Pediatric Spinal Cord Injury

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Abstract Traumatic spinal cord injury (SCI) occurs much less commonly in children than adults. Children can also experience spinal cord dysfunction from birth injuries, skeletal dysplasias, neoplasms, infections, and autoimmune causes. There are special considerations for determining the level and completeness of injury in children under 6 years of age. Children with SCI experience some unique secondary complications such as scoliosis, and other complications such as autonomic dysreflexia require modifications in management due to pediatric physiology. The rehabilitation of children with SCI typically includes compensatory strategies and exercise, and new methods of exercise including functional electrical stimulation and activity-based locomotor training are being researched for efficacy in restoration of function. Studies of psychosocial health of children with SCI highlight the importance of peer interactions and participation in activities outside the home. Practitioners also need to be mindful of the stress an injury places on siblings, parents, and other caregivers.

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Introduction

This review of pediatric spinal cord injury (SCI) will focus on recent advances in knowledge and highlight differences in rehabilitation and secondary complications compared to adults with SCI.

Epidemiology

The incidence of SCI in the United States is reported to be 39 per million with children under 15 years comprising only 10 percent of injuries [1]. The incidence of pediatric SCI (0–17 years) in the United States has been estimated to be 17.5 per million-population [2]. The median age at injury is 15 years and 72.5 % of children with SCI are boys. Estimates from European countries range from 0.9 to 21.2/million children [3]. From 2005 to 2011, the National SCI Database and the National Shriners SCI Database identified 384 children ages birth to 15 years of age with SCI. The most common causes of injury in these children were automobile crashes (40.1 %), medical/surgical (12.8 %), gunshot (8.1), fall (7.6 %), diving (5.7 %), and other sports (4.2 %) [1].

While most national incidence data report traumatic SCI, data from Australia highlight the importance of non-traumatic causes of spinal cord disorders in children under 15 years [4]. The researchers estimated the incidence of traumatic and non-traumatic SCI to be 3.8 and 6.5 per million children, respectively. The most common non-traumatic causes were neoplasm and transverse myelitis.

SCI in children may also occur in association with birth injuries, skeletal dysplasias, juvenile idiopathic arthritis, and Down syndrome [5].

No comparative studies have examined whether children with traumatic SCI have a better or worse prognosis than adults with SCI [6]. Long-term survival analysis for non-ventilator dependent children with SCI injured before age 16 years has shown a 31 % increased chance in the annual odds of dying compared to persons injured at an older age [7]. There were no differences in survival in those injured at ages 0–4 versus 5–9 versus 10–15 years. Life expectancies for those injured before age 16 years are reduced compared to both the general population as well as persons with SCI injured at 16 or more years of age [7]. The reasons for this heightened mortality and reduced life expectancy are not clear but may be related to a longer exposure to SCI complications and secondary conditions, as well as consequences of developing SCI prior to achieving skeletal maturity (low bone mineral density, scoliosis, restrictive lung disease, etc.).

SCIWORA

The child's cervical spine is characterized by ligamentous laxity, incomplete ossification of the vertebrae, anterior wedging of vertebrae, shallow angle of facets, and relatively underdeveloped neck muscles compared to teenagers and adults. As a result, forces on the neck and head can result in greater stretching of the ligaments and spine without resultant fracture but with injury to the spinal cord. Spinal cord injury without radiographic abnormality, or SCIWORA, was originally coined to describe this phenomenon of myelopathy with muscle weakness or sensory changes accompanied by a lack of abnormal findings on computed tomography (CT) or radiographs. With the advent of magnetic resonance imaging (MRI), more cases of SCIWORA were found to have spinal cord hematoma or edema, ligamentous injury, or end plate fractures. However, MRI can still be normal in a significant number of cases, particularly in those with less severe trauma [8]. Children with SCIWORA as a result of sports injuries are more likely to have normal MRIs and have resolution of neurologic deficits. Those with more severe mechanisms of injury with abnormal MRIs are more likely to have persistent neurologic deficits and the injuries may require surgical intervention [8].

Evaluation of Neurologic Level

As in adults, the American Spinal Injury Association Impairment Scale (AIS) is used to classify neurologic

impairment in youth with spinal cord injury. However, there are a few caveats when using the AIS in children. Children younger than 6 years old are not able to fully participate in the sensory examination [9]. From a developmental perspective, children at this age are not able to comprehend the directions given for the sensory exam. Moreover, they are unable to distinguish between normal and reduced sensation. If a child has not achieved bowel continence before their injury, they will not understand how to produce sphincter contraction or appreciate pressure sensation during the rectal examination. Studies have shown that for children older than 6 years, there is high intra-rater agreement on the sensory and motor exam scores of the AIS [10]. However, the agreement on light touch and pinprick sensation, anal contraction, and deep anal pressure for the rectal examination is more variable, especially when evaluating different age groups and comparing those with tetraplegia versus paraplegia [11].

Determining completeness of injury is an important factor in providing education to the children and their families on SCI and prognosis for recovery of function. Mulcahey et al. [12] studied the differences in diffusion tensor imaging (DTI) for children with chronic cervical SCI. They found significant differences in values for fractional anisotropy, axial diffusivity, and radial diffusivity for those with complete or incomplete SCI as compared to healthy controls. Various combinations of the DTI indices showed moderate sensitivity and specificity for predicting each component of the rectal examination except deep anal pressure. The sensitivity and specificity for sensation at S4–5 were 80 and 81 %, respectively, while they were 80 and 71 % for anal contraction. Further studies are needed to compare the DTI indices for children in each AIS classification to determine reliability of these values in identifying completeness of injury, especially in acute injuries.

Secondary Complications

Scoliosis and Bracing

Neuromuscular scoliosis develops in nearly all children who experience SCI prior to skeletal maturity. Age at the time of injury is the most important predictor of those who will develop severe curves and require spinal fusion. Children injured before age 12 are 3.7 times more likely to have a spinal fusion compared to older children [13]. Neurological level, motor level, and severity of injury are not strong predictors for scoliosis development. Research on attenuation or prevention of neuromuscular scoliosis in children with SCI is scarce, and practice patterns vary widely with regard to bracing, surgery or other therapeutic

interventions [13]. Use of a thoracolumbosacral orthosis (TLSO) may retard progression of curves less than 20 degrees [14], but it can adversely affect functional independence and time to complete daily activities, and children preferred to not wear the TLSO when doing such activities [15].

Definitive surgical treatment for scoliosis involves spinal fusion with rod instrumentation and is generally considered for curves approaching 40 degrees when children are 10 years of age or older. Treatment of scoliosis in a younger child with a growing spine has unique challenges. Spinal fusion would result in a short trunk and impaired lung development. Also the anterior portion of the spine continues to grow after posterior fusion in a young child, resulting in rotational deformities, known as a crankshaft phenomenon [16]. Procedures such as single or dual growing rods or vertical expandable prosthetic titanium ribs have been successfully used in young children with neuromuscular scoliosis to achieve curve correction, improve thoracic height and allow for continued spine growth until the child is old enough for definitive fusion [16, 17].

Autonomic Dysreflexia

Children have lower BP and higher resting heart rates than adults. Blood pressure values in able bodied children are related to age, gender, and height [18], so it is more complicated to determine when a child with spinal cord injury has an abnormal blood pressure (BP). BP and heart rate in children with SCI are related to age, body mass index (BMI), and level and completeness of injury [19•]. With increasing age, BP increases and heart rates decrease [20]. BP is positively correlated with BMI and is higher in children with incomplete injury and paraplegia. Children with SCI should have baseline blood pressures documented on an annual basis as they age to help determine appropriate levels to initiate autonomic dysreflexia (AD) protocols.

There is no evidence to indicate at which point elevated blood pressure (BP) during autonomic dysreflexia is either dangerous or requires medication. In a review of life threatening outcomes of autonomic dysreflexia, individuals who survived their episode had a mean systolic BP of 181 mm Hg, compared with a mean systolic BP of 214 mm Hg in the group of cases that resulted in fatality, but the difference was not statistically significant and only 1 of the 32 individuals was less than 20 years of age [21]. Most practitioners rely on the Clinical Practice Guidelines developed by the Consortium for Spinal Cord Medicine [22] to determine when a child's BP needs to be managed. AD management is typically initiated when the systolic BP is elevated 15 mm Hg over baseline in a child and 15–20 mm Hg over baseline for an adolescent. Medications are used when the systolic BP exceeds 120 mm Hg in children under 5 years, 130 mm Hg in children

6–12 years, and 140 mm Hg for adolescents. Both topical nitroglycerin 2 % (1 inch) as well as nifedipine (0.25–0.5 mg/kg per dose; maximum 10 mg per dose) have been recommended for use in children. [23]

Bone Health

Bone modeling is a continuous process of bone formation and resorption. Normally, bone modeling results in bone mass that increases throughout childhood, with peak bone mass being reached before age 30. Following spinal cord injury, children experience loss of bone mineral density due to an imbalance between bone formation and bone resorption. Additionally, onset of SCI prior to puberty prevents attainment of the typical peak in bone mineral density. As with adults, bone density in children is typically measured using Dual-energy X-ray Absorptiometry scans (DXA). For children, a z score is assigned rather than a t score as children have not yet reached peak bone mass. The z score is the standard deviation from the mean of age, sex, and ethnicity matched controls. An NIH-sponsored multicenter study has resulted in publication of z scores for children for lumbar spine, hip, and total body [24]. By consensus, children are defined as having low bone mass for chronological age when the z score is less than –2, and osteoporosis if the z score is less than –2 and the child has experienced 2 or more fractures by age 10 or 3 or more fractures by age 19. Presence of a pathologic (minimal force) fracture will make it more likely that the child will require specific treatment for the low bone mass.

Children with chronic SCI typically have bone mineral densities at the hip and knee that are about 60 % of normal [25]. They can experience fractures with minimal trauma, most commonly affecting the supracondylar knee, tibial plateau and femoral neck. Treatments such as electrical stimulation or medications to prevent low bone mass or osteoporosis in pediatric spinal cord injury have remained elusive. A comparative study of functional electrical stimulation (FES) cycling vs passive cycling vs electrical stimulation for 60 min a day, 3 days per week for 6 months did not reveal any differences in bone mineral density in the femur, hip or tibia either between or within groups over the course of the study [26]. In a sample of 82 children with spinal cord injury, 40 % had vitamin D insufficiency and 39 % had vitamin D deficiency [20]. Supplemental calcium and vitamin D are commonly recommended in cases of low bone mass, but there are no studies in children with disabilities to demonstrate that these improve bone mineral density or reduce risk of fracture. Nevertheless, given the known roles of calcium and vitamin D in bone metabolism, it seems prudent to assess vitamin D levels in children with SCI and replete as indicated. A recent case study using the bisphosphonate zoledronic acid in a child with a fragility

fracture due to C3 AIS C injury did show improvements in z scores in the tibia and radius over 18 months of treatment [27]. The optimum duration of bisphosphonate treatment is unknown as are long term risks in growing children. Studies in children with diagnoses including Duchenne muscular dystrophy and cerebral palsy have shown loss of improvements in bone mineral density by 2 years after treatment [28, 29].

Neurogenic Bladder

Bladder capacity in children can be estimated using equations based on age. Koff [30] proposed: bladder capacity (ounces) = age in years + 2. Kaefer et al. [31] derived slightly different but similar formulae for children under 2: capacity (ounces) = $2 \times \text{years} + 2$ and for children 2 years and older: capacity (ounces) = $\text{age (years)}/2 + 6$. Bladder capacity in children with spinal cord injury has been found to be less than expected in 80 % of those with cervical injuries, 58 % of those with thoracic injuries and 50 % of those with lumbar injuries [32]. In children with neurogenic bladder, goals of treatment are attaining and preserving a bladder reservoir of adequate capacity with low storage and voiding pressures.

Many children respond well initially after injury to clean intermittent catheterization and oral anticholinergic medications [33]. However, reaching a smaller than expected bladder capacity as the child ages can result in need for impractical frequency of catheterization or incontinence. In studies involving only a few children with SCI, methods that have been shown to increase bladder capacity include daily intravesical oxybutynin [34] and onabotulinumtoxinA injections [35] into the bladder detrusor. There are no studies published to guide the frequency at which repeated botulinum toxin injections should be performed [36].

When oral or intravesical medications fail to result in an adequate bladder capacity, augmentation cystoplasty can be performed. However, the use of gastric or intestinal tissue for augmentation can have significant complications including intestinal adhesions, metabolic disturbances, urolithiasis, excess mucus production and malignancy [37]. Recent research efforts to augment the bladder using tissue engineering technology are promising. Researchers have successfully used implants such as small intestinal submucosa from pigs to act as a bioscaffold in human bladder augmentations over which urothelial cells migrate, resulting in increased bladder capacity and decreased maximum detrusor pressures [38*].

Neurogenic Bowel

The management of SCI-related neurogenic bowel depends on the type of injury incurred: upper or lower motor

neuron. Bowel program goals are: continence of stool, simple, controlled and independent (if possible) defecation and prevention of gastro-intestinal complications. The bowel program is usually a comprehensive, individualized treatment plan that includes consideration of diet, physical activity level, equipment, oral or rectal medications and scheduling of bowel care (the specific procedure devised to periodically evacuate stool from the colon). While usual bowel programs consist of non-invasive dietary and pharmacologic methods to modulate stool consistency, promote gastrointestinal transit and insure timely stool evacuation, the antegrade continence enema (ACE) procedure described by Malone et al. [39] has gained acceptance in the management of neurogenic bowel in children with myelomeningocele. The ACE procedure entails using the appendix or other segment of intestine to connect a stoma on the abdominal wall with the large intestine. The patient or caregiver can insert a catheter through the stoma and flush a small quantity of irrigant (typically water or glycerin water mixture) to stimulate peristalsis [40]. While there have been numerous reports of improved bowel management in children with myelomeningocele, few outcome studies have included children with SCI [41]. The procedure has been reported to improve constipation and fecal incontinence and reduce episodes of autonomic dysreflexia associated with bowel programs in adults with SCI [42, 43]. It is not clear if the paucity of literature describing use of the ACE in children with neurogenic bowel due to SCI is due to infrequent use in this population or the low incidence of SCI in children. In the authors' experience, the ACE has been helpful in managing neurogenic bowel in patients with both upper and lower motor neuron disorders, although in the former, it does not eliminate the need for digital stimulation during the bowel program.

Respiratory Insufficiency

Diaphragm pacing stimulation (DPS) utilizes electrical stimulation to liberate an individual with chronic respiratory insufficiency or failure due to high cervical SCI from dependence on mechanical positive pressure ventilation (PPV) via a tracheostomy [44, 45]. Diaphragm pacing includes options of *phrenic nerve pacing* and *laparoscopic diaphragm pacing*. Both generate negative pressure ventilation by recreating the natural descent and contraction of the diaphragm to generate inspiration, followed by passive exhalation. Both are open loop systems comprised of implanted electrodes that control diaphragm activity with stimuli from a battery-operated programmable external device. In general, candidates for diaphragmatic pacing must have intact phrenic nerves and diaphragm confirmed by electrodiagnostic and fluoroscopic studies, have no chest wall deformity and be free from primary lung and

muscle disease. Implantation typically occurs at least 12 months following SCI, to allow maximal natural recovery. Laparoscopic diaphragm pacing utilizes a laparoscopic probe to identify and map the motor points in each hemidiaphragm and implant percutaneous intramuscular electrodes bilaterally [44, 45]. Successful transition from chronic PPV to diaphragm pacing requires progressive diaphragm conditioning using the pacing system, along with a step-wise reduction in mechanical PPV time. The goal is to achieve full-time or maximal periods of continuous pacing [46, 47••]. Case reports suggest that age and duration of injury correlate with the time required to achieve four hours of continuous diaphragm pacing, ranging from one to twenty-one weeks [48, 49]. There are no formal standards of care at this time that address progressive pacing protocols.

Phrenic nerve pacing systems used to require thoracotomy, but with the advent of minimally invasive approaches (thoracic or cervical) the act of placing an electrode on the phrenic nerve is easier to accomplish. The electrodes are attached to a radiofrequency receiver placed in the subcutaneous tissue over the anterior chest wall. During use, an external antenna is positioned over the receiver site, and transmits the programmed stimulus from the control device. Some features allow trans-telephonic monitoring, and bio-feedback control from oximetry and carbon dioxide monitoring (Avery Mark IV; Avery Biomedical Devices) [47••]. In earlier reports, difficulty achieving long periods of pacing was attributed to high chest wall compliance in infants and younger children, but improvement was noted by age 10–15 [50]. At this time, one laparoscopic diaphragm pacing system (NeuRX®, Synapse Biomedical) has received U.S. Food and Drug Administration approval under a humanitarian device exemption program to be used in individuals at least 18 years old with spinal cord injury-related ventilator dependence. Given the recent approval, age parameters, and low target population prevalence, there are few preliminary studies that describe the experience and outcomes of laparoscopic DPS for pediatric-onset SCI. One study reported results from 10 adults who had sustained pediatric-onset SCI and received laparoscopic DPS. Four succeeded in using DPS full-time, and four achieved daytime pacing. Two individuals required surgical correction of scoliosis prior to implantation. All reported preference for DPS-triggered breathing over tracheal mechanical PPV, and four individuals identified DPS as facilitating integration into community activities [51].

A prospective study of six pediatric patients aged 5–17 years with SCI-related ventilator dependence and laparoscopically implanted DPS under a compassionate humanitarian device use program revealed considerations specific to this population. Five of the individuals were candidates for DPS, the smallest weighing 15 kg. All

patients achieved tidal volumes above basal needs and sufficient for ventilation [51]. Four of the children under age 10 developed anxiety with the conditioning onset, which may contribute to a longer period of conditioning. No device-related complications were noted over the duration of the study. Due to growth of the children over time, the DPS required reprogramming to keep pace with ventilatory needs of each patient. One patient experienced a growth spurt that ultimately required scoliosis surgical correction to successfully wean from positive pressure ventilation, and was successfully decannulated. One death was attributed to unrelated urosepsis [52].

Potential benefits of DPS include decannulation and tracheostomy closure and improved olfaction, speech, ease and flow of communication, and satisfaction with life [53, 54]. Formal data on the rate of respiratory complications, survival and cost of care versus standard mechanical PPV is not yet available.

Implant-related complications from laparoscopic DPS in adults with SCI include capnotherax or air trapping in the chest from abdominal insufflation during laparoscopic surgery. This occurred in 42 % of participants and was treated conservatively with ventilator volume management or by aspiration, and without reported associated respiratory or hemodynamic instability [55]. One of the participants developed a wound infection at the percutaneous electrode entry site (2 %). No device-related complications were noted in this study.

In cases where the phrenic nerve is injured, the development of microsurgical nerve grafting techniques has enabled anastomosis of a functional nerve, such as the fourth intercostal nerve, to the phrenic nerve. When utilized in combination with phrenic nerve pacing, this technique has had preliminary success in a small number of adults with SCI [56].

Benefits of Exercise

SCI has a number of consequences that impact the general health of the individual, leading to higher rates of obesity, insulin resistance and diabetes, metabolic syndrome, and cardiovascular disease than the general population [57•]. The focus of rehabilitation in SCI has been on compensatory strategies for limitations, but at the forefront are new techniques and interventions for restoration of function. These have shown promise in improving overall health and quality of life [58•, 59].

Electrical Stimulation

Neuromuscular electrical stimulation (NMES) and functional electrical stimulation (FES) are used to promote muscle activity and improve strength. Prior studies have

focused on adults with SCI and have used either implanted or external devices. One study in 7 children ages 7–20 years with thoracic motor complete SCI used an implanted FES device [60]. Participants worked on strengthening activities while supine for 2 weeks and progressed to standing and walking activities. Activities such as transfers in an inaccessible bathroom, transfers to a surface higher than their wheelchair and standing/reaching activities improved with FES when compared to the use of long leg braces. However, implantable devices are not currently being used in children for a variety of reasons. Consequently, external devices have gained more ground. A study of 30 children ages 5–13 years with chronic SCI randomized them to FES cycling, passive cycling, or NMES [61]. Each group exercised 1 h per day 3 times per week for six months. Assessments showed improved muscle volume in both the NMES group and FES cycling group, but those who exercised with FES cycling also saw improved muscle strength. The passive cycling group showed no changes in either strength or muscle bulk. Further studies are needed to determine the long term effects of FES cycling on function, strength, and markers of general health.

Activity-based Locomotor Training

There are 7 centers as part of the NeuroRecovery Network that focus on activity-based locomotor training [58•]. Most include therapies for adolescents and one has adapted protocols for children <14 years old [62•]. The goal of locomotor training is to improve lower extremity weight bearing, postural control, and mobility without compensation or use of assistive devices. Individuals use body weight support treadmill (BWST) training and other therapeutic interventions to learn standing and stepping kinematics. Several studies in adults have shown improvements in mobility and increased walking speed after locomotor training. In a recent case series by Behrman et al. [62•] 3 adolescents with incomplete SCI, 1 with cervical AIS D and 2 with thoracic AIS C & D, underwent the intensive locomotor training protocol, and each improved in their ability to ambulate household and community distances, minimizing the use of assistive devices. Two of the 3 who had neurogenic bowel and bladder also saw improvements in their volitional control. Each adolescent demonstrated increased community participation and engagement in activities enjoyed prior to their injury. Further studies are needed to assess the long-term outcomes and effects of these interventions.

Psychosocial Health and Outcomes

The psychosocial impact of pediatric-onset SCI is distinguished from the adult experience by the relatively long

lifespan facing youth with SCI, their heightened and frequently prolonged level of dependence on family and caregivers, and the actively evolving psychological and social developmental processes. Psychosocial health is “the state of being mentally, emotionally and socially well,” and encompasses interrelated dimensions such as quality of life (QOL), participation, and mental health [63•].

Health-related Quality of Life

In pediatrics, health-related QOL (HRQOL) is a subset of QOL that captures the subjective impact of health and treatment on physical, emotional, social, and academic function of youth with chronic illness [64]. Children and youth with spinal cord dysfunction due to SCI or spina bifida, and their caregivers, reported lower HRQOL scores across all domains of the pediatric quality of life inventory [65] than their peers without mobility impairment [63•, 64, 66]. As noted in adults with SCI, HRQOL showed stronger association with negative psychological states such as anxiety and depression, rather than injury severity [64, 67–70]. However, children with paraplegia indicated higher HRQOL than those with tetraplegia.

Parents or caregivers of youth with SCI often provide the assessment of the child’s function and make treatment decisions. However, there was only moderate consistency of the responses when examining the agreement between child and caregiver assessment of HRQOL. In general, youth with SCI rated their HRQOL higher than their caregiver’s impression. Regression analysis demonstrated that the mental health of the caregiver was a stronger predictor of the child’s HRQOL than the youth’s own mental health. Rehabilitation care recommendations for pediatric-onset SCI, therefore, include obtaining multiple perspectives in the assessment of pediatric QOL and addressing the parent or caregiver’s mental health as well [71].

Participation

Participation describes involvement in life situations resulting from peer interactions and includes age-appropriate activities such as play, attending school, joining community activities, performing chores, marital and employment status, and independent living [72–74•]. Participation is crucial to achieving psychosocial milestones by providing children opportunities to shape social identity and self-direction, acquire communication skills, develop understanding of roles and expectations, and build and maintain relationships.

Adults with pediatric-onset SCI are overall less likely to drive or live independently, and have decreased marriage

rates compared to the general population [75]. Participation rates among youth with SCI are below their nondisabled peers and more frequently involve sedentary activities [63•]. Up to 62 % of children with SCI reported no involvement in organized community activities [76]. Among youth with AIS A, B, and C, those with paraplegia had higher participation rates than youth with tetraplegia [77].

In pediatric SCI, Kelly et al. [75] reported a stronger correlation between overall QOL and participation *context* than with the *frequency* of their involvement. In particular, *where* children (ages 6–12 years) participated, and *with whom* adolescents interacted emerged as important variables. Among the children ages 6–12 years, participation in activities further from home that were recreational, physical, social, skill-based, and addressed self-improvement, yielded higher ratings of social, school, and overall psychosocial QOL. Among the adolescents, a higher emotional QOL was associated with a more diverse peer group. Increased diversity of physical activities was also associated with higher emotional, social, and overall psychosocial QOL.

This highlights potential interventions to improve QOL of youth with SCI by focusing on engagement outside the home and involvement with a diverse set of peers. Enhanced participation can be achieved by addressing transportation needs, promoting the concept of inclusiveness at the family and community levels in planning and providing opportunities for community engagement, and including diverse organized sports and recreation activities. Intervention to support participation should focus on children and youth with tetraplegia AIS A, B, and C.

Mental Health

Previous studies have reported higher rates of anxiety and depression among adults with SCI versus the general population [78–82]. However, studies suggest that youth with SCI experience mental health symptomatology at a rate commensurate with their peers without SCI.

Using the Revised Children's Manifest Anxiety Scale to assess occurrence of anxiety in youth with SCI, researchers described no significant difference from the normative group (9 vs 16 %) [71, 83]. Similarly, cross-sectional studies of youth with SCI scored within the average normative range for clinically significant depression (5 vs 7 %, respectively) [84]. Further research confirmed this finding except in youth ages 13–15, whose scores for depression and anxiety fell *below* the average of the normative group [63•]. Decreased community participation was associated with the occurrence of depression but not anxiety. Youth with SCI demonstrated higher rates of posttraumatic stress disorder. [85]

Longitudinal studies characterize typical mental health symptom trajectories through various developmental stages and are suggestive of resilience following pediatric SCI. One such longitudinal study of depression in adults with pediatric-onset SCI revealed that despite nonlinear fluctuations in symptoms over time, these individuals experienced a significantly lower overall prevalence of major depressive disorder (MDD) (8 %) when compared to the general U.S. population (16.5 %) [86•]. This confirmed findings from a prior cross-sectional study reporting only 3 % of adults with childhood-onset SCI meeting criteria for MDD [68]. In the longitudinal study, factors predictive of increased depression symptoms among adults with pediatric-onset SCI included increased hazardous alcohol consumption, incomplete SCI, bladder incontinence, and decreased community participation, with one of the most robust predictors identified as activity-limiting pain. These findings uncover potential strategies to decrease depression rates in adults who sustain SCI as youth, including a focus on improving pain management, providing education regarding potential effects of alcohol use and misuse, and promoting engagement in community activities.

Life Satisfaction

Satisfaction with life scale (SWLS) ratings among adults who sustained pediatric SCI were significantly lower than those without a disability [87]. A longitudinal study of life satisfaction trends showed only a marginal increase over nine years of observation [88]. Socio-demographic factors associated with higher life satisfaction included marriage or living with a partner, being female, and having a lower level of SCI (T7–S5). Lower SWLS scores were associated with illicit drug use and poor psychological functioning, and no association was detected with duration of injury and physical health as assessed by the Short Form Health Survey (SF-12). Experiencing medical complications in the past year was associated with lower baseline SWLS and a small increase in score in the following year. This suggests that illness does not necessarily lead to long-term negative effect on well-being. SWLS improved in those who maintained employment. Addressing factors that affect mental health, encouraging community engagement, fostering employment retention, and counseling against illicit drug use are potential targeted interventions to improve baseline and long-term life satisfaction.

Coping

Among coping strategies used by youth with SCI, only cognitive restructuring was associated with reduction in depression. Social support increased participation. Youth who reported greater self-efficacy in using coping

strategies had more positive psychosocial outcomes [71, 89]. Adolescents aged 13–17 years who sustained an SCI report the most effective coping strategies are social support, emotional regulation, and cognitive restructuring. The use of escape-oriented or avoidant coping was linked to lower psychosocial QOL and heightened symptoms of depression and anxiety [89]. Coping interventions may therefore emphasize training in and harnessing cognitive restructuring and social support while decreasing long-term reliance on escape-oriented coping strategies.

Employment

Achieving and maintaining employment after pediatric SCI contributes positively to psychosocial outcome, resulting in improved psychological adjustment, greater satisfaction with life, independence, and general health [90]. However, employment rates for young adults with pediatric-onset SCI was significantly below that of their non-injured peers (51 vs 81, 42–69, vs 93–94 %), but estimates reveal these rates to be higher than rates observed in adult-onset SCI [75, 91]. Both cross-sectional and longitudinal studies suggest relative stability of employment status over time [92, 93]. Risk of depression was increased in those who were unemployed throughout the study. Employment rates were higher in participants who were women, had advanced degrees, were married, and had less severe neurological impairment [75, 77]. Occurrence of secondary health conditions such as severe urinary tract infections, autonomic dysreflexia, spasticity, or another chronic health condition decreased the odds of employment, suggesting value in targeted interventions for these conditions and in educational preparation for employment.

Substance Use

A study of young adults aged 21–25 years who had pediatric-onset SCI revealed lower prevalence rates of substance use than age-matched nondisabled peers [94]. However, tobacco use rates were elevated when compared to those with adult-onset SCI.

Siblings and Caregivers

In one study, caregivers of youth with SCI reported relatively high rates of moderate to severe anxiety (20 %) and moderate to severe depression (22 %) [71]. Caregiver anxiety and depression were, in turn, related to decreased emotional, social, and school QOL for the child. Anxiety was greatest in caregivers of young children and adolescents.

A small, qualitative study focused on siblings of youth with SCI suggests that these siblings are at heightened risk for adverse psychosocial outcomes due to disruption in

family structure, interactions and roles [95]. Siblings also described difficulty building relationships with parents or siblings with SCI due to multiple factors, including challenges maintaining an identity separate from the sibling with SCI, competing for parents' attention, and feeling their own needs were not being met.

Clinical recommendations arising from these observations include maintaining sibling contact and building participation by siblings in the rehabilitation program, education of parents of youth with SCI on the potential impact of the SCI on siblings, and surveillance and intervention for mental health difficulties among parents or caregivers.

Conclusions

While the incidence of SCI in children is low compared to adults, there are important differences practitioners should be aware of due to the impact on health and psychosocial well-being. Age at injury and skeletal maturity are important factors when considering the child's functional goals and risk for long-term complications such as scoliosis and fractures. Equally important are the metabolic changes that occur as a result of SCI, and children are at higher risk for developing obesity, diabetes and cardiovascular disease. Researchers are evaluating various modes of exercise in youth with SCI, attempting to lessen the impact of SCI on bone, muscle and metabolic health. Quality of life is shaped by the child's physical health, the secondary complications of SCI the child experiences, and their active participation in the family and community. Developing a sense of self, establishing independence, and engaging with people and activities outside the home can lead to greater satisfaction with life, higher rates of employment and improvements in mental health.

Compliance with Ethics Guidelines

Conflict of Interest M Osorio, MR Reyes, and TL Massagli all declare no conflicts of interest.

Human and Animal Rights and Informed Consent This article does not contain any studies with human or animal subjects performed by any of the authors.

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