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# Psychosocial Outcomes Among Youth with Spinal Cord Injury and Their Primary Caregivers

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**Background:** Past research has found youth with disabilities to experience poor psychosocial outcomes, but little is known about factors related to psychosocial health among youth with spinal cord injury (SCI). **Objective:** To describe psychosocial health among youth with SCI, examine relationships between psychosocial outcomes and demographic and injury-related factors, and examine relationships between aspects of psychosocial health. Youth activity, participation, quality of life (QOL), coping, anxiety and depression, and caregiver mental health were included. **Methods:** Data were collected as part of a prospective study of 420 youth with SCI ages 1-18 and their primary caregivers. Activity data were also presented from a study developing a computerized adaptive testing (CAT) platform with 226 youth with SCI ages 8-21. **Results:** Although relationships varied by factor, youth outcomes were related to youth age, sex, age at injury/injury duration, and level/extent of injury. Caregiver mental health related to child age and age at injury. Further, relationships were uncovered between aspects of psychosocial health: aspects of youth mental health were related to youth participation and QOL, youth coping was related to youth mental health, participation, and QOL, and caregiver mental health was related to child mental health and QOL. **Conclusion:** Psychosocial outcomes relate to each other and vary by child and injury-related factors and should be understood in a comprehensive, developmental context. Identifying best measures of activity and psychosocial functioning among youth with SCI and understanding factors related to their psychosocial health is critical to improving outcomes for the pediatric-onset SCI population. **Key words:** caregivers, outcomes assessment, psychosocial factors. spinal cord injuries, youth

At any age, sustaining a spinal cord injury (SCI) comes with significant physical, psychological, and social consequences. Sustaining an SCI during childhood, however, can be particularly difficult due to the dynamic nature of the child's growth and development as well as the integral role family and caregivers play in the child's postinjury adjustment.<sup>1</sup> These youth and their families face significant challenges. Past research has found youth with disabilities to experience lower rates of participation,<sup>2</sup> and youth with SCI in particular have been found to have lower quality of life (QOL)<sup>3</sup> and higher rates of psychological issues such as posttraumatic stress disorder (PTSD).<sup>4</sup> Further, youth with more severe injuries have been shown to have decreased participation compared to their peers with less severe injuries.<sup>5</sup> Although sustaining an SCI should not be seen as detrimental to functioning, youth often require specific supports to navigate their new disability. Resources put in place by environments of care can provide the support needed for youth to successfully adjust to their new injury and

achieve the ultimate goal of rehabilitation, which is full integration back into the community. As the primary environment of care for a child, the family as well as characteristics of parents or other significant caregivers have the ability to influence outcomes among children. Although parents and family support are important to all youth, youth with disabilities face a greater potential for social isolation from peers and, as such, may be particularly tied to and dependent on family relationships and support.<sup>6</sup>

The purpose of this article is to describe psychosocial health among youth with SCI, the relationships between psychosocial outcomes and key demographic and injury-related factors, and how aspects of psychosocial health relate to each other. Data will be presented from a prospective

study of 420 youth with SCI who are 1 to 18 years old, and 380 of their primary caregivers (primarily mothers). In addition, activity data will be presented from a study developing a computerized adaptive testing (CAT) platform with 226 youth with SCI who are 8 to 21 years old. Youth from both studies were receiving care at 1 of 3 pediatric SCI centers within one hospital system in the United States. The goals of these projects were to understand factors related to psychosocial health among youth with SCI and to determine the best measures of their activity and psychosocial functioning. The article will include an overview of pediatric SCI and psychosocial health among youth with SCI. This will be followed by presentations on 6 constructs critical to psychosocial health among youth with SCI: activity, participation, QOL, coping, anxiety, and depression. Because of the critical role of family and parents in the lives of youth with SCI, there will also be a discussion of caregiver outcomes and how these relate to outcomes of youth.

A major challenge in the evaluation and follow-up of children with SCI is the paucity of measures for body function and structure and for activity and participation that are appropriate for individuals throughout the developmental spectrum, ranging from infants, toddlers, preschoolers, school-aged children, to adolescents. In respect to body function and structure, standardized measures such as the International Standards for Neurological Classification of Spinal Cord Injuries have limited utility in children less than 8 years of age.<sup>7,8</sup> Similarly, measures of activity, such as the FIM<sup>\*</sup> instrument, or measures of participation, such as the Craig Handicap Assessment and Reporting Technique (CHART), may not be applicable to younger children. Measures utilized in adults for the assessment of psychosocial health including the constructs of depression, anxiety, and life satisfaction are generally not applicable for the pediatric population. Additional challenges are the longitudinal follow-up of individuals with pediatric-onset SCI and the need for proxy

report for younger children. Different measures may be needed at varying ages, raising issues of comparability of these measures as individuals pass through successive stages of development. Because of cognitive development, parent report is necessary for many of the measures to assess functioning in children younger than 5 to 8 years of age. In addition, understanding parents' or caregivers' perception of the child's functioning adds an important dimension in caring for children with an SCI.

### Activity

A functional outcomes tool that would monitor a child's progress throughout childhood and adolescence would be beneficial. The ideal measure would have the capacity to monitor change longitudinally, to detect change following an intervention, to evaluate varying age groups and levels of impairment, and to provide information on functioning in daily routines and leisure activities. This presentation will discuss the development process of such a measure among youth with SCI.

Computerized Adaptive Testing (CAT) reflects modern measurement methodology and is uniquely positioned to eliminate problems associated with long and burdensome questionnaires, inappropriate items, ceiling and floor effects, and inadequate content range. CATs are based on item response theory (IRT), which provides a means to calibrate sets of items, referred to as *item banks*, based on the information each item contributes toward characterizing the underlying test construct.

This project developed tools to assess mobility, daily routines, and self-care activities by children with SCI utilizing CAT. Children respond to a minimal number of appropriate items, which are selected based on their responses to filter questions (eg, age, gender, school environment, wheelchair use) as well as answers to previous items, and estimates of their activity are obtained. With CAT, children complete an assessment in 5 to 10 minutes and are never presented with an item irrelevant to their situation (eg, an item about walking would never be presented to a child who uses full-time

<sup>\*</sup>FIM<sup>TM</sup> is a trademark of Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc.

wheeled mobility) nor would they answer items that are too difficult or too easy.<sup>9</sup>

## Participation

The World Health Organization (WHO) defines participation as “involvement in a life situation” and the result of peer interaction within an individual’s social and physical environment.<sup>10</sup> Participation is essential to the development of children. It is often through participation that children learn about societal expectations, develop communication skills, build friendships, and conquer important milestones. Research has found that involvement, particularly in physical recreation and sports, is highly related to overall health, disease prevention, functional independence, and life satisfaction.<sup>11,12</sup> Unfortunately, current societal trends for participation raise concerns about the participation levels of all children, particularly those with disabilities. In an era of increasingly sedentary lifestyles, participation has become more important yet research suggests rates of participation are not at optimal levels.<sup>13</sup>

Participation among youth with SCI was evaluated using the Children’s Assessment of Participation and Enjoyment (CAPE).<sup>14</sup> The CAPE measures participation for children with disabilities according to 5 types of activities: quiet recreation, active physical, social, skill-based, and self-improvement while addressing issues of frequency (diversity and intensity), enjoyment, and context (with whom and where) of participation. In terms of demographic characteristics and injury-related factors, results indicate that participation frequency is related to current age, age at injury, gender, and level and extent of injury. Girls, youth who are younger and were younger at injury, youth with paraplegia, and youth with incomplete injuries reported participating in more activities (diversity) and participating more often (intensity). Girls, younger youth, and youth injured at a younger age also reported enjoying their participation more. However, older youth and those injured at an older age were more socially engaged with their participation as they reported participating in activities with a more diverse group and participating further from home.

## Mental Health

Depression<sup>15,16</sup> and anxiety<sup>17</sup> have been reported in several studies of individuals, primarily adults, with SCI. Until recently, there has been no information available about depression or anxiety in children or younger adolescents with SCI.<sup>18</sup> One of the goals of the present project was to assess levels of anxiety and depression in pediatric-onset SCI and to determine how those levels were associated with demographic and injury-related factors. In addition, the relationship between anxiety and depression and the outcomes of participation and QOL were investigated in youth with SCI.

The Revised Children’s Manifest Anxiety Scale (RCMAS) was used to measure anxiety. The SCI sample scored within the average range compared to the test norms.<sup>19</sup> Of those with SCI, 9% scored above the cutoff level that would indicate significant clinical concern, compared with 16% of the normative group.<sup>19</sup> When the group was divided into children (7-12 years old) and adolescents (13-17 years old), both groups scored within the average range of anxiety. The Children’s Depression Inventory (CDI) was used to measure depression, and again the SCI sample scored within the average range compared with the norms.<sup>20</sup> In the SCI sample, 5% scored above the cutoff that would indicate clinically significant depression compared with 7% in the normative group.<sup>20</sup> There were no significant associations of anxiety or depression with any of the demographic or injury-related factors, except that more anxiety was associated with being female and having a shorter duration of injury. Depression, but not anxiety, was associated with decreased community participation. Both increased depression and increased anxiety were associated with decreased QOL.

## Quality of Life

Health-related QOL has been discussed as 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.”<sup>3</sup> For this study, data were gathered using the psychosocial scales of the Pediatric Quality of Life Inventory, which assesses parent and child perceptions of youth QOL, including youth emotional, social, and school functioning.<sup>21</sup> This study examined agreement between child self-report and parent proxy report; assessed relationships between QOL and demographic, injury-related, and mental health variables; and examined relationships between child and parent mental health and self- and proxy report of youth QOL. When comparing self- and proxy ratings of youth QOL, agreement was moderate at best, with youth rating their QOL as higher than their caregivers. Further, aspects of self- and proxy-report QOL were related to child sex, age at injury, injury duration, current age, and level of injury; however, most consistent relationships emerged between aspects of QOL and child anxiety and depression. Finally, regression analyses were conducted to evaluate relationships between child and caregiver mental health, and self- and proxy-report child QOL. Results revealed that child mental health significantly predicted self-report QOL, whereas child and caregiver mental health significantly predicted proxy-report QOL. In fact, caregiver mental health was a stronger predictor of how caregivers rated the QOL of their children than child mental health. Results suggest that it is important to take into account both child and caregiver perceptions throughout the pediatric rehabilitation process. Further, results confirm that child mental health should be addressed as part of rehabilitation, as across the various factors examined, child anxiety and depression were most closely related to youth QOL. Finally, results suggest that parents’ mental health should be addressed as part of their children’s rehabilitation; parents are likely driving treatment decisions related to their child’s care.

### Coping

Coping has been defined as cognitive and behavioral efforts to manage external and/or internal demands that exceed the resources of the individual.<sup>22</sup> Specific to the context of

the rehabilitation of children with SCI, coping is important for the potential role it plays in psychological adjustment. Although there has been research on coping among children with other medical issues<sup>23-26</sup> and some research on coping with adults with SCI,<sup>27-32</sup> no previous studies have addressed coping among children with SCI.

Therefore, one of the objectives of this study was to investigate the relationship between coping and demographic characteristics, injury-related factors, psychological outcomes, and participation in youth with SCI. Youth completed the Kidcope, a pediatric measure that assesses the frequency of use and effectiveness of 11 coping strategies.<sup>33</sup> Use of coping strategies was related to child sex, age, age at injury, duration of injury, level of injury, and extent of injury. With regard to psychological outcomes, use of most strategies correlated with increased anxiety, increased depression, and decreased quality of life. Resignation, which may be better named acceptance, was not related to poor outcomes, whereas problem solving and social support were each only related to increased anxiety. Cognitive restructuring was the only strategy that related to psychological outcomes in a positive way, in that youth who use cognitive restructuring experienced decreased depression. With regard to frequency of participation, use of self-criticism correlated with less participation, while use of social support was related to increased participation. Across several strategies, youth who reported feeling effective when coping also reported more positive outcomes and more enjoyment while participating. In summary, youth who experienced poor mental health and decreased QOL reported using more coping strategies overall. However, youth feeling more effective in their use of coping strategies correlated with more positive outcomes. This information can help to generate coping interventions, possibly focused on enhancing the use of cognitive restructuring, acceptance, problem solving, and social support among youth with SCI, with the goal of improving their psychosocial outcomes.

## Caregiver Outcomes

Caregiver functioning has been linked with the functioning of their children among youth with disabilities<sup>34,35</sup> and youth with SCI in particular.<sup>36</sup> In the current study, 76% of caregivers were mothers, 16% were fathers, and 66% were married. Fourteen percent of caregivers had less than a high school degree, 23% were high school graduates, 41% had some college, and 22% had completed college or beyond. Among the 379 caregivers who completed psychological measures, 20% fell in the range of moderate or severe anxiety, and 22% of moderate or severe depression. Female caregivers were more likely to be anxious and depressed. Caregivers with more education and those who were married were less likely to be anxious. Caregiver anxiety and depression were related to the age of the child at injury, in that caregivers of youth injured at an older age experienced higher anxiety and depression. Caregiver anxiety alone was related to the current age of the child, though analyses

indicated a curvilinear relationship between these variables, in that anxiety is highest among caregivers of young children and adolescents. Increased caregiver anxiety and depression were related to decreased child emotional, social, and school QOL and increased child anxiety and depression. Caregiver mental health was not related to child participation. Results suggest caregiver mental health should be addressed in pediatric rehabilitation.

## Conclusion

Psychosocial outcomes relate to each other and vary by child and injury-related factors and should be understood in a comprehensive, developmental context. Identifying best measures of activity and psychosocial functioning among youth with SCI and understanding factors related to their psychosocial health is critical to improving outcomes for the pediatric-onset SCI population.

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