

ORIGINAL ARTICLE

Relationships between the psychological characteristics of youth with spinal cord injury and their primary caregivers

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Study design: Cross-sectional survey.

Objectives: To describe anxiety and depression among caregivers of youth with spinal cord injury (SCI), examine predictors of caregiver psychological functioning and evaluate relationships between caregiver and child psychological outcomes. The protective factor of youth social relationships was also included to examine its impact on relationships between caregiver and child psychological functioning.

Setting: Families received services at one of three pediatric specialty hospitals within a single hospital system in the United States.

Methods: The study included English-speaking youth with SCI, aged between 7 and 17 years, who had been injured at least one year before, and their self-identified primary caregivers. Participants completed surveys assessing their anxiety, depression and youth's perceived social relationships.

Results: The study included 203 youth with an average age of 12.70 years (s.d. = 3.15), and among them 70% had paraplegia. Seventy-eight percent of caregivers were mothers, 14% fathers and 8% other family members. In all, 16 and 21% of caregivers scored in the range of moderate/severe anxiety and depression, respectively. Being female and having a child with mental health problems predicted caregiver anxiety and depression. In addition, having a child who was older at the time of injury predicted caregiver depression. Poor social relationships, having a caregiver with mental health problems and having a caregiver with less education predicted both child anxiety and depression.

Conclusion: Caregiver sex, child age at injury and child mental health were related to caregiver outcomes; caregiver education, marital status and child age were not. Caregiver mental health and education and child social relationships predicted child outcomes. Neither injury level nor injury severity was related to caregiver or child outcomes.

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Introduction

Children depend on caregiver support, typically provided by their parents. For children with significant disabilities such as spinal cord injury (SCI), caregivers become even more critical, as youth negotiate both typical and disability-specific challenges throughout childhood. Therefore, if a caregiver is struggling with psychological issues, improving their functioning is important both for their own and their child's well being. This study assessed anxiety and depression among a group of primary caregivers of youth with SCI, examined factors contributing to caregiver psychological

functioning, and evaluated relationships between caregiver and child psychological functioning.

Although not yet studied among youth with SCI, research has documented the experiences of parents of youth with other health conditions, and caregivers of adults with SCI. Parents of youth with disabilities experience more stress than parents of able-bodied youth.^{1,2} Similarly, caregivers of adults with SCI report experiencing a low quality of life,^{3,4} burden⁵ and psychological distress.⁶ Factors associated with poorer caregiver outcomes include less education,⁶ not having a partner,² being female,^{5,6} having a child of older age² and caring for a person/child with behavioral/emotional problems.² The impact of injury severity and injury duration is unclear, as some researchers⁵ have found that these factors predict poor caregiver outcomes, whereas others⁶ have found no such relationship.

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Research also shows relationships between outcomes of caregivers and those receiving care. Negative caregiver problem-solving predicted lower acceptance of disability among adults with SCI at the time of discharge and occurrence of pressure sores 1 year after discharge.⁷ Among youth with various disabilities, parental functioning has been found to predict child adjustment.^{8,9} A group investigating posttraumatic stress disorder (PTSD) among youth with SCI and their caregivers found that mothers' PTSD predicted patients' and fathers' PTSD, and that patient's PTSD predicted mothers' PTSD.¹⁰ Among youth with limb deficiencies, poor parental mental health predicted child's mental health; however, this relationship was statistically eliminated when taking into account children's perceived social support.¹¹ Identifying protective factors such as social relationships can foster interventions that enhance positive outcomes instead of just reducing negative ones.

This research forms a preliminary understanding of caregiver outcomes and their relationship to outcomes of those being cared for, both among adults with SCI and youth with other disabilities. However, little is known about these issues among caregivers and youth with SCI. Caregivers of these youth may face particular stress because their child's disability is acquired, not congenital; traumatic injury during childhood can impact the psychological functioning of the child and his/her family. This study aimed to describe anxiety and depression among primary caregivers of children with SCI; examine predictors of anxiety and depression among caregivers, including demographic, injury-related and child mental health factors; and examine how caregiver mental health and the protective factor of child-perceived social relationships impact the anxiety and depression of children with SCI. It was hypothesized that caregiver anxiety and depression would be predicted by being female, having less education, being unmarried and having a child who is older and has mental health problems. Further, it was hypothesized that caregiver anxiety and depression and poor social relationships would be associated with child anxiety and depression. Finally, relationships between injury-related factors and caregiver and child mental health were explored.

Materials and methods

Recruitment

Participants were part of a larger project assessing psychosocial outcomes of youth with SCI and their caregivers. English-speaking youth with SCI aged 7–17 years who had been injured at least 1 year before and were receiving services from one of three pediatric specialty hospitals within a single hospital system were recruited, along with their self-identified primary caregivers.

Instruments

Demographic/injury-related information. Caregivers completed a questionnaire assessing their relationship to the patient, their marital status and education. Patients' sex, injury date, level and severity were obtained from medical records.

Injury level and injury severity were assessed using the International Standards for Neurological Classification of Spinal Cord Injury.

Caregiver psychological outcomes. The Beck Anxiety Inventory¹² is a 21-item self-report measure of adult anxiety shown as reliable and valid.¹² Good internal consistency reliability was maintained with the current sample ($\alpha = 0.90$). The Beck Depression Inventory-II¹³ is a 21-item self-report measure of adult depression shown as reliable and valid.¹³ Good internal consistency reliability was indicated for the current sample ($\alpha = 0.94$).

Child psychological outcomes. The Revised Children's Manifest Anxiety Survey¹⁴ is a 37-item self-report measure of youth anxiety with adequate internal consistency and construct validity.¹⁴ Good internal consistency reliability was shown with the current sample ($\alpha = 0.82$). The Children's Depression Inventory¹⁵ is a 27-item self-report measure of youth depression with adequate internal consistency and validity.¹⁵ Good internal consistency reliability was shown with the current sample ($\alpha = 0.86$).

Child-perceived social relationships. The Pediatric Quality of Life Inventory 4.0 (PedsQL; Generic Core Scales)¹⁶ is a reliable and valid measure of children's health-related quality of life. The 5-item child-report social functioning subscale was incorporated in this study as a measure of youths' relationships with others. Adequate internal consistency reliability was shown with the current sample ($\alpha = 0.72$).

Procedures

After obtaining informed consent and assent, surveys were administered during regularly scheduled in-patient or out-patient visits. Data collection took 45–75 min.

Data analysis

Preliminary data screening showed two multivariate outliers; these two participants were dropped from the sample. Depending on whether measured at the categorical or continuous level, point biserial and Pearson correlation coefficients assessed relationships between demographic, injury-related and protective factors, and between caregiver and child outcomes. Factors with significant univariate relationships with each dependent variable were included in subsequent regression analyses as independent variables.

Multiple regression analyses were conducted to identify predictors of caregiver anxiety and depression. Hierarchical multiple regression analyses were used to assess whether caregiver outcomes and child social relationships contributed significantly to child anxiety and depression, above and beyond demographic and injury-related factors. Because of the high correlations between caregiver anxiety and depression ($r = 0.690$) and child anxiety and depression ($r = 0.715$), the two caregiver or two child variables were not included as separate predictors in the same regression equation. Instead, caregiver and child composite variables were created that summed overall raw scores from the Beck Anxiety Inventory

and Beck Depression Inventory-II, and Revised Children's Manifest Anxiety Survey and Children's Depression Inventory, respectively. Although anxiety and depression are only components of mental health, these composite scores were used as proxy variables for caregiver and child mental health, and were included as independent variables in the regression equations. Finally, scores from the Beck Anxiety Inventory, Beck Depression Inventory-II and Children's Depression Inventory were subjected to log transformations because of nonnormal distributions, and the transformed variables were used as dependent variables in the regression equations.

We certify that all applicable institutional and governmental regulations with regard to the ethical use of human volunteers were followed during the course of this study.

Results

Participants

Of the 203 youths, 53% were male, 70% were Caucasian; mean age was 12.70 years (s.d. = 3.15) at interview and 7.04 years (s.d. = 5.44) at injury. Seventy percent had paraplegia and 50% had complete injuries. Of the 203 caregivers, 78% were mothers, 14% were fathers, 5% were grandmothers, 1% were stepmothers, 1% were grandfathers and 1% were aunts; 85% were female; 78% were Caucasian; 72% were married and 15% were divorced. Nine percent of caregivers did not complete high school, 23% graduated high school, 47% completed some college or an associates degree and 21% completed a bachelor's degree or higher.

Caregiver outcomes

Regarding anxiety, caregivers scored an average of 8.45 on the Beck Anxiety Inventory (s.d. = 8.43, Range = 0–45), fall-

ing in the 'mild' range, and 16% of caregivers (33) scored in the moderate/severe range, as defined in the Beck Anxiety Inventory manual. Regarding depression, caregivers scored an average of 11.37 on the Beck Depression Inventory-II (s.d. = 10.07, Range = 0–49.50), falling in the 'minimal' range, and 21% (41) fell in the moderate/severe range, as defined in the Beck Depression Inventory-II manual. Nine percent (19) of caregivers fell in the moderate/severe range for both anxiety and depression. Table 1 provides a breakdown of scores by severity categories, and caregiver sex, marital status and education.

Predicting caregiver anxiety and depression

Table 2 presents associations between caregiver anxiety and depression and demographic, injury-related and child mental health variables. Caregiver anxiety and depression were each associated with caregivers being female, older child age at injury, and child anxiety and depression. Regression analyses revealed that being female and having a child with mental health problems (measured by the composite anxiety plus depression variable) explained 14% of the variance in caregiver anxiety ($R^2 = 0.136$, $F = 10.19$, $P < 0.001$) (Table 3). Being female, having a child who was older at the time of injury and having a child with mental health problems explained 19% of the variance in caregiver depression ($R^2 = 0.192$, $F = 15.08$, $P < 0.001$) (Table 3).

Caregiver and child psychological outcomes

Finally, we evaluated relationships between caregiver and child psychological outcomes. Table 4 presents associations between child anxiety and depression and demographic, injury-related, protective and caregiver mental health variables. Child anxiety and depression were each significantly related to less caregiver education, lower-rated child social

Table 1 Caregiver anxiety and depression: how caregiver subgroups fall into instrument scoring categories

	Range	Sample: n (%)	Distribution of responses by caregiver demographics					
			Sex		Marital Status ^a		Education ^b	
			% of females in each category	% of males in each category	% of married caregivers in each category	% of unmarried caregivers in each category	% of caregivers with college experience in each category	% of caregivers without college experience in each category
<i>Anxiety</i>								
Minimal	0–7	119 (59%)	96 (56%)	23 (77%)	91 (64%)	26 (46%)	83 (61%)	33 (53%)
Mild	8–15	51 (25%)	44 (25%)	7 (23%)	35 (24%)	14 (25%)	31 (23%)	18 (29%)
Moderate	16–25	21 (10%)	21 (12%)	0 (0%)	7 (5%)	14 (25%)	14 (10%)	7 (11%)
Severe	26–63	12 (6%)	12 (7%)	0 (0%)	10 (7%)	2 (4%)	8 (6%)	4 (7%)
Total		203 (100%)	173 (100%)	30 (100%)	143 (100%)	56 (100%)	136 (100%)	62 (100%)
<i>Depression^c</i>								
Minimal	0–13	125 (63%)	101 (59%)	24 (80%)	90 (63%)	32 (58%)	83 (62%)	37 (60%)
Mild	14–19	34 (17%)	31 (18%)	3 (10%)	22 (16%)	12 (22%)	23 (17%)	11 (18%)
Moderate	20–28	24 (12%)	21 (12%)	3 (10%)	18 (13%)	6 (11%)	14 (11%)	10 (16%)
Severe	29–63	17 (8%)	17 (10%)	0 (0%)	12 (8%)	5 (9%)	13 (10%)	4 (6%)
Total		200 (100%)	170 (100%)	30 (100%)	142 (100%)	55 (100%)	133 (100%)	62 (100%)

^aFour caregivers were missing data on marital status.

^bFive caregivers were missing data on education.

^cThree caregivers were missing data on the Beck Depression Inventory-II.

Table 2 Correlations between caregiver outcomes and demographic, injury-related and child mental health variables

	Caregiver outcomes		
	Anxiety	Depression	Composite (anxiety+depression)
<i>Caregiver demographics</i>			
Sex (female)	0.220**	0.213**	0.233**
Marital status (married)	-0.116	-0.002	-0.054
Education	-0.046	-0.028	-0.041
<i>Child demographics</i>			
Sex (female)	0.018	-0.047	-0.027
Current age	0.134	0.085	0.109
<i>Injury-related factors</i>			
Age at injury	0.143*	0.158*	0.156*
Time since injury	-0.086	-0.137	-0.118
Level of injury (paraplegia)	-0.098	-0.061	-0.086
Severity of injury (complete)	-0.055	0.013	-0.013
<i>Child psychological outcomes</i>			
Anxiety	0.209**	0.236**	0.237**
Depression	0.217**	0.248***	0.249***
Composite (anxiety+depression)	0.229**	0.259***	0.261***

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

Table 3 Summary of regression analyses predicting caregiver anxiety and depression

Variable	Caregiver anxiety (n = 198) ^a			Caregiver depression (n = 195) ^b		
	B ^c	s.e. B	β	B ^c	s.e. B	β
Caregiver sex (female)	0.307	0.081	0.254***	0.356	0.086	0.269***
Child age at injury	0.008	0.005	0.100	0.016	0.006	0.187**
Child mental health	0.009	0.003	0.241***	0.012	0.003	0.283***

** $P < 0.01$, *** $P < 0.001$.

^a $R^2 = 0.136$ ***

^b $R^2 = 0.192$ ***

^cB = unstandardized coefficient.

relationships and increased caregiver anxiety and depression. Child anxiety was also related to younger current age and shorter injury duration. Two hierarchical regression equations were then conducted, the first with child anxiety and the second with child depression as the dependent variable. For child anxiety, significant demographic and injury-related factors were entered in the first step, child social relationships in the second step and significant caregiver factors in the third step. For child depression, because there were no significant demographic or injury-related factors, child social relationships was entered in the first step, and significant caregiver factors in the second step. Poor social relationships, caregiver mental health problems and less caregiver education accounted for 36 and 26% of the variance in child anxiety and depression, respectively (Tables 5 and 6).

Table 4 Correlations between child outcomes and demographic, injury-related and caregiver mental health variables

	Child outcomes		
	Anxiety	Depression	Composite (anxiety+depression)
<i>Caregiver demographics</i>			
Sex (female)	-0.030	-0.004	-0.027
Marital status (married)	-0.014	-0.042	-0.029
Education	-0.230**	-0.205**	-0.231**
<i>Child demographics</i>			
Sex (female)	0.021	-0.039	-0.014
Current age	-0.146*	0.023	-0.066
<i>Injury-related factors</i>			
Age at injury	0.038	0.103	0.077
Time since injury	-0.152*	-0.117	-0.146*
Level of injury (paraplegia)	-0.104	-0.097	-0.106
Severity (complete injury)	-0.046	-0.002	-0.021
<i>Protective factor</i>			
Social relationships	-0.557***	-0.504***	-0.572***
<i>Caregiver psychological outcomes</i>			
Anxiety	0.209**	0.217**	0.229**
Depression	0.236**	0.248***	0.259***
Composite (anxiety+depression)	0.237**	0.249***	0.261***

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

Table 5 Summary of hierarchical linear regression analysis predicting child anxiety (n = 185)

Variable	B ^a	s.e. B	β
<i>Step 1</i>			
Age at interview	-0.263	0.134	-0.143
Time since injury	-0.015	0.008	-0.140
<i>Step 2</i>			
Age at interview	-0.026	0.118	-0.014
Time since injury	-0.010	0.007	-0.091
Social relationships	-0.157	0.019	-0.534***
<i>Step 3</i>			
Age at interview	-0.117	0.116	-0.063
Time since injury	-0.009	0.007	-0.083
Social relationships	-0.142	0.019	-0.481***
Caregiver mental health	0.048	0.021	0.140*
Caregiver education	-1.245	0.405	-0.187**

Note. $R^2 = 0.040$ * for Step 1; $\Delta R^2 = 0.266$ *** for Step 2; $\Delta R^2 = 0.054$ ** for Step 3.

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

^aB = unstandardized coefficient.

Discussion

This study described anxiety and depression among a group of primary caregivers of youth with SCI, and examined factors contributing to caregiver anxiety/depression and relationships between caregiver and child outcomes. Results revealed that 16 and 21% of caregivers experienced moderate/severe symptoms of anxiety and depression, respectively. Previous research conducted with parents of preadolescents with spina bifida found that 19% of mothers and 26% of

Table 6 Summary of hierarchical linear regression analysis predicting child depression ($n = 184$)

Variable	B^a	<i>s.e. B</i>	β
<i>Step 1</i>			
Social relationships	-0.009	0.001	-0.456***
<i>Step 2</i>			
Social relationships	-0.008	0.001	-0.416***
Caregiver mental health	0.003	0.002	0.144*
Caregiver education	-0.075	0.029	-0.167*

Note. $R^2 = 0.208$ *** for Step 1; $\Delta R^2 = 0.050$ ** for Step 2.

* $P < 0.05$, ** $P < 0.01$, *** $P < 0.001$.

^a B = unstandardized coefficient.

fathers had significant scores on the Global Severity Index, which assesses severity of psychological symptoms across a variety of DSM-IV diagnoses.¹⁷ This is comparable to the experiences of female caregivers in this study (19% moderate/severe anxiety and 22% moderate/severe depression), but not to male caregivers, as none experienced moderate/severe anxiety, and only 10% experienced moderate depression. Male caregivers in this study may have underreported psychological symptoms, or this small sample of males ($n = 30$) may not be representative of fathers' caregiving experiences. Another explanation is that having a child with an acquired disability such as SCI may be less stressful for male caregivers than having a child with a congenital disability such as spina bifida. Future research should incorporate the experiences of male caregivers of youth with SCI as they are often overlooked in family research.

As expected, caregiver anxiety was associated with being female and having a child with mental health problems; caregiver depression was associated with being female, older child age at the time of the injury and having a child with mental health problems. This suggests that interventions should target females and caregivers of youth injured at an older age to provide extra support after their child's injury. Further, as hypothesized, poor social relationships, poor caregiver mental health and less caregiver education significantly predicted child anxiety and depression. These results indicate that social relationships can positively influence children's mental health even in the face of negative caregiver outcomes. Efforts should be made to build positive relationships among youth.

Contrary to previous research on caregiving among adults with SCI^{5,6} and among youth with spina bifida², caregiver education, marital status and current child age were not associated with caregiver psychological outcomes. It could be that for parents of youth with SCI, past education is not as important as current education/resources related to their child's injury, and marital status may not be as important as having other types of social support. In addition, child's age at injury seems to be more important to parental psychological outcomes than child's current age. This may mean that parents are affected differently when their children are injured at different stages of childhood. Research should continue to investigate these relationships, including the unique impact of child's age and age at the time of injury on psychological outcomes, and whether education and marital

status or other social supports can serve as protective factors for caregivers of youth with disabilities.

Consistent with earlier research, results suggest a reciprocal relationship between child and caregiver mental health.¹⁰ It is likely that children and their parents continue to influence each other over the course of living with an SCI. However, longitudinal data are necessary to better understand these relationships. Interestingly, neither injury level nor injury severity was related to any caregiver or child mental health measures. This finding echoes earlier research among youth with spina bifida suggesting that perceived maternal stress is more important than disability severity for maternal psychological adjustment.¹⁸ Further, earlier studies related to quality of life and SCI have found a weak association between quality of life and impairment, but a stronger one between quality of life and the manner in which the impairment manifests itself in society.¹⁹ Research should continue to investigate the manner in which injury characteristics relate to child and caregiver mental health, particularly over time as this relationship will likely evolve.

This study had several limitations. First, because data were collected within a single hospital system, the sample may not be representative of the general population of youth with SCI. Second, caregivers were mostly female; therefore, findings linking caregiver sex with outcomes should be interpreted with caution. Further, only the self-identified primary caregiver of each child was surveyed; future research should examine the perspectives of multiple caregivers as many families share caregiving responsibilities. Third, data were cross-sectional in nature; longitudinal data are necessary for making conclusions regarding the directionality of relationships. Fourth, this study did not include a comparison group of families without disabilities; this is needed to identify factors important to the psychological functioning of families of youth with SCI. Finally, although caregiver education is one aspect of socioeconomic status, this study did not incorporate a comprehensive measure of socioeconomic status that included other elements such as caregiver occupation.²⁰ Future research should examine the relationship between psychological outcomes and socioeconomic status, a variable that likely affects the family's functioning.

Future research should explore caregiver outcomes over time, as past work has highlighted caregiving as a dynamic process.²¹ This may be particularly true in the area of pediatric SCI as youths' needs may change as they/their injuries age. Further, this study examined anxiety and depression in caregivers and youth at one time point only. Future research should examine how short- versus long-term mental health issues affect family outcomes. In addition, this study examined child/caregiver anxiety and depression together as predictors of caregiver/child functioning; future efforts should attempt to discern the unique effects of anxiety and depression in order to develop appropriate interventions. Further, although this study included protective factors for youth, future research should examine factors that might facilitate positive outcomes among caregivers, including social support,²¹ healthy coping and financial resources. Finally, future research should highlight the

resilience and life experiences of youth and families who are not experiencing mental health problems.¹ Understanding the experiences of these families could help to develop interventions that bolster the individual strengths and community supports necessary for youth and caregiver success.

Conflict of interest

The authors declare no conflict of interest.

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References

- 1 Holmbeck G, Greenley RN, Coakley RM, Greco J, Hagstrom J. Family functioning in children and adolescents with spina bifida: an evidence-based review of research and interventions. *J Dev Behav Pediatr* 2006; **27**: 249–277.
- 2 Vermaes I, Janssens J, Bosman A, Gerris J. Parents' psychological adjustment in families of children with Spina Bifida: a meta-analysis. *BMC Pediatr* 2005; **5**: 32.
- 3 Blanes L, Carmagnani MIS, Ferreira LM. Health-related quality of life of primary caregivers of persons with paraplegia. *Spinal Cord* 2007; **45**: 399–403.
- 4 Unalan H, Gencosmanoglu B, Akgun K, Karamehmetoglu S, Tuna H, Ones K et al. Quality of life of primary caregivers of spinal cord injury survivors living in the community: controlled study with short form-36 questionnaire. *Spinal Cord* 2001; **39**: 318–322.
- 5 Post MWM, Bloemen J, de Witte LP. Burden of support for partners of persons with spinal cord injuries. *Spinal Cord* 2005; **43**: 311–319.
- 6 Raj JT, Manigandan C, Jacob KS. Leisure satisfaction and psychiatric morbidity among informal carers of people with spinal cord injury. *Spinal Cord* 2006; **44**: 676–679.
- 7 Elliott TR, Shewchuk RM, Richards JS. Caregiver social problem-solving abilities and family member adjustment to recent-onset physical disability. *Rehabil Psychol* 1999; **44**: 104–123.
- 8 Friedman D, Holmbeck GN, Jandasek B, Zukerman J, Abad M. Parent functioning in families of preadolescents with spina bifida: longitudinal implications for child adjustment. *J Fam Psychol* 2004; **18**: 609–619.
- 9 Witt WP, Riley AW, Coiro MJ. Childhood functional status, family stressors, and psychosocial adjustment among school-aged children with disabilities in the United States. *Arch Pediatr Adolesc Med* 2003; **157**: 687–695.
- 10 Boyer BA, Knolls ML, Kafkalas CM, Tollen LG, Swartz M. Prevalence and relationships of posttraumatic stress in families experiencing pediatric spinal cord injury. *Rehabil Psychol* 2000; **45**: 339–355.
- 11 Varni JW, Setoguchi Y. Effects of parental adjustment on the adaptation of children with congenital or acquired limb deficiencies. *J Dev Behav Pediatr* 1993; **14**: 13–19.
- 12 Beck AT, Steer RA. *Manual for the Beck Anxiety Inventory*. The Psychological Corporation: San Antonio, TX, USA, 1993.
- 13 Beck AT, Steer RA, Brown GK. *Manual for the Beck Depression Inventory*, 2nd edn. The Psychological Corporation: San Antonio, TX, USA, 1996.
- 14 Reynolds CR, Richmond BO. *Revised Children's Manifest Anxiety Scale (RCMAS): Manual*. Western Psychological Services: Los Angeles, CA, USA, 2000.
- 15 Kovacs M. *Children's Depression Inventory (CDI): Technical Manual Update*. Multi-Health Systems Inc.: North Tonawanda, NY, USA, 2003.
- 16 Varni JW, Seid M, Kurtin PS. PedsQL 4.0: Reliability and validity of the Pediatric Quality of Life Inventory version 4.0 generic core scales in healthy and patient populations. *Med Care* 2001; **39**: 800–812.
- 17 Holmbeck GN, Gorey-Ferguson L, Hudson T, Seefeldt T, Shapera W, Turner T et al. Maternal, paternal, and marital functioning in families of preadolescents with Spina Bifida. *J Pediatr Psychol* 1997; **22**: 167–181.
- 18 Kronenberger WG, Thompson RJ. Medical stress, appraised stress, and the psychological adjustment of mothers of children with myelomeningocele. *J Dev Behav Pediatr* 1992; **13**: 405–411.
- 19 Dijkers M. Quality of life after spinal cord injury: A meta analysis of the effects of disablement components. *Spinal Cord* 1997; **35**: 829–840.
- 20 Cirino PT, Chin CE, Sevcik RA, Wolf M, Lovett M, Morris RD. Measuring socioeconomic status: Reliability and preliminary validity for different approaches. *Assessment* 2002; **9**: 145–155.
- 21 Shewchuk RM, Richards JS, Elliott TR. Dynamic processes in health outcomes among caregivers of patients with spinal cord injuries. *Health Psychol* 1998; **17**: 125–129.