada. All individuals who had received care at the SCI Programs of the Shriners Hospitals for Children in Chicago or Philadelphia were potential subjects for this study. Care is provided free of charge, and there are no financial or insurance restrictions. There are no requirements for acceptance into the Shriners Hospitals for Children SCI programs. Patients are permanently discharged from the system when they reach the age of 21 years.

Procedures

All eligible patients were identified and searched for by the following methods: review of contact information from Shriners Hospitals for Children medical charts, a computer search of White Page directories such as TheUltimates.com and the Social Security Death Index, and search by a professional search service. In accordance with the policies of the Chicago Shriners Hospitals for Children's Institutional Review Board, each patient contacted was informed of the purposes, procedures, confidentiality, and voluntary nature of participation in the study. After obtaining written informed consent, the participants were enrolled in the study and interviewed by telephone. In addition, medical chart reviews and the Shriners Hospitals for Children SCI database were used to obtain injury-related information. Two follow-up interviews were conducted, each 12 to 24 months after the previous interview.

Instruments

A structured questionnaire designed for this study was used to determine demographic information such as employment status, education level, marital status, living situation, ambulation, and medical complications. The medical complications identified for this study included experience over the past 3 years of urinary tract infections (UTIs) requiring intravenous antibiotics or necessitating hospitalization, pressure ulcers of any grade, or hospitalizations. In addition, the occurrence of spasticity or pain since injury, excluding the immediate postinjury period were identified, as well as current experience with bowel incontinence. In addition, participants were asked to identify current use of illegal substances, and use of any illegal substance was coded as positive for purposes of analysis. The standardized measures used to assess body functions and structures were the neurological levels, ASIA Impairment Scale, and ASIA Motor Score as defined by the American Spinal Injury Association and the International Medical Society of Paraplegia (ASIA/IMSOP) *International Standards for the Neurological Classification of Spinal Cord Injury* (16). These measures reflect the severity of injury. Activity was measured with the Functional Independence Measure (FIM), motor component (17–19). This is a 13-item tool that assesses areas of self-care, mobility, and sphincter control. It uses a 7-point rating scale to identify the level of independence with which an individual performs activities of daily living. Ratings are accumulated across items to indicate overall severity of disability (19). Higher scores indicate more functional independence. Participation was measured by the Craig Handicap Assessment and Reporting Technique (CHART) (20,21). CHART produces a total score and scores for 6 separate subscales: physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency. Higher scores indicate greater participation. Health status was assessed with the Short-Form-12 (SF-12), which includes 12 questions from which mental and physical component summary scores are generated (22). This standardized measure assesses an individual's perception of health, with higher scores indicating greater perceived health. Subjective, global life satisfaction was assessed with the Satisfaction with Life Scale (SWLS). This measure consists of 5 statements that an individual rates on a 7-point scale from "strongly agree" (a higher score indicating greater life satisfaction) to "strongly disagree" (a lower score indicating less life satisfaction) (23,24). All of the standardized measures used have adequate reliability and validity and have been widely used for assessing outcomes with patients with SCI.

Table 1. Comparison of Study Subjects Who Completed Only 1 or 2 Interviews and Those Who Were Never Interviewed

	Completed 3 Interviews	Completed 1 or 2 Interviews	Completed 0 Interviews
Number of subjects	166	55	195
Sex			
Male	115 (69%)	35 (64%)	149 (76%)
Race/ethnicity			
White	151/164 (92%)*†	42/53 (79%)†	128/170 (75%)†
Age at injury (years)			
Mean (SD)	14.2 (4.0)	13.3 (4.2)	13.9 (3.8)†
Level of injury			
Tetraplegia	106 (64%)*	26 (47%)	88/194 (45%)†
ASIA motor score			
Mean (SD)	36.5 (22.8)	38.7 (21.5)	41.1 (23.2)†
ASIA impairment scale			
A	105 (63%)	39 (71%)	121/176 (69%)†

*Statistically significant differences between those who completed 3 interviews compared with those who completed only 1 or 2 interviews or those who were never interviewed ($P < 0.050$).
†Data not available for all subjects.

Analyses

Data were analyzed in the following sequence. (a) A comparison was made between individuals who were followed for a total of 3 consecutive interviews with those who were never interviewed and compared with those who failed to be interviewed after the first or second interview. (b) The stability of independent living, employment, and life satisfaction were described by analyzing how many individuals had successful outcomes at all 3 interviews, how many had successful outcomes at 1 or 2 interviews, and how many had unsuccessful outcomes at all interviews. Independent living was defined as living away from parents. Employment was defined as employed either full time or part time. Life satisfaction was dichotomized as SWLS scores of at least 26 (representing the categories of satisfied to extremely satisfied) as representing "satisfaction" and scores of no more than 19 (representing the categories of "slightly dissatisfied" to "extremely dissatisfied") as "dissatisfaction." (c) The factors associated with consistent independent living, employment, and satisfaction were determined by univariate analysis and logistic regression analyses. For each of the key outcomes, analyses were done to compare those successful at all 3 interviews with those with unsuccessful outcomes at all interviews.

Comparisons included demographic factors, body structure and function, activity, participation using subscales of the CHART, life satisfaction, and medical complications, dichotomized as present or not. For continuous data, *t* tests were used to determine statistically significant differences, and for dichotomized data, chi-square tests were used. Finally, logistic regression analyses, using a forward stepwise procedure, were used to determine predictive factors. The independent factors included in the regression analyses were all of the factors that were significantly associated with a particular outcome in univariate analysis. Marriage was not included in the regression analyses as an independent factor because there were no married individuals who were living with parents, unemployed, or dissatisfied.

RESULTS

In this series, 308 adults with pediatric-onset SCI were interviewed at least once. Of those 308 individuals, 221 individuals would have been eligible for at least 2 annual follow-up interviews at the time of this data analysis. Of the 221, 166 (75%) completed all 3 interviews. Of the 55 individuals who did not complete all 3 interviews, 35 completed 1 interview, and 20 completed 2 interviews. Of those 55, 7 had died, 18 refused participation, and 30 could not be located. In addition, there was another group of 195 individuals who were eligible for the study but were never interviewed because they could not be located or they elected not to participate. The differences between those who completed 3 interviews and those who were never interviewed or did not complete all 3 interviews are summarized in Table 1. Those who completed 3 interviews were more likely to be white and to have tetraplegia than either those who were never interviewed or those who did not complete 3 interviews.

Of the 166 participants completing all 3 interviews, 106 (64%) lived independently at the initial interview. Of those 106, 95 (90%) continued to live independently for the remaining 2 follow-up interviews. Of the 60 who were not living independently at the first interview, 48 (80%) did not live independently at any interview. Table 2 compares those who lived independently at all 3 interviews to those who never lived independently. Those

Table 2. Comparison of Those Who Were Living Independently at All 3 Interviews With Those Who Lived With Parents at All 3 Interviews

	Living Independently at All 3 Interviews	Living With Parents at All 3 Interviews	Significance
Number of subjects	95	48	
Sex			$P = 0.118$, $\chi^2 = 2.450$
Male	61 (64%)	37 (77%)	
Female	34 (36%)	11 (23%)	
Race/ethnicity			$P = 0.239$, $\chi^2 = 1.388$
White	90 (95%)	42 (89%)*	
Age at injury (years)			$P = 0.979$
Mean (SD)	14.2 (4.1)	14.3 (4.0)	
Age at interview (years)			$P = 0.099$
Mean (SD)	29.1 (3.9)	28.0 (3.2)	
Range	24–36	24–34	
Duration of injury (years)			$P = 0.249$
Mean (SD)	14.4 (4.6)	13.5 (4.2)	
Range	8–30	7–24	
Level of injury			$P = 0.165$, $\chi^2 = 1.931$
Tetraplegia	56 (59%)	34 (71%)	
Paraplegia	39 (41%)	14 (29%)	
ASIA impairment scale			$P = 0.487$, $\chi^2 = 0.484$
A	63 (66%)	29 (60%)	
B, C, D	32 (34%)	19 (40%)	
Highest education			
BA or higher	34 (36%)	13 (23%)	$P = 0.295$, $\chi^2 = 1.095$
FIM motor items, mean (SD)	61.8 (21.7)	48.5 (23.7)*	$P = 0.001$
SF12, mean (SD)			
Physical component	46.7 (8.7)	43.7 (10.0)*	$P = 0.061$
Mental component	52.9 (7.1)	51.5 (7.3)*	$P = 0.278$
CHART, mean (SD)			
Physical	93.1 (10.6)*	79.3 (26.4)*	$P < 0.001$
Cognitive	97.2 (4.0)	95.2 (5.5)*	$P = 0.015$
Mobility	95.5 (9.8)	81.3 (19.6)	$P < 0.001$
Occupation	92.3 (17.2)*	68.5 (33.5)*	$P < 0.001$
Social integration	93.2 (12.9)*	87.4 (17.9)*	$P = 0.030$
Economic self-sufficiency	84.8 (27.6)*	80.4 (31.0)*	$P = 0.511$
Total CHART	557.4 (47.6)*	496.7 (77.4)*	$P < 0.001$
Married	40 (42%)	0	$P < 0.001$, $\chi^2 = 28.059$
Employed†	59 (75%)	14 (33%)	$P < 0.001$, $\chi^2 = 19.591$
Illegal drug use	15 (16%)	5 (11%)*	$P = 0.406$, $\chi^2 = 0.689$
Satisfaction with life‡			
Mean (SD)	26.4 (7.6)	21.5 (8.2)	$P = 0.001$
Range	5–35	5–35	
Medical complications			
Spasticity	45 (47%)	35 (73%)	$P = 0.004$, $\chi^2 = 8.445$
Pressure ulcer	30 (32%)	24 (50%)	$P = 0.032$, $\chi^2 = 4.604$
Severe UTI	10 (11%)*	14 (29%)	$P = 0.005$, $\chi^2 = 7.767$
Pain	70 (74%)	34 (71%)	$P = 0.718$, $\chi^2 = 0.131$
Hospitalization	18 (19%)	13 (27%)	$P = 0.265$, $\chi^2 = 1.243$
Bowel incontinence	10 (11%)	2 (4%)	$P = 0.206$, $\chi^2 = 1.598$

*Data not available for all subjects.
†Students and homemakers excluded.
‡Reported at third interview.

Table 3. Logistic Regression Analysis for Independent Living

	Coefficient			Nagelkerke R^2
	β	SE	Significance	
Independent living				0.39
CHART physical	0.037	0.013	$P = 0.005$	
CHART mobility	0.036	0.017	$P = 0.038$	
CHART occupation	0.029	0.010	$P = 0.003$	

consistently living independently were not statistically different in any demographic or body structure and function factors. Overall, those who were living independently were more functionally independent and more likely to be participants in the community as indicated by total CHART and all subscales except economic self-sufficiency. Those living independently were also significantly more likely to be employed and more satisfied with their lives. Of those consistently living independently, 42% were married and, not surprisingly, none of those living with parents were married. In addition, those living independently were less likely to have the medical complications of spasticity, pressure ulcers, and severe UTIs than those who were living with parents. Using logistic regression analysis, the factors that were most predictive of consistent independent living were CHART physical independence, mobility, and occupation scores (Table 3). Those factors accounted for an estimated 39% of the variance.

Excluding students and homemakers, there were 113 individuals who completed 3 interviews. Of those 113 subjects, 72 (64%) were employed at the first interview, and 60 of the 72 (83%) continued to be employed at the remaining 2 interviews. Of the 41 who were not employed at the first interview, 34 (83%) remained unemployed at all interviews. Table 4 compares those employed at all 3 interviews to those who were never employed. Those employed at all 3 interviews included a larger percentage of women (81%) than men (57%), a larger percentage of whites (68%) than nonwhites (17%), a larger percentage of those with paraplegia (82%) than tetraplegia (54%), and a larger percentage of those with college degrees (80%) than those with less education (20%). Those employed were more functionally independent and participated more in the community, as indicated by the CHART subscales of physical independence, cognitive independence, mobility, and social integration. The subscales of occupation and economic self-sufficiency were not included in that analysis because of their close ties to employment. Those consistently employed were also more likely to be married, to live independently, and to have greater life satisfaction. Those employed at all 3 interviews were also less likely to have spasticity than those unemployed. Of those with spasticity, 50% were employed, and of those without spasticity, 85% were consistently employed. Using logistic regression analyses, the factors most predictive of stable employment were being female, being white, having greater cognitive independence and community mobility on the CHART, and living independently (Table 5). Those factors accounted for an estimated 71% of the variance.

In this paper, employment was defined as either full-time or part-time employment, and by that definition, women were significantly more likely to be employed than men. If only full-time employment (35 hours or more per week) was considered, 55% of men and 75% of women were consistently employed full time. This is not a statistically significant difference, although the trend still favors women. However, focusing just on those employed, men were more likely to work full time (92%) than women (68%) ($\chi^2 = 5.742$, $P = 0.017$).

Of the 166 participants, 80 (48%) had SWLS scores indicative of satisfaction at the first interview, and 64 (84%) of those subjects also had scores indicating satisfaction at both of the following interviews. There were 86 (52%) who had SWLS scores indicating dissatisfaction at the first interview and, of those, 56 (65%) remained dissatisfied on the SWLS at all interviews. Comparing those consistently having SWLS scores indicating satisfaction to individuals who were never satisfied, no demographic or body structure and function factors were significantly associated with stable satisfaction (Table 6). Factors significantly associated with high life satisfaction scores included functional independence, perceived mental health, participation in the community (total CHART and subscales of mobility, occupation, and economic self-sufficiency), and fewer medical complications (pressure ulcers, UTIs, and pain). Marriage, living independently, and being employed were also associated with consistently high life satisfaction scores. Using logistic regression analysis with life satisfaction as the dependent variable, the predictive factors were CHART occupation subscale and fewer pressure ulcers (Table 7). An estimated 56% of the variance was accounted for by this model.

Table 8 provides a summary of the variables that are associated with stable, successful independent living, employment, and life satisfaction in the regression models. Participation variables were most likely to be predictive, 3 being predictive of employment and independent living, and 1 being predictive of life satisfaction. The only medical complication to be a predictive factor was pressure ulcers, which were predictive of decreased life satisfaction. The only demographic factors that were predictive were sex and race, and they were predictive only of employment and not indepen-

Table 4. Comparison of Individuals Who Were Employed at All 3 Interviews With Those Who Were Unemployed at All 3 Interviews

	Employed at All 3 Interviews	Unemployed at All 3 Interviews	Significance
Number of subjects	60	34	
Sex			$P = 0.024$, $\chi^2 = 5.112$
Male	38 (63%)	29 (85%)	
Female	22 (37%)	5 (15%)	
Race/ethnicity			$P = 0.001$, $\chi^2 = 6.415$
White	59 (98%)	28 (85%)*	
Age at injury (years)			$P = 0.383$
Mean (SD)	15.0 (3.1)	14.4 (3.6)	
Range	0–18	3–18	
Age at interview (years)			$P = 0.521$
Mean (SD)	29.8 (3.6)	29.3 (3.7)	
Range	24–36	24–37	
Duration of injury (years)			p=0.676
Mean (SD)	14.3 (4.0)	14.7 (5.1)	
Range	6–30	7–28	
Level of injury			$P = 0.008$, $\chi^2 = 7.127$
Tetraplegia	33 (55%)	28 (82%)	
Paraplegia	27 (45%)	6 (18%)	
ASIA impairment scale			$P = 0.188$, $\chi^2 = 1.730$
A	40 (67%)	18 (53%)	
B, C, D	20 (33%)	16 (47%)	
Highest education			
BA or higher	32 (53%)	8 (23%)	$P = 0.005$, $\chi^2 = 7.886$
FIM motor items, mean (SD)	62.6 (22.4)	46.9 (23.6)*	$P = 0.002$
SF12, mean (SD)			
Physical component	47.1 (8.4)	44.5 (10.3)	$P = 0.188$
Mental component	54.7 (5.4)	52.2 (7.1)	$P = 0.057$
CHART, mean (SD)			
Physical	94.1 (9.2)	82.8 (23.5)*	$P = 0.002$
Cognitive	98.4 (2.9)	95.6 (4.4)*	$P < 0.001$
Mobility	97.4 (7.7)	78.9 (20.1)	$P < 0.001$
Social integration	95.4 (10.2)*	83.6 (17.5)*	$P < 0.001$
Married	26 (43%)	0	$P < 0.001$, $\chi^2 = 20.367$
Living independently			
At all 3 points	47 (78%)	8 (24%)	$P < 0.001$, $\chi^2 = 26.851$
Illegal drug use	10 (17%)	8 (24%)	$P = 0.376$, $\chi^2 = 0.738$
Satisfaction with life†			
Mean (SD)	27.3 (6.3)	19.4 (9.3)	$P < 0.001$
Range	9–35	5–35	
Medical complications			
Spasticity	27 (45%)	27 (79%)	$P = 0.001$, $\chi^2 = 10.513$
Pressure ulcer	21 (35%)	16 (47%)	$P = 0.250$, $\chi^2 = 1.322$
Severe UTI	5 (8%)	7 (21%)	$P = 0.087$, $\chi^2 = 2.927$
Pain	40 (67%)	28 (82%)	$P = 0.102$, $\chi^2 = 2669$
Hospitalization	8 (13%)	7 (21%)	$P = 0.356$, $\chi^2 = 0.852$
Bowel incontinence	5 (9%)	0	$P = 0.081$, $\chi^2 = 3.045$

*Data not available for all subjects.
†Reported at third interview.

Table 5. Logistic Regression Analysis for Employment

	Coefficient			
	β	SE	Significance	Nagelkerke R^2
Employment				0.71
Sex	6.146	2.547	$P = 0.016$	
Race	−3.654	1.925	$P = 0.058$	
CHART cognitive	0.272	0.113	$P = 0.016$	
CHART mobility	0.190	0.067	$P = 0.004$	
Independent living	−1.582	0.761	$P = 0.038$	

dent living or satisfaction. Impairment and activity limitations were not predictive of any of the outcomes.

DISCUSSION

Using independent living, employment, and life satisfaction as hallmarks of successful transition to adulthood, one of the goals of this study was to determine (a) how many adults with SCI reached any of those successful outcomes, and (b) of those, how many individuals maintained the successful outcomes over 2 additional annual follow-up interviews. Forty-eight percent to 64% of the study subjects reached successful transition goals, and 83 to 90% of those maintained that status over the 3 interviews. On a less positive note, those who reported unsuccessful outcomes at the first interview were also likely to maintain that status: 80% remained living with parents, 83% remained unemployed, and 65% remained dissatisfied. This poses a challenge for health care professionals. Understanding the factors associated with either stable successful or unsuccessful outcomes should provide guidance for improving the outcomes of those less successful.

Those who were consistently dissatisfied are certainly individuals that should be carefully examined for risk factors. The fact that no demographic or injury-related factors are associated with consistent dissatisfaction is noteworthy because it is natural to assume that there is a strong correlation between severity of injury and life satisfaction. A previous study of life satisfaction of adults with pediatric-onset SCI, using cross-sectional data, found that those with tetraplegia showed lower life satisfaction than those with paraplegia in univariate analyses but not in multiple regression analyses. The strongest predictors of life satisfaction in that study were community participation and medical complications (4). Similarly, in studies that involve adults who primarily have adult-onset SCI, medical complications and/or community participation have also been found to be factors associated with life satisfaction (25,26). The fact that this study found CHART occupation subscale to be predictive of stable life satisfaction is one indicator of where efforts should be targeted in preparing children or adolescents for successful, stable outcomes. That subscale is not synonymous with employment but does reflect involvement in meaningful activities, whether employment, volunteer activities, homemaking, studies, or leisure activities. In this study, pressure ulcers were also a strong predictive factor for decreased life satisfaction. The fact that medical complications are associated with consistently decreased life satisfaction is not a unique finding. Pressure ulcers were associated with decreased life satisfaction in a cross-sectional study of adults with pediatric-onset SCI (9). Preventing pressure ulcers is clearly critical, and making that a focus of rehabilitation efforts is warranted.

Unlike subjective reports of overall life satisfaction, employment is an objective goal that society typically associates as a hallmark of successful adulthood (10). In this study, 64% of participants were employed at the first interview, which is a considerably higher employment rate than is typically reported for individuals with adult-onset SCI of about the same age (27). In this study, employment is the only outcome in which sex was a significant factor. A larger percentage of women than men were employed over 3 interviews. A similar trend was noted in the analysis of cross-sectional data of adults with pediatric-onset SCI (2). In that study, sex was not a significant predictor in regression analysis in contrast to the findings in this study. Recent data from the Model SCI Systems did not show a statistically significant sex difference in percentage employed, but that study reported that men were more likely to work full time and women were more likely to work part time. (27). In this study, of those employed, men were more likely to be employed full time than women. However, because only 57% of men were consistently employed, compared with 81% of women, men, in particular, represent a risk group that deserves more intervention. Because adolescents with SCI have reported less work experience than nondisabled peers, one type of intervention would be to encourage adolescents to obtain paid part-time work or participate in volunteer experiences (28). The other demographic variable that was associated with employment in the logistic regression analysis was race, with whites more likely to be consistently employed than nonwhites. This

Table 6. Satisfaction With Life Group Comparisons: Demographics and Outcomes

	SWL Score Is 26 or Higher at All 3 Interviews	SWL Score Is 19 or Lower at All 3 Interviews	Significance
Number of subjects	64	21	
Sex			$P = 0.305$, $\chi^2 = 1.053$
Male	41 (64%)	16 (76%)	
Female	23 (36%)	5 (24%)	
Race/ethnicity			$P = 0.837$, $\chi^2 = 0.043$
White	60 (94%)	19 (95%)*	
Age at injury (years)			$P = 0.987$
Mean (SD)	14.1 (3.9)	14.1 (4.7)	
Age at interview (years)			$P = 0.986$
Mean (SD)	28.0 (3.5)	28.0 (3.8)	
Range	24–37	24–35	
Duration of injury (years)			$P = 0.994$
Mean (SD)	13.6 (4.8)	13.6 (4.6)	
Range	6–30	7–24	
Level of injury			$P = 0.204$, $\chi^2 = 1.611$
Tetraplegia	39 (61%)	16 (76%)	
Paraplegia	25 (39%)	5 (24%)	
ASIA impairment scale			$P = 0.965$, $\chi^2 = 0.002$
A	43 (67%)	14 (67%)	
B, C, D	21 (33%)	7 (33%)	
Highest education			
BA or higher	27 (42%)	6 (29%)	$P = 0.267$, $\chi^2 = 1.234$
FIM motor items, mean (SD)	61.3 (23.1)*	44.2 (18.8)*	$P = 0.003$
SF12, mean (SD)			
Physical component	47.8 (7.4)*	43.6 (11.4)	$P = 0.055$
Mental component	55.4 (5.8)*	49.1 (5.8)	$P < 0.001$
CHART, mean (SD)			
Physical	90.0 (16.2)*	83.9 (17.9)*	$P = 0.182$
Cognitive	97.6 (4.7)*	96.3 (4.0)*	$P = 0.273$
Mobility	94.0 (13.3)	83.3 (18.0)	$P = 0.005$
Occupation	90.7 (20.2)*	61.7 (34.6)*	$P < 0.001$
Social integration	93.3 (16.7)	86.2 (14.0)*	$P = 0.094$
Economic self-sufficiency	87.4 (27.6)*	60.7 (35.0)*	$P = 0.003$
Total CHART	562.3 (48.8)*	477.6 (84.0)*	$P < 0.001$
Married	27 (42%)	0	$P < 0.001$, $\chi^2 = 12.984$
Living independently			
At all 3 points	44 (69%)	7 (33%)	$P = 0.004$, $\chi^2 = 8.264$
Employed†	37 (71%)	6 (32%)	$P = 0.003$, $\chi^2 = 9.125$
Illegal drug use	7 (11%)	3 (14%)	$P = 0.679$, $\chi^2 = 0.171$
Medical complications			
Spasticity	35 (55%)	14 (67%)	$P = 0.335$, $\chi^2 = 0.929$
Pressure ulcer	17 (27%)	11 (52%)	$P = 0.029$, $\chi^2 = 4.771$
Severe UTI	6 (10%)[b]	6 (29%)	$P = 0.031$, $\chi^2 = 4.667$
Pain	38 (59%)	18 (86%)	$P = 0.027$, $\chi^2 = 4.880$
Hospitalization	14 (22%)	5 (24%)	$P = 0.854$, $\chi^2 = 0.034$
Bowel incontinence	4 (6%)	1 (5%)	$P = 0.790$, $\chi^2 = 0.071$

*Data not available for all subjects.
†Students and homemakers excluded.

Table 7. Logistic Regression Analysis for Satisfaction With Life

	Coefficient			
	β	SE	Significance	Nagelkerke R^2
Satisfaction with life				0.56
CHART occupation	0.089	0.030	0.003	
Pressure ulcers	−3.200	1.378	0.020	

finding is consistent with the literature of adults with adult-onset SCI. (27,29–32). However, in this study, there were only 7 individuals included in the employment analysis who were nonwhite compared with 87 who were white. The lack of diversity is one limitation of the study, and generalizations about race/ethnicity would require a larger study population. Participation, as reflected by independent living and the CHART subscales of cognitive independence and mobility, are predictive of consistent employment in this study. The circularity of needing employment to afford transportation and needing transportation to obtain employment is an issue, whether or not one is disabled.

Not surprisingly, living independently at 3 interviews was associated with the physical independence, mobility, and occupation subscales of the CHART. Although marriage could not be included as an independent variable in the regression analyses, it was strongly associated with all 3 outcomes of independent living, employment, and life satisfaction. Marriage was also associated with employment and life satisfaction in cross-sectional studies of this population (1,2).

Among the factors that were not associated with stable, successful outcomes were age at injury, age at interview, or duration. One could hypothesize that those with SCI would be slower to transition to adult life because of disability-related issues but would catch up with peers as they moved into their 30s or 40s. There is no evidence from this study to support this hypothesis. However, a larger sample size with longer-term follow-up is needed to adequately address this issue. Other variables that were not predictive of stability, using logistic regression analyses, included severity of injury, functional independence, and perceived mental or physical health. Substance abuse was also not predictive of stability in this study, although this is a self-report measure and, even with confidentiality assured, this may be an underestimate of actual substance abuse.

Participation factors and medical complications, particularly pressure ulcers, were important predictors of consistent successful outcomes. Although community mobility was not associated directly with life satisfaction, it was associated with both employment and independent living, which are, in turn, associated with life satisfaction. Similarly, the CHART occupation subscale was predictive of both independent living and life satisfaction. That subscale includes employment but also other meaningful activities such as housework and household maintenance, volunteer work, and recreation. Encouraging these kinds of community participation from the time of childhood and adolescence may represent an important way of transitioning individuals with pediatric-onset SCI to more successful outcomes.

CONCLUSIONS

In summary, this study presents the first longitudinal outcome data on adults with pediatric-onset SCI and

Table 8. Multiple Regression Analysis

	Living Independently at All 3 Interviews	Employed at All 3 Interviews	SWLS 26 or Greater at All 3 Interviews
Sex		$P = 0.016$	
Race		$P = 0.058$	
CHART physical	$P = 0.005$		
CHART cognitive		$P = 0.016$	
CHART mobility	$P = 0.038$	$P = 0.004$	
CHART occupation	$P = 0.003$	NA	$P = 0.003$
Independent living	NA	$P = 0.038$	
Pressure ulcers			$P = 0.020$

NA, not applicable.

the first opportunity to assess short-term stability of outcomes. This work forms the basis for future studies that will include 5- to 10-year follow-ups of pediatric-onset SCI.

The data for this longitudinal study included 3 annual interviews covering a period of 2 to 3 years. This is a relatively short period of time, and longer periods of follow-up are needed to determine the significant trends in the adult lives of these patients. In addition, the terms "consistent" or "stable" outcomes have been used in this article, although the outcomes were assessed at discrete interviews at 3 time periods, and the participants were asked for their status on the day they were interviewed. It is likely, but certainly not guaranteed, that just because they were employed, living independently, or satisfied at the time of 3 separate interviews, they actually maintained that status throughout the year.

Another limitation of this study is that all of the participants were only from 2 hospitals. Therefore, it is not possible to generalize these findings to all adults with pediatric-onset SCI. In addition, it is possible that whites and those with tetraplegia were overrepresented because those individuals were more likely to complete 3 interviews. Individuals who could be located for all 3 interviews may be those who were more likely to remain at the same address over time.

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