Depression in Adults Who Sustained Spinal Cord Injuries as Children or Adolescents

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Abstract

Study design: Interview survey.

Objective: To assess depression in adults with pediatric-onset spinal cord injuries (SCI) and to determine demographic and injury-related factors, and outcomes associated with depression, and to determine which other outcomes are associated with depression.

Methods: Subjects were adults with pediatric-onset SCI who sustained SCI at age ≤ 18 years and were interviewed at age ≥ 24 years. This is part of a longitudinal study for which there were 864 eligible participants; 353 (41%) were interviewed. Of these, 232 were assessed for depression. A telephone interview was conducted that included a structured questionnaire and standardized measures (Functional Independence Measure, Craig Handicap Assessment and Reporting Technique, Short-Form 12 measure of health-related quality of life, Satisfaction with Life Scale, and Patient Health Questionnaire-9 to screen for depression).

Results: Twenty-seven percent reported depressive symptoms ranging from mild to severe, and 7% reported having suicidal thoughts within the last 2 weeks, and 3% reported symptoms consistent with probable major depressive disorder (MDD). Depression was not significantly associated with any demographic factors but it was associated with incomplete injury ($P = 0.013$). Depression was also associated with many participation outcomes, health-related quality of life, life satisfaction, and medical complications.

Conclusions: Depression is a significant problem among adults with pediatric-onset SCI and is associated with poorer outcomes and lower quality of life. These findings should be addressed as clinicians prepare children and adolescents with SCI to transition to adulthood.

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Key Words: Depression; Spinal cord injuries; Children; Adolescence

INTRODUCTION

When spinal cord injuries (SCI) occur to children or adolescents, the goal of rehabilitation is not only to return these individuals as quickly as possible to their communities, but also to prepare them to lead satisfying and productive adult lives. Identifying the adult outcomes of these individuals and the risk factors associated

with poorer outcomes is a step toward understanding how pediatric rehabilitation for these patients can be improved (1–5). One important outcome to address is the emotional status of the individual as an adult, and specifically, whether there is significant depression. Among individuals with and without disabilities, depression is known to interfere with a person's ability to participate in activities and enjoy life. In studies that have primarily focused on individuals with adult-onset SCI, depression is typically reported to occur in 20% to 40%, depending on the definition of depression, the time since injury, and the duration of the study (6–8). For example, one study reported clinical depression in 27% of individuals during the first year postinjury (7). Similar

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Table 1. Demographic and Injury-Related Characteristics of Participants

Number of subjects	232
Gender	
Male	145 (63%)
Female	86 (37%)
Race/ethnicity	
White	206 (91%)
Nonwhite	21 (9%)
Age at injury, y	
Mean (SD)	14.2 (4.1)
Range	0–18
Duration of injury, y	
Mean (SD)	16.1 (6.2)
Range	5–34
Age at interview, y	
Mean (SD)	30.8 (5.1)
Range	24–42
Level of injury	
Tetraplegia	136 (59%)
Paraplegia	96 (41%)
Severity of injury	
Complete	158 (68%)
Incomplete	73 (32%)

data are not available for adults with pediatric-onset SCI, although one study reported no difference in depression scores among adults with pediatric-onset SCI compared to adult-onset SCI (9). If it is determined that depression is a significant problem for adults with pediatric-onset SCI and that it interferes with quality of life, then understanding the risk factors will provide important guidance toward addressing or decreasing depression.

Several issues have arisen in the past when assessing depression in individuals with SCI (10). Typically, depression questionnaires are long and time consuming, putting a significant burden on the respondent. In addition, these questionnaires do not correlate well with the diagnostic criteria as listed in the DSM-IV (11). Finally, the vegetative symptoms of depression are complex to assess, since many of these symptoms, like fatigue or loss of appetite, are similar to symptoms that may be associated with the SCI (10,12). Recently, Bombardier and colleagues evaluated the use of the Patient Health Questionnaire-9 (PHQ-9) for assessing depression in an adult SCI population (11). This measure includes just 9 items, all of which map directly to the diagnostic criteria for depression. Bombardier et al reported in their preliminary findings that this instrument shows promise for assessing depression in the SCI population because it is brief and accurate enough for a screening tool. The authors also argue, on the basis of their analyses, that an inclusive approach should be used, using all items, rather

than attributing some of the symptoms (eg, loss of appetite) to nonspecific effects of SCI (11). The PHQ-9, then, provides a valid instrument that can be used to determine, for the first time, the rate of depression in adults with pediatric-onset SCI and the risk factors for that outcome.

The goals of this study are to use the PHQ-9 to (a) assess depression in adults with pediatric-onset SCI and (b) determine which demographic factors, injury-related factors, and outcomes are associated with depression.

METHODS

Participants

Eligible subjects were individuals who sustained an SCI at age 18 years or younger, were age 24 years or older at followup, did not have a 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, Philadelphia, or Northern California were potential subjects for this study. Care is provided free of charge and there are no financial or insurance restrictions. Patients are permanently discharged from the system when they reach the age of 21 years.

The present study is part of a larger follow-up study that has been ongoing for the past decade (1–5). Of the 864 subjects eligible for this overall study, 353 (41%) completed interviews, 11% were lost to follow-up, 5% had died, 10% refused, and for 33% attempts to contact them are still being conducted. Of the 353 interviewed, 232 individuals completed the PHQ-9 since that was added to the follow-up protocol in 2003. A description of the participants is shown in Table 1. The subjects included 63% men. Race/ethnicity is dichotomized to white and nonwhite. Of the 21 nonwhite individuals, 10 were of Hispanic origin, 6 were African American, 3 were Asian, 1 was American Indian, and 1 was other, unclassified. The mean age at injury was 14 years and the mean age at interview was 31 years; 59% had tetraplegia and 68% had complete injuries.

Procedures

This project was approved by the Institutional Review Boards at the Shriners Hospitals in Philadelphia, Chicago, and Northern California, and all institutional regulations concerning the ethical use of human volunteers were followed during the course of this research. Eligible patients were identified and then contact information for them was sought using the following methods: review of contact information from Shriners Hospital for Children medical charts; a computer search of White Pages directories, such as TheUltimates.com, and the Social Security Death Index; and search by a professional search service. Each patient contacted was informed of the purposes, procedure, confidentiality, and voluntary nature of participation in the study. After signed informed consents were obtained, the participants were enrolled in

the study and interviewed by telephone. All interviews were conducted by research assistants who had not participated in the care of the patients. In addition, medical chart reviews and the Shriners Hospitals for Children SCI database were used to obtain injury-related information, such as level of injury, completeness of injury, and date of injury.

Instruments

A structured questionnaire designed for this study was used to determine demographic information such as employment status, education level, living situation, and medical complications. The 6 medical complications included in this study were defined as pressure ulcers or severe urinary tract infections requiring intravenous antibiotics or hospitalizations (UTI), respiratory complications, shoulder pain, pain at any site, or spasticity requiring treatment, within the past year. The following standardized measures were also used. All are commonly used with SCI populations, and information on the reliability and validity of the measures is included in the references. Impairment was measured using neurological level as defined by the International Standards for the Neurological Classification of Spinal Cord Injury (13). Functional limitations were assessed with the telephone version of the Functional Independence Measure (FIM) (14–16). The motor portions of this instrument, which include 13 items assessing self-care, mobility, and sphincter control, were used. A 7-point scale is used to identify the level of independence with which an individual performs each activity. Higher scores indicate more functional independence. Health status was assessed with the Short-Form-12 (SF-12), which includes 12 questions from which mental and physical component scores are generated (17). This standardized measure assesses an individual's perception of health, with higher scores indicating greater perceived health. Each of the component scores has a mean of 50 and a range of approximately 10 to 70 in the normative population. Community participation was measured by the Craig Handicap Assessment and Reporting Technique (CHART) (18,19). The CHART produces a total score as well as scores for 6 separate subscales: physical independence, cognitive independence, mobility, occupation, social integration, and economic self-sufficiency. The physical independence subscale assesses how much assistance one needs and takes into account those who are able to direct their own care as being more independent than those who cannot. The cognitive independence subscale assesses the amount of assistance needed for cognitive problems such as remembering, decision making, and judgment. The mobility subscale assesses ability to move about effectively in the community, including being able to go when and where the individual wishes. The occupation subscale assesses how individuals productively use their time, including school, work, household activities, volunteer activities, and hobbies, but not

including activities such as watching television or sleeping. The social integration subscale assesses the ability to participate in and maintain adult social relationships. The economic self-sufficiency subscale assesses the ability to maintain customary financial independence. Each dimension is scored on a 100-point scale, with higher scores indicating greater community integration. Perceived global life satisfaction was assessed with the Satisfaction with Life Scale (20). This scale consists of 5 statements that individuals rate on a 7-point scale, strongly disagree to strongly agree, with higher scores reflecting more satisfaction.

To assess depression, the screening tool PHQ-9 was used (21). This tool consists of 9 statements that reflect the diagnostic elements of depression as given in the Diagnostic and Statistical Manual (22). Participants are asked to score each item based on how much they have been bothered by it over the past 2 weeks: not at all (0), several days (1), more than half the days (2), or nearly every day (3). Either a total score or a category score can be used. Category scores include the following: No depressive symptoms (0), minimal depressive symptoms (scores 1–4), mild depressive symptoms (scores 5–9), moderate depressive symptoms (scores 10–14), moderate/severe depressive symptoms (scores 15–19), severe depressive symptoms (scores 20–27). The publishers of the PHQ-9 recommend that individuals scoring more than 4 on this screening tool may need further assessment for depression (23). For the purposes of this study, individuals who scored 5 or higher on this measure will constitute the group that report depressive symptoms. In addition, there is a score designated as probable major depressive disorder (MDD) that is determined by specific criteria. At least one of the two essential criteria, depressed mood or anhedonia, has to be present more than half the days over the past 2 weeks, and a total of 5 or more other symptoms have to be present more than half the days (suicidal thoughts are counted if they occur at all).

Data Analysis

Range of scores and frequency of scores falling within each PHQ-9 category of severity were first determined. Using scores as a continuum, these scores were compared with demographics, injury-related factors, and outcomes using *t* tests or Pearson correlations, as appropriate. In addition, for complete and incomplete injuries, individuals with paraplegia and those with tetraplegia were analyzed separately for depression, using *t* tests. A multiple linear stepwise regression analysis was conducted, with depression scores as the dependent variable and demographics (sex, race as white/nonwhite, age), injury-related factors (age at injury, duration, ASIA motor score, ASIA impairment scale as complete (ASIA A) or incomplete (ASIA B, C, D), FIM score, and some outcomes (CHART subscales, education, employment, independent living, marriage, driving status, illegal drug

Table 2. Rates of Depression Symptom Severity

Label	PHQ-9 Scores	n (%)
No depressive symptoms	0	48 (20.7)
Minimal depressive symptoms	1 to 4	121 (52.2)
Mild depressive symptoms	5 to 9	46 (19.8)
Moderate depressive symptoms	10 to 14	13 (5.6)
Moderate/severe depressive symptoms	15 to 19	3 (1.3)
Severe depressive symptoms	20 to 27	1 (0.4)

use, SF-12, and 6 medical complications) as independent variables. In addition, the frequency of MDD was determined. Finally, the frequency of suicidal thoughts was described and a comparison of those with and without suicidal thoughts was conducted for demographics, injury-related factors, and outcomes, using *t* tests or Chi-square analyses. SPSS software 11.5 was used for the analyses (24).

RESULTS

Rates of depression severity on the PHQ-9 are shown in Table 2. Seventy-three percent showed no/minimal depressive symptoms, 20% showed mild symptoms, and 7% showed moderate/severe symptoms. As described in the methods section, those scoring 5 or higher constitute a group that we are defining as reporting depressive symptoms; 27% fell in that group. Using scores of the PHQ-9 as a continuous measure, the mean score was 3.50, the median score was 2.00, and the range was 0 to 21. Table 3 shows associations between depression and other study factors. There were no significant differences in depression based on gender, race, age at injury, age at interview, or duration of injury. There was a significant difference between those with complete and incomplete injuries. Those with incomplete injuries showed significantly more depression than those with complete injuries did. When tetraplegia and paraplegia were analyzed separately, among those with tetraplegia, individuals with incomplete injuries were significantly more depressed than those with complete injuries ($P = 0.036$). Among those with paraplegia, there was no significant difference in depression between those with complete and incomplete injuries.

A comparison of outcomes shows that, except for the CHART subscale of physical independence, all the other subscales and the total CHART scores show significant differences based on depression level. In addition, more depression is associated with less employment, less income, less health-related quality of life as measured by the mental component summary score, and less life satisfaction. Of the 6 medical complications, only pressure ulcers, shoulder pain, and pain at any site were associated with increased depression.

Regression analyses, as described in the data analysis section, were used to determine which factors were most

predictive of depression in this group. The factors most predictive of depression were perceived mental health (SF-12), incomplete injuries, and CHART cognition and occupation subscales (Table 4). Those factors accounted for 50% of the variance.

Using the PHQ-9, MDD, as defined in the procedure section, was found in just 7 subjects (3%). Of additional interest is the one question that asks about suicide: "Over the last 2 weeks, how often have you been bothered by thoughts that you would be better off dead or hurting yourself in some way." Of the 232 subjects, 216 (93%) reported never having suicidal thoughts, 12 (5%) reported having suicidal thoughts on several days, 2 (1%) on more than half the days, and 2 (1%) had suicidal thoughts nearly every day. Compared to the rest of the patients, the 16 individuals who reported suicidal thoughts had significantly higher mean depression scores on the PHQ-9 (3.02 and 9.9, respectively, $P < 0.001$). Those reporting suicidal thoughts were more likely to be male and to have less motor function ($P = 0.035$ and $P = 0.043$, respectively). There were no differences in the groups in other demographic or injury-related factors. Those reporting suicidal thoughts were also less likely to participate in the community ($P < 0.05$ for all CHART subscales and total), less employed ($P = 0.001$), and less likely to live independently ($P = 0.014$) or to drive ($P = 0.014$) and showed lower perceived mental health ($P < 0.001$) and lower life satisfaction ($P < 0.001$).

DISCUSSION

The mean and median levels of depression in this group of individuals with SCI were quite low and 73% were within the categories of "no depressive symptoms" or "minimal depressive symptoms." Only 3% met the criteria for MDD, which is comparable to the 3.8% reported in a population-based sample (25). These findings represent a positive outcome for most adults with pediatric-onset SCI in the area of emotional adjustment. Nevertheless, more than one fourth of the adults with pediatric-onset SCI in this study reported depressive symptoms and 7% reported having suicidal thoughts in the past 2 weeks. These findings are a cause for concern and provide challenging feedback for clinicians who are preparing children and adolescents with SCI for adulthood. This study also reflects the

Table 3. Associations Between Depression and Demographics, Impairment, and Outcomes

	PHQ Total Score	Significance
Number of subjects	232	
Gender		$P = 0.885^*$
Male (63%)	3.53	
Female (37%)	3.45	
Race/ethnicity		$P = 0.835^*$
White (91%)	3.51	
Nonwhite (9%)	3.33	
Age at injury		$P = 0.456^\dagger$
Age at interview		$P = 0.595^\dagger$
Duration of injury		$P = 0.295^\dagger$
Level of injury		$P = 0.596^*$
Tetraplegia (59%)	3.61	
Paraplegia (41%)	3.34	
Severity of injury		
Complete (68%)	3.10	$P = 0.013^*$
Incomplete (32%)	4.41	
ASIA motor score		$P = 0.719^\dagger$
FIM		
Motor items		$P = 0.425^\dagger$
CHART		
Physical		$P = 0.086^\dagger$
Cognitive		$P < 0.001^\dagger$
Mobility		$P < 0.001^\dagger$
Occupation		$P < 0.001^\dagger$
Social integration		$P < 0.001^\dagger$
Economic self-sufficiency		$P < 0.001^\dagger$
Total		$P < 0.001^\dagger$
College degree		$P = 0.039$
Yes (39%)	2.87	
No (61%)	3.91	
Employed (59%)	2.41	$P < 0.001^*$
Unemployed (41%)	4.55	
Living independently (60%)	3.18	$P = 0.108^*$
Living with parents (40%)	3.99	
Married (23%)	2.93	$P = 0.220^*$
Not married (77%)	3.97	
Drives independently (60%)	3.16	$P = 0.093^*$
Does not drive (40%)	4.01	
Illegal drug use		$P = 0.028^*$
Yes (13%)	4.90	
No (87%)	3.29	
Personal yearly income SF12		$P = 0.002^\dagger$
Physical component		$P < 0.001^\dagger$
Mental component		$P < 0.001^\dagger$
SWLS		$P < 0.001^\dagger$

Table 3. Continued

	PHQ Total Score	Significance
Pressure ulcers		$P = 0.016^*$
Yes (32%)	4.37	
No (68%)	3.10	
Severe urinary tract infection		$P = 0.703^*$
Yes (9%)	3.81	
No (91%)	3.48	
Spasticity		$P = 0.071^*$
Yes (47%)	3.97	
No (53%)	3.08	
Respiratory complications		$P = 0.607^*$
Yes (4%)	2.90	
No (96%)	3.53	
Shoulder pain		$P = 0.022^*$
Yes (59%)	3.97	
No (41%)	2.82	
Pain at any site		$P = 0.007^*$
Yes (68%)	3.95	
No (32%)	2.54	

**t* test.

†Pearson.

interaction between depression and other outcomes; depression was associated with less community participation, lower quality of life, and more medical complications.

The 27% of participants who reported depressive symptoms in this sample of adults with pediatric-onset SCI are within the range reported in studies of adults who primarily sustained their SCI in adulthood. Typically, rates of 20% to 40% have been reported (6–8). However, rates may range as low as 11% (26) and as high as 44% to 50% (27,28). One of the problems in comparing studies is that different measures of depression have been used (29). There is a recent study using the same measure, PHQ-9, that was used in the present study (11). Since that study involved individuals who were injured as adults (age 17–88 y), it would be interesting to compare their findings to the present study of pediatric-onset SCI. Using the criteria that those who score 5 and above on the PhQ-9 are reporting depressive symptoms, the adult-onset study reported 42% compared with 27% for the present study. Unfortunately, there are other confounding factors, especially duration since injury. Bombardier et al were assessing individuals 1 year postinjury, compared to the present study with an average duration of 16 years postinjury. Not surprisingly, Bombardier et al found 11% with MDD, while the present study only found 3%, using the same definition of MDD (11). In fact, in the age range (25–49 y) most similar to the age of our study population (24–42 y), those investigators found a 15% rate of MDD

Table 4. Multiple Regression Model for Depression

	Coefficient			95% Confidence Interval for β	
	β	Standard Error	Significance	Lower	Upper
SF-12 mental component	−0.206	0.028	$P < 0.001$	−0.262	−0.150
CHART occupation	−0.026	0.007	$P < 0.001$	−0.040	−0.012
CHART cognitive	−0.196	0.061	$P = 0.002$	−0.317	−0.075
Complete/incomplete injury	0.868	0.409	$P = 0.036$	0.059	1.678

(11). Again, these comparisons are confounded by duration of injury. Additionally, all of the participants in the present study were given the PHQ-9 during an interview. Bombardier et al reported that those who completed the form on their own were more likely to report symptoms of MDD than were those who were given the PHQ-9 by an interview method (11).

In the regression analysis, the factors most closely associated with the outcome of depression were perceived mental health-related quality of life, lower scores on CHART cognitive independence and occupation, and incomplete injuries. It is rather paradoxical to find that depression is more associated with incomplete than complete lesions. This association of incomplete injuries with depression as measured by the PHQ-9 was not found by Bombardier et al in his adult-onset SCI group (11). However, there have been other studies that have reported both depression and suicide to be associated with minimally disabled incomplete categories of SCI (30,31). One hypothesis may be that these individuals with incomplete injuries are provided with less support, and their symptoms of fatigue and frustration are more easily overlooked than are the more obvious symptoms of those with complete injuries. Further investigation is needed to understand this association, but incomplete injuries appear to be a risk factor for depression in this study.

The fact that CHART subscales, especially the occupation subscale, were associated with depression is not surprising. In individuals with adult-onset SCI, more depression is associated with fewer activities and less community participation (27,32). Community participation has been reported to be associated with greater life satisfaction in individuals with adult-onset SCI (33–36) and in adults with pediatric-onset SCI (4). Employment was associated with less depression in the present study, and the occupation subscale of the CHART includes employment. However, the occupation subscale is also focused on a variety of activities, including educational, recreational, leisure, and volunteer activities. The importance of these kinds of activities for both pediatric and adult-onset patients with SCI has previously been recognized (35–37).

Finally, the association of depression with medical complications needs to be considered. Pain has been

reported to be associated with depression (38,39). In this study, pain at any site and shoulder pain were both associated with depression. Since this was a relatively young group of patients, the issue of pain may become even more of a cause for concern over time. Not surprisingly, pressure ulcers were related to depression. These medical complications often disrupt activities and keep individuals isolated.

The limitations of this study include the fact that all participants received rehabilitation from a single hospital system and therefore may not be representative of the general population of adults with pediatric-onset SCI. Further, only 41% of eligible participants were interviewed, with 44% who could not be located or were still in the process of attempted location. Because there are so few data available on adults with pediatric-onset SCI, it is not possible to evaluate how this sample differs from others. In addition, because it was a telephone interview, all of the data are self-reported, reflect the situation at a single point in time, and are correlational. A further source of concern is that the depression screening measure, with only 9 questions, may not be giving an adequate enough description of emotional adjustment in individuals with SCI to warrant strong conclusions. Further studies with more extensive assessment of depressive symptoms and more longitudinal data would provide a better basis for improving rehabilitation.

CONCLUSIONS

Depression is a significant problem among adults with pediatric-onset SCI and is associated with poorer outcomes of participation and quality of life. These findings should be addressed as clinicians prepare children and adolescents with SCI to transition to adulthood and in follow-up of these patients throughout adulthood. Patients particularly at risk include those with incomplete injuries and those participating less in their communities.

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