Health-Related Quality of Life after Pediatric Spinal Cord Injury

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Objective To describe health-related quality of life (HRQOL) among youth with spinal cord injury (SCI), examine agreement between child and caregiver report HRQOL, investigate relationships between HRQOL and demographic, injury and psychological variables. Methods Caregivers and youth with SCI completed a pediatric HRQOL measure and mental health measures; injury information was gathered from medical records. Results One hundred and ninety-seven youth with SCI and their caregivers participated. HRQOL was associated with current age, age at injury, level of injury and child and caregiver anxiety/depression. Child mental health significantly predicted child-report HRQOL ($p < .001$, $f^2 = 1.07$), whereas child ($p < .001$, $f^2 = 0.098$) and caregiver ($p < .001$, $f^2 = 0.277$) mental health both significantly predicted caregiver-report HRQOL. Agreement between child-report and caregiver-report was moderate at best, with youth rating their HRQOL as better than their caregivers. Conclusion Mental health of youth and caregivers is critical to HRQOL in pediatric SCI. Interventions to optimize psychological adjustment should be provided to both caregivers and youth.

Key words adolescents; assessment; parents; quality of life; spinal cord injury.

Introduction

Children and adolescents who sustain spinal cord injury (SCI) face a myriad of life-altering changes. These changes present both physical and psychological challenges. Physical limitations, medical complications, and hospitalizations not only result in a loss of independence, privacy and control, but present challenges to ongoing participation in academic and social activities. Changes in appearance and activities precipitate identity struggles. Families are faced with the need to alter routines and to readjust roles. Often, affected youth and their families manage these new circumstances in the aftermath of traumatic, life-threatening events associated with the injury. In fact, investigators have found an increased incidence of depression and anxiety disorders in children and adults with SCI (Boyer, Knolls, Kafkalas, Tollen & Swartz, 2000; Chevalier, Kennedy & Sherlock, 2009; Craig, Tran & Middleton, 2009). How these injury-related changes and associated emotional turmoil impact the affected youth’s quality of life (QOL) is an area of concern for all involved, particularly given the relatively long life span of youth with SCI. However, few studies have looked at QOL following pediatric SCI (Abresch, McDonald, Widman, McGinnis, & Hickey, 2007; Oladeji, Johnston, Smith, Mulcahey, Betz, & Lauer, 2007) and none have examined the association between QOL and psychological functioning in children with SCI. There is therefore a need for research to generate data that could inform the development of interventions aimed at optimizing adjustment and QOL after injury.

Measures of QOL are found in many outcome studies of individuals with chronic illness, including SCI (Dijkers, 2005). The concept of QOL, however, is understood in many different ways, including subjective well-being, satisfaction with life, achievement of personal goals and social
utility, among others (Dijkers, 2005; Tate, Kalpakjian, & Forchheimer, 2002). The different approaches to the conceptualization and measurement of QOL have resulted in a complex literature that is often difficult to interpret. This article will focus on Health-Related Quality of Life (HRQOL), a multidimensional construct within the broader area of QOL that represents the subjective assessment of the impact of health and treatment variables on physical, emotional, social and academic functioning (Varni, Seid, & Kurtin, 2001).

When comparing HRQOL of adults with SCI to the general population, the greatest discrepancy is found in scores that reflect physical health or the impact of physical health on activities and role fulfillment (Dijkers, 2005). Injury severity appears to have at most a weak association with QOL while negative psychological states and pain intensity have been found to be associated with lower HRQOL (Anderson, Krajci, & Vogel, 2002; Anderson, Vogel, Chlan, Betz & McDonald, 2007; Craig, Tran, & Middleton, 2009). Pediatric HRQOL has been studied in many disease conditions. Using a measure developed by Varni et al. (2001), Varni, Limbers, and Burwinkle (2007b) examined data obtained from over 2500 pediatric patients in 10 disease clusters, including diabetes, asthma, cancer and cerebral palsy, among others. Results indicated that children in all disease clusters reported lower HRQOL than healthy children. This study, however, did not include children with SCI. Using the same measure, Abresch et al. (2007) found that children with spinal cord dysfunction associated with SCI or spina bifida reported significantly lower HRQOL than children with no mobility impairments. Additionally, the authors indicated that the relative reductions in HRQOL were greater in this population than those reported in the literature for children with other chronic diseases. Paralleling the adult literature, a study of 28 children with SCI conducted by Oladeji et al. (2007) found no significant differences in HRQOL associated with level of injury.

Given the association that has been found between HRQOL and psychological functioning in adults with SCI (Anderson et al., 2007), and the findings presented earlier that suggest difficulties with psychological adjustment following SCI, the study of HRQOL in youth with SCI should include an examination of psychological functioning as well. When assessing youth, however, one must move beyond the child and also consider caregiver adjustment due to its association to child outcomes. In a review of 38 studies of correlates of children's psychological adjustment to physical disorders, Lavigne and Faier-Routman (1993) found that parent/family characteristics were more strongly correlated to adjustment than disease/disability factors. In addition, caregivers often develop significant psychological distress in response to their children's situation (Blakeney, Moore, Broemling, Hunt, Herndon, & Robson, 1993; Boyer, Hitelman, Knolls & Kafkalas, 2003; Stuber & Shemesh, 2006). Given the high incidence of parental distress in pediatric medical disorder, and the association between parental distress and child and adolescent distress, measures of caregiver and youth anxiety and depression were included in this study.

Finally, the measurement of pediatric QOL presents particular challenges. One of these is the issue of self-report versus proxy-report. Although most authors suggest that the patient should be the first source of information regarding HRQOL (Varni, Katz, Colegrove, & Dolgin, 1995; Varni, Limbers, & Burwinkle, 2007a), investigators have often relied on proxy-reports in circumstances when the individual is incapable of providing information. The need to make use of proxy-reports is particularly evident in the area of pediatric HRQOL where developmental issues, severity of illness/disability, and/or cognitive issues often limit the availability of child self-report. Agreement between self- and proxy-reports, however, has been less than optimal (Eiser & Morse, 2001; Varni et al., 1995; Varni, Limbers, & Burwinkle, 2007d). Agreement tends to be higher in the area of directly observable functions and behaviors, and relatively poor in more subjective domains, such as emotional or social functioning. Creemers, Eiser, and Blades (2006) suggest that agreement can be affected by the statistical methods used to evaluate agreement, by domains measured and by child age. Eiser and Morse (2001) highlight that choice of proxy reporter, caregiver or teacher, for example, may also play a significant role in agreement. Compounding this issue of choice of proxy reporter is the matter of the proxy reporter’s own mental health and adjustment to the caregiving role. Lack of agreement, however, does not detract from the importance of obtaining both reports, since parental perception of HRQOL will frequently drive treatment choices and therefore constitutes important information for providers and investigators (Varni, Seid, & Rode, 1999).

This article presents results of a study on HRQOL among a sample of pediatric patients with SCI. The objective of the study was to extend understanding of HRQOL outcomes in SCI to the pediatric realm since to date most studies have focused on the adult population. The specific aims of the study were to: (1) describe HRQOL in youth with SCI, including by comparing their scores to those previously published from a sample of healthy youth (Varni, Limbers, & Burwinkle, 2007b), (2) examine child and caregiver agreement on children's HRQOL by comparing child self-reports and caregiver proxy-reports using the
Peds QL™ 4.0 Generic Core Scales, and (3) examine the relationship between child-report and caregiver-report HRQOL and demographic variables, injury-related characteristics, and child and caregiver psychological functioning. Based on the literature above, it was expected that: the HRQOL scores of the present sample would be significantly lower than those of the healthy sample; there would be significant disagreement between youth self-report and caregiver proxy-report on HRQOL; and HRQOL would be related to child and caregiver mental health, but not level of injury.

Method
Participants
Participants were a convenience sample being recruited as part of a larger project examining the psychosocial adjustment of children with SCI and their primary caregivers (typically parents). This larger project includes several hypotheses regarding psychosocial adjustment among youth with SCI and thus far published reports have addressed youth anxiety and depression (Anderson et al., 2009), participation (Gorzkowski, Kelly, Klass, & Vogel, 2010; Klass, Kelly, Gorzkowski, Homko, & Vogel, in press), and caregiver perspectives (House, Russell, Kelly, Gerson, & Vogel, 2009). Although the relationship between HRQOL and child anxiety and depression has been explored (Anderson et al., 2009), the current study is the first from this data set to compare HRQOL to previously published findings, examine child-caretaker agreement on children’s HRQOL, and assess the correlates of child- and caretaker-report HRQOL.

All children and adolescents with SCI between 1 and 18 years of age who had been injured at least one year, spoke English or Spanish, and were being seen at one of three pediatric specialty hospitals within a single hospital system were recruited for participation. From March 2007 to November 2008, 256 youth were enrolled into the project and 37 youth refused participation. Of the 256 youth enrolled, 225 were between the ages of 5 and 18 and were considered for inclusion in this article, however, 28 of these youth were excluded from the current study because of either significant amounts of missing caregiver data \((n = 23)\), child data \((n = 4)\) or both \((n = 1)\). This left 197 children and adolescents with SCI and their caregivers as the participants of the current study.

Of the 197 participants, slightly over half (54%) were male. Mean age at interview was 12.81 years \((SD = 3.66)\), mean age at injury was 6.81 years \((SD = 5.63)\) and mean time since injury was 5.98 years \((SD = 4.66)\). Sixty-five percent of participants were Caucasian, 19% Hispanic, 6% African-American, 2% Native American and 2% Asian, with an additional 6% endorsing the category “other”. Sixty-nine percent of participants had paraplegia and 31% tetraplegia. Caregivers consisted mostly of mothers (80%) and fathers (12%), although other family members were also represented (grandmothers 5%, step-mothers 1%, grandfathers 1%, others 1%). Fifty-two percent of caregivers were employed outside the home. Of the caregiver group, 19% had completed college, 43% had some college or had obtained an associate’s degree, 24% had graduated from high school and 14% had less than a high school education.

While no data are available for the 37 youth who refused participation in the study, we examined differences between the 197 youth who were included and the 28 youth who were not included due to missing data. Analyses revealed that the 28 non-participants were older \((p < .001)\), older at time of injury \((p < .001)\), and had a shorter injury duration \((p = .002)\) than the 197 participants. These results are likely due to the fact that caregiver missing data was more common among youth participants who were older. There were no other differences between the two groups in terms of the demographic variables discussed above.

Instruments
Several instruments were used to assess psychosocial outcomes among youth.

Review of Medical Record
A medical record review form was completed for all patients that included patient’s gender, date of birth, date of injury, and level of injury.

Pediatric Quality of Life Inventory™ Version 4.0 (PedsQL™ 4.0) Generic Core Scales
The PedsQL™ 4.0 Generic Core Scales are a measure of children’s health-related quality of life. The 23-item Generic Core Scales are designed for use with both healthy children and children with chronic conditions (Varni et al., 2001), and include parallel child self-report and parent proxy-report formats. Each age-specific module includes Emotional, Social, and School Functioning scales, and these are combined to create the overall Psychosocial Health Summary Score (PHSS). A fourth scale, Physical Functioning, was not included in the present study due to the large amount of missing data that would have resulted given the mobility impairments of the sample. This decision is consistent with Varni’s recommendation that scale scores not be computed if more than 50% of the items in a scale are missing (Varni et al., 2001). Several
studies have demonstrated the reliability and validity of the PedsQL™ 4.0 across groups of youth with a variety of health conditions (Varni, Limbers, & Burwinkle, 2007c; Varni et al., 2007b).

**Revised Children’s Manifest Anxiety Survey (RCMAS)**
The RCMAS is a 37-item self-report measure of anxiety for youth between the ages of 6 and 19 years (Reynolds & Richmond, 1985). Items list typical anxiety symptoms and youth are asked to answer whether or not they have experienced each. Reynolds and Richmond (1985) cite a number of studies that have demonstrated adequate reliability and construct validity of the RCMAS. The overall anxiety score was used in the current analyses.

**Children’s Depression Inventory (CDI)**
The CDI (Kovacs, 1992) is a 27-item self-report measure of depression for children and adolescents 7–17 years old. Each item lists three statements and youth are asked to pick which is most true for them in terms of their feelings over the last 2 weeks. The measure has been used extensively and has been demonstrated to have good validity and reliability (Barreto, 1994; Kovacs, 1992). The overall depression score was used in the current analyses.

**Beck Anxiety Inventory (BAI)**
The BAI (Beck & Steer, 1990) is a 21-item self-report measure of anxiety in individuals ages 17-80. Items describe subjective, somatic, or panic-related symptoms of anxiety and are rated on a scale from 0 to 3. The measure has been demonstrated to have good validity and reliability (Beck & Steer, 1990). The overall anxiety score was used in the current analyses.

**Beck Depression Inventory-II (BDI)**
The BDI (Beck, Steer, & Brown, 1996) is a 21-item self-report measure of depression for adults and adolescents age 13 years and older. The BDI assesses presence and degree of depressive symptoms and has been demonstrated as having strong reliability and validity (Beck et al., 1996). The overall depression score was used in the current analyses.

**Procedures**
Surveys were administered during regularly scheduled inpatient hospital stays or outpatient clinic visits. Caregivers of all patients meeting eligibility criteria were approached by project staff and asked to participate. When possible, caregivers were contacted prior to their child’s appointment, otherwise caregivers were approached once they arrived at the hospital. If caregivers and youth agreed to participate, age-appropriate consent and assent forms were signed by caregivers and youth, and surveys were administered during the appointment, generally taking between 45 and 75 min. The project secured approval from the Institutional Review Boards at all three hospitals and ethical treatment of human subjects was followed throughout the research process.

**Data Analyses**
Consistent with past research, data were first examined to assess the practicality of using the PedsQL™ 4.0 Generic Core scales and the PHSS with pediatric patients with SCI and their caregivers. First, the percentage of missing item responses was calculated for both the child- and caregiver-report forms. Second, internal consistency reliability, the extent to which item scores correlate with each other, was assessed using Cronbach’s alpha.

All data were screened for the presence of outliers and the assumption of normality. Descriptive statistics were used to assess central tendency and variability for each of the child- and caregiver-report scales. Mean scores on all scales and the PHSS were compared with previously published PedsQL™ 4.0 data obtained from a sample of healthy youth (Varni et al., 2007b). Although published norms do not provide for an ideal comparison (Sandberg, Meyer-Bahlburg, & Yager, 1991), these data were used to provide some context for interpreting youth scores.

Also consistent with past research, agreement between child- and caregiver-report was assessed using Pearson correlation coefficients, group mean comparisons, and intraclass correlation coefficients (ICC, two-way mixed-effects model) (Marshall, Hays, & Nicholas, 1994; Varni et al., 2007d). Pearson correlation coefficients represent a useful indicator of the strength of association between self- and proxy-reports, where values smaller than 0.3 are categorized as small, values between 0.3 and 0.5 as medium, and values equal to or greater than 0.5 as large (Chang & Yeh, 2005; Varni, Burwinkle, Katz, Meeske, & Dickinson, 2002). Despite the benefit of understanding the strength of the association, these coefficients provide little information regarding agreement between reporters, in this case parent and child. As a compliment to Pearson coefficients, comparisons of group means provide important information regarding the agreement between alternative assessment methods, in this case alternative reporters, as well as information regarding the nature of the difference between mean scores when it is present. Group mean comparisons were conducted using paired samples t-tests, and Cohen’s d was computed for each significant finding as a measure of effect size, where .20 was a small effect.
Individual predictors. Finally, Cohen’s tests to both the multiple correlation and significance of as seen in Tabachnick & Fidell, 1996) for adequate power size exceeded the requirement suggested by Green (1991; missing data on their mental health measures. This sample of 164; 11 youth were too young to complete the mental health measures, 16 youth were too old to complete the CDI, and 3 youth and 3 caregivers had missing data on their mental health measures. This sample size exceeded the requirement suggested by Green (1991; as seen in Tabachnick & Fidell, 1996) for adequate power to test both the multiple correlation and significance of individual predictors. Finally, Cohen’s $f^2$ was used to assess the effect size for each significant predictor in the regression equation, where .02 was considered to be a small effect, .15 a medium effect, and .35 a large effect (Cohen, 1988).

Results

Data Screening

Among the 197 participants, data screening revealed 11 univariate outliers across 8 variables. Specifically, youth had extremely low scores on child-report: emotional QOL ($z = -3.48$), social QOL (3 youth: $z = -3.83, z = -3.32, z = -3.32$), school QOL ($z = -3.35$), and overall PHSS ($z = -3.35$); youth had extremely high scores on the CDI (2 youth: $z = 3.58$ and $z = 3.73$); and caregivers had extremely high scores on the BAI ($z = 5.48$), BDI ($z = 3.55$), and the caregiver mental health composite variable ($z = 4.36$). In addition, the CDI and BAI experienced significant kurtosis. Logarithmic transformations resolved the kurtosis and the outliers related to the latter four variables, however, outliers related to the former four variables persisted. Score substitution was instead used with these variables, and six of the original scores were changed to 1 unit less than the next closest value; hence, the score kept its place in the distribution but was less extreme. Using Mahalanobis distance with $p < .001$, no multivariate outliers were detected. Variables included in the multivariate analyses were also screened and the assumptions of linearity and homoscedasticity were met.

Feasibility

The percentages of missing item responses were relatively low for both child- and caregiver-report forms (maximum for child-report was 4.6%, caregiver-report 3%). Consistent with reports by Varni et al. (2007d), most missing responses were for School questions that were not relevant to some participants. These findings indicate that the PedsQL™ 4.0 Psychosocial Scales items are applicable to the pediatric SCI population.

Table 1 includes Cronbach’s alpha for all scales of the PedsQL™ 4.0. The child- and caregiver-report PHSS exceeded the recommended minimum reliability standard of .70 for group comparisons (McHorney, Ware, Lu, & Sherbourne, 1994; Varni et al., 2007d). The child- and caregiver-report Social scales fell below the .70 standard with the lowest alpha reported for the child-report Social scale ($\alpha = .67$). Cronbach’s alpha for the remaining measures incorporated in the present study were well above the .70 standard: RCMS $\alpha = .82, n = 167$; CDI $\alpha = .87, n = 157$; BAI $\alpha = .89, n = 186$; BDI $\alpha = .94, n = 180$.

Comparing HRQOL Scores to Those from a Healthy Sample

Table 1 presents the mean, standard deviation and range for child- and caregiver-report data on each of the QOL PedsQL™ 4.0 scales. As expected, comparisons with
previously published data (Varni et al., 2007c) revealed that the child- and caregiver-report scores on each of the subscales and the PHSS from the SCI sample were significantly lower than child- and caregiver-report scores from youth without chronic health conditions ($p < .001$).

**Agreement Between Child- and Caregiver-Report**

Table I presents indices of agreement between child self-report and caregiver proxy-report on the PedsQL™ 4.0 scales. Pearson product-moment correlation coefficients generally indicated a moderate degree of association between child- and caregiver-reports (ranging from .34 to .54). However, as expected, group mean differences were significant across all scales, and Cohen’s $d$ indicated small effect sizes for the Emotional (.31) and School (.19) child-caregiver comparisons, and medium effect sizes for the Social (.66) and Overall PHSS (.51) child-caregiver comparisons (Cohen, 1988). Children consistently rated their QOL of life as better than did the caregiver-reporters. Furthermore, ICCs were within the poor to moderate level of agreement, ranging from .34 (Social) to .54 (Psychosocial).

**QoL and Demographic and Injury-Related Variables and Mental Health**

Table II presents relationships between child- and caregiver-report scores on the PedsQL™ 4.0 and continuous demographic, injury-related, and mental health variables of interest. Child’s age at interview was significantly associated with HRQOL, where younger age was associated with higher Emotional HRQOL in the caregiver-reports, but lower social HRQOL in the child-reports. Age at injury was significantly associated with caregiver-report emotional HRQOL in that children injured at an earlier age tended to be seen as having better HRQOL. As hypothesized, child anxiety and caregiver depression were significantly related to all aspects of child- and caregiver-report HRQOL. HRQOL did not vary by gender; however, contrary to expectations, youth with paraplegia (mean = 76.21) reported higher social HRQOL scores than youth with tetraplegia (mean = 70.37), $t(195) = -2.01, p = .046$.

In order to evaluate the predictive nature of the relationships between HRQOL and child and caregiver mental health, two regression equations were conducted with child-report PHSS and caregiver-report overall PHSS as the two dependent variables. The composite child- and caregiver-mental health variables were used as the two predictor variables in each regression equation. The first equation predicted child-report PHSS; the model accounted for 57% of the variance, and although caregiver mental health trended towards contributing significantly ($p = .061$), child mental health was the only significant predictor (see Table III). Cohen’s $f^2$ indicated a large effect size for child mental health (.106) in terms of child-report PHSS. The second equation predicted caregiver-report PHSS; the model accounted for 35% of the variance and child and caregiver mental health were both significant predictors (see Table III). Cohen’s $f^2$ indicated a small effect for child mental health (.098) and a medium effect for caregiver mental health (.277) in terms of caregiver-report PHSS.

**Discussion**

Three clear conclusions can be drawn from the data for this sample. First, the data provide support for the hypothesis that, when compared with scores from a group of healthy...
Table II. Correlations between QOL Scales and Continuous Demographic, Injury-Related, and Mental Health Variables

<table>
<thead>
<tr>
<th>Variable</th>
<th>Emotional</th>
<th>Social</th>
<th>School</th>
<th>PHSS*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at interview</td>
<td>.044</td>
<td>.339***</td>
<td>−.093</td>
<td>.138</td>
</tr>
<tr>
<td>Age at injury</td>
<td>−.036</td>
<td>.140</td>
<td>−.141</td>
<td>−.006</td>
</tr>
<tr>
<td>Time since injury</td>
<td>.075</td>
<td>.103</td>
<td>.097</td>
<td>.117</td>
</tr>
<tr>
<td>Child anxiety</td>
<td>−.667***</td>
<td>−.584***</td>
<td>−.440***</td>
<td>−.746***</td>
</tr>
<tr>
<td>Child depression</td>
<td>−.584***</td>
<td>−.445***</td>
<td>−.480***</td>
<td>−.658***</td>
</tr>
<tr>
<td>Child mental health b</td>
<td>−.675***</td>
<td>−.556***</td>
<td>−.465***</td>
<td>−.745***</td>
</tr>
<tr>
<td>CG anxiety</td>
<td>−.307***</td>
<td>−.161</td>
<td>−.198**</td>
<td>−.277**</td>
</tr>
<tr>
<td>CG depression</td>
<td>−.306***</td>
<td>−.213**</td>
<td>−.316***</td>
<td>−.361***</td>
</tr>
<tr>
<td>CG mental health b</td>
<td>−.328***</td>
<td>−.220**</td>
<td>−.276***</td>
<td>−.352***</td>
</tr>
</tbody>
</table>

Table III. Summary of Regression Analyses for Child-Report and Caregiver-Report Quality of Life

<table>
<thead>
<tr>
<th>Variable</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>R²</th>
<th>B</th>
<th>SE B</th>
<th>β</th>
<th>R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child mental health</td>
<td>−.908</td>
<td>.069</td>
<td>−.715***</td>
<td>1.07</td>
<td>−.356</td>
<td>.090</td>
<td>−.266***</td>
<td>.098</td>
</tr>
<tr>
<td>Caregiver mental health</td>
<td>−3.145</td>
<td>1.664</td>
<td>−1.03</td>
<td>−</td>
<td>−14.39</td>
<td>2.150</td>
<td>−.449***</td>
<td>.277</td>
</tr>
</tbody>
</table>

*Child-Report (n = 164)*

children and their caregivers (Varni et al., 2007b), youth with SCI and their caregivers scored significantly lower on HRQOL. Second, agreement between caregiver proxy-reporters and self-report HRQOL is moderate at best. Third, psychological functioning appears to be more closely related to the subjective assessment of QOL than injury-related or demographic variables. Only anxiety and depression were consistently correlated with HRQOL across reporters and across scales, indicating that psychological functioning is intimately associated with HRQOL. While similar findings have been reported in the literature on adults with SCI, to date no studies on youth HRQOL using youth and caregiver report have examined the association with psychological variables.

Given that HRQOL measures a subjective view of functioning, it is not surprising that psychological variables play such an important role. However, the nature of this association merits further investigation. Whether depression and anxiety have an impact on the evaluation of functioning or, conversely, whether functional limitations result in increased psychological distress, remains to be determined. It is notable that while, as expected, child-report HRQOL was predicted by child psychological functioning, caregiver-report HRQOL was predicted by both child and caregiver psychological functioning. This relationship reminds us of the need to focus our attention and intervention not only on the injured youth but also on those who are closely involved in the child’s life, particularly if we are relying on caregiver reports to guide treatment decisions.

In the area of injury and demographic variables, current age, age at injury and injury level showed an association with HRQOL, although these associations were not consistent across domains. In contrast to results obtained by Oladeji et al. (2007) in their study of youth with SCI, in this sample level of injury was associated with self-report social HRQOL. Specifically, youth with paraplegia reported better social HRQOL than those with tetraplegia, pointing perhaps to the increased obstacles in interpersonal relationships associated with higher injuries. Self-report scores in the social domain of HRQOL were also positively associated with age at interview, indicating that older youth appear to have a more positive view of their interactions with peers. The findings in the area of age and HRQOL highlight the need to incorporate understanding of developmental stages and associated age-appropriate interests and tasks into the assessment of HRQOL (Taylor, Gibson, & Frank, 2008). For example, a negative
association between youth age at injury and at interview and proxy-report emotional HRQOL emerged for this sample. This finding might be associated with developmental changes in adolescence that bring about a reevaluation of body image and increased concern regarding acceptance by peers as well as increased striving towards independence. These issues could result in greater emotional turmoil for the youth and in more conflict in the relationship with the caregiver and could lead to a more negative evaluation of youth emotional functioning by the caregiver. Younger children might accept care more readily and therefore be perceived as less distressed by the caregiver. Clearly, the relationship between age and caregiver report merits further examination.

The study found only moderate agreement between child self- and caregiver proxy-reports, as hypothesized by the authors. This finding is consistent with the literature (Oladeji et al., 2007; Varni et al., 2007d). When compared with caregivers, youth with SCI report their HRQOL as better across all scales. It has been proposed that caregivers’ views may be influenced by the burden of caregiving as well as by caregiver health and psychological adjustment (Eiser & Morse, 2001). Varni et al. (1995) emphasize the usefulness of obtaining multiple reports in order to fully assess the child’s functioning and to establish a comprehensive psychosocial treatment plan, suggesting that different informants may be more sensitive to certain aspects of functioning than others.

Several questions are left for future research. The potential benefits of developing an SCI-specific module for the PedsQL™ 4.0 might be considered. This kind of condition-specific module has been developed for other medical conditions, including pediatric cancer and asthma (Chan, Mangione-Smith, Burwinkle, Rosen, & Varni, 2005; Varni, Burwinkle, & Lane, 2005) and might allow investigators to target aspects of functioning that are not captured by the Generic Core Scales, in particular those in the physical arena. Additionally, the relationship between QOL and mental health should continue to be investigated. In the first place, the exact nature of the association between HRQOL and psychological functioning should be examined in more detail. Not only is the directionality of the association unclear but, the overlap between the mental health measures and the Emotional Functioning scale in particular was high. Future research should assess whether this relationship is maintained when using other measures of HRQOL. Finally, the association between age and HRQOL should be clarified further. For example, are the findings related to caregiver-report emotional QOL due mostly to the child’s age at the time of injury or, rather, are they a result of the child’s age at the time of completing the measures? How does the evaluation of HRQOL vary across developmental stages? Is there an age at which intervention takes on additional importance? These questions are important to understanding and maximizing QOL among youth with SCI.

This study has several limitations. The decision to exclude the Physical Functioning Scale from the PedsQL™ 4.0 administration has resulted in a lack of information regarding HRQOL and agreement between reporters in that area. In retrospect, the scale might have been included and the pattern of missing answers might have provided important information regarding the limitations of the scale as well as provided guidance for the development of an SCI-specific module. It should be noted as well that, while reliabilities for most scales were above .70, both social functioning scales fell slightly below this cutoff and therefore results should be interpreted with some caution. Perhaps additional measures of HRQOL should have been considered although the age range included in this study imposed limits on these choices. In addition, results of this study may not be easily generalized to the broader population of youth with SCI since the current sample was drawn from 3 hospitals that share several characteristics given that they belong to a single hospital system. For example, since our hospitals generally do not accept patients on ventilators, no such patients are included in the study. In regards to group comparisons, we compared youth HRQOL scores to those published from a published sample of youth without disabilities. Past research has questioned the comparability of sample scores to published norms, so conclusions resulting from comparisons should be considered preliminary until they can be repeated with a matched comparison group (Sandberg et al., 1991). Finally, our hospitals recruit patients from areas that may be removed from the hospital location and therefore the patients and caregivers interviewed were often far from their home environment, potentially altering their subjective experiences at the time of interview.

In conclusion, the findings extend reports found in the adult literature that indicate that mental health variables play a far more significant role in the subjective evaluation of HRQOL than injury-related factors, including injury severity. The psychological functioning of both the affected youth and their caregivers appear to be associated with HRQOL. Therefore, interventions to optimize psychological adjustment in both the youth and their caregivers should be initiated early and follow-up of youth with SCI should include ongoing assessment of child and caregiver mental health. Additionally, findings highlight the need to incorporate understanding of the youth’s developmental stage when planning interventions following SCI. Finally,
given that youth and caregiver perspectives can differ significantly when it comes to the evaluation of HRQOL, and that both are involved in decisions regarding treatment, it is important to obtain both reports to optimize treatment planning and intervention.

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